



# Erectile Dysfunction: is it really that difficult to talk about? An interpretative phenomenological exploration.

---

Catherine Jane Dunn

7/6/2016

## **Abstract**

### **Background**

This thesis explores the disclosure of erectile dysfunction to healthcare professionals by asking men with erectile dysfunction, their partners and healthcare professionals to recall their experiences of such conversations. Erectile dysfunction can be a difficult subject to broach or disclose, and as a result, it is considered that the condition is under reported and therefore under diagnosed. In the light of erectile dysfunction being considered a possible marker of cardiovascular risk this thesis seeks to highlight the issues around disclosing the condition with a view to improving disclosure rates and therefore informing subsequent cardiovascular risk assessment.

### **Literature**

There is a body of literature which demonstrates that erectile dysfunction is a common issue which is correlated with many physical and mental health conditions. Specifically within populations of men with known cardiovascular disease prevalence rates of erectile dysfunction can be as high as 70%. Literature which explores the experience of having erectile dysfunction and disclosing it to a healthcare professional demonstrates that this is a conversation which is complex and is often avoided by both men with erectile dysfunction and healthcare professionals alike. In light of literature which demonstrates that ED and cardiovascular disease are linked, and that which demonstrates that disclosing ED is difficult there is a gap in the literature which specifically explores the disclosing of ED when it is a known marker of cardiovascular disease risk.

### **Research Process**

Following a cardiac event, men who identified themselves as having erectile dysfunction, their partners and healthcare professionals to whom a disclosure may be given, were approached and asked to describe their experiences. The study was designed using a phenomenological perspective so as to allow the thoughts and experiences of the participants' and researcher to be used to provide an illustration of the disclosure of erectile dysfunction, particularly

when considered as a precursor and marker of cardiovascular risk. The initial analysis used a thematic approach but this was found to be problematic in relation to the depth of the data that was captured and therefore a second analysis was undertaken, the results of which are presented as the findings of this study. The second analysis of data used a staged approach favoured in interpretative phenomenological analysis (Smith et al. 2009), which facilitated an analysis of the interview transcripts descriptively, interpretatively and linguistically. This latter analysis provided a unique perspective in relation to the topic which is acknowledged as difficult to discuss, and resulted in the linguistic tools which were used by the participants being identified as evidence for the embarrassment; this was identified as one of the themes which emerged from the descriptive analysis.

### **Analysis and Findings**

Analysis of the interview data with men and their partners identified the themes of: the impact that erectile dysfunction has had on their lives, disclosure (or not) of erectile dysfunction and erectile dysfunction in contemporary society. The interviews with healthcare professionals generated themes which resonated with those from the men as well as focusing on professional issues of ownership in relation to ED disclosure, anxieties in relation to such discussions and experience of receiving disclosures.

All of the themes have been extensively written about in relation to other health related issues but they have not been explored explicitly in relation to the disclosure of erectile dysfunction and therefore a unique position of the findings in relation to the existing literature is evidenced within Chapter Nine. The discussion located the findings specifically within existing literature related to embarrassment, stigma and medicalisation. The discussion of the analysed data within the context of the existing literature is then extrapolated to the current clinical environment and changes to clinical practice are suggested by linking the findings to practice. Suggested adaptations to clinical practice focus on improving the confidence of all involved in the disclosure of erectile dysfunction in having such conversations, by increasing the opportunities for them to occur and improving the confidence of all involved in managing such situations.



## Table of Contents

<b>ABSTRACT</b>	<b>4</b>
Background	4
Literature	4
Research Process	4
Analysis and Findings	5
Table of Contents	7
<b>CHAPTER ONE: INTRODUCTION AND BACKGROUND</b>	<b>12</b>
Introduction	12
Clinical context	13
Anticipated outcomes	16
<b>CHAPTER TWO: LITERATURE REVIEW</b>	<b>18</b>
<b>Defining Erectile Dysfunction</b>	<b>19</b>
Classifications of erectile dysfunction	22
Psychogenic Erectile Dysfunction	23
Organic Erectile Dysfunction	24
Are definitions used or understood?	25
<b>Prevalence of erectile dysfunction in the general population</b>	<b>26</b>
Prevalence in men with cardiovascular disease	28
<b>Links between ED and cardiovascular disease</b>	<b>29</b>
Shared Risk Factors	29
Age	30
Diabetes	31
Hypercholesterolaemia	31
Hypertension	32
Cigarette smoking	33
Exercise and Obesity	33
Depression	34
Cumulative risk factors equate to greater risk	34
Biological Mechanisms that link Erectile Dysfunction with Cardiovascular Disease.	36
Established Cardiovascular Disease	36
Endothelial Dysfunction	37
As a marker of silent cardiovascular disease or a predictor of future cardiovascular disease	39

<b>Living with Erectile Dysfunction</b>	<b>44</b>
Psychological impact of ED	44
Seeking help and disclosing erectile dysfunction	47
Why seek help?	49
Partners	50
<b>Social attitudes and influences</b>	<b>51</b>
The influence of Viagra	53
Media	56
Embodiment	57
<b>Current Clinical Context</b>	<b>60</b>
Professional ownership	60
Medical speciality ownership	62
Who should receive referrals?	62
Which healthcare professionals ask?	63
<b>Barriers to asking about erectile dysfunction</b>	<b>65</b>
Discomfort	65
Embarrassment	66
Lack of knowledge and time	69
<b>CHAPTER THREE: RESEARCH DESIGN</b>	<b>73</b>
<b>Brief overview</b>	<b>73</b>
<b>Aims and Objectives</b>	<b>76</b>
<b>Methodology</b>	<b>77</b>
Philosophical underpinnings	77
Epistemology of Hermeneutic Phenomenology	79
Time and Space	80
Background and Pre-understanding	81
Co-constitution	82
The Life World	83
Interpretation	84
The Hermeneutic Circle, essential parts	85
Using Phenomenology to explore hidden subjects	86
<b>Rigour, Reliability and Credibility</b>	<b>87</b>
The Author's Pre-understanding and Background	90
My Fore-structure	91
<b>Methods</b>	<b>93</b>
Sampling	93
Sample of men and their partners	94
Sample of Healthcare professionals	94
Sample size	94
Recruitment	95
Cardiology; the setting for recruitment	95
Access and Recruitment of Healthcare Professionals	96
Access and Recruitment of Men	97
Ethical permissions	99

Confidentiality and Data Protection	100
Data Management	101
Researcher involvement; the author's role as interviewer	101
<b>CHAPTER FOUR: ANALYSIS</b>	<b>105</b>
<b>The In-depth semi-structured interviews</b>	<b>105</b>
Interviews with men who had identified themselves as having erectile dysfunction	107
Interviews with Healthcare Professionals	110
The questionnaire	112
<b>Undertaking the data analysis</b>	<b>113</b>
<b>CHAPTER FIVE: DESCRIPTIVE ANALYSIS OF DATA FROM INTERVIEWS WITH MEN</b>	<b>123</b>
<b>Themes Emerging from Interviews with Men.</b>	<b>123</b>
<b>The Impact of Erectile Dysfunction</b>	<b>124</b>
Acceptance of ED and its importance	124
<b>Disclosure</b>	<b>129</b>
Factors influencing the decision to disclose erectile dysfunction	129
Experiences of Disclosure	133
<b>Erectile Dysfunction in contemporary society</b>	<b>139</b>
<b>CHAPTER SIX: DESCRIPTIVE ANALYSIS OF DATA FROM INTERVIEWS WITH HEALTHCARE PROFESSIONALS</b>	<b>143</b>
<b>Themes Emerging from Interviews with Healthcare Professionals</b>	<b>143</b>
<b>Professional roles, ownership and practice</b>	<b>144</b>
Professional and medical speciality ownership	144
Confidence, competence and training	144
Using personal beliefs to guide practice	145
<b>Anxiety and Misunderstanding</b>	<b>146</b>
<b>Experience of Disclosures</b>	<b>147</b>
Disclosure is a rare event	147
Mental preparation	148
Routine questioning	149
Adjuncts to practice	150
<b>CHAPTER SEVEN: LINGUISTIC ANALYSIS</b>	<b>152</b>
Metaphor	155
Metonymy	155
Euphemism	155
Power	158
Analogy	159

Double entendre	160
Humour	160
Analysis of the interviewer's language	165
<b>CHAPTER EIGHT: DISCUSSION OF EMERGENT THEMES</b>	<b>169</b>
<b>Embarrassment</b>	<b>170</b>
Audience	173
Effects of embarrassment	176
Embarrassment and Anxiety or Danger	178
Managing Embarrassment	181
Avoidance and Dismissal	181
Humour	183
Laughter	184
Direct Language	185
<b>Subordinate themes</b>	<b>186</b>
Stigma	186
Sense of self and change of identity	190
Managing Disclosure	192
Medicalisation	194
<b>CHAPTER NINE: DISCUSSION OF RESEARCH METHODS</b>	<b>199</b>
<b>Researching sensitive issues</b>	<b>199</b>
The men's perspective	200
The healthcare professional's perspective	202
The difficulties of discussing sensitive subjects in interviews	203
<b>The outsider perspective</b>	<b>205</b>
<b>The insider perspective</b>	<b>207</b>
<b>Issues of confidentiality</b>	<b>208</b>
<b>CHAPTER TEN: CONCLUSIONS</b>	<b>211</b>
<b>Summarising the thesis</b>	<b>211</b>
<b>Summary of Emergent Themes</b>	<b>212</b>
<b>Issues arising from the methodology</b>	<b>216</b>
<b>Where next?</b>	<b>217</b>
Dissemination of findings from this study	217
Implications for future research	218
Implications for clinical practice	219
Reflections on what I have learned	221
<b>REFERENCES</b>	<b>224</b>



<b>APPENDICES</b>	<b>246</b>
Appendix One	247
Appendix Two	248
Appendix Three	250
Appendix Four	254
Appendix Five	261
Appendix Six	266
Appendix Seven	271
Appendix Eight	272
Appendix Nine	273
Appendix Ten	275
Appendix Eleven	278
Appendix Twelve	291
Appendix Thirteen	318
Appendix Fourteen	336
Appendix Fifteen	364

## **Chapter One: Introduction and Background**

### **Introduction**

This thesis focuses on the disclosure of erectile dysfunction to healthcare professionals and whether this discussion can be used as a prompt for further evaluation of cardiovascular risk. Erectile dysfunction (ED) has been identified as a pathological risk factor for cardiovascular disease (CVD), but can it effectively be used to identify men at risk of cardiovascular disease? This research is based on the idea that men do not want to talk about erectile dysfunction and if they are not willing to disclose ED how can it be used as a marker of coronary disease risk? In order to investigate these ideas the concepts of erectile dysfunction and disclosure will be explored using semi-structured interviews with men who have ED and healthcare professionals who may receive a disclosure. These healthcare professionals may not only be in receipt of the disclosure, but it is anticipated that they could use the information to prompt cardiovascular risk profiling of the patient.

The theoretical position underpinning this thesis is that of phenomenology, which allows for a detailed exploration of lived experience (Paley 1998). Having ED and talking about it are highly personal experiences, so people's thoughts and perceptions regarding why they would choose to discuss the issue, or not, can only be approached from a perspective which allows them to express their understandings and experiences. Phenomenology allows both participants and researchers to consider a particular phenomenon from a holistic perspective, rather than a reductionist stance and is therefore considered to aid a broader exploration of a situation (Paley 1997).

Phenomenology also allows the participants and the researchers to recognise themselves in the research process and to acknowledge the influence that each will have over the other in all phases of the research. This is particularly relevant within this thesis because I have worked within an erectile dysfunction clinic as a nurse for several years, therefore it would be inconceivable to effectively suspend my experience and knowledge. The impact of the researcher on research is recognised by Heidegger, who acknowledged that there is no such thing as interpretation which is free of judgement or the

influence of the researcher; hence this influence will be explicitly recognised within all stages of the research (McConnell-Henry et al. 2009).

Interpretative Phenomenological Analysis (IPA) is one of a number of approaches used in psychology and allows the researcher to maintain an idiographic focus on the participants' story (Smith et al. 2009). IPA is usually an underpinning philosophy for a whole research thesis but, as will be discussed within the methods chapter of this thesis, here IPA has been particularly used to provide structure to the data analysis. The obvious benefit of IPA is that it allows the participants' words and language to be examined, this is essential when exploring a topic which may be considered private or embarrassing, or where an understanding is shared or implicit, because there may be meaning in an apparent lack of language and IPA allows the researcher to take these linguistic elements into consideration (Smith et al. 2009). IPA has been demonstrated to be a useful way of exploring people's experiences and their understanding of those experiences in relation to health, or ill health; it permits an exploration of the experience individually, collectively and holistically, taking into account the influences on the participants as individuals and groups, their thoughts and beliefs (Annells 1996). It is recognised that there is a degree of subjectivity, and rather than objective findings, the result of phenomenological and IPA studies is a presentation of both collective experience and those experiences which are unique to the individuals (Kleiman 2004).

### **Clinical context**

Healthcare maybe considered as comprising of three systems, micro (individual patient or healthcare professional, service delivery), meso (organisational) and macro (public health or strategic) (Nelson et al. 2008). These systems interact with one another and none exists in isolation of the other, therefore things which impact on one will influence the other and vice versa (WHO 2002). Hence it is valuable to consider the research focus in relation to these levels of healthcare so that early consideration is given to how the research question may impact at each of the levels of healthcare provision

(Nelson 2008), providing some indication as to how far reaching any potential findings may be.

At the micro level the individual patients' and healthcare professionals' experiences are imperative to provide an insight into the lived experiences of those who are living with and having conversations about ED. The experiences of the men about how or why they make decisions about ED can provide, not only their personal perspectives, but also can illustrate how, as a member of a wider society, they perceive the issue and therefore the findings can inform the other strata (meso and macro) of healthcare. Individual healthcare professionals can similarly provide the perspective of their position as an individual, as a member of a healthcare profession and as a member of a broader society. Therefore the information gained from individuals can not only be used to highlight experiences which can be utilised to inform healthcare at meso and macro levels but also in a cyclical manner will feedback into service provision and thereby impact upon an individual's own experience.

The experiences of individuals can provide insight into how an organisation delivers care and therefore the findings from studies which ask about experiences can inform healthcare providing organisations about their service delivery. Healthcare providers typically make explicit their agenda and the aims of their organisation; therefore if this meso level is informed by individuals' (micro level) requirements from a healthcare provider then the priorities of the organisation are often designed to reflect those needs. Meso level organisations are often budget holding organisations, such as hospitals, which aim to balance the expectations of the population that they serve, with the resource constraints which are placed upon them from the macro or budget granting level strata. ED disclosure and increasing the ease with which such conversations take place will potentially improve the experience of service users, and if ED is used as a prompt for cardiovascular risk assessment then earlier risk reducing interventions may help prevent symptomatic CVD, preventing hospital treatment and the life-long treatment costs which are incurred by meso-level organisations.

Meso level organisations are under a significant influence from the higher macro level strata which is often national governmental departments. When considering ED as a risk factor and marker for cardiovascular disease risk, the implications to clinical practice at a macro level can be used to impact on the general populace, potentially reducing the over-all coronary risk of the male population. Currently 8% of expenditure within the Welsh National Health Service is spent on cardiovascular disease management (WG 2014). The Welsh Government document “Together for Health- a Heart Disease Delivery Plan” (2013) sets out priorities for the Welsh nation in relation to heart disease with the primary aim of reducing preventable heart disease. The vision, as set out by the Welsh Government, is to reduce the risk factors for heart disease within the whole population, by using all available means to identify and treat modifiable risk (WG 2012). Available means include interactions with a variety of healthcare professionals: community pharmacists, general practitioners, practice nurses and healthcare professionals within hospital settings. Although there is a drive to capitalise on all given opportunities for risk reduction there is no recognition of ED as a risk factor or marker of risk within this delivery plan.

The Welsh Government recognises that many risk factors, such as high blood pressure and high cholesterol “*share common ground*” with other long term conditions (WG 2013 p8). Therefore, by reducing the risk of cardiovascular disease, for example, the risk of diabetes could also be reduced. There is recognition that most risk reducing measures require a significant commitment from the individual with many lifestyle changes which need to be made. The Welsh Government document recognises the responsibility of the individual in managing their own health and makes the explicit statement that

*“The people of Wales also have a role to play”* (WG 2012 p6).

This demonstrates a clear requirement on the part of Government for members of society to take responsibility and ownership of their health; the onus being not solely on healthcare professionals to improve the health of the nation. To raise awareness of how to effectively manage risk factors health board’s (HB’s) have been tasked with increasing awareness; both within the general population and with healthcare professionals. The overall aim of Welsh

Government health and social care policy is to empower people to engage in self-care and monitoring at all ages which they have identified as the concept of co-production (WG 2013). Co-production and prudent healthcare; the appropriate and careful use of healthcare resources are both clearly evident within the Welsh Government manifesto and underpin the most recent reports on cardiac services (Drakeford 2015). Strategic plans aim to impact on people living within Wales by encouraging all to take responsibility for their own health, by informing all concerned how this can be achieved. ED is a recognisable risk factor which can be used to identify cardiovascular risk; hence there is a potential prompt for risk management (ED) which is currently not being used as such.

Using erectile dysfunction as a marker of early cardiovascular disease could impact upon all levels of healthcare provision within the United Kingdom, this thesis aims to improve understanding related to disclosure and subsequent discussions about erectile dysfunction; thereby answering the research question

“what are the barriers and enablers to disclosing erectile dysfunction?”

This question will be explored by reviewing the existing literature and undertaking interviews with people who have experience of the condition from both patient and professional perspective. Findings will be explored within the existing literature and theories of embarrassment, stigma and medicalisation in order to situate the findings of this study within existing understandings.

### **Anticipated outcomes**

The anticipated aims would potentially be:

- 1) To increase our understanding of how men perceive their disclosure of ED and whether they have any knowledge or understanding of the link with cardiovascular disease.
- 2) To increase our understanding of healthcare professionals' beliefs with regards to the disclosure of ED, highlighting issues which may be

impacting upon their practice, thereby enabling them to adopt behaviours which may encourage disclosure.

- 3) To explore whether erectile dysfunction could be used as an acceptable prompt for cardiovascular disease assessment

To summarise, this thesis aims to look at the disclosure of erectile dysfunction. Given ED is considered as a risk factor for cardiovascular disease conversations about it could act as a prompt for further risk assessment and thereby ultimately decrease the incidence of symptomatic CVD in men. Disclosing erectile dysfunction is often the first step for a man to take in seeking treatment for ED, and may be considered as providing an indication of wider health implications. Therefore such conversations can be pivotal on an individual basis and to a wider population (in terms of risk management).

Phenomenology and IPA are both methodologies which enable researchers to ask individuals about their experiences and thoughts or understandings, therefore they will facilitate participants involved in this thesis to tell their stories and explain their thoughts so that findings from this study can improve such conversations, thereby increasing the number of risk reducing interventions that healthcare providers can facilitate and ultimately decrease the incidence of cardiovascular disease in Wales.

## Chapter Two: Literature Review

Literature which explores ED, or impotence as it was previously known, has historically been situated within a variety of specialities from psychology to sociology. It is currently believed that there are multiple causes for ED which can be psychological, physiological and in some cases environmental or sociological. The complexity and vastness of this body of literature is acknowledged and particular elements will be discussed in greater depth within this chapter. In contrast the body of literature which specifically explores the disclosure of erectile dysfunction appears to be sparse and no publications could be identified which focus on the disclosure of erectile dysfunction when considered to be a risk factor for cardiovascular disease, identifying a clear gap in the existing literature.

Having highlighted a gap in current knowledge systematic literature searches were undertaken (for an example see appendices 1 and 2) which aimed to identify literature which would provide an understanding of erectile dysfunction and how it has been demonstrated to be a marker of cardiovascular risk and how men live with erectile dysfunction and what impacts upon their help seeking behaviours. Search terms such as “erectile dysfunction”, “impotence”, “cardiovascular disease”, “ischaemic heart disease”, “coronary heart disease” and “disclosure” or “discussion” were initially used to gain a sense of the existing literature. These searches were then broadened to include “help seeking” behaviours and “barriers” and “enablers” to discussing “erectile dysfunction” and “sexual health”. This body of literature provided an illustration of the historical and linguistic background, particularly in relation to the diagnostic difficulties of ED and its impact on men. The literature which explores aspects of living with ED was also addressed, because although not recognising the ED CVD link explicitly, the findings about living with ED and the effect that this can have on a man and his partner are considered equally relevant; whatever the underlying pathological cause of the ED.



## **Defining Erectile Dysfunction**

Due to the hidden nature and personal experience of erectile dysfunction (ED) it is often difficult to establish whether people are describing the same symptoms. Colloquial language, euphemisms, changing professional ownership and a lack of clear understanding of the symptoms have all contributed to a sense of confusion about what erectile dysfunction actually is (Bortolotti et al. 1998). In 2000BC medical records documented “*men’s perennial problem of impotence*” and cases of men who were “*incapable of doing their duty*” (McLaren 2007 p.3). Men were described as attempting to “*restore potency*” and fearing the “*dreaded malady*” and having “*acquired erectile weakness*” (McLaren 2007 p.3). All these terms were used interchangeably and until the end of the 20<sup>th</sup> century “*impotence*” was the overarching label used when discussing a myriad of male sexual dysfunctions; premature ejaculation, retrograde ejaculation, loss of libido and performance anxiety; all of which have differing causes which can be as a result of pathophysiological or psychogenic processes, and as a result differing treatments (Lue et al. 2004, Wyllie 2005). The use of colloquial terms and assumptions has resulted in terminology which is vague and lacking in clarity for both men and healthcare professionals.

As long ago as 1858 Copland’s Medical Dictionary attempted to define “*impotence*”, by providing four types or underlying causes;

- 1) *Organic due to hypogonadism*
- 2) *Functional as a result of excessive or premature sexual indulgence and smoking*
- 3) *Moral or mental impotence due to psychological causes such as fear of incapacity, of not being loved, timidity, shame, disgust, hatred, jealousy, suspense, terror etc. and*
- 4) *Constitutional impotence inherited genetically”* (Copland 1858 p.823)

This definition was complex and used many descriptors, which practitioners and men alike would have had difficulty in accurately measuring or quantifying

for example how are timidity, disgust or suspense measured or identified. Subsequent definitions perpetuated this ambiguity, however, Kaplan sought to simplify with the definition so that

*“the chief clinical feature of impotence is the failure to attain or maintain an erection firm enough for vaginal intercourse”* (Kaplan 1974 p.255)

Kaplan’s definition highlights two issues, the negative emotional connotations which can be associated with ED and the two subdivisions of erectile dysfunction which are based on the underlying cause: psychogenic and organic. This bifurcation of underlying causes is still evident within much of the assessment and treatment of erectile dysfunction today (McLaren 2007). By the 1990’s there were efforts to establish a more easily quantifiable definition of erectile dysfunction but by 1999 there had been no resolution to the ambiguity of the terminology, impotence and erectile dysfunction continued to be utilised interchangeably. The first international consultation on erectile dysfunction was held in Paris and the committee stated that the term *“impotence”* should be replaced and that there was little understanding of risk and treatment of erectile dysfunction (Debusk et al. 2000). The 1<sup>st</sup> Princeton Consensus statement, as a result of this meeting, expressed the opinion that the definition of erectile dysfunction required further clarity (Debusk et al. 2000 p.175) and the definition, which was agreed upon stated that

*“erectile dysfunction is the recurrent inability to achieve or maintain an erection sufficient for sexual activity”* (Debusk et al. 2000 p.175).

Notably this definition only includes men who experienced ED for more than three months, which does indicate a persistent problem but may delay appropriate help seeking and thereby action by healthcare professionals (Miner and Kuritzky 2007).

Eardley et al. (1999 p.6) characterised erectile dysfunction as *“the inability to achieve an erection that is adequate for intercourse to the mutual satisfaction of both partners”*. Eardley’s definition included the satisfaction of both partners,

which was not only designed to address the aspect of sustaining the erection, but also acknowledging the impact on the sexual partner (Eardley 1999). The temporality or permanency of the symptoms within the definition, were not made explicit. Diedrich et al. (1992 cited Sookdeb 2007 p.77) attempted to address this with the inclusion of “*recurrent*” and “*persistent*”, thereby discounting men who had experienced a singular event but this aspect of ED definition has not been incorporated into the most widely accepted definition from the Princeton Consensus statement.

The American Psychiatric Association’s (1994 p.56) definition does incorporate the persistent nature of ED and highlights three essential diagnostic criteria

- *persistent or recurrent inability to attain or maintain until completion of the sexual activity, an adequate erection*
- *the disturbance causes marked distress or interpersonal difficulties*
- *the erectile dysfunction is not better accounted for by another axis 1 disorder (other than a sexual dysfunction) and is not due exclusively to the direct psychological effects of a substance (e.g. drug abuse, a medication or general medical condition).*

These diagnostic points resulted in discussion within the literature with regards to the relevance of distress and interpersonal difficulties. Many men attribute erectile dysfunction to advancing age and are accepting of this as an inevitable part of growing older, therefore they may not recognise distress or interpersonal difficulties or feel the need to express them to a healthcare professional; so they would not seemingly meet the criteria for a diagnosis (Gott and Hinchliff 2004, McCabe and Matic 2008). Reaching a diagnosis based upon this definition could be problematic, if the men with erectile dysfunction are not distressed they will not meet the criteria for diagnosis and therefore this symptom may not be used as an indication of other health problems such as cardiovascular disease or diabetes. Definitions of ED usually include the lack of erection, a lack of sexual satisfaction, the sense of distress felt as a result of being unable to achieve an erection and the permanency of

this state. Within the literature it is common for individual authors to provide their own definitions in their reports and a unanimous consensus within the literature has yet to be achieved. Notably researchers do not often ask men or healthcare professionals for clarity or their understanding of a definition.

### **Classifications of erectile dysfunction**

Sexual function is a psychosomatic process and therefore anything which affects the physical or the psychological aspects of this process can cause a sexual dysfunction (Davis-Joseph et al. 1995). ED is just one of a myriad of erection difficulties, many of which are specifically related to ejaculatory problems. Erectile dysfunction is further classified using the underlying causes; organic ED is caused by pathological processes and psychogenic erectile dysfunction is related to psychological issues such as performance anxiety or depression. Men who have elements of both organic and psychogenic are described as having ED of mixed aetiology (Araujo 1998, Gareri et al. 2014). The World Health Organisation (1992) provided guidance which was designed to assist clinicians in reaching a diagnosis of either organic or psychogenic erectile dysfunction:

*“If erection occurs normally in certain circumstances e.g. during masturbation or sleep or with different partners, the causation is likely to be psychogenic.”*  
(WHO 1992 ICD-10 F52.2).

Although preceding DeBusk et al. (2000) this definition remains clinically utilised to differentiate between ED of psychogenic or organic cause (McLaren 2007). In men where psychological issues, rather than an organic disease process, are causing ED, erections will be achieved in some situations, for example early in the morning but not in others for example with a particular partner. Men with ED who have an underlying organic disease process will not achieve sufficient erections in any situation because of altered pathology of blood vessels or nerve pathways (Jackson 2006).

## Psychogenic Erectile Dysfunction

Psychogenic ED is caused by a variety of psychosocial factors which do not necessarily result in pathological changes, but which impact on the psychological components of sexual behaviours and therefore can manifest as ED (Davis-Joseph et al. 1995). The complexity of this myriad of causes, whilst recognised, is not discussed in depth within this thesis because of the broad reach of this set of issues and the need to maintain a focus on the pathological causes, particularly related to cardiovascular disease. Psychogenic erectile dysfunction may result from issues such as performance anxiety, relationship conflicts, sexual inhibitions or fear and is highly correlated with depression and anxiety (Davis-Joseph et al. 1995, Araujo 1998, Gareri et al. 2014). These psychological or interpersonal factors should be clearly established by taking a history from the man and typically men with psychogenic ED describe an abrupt onset, with the continued presence of early morning erections and a sense of situational dysfunction (Davis-Joseph et al. 1995), in stark contrast to ED which has an insidious onset and organic or pathological causes.

Historically psychogenic ED has been diagnosed using nocturnal penile tumescence testing to determine whether the man experiences erections during sleep, however these tests have been shown to give both false positive and false negative results. Therefore clinicians must holistically assess a patient being mindful of the fact that in the presence of an organic disease process, diabetes for example, it may not be the diabetes which is causing the ED, similarly anxiety may be as a result of an organic ED rather than the cause of a psychogenic ED (Rosen 2001). When a diagnosis of psychogenic ED is made, psychosocial factors should be the predominant or exclusive cause and treatment should be aimed at addressing the issues which are the underlying causes, this usually necessitates talking therapy such as psychoanalysis, cognitive behavioural therapy or marital counselling (Davidson 1987, Ritvo 1974).

Ludwig and Phillips (2013) note that younger men were historically assumed to have psychogenic ED because their young age precluded them from having pathological causes, but currently between 15-72% of ED in men under the

age of 40 is thought to have an organic cause. They recognise that younger men have a greater risk of vascular disease than has been previously recognised and Papagiannopoulos et al. (2015) support this finding, identifying that young men commonly have vascular, neurologic and endocrine causes for ED.

### Organic Erectile Dysfunction

Organic erectile dysfunction is caused by a disease process, or pathological causes, which affects the somatic elements required to achieve an erection (Sakheim et al. 1987). The process of achieving an erection requires neurological, vascular and hormonal processes to be intact; therefore any disease process which causes damage to any of these can result in erectile dysfunction (Melman and Gingell 1999, Sakheim et al. 1987). Commonly cited disease processes that can cause ED include diabetes due to the damage to nerve fibres, atherosclerosis because of the reduced capacity for blood flow and hypogonadism which can cause low testosterone levels (Gareri et al. 2014, Celik et al. 2014). The list of diseases which can cause ED is extensive. However, they all impact on one or more of the neurological, vascular or hormonal processes.

Treatment for men with a diagnosis of organic ED is usually targeted at the underlying cause, for example treating a low testosterone level with testosterone replacement. However this may not always result in a resolution of the problem and pharmacological interventions, such as PDE5 inhibitors may be required in addition (Jackson 2006). This is because the damage to nerve cells and the endothelial lining caused by diabetes is not reversible simply by normalising blood sugar levels; therefore men are often treated for their diabetes (including risk reducing measures for their blood pressure) and then prescribed treatment to improve their erections.

The complexity of the causes of ED means that there is rarely a singular cause and often there are elements of psychological and organic disease processes which impact on a man with ED, particularly in relation to men who have a primary organic cause but their anxiety, as a result of experiencing ED, is

exacerbating the situation (Melman and Gingell 1999). This mixed aetiology has been more recently identified as the most significant and common clinical scenario and recent guidelines have sought to ensure that clinicians address both psychological and physiological components within their treatment plan. Melnick, Soares and Nasello (2008) published a systematic review which acknowledged that the psychological effects of erectile dysfunction and pharmacological interventions to address biological causes are often only part of the treatment required. This systematic review demonstrates that combination therapy was most effective; using talking therapies and PDE5 inhibitors would be the treatment plan of choice for erectile dysfunctions of all causes. Current thoughts are therefore that both organic and psychogenic ED should be treated with combination therapy, because all cases of ED will have a psychological component, be they the cause of ED or as a result of ED, and pharmacological agents are useful to improve both confidence and blood flow (Gareri et al. 2014, Rerkpattanapipat et al. 2001).

Historically ED was thought to primarily be caused by psychological issues and with time evidence suggested that organic or pathological causes were the underlying reason. The literature has demonstrated the complexity and ever changing beliefs about the causes of ED, however the current evidence and thinking of scholars suggests that both psychological and organic causes interact in most cases of ED. Therefore current clinical practice is focused on identifying all underlying causes and issues which may be exacerbating the situation, addressing them and acknowledging that they can be of equal impact.

#### Are definitions used or understood?

The confusion surrounding definitions and diagnosis of ED is reflected in clinical practice and the lack of clarity has become an issue for professionals and men alike, despite DeBusk et al.'s (2000) definition there still appears to be some confusion as to what ED is and how to diagnose it (Abdulmohsen et al. 2004). Low et al. (2002) demonstrated a lack of understanding when Malaysian men incorrectly defined ED. They did not just demonstrate a slight misunderstanding, they thought that erectile dysfunction was either evidence

of homosexuality or premature ejaculation; highlighting the confusion which can occur when medical terminology is used to describe specific sexual issues. Fisher et al. (1) (2005) noted that in defining or describing ED men tended to use colloquial language which often required further clarification by those interviewing them in order to reach a mutual or shared understanding.

Assessment of healthcare professionals' understanding of the definition of ED and the underlying causes equally demonstrates a lack of understanding similar to the findings from men. Notably healthcare professionals were unable to provide a specific definition and they often believed that ED was primarily caused by purely psychogenic causes, this is interesting when it is acknowledged that the participants in these studies were all recruited because they have a higher than average interest in the subject; for example in Abdulmohsen et al. (2004) participants were recruited at a conference where the attendees had a specific interest in urology-related medicine and therefore a higher than average understanding would be anticipated (Abdulmohsen et al. 2004, Ng et al. 2004, Fisher et al. 1&2 2005). It is unclear why men and healthcare professionals do not have a clear understanding of what ED is. This lack of understanding has been identified but there has been not exploration as to why there is such confusion.

Reviewing the literature which examines the definition and classification of erectile dysfunction it becomes apparent that erectile dysfunction has been poorly defined and this has resulted in a lack of clarity within this body of literature; this lack of clarity calls into question the size of the problem. If there is difficulty in defining the issue, then in reality how many men could ED be affecting? The literature which seeks to establish prevalence rates of ED will now be reviewed in order to contextualise the size of the problem.

### **Prevalence of erectile dysfunction in the general population**

The wide variance in prevalence rates of ED and possible inaccuracies are often attributed to the embarrassment attached to admitting having ED and the complexities in establishing a definition and diagnosis. As a result, prevalence rates of erectile dysfunction within a general population vary from two per cent



to eighty six per cent (Prins et al. 2002). Authors have suggested that the specific culture of the men that they are studying may make it more difficult for them to admit to having ED. (Ng et al. 2004, Sookdeb 2007). However all authors from across the world feel that they have been trying to access this information from a culture that is not open to talking about ED and the prevalence rates vary within cultures; it may be postulated therefore that all cultures find ED a difficult topic to talk about (McLaren 2007).

The landmark study of the epidemiology of erectile dysfunction is the Massachusetts Male Aging Study (MMAS), this large scale longitudinal study based on the randomly selected sample of one thousand seven hundred and nine Massachusetts men aimed to study how this population aged (Levy 2002). In a healthy New England population, 52% of men aged between forty and seventy years of age had "*impotence*" to some degree (Feldman et al. 1994). Johannes et al. (2000) studied a subset of the data from men aged 40 to 69 years old, they concluded that the annual incidence rate of ED increased with each decade of age, establishing the risk of erectile dysfunction of 26/1000 men annually. The authors of this report expressed surprise at the significant numbers of men who experience ED, particularly because they identified that this was probably a conservative estimate.

The difficulty in establishing prevalence rates is highlighted by Diokno et al. (1990) who used a household survey of people aged over 60 to explore the medical, epidemiological and social aspects of aging. Within the subsection of the survey which explored "*difficulty getting or maintaining an erection - impotence*", of the almost 1000 men who completed the survey, only 283 responded to this section. 40.3% of the 283 reported difficulties, from which the adjusted estimate for those having difficulties was given as 35.3%. Accurate prevalence rates are notoriously difficult to establish and the wide variance is obvious, however there have been some consistent results with Bacon et al.'s (2003) findings of 33% having a striking similarity in prevalence to Virag et al.'s (1985) findings twenty years earlier and Diokno et al. (1990).

Kubin et al. (2003) published a review of the epidemiological data on erectile dysfunction. They concluded that between 5 and 20% of men in the general

population have moderate to severe ED. This variation was considered to be due to differing definitions of ED, age distributions and concomitant medical conditions and differing methodologies. Importantly they found that the widely quoted 35% prevalence rate described in the MMAS was not reflected in other studies. Kubin et al. (2003) concluded that even at these lower limits (5%) ED would appear to be a relatively commonly experienced symptom which affects a significant number of men in the general population and within a population of men with known cardiovascular disease the prevalence would be significantly higher.

### **Prevalence in men with cardiovascular disease**

Hood and Robertson (2004) specifically studied the rate of erectile dysfunction within a population of men with cardiovascular disease. They reported a prevalence rate of 61%, which increased to 75% in men over 55 years of age. The authors concluded that they identified a higher than previously reported prevalence of erectile dysfunction in male patients with CVD. Kloner et al. (2003) also found prevalence of 70- 75% of ED in a group of men with known cardiac disease, however the prevalence of ED in populations of men with CVD varies from 33% to 75%; with as many studies providing rates below 50% (Soloman et al. 2002, Montorsi et al. 2003, Byrne et al. 2013), as those with rates over 50% (Kloner et al. 2003, Soloman et al. 2002). Soloman et al. (2002) established that symptoms of ED were volunteered by 45% of the men (59) although 65% (86) scored less than 21 on the IIEF (a validated self-assessment tool) thereby suggesting a diagnosis of ED in 65%, highlighting a lack of understanding or possibly a lack of concern in men who experienced ED but did not recognise it as such.

More recently, the Cardiac Health and Assessment of Relationship Management and Sexuality study (CHARMS) (Byrne et al. 2013) cited a prevalence rate of ED in men undertaking cardiac rehabilitation to be thirty three per cent; this was lower than most prevalence rates in such a population but has to be considered in light of a thirty two per cent response rate, a non-face to face data collection and the absence of a validated tool for diagnosis. None of the authors who have reported on prevalence rates of ED within

populations of men with known CVD commented on whether they had classified the men's ED as organic or psychogenic in cause, this will be discussed later in the chapter. There is a significant correlation between organic risk factors for CVD and ED and a similarly high incidence of depressive disorders in men with CVD and men with ED; therefore these figures may not ever be clearly established. The wide variance in prevalence rates have been cited by all authors as being due to the embarrassing subject matter (Baldwin et al. 2003, Byrne et al. 2013, Low et al. 2002, Ng 2004, Pontin et al. 2002) and, as demonstrated by Soloman et al. (2002), makes an accurate diagnosis difficult. Specific to this population there is also recognition that having experienced a life threatening event such as a heart attack, the priorities of a man may not be his sex life (Jaarsma et al. 2010).

As discussed, the evidence suggests that ED is a common issue which may be under reported because men do not want to discuss it, they possibly find it embarrassing and specifically within a population of men with cardiovascular disease there may be priority given to surviving a life threatening event rather than considering their sex life. Higher prevalence rates of ED in men with known cardiovascular disease are evident, but why are ED and CVD linked?

## **Links between ED and cardiovascular disease**

### **Shared Risk Factors**

By 1960 a number of epidemiological studies had established a direct association between elevated cholesterol and myocardial infarction (MI) (Zukel, Paul and Schnaper 1981 p387), with additional risk factors for MI identified in the period 1960- 1970 including diet, hypertension, diabetes and smoking; by the late 1980's cardiac risk factors were clearly influencing medical practice in aiming to reduce risk and thereby rates of coronary disease (Wilson et al. 1998). Risk factor management has involved careful monitoring and interventions to control blood pressure, cholesterol levels, blood glucose monitoring, body mass index, smoking and exercise levels (WG 2013). Primarily current clinical practice is targeted at minimising the impact of these modifiable risk factors within the context of the un-modifiable risk factors, the

patient's age and their family history (Montorsi et al. 2003). The Welsh Government recognise that

*“The risks of heart disease are influenced by cross-cutting primary risk factors which affect a number of chronic conditions”* (WG 2014 p4),

For example, reducing an individual's body mass index will reduce their risk of developing cardiovascular disease and improve their diabetic blood sugar control. Therefore minimising the impact of each risk factor will reduce the impact of all associated disease processes.

The MMAS study (O'Donnell et al. 2004) and Virag et al. (1985) were early studies which demonstrated that ED shares a number of risk factors with CVD: smoking, lack of physical activity, hypertension, hyperlipidaemia and diabetes and are important risk factors for both conditions. Cigarette smoking at baseline almost doubled the incidence of ED by first follow-up, eight years later in the MMAS study (Feldman et al. 2000). The authors describe how their preliminary analysis showed an increased risk of CVD among men with ED at the beginning of the study. The age adjusted risk of having ED was higher in men with diabetes, heart disease and hypertension and the risk of developing erectile dysfunction increased with age, lower education, diabetes (tripling the risk), heart disease (quadrupling the risk) and hypertension. Risk factors for CVD have since been identified as hyperlipidaemia, lack of exercise, family history, obesity, alcohol consumption, elevated levels of stress, depression and smoking (Halcox et al. 2010). All the modifiable risk factors are routinely minimised by medical interventions and there is a vast evidence base to support such actions (Halcox et al. 2010). Many of these risk factors have also found to be independent risk factors for erectile dysfunction.

### Age

Increasing age has consistently been positively correlated with ED prevalence (Bacon et al. 2003, O'Sullivan and Savage 2009 p171, Rosen 2004, Barrett-Connor 2005). Although there has been a variance in prevalence rates at differing ages, the overall trend of increasing prevalence with increasing age is

consistent (Selvin et al. 2007). Similarly, the increasing number of risk factors and of cardiovascular disease also correlates with increasing age (Feldman et al. 2000). Bacon et al. (2003) describe how many of the aspects of sexual functioning decrease sharply with each decade after 50 years of age, a finding corroborated by Bortz et al. (1999), Araujo et al. (2004) and DeRogatis and Burnett (2008). Age is clearly not medically modifiable but indicates a high likelihood of the existence of other risk factors for CVD and ED; which all correlate with increasing age.

### Diabetes

Diabetes is also positively correlated with erectile dysfunction (Bacon et al. 2003, Bortolotti et al. 1998, Rosen 2004). Selvin et al. (2007) document that among men with diabetes the crude prevalence rate was 51.3%, which is much higher than in the general population studies but the prevalence of ED in diabetic men is not thought to be as high as populations of patients with cardiovascular disease (Diokno et al. 1990, Bacon et al. 2003, Rosen et al. 2004, Bai et al. 2004, Kloner et al. 2003, Hood and Robertson 2004). Uniquely the Rancho-Bernardo study (Barrett-Connor 2005) found no association between ED and diabetes, however there were significant differences in the testing and threshold levels between 1972 and 1998, therefore the two sets of data could not be effectively compared with each other or the current diagnostic thresholds for diabetes. The authors suggest that the combination of low prevalence at baseline, misclassification and survivor bias may explain the absence of the expected association and they recognise that their findings are incongruous with much of the other evidence (Barrett-Connor 2005).

### Hypercholesterolaemia

Bacon et al. (2003), Rosen (2004) and Vlachopoulos et al. (2005) all found significant correlations between hypercholesterolaemia and erectile dysfunction. In the Ranch-Bernardo prospective study (Barrett-Connor et al. 2005), hypercholesterolemia was the most prevalent risk factor at baseline. In this study age adjusted categorical coronary artery risk factors were assessed and men with hypercholesterolemia at baseline were more likely to have moderate ED than no ED at follow-up. Later work by Chew et al. (2008) concluded that hypercholesterolaemia was not significantly associated with

ED. Hypercholesterolaemia is extensively documented as being closely associated with endothelial dysfunction and for the purpose of laboratory research this is usually confirmed using venous blood samples (Stewart and Monge 1993), however, in Chew et al.'s study (2008) hypercholesterolaemia was self-reported. Only 54.2% of the participants who claimed to have hypercholesterolaemia were receiving lipid lowering medications, which may provide evidence as to why Chew et al.'s (2008) finding is at odds with the other authors because they were not using standardised testing to establish a diagnosis of hypercholesterolaemia.

Lee et al. (2008) found a positive correlation between ED and high triglyceride levels. Triglycerides are a specific blood lipid which, when elevated, act as an independent indicator of atherosclerotic risk (Miller et al. 2011), independent from low density lipoprotein levels and other substrates of cholesterol profile. High triglycerides are a potent marker of CVD risk and therefore correlate closely with the risk associated with both issues (Halcox et al. 2010). Therefore there is evidence which suggests that elevated cholesterol levels and elevated triglycerides are positively correlated with ED.

### Hypertension

Hypertension positively correlates with erectile dysfunction in several studies and historically ED was thought to be a side effect of medications used to control hypertension, however the current thinking is that the endothelial cellular processes which result in hypertension also affect the vascular lining of the pudendal arteries and therefore these changes are the initial cause of the ED rather than the anti-hypertensive medications (Gidaro et al. 2006, Selvin et al. 2007). Burchardt et al. (2000) concluded that erectile dysfunction is not only more prevalent in men with hypertension but that erectile dysfunction is more severe in those with hypertension than the general population of men with ED. In the presence of arterial hypertension, both morphological and functional alterations to the endothelium are noted, causing endothelial dysfunction- a malfunction of the inner lining of blood vessels. Endothelium-derived nitric oxide is greatly reduced in the presence of endothelial dysfunction and nitric oxide is crucially involved in blood pressure regulation; therefore it is

considered that hypertension contributes to the dysfunction of the endothelium and endothelial dysfunction to hypertension (Drexler 1997). The exceptions to these findings are studies reported by Virag et al. (1985) and Barrett-Connor (2005), who found no correlation between hypertension and ED. It has been suggested that the diagnosis of hypertension in the 1990s had changed significantly from the 1970's and thus the findings were incomparable, this may have obscured any notable association. Welsh Government figures record hypertension as the only cardiovascular risk factor which continues to rise in prevalence (WG 2014) and therefore the Welsh Government agenda is focused on appropriate and consistent management of this particular risk factor.

### Cigarette smoking

Smoking is thought to potentiate endothelial dysfunction by inhibiting nitric oxide production (Heitzer et al. 1996). Vlachopoulos et al. (2005) documented that 64% of men experiencing erectile dysfunction smoked, which they felt was a significant finding and similar to that found by Virag (1985), Feldman (2000), Bacon et al. (2003) and Kim et al. (2001) who all concluded that smoking at the time of enrolment to a study was the most common risk factor for erectile dysfunction, however no significant correlation was noted by Bai et al. (2004), Rosen et al.(2004) or Diokno et al. (1990). These authors suggest that the results may have been influenced by cultural factors which made both erectile dysfunction and smoking habits difficult subjects for men to talk about and therefore neither were accurately represented in their findings.

### Exercise and Obesity

Selvin et al. (2007) in their multi-variant analyses described ED as significantly and independently associated with a lack of physical activity, whilst Bacon et al. (2003) reached the same conclusion by reporting that increased physical activity lowers the risk of erectile dysfunction. Obesity was associated with a higher risk (relative risk 1.3) of developing ED, (Selvin et al. 2007) a finding similar to that of the MMAS study (O'Donnell et al. 2004). Smoking, alcohol consumption and television viewing time were also associated with a higher risk of erectile dysfunction, when television watching is assumed to relate to

inactivity it could be anticipated that this is the reverse of the beneficial effects of increased activity (Selvin et al. 2007). Lack of exercise and increased obesity are correlated with each other and increase an individual's risk of hypertension, high cholesterol, depression and diabetes; therefore exercise and obesity can influence the overall risk accumulation significantly (WG 2014).

### Depression

Depression is a known risk factor for cardiovascular disease and cardiovascular disease is a recognised precursor to depression (Suls and Bunde 2005). Depression in patients who have known cardiovascular disease has been demonstrated to result in higher rates of morbidity and mortality (Barth et al. 2004, Lichtman et al. 2008), hence this is a significant issue of concern for healthcare professionals working with patients who have, or who are at risk of cardiovascular disease.

Erectile dysfunction is also correlated with depression; Araujo et al. (1998) used the MMAS data to highlight this link and concluded that, because depression precedes ED, depression can be used as an independent risk factor for ED. Similarly ED can cause or exacerbate depression. Simmonds et al. (2013) noted this to be particularly pertinent when the man feels emasculated in the presence of CVD. Depression is linked with CVD and depressive symptoms represent an independent risk factor for reduced sexual activity, therefore Corona et al. (2013) advocate using reduced sexual activity as a marker of risk for ED and CVD. The discussion of depression as a risk factor for cardiovascular disease and ED, as well as being a result of ED and CVD, clearly demonstrates the need for clinicians to consider ED to be of mixed aetiology in most cases rather than differentiating between organic and psychogenic causes.

### Cumulative risk factors equate to greater risk

Whilst there is much evidence correlating erectile dysfunction with specific risk factors, there is also evidence stating that the risk of having ED increases with the cumulative number of those risk factors in a similar way to cardiovascular disease. The higher the number of risk factors, the greater the overall risk of



subsequent atherosclerotic disease, be that cardiovascular disease or ED (Barrett-Connor et al. (2005), Feldman et al. 2000, Bacon et al. 2003 and O'Sullivan and Savage 2009). Vlachopoulos et al. (2005) found that 70% of erectile dysfunction sufferers had two or more risk factors, similar to findings of twenty years previous by Virag et al. (1985) who stated that in the presence of two or more risk factors, the penile blood pressure index was significantly lower, indicating a degree of impaired arterial blood flow and therefore ED. The Rancho-Bernardo study (Barrett-Connor et al. 2005) states that 1 in 5 men had 3 or more risk factors and were at a 2.2 fold increased risk of ED, when viewed with respect to Sattar et al.'s findings (2003) whereby they state that having 4 or 5 risk factors raises the risk of CAD by 3.7 times. It can be illustrated that these men are at a significantly higher risk of CVD and ED and will require more input from healthcare resources in the future. Sattar et al. (2003) therefore conclude that improving coronary artery risk factors in midlife may decrease ED risk. More recently Corona et al.(2010) agreed that sexual health declined as the number of concomitant risk factors increased in European men, as a function of age and because the burden of general and sexual health is greater. Conversely, Selvin et al. (2007) described the prevalence of ED to be particularly high amongst men with a singular cardiovascular risk factor. This finding seems to indicate that far more men would be at risk than other authors would suggest and highlights the need for healthcare professionals to be mindful that both multiple risk factors and singular risk factors could indicate underlying disease processes.

When considering the sharing of risk factors between cardiovascular disease and erectile dysfunction there is clearly a body of evidence that suggests similarities. Whilst each individual risk factor has evidence which supports this link, there are a minority of reports which dispute each. Increasing age is the only risk factor for which there is no evidence to contradict the link, however the balance of evidence does suggest that if the concept of risk factors is to be considered useful and predictive then they are equally as useful in both CVD and ED. Similarly, the critical number of cumulative risk factors has been debated and no clear conclusions reached. Hence it could be argued that one or multiple risk factors have evidence to correlate them with risk of erectile

dysfunction and if, as is about to be discussed, this is correct then many people could benefit from disclosing this identifier of risk.

### **Biological Mechanisms that link Erectile Dysfunction with Cardiovascular Disease.**

In the light of the body of evidence which highlights the shared risk factors for cardiovascular disease and erectile dysfunction, there has been an interest in whether the pathological mechanisms of disease are also shared.

Cardiovascular disease and the progressive nature of the disease have been extensively studied, but within the last fifteen years attention has turned to whether the processes which affect the coronary vessels could be applicable to the penile vasculature.

#### Established Cardiovascular Disease

The gold standard diagnostic test for the presence of cardiovascular disease is coronary angiography. This requires the injection of a radio-opaque isotope into the coronary arteries to look for obstructions to flow; unfortunately this test is unable to identify the earliest stage of cardiovascular disease, endothelial dysfunction, because this happens at a cellular level (Drexler 1997). However angiography does identify obstructions to flow caused by atherosclerotic plaque formation; a later stage of cardiovascular disease (Montorsi et al.2006). Soloman et al. (2002) used angiography to correlate coronary disease with erectile dysfunction. There was a correlation between the IIEF (a validated self-assessment tool used to diagnose ED) and the plaque burden (Gensini score); a proxy measure of disease severity (Soloman et al.2002). Therefore the increase in severity of ED correlated with an increase in plaque burden in coronary arteries.

Montorsi et al. (2003) assessed 300 consecutive patients with acute chest pain, a large study with more than double the sample size of other studies. Angiography showed single coronary vessel disease in 32.6%, double vessel disease in 29.3% and triple vessel disease in 38% of patients; their measure of disease was of the number of diseased vessels rather than the plaque burden and they concluded that the presence of ED indicated coronary disease but did

not indicate the number of vessels. When compared to Greenstein et al.'s findings (1997) these are not dissimilar 37.5%, 20% and 42.5% respectively. Montorsi et al.'s further work in 2006 (The COBRA trial) explored whether there was a link between erectile dysfunction and the clinical presentation of cardiovascular disease, acute coronary syndrome or chronic coronary syndrome. The authors suggested that despite a similar presentation, ED in the presence of acute coronary syndrome differs according to the extent of coronary disease. Patients with acute coronary syndrome were found to have a four-fold increase in the risk of having two or three coronary vessel involvement, indicating a greater degree of heart disease, as compared to one vessel (Montorsi et al.2006). In patients with established CVD, ED precedes CVD in the majority of cases by an average of 2-3 years (Montorsi et al.2006). Banks et al. (2013) reported on their prospective population based study of 95,038 men in Australia and their conclusions correlated with Montorsi et al.(2006). They concluded on statistically significant results between the severity of cardiovascular disease and the self-reported severity of erectile dysfunction. These findings suggest that in assessing patients for coronary artery disease, practitioners should make efforts to establish the existence and importantly the severity of erection problems in order to pre-emptively assess the degree of the disease, particularly in acute presentations of CVD.

The evidence linking erectile dysfunction with angiographic demonstration of atheromatous plaque formation and the degree of cardiovascular disease suggests that there are significant implications for men who are experiencing ED and CVD. Men are at greater risk of having more severe cardiovascular disease if they experience ED and the presence of ED can help provide clinical information prior to more invasive testing such as angiography.

### Endothelial Dysfunction

The endothelium is the inner lining of cells within blood vessels with a significant role in the control of vascular tone and homeostasis; endothelial cells produce and release nitric oxide which is a molecule vital for vaso-dilation (Drexler 1997 p.286). A dysfunctional endothelium is thought to produce less nitric oxide and be less receptive to that nitric oxide which is present in arterial

blood, resulting in a reduction in vaso-dilation and therefore decreased blood flow (Zeicher et al.1991). This reduction in ability to vaso-dilate is the main marker of endothelial dysfunction and is considered to be an early indicator of cardiovascular and other vasculogenic disorders, including hypertension (Drexler 1997 p. 287).

Between 1998 and 1999 many biological studies were published in scientific journals examining endothelial dysfunction and the role of nitric oxide in vasodilatation (Vatter et al.2007). The consensus of opinion was that a cellular defect in endothelial cells results in the decreased production or activity of nitric oxide causing endothelial dysfunction; this is indicated by impaired endothelium-dependent vaso-dilation. PDE5 inhibitors, Viagra and similar pharmacological agents, potentiate the effect of nitric oxide and thereby improve vaso-dilation particularly within the pudendal arteries; due to the high concentration of PDE5 receptors in the corpus cavernosum (Corbin and Francis 1999 p13729). Smoking decreases the amount of available nitric oxide (Ignarro et al.1987) therefore it is widely considered that smoking impairs the nitric oxide mediated endothelial vaso-dilation mechanism, resulting in a lack of vaso-dilation and early atherosclerotic processes (Ichiki et al.1996). This potentially explains the correlation between ED, hypertension and smoking.

Kaiser et al. (2004) conducted research to determine whether patients with vascular erectile dysfunction and no other clinical cardiovascular disease have structural and functional abnormalities of other vascular beds, indicating early stages of CVD or vascular disease. They concluded that patients with ED but no cardiovascular disease have a peripheral vascular defect in endothelium-dependent and independent vaso-dilation (endothelial dysfunction) which happens before the development of overt functional or structural systemic vascular disease. Crucially they concluded ED to be independent of other traditional cardiovascular risk factors (Kaiser et al.2004).

The role of declining nitric oxide in both the vascular and autonomic function studies is considered to be the common aetiological factor which explains the success of phosphodiesterase inhibitors; they potentiate the available nitric

oxide (Mullershausen et al.2003, Montorsi et al.2005, Stuckey et al.2007). Men with idiopathic ED have evidence of endothelial dysfunction in forearm resistance vessels, increased pulse pressure and impaired heart rate variability; all of these measures being used as proxy measures of endothelial dysfunction and the results extrapolated to the pudendal artery. This supports the theory that erectile dysfunction is a predictor of endothelial dysfunction and therefore a precursor of clinical cardiovascular disease.

Stuckey et al.'s (2007) and Montorsi et al.'s (2005) findings are therefore consistent with the "*small artery hypothesis*" put forward by Montorsi et al.(2005). The artery size hypothesis is a patho-physiologic mechanism proposed to address the association between CAD and ED (Montorsi et al.2005). Atherosclerosis is a systemic disease process which should thereby affect all major vascular beds, however symptoms in various sites often appear independently; larger vessels are able to cope with a larger plaque load than smaller ones. Because of its smaller diameter the pudendal artery will be severely narrowed and symptomatic prior to the coronary arteries thereby suggesting a mechanism for the frequent co-existence of sexual and anginal symptoms.

The links between cardiovascular disease and erectile dysfunction have been identified. Not only is ED commonly experienced by men with CVD but also there are many shared risk factors and pathological changes which it would appear cause both CVD and organic ED (when the cause is vasculogenic). When these cellular changes are considered as early markers of CVD then there may be an indication that ED would be noted before the typical presentation of CVD- chest pain.

#### As a marker of silent cardiovascular disease or a predictor of future cardiovascular disease

Gazzuruso et al. (2004) investigated whether ED was associated with asymptomatic coronary artery disease in men with type two diabetes; a population known to have a high incidence of silent cardiovascular disease. The disease processes of diabetes often result in nerve damage and as a

result an atypical clinical expression of CVD, a lack of chest pain or “silent” CVD (Meena et al.2009). The prevalence of ED was significantly higher in those with silent cardiovascular disease than those without (33.8% vs. 4.7%). The authors argued that clinicians assessing patients for risk of cardiovascular disease, especially in the presence of diabetes, should ask about erectile dysfunction as a clear indicator of risk because chest pain and more traditional expressions of cardiac disease in this group of patients may not be typically experienced (Meena et al.2009). Multiple logistic regression analyses showed that ED, apolipoprotein (a), polymorphism, smoking, micro-albuminuria, HDL and LDL were significantly associated with silent CVD: among these risk factors ED appeared to be the most efficient predictor of silent CVD, which would place it as the primary indicator for vascular disease in diabetic patients (Gazzuruso et al.2004).

Vlachopolous et al. (2005) similarly explored “*silent*” cardiovascular disease, but not specifically in men with diabetes. Angiography was performed on ten patients (nine men had positive exercise test results and one had an acute myocardial infarction); one patient had three vessel disease, two patients had two vessel disease and six patients had single vessel disease. The results appear to be at odds with Greenstein et al. (1997) and Montorsi et al. (2003) who showed an increasing number of vessels with increasing erectile dysfunction; however they did demonstrate the existence of CVD in all the men in the study. The authors concluded that 19% of patients with non-hormonal, non-psychogenic ED have angiographically documented silent coronary artery disease, this is less than the 27% described by Hatzichristou et al.(2002), but does remain one in five men, a significant number in the general population.

Soloman et al. (2002) established that of men with erectile dysfunction 58% (34 men) reported having experienced ED before their diagnosis of CVD. In Montorsi et al.’s sample (2003) of patients with ED, the symptoms were noted prior to cardiac symptoms in 67% of patients, with a mean interval time of 38.8 months. This is 9% higher than the findings of Soloman et al. (2002); however this difference may be due to the different populations being studied. Soloman et al.(2002) were exploring the coronary vessels of people considered fit

enough for a day case procedure, probably with relatively stable, chronic disease; as opposed to Montorsi et al.(2003) who were studying people with acute chest pain, possibly experiencing a myocardial infarction. This may indicate that ED is a more specific marker of early cardiovascular disease which may be susceptible to acute coronary thrombus or plaque rupture (Jousilahti et al.1998). This finding is pivotal from the perspective of identifying erectile dysfunction as a predictor or harbinger of early coronary artery disease, which may potentially be managed with other risk reducing measures; providing a window of opportunity for risk reduction which may prevent the development of critical CVD (Montorsi et al.2003, Vlachopoulos et al.2005).

Ponholzer et al. (2005) were similarly looking to evaluate the role of erectile dysfunction as a predictor for cardiovascular disease and stroke. They were not studying a population of men with specific diseases and were therefore looking at predictors within a general population. In the CVD risk cohort, men with moderate to severe ED had a 65% increased relative risk for developing CVD within the next ten years, compared to those without ED. The relative risk varied with age; 13.9% for those aged 30-39, 42.2% aged 40-49, 27.7% aged 50-59 and 27.1% aged 60-69 years, in contrast to Speel et al.'s (2003) findings which identified the 50-59 age group as having a higher risk profile. Younger age groups are more likely to seek medical advice for sexual dysfunction and therefore if erectile dysfunction is more of a sensitive marker in these groups then healthcare professionals should be using a disclosure to prompt a broader risk assessment and risk reducing interventions (McCabe and Matic 2008).

Bohm's et al's (2010) outcome study found that erectile dysfunction was predictive of all-cause mortality. The authors concluded that ED is a potent predictor of all cause death and the composite of cardiovascular death, myocardial infarction, stroke and heart failure in men with cardiovascular disease. They advocate establishing early in the patient's trajectory whether they suffer from ED, because this may be an indicator of significant or accelerated disease processes in the future. Bohm et al.'s (2010) findings were corroborated with a systematic review and meta-analysis undertaken by

Vlachopoulos et al.(2013), who reviewed fourteen studies with a total of 92,757 participants. They found ED to be associated with an increased risk of cardiovascular events and all-cause mortality, relative risk being higher in younger age groups, particularly in those with an intermediate level of risk of cardiac disease (Vlachopoulos et al.2013).

Thompson et al.(2005), Bohm et al.(2010) and Chew et al.(2010) refer to the multiple articles that provide evidence for the pharmacological and behavioural interventions associated with reducing cardiovascular risk and state that the identification of a predictive symptom would allow for even earlier intervention, possibly further reducing morbidity and mortality. They considered this specifically useful in patients who do not regularly attend for medical assessments or who are inadequately assessed or treated for cardiovascular disease risk factors.

In the 1<sup>st</sup> Princeton consensus statement (DeBusk 2000) the experts stated that erectile dysfunction should act as a marker for early cardiovascular disease, in advance of much of the supporting evidence (Jonas 2001 pS3). By 2006 the same panel were categorical in their statements, based on their review of the expanding evidence base. As a result of this meeting they agreed that

*“erectile dysfunction is a warning sign of vascular disease with the practical recommendation that a man with ED and no cardiovascular symptoms is a cardiac or vascular patient until proven otherwise.”*(Jackson 2006 p.28)

The contributors to the Princeton consensus statement advised that ED, in otherwise asymptomatic men, is a marker of silent vascular disease and represents an important means of identifying those at risk of vascular disease. ED is an early symptom or harbinger of cardiovascular disease, a potential warning of silent cardiovascular disease. These guidelines were incorporated into Hatzichristou et al.'s (2002) practice guidelines which suggest that baseline diagnostic evaluation for erectile dysfunction can identify the



underlying pathological condition or associated risk factors in 80% of patients. Such screening may diagnose reversible causes and also unmask medical conditions that manifest with ED as the first symptom.

In summary, it appears that ED and cardiovascular disease share risk factors, an underlying pathology and that ED may precede a cardiovascular event by as much as 5 years (Hodges et al.2007). Men with ED should be specifically targeted for CVD preventative strategies in terms of lifestyle changes and appropriate pharmacological treatments. Erectile dysfunction may indicate more severe or widespread coronary disease patterns and indicate poorer long term outcomes for men who experience ED. Therefore ED is a significant clinical symptom to be asked about, especially in men aged 40-59 years of age, but it would appear that ED may not be as easy to enquire about as cholesterol or blood pressure; as prevalence reporting may have alluded to. Erectile dysfunction, whether the cause be organic or psychogenic can have a significant impact on the psychological well-being of a man who experiences it, which contributes to the imperative to ask (Tiefer and Schuetz-Mueller 1995).

This literature has not only discussed the research which demonstrates a link between cardiovascular disease and ED, but in doing so has identified several aspects relating to these topic which have yet to be studied. The lack of a clear definition has been highlighted and a confusion in relation to assessment tools has been demonstrated however, the confusion for men and healthcare professionals as to what ED is remains, but there is no evidence which has sought to clarify why this confusion exists, therefore there is a gap in the literature which explores peoples' understanding of the problem.

## **Living with Erectile Dysfunction**

Although there is evidence to highlight the prevalence of erectile dysfunction, particularly within populations of men who have known cardiovascular disease and to support the use of ED as a marker of cardiovascular risk, there is a sense that the subject is hidden. Many of the authors who reported prevalence rates comment on the problems of accuracy because of the hidden nature of the issue. The literature which focuses on the experience of living with erectile dysfunction will now be explored in order to gain some insight in to why this topic may not be willingly and openly discussed. Much of the available literature focuses on the psychological impact of having ED, seeking help and having conversations about the subject, motivators for seeking treatment, the effect that ED can have on a relationship and how society can influence all these aspects. These issues are closely correlated with the research aims of exploring thoughts and conversations about ED and whilst none of the published literature which focuses on disclosing or living with ED explicitly considers it as a marker of cardiovascular risk, the findings in the published literature about the impact of having ED will presumably resonate with the men who have ED and CVD.

### **Psychological impact of ED**

Potts et al. (2004) were the only authors to find positive attitudes towards erectile dysfunction from men and the partners of men. They reported that not all the men felt an affinity with the men portrayed in media campaigns of a man greatly relieved and happy when he found a cure for ED. Potts' team spoke to men who believed that erectile dysfunction was not a dysfunction, but a natural response to aging and that the use of Viagra was a quick fix which they did not need; they had discovered other ways to interact intimately. Although some of the men in Potts et al's (2004) study portrayed a positive sense, most of the men interviewed had less positive thoughts and a sense of resignation to the issue.

Accepting erectile dysfunction as a normal and inevitable part of aging is a common theme in the literature that focuses on attitudes to ED. This acceptance seemingly causes men to feel that resources should be focused

on younger men and older men with ED are sympathetic to younger men; feeling them to be much more worthy of treatment (Low et al.2002, Pontin et al.2002). Resignation due to increasing age is a commonly identified attitude to ED discussed within the existing literature, but the most commonly discussed attitude towards ED is a negative attitude because of a perception of one's self at not being able to achieve an erection.

In McCabe and Matic's study (2008) men with ED were found to have poorer scores pertaining to self-esteem, quality of life and sexual satisfaction than their partners. Based on this finding the authors concluded that men with ED felt that having ED was a negative experience and that this feeling was more significant for the men than their partners. The topic of treatment failure was also identified, Miner and Kuritzky (2007) make reference to the interventional trials which have proven that restoration of sexual function improves quality of life for both partners and thereby identifies the wider implications of erectile dysfunction such as treatment failure and changes in the sense of self; an important aspect which must not be overlooked particularly if considering erectile dysfunction from a purely medical perspective.

Low et al. (2002 p.443-444) reported that men felt that erectile dysfunction was "*abnormal*". They reported that participants felt "*useless*", "*hopeless*" and "*less of a man*", but were viewed with "*sympathy and pity*" by most women and "*despised*" by others; they concluded that men felt isolated, a theme which is echoed by Pontin et al.(2002 p264) who identified themes of "*loss*" and "*being alone*". Fisher et al.(1) (2005) report that common responses to ED were denial, depression and anger. Similar concepts were identified by Beltran and Giami (2009 p.254) who concluded that men perceive their condition subjectively, considering the experience to be unique to themselves and as a result internalise most of their thoughts and coping strategies. Tomlinson and Wright (2004 p.1040) reported similar negative feelings as a result of erectile dysfunction, qualifying the feelings as "*emasculatation*". This is particularly important when viewed in relation to the correlation with depression and Simmonds et al.(2013) commented on the sense of emasculatation associated with experiencing CVD, therefore men may be feeling this because of both ED and CVD.

Men report feelings of embarrassment and humiliation as reasons why they have not discussed erectile dysfunction with their partners and healthcare professionals (Low et al.2002, Pontin et al.2002). The subject being considered “*taboo*” and a “*waste of the professional’s time*” were cited in Fisher et al.’s research (1 & 2 2005). The term embarrassment is not explored in any particular depth in any articles, an assumption of a common understanding of what this meant and why it did not require further analysis seems to have been made by the authors (Low et al.2002, Pontin et al.2002, Fisher et al.2005). It becomes obvious that ED and talking about it is more than simply a clinical marker of risk.

Men with erectile dysfunction expressed concern and worry about the cause of their ED, which was often what had prompted them to seek medical advice (Fisher et al.(2) (2005). Some men knew that particular medical conditions may precipitate ED, however they were unable to state which conditions and how they may have had such an effect (Pontin et al.2002). Despite concern over medical causes, men were unclear as to the causes of erectile dysfunction and felt that it was primarily psycho-social causes, emphasising a concern with psychogenic ED and reflecting previous theories of purely psychological causes (Low et al.2002). The CHARMS study identified that the most likely professional that patients would speak to about sexual issues would be a psychologist (Byrne et al.2013) and it was acknowledged by these authors that very few patients have access to such resources, describing a wide variation in access even within one country. If men consider the causes to be psychological and social the question remains as to why their initial port of call for assistance is a medical practitioner? This may be due to a lack of access to psychology services; however their use of the general practitioner to seek treatment may be an ideal opportunity to access further medical assessment and treatment for related risk factors.

Men believe that disclosing ED requires a psychological strength and courage and that having found this they should be seen quickly before they become too accepting of or apathetic about their condition (Fisher et al.(1) (2005). Sookdeb (2007) documented the waiting times of men from first experiencing erectile dysfunction to having an appointment to see a specialist, this varied from one

month to ten years. Most men waited in excess of six months before disclosing their condition because of the emotional impact described earlier (ibid). When these waiting times are viewed in conjunction with emotion laden statements about miscommunication, it can be seen that erectile dysfunction can have a significant effect on couples and that the longer the time from onset to disclosure, the greater the potential for more associated psychological problems to manifest. Regardless of the length of time that men had been experiencing ED they seemed to be unsure as to the temporality or permanency of their erectile dysfunction (Pontin et al.2002), conversely men considered ED to be a natural part of aging, something they were accepting of (Low et al.2002, Pontin et al.2002, Fisher et al.(1), Fisher et al.(2). Temporality seems juxtaposed with acceptance of aging; however this was not explored in depth by any of the authors.

In light of these predominantly negative feelings and emotions which are affiliated with ED it is not surprising that several authors document poor disclosure rates, Kubin et al.(2003) state that 70% of men with ED do not seek help. Byrne et al. (2013) and Granger et al.(2002) found similar findings of 66%. Negative thoughts have resulted in poor disclosure rates and inaccurate prevalence rates and therefore may prevent ED being a useable risk factor for CVD; this highlights another significant gap in the literature, because no one has ever sought to establish whether ED could be used as a prompt for cardiovascular risk assessment.

### **Seeking help and disclosing erectile dysfunction**

Pertulla (1999) found that only 22% of patients had documentation of discussions regarding erectile dysfunction in their medical notes, which may be a realistic indication of how often such conversations are undertaken. Hakim et al. (2002) conducted data collection after the worldwide launch of Viagra; this is thought to have contributed to a greater freedom to talk about ED (Fox and Ward 2008). Eighty three per cent of the respondents had primary care physicians and of those 23% had been screened for erectile dysfunction. Of those screened, 58% had initiated discussion with their physician, which is nearly twice the rate of help seeking behaviour documented by Holden et al.

(2005), of 30%. The patient taking the initiative to discuss the subject was further explored by Kitai et al.(2002) who concluded that ED is reported rarely to GP's and that their anonymous questionnaire on the subject increased awareness and in turn increased the number of disclosures, hence they may have over-estimated the true rates. Haro et al.'s pan-European prospective, observational study (2006) explored treatment seeking behaviour in 8,186 men recruited in clinics in nine European countries. The authors concluded that the unmet need for treatment of ED is high, 66% of patients had experienced symptoms for one year or longer when they began looking for treatment and that increased severity of ED seems to be related to treatment seeking motivation.

It is worthy of note that none of the studies clarified whether they had captured the thoughts or experiences of men who had not disclosed ED to any healthcare professionals. It may have been that the experiences of these men were captured but they were not identified as such and therefore this leaves a significant gap in the literature, what are the thoughts and experiences of men who have never disclosed their ED? Why have they chosen not to seek help?

Holden et al. (2005) conducted telephone interviews to assess reproductive health, 90% of the men surveyed had visited a doctor in the previous year; therefore in principle most of these men had an opportunity to access help and information regarding erectile function. Only 30% of men who experienced ED had sought medical help, which is less than the previous 48% documented by Hood and Robertson in 2004 and 58% by Rosen et al.in 2004, less than 50% by Tan et al.(2004) and 38% by Corona et al.(2010). In the younger age groups, help seeking behaviours reached 50% declining with increasing age to 20%. The increased willingness of younger men to seek help may be encouraging when viewed in light of Chew et al.'s (2010) findings whereby ED may be a more significant marker of CAD risk in younger men.

Reasons for not seeking medical help have been documented as including the belief that ED was caused by other medications or disorders, relationship difficulties and inability to discuss sexual problems. Erectile dysfunction has, predominantly, a negative impact on the lives of the men it affects and this is

underpinned by a lack of knowledge, embarrassment, depression and lack of motivation. Therefore ED is possibly more than a simple medical risk factor for cardiovascular disease and maybe it is too simplistic to be able to consider it as such.

### Why seek help?

The drivers cited by men for disclosing ED are attached to the hope for a resolution to their ED, assisted by the availability of a palatable treatment. They also felt a need to sexually satisfy their partner (Potts et al.2004, Sookdeb 2007), drivers which were reiterated in Low et al.'s findings (2002). Some men have concerns regarding the cause of the ED and therefore seek reassurance that there are no related medical conditions associated with the onset (Pontin et al.2002), however the most commonly cited reason for disclosure of erectile dysfunction is as a response to being directly asked about it by a healthcare professional (Low et al.2002, Pontin et al.2002, Granger et al.2002, Fisher et al.(2) (2005). None of those asked reported that they would object to being asked about erectile dysfunction by a healthcare professional (Granger et al.2002), this again may be a reflection of the fact that they are happy to talk about the subject and take part in the studies so they would not be offended by the subject because, as was noted earlier the views of men who had not disclosed ED were not specifically sought.

The impact that erectile dysfunction has on a relationship is also discussed frequently in the literature. The men in Low et al.'s study (2002 p.443) reported a fear of their partners having extra-marital affairs because life without sex had become "*meaningless*". This fear of marital breakdown is clearly identified by Pontin et al.(2002), where there is exploration of the further breakdown in communication, which leads to greater misunderstandings and feelings from both partners that they no longer find each other attractive. Fisher et al.(1) (2005 p.68) describes "*ironic miscommunication*" whereby men perceive support from their partner as rejection and humiliation. Tomlinson and Wright (2004) describe the impact of a loss of confidence on the relationship as causing isolation and despondency. All the papers portray the effect of erectile dysfunction in a negative way and Potts et al.(2004) recognise the negative

effects that ED can have on a relationship but they also report on the rarer positive responses.

### Partners

Gott and Hinchliff (2003) identified that men were more likely to seek help for erectile dysfunction if they were in a relationship, the presence of a partner being the most commonly cited reason to speak to a healthcare professional about treatment, which was a finding supported by Tan et al.(2004).

Fisher et al (1 2005 p.76) collected data from married couples, but the data was collected separately and not linked into marital dyads during the data analysis, which makes their finding that there was

*“convergence in valuing their sexual relationships and indication that taking action to address ED is often seen as having a more positive effect than taking no action to”.*

all the more remarkable. This convergence of findings may provide an indication that this problem is not just an issue for the man but of equal concern for the partner. In neither of Fisher’s studies (2005 parts I and II) was there an identification of partners as anything other than being women, in fact they were described as “*women*” in both studies. Male partners have not been identified or discussed in any of these papers and this would certainly be a void in the evidence base.

In conclusion the impact of living with erectile dysfunction has been explored from differing perspectives however it has become apparent that there are gaps within this literature because the views and experiences of men who have not disclosed ED and partners who are not wives have either not been sought or have not been identified as being from these groups of people. This body of evidence has identified that experiencing ED is primarily considered as a negative and embarrassing experience but there has been no in depth research which has sought to find out why people have these perceptions.



## **Social attitudes and influences**

Discussion of sex and sexual dysfunction from psychological and organic origins cannot be explored without placing the discussion into the context of the society in which the men are living. Discussion of sex in most societies is unacceptable to a degree and has long been “*hidden*” (Lawler 1991). Freud was the first author to write a socially acceptable text about sex and sexual dysfunction. He advocated psychoanalysis to address unresolved developmental issues. His text and therapies were widely acknowledged in Victorian society and appeared to some authors to change the societal perception of discussing and treating sexual problems (McLaren 2007). Subsequently, books were written which influenced societies views on successful sex, the most famous writers were Freud, Kinsey, Masters and Johnson and Hite (Brown and Fee 2003 p.894). Kinsey (1948) conducted what he described as “*research*” with the aim of proving that there was no such thing as sexual dysfunction, all sexual behaviours could be considered normal. It is thought by some that Kinsey’s extensive writings and place in popular culture may have contributed to a change in moral codes and behaviour of western society, allowing a far more permissive and accepting society (Szreter 1996), certainly his literature did make its way into popular culture and was recognised as texts which were acknowledged by general society.

Masters and Johnson built on Kinsey’s research and continued to push the boundaries of sexual research and therefore social acceptability (Siraj 2010). At the time there was an air of optimism about their work, it was hoped that sexual dysfunction would be eradicated and thereby halt the rising divorce rate in America (Szreter 1996). They made recommendations on physical aspects of sexual intercourse rather than, as was the fashion at the time, focusing on communication and emotions within couples (not the disclosure of sexual dysfunction). Their publication “*Human Sexual Response*” (Masters and Johnson 1966), claimed to be the first scientific study of the mechanics of sexual intercourse. They used methods similar to that of Kinsey: observation and participation, but took biological measurements during sex acts in an attempt to address societal concerns. In undertaking such measurements they

were able to describe their work in scientific terms and thereby fend off allegations of inappropriate motivations (McLaren 2007 p.221). They purposefully used terms which sounded like medical conditions; erectile dysfunction rather than impotence and female sexual arousal disorder rather than frigidity, which provided distance between their work and that of the psychoanalysts (McLaren 2007). Their writings were described as having reached the populist culture and described as a “*best seller*” which was translated into several languages. As an indication of the social acceptance which they achieved, they featured on the cover of the Time magazine (McLaren 2007).

During the 1970s sexual therapy continued to gain in popularity and the amount of literature discussing this intervention expanded dramatically, often citing Masters and Johnson and Kinsey’s work (O’Donohue and Swingen 1999). Shere Hite felt that problems with erections stemmed from a man’s perception of competition with other men, rather than a desire to pleasure women (McLaren 2007 p.226). In her work “The Hite Report on Men and Male Sexuality”, she postulates that elements of the rising power of women within society added to men’s perceptions of a pressure to perform (Hite 1981).

The 1980s saw a greater understanding of the underlying pathology of erectile dysfunction and the diagnostic testing for the condition, but this was also the time when a pharmacological treatment was being sought. Virag (1982) wrote about his accidental injection of a muscle relaxant into a patient’s penis, which resulted in an erection. A year later, Giles Brindley experimented on himself by injecting a similar muscle relaxant. To prove the effectiveness of this pharmacological agent, he displayed its effects on his own penis at the 1983 meeting of the American Urology Association in Las Vegas (McLaren 2007 p.237), although this caused some surprise within the conference hall this may have been an indication of a more accepting medical society, if not society in general. As a result, authors pondered whether the process of erection was in any way connected to the psychological self, as had clearly been the previous belief; if a man can demonstrate an erection in a conference centre utilising only pharmacological agents, presuming this was not an environment in which

he would normally have experienced an erection (McLaren 2007). This discussion makes clear that the society within which a person lives can be significantly influenced by the writings of individuals that they consider to be experts within a specific area, this demonstrates how such writings can impact on the general populations understanding of a condition (such as ED) and therefore it is imperative that the time and context within which a person lives should be taken into account when asking about their rationalisations. None of the published research which focuses on the disclosure of ED has used a technique which allows the participants to discuss their understanding or rationalisation of the situation in any depth, often due to a questionnaire design. Hence there is a paucity of published research which explores why people believe what they believe about ED and its disclosure.

### **The influence of Viagra**

In 1998 Viagra was launched as the first tablet which could overcome "*impotence*", previous treatments for erectile dysfunction had often been considered by many men to be unpalatable or "*not worth the effort*" (Potts et al.2004 p490). The acceptance and use of this new treatment was rapid, within the first three months after licensing sales reached 400 million dollars in the United States of America (Keith 2000 p.148). Within two years of its United States launch, Viagra was licensed in fifty countries worldwide (Keith 2000 p.149). Pfizer, the pharmaceutical company which developed and produced Viagra, undertook a worldwide multi-media advertising campaign aimed at men and their partners; the focus being the convenience of taking a tablet and returning to sexual activities (Potts et al.2004). In the ten years following the licensing of Viagra in the UK, 37 million PDE5 inhibitors were prescribed (Nehra 2009). More than 30 million men in 120 countries have been prescribed Viagra; in addition there are also those who have acquired tablets without a prescription (Jackson 2006). Viagra has been held up as an example of how the medical profession influence the behaviour of a population and as a result some authors have suggested that Viagra has "medicalised" erectile dysfunction (Fox and Ward 2006).

During the last twenty five years, the body of evidence regarding erectile dysfunction and its treatment has grown exponentially and the credibility within medical discourse of the problem has dramatically improved with the advent of pharmacological treatment (McCabe and Matic 2008 p.51). The availability of treatment in tablet form and the worldwide advertising campaign has been identified as the impetus for changing the social perception of discussing erectile dysfunction (McCabe and Matic 2008). Despite the perception that PDE5 inhibitors would help couples to maintain a close and loving relationship, the drug is increasingly being cited in divorce cases (Smith et al.2010). It has been suggested that men are able to resume an active sex life and this return to functionality has been the cause of extra-marital activities. The rates of sexually transmitted diseases in retirement communities of the United States of America are rising and professionals such as divorce lawyers, general practitioners and marriage counsellors are increasingly expressing concern at this phenomenon (Spearman and Bolden 2005, cited Gibson 2008 p.10). Sexual attitudes would appear, for the first time to be linked to sexual capability rather than religion or issues of morality (McLaren 2007).

Viagra and other PDE5 inhibitors, remain “prescription only medications” in the United Kingdom (Joint Formulary Committee 2012 p.538), although legal means of accessing medications without seeing a doctor are now available; for example specially trained pharmacists and nurses can clinically assess men and provide treatment for the condition (Fox and Ward 2008). Prior to these ways of receiving treatment without the intervention of a medical practitioner, a significant illicit trade in PDE5 inhibitors had evolved (Smith and Romanelli 2005). Illicit trading has been greatly facilitated by the internet, allowing people to access treatment from their own homes without adequate assessment or medical supervision. The main benefit of seeking treatment this way would seem to be the anonymity it affords (Fox and Ward 2006, Schnetzler et al.2010). The combination of an “*acceptable*” treatment and a way of anonymously accessing it has apparently changed the landscape surrounding erectile dysfunction, bringing the condition out of the dark and into a wider medical and social arena (Fox and Ward 2006 p.461). However it could be

argued that if men feel the need to remain anonymous then the social acceptability of the topic has not changed that much.

Viagra is believed to be the most counterfeited pharmacological agent worldwide (Loe 2008 p.16). Despite Fox and Ward's (2006) assertion that society is more open in talking about erectile dysfunction, this illegal trade would serve to illustrate that there is still significant embarrassment associated with the condition, yet successful sexual functioning is considered important enough for individuals to risk taking illicit and potentially harmful substances (Korkes et al.2008, Olivero 2004). Having such a global impact and a reputation for successful treatment has, some would say inevitably, resulted in the misuse of PDE5 inhibitors by men who do not suffer from erectile dysfunction (Potts et al.2004). There is now a young generation of men who have experimented with the drug and have developed a psychological dependency which leaves them unable to acknowledge the emotional and psychological aspects of a sexual relationship (Marshall 2006). The long term use of these medications is not known and it is hypothesised that continued and sustained use may be linked to infertility (Glenn et al.2009). For those who utilise PDE5 inhibitors when there is no clinical need, this could have a significant impact. Men who are 40 years and younger account for at least 8% of all sildenafil prescriptions according to Pfizer (Olivero 2004), there is therefore concern amongst social observers about the numbers of men acquiring the tablets illicitly.

Social observers comment that sildenafil has threatened social "*norms*" by elevating the standards of "*normal sex*" to the level whereby "*normal*" could only be achieved by pharmacological or surgical intervention (Peters et al.2007). They likened it to the previously "*direct to consumer*" marketed drug Prozac. Both were considered to endorse social stereotypes, sildenafil to enhance male virility and Prozac to assist in the maintenance of an even mood and air of serenity (Loe 2008). These two drugs are considered "*quality of life enhancers*" and not life savers, from which pharmaceutical companies were making money from the social ideals and insecurities of the general population (Loe 2008). In an attempt to truncate social debate which sildenafil appeared

to have triggered, a delegation from Pfizer was sent to the Vatican, as a result of this visit sildenafil received the blessing of the Roman Catholic Church on the basis of its potential for improving family relations (Olivero 2004). This religious endorsement was thought to be crucial in maintaining the success of Viagra, because the church promoted active sex lives for followers who were within marital relationships. Subsequent to the licensing of Viagra, the British Government set prescribing limits of four Viagra tablets per man, per month (Chisholm 1999). This generated a debate about whether the sex lives of the British public should be governed by Parliament and if this was to be the case, how was the frequency of sexual intercourse to be decided upon. From the government to religious institutions, all aspects of society can provide examples of some discourse with regards to sexual relationships and the complexity of such could provide a thesis in itself, but what is apparent is that sex is not simply an intimate meeting of two people; the implications are far reaching, especially when viewed from a population perspective.

## **Media**

The success of PDE5 inhibitors has been in part due to the use of the worldwide media, the internet and television advertising have been credited with facilitating the widespread awareness of Viagra and similar medication (Potts et al.2004, Tomlinson and Wright 2004, Fisher et al.2005 1 & 2). As an indication of how well known Viagra has become, some men are not aware of the alternatives (Low et al.2002, Fisher et al. (1 & 2 2005). They discuss how influential the advertising campaigns have been in promoting the sense of failure associated with erectile dysfunction, which Viagra producers claim to be able to alleviate by using their product. There is however a recognition by Potts et al.(2004) that these advertising campaigns raised the public awareness of the problem and as a result prompted a more open discussion and debate. Media coverage and accessibility of PDE5 inhibitors has, according to some healthcare professionals, transformed a generation of people who would not previously discuss sex, let alone sexual failings, into a generation who are comfortable to discuss their problems openly with friends, partners and healthcare professionals alike (Matic and McCabe 2008). With this in mind it is feasible to believe that erectile dysfunction could be used by public health

physicians to alert men to their risk of cardiovascular disease, this research question has not been addressed in the published literature.

Potts et al. (2004) describe how the positive advertising of these products has led many men to have a false hope of a fail proof treatment, seeming to explain any exacerbated sense of disappointment. Similarly the trade from illicit sources would seem to contradict the argument of a changed social acceptance of the subject, it is considered that the embarrassment felt around the subject is what is keeping the illicit trade active (Keith 2000).

### **Embodiment**

The media and the way it portrays members of society not only illustrates societal “ideals” of particular groups of people but it also influences the audience to believe that the image portrayed is something to aspire to (McLaren 2007). Having established that the context and society within which a man lives has a significant impact on how they contemplate issues relating to sex and sexual dysfunction, the concept of embodiment appears to be relevant. Within this concept the body is acted upon by forces or influences, such as the media, which cause the body to behave in a particular way, which is considered socially acceptable (Allen 2004). The messages that a society gives to a male member about how to behave is a “*taken for granted*” set of behaviours and beliefs and within Western society this is often “*hegemonic masculinity*” (Powell and Biggs 2003). Hegemonic masculinity is concerned with typically male features such as high muscle definition, the ability to achieve an erection or body hair growth, which are used by a person to identify themselves as a man (Mishkind et al.1986). Lack of these typical features can cause a negative effect on self-esteem and sense of self (ibid). The embodiment of sexuality and aging have singularly and in combination been studied, Marshall and Katz (2002) explored how, for men, masculinity could be grounded in the ability to perform sexually and decline in this ability, particularly with advancing age, is associated with feelings of emasculation. They describe impotence as “*a disease of the young and a condition of the old*” (Marshall and Katz 2002 p.74), identifying the influence of society and medicine causing men to believe that ED is a predetermined factor of growing

old, but they then discuss how this is not accepted in the same way as other physical symptoms of aging such as failing eye sight.

*“no malfunction of the human apparatus, not even cancer or heart disease, can be more painful to the male ego or catastrophic to the male psyche than sexual impotence”* (Marshall and Katz 2002 p.68)

The embodiment of an identity, such as being a male, incorporates both the objective (physical) body and the subjective body; the body as an individual experiences it, thus embodiment is the way societal rules and discourses are internalised within the body and then how the behaviour of the body is impacted upon as a result (Lawler 1991). History, culture, education, political influence and life experience can all impact on the process of embodiment and the study of this concept has been widely theorised by authors such as Foucault (1973), Goffman (1956), and Sartre (1943). The influence of these powerful external forces becomes internalised during a life time and often operates unconsciously (Levy 2009). The influence of the medical profession in changing societal views of particular bodily functions is well documented and the process of medicalisation often impacts on societal beliefs about what is a legitimate medical condition, for example the treatment of *“low mood”* with Prozac or the *“encouragement of promiscuity”* with the contraceptive pill; both were considered life style enhancement when first introduced but with the passage of time they have become considered by society as medical interventions, owned by the medical profession (Fox and Ward 2006).

A sense of embodiment, whilst individual, can have similarities with others; particularly within cultures due to a shared understanding which may encompass religious beliefs, political influences, legal imperatives or linguistic usage. Therefore in studying problems of *“the body”* the need to contextualise the *“the body”* is key, it cannot be considered a singular entity but rather something with intrapersonal, interpersonal, philosophical, social, sexual, biological, historical and existential components (Lawler 1991 p. 59). There is no published research which explores the concept of embodiment in relation to cardiovascular disease and erectile dysfunction. There is some research which has discussed the concept of embodiment in relation to ED or cardiovascular



disease; however there is none which looks at both issues within the same project.

Therefore within a society in which ED is ill defined for both men and healthcare professionals, there is difficulty in knowing what it is and how to treat it and whether it should be "*treated*". There are both pathological and psychological causes which make defining ED more difficult. ED can be used as a risk factor for many conditions but due to the lack of understanding and embarrassment it can be difficult for men to talk about. Society would appear to be more accepting of discussion now than it has ever been and the media has been used to facilitate this, however issues which affect the sense of self are not simple to explore and require a method which will allow the researcher to take into account all the influences which have played a part in forming the participants' embodied sense of self.

## **Current Clinical Context**

Thus far, evidence has been explored to explain the link between cardiovascular disease and erectile dysfunction and how having erectile dysfunction can impact on a man who is affected. In order to consider the aims and potential outcomes of this project, the third element which requires understanding is the current clinical context and therefore the understandings and views of healthcare professionals to whom a disclosure of erectile dysfunction may occur. Findings from the literature support the approach to data collection taken within this thesis and the use of IPA and a phenomenological approach by considering the experience of all participants within such scenarios, men and healthcare professionals.

It is clear that men often do not know what ED is and who to disclose it to in order to receive treatment; it would appear from the literature that this may also be the case with healthcare professionals. The following discussion will illustrate aspects of current thinking in relation to healthcare professional ownership and the considerations by some authors that this ownership has been a driver for the medicalisation of ED. By examining the literature which focuses on the thoughts of healthcare professionals so understandings of referral behaviour and rationalisation of the barriers to having difficult conversations, such as asking about ED, will be discussed. A lack of literature specifically exploring healthcare professionals undertaking conversations about ED has necessitated a broader reach for this literature review, hence the exploration of potentially transferrable literature which focuses on other difficult discussions.

### **Professional ownership**

Knowing there are both biological and psychogenic causes for erectile dysfunction provides some understanding as to why professional ownership of this condition is not easily defined. Prior to the 19<sup>th</sup> century, in Western Europe, erectile dysfunction was considered the result of curse or witchcraft, but with the professionalization of medicine came tentative steps to include the condition within a medical remit, but where within that remit? Psychiatry was often regarded as the moral arm of medicine, due to the focus of this speciality

on the correction of socially “*deviant behaviours*” and altering the function of the brain (Szreter 1996 p.137). In the first half of the 19<sup>th</sup> century people were committed to mental institutions, under the care of psychiatrists and treatment regimens for “*inappropriate sexual behaviour*” included hormonal treatments and castration (Szreter 1996 p.140). Due to the hidden nature of erectile dysfunction it was rare for a psychiatrist to be approached to treat this particular sexual problem and therefore no medical speciality took ownership. The influence of Freud’s (a medically trained neurologist) and Kinsey’s (a biologist with no medical training) theories and practices is evident in both psychiatry and clinical psychological practice today (Moynihan et al.2002). Subsequent to the work of Giles Brindley, a physiologist and academic, with his medically induced erection (papaverine- a smooth muscle relaxant) there was an acknowledgement that there may be an underlying pathology, particularly related to blood flow which caused impotence and the focus of study shifted from psychological causes to pathological or organic causes (Andersson 2001).

Whilst many authors have been quick to associate the medicalisation of sexual dysfunction and specifically erectile dysfunction with the introduction of Viagra, it is clear that this change started in the decade prior to the Viagra launch (CEC 1999, Moynihan 2005). However, there is a clear delineation between the era when such dysfunctions were believed to stem predominantly from psychogenic or behavioural causes (the era when pathological causes were the primary focus of treatment) and the most recent era when it has been acknowledged that there is a significant pathological underpinning as well as psycho-social aspects and influences (McLaren 2007). As the 1980s progressed, so the research pendulum swung from psychogenic causes to biochemical causes and it has currently settled in the middle ground of both schools of thought. The current belief is that very few individuals have a singular cause for their erectile dysfunction, for example as a result of failing erections there are often associated issues relating to performance anxiety or ejaculation, thus there is a move in assessment towards a holistic assessment rather than the need to achieve a specific diagnosis of organic or psychogenic ED (McLaren 2007).

With the advent of an effective medical solution (PDE5 inhibitors), erectile dysfunction has become defined as medically treatable, according to some authors (Fox and Ward 2006). Further medicalisation of what had previously been considered by many as a natural part of the process of aging, provided sufferers of erectile dysfunction with the label of a legitimate medical condition with an underlying pathology, which could be treated (Hart and Wellings 2002). In doing so, what had previously been considered as a professionally un-owned personal problem became one that was considered worthy of investigation and treatment by both counsellors and medical practitioners alike. Consequently there continues to be uncertainty as to which medical speciality is best placed to diagnose, treat and manage this condition.

#### Medical speciality ownership

Professionals within medical specialities that currently have an interest in this subject are varied: including neurology, endocrinology, cardiology, vascular surgery, infectious diseases, psychiatry, general practice and many more (Abdulmohsen et al.2004). However medical specialities often identify other specialities as the most appropriate to broach the subject. 45% of geriatricians felt that general practitioners were best placed to enquire about sexual health (Granger et al.2002). General practitioners felt that ED diagnosis and treatment should be managed by a “*specialist*” and not themselves (Ng et al.2004 p.63).

#### Who should receive referrals?

Sookdeb (2007) collected data prior to the launch of Viagra and identified that 81% of the general practitioners asked would refer to a urology specialist as a first treatment option; this may now be a historical behaviour as treatment options prior to Viagra were considered more complex than taking a tablet. Previous treatments required surgery or injections into the shaft of the penis therefore requiring knowledge of the anatomy of the penis in order that such interventions are prescribed appropriately. In treating ED, 70% of general practitioners would refer to another specialist when trials with a PDE5 inhibitor had failed, stating that they were not competent to prescribe and manage other

treatment modalities (Rutchik 2001). This referral pattern was less likely to be repeated when the physician had more experience, such physicians expressed a greater comfort with utilising other therapies (ibid). The general practitioners who participated in Ng et al.'s study (2004) felt that they should always refer patients to a specialist, believing that they should not be seen to be encouraging men to take a *"life-style enhancing"* medication and thereby may be considered to be profiting from such drugs. This finding highlights that healthcare professionals are also individuals who will have their own beliefs and morals which guide their judgement and will influence their practice. Beltran and Giami (2009) observed the consultations of a urology consultant and a psychiatry consultant whereby the patient was presenting with erectile dysfunction. Although not an assessment of knowledge, they concluded that the consultations differed in the information that they gathered and that the urologist favoured pharmacological interventions whilst the psychiatrist utilised a combination of therapies, therefore demonstrating that there is no categorically correct medical speciality to receive a referral and similarly not a definitively correct method of assessment or treatment.

#### Which healthcare professionals ask?

Research has demonstrated a mixed picture of self-assessing healthcare professionals reporting on whether they ask about sexual health issues (Pertulla 1999). The disparity between what healthcare professionals believe about what should be happening and what actually occurs in practice may be explained by 73% feeling that they only addressed the issue with high risk patients in about 50% of cases. It is worth noting with this study that the data was collected prior to the launch of Viagra which may have influenced both groups' thoughts on the subject. Haboubi and Lincoln (2003) found that 94% of staff were *"unlikely"* to ask about sexual issues and Ho and Fernandez (2006) found that 92% of staff *"never"* ask. The CHARMS study identified that 66% of cardiac rehabilitation patients are not given the opportunity to discuss sexual problems but that they would not be offended if they were asked and would appreciate being asked more often (Byrne et al. 2013), a similar finding to that of Granger et al. (2002). Rutchik et al. (2001) found that 51% of family physicians claimed that they would enquire about erectile dysfunction when a

patient had identifiable risk factors and only 15% routinely asked men over 40 years of age. In Granger et al's study (2002) routine enquiry was reported to be much lower at 9.1%. All of these studies were based on the self-assessment and self-reporting of professionals, which can be difficult to do with any degree of accuracy. Notably the GPs who participated in Ng et al.(2004) focus groups concluded that they should not directly ask, but may ask indirect questions. The authors of this report indicate that this may be a cultural behaviour as there was a perceived pressure on GPs not to be seen to be encouraging promiscuity, something which may not be considered by professionals elsewhere in the world.

## **Barriers to asking about erectile dysfunction**

### **Discomfort**

Healthcare professionals reported feeling comfortable discussing ED - 83% (Rutchik et al.2001) and 100% in Fisher et al.'s study (part 2) (2005). These high percentages may be related to the samples, Rutchik et al.(2001) recruited attendees at an erectile dysfunction conference and Fisher et al.(2) (2005) recruited professionals who treated erectile dysfunction; therefore the findings are not surprising. In Green et al.'s (2009) study, only 45% of the nurses in the sample were comfortable discussing ED, this may be more representative of other healthcare professionals because they were recruited from a professional web-site and no specific interest in the subject can be assumed, other than that they had completed the questionnaire. More commonly, healthcare professionals believe that their embarrassment and the embarrassment on the part of the patient prevents an open conversation (Fisher et al.2005 parts I and II).

Whilst healthcare professionals report feeling comfortable in discussing erectile dysfunction this may be a reflection of their training or the profession's considered response because the "*comfort*" does not appear to be demonstrated in actuality. Professionals sometimes "*confess*" to "*fishing*" for disclosure rather than asking direct questions and in both self-reporting and in observational studies there are no reports of pro-active enquiry (Ng et al.2004 p62). Physicians report that they do not enquire about erectile dysfunction for similar reasons as patients, they do not feel that they should be asking intrusive questions; if the patient wants to discuss ED then they are happy to do so but they assume a passive role (Ng et al.2004). Culturally there are some reasons that GPs will not engage in such discussions, in Malaysia some believe that it is inappropriate for an unmarried doctor to discuss sexual relationships and that GPs have a social responsibility not to encourage extra-marital affairs (Ng et al.2004). Whilst healthcare professionals profess to be comfortable discussing ED they also express a degree of embarrassment which would seem to be underpinned by a lack of confidence with regards to

their communication skills and their knowledge regarding ED (Fisher et al.2005, Julien et al.2010, Tsimtsiou et al.2006).

The two national Irish surveys which were undertaken with cardiac rehabilitation teams (Doherty et al.2011) and general practitioners (Byrne et al.2010), identified how these practitioners did not feel that they engaged in discussing sexual issues on a regular basis. Jaarsma et al.'s (2010) study of attendees at a cardiac nursing conference reported significant concerns regarding causing offence to the patient in addition to concerns of a lack of time and knowledge.

Interestingly, by comparing the responses from patients with the responses of healthcare professionals Byrne et al. (b 2013) were able to identify that patients perceive fewer barriers to discussion than healthcare professionals. They describe a gap between patients who want to have such discussions and do not identify many barriers, and healthcare professionals who fear a potentially uncomfortable and anxiety inducing situation.

### **Embarrassment**

Embarrassment is often considered to be an emotion expressed as a specific response to experiencing something which makes us feel uncomfortable, anxious or surprised and Lawler (1991 p.135) recognises this as an *“unpleasant psychological state”* which is as the result of having broken societal rules. All societies have organisational rules making explicit what is and what is not acceptable behaviour; when these rules are broken embarrassment is experienced. Edelman et al.(1984) talked of five essential components: knowledge of social rules, protective self-preservation, self-awareness and labelling and dealing with embarrassment. Therefore embarrassment can be considered as a mechanism for social control.

Lawler (1991) studied how nurses care for patients, particularly their physical needs, and as a result she established that much embarrassment is attached to issues of the body. We are taught through social interaction that we should control our bodies when in public and that our bodies should be covered up in *“civilised”* society. Similarly issues with regards to a failing body are often not



discussed in public. Lawler (1991) specifically talked of the social rules which do not permit people to talk about sexuality and sex, both of which are “*taboo*” subjects and which will result in those involved feeling embarrassed. This may be particularly pertinent to men because Lawler (1991) believes that male sexuality and masculinity are both genital and physical constructs, making them highly embarrassing to address. Corona et al.(2013) concluded that sexual activity in the more elderly population was an embarrassing topic for healthcare professionals to broach, the elderly body and sexual activity both being socially unacceptable topics for discussion, findings corroborated by Taylor and Gosney (2011) and Hayward et al.(2012).

Embarrassment can be demonstrated by changes in facial expression, language and physical movements. Minimising eye contact, blushing and characteristically uncomfortable physical movements (shifting around in a chair) are often identified and are accompanied by changes in speech patterns, use of humour when it would seemingly be inappropriate and smiling even though the subject matter may not be considered happy; all are universally recognised expressions of embarrassment (Lawler 1991 p.137, Meerabeau 1999). The experiments and writings of Goffman (1956, 1963), and Gross and Stone (1964) have identified these physiological demonstrations of embarrassment within laboratory settings and Lawler (1991) used their findings to explore the embarrassment experienced within hospital settings.

Embarrassment requires an audience, if there is no-one to witness or participate in the breaking of the social rules then the perpetrator will not feel the sense of embarrassment, they will likely experience shame instead (Edelman 1981). This is highly significant because embarrassment often relates to bodily functions. Nurses and healthcare professionals are often called upon to help patients with issues relating to their body and therefore they can become the audience which will facilitate the sense of embarrassment; this is more acutely felt when the audience is a stranger, often the case in healthcare settings. Equally the healthcare professional may be the embarrassed individual, having to broach a particular subject or task with a patient. Embarrassment therefore significantly impacts on social interactions and could be considered to inhibit a therapeutic relationship (Lawler 1991).

Meerabeau (1999) describes embarrassment as “*infectious*”, resulting in all involved in a situation demonstrating a shared embarrassment and usually taking measures to ensure that the situation is ameliorated as quickly as possible. Often those with experience in a given situation are able to “*rescue*” the situation with tact and wit (Meerabeau 1999).

Nurses learn about their practice and how to minimise embarrassment through experience because society allows them within their professional role to break societal rules. They treat issues of the body as “*natural*” and by managing their own embarrassment they are often able to minimise the embarrassment felt by their patients (Lawler 1991 p.141). Nurses are thought to be able to professionally manage embarrassing situations by “*asexualising*” their patients, which works well in situations where they are providing physical care, but can be prohibitive when a conversation about sexual health is required (Katz 2000). Healthcare professionals often cite embarrassment as a reason for not asking about sexual health and this is usually accompanied by feelings of a lack of knowledge and understanding of issues such as gender, age, culture and ethnicity (Gott et al.2004, Levine and Kloner 2000, Stead et al.2003, Taylor and Gosney 2011). When embarrassment is seen as a breaking of cultural or societal rules it becomes more obvious that they are embarrassed because they do not understand the societal rules or the acceptability of the conversation; rather than a literal lack of training in respect to a particular condition (Haboubi and Lincoln 2003). Magnan et al.(2005) talks of how staff feel morally unable to have some conversations, where morals have been religiously and socially learned over a life time it becomes clearer that this requires a complex understanding of societal rules.

Embarrassment is a shifting concept within an individual’s life and experience and can contribute to greater or lesser feelings of embarrassment. When patients are seriously ill they may not express the same sense of embarrassment in relation to physical care, because their priorities have shifted to survival rather than adhering to societal expectations (Magnan et al.2005). Several authors have considered the timing in a person’s life as influencing whether they are embarrassed by a situation, in a scenario where existence is threatened then a sense of embarrassment is not portrayed

(Jaarsma et al.2010, Herson et al.1999, Quinn et al.2011). Particularly pertinent is Jaarsma et al.'s (2010) finding that healthcare professionals who worked with patients with cardiac disease believed their patients do not prioritise their sex lives so soon after a life threatening event, but they did not comment on an overt sense of embarrassment, as time moved on from an acute cardiac event.

Not all authors have found that healthcare professionals admitted to feeling embarrassed by disclosures of erectile dysfunction, reporting more practical issues as being the reason for a lack of enquiry (Byrne et al.2010, Doherty 2011). Although these authors acknowledged that these were legitimate constraints upon clinical practice they also hypothesised that more practical constraints were used as a quick answer which had not been well considered and potentially were used to hide embarrassment.

### **Lack of knowledge and time**

A lack of time was a commonly reported barrier to entering discussions about erectile dysfunction (Doherty et al.2011, Byrne et al.2010), with Fisher (part 2 2005) demonstrating this as a misunderstanding because the participants believed that having a conversation about erectile dysfunction would require a significant amount of time. Similarly Jaarsma et al. (2010) identified both a lack of time and a lack of knowledge as the most common reasons that cardiac rehabilitation nurses would avoid engaging in a conversation about erectile dysfunction. Although not explored in any depth they hypothesised that both of these reasons were underpinned by discomfort about the topic and that the perception of a lack of time was misinformed, believing such conversations to be complex and beyond their abilities.

All of these authors cited a lack of knowledge or understanding as a barrier to engaging in conversations about ED, they also positively demonstrated that the healthcare professionals within their studies wanted more training in having such conversations and were open to having such discussions with the appropriate training and confidence (Byrne et al.2010, Doherty et al.2011, Jaarsma et al.2010).

Healthcare professionals' knowledge of the pathological causes of erectile dysfunction and appropriate management of the condition was assessed by Abdulmohsen et al.(2004), the only study to assess healthcare professionals' knowledge. The overall mean score from a knowledge and skills test fell below the accepted standard for medical students and this was within a sample taken from a urological conference where the assumption was that knowledge levels would be higher than among the average population of physicians (ibid). 52% of physicians in Abdulmohsen et al.'s study (2004) believed erectile dysfunction has mainly a psychogenic cause, but reported that their initial testing would focus on pathological causes; identifying some confusion in the assessment of erectile dysfunction. This finding was corroborated by Ng et al.(2004) when most of the general practitioners' interviews cited psychological causes and Fisher et al.(1&2) (2005) who reported that 80% of physicians felt that the causes were psychological in origin; again somewhat at odds with their actions as they reported focusing on organic causes in order to treat ED.

From this literature it is clear that internationally healthcare professionals have common issues which hinder conversations about sexual health, a lack of time, education, knowledge and confidence are easily identified, but what underpins these beliefs? There is also a sense in the literature that no one particular clinical speciality has ownership of ED, probably because of historical contexts and the complexity of underlying causes. All the authors who have written about erectile dysfunction say that embarrassment has a significant impact on the disclosure of erectile dysfunction, from the perspectives of both the healthcare professional and the men who have ED, and it has been suggested that the sense of embarrassment may be beginning to decrease because of the international acknowledgement of treatments such as Viagra, however there is a lack of evidence which explores the concept in depth or explores why people find the topic embarrassing.

To conclude the literature which has informed this literature review suggests there is a sense that erectile dysfunction has historically been difficult to define and therefore diagnose, however recent thinking has correlated ED with CVD both in terms of shared risk factors and shared pathological causes, with ED now being considered as a marker of early CVD. The prevalence of ED within

the general population and specifically in men with known CVD is significant and therefore this issue is something which impacts upon a large proportion of the population and could be used to reduce the potential risk of CVD in a number of the population; which in time would reduce the demands made on the healthcare system by reducing the amount of symptomatic CVD.

Erectile dysfunction impacts upon the men it affects and their partner in more than just a physical way and this then influences their behaviour, specifically in relation to disclosure of ED; hence there may be issues pertaining to the use of ED as a useable marker of CVD risk. The literature demonstrates that the issues relating to the disclosure conversation do not only relate to the men and their partners, but also impact upon healthcare professionals and thereby their clinical practice. How the disclosure of this risk factor may be facilitated in practice is not clear from the existing literature, nor is there any evidence which presents an exploration of disclosures of ED from all sides of the conversation; the man, their partner and the healthcare professional. Therefore this thesis aims to ask men, their partners and healthcare professionals about such conversations.

In conclusion it is clear from the existing literature that erectile dysfunction is an embarrassing concept and that men and healthcare professionals find such conversations difficult. There is no evidence which helps to explain why men or healthcare professionals find these particular conversations challenging, other than to identify embarrassment and therefore this thesis aims to explore the thoughts of men, their partners and healthcare professionals in this respect. There is no exploration as to why some men would not disclose ED to a healthcare professional, therefore the body of existing literature is drawing on the thoughts of men who have felt able to have a conversation with a healthcare professional, thereby only being able to present the rationalisations of disclosing individuals. Therefore this project will attempt to seek the views of men who have not disclosed ED to a healthcare professional and to ask why they have made this decision. The evidence for a link between cardiovascular disease and erectile dysfunction has been discussed and many authors conclude that ED should prompt a cardiovascular risk assessment however, whether ED would be a socially acceptable marker of risk for men or

healthcare professionals has not been explored and therefore this thesis will aim to seek the thoughts of all involved in answering this question.

## Chapter Three: Research Design

In order to understand the origins of this research thesis it is imperative that the background is described and the scene set. This chapter will provide an understanding of how and why the research question was arrived at and explain the environment in which the thesis was conducted. A discussion of how the research was planned and subsequently carried out, with ongoing consideration of the relevant ethical issues will also be provided.

### **Brief overview**

The central premise of this thesis is: that erectile dysfunction is a common problem for men with cardiovascular disease which is often under diagnosed and under addressed. Why is this so? This study will hence ask men, post-myocardial infarction about whether they experienced ED prior to their cardiac event and whether they disclosed this to a healthcare professional. It will focus on their experience and seek to identify the elements that supported or act as barriers to disclosure. Healthcare professionals involved in cardiac care will be asked about their experiences of receiving such disclosures and similarly what their perceptions about barriers and enablers to such conversations are. By increasing understanding about such conversations it is hoped that recommendations for clinical practice can be identified, helping healthcare professionals to have such conversations based on the information provided by those who have done so. In exploring these experiences, so evidence may be gathered to suggest whether it is realistic to use ED as a marker to prompt cardiovascular risk assessment.

This qualitative study utilised a phenomenological lens to explore peoples' perceptions of ED disclosure. This was felt to be most appropriate because it allows the researcher to ask participants about their experience of erectile dysfunction disclosure and their understanding of those discussions (Schutz 1967 p.45). Sexual relations and discussions around this topic are complex, individually experienced and private affairs, which cannot be easily understood by observation or quantification. When Heidegger (1962) states that "*whatever we do in the world we do together*", he is describing the concept that no man is

an island and that everything we do, think and say is influenced by the people that we have had an interaction with and the world in which we live. Never would this be truer than to experience a sexual dysfunction. Sex is an important element of relationships which can then impact on a myriad of other personal and social issues (Bertero 2001, Pascal, Johnson, Dore and Trainor 2010). When the subject matter is considered to be a private and personal topic, that is not openly discussed, phenomenology may allow the participants to share their thoughts and feelings with the researcher, who acknowledges that the language and experiences between individuals may differ, but that common themes can be drawn together to reach cohesive and robust findings (Caelli 2001).

A qualitative approach was considered to be most appropriate because there is only a small body of evidence which provides any understanding of the disclosure of erectile dysfunction; individuals' perceptions of the problem and discussions or disclosures of ED. Asking people about how and why they had made decisions about disclosing ED was thought to be the most appropriate way of addressing the research aims, gaining understanding and rationalisation of experience; therefore semi-structured interviews were used with men with ED and healthcare professionals. Semi-structured interviews were chosen in order to give some initial focus to the discussion. This is a difficult subject matter and it was thought that a guide would facilitate the interview.

Due to the sensitive nature of the discussion it was suggested, during a peer review process, that few men would volunteer to be interviewed about this topic and therefore an anonymous questionnaire should be incorporated to capture the experiences of the wider group of men; because they would not want to identify themselves as having ED and would not want to participate in an interview. The questionnaire was designed to focus on the anticipated topics for discussion in interview. It was designed to be in keeping with the semi structured style of interview; therefore space was left for the men to expand on their answers if they wished.



The men with erectile dysfunction (ED) were recruited from those attending a cardiac rehabilitation class, following a myocardial infarction. Within the population of men attending such classes the prevalence rate of erectile dysfunction is, at the lowest estimate, thirty three percent (Byrne et al.2013); therefore it was anticipated that sufficient numbers of men could be recruited. The healthcare professionals, to whom a disclosure may be given, were provided with the research information by the clinical lead and the lead nurse for cardiac rehabilitation, they then volunteered if they were happy to be interviewed.

Two hundred men attending cardiac rehabilitation classes over a period of one year were given the questionnaire; this resulted in ten completed questionnaires. Nine semi-structured interviews were also conducted with men with ED who had volunteered to participate; two of these interviews were conducted with both the man and his wife. Men were self-selecting and had identified themselves as having erectile dysfunction based on the information they had received in the rehabilitation class and from the recruitment information sheets. The research was originally planned on the basis of twenty interviews with men with erectile dysfunction. However, there were insufficient volunteers therefore these numbers could not be achieved. Nineteen complementary interviews were conducted with healthcare professionals; this group included nurses, medical staff and pharmacists.

The initial analysis of data used thematic analysis and all twenty seven interviews were analysed using this process. This resulted in an unmanageable amount of data and themes which were thought to not truly represent the thoughts and perceptions of the participants. Therefore a second analysis of the data was undertaken using an interpretative phenomenological approach, which maintained coherence with the epistemological and ontological perspectives which had been identified at the beginning of the project, but provided a more structured approach to the analysis phase. Because of this structure and the new depth which could be achieved using this process of analysis the amount of data had to be addressed, it was decided that only half of the interviews with healthcare professionals would be

analysed, which would match the numbers of men who had been interviewed and thereby provide equal weighting to the voices of both groups.

The emergent themes from this second analysis had similarities with those identified during the initial thematic analysis. There was however a significant shift in the significance of some of the themes; for example embarrassment was recognised during the thematic analysis as a sub theme of stigma, however when IPA was utilised the superordinate theme of embarrassment became more significant because the systematic and graphic representations used within IPA analysis as well as the repetitive nature of the analysis provided evidence in a variety of formats; demonstrating the shift in weighting of evidence for each of these themes.

### **Aims and Objectives**

Erectile dysfunction is thought to be a common problem which is under diagnosed and untreated, ED is associated with CVD and therefore is particularly common in populations of men with known CVD. This study aims to gain a better understanding of peoples' thoughts on ED disclosure by asking men with CVD about their experiences of ED, whether they, as the literature would suggest, experienced ED prior to CVD and their thoughts on disclosing their ED. The healthcare professionals, to whom these disclosures were made, will also be asked about their experiences of such conversations so that a picture of such conversations can be demonstrated; with particular focus on the barriers and enablers identified by both men and healthcare professionals to having such discussions.

Literature suggests that such conversations can provide an indication of the severity of cardiovascular disease in patients with known cardiovascular disease and can act as a prompt for cardiovascular risk assessment in patients who are within the early stages of cardiovascular disease, therefore the findings of this study may have implications for clinical practice which are further reaching than the particular group of healthcare practitioners involved in this study. Qualitative research is concerned with words and expression of meanings rather than numerical data and therefore this form of inquiry lends itself to answering the aims of this study. It permits researchers to study a topic

within a context and take account of the variety of factors which shape or impact upon an experience or understanding (Smith 2004).

The use of a qualitative approach enables researchers to explore the meaning that participants attach to a particular topic and to situate this within the context from which they have come, therefore when exploring a personal issue such as a sexual dysfunction the peripheral understandings or issues which may impact but are not literally a cause of the dysfunction can also be considered (Smith 2004). Because qualitative inquiry is focused on the personal experience and meanings which are derived from this experience, the emphasis is not on achieving an objective and absolute truth; but to demonstrate an understanding of the meaning that people with a specific experience have attributed to this and to look for coherence and disparity between individuals expressions of similar experiences (Smith 1996). Qualitative inquiry by its very nature facilitates a holistic inquiry and thereby enables researchers to acknowledge, and in some situations utilise, themselves within the research (Smith 2004). Within this thesis the position of the researcher as a clinical nurse can therefore be acknowledged and utilised to provide a reflexive account in relation to all elements of the research.

## **Methodology**

### **Philosophical underpinnings**

It may seem obvious that in order to enquire about peoples' experience of disclosing erectile dysfunction the most appropriate method would be to ask people with experience of such events. However, Koch (1995) warns against allowing research to be method driven because this may fail to take into account relevant ontological or epistemological issues, ultimately leaving the researcher floundering without a framework to guide their enquiry; reporting superficial findings with a lack of focus. A failure to identify a philosophical perspective from the outset may also leave readers of the findings unable to comprehend the positioning of the researcher whilst they were undertaking the study (ibid). Clearly identifying a theoretical approach from the outset allows decisions about the design and conduct of the study to be made explicit (Lopez and Willis 2004).

Phenomenology is an interpretive research philosophy and methodology which allows research questions to be asked regarding the nature of existence, this is entirely relevant when discussing sexual dysfunction because of the complexity of the issue and the range of interpretations and subsequent implications (Heidegger 1962, McNamara 2005). Using a phenomenological lens, akin to hermeneutic phenomenology, allows a researcher to take into account the fact that all participants in the research, including the researcher have prior understandings, or perspectives on the subject and that these need to be accounted for and used within the research process in order to enhance the quality of the findings (Oiler 1982). As a clinician the author's prior knowledge and understanding can be utilised, rather than temporarily removed or "bracketed", as is the requirement in some other forms of phenomenological inquiry (Kleiman 2004).

Interpretive research allows researchers to understand experiences rather than to look for causal relationships. Interpretive research is conducted within a framework which originates from the specific ontological perspective that there are many realities which can all be interpreted and reconfigured in many ways by those who have the experience and those who are interpreting the data, hence interpretative research by the very nature of the underpinning ontological perspective facilitates a holistic study of multiple realities (Koch 1995). This type of research is qualitative in nature and researchers who undertake such studies aim to understand and explore peoples' experience and knowledge, which is particularly helpful when exploring the lived experience of people within a healthcare setting, allowing the context of the experience and the understandings associated with it to be illuminated (Lopez and Willis 2004). It is hence acknowledged that experiences and understandings differ and therefore an exploration of a variety of realities will rarely result in a uniform experience, they are likely to be divergent and present various perspectives. When exploring a disclosure there are many aspects which will impact upon the person's perception of that experience and therefore using an interpretive approach would capture the complexity of a multifaceted experience.

## Epistemology of Hermeneutic Phenomenology

Hermeneutic phenomenology specifically considers that all knowledge exists within people and that these people are living within their world, therefore such research seeks to understand the people and the conditions in which their understanding of a phenomenon take place (Heidegger 1962). Such research asks people what it is like to be a person with experience of living with the studied phenomenon and therefore aims to understand the meaning of “being” for these people. It is therefore acknowledged that there are inextricable links between the knower and the known, they are inseparable and the aim of phenomenological research can be to explore links and interactions between the knower and the known, but not to identify categorical cause and effect; which would be impossible because such research seeks to develop an idiographic body of knowledge, which may not be generalizable (John 2004).

The idea that people live in a world with many influences, and that these influences shape the way that they see and interpret things is described by Heidegger as “*Dasein*” (Heidegger 1962). Koch (1995) considers *Dasein* to be the state in which humans are self-aware and therefore ponder on their existence, it describes the all-encompassing experience of being in a world; for example we are socialised from birth to utilise similar coping strategies, moods and possibilities in life; or “*embodied knowledge*” (Lavery 2003 p.24). In its simplest terms it is the “*basic activity of being in the world*” or “*the human way of being*” (Draucker 1999 p.361). Humans are considered within hermeneutic phenomenology to live hermeneutically because they identify meaning or significance within their world. However, much of what humans do does not require conscious thought but everyday coping, and it is how this is achieved that is of particular interest to researchers (Draucker 1999 p.362).

By asking researchers and participants to think about their experiences, often more deeply than they would have naturally considered, this allows researchers to illuminate the essence of the thing being studied, which will in turn provide new light on elements of phenomena (McNamara 2005). In talking about a difficult subject it may be that a deep consideration is too difficult or painful to achieve; however the concepts of hermeneutic phenomenology allow

the participants to determine the depth of consideration that they are willing to give to a topic, thereby giving the researchers insight about the topic itself.

There are particular concepts or elements of an experience which Heidegger considers essential when undertaking a hermeneutic phenomenologist study: time and space, background and pre-understanding, co-constitution and interpretation (Lavery 2003). Prior to undertaking such a study, researchers must become familiar with these concepts because they influence all aspects of a research project from conception to dissemination. A common fault of those claiming to undertake such studies is that they retrospectively apply the concepts of this philosophy after the data has been generated because they do not have a firm understanding of the concepts prior to undertaking the study; in effect they mould existing data into a hermeneutic phenomenological philosophy (McNamara 2005), rather than give consideration to relevant elements continually throughout the research.

### Time and Space

Heidegger identifies time and space as essential facets of any experience that should be considered when studying someone's perspective of being in the world (Lavery 2003). Time is the temporal aspect, in the current or in the past or future, whilst space is the location or place, which may be metaphorical or literal (ibid). Time is a fundamental framework within which humans function, be it related to the twenty four hour clock, the seasons of the year or a time of one's life. Heidegger believes that all understandings of being are anchored to a horizon of time and therefore to interpret being, the concept of temporality must be considered. Similarly space and location are equally as important. Everything belongs somewhere and in positioning oneself so participants can make themselves closer or more distant from a phenomenon, they are indicating perhaps their priorities and concerns. Heidegger (1962) describes such concern as "*sorge*" which he believes to be the most significant and unifying of all human ways of being, to be in the world in a state of care or concern is, he believes, revealing of being. In the practical application of these concepts Koch (1995) alerts potential phenomenologists to listen to where participants are situating themselves, close to or far from the phenomena and

to pay equal attention to that which is placed in the background or remotely because this does not necessarily indicate a lack of concern. These two concepts, space and time, are closely linked because time may put metaphorical space between a person and an experience, hence they are often taken into account together (Heidegger 1962).

Within this study men and healthcare professionals used time and space when discussing the expectations of aging particularly. They also had more literal discussions of the spaces that they work in or would feel comfortable having such conversations in and often used both concepts to distance themselves from the topic when they began to feel uncomfortable, all of which will be discussed within the analysis chapter and are particularly apparent within the analysis of the linguistics.

#### Background and Pre-understanding

An individual's background in hermeneutic phenomenological terms comprises of all the knowledge and understanding of their life so far, their culture and societal influences which provide them with their fundamental understanding of the world and their place in it (Koch 1995). This historical knowledge can be a culmination of social, cultural and historical influences, which may be so central to their being that Heidegger (1962) believes they cannot always be made explicit; they are simply understood to be that way. As a result hermeneutic phenomenology recognises that individuals always come to a situation with a story or their pre-understanding (Koch 1995), it is the language and practices of the culture within which they live, therefore pre-understanding is with us in the world and therefore cannot be removed or discounted (Lindseth and Norberg 2004 p.145).

The epistemological understandings provided by hermeneutic phenomenology presuppose a relationship between the knower and the known, and because both of these hold a set of values and understandings the notion of value free research is questioned. Aspects of human experience and meanings from such experiences are lost in reductionist methods but highlighted when there is a two way interaction between the researcher and the person with the studied experience (McNamara 2005). Heidegger believes that "*fore-structure*" or the

understanding of the researcher augments interpretation, recognising the researcher as essential to shape understanding. He argues that the researcher's perspective is always a fundamental and legitimate part of the research, believing the researcher's ability to ask pertinent questions relies on previous knowledge and understanding (ibid). Lowes and Prowse (2001) believe it impractical and not necessary to exclude the prior knowledge of the researcher in the pursuit of rigour, they believe that since data generated from interviews is created by the interviewer and interviewee then rigour and trustworthiness can be assessed by the researcher by making clear their pre-understanding and contribution to the interview. These pre-understandings are therefore an essential element of the data generation and analysis (McNamara 2005).

Within this study there were particular difficulties in making explicit the participants' pre-understandings, especially when trying to understand how culture and societal influences may have impacted upon them. The shared understanding, which will be discussed within the analysis, made exploring this particular aspect difficult because the reciprocal understanding facilitated a conversational flow which inhibited the in-depth discussion of pre-understanding.

### Co-constitution

Heidegger (1962) stated that because an individual and the world in which they live co-constitute one another they (the person) have been developed within the world and their world has been constructed based on their experience and background. Hence the two entities, the individual and the world are indivisible and each must be viewed with respect to the influence of the other (Koch 1995). Whilst co-constitution is the term used within hermeneutic phenomenology to describe this connection, it is also used by scholars of Heidegger to discuss the fusion of data from the participants, the experience of the researcher and the context from which this is emerging; the co-constitution of data (Draucker 1999). Hence this term requires clarity when it is used because it may or may not be referring to the contextualisation of the data.



Within this study there was an attempt to use both definitions of co-constitutions, however for many of the same issues as the difficulties with discussing pre-understanding it was at times impossible to ask participants to consider deeply how the world, on a deeper level, had influenced their thoughts on sexual dysfunction.

### The Life World

Heidegger (1962) refuted much of the work of his mentor Husserl, however they agreed in relation to the concept of the life world and acknowledging the pre-understanding. They both held the epistemological stance that lived experiences demonstrate life. These experiences are often shared with others; however they can also be individual. People experience life in individual ways and there are often similarities, which it is for the researcher to illuminate (Heidegger 1962).

The concept of the life-world recognises that individuals live within a world that they understand, which consists of internal experience; their body, perceptions, relationships with others and the external world within which they live and interact. The thoughts of the participant in relation to aspects of the lived-world can provide evidence and truth with regard to rationalisations of their experience. Heidegger specifically describes this concept as “being” in the world, meaning that the participant cannot separate themselves from the world in which they live, nor can the world in which they live be separated from themselves. Heidegger recognises that within this sense of being, an individual is situated with a past, a current situation and a future; all of which influence where they situate themselves and which impact on how they express themselves and how this expression will be interpreted by those exploring the topic. The complexity and interpretation involved in the life-world mean that understandings can be dynamic, meanings can be complex and often multiple. As a result, meaning making is never categorical and often evolves based on the multiple influences from the life-world.

Clearly the expression of the life-world is usually achieved through linguistic expression, however Merleau-Ponty (1950) recognises that this carries limitations particularly in relation to expressing subconscious or pre-

understandings which are often considered as “common sense” and not easily articulated. As a result, Gendlin (1997) believes that linguistic analysis of the elements of the life-world will provide some insight; however there will always be more interpretation and understanding to be gleaned.

### Interpretation

A key aspect of analysis is interpretation, no part of a study undertaken using a phenomenological lens is free from interpretation and IPA actively supports interpretation (Smith et al 2009); humans are self-interpreting beings therefore every aspect of research which seeks to understand human experience will be passed through several different interpretations as part of the overall process (Koch 1995). For example, the men with erectile dysfunction in this study will have given thought to their problem at many junctures: when they first noticed the problem, when they talked to their partner, when they decided to speak to a healthcare professional. All of these thoughts and experiences will have been interpreted and processed by the individual based on their previous thoughts and interpretations. Interpretation is required at all stages of the research process and explication of how each interpretation is achieved is the underpinning specifically of hermeneutic phenomenology, but also all research undertaken in a phenomenological manner such as Interpretative Phenomenological Analysis (IPA) (McNamara 2005). The explication of these interpretations is recognised as a demonstration of rigour and will be explored within the discussion of the analysis.

Thematic analysis allows for interpretative analysis of data, however as will be discussed within the discussion chapters, the lack of structure associated with this method and the complexity of interpretation resulted in a later decision to undertake a second analysis using a more structured analysis process in order to be able to fully explore the language used and some of the things that were “left unsaid”; the second IPA analysis of data being presented within this thesis. IPA is a qualitative research methodology which has found particular use in researching issues of the body and mind because it allows researchers to explore how participants make sense of their experiences and help others to understand them (Smith et al.2009); the theoretical underpinnings of IPA lie

within both Husserl's and Heidegger's phenomenology (Biggerstaff and Thompson 2008) and therefore this epistemological and ontological perspective is maintained throughout this thesis. Crucially IPA adopts the same belief as Heidegger in allowing the researcher's influence to be acknowledged and the interpretation of the dialogue within an interview will necessarily acknowledge the position and understanding of the researcher as well as the participant (Biggerstaff and Thompson 2008). IPA differs from other methodologies because it considers that, through careful consideration and interpretation, a researcher should be able to access individuals' cognitions (Biggerstaff and Thompson 2008). Although this aspect of IPA should be utilised throughout the research process, including the interview itself, it can also be applied specifically to the analysis; examining the role of language and how people ascribe meaning to their experiences. These particular facets of IPA, in the light of data which lacks apparent rich description, can be considered beneficial in helping to analyse the data in a systematic way, permitting a careful consideration of the language used by participants, which should assist in illuminating their life world (Smith et al.2009).

#### The Hermeneutic Circle, essential parts

The hermeneutic circle is a cyclical way of understanding the whole hermeneutic phenomenological research process whereby the researcher moves between the parts of an experience, to the whole and back again to the parts as many times as is considered necessary to grasp the deep meanings within the dialogue that they are having with a participant or within the text of the interview transcript (Kvale 1996). These circles happen on a micro level whilst designing the research or undertaking an interview and then move to a macro level where the circle rotates between interviews and then groups of interviews. Moustakas (1994 p.90) writes that the production of meaning is achieved through "*looking and describing, looking again and describing again and so on and so on*" until the data becomes a "*phenomenological reduction*" whereby the researcher has reached a sensible meaning of the experience, which is free from contradictions.

During this study the interviews were conducted as volunteers presented, hence they were undertaken over a period of eighteen months and this was longer than anticipated because recruitment was slow. The time between interviews allowed reflection on previous interviews and the use of subsequent interviews to explore emerging themes, so there was a benefit to this time delay. The hermeneutic circle was utilised within all phases of the project, including the design, data collection and the initial thematic analysis, however the more formal and structured visiting and revisiting of the data required in an IPA analysis also seems to utilise this repetitive, cyclical reconsidering of data in relation to themes and therefore this cyclical revisiting was maintained during the second analysis.

### **Using Phenomenology to explore hidden subjects**

Heidegger's concept of *Dasein* is particularly pertinent when discussing erectile dysfunction since men often attach beliefs about their identity and role to their ability to perform sexually (Walfish et al.1980); thus it is imperative to explore this concept from more than just a physical perspective. Although erectile dysfunction is a physical symptom it is inextricably linked to a myriad of other concerns such as manhood, masculinity and sexual and marital relations (ibid). The act of sexual intercourse is in itself is a highly complex act involving both the physical and emotional self and that of the man's partner (ibid). Therefore Heidegger's recognition of the impossibility of separating the body from "I" and both the body and "I" from the world, co-constitution becomes crucial. "I" cannot be separated from the world, "I" is a bodily being which lives within the world; a being in which mind and body cannot be separated (Caelli 2001). Such discussion shares similarities with the concepts discussed within the literature review of embodiment and it is notable that both concepts are used interchangeably within the interviews.

Heikkinen (2000) uses hermeneutic phenomenology in relation to the aging process and concludes that with age we develop an increasing ambivalence to our body. This confusion or doubt becomes increasingly noticeable with the onset of illness and with increasing age when previously taken for granted functions begin to fail. We begin to notice that our body is increasingly turning

its attention to itself and concern with one's physical being becomes an explicit issue of concern with advancing age (Heikkinen 2000). It may be that ED marks the beginning of this awareness; its increasing prevalence with age meaning that the concept becomes pertinent to the population of men with erectile dysfunction. A phenomenological approach to questions related to the body requires an analysis of human experiences, of their meanings in people's lives and of the ways in which this bodily experience influences the ways in which we exist in this world (Pascal et al.2010). The ailments and symptoms that come with increasing age and the objectification of the body or certain parts of it changes people's experiences and accordingly their meaning (Heikkinen 2000). Whilst sexual function is often taken for granted and erectile dysfunction often blamed on age, the meeting of this symptom with greater age may bring into the conscious mind the idea of a failing physical form; more so than it had previously been. Therefore phenomenology can be used to focus on the participants' understanding of their health condition and their impressions of discussions they have had with friends' family or healthcare professionals about both experiencing erectile dysfunction and disclosing it to a variety of audiences.

### **Rigour, Reliability and Credibility**

Phenomenological inquiry is value bound; this is clearly the case when undertaking studies where external influences cannot be removed, unlike positivist research (Crotty 1998). The values of the researcher, the paradigm explicitly used to guide a study, the theory which has guided the data collection and analysis and the context within which the study is being conducted will all impact upon the findings and therefore need to be made explicit in order to provide a specific perspective through which one should appreciate the findings (Crotty 1998). For a study to have a congruence in relation to the values which underpin the study (value resonance) the values relating to the problem, the paradigm, the choice of substantive theory and the context within which the problem is being lived or studied must be coherent. Value resonance across all of these elements helps to ensure that results will be meaningful; a dissonance in these values can result in a lack of clarity and meaning to the findings (Smith 2004).

The reactive effect of the interviewer is not considered to introduce a bias in most types of phenomenology because the aim of the interview is to engage in meaningful conversation, therefore the interviewer would participate and assist the participant in thinking about the phenomena in ways they had not before (Lopez and Willis 2004). Similarly, participants will have given thought to their own pre-understanding and background, although they may not recognise this as such, to identify what is underpinning a particular interaction or response (Lopez and Willis 2004). The requirements of the ethics committee and, more significantly the need for shared understanding, which will be discussed within the analysis chapter, may have hampered to a degree the depth to which pre-understanding and background could be explored.

The rigour of qualitative research methodology is often debated and those who use quantitative methods might find it hard to identify the key aspects of interpretative research which will increase and clearly demonstrate the reliability and validity (Hall and Stevens 1991), often this is said to be because of a lack of predetermined criteria by which trustworthiness can be measured. Oiler (1982 p.179) describes this as a “*lack of common language*” in the description of rigour in qualitative research. However, clear acknowledgement of the values (as discussed above) and the multiple circles of interpretation and documentation of how themes have emerged from this interpretive circle are thought to greatly enhance the reliability of findings thus increasing the credibility of qualitative studies (Lavery 2003). By ensuring that circles of analysis are made explicit, the reader can assess the findings for trustworthiness and authenticity (Lopez and Willis 2004) (see Appendices 11, 12 and 13).

The overt reflexivity of the researcher, and those involved in the data analysis, is imperative to ensure credibility of findings and to maintain rigour throughout the research. The initial interest and knowledge of the researcher into the topic being studied, is thought in Heideggerian phenomenology to augment the trustworthiness and strengthen the validity of a study (McNamara 2005). Bourdieu (Finlay and Gough 2003 p41) states that researchers “consider as important and interesting that which stands a good chance of being recognised by others as important and interesting”, however it is important to note that a

pre-occupation with what an individual finds interesting, or one's own emotions and experience may bias the research, privileging the researcher's voice above others. Therefore care must be taken, by constant review and grounding with a supervisor, to maintain a realistic perspective and to allow the voices of participants to be expressed. The continued self-awareness of the researchers, their explication of this on-going process and its use in analysing the data underpins the credibility of the whole thesis (Hall and Stevens 1991, Lowes and Prowse 2001). This overt reflexivity was in part achieved by regular and honest discussions between those who had analysed the interview transcripts and a frequent revisiting of the interview text in relation to the diary notes which had been contemporaneously documented; this helped to illuminate the thoughts and feelings at the time of the interview and thereby offered support, confirmation or questioning of emerging themes in relation to the impressions which were documented during the interview.

Oiler (1982 p.180) concludes that phenomenological studies are valid forms of research where the final description "*resonates with those who lived the experience*". This "*vivid and faithful*" description of experience is where Hall and Stevens (1991 p21) believe the credibility of the findings resides and critically these descriptions must connect with both "*insiders and outsiders*" (Hall and Stevens 1991 p26). In order to provide further validation of the findings, those who have contributed to the data generation are sometimes asked to validate the findings by assessing how well they consider them to portray their experience and thoughts. However, this can be problematic if the subject is "difficult" and one which participants do not feel that they want to revisit repeatedly (Sandelowski 1993). Their concern with their own perspective and lack of understanding of the abstraction of many stories into one can also lead to concern, therefore a lack of participant validation should be undertaken with caution but a lack of its use does not necessarily indicate a lack of validation measures (McNamara 2005). This became an evident problem during the interviews, when none of the men who had been interviewed were willing to review the findings; they implied that this was because they had a sense of trust that their stories would be accurately portrayed. However, it was to become evident within the analysis of the data

that there may have been deeper meanings, akin to Sandelowski's (1993) work in which participants meanings change with time when they have particular emotional connotations, indicating that some subjects are not easily or reliably revisited by participants.

### **The Author's Pre-understanding and Background**

In order to undertake a study such as this, it is important that the researcher makes explicit their personal position based on their previous experience. I have been a cardiovascular nurse since qualifying in 1998. As a twenty year old staff nurse I probably felt that people with cardiovascular disease were "too old" to have an active sex life, but now in my late thirties I am aware that time passes with increasing speed so have developed the belief that many people want, and need, to have an active sex life for as long as is possible.

Having spent a career nursing people with cardiovascular disease I am well aware of the debilitating effects both physically and mentally that a diagnosis of cardiovascular disease can have on an individual and their life partner and family. If a normal daily activity, such as sexual intercourse can be used as a marker which will help prevent such disease then efforts should be made to facilitate disclosure.

Nine years ago I was a member of the team in Wales which set up the Male Sexual Health Clinic because experience working with patients with cardiac disease led to a belief that the men with erectile dysfunction were not having this condition assessed or managed appropriately by any services. Over the years, and with a growing body of evidence that erectile dysfunction is a precursor to cardiovascular disease, the referral criteria have widened and currently the Male Sexual Health Clinic takes referrals from any healthcare professional who has received a disclosure of erectile dysfunction where the man is thought to have an increased risk of cardiovascular disease. Typically these referrals come from other healthcare professionals in the cardiology and cardiothoracic departments, general practice, other clinical specialities such as urology or sexual medicine and, following media attention, some men refer themselves. It was felt that this all inclusive referral policy was the most likely



method of ensuring that men would be able to achieve a quick and direct referral to a clinician who would be able to assess and treat them.

The men with an existing diagnosis of cardiovascular disease that we were seeing in the Male Sexual Health clinic commonly told us that they had been experiencing erectile dysfunction prior to their coronary event but had either decided not to discuss the problem with their general practitioner or they had spoken about the problem and been prescribed treatment. They had not been made aware that they may have been at a higher risk of cardiovascular disease. Anecdotal evidence from all the staff in the clinic indicated that most of the men had noticed their erectile dysfunction prior to their cardiac event, often between three and five years before, which aligns with the current literature (Montorsi et al.2003). Despite this lead time it would seem that only rarely had steps been taken by their clinicians to reduce their cardiac risk and they have subsequently experienced a cardiac event; therefore as a team we wondered why?

Erectile Dysfunction is commonly treated by general practitioners, but during the early years of the Viagra license there were reports of men dying following the concomitant use of PDE5 inhibitors and nitrate medication (Shah 2002). Both of these medications are designed to dilate arteries and the effect of taking both at the same time resulted in catastrophic hypotension and resultant myocardial infarction. Despite the subsequent change in prescribing guidance these incidents have left the legacy of general practitioners often being reluctant to treat men with ED when they are known to have a history of cardiovascular disease (Kekilli et al.2005, Wagner 2005).

### My Fore-structure

In order to make explicit any prior understanding and beliefs and establish my fore-structure the “why questions” as described by Gough (Finlay and Gough 2003 p.21) were answered. This required a deconstruction of the essential elements of the research questions and identification of my personal drivers for the study, the latter having been discussed within the background section.

The research aims were therefore considered in the terms: barriers, enablers and disclosure/ experience of erectile dysfunction.

**Barriers** can be real or perceived and cause people to feel that they cannot tell someone else about their erectile dysfunction. These barriers may or may not be observable and would be a person's perceptions. They (the barriers) may have prevented or potentially could prevent the person from expressing their condition to someone else. My perception as someone who has worked in several clinical environments where such disclosures could take place is that men are not keen to talk about erectile dysfunction, therefore barriers must exist; however I have never clarified what those barriers are. Such barriers may be related to gender, age or culture. Disclosing sexual dysfunction is not considered an easy thing to do, in a society where sex is very rarely discussed and often met with humorous dismissal. As human beings, talking about intimate things is difficult and therefore it is recognised that being able to overcome the associated fear and embarrassment may play a significant role in addressing a critical barrier.

**Enablers** can also be real or perceived/ hypothesised by the participant to assist in the process of telling someone about their condition. They may have experience of these enablers or feel that in another situation they would have been helped to disclose if certain processes, behaviours or knowledge were present. Healthcare professionals have good practice guidelines which are designed to help them to practice in an open and approachable manner, which in turn should allow patients to feel comfortable enough to discuss their health status freely. Logic would dictate that the enablers to disclosure would, by definition, be those which oppose the barriers; however this may not be the case.

**Disclosure** of erectile dysfunction is the process whereby a man who believes that he is experiencing problems with his erections tells someone else of his symptoms, this person maybe a healthcare professional, friend, relative or complete stranger. The process of verbalising their symptoms is what is of interest. I am used to directly asking people about their health status, however disclosure may not be as a result of direct questioning and one must therefore

be mindful of not limiting the discussion to the more obvious disclosure scenarios.

The aim of this thesis is then to ask individuals about their experiences of disclosure and by reflecting upon such experiences identify the barriers and enablers to the disclosure of erectile dysfunction; with the hope that an increased understanding of the kinds of interaction that lead to the better clinical management of disclosures and thereby subsequent treatment. Utilising a phenomenological perspective, particularly IPA, allows for my previous work experience and understanding to be utilised at all stages of the thesis exploring a subject which other researchers may find difficult. A discussion on how the philosophical perspective impacted both positively and negatively on the thesis will follow within the discussion chapter, using the experience of data collection and analysis to illustrate some of the issues.

## **Methods**

### **Sampling**

The aim of sampling in phenomenology is to select people who have experience of the phenomena being studied and crucially are willing to talk about that experience (McNamara 2005, Morse 2000). The aim is to achieve a sample that is diverse enough to provide rich and unique stories about the phenomenon (McNamara 2003). It has been acknowledged that the topic for discussion at interview would be uncomfortable for many and therefore both healthcare professionals and men with ED are potentially populations who may not wish to engage in research (Potts et al.2004). Accessing hard to reach populations has been extensively written about, especially in relation to topics that the participants may find uncomfortable or embarrassing (Corbin and Morse 2003). Often sampling and recruitment techniques for such groups are facilitated by participants providing access to other participants due to a shared identity; for example Muhib et al.(2001) utilised a venue-based technique to achieve a sample of teenagers who would not otherwise engage in research and Faugier and Sargeant (1997) used a snowball sample in their study of people with the stigmatising condition HIV. However, from the existing literature it would seem that men with erectile dysfunction do not discuss this

with anyone, therefore would be unable to identify fellow sufferers and could not create a snowball sample (Pontin et al.2002).

### Sample of men and their partners

The men with erectile dysfunction who were recruited for this study were attending the cardiac rehabilitation course at the hospital in which the Male Sexual Health Clinic is held in South Wales. A convenience sample of men who identified themselves as having erectile dysfunction were recruited as they volunteered; had there been more volunteers than anticipated then later interviews could have formed a purposive sample, but in the initial stages self-selecting recruitment and reporting was the only option. They were invited to include their wife, if they wished, and they would be interviewed together.

### Sample of Healthcare professionals

The sample of healthcare professionals was identified and individuals were asked to participate by the clinical lead for the research (the consultant cardiologist in charge of the Male Sexual Health clinic) and the lead nurse for cardiac rehabilitation in order that potential participants did not perceive any undue pressure or coercion by the researcher. These two clinicians were aware that a broad sample of clinical roles and experience would provide a sample with a greater breadth of experiences and understanding, therefore within this purposive sample efforts were made to approach and include the widest variety of individuals.

### Sample size

According to Morse (2000), the sample size in a qualitative study is dependent on several factors and there is no absolute method for this calculation. The aim of qualitative research can be to reach a point of data saturation or to present an idiographic account of participants' experiences of a particular phenomenon. Therefore when establishing a sample size the quality and depth of the data, the breadth of the study or topic, the amount of data anticipated to come from each individual and the number of interviews per individual must all be taken into consideration and often there are no predetermined sample sizes to be achieved (Morse 2000 p.3). For example if an individual is going to be

interviewed several times over the course of an experience and the anticipated data is thought to be deep and rich, then the number of participants would be fewer than in a study where the scope of the study is broad and the depth achieved in each interview is less easily gained; in such studies a larger sample is required. Morse (2000) suggests that when a topic is difficult or awkward to talk about, in order to reach saturation the number of participants will need to be increased.

Due to the anticipated difficulty in engagement because of the challenging topic and the single interview method a relatively large sample number, by comparison to other phenomenological studies, was decided upon. The aim was to interview twenty men who identified themselves as having erectile dysfunction and twenty healthcare professionals to whom a disclosure of erectile dysfunction may occur. Originally the sample of men, from cardiac rehabilitation, had been set at forty; however this was decreased to twenty at the request of the health board's research and development department, citing resource limitations. From the theoretical perspective this would be considered problematic because the smaller sample size could potentially result in a small amount of data, which might also lack depth because of the topic. A larger amount of data would help negate the lack of depth, a problem less easily overcome with a smaller sample size. However, the subsequent issues of recruitment meant that even the lower sample numbers were not achieved; an issue which will be discussed within the next section.

## **Recruitment**

### Cardiology; the setting for recruitment

Men with cardiovascular disease are considered to have a high prevalence of erectile dysfunction, in cardiac rehabilitation classes the prevalence ranges from thirty three percent (Bryne et al.2013 a) rising to seventy five percent in men over fifty five years of age (Hood and Robertson 2004); therefore within a cardiology setting it was anticipated that there would be sufficient numbers of men with erectile dysfunction and healthcare professionals to whom a disclosure has or would occur, to recruit to the study. The cardiology

department from which the men were recruited is a tertiary care centre and also where the Male Sexual Health clinic is based.

On discharge from the hospital, following a cardiac event, patients are offered a cardiac rehabilitation course facilitated by the cardiac rehabilitation team. The cardiac rehabilitation nurses visits patients whilst they are in hospital, then at home soon after discharge and then they facilitate the cardiac rehabilitation course. This course lasts six weeks and is designed to educate patients about their condition and life style changes, which will assist their recovery. Each class consists of a closely monitored gym session, an education session on a variety of topics and a relaxation session. Once the patients have successfully completed their six week course, they are offered the opportunity to attend less formal gym sessions in order to maintain their exercise regime. The multiple meetings, between the cardiac rehabilitation nurses and the patients, are unique in the care of patients who have experienced a myocardial infarction; they will not be given the opportunity to see any other members of staff with such regularity or frequency. These meetings help patients to build a good relationship with the cardiac rehabilitation team (Beswick et al.2005), trust is a fundamental aspect of recruiting patients, particularly to research (Brooks 1974). Ross et al.(1999) cite this as one of the three essentials for successful recruitment in addition to explicit research aims and sufficient planning. In volunteering for this study the men would be disclosing their erectile dysfunction, therefore the trust they must have in the recruiting staff was essential for recruitment to be successful.

#### Access and Recruitment of Healthcare Professionals

Healthcare professionals were asked to participate by the clinical lead physician and the lead cardiac rehabilitation nurse, both of whom work within the cardiology department; this is an accepted technique of access and recruitment which minimises the potential for perceived pressure or coercion to participate (Cook et al. 2009). They asked healthcare professionals in person and provided them with an envelope containing the research information and a Consent-to-Contact form (see Appendix 3). The potential interviewees were asked to return a Consent-to-Contact form to the lead researcher if they felt

able to participate. These forms were designed to accommodate a variety of forms of communication because some individuals may not have wanted to be contacted at work, or conversely at home. This led to a rather complex series of interactions in order to arrange meetings and led to the loss of four healthcare professionals; a letter was sent to their home address as requested, to which they did not respond. Despite these losses nineteen healthcare professionals were finally interviewed.

Recruiting healthcare professionals to talk about their experience of clinical practice can be challenging because they are asked to examine their own practice, in relation to this subject area this may be difficult (Haboubi and Lincoln 2003, Cook et al.2009). The most commonly cited barrier, by healthcare professionals, to participating in research is a lack of available time (Mapstone et al.2009) and therefore it may have been anticipated that this group would also be hard-to-reach, because of the topic and the data collection method. In order to minimise the disruption that taking part may cause, the interviews were conducted at a time and location that was suitable for the healthcare professional. This would seem to have not only facilitated sufficient volunteers but also a degree of comfort which allowed them to speak freely.

#### Access and Recruitment of Men

Access to the men attending the cardiac rehabilitation classes was negotiated with the lead nurse for cardiac rehabilitation services at the health board and onward referral for treatment of erectile dysfunction was agreed with the consultant cardiologist/ clinical lead for this research, who also heads the Male Sexual Health clinic.

Only one hospital was approached for permission to recruit patients because this was the only hospital in the country to have a clinic and consultant who would be able to manage any patients for both their cardiac condition and erectile dysfunction. Erectile dysfunction is recognised as having many physical and psychogenic causes and thus discussion of such a health complaint may uncover a collection of issues which require careful future assessment and management (Tomlinson and Milgrom 1999). Having a

referral mechanism in place was imperative for the safe onward management of the patients and because this clinic is unique these patients had to be under the care of the hospital in which the clinic is conducted.

The timing of recruitment was critical; the patients attending cardiac rehabilitation would have been considered stable with respect to their heart disease but would not have attended the Male Sexual Health clinic at this time. Thus they would not have received extensive information about their condition and, more importantly, would be able to consider me as a researcher during the interview as well as a clinic nurse. It was hoped that the concept of “*social distance*”, whereby people are used to talking to some types of people and not others (Dohrenwend et al.1968), might facilitate both the healthcare professionals and the men with erectile dysfunction in feeling able to talk about the subject matter. Both groups would be used to talking to nurses, and because they were aware of the dual role of the researcher, this might assist in the reduction of the social distance; potentially allowing the receptive and meaningful dialogue to be achieved.

Having attended the scheduled talk, within the rehabilitation programme on sexual activity, potential participants would be able to decide whether they were experiencing erectile dysfunction and then after the talk they would be told about the research and given the recruitment envelope. The recruitment envelope contained an information sheet about the study, a questionnaire, a Consent-to-Contact form and two envelopes so that the forms could be returned independently of each other (see Appendix 4). They were told that they were perfectly at liberty to return none, one or both of the forms. The questionnaires had contact details so that should a man not want to participate, but had questions about the study or the erectile dysfunction clinic he could contact me to discuss further. In an attempt to limit disruption or potential embarrassment to the participants the Consent-to-Contact form had options for the participants to circle in order to indicate how they would like to be contacted. This was felt to be necessary as they might, for example, have shared their phone line with a number of people or not had access to an email account.



Recruitment rates might have been improved by making it explicit within the recruitment material that participants would not have to state whether they had erectile dysfunction. In Low et al.(2002) and Granger et al.'s (2002) study they did not ask participants whether they had erectile dysfunction and did not report significant recruitment problems. However this study was designed to explore experiences of having and disclosing ED therefore an adequate understanding of the phenomenon could only be achieved by talking to people who had lived experience.

### **Ethical permissions**

At all stages within the design and conduct of this study ethical principles were given paramount consideration, therefore all choices made and justifications given were fundamentally ethically driven. Due process was followed with the submission of the planned research to the School of Nursing and Midwifery's Ethics Committee, the Regional Research Ethics Committee and the local health board's research and development department (including site specific access agreement) (see Appendix 5), all of which were granted sequentially. Research governance processes were ensured by gaining approval from all these bodies by the completion of an on-line Integrated Research Application System (IRAS) form.

The study was guided by and committed to the principles governing ethical conduct of research by The Nursing and Midwifery Council (NMC 2008, NMC 2015). The research proposal was also peer reviewed by Research Collaboration Building Capacity Cymru prior to a funding agreement being issued and quarterly progress reports were required in order to maintain this funding stream (see Appendix 6). Similarly, annual reports were required by the university's and the hospital's research and developments department and the local ethics committee. Attendance at the ethics committee was required prior to permission to proceed being granted. This was a positive experience which required that I confirmed that "implied consent" with regards to the anonymous questionnaire meant that by filling in and returning the questionnaire, men with ED were giving their consent to provide that data. No other questions were asked.

## Confidentiality and Data Protection

During the ethical review processes it was made explicit that participants were to be informed that all information collected would be confidential and that no names would be attached to data, ensuring that confidentiality would be maintained. All de-identified data and corresponding information was to be locked in separate filing cabinets to avoid participants being linked to the research study. All documentation was kept in accordance with the Data Protection Act (Great Britain 1998) and University Policy on the retention and storage of confidential information. Due to the private and sensitive information which could potentially be discussed, or which may make some people feel that they did not want to participate, aspects of confidentiality were made explicit in all the recruitment information and again when people were interviewed. It became apparent during the interviews that anonymity of interview participants was their significant concern, even though they had agreed to participate. These risks can potentially exist when undertaking any research, especially when the topic is likely to provoke powerful emotions (Corbin and Morse 2003), however by maintaining all of these safeguarding measures in relation to anonymity and data protection it was anticipated that some participants might be able to overcome these concerns and identify benefits as a result of participating: for example self-acknowledgement and validation, a sense of purpose, a sense of empowerment, healing and potentially and most applicable for topics such as this, giving a voice to the voiceless and disenfranchised (Corbin and Morse 2003 p.349)

Conducting interviews with healthcare professionals carried its own challenges, only one of the men with erectile dysfunction had overt concerns with regard to anonymity and confidentiality but several of the healthcare professionals joked during the interview about anonymity and the maintenance of confidentiality. I felt the need to remind them that as a nurse I remained bound by professional body regulation (Nursing and Midwifery Council) regardless of my current role and the requirements placed upon the conduct of those involved in the research by the committees which had granted ethical permissions.

## Data Management

Interviews were digitally recorded on a handheld digital voice recorder and transcribed for analysis within twenty four hours of recording. The recordings and transcriptions were stored on a specific, password protected computer within a university office which was locked when unoccupied, facilitating safe data management and accurate recall on my part to be able to verify the transcriptions. Although the interviews were conducted in a variety of environments, the quality of the recordings was sufficiently good for accurate transcription, which was at times helped by the fact that I had conducted the interviews and undertaken the transcription.

## **Researcher involvement; the author's role as interviewer**

Due to the informal design of the interviews it was anticipated that there would be questions asked of myself, not only as a researcher but also as a clinical nurse. A conscious decision was made before conducting any interviews that clinical questions would be addressed after the interview and, if required, I would discuss referring any men to the clinic. Potentially people may have discussed illegal behaviours or malpractice with myself and also life changing decisions, such as the decision to seek treatment without their partners consent. Clearly defined clinical supervision was in place prior to starting the research, for my own protection and that of the patients. The default position was always to adhere to the Nursing Code of Conduct (NMC 2008). This was explicit within the recruitment information and revisited at the beginning of each interview.

I fulfilled the role of interviewer for all the interviews. This was considered from the outset to be a benefit to the study because of my training as a cardiac nurse and experience of having worked within the erectile dysfunction clinic for the last six years; therefore the safeguarding concerns of the ethics committee were addressed. It was acknowledged that I might have had a greater than average confidence in broaching this topic and also an experiential sense of when to terminate discussion. Such experience would also allow for questions from the interviewee to be answered and appropriate referral of men to the erectile dysfunction clinic when required.

This prior experience did prove problematic however because I tended to use a more clinical style of questioning to elicit responses when it was felt that prompting was necessary. On listening to an interview with a healthcare professional, when I asked “what is it do you think that stops people disclosing erectile dysfunction, do you think it is embarrassment”, it became clear that such a closed question would not facilitate deep or rich discussion. In another interview, the man said “no one is going to say oh I can’t get an erection it’s a different ball game” to which I responded “yeah it’s not having a broken leg is it” to which he responded “yeah”. With reflection it would have been more enlightening to ask “Why is it not like discussing a broken leg?” and this might have received a more in-depth and illuminating answer, however there is a difficult path to be tread between asking for deeper meaning and fostering mutual understanding in which the participant feels that the interviewer genuinely understands them.

With practice I felt more comfortable allowing the discussion to be led by the participant rather than requiring answers to diagnostic questions, as this confidence improved the data appeared to become richer, but the interviews shorter; less time was being spent on easing the participant into the interview and greater confidence allowed me to challenge or seek clarification on issues when required. With increasing researcher confidence key reference questions were used with less frequency and interviews became more free-flowing.

I was not known to any of the men who were interviewed. However, those who have subsequently been referred to ED clinic would be met again, with differing role as patient and healthcare professional rather than interviewer and interviewee. Clear role differentiation was imperative and could only be achieved by moving from researcher to nurse, had I met the men first as a nurse they would always have considered me as such and they would possibly have talked to me in a more clinical way than they would as a researcher (Yanos and Ziedonis 2006).

The interviews conducted with healthcare professionals, when we were unknown to each other, were greatly assisted by the confidence gained from initiating discussions in clinic. Conversely, in the interviews with healthcare

professionals with whom I had an existing relationship, opening dialogues were less awkward and there appeared to be less of a degree of professional guardedness. During interviews healthcare professionals often used truncated terms and jargon, speaking to me very much as they would have done when working together. This was useful because it meant that little time was wasted clarifying abbreviations but it did assume some prior knowledge on my part. If terminology was foreign I did my best to ask for clarification, however was mindful that practitioners would potentially refer patients to the clinic in which I worked and therefore I did not want to excessively simplify the questioning. In undertaking these interviews I found myself in a difficult position; I had a good clinical knowledge of the topic, more so than just an interactional expertise. In some respects it could be considered that it was the healthcare professionals in these interviews who had enough linguistic knowledge on the topic to be considered interactional experts, whilst I, as the researcher who works in an ED clinic, had only a contributory expertise (Collins 2004).

Having conducted and transcribed the interviews myself, I was able to understand the unspoken communications far better than if I had just read the transcripts. During the latter IPA analysis it became obvious that there were pauses and episodes of laughter which seemed incongruous when looked at in a verbatim transcript. Having participated in these discussions I was better placed to interpret the whole situation and the context in which they happened. A similar benefit was noted with reference to the use of euphemism and humour. When read, in the transcripts, these often appeared as defensive or aggressive comments but at the time this did not seem to be the case.

This chapter has set out the methodology and philosophical underpinning of the thesis and how this has been used in order to frame the design of the research and the thesis. The study was designed from a phenomenological perspective which allowed the experience and understandings of the researcher to be recognised, this was pertinent because of the pre-understandings of the researcher and the influence that these would have over the interpretative analysis which would follow. The study was designed to comply with university, health service and professional ethical regulations and

undertaken adhering to these principles. The data collection undertaken and the analysis of this data will be discussed within the following chapters.

## **Chapter Four: Analysis**

This chapter will explore in detail how the analysis of the interview data was undertaken. The samples will first be described so as to offer a sense of the groups that were interviewed, and evidence will be provided of how each interview transcript was analysed, so as to identify themes from individuals, groups and the whole sample.

### **The In-depth semi-structured interviews**

Phenomenology is a research approach which permits exploration of personal and emotional aspects of a participant's experience; hence methods used are often unstructured interviews, allowing for the full sense of the participant's perception of a situation to be captured (Pascal et al.2010), for this subject area it was considered that participants would require some direction especially in the initial stages of the interview. Semi-structured interviews were therefore chosen as a way of helping participants to discuss the phenomenon and prioritise the specific aspects that they felt were important. The list of prompt questions which were agreed for use by the ethical committees were designed in conjunction with the clinical lead for the research and the lead nurse for cardiac rehabilitation, using their extensive clinical experience and their understanding of both the research aims and the population being studied, they identified areas of focus which would be informative but also not cause offence to participants.

A Heideggerian influenced approach to interviewing aims to foster a situation where there is a dialogue of inter-subjective depth and mutual understanding (Miller and Glassner 1997); it permits participants the opportunity to describe their reality as a complex whole; rather than measureable parts. Such interviews have been described as a mutual dialogue which should be undertaken in an environment of trust and safety between the interviewer and the interviewee, this needs to be maintained throughout the research process not just during the interview (Marcel 1971). Lowes and Prowse (2001) believe that the outcome of interviews undertaken in this way is a reciprocal dialogue where feelings of curiosity and respect are fostered on an emotional and

cognitive level; however they do warn that a degree of detachment is required in order to manage the interaction, within the discussion of the methods this particular aspect of interviewing will be highlighted as a difficulty and discussed in greater depth.

There is plenty written on how to undertake an interview and Laverly (2003) suggests that at the beginning of an interview the researcher should ask about normal or day to day aspects of life, which are often considered so mundane or taken for granted that they are not routinely considered by the research participants, because this helps to illuminate the sub consciousness. It was anticipated that none of the participants would feel comfortable launching into their own monologue about this subject and therefore the permission giving facilitated in a semi-structured style of interview made the discussion easier. The adaptability permitted by a semi-structured interview means that the interviewer does not have to rigidly adhere to a predetermined schedule, but can take the conversation where the participants lead it, which is more akin to hermeneutic inquiry (Laverly 2003).

One to one interviews were conducted at times and locations suitable to the participants in the belief that they would choose a setting in which they felt comfortable and confident to talk, some choosing to have their partners present during the interview. This particular choice provided an opportunity to foster a sense of openness and supportive behaviours and improved the likelihood of open discussion because it has been demonstrated that dyads containing a female are most likely to disclose personal issues (Brooks 1974). The participants were informed that they were in control of the interview and had the right to withdraw from the discussion at their will.

It was hoped that the concept of “*social distance*” whereby people are used to talking to some types of people and not others (Dohrenwend et al.1968), might facilitate both the healthcare professionals and the men with erectile dysfunction in feeling able to talk about the subject matter. Both groups would be used to talking to nurses, and because they were aware of the dual role of the researcher, this may assist in the reduction of the social distance; potentially allowing the receptive and meaningful dialogue to be achieved.



## **Interviews with men who had identified themselves as having erectile dysfunction**

Nine men returned the consent to contact form and all nine were interviewed. They ranged in age from forty seven to seventy eight years. All were married and had been for more than twenty years. Eight of the men described themselves as white British and one described himself as British but of immigrant parents. All had attended the whole of the cardiac rehabilitation course and were planning on attending the follow-up sessions at the local gym. None were currently working, eight having retired and one being unable to work. Two of the men were interviewed with their wives. Three of the men, none of whom had been interviewed with their partners, had not disclosed erectile dysfunction to anyone prior to taking part in the interview, their discussion was the first they had engaged in with anyone that they recognised as a healthcare professional; a unique aspect of this study. There is currently no published literature that identifies any of the participants as non-disclosers and therefore there is no data which has been identified as having been provided by men who have not previously disclosed their ED.

The location of the interviews was usually, at the suggestion of the men, in a consulting room; if possible this was married to existing hospital appointments to prevent multiple trips. Some of the men kindly invited me to their houses and I was made to feel very welcome.

The list of guiding questions was used although the participants were free to discuss whatever they felt was relevant (see Appendix 7). Questions can provide useful guidance when a topic is perceived as “uncomfortable” and helps both the interviewer and participant to focus on the topic in order to achieve the outcomes of the research. Similarly it is essential to provide review panels, such as the ethics committee, with details of the potential discussions so that they can make an informed decision as to whether the research meets with ethical principles. Some initial questions focused on their recent admission to hospital and their heart disease, which helped them to get used to talking whilst being recorded and reduced any fear that they may have had about what they were going to be asked; what they may have considered to be probing questions. This was also useful in getting a broad understanding of

their background, considerations to their health and pre-understanding in phenomenological terms. I would then remind them of the research topic and ask if they could recall any experiences, the conversation usually flowed from that point forward, exploring the men's experience of having erectile dysfunction, how long they had been experiencing it, how it made them feel, how it had affected them and to whom they had spoken about it. Their thoughts on erectile dysfunction as a marker of cardiovascular disease were explored and whether they felt this marker would have influenced their disclosing behaviour.

The nature of this more informal one to one interview allowed for a relatively candid conversation. The level of embarrassment although ever present, was greatly lessened by the informality and minimised by affording the interview as much privacy as possible. None of the participants refused to discuss any of the topics and although it was anticipated that the gender of a female researcher could make some men feel uncomfortable, this transpired not to be the case. Whilst the gender of the interviewer is considered to be an important and influential aspect of the interview process it is notable that Burd et al.(2006) and Dindia and Allen (1992) concluded that men feel more comfortable disclosing sexual health problems to a woman than to another man, and that women are more inclined to talk to women also. Therefore the interviews all being undertaken by a women may increase the likelihood of deeper and more forthcoming discussions.

Williams and Heikes (1993) concluded that people use different language and emphasise different aspects of their thoughts depending on their gender in relation to the gender of the interviewer, suggesting that men are more comfortable talking to women about emotions and feelings than they would be talking to another man. They also discussed how people cross check with their interviewer to ensure that there is a shared comprehension, which may be felt to be necessary when talking about gender specific issues (ibid). The topic for discussion will however influence these disclosing behaviours as, whilst discussing emotions with a woman may feel more comfortable for a man, when the topic is about exclusively "male" subjects then displays of hegemonic masculinity may impede data collection. For example Pini (2005) found it

difficult to elicit open answers from male farmers when she asked them about their male dominated profession. During the peer review processes, in order for this research to gain official approvals, it was highlighted that the men in particular may not feel comfortable talking to a woman about a male sexual health problem; however, both my experience from clinic and the published literature appeared to contradict this concern.

Self-reporting can offer the opportunity to gather retrospective data and future plans as well as feelings, values, opinions and motives but issues of validity and accuracy are problematic because the researcher has to assume that participants are telling their truth. There is a human tendency to present ourselves in a positive light and this may result in a social acceptability bias as participants modify or enhance their story (Stokes et al.1981). Due to the embarrassment attached to the topic, symptoms and effects can often be de-emphasised; however within phenomenological studies the story of the participant is their truth and should be taken as such. I found this aspect problematic, as a nurse I was used to taking what I was told at face value and not questioning or delving further, all skills at which Kleiman (2004) considers nurses are adept. One way of overcoming this was to repeatedly remind oneself that in terms of the analysis, what the researcher is being told may not always be taken literally and with practice I began to ask more open questions which made it easier for the interviewees to naturally expand upon their answers and thoughts. This is an acknowledged problem where clinicians become researchers, and must be identified prior to the interviews so that the researcher is conscious of their discussions throughout the interviews (Chew-Graham, May and Perry 2002).

Often there were practical constraints such as time or environment which seemed to limit the interview. Interviewees often commenced the interview with an explanation that they needed to have completed the interview within a given time and this limit not only impacted upon the descriptions the men could give but also impinged upon the rapport which could be built. On reflection the use of a lack of time, by most of the interviewees may have been a way of them maintaining control of the interview and purposefully limiting the depth which could be achieved. This had to be respected and the potential risk associated

with asking someone to revisit a difficult subject had to be taken into consideration (Semin and Smith 1999).

The men were quite explicit in their motivation for participating. They had all recently been under the care of the hospital and the cardiac rehabilitation team following what most considered a life threatening event. They were all keen to help these departments in any way they could and felt that volunteering to take part in this study was paying back the people who had cared for them. They were also now aware that erectile dysfunction could be a precursor to cardiovascular disease and therefore adopted a utilitarian attitude, hoping that the information they provided may be used for the greater good. As a result of this motivation nine men were recruited to participate in the study, had the motivation not been there I am not sure that sufficient recruitment would have been achievable. So whilst the motivation may have influenced the priorities and fore-structure of the participants it may also have played an important part in facilitating the study.

### **Interviews with Healthcare Professionals**

Nineteen interviews were conducted with healthcare professionals who formed a purposive sample; having been recruited by the recruiting clinicians. The individuals were approached specifically to make the sample as varied as possible with respect to their profession and their clinical experience. The sample consisted of ward nurses, clinical nurse specialists, practice nurses, medical registrars, consultant cardiologists, general practitioners and pharmacists. Thirteen of the nineteen were female, seventeen worked in hospital settings and two in general practice. Most of the sample had been working in their current profession for more than ten years; the least experienced interviewee had been qualified for four years. The original target of twenty interviews was not reached because data saturation with this sample was achieved after nineteen interviews. Ultimately nine interviews were analysed, and this decision will be discussed later in this chapter.

Again, once the participant had made contact, we arranged a mutually agreeable time and location for the interview; this was usually their suggestion and most often took place in the clinician's offices. Some participants kindly

invited me to their homes, believing that their clinical work load would prevent them from being able to commit to an interview during a working day.

The brief list of prompt questions was used in the initiation of the interview to help focus the discussion on the aims and objectives of the research and also to provide review panels with an indication of potential discussions (see Appendix 8). Equally as much support may have been required for healthcare professionals as with the men with ED; they were talking and considering their own practice and this may have been difficult for some. The interview commenced with a brief review of the study information. In order for them to get used to talking on the voice recorder some initial questions were asked about their overall clinical experience and their current clinical role, this information was useful to gain an understanding of their past experience and pre-understanding. The guiding questions focused on their experience of disclosures and how they felt they had managed the situations, their knowledge of erectile dysfunction as a marker for cardiovascular disease and their training in this particular area.

Healthcare professionals seemed willing to participate because they had been asked by a colleague. They were keen to help and were happy to spare the time. Many refer patients to the Male Sexual Health Clinic and knew of my role within the clinic so they would often make assumptions about my knowledge and understanding, using abbreviations and technical jargon which did not help when the transcripts of the interview were supposed to be giving an “*atmosphere*” (Corbin and Morse 2003 p339). It became apparent, as more healthcare professionals asked questions of me, that they may have considered me as having “*contributory expertise*” and therefore felt that the power in terms of knowledge of the subject was situated with me (Collins 2004 p.126). Interviewing fellow professionals can have positive implications for the data, because the professionals being interviewed do not feel that they are being tested but are engaged in a conversation, hence are likely to be more open and honest about their true thoughts and feelings (Chew-Graham et al.2002). However if a power differential is perceived by either the interviewer or the interviewee this may have an influence over the conversation, something the interviewer and the analyst must be mindful of during both

interviews with professionals, and as a professional interviewing patients (ibid). Often participants wish to please the interviewer, especially in situations where such perceptions of power exist, and their responses are altered accordingly, this can in turn bias the responses, a significant methodological consideration (Dohrenwend et al.1968).

### **The questionnaire**

The “*difficult to reach*” population of men with erectile dysfunction were considered, by the RCBC peer review panel, to be unlikely to engage in this research because they would not feel comfortable participating in a face to face interview; therefore an anonymous questionnaire was designed in order that funding for the research would be granted. The aim of this method of data collection was therefore to gain data from men who had ED but would not be willing to talk about it in an interview scenario. This method of data collection does not naturally fit as a method used within phenomenological enquiry because by the very nature of a questionnaire it is difficult to allow the freedom of expression facilitated by interviews (Annells 1996), however a questionnaire was incorporated which was designed to ask questions which were also provided as the prompt questions for the semi-structured interviews and thereby provide an insight from the men who were unwilling to discuss ED.

This questionnaire filled one side of A4 paper and asked about participants’ age, their heart condition, how long they had been experiencing erectile dysfunction, whether they had disclosed it to a healthcare professional and why they had decided to disclose or not to disclose (see Appendix 4). Space was left for them to expand on their answers and to provide any other information they felt was important, as a way of allowing participants to express, to a degree, their priorities and thereby adhere to some of the principles of phenomenological enquiry.

Ten questionnaires were returned, of which nine were in the same envelope as a “Consent to Contact” form, thereby invalidating the anonymity. One anonymous questionnaire was returned from a man whose demographic details fell within the range of the men who volunteered for interview. Two hundred questionnaires were given out over the recruitment period therefore

the return rate was five percent. The one survey which had remained anonymous was reviewed in light of the emerging themes from the interviews; and was considered to align with them, however the responses were singular words and the space to provide other information was not utilised; therefore the decision was taken by myself and my supervisor that the singular questionnaire would be kept but not written up as an exclusive finding, this could have potentially resulted in the man who had returned this questionnaire being able to identify himself within the thesis, breaking confidentiality and anonymity requirements. The information within the questionnaire was not discounted, once the interviews were analysed and themes emerged, the answers in the questionnaire were reviewed to establish whether they aligned with those which had been generated from the interviews. The lack of engagement by men with this method of data collection also informed some of the questions in interviews and when one of the men was asked why he thought it had yielded so few responses his reply was *“when they are ready to talk they will talk”*.

### **Undertaking the data analysis**

Heidegger recognised that the truth about an experience as professed by one person might differ markedly from that believed by another person; however the truth is intertwined with perception and experiences, which whilst unique, may still resonate with one another. Therefore the aim of analysis in phenomenological studies is to dig, as deeply as is possible, into each participant story to identify and elaborate on the essential or core elements of the experience (Laverty 2003 p.24). Analysis of this data then explores all the influences that have been expressed during the data collection (Pascal et al.2010), incorporating both actual and intended meaning (Laverty 2003).

During the initial thematic analysis mind maps were created for each interview and written at the end of each interview transcript, (see appendix nine). This helped to identify the aspects of each interview that were presenting themselves. Mind maps are a visual way of displaying the reader's thoughts or impressions in a single frame and therefore are very minimal in the information they contain; focusing on the more overt issues (Braun and Clarke 2006).

These mind maps were then considered in relation to the other mind maps to identify areas of commonality and aspects of uniqueness.

Once mind maps had been created for all of the interviews (for examples of original mind maps see Appendix 9), similar thoughts were grouped together and given an arbitrary title so that a more specific look at each transcript could identify all the quotes thought to relate (see Table one as an example of the theme ‘Professional self’ and the data which Rebecca and Jeremy’s interviews provided on this theme, full tables are provided in Appendix 10). To assist in this process, the computer programme NVivo was used. This programme facilitates the storage of data in a variety of formats so that the emerging themes can be seen and considered in differing ways. Although used in this early stage of analysis I found the programme cumbersome and at times the detail on the screen prevented focus on the data. Having conducted and subsequently read each interview several times I found that I knew where the data was in each interview and found it easier to dispense with NVivo. I reverted to printing the transcripts and physically deconstructing the interview transcripts into themes.

Table One

Theme: Professional self

<b>Rebecca (interview 2)</b>
Lots of training and cardiac experience over 15 years but none related to erectile dysfunction
Did not want to build into clinical practice routinely asking about ED
Did not think that professional colleagues would want to know about ED

<b>Jeremy (interview 4)</b>
Professional self not discussed in terms of training- shared understanding
Men do not disclose because of his professional role
Happier to discuss in terms of research “clinical phenomenon”
Is it rehab’s job?

Once a set of initial themes had been identified and reviewed by myself and my supervisor, I returned to the interviews. On re-reading the transcripts, and mindful of the initial themes, I was able to look at the broader context around each of the statements which I thought contributed to a theme. This provided



me with a greater understanding of where each statement was anchored which would then often drive me to reconsider the meaning of the statement. This process was undertaken several times over, with each cycle being reviewed and considered by my supervisor to maintain perspective and rigour. Koch (1995) describes this process as immersion in the data, during which the researcher goes beyond literal meaning to grasping fore-structures and themes, moving from overt themes to covert essences. The use of thematic analysis is widely acknowledged to be a flexible form of analysing qualitative data, however because of this lack of structure there can be commonly identified pitfalls. Due to the interpretive nature and scope to approach the process in a variety of ways, there is the potential for the researcher to, in a sense; forget the original question during the process of analysis (Braun and Clarke 2006). Similarly the themes become so abstracted from the data that when the researcher comes to apply the themes to the existing literature it is difficult to see how the data in the verbatim transcript tallies with the theory that the researcher has identified (Braun and Clarke 2006). This is in essence what happened with this thesis. The lack of depth in the data, which will be discussed within the analysis and discussion chapters, resulted in it being very difficult to convincingly carry out a thematic analysis of the transcripts because often very few words were used and there was a significant amount of shared understanding within the text. These statements were often lacking in depth or weight when used to support a theme that was being discussed. Therefore a pragmatic decision was taken to reanalyse the data using a more structured format, interpretative phenomenological analysis (IPA) to support data analysis and to revisit the data to obtain a more in-depth understanding. IPA can be considered as a method of analysis although some consider it a philosophy which should guide a research project from its inception (Smith 1996), however for the purposes of undertaking a second analysis IPA was used to undertake a systematic revisiting of the interview transcripts and then to revisit the literature; as is anticipated in IPA. Although IPA analysis takes a structured format there is a flexibility associated with this method which specifically facilitates the exploration of emotional and sensitive responses which might not be easily verbalised. Its use with this data set, which after the initial analysis seemed to be lacking in depth, was therefore appropriate and would

potentially facilitate the finding of themes which had not previously been identified. IPA has been used to study topics which have been multifaceted and complex particularly in relation to healthcare and it has been demonstrated to facilitate analysis of interviews where the topic is considered difficult or not easily discussed, therefore the use of this approach to analysis, based on the initial understanding of the data would be congruent (Smith 2004). This late change in a fundamental element of the research process required that the values of the project were maintained, in order to maintain the value resonance. IPA and phenomenology have clearly shared characteristics, IPA having originated from the earlier phenomenological authors. Both note the objectivity in the process and that they are searching for how participants make sense of an experience rather than simply documenting a description. Phenomenology and IPA both seek to revisit the data in light of the previous analytical thought and use the hermeneutic tradition to achieve this emersion in the data (Smith 2004). Therefore the values which were explicit in using phenomenology hold true in the use of IPA and thereby provide continuity in relation to maintaining a value resonance throughout this thesis.

The analysis phase of an IPA study begins with a detailed case by case analysis of the individual transcripts (Chapman and Smith 2002); the aim of this stage is to consider the thoughts and cognitions of the particular group of individuals (Chapman and Smith 2002). I read the transcripts of the men's interviews as one group and the interviews of the healthcare professionals as another. The detail which is required at this stage of analysis can mean that a single interview can take at least a day to analyse and therefore typically researchers who are conducting IPA research have smaller numbers within their sample. At this stage it was decided that twenty eight interviews would be unmanageable in terms of the in-depth data analysis and the IPA research community were accessed for their opinion on only using some of the interviews with healthcare professionals, reducing this number from eighteen to nine; providing equal weighting with the interviews with men. The opinion was supported, a random selection of half (nine) of the healthcare professional interviews were identified for analysis (Personal communications via IPA online research interest group [www.ipa.bbk.ac.uk](http://www.ipa.bbk.ac.uk)). Therefore all the interviews with

men and half the interviews with healthcare professionals were analysed in this way.

Initially each interview transcript was put into a table with a blank column either side, and as the transcript was read initial thoughts about anything were noted in the left hand column, either within the text or periods of silence (see Appendix 11 as an example); these were descriptive comments (Smith et al.2009). This process was difficult because of the pre-existing analysis and so a conscious effort to read every word was made. In reading the transcripts and taking notes the first two steps of Smith et al.'s (2009) guide to undertaking IPA analysis were amalgamated. They describe the note taking as a second stage, with the first being the reading of the transcripts, but having read and reread the interviews, stages one and two were undertaken together. The benefit of these stages is that they can be undertaken as many times as is necessary, so the transcripts were revisited several times each, often identifying new elements or discounting previously considered aspects in light of having read further through the transcript. These stages were akin to completing hermeneutic circles, but because of the more prescriptive format for documenting the initial thoughts, they resulted in a clearer and more focused exploration of the text.

Within the descriptive stage, elements of language were identified and also highlighted within the left hand column. This involved not only the literal words but also the meaning which the participant may have applied and their potential explanation of their thoughts. Within this phase, whilst considering the language, it became more obvious that there was a significant amount of shared understanding between myself and the participants, which reduced the amount of thick description which could be identified; this will be discussed in greater detail within the analysis. The final element of this stage of analysis involves populating the right hand column with conceptual thoughts and questions (Smith et al.2009); this stage required a re-reading of the description and constant asking questions of the text. Many of the questions that were asked at this stage resulted in no further analysis, however this is not unusual

and Smith et al. (2009) describe this stage as the opening up of a range of meanings.

Table Two provides an example of a page of interview transcript as an illustration of these stages.

Table Two

Life changing moment Euphemism	CD: it was wasn't it but it was it was a glowing report on your general state of health Mrs A: yes yes Mr. A: well not bad then (laugh)	Change in identity- something has changed at a particular (not defined) age What falls off?  This is his wife
No clear onset/ downplaying	CD: (laugh) but generally you have been quite fit haven't you you have not had any major operations or anything Mr. A: no no never no	Language Is she demonstrating that to her is does not matter, but to him it does?
Memorable incident	Mrs. A: he was fit until he was 69 and then Mr. A: then it all falls off (laugh)	Why defer to the wife? Time
Life changing, slow creep One specific time-questioning	CD: (laugh) all falls off Mrs. A: he never took time off work you know odd cold things like that but nothing else CD: so when did you first notice your ED? When what sort of age were you do you reckon when you started noticing?	Time/ context  Awful questioning technique
Delay in seeking help Sense of this being a long	Mrs. A: do you know I can't think Mr. A: because you are better on dates than I am (laugh) Mrs. A: about five years ago Mr. A: no it was longer than that Mrs. A: longer than that? Mr. A: longer yeah it's got to be when we were in the Isle of Wight ten years ago? Mrs. A: OK CD: was it a sort of gradual onset or did you think	Knowledge/ understanding/

Stage three, according to Smith et al. (2009), aims to reduce the large quantity of notes taken in stages one and two, reducing the volume of detail so that emergent themes can be seen (Table Three and Appendix 12 as examples). I found this stage easier to achieve by working with my notes on each transcript initially and then once a theme emerged going back to the original transcript to consider whether the text would support that theme. The revisiting of the data with consideration to the emergent themes is one way of completing a single

hermeneutic cycle (Chapman and Smith 2002). This process was completed several times over, revisiting the interview transcript with the themes and the themes within the interview transcript.

Table Three

<b>Funnelling</b>	<b>How life changes with age</b>	<b>ED and what it means personally</b>	<b>ED and what it means in terms of disclosure</b>
Reducing tension	Language- medical and negative	“it”- euphemism	Language- need for medical language
Power/ status	Previous self (MI was life changing)	Shared understanding	Shared understanding
Participant closing down discussion	Current self (impact of age)	Maleness	Knowledge of treatment and causes required in advance of disclosure
Managing difficult statement- changing subject		Sense of self- alone	Risk associated with disclosure
Connection ie putting interviewer into context		Context determines level of importance	Personal feelings after disclosure
		Acceptance- contradicting thoughts	Trust in HCP- stronger in relation to MI than ED

Stage four involved looking for connections between the themes within each individual case (as described by Smith et al.2009), as I had worked through the interview, thoughts on themes would be documented chronologically and in the fourth stage I found it easiest to write a list of themes at the end of the interview and see where there were similarities or particularly, contradictions (Smith et al.2009). These thoughts were then tabulated at the end of each interview (see Appendix 12 as an example).

Step five involved taking the themes into other interviews (all of which had been analysed using stages one to four) and seeing which would hold true to all the participants' stories (see Appendix 13 as an example), only some of the stories or those which were unique to the individual. This stage was challenging because it was difficult to suspend the thoughts and emerging themes from the other interviews as well as the thoughts of the previous analysis; however it is necessary in order to maintain the idiographic commitment of IPA (Smith et al.2009). Often themes would, on revisiting the interview, not hold true, or on taking a theme from one interview to another similarly, have no evidence with any other participant. However within IPA there is the capacity for the researcher to retain the idiographic nature of an individual's story and present it as a singular phenomenon or understanding (Biggerstaff and Thompson 2008). In order to identify these individual stories they were highlighted within the text box of the interview and used in the idiographic description of each of the participants' (see Appendix14).

To begin to tie the cases together my supervisor and I, independently and then together, used the lists of the themes emerging from each case to plot out a visual mind map of the emerging themes (see Appendix 15) and how they would relate to the individuals and the group as a whole. This helped to pictorially demonstrate how the themes may correlate, particularly any overlap, as well as the demarcation between themes and a superordinate theme (Smith et al.2009). This process was useful in order to begin to think on a more theoretical level about each theme and how the individuals represented in the analysis related to one another and the world within which they are living. This change in process for the analysis phase of this thesis gave me an opportunity to revisit the data having put some time and distance between the interview being conducted and the analysis process being undertaken; this allowed the space to consider a different perspective on the data and the individual stories which were contained within it.

Having plotted the thoughts and tentative themes, IPA permits a researcher to revisit the existing literature and to consider this within the context of the themes that they believe are emerging (Biggerstaff and Thompson 2008). This

will not only reiterate some of the concepts that were identified before the data was collected; the introductory literature review, but also should take a researcher into new and unanticipated literature (Smith et al.2009). An exciting aspect of IPA in relation to the analysis phase is that unanticipated themes and ideas may present themselves and therefore a revisiting of the literature after the analysis would be expected; as a result new literature will be identified within the discussion alongside the literature which was highlighted in the initial stages of the thesis (Smith et al.2009). Having plotted the emergent themes and written an interpretive account of the themes, the existing literature review was revisited and a new review of the literature, based on the emergent themes was conducted in order to underpin the discussion chapter. The descriptive discussion chapter which follows will discuss the themes which have emerged following the process of analysis as described above and will make explicit how each theme was decided upon and what evidence from the interview transcripts would support each theme. The descriptive analysis of the interview transcripts will be followed by an analysis of the particular language used in each interview and how this may then further inform each theme. The themes and the language analysis will then be placed into context by using existing literature to locate the findings within current thinking and theory. In conclusion this study was designed using a phenomenological lens to explore people's thoughts and experiences of disclosing erectile dysfunction with the aim of gaining a better understanding of people's rationalisations of the topic and thereby identifying barriers and enablers to using ED as a prompt for cardiovascular risk assessment. Men with ED, their partners and healthcare professionals to whom a disclosure may occur were asked to participate and their thoughts sought using interviews and anonymous questionnaires. Recruitment of men to take part in the study for both interviews and in completing an anonymous questionnaire was less than anticipated and interview data lacked the depth and richness required to undertake the planned thematic analysis effectively, therefore a second analysis using a structured IPA process was followed. This second analysis was underpinned with similar phenomenological ideologies specifically hermeneutic phenomenology and therefore the epistemology and ontology of the study is essentially unchanged. Hence this study is a qualitative study which explores

the understanding and experiences of disclosing erectile dysfunction, using a phenomenological lens and IPA framework to support the analysis and subsequent discussion.



## **Chapter Five: Descriptive analysis of data from interviews with men**

The interview transcripts were analysed using the five step process as described in Chapter Four and the emergent themes will be discussed in greater depth within this chapter and those which follow. The data was analysed in two groups; men and their partners and healthcare professionals, hence the themes which emerged from the men and their partners will be discussed here followed by the themes from the healthcare professionals in Chapter Six.

In order to adhere to professional and ethical principles the names of all of the participants have been changed, so as to preserve confidentiality and anonymity (NMC 2008, 2015).

### **Themes Emerging from Interviews with Men.**

The interviews with the men were analysed individually, as previously discussed in the methods chapter and then as a group of men. The healthcare professionals' interviews were also analysed in the same way and grouped as healthcare professionals. The decision was taken to work with the data in two separate groups because, although there was a significant overlap in emerging themes, there were also specific themes that were only identified in relation to either the men or the healthcare professionals. The subsequent analysis of the language was undertaken as a single set of data, because of the similarities which ran throughout all the interviews. The themes which emerged from the interviews with men are notably not presented in an order reflective of any importance or weighting to each theme, however they do seemingly present themselves in a relatively similar order to that which occurred in most of the interviews; the impact of erectile dysfunction, thoughts and experiences of disclosure and how contemporary society considers sexual dysfunction.

## **The Impact of Erectile Dysfunction**

### **Acceptance of ED and its importance**

Early in the interviews all the men talked in seemingly accepting terms of having erectile dysfunction, Mr Andrews summed this attitude up as *“it is just something that happens you have to put up with it”*. They explained this acceptance because they believed advancing age to be a reason for their erectile dysfunction. Mr Hobbs said that *“I thought it was a natural aging process”* and Mr Franks exclaimed at the onset of his ED *“oh I am getting old now!”* This demonstrated how, to the men, ED was an indication or marker of them becoming *“old”*. The acceptance or apathy that they appeared to demonstrate was seemingly because they could have no control over their age and therefore because ED came with age they had to accept both.

The context of the mens' sex lives was also used to explain acceptance or rationalisation of the situation. Mr Evans considered both advancing age and the current situation where his wife was, to his mind, not interested in a sexual relationship.

*“I put it down to age, but can't practice with anyone like you know what I mean, so that's about it, I have virtually accepted the fact so there is no point in discussing it really”*.

He felt that his wife's disinterest in sex and his obligation to remain monogamous meant that erectile dysfunction became an issue not worthy of discussion because there was little influence he could have over either and this will be discussed in greater depth later in the chapter. Although Mr Evans saw no point in discussing his sex life he had volunteered to be interviewed and therefore he must have placed a greater importance on the subject than this quote would illustrate.

Thinking about the situation that the men and their partners were in, was key to understanding a decision not to seek help; which might be different from truly accepting the situation. A decision not to seek help being that they had not given up hope of ever having sex again, compared to an acceptance that

this would be the status quo for their remaining life together. The men seemed to think that there would be no reason to disclose erectile dysfunction, if the only reason was to receive treatment and you would not be able to use that treatment. They did not seem to consider that there would be any reason to disclose other than to seek treatment.

Mr Bridges described how he did not prioritise treatment of ED over the pharmacological regime that he was taking to treat his heart condition; he did not want to treat his ED and risk the balance of his heart medications being destabilised

*“they said they can rejig your medication but I thought well I don’t know I have settled down touching wood very well on these, I felt I didn’t want to change”.*

His thoughts were importantly within the context of being a carer for his wife, at the time of the interview she was undergoing life-saving treatment, so it was imperative that he was physically fit enough to perform this role as carer; this was clearly his priority and having recovered from a significant heart condition his concern was maintaining this degree of health. Mr Bridges, similarly to Mr Evans, further explained that there would be no point in seeking treatment because of his wife’s condition, therefore the alternative was to project an acceptance of the situation,

*“I don’t want to get back to normal and have nowhere to go with it basically, if you know what I mean, you are not pestering your wife for sex when she has got cancer (laugh)”*

Although there were different scenarios for Mr Bridges and Mr Evans, neither felt the need to disclose their ED because of their wives. Significantly the context of their love life influenced their thoughts about telling a healthcare professional about their ED, the only motivation for having such a conversation would appear to be to receive treatment and if they did not feel this appropriate in their lives then they did not feel it necessary to have such a conversation. None of the men, even those who had sought help for their ED, expressed great distress at having ED and it is important to note that they had all relatively recently been through a life threatening event and this had inevitably

caused them to re-evaluate their life and they had not necessarily placed their sex life in a position of importance.

These discussions of apparent acceptance were noted to be in the early stages of each interview and were initially difficult to overcome. If the men were not concerned about the erectile dysfunction, to the extent that they felt it was not a significant part of their life how was the interview going to tell me anymore! With time and continual rapport building, all the men made statements later in the interview which juxtaposed these thoughts of acceptance with discussion of how it had affected them as a person. Mr Davies joked that

*“there you go, you have had your good times (laugh), you know forget it all in a way, but er I have had my days now it is time to stop, put your key in your pocket and that’s it”* and then later said that *“I think Oh Christ there is still life out there, I do feel that I should still be functional”*.

The sense of not functioning or having lost a reason for *“being”* was discussed by all the men, this loss was not something that they discussed in matter of fact terms such as losing a body part, but in rather more emotional terms having lost a part of their sense of self.

Mr Bridges described his recent sex life as *“a bit of a failure, I thought this is the lowest moment of my life”*.

This was in stark contrast to the earlier discussions of how ED was something to be accepted with age. The more personal discussions and movement away from acceptance of an aging related ailment moved the thoughts of the men to focus on how ED had affected what they thought of themselves. The sense of something failing or being a failure was a common sentiment with most of the men indicating that they were now *“unsuccessful”*.

Mr Davies described himself as *“not completely right, put it like that”* and Mr Andrews felt that he was *“a bit of a failure”*, indicating that they felt ED to be something which had changed them and the way that they viewed themselves. None of the men described erectile dysfunction in positive or even neutral

terms; they all described how it had somehow deprived them of part of themselves.

Mr Andrews said *"it is a man thing, it's an ego thing, it is I can't do that, you are not a man, you can't do it"* and Mr Evans said *"it is not a manly think to talk about cos you lose your manhood like"*. Mr Collins went as far as to describe himself as having lost his *"prowess"*.

Describing life without sexual intercourse was equally as negative for these men, Mr Davies described himself as *"surviving"* and Mr Groves felt that his love life had *"gone down the drain"*. Mr Evans, described how

*"it is frustrating when you get to a certain point with your wife like and nothing happens, it is not a very nice thing to cope with, I have stopped functioning, it is the end of sports"*

The sentiment that he feels he is coping, is interesting. People normally cope with illness; however none of the men refer to ED as an illness, more of a change in themselves as a person, rather than a physical ailment.

There is a sense that these men are not used to talking about their sex lives or erectile dysfunction and took a while to get used to talking about the subject; possibly explaining why the answers they provided were short and felt awkward. In an attempt to overcome the awkwardness I tried to place the ED into the context of it being very common and the responses to this discussion were quite revealing. The men knew that this was a common problem but this seemed to do little to help them to feel more comfortable with the topic and they still described being alone or isolated, they felt that no-one else would really understand what they were experiencing. Mr Evans said *"I think this is only my personal thing"* and Mr Davies, when considering himself within the population, wondered whether *"I don't know whether it works for everybody (Viagra), or whether sort of my problem could be worse"*. Although the men in the study were disinclined to use other people to situate themselves within a population of men with ED, they talked about their need to seek information which if they truly believed that they were alone, they would not have been

able to find; because if they were truly that unique the literature probably would not exist.

Mr Andrews had researched the prevalence and knew that ED was a common problem

*“yes I read that it was more common but...”*

The “*but*” at the end of the sentence was telling, he knew ED was common, but knowing this was not useful to him personally; in a similar way as Mr Davies had felt that he may not be the same as the rest of the population with ED.

The contradictions of seemingly accepting the situation, acknowledging how they as a person in their own mind had changed and then still feeling hope that the situation could be resolved were common. Mr Davies still hoped that he would meet ladies

*“when I am out walking the dog more now, trying to find ladies out there with their dogs”*

This sense of hope that this was not the end of their sex life was similar to Mr Franks who joked

*“I will have to find somebody to do it with (laugh) is there any volunteers”.*

All of the men demonstrated hope that the situation was not permanent, even those who had been experiencing ED for several years. The temporality and hope of “*getting back to normal*” seemed to be something that never left them and indicated that their initial descriptions of acceptance were not their absolute truth.

Not only were the rationalisations and descriptions often contradictory but Mr Andrews described how his initial thoughts were not congruent with his behaviour; early in the interview he talked about an initial consultation which he did not feel went well and he ended the description of the conversation with “*and that was that really*”. Later he described how he went to see another doctor because he was “*fed up of waiting*” and when the treatment failed he “*just left it in abeyance then, it’s just something that happens*”, however since

leaving the situation in abeyance he had again sought treatment. Despite the initial tone of resignation there had been several attempts to seek help, despite feeling as though he had given up, hope remained and he continues to seek an effective treatment.

Mr Hobbs was the only man who did not express some hope that this was not the end of his sex life. He was accepting of the situation and after describing himself as *“grateful to be alive”* it could have been concluded that he was not prioritising his sex life, however he explained that he and his wife had a close and loving relationship but that they had not had sexual intercourse for years and that

*“it does not bother me, it is not a great part of my life now really”*

It is worthy of note that this was a difficult interview and many of Mr Hobbs' responses were single words, therefore he may have only felt comfortable expressing this reserved opinion and not wanted to explore his thoughts on how erectile dysfunction had affected him.

It became clear that the initial discussions of the men in this study are accepting of ED and rather dismissive of their sex lives. This may be because of their recent cardiac event and their prioritising of issues as a result of this or it may be because these were the issues which were covered in the early stages of all the interviews and there was a period of adjusting into the discussion and evaluation of what thoughts were appropriate to express. The men began to express their sense of personal loss or change in their perception of themselves which was juxtaposed with their initial acceptance and would indicate that the initial discussions were possibly not a reflection of their actual thoughts.

## **Disclosure**

### **Factors influencing the decision to disclose erectile dysfunction**

The men discussed a variety of factors which both positively influenced their decision to disclose, such as the influence of a supportive partner and more commonly negatively impacted, such as embarrassment, their age, cultural

behaviours and past experience. These factors were pivotal in influencing their behaviour and may be key in identifying barriers and enablers to the disclosure of ED.

All the men who had sought medical help for ED talked about the influence of their relationship with their wives on making a decision to seek help. Mr Andrews had talked about how he had arranged an appointment with his general practitioner to discuss his sexual health and on the day he felt that he did not want to go through with it, but did because he had told his wife that he was going

*“like I said to Mrs Andrews, I am going to go, and that was it”*

Mr Andrews' wife was present during the interview and her support had been what he credited as being the driving force for him seeking help. Mr Innes also discussed seeking treatment with his wife and had felt that her thoughts on the subject were congruent with his

*“we had a loving relationship and we still have a loving relationship and we had a discussion about it, well as she said, you know I don't fancy that (taking tablets), I mean when I feel like sex she said I want it then you know, not wait while you get your bottle out”.*

In opposition to having a supportive spouse, the men who had not sought help and rationalised this with talk of their wives disinterest or “being cold”, this seemed to provide them with a reason for not seeking help or continuing to live with ED. The resulting sense of isolation was clearly demonstrated by Mr Evans, who was married but still felt alone in the situation

*“so I was beginning to think I can't be doing with this and of course my wife was the same she just didn't want to know, my wife was taking it a bit personal as well like, it was nothing to do with her really, I knew the problem was with me but being a woman I suppose she thought you don't fancy me or whatever”.*

All the men described how ED was a threat to their sense of being a man and those without a supportive wife felt “alone” in the situation. When considered



within the context that these men would only disclose ED to seek treatment, it becomes clear why a supportive wife or partner is a significant influence. Not being a *“manly thing to talk about”* was explained as ED being an *“embarrassing”* thing to have and thus to talk about. The discussion around embarrassment although brief was enlightening, the men felt uncomfortable and once they had said that the topic was embarrassing there was a shared understanding between themselves and myself of what that meant, and the conversation moved on to prevent any further embarrassment, which will be discussed further within the linguistic analysis.

All the men described how sex lives are private and not something that is normally discussed. Both Mr Andrews and Mr Bridges used the word *“taboo”*, with Mr Bridges expanding to say

*“It is overladen with all sorts of taboos isn’t it, it is the last thing you are going to speak to your friends about”* and Mr Andrews explaining that *“you are talking about a rather personal part of your body, which is something which is not talked about”* and because the part of the body which identifies a man as a man is not working, it is embarrassing.

Mr Collins believed that this sense of embarrassment was not only felt by him, but it was the reason that most men would not want to disclose ED. In response to being asked why people do not talk about erectile dysfunction he said

*“well it is your old friend embarrassment isn’t it, I am comfortable (with healthcare professionals) but it is a little bit embarrassing, it is the embarrassment side of getting over these things”.*

Mr Franks felt that his embarrassment was rooted in his personality; being *“shy”* he felt that he had not previously felt comfortable having such conversations and that this was directly related to his culture, later in the interview he discussed how he thought other cultures would find such conversations far easier.

The only man who did not use the word embarrassment was Mr Bridges who had worked in a healthcare setting and felt that he would not be embarrassed

having a conversation specifically with a healthcare professional. He did say that he would not have such a conversation with friends and when I asked him why he had not used the term embarrassment, he said that he understood that it was an appropriate conversation to have with a healthcare professional, but he had not contemplated speaking to anyone else.

The men demonstrated some of their pre-understanding and the elements of themselves within this discussion, Mr Franks demonstrated how his culture had impacted on his understanding of the social acceptability of conversations about sex, Mr Bridges wondered whether his previous profession had impacted on his confidence in having such conversations and the social acceptability of disclosing personal subjects to healthcare professionals as explained by Mr Collins.

As an illustration of how embarrassing the subject was, the men discussed the use of illicit treatments, most having experience of having been offered them, as Mr Davies describes *"I have had offers you know if you are getting into trouble take these, in the local crappers on the corner or down the pub"*. They believed that embarrassment drove other men to taking a significant risk by taking medication from illicit sources, however none of the men admitted to having used any therapies from illicit sources.

Mr. Collins said *"it is a silly thing I think to be honest with you it is a bit dangerous actually you can have your prescription done on a website, honestly you just go through a questionnaire you can order, oh you are James Reilly (not his real name) yeah take that and you could end up in hospital minimum or killing yourself"*

It has to be recognised that although they did not admit to accessing treatment in this way they may have done and had chosen not to disclose this. All the men in the study demonstrated a degree of knowledge of this illicit trade, therefore the denial of using the black market may have been a socially acceptable story rather than a truthful and accurate representation for some of the men in this study.

Although none of the participants admitted to having use such treatments they all felt that younger men may be more likely to access treatment this way and associated this with a greater degree of bother at a younger age, as Mr Bridges specifies *“so it is not going to be a big problem for them (men of his age), but it will be amongst younger men, men in their 30s and 40s”*. Mr Hobbs felt that had he been a younger man, he too may have sought help in this way.

*“no but there again it affects men differently the degree that they are worried about it, doesn't it really, I mean my age, now if I was 29 it would be different”*

This sense that their age impacted upon their level of bother and that their previous sex life had been far more active was discussed by all the men and none felt that they had experienced a declining sex life at a particularly young age. In conclusion it became more obvious as the interviews progressed that the men initially felt uncomfortable discussing the subject and as a result portrayed a sense of not being bothered by their erectile dysfunction, however as they became more comfortable in discussing the topic and realised that they were not going to be asked for graphic details, they began to discuss how ED was affecting them in a personal way. They felt isolated and embarrassed by the issue and unless they were in a relationship which they considered mutually supportive, then they were not inclined to seek medical help, the motivation being to seek treatment. Their conversation around the illicit drug treatment was used by the men as a way of illustrating how the topic is embarrassing and that the need to remain anonymous is what drives this illegal trade. This sense of embarrassment will be further discussed within the linguistic analysis.

### **Experiences of Disclosure**

The theme of disclosure not only explores the experience of the men who have disclosed ED but also the thoughts of the men who have not disclosed, but they have considered this action and the reasons that they came to a decision not to disclose. Within the group there were men who had disclosed and who discussed this experience; there were also men who had not discussed ED with anyone. All the men however had sought information on ED, as a precursor to disclosure. The theme of disclosure will therefore explore the

experiences of those who have had discussions with healthcare professionals, information gathering undertaken by all the men, the privacy which is required in order to facilitate a conversation and outcomes from disclosures, both positive and negative.

The men had sought information from a variety of sources including the newspaper, the library and the internet; the common rationale for their choice was that they could access the information privately. Mr Collins explained that this was due to societal attitudes and the embarrassment felt by men.

*“there is a stigma involved and what you can do in a closed house, you will find that most of these men have erectile dysfunction and access to a computer will know all the symptoms and know all the remedies, you know go to an anonymous source first rightly or wrongly”*

Privacy and anonymity were concepts which resonated with all the men in relation to how they sought information, be this in anonymous formats such as the internet or being in a position whereby they were given the information, such as in poster form so that they could make a decision in their own time as to whether they wanted to tell a healthcare professional. Mr Andrews had sought information from all these sources over a period of fifteen years but was still searching for answers to the causes of his ED. His frustration at the lack of answers was clear

*“I could never find anything or read anything or find any information anywhere as to why, because nobody seemed to know, it was just something that happened”*

This frustration seemed to remain with him at the time of the interview, despite now having access to the internet; he remained sceptical of the answers he had found.

All the men who had disclosed ED had sought information before talking to a healthcare professional none had spontaneously decided to engage a healthcare professional in discussion without seeking information first. The information seeking prior to disclosure would appear to be part of the mental preparation that the men made prior to deciding to disclose erectile dysfunction

to a healthcare professional. Mr Collins described this step *“as making the next move from the privacy of your own home to open up to the GP or nurse”*.

Knowing that they were going to be asking a legitimate medical question, as a result of seeking information, seemed to empower the men to begin a conversation with a healthcare professional.

The men who had experience of disclosing erectile dysfunction had positive and negative recollections of these interactions. Those regarded positively were when open conversations were facilitated and appropriate referrals to specialists were made. Mr Collins described how his practice nurse had recently asked him about ED for the first time during a regular review.

*“she just put it as an aside issue as part of my examination, I have to ask you about your erectiles, I am not bothered, no I am not any more to be honest in all fairness I have gone past the thing, you need to be approached as an individual”*

It is worthy of note that he has diabetes and is asked regularly as part of his annual reviews, therefore this was not the first time that he had been asked. As a result of this conversation Mr Collins had been referred to a specialist who he hoped would be able to prescribe a treatment regime.

Mr Evans had *“no joy with prescribed medications, the Chinese ones out of all of them did me more good”*.

Mr Evans had felt the disclosure to the Chinese medical practitioner was a success, because he had received a treatment which he considered to be successful and Mr Collins had hope that he would also soon receive a successful treatment; hence they both felt that these conversations were constructive.

There were significantly more men who discussed less positive recollections of disclosure. Mr Andrews came home from seeing his GP to tell his wife *“well that was a waste of time”*. He was told by his GP that there was *“trauma”*, which several years later he was still confused about. He said *“I ended up with him, all he said was uhm yes oh Peyronies oh and he sat me on the table and oh yes a bit of trauma and basically hard luck and that was that”*. This

confusion meant that subsequently when he was given the choice of being referred to an ED specialist he refused to see the GP that he had initially seen. The GP he saw had a specialist interest in sexual health but Mr Andrews rather dismissively described this as *“it was his little thing”* and when given the choice *“I said forget Dr. B I don’t want to know that one”*; all of this seemingly stemming from the confusion over the word *“trauma”*.

Similarly Mr Evans had given up on seeking help from his GP *“I wouldn’t go to my doctor, I had stopped going there like, I had tried tablets but didn’t have any joy with them”*. Both the descriptions demonstrate how these men gave up seeking help from individual practitioners based on singular consultations, in which they were left confused and disappointed because of the communication issues and treatment failures.

Mr Innes had received a sympathetic response *“oh I am terribly sorry, it’s one of the side effects”* (of a prescribed antihypertensive medication). The sympathy and lack of hope was not well received by Mr Innes, who then decided that there was nothing more to be done.

Mr Collins, who previously talked about a positive experience with his practice nurse made a conscious decision to criticise his GP because he felt that having prescribed a treatment it was the GP’s responsibility to revisit the subject and to enquire as to the effectiveness of the treatment.

*“yes I will criticise my doctor, he mentioned it (ED) once or twice but it (Viagra) was never carried on, so I never had, whatever they stopped the pills”*

Mr Collins felt that having prescribed Viagra, his GP should have assessed their efficacy and inquired as to whether further prescriptions were needed. As a result of this lack of enquiry Mr Collins had not been prescribed any more Viagra and therefore had not taken treatment for years. The perceptions of success or failure of the consultation seems to be rooted in the communication skills of the healthcare professionals and whether the prescribed treatment, if indeed there is any treatment prescribed, is effective.

The men who had not disclosed their ED were asked whom they would be happy to talk to and as a result they had hypothetical discussions which

focused on the age and the gender of the healthcare professional. Mr Groves said *“it’s a man thing, if I had the preference I would rather talk to a man”*, however when they considered healthcare professionals that they know, they seemed more open to considering talking to women or people of other cultures. Mr Davies thought about the female GP at his practice *“even the lady doctor there you can talk to them”*, however he later contradicted himself with *“it is the same as buying durex over the counter isn’t it I mean you get a toothbrush because there is a woman behind the counter”*. Mr Bridges talked about his GP *“I mean he is a guy my age, although he is Asian, you feel I can ask him anything like that, it wouldn’t be something I would discuss with anyone other than well you know a professional person really”*

The men commented on the age, gender and culture of the healthcare professional that they would be willing to speak to; interestingly they described a preference in a hypothetical sense for speaking to a male, who was not young and seemingly not too dissimilar to themselves. However when they then thought about their own doctor they were seemingly happier to speak to someone they knew and then age and gender did not seem to play such a significant role.

The common experience that all but one of the men had was that of attending the sex talk in the cardiac rehabilitation course. The perceptions of those who had watched the DVD were quite different. Mr Franks felt a connection with the actors and believed that knowing people of his culture could discuss this topic had empowered him to volunteer for this research; he said *“they more or less interviewed the majority of different types and different age people, that’s where I found myself thinking oh right! we don’t want to talk about it, it’s embarrassing but now I feel after watching the video that I don’t feel embarrassed anymore”*

Mr Bridges also felt that the DVD was a positive thing although he did not learn anything by watching it, but he felt that the way it was presented was useful, he appreciated the *“matter of fact”* discussion and felt that as a British Heart Foundation production it was useful to see. His background in healthcare may

have influenced his thoughts in appreciating a charity providing educational material.

In stark contrast, Mr Collins and Mr Groves felt disconnected from the DVD with Mr Groves describing it as “a waste of time”, he continued *“I might sound a bit racist, they had a Pakistani guy on there who couldn’t speak a word of English, they had subtitles when he spoke and I thought perhaps they have got to do that to show they are not discriminating. I wasn’t taking a blind bit of notice of what he was saying, I kept on thinking what a waste of time, to be honest it didn’t tell me anything I didn’t already know”*.

Mr Collins described the session as *“the DVD is outdated, and it annoyed me to be honest, now this is an ethnic thing or not, what they are doing, they had an Asian couple on there which is fine, I am not prejudiced but this guy can’t speak English, he is speaking in whatever and the subtitles come up and I felt affronted, I felt by that. There is enough people out there they could have chosen rather than it’s not, just him being a typical well I don’t know I am typifying people now and I shouldn’t but that bit annoyed me. Uhm education wise yes it opens up but what it also did (laugh) and I know it does affect a lot of people, this is what the stigma is, it affects people of age, it is a stigma and you will probably tell me different and I am sure that it’s the case that a lot of people are a lot younger than me probably still have the same problem but this DVD had old people sorry”*.

Whilst Mr Groves had not connected with the actor on cultural grounds, Mr Collins felt disconnected because of both the culture and age of the actors, which is interesting because Mr Collins was the older of the two participants. This disconnection or isolation resonates with the previous discussion around feelings of being alone. The previously discussed isolation seems to have abated for Mr Franks because he connected with the actors, but the isolation is exacerbated for Mr Collins and Mr Groves because they could not recognise themselves within the film.

The sense of connecting with the people chosen to portray a message was not only discussed in relation to the DVD used in the cardiac rehabilitation class, but more broadly in the general media. The men hoped that the more positive



images of younger people, in the adverts for Viagra as an example, may portray the issue in a more positive way, as Mr Collins explained

*“because you look at any advert on impotence even on the web they are young couples I don’t care what you say there they are. I have not seen when people are advertising their wares whatever it is doesn’t matter, uhm pills potencies whatever you call them, there are young people depicted on that probably actors who are not impotent but that is not the point, it gives you that sort of feel good factor”*

The sense of connection or disconnection to the educational and advertising material is clear. It had such a positive effect on Mr Franks that he felt able to not only disclose his erectile dysfunction but also to take part in the study. Conversely, for those who did not feel connected to the actors, this disconnect resulted in them not taking any information and not being able to see themselves in the position that the actors were portraying.

In conclusion, some of the men had disclosed their ED and some had not. The experiences of disclosing ED varied from those which were perceived as positive and those which were less well received. All the men had accessed some information on ED and those who had disclosed had sought out this information before engaging a healthcare professional in a conversation. The information which the men had accessed can have a significant and positive impact on a man who feels connected with the actors portraying the message and conversely will have a negative impact on men who do not feel that they are being addressed. The impact of how a healthcare professional communicates during a disclosure of ED can also have a long lasting effect on the man and will influence whether they feel able to engage in a dialogue about their concerns for a significant length of time.

### **Erectile Dysfunction in contemporary society**

The men talked about how ED makes them feel and their thoughts about disclosing this to a healthcare professional, but much of what the men talked about was not expressed as their own thoughts, rather they talked about what other people think about sex and how the general population react to such

things. This may have been a way of distancing themselves from the topic slightly and presenting thoughts without taking ownership of them, but it may also be a demonstration of their pre-understanding and how they believe the world in which they live influences their thoughts.

The men felt that sex is important to “*men*” as a whole group and those men spend a great deal of time thinking about sex. The men in the study felt that, in an ideal scenario, the epitome of a man would be having a lot of sex. The men discussed how men as a whole use sex to boast and show off about their manliness.

Mr Collins *“a man is always going to think yeah I will do it four times a night til he has done it once you know and then these sort of dreams go out of the window straight away”*

Mr Evans *“a man can do it if he has got a young woman”*

Mr Franks *“men have a strong desire for sex, sex drive in a man can cause them to go to the extreme”*

The sense of overtly demonstrating an active sex life and it being an important part of a man’s life is seemingly opposite to the men’s discussion of how sex and specifically sexual dysfunction is not talked about. In general society sexual dysfunction is not a topic for open discussion, it is hidden and the men in this study felt that if it was discussed people would somehow lose control and this could result in hurtful jokes being made. Mr Evans said that ED is only ever discussed in a joke and *“if you talk about it in the pub they can make your life hell, only joking they don’t mean to be serious, I suppose that is another reason why you don’t discuss it”*. Although this has been described in a negative way and Mr Evans would find such discussions hurtful, it became clear from all the men that the only way to have a discussion about sexual dysfunction would be in the context of jokes or conversations that would not be taken very seriously.

Mr Andrews hypothesised about what would happen if he started a discussion in the golf club and concluded that there would be a loss of control as a result of it being *“a hidden subject which is taboo”*. He said that if he mentioned it in

the golf club there would be *“uproar” “you might look round, cos I play golf and you think twenty of you are round a table, you think well I have got it have any of you got it, cos we are quite friendly but you wouldn’t, I wouldn’t go up and say have you got ED, they would go WHAT! You would cause absolute, the place would be in uproar”*, this was in spite of knowing that statistically others there would also have erectile dysfunction and the medical causes therefore the social aspects would override logical thought.

Because of this sense of hilarity or the conversation not being taken seriously, Mr Collins felt that most men’s response would be to lie, if asked about ED; seemingly a way of covering the embarrassment or maintaining some control over the conversation *“now a guy is going to do one of two things, he is going to lie like hell because he is embarrassed or he is going to say yeah I do need help”*, but as Mr Bridges acknowledges, recognising to yourself that you have a problem may be the first step to being able to discuss erectile dysfunction because *“it is always someone else’s problem, never their own problem, no-one wants to recognise it”*. This discussion returns to the earlier discussion of talking about “men” as a separate entity from themselves and thereby maintaining a distance between themselves and the topic.

In this study men did not want to talk to people who are not of their generation, Mr Collins said *“if you ask my children I shouldn’t be having sex at my age (58) you know (laugh) it is taboo. I know my kids would think it is disgusting if they found that their mother and I were having sex” “I could not dream of having this conversation with my sisters who are a bit older than me” “nowadays it is far more blatant”*. He did not want to talk to people older or younger than himself; similarly Mr Franks said that he would not have a conversation with his father or his children. He did feel that his daughter would be happier to talk about sex because *“she knows more than us, she grew up here”*. The idea that the generations younger than the men would be happier to talk about sex was common as Mr Evans explained *“I think it depends on the generation you were brought up in, I mean you can talk today and you can talk about virtually anything, there are no barriers but men of my age find it hard to talk about because I suppose we have been conditioned that way”*

The perception was that younger people are freer to talk and that generations older than themselves were even more restrained than the men in the study. These discussions around issues related to sex but not portraying their personal thoughts were interesting, they were demonstrating their beliefs about what society expects of them as a member but using societal views to justify their personal views, rationalisations and behaviours.

In conclusion, the men's discussions moved from initial dismissive or accepting statements about how ED and their sex lives are not given priority any more. This may have been as a result of their recent health scare or as a reflection of their understanding of a socially acceptable topic of conversation. They described how having ED had made them feel and this was often in terms of how they were now less of a man than they had previously been, again as an illustration of what they believe society understands men to be. They had a mixed experience of disclosing ED and the ongoing effects of these conversations could be long lasting. In discussing what "men" do and how society views "men", the men in this study were able to express views without taking personal ownership of them and therefore they were able to express opinions with an element of distance between them and the idea.

## **Chapter Six: Descriptive analysis of data from interviews with healthcare professionals**

This chapter describes the themes which emerged from the interviews with healthcare professionals. The healthcare professionals did not talk about specific patients within their interviews in order to adhere to their own professional codes of conduct and therefore mainly focused on their own thoughts and more general recollections rather than specific cases. They discussed their personal clinical experience, a lack of understanding about ED and their thoughts about which medical speciality was responsible for treating ED, the rarity of a disclosure, how they personally manage such conversations and how they use their personal beliefs to guide their practice; often over and above any guidance from their professional bodies.

### **Themes Emerging from Interviews with Healthcare Professionals**

All the healthcare professionals seemed to feel most comfortable when discussing their professional experience in terms of the years that they had been working in their speciality and the education that they had undertaken. This discussion not only helped them to relax into the interview but also served to highlight that all the participants had been working clinically for more than eight years. They were confident in their current roles and all of them said that they understood that there was a link between cardiovascular disease and erectile dysfunction. Although they had a significant collective clinical experience, extensive training and an understanding of the link between cardiovascular disease and erectile dysfunction, none of the participants could recall having any formal or informal training on erectile dysfunction. Although this early discussion was utilised to build rapport and set the tone of the interview it was also an important way of establishing some of the healthcare professionals understandings of themselves, their professional self and the position from which they were entering the conversation; their pre-understanding. The themes which emerged focused on professional roles and ownership of ED, anxieties relating to being misunderstood and experiences from clinical practice.

## **Professional roles, ownership and practice**

### **Professional and medical speciality ownership**

All the medical professionals discussed how they had been taught in medical school that erectile dysfunction was regarded as a problem which should be treated by the medical speciality concerned with urological conditions. They had been to medical school as recently as eight years previously and as much as twenty five years ago and no-one identified any other medical speciality that they would consider referring patients with erectile dysfunction to. They talked about how they had not had any teaching about ED and the medical staff who worked within cardiology wondered whether this aspect of clinical practice now fell within the remit of the cardiac rehabilitation nurses. Clearly some of the cardiac rehabilitation nurses, such as Angie, also felt that this was the case; they were seeking training on erectile dysfunction in their own time and funded by themselves. The lack of clarity, in relation to which clinical speciality or profession, was discussed by all of the professionals, none knew categorically who they should refer to and some looked for answers during the interview. This lack of professional ownership was not regarded by any of the participants as a professional void, merely something that simply is not owned by any speciality.

### **Confidence, competence and training**

Due to lack of training and infrequent disclosures, all the healthcare professionals said that they were not confident or competent in conducting an assessment or providing treatment for erectile dysfunction. All the professionals said that they would refer the patient on. Thomas talked about how he did not make treatment decisions about ED and would refer to his colleague, however when he was approached by general practitioners for advice about ED treatment in conjunction with cardiology treatment, he was happy to provide reassurance. The lack of competence and confidence for many appeared to be underpinned by the lack of training and their own perception of a personal lack of knowledge; as a result they often used their own thoughts and values to guide and justify their practice. They considered who they personally would prefer to talk to, Thomas said *"I have got a very old*

*senior GP, I could tell her anything” but later in the interview he contradicted himself by saying “it’s a man thing, I would talk to a man”.*

### **Using personal beliefs to guide practice**

Several of the female healthcare professionals thought about how people that they know very well might react if they were asked about erectile dysfunction and used these thoughts to guide their practice. Angie felt that *“my parents would fall off their chair if someone mentioned it”* and *“I think that maybe they might feel that it is intrusive because if you are younger you might think well that’s none of your business again thinking of personal you know what would my husband think if a nurse said you know about his sex life I think he would have a bit of a shock yeah”*. When describing how she brings the subject up within the cardiac rehabilitation class she said *“you have to be careful, you could really tread on someone’s personal life”* and this was a typical rationalisation of how professionals were practising based on how they expected people they knew well would respond. Alison was talking about scenarios where she has not asked about erectile dysfunction because of the presence of a family member, she described how she thought her father might react if he was asked about ED in the presence of his daughter;

*“I just don’t mention it because I don’t think my father would like to talk about it if I was there (laugh) and I wouldn’t like to know what my father was up to either”.*

All of the healthcare professionals demonstrated how they use their own personal thoughts and feelings to guide their practice, rather than a professionally trained response. However none of them talked of having had such conversations with their relatives, so how they could know what their loved ones responses might be remains a mystery and in light of the discussion with the men who did not want to talk to other generations about ED, it is possible that although the professionals may have a very close relationship with their family, they may well not know their thoughts on this subject.

The healthcare professionals talked about erectile dysfunction with sympathetic tones, Thomas described the treatments as “*pretty horrific*” and Jeremy said “*it is a serious problem which needs to be taken seriously*”, it was not just the male professionals who had sympathy, Angie said “*it is horrible isn't it*” and this sympathy might have been related to the fact that they found the subject embarrassing to talk about, therefore they knew that the men would too. All the healthcare professionals admitted that they found the subject embarrassing and in a similar way to the men, they drew this line of discussion to a close at this point. Alison, who had been quite open and who regularly asked men about erectile dysfunction said that she felt embarrassment in particular situations and when I tried to ask her why:

*“also I do feel a bit if it's like I said if its relatives we get a lot of people who can't speak English that well so they will bring a relative in so I wouldn't go there and also I do feel a bit funny asking Indian men I don't know why (laugh) yeah I would I don't know why it's probably I just don't know why I just don't feel that I can (laugh)”* she stopped the conversation with “*I don't know why*”.

### **Anxiety and Misunderstanding**

The fear associated with having such conversations was clear with Alison who had a specific worry of asking men from a culture that she did not feel she understood. Other healthcare professionals also demonstrated a fear of having a conversation that they did not feel in control of; or as Thomas put it, “*opening a can of worms*”. Jeremy had concerns over being misunderstood

*“you know maybe someone else that's important for them to understand why you are asking rather than the you know (laugh) strange interest”*

The concern over being misunderstood was also held by Angie, who was specifically concerned over the language that she should use in order that she is understood but still maintains a professional image “*you are not sure what you are going to say, as a nurse you are going to be a bit scientific*”, but she felt that this might not be easily understood.

Alison, Angie and Anna all had aspects of their current role which meant that they had to discuss sex with their patients, whether this was directly seeking a



disclosure or providing a more general education session. These three healthcare professionals felt that this was part of their role but all had specific scenarios where they would not ask, they used this as a means of maintaining control. Alison did not ask men of an *“Indian background”*, Angie did not ask men who were *“widowers”* and Anna made decisions based on the age of the man she was talking to. None of these professionals wanted to discuss any rationalisations for their behaviour other than a very cursory explanation of not wanting to offend. This fear of offending was clear, but none of the healthcare professionals talked of any occasion that they had caused, or were aware that they had caused offence.

The healthcare professionals, who did not consider themselves to routinely ask about erectile dysfunction, were not keen to build this into their clinical questioning. Rebecca, who was in the process of setting up a new nurse led clinic, when asked whether she would be building this questioning into her repertoire responded with *“no no no (laugh)!”* Thomas said that because he found the topic *“slightly embarrassing so it is not something I would actively seek out”* and Angie very truthfully said *“I have got to be honest haven’t I, I think I would rather them not ask me, I am pushing that it is nothing to do with me aren’t I in a way”*. There were many uncomfortable laughs during these discussions, they told me that they understood the scientific evidence and they knew there was a sound rationale for asking but they did not feel able to confidently engage in a conversation. This will be discussed in further depth within the analysis of the linguistic tools used; however it is important to note that these participants were not willing to change their practice in order to include an element of practice that they had already identified as pertinent.

## **Experience of Disclosures**

### **Disclosure is a rare event**

The incidence of the disclosure of erectile dysfunction was described by all the healthcare professionals as rare; Rebecca could only recall having one disclosure and Steve said that he could *“count on one hand the number”* over his whole career, of fifteen or more years. This description was the same for both the individuals who did not ask for disclosures and those who proactively

asked, such as Alison; despite telling most of the men who came to her clinic that they could disclose ED to her, she felt that the number who do is “very few”. The context in which these healthcare professionals were gauging the lack of disclosures was one in which they knew the prevalence rates of ED and believed there to be far more cases than disclosures.

When thinking about why the disclosure of erectile dysfunction was a rare event, the medical professionals thought that men may not consider them as the right person to tell because of their role. Jeremy (a university professor and clinical consultant) said that men might think that he was “*not the right person to talk to*” and Thomas said that they might have a perception of him as an “*important hospital consultant*”; he did then later contradict himself with talk of why men will tell him “*because I am the heart doctor who started the pills*”. Having described the number of men who had disclosed to them personally as low, all the health care professionals thought that their colleagues had received more disclosures. Sian thought that “*as a relatively young female GP*” men might choose to talk to her male colleagues, Thomas and Jeremy (both hospital consultants) felt that men would prefer to talk to their GP, with whom Jeremy believed they would have more of a relationship and Thomas felt that “*far more discuss it with their GP, hospital doctors are far less approachable than GPs*”. The nurses joked about specific colleagues who they believed received more referrals; Rebecca talked about one colleague who she said “*they are always asking her, I joke with her, did they ask about that!*” One cardiac rehabilitation nurse Anna, talked about how she believed that she received more disclosures of ED than some of her colleagues, which seemed to cause her to feel uncomfortable and as she tried to rationalise why this may be, she decided that it was because she asks about ED and puts the question in terms that her patients understand.

### **Mental preparation**

The healthcare professionals who revealed that they asked about ED, described men mentally preparing to disclose erectile dysfunction; making a conscious decision to start a conversation. Alison described the men as “*psyching themselves up*” before they tell her about erectile dysfunction and

this might indicate that the men are considering which healthcare professional they would choose to speak to, as Sian describes:

*“but it is like anything you know you will get patients come in and they will say I have got a sore throat and it is only as they go out of the door they say actually I have got a breast lump because they are sussing you out first and getting the courage to”*

The mental preparation described by the healthcare professionals would appear to correlate with the men’s description of gathering information prior to making a disclosure and then making a decision within the consultation about whether they feel able to disclose to the healthcare professional in front of them.

### **Routine questioning**

The nurses who said that they asked most of the men that they saw in clinic had built it into the clinic routine, a routine patten which included; this is a common problem, there are treatments, you don’t have to tell me now, here are contact details. This routine and planned conversation had been achieved with experience and the nurses who used these key points felt that they were covering the issue without forcing a man into telling them that they had erectile dysfunction. Alison described how she broached the subject using her routine:

*“no I think sometimes you just sort of offer I try and do it with the majority of patients I say any problems with sexual activity you don’t have to talk about it if you don’t want to but the option is there because there is help available and a lot of people suffer from it and uhm except it without doing anything about it so a lot of people will say no problem and a lot of people will say there is, some people will I offer them to refer them to XXX some patients will accept it and some patients will say they will think about it so I write his name down and say to them your GP can refer at a later time if you change your mind”*

Alison described how she used this routine to ask men about ED and that in her experience it worked because it made them aware of the evidence underpinning the link between ED and CVD, it made them aware of the prevalence of the problem and it did not force them into disclosing ED there

and then. However in making this such a routine speech, which seeks to merely deliver information, there would appear to be a risk that the patient would receive this with the subconscious message that Alison is disengaging from the subject and putting the onus on them to speak up if ED is a problem for them, and potentially she would rather that the disclosure was not to her.

Angie felt that when she was covering for her colleague's clinic she had a professional pressure on her which meant that she should ask about erectile dysfunction, so that she could tick the box on the proforma:

*"they are more ready but if R is off I do the PCI clinic in the afternoon so I have had the thing where you have to ask the question because it is on the piece of paper and there is a tick (laugh) so uhm yeah I have done that three times for her yeah because it's a little box and uhm it's have you seen it it's something like do they uhm need any advice or something, so you have to mention it but it's at the end typical isn't it left til you see it as you are coming down and you think ah its coming it's coming I am going to have to ask it (laugh) yeah I just and I do hand on my heart I do ask them because it is on that bit of paper its funny isn't it and I am covering R and I think god I can't let the side down"*

Despite feeling this sense of dread Angie did say that she felt more confident having such conversations with her increasing age, she said that she would have felt uncomfortable having conversations about sex as a younger nurse and that she *"feels sorry"* for the younger nurses, considering that they would feel more uncomfortable.

### **Adjuncts to practice**

Angie used two adjuncts or prompts in practice, a clinic check list and a DVD provided by the British Heart Foundation, she particularly commented on her perception of the quality of the British Heart Foundation DVD which she used as part of the rehabilitation session. In a similar way to the men who had watched it, she felt the need to connect with the characters. Angie commented on the nurse as a reflection of her profession.

*“nothing no just a crappy two minutes, have you seen the BHF video, the sex one? The nurse she really puts you off, there is a pump on the table, honestly it is terrible”*

This DVD seemed to cause her some professional embarrassment and she did not want to be considered as similar to the nurse who was portrayed. It is not clear from Angie’s discussion why she felt so disconnected from the nurse in the DVD, but she seems to be offended by the vacuum pump which was on the table in the film and earlier in the interview she discussed the need for privacy in relation to having such conversations and the need to make them covert rather than as obvious as it would appear to be in the DVD.

The healthcare professionals were an experienced group of clinicians who were all working in clinical roles with patients who would have a prevalence of erectile dysfunction, despite this they all described the disclosure of erectile dysfunction as rare. They were all unsure about whether a particular clinical speciality had ownership of assessing and treating erectile dysfunction, however many were sure that the ownership was not exclusively with their profession. None felt confident in their own knowledge of ED and primarily blamed a lack of training for this. They managed their own embarrassment by either not asking about erectile dysfunction or putting as much distance between themselves and the subject as possible, signposting patients to other healthcare professionals and disengaging from the conversation.

## Chapter Seven: Linguistic Analysis

Chapters Five and Six demonstrate the themes which emerged from the interview transcripts, however during the process of analysis it became clear that there was much which remained unsaid; often because there appeared to be a shared understanding between all involved in the interview. In light of the existing literature which suggests that discussion of erectile dysfunction may be difficult and the sense that the interview data lacked “depth”, an analysis of the words and the linguistic tools was undertaken.

Language is the most overt and obvious way that humans express their understanding and rationalisation of experiences, therefore the analysis of language within the context of a phenomenological study would be considered justifiable and appropriate (Smith, Flowers and Larkin 2009). The language that an individual chooses to use offers an indication of their interpretation of an event and can imply differences in the experience between individuals who have seemingly lived through the same event. Therefore language can offer individuals a way of expressing differing versions of an experience and as a result it must be recognised that language is an expression of an individual’s own interpretation and meaning of a situation, which may vary considerably from others (Weedon 1987). Some would therefore argue that the fluidity of meaning from one person to another, and even in one person’s expression from one conversation to another, make the analysis of language not only impossible but in itself meaningless, because of the inability of a researcher to “fix” the meaning of the words (Anstey 2012). Similarly Derrida (1973) warns that linguistic expression is only capable of portraying what the individual has the words to express and as a consequence this often results in them being unable to illustrate their thoughts and feelings in their entirety, as a result Mintz (1992) believes that language can provide a distorted reflection of reality. However, language and linguistic expression are culturally learned and form part of an individual’s lived experience and life world, therefore when conducting a study which recognises the lived experience, the use of such fundamental life tools must be taken into consideration; because they in themselves provide an insight into an experience (Husserl 1962).

The use of a common language can demonstrate on some levels a shared understanding, not only from using the same dialect but from a shared common perspective, for example the healthcare professionals would have a professional language and shared understanding which provides some insight into the life world which they as a group inhabit. Similarly all the participants within this study lived within a small geographical area and therefore localised uses of language not only demonstrated their understanding and living within the local culture, but also permitted a dialogue within the interviews due to the shared understanding between them and me. Analysis of linguistic elements therefore serves to support the search for this shared understanding, making such rationalisations explicit and therefore improving the rigour of the research (Shinebourne 2011).

Phenomenologists recognise that the experience as expressed by an individual is their *"truth"* and a significant part of this expression is undertaken linguistically, therefore the analysis of the linguistic strategies employed by the participants in a study can provide the researcher with a mechanism for exploring the literal meanings and the more hidden (Husserl 1962). In exploring subjects which are less well socially tolerated, and therefore hidden, there is a need to examine not only the language used, but also the language which is omitted and the linguistic tools, such as metaphor and euphemism, which are employed to be able to express thoughts and experiences within the social boundaries which often do not provide the direct language to be able to directly explain themselves (Chandler 1994). Language is considered, from a phenomenological perspective, to be a means of expressing an experience, with the experience predating the considerations of the language used to explain the experience (Husserl 1962), however post modernists consider that the experience itself is a construction of the language one uses (Polkinghorne 2005). Although these differing perspectives provide little clarity to the order in which these events and rationalisations occur, they do serve to demonstrate that experience and the linguistic expression of scenarios cannot be separated and therefore the one cannot be considered in isolation of the other.

Given the complexity and many facets of the lived world and the impact that this has on the language and vice versa there is thought to be little gained from

a frequency tally of the number of times that a particular word is used within a text, particularly when the subject is difficult to discuss and therefore direct words and overt discussion are not likely to have been demonstrated (Anstey 2012). Therefore within IPA analysis the purpose of exploring language is to supplement or enhance the descriptive and interpretive accounts and because interpretation is a recognised element of IPA, the interpretation by the participant and then the subsequent interpretation by the reader of the language supports the double hermeneutic process permitting the interpretation by participants and then by the researcher (Smith, Flowers and Larkin 2009).

Many linguistic tools, such as metaphor, euphemism and analogy can only be used effectively where there is a shared understanding between all involved in the conversation, simply because the meaning is not obvious! Metaphors are often utilised when a subject is difficult to discuss, for emotional or psychological reasons when the use of more direct language would be too uncomfortable (Shinebourne and Smith 2010). Similarly metaphors can be used when an individual feels that they do not have the words to be able to accurately portray their feelings and have to find a way of expressing themselves so that their emotions will resonate with the person that they are talking to (ibid). The thought processes which have to be undertaken in order to utilise metaphors mean that there is a level of conscious decision making with this type of verbal expression and this can contribute to deliberate word use and a degree of abstraction from the experience; some may criticise this in relation to the ability of the research to present a true and accurate illustration of the experience (Shinebourne 2011). However the counter argument from experienced IPA researchers is that there is something within the life world which has influenced the participants who feel that the need to use metaphor or other linguistic tools to express their experience is appropriate and this should, in itself, be of interest (Sontag 1989). This can enhance the richness of the data by opening up the meaning, allowing those reading the script to connect with the participant using their own experiences and metaphors.



## **Metaphor**

Metaphors are linguistic tools which are used daily and demonstrate our understanding of the world, which is shared with those around us (Shinebourne and Smith 2010). Metaphor is the change of sense and meaning from one situation to another, hence a high degree of shared understanding is required for metaphor to be used and this is why, within IPA, the identification of metaphors can assist in the bridging of descriptive and conceptual notes (Smith, Flowers and Larkin 2009). Clow (2001) believes that metaphors not only help to explain a situation, by comparing it with something similar yet different, but also for an individual telling their story metaphors are a mechanism of understanding and making sense of that experience by positioning it with something that has similarities and differences. Therefore within the context of IPA, metaphors are a mechanism by which participants can demonstrate their thinking and rationalisation of the situation.

## **Metonymy**

Metonymy is a particular type of metaphor whereby a feature of the thing that is being discussed is substituted for the name of the thing, for example the *"little blue pill"* being used rather than the name of the pill *"Viagra"* as demonstrated by Mr Davies who described the Viagra tablets as *"purple hearts"* and then *"blue diamonds"*. Synecdoche is another form of metaphor, whereby a part of something is used to refer to the whole, for example *"wheels"* being used to describe a car. This type of metaphor was not used by the participants, possibly because this requires a deconstruction of a given thing and therefore requires a demonstration of a significant knowledge of the constituent parts, demonstrating a relatively in-depth understanding of a phenomenon (Shinebourne and Smith 2010). This level of understanding would not fit with the initial dismissive comments of the men, when they tended to distance themselves from the subject rather than demonstrate a level of interest or understanding.

## **Euphemism**

Euphemism is a similar linguistic tool to metaphor, but it differs because euphemism is used to describe something which the person does not wish to

directly say, usually because the topic is socially or culturally sensitive (Kinsman and Major 2008). The purpose of euphemism is to avoid or disguise speaking about a subject as compared with a metaphor where the aim is to reinforce or illuminate understanding (Bennett 2003). Both euphemism and metaphor are commonly used to manage embarrassing conversations and Lawler (1991) believes them to be more advanced skills when used by healthcare professionals, because of the need for a shared understanding. The use of the word “it” was common throughout all the interviews as a substitute word or euphemism. Steve described a man disclosing Peyronie’s disease as “*it scared me for life (laugh)*”, to which I responded “*yeah it would (laugh)*”, we both knew that Peyronie’s disease manifests itself as a bend in the penis when in an erect state and therefore we both understood why such a disclosure may be uncomfortable, his laughter being an expression of feeling uncomfortable and mine agreeing with him; this demonstrated how euphemism can only be used effectively when an understanding is commonly held or shared. A more simple example of a shared understanding between myself and Thomas was his statement that “*it is slightly embarrassing isn’t it?*” to which I responded “*yeah*”. I had assumed that the “it” he was referring to was asking about ED, but did not seek clarification.

All the interviewees used the word “it” to describe sex, erectile dysfunction and talking about erectile dysfunction. Mr Andrews said “*you are a man and you can’t do it, it goes wack and you are down*”. Within this sentence he uses “it” firstly to talk about having sexual intercourse and then secondly to talk about experiencing ED, but because of the sense of a shared understanding we both knew that he was using the same word to describe two different things. Mr Franks said that he had to “*deal with it*” and again no clarification of the word “it” was sought.

The word “it” was commonly used to substitute the words “sex” or “erectile dysfunction”, similarly “that” and “things” were also used. Mr Collins talked about how he had not been asked about ED by his GP and said “*you know it has been 12 years and he has not mentioned that*” and Mr Davies told me that “*things weren’t completely right, put it like that*”. Such replacement words were not only used by the men in the study they were also commonly used by

healthcare professionals who would say, such as Thomas that he was *“happy to discuss it if they brought it up”*. When talking about some subjects, such as sex, we all have an almost innate sense of what the other person is saying. Mr Franks talked about when he was discharged from hospital and said *“so we done what we done and that was fine”*. I understood him to be telling me that he had had sexual intercourse with his wife and that there were none of the problems that he had anticipated, such as chest pain, but he did not directly use these words. Euphemism and word substitution are commonly used to express a discomfort in saying specific words and thereby infer a social unacceptability of the particular words or discourse which would necessitate their use (Mintz 1992). Embarrassment is felt when social rules are breached and therefore euphemistic language and embarrassment are often identified within similar scenarios, one being an expression of the other (ibid).

Although there were many occasions where the use of words such as *“it”* were employed to avoid using more explicit language, there were also several occasions when the language used was surprisingly explicit. Mr Bridges told me that he had previously had a *“riotous sex life”* and that he was previously happy to *“wank”* or *“masturbate”*. This was probably the most overt use of sexually explicit language from any of the participants, however other uses of phrases such as *“disco stick”* and *“there is a crappy two minutes”*, from healthcare professionals also serve to illustrate how people’s language swung from formal medical language to what may be considered less professional and more informal use of words. The use of the more explicit language was notably used within the latter stages of the interview, possibly demonstrating an increasing comfort within the interview which allowed the participants to feel that such language would be acceptable.

The word *“it”* seems surprisingly dismissive when considered in relation to the other words that the men used to describe what ED had meant to them. Mr Collins used the word *“prowess”* and said that with ED his *“prowess”* had now ended and Mr Hobbs described having ED as his *“demise”*. Both of these words seem to have been used in emotionally powerful sentences which are undervalued when the word *“it”* is used interchangeably for so many aspects of these discussions. Dismissing a subject that is considered to be painful or

emotional is a way of managing an uncomfortable conversation, it is also a way of managing embarrassment (Lawler 1991, Mintz 1992) and it may be considered that the latter discussions of "*prowess*" and "*demise*" are the truer representation of the thoughts of the men. However because of their understanding of the conversation (their pre-understanding) and their need to conduct the conversation in a socially acceptable way and one in which they maintained control, they used the substitution words in order to achieve these aspects.

### **Power**

The power which can be inferred in the use of specific words can also demonstrate how the person situates themselves; Jenkins (2002) believes that the force associated with words can demonstrate how the person who is using those words is positioning themselves socially. From the use of words such as "*prowess*" it may be that Mr Collins was demonstrating his perceived decrease in social position or position as a man. So he had previously considered himself as being a competent male and now had lost a fundamental element of being a man, as he understood men to be. The interviews with the healthcare professionals also demonstrated social positioning or power through the use of medical terminology. Jeremy described erectile dysfunction as a "*clinical phenomenon*" and Steve told me that he would not "*actively pursue it as a symptom*". Medical language can be used by healthcare professionals as a means of maintaining a social distance between themselves and their patients, which may also be transferred into conversations that professionals have with researchers and individuals that they believe are "outside" of their professional grouping; thereby allowing healthcare professionals to maintain a power differential in a variety of conversations (Mintz 1992). However, because of our previous working relationship there was also a degree of common language and although much medical language was used during the interviews, there was a mutual understanding which seemed to facilitate conversation and enabled the healthcare professionals to speak as though they were talking to a colleague rather than a researcher; which again may be argued would encourage them to express an opinion closer to the truth than such a conversation with a non-professional (Weedon 1987).

Whilst the use of medical terminology was common within the interviews with healthcare professionals there was also a notable use of medical words by Mr Andrews, who spoke in eloquent terms about his experience of having Peyronie's disease diagnosed and having a Nesbitt's procedure to correct it. Being able to use these medical terms seemed to provide him with a confidence. Social distancing is frequently used by healthcare professionals because it enables them to position themselves away from the patient, ensuring that there is less emotion felt within a conversation and is seen by some as a self-preserving mechanism, especially when conversations are emotionally charged and repeated exposure to such conversations can be emotionally draining for a healthcare professional (Mintz 1992). However it may be that Mr Andrews was using this language to distance himself from the more personal elements of the discussion, illustrating his problem as a medical condition was more comfortable for him than discussing a change in his perception of himself as a man.

### **Analogy**

Analogy is often used as a comic tool and results in a humorous response. The similarity of the features of two things allows the person to describe one thing as the other and, in a similar way to euphemism the actual thing is not spoken of, but because of a shared understanding of both things an analogy allows the person to talk about it without saying potentially offensive words (Bennett 2003). When Alison was describing men telling her about problems with their erect penis she said that they describe their penis as a "*disco stick*". If explored in literal terms a disco is a social event, which is often attended in the evening or at the weekend, it is an enjoyable activity that is typically associated with young people and often alcohol- having many similarities with the western perception of situations within which people will engage in sexual intercourse. A stick usually consists of wood (another euphemism for an erect penis) and it is firm, taking a similar cylindrical form as an erect penis and therefore the word stick can be seen as an analogy for an erect penis. Clearly this type of linguistic tool requires a significant amount of shared understanding because the consequence of seeking clarification when people are using analogy can result in a breakdown of the conversational flow

(Shinebourne and Smith 2010). When Mr Davies said that *“it’s time to stop and put your key in your pocket”* he was saying that his sex life had finished and that the memories would be kept safely locked and close to his heart (in his breast pocket) and I did not feel the need to seek clarification. Analogy is a conscious use of finding the similarities between two things and is a purposeful linguistic tool used to describe an often socially unacceptable phenomenon; double entendre also uses the similarity of two things, however it is considered that this expression is often the result of less conscious thought processes (Bennett 2003).

### **Double entendre**

Double entendre or innuendo appeared often within the interviews and seemed unrehearsed, catching the person who said it by surprise, resulting in laughter from both the person and myself. Jeremy talked about how the public awareness of erectile dysfunction was improving, but he explained this by saying *“so it is definitely something where the awareness has risen (laugh)”*. Because the conversation was about erections the use of the word *“risen”* and the now obvious double meaning made both of us laugh. Similarly when he used the word *“empowered”* to describe how people should be trained to ask about ED he laughed, at the thought of healthcare individuals with a specific super power being able to ask about sexual dysfunction. This realisation of a double entendre caused an often uncomfortable laugh which was akin to the realisation of a Freudian slip, the laugh being an indication of subconscious thoughts being realised and the reciprocal laughter a demonstration of the shared understanding of both of the meanings which had just been expressed. Freudian slips are thought to be an expression of subconscious and although much language is consciously mediated it is considered that Freudian slips may provide a glimpse into the less well considered thoughts (Westen 1998). The embarrassment felt at realising what has been said, for all involved in the conversation, is also acknowledged by the subsequent laughter.

### **Humour**

Unintentional humour was not the only demonstration of humour in the interviews; there were some conscious decisions to use humour as a way of

managing the conversations. When Mr Davies was asked a question about ED he said *“excuse me I have got a few phone calls to make (laugh), no sorry I am only joking”*, this joke gave him time to think about the answer to the question that he had been asked and allowed him to take control of the conversation because he had made me laugh with him. Mr Franks also used humour to help him to tell the story of his recent myocardial infarction; a life threatening event. He was talking about his wife who was being bothered by a wasp while they were in the ambulance on the way to hospital and he said *“do you want to shut up like, I am dying here (laugh)”*. Clearly this was not a funny scenario but he used humour to be able to talk about the situation and then went on to say *“I have got to be honest I laugh and joke about it you know I said like even the devil don’t want me and all that nonsense but it was flipping heck”*. Lawler (1991) describes the purposeful use of humour as a coping mechanism used by both patients and healthcare professionals to express their discomfort with a conversation and allow them to withdraw without causing offence. She also believes that this buys the embarrassed individual time to regain their composure, take control of the conversation and gain time to consider where to take the conversation, all of which were demonstrated by the men in this study.

The use of humour or laughter when feeling uncomfortable was also used by healthcare professionals. Thomas had talked about how he understood the evidence base for ED being linked to CVD but laughed uncomfortably as he explained that this had not influenced his practice, which may have been considered as a professional failing *“not that it has changed my practice but er (laugh) particularly, I may be more aware of it but uhm”*. Rebecca responded in a similar manner when discussing the setting up of a new clinic and what she would be asking her patients *“no, no, no, he (the consultant that she worked with) won’t want to know (laugh), so that is my only dealing with it in a professional sense (laugh)”*. Kinsman and Major (2008) identify this uncomfortable laughter as an expression of embarrassment and a mechanism for managing the emotional response to feeling embarrassed. Lawler (1991) and Meerbeau (1999) both identify this as a rudimentary communication of discomfort, categorising this management of embarrassment by healthcare

professionals as relatively simplistic. These healthcare professionals were not experienced in receiving disclosures and were the two participants who categorically stated that they would not be proactively asking.

In many respects Alison was quite different from Thomas and Rebecca because she had been quite confident during the interview and reported that she regularly asked about ED, but when the conversation became awkward for her she laughed to demonstrate her discomfort *“I do feel a bit funny asking Indian men, I don’t know why I just do (laugh)”*. Described by Lawler (1991 p144) as *“hollow laughter”*, there is an understanding from reading the transcript and listening to Alison’s interview recording that this was different from her laughter which was as a response to humour or any of the other linguistic tools that she used, such as euphemism.

Alison, Rebecca and Thomas appeared to laugh when they were discussing how and why they did not ask about erectile dysfunction; however Sian, who did ask about erectile dysfunction and had received several disclosures, laughed when talking about her proactive practice. When she was considering what makes men decide to tell her about ED she said *“maybe it’s me (laugh), I would like to think I do give them the time”*. As she wondered what it might be about her that made men feel able to talk to her, this amused her and seemed to cause her embarrassment simultaneously. Flattery can cause embarrassment in cultures which are not used to receiving compliments and whilst paying a compliment can serve to reduce feelings of embarrassment it can also cause those who are not used to such conversations to feel embarrassed (Eylon and Heyd 2008), Sian had identified a positive aspect of her practice and laughed uncomfortably.

There are linguistic benefits of interviewing people who have the same local dialect as the interviewer because local phrases and sayings are understood by both parties; therefore there is a conversational flow to the interview (Bennett 2003). However this shared dialect sometimes impacts upon the researcher’s ability to seek clarification. Locally, the use of the phrase *“you know?”* at the end of a sentence is a way of checking that the person understands what you are saying and it is almost routinely responded to with a



positive “yes”. It would be a very rare occasion that someone would ask for clarification after a “*you know*”, and the response, “*no I am sorry I don’t know*” may be considered rude; impacting on the rapport building that can be achieved. Humour and the previously discussed linguistic tools can help to bridge this gap, however they all rely on a shared understanding and therefore clarification would hinder their use (Bennett 2003). On analysing the transcripts of the interviews all the participants used “*you know?*” many times during each interview which ultimately resulted in a positive response from me and then a changing in direction of the conversation. For example Mr Evans said “*it has taken its toll you know*” to which I responded “*yeah*”. We both understood that he felt that ED had negatively affected him, but in saying that I understood what he meant, I missed the opportunity to ask what price he felt he had paid, what was the toll that had been taken? Similarly Mr Davies said “*getting back to normal and having nowhere to go with it basically, you know what I mean? (laugh)*” to which I responded “*yes (laugh)*”, assuming that what he meant was that there was no point in seeking a treatment for ED because he did not have sexual intercourse with his wife, but I did not seek to clarify this. Lawler (1991) may consider this as a demonstration of my own embarrassment, redirecting the conversation away from the source of embarrassment, an example of avoidance, rather than a demonstration of a shared understanding.

Although most of the interviews contained humour, analogy, euphemism and laughter, the interview with Mr Hobbs was the most challenging because he did not readily use many of these linguistic tools. He provided many one word answers and as a result I found myself giving him statements and seeing if he agreed with them. When he did begin to open up his discussion, he managed the conversation so that it moved away from the topic that he was not comfortable with. The conversation prior to this excerpt was around how men do not like talking about ED to which he responded

Mr Hobbs: “*yeah I don’t have any problems in talking to anyone about it, none at all*”

CD: *"has anyone ever asked you like when you have been to the GP for a well man check or anything sort of routinely has anyone ever said to you do you have a problem with your erections?"*

Mr Hobbs: *"no"*

CD: *"as part of a, so no, so it has never been part of a health screening sort of thing?"*

Mr Hobbs: *"no, no not at all"*

CD: *"OK if they did how would you feel about that?"*

Mr Hobbs: *"if that had before and said it could result in a heart problem later on uhm go and have your blood pressure tested or you cholesterol tested I would be a fool not to go"*

CD: *"yeah yeah"*

Mr Hobbs: *"I would say yes"*

CD: *"it wouldn't cause you offence; you would think there was a logical explanation"*

Mr Hobbs: *"yeah exactly yeah"*

CD: *"cos I think there are a lot of healthcare professionals who worry that they are just going to embarrass people by asking"*

Mr Hobbs: *"no"*

CD: *"from our perspective and I guess"*

Mr Hobbs: *"er I suppose 2 years ago I had a problem with excessive yawning right so I am thinking I would get a period of yawning and I was thinking well this is what's happening here you know it's not lack of sleep or anything like that and I went to see the doctor about that. I thought this can't be right you know..... so I went to see him and he put it down to the aging process but at least I know if it was anything serious he would have investigated it"*

Mr Hobbs said at the beginning of this excerpt that he did not mind telling healthcare professionals about ED, but he managed the conversation so that he could talk about another occasion that he visited the doctor about a yawning problem. Mr Hobbs demonstrated most clearly how he could take the conversation in a direction that he was comfortable with, other men and healthcare professionals also used this technique but it was most apparent with Mr Hobbs because of his previous use of single word answers. Maintaining control of a conversation is according to Lawler (1991) another less advanced form of managing communication during an embarrassing scenario; euphemism, humour and analogy being more advanced communication techniques. This transcript demonstrates how my discomfort also impacted upon some of the interviews and therefore within the analysis of the language it became clear that my language also needed exploration, because I had facilitated Mr Hobbs in giving single word answers and allowed him to take the conversation away from the subject of ED.

All the participants, both men and healthcare professionals, used all these linguistic tools to varying degrees during their interviews and it became clear by analysing the use of these tools that they were being used consciously and subconsciously to engage with me in a dialogue. Because phenomenological studies require the influence of the researcher within the interview dialogue to be acknowledged and in light of the clear impact of the linguistic tools on the outcomes of this study, it is imperative that my language is also analysed. This analysis will help demonstrate reflexivity and rigour (Shinebourne 2011).

### **Analysis of the interviewer's language**

Clearly the use of all these linguistic tools required a shared understanding between all involved in the interviews and those who were analysing the interview transcripts in order that the hidden or obtuse meanings could be understood. When Mr Andrews described "*brewers droop*" I laughed, he laughed and so did his wife. Everyone knew that he was talking about the belief that too much alcohol can cause erection problems. Later in this conversation they were talking about the anticipated response if the men in the golf club were asked by Mr Andrews about their sex lives. He said that he

could imagine the uproar and I responded with *“that’ll be your membership card ripped up (laugh)”* causing laughter from both Mr and Mrs Andrews. The use of humour is described by Lawler (1991) as an advanced skill used by healthcare professionals to manage difficult and embarrassing conversations and it may be that I was drawing on previous experience as a healthcare professional. Humour is also described as a rapport building tool which researchers can employ in the initial stages of an interview to identify common understanding and build trust, which was important given the topic (Meerabeau 1998).

I inadvertently used double entendre when she said to Mr Collins that *“well yeah we had a spate of them when I was in H\*\*\*\*\* just after I suppose when Viagra had sort of come out and”*, to which Mr Collins laughed at the sexual implications of *“coming out”* so I then tried to regain my composure with a laugh and a rephrasing of what I had said *“yeah (laugh) we had a spate of men coming in you know who had had Viagra”*. Lawler (1991) would again suggest that this is a demonstration of my coping mechanism for dealing with my own embarrassment, regaining composure during the laughter and then reformulating the sentence construction so that there was not a potential double meaning.

The use of humour did help to develop the rapport in all the interviews, as did my use of compliments. Typically I asked the men how old they were and then made a reference to them looking younger than their chronological age and similarly I asked the healthcare professionals about their clinical experience and their degree of specialist knowledge. Complementing the participants appeared to work well in terms of rapport development and it has been recognised that compliments can be a proactive way of managing embarrassment (Lawler 1991). It may have been that in anticipation of an embarrassing conversation I was seeking to mitigate this discomfort from the beginning of the conversation. However, I demonstrated an uneasy laugh when complimented in return. When I asked Alison where she got her information from she replied *“you (laugh)”* to which I responded *“right answer (laugh)”*. This was similar to Sian and her laughter at receiving a compliment about her clinical practice; Eylon and Heyd (2008) suggest that this behaviour

is socially learned and particularly pertinent for more subservient professions such as nursing, therefore this may provide an indication of my pre-understanding or existing beliefs about herself and her profession.

I did ask some naive questions which may have been thought of by the participant as a reflection of my practice, this caused me to feel embarrassed. For example I said to Mr Andrews *“now this is going to sound like a silly question but it is only because it is based on talking to the boys in work, do you ever discuss such things with your peers, you know other men your age?”* Mr Andrews’ response was *“that is not something one does”* to which I rather meekly said *“no I thought not (laugh)”* and then moved the conversation on; this avoidance being congruent with Lawler’s (1991) description of relatively novice coping strategies, similar to Mr Hobbs I was keen to avoid the discussion and therefore move the topic on.

Similarly I demonstrated simplistic coping strategies when Mrs Andrews was talking about how she thought that her husband’s ED was as a result of his smoking, which he then defensively responded with *“as you do”*. I felt as though I was in the middle of a long running argument and as a result laughed nervously before changing the subject. I also did this when social stereotypes which I personally did not agree with, were used. Mr Collins said *“if you ask my children I shouldn’t be having sex at my age you know (laugh) it is taboo”*, to which I then inadvertently agreed and nervously laughed when realising what I had done. Meerabeau (1999) suggests that this type of embarrassment is rooted within my own pre-understanding and personal life world, within which it is not socially acceptable to discuss older people having sexual intercourse. Similarly the discussion between Mr and Mrs Collins was a discussion which would typically be held in private and it seemed as though their public performance had temporarily been suspended, which provided an insight into their private life world, it resulted in me feeling embarrassed and responding as I would normally do by moving the discussion away from the topic, a more experienced researcher may have been able to overcome it in order to gain more of an insight into a world not normally accessed (Meerabeau 1998).

The analysis of language and linguistic tools has to be undertaken with caution because of the previously discussed inherent issues of the words that people use and the influence that their life world will have on their linguistic expressions. The language that they demonstrate can illuminate part of their life world and the relationship between those involved in the conversation, for example socially perceived power differentials; however there will be aspects of this world which they will never be able to linguistically express and this has to be recognised. Metaphors can be used to express some difficult issues, but not all and the unsaid is often as worthy of study as the spoken word, thus there may be a void between that which can be expressed and that which cannot and resides exclusively within the life world (Anstey 2012).

In undertaking the linguistic analysis it has become clear that not only was the topic embarrassing but that all the participants, myself included, found the interview itself uncomfortable and embarrassing. Several linguistic techniques were employed to manage the embarrassment including avoidance, euphemism, analogy and double entendre, all of which have similar aims; to avoid saying specific terms which might be considered socially unacceptable. The words which were not used in any of the interviews were equally as enlightening because they were the terms which referred directly to the subject that was being discussed.

Analogy, metaphor, double entendre, innuendo and euphemism are all ways of talking about a subject without actually saying specific words and although these linguistic devices were used in abundance, there was also some evidence of participants using direct language. However, even the more overt language at times lacked clarity and required a shared understanding in order that the conversation made sense. The analysis of the linguistic elements of the interviews identified a significant effort on the part of all concerned to avoid using language which may be considered by some as offensive and as a result has demonstrated how individuals within a British society do not feel comfortable openly discussing sexual issues. In expressing ourselves in this way we have illustrated our unease with the subject and have utilised both high level communication techniques and less analytical ways of managing what would appear to have been an embarrassing conversation.

## **Chapter Eight: Discussion of emergent themes**

Although the data from the men and the healthcare professionals was analysed and reported separately, there were similar themes which appeared to emerge from both sets. The themes were established using several hermeneutic circles, whereby the interview transcripts were revisited several times by myself and my supervisor; each time allowing the consideration of emergent themes in relation to previous thoughts on potential themes. As each interview was revisited emergent themes, which were commonly seen in all the interviews, were identified and grouped whilst those which were unique to a particular individual were identified as such. This is a particular benefit of using IPA in the analysis of data because it not only allows a collective story to be told, but also unique experiences and rationalisations to be portrayed (Smith et al.2009). This process helped in identifying themes which were not as strongly illustrated in a number of the interviews to be reconsidered, and in some cases removed. Similarly this process helped to identify those themes that were clearly evidenced in all the interviews and these were then considered in relation to the super-ordinate theme.

The aim of this chapter is to locate the analysis that has been discussed in the previous three chapters within both historical and contemporary literature, some of this literature was identified prior to the data collection and some was noted as relevant because of the data analysis. IPA is a methodology which permits researchers to revisit literature once the data analysis phase is complete because there may be emergent findings which were not anticipated prior to data collection; a benefit being that IPA permits unanticipated themes to be explored fully with newly generated data in mind (Smith et al.2009). This is particularly relevant to subjects of which little is known, such as the disclosure of ED; because it allows the researcher to revisit previously explored literature in light of their findings and to also explore previously unconsidered literature and concepts if they have become obvious during the data analysis. The aim of this thesis was to explore the disclosure of erectile dysfunction, a subject of which there is a scarcity of literature so following data collection it became clear that some previously unanticipated concepts and

literature, although not directly relating to erectile dysfunction disclosure, did have aspects which appeared to correlate with the emergent themes.

The super-ordinate theme which emerged from the data following IPA analysis was that of embarrassment, which seemed to affect all of the people involved in the interviews, myself included. Within the theme of embarrassment there are several subordinate themes; stigma, medicalisation, disclosure and self-identity all of which will also be explored following the discussion of embarrassment.

## **Embarrassment**

The concept of embarrassment is commonly identified within the literature which explores the disclosure of sexual health; this has particularly been studied with gay and lesbian populations and much of this literature identifies embarrassment as a barrier for both healthcare professionals and patients in having conversations about sexual health (Hinchliff et al.2005, Marshall 2002). Taylor and Gosney (2011) also found that healthcare professionals report embarrassment when talking to “older people” about sexual health. Although these authors discuss embarrassment as experienced when discussing sexual health with specific groups of people, literature also demonstrates that embarrassment is a concept which impacts upon all discussions regarding sexual health, however there is little or no exploration of what is meant by embarrassment. Skelton and Matthews (2001 p.606) concluded that other reasons that participants provided, such as a lack of time, were mainly a “cover up” for embarrassment and that embarrassment is the underpinning reason for all lack of enquiry into sexual health.

As previously discussed embarrassment is the uncomfortable feeling experienced when social rules have been broken, it usually involves a loss of pride or dignity and is thought to be a mechanism of social control; we learn the rules of the society in which we live and when broken, the unpleasant feeling of embarrassment acts to stop us repeating the scenario (Meerabeau 1999). Hence Goffman (1956) believes that humans are driven to avoid embarrassment and thereby to maintain an acceptable position in society. Within most Western societies sex is not normally discussed openly and



sexual dysfunction even less so; society accepting sexual activity as a personal and private activity therefore the discussion of sex and particularly sexual dysfunction are not socially acceptable topics. Discussing sex with “older people” is equally socially difficult because there is often a perception of a generation gap; people not wishing to talk to people older or younger than themselves. This generational divide and its impact on discussions of sexual issues is a widely acknowledged and possibly an implicit social rule, therefore when this subject is broached those involved feel embarrassed (Baldwin et al.2003, Corona et al.2013, Levine and Kloner 2000, Stead et al.2003).

Sexual behaviour is, by its very nature personal and private and therefore is not openly discussed within “*polite*” company (Stead et al.2003). By describing the subject as “*taboo*” and “*embarrassing*” the men in this study explain that they believe such discussions are breaking social rules; as they understand them. This sense of rule breaking was also illustrated by the men’s discussion of the “*uproar*” which would ensue if the subject was broached with their friends and family. Mr Andrews’ description of a social rule break within a golf club, a place where there are known to be strict rules of behaviour, illustrated how the discarding of social convention and the resulting sense of embarrassment can result in, what he perceived to be, anarchy.

To aid the exploration of embarrassment in light of the data analysis Lawler’s (1991) ethnographic study, which explores the aspects of nursing work which are often left unsaid or hidden, was revisited. Hidden nursing care is usually focused on meeting the basic physical needs of patients, these needs are usually met by the individual themselves privately, when nurses undertake them for patients they also do so in private. These aspects of nursing care are often considered to be embarrassing; for the patient and the healthcare professional, the need to ask another human being to perform self-caring activities can alter an individual’s perception of themselves and highlights to them the failing of their previously un-noticed body (Lawler 1991). Although considered “hidden”, it is acknowledged by nursing as a profession and the society within which nurses’ practice that nurses are permitted to access the “private lives” of their patients in order to do their jobs, thereby fulfil the expectations society has of them as care providers.

It is worthy of note that some nursing activities in 1991 were different from nursing in 2015, the aims of nursing have remained the same however, the ways in which these activities are achieved has changed with the focus now being less parental and more collaborative, with patients and nurses working together to achieve positive health outcomes (Hallam 1998, Suero et al.2001). When Lawler conducted her study she may have witnessed nurses working with a different patient cohort and within a different clinical context, with different societal expectations of nurses' roles and a differing degree of social rule breaking. Nurses', within any historical context, can only perform the role that society allows, or expects of them, but these expectations have always allowed nurses to break more societal rules than would be accepted from a different professional group; hence nurses' are socially acceptable rule breakers. Although Lawler's (1991) study primarily focused on the physical aspects of care and the findings from this study are focused on the conversational aspects of care, there are transferable elements in relation to the "hidden" elements of both aspects of a nurses' role. The men in this study talked about how they perceive society now to be more open to talking about sex, which may have been more an expression of their hope rather than an accurate reflection of what is happening in society. The analysis of the linguistic tools may have provided evidence that such conversations are still uncomfortable to have and that open conversations are still constrained by embarrassment.

Lawler (1991) described physical care as "*dirty work*" which is hidden away and although this description from Lawler is based on her observations of physical work conducted by nurses in a hospital setting, her description around embarrassment in relation to nurses' work can be transferred to the context of having difficult or embarrassing conversations with patients; both feel uncomfortable with the perceived social rule break that they are making. There may be contextual differences when applying Lawler's work today, for example Viagra was not available in 1991 and therefore there had not been a mass media campaign to advertise it; but there have seemingly been few changes in relation to the sense of discomfort felt when having embarrassing conversations. Lawler (1991 p144) describes these conversations as

*“dangerous”* because they can cause embarrassment for both parties and *“hidden”* because they usually take place out of public sight. The healthcare professionals in this study talked about making sure that they maintained confidentiality, and Skelton and Matthews (2001) may suggest that this was merely an excuse to avoid an embarrassing conversation, but by ensuring a private area was available and in doing so they were making such encounters hidden. In making these conscious decisions to hide, they are demonstrating that the conversation is difficult and potentially dangerous (Lawler 1991 p144).

The analysis of the language used in the interviews demonstrates a significant amount of shared understanding, and whilst this may superficially appear to be a failing of the data collection it may also illustrate some of the hidden elements of these dangerous conversations. By both healthcare professionals and men making efforts not to use overt or direct language, the participants demonstrated how they can have a *“dangerous conversation”* and to a degree keep it relatively *“hidden”* by not using explicit language (Lawler 1991). For example Mr Franks saying *“we done what we done”* was using a form of linguistic shorthand based on a shared understanding which enabled him to hide what he was saying. Mr Franks is explaining that he had sexual intercourse without saying the words sexual intercourse, because this would be breaking a social rule which is dangerous and could cause all involved to feel the discomfort of embarrassment.

### **Audience**

Embarrassment can usually only be felt when the person has an audience, a person may feel a sense of shame when on their own, but the physical and emotional responses of embarrassment as noted by Lawler (1991) are only experienced when there is an audience to witness the social rule break. Goffman (1963) also discusses the need for an audience in order to feel stigmatised which will be discussed in further detail later in the chapter. Therefore it is worthy of note that the audience plays a significant role in the discomfort of both embarrassment and stigma.

Having to disclose ED to an audience is potentially why embarrassment was expressed by the men in this study, the healthcare professional would be

considered as the audience with whom they need to engage in a discussion. Similarly the healthcare professionals describe their own embarrassment, as the person who has to ask about erectile dysfunction, they break the social rules and are witnessed doing so by the patient. The healthcare professionals worried about how they would be perceived, wanting their audience to believe them to be professional and that they could potentially be misunderstood or thought to be portraying themselves as unprofessional. Conversely healthcare professionals can feel embarrassed, thinking of themselves as the audience. When approached by a patient the unexpected nature of the disclosure, can cause the healthcare professional to feel embarrassed because they have not anticipated this social rule break and therefore the element of surprise can result in them displaying their discomfort to the patient.

Lawler's (1991) study demonstrates that the degree to which a person feels embarrassed is related to whether the audience is a stranger or someone that they know well and people feel more acutely embarrassed the less they know the audience. This is highly pertinent in healthcare settings where people do not often meet a healthcare professional more than once, hence men would feel a heightened sense of embarrassment talking to someone they had not met before and were unlikely to meet again. The men in this study discussed whom they would like to discuss ED with and their thoughts were mixed, some agreed with those of Lawler (1991) and wanted to be able to trust the healthcare professional that they were going to talk to by building a relationship that would develop over time. The cardiac rehabilitation nurses' identified how they thought their relationships with their patients facilitated disclosures of ED, which they felt were as a result of repeated meetings.

Within the context of a healthcare system where patients do not meet the healthcare professionals repeatedly, there may be men who do not feel that the opportunity to disclose ED would ever exist, because they are not able to build a trusting relationship with healthcare professionals. However, some men wanted to be able to talk to someone that they did not know and who they thought they were unlikely to meet in any other context. The literature which explores gender differences in disclosing behaviour suggests that there is a difference between men and women with respect to talking to a known person

or a stranger; with men demonstrating a greater inclination to disclose concerns to a stranger (Dindia and Allen 1992). Dindia and Allen's (1992 p.116) study concluded that this behaviour was particularly apparent when the man considered the information that he was disclosing to be "personal", and that such a discussion would be purposefully avoided by men to someone that they knew well. Effective self-disclosure was thought by Stokes et al.(1981) to be reliant on male and female aspects to an individual's personality and Dindia and Allen (1992) concluded that for a man to be able to communicate effectively with his close partner as well as healthcare professionals he would need to have both male and female elements to their personality; which may to some degree provide an explanation as to why the men in this study did not have a categorical view on who they would want to disclose to, a stranger or someone they knew. What is clear is that there is no single way of approaching this issue, there is variability in relation to what individuals will respond to and therefore making recommendations for practice becomes difficult.

The men in this study presented a mixed picture in relation to communicating their embarrassment within their marital relationship; potentially their closest audience. The men's' partners would have known about their ED presumably, although this was not explored explicitly in the interviews, they could not hide it from them. Lawler (1991) suggests that in knowing each other well there would be less embarrassment felt. This did not always seem to be the case, for example Mr Evans' felt alone with the problem and had not discussed his ED with his wife, but he had volunteered to talk to a stranger which is more akin to the findings of Dindia and Allen (1992). Goffman (1956) suggests that in situations where communication is good, both partners adopt a team approach to managing the situation to the outside world putting on a performance and seemingly, because the partner is well known to the man, he feels a lesser sense of embarrassment. In the interview with Mr and Mrs Andrews they were clearly open with each other and as a result presented a very coherent and unified performance which indicated a low degree of embarrassment between them. Conversely, as with Mr Evans, where the communication within their marital dyad is weak then the sense of embarrassment is greater. Therefore it

is important for healthcare professionals to note that being a married couple may not necessarily equate to a close relationship which would minimise embarrassment between them. Not communicating with each other may affect a couples' ability to communicate between themselves and the outside world because they are not able to manage a performance and therefore not engage in a discussion.

### **Effects of embarrassment**

Embarrassment is thought to be related to shame, when a shameful aspect of a person is demonstrated to an audience then the person will feel embarrassed (Meerabeau 1999), and the men in this study demonstrated a sense of shame at not being able to perform sexually and demonstrate their *"reason for being"* or as Mr Andrews stated *"you are a bit of a failure"*. The change in the physical functioning of their body resulted in them feeling differently about themselves, feeling that they were losing a function or ability.

Erectile dysfunction would not be an overt or obvious problem to people outside their marital dyad and therefore the men had a choice as to whether or not to disclose their ED. In a sense this is crucial for the men in this study, because this choice did exist. They could have prevented any embarrassment that they felt by not disclosing their ED, but they decided to volunteer for the study and some had spoken to other healthcare professionals, demonstrating that embarrassment may be an unpleasant experience but not a totally disabling one, it can be overcome by other motivating factors. Apsler (1975) conducted psychological experiments whereby people were observed in constructed embarrassing situations and concluded that people who are embarrassed try to make themselves feel better about themselves by complying with requests made of them. This may serve to explain why the men in this study, although they found the subject embarrassing, did volunteer to participate, or had answered honestly when asked about ED by a healthcare professional, they did not want to lie and complied with the request.

The men also had a sense of debt to the healthcare professionals who had cared for them when they recently experienced a myocardial infarction, similar to Jaarsma et al.'s findings (2010) which found that patients within a cardiac

rehabilitation programme volunteered to participate in research because of a sense of debt after surviving a life threatening event. The men in this study were asked to participate by the cardiac rehabilitation team, with whom they had a relationship and ongoing interaction. This relationship undoubtedly assisted in recruitment but may also have helped to minimise the feelings of embarrassment associated with the topic.

Less positively, Mr Collins believed that the embarrassment felt by men would cause them to lie about erectile dysfunction in order to maintain a positive image and uphold people's previous perceptions of them. Fergus et al.(2002), in their study of men with ED who had undergone prostate removal for treatment of cancer, identified that there was a need for these men to be able to maintain an image of themselves as the man they were before their surgery. They identified within their theme of "*disrupting a core performance*" that it was important for the men to be able to maintain control of information that was given to other people and that in order to do this and maintain their image sometimes they had to lie, demonstrating that embarrassment cannot be relied upon as a mechanism to facilitate honest discussion.

All of the men in this study used the illustration of illicit drug acquisition, specifically the illegal trade in Viagra, as a way of demonstrating how embarrassing and hidden the issue of ED can be; however none of them admitted any illicit drug usage personally. Although they believed that the illicit drug trade existed because of embarrassment they had not seemingly felt the need to utilise this to access treatment, or they were not willing to discuss this in the interview and were confirming Mr Collins' thoughts on lying. Schnetzler et al (2010) explored the trade in Viagra and concluded that embarrassment was the vulnerable aspect which ensured the success of the illicit trade in ED treatments and would continue to do so until there was a change in societal acceptance of dialogues about ED. Embarrassment can therefore be considered as a negatively impactful emotion which can have significant impact on the actions of those who are feeling it; however these impacts do not always lead to negative actions and therefore healthcare professionals can

utilise some of the positive responses to embarrassment to facilitate discussion.

### **Embarrassment and Anxiety or Danger**

Heatherton et al.(2000 p201) describe situations which cause people to feel embarrassed as “*awkward moments*”, similar to Lawler’s (1991) “*dangerous conversations*”, both of which are often, when anticipated, preceded by feelings of anxiety. This may explain why in the interviews for this research, there was a necessity for varying degrees of funnelling; talking around other issues and developing a relationship before asking about the main subject so as to minimise the feelings of anxiety (Smith et al.2009). Anticipation and anxiety may also explain why the men particularly, were avoiding or dismissing the topic in the early stages of the interview. They used avoidance of the topic or dismissing the relevance of ED to minimise and manage their anxiety, which was clearly demonstrated in the analysis of the language and with significant amounts of funnelling identified in all of the interviews.

It is not only those with the embarrassing condition that feel a sense of anxiety in relation to these awkward moments. Heatherton et al. (2000) refer to non-stigmatised people (within disclosure scenarios these would be healthcare professionals) who feel anxious because they fear their own lack of understanding of the condition they are talking about and because they are potentially violating societal norms and expectations. These fears were evident within the data from the healthcare professionals’; they discussed anxieties related to being misunderstood and causing offence. Jeremy, Angie and Alison all talked of a fear of asking men from particular cultures, of particular ages and of differing generations about ED which ultimately prevented them from asking at all; their lack of understanding not only being of ED but of differing cultures and generations.

Magnan et al.(2005) consider that healthcare professionals feel a sense of danger or anxiety when specifically asking about sexual health. They asked nurses who worked in a variety of clinical settings, none of which were sexual health specialities about such conversations and concluded that nurses felt a sense of anxiety because of their perception that they are involved in a



conversation which has moral implications. Such conversations were therefore difficult because nurses believed that they should be practising in a non-judgemental manner, but were influenced by their personal beliefs and the societal beliefs of the culture within which they lived and practiced. The nurses in the study did not feel that they are in a position to manage and were not prepared for such discussions, which Katz (2005) hypothesised is due to a lack of professional training (Katz 2005, Roach 2004). In light of this lack of training and because healthcare professionals are individuals with their own beliefs and morality they are having to use these to inform their practice in the absence of professional training. Using one's own belief system was clearly demonstrated by all the healthcare professionals in this study who were using their own thoughts and perceptions as well as their understanding of the beliefs of their relatives in order to justify their clinical practice. When the "dangerous conversations" described by Lawler (1991) are considered in terms of moral implications and social rule breaking it can be understood why healthcare professionals would identify this as a potential danger in their practice, because of the high risk that they would be breaking social and professional boundaries (Magan et al.2005, Tsimtsiou et al.2006). The healthcare professionals in this study claimed that it was embarrassment which stopped them from engaging in such conversations but when the meaning of embarrassment is explored it becomes clear that there are many influencing factors which cause them to feel embarrassed. Ultimately it is the social rule break which causes the discomfort and this is often underpinned by a lack of understanding.

When talking about situations when a disclosure would not be sought healthcare professionals identified that they would not talk to men whom they considered older, or from a culture that was not their own or where they were unsure of the marital status of the patient. All of these perceived barriers have been cited in literature exploring healthcare professionals' behaviour in relation to asking more generally about sexual health (Hayward et al.2012) and although this may be grounded in a lack of knowledge, the sense of not understanding issues can cause professional embarrassment. The healthcare professionals within this study knew of the evidence linking cardiovascular

disease and ED, yet still some could not overcome the embarrassment that they felt to be able to ask. This was demonstrated within the analysis of the linguistic elements, when healthcare professionals talked about understanding the evidence but did not feel able to utilise this in practice and as a result demonstrated feelings of embarrassment with hollow laughter and subject changes.

Although healthcare professionals said that they found such conversations embarrassing Lawler (1991) believed that professionals use a different definition of embarrassment which is broader; including more aspects of the individual's person, vulnerability, dependence, social discomfort and dignity, hence when a healthcare professional does not want to cause offence or embarrassment they are giving consideration to much more than a fleeting emotional response. Healthcare professionals were not asked to explain what they meant by embarrassment but they discussed how they did not want to upset their patients and demonstrated a professional sense of not wishing to offend or cause embarrassment, similar to that described by Lawler (1991). When a healthcare professional has caused embarrassment this is considered as a professional failure because they have not used professional levels of tact and expert social skills to avoid embarrassment; this is an insult to their professional self which can negatively impact upon their own sense of self (Lawler 1991). Healthcare professionals sometimes take measures to avoid such scenarios to ensure that they are not professionally compromised, such as Rebecca who categorically did not want to ask about erectile dysfunction. Whilst this may have been a failing on her part, similarly she did not want to ask and cause embarrassment which would equally be a professional failing. Her laughter demonstrated uneasiness about being in, what she perceived to be, an impossible position.

Healthcare professionals, as previously discussed, may fear "*dangerous conversations*" (Lawler 1991) because they may be misunderstood or cause offence and their motivations may be questioned, therefore they try to manage their language in order to minimise the risk, but often their wish to not offend is used as justification for not engaging in a conversation (Taylor and Gosney 2011, Hinchliff et al. 2005). Heatherton et al.(2000) believe that the only

socially acceptable way for an embarrassing subject to be introduced into a conversation is to be introduced by the person who is experiencing it and some of the healthcare professionals said that they were quite happy for the men to start a conversation about ED. However, the members of staff who actively enquire are potentially breaking this social rule and in doing so can cause themselves significant anxiety (Meerabeau 1999). This anxiety was described by Angie, as she approached the subject on a check list of topics that she had to discuss with her patients. Literature suggests that in avoiding, or suppressing the need to talk about a particular issue, the healthcare professional may inadvertently demonstrate a heightened awareness of the issue and thereby equally cause a sense of embarrassment for all (Heatherton et al.2000), as Meerabeau (1999 p.1507) describes the “*infectiousness*” of embarrassment.

Interestingly all the literature which provides guidance to healthcare professionals on how to have conversations about sexual health suggests a relatively direct approach, believing that any ambiguity will inhibit a disclosure (Hinchliff et al.2005, Katz 2005, Skelton and Matthews 2001). This literature suggests a structured and direct approach which would not be supported by Goffman (1963) who believes that people with a condition should be in control of disclosure. However the guidance does provide healthcare professionals with training in the form of mental preparation which may help to negate some of the anxieties that they may feel (Skelton and Matthews 2001).

## **Managing Embarrassment**

### Avoidance and Dismissal

Unlike the healthcare professionals, the men in the study did not particularly talk about how they managed embarrassment; however the analysis of the language highlighted that they were possibly managing their embarrassment during the interview. They began the conversation with dismissive statements about how they were not seemingly bothered by ED, implying that sex was not important in their lives anymore; this may have been interpreted as avoidance or dismissal. Heatherton et al. (2000) describe avoidance as a strategy for managing embarrassment by minimising or avoiding the situation or topic

altogether, while Lawler (1991) also talks of dismissal as a management strategy. Lawler (1991) identifies that men manage embarrassment by demonstrating a lack of concern for a given topic by making defensive statements and that in using these strategies a man can regain composure and control of a conversation (Meerabeau 1999). This control may have been demonstrated in the early phases of the interviews by all of the men. Avoidance was clearly demonstrated in the interview with Mr Hobbs who managed the conversation so as to talk about another medical disclosure that he had made. As the other interviews progressed all the men moved away from discussing how they were not bothered by ED and began to explain how ED was a concern to them, with the increased rapport and relationship development their levels of anxiety decreased and therefore they invested less effort in avoidance and dismissal.

Because embarrassment can result in this use of avoidance or dismissal it becomes clear that these are techniques used to manage the comfort levels of those involved in the conversation (Lawler 1991). In doing so the conversation is often deviated away from the source of the embarrassment and results in the subject not being revisited (Lawler 1991). Mr Andrews demonstrated this with his lengthy discussion of the word "*trauma*", about which he felt unable to seek clarification from his doctor. When a conversation is moved on to another topic very quickly and is not revisited, within the context of embarrassment being "*infectious*" (Meerabeau 1999), it becomes clearer to see why there is a sense of "*shutting down*" a "*dangerous conversation*". Because the conversation becomes truncated and the embarrassment is reciprocal, the subject is highly unlikely to be revisited and as a result this exacerbates the embarrassment felt on both sides of the conversation, increasing the chances that neither party would raise the subject again (Lawler 1991).

When healthcare professionals discussed how they manage awkward conversations, they described how they used their own belief system to guide their practice in the absence of professional training and in doing so they demonstrated empathy, a shared embarrassment and a shared understanding with the men, with statements such as "*it is awful isn't it*". Heatherton et al.(2000) found that a misguided understanding of the issue and how people

choose to live with a problem can result in misplaced sympathy; the healthcare professionals may have been over estimating the effect of the problem and thereby demonstrating the misplaced sympathy that Heatherton et al.(2000) describes. The men in this study did not seem to feel sorry for themselves, but they did feel sympathy for men younger than themselves who experienced ED.

Lawler (1991) suggests that nurses have to learn how to manage their own embarrassment before they can help to manage the embarrassment felt by their patients. Having knowledge of pathological causes of ED is not enough to overcome embarrassment, because embarrassment is based on the life-long socialisation of the individual healthcare practitioner. Therefore conscious and predetermined efforts on the part of the healthcare practitioner have to be made in order to professionally manage such situations. Healthcare professionals often cite their own increasing age as decreasing the amount of embarrassment that they feel in opening up "*dangerous conversations*", but both Lawler (1991) and Julien et al. (2010) believe this decrease in embarrassment not to be as a direct result of increasing age, but as a result of professional experience and the development of more advanced communication techniques, such as the linguistic tools identified in the analysis of language.

### Humour

Lawler (1991) cites the use of humour as a advanced tool for managing the embarrassment of the patient and of the healthcare professional. The specific use of humour is often justified using professional judgment "*it depends on the patient*" (Lawler 1991 p.144), requiring an assessment of the situation and a decision regarding the appropriateness of the humour. These advanced communication skills were particularly demonstrated by the nurses in this study who identified themselves as proactively asking about ED and therefore having more experience of such conversations, Angie said that "*you have to be careful, you have to go with how they are a bit*" and then went on to discuss her "*light hearted*" approach to the topic. Lawler (1991) believes this aspect of clinical judgement requires significant skill which is usually learned from

experience and this would seemingly have been identified by the more experienced staff in the study, using humour to manage disclosures.

The use of unintentional humour, for example finding a Freudian slip funny was highlighted throughout the language analysis. There is a suggestion that these “slips” are an indication of the real or truthful thoughts of the participants and that they have almost “escaped” their conscious thought filter (Fergus et al.2002 p310). Bargh and Morsella (2008) discuss the ongoing debate about how much conscious interpretation should be undertaken in relation to the subconscious and conclude that potentially humans will never understand the sub conscious or unconscious. However, they did acknowledge that subconscious thought is potentially where people’s deepest thoughts and understandings of their world are; maybe then subconscious expressions can provide some illustration of pre-understanding or situating of oneself in the world.

### Laughter

Laughter can be a response to humour but it can also be used to demonstrate a sense of feeling embarrassed; it can demonstrate a shared understanding or empathy and a need to move the conversation to another topic (Merrabeau 1999). Empathic embarrassment is described by Goffman (1956) as helping to help break down ego boundaries and thereby facilitate rapport building and shared understanding; hence the demonstration of embarrassment by laughing can be helpful in some situations. Both the men and the healthcare professionals described laughter in scenarios where there were several people present, such as the cardiac rehabilitation class. During the interviews there was frequent evidence of laughter, used as a response to humour and perhaps as an expression of unease. Goffman (1956) describes how people who are feeling embarrassed can become flustered and unable to regain their composure, an expression of this is in a hollow laugh, which was identified within the interview transcripts as an “*uneasy or uncomfortable laugh*” during the first and second analysis of the text. Laughter can therefore be considered as both expressions of positive and negative feelings because a sharing of humour and feelings of discomfort, Lawler (1991) believes it can take an

experienced individual to be able to determine for which purpose laughter is being expressed and to use it as an indication to guide the conversation.

As well as laughter Goffman (1956) also discusses how a flustered individual may use compliments to be able to regain their composure and counteract the negative feelings of embarrassment. There was evidence of this within the interviews, both with myself giving the participants compliments and them giving compliments to me. Although the use of compliments was evident within the transcripts and was regarded in the most part to be a reflection of embarrassment it must also be acknowledged that complimenting someone is also an effective way of building rapport and decreasing social distancing, therefore ways of managing embarrassment can also be used to enhance relationship development (Parisi and Wogan 2006).

### Direct Language

All the participants within this study talked about how direct and clear language are key to having effective difficult conversations, leaving those involved knowing that they all have the same understanding of the situation. Often in embarrassing situations there is a perception that the conversation needs to be stopped or hidden/coded and therefore healthcare professionals use closed questions and jargonised terms in order to truncate or minimise the conversation (Lawler 1991), this was clearly demonstrated in the interviews, particularly the interview with Mr Hobbs. The literature which provides guidance for healthcare professionals acknowledges that direct language should be used, as discussed earlier, but they do not provide clarification on the particular terminology that is acceptable (Hinchliff et al.2005, Skeleton and Matthews 2001, Taylor and Gosney 2011) this is left to individuals' judgement seemingly causing the healthcare professionals in this study some concern because they expressed a wish to know what terms they as a professional could use.

The lack of clarity and hidden nature of these discussions if thought to be underpinned by embarrassment because it is an unpleasant emotional response to a perceived social rule breaking and usually causes those involved a degree of anxiety, particularly when the rule break has been

anticipated. Although predominantly considered a negative experience, embarrassment can be useful as a clearly shared experience between two or more people, which will help them to have a shared understanding of a situation and a connection on an emotional level that words alone will not be able to achieve. Embarrassment results from being witnessed breaking a social rule and therefore an audience is an essential component of embarrassment, hence people often manage embarrassing situations by putting on a performance and maintaining a public (rather than private) persona. Within this study, all of the participants not only discussed embarrassment but also demonstrated that they found the topic embarrassing to talk about. Although there was some discussion of how the subject was embarrassing it was the linguistic analysis which demonstrated how the participants used linguistic techniques in order to manage their embarrassment, clearly demonstrating how difficult this topic is to discuss.

### **Subordinate themes**

#### **Stigma**

During the initial stages of analysis the theme of stigma was given a high priority and resulted in its initial identification as a super-ordinate theme. However, when revisited using IPA, rather than a thematic analysis, it became clear that whilst stigma was still a relevant theme it was not the super-ordinate theme. Stigma has a significant influence on feelings of embarrassment and vice versa, therefore the two concepts are inextricably linked and stigma became a subordinate theme related to embarrassment. For example erectile dysfunction was described by Mr Bridges as a “*stigma*”, however this was a passing reference to stigma and on deeper analysis of the language it became more apparent that there might be a perception of stigma, as a result of the feelings of embarrassment. However the embarrassment appeared to be more keenly felt as a result of having socially awkward conversations rather than as a result of possessing an overtly stigmatising condition.

Goffman (1963 p15) describes having a stigma as having an undesirable difference which leaves the person feeling discredited and having “*failed to perform*” a particular role; often impacting on their sense of identity and how



they live with and within their body. Although he wrote predominantly about physical and observable difference, such as a loss of a limb, he also discussed less obvious differences which only the sufferer and close others may know about, such as mental health problems; such people he called “*passers*” because they can live without anyone else knowing of their difference. The difference that the men in this study perceived was not only between themselves and other men but also between themselves and how they used to be; they are not now the man they once were, they have become a type of man that they had not previously considered themselves to be.

The perception of stigma was discussed by the men who had experienced ED as a result of treatment for prostate cancer in Fergus et al.’s (2002 p.311) study. They identified a theme of “*bearing an invisible stigma*”, in which they portrayed the men in their study as “*living in fear of public exposure*” and when they had considered disclosing their sexual problems they felt as though there was a “*wall of socially constructed shame and embarrassment*”. The idea of stigma is also highlighted within other literature which explores disclosing sexuality (Hinchliff et al.2005) and Cunningham et al. (2002) describe the stigma felt when diagnosed with a sexually transmitted disease in a westernised population (Dindia and Allen 1992). These authors discuss how socially held misunderstandings about the cause of a sexual problem can result in stigmatisation when an individual has previously held beliefs which are akin to the society in which they live, but now they find themselves experiencing the stigmatising condition and this can affect their sense of self significantly.

Perceiving oneself to have a stigmatising condition can lead to the person describing themselves as embarrassed, in particular when that condition is related to a sexual issue, which in current society is considered a “*taboo subject*” (Meerabeau 1999). In order to have a stigmatising condition, in a similar way to feeling embarrassed, it would be anticipated that there would be an audience (Goffman 1963), otherwise the individual could exist as a “*passer*” and no-one other than themselves would ever know about the existence of the condition (Goffman 1956 p71). Some men would therefore be passers, however when a person with a sexual dysfunction has a sexual partner there is

no capacity for “*passing*” because avoiding the subject will impact on their relationship, as described by Mr Evans, or result in an open conversation as with Mr Andrews. Either way the condition will not be kept as a secret solely by the man experiencing ED; they become a team to manage the performance. The team performance by Mr and Mrs Andrews was a coherent collegiate performance, whilst Mr Evans talked about how he and his wife had not talked about their sex life but remained married and the outside world still viewed them as a marital dyad with all that this entails. Both these couples were teams who had overtly or covertly decided on how they would continue to perform to the audience (or outside world). Goffman (1956) talks about how sharing a stigma as a team, becomes a successful coping strategy so that members of the team can support each other and share the burden of the stigma.

In relation to disclosing a stigmatising condition the men in this study did demonstrate some of the behaviours and rationalisations discussed by Goffman (1956). Literature which has explored the concept of disclosing a stigmatising condition indicates a reluctance to disclose sensitive information to people that are known to the individual, with a preference for telling a stranger (Lynn 1978), this was discussed by the men in relation to not wanting to talk to friends and feeling more comfortable talking to a healthcare professional. However this was contradicted in their wish to have trust in a healthcare professional which they had built over time. Goffman (1956) and Lynn’s (1978) work appears to be at odds with the work of Lawler (1991) who believes that embarrassment is more notable when talking to a stranger and these divergent findings are reflected in the discussions by the men in this study, some of whom wanted to talk to strangers and some of whom wanted to be able to evaluate the trust that they had in a given professional. Gott et al. (2004) discuss the need for a trusting relationship to exist in order for a man to talk to a healthcare professional, which would be logical when embarrassment is lessened when the audience is known.

When considering who would be the best person to disclose ED to, all the men thought that older male doctors would be the most approachable group of healthcare professionals. This does not seemingly link with the literature which suggests that men are more comfortable talking to women about personal

issues, possibly because whilst they can empathise they will not judge from a position of being a man without ED (Burd et al.2006). Men have demonstrated a preference for talking to women about emotional topics and are more likely to feel comfortable opening a conversation with a woman about difficult topics (Brooks 1974, Dindia and Allen 1992), and although the men felt that in a hypothetical scenario they would prefer to talk to a man, in reality when considering situations or healthcare professionals that they know they felt that they could talk to any of their General Practitioners that they trusted.

The requirement for confidentiality and professional standards which are associated with healthcare professions help reinforce an individual's ability to control the information which is being divulged, because of the societal perception of healthcare professionals being safe recipients of private or personal information. Goffman (1963) considers this control to be critical for a "*passer*" when making a decision as to whether or not to risk their status as a "*passer*". Because of the imperative to maintain control over the information, Goffman (1963) stresses the importance of not forcing the individual into disclosing a hidden stigma, which would potentially exacerbate their feelings of embarrassment and as Mr Collins explained, cause them to lie. The men within this study were unanimous in their need to control the disclosure and were keen to maintain confidentiality, however they did not seem to mind when they were asked directly about having ED, a situation where they were not considered in control of the conversation. Such direct questioning can be used to reduce a sense of both stigma and embarrassment, because of the direct nature of the conversation; the healthcare professional demonstrating a lack of embarrassment about a topic can have the reverse effect of the "*infectious*" embarrassment talked about by Meerabeau (1999), when the person with the condition is left to make the assessment of whether or not to disclose ED (Antoniou et al.2002). However this is not considered appropriate by authors such as Goffman, who feel that people should not be forced into a position where they have to lie and therefore he disagrees with the literature which suggests that the subject should be introduced by the person without the condition (Heatherton et al.2000). Goffman (1963) and Heatherton et al.(2000) believe that healthcare professionals should not directly ask about

embarrassing and stigmatising conditions because this will force the person to lie resulting in a break down in any therapeutic relationship. The complexity of being able to ask about a hidden stigma in a way which is understood by the patient and whereby they can maintain control is a complicated issue for which literature can support multiple perspectives.

There is clearly a significant overlap between aspects of embarrassment and stigma, primarily because stigma can cause embarrassment, so many of the expressions of the two and management techniques are similar. There remains debate within the literature as to how healthcare professionals should approach such subjects and whether it is advisable to directly ask for disclosures or whether a person should be responsible for making a decision as to whether they want to disclose, either way this will have a significant impact on how and when healthcare professionals can manage health related problems that are considered socially unacceptable to talk about.

### **Sense of self and change of identity**

Fergus et al. (2002 p303) described the themes which emerged from their interviews with men with ED as *“disrupting the core performance, bearing an invisible stigma and working around loss”*. Similarly the men in this study described in predominantly negative terms how they felt ED had caused them to think of themselves differently, being *“less of a man”* or *“losing their prowess”*. In the early stages of the interview when they were dismissive or diminishing the impact of ED they talked in accepting terms of ED being as a result of growing old, although they later described ED in less accepting terms. This early accepting stance may have been a socially acceptable response, the expectation of an older person being that they will have less sex (Potts et al.2006). However this may be a rather superficial explanation. The men in this study had all relatively recently experienced a life threatening event (a myocardial infarction) and had all given due consideration to this being potentially life ending. According to socio-emotional selectivity theory people with increasing age and a perception that they are nearing the end of their lives change the way they consider things, having a more accepting and less ambitious attitude to life events (Lang et al.1998). Although the men in this

study did not now consider themselves to be dying, they did all discuss their sense that they could have died. Carstensen et al. (1999) identified age related changes in social goals and how more social contacts seem superficial when time is perceived as limited. Older people tend to appreciate what is good in their relationship rather than seek new solutions and when people consider themselves to be nearing the end of their life they prefer to have emotionally close partners and usually reduce the number of more superficial social contacts (Carstensen et al.1999). In reducing their social circle to only include close friends and family so they are developing a sense of social embeddedness, which for older people is important (ibid). This may explain why the men were describing how sex was not a significant thing in their lives anymore, they were appreciating the close relationships that they had and rather than this being a lack of bother, they were appreciating what they had (Potts et al.2004). For older people their spouse and children are their social resources with friends further out on the periphery, with less importance, which also may account for the men not feeling close enough to tell friends about ED (Carstensen et al.1999). Older people prefer social partners who are familiar to them and Lang et al. (1998) believe that older people adapt to what they have at any given time, this may also explain their seeming lack of bother and may be an expression of how they are simply adapting to life as it is now. While this may seem an appropriate adaptive technique, there may be issues when older people focus their attention purely on the present, there is an obvious risk that they are not inclined to consider risk reduction to influence future health and this may impact on their inclination to use ED as a marker of risk on which they may act.

Carstensen et al.(1999) explored the perceptions of people who considered that they were in the latter years of their lives and found that older people always consider the past as the time when they were at their most potent, giving sexual intercourse less current importance from a position of thinking that they will never be as potent as they have previously been; the men in this study talked about their prior sex lives in positive terms just as Carstensen describes, all being keen to illustrate a previously active sex life.

Within this study the temporality associated with making a decision about disclosure was expressed by using the men's age as a reference point they are less inclined now than they would have been previously. These findings were similar to Gott and Hinchliff (2003) and Stead et al. (1997) who asked old people if they placed much importance on having sex and concluded that they did not prioritise sex because priorities change with age, however they would be more likely to seek help if they had a partner, as was demonstrated by some of the men in this study. With increasing age comes the increased experience of ill health and therefore older people decrease the importance that they have previously given to things such as a career, ambition and their sex lives (Carstensen et al.1999). This lack of drive in relation to seeking a solution for ED in older men may impact on their motivation to disclose an in itself may present a barrier to using ED as a prompt for cardiovascular assessment.

### **Managing Disclosure**

Both the men and the healthcare professionals in this study talked about how the men mentally prepare to disclose ED. Mental preparation is important to provide the men with knowledge and information which results in them feeling that a disclosure is a legitimate course of action (Hayward et al.2012). The men described how they usually went about this by seeking information in an anonymous format, particularly using the internet or newspapers, therefore they would not have to risk potential embarrassment and in doing so they were empowered to overcome the feelings of discomfort in order to disclose. Hillman (2000) describes such attempts to gain information as useful because they help to manage the expectations of a consultation and Taylor and Gosney (2011) describe such attempts as providing permission to engage in such conversations.

Although the men described mental preparation and the healthcare professionals recognised this as "*psyching themselves up*", very few of the healthcare professionals prepared themselves and were surprised by unsolicited disclosures. The few healthcare professionals who did prepare themselves described these preparations in negative terms, such as Anna who

knew that she “had” to ask about ED as part of a clinical protocol. Hayward et al. (2012) believe that healthcare professionals need to mentally prepare for difficult conversations, because when they are unprepared they will respond with a sense of embarrassment and then exacerbate the embarrassment felt by their patient. By being trained to recognise their own anxieties, they would be able to manage their communication from all aspects so that their patients would not be able to recognise the healthcare professionals’ discomfort. Hayward et al (2012) believe that this mental preparation should be included within communication training and should be embedded within curriculums of all healthcare professionals from the early stages of a professional training in order that practitioners can evaluate their own beliefs and practice thereby minimising the effect (Hayward et al. 2012).

Routine clinical patter can help to mentally prepare and minimise embarrassment and is a technique which can be used by less experienced staff in order to address difficult topics, this helps the healthcare professional to almost “*asexualise*” the patient and thereby put distance between them and the topic that they are about to discuss (Katz 2000 p.40, Lawler 1991). This “*asexualising*” of the patient and the topic is a documented coping strategy for dealing with many aspects of nursing work and is often considered as managing an issue in a “clinical manner” (Meerabeau 1999). Alison and Angie talked about their clinical routine and using check lists to build in an opportunity for men to disclose ED to them in clinic. In using aids such as checklists to assist the conversation, the healthcare professional is thought to be coaching the patient through the conversation by demonstrating that the situation is not embarrassing and therefore not uncomfortable (Lawler 1991). Lawler (1991) demonstrated how nurses negotiate social rule breaking by making the purpose of the conversation explicit, then all involved should feel that the conversation is more acceptable and manageable (Katz and Marshall, 2004).

The use of health promotion materials as well as check lists was also discussed by the men and the healthcare professionals in the study, with mixed responses. Two of the men did not feel connected with the characters portrayed in the video that they had watched in the cardiac rehabilitation class,

and one man felt that because he had connected culturally with the characters he was able to volunteer to be interviewed for this research and thereby disclosed his ED. Culturally competent healthcare is essential if people are going to feel connected enough with the characters to realise that they are the target of the health messages (Hayes-Bautista 2003). Cultural competence addresses not only language but non-verbal communications and the beliefs and ethical beliefs of particular cultures (Anderson et al. 2003), including religious, ethnic, racial and broader cultural beliefs (Engebretson et al. 2007; Hayes-Bautista 2003). Materials that are developed for the majority of a population can cause feelings of isolation for those who do not feel connected and therefore the actors need to represent the target audience. Within the cardiac rehabilitation class where the men watched a video, the men who had felt disconnected from the actors were white British and they seemingly had concerns because the man in the video was not speaking in English. Nyman et al. (2011) state that people feel most connected when they can see themselves in the people being portrayed and when it is a positive portrayal this is more likely to invoke the changes that the health promotion agencies are wanting, as was demonstrated by Mr Franks who volunteered for study after watching an Indian man talking about ED in an educational video. Lee (2007) studied how well intended sexual health messages miss their intended audience particularly in relation to HIV health promotion in homosexual populations and this may well be what happened with the British Heart Foundation video, the intention was to appeal to audiences historically not targeted, but in doing so other populations failed to connect. So it becomes clear that targeting your audience is crucial, but this can be difficult in a multi-cultural society (Kreuter et al. 2002). Managing disclosure is therefore complex. Societal beliefs and understandings impact on whether people consider healthcare professionals as the right people to disclose sensitive issues to and conversely healthcare professionals seem uncertain whether they are the correct people to seek a disclosure.

### **Medicalisation**

Medicalisation is the process whereby, a previously considered routine problem becomes defined as a medical illness. This illness is accepted as



such by society and can be treated with medical therapies; for example the identification and treatment of depression with Prozac (Conrad and Leitner 2004). Since the licensing of Viagra there has been much discussion in the sociological and medical literature about the “*medicalisation*” of erectile dysfunction (Conrad 2005, Fox and Ward 2008, Teifer et al. 2006). The process of medicalisation typically requires a series of changes to have been demonstrated; including technologies or treatment availability, medical knowledge of the causing pathology and the perception of the wider society as a medical problem (Conrad and Leitner 2008). Literature argues that treatment with PDE5 inhibitors, the knowledge of the underlying pathological causes of ED and a world-wide advertising campaign for Viagra demonstrate that all these aspects have been fulfilled (Fox and Ward 2008), however the data from this study may provide some evidence that this process has not yet been fully realised.

The men in this study tentatively talked about how society’s attitudes were changing and how they hoped that more open discussions would take place around sexual dysfunction, believing this to be related to the increasing medical understanding. However, they themselves demonstrated that society does not openly discuss sexual dysfunction during their discussion of embarrassment, the lack of disclosing behaviours and the analysis of the language used in this study; indicating that these are not commonly held conversations. Skelton and Matthews (2001) believed that western society may be on the brink of a significant change, however Taylor and Gosney (2011) ten years later were still hoping for such a change in relation to discussing sexual health.

The men were all able to name medical treatments for erectile dysfunction, discussing in relative detail the advertising campaign for Viagra in particular. This advertising campaign has been scrutinised as a text book example of how to embed an idea into societal beliefs so that a previously non-medical complaint became an accepted medical condition (Fox and Ward 2008). Whilst the men in this study could identify the campaign and hoped that it would improve the confidence of men in disclosing ED, they also identified that in the fifteen or more years that this campaign has been running there has been little

impact in reducing the embarrassment felt, because they still believe that men do not feel comfortable talking about ED. Hence we have a socially unacceptable topic yet society has, to a degree, accepted an advertising campaign which the men in the study considered as a glamorous portrayal of the problem.

The men felt that knowing there was a pathological cause for ED, that could be correlated with the same processes that caused heart disease, also helped to medicalise the condition, providing a justification for disclosure; an obvious benefit of medicalisation because identification and treatment would result (Rosen 1996). This underlying pathological understanding was also understood by the healthcare professionals and recognised as a robust evidence base; an essential element of the medicalisation process (Conrad and Leitner 2004). Although the healthcare professionals recognised this initial step in medicalisation they did not identify the other aspects required for medicalisation. Although a societal acceptance of a condition is required, it would appear from the reluctance of the professionals in this study to engage in discussion with their patients, that they are not keen to adopt ED as a medical concern. Whilst a general societal consideration is required there also has to be an ownership on the part of the medical professions and until this is demonstrated then medicalisation cannot be said to have occurred (Herson et al. 1999, Rerkpappanapipat et al. 2001, Teifer et al. 2006).

Healthcare professionals in this study discussed how they were not sure which speciality or profession should take responsibility for asking about erectile dysfunction; even cardiologists who know that there is a link do not ask, a finding similar to that of Rerkpappanapipat et al. back in 2001. Being unable to treat a medical condition and having to refer on to another professional can distance the receiver of the disclosure from the topic (Quinn et al. 2011), making them feel that it is not within their professional remit and is therefore not their responsibility, as discussed by Thomas who seemed to feel as though he had failed in his role if he had to refer patients on to another professional. Mental health nurses have identified this distancing as being a result of having to refer to other healthcare professionals. Historically sexual dysfunction has been treated by the medical speciality of psychiatry and therefore this would

be a group of professionals that may have been considered more accepting of this aspect of clinical practice (Quinn et al. 2011). If mental health nurses identify such problems how can other healthcare professionals' begin to adopt ED as a medical problem?

Healthcare professionals in this study who indicated that they were not confident and lacked the knowledge to treat ED would refer to another healthcare professional for assessment and treatment; this is often cited in the literature as being due to a lack of training and knowledge (Haboubi and Lincoln 2003, Stead et al. 2003, Taylor and Gosney 2011). This perceived lack of training suggests that professional education and thereby the institutions in which they have been professionalised do not recognise ED as a medical problem. Therefore when medicalisation is explored in relation to erectile dysfunction and specifically the disclosure of erectile dysfunction, it would appear that only two of the three essential elements do exist. There is an effective and acknowledged treatment and there is an understanding of the underlying pathological causes, however there is still a degree of social attitude which seems to be impeding the disclosure of ED and therefore it could be argued that the process of medicalisation has yet to have truly occurred.

In conclusion, embarrassment is the most clearly demonstrable theme within all the interviews and throughout all the analyses, the multiple revisiting of the transcripts and the analysis of the linguistic tools. Within embarrassment there is clear overlapping with the thoughts on stigma particularly in relation to how people identify themselves, their self-perception and how they cope with these issues. The management of embarrassment and elements of stigma impact on how men and healthcare professionals manage disclosures and although this can often be reported in a negative way, there is much to be learned from how a shared sense of embarrassment can help build therapeutic relationships, particularly when the healthcare professional can utilise some of the more advanced communication techniques demonstrated within the analysis of linguistic tools. This linguistic analysis also helped to demonstrate how all of the participants were embarrassed during the interviews embarrassing and

therefore provided evidence that the social acceptance of such conversations is yet to be achieved.

## **Chapter Nine: Discussion of research methods**

In order to demonstrate reliability and quality when reporting qualitative research it is imperative that the researcher makes explicit any issues which impacted upon the research process; primarily to ensure clarity, reliability and rigour (Hall and Stevens 1991). From the conception of this thesis, safeguards have been incorporated to maintain the rigour and standards of the study because, as with all qualitative research, the drive to prove rigorous practice is essential as a measure of the truthfulness of the findings (Mays and Pope 1995). An accurate discussion of the research design and process is therefore essential to demonstrate how issues which came to light during the research process may have impacted upon the quality of the research and also to provide researchers with an opportunity to reflect upon the experience and identify learning which will influence future research efforts.

### **Researching sensitive issues**

Within a research setting “hard-to-reach” populations are often thought to be populations that are hidden away from general society because of social stigma, embarrassment and the obvious concerns over confidentiality when participating in a research project (Penrod et al. 2003). The previous research focusing on erectile dysfunction concluded that men with erectile dysfunction are a “*hard-to-reach population*”, who are often not willing to participate in research for fear of being identified to a wider audience thereby demonstrating the effect that embarrassment has on them (Pontin et al. 2002, Fisher et al. 2005). The recruitment rate of men to this study was smaller than hoped for and it can be concluded that the sense of embarrassment, as demonstrated by all involved within the study, had impacted upon recruitment.

During the design of this research the population of men was identified as “hard-to-reach” and therefore several adaptations were made to improve potentially poor recruitment; anonymous questionnaires, general recruitment information to whole classes and several confirmations of anonymity assurance. Despite these adaptations there remained problems with

recruitment and therefore these techniques require further analysis in relation to this project from the perspectives of those involved.

### **The men's perspective**

Traditionally, in research which aims to study hard-to-reach populations snowball sampling or chain referral methods are utilised to gain access to members of the population being studied, via other members of their community (Penrod et al. 2003). Associated with such methods of sampling is a risk to the participant of losing their anonymity because the method necessitates that they are able to speak to others with a shared experience. Men with ED often resist talking to anyone about their problem and therefore would potentially be unaware of anyone else with ED, thus such sampling methods would not be feasible due to a lack of supportive networks and open discussion about the topic (Pontin et al. 2002). Convenience sampling may be less likely to minimise issues of variability and representativeness (Atkinson and Flint 2001), however the men who volunteered were self-selecting and identified themselves as having ED, which in itself tells us something of the character of men willing to engage in such discussions.

Willison et al. (2009) explored the extent to which people with stigmatising conditions were willing to take part in research and they found that there was substantial variation in the control that people wished to exert over their personal information and that this did not correlate with their condition but was associated with their individual attitude. They also found a slightly more permissive attitude demonstrated by those with a stigmatising condition than the attitude of a general population. The literature which explores embarrassment would also suggest that in order to manage embarrassment, people are more likely to comply with requests made of them and this may be what happened in this case (Apsler 1975). The men who did volunteer to take part in this study may have been motivated as such and therefore there are factors which will positively facilitate the study of hard to reach populations.

From the population of cardiac rehabilitation attendees only nine men volunteered to participate, this is an indication of just how difficult a population these men are to access and that the positive things which impact are not to

be relied on! The sample of men with ED, were representative of the men who attend cardiac rehabilitation, from age and cultural perspectives, but not representative of the male population as a whole lacking younger men and men from a variety of ethnic backgrounds; which tends to be replicated within the populations of men who do attend cardiac rehabilitation classes (Beswick et al. 2005). Whilst it may be considered that the recruitment rate was poor because of the hidden nature of the topic, the stage of recovery may also have been an influence. Research has indicated that patients can experience psychological and emotional adjustment issues for as many as six months after an initial cardiac event (Timmins and Kaliszer 2003, Jaarsma et al. 2010), many of the men in the cardiac rehabilitation class may not have felt that they were ready to participate in research, so soon after a myocardial infarction (MI). Their MI may have negatively impacted upon their sense of self in addition to the perception they have of themselves as a man with erectile dysfunction (Steinke 2013). Conversely because embarrassment is not felt as acutely when there is a greater threat to life or increasing age and because of shifting priorities as a result of a life threatening event, it becomes multi-factorial as to why the men in this study felt that ED was not a significant issue at times but that they felt able to participate in this study (Lawler 1991).

Recruitment paperwork was designed to reflect the private nature of the topic; however this did not seemingly encourage men to participate. The cardiac rehabilitation nurses, who were responsible for distributing the recruitment paperwork expressed disappointment at the low response rates and one offered her thoughts on the recruitment paperwork as being too lengthy and complex which she felt may have dissuaded people from participating; although she was happy to actively recruit and provide information if required. Writing to the participant at his home address and asking him to contact me to arrange the interview added an extra step to the recruitment process, which could have potentially caused a loss of participants. Mapstone et al. (2009) conducted a Cochrane review on methods of improving recruitment to research and concluded that it was not possible to predict the most effective ways of recruiting, however they did identify several papers which concurred with the view that additional information prior to undertaking the study does

little to encourage participation, as suggested by the cardiac rehabilitation nurses who believed that six pages (see appendix four) was too much information. The need for sufficient recruitment information is discussed by Smith (2008) and Asch et al. (2000) who both express the view that whilst a certain amount of information is required in order for the participants to give informed consent, too much information, which they believe is often requested by ethics committees, can discourage participation and may be what the cardiac rehabilitation nurses were describing.

Trust between the staff recruiting to research and the participants is crucial if potential participants are to feel confident enough in the conduct of the researchers, to volunteer (Mapstone et al. 2009). It became clear during the interviews that the men trusted the cardiac rehabilitation nurses and felt a sense of gratitude to them; volunteering for an interview would repay the healthcare professionals for the care they had given. This gratitude may have influenced their responses, placing an overly positive perspective on the situation at times, especially in relation to their recovery from the heart attack. However since the interviews were aiming to capture their perceptions, their considerations at the point of being interviewed were their truth. Researchers must acknowledge the bias which exists when participants feel a debt to the recruiters; which may manifest in participants feeling compelled to portray a story which they believe the researcher wants to hear (Lowes and Prowse 2001).

### **The healthcare professional's perspective**

In order to minimise the influence of coercion, a stipulation of the ethical review panel was that healthcare professionals must be asked to participate by the clinical lead or lead nurse for cardiac rehabilitation; as a means of protection for the hospital staff from perceived pressure from the researcher. This mechanism adhered to ethical principles but resulted in a sample of professionals who were known to the recruiting individuals (Hewison and Haines 2006), therefore this somewhat biased the sample, because they were potentially more aware of the topic than others; an issue which was highlighted in several of the interviews. Asch et al. (2000) discuss the benefits of such



recruitment methods, due to the personal relationships between colleagues there is usually a favourable response rate, as was the case in this study and subsequently the participation is quite honest. However they recognise that this recruitment technique limits the variability of the sample and introduces a bias towards a group of people who are known to the recruiting professional (ibid).

### **The difficulties of discussing sensitive subjects in interviews**

As a researcher and nurse I was considered to have dual roles during all the interviews, with men with ED and healthcare professionals. This can influence the responses provided by the participants because they may tailor their response to suit the researcher, introducing a degree of social acceptability bias (Lowe and Prowse 2001, Williams and Heikes 1993 p.285). Because interviews are an interactive process it was recognised from the outset that each interview would represent the interaction between the researcher and the participant (Lowe and Prowse 2001), therefore this influence was observed for and acknowledged throughout the process using a reflexive diary and regular discussion with my supervisor. When the interviewer and interviewee are both engaged in a dialogue each response is influenced by the previous; therefore a mutual understanding is often reached with few words (ibid). Silences and affirming statements are often an indication of this shared comprehension (Lowe and Prowse 2001) and where an understanding is achieved these situations can foster positive feelings and demonstrate that a rapport has been built (ibid).

The fostering of a shared understanding and mutual respect may have somewhat impacted upon the depth achieved during the interviews. For example when men with ED stated that they had not disclosed to a healthcare professional because it was embarrassing, they would often say “*well you know it’s embarrassing*” which left me agreeing with them, not wanting to embarrass them any further. We understood what it feels like to be embarrassed and displayed feelings of embarrassment, therefore neither of us wanted to induce any further feelings of discomfort, because we both understood the discomfort of embarrassment, embarrassment can cause a

conversation to come to a sudden halt (Schudson 1984). The fine line between developing a rapport and asking more probing questions is often a problem for novice researchers and resolved to some degree with practice (Britten 1995), however this can also present as a problem to those with more experience particularly when the topic is sensitive (Roulston et al. 2003). Goffman (1956) describes how mutual embarrassment can help reduce ego boundaries and may help with rapport building, therefore mutual embarrassment should not be considered as completely negative in respect to interviewing; it may be used to facilitate rapport building and therefore conversation.

The topic and the personal beliefs of the interviewer will inevitably impact upon the dialogue; hence the efforts to identify my pre-understanding prior to the research being conducted were imperative. Whilst the aim of an interview in a phenomenological study is to achieve deep rich data this should surely not be at the expense of rapport building and ensuring that all parties involved feel comfortable, in order to be able to achieve a balance between the two. Lowes and Prowse (2001) warn that a degree of detachment is required if interviews are to be managed effectively, which has to be achieved within the context of a dialogue. As an example humour can be used within an interview to manage feelings of uneasiness and relieve tension (Meyer 2000), jovial “*brush offs*” and tending to join in with the banter demonstrating a shared understanding but also being used to maintain distance between the interviewer and the topic, however this can result in the discussion moving on and potentially in-depth data, particularly in the study, being forfeited as a result. This is a common problem for novice researchers, particularly within the context of sensitive research and can often only be overcome with practice and increasing confidence (Dickson-Swift 2007). A pragmatic way to build such confidence is to build into a research methodology multiple meetings, so that the researcher is not under pressure to build a relationship and gather in-depth data within one meeting. However when asked whether they would be willing to review the findings in order to assess their truthfulness, the men with erectile dysfunction were reluctant to participate. This discussion was not captured within the interviews but the men gave the impression that having undertaken the interview it would be too much of a burden to ask for further involvement. Such

behaviour is often noted with people who have a stigmatising condition as they do not wish to repeatedly revisit a topic they feel they have dealt with (Kitson et al. 1996). Therefore participant validation was not undertaken as it was clear that none of the men were keen to participate in this particular part of the research and made it clear that they trusted me to portray their stories, one saying “*no love I don't need to check it*”. If repetitive interviewing had been used this may have been prohibitive to recruitment because it has been acknowledged that with participants who are hard-to-reach, committing to more than one interview can impeded recruitment (Kitson et al. 1996), therefore in reality the recruitment and reliability of this study may not have been enhanced by using multiple interviews.

### **The outsider perspective**

As a woman interviewing men there was discussion during peer review as to whether men would prefer to talk to a man about specific male problems. The literature provides a mixed picture as to disclosing behaviours and suggests that the topic for discussion is pivotal in determining whether men will talk to women; for example Pini (2005) studied a male dominated profession with men within that profession and concluded that she had received very different responses from her male colleague, who was also conducting interviews. As discussed earlier, men have been shown to be more likely to discuss topics which are thought of as relating to their emotions with a woman rather than a man (Brooks 1974, Dindia and Allen 1992). During the interviews with men they were asked who they would prefer to disclose to, several made reference to the fact that they felt quite comfortable during the interview therefore they would be quite happy talking to a woman; my gender seemingly facilitating discussion rather than limiting it. When a gender difference exists between the interviewer and interviewee there is a tendency for continual checking, as with this topic the men would be unsure as to whether I understood what they were discussing, but if they were talking to a man there would be an even greater degree of shared understanding (Williams and Heikes 1993). Although this may have facilitated greater feelings of comfort the sense that men would check with a woman about their understanding of what they were saying could

have been utilised within this study to seek greater explanation and thereby resulted in richer data.

In studying the subject of erectile dysfunction, the issue of social acceptability bias was inevitably going to influence the findings. The men indicated that they modified their language from that used in other situations and healthcare professionals to a degree gave answers acceptable to their professional self. There is no definitive method for reducing social acceptability bias and the truth as expressed by an individual in that moment has to be considered as just that (Leung 2001). Undertaking linguistic analysis specifically does help to explore this bias and assists the researcher in seeing past the superficiality of some answers; therefore in a topic area where this bias is a significant risk to rigour, the research perspective can assist in minimising the effects. Interestingly the findings of the study go some way to illustrate the degree to which this affects the participants and the findings. Embarrassment impacted upon the depth of the discussion and the modification of language used by the participants in expressing their thoughts.

The interviews which took place when a wife was present were seemingly easier to conduct, because there was not such a focus on the man himself and often the women seemed to find talking easier than the men. Brooks (1974) concluded that couples which contain a woman and have a stigmatising condition, are the most likely combination to disclose sensitive issues; whether the issue relates to the woman directly or not. Although it would be tempting to include the partners of all the men it has to be noted that several of the men in this study had not discussed their ED with their partners. If the study was designed to include every partner then these men would probably not have participated and vital data from the perspective of men who had not disclosed ED would have been lost. The perspectives of the men who had not previously disclosed their ED to anyone was a unique aspect of this project, in no other research have such a group been identified as participants

Several of the men commented on my age, seemingly thinking that I was too young to talk to, often people would prefer to talk to people of their own age (Kitson et al. 1996). Within the spirit of rapport building and researcher self-

disclosure and in order to break down this potential barrier I was keen to tell them that I was thirty seven, which seemed to allay their apprehensions and often resulted in comments about looking good for my age! This reciprocal sharing of information is thought to facilitate a mutual respect and balance in the relationship, reducing any perceived power differential and thereby fostering a more open relationship (Lawler 1991, Dickson-Swift et al. 2007).

### **The insider perspective**

The healthcare professionals had all known me in my role as a nurse and some as the nurse in the Male Sexual Health Clinic. These role divisions influenced several aspects of the interview; the use of jargonised language, their perception of my expertise and their perception of me as a previous colleague. Whilst being considered an insider or emic researcher can have benefits such as a lack of guarding behaviours or having a shared understanding it also has its detriments; the researcher can be blind to some elements which a researcher naïve to an area may readily identify (Mannay 2010). The continual revisiting of the data for the purposes of analysis helps to reduce the effect of insider blindness because researchers are made to revisit the text and are encouraged to see new things each time, interrogating their previous understandings to the extent that this blindness has less of an impact. Had IPA been used from the beginning of this research, rather than only within the analysis phase, this effect may have been reduced even further. However the careful application of IPA during the analysis of the data did allow for some previously unidentified elements of emic blinding to be acknowledged, which when coupled with the influence of the embarrassment may have exacerbated the problem of a lack of in-depth questioning.

The use of jargonised language was a convenient way of establishing a shared professional understanding; whilst this understanding was mainly beneficial, it did result in a lack of depth or explanation at times within some of the interview transcripts. A lack of clarity was managed with the use of a reflexive diary, however a common mistake when novice researchers interview colleagues, be they senior or junior, is to fail to ask for clarification in an attempt to maintain their previous knowledgeable or professional status (Goldman and Swayze

2012, Chew-Graham et al. 2002). The opposite was also true, whereby healthcare professionals considered me to have more knowledge of the topic and in an attempt to demonstrate their understanding, they displayed aspects of *“interactional expertise”* (Collins 2004 p.125), whereby they utilised specific language regarding erectile dysfunction but then would seek clarification from me in relation to what that would mean within practice. These dynamics were evident; however they did not seem to impact on the honesty and interest demonstrated by these participants. Specifically within a phenomenological study, researchers are participants and so are allowed to demonstrate where they are situated philosophically along with the participants and therefore the dynamic is identified and openly acknowledged (Smith et al. 2008).

### **Issues of confidentiality**

Ten questionnaires were returned, nine of these were from the men who had kindly agreed to be interviewed. Only one man responded anonymously. This may indicate that once men have made a decision to discuss the topic, in whatever format, they will do so; but not before (Tourangeau and Yan 2007). Two hundred questionnaires were given out to men in the cardiac rehabilitation classes, where the incidence of erectile dysfunction would be as high as sixty percent (Hood and Robertson 2004). If this statistic is accurate one hundred and twenty men who were given the questionnaire would have been experiencing erection problems. An attempt to establish why this data collection had yielded so little information was made in some of the interviews and the response summed up by Mr Bridges who made a comment which was not recorded but in which he said *“men will talk when they are ready to talk”* and this would appear to be in any form, written or verbal. Using a survey to access sensitive information may not be the most effective method because to divulge sensitive information understandably participants prefer to have support and positive reinforcing messages from an interviewer (Tourangeau and Yan 2007). Surveys are often used to collect data on sexual issues because they can be distributed to a wide audience, this will increase the potential number of participants and therefore the number of responses (Fenton et al. 2001), however if they yield few responses or the data lacks depth then their applicability has to be questioned.

The return rate of the questionnaires may have been improved had the men been asked to complete the questionnaires whilst in the class, but it was considered that this may have caused greater discomfort and possibly would have required a greater involvement by the cardiac rehabilitation staff. Such a method may have also placed men under a perceived pressure to participate in order to please the staff (Dickson-Swift et al. 2007). Further effort at reminding participants to return questionnaires could have proved equally as intrusive and may have acted as a further deterrent (Fenton et al. 2001), this is particularly pertinent in relation to Goffman's (1963) belief that people should not feel that they are being forced into disclosing conditions and that in doing so this may be detrimental to them.

In conclusion the methods used in this study seemingly facilitated data collection and analysis, which has demonstrated the appropriateness of the methods when studying a hard to reach population; sufficient recruitment was achieved in order to conduct the study. Undertaking interviews when the subject is a sensitive topic has its challenges and cannot be thought to be the same as taking a clinical history, therefore this skill has to be practiced and constantly reviewed for effectiveness especially when the researcher has dual roles (Yanos and Ziedonis 2006). It has been identified at every level of the analysis and discussion of this thesis that the subject matter impacted on the depth of information and engagement that could be achieved during the interviews and this is acknowledged as a shortfall, both in the planning and execution phases of the research. However it is clearly a skill that can be developed and will be taken forward as a clear element of interviewing and project development for the future. The subject matter, my novice skills, the mixed role of researcher and nurse and not using IPA from the conception of the thesis, have only served to demonstrate the need for each of these elements to be addressed early in a piece of research for a coherent and in depth exploration of a topic to be achieved.

The data that was generated demonstrated how difficult erectile dysfunction can be to discuss and people's cognitions and rationalisations about why this may be so were demonstrated within the interviews. The interviews may have lacked depth and richness, however this may be a reflection of how deeply

people are willing to consider this topic; on some levels this lack of depth may provide an indication of just how difficult the topic is to discuss.



## **Chapter Ten: Conclusions**

### **Summarising the thesis**

This chapter seeks to summarise the previous nine chapters and identify the key elements of each so that they can be taken forward into a discussion of the future influence that they may have. This project has sought to explore men and healthcare professionals' experiences of the disclosure of erectile dysfunction by asking them about such conversations; the aim being to explore these conversations so that barriers and enablers could be identified. Potential outcomes could then be used to facilitate the disclosure of ED and discussion with healthcare professionals perhaps improving rates of disclosure and diagnosis.

Early in this thesis there is a discussion of the complexities of ED and the multiple causes for this sexual dysfunction. The specific evidence for ED being a marker of cardiovascular risk has been presented along with the literature which suggests that the disclosure of ED should prompt a full cardiovascular risk assessment by healthcare professionals. This literature highlights the importance of ED as a clinical marker of risk and supports the recruitment to this study of men from the cardiac rehabilitation class and healthcare professionals who work with patients with heart disease. Utilising a phenomenological philosophy supported the design of this research because it permitted a broad exploration of the topic; a lack of any specific evidence from these populations made it essential that freedom of expression was permitted in order that participants would be able to discuss their own thoughts, experiences and priorities.

Research methods which, it was hoped, would facilitate recruitment were used with this potentially hard to reach population and resulted in data collection from nine men and nineteen healthcare professionals (of which nine were analysed using IPA analysis). The interview transcripts were initially analysed using thematic analysis and subsequently an IPA approach. The IPA approach facilitated a descriptive analysis of the text from the interview transcripts and a linguistic analysis in a staged manner. A benefit of IPA is that it permits the

revisiting of existing literature once the emergent themes have been identified and this was particularly useful within this thesis because, prior to data collection, there was very little published literature to provide a suggestion of what the experiences might be. The linguistic element of the analysis also served to highlight how the participants were expressing embarrassment via the linguistic tools that they were using during the interviews. From these analyses the themes were located within contemporary literature which focused on embarrassment, stigma and medicalisation.

### **Summary of Emergent Themes**

The themes which emerged from the data were evident in current literature but not in relation to ED and its disclosure, therefore the discussion chapter sought to situate the concept of the disclosure of ED with theory which has not previously been used to provide an explanation of ED disclosure; thereby demonstrating a new understanding of ED and how it is located within current thinking.

The theme of embarrassment highlights how the disclosure of erectile dysfunction is embarrassing for both men and healthcare professionals. Talking about sex is a breaking of socially accepted rules and therefore embarrassment is experienced because of the social dislike for the subject. Lawler (1991) discusses how society permits healthcare professionals, and nurses in particular, to break social rules but that the discussion of some subjects, such as sex, can remain “dangerous” and are therefore purposefully avoided. Lawler (1991) talks of how nurses are not averse to social rule breaking and how healthcare professionals hold a social position which permits them to break these rules. However social rule breaking in relation to discussions of sexual dysfunction does not appear to be something that healthcare professionals’ are willing to undertake. Healthcare professionals need to consider themselves as a valid audience to receive disclosures of ED because the men in this study believe them to be but the healthcare professionals seemingly did not have such a self-belief.

Strategies were identified which can help to manage embarrassment, such as preparing for the conversation with the acquisition of knowledge and ensuring

that control is maintained during the disclosure; concepts which were discussed by men and healthcare professionals alike. Confidentiality and privacy were identified as key if the men were to consider disclosing ED and the healthcare professionals identified these issues as pivotal, but within some healthcare settings they felt that these were difficult to facilitate. Despite the negative connotations associated with the sense of embarrassment, the literature suggests that mutual embarrassment can help to build a relationship between the man and the healthcare professional and that the sense of embarrassment can facilitate an honest and helpful response from those who are embarrassed (Apsler 1975); hence with experience and advanced communication skills healthcare professionals can identify embarrassment but do not need to abort a line of enquiry simply because it may embarrass.

The analysis of the linguistic tools and language used in the interviews demonstrated that embarrassment can be identified in many ways, for example laughter is not always an expression of finding something funny, it can be used to divert attention away from an embarrassing topic and for maintaining control over a conversation. The analysis of the language also demonstrates how such conversations require a level of shared understanding, so that meanings do not need to be made explicit for the participants to be able to understand one another; neither participant is required to use language that they are not comfortable using in order to make themselves understood.

The sub-theme of stigma overlaps with the findings and literature regarding embarrassment because feelings of embarrassment are often as a result of believing oneself to have a stigmatising condition. The men felt a specific sense of stigma because they were reconsidering their identity compared with their previous self; who did not have ED. They were therefore able to view themselves as a person who they may have previously held stigmatising views of. The sense of having failed was clear from the men in this study, as was the sense of pity for them, from the healthcare professionals. The literature which explores the disclosure of a stigmatising condition is similar to the literature on embarrassment in that it identifies the need for privacy and confidentiality and that feelings of embarrassment are inherent in these conversations. The men demonstrated a sense of embarrassment because they believed themselves to

have a stigmatising condition and this condition had significantly impacted on their sense of self.

The change in their own perceptions of themselves as a fully functioning man were negatively described by the men as a loss or "*being less of a man*", and these feelings were what underpinned their embarrassment and feelings of stigmatisation. Although in the main this was a negative perception the men and the healthcare professionals discussed the socially accepted views of decreasing sexual activity with increasing age, thereby fitting with socio-emotional selective theory; that people's priorities change in relation to their age and that ED might have genuinely not been a concern in later life (Carstensen et al 1999), this has called into question whether men with advancing age would use ED as a prompt to seek medical advice and that it may not be the most useful prompt for risk assessment.

The preparation that the men undertook before considering disclosing ED was identified by them and the healthcare professionals as a key step in the disclosure process. The acquisition of knowledge empowered them to disclose ED because they were confident that there is a legitimate pathological cause. The process of medicalisation therefore may have begun, with a medical treatment being available and, using the men in this study as a representation of society and their views, that society are beginning to believe ED to be a valid medical condition. However, the healthcare professionals in this study seemed to be less convinced or hopeful of this process having been completed. They were less keen to take professional ownership and looked for other healthcare professions to take the lead in seeking disclosures.

These themes have therefore been presented as the interpretive analysis of the data and have culminated in the finding that disclosing ED is difficult for both men and healthcare professionals due to issues of communication which can be rooted in personal beliefs and cultural sensitivities and manifest as embarrassment; however those who have had such conversations have never found themselves causing offence or being constrained by embarrassment. The fear of negative responses to such disclosures appears to be misplaced

and unfounded, but importantly this fear can impact on the clinical practice of healthcare professionals and potentially the clinical outcomes for men.

In summary the findings from this study are that:

- 1) Disclosure of erectile dysfunction is a “dangerous” conversation and is therefore often avoided by both men and healthcare professionals
- 2) Discussing any sexual dysfunction is embarrassing, even for healthcare professionals who have to break social rules in order to do their jobs
- 3) Men feel stigmatised by having erectile dysfunction but healthcare professionals do not seem to stigmatise men with ED
- 4) There is no clearly identifiable professional group who take ownership of seeking disclosures
- 5) Knowledge for men with ED and preparation in terms of rehearsal for healthcare professionals both help to facilitate disclosure.
- 6) Erectile dysfunction is a complicated physical, psychological and social issue and this complexity means that it cannot be taken for granted that this would be an easily used marker of cardiovascular risk. Therefore careful consideration has to be given as to how ED might be used as a marker of cardiovascular risk.

These findings and the analysis of the language used in the interviews serve to demonstrate that erectile dysfunction is a difficult and uncomfortable subject to broach, one which is considered “dangerous” by all involved. Despite the uncomfortable nature of the conversations there was such a shared understanding about the topic that highly complicated and complex personal issues were discussed using linguistic shorthand; the use of the word “it” was used by all involved in the interviews to more than adequately make themselves understood. This shared understanding was acknowledged to have potentially impacted upon the richness of the data that could be achieved during the interviews, but in recognising this during the second analysis shared understanding also became a significant finding in itself.

## **Issues arising from the methodology**

With these findings in mind it becomes clear that many of the challenges which became apparent during the study are related to the subject area and issues associated with studying a hard to reach population who were being asked about a socially unacceptable topic. Although there was an early identification by the RCBC review panel of a potential problem in being able to recruit sufficient numbers of participants, with hindsight it has become clear that recruitment yielded even fewer participants than anyone had anticipated. Due to my pre-understanding and confidence within a clinical setting where ED is discussed regularly, there was an over estimation of the number of men and healthcare professionals who would be willing to undertake an interview.

The use of the anonymous questionnaire was designed to provide a method of engagement for men who did not feel able to undertake an interview; however this did not seemingly encourage their participation. Some men volunteered to be interviewed and had not disclosed their ED to a healthcare professional therefore conclusions can be reached as to how the complexity of factors that were influential in relation to the men and their decisions to take part. It was not simply the case that the men who had previously disclosed chose to take part in the interview and those who had not preferred the anonymity of the questionnaire. The failure of the questionnaire to yield responses may provide information in itself. This method of data collection was considered by several reviewing bodies to be the method of choice in order to access this hard to reach population and the reasons for its failure may be grounded within the theme of embarrassment.

The difficulties of undertaking this study because of the topic and my pre-understanding, which led to an over estimation of the ease with which such conversations are had, significantly impacted on both the design of the research and the undertaking of the data collection and the initial analysis. Due to these issues the second analysis of the interview transcripts using an IPA approach allowed for a fresh methodical and structured analysis of the data, providing the opportunity to reconsider the emergent themes in light of this revisiting of the text. If the research had been designed with an IPA

methodology from the inception there may have been a clearer and more apparent philosophical perspective to the thesis, however the pragmatic use of IPA principles in order to revisit the data was useful in light of what initially appeared to be “superficial” data and allowed for the voices of the participants to be expressed in a coherent and illuminative manner.

This thesis sought to explore the thoughts of men with ED, their partners and healthcare professionals relating to the disclosure of ED and there is no existing literature which specifically seeks to understand the thoughts or experiences of all participants in such conversations. Therefore the multiple perspectives provide a unique representation, most notably the perspective of men who had not spoken to anyone about their ED which appears absent in published literature.

The methodological choice of IPA as a particular phenomenological perspective, in relation to the research aim and focus is also unique. IPA has been used to explore other subjects which are also considered to be socially “hidden”, but this is the first exploration of the topic of ED disclosure using IPA to support data analysis. Therefore this study used IPA to study a previously unexplored topic and the recruitment process and skills of the interviewer enabled men who had not spoken to anyone about ED to participate and share their experiences; these elements culminating to demonstrate a unique perspective on the subject of ED.

### **Where next?**

#### **Dissemination of findings from this study**

Although innovative methods are suggested as a means to recruit to future research, the findings of this thesis may be best disseminated through more traditional methods such as journal publications, in order to reach currently clinical professionals. The findings of this thesis may resonate with healthcare professionals of all clinical specialities and therefore the target journals would be both specialist in their focus (cardiac specifically) and generalist. It would be anticipated that journal publication would be an effective means of findings dissemination because of the reliance of the healthcare professionals, within

this study, to maintain their clinical knowledge and competence by appraising clinical evidence read in journals.

The publication of the findings within professional journals is an initial step in developing an acceptance by each healthcare profession of ED as a medical or health related concern. The more publications on the subject, the greater the awareness and so a shift may be anticipated towards the beginning of professional ownership of ED; further progressing the medicalisation of erectile dysfunction. A shift in professional acceptance in conjunction with an increasing social acceptance of the topic could potentially reduce the stigma and embarrassment felt in disclosing ED and thereby increase the opportunities afforded to healthcare professionals to undertake full cardiovascular risk assessments. Although it is recognised that this study has captured information from groups previously identified as under studied, and in the case of non-disclosing men who have never been studied, the findings have perhaps identified more questions than answers.

### **Implications for future research**

Early within this thesis the lack of literature which explores the disclosure of erectile dysfunction was discussed and therefore used as a justification for undertaking this piece of research and although this study may have identified some explanations for findings within existing literature it is clear that issues from the findings and the analysis of the methodology can be identified in order to guide future research.

The themes which have emerged from this thesis have for the first time been located within the existing literature and therefore future research would seek to explore each theme in greater depth. Therefore future research questions would focus on:

- 1) What other “dangerous” conversations do healthcare professionals have in contemporary society?
- 2) How can the “danger” be removed from such conversations?
- 3) How can healthcare professionals better facilitate “dangerous” conversations?



- 4) How could erectile dysfunction be used as an alert to cardiovascular risk?

Due to the recruitment issues highlighted within this thesis future research would need to be innovative in relation to recruiting participants and the use of anonymous formats would need to be given greater consideration. With increasing access to the internet it may be that this would provide a more acceptable portal through which men would be willing to participate and thereby provide information on how and why people can be encouraged to engage in research which focuses on hard to reach populations or socially unacceptable topics.

Further research could be undertaken to explore the acceptability of specific language in contemporary society thereby providing clarity for men and healthcare professionals involved in dangerous conversations so as to minimise the fear of offending. Such a study would either need to be of a large scale so that all cultural, ethnic and regionally specific (linguistic use) understandings would be captured, possibly using quantitative methods or qualitative methods within specific groups of men (culturally, ethnically or regionally), either would result in educational material that would be able to engage all of the men that it was designed for. Although this study has highlighted areas of practice that would benefit from further research there are clearly implications from this study which could influence current practice.

### **Implications for clinical practice**

A finding of this study, which has implications for all healthcare professionals, was the personal use of self-beliefs to guide clinical practice; discussed by all of the professionals interviewed for this study. On an individual basis it is imperative that practitioners reflect on their practice whilst identifying their personal beliefs so that they are able to acknowledge how these may impact on their practice and thereby gain a better understanding of whether their personal self is positively or negatively impacting upon their professional practice, however the healthcare professionals in this study did not seem to acknowledge a conscious recognition of this influence. Therefore it is

suggested that healthcare professionals are encouraged as individuals to openly and honestly reflect upon their personal beliefs in order to understand the impact that they may be having on their current and future practice. Reflection as a formal process is encouraged by all professional bodies and accepted by healthcare professionals as a legitimate method of appraisal and learning (NMC 2015). Reflection is rarely undertaken to evaluate the impact of the practitioners personal beliefs on clinical practice and it may be that individual practitioners should be encouraged to consciously explore their impact both positively and negatively, this may also be enabled by clinical supervision.

This thesis has highlighted the considerable communication skills which are required by healthcare professionals in order to effectively facilitate disclosures of erectile dysfunction. This requires that individuals are able to evaluate their own communication skills, both verbal and non-verbal in order that they can assess the messages that they are portraying to their patients. These skills are advanced and require experience as well as insight to be able to perform them effectively, hence communication training which incorporates self-reflection from an early stage within professional training may be an area of clinical practice which can be explored in the future with incorporation of such skill acquisition early in a professional training; which may decrease anxieties of professionals about having difficult conversations and thereby improve disclosure rates.

The healthcare professionals within this study did not talk specifically about communication training, but highlighted that they felt they were lacking in training specific to erectile dysfunction. They wanted to know more about the underlying pathology and more pragmatic knowledge, such as what language could be used when specifically asking about ED so they would be understood but not cause offence when asking about ED.

The need to be able to maintain and protect confidentiality and privacy were key issues which were discussed by all of the participants and therefore consideration to the environment in which such conversations are held would also need to feature in training which focuses on having “dangerous”

conversations and future designs of clinical areas. Although this seems to be a physical consideration of private space this would also incorporate the elements of trust, which the men in the study talked about, in terms of being able to ensure that they felt confident in knowing that the person they were talking to would not break that confidence, and that they would not be overheard by others.

Any training that healthcare professionals receive may also benefit from informing them of the useful elements of embarrassment and that as such embarrassing conversations do not need to be stopped, embarrassment can be used positively to build a rapport; therefore it can be positively used as a communication tool. Although the discussion around socio-selective theory may suggest that men will not prioritise disclosing ED, healthcare professionals can ask and use the shared sense of embarrassment in order to build a relationship without causing offence or damaging their professional standing.

Much of the discussion around why such conversations are “dangerous” focused on the moral, ethical and cultural discomfort with discussing sex and many of the men had sought information about the topic prior to seeking help, therefore it may be suggested that a national educational advert which empowers people to talk about erectile dysfunction may facilitate a change in cultural and societal acceptance of such conversations. The benefits of early disclosure would need to be made clear, so that men knew that discussing ED with a healthcare professional would be a legitimate course of action and so that healthcare professionals would know to utilise this opportunity to undertake a full risk assessment. Such a campaign would need to be carefully designed so as to engage the target audience and minimise feelings, as expressed by some of the men in this study, of disengagement. Long term mapping of social acceptability of ED disclosure against HCP’s knowledge of ED as a precursor and CVD rates could then be undertaken to assess whether CVD incidence is decreasing as a result of ED being used as an early marker.

### **Reflections on what I have learned**

Undertaking this PhD has been a learning experience like no other and it would be impossible to explicate all of the learning during this period. There have been some specific learning opportunities, in relation to undertaking the research and some opportunities which have resulted in more personal development.

The issues which have resulted in learning from undertaking the study have been discussed within the analysis and discussion chapters, because the topic and the congruence with a philosophical perspective were a clear challenge. It became apparent that, even for me, ED was not an easy topic to discuss and that the men I wanted to talk to were a hard to reach population. Despite this challenge, accessing men with ED was not impossible and when they are provided with a rationale for a study and have appropriate motivation hard to reach populations can be reached and thereby studied.

The lack of a coherent philosophical perspective from the outset of this study has resulted in difficulties in creating a logical flow or coherence to this thesis. It has only become obvious to me that this is the case in the latter stages of this process and had I understood the necessity for a clear philosophical perspective earlier on I am sure that this would have influenced my interviews and thereby potentially would have improved the richness of the conversations that I had with the participants. Having a better understanding of the philosophical lens may also have enabled me to be more efficient in my working, because I would have been sensitive to the particular aspects of phenomenology to which needed particular attention.

Based on my pre-understanding of men with ED I felt that I knew this clinical topic and set out to conduct research which would potentially confirm what I thought I knew. However it became apparent that, just because I was comfortable in the clinical setting it did not mean that I understood it. The analysis of the language particularly, identified the level of shared understanding which was being utilised during the conversations and the almost intuitive communication that was occurring. The use of some words which appeared as throw away or not well considered, such as embarrassment, were underpinned with several meanings and demonstrated

the complexities of conversations that healthcare professionals have regularly. My initial appraisal of my own ability as a clinical nurse completely underestimated these complexities and with reflection I can see that I was unprepared for having the conversations in the first place and for the emotional investment that looking at these issues more closely would require.

In undertaking this project I have developed a sense of autonomous working and the imperative for adhering to deadlines, as I would have probably expected from the outset and, to a degree, are skills which could easily be imported from clinical practice. However, an unanticipated outcome is that I am now more questioning of life in general. Prior to undertaking this study I worked with protocols in clinical practice and was trusting of information that was given to me in the format that it was presented, both professionally and personally. Now I am more questioning of information and less inclined to accept things at face value, this is not a sense of scepticism, more a realisation that things are rarely black or white and usually require a more in-depth analysis or consideration than I would have previously afforded them. I have changed as a person, from a superficial thinker to someone willing to consider issues from several perspectives and to greater depths.

The primary outcome of this thesis has therefore been to identify that erectile dysfunction is difficult to talk about and that there are several reasons for this; many of which are not immediately obvious. The IPA analysis helped to identify these reasons by permitting a systematic and deeper analysis of the data and could potentially, in the future, be used to explore this topic further. Interestingly, many of the barriers perceived by healthcare professionals, are not considered to be problematic by the men with ED and they would rather be asked about ED than have the issue ignored. Therefore although this thesis identifies the difficulties in having such conversations it also demonstrates that there is work to be done in facilitating such conversations and hope remains that one day erectile dysfunction can and will be used as a clinical marker of cardiovascular risk.

## References

- Abdulmohsen, M. et al. 2004. Physician's knowledge, attitude and practice towards erectile dysfunction in Saudi Arabia. *Eastern Mediterranean Health Journal* 10 (4/5), pp. 648-654.
- Allen, D. 2004. Fishing for Foucault. *Nursing Standard* 18(38), pp. 20-21.
- Anderson, L. et al. 2003. Culturally Competent Healthcare Systems; a systematic review. *American Journal of Preventative Medicine* 24(3S), pp. 68-79.
- Andersson, K. 2001. Pharmacology of Penile Erection. *Pharmacological Reviews* 53(3), pp. 417-450.
- Annells, M. 1996. Hermeneutic phenomenology: philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing* 23, pp. 705-713.
- Anstey, S. 2012. *Clinical thinking, knowledge and the referral practices of consultant physicians to specialist palliative care services- an interpretative phenomenological analysis*. Cardiff University.
- Antoniou, J. 2002. Commentary. *Alimentary Pharmacology and Therapeutics* 8, p. 324.
- Apsler, R. 1975. Effects of Embarrassment on Behaviour Towards Others. *Journal of Personality and Social Psychology* 32(1), pp. 145-153.
- Araujo, A. et al. 1998. The Relationship between Depressive Symptoms and Male Erectile Dysfunction: Cross-sectional Results from the Massachusetts Male Aging Study. *Psychosomatic Medicine* 60, pp. 458-465.
- Araujo, A. et al. 2004. Changes in Sexual Function in Middle-Aged and Older Men: Longitudinal data from the Massachusetts male Aging Study. *Journal of the American Geriatrics Society* 15, pp. 1502-1509.
- Asch, S. et al. 2000. Problems in Recruiting Community-based Physicians for Health Services Research. *Journal of General Internal Medicine* 15(August 15), pp. 591-599.
- American Psychiatric Association (APA) 1994. *The Diagnostic and Statistical Manual of Mental Disorders 4th Edition* United States of America.
- Atkinson, R. and Flint, J. 2001. Accessing Hidden and Hard to Reach Populations: Snowball Research Strategies *Social Research Update* 33 (Summer), pp. 1-8.

Bacon, C. et al. 2003. Sexual Function in Men Older than 50 years of Age: Results from the Health Professionals Follow-up Study. *Annals of Internal Medicine* (139), pp. 161-168.

Bai, Q. et al. 2004. Prevalence and Risk Factors of Erectile Dysfunction in three cities of China: a community based study. *Asian Journal of Andrology* (6), pp. 343-348.

Baldwin, K. et al. 2003. Under-reporting of erectile dysfunction among men with unrelated urologic conditions. *International Journal of Impotence Research* 15, pp. 87-89.

Banks, E. et al. 2013. Erectile Dysfunction Severity as a Risk Marker for Cardiovascular Disease Hospitalisation and All-Cause Mortality: A Prospective Cohort Study. PLoSMed Cardiff University

Bargh, J. and Morsella, E. 2008. The Unconscious Mind. *Perspectives on Psychological Science* 3(1), pp. 73-79.

Barrett-Connor, E. 2005. Heart Disease Risk Factors Predict Erectile Dysfunction 25 Years Later (The Ranch Bernardo Study). *The American Journal of Cardiology* 96(12B Supp), pp. 3m-7m.

Barth, J. et al. 2004. Depression as a Risk Factor for Mortality in Patients with Coronary Heart Disease: A Meta-analysis. *Psychomatic Medicine* 66, pp. 802-813.

Beltran, L. and Giami, A. 2009. Interaction process in medical consultations: Different approaches to male impotence. *Sexologies* (18), pp. 251-254.

Bennett, H. 2003. Humour in Medicine. *Southern Medical Journal* 96 (12), pp. 1257-1261.

Bertero, C. 2001. Altered Sexual Patterns after Treatment for Prostate Cancer. *Cancer Practice* 9 (5), pp. 245-251.

Beswick, A. et al. 2005. Improving uptake and adherence in cardiac rehabilitation: literature review. *Journal of Advanced Nursing* 49(5), pp. 538-555.

Biggerstaff, D. and Thompson, A. 2008. Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology* 5(3), pp. 214-224.

Bohm, M. et al. 2010. Erectile Dysfunction Predicts Cardiovascular Events in High-Risk Patients Receiving Telmisartan, Ramipril or Both. *Circulation* 121, pp. 1439-1446.

Bortolotti, A. et al. 1998. The Epidemiology of Erectile Dysfunction and its Risk

- Factors. *International Journal of Andrology* 20(6), pp. 323- 334.
- Bortz, W. et al. 1999. Sexual Function in 1,202 Aging Males: Differentiating Aspects. *Journal of Gerontology* 54A (5), pp. M237-241.
- Braun, V. and Clark, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), pp. 77-101.
- Britten, N. 1995. Qualitative interviews in medical research. *British Medical Journal* 311, pp. 251-253.
- Brooks, L. 1974. Interactive Effects of Sex and Status on Self-Disclosure. *Journal of Counselling Psychology* 21(6), pp. 469-474.
- Brown, T.M. and Fee, E. 2003. Sexual Behaviour in the Human Male. *American Journal of Public Health* 93(6), pp. 894-898.
- Burchardt, M. et al. 2000. Hypertension is Associated with Severe Erectile Dysfunction. *The Journal of Urology* 164, pp. 1188-1191.
- Burd, I. et al. 2006. Impact of Physician Gender on Sexual History Taking in a Multispecialty Practice. *Journal of Sexual Medicine* 3(2), pp. 194-200.
- Byrne, M. et al. 2010. General Practitioner views about discussing sexual issues with patients with coronary heart disease: a national survey in Ireland. *BMC Family Practice* 11(40), pp. 40-45.
- Byrne, M. et al. 2013 (a). The CHARMS Study: cardiac patients' experiences of sexual problems following cardiac rehabilitation. *European Journal of Cardiac Nursing*.
- Byrne, M. et al. 2013 (b). Communicating about sexual concerns within cardiac health services: Do service providers and service users agree? *Patient Education and Counselling* Article in Press, pp. 1-6.
- Caelli, K. 2001. Engaging with Phenomenology: Is it more of a Challenge than it Needs to be? *Qualitative Health Research* 11(2), pp. 273-281.
- Carstensen, L. et al. 1999. Taking Time Seriously; the theory of socioeconomic selectivity. *American Psychologist* 54(3), pp. 165-181.
- Celik, O. et al. 2014. To Evaluate the Etiology of Erectile Dysfunction: What Should We Know Currently? *Archivio Italiano di Urologia e Andrologia* 86 (3), pp. 197-201.
- Chandler, D. 1994. *Semiotics for Beginners*.  
<http://www.aber.ac.uk/media/documents/S4B>: Bangor University
- Chapman, E. and Smith, J. 2002. Interpretative Phenomenological Analysis and the New Genetics. *Journal of Health Psychology* 7(2), pp. 125-130.



- Chew, K. et al. 2008. Male Erectile Dysfunction and Cardiovascular Disease: Is there an Intimate Nexus? *Journal of Sexual Medicine* (5), pp. 928-934.
- Chew, K. et al. 2010. Erectile Dysfunction as a predictor of subsequent atherosclerotic cardiovascular events: findings of a linked-data study. *The Journal of Sexual Medicine* 7(1 part 1), pp. 192-202.
- Chew-Graham, C. et al. 2002. Qualitative research and the problem of judgement: lessons from interviewing fellow professionals. *Family Practice* 19(3), pp. 285-289.
- Chisholm, J. 1999. Viagra: a botched test case for rationing. *British Medical Journal* 318, pp. 273-274.
- Clow, B. 2001. Who's afraid of Susan Sontag? Or the myths and metaphors of cancer reconsidered. *Social History of Medicine* 14(2), pp. 293-312.
- Collins, H. 2004. Interactional expertise as a third kind of knowledge. *Phenomenology and the Cognitive Sciences* 3, pp. 125-143.
- Conrad, P. 2005. The Shifting Engines of Medicalisation. *Journal of Health and Social Behaviour* 46(3), pp. 3-14.
- Conrad, P. and Leiter, V. 2004. Medicalisation, Markets and Consumers. *Journal of Health and Social Behaviour* 45, pp. 158-176.
- Conrad, P. and Leiter, V. 2008. From Lydia Pinkham to Queen Levitra: direct-to-consumer advertising and medicalisation. *Sociology of Health and Illness* 30(6), pp. 825-838.
- Consultative Ethics Committee. 1999. *The medicalisation of sexuality: The case of Viagra. Reply to the Secretary of State for Health*
- Cook, J. et al. 2009. Response rates to postal surveys of Healthcare Professionals between 1996 and 2005: An observational study. *BioMed Central Health Services Research* 9(160), pp. 1-8.
- Copland, J. 1858. *A Dictionary of Practical Medicine*. London: Longman, Brown, Green, Longmans and Roberts.
- Corbin, JD. and Francis, SH. 1999. Cyclic GMP Phosphodiesterase-5: Target of Sildenafil. *The Journal of Biological Chemistry* 274(20), pp. 13729-13732.
- Corbin, J. and Morse, J. 2003. The Unstructured Interactive Interview: issues of Reciprocity and Risks when Dealing with Sensitive Topics. *Qualitative Inquiry* 9, pp. 335-354.
- Corona, G. et al. 2010. Age related changes in General and Sexual Health in Middle Aged and Older men: Results from the European Male Ageing Study

(EMAS). *Journal of Sexual Medicine* 7(4), pp. 1362-1380.

Corona, G. et al. 2010 (b). Is obesity a further cardiovascular risk factor in patients with erectile dysfunction? *European Congress of Endocrinology Conference Prague 2010 (poster no 151)*.

Corona, G. et al. 2013 (a). Sexual function of the aging male. *Best Practice and Research Clinical Endocrinology and Metabolism* 27, pp. 581-601.

Corona, G. et al. 2013 (b). Frequency of sexual activity and cardiovascular risk in subjects with erectile dysfunction: cross-sectional and longitudinal analyses. *Andrology* 1, pp. 864-871.

Crotty, M. 1998 *The Foundations of Social Research* London: Sage Publications

Cunningham, S. et al. 2002. Attitudes about sexual disclosure and perceptions of stigma and shame. *Sexually Transmitted Infections* 78, pp. 334-338.

Davidson, A.I. 1987. How to do the history of Psychoanalysis: A Reading of Freud's "Three Essays on the Theory of Sexuality". *Critical Inquiry* 13 (2) pp. 252-277.

Davis-Joseph, B. et al. 1995. Accuracy of the Initial History and Physical Examination to Establish the Etiology of Erectile Dysfunction. *Urology* 45 (3), pp. 498-502.

DeBusk, R. et al. 2000. Management of sexual dysfunction in patients with cardiovascular disease: the Princeton Consensus Panel. *American Journal of Cardiology* 86, pp. 175-181.

DeRogatis, L. and Burnepp, A. 2008. The Epidemiology of Sexual Dysfunctions. *Journal of Sexual Medicine* 5, pp. 289-300.

Derrida, J. 1973. *Speech and Phenomenon*. Evanston, Illinois: North-western University Press.

Dickson-Swift, V. et al. 2007. Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research* 7 (3), pp. 327-353.

Dindia, K. and Allen, M. 1992. Sex Differences in Self-Disclosure: A Meta-Analysis. *Psychological Bulletin* 112(1), pp. 106-124.

Diokno, A. et al. 1990. Sexual Functioning in the Elderly. *Archives of Internal Medicine* 150(1), pp. 197-200.

Doherty, S. et al. 2011. Cardiac Rehabilitation Staff Views about Discussing Sexual Issues with Coronary Heart Disease Patients: A National Survey in Ireland. *European Journal of Cardiovascular Nursing* 10, pp. 101-107.

- Dohrenwend, B. et al. 1968. Social Distance and Interviewer Effects. *Public Opinion Quarterly* 32(3), pp. 410-422.
- Drakeford, M. 2015. *Keynote address by Minister for Health and Social Services*. Welsh NHS Confederation Conference. Cardiff City Stadium. Keynote address by Minister for Health and Social Services:
- Draucker, C. 1999. The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing* 30(2), pp. 360-373.
- Drexler, H. 1997. Endothelial Dysfunction: Clinical Implications. *Progress in Cardiovascular Diseases* 39(4), pp. 287-324.
- Eardley, I. et al. 1999. *Erectile Dysfunction: A Guide to Management in Primary Care*. London: Mosby-Wolfe.
- Edelmann, R. et al. 1984. The effect of embarrassment on helping. *Journal of Social Psychology* 124 (2), pp. 253-254.
- Engebretson, J. et al. 2007. Cultural Competence in the era of Evidence Based Medicine. *Journal of Professional Nursing* 24(3), pp. 172-178.
- Eylon, Y. and Heyd, D. 2008. Flattery. *International Phenomenological Society* 77(3), pp. 685-704.
- Faugier, J. and Sargeant, M. 1997. Sampling hard to reach populations. *Journal of Advanced Nursing* 26, pp. 790-797
- Feldman, H.A. et al. 1994. Impotence and its psychosocial correlates: results of the Massachusetts Male Aging Study. *Journal of Urology* (151), pp. 54-61
- Feldman, H.A. et al. 2000. Erectile Dysfunction and Coronary Risk Factors: Prospective Results from the Massachusetts Male Aging Study. *Preventive Medicine* (30), pp. 328-338.
- Fenton, K. et al. 2001. Measuring sexual behaviour: methodological challenges in survey research. *Sexually Transmitted Infections* 77, pp. 84-92.
- Fergus, K. et al. 2002. Sexual Dysfunction and the Preservation of Manhood: Experiences of Men with Prostate Cancer. *Journal of Health Psychology* 7(3), pp. 303-316.
- Finlay, L. and Gough, B. 2003. *Reflexivity A Practical Guide for Researchers in Health and Social Sciences*. Blackwell Publishing.
- Fisher, W. et al. 2005 (a). Communication about erectile dysfunction among men with ED, partners of men with ED, and physicians: the Strike Up a Conversation study (Part II). *Journal of Men's Health and Gender* 2(3), pp. 309.e301- 309.e312.

Fisher, W. et al. 2005 (b). Communication about erectile dysfunction among men with ED, partners of men with ED and physicians: The Strike Up a Conversation Study (Part 1). *Journal of Men's Health and Gender* 2(1), pp. 64-78.

Foucault, M. 1973. *The Birth of the Clinic*. Tavistock Publications Limited.

Fox, N. and Ward, K. 2006. Health identities: from expert patient to resisting consumer. *Health* 10 (4), pp. 461-479.

Fox, N. and Ward, K. 2008. Pharma in the bedroom..and the kitchen .....The Pharmaceuticalisation of daily life. *Sociology of Health and Illness* 30(6), pp. 856-868.

Gareri, P. et al. 2014. Erectile Dysfunction in the Elderly: An Old Widespread Issue with Novel Treatment Perspectives. *International Journal of Endocrinology* 2014, pp. 1-15.

Gazzaruso, C. et al. 2004. Relationship between Erectile Dysfunction and Silent Myocardial Ischemia in Apparently Uncomplicated Type 2 Diabetic Patients *Circulation* (110), pp. 22-26.

Gendlin, E. 1997 (paper edition). *Experiencing and the Creation of Meaning*. North-western University Press.

Gibson, R.V. 2008. Physicians communications with older patients, particularly older African American women about sexual health and sexual risk behaviours for HIV and AIDS. Arkansas USA: University of Arkansas. t. 10.

Gidaro, B. et al. 2006. Hypertension and erectile Dysfunction. *High Blood Pressure and Cardiovascular Prevention* 13(1), pp. 7-11.

Glenn, D. et al. 2009. Sildenafil citrate (Viagra) impairs fertilization and early embryo development in mice. *Fertility and Sterility* 91(3), pp. 893-899.

Goffman, E. 1956. Embarrassment and Social Organisation. *American Journal of Sociology* 62(3), pp. 264-271.

Goffman, E. 1963. *Notes on the Management of Spoiled Identity*. London: Penguin Books.

Goldman, E. and Swayze, S. 2012. In-Depth Interviewing with Healthcare Corporate Elites: Strategies for Entry and Engagement. *International Journal of Qualitative Methods* 11(3), pp. 230-243.

Gott, M. and Hinchliffe, S. 2003 (a). Barriers to seeking treatment for sexual problems in primary care: a qualitative study with older people. *Family Practice* 20 (6), pp. 690- 695.

Gott, M. and Hinchliffe S. 2003 (b). How important is sex in later life? The

views of older people. *Social Science and Medicine* 56, pp. 1617- 1628.

Gott, M. et al. 2004 (a). General practitioner attitudes to discussing sexual health issues with older people. *Social Science and Medicine* 58, pp. 2093-2103.

Gott, M. et al. 2004 (b). "Opening a can of worms": GP and practice nurse barriers to talking about sexual health in primary care. *Family Practice* 21(5), pp. 528-536.

Granger, A.S. and Wilkinson, T.J. 2002. Impotence in older men: do geriatricians have a role? *Australasian Journal on Ageing* 21(1), pp. 21-24.

Great Britain. 1998. The Data Protection Act. Great Britain Government. London: HMSO.

Green, R. and Kodish, S. 2009. Discussing a sensitive topic: Nurse practitioners' and physician assistants' communication strategies in managing patients with erectile dysfunction. *Journal of the American Academy of Nurse Practitioners* (21), pp. 698-705.

Greenstein, A. et al. 1997. Does severity of ischemic coronary disease correlate with erectile dysfunction? *International Journal of Impotence Research* (9), pp. 123-126.

Gross, E. and Stone, G. 1964. Embarrassment and the Analysis of Role Requirements. *American Journal of Sociology* 70(1), pp. 1-15.

Haboubi, N. and Lincoln, N. 2003. Views of health professionals on discussing sexual issues with patients. *Disability and Rehabilitation* 25(6), pp. 291-296.

Hakim, J. et al. 2002. Quality control in the screening of erectile dysfunction- result of a survey. *Urology* 60(1), pp. 125-129.

Halcox, J. 2010. *Vascular Risk Management*. Cardiff: Welsh Assembly Government.

Hall, J. and Stevens, P. 1991. Rigour in Feminist Research. *Advances in Nursing Science* 13(3), pp. 16-29.

Hallam, J. 1998. From angel to handmaidens: changing constructions of nursing's image in post-war Britain. *Nursing Inquiry* (5), pp. 32-42.

Haro, J. et al. 2006. Treatment Seeking Behaviour of Erectile Dysfunction Patients in Europe: Results of the Erectile Dysfunction Observational Study (EDOS). *Journal of Sexual Medicine* (3), pp. 530-540.

Hart, G. and Wellings K. 2002. Sexual Behaviour and its Medicalisation: in sickness and in health. *British Medical Journal* 324(13), pp. 896-899.

- Hatzichristou, D. et al. 2002. Diagnostic Steps in the Evaluation of Patients with Erectile Dysfunction. *The Journal of Urology* 168, pp. 615-620.
- Hayes-Bautista, D. 2003. Research on Culturally Competent Healthcare Systems. *American Journal of Preventative Medicine* 24(3S), pp. 8-9.
- Hayward, L. et al. 2012. Inappropriate sexual behaviour and dementia: An exploration of staff experiences. *Dementia* 12(4), pp. 463-480.
- Heatherton, T. et al. 2000. *The Social Psychology of Stigma*. London: Guilford Press.
- Heidegger, M. 1962. *Being and Time*. Oxford, United Kingdom: Blackwell Ltd.
- Heikkinen, R. 2000. Ageing in an autobiographical context. *Ageing and Society* (20), pp. 467-483.
- Heitzer, T. et al. 1996. Cigarette smoking potentiates endothelial dysfunction of forearm resistance vessels in patients with hypercholesterolaemia. *Circulation* 93, pp. 1346-1353.
- Herson, L. et al. 1999. Identifying and Overcoming Barriers to Providing Sexuality Information in the Clinical Setting. *Rehabilitation Nursing* 24(4), pp. 148-151.
- Hewison, J. and Haines, A. 2006. Confidentiality and consent in medical research. Overcoming barriers to recruitment in health research. *British Medical Journal* 333, pp. 300-302.
- Hillman, J. 2000. *Clinical Perspectives on Elderly Sexuality*. New York: Kluwer Academic/ Plenum Publishers.
- Hinchliff, S. et al. 2005. "I dare say I might find it embarrassing": general practitioners perspectives on discussing sexual health issues with lesbian and gay patients. *Health and Social Care in the Community* 13(4), pp. 345-353.
- Hite, S. 1981. *The Hite Report on Men and Male Sexuality*. Ballantine Books.
- Ho, T. and Fernandez, M. 2006. Patient's Sexual Health: Do we care enough? *Journal of Renal Care* 32(4), pp. 183-186.
- Hodges, L. et al. 2007. The temporal relationship between erectile dysfunction and cardiovascular disease. *International Journal of Clinical Practice* 61(12), pp. 2019-2025.
- Holden, C.A. et al. 2005. Men in Australia Telephone Survey (MATeS); a national survey of the reproductive health and concerns of middle-aged and older Australian men. *Lancet* (366), pp. 218-224.
- Hood, S. and Robertson, I. 2004. Erectile Dysfunction: A Significant Health

Need in Patients with Coronary Heart Disease. *Scottish Medical Journal* 49(3), pp. 90-92.

Husserl, E. 1962. Ideas: General Introduction to Pure Phenomenology Translated by WR Boyce Gibson London, New York: Collier, Macmillan.

Ichiki, K. et al. 1996. Long-term Smoking Impairs Platelet-Derived Nitric Oxide Release. *Circulation* 1996(94), pp. 3109-3114.

Ignarro, L. et al. 1987. Endothelium-derived relaxing factor produced and released from artery and vein nitric oxide. *Proceedings of the National Academy of Sciences of the United States of America* 84, pp. 9265-9269.

Jaarsma, T. et al. 2010. Sexual Counselling of Cardiac Patients: Nurses' Perception of Practice, Responsibility and Confidence. *European Journal of Cardiovascular Nursing* 9(1), pp. 24-29.

Jackson, G. 2006. Erectile Dysfunction and Vascular Risk: let's get it right. *European Urology* 50(200), pp. 660-661.

Jenkins, R. 2002. *Pierre Bourdieu*. Routledge.

Johannes, C.B. et al. 2000. Incidence of erectile dysfunction in men 40 to 69 years old: Longitudinal results from the Massachusetts Male Aging Study. *The Journal of Urology* 163, pp. 460-463.

Joint Formulary Committee. 2012. *British National Formulary*. 63 arg. London: BMJ Group and Pharmaceutical Press.

Jonas, U. 2001. The history of erectile dysfunction management. *International Journal of Impotence Research* 13(Supplement 3), pp. S3-S7.

Jousilahti, P. et al. 1998. Serum Cholesterol Distribution and Coronary Heart Disease Risk. *Circulation* (97), pp. 1087-1094.

Julien, J. et al. 2010. Identification of Barriers to Sexual Health Assessment in Oncology Nursing Practice. *Oncology Nursing Forum* 37(3), pp. E186-190.

Kaiser, D. et al. 2004. Impaired brachial artery endothelium dependent and independent vasodilation in men with erectile dysfunction and no other cardiovascular disease. *Journal of the American College of Cardiology* 43(2), pp. 179-184.

Kaplan, H. 1974. *The New Sex Therapy*. New York: Brunner-Routledge.

Katz, A. 2000. Birds do it, Bees do it, Let's Talk about it. *AWHONN Lifelines* 4(5), pp. 40-41.

Katz, A. 2005. Do Ask, Do Tell. Why do so many nurses avoid the topic of sexuality? *American Journal of Nursing* 105 (7), pp. 66-68.

Katz, S. and Marshall, BL. 2004. Is the Functional "Normal"? Aging, Sexuality and the Bio-marking of Successful Living. *History of the Human Sciences* 17(1), pp. 53-75.

Keith, A. 2000. The Economics of Viagra. *Health Affairs* 19(2), pp. 147-157.

Kekilli, M. et al. 2005. Acute Myocardial Infarction after Sildenafil Citrate Ingestion. *The Annals of Pharmacotherapy* 39, pp. 1362-1364.

Kim, S.W. et al. 2001. Potential Predictors of Asymptomatic Ischemic Heart Disease in patients with vasculogenic erectile dysfunction. *Urology* 58(3), pp. 441-445.

Kinsey, AC 1948. *Sexual Behaviour in the Human Male*. Philadelphia: WB Saunders.

Kinsman, R. and Major, J. 2008. From critical care to comfort care: the sustaining value of humour. *Journal of Clinical Nursing* 17, pp. 1088-1095.

Kitai, E. et al. 2002. Erectile Dysfunction- the effect of sending a questionnaire to patients on consultations with their family doctor. *Family Practice* 19 (3), pp. 247-250.

Kitson, G. et al. 1996. Research on Difficult Family Topics: Helping New and Experienced Researchers Cope with Research on Loss. *Family Relations* 45(2), pp. 183-188.

Kleiman, S. 2004. Phenomenology: to wonder and search for meanings. *Nurse Researcher* 11(4), pp. 7-19.

Kloner, R.A. et al. 2003. Erectile Dysfunction in the Cardiac Patient: How common and should we treat? *The Journal of Urology* 170(Supplement), pp. S46-S50.

Koch, T. 1995. Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing* 21, pp. 827-836.

Korkes, F. et al. 2008. Recreational use of PDE5 inhibitors by Young Healthy Men: recognising this issue among medical students. *The Journal of Sexual Medicine* 5(10), pp. 2414-2418.

Kreuter, M. et al. 2002. Achieving Cultural Appropriateness in Health Promotion Programs: Targeted and Tailored Approaches. *Health Education and Behaviour* 30 (2), pp. 133-146.

Kubin, M. et al. 2003. Epidemiology of Erectile Dysfunction. *International Journal of Impotence Research* 2003(15), pp. 63-71.

Kvale, S. 1996. *Interviews: An Introduction to Qualitative Research*. Thousand



Oaks California: Sage.

Lang, F. et al. 1998. Perspectives in Socioemotional Selectivity in Late Life: How Personality and Social Context Do (and Do Not) Make a Difference. *Journal of Gerontology* 53B (1), pp. 21-30.

Laverty, S. 2003. Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods* 2(3), t. Article 3.

Lawler, J. 1991. *Behind the Screens Nursing, Somology and the Problem of the Body*. Melbourne, Australia: Churchill Livingstone.

Lee, H. 2007. Why Sexual Health Promotion Misses Its Audience. *Journal of Health Organization and Management* 21(2), pp. 205-219.

Lee, J. et al. 2008. Erectile Dysfunction as a Coronary Artery Disease Risk Equivalent. *Journal of Nuclear Cardiology* 15(6), pp. 800-803.

Leung, W. 2001. How to design a questionnaire. *British Medical Journal* 9, pp. 187-189.

Levine, L.A. and Kloner, R.A. 2000. The Importance of Asking Questions about Erectile Dysfunction. *The American Journal of Cardiology* 86, pp. 1210-1213.

Levy, J. 2002. Impotence and its medical and psychosocial correlates: results of the Massachusetts Male Aging Study. *Journal of Urology* 2(4), pp. 278-280.

Levy, B. 2009. Stereotype Embodiment: A Psychosocial Approach to Aging. *Current Directions in Psychological Science* 18(6), pp. 332-336.

Lichtman, J. et al. 2008. Depression and Coronary Heart Disease: Recommendations for Screening, Referral and Treatment: A Science Advisory from the American Heart Association Prevention Committee of the Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Epidemiology and Prevention and Interdisciplinary Council on Quality of Care and Outcomes Research: Endorsed by the American Psychiatric Association. *Circulation* 118, pp. 1768-1775.

Lincoln, Y.S and Guba, E.G. 1985 *Naturalistic Inquiry* California: Sage Publications

Lindseth, A. and Norberg, A. 2004. A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Science* 18, pp. 145-153.

Loe, M. 2008. The prescription of a new generation. *Contexts* 7(2), pp. 46-49.

Lopez, K. and Willis, D. 2004. Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research* 14(5),

pp. 726-735.

Low, W. et al. 2002. Malaysian cultural differences in knowledge, attitudes and practices related to erectile dysfunction: focus groups discussions. *International Journal of Impotence Research* (14), pp. 440-445.

Lowes, L. and Prowse, M. 2001. Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies* 38(4), pp. 471-480.

Ludwig, W. and Phillips, M. 2013. Organic Causes of Erectile Dysfunction in Men Under 40. *Urologia Internationalis* 92, pp. 1-6.

Lue, T.F. et al. 2004. Summary of the Recommendations on Sexual Dysfunctions in Men. *Journal of Sexual Medicine* 1(1), pp. 6-25.

Lynn, S. 1978. Three Theories of Self-Disclosure Exchange. *Journal of Experimental Social Psychology* 14, pp. 466-479.

Magnan, M. et al. 2005. Barriers to Addressing Patient Sexuality in Nursing Practice. *Medsurg Nursing* 14(5), pp. 282-289.

Mannay, D. 2010. Making the familiar strange: can visual research methods render the familiar setting more perceptible? *Qualitative Research* 10(1), pp. 91-111.

Mapstone, J. et al. 2009. *Strategies to improve recruitment to research studies (Review)*. London: John Wiley and Sons Ltd.

Marcel, G. 1971. *The Philosophy of Existence*. Philadelphia: University of Pennsylvania Press.

Marshall, B.L. 2002. "Hard Science": Gendered Constructions of Sexual Dysfunction in the "Viagra Age". *Sexualities* 5(2), pp. 131-158.

Marshall, B.L. 2006. The New Virility: Viagra, Male Aging and Sexual Function. *Sexualities* 9(3), pp. 345-362.

Marshall, B.L. and Katz, S. 2002. Forever Functional: Sexual Fitness and the Ageing Male Body. *Body and Society* 8(4), pp. 43-70.

Masters, W. and Johnson, V. 1966. *Human Sexual Response*. Toronto, New York: Bantam.

Matic, H. and McCabe, M. 2008. Duration of erectile dysfunction and its relationship to treatment seeking and satisfaction with treatment using PDE5 inhibitors. *International Journal of Urology* 15(4), pp. 346-349.

Mays, N. and Pope, C. 1995. Rigour and qualitative research. *British Medical Journal* 311, pp. 109-112.

McCabe, M. and Matic, H. 2008. Erectile dysfunction and relationships: views of men with erectile dysfunction and their partners. *Sexual Relationship Therapy* 23(1), pp. 51-60.

McConnell-Henry, T. et al. 2009. Husserl and Heidegger: Exploring the Disparity. *International Journal of Nursing Practice* (15), pp. 7-15.

McLaren, A. 2007. *Impotence: A cultural history*.

McNamara, M. 2005. Knowing and doing phenomenology: The implications of the critique of "nursing phenomenology" for a phenomenological inquiry: A discussion paper. *International Journal of Nursing Studies* 42(6), pp. 695-704.

Meena, B. et al. 2009. Association between erectile dysfunction and cardiovascular risk in individuals with type two diabetes without overt cardiovascular disease. *International Journal of Diabetes in Developing Countries* 29(4), pp. 150-154.

Meerabeau, L. 1999. The management of embarrassment and sexuality in healthcare. *Journal of Advanced Nursing* 29(6), pp. 1507-1513.

Melman, A. and Gingell, J. 1999. The Epidemiology and Pathophysiology of Erectile Dysfunction. *The Journal of Urology* 161, pp. 5-11.

Melnick, T. et al. 2008. The Effectiveness of Psychological Interventions for the Treatment of Erectile Dysfunction: Systematic Review and Meta-Analysis, Including Comparisons to Sildenafil Treatment, Intracavernosal Injection and Vacuum Devices. *The Journal of Sexual Medicine* 5(11), pp. 2562-2574.

Merleau-Ponty, M. Translator- Silverman, H. 1950 translated 1973. *Consciousness and the acquisition of language*. Evaston: Northwestern University Press.

Meyer, J. 2000. Humour as a Double-edged Sword: Four Functions of Humour in Communication. *Communication Theory* 10(3), pp. 310-331.

Miller, J. and Glassner, B. 1997. The "inside" and the "outside": finding realities in interviews. *Qualitative Research Theory, Method and Practice*. London: Sage Publications, pp. 99-112.

Miller, M. et al. 2011. Triglycerides and Cardiovascular Disease. *Circulation* 123, pp. 2292-2333.

Miner, M.M. and Kuritzky, L.K. 2007. Erectile Dysfunction: a sentinel marker for cardiovascular disease in primary care. *Cleveland Clinic Journal of Medicine* 74(supp 3), pp. S30-S37.

Mintz, D. 1992. What's in a Word: The Distancing Function of Language in Medicine. *The Journal of Medical Humanities* 13(4), pp. 223-233.

Mishkind, M.E. et al. 1986. The Embodiment of Masculinity: Cultural, Psychological and Behavioural Dimensions. *American Behavioural Scientist* 29(5), pp. 545-562.

Montorsi, F. et al. 2003. Erectile Dysfunction Prevalence, Time of Onset, and Association with risk factors in 300 consecutive patients with Acute Chest Pain and Angiographically Documented Coronary Artery Disease. *European Urology* 44, pp. 360-365.

Montorsi, P. et al. 2005. The artery size hypothesis: A macrovascular link between erectile dysfunction and cardiovascular disease. *The American Journal of Cardiology* 96(12 supp 2), pp. 19-23.

Montorsi, P. et al. 2006. Association between erectile dysfunction and coronary artery disease. Role of coronary clinical presentation and extent of coronary vessel involvement: the COBRA trial. *European Heart Journal* (27), pp. 2632-2639.

Morse, J. 2000. Determining Sample Size. *Qualitative Health Research* 10(3), pp. 3-5.

Moustakas, C. 1994. *Phenomenological Research Methods*. California: Sage.

Moynihan, R. 2005. Reviews: The Rise of Viagra: How the Little Blue Pill Changed Sex in America. *British Medical Journal* 330, pp. 424-427.

Moynihan, R. et al. 2002. Selling sickness: the pharmaceutical industry and disease mongering. *British Medical Journal* (324), pp. 886-891.

Muhib, F. et al. 2001. A Venue-Based Method for Sampling Hard-to Reach Populations. *Public Health Reports* 116 (supplement 1), pp. 216-222.

Mullershausen, F. et al. 2003. Direct activation of PDE5 by cGMP: long-term effects within NO/cGMP signalling. *The Journal of Cell Biology* 160(5), pp. 719-727.

Nehra, A. 2009. Erectile dysfunction and cardiovascular disease: Efficacy and Safety of phosphodiesterase type 5 inhibitors in men with both conditions. *Mayo Clinic Proceedings* 84(2), pp. 139-148.

Nelson, E. et al. 2008. Clinical Microsystems, Part 1 The Building Blocks of Health Systems. *The Joint Commission Journal on Quality and Patient Safety* 34(7), pp. 367-378.

Ng, C. et al. 2004. The role of general practitioners in the management of erectile dysfunction- a qualitative study. *International Journal of Impotence Research* (16), pp. 60-63.

Nursing and Midwifery Council (NMC). 2008. *The Code: Standards of conduct*,

*performance and ethics for nurses and midwives*. London: NMC.

Nursing and Midwifery Council (NMC) 2015. *The Code: Professional standards of practice and behaviour for nurses and midwives*. London: Nursing and Midwifery Council.

Nyman, S. et al. 2011. Representations of old age in falls prevention websites: implications for likely uptake of advice by older people. *British Journal of Occupational Therapy* 74(8), pp. 366-374.

O'Donnell, A. et al. 2004. The Health of Normally Aging Men: The Massachusetts Male Aging Study (1987-2004). *Experimental Gerontology* 2004(39), pp. 975-984.

O'Donohue, W. and Swingen, D. 1999. Psychotherapy for Male Sexual Dysfunction: A review. *Clinical Psychology Review* 19(5), pp. 591-630.

Oiler, C. 1982. The Phenomenological Approach in Nursing. *Nursing Research* 31(3), pp. 178-181.

Olivero, H. 2004. Thrill Quest: Young men experiment with Viagra. *Anchorage Daily News*.

O'Sullivan, B. and Savage, ES, 2009. Erectile dysfunction and CHD: Related risk factors and implications for nursing practice. *British Journal of Nursing Practice* 4(4), pp. 170-176.

Paley, J. 1997. Husserl, Phenomenology and Nursing. *Journal of Advanced Nursing* (26), pp. 187-193.

Paley, J. 1998. Misinterpretive Phenomenology: Heidegger, ontology and nursing research. *Journal of Advanced Nursing* (27), pp. 817-824.

Papagiannopoulos, D. et al. 2015. Evaluation of Young Men with Organic Erectile Dysfunction. *Asian Journal of Andrology* 17, pp. 11-16.

Parisi, C. and Wogan, P. 2006. Compliment Topics and Gender. *Woman and Language* 29(2), pp. 21-22.

Pascal, J. et al. 2010. The Lived Experience of Doing Phenomenology: Perspectives from Beginning Health Science Postgraduate Researchers. *Qualitative Social Work* 10(2), pp. 172-189.

Penrod, J. et al. 2003. A Discussion of Chain Referral As a Method of Sampling Hard-to Reach Populations. *Journal of Transcultural Nursing* 14(2), pp. 100-107.

Pertulla, E. 1999. Physician Attitudes and Behaviour regarding Erectile Dysfunction in At-Risk Patients from a Rural Community. *Postgraduate Medical Journal* 1999(75), pp. 83-85.

- Peters, R. et al. 2007. Beliefs and Social Norms about Sildenafil Citrate (Viagra) Misuse and Perceived Consequences among Houstonian Teenage Males. *American Journal of Mens Health* 1(3), pp. 208-212.
- Pini, B. 2005. Interviewing men: Gender and the collection and interpretation of qualitative data. *Journal of Sociology* 41(2), pp. 201-216.
- Polkinghorne, D. 2005. Language and Meaning: Data Collection in Qualitative Research. *Journal of Counselling Psychology* 52(2), pp. 137-145.
- Ponholzer, A. et al. 2005. Prevalence and risk factors for erectile dysfunction in 2869 men using a validated questionnaire. *European Urology* 47(1), pp. 80-86.
- Pontin, D. et al. 2002. Investigating the effect of erectile dysfunction on the lives of men: a qualitative research study. *Journal of Clinical Nursing* 11(2), pp. 264-272.
- Potts, A. et al. 2004. "Viagra stories": challenging "erectile dysfunction". *Social Science and Medicine* 59, pp. 489-499.
- Potts, A. et al. 2006. "Sex for life?" Men's counter-stories on "erectile dysfunction", male sexuality and aging. *Sociology of Health and Illness* 28.
- Powell, J.L. and Biggs, S. 2003. Foucauldian Gerontology: A Methodology for Understanding Aging. *Electronic Journal of Sociology*  
[http://www.sociology.org/content/vol7.2/03\\_powell\\_biggs.html](http://www.sociology.org/content/vol7.2/03_powell_biggs.html).
- Prins, J. et al. 2002. Review Prevalence of erectile dysfunction: a systematic review of population-based studies. *International Journal of Impotence Research* 14, pp. 422-432.
- Quinn, C. et al. 2011. Talking or avoiding? Mental health nurses' views about discussing sexual health with consumers. *International Journal of Mental Health Nursing* 20, pp. 21-28.
- Rerkpappanapipat, P. et al. 2001. Sex and the heart: what is the role of the cardiologist? *European Heart Journal* 22, pp. 201-208.
- Ritvo, LB. 1974. The impact of Darwin on Freud. *Psychoanalysis Quarterly* 1974(43), pp. 177-192.
- Roach, S. 2004. Sexual behaviour of nursing home residents: staff perceptions and responses. *Journal of Advanced Nursing* (48), pp. 371-379.
- Rosen, R. 1996. Erectile Dysfunction: The Medicalisation of Male Sexuality. *Clinical Psychology Review* 16(6), pp. 497-519.
- Rosen, R. 2001. Psychogenic Erectile Dysfunction: Classification and Management. *Urologic Clinics of North America* 28(2), pp. 269-278.

- Rosen, R.C. et al. 2004. The multinational Men's attitudes to Life Events and Sexuality (MALES) study: 1 Prevalence of erectile dysfunction and related health concerns in the general population. *Current Medical Research and Opinion* 20(5), pp. 607-617.
- Ross, S. et al. 1999. Barriers to Participation in Randomised Controlled Trials: A Systematic Review. *Journal of Clinical Epidemiology* 52(12), pp. 1143-1156.
- Roulston, K. et al. 2003. Learning to Interview in the Social Sciences. *Qualitative Inquiry* 9(4), p. 643.
- Rutchik, S. et al. 2001. Practice Patterns in the Diagnosis and Treatment of Erectile Dysfunction among Family Practice Physicians. *Urology* (57), pp. 146-150.
- Sakheim, D. et al. 1987. Distinguishing Between Organogenic and Psychogenic Erectile Dysfunction. *Behaviour Research and Therapy* 25(2), pp. 379-390.
- Sandelowski, M. 1993. Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science* 16(2), pp. 1-8.
- Satre, J. 1943. *Being and Nothingness*. Paris: Routledge.
- Sappar, N. et al. 2003. Metabolic Syndrome with and without C-reactive protein as a predictor of Coronary Heart Disease and Diabetes in the West of Scotland Coronary Prevention Study. *Circulation* (108), pp. 151-157.
- Schnetzler, G. et al. 2010. Characteristics, Behaviours and Aptitudes of Men Bypassing the Healthcare System When Obtaining Phosphodiesterase Type 5 Inhibitors. *Journal of Sexual Medicine* 7, pp. 1237-1246.
- Schudson, M. 1984. Embarrassment and Erving Goffman's Idea of Human Nature. *Theory and Society* 13(5), pp. 633-648.
- Schutz, A. 1967. *The Phenomenology of the Social World*. Illinois USA: Northwestern University Press.
- Selvin, E. et al. 2007. Prevalence and risk factors for ED in the US. *The American Journal of Medicine* (120), pp. 151-157.
- Semin, G. and Smith, E. 1999. Revisiting the Past and Back to the Future: Memory Systems and the Linguistic Representation of Social Events. *Journal of Personality and Social Psychology* 76(6), pp. 877-892.
- Shah, J. 2002. Erectile dysfunction through the ages. *British Journal of Urology International* 90, pp. 433-441.
- Shinebourne, P. 2011. The Theoretical Underpinnings of Interpretative

Phenomenological Analysis. *Journal of the Society for Existential Analysis* 22(1), pp. 16-31.

Shinebourne, P. and Smith, J. 2010. The communicative power of metaphors: An analysis and interpretation of metaphors in accounts of experiences of addiction. *Psychology and Psychotherapy: Theory, Research and Practice* 83, pp. 59-73.

Simmonds, R. et al. 2013. Patients' perceptions of depression and coronary heart disease: a qualitative UPBEAT-UK study. *BMC Family Practice* 14(38), pp. 1-9.

Siraj, Q. 2010. *A Short History of Impotence* <http://knol.google.com/k/a-short-history-of-impotence>

Skelton, J. and Matthews, P. 2001. Teaching sexual history taking to healthcare professionals in primary care. *Medical Education* 35, pp. 603-608.

Smith, J.A. 1996 Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health* 11, pp261-71

Smith, J.A. 2004 Reflecting on the development of IPA and its contribution to qualitative research in psychology. *Qualitative Research in Psychology* 1 pp39-54

Smith, J. et al. 2009. *Interpretative Phenomenological Analysis. Theory, Method and Research*. London: Sage Publications Ltd.

Smith, K.M. and Romanelli, F. 2005. Recreational Use and Misuse of Phosphodiesterase 5 Inhibitors. *Journal of the American Pharmacists Association* 45(1), pp. 63-75.

Smith, L. 2008. How ethical is ethical research? Recruiting marginalised, vulnerable groups into health services research. *Journal of Advanced Nursing* 62(2), pp. 248-257.

Smith, P. et al. 2010. No Sex Please! We're over 50. *Working with Older People* 14(3), pp. 40-43.

Soloman, H. et al. 2002. Relation of Erectile Dysfunction to Angiographic Coronary Artery Disease. *The Journal of Cardiology* 91, pp. 230-231.

Sontag, S. 1989. *Illness as a metaphor and AIDS and its metaphors*. London: Penguin.

Sookdeb, S. 2007. An investigation of factors that determine when men with erectile disorder present for treatment. *Nurse Researcher* 14(4), pp. 76-88.

Speel, T. et al. 2003. The risk of coronary heart disease in men with erectile



dysfunction. *European Urology* 44(3), pp. 366-371.

Stead, M. et al. 2003. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer* 88, pp. 666-671.

Stead, M. et al. 1997. A qualitative study of older people's perceptions of ageing and exercise: the implications for health promotion. *Health Education Journal* 56(1), pp. 3-16.

Steinke, E.E. et al. 2013. Sexual Counselling for Individuals With Cardiovascular Disease and Their Partners. *European Heart Journal* Article in Press, pp. 1-23.

Stewart, D. and Monge, J. 1993. Hyperlipidemia and endothelial dysfunction. *Current Opinion in Lipidology* 4(4), pp. 319-324.

Stokes, J. et al. 1981. Gender and Sex Roles as Predictors of Self-Disclosure. *Journal of Counselling Psychology* 28(6), pp. 510-514.

Stuckey, B. et al. 2007. Erectile dysfunction predicts generalised cardiovascular disease: Evidence from a case-control study *Atherosclerosis* 194, pp. 458-464.

Suero, J. et al. 2001. Procedural outcomes and long-term survival among patients undergoing percutaneous coronary intervention of a chronic total occlusion in native coronary arteries: a 20 year experience. *Journal of American College of Cardiology* 38(2), pp. 409-414.

Suls, J. and Bunde, J. 2005. Anger, Anxiety and Depression as Risk Factors for Cardiovascular Disease: The Problems and Implications of Overlapping Affective Dispositions. *Psychological Bulletin* 131(2), pp. 260-300.

Szreter, S. 1996. Victorian Britain 1831-1963: towards a social history of sexuality. *Journal of Victorian Culture* 1(1), pp. 136-149.

Tan, N. et al. 2004. What are the barriers faced by doctors in the management of erectile dysfunction in general practice? *Asia Pacific Family Medicine* (4), pp. 1-6.

Taylor, A. and Gosney, M. 2011. Sexuality in older age: essential considerations for healthcare professionals. *Age and Aging* 0, pp. 1-6.

Teifer, L. 2006. The Viagra Phenomenon. *Sexualities* 9(3), pp. 273-294.

Thompson, I. et al. 2005. Erectile Dysfunction and subsequent Cardiovascular Disease. *JAMA* 294(23), pp. 2996-3002.

Tiefer, L. and Schuetz-Mueller, D. 1995. Psychological issues in diagnosis and treatment of erectile disorders. *The Urologic Clinics of North America* 22(4),

pp. 767-773.

Timmins, F. and Kaliszer, M. 2003. Information Needs of Myocardial Infarction Patients. *European Journal of Cardiovascular Nursing* 2, pp. 57-65.

Tomlinson, J. and Milgrom, E. 1999. Taking a sexual history. *Western Journal of Medicine* 170(May 1999), pp. 284-286.

Tomlinson, J. and Wright, D. 2004. Impact of Erectile Dysfunction and its Subsequent Treatment with Sildenafil: qualitative study. *British Medical Journal* 328, pp. 1037-1041.

Tourangeau, R. and Yan, T. 2007. Sensitive questions in surveys. *Psychological Bulletin* 133(5), pp. 859-883.

Tsimtsiou, Z. et al. 2006. Predictors of Physicians' Involvement in Addressing Sexual Health Issues. *Journal of Sexual Medicine* 3, pp. 583-588.

Vatter, H. et al. 2007. Persistence of the nitric oxide-dependent vasodilator pathway of cerebral vessels after experimental subarachnoid haemorrhage. *Neurosurgery* 60(1), pp. 179-187.

Virag, R. 1982. Intracavernous Injection of Papaverine for Erection Failure. *The Lancet* 320 (8304), p. 938.

Virag, R. et al. 1985. Is Impotence an Arterial Disorder? *Lancet* 26(1), pp. 1105-1108.

Vlachopoulos, C. et al. 2005. Prevalence of Asymptomatic Coronary Artery Disease in Men with Vasculogenic Erectile Dysfunction: A Prospective Angiographic Study. *European Urology* (48), pp. 996-1003.

Vlachopoulos, C. et al. 2013. Prediction of Cardiovascular Events and All-Cause Mortality with Erectile Dysfunction: A systematic Review and Meta-Analysis of Cohort Studies. *Circulation Cardiovascular Quality and Outcomes* 6, pp. 1-11.

Wagner, G. 2005. Sexual medicine in the medical curriculum. *International Journal of Andrology* 28(suppl 2), pp. 7-8.

Walfish, S. and Myerson, M. 1980. Sex Role Identity and Attitudes Toward Sexuality. *Archives of Sexual Behaviour* 9(3), pp. 199-203.

Weedon, C. 1987. *Feminist practice and poststructuralist theory*. Oxford: Blackwell.

Welsh Assembly Government (WAG). 2012. *Together for Health- a Heart Disease Delivery Plan. A Delivery Plan up to 2016 for Wales and its Partners*. Welsh Government.

Welsh Assembly Government (WAG) 2014. *Together for Health Heart Disease Delivery Plan, Annual Report 2014*. Welsh Government.

Westen, D. 1998. The Scientific Legacy of Sigmund Freud: Toward a Psychodynamically Informed Psychological Issue. *Psychological Bulletin* 124(3), pp. 333-371.

Williams, C. and Heikes, E. 1993. The Importance of Researcher's Gender in the In-Depth Interview: Evidence from Two Case Studies of Male Nurses *Gender and Society* 7(2), pp. 280-291.

Willison, D. et al. 2009. Consent for use of personal information for health research: Do people with potentially stigmatizing health conditions and the general public differ in their opinions? *BMC Medical Ethics* 10(10), pp. 1-12.

Wilson, PWF, et al. 1998. Prediction of coronary heart disease using risk factor categories. *Circulation* (97), pp. 1837-1847.

World Health Organisation (WHO) 1992. *The ICD-10 Classification of Mental and Behavioural Disorders. Clinical descriptions and diagnostic guidelines*. Geneva. The ICD-10 Classification of Mental and Behavioural Disorders. Clinical descriptions and diagnostic guidelines: World Health Organisation.

Wyllie, M. 2005. The underlying pathophysiology and causes of erectile dysfunction. *Clinical Cornerstone International* 7(1), pp. 19-26.

Yanos, P. and Ziedonis, D. 2006. The Patient-Orientated Clinician-Researcher: Advantages and Challenges of Being a Double Agent. *Psychiatric Services* 57(2), pp. 249-253.

Zeiger, A. et al. 1991. Endothelial dysfunction of the coronary microvasculature is associated with coronary blood flow regulation in patients with early atherosclerosis. *Circulation* 84(5), pp. 1984-1992.

Zukel, W. et al. 1981. The Multiple Risk Factor Intervention Trail (MRFIT). *Preventive Medicine* 10, pp. 387-401.

## Appendices

## **Appendix One**

Database	Period Searched*
British Nursing Index	1985-July 2015
CINAHL	1982- July 2015
Medline	1950- July 2015
PubMed	1915- July 2015
AMED	1985- July 2015
ASSIA	1960- July 2015
Cochrane	1993- July 2015
HMIC	1983- July 2015
SCOPUS	1960- July 2015
TRIP	1997- July 2015
Web of knowledge	1933- July 2015

## **Appendix Two**

### **Search One:**

“Erectile dysfunction” OR “impot\* (impotence)” AND “cardiovascular dis\* (disease) or  
“ischemic heart dis\* or “ischemic heart dis\*” AND “disclos\*” (disclosure) OR “consult\*”  
(consultation).

### **Search Two:**

“Erectile dysfunction” OR “impot\*” AND “disclos\*” OR “consult\*”

### **Search Three:**

“Erectile dysfunction” OR “impot\*” AND “disclos\*” OR “consult\*” AND “qualitative  
research”

### **Search Four:**

“Erectile dysfunction” OR “impot\*” AND “qualitative research”

Database	Search One	Search Two	Search Three	Search Four
British Nursing Index	0	6	0	13
CINAHL	0	15	617	573
Medline	20	185	0	101
PubMed	14	1	0	5
AMED	0	1	0	1
ASSIA	0	2	207	207

Cochrane	0	12	10	9
HMIC	0	5	0	0
Scopus	30	265	4	243
Trip	28	55	10	5
Web of Knowledge	9	2,012	0	0
Total	101	2559	848	1157

As a result of reviewing the articles in **search one** all of the literature obtained could be categorised; case study, editorial, review article, quantitative research or erroneously identified. With broader search terms **search two** identified a wider span of literature, but this resulted in more articles pertaining to specific medical conditions which were not cardiac, such as diabetes, neurological disorders and prostate cancer. **Search three** sought to identify qualitative studies and this was broadened within **search four** to identify qualitative research pertaining to erectile dysfunction but not specifically disclosure.

## **Appendix Three**



Building Research Capacity for Nursing  
& Allied Health Professionals

Cynyddu Gwaith Ymchwil ar gyfer Nyrso  
& Gweithwyr Proffesiynol Cysylliedig



Cyngor Cytido Adding Uwch Cymru  
**hefcw**  
Higher Education Funding Council for Wales



Chief Investigator: Catherine Dunn

You are being invited to take part in a research study. Before you decide whether you would like to take part or not it is important that you understand why the research is being done and what taking part will involve. Please take time to read the following information. Please ask the Chief Investigator if there is anything which is not clear or if you would like more information.

### **What is the purpose of the study?**

Erectile dysfunction is the inability to sustain an erection satisfactory for sexual intercourse. Many men with cardiac conditions suffer from erectile dysfunction and many men with erectile dysfunction subsequently suffer from heart disease. We would like to explore people's experience of telling healthcare professionals about erectile dysfunction, what made the process difficult, what would make it easier and what prevents people from telling anyone about their condition.

### **Why have I been chosen?**

As a healthcare professional to whom a disclosure of erectile dysfunction may occur and as an employee of the \*\*\*\*\*Health Board you have been invited to take part in this study.

### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form, however you may still withdraw at any time and will not need to give a reason.

### **What will happen to me if I take part?**

Because this study is exploring barriers to telling healthcare professionals about erectile dysfunction we would like to ask you about your experiences or thoughts on the subject. If you have ever had a patient who has disclosed erectile dysfunction to you, or there is potential within your current role for this to happen we would like to interview you.

### **What do I have to do?**

If you feel that you would be happy to participate in an interview please contact the Chief Investigator by filling in the details at the bottom of this letter. The Chief



Investigator will then contact you to arrange a date and time for the interview. The interview can be at your place of work or within Cardiff University, whichever you would prefer. The interview will last at most one hour and will be digitally recorded. This recording will be anonymous and all records will be held anonymously.

**What are the risks or disadvantages of taking part in this research?**

We are not aware of any specific risks or disadvantages to you in taking part in this research.

**What if something goes wrong?**

We do not anticipate any harm coming to you as a result of your involvement in this study. However if you do wish to complain, or have any concerns about any aspects of the study then the normal National Health Service complaints procedures are available to you.



## **Participant Information Sheet (Healthcare Professionals)**

### **An Exploration of the Barriers to the Disclosure of Erectile Dysfunction as an Early Warning of Coronary Heart Disease.**

#### **Additional Study Information**

##### **Will my taking part in this study be kept confidential?**

All information that you provide during this study will be strictly confidential and all documentation held in accordance with the data protection act and in agreement with the Data Protection Officer at \*\*\*\*\* Health Board. All information will be stored within locked cabinets within a locked room to which the Chief Investigator has access, within the School of Nursing and Midwifery at Cardiff University.

Interviews will be recorded and the following day transcribed, after which the recording will be erased. The transcriptions will be retained by Cardiff University in accordance with their policy on data storage and disposal for 5 years, after which they will be destroyed. Direct quotations may be presented in the final research report to emphasise specific findings, these too will be anonymous.

##### **What will happen to the results of the research study?**

We will aim to publish the results of this study in medical and nursing journals. A research report will be produced and you will be sent a summary of the findings. We will ensure that service and charitable organisations such as the British Heart Foundation are also aware of the findings. You will not be personally identified in any of the publications.

##### **Who is organising and funding the research?**

The Chief Investigator is undertaking this study in order to fulfil the requirements for a PhD award. Research funding has been provided by an external funding body (Research Capacity Building Collaboration) to Cardiff University for the duration of this project.

##### **Who has reviewed the study?**

RCBC multi-disciplinary review panel, Cardiff University School of Nursing and Midwifery Ethics Panel, Cardiff and Vale University Health Board Research and Development Panel and South East Wales Research Ethics Committee have all reviewed and approved this project.

##### **Next steps.....**

If you would like to take part in the research please fill in the attached form and return it in the prepaid envelope, the Chief Investigator will then contact you or contact

Miss Catherine Dunn

Rm 415 Eastgate House,

Newport Road, Cardiff, CF24 0

e-mail: [dunnc5@cardiff.ac.uk](mailto:dunnc5@cardiff.ac.uk)

tel no: 02920 927727

Thank you for taking the time to read this information and for considering participating in this study.

## **Appendix Four**



### **Participant Information Sheet (Patients- Interviews)**

#### **An Exploration of the Barriers to the Disclosure of Erectile Dysfunction as an Early Warning of Coronary Heart Disease.**

Chief Investigator: Catherine Dunn

You are being invited to take part in a research study. Before you decide whether you would like to take part or not it is important that you understand why the research is being done and what taking part will involve. Please take time to read the following information and discuss it with others if you wish. Please ask the Chief Investigator if there is anything which is not clear, or if you would like more information.

#### **What is the purpose of the study?**

Erectile dysfunction is the inability to sustain an erection satisfactory for sexual intercourse. Many men with cardiac conditions suffer from erectile dysfunction and many men with erectile dysfunction subsequently suffer from heart disease. The disease processes which affect the coronary arteries also affect other arteries including the penile arteries, being smaller these arteries become symptomatic earlier in the disease process. Knowing that erectile dysfunction is an early warning sign of coronary heart disease we would like to explore people's experience of telling healthcare professionals about erectile dysfunction, what made the process difficult, what would make it easier and what prevents people from telling anyone about the condition?

#### **Why have I been chosen?**

You attend the Cardiac Rehabilitation classes run by the Cardiac Nurses based at the Hospital, they provide you with an educational talk about erectile dysfunction and will then offer all the men in the class the opportunity to participate in the research project.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. Once you have signed a consent form you may still withdraw at any time and will not need to give a reason. A decision to withdraw or not to take part will not affect any of the medical or nursing care that you receive.

### **What will happen to me if I take part?**

Because this study is exploring barriers to telling healthcare professionals about erectile dysfunction we would like to ask you about your experiences or thoughts on the subject. If you have ever suffered from erectile dysfunction or currently suffer and have either told a doctor or nurse about it, or whether you have never told anyone we would like to interview you.

### **What do I have to do?**

If you feel that you would be happy to participate in an interview please contact the Chief Investigator by filling in and returning the form at the end of this leaflet. The Chief Investigator will then contact you to arrange a date and time for the interview. The interview can be in your house, a location suitable to yourself or at Cardiff University, whichever you would prefer. The interview will last approximately one hour and will be taped. This recording will be anonymous and all records will be held in an anonymous format.

### **What are the risks or disadvantages of taking part in this research?**

We are not aware of any risks or disadvantages to you in taking part in this research.

### **What are the possible benefits of taking part?**

Although there may not be any direct benefits to you, the information you provide may help patients and healthcare professionals in future practice.

### **What if there is a problem?**

If you have any complaints regarding this research project then normal National Health Service complaints procedures are available to you.

### **Will my taking part in the study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in "additional information".



Building Research Capacity for Nursing  
& Allied Health Professionals  
Cynyddu Gwaith Ymchwil ar gyfer Nysio  
& Gweithwyr Proffesiynol Cysylliedig



Cyngor Cytida Adding Swth Cymru  
hefew  
Higher Education Funding Council for Wales



## **Participant Information Sheet (Patients- Interviews)**

### **An Exploration of the Barriers to the Disclosure of Erectile Dysfunction as an Early Warning of Coronary Heart Disease.**

#### **Additional Information**

##### **What will happen if I do not want to carry on with the study?**

You are free to withdraw from the study at any point and identifiable data which you have provided will be withdrawn from the study. Data which is not identifiable to you will be retained.

##### **What if something goes wrong?**

We do not anticipate any harm coming to you as a result of your involvement in this study, however if you have any concerns please feel free to contact the Chief Investigator on the telephone number provided below. If you do wish to complain then the normal National Health Service complaints procedures are available to you at \*\*\*\*\* University Health Board on: \*\*\*\*\*

##### **Will my taking part in this study be kept confidential?**

All information kept about you during this study will remain strictly confidential. Any information you provide will be stored separately from your contact details thereby preventing any link between the two. All information will be stored within locked cabinets, within a locked room to which the Chief Investigator has access, within the School of Nursing and Midwifery at Cardiff University.

Interviews will be recorded and the following day transcribed, after which the recording will be erased. The transcriptions will be retained by Cardiff University in accordance with their policy on data storage and disposal for 5 years, after which they will be destroyed.

Direct quotations may be presented in the final research report to emphasise specific findings, these too will be anonymous.

##### **Will my General Practitioner be informed of my participation?**

No your General Practitioner will not be informed of your participation.

### **What will happen to the results of the research study?**

We will aim to publish the results of this study in medical and nursing journals. A research report will be produced and you will be sent a summary of the findings. We will ensure that service and charitable organisations such as the British Heart Foundation are also aware of the findings. You will not be personally identified in any of the publications.

### **Who is organising and funding the research?**

The Chief Investigator is undertaking this study in order to fulfil the requirements for a PhD award. Research funding has been provided by an external funding body (Research Capacity Building Collaboration) to Cardiff University for the duration of this project.

### **Who has reviewed the study?**

RCBC multi-disciplinary review panel, Cardiff University School of Nursing and Midwifery Ethics Panel, \*\*\*\*\* Health Board Research and Development Panel and \*\*\*\*\* Research Ethics Committee have all reviewed and approved this project.

### **Next steps.....**

If you would like to take part in the research please fill in the attached form and return it in the prepaid envelope, the Chief Investigator will then contact you or contact

Miss Catherine Dunn or

Dr. K Featherstone. Director of Postgraduate Studies Rm 415 Eastgate House,  
Newport Road, Rm 417 Eastgate House, Newport Road,

Cardiff, CF24 OAB

e-mail: [dunnc5@cardiff.ac.uk](mailto:dunnc5@cardiff.ac.uk)

tel no: 02920 917727

Thank you for taking the time to read this information and for considering participating in this study.



Building Research Capacity for Nursing  
& Allied Health Professionals

Cynyddu Gwaith Ymchwil ar gyfer Nyrso  
& Gweithwyr Proffesiynol Cysylliedig



Cyngor Cytifedd Adfydd Iechyd Cymru

hefcw

Higher Education Funding Council for Wales



## **Participant Information Sheet (Questionnaire)**

### **An Exploration of the Barriers to the Disclosure of Erectile Dysfunction as an Early Warning of Coronary Heart Disease.**

Chief Investigator: Catherine Dunn

You are being invited to take part in a research study. Before you decide whether you would like to take part or not it is important that you understand why the research is being done and what taking part will involve. Please take time to read the following information and discuss it with others if you wish. Please ask the Chief Investigator if there is anything which is not clear, or if you would like more information.

#### **What is the purpose of the study?**

Erectile dysfunction is the inability to sustain an erection satisfactory for sexual intercourse. Many men with cardiac conditions suffer from erectile dysfunction and many men with erectile dysfunction subsequently suffer from heart disease. The disease processes which affect the coronary arteries also affect other arteries including the penile arteries, being smaller these arteries become symptomatic earlier in the disease process. Knowing that erectile dysfunction is an early warning sign of coronary heart disease we would like to explore people's experience of telling healthcare professionals about erectile dysfunction, what made the process difficult, what would make it easier and what prevents people from telling anyone about the condition?

#### **Why have I been chosen?**

You attend the Cardiac Rehabilitation classes run by the Cardiac Nurses based at the \*\*\*\*\* Hospital, they provide you with an educational talk about erectile dysfunction and will then offer all the men in the class the opportunity to participate in the research project.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to complete a confidential questionnaire, which will not ask for your name. A decision not to complete the questionnaire will not affect any of the medical or nursing care that you receive.

#### **What will happen to me if I take part?**



Because this study is exploring barriers to telling healthcare professionals about erectile dysfunction we would like to ask you about your experiences or thoughts on the subject. If you have ever suffered from erectile dysfunction or currently suffer and have either told a doctor or nurse about it, or whether you have never told anyone we would be grateful if you completed this questionnaire.

What do I have to do?

If you feel happy to complete the questionnaire please do so in your own time and return the completed form in the pre-paid envelope.

What are the risks or disadvantages of taking part in this research?

We are not aware of any risks or disadvantages to you in taking part in this research.

What if something goes wrong?

We do not anticipate any harm coming to you as a result of your involvement in this study. However if you do wish to complain, or have any concerns about any aspects of the study then the normal National Health Service complaints procedures are available to you.

Will my taking part in this study be kept confidential?

In completing the questionnaire you are not asked for your name or other confidential information which may allow someone to identify you.

What will happen to the results of the research study?

We will publish the results of this study in medical and nursing journals. We will ensure that service and charitable organisations such as the British Heart Foundation are also aware of the findings.

Who is organising and funding the research?

The Chief Investigator is undertaking this study in order to fulfil the requirements for a PhD award. Research funding has been provided by an external funding body (Research Capacity Building Collaboration) to Cardiff University for the duration of this project.

Who has reviewed the study?

RCBC multi-disciplinary review panel, Cardiff University School of Nursing and Midwifery Ethics Panel, \*\*\*\*\* Health Board Research and Development Panel and \*\*\*\*\* Research Ethics Committee have all reviewed and approved this project.

Next steps.....

If you would like to take part in the questionnaire part of this research project please complete the questionnaire and return it in the pre-paid envelope. If you have any

questions or would be willing to participate in an interview for this project please contact either

Miss Catherine Dunn

School of Nursing and Midwifery, Cardiff University.

Rm 415 Eastgate House, Newport Road, Cardiff, CF24 0AB

e-mail:      tel no: 02920917727

Or

Dr. Katie Featherstone

Director of Postgraduate Studies (Research).

School of Nursing and Midwifery, Cardiff University.

Rm 417 Eastgate House, Newport Road, Cardiff, CF24 0AB

Thank you for taking the time to read this information and for considering participating in this study.

## **Appendix Five**

27 August 2010

Dear Cath

### **An exploration of barriers to the disclosure of erectile dysfunction as an early warning of coronary heart disease**

Thank you for submitting your proposal to the SONMS Research Review and Ethics Screening Committee for:

- scientific review;
- ethics screening;

The Committee has now had the opportunity to review your proposal, and is happy to approve your plans with no amendments.

#### **Please see helpful comments below**

The Participant Information Sheet asks participants to contact the Chief Investigator if anything is unclear or for further information about the research, however only an email address is given. Email would identify participants who might wish to remain anonymous whilst gaining information. An office telephone number to contact might help to overcome this issue, where participants would not need to give their name.

In the Participants Information Sheet it states that interviews will be arranged in the participant's house or at Cardiff University. You might like to consider also giving an option on NHS premises after a Cardiac Rehabilitation session, as this might be a more convenient option for some participants as they would be already on the premises. As long as the venue is not obviously connected to the research project this might help willing participants to attend interview.

I suggest that you pilot your Anonymous questionnaire to make sure that it yields the data in the first stage of your study.

A few minor typographical errors are noted so the committee suggests a final proof reading

The Committee has also determined that your proposal will need to be submitted for approval through NHS research governance and ethics review procedures. Further information can be found in the 'Research ethics guidance for staff and students' document, which can be downloaded from the RRESC website.

We wish you well with your project.

Yours sincerely

Rosemary Williams  
EO: Research Administration

28 February 2011

Miss Catherine Dunn  
Full time PhD student  
Cardiff University School of Nursing and Midwifery.  
Room 415 Eastgate House,  
Newport Road,  
Cardiff.  
CF24 0AB

Dear Miss Dunn

**Study Title:** An exploration of barriers to the disclosure of erectile dysfunction as an early warning of coronary heart disease.  
**REC reference number:** 11/WA/0005  
**Protocol number:** SPON 873-10

Thank you for your letter of 16 February 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Mrs A. Dowden.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

---



GIG  
Gũũfwrdd Iũũ  
NHS  
Wales

Canolfan Gwasanaethau  
Busnes  
Business Services  
Centre

## South East Wales Research Ethics Committee Panel B

Telephone: 02920 376022/3023

20 February 2011

Miss Catherine Dunn  
Full time PhD student  
Cardiff University School of Nursing and Midwifery,  
Room 415 Eastgate House,  
Newport Road,  
Cardiff,  
CF24 0AB

Dear Miss Dunn

**Study Title:** An exploration of barriers to the disclosure of erectile dysfunction as an early warning of coronary heart disease.  
**REG reference number:** 11/WA/0005  
**Protocol number:** SPON 873-10

Thank you for your letter of 16 February 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Mrs A. Cowden.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation (as revised), subject to the conditions specified below.

### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

*Management permission ("R&D approval") should be sought from all NHS organisation(s)*

Canolfan Gwasanaethau Busnes  
Ty Churchill  
17 Ffordd Churchill  
Caerdydd, CF10 2YW  
Ffôn: 029 20 376020/3023  
Ffacs: 029 20 376026



Business Services Centre  
Churchill House  
17 Churchill Way  
Cardiff, CF10 2YW  
Telephone: 029 20 376020 WH: N. 1808  
Fax: 029 20 376026

Canolfan Gwasanaethau Busnes / Busnes Services Centre / Busnes Teaching Local Health Board

Dear Dr Ossei-Gerning

**Project ID : 10/CLC/4989 : An Exploration Of Barriers To The Disclosure Of Erectile Dysfunction As An Early Warning Of Coronary Heart Disease**

Thank you for your recent correspondence addressing the points raised about the above project and supplying the following revised documents:

Document	Version/Serial number	Date
NHS R&D form		Rec'd 02/12/10
NHS SSI form		Rec'd 02/12/10
Protocol	2	

Your response and revised documents were reviewed by the Cardiff and Vale Research Review Service (CaRRS).

I am pleased to inform you that the Panel now has no objection to your proposal. You have informed us that Cardiff University has agreed to act as Sponsor under the Research Governance Framework for Health and Social Care.

Cardiff & Vale UHB R&D approval is subject to:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee
- Letter of access being issued for Catherine Dunn

Once the above are in place, Cardiff and Vale UHB will be happy for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D office if any external or additional funding is awarded for this project in the future
- Inform the R&D office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act 2004 (for further information please contact Sharon Orton, HTA Coordinator [OrtonS@cf.ac.uk](mailto:OrtonS@cf.ac.uk)).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,



**Professor Jonathan I Bisson**



GIG  
Gũũfwrdd Iũũ  
NHS  
Wales

Canolfan Gwasanaethau  
Busnes  
Business Services  
Centre

## South East Wales Research Ethics Committee Panel B

Telephone: 02920 376022/3023

20 February 2011

Miss Catherine Dunn  
Full time PhD student  
Cardiff University School of Nursing and Midwifery,  
Room 415 Eastgate House,  
Newport Road,  
Cardiff,  
CF24 0AB

Dear Miss Dunn

**Study Title:** An exploration of barriers to the disclosure of erectile dysfunction as an early warning of coronary heart disease.  
**REG reference number:** 11/WA/0005  
**Protocol number:** SPON 873-15

Thank you for your letter of 16 February 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Mrs A. Cowden

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation (as revised), subject to the conditions specified below.

### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

*Management permission ("R&D approval") should be sought from all NHS organisation(s)*

Canolfan Gwasanaethau Busnes  
Ty Churchill  
17 Ffordd Churchill  
Caerdydd, CF10 2YW  
Ffôn: 029 20 376020/3023  
Ffacs: 029 20 376026



Business Services Centre  
Churchill House  
17 Churchill Way  
Cardiff CF10 2YW  
Telephone: 029 20 376020 WH: N. 1808  
Fax: 029 20 376026

Canolfan Gwasanaethau Busnes / Busnes Services Centre / Busnes Teaching Local Health Board

## **Appendix Six**

Gary Rolfe Review of Catherine Dunn

### SECTION A:

Title: An exploration of barriers to the disclosure of erectile dysfunction as an early warning of coronary heart disease

Significance/Relevance: (Importance, potential impact, original/duplication)

#### Comments

Although a link has been established between CHD and ED, it would appear that little or no work has been carried out into the experiences of patients and healthcare practitioners of disclosure (or lack of) of ED. This study is therefore timely and has a potential impact on health education programmes and early detection of CHD.

Approach: (Study design, methodology, analysis, statistics, time frame, ethical considerations)

#### Comments

A qualitative approach using in-depth interviews is most appropriate for this study. The researcher is proposing to employ well-established methods of data collection, although detail is lacking regarding data analysis methods. Recruitment to the study is potentially problematic, particularly to the 'no previous disclosure' arm. There are many reasons why patients might not have previously disclosed their ED, and some of these reasons might preclude later disclosure for research purposes, leading to possible recruitment difficulties and a potentially skewed sample. Furthermore, given that the researcher will have no information about the reasons for non-disclosure of patients who do not volunteer for the study, there is no way of knowing whether the sample is representative of the wider population. In addition, no figures are provided on the total numbers of patients attending the classes during the time period of the study, making it difficult to gauge whether the target of 40 patients is realistic. The time-frame for the study translates to roughly one interview, transcription and analysis per week, which is feasible for a full-time student.



Investigator: (Experience)

Comments

The investigator has experience of conducting a Masters level quantitative study, but it is unclear whether she has any prior experience of qualitative work. Her extensive experience of working with patients with ED will set her in good stead for data collection, but she is likely to need support at the analysis stage.

Institution/Environment: (Infrastructure, collaborators)

Comments

The institution has a robust research infrastructure and the proposed supervisors are well qualified and experienced.

Budget (Is the budget justified in terms of the science proposed)

Comments (Good value for money, budget not justified over/under estimated)

The proposed budget is modest and good value for money, although there is no justification for the purchase of a laptop computer in addition to the networked PC provided by the institution. The budget for conference presentations will, of course, depend on the applicant having papers accepted at the specified conferences.

## PROJECT ASSESSMENT

Please indicate your assessment on a scale of 1-7 (where 1 = do not fund and 7 = highly recommended)

5 – this is a viable project subject to further information, particularly regarding numbers available for recruitment

1            2            3            4            5            6            7

OVERALL COMMENTS TO APPLICANT (e.g. feasibility, revision recommended)

This is a viable, timely and worthwhile study. I would have liked to have been given more information regarding your data analysis strategy with regard to coding into themes and categories. It would also have been helpful to have been given some indication of the numbers of patients attending the classes during the timeframe of the study, the approximate numbers suffering from ED and the breakdown of those who had and had not previously disclosed this. Without this information it is difficult to make an assessment about whether you are likely to recruit your anticipated numbers during the course of your study.

(Continued overleaf)

#### SECTION B: FUNDING RECOMMENDATION TO RESEARCH GRANTS COMMITTEE

This is a potentially valuable and timely study. My main reservations concern the lack of information regarding potential recruitment numbers, making it difficult to assess whether the study is feasible in the stated timeframe. I also have a slight concern about the lack of detail and the applicant's apparent lack of previous experience with qualitative data analysis.

Section B will not be forwarded to the applicant. On collating reviewers' comments in conjunction with the research panel decision, consensus ranking and summary of additional comments will be forwarded to the applicant.

#### OVERALL RANKING

Please select the statement that best describes the proposal by marking one box with X

STATEMENT THAT BEST DESCRIBES THE PROPOSED PROJECT	RANKING
Research at the forefront nationally or internationally	
Research with the potential to advance or impact on understanding, practice or policy	X
Research that is nationally competitive	
Research that is nationally competitive but of lower priority in the competition for funds	
Work that is judged not suitable for support	

#### COMMENTS TO RESEARCH GRANTS COMMITTEE

Please place any additional comments that may assist in making an informed funding decision.

REVIEWER: Gary Rolfe

EMAIL: g.rolfe@swan.ac.uk



Research Capacity Building Collaboration Wales  
For Nursing & Allied Health Professionals

Cynyddu Gwaith Ymchwil ar gyfer Nyrsio  
& Gweithwyr Proffesiynol Cysylltiedig

14/10/2009

Catherine Dunn  
3 Charlotte Square  
Rhiwbina  
Cardiff  
CF14 6ND

Dear Catherine

**rcbcwales PhD Fellowship**

I am pleased to advise that you were successful in your application for a full-time PhD Fellowship with the working title as follows:

*'An exploration of barriers to the disclosure of erectile dysfunction as an early warning of coronary heart disease'.*

Your period of funding will run for 3 years (from a start date to be confirmed by Cardiff University). You will be required to attend the community of scholars, which is facilitated by Dr Rachel Iredale at the University of Glamorgan. I will pass on your contact details to her so she can send you details of the upcoming meetings. I will also provide you with a template for you to complete quarterly progress reports which are to be submitted to me.

The funding available for your project is provided in the table below. I will make arrangements for the transfer of payment to be made to Cardiff University by BACS transfer. Payments will be made on a quarterly basis and I will provide Cardiff University with a detailed payment schedule once your start date has been confirmed.

Total funding = £51,558 (broken down as follows)

	Bursary	Fees	Travel & Conference	Research Costs	Total
Year 1	12,600	3,254	500	1,200	17,554
Year 2	12,600	3,352	500	500	16,952
Year 3	12,600	3,452	500	500	17,052
<b>Total</b>	<b>37,800</b>	<b>10,058</b>	<b>1,500</b>	<b>2,200</b>	<b>51,558</b>

If you have any issues you would like to discuss please contact me by telephone on 01443483892, or email to [ahale@glam.ac.uk](mailto:ahale@glam.ac.uk)

We wish you the very best for a successful completion of your studies.

Yours sincerely

**Andrew Hale**  
Administration Assistant  
On behalf of Administrator for the Recipient rcbcwales, Professor Donna Mead OBE

cc Dr Annette Lankshear

## **Appendix Seven**

Potential Topics/ Information to be discussed in One-to-One interviews.

Interviews with Patients

Question areas will cover:

Age

Profession

Cardiac Condition

How long they have suffered from ED

Plotted history of ED and cardiac condition

Has the ED been disclosed, who to and when

Why did they disclose

Why have they not disclosed

What helped or would help to disclose

What would stop/ prevent disclosure

Do they know any "risk factors" for ED

Were they aware of the link with coronary heart disease?

Knowing this would they change their disclosing behaviours?

## **Appendix Eight**

### **Potential Topics/ Information to be discussed in One-to-One interviews**

#### **Interviews with Healthcare Professionals**

Questions will cover:

Current professional role (? Length of time in role?)

In what situations would they envisage or have patients disclosed ED

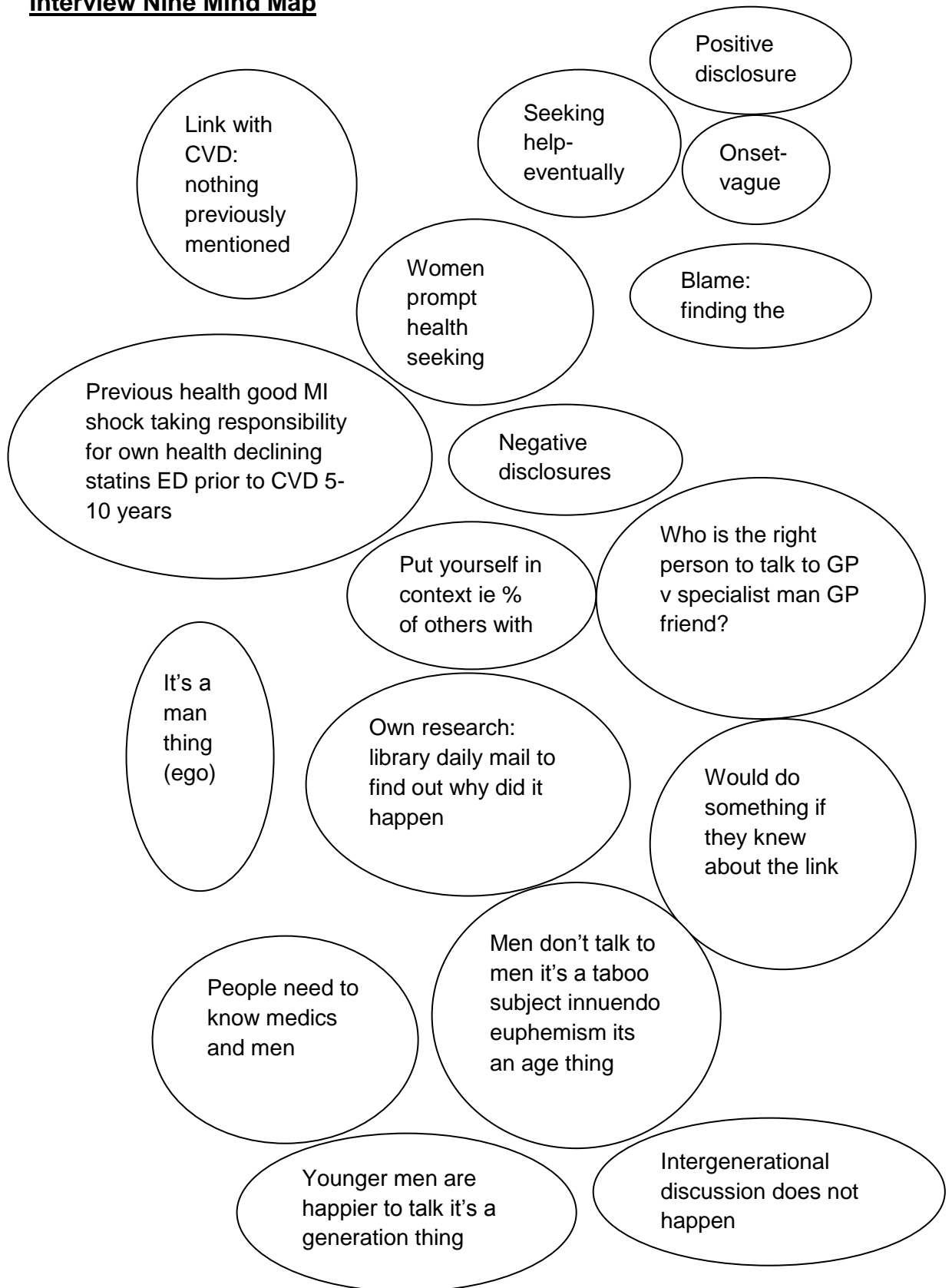
What was the response in that situation?

How would they plan to clinically manage a patient who disclosed ED?

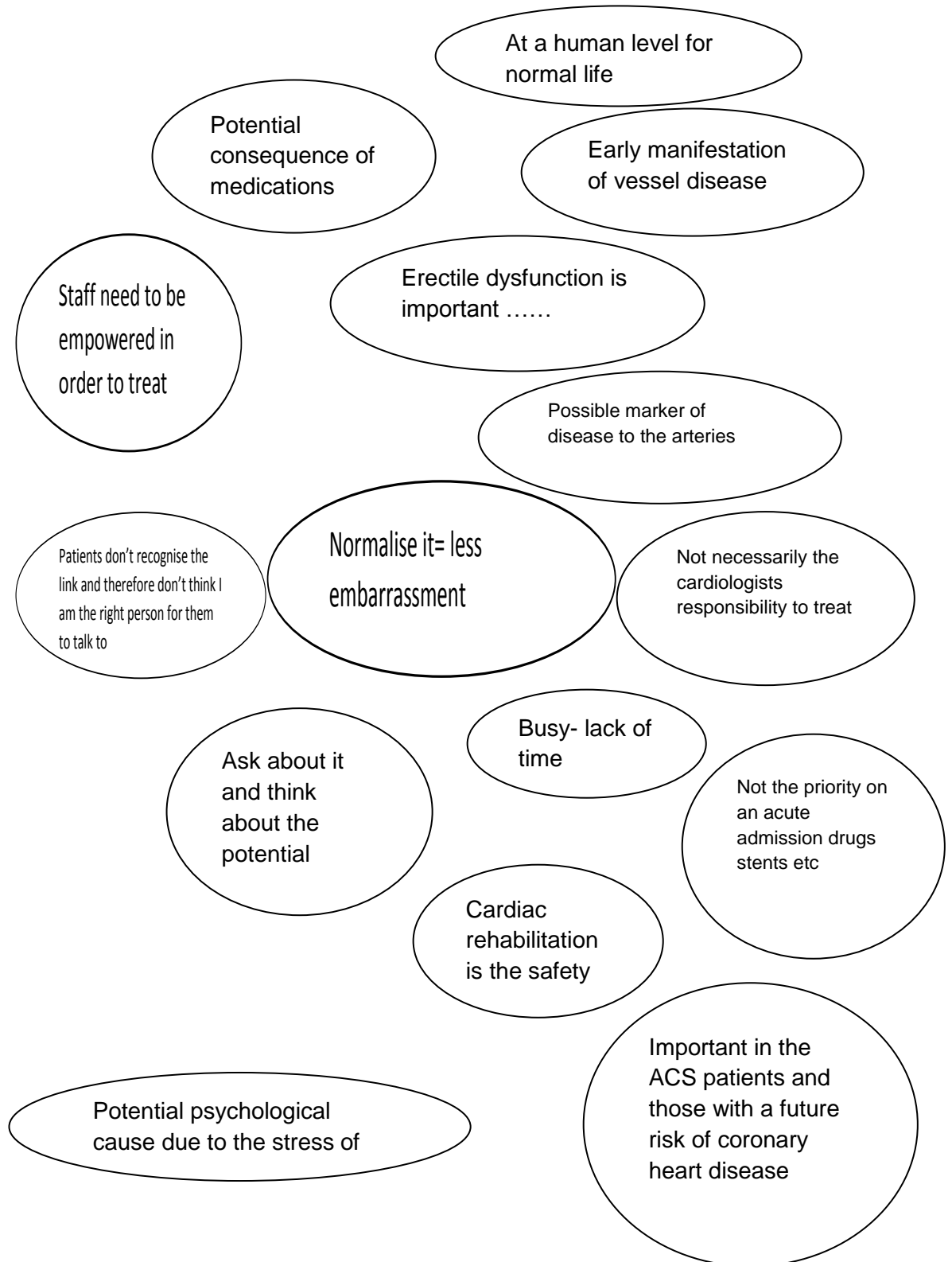
What barriers or enablers to disclosure would they consider with regards to ED?

What are their beliefs about the treatment of ED in patients with known coronary heart disease?

**Appendix Nine**  
**Interview Nine Mind Map**



## Interview Four Mind Map





## **Appendix Ten**

Themes emerging from interviews with men

<b>Initial Themes</b>	<b>Working Themes</b>	<b>Final Themes</b>
Blame or cause	Something to blame	General health
Cardiac rehab and sex talk	Cardiac rehab and sex talk	The heart attack
If asked would you answer honestly	Honesty	Making sense of ED
Intergenerational discussion	Intergenerational discussions	Embarrassment
Level of bother	Level of bother	Loss and regret
Link between ED and CVD	Link between ED and CVD	Blame/ cause
Men talk to men	Do men talk to other men	Context of self with others
Motivation for taking part	Motivation for taking part	Impact on relationship
Onset of ED	Onset of ED	Silence
Own research techniques	Own research	Other generations
Partners and their influence	Partners and disclosure	Own generation (other men)
Personal attributes for disclosure	Who discloses	Strategies to maintain control
Personal response to having ED	How does it affect you	Misunderstandings
Previous health status	Previous health	Illicit behaviours
Putting self in context	Putting self into wider context	ED and cardiovascular disease
Risky behaviours	Risk taking, demonstrates desperation	Disclosure
Treatment seeking	Help seeking	Experiences
Urban myths	Urban myths	Who would you like to speak to
Who have you spoken to	Disclosures	
Who would you speak to	Who would you speak to and why	

Themes emerging from interviews with Healthcare Professionals

<b>Initial Themes</b>	<b>Working Themes</b>	<b>Final Themes</b>
Active or passive enquiry	Ever gone wrong	Experience and titles influence disclosure
ED as a marker of cardiovascular disease	ED as a marker or cardiovascular disease	Appraising the evidence
Embarrassment	Embarrassment	Is ED a risk factor
Euphemism and humour	Euphemism and humour	No experience
Facilitating disclosure	Facilitating disclosure	Limited Experience
How many people	Couching	Active enquiry
Incentives to ask	Giving hope	What does a disclosure look like
Typical patient	Typical patient	Who discloses
Making assumptions	Terminology	How do you broach the subject
Reasons for not asking	Reasons for not asking	How do patients respond
Roles	Normalising	Where do people disclose
Timing or priorities	Timing	Changing priorities
Training	Permission giving	Prompts or adjuncts
What to do with the information	Personal barriers	Justifications for not asking
Who is it appropriate to disclose to	Typical member of staff	Training
Why is it important to ask	Why is it important to ask	Time
	Practical constraints	Ownership
	Other reasons for not asking	Diagnosis and treatment
		Judgements and

		perceptions
		Potential outcomes of enquiry
		How would I like the subject to be broached
		Colleagues
		Influences on practice

## Appendix Eleven

<p>Humour</p> <p>These are all loaded question as I knew the answers</p>	<p><b><u>Interview Two</u></b></p> <p>Conducted: 28/04/2011 Transcribed: 03/05/2011</p> <p>CD: And we're off! (laugh) So R you are an arrhythmia nurse just so that when I am typing this REBECCA: yes yeah CD: How long have you been in this post now? REBECCA: uh just over three years CD: and prior to that REBECCA Cardiac day case unit and coronary care CD: right REBECCA: so that's about what 15, 16 years cardiology experience in total CD: you don't look old enough R (laugh) REBECCA: I feel it and I looked at that the other day and I thought dear God (looking at ID badge) I sort of don't look like that anymore! A few years down the line (laugh) CD: and they won't give you a new photo or not? Right so you have got CCU, Cardiac Day case and arrhythmia experience REBECCA: yeah CD: right e o! So what course have you done REBECCA: oh right along the way? CD: yeah REBECCA: oh golly I am going to have to think of those now. I was originally Project 2000 so that was diploma level then I did right I think it was the foundation, the cardiac foundation course I did that 2 years after qualifying then I did the double credit cardiology whatever that was I can't even remember that might have been like a diploma type qualification double credit whatever it was 60 points CD: (laugh) REBECCA: I did that then I did the</p>	<p>Language rapport funnelling</p>
<p>Professional qualifications</p>	<p>REBECCA: oh right along the way? CD: yeah REBECCA: oh golly I am going to have to think of those now. I was originally Project 2000 so that was diploma level then I did right I think it was the foundation, the cardiac foundation course I did that 2 years after qualifying then I did the double credit cardiology whatever that was I can't even remember that might have been like a diploma type qualification double credit whatever it was 60 points CD: (laugh) REBECCA: I did that then I did the</p>	<p>Professional self</p>
<p>Lots of qualifications</p>	<p>REBECCA: I did that then I did the</p>	<p>Professional self</p>

<p>Categorical statement of no education in relation to ED</p>	<p>cardiac and rehabilitative preventative I think that's what it was which was which way round was that another module in cardiology with rehab background risk factor management about 2 years after that and then currently just finished the double <b>uhm MSc module for non-medical prescribing</b></p>	<p>In spite of numerous courses has not received education in relation to ED, and its specific link to CVD</p>
<p>Knows of clinic but unsure of details</p>	<p>CD: yeay!! REBECCA: Yeah I passed everything, portfolio has gone in I have just got to wait for the end results</p>	<p>Checking information</p>
<p>Sense of embarrassment at lack of knowledge</p>	<p>REBECCA &amp; CD: clapping REBECCA: So that's module 2 and 3 and I also did an arrhythmia masters module at London South Bank 30 credits so if I pass this then I have got 90 credits at Masters level</p>	<p>No formal professional education</p>
<p>Information sources</p>	<p>CD: Yes! REBECCA: <b>so that's about me professionally that are recognised</b></p>	<p>Knowledge gained informally</p>
<p>Has engaged in referring a patient</p>	<p>CD: so on any of those, cos you have got a wide range of courses there any of those has anyone ever talked about ED or mentioned ED or done any formal teaching? REBECCA: no CD: nothing? REBECCA: nothing at all CD: nothing at all? REBECCA: no nothing at all no not even on the rehab module <b>nothing at all no no</b></p>	<p>Husband and wife dynamics</p>
<p>Experience of disclosure</p>	<p>CD: OK REBECCA: <b>never been addressed</b></p>	<p>Shared understanding expressed as laughter</p>
<p>Not because it's funny, can relate to the situation</p>	<p>CD: so where would you say you have heard anything about it? Where would you have picked up any information REBECCA: Only really knowing that we have got an ED clinic here at UHW <b>uhm</b></p>	<p>Language Professional questioning</p>
<p>Seeking clarification</p>	<p>CD: right REBECCA: there is designated <b>nurses attached to the clinic isn't it?</b> You know and being friends with yourself professionally! Uhm</p>	<p>Description of embarrassment</p>
<p>They had already sought help but did not trust the outcome</p>	<p>CD: laugh REBECCA: <b>really that's all not major awareness elsewhere only that through</b></p>	

<p>Know when not to push the discussion any further</p>	<p><b>common knowledge</b>  CD: yeah just word of mouth  REBECCA: <b>friends and colleagues</b>  yeah and I suppose I wouldn't know unless I knew you who to formally refer to</p>	<p>Professional behaviour</p>
<p>Minimal involvement</p>	<p>CD: right  REBECCA: I wouldn't know of the referral process and things like that other than working in the clinic and sharing an office with yourself</p>	
<p>Humour to express discomfort</p>	<p>CD: yeah  REBECCA: yeah</p>	<p>It is a rare conversation</p>
<p>Very few discussions</p>	<p>CD: just bumping into people  REBECCA: yeah  CD: right OK</p>	
<p>Apologetic at lack of disclosures</p>	<p>REBECCA: <b>but I have referred A patient</b>  CD: and what happened when that patient  REBECCA: the patient came to the syncope clinic he was seen in syncope clinic he was treated by Dr. OC on midodrene and uhm I titrated from 7.5 to 10 cos he had had a recent syncopal event <b>and his wife was present in the room and she said there is one other thing we'd like to discuss and he said NO we don't and she said YES we do</b></p>	<p>Professionally rewarding to be approached</p>
<p>Felt good to be approached</p>	<p><b>REBECCA and CD: laugh</b>  REBECCA: so I said what do you think I can help? And he said well she said yes so I said OK so tell me what it is so he went very red and then she said he's having problems she said <b>in the bedroom</b> she said <b>so I said do you want to tell me a little bit more?</b> And she said basically he is having an erection but he is not sustaining it do you know is there anyone who can help? <b>We have been to the GP</b> and he just said it's stress related he said it will be fine so but by his time <b>he was just like under the table</b> but she kept on it was her that sort of instigated things so I said I do know of someone there is a clinic a designated clinic within UHW and I will refer you to Dr. G. and that's what I did so when I did at the bottom of the letter I just added a note then</p>	<p>Professionally rewarding</p>
<p>Too shy</p>	<p>REBECCA: so I said what do you think I can help? And he said well she said yes so I said OK so tell me what it is so he went very red and then she said he's having problems she said <b>in the bedroom</b> she said <b>so I said do you want to tell me a little bit more?</b> And she said basically he is having an erection but he is not sustaining it do you know is there anyone who can help? <b>We have been to the GP</b> and he just said it's stress related he said it will be fine so but by his time <b>he was just like under the table</b> but she kept on it was her that sort of instigated things so I said I do know of someone there is a clinic a designated clinic within UHW and I will refer you to Dr. G. and that's what I did so when I did at the bottom of the letter I just added a note then</p>	<p>Shyness/embarrassment</p> <p>Professional knowledge</p>

<p>Changes in role, may broaden clinical practice</p> <p>Not looking forward to asking but acknowledges that it is necessary</p> <p>2 people are effected by ED</p> <p>It was a conscious decision to open the discussion</p> <p>He showed physical signs of embarrassment and she felt sympathy for him</p> <p>Professional reading of the situation</p>	<p>with some brief details and then Nick did make an appointment but he didn't turn up</p> <p>CD: oh</p> <p>REBECCA: so I made a second appointment and he didn't turn up for that either</p> <p>CD: oh dear</p> <p>REBECCA: so the subject was never approached then again and I have seen him twice since then</p> <p>CD: right</p> <p>REBECCA: and I thought well I have done my bit you know</p> <p>CD: yeah</p> <p>REBECCA: so that's my only involvement ever (laugh) with ED (laugh)</p> <p>CD: (laugh)</p> <p>REBECCA: well professionally! (laugh)</p> <p>CD: has anyone on the day case unit or uhm up on CCU ever</p> <p>REBECCA: no nothing</p> <p>CD: no?</p> <p>REBECCA: no no other patients have actually suggested or said anything either no in the whole time that I have worked</p> <p>CD: right</p> <p>REBECCA: no not even sort of a comment or nothing like that or disclosed anything</p> <p>CD: yeah no</p> <p>REBECCA: no nothing</p> <p>CD: just the one</p> <p>REBECCA: yeah yes sorry that's it yeah</p> <p>CD: yeah no that's fine, how did it make you feel when he started discussing it with you? Or when his wife started discussing it with you</p> <p>REBECCA: I uhm I was fine actually because I think when she said it was nice that she actually instigated it was something that had actually been discussed in advance that she was going to mention it when they came to the clinic because when then I says any other questions or anything like that she was straight</p>	<p>Will personally feel uncomfortable having discussions</p> <p>Not just a male issue</p> <p>Disclosure takes mental preparation</p> <p>Personal connection Professional behaviour</p>
---	--	--

<p>Sex is not a concern of AF patients?</p> <p>HCP's don't want to know</p> <p>Influence of recent learning</p> <p>Uncomfortable laugh Justifying decision</p>	<p>Phone rings (5mins 31 secs)</p> <p>REBECCA: well it was fine I think I appreciated that she had actually approached the subject. There was obviously something that was relevant to the both of them but I think he was to shy to actually uhm approach the subject and she felt that maybe it was better or easier coming from herself and she was she was quite verbal</p> <p>CD: were they quite a young couple? Or</p> <p>REBECCA: yeah he's oh how old is A, A is about 49 50</p> <p>CD: right</p> <p>REBECCA: and she was a bit younger than that and this had been an ongoing problem for quite a couple of months</p> <p>CD: ah OK</p> <p>REBECCA: yeah but uhm</p> <p>CD: so when you are doing I was thinking more in your prescribing role now that you are taking on and you are prescribing drugs and things uhm with all of the stuff that you have looked into on your course are many of the drugs that you are going to be prescribing have got ED as a side effect or potential</p> <p>REBECCA: well yeah beta-blockers isn't it for one for certain</p> <p>CD: yeah</p> <p>REBECCA: cos we're going well most probably will be responsible for the AF patients</p> <p>CD: right</p> <p>REBECCA: titrating those depending on rate or rhythm control so yes yes there will be potentially yes there will I will have to</p> <p>CD: so potentially you might be referring</p> <p>REBECCA: I'll have to go through yes it's difficult and I suppose you would have to broach the subject then there is a potential side effect of</p> <p>CD: yeah</p>	<p>Thoughts based on experience</p> <p>Clinical priorities</p> <p>Language</p> <p>Shared understanding in relation to clinical resources</p> <p>Acknowledgement and interpretation of professional learning</p> <p>Interpretation of understanding</p>
--	--	--



<p>One member of the team receives all disclosures</p> <p>Laugh? Humour? Relief it is not her</p> <p>Services have to be in place for this to happen ? bouncing</p>	<p>Phone rings (1 min 10 secs)</p> <p>CD: right so based on your extensive one patient</p> <p>REBECCA: (laugh) yeah?</p> <p>CD: uhm what was it you what do you think was stopping him telling people? Was he just totally embarrassed do you think? Or</p> <p>REBECCA: yes I suppose he was yes I think he is embarrassed er or was embarrassed cos to actually sort of admit to them that for him maybe was a problem uhm <b>but I think what she highlighted wasn't all about him</b></p> <p>CD: right</p> <p>REBECCA: <b>they were in a relationship and it was affecting her as well</b></p> <p>CD: right</p> <p>REBECCA: so that's why she was quite open about it you know something needed to be done uhm so yes I suppose it was embarrassing but he had gone to the GP and hadn't got anywhere and the GP had said just like stress so I think he thought oh right maybe there is something that I have to accept or whatever</p> <p>CD: right</p> <p>REBECCA: uhm</p> <p>CD: so the GP hadn't referred him to anyone?</p> <p>REBECCA: pursued no</p> <p>CD: or given him any treatment or anything</p> <p>REBECCA: no nothing at all I think he had gone to the GP on his own and had come away from there but I think she was adamant when she was coming here obviously it was for syncope reasons but I think <b>she came with the intention</b> that she was going to mention it and they were going to get something done you know</p> <p>CD: she was a woman on a mission</p> <p>REBECCA: yeah she was but <b>he was and he was very embarrassed he was ah he was puce bless him</b> and he went quite quiet so that's why <b>I didn't pursue any of the finer details</b> it was just</p>	<p>Some people are approached more than others</p> <p>One member of staff always approached</p> <p>Professional referral</p>
---	---	--

<p>Asking questions of me</p>	<p>something that they both acknowledged and then I said I know a man that can sort you out and that's what we did and he didn't turn up  CD: never mind  REBECCA: unless things well it was stress related and things have you know  CD: yes quite a lot of the patients who come to clinic don't come for follow-ups and when you do eventually get hold of them they say oh no it's all working fine now so that's why we didn't bother to come really  REBECCA: yeah  CD: it's frustrating because you would rather know it was working fine than have them not turn up but I guess if you don't have to talk about it you won't will you  REBECCA: yeah  CD: do I have anything else that I want to ask you? Uhm do you ever routinely ask I suppose really your patients are a bit younger than the average cardiology patient aren't they? So you don't routinely ask like all of your patients about ED  REBECCA: No no you wouldn't no  CD: it wouldn't be something that you would uhm like you wouldn't yeah you wouldn't be on your mental check list of things to check with them  REBECCA: no it wouldn't be part of our assessment I would say no cos even like with the no even with the AF patients their main concern is their rhythm it's not something that they ever it's not a subject that they bring up or approach but he syncope patients as well they are younger and the majority of them are female  CD: right  REBECCA: they are the mad syncope patients  CD: right yeah  REBECCA: so it's not no I don't routinely bring it up no  CD: I mean in terms of your AF clinic do you think maybe well I suppose</p>	
-------------------------------	--	--

	<p>yeah those patients if you look at risk factors for ED they are going to have a lot more of them aren't they?</p> <p>REBECCA Yeah yeah and I think that may change because I am going to be seeing Dr. F's follow-up ablation patients at six weeks and they are a younger more male dominated uhm population who are on essentially all on flecanide and sotalols and bisoprolols and things like that they are</p> <p>CD: so they have got all the risk factors</p> <p>REBECCA: they may be yeah it's something that will maybe come to light but then again whether I would because of the nature of the clinic is just to assess their rhythm and symptoms related to that and then off you go</p> <p>CD: right</p> <p>REBECCA: I don't know whether we will delve any deeper than that. Dr. F will want to I think is just to see them say hello do an ECG check they are all OK and then get rid of them again you know?</p> <p>CD: right</p> <p>REBECCA: but uhm maybe obviously in the future as because of the clinical patient assessment module and then with prescribing as you said yeah that may change</p> <p>CD: yeah</p> <p>REBECCA: but I don't think routinely I would I won't add it to my patient assessment questionnaire I won't (laugh) cos they are not some much cardiology patients are they I suppose with chest pains and atheroma and things like that</p> <p>CD: no that's it you are not thinking the same processes are happening upstairs and downstairs are you?</p> <p>REBECCA: no</p> <p>CD: it's the electrics</p> <p>REBECCA: yeah that's right I tell you who you need to speak to is her cos uhm the ICD support group there is always one or two patients that mention, did you send her a</p>	
--	---	--

	<p>questionnaire?  CD: no I haven't yet no  REBECCA: because there is always one or two patients that ask about it on that afternoon  CD: in the support group scenario?  REBECCA: not verbally open but she is always pulled aside and I would say that has happened quite a few times  CD: good grief!  REBECCA: yeah definitely cos they almost feel that they can you know speak to her about it  CD: right  REBECCA: cos I know there was a RP in the last one who asked her about it in the end  CD: and it's not as if they are having a talk on it in that scenario  REBECCA: no  CD: so they come to a support group with a talk on anything and everything  REBECCA: yeah  CD: and they decide that it's a Saturday afternoon in a church hall they will have a chat  REBECCA: yeah cup of tea I don't know how many patients she has referred to Nick there has been quite a few for our ICD patients she have definitely  CD: interesting  REBECCA: P lets see some letters  CD: you would have thought that would be the least likely scenario  REBECCA: yeah  CD: wouldn't you to go cos its usually in a church hall isn't it on a Saturday afternoon  REBECCA: did she say that a patient rang her and I joke with her that patients only phone with ED problems (laugh)  CD: (laugh)  REBECCA: Well I can't find the stuff I know a few times we have been there on a Saturday afternoon  CD: yeah  REBECCA: and they have but it's funny cos there's three of us there</p>	
--	--	--

	<p>CD: yeah</p> <p>REBECCA: and it's M that they approach</p> <p>CD: they always go to her</p> <p>REBECCA: yeah which is quite interesting</p> <p>CD: yeah quite an interesting PhD study in itself (laugh)</p> <p>REBECCA: yeah it would I don't know where it's filed</p> <p>CD: I suppose now it's a bit more uhm it's a bit easier to deal with because there is a clinic that you can refer to isn't it?</p> <p>REBECCA: yeah</p> <p>CD: so you know you can say straight away there's you know yes I have got an answer for you</p> <p>REBECCA: yep</p> <p>CD: we will refer you rather than</p> <p>REBECCA: I have not got the answers but I can refer you to someone who will do the necessary assessment and then go from there</p> <p>CD: for years you didn't have anyone to refer to did you cos what would you have done if that had happened with that gentleman before Nick had set the clinic up?</p> <p>REBECCA: well I don't know I would just have to write to the GP and get consent from him to write back to the GP to say that he has been once and would he be happy to do a review again as it is obviously troubling him</p> <p>CD: yeah</p> <p>REBECCA: and his wife but uhm still do many people know about the clinic? Or?</p> <p>CD: Uhm? Well certainly enough to keep us busy</p> <p>REBECCA: yeah</p> <p>CD: uhm and N*** does speak to the consultant meetings and things uhm quite frequently and all the registrars know</p> <p>REBECCA: yeah</p> <p>CD: but I don't know about the nurses and nurse led clinic. AP refers people every whip stitch</p>	
--	---	--

	<p>REBECCA: well I know she asks CD: she is prolific referrer she is REBECCA: well she asks the questions so doesn't she cos I was talking to her about it the other day uhm and she was saying about uhm cos of the risk factors she asks CD: yeah REBECCA: and then I had a uhm patient how about this chap then is he one of yours? MW? CD: I recognise the name yeah REBECCA: what uhm CD: yeah I do recognise the name oh I think you might be busy with this AF clinic now R there will be lots of letters coming in our direction REBECCA: uhm (laughs) CD: yeah cos AP does routinely ask on her list I think REBECCA: yeah she does doesn't she CD: yeah she does seem to generate quite a few referrals for us REBECCA: he was in AF during his appointment so with in the clinic then what other assessment do you do an ECG? CD: no uhm we can do I have been known to run over and get the ECG machine from B1 only if Nick has felt an irregular pulse REBECCA: yeah CD: uhm so usually we don't have to do much physical assessment because they have come as a referral via cardiology anyway so there is all of their notes there anyway so we do uhm a self-rating score thing where you rate yourself from 0-5 on several different questions and you get a score a SHIM score and then if you get below a certain score then you have got ED and we just take a history from them about when it started whether it was gradual or sudden REBECCA: yeah CD: have a look at their medications because obviously they shouldn't have nitrates and PDE5's REBECCA: yeah</p>	
--	---	--

	<p>CD: uhm and then usually N*** sees them and kind of just confirms the diagnosis either of organic ED which most of ours are uhm and then we come up with a bit of a treatment plan but you know it's not as it's not complicated really</p> <p>REBECCA: and that's they you write to the GP then to initiate anything if as and when required</p> <p>CD: yeah cos quite often it's just a case of a cardiologist giving the GP permission to prescribe because a lot of GP's won't prescribe</p> <p>REBECCA: yeah</p> <p>CD: because they are cardiac patients and they will say no its not safe to but that's an old wives tale so quite often as long as they have got a letter from the Cardiologist saying</p> <p>REBECCA: to confirm</p> <p>CD: I have assessed everything</p> <p>REBECCA: he can take full responsibility for everything</p> <p>CD: yeah exactly</p> <p>REBECCA: how is this cos this is from Dr M this is what confused me</p> <p>CD: yeah</p> <p>REBECCA: and he said he was noted to be in AF during his appointment at the ED clinic last week so I was just wondering how</p> <p>CD: he must have uhm we must have seen him on the Tuesday night and he must have had an appointment in cardiology I have done a couple of ECG's if Nick has said checked somebody's pulse usually while he is doing a medication review he will check their pulse and</p> <p>REBECCA: yeah</p> <p>CD: if he thinks it's irregular then we get an ECG so but obviously he had two appointments in quick succession but uh</p> <p>REBECCA: yeah so he will be coming in soon</p> <p>CD: right jolly good I don't think there is anything else</p> <p>REBECCA: that's it (laugh)</p>	
--	--	--

	11 mins and 7 secs Total 17 mins 48 secs	
--	---	--



## Appendix Twelve

	<u>Interview Nine</u>	
	<p>Conducted: 22/06/2011            Transcribed: 23/06/2011</p>	
Reducing tension	CD: Ah it looks like it is doing something fingers crossed I managed to erase a whole interview	Power/ positioning Use to discuss how Mr. Andrews interviews developed
Other people have taken part	Mr. Andrews a couple of weeks ago one of the girls I was in her office and the phone rang so obviously I turned it off half way through and then as we turned it back on she was joking around about something and I just pressed delete and the whole lot went	
You are important.	MR. ANDREWS: (laugh) MRS. ANDREWS: (laugh) CD: I am going to put it over there because my voice isn't very important but yours is more important than mine, I will end up listening to my own voice can I just recap because I know I have seen you in clinic but my memory is shocking what did you do for a job before you retired	
Reducing tension, easing into questions	MR. ANDREWS: I was an electrician CD: an electrician MR. ANDREWS: yes CD: right so would you say that was quite a manual MR. ANDREWS: yes yes at times CD: you are quite fit and you know MR. ANDREWS: yes CD: and you were described in your medical notes as what was it? Very fit or	
Life changing moment. Euphemism	MR. ANDREWS: reasonably fit CD: oh I thought it was better than reasonably fit (laugh) MR. ANDREWS: (laugh) CD: I thought it was quite positive MRS. ANDREWS: yes it was CD: yeah MRS. ANDREWS: I can't think what	Change in identity- something has changed at a particular (not defined) age What falls off?

No clear onset/ downplaying	now cos it was quite funny CD: it was wasn't it but it was it was a glowing report on your general state of health	This is his wife
Memorable incident	MRS. ANDREWS: yes yes MR. ANDREWS: well not bad then (laugh) CD: (laugh) but generally you have been quite fit haven't you you have not had any major operations or anything	Language Is she demonstrating that to her is does not matter, but to him it does?
Life changing, slow creep One specific time- questioning	MR. ANDREWS: no no never no MRS. ANDREWS: he was fit until he was 69 and then MR. ANDREWS: then it all falls off (laugh) CD: (laugh) all falls off	Why defer to the wife? Time  Time/ context
Delay in seeking help Sense of this being a long time	MRS. ANDREWS: he never took time off work you know odd cold things like that but nothing else CD: so when did you first notice your ED? When what sort of age were you do you recon when you started noticing?	Awful questioning technique  Knowledge/ understanding/ interpretation- why would one time specifically you notice? Time- delay
Another issue "started or ended up" Peyronies resolved but ED not?	MRS. ANDREWS: do you know I can't think MR. ANDREWS: because you are better on dates than I am (laugh) MRS. ANDREWS: about five years ago MR. ANDREWS: no it was longer than that MRS. ANDREWS: longer than that? MR. ANDREWS: longer yeah its got to be when we were in the Isle of Wight ten years ago?	Behaviour- lack of help seeking as an example  "it" = penis external to himself? "ended up" - ? fatalistic or luck Medical language Closing the experience Was that it? He sought more help later
? bad luck	CD: Yeah that's not doing what it used to do	Language/ perception- a negative experience ? acceptance- does
Table- impersonal	MR. ANDREWS: no no and that's it CD: did you go straight to the GP? Or did you sort of procrastinate in a manly fashion for a while?	
Closed experience	MRS. ANDREWS: OK CD: was it a sort of gradual onset or did you think MR. ANDREWS: yes CD: so it was sort of MR. ANDREWS: yes a gradual something you don't notice until one time and you think why is that? CD: Yeah that's not doing what it used to do	
Despondent		
Positive action		

<p>taken Disappointment Lack of knowledge</p> <p>“that”!</p> <p>Disappointment</p> <p>Acceptance</p> <p>Routine health screen, matter of course</p> <p>One incident has had lasting impact</p> <p>Time indicates priority</p> <p>It is important Causes</p> <p>ED is a negative thing</p> <p>? knowing of another cause I am changing the subject</p> <p>Lack of knowledge</p>	<p>MR. ANDREWS: no I didn't go straight away because</p> <p>CD: (laugh)</p> <p>MR. ANDREWS: not for quite a while and then eventually I did go</p> <p>CD: what sort of prompted you to go? Or was it just that you were thinking you know I've been</p> <p>MR. ANDREWS: well because because it started or ended up with it being Peyronies disease</p> <p>CD: that's right yeah I remember yep</p> <p>MR. ANDREWS: and that's what started it all off and I ended up going because there was it was</p> <p>CD: yeah</p> <p>MR. ANDREWS: so then I went to see err Dr. B</p> <p>CD: and did they did they book you in for a normal appointment or did you get an extra-long appointment</p> <p>MR. ANDREWS: no no just er can I see the doctor and I ended up with him</p> <p>CD: and how did that go when you talked to him?</p> <p>MR. ANDREWS: uhm all he said was “oh yes uhm Peyronies oh” and he sat me on the table and “oh yes a bit of trauma” and basically “hard luck”</p> <p>CD: oh right I see right</p> <p>MR. ANDREWS: and that was it</p> <p>CD: so he didn't refer you to anybody</p> <p>MR. ANDREWS: no</p> <p>CD: or suggest any treatments or anything?</p> <p>MR. ANDREWS: not a thing</p> <p>CD: OK and then so it must have been a couple of years after that then that you came in with your heart attack</p> <p>MR. ANDREWS: no no after that I went to I got fed up with the waiting and I went to see uhm Dr. C</p> <p>CD: oh right yes yeah</p> <p>MR. ANDREWS: and he said “oh right OK then yes right we will he</p>	<p>not prove to be the case in later discussions</p> <p>Time/ urgency- felt a need to seek further advise</p> <p>Knowledge- had assumed Viagra would provide a magic answer</p> <p>Some confusion in relation to the medical speciality dealing with Peyronies disease Language- “with that”</p> <p>Medical language- shared understanding</p> <p>Acceptance of this change in self</p> <p>Positive action despite previous statement</p> <p>Language- very negative attitude</p> <p>Time- “forgotten”</p> <p>Identity Knowledge/ rationalisation of causes</p>
--	--	---

<p>“Pet topic” Lack of professional knowledge-caused frustration and lack of confidence</p>	<p>gave me some Viagra which as far as I was concerned didn't work but uhm since I realised you should go through a whole performance yeah CD: yeah MR. ANDREWS: ongoing thing but anyway so he said “well I will get I will refer you so then that's when I went to the hospital and got involved with Dr. I don't know can't remember his name Anderson? No that was the MRS. ANDREWS: heart MR. ANDREWS: heart MRS. ANDREWS: Matthews? MR. ANDREWS: yeah Matthews and yes and he said oh yes we can sort we can do things with that CD: right MR. ANDREWS: and that's when I had the what do you call it Nesbitts procedure so I had that CD: right (laugh) MR. ANDREWS: so uhm (cough) and I didn't think it was that effective CD: right MR. ANDREWS: because things didn't improve and so it was just left and just left it in abeyance and then of course I had the heart attack and uhm MRS. ANDREWS: that was only last year MR. ANDREWS: yeah last year and then in one of the things that was said you know if you've got ED and I ticked and I had a choice of what's his name Mr. CD: Oh Dr. G yeah MR. ANDREWS: Dr. G or B and I said forget B I don't want to know that one and er that's how I ended up CD: right MR. ANDREWS: and then well I just thought it had been forgotten because it had been so long and then of course the letter came and that's when I came to the hospital</p>	<p>? blame/ responsibility/ why me? Looking for a cause, has given it some consideration</p>
<p>Lack of help, alone with it</p>	<p></p>	<p>Knowledge- did he know or think it was something else?</p>
<p>Looking for causes</p>	<p></p>	<p>This could be an example of moving the conversation on- didn't want Mr. Andrews to cause any marital issues</p>
<p>Not something I do but others do</p>	<p></p>	<p>Managing difficult previous statement</p>
<p>Understanding of male behaviour</p>	<p></p>	<p>Knowledge and professional “down playing” of the subject “iffy about it”- not much faith in medical knowledge Fatalistic</p>
<p>Hidden, socially banned</p>	<p></p>	<p>Knowledge- was not an answer Language  Improving knowledge by various means</p>
<p>Lack of knowledge at the time stopped him talking about it</p>	<p></p>	<p>Other people talk to friends, but he does not Language</p>
<p></p>	<p></p>	<p>We= men ie men saying they need</p>

Frustration at the lack of knowledge	and that was and that's it (laugh) CD: (laugh) and there we are to current date MR. ANDREWS: that's my life story (laugh)	Viagra Language Understanding
Fatalistic in the face of no other options Men are closed to discussion	MRS. ANDREWS: I used to think it was something to do with smoking you see CD: right MRS. ANDREWS: yes CD: yeah	Exclamation of relief Language, shared understanding, Language
Revisiting previous concerns re: understanding	MRS. ANDREWS: I used to think it was to do with that that's why he had these problems CD: certainly doesn't help MRS. ANDREWS: no MR. ANDREWS: it didn't help but it was	Context- when he first sought help Knowledge
Failed to build rapport or trust- disappointed	MRS. ANDREWS: he wouldn't have that MR. ANDREWS: no it wasn't that but anyway CD: so kind of going back to Dr. B and then the subsequent Dr. C did anybody mention cardiac risk factors or did anybody make any link with cardiac risk factors?	Is health behaviour motivated by knowing causes? Professionals lack of knowledge specifically in relation to causes Just happened- is it there more difficult to accept? Becomes frustration
Mental preparation	MR. ANDREWS: nothing at all CD: so that came out totally out of the blue as such	Becomes frustration
There is a need  Telling partner of plan, therefore had to go Waste of time	MR. ANDREWS: yes yes no it wasn't nothing was mentioned they the only thing B did say that eh he was sort of it was his sort of little thing and uhm nobody really knows why and I mentioned the part the smoking bit and he said uhm yes could possibly but no he was all iffy about it CD: right	Male identity- from womans perspective
Interpretation of typical male behaviour	MR. ANDREWS: and er as though well you've got it there's nothing you can do about it you've just got to live with it and that was it and I did read up about it or what I could	Understanding- not aware of what was meant by trauma
Not using specific words Save- ie exposing themselves to harm	CD: uhm MR. ANDREWS: and even there there was no sort of you know this is what causes it CD: right nothing definitive	Still does not know what was meant  Disappointment at lack of action/ understanding

<p>Not talked about Having information is a positive thing</p> <p>Actively sought information but also passively gained understanding- ? heightened awareness</p> <p>All male sexual health is the same?</p> <p>Not convinced by the link between CVD and ED, but can see how it would be useful</p> <p>Associated with excessive alcohol intake</p> <p>Searching for the truth- facts</p>	<p>MR. ANDREWS: no  CD: where did you read up on  MR. ANDREWS: oh in the library  MRS. ANDREWS: and the Mail  MR. ANDREWS: and the Daily Mail you occasionally in the papers  CD: yeah our Prof of Cardiology quite frequently writes in the Daily Mail  MR. ANDREWS: oh yes this is well oh well that's it and that was it  CD: now this is going to sound like a silly question but its only because its based on talking to the boys in work do you ever discuss such things with your peers you know other men of your age  MR. ANDREWS: that is not something one does  CD: no I thought (laugh)  MR. ANDREWS: its not a thing because well you know you do hear people say "oh you need the blue tablet" and  CD: right  MR. ANDREWS: and that's all we hear the boy thing  CD: it's more the urban myth sort of thing  MR. ANDREWS: but you don't know who's got what or whatever or why that's never it's not a thing  CD: that men discuss  MR. ANDREWS: no its not a thing that isn't you would go phew!  CD: yeah I said to the boys  MR. ANDREWS: it's a taboo subject  CD: I said to them its important it's a marker for cardiovascular disease and they went I don't know what you think we talk about in the pub Cath but it is not that (Laugh)  MR. ANDREWS: it ain't that no  MRS. ANDREWS: no  MR. ANDREWS: that is not it but no there was no link between the two lets put it that way  CD: yeah if there had been if there was an obvious if people knew</p>	<p>Long term effects of poor HCP communication  Damage- a persistent concern which remains Broaching the subject  Disappointment - had verbalised plan so had to see it through</p> <p>Hidden subject</p> <p>Language- bluff and bravado  Men use innuendo  Shared understanding</p> <p>Hidden- female perspective of male behaviour  Knowledge/ access to health information  Had tried to find information</p> <p>Efforts to gain knowledge</p> <p>Reference to other sexual health issues</p>
--	---	--



<p>Not the cause for him, defending his identity</p>	<p>there was a link between the two do you think they would be more keen to speak to somebody about it? MR. ANDREWS: well I think so CD: yeah</p>	<p>Knowledge</p>
<p>Sympathy, fatalistic</p>	<p>MR. ANDREWS: you know if one of these had said to me well you know if you don't do this or not do that this has happened to you that happened to me but that has got nothing to do with anything else its just something that has occurred but we don't know why and I could never find anything or read anything or find any information anywhere as why because no-body seemed to know</p>	<p>Language- "bits and pieces"</p>
<p>Reductionist, scientific</p>	<p>CD: right MR. ANDREWS: it was just something that happened</p>	<p>Language Knowledge- historical context and has thought about the topic</p>
<p>Wife has major role in addressing sexual health issues</p>	<p>CD: right MRS. ANDREWS: men are not open like women are they CD: no I am coming to realise this (laugh) MR. ANDREWS: well like B said it was a trauma but he didn't explain to me what a trauma meant</p>	<p>Knowledge Language –"fact"</p>
<p>Managing risk and complying with medical advise</p>	<p>CD: uhm yes MR. ANDREWS: in that respect CD: yeah physical trauma or emotional trauma or could be MR. ANDREWS: yeah I don't know CD: could be either, both or neither isn't it?</p>	<p>Identity ie not an alcoholic!</p>
<p>Hope</p>	<p>MR. ANDREWS: if I MRS. ANDREWS: he wasn't impressed with him when he came back he said well that was a waste of time</p>	<p>Cause, or lack of it Wants to know cause so that it can be addressed Search for a cause Making sense, interpreting</p>
<p>Taking medical advise</p>	<p>MR. ANDREWS: If I had had damage there CD: you work yourself up to tell someone don't you MR. ANDREWS: yeah it took me long enough to go you know</p>	<p>Cause, or lack of it Wants to know cause so that it can be addressed Search for a cause Making sense, interpreting</p>
<p>Not blindly trusting, but likewise</p>	<p>CD: yeah MR. ANDREWS: oh I've got to go and CD: yeah</p>	<p></p>

alternative sources dismissed as "stories"	MR. ANDREWS: but in the end you've got to go because of whatever	
Reflection	CD: yeah MR. ANDREWS: and like I said to MRS. ANDREWS I'm going to go and that was it so but it didn't there was no I might just as well have not have gone	Help seeking- motivated by wife
Seeking understanding	CD: right MR. ANDREWS: to be perfectly honest CD: and probably that puts you off trying to tell anyone else then as well doesn't it	Trying to reduce risk of health concerns.
Accepting of advise	MR. ANDREWS: oh yeah yeah CD: you think well I tried MR. ANDREWS: yeah well you don't know because there's not as you say its not a subject that blokes talk about	Acknowledging that medical science is not fool proof
Expectations of health associated with age		
Self-managed risk reduction	CD: unless you find yourself in the ED clinic	
Taking responsibility	MRS. ANDREWS: yeah MR. ANDREWS: its all innuendo oh yeah and you say yeah yeah yeah and all the rest	Knowledge and understanding of healthcare associated risk- especially with increasing age
Too easy- quick fix	MRS. ANDREWS: it's a shame really because they could save themselves so much like you know talking about it and I've had that right get to the doctors CD: yes yeah MRS. ANDREWS: but they don't its taboo	Interpretation
Questioning of medical knowledge	MR. ANDREWS: no because well its all to do with the well there's more information now than there used to be CD: that's true MR. ANDREWS: there was never the information	Seeking knowledge ? from me ? metaphorical question
Recognising an individual's competence	CD: yeah and you can access it sort of privately really MRS. ANDREWS: Yes CD: can't you you don't have to sort o put your hand up and go MR. ANDREWS: no you can you know you can go on the computer or whatever but even there it was	Blind trust, behaviour- contradicting at times  Other people- tablets Lack of personal



<p>Feeling talked about rather than with</p> <p>Previously fit and well</p>	<p>not a lot on things either  CD: right  MR. ANDREWS: you know as I said I went to the library at that stage and sort of read about it there and then there's bits and pieces that you can pick up in the papers on the health bits and things and uhm just my information has basically come there</p>	<p>responsibility</p> <p>Personal responsibility</p>
<p>ED is a negative thing</p>	<p>CD: it needs to be more out you know more obvious  MRS. ANDREWS: absolutely it's the same with prostate and everything isn't it  CD: yes yeah  MRS. ANDREWS: all things like that</p>	<p>Knowledge Power</p>
<p>Managing interview</p> <p>Distancing from topic</p>	<p>CD ; big campaigns like that do do work you know when they put out the big poster  MR. ANDREWS: yes you can see that you know looking back you can see the logic of now what their or what people are thinking and they are thinking there may be a link between that  CD: yeah  MR. ANDREWS: and other bits and pieces</p>	<p>Professional responsibilities</p>
<p>Male behaviour</p> <p>That is an obstacle</p>	<p>CD: and it's always been thought of as something that's a natural aging process hasn't it you know people haven't really given it more thought than that and then there was quite a long period when people thought it was a psychological problem rather than an actual physical problem  MR. ANDREWS: uhm yeah  CD: you know so there has been quite a lot of I think probably medical science got a bit skewed in terms of psychological interventions for ED for quite a long time really and so therefore people don't want to talk about it because they think people are going to think I am a bit</p>	<p>Lack of connection with HCP's</p>
<p>Hidden part of the body, hidden subject</p>	<p>MR. ANDREWS: yeah it used to be called what was it it used to be associated with drinking brewers</p>	<p>Self-identity</p> <p>This is all about sense of self</p>
<p>He does not have a friend he would tell</p> <p>Would not tell a person he did not know either</p>	<p>MR. ANDREWS: yeah it used to be called what was it it used to be associated with drinking brewers</p>	<p>Change in identity</p>
<p>Male identity</p>	<p>MR. ANDREWS: yeah it used to be called what was it it used to be associated with drinking brewers</p>	

Failed at being a man	<p><b>droop</b>  CD: (laugh) oh yeah  MR. ANDREWS: (laugh)  MRS. ANDREWS: (laugh)  MR. ANDREWS: that was the uhm</p>	Personal responsibility to address it
Deep personal implications Failed	<p>that was the thing  MRS. ANDREWS: trust you to come up with that  MR. ANDREWS: <b>well no it was fact it was too much drinking</b>  MRS. ANDREWS: yeah  MR. ANDREWS: too much drink and that's why you  MRS. ANDREWS: <b>that wasn't his problem though</b>  MR. ANDREWS: <b>no (laugh) no not it was just I was trying to think about did it occur before but that's just another sort of</b></p>	Part of your identity Language- "personal part"
Knowing the common nature does not help	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	Shared understanding Language- why do people joke?  Other people Risk in sharing information
Confusion over whether this knowledge helps	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	Identity- this is where he put his fist to his chest  Personal identity  Language- "can't do it"  Personal identity  Identity
Socially unacceptable to discuss	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	Identity- this is where he put his fist to his chest  Personal identity  Language- "can't do it"  Personal identity  Identity
Loss of control of the situation	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	Language- "can't do it"  Personal identity  Identity
Lack of knowledge? Can't apply logical thought?	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	"but"- rationalisation, very personal feelings Personal identity, does not need to know about other people
Age is a cause, loss and acceptance	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	Personal identity, does not need to know about other people
easy fix risk taking step	<p>CD: yes  MR. ANDREWS: direction  CD: yeah  MR. ANDREWS: that was another cause of what was to do with it  CD: yeah and that's half the problem as well is establishing what the problem is because  MRS. ANDREWS: oh absolutely  CD: everybody uses different terminology you know  MRS. ANDREWS: yes yeah  CD: well like you say he said it was trauma but what is trauma  MR. ANDREWS: yeah what does if he had said <b>well you know I am sorry but</b> it is a furring of your arteries er and then you think well alright what is causing the furring of the arteries  CD: yes  MR. ANDREWS: <b>logical step by step then you can work it out</b> you know I was thinking if he had said at the time oh that start taking an aspirin a day to thin the blood out  CD: yeah  MR. ANDREWS: to make it go around faster and whatever  CD: yeah so he didn't put you on anything they didn't check your</p>	Interpretation, making sense of things Other people

<p>sweets for children, polar opposite from what is want making a big statement</p>	<p>cholesterol or anything blood pressure MR. ANDREWS: no CD: or any of those sort of things MR. ANDREWS: no no its only in er well even with the prostate its only you saying well you've got to go for your she organised it (laugh) MRS. ANDREWS: for about the last ten years</p>	<p>Social acceptability Lack of control</p>
<p>lack of current understanding</p>	<p>CD: its always worth having management isn't it (laugh) MR. ANDREWS: yes MRS. ANDREWS: yes for the last ten years you know I make an appointment every year to go for a prostate thing CD: yeah MRS. ANDREWS: uhm you know whether it does any good or not I don't know but they always check on your blood count so</p>	<p>Decision making ? previously emotional Loss- related to aging Expectations of life</p>
<p>It is a legitimate medication</p>	<p>CD: yes yeah MRS. ANDREWS: but uhm MR. ANDREWS: no better go wise I went I can't remember now and the doctor was around I went for my knee that was it and then he said oh yes oh oh I will put you on statins and that was a couple of years ago wasn't it</p>	<p>"Magic" Risk, timing Risk</p>
<p>Demonstrating my knowledge</p>	<p>MRS. ANDREWS: about four years ago MR. ANDREWS: yeah and I said oh fair enough then because of my age I thought oh right oh then and then I came back and I said well why have I got to take these you know I am ok and then there was a lot of stories about what it did to you so I said no I am not taking them so I didn't bother didn't even get the prescription filled in MRS. ANDREWS: maybe would that have helped the situation MR. ANDREWS: maybe MRS. ANDREWS: you don't know with hindsight do you CD: no MR. ANDREWS: you know cos I've</p>	<p>Identity Risk Knowledge Other people Knowledge Time, context</p>

<p>Personal connection</p>	<p>got cos I've had the heart attack now that I am on statins  CD: yes you are on your  MR. ANDREWS: I am on a statin now on the medication but then what did this actual statin do exactly  CD: yeah as long as you know why people are giving you things  MRS. ANDREWS: yes yes but then you can you know my way of thinking I have never ever liked taking tablets I would rather tell me what my problem is can I get around it without taking tablets tell me what I can do  CD: yeah try the other options first  MRS. ANDREWS: yes cos I mean it wasn't until about three years ago that I started taking blood pressure tablets and I mean he is sixty nine and he is you know he had the heart attack and he hadn't taken tablets up until then and we eat healthily and you know we are out and about sort of thing and uhm you think there's they write a prescription and then you hear about these people who are taking so many tablets of all the different side effects</p>	<p>Knowledge</p>
<p>Didn't tell daughters</p>	<p>CD: yeah and you just end up collecting them rather than cos no-one ever goes through them and says you don't need that anymore or  MRS. ANDREWS: it's so easy just to write out a prescription isn't it  CD: yeah and a lot of people will just routinely take them cos they are given them because they are given them  MR. ANDREWS: oh yes  CD: they won't bother to find out what they are or why they have got them  MRS. ANDREWS: no  CD: won't go to the library or anything  MR. ANDREWS: no the doctor says so that its got to be right because</p>	<p>Managed information giving</p>
<p>Lack of discussion</p>	<p>CD: yeah and you just end up collecting them rather than cos no-one ever goes through them and says you don't need that anymore or  MRS. ANDREWS: it's so easy just to write out a prescription isn't it  CD: yeah and a lot of people will just routinely take them cos they are given them because they are given them  MR. ANDREWS: oh yes  CD: they won't bother to find out what they are or why they have got them  MRS. ANDREWS: no  CD: won't go to the library or anything  MR. ANDREWS: no the doctor says so that its got to be right because</p>	<p>Managed information giving</p>

<p>Want HCP's to be aware</p>	<p>he is the doctor (laugh)  CD: yeah (laugh)  MRS. ANDREWS: it's not always so is it you know  CD: no no exactly and there are so many more drugs these days now you can't expect one person to know everything  MRS. ANDREWS: no no  CD: but at least you know a rationale for why  MRS. ANDREWS: yeah your family doctor you can't expect him to know all the things that you would go to a hospital for and see you know cardiologist</p>	<p>Lack of discussion with people- even closest relatives</p>
<p>Main concern for patient is to have it sorted out and acknowledging the problem</p>	<p>CD: yeah exactly there's all those specialities you can't expect you GP necessarily to pull it all together</p>	
<p>Hidden</p>	<p>MRS. ANDREWS: no so  CD: you would like to think that they would know where to send you for the right thing</p>	
<p>Causes but still questioning of this one</p>	<p>MRS. ANDREWS: well yes yes  MR. ANDREWS: and it's a when I was reading the letter from Dr. G sent to Dr Mayo and I did see one bit and it did say about referring me he said you must know him well he doesn't cos I have never gone there  CD: (laugh)  MR. ANDREWS: I never go to the doctors you know</p>	<p>To act as mental preparation</p>
<p>Causes and understanding</p>	<p>MRS. ANDREWS: I mean he must have a file in the doctors like that  CD: he was just assuming that you  MR. ANDREWS: yeah everyone else's like that  CD: he hadn't read your "very well fit" whatever it was comment  MR. ANDREWS: I just didn't go to the doctor it just wasn't something that</p>	<p>How to change professionals practice</p> <p>Taking positive action</p>
<p>Still not quite believing the evidence</p>	<p>MRS. ANDREWS: no there was no need was there you weren't ill and you know you didn't have problems  MR. ANDREWS: no now its all falling to bits (laugh)  CD: once they have got their hands on you they start finding things all</p>	

<p>Blame/ cause</p>	<p>over the place honestly once they start looking that's the thing I have got myself a check list here because I knew I would forget or go off on a tangent as to what I am supposed to be asking you yes uhm what do you think would help sort of other men to disclose ED because talking to healthcare professionals they say things like oh the environment has got to be right or uhm I only ask some patients some I don't feel comfortable with is it the same for patients do they look at like perhaps lady doctors and think like oh I won't tell her or do they choose a man my own age MR. ANDREWS: more than likely yes uhm it is a man to man thing but you have still got to get over that</p>	<p>Knowledge</p> <p>Knowledge and rationalising</p> <p>Understanding and interpretation</p>
<p>Listening to medical comment Blame</p>	<p>CD: even that is difficult? MR. ANDREWS: you have got to get over that stage you are talking about a rather a personal part of your body which something which is not talked about at all CD: right</p>	
<p>Men don't talk</p>	<p>MR. ANDREWS: you joke and everything else amongst your friends and whatever about your sexual bits and pieces but never pin point and say I have so and so CD: right yeah so even to another man</p>	<p>Rationalising behaviour- ? health beliefs</p>
<p>Women talk and this is beneficial</p>	<p>MR. ANDREWS: yeah its still you have to be a very friends great friends I should imagine to be able to discuss somebody who have been your friends for years and years and years not some just acquaintance or whatever CD: yeah</p>	
<p>Men's' behaviour is stupid! Ignore it</p>	<p>MR. ANDREWS: it's just not CD: it's a conversation stopper rather than a starter isn't it MR. ANDREWS: you know it is a man thing you know</p>	<p>Blind faith in the medical profession</p>
<p>Male behaviour/ rationalisation</p>	<p>CD: right MRS. ANDREWS: I am a failure</p>	

<p>Male behaviour</p>	<p>MR. ANDREWS: well possibly yes  CD: its not like breaking your arm or something is it</p>	<p>Gendered behaviour</p>
<p>Debilitating</p>	<p>MRS. ANDREWS: no  MR. ANDREWS: its an ego its an ego  CD: right its got wider implications</p>	<p>Men v women</p>
<p>Knowing other people have it does not help with disclosure</p>	<p>MR. ANDREWS: yeah it's an ego thing it is oh no I can't do that and as C said you are not a man and you know you can't do it  CD: does it make it when you see things like uhm we went to Hawaii a couple of years ago and on the television over there there were adverts for Viagra and Cialis and things and they have the statistics that you know 60% of men over the age of 60 have ED does that sort of thing help you to think oh actually it is more common or its not just me or</p>	<p>Risk taking</p>
<p>Removed from a group</p>	<p>MR. ANDREWS: yes I read that it is more common but  CD: or is it just such a personal thing you think I don't really care about anybody else</p>	<p>Male identity</p>
<p>You cannot change the behaviour of older people</p>	<p>MR. ANDREWS: well no you know well yes I've got that but and then you might look around like I play with a group of chaps playing golf and you think twenty of you around a table you think well I've got it have any of this lot got it you know cos we are quite friendly and what not but  MRS. ANDREWS: but you wouldn't talk about it  MR. ANDREWS: you wouldn't I wouldn't go up and say have you got ED?  CD: (laugh) yeah just do a straw pole  MR. ANDREWS: they would go WHAT! (laugh) what the you would cause absolute the place would be in uproar you know you know I could see me doing that to some of them (laugh)  CD: (laugh)</p>	<p>Sense of identity  Identity taken  Putting self into context is not helpful</p>
		<p>Language</p>



	<p>MRS. ANDREWS: (laugh)  MR. ANDREWS: and that's it  MRS. ANDREWS: you know it's an ice breaker isn't it! (laugh) go for it  CD: do you think men would be more inclined to tell someone though if they thought to themselves that it is a genuine medical problem that could mark out  MR. ANDREWS: well I would have thought <b>so your own common sense</b> would say well yes well I will get this sorted  CD: yeah  MR. ANDREWS: but hum are they prepared you know because <b>of its that end of your life</b> then it is an age thing  CD: right  MR. ANDREWS: <b>it is something that happens and you have just got to put up with it and what not</b>  CD: right  MR. ANDREWS: you know and then they think of <b>the magic pill</b> and oh we'll go and get that but until <b>they make that step to go and see someone</b> cos you can't I know you say <b>they can buy it on the internet</b> and all the rest it's not as but perhaps maybe that's a bad thing that they can  CD: yeah  MR. ANDREWS: maybe you know how do they say that it's no good because it could be anything it could <b>be smarties</b> for all you know  CD: yes yeah  MR. ANDREWS: but to actually go to the doctor to get to that it's that step  CD: yeah  MRS. ANDREWS: <b>and then they had a bad report didn't they Viagras</b> and things where people were taking them and they were dying <b>having heart attacks</b>  CD: yes  MRS. ANDREWS: and things like</p>	<p>Generational identity</p> <p>Awareness via media</p>
--	--	---



	<p>that</p> <p>MR. ANDREWS: yeah that was because that was people taking t when they didn't know their medical history</p> <p>MRS. ANDREWS: yeah well we know that now</p> <p>MR. ANDREWS: but at the time</p> <p>MRS. ANDREWS: you didn't realise that</p> <p>CD: no</p> <p>MRS. ANDREWS: you know</p> <p>CD: and and it was quite scary I was working in H***** at the time and we had a couple of gents come in you know who had no history of heart disease and all of a sudden they had taken a Viagra and everyone was thinking crickey what is this Viagra doing to them you know they thought the Viagra was literally causing their heart disease but like you say they just didn't know that they had lots of risk factors</p> <p>MR. ANDREWS: now you read about Viagra that for the erection problems it wasn't designed for that it was to do with the heart thing wasn't it</p> <p>CD: yes yeah</p> <p>MR. ANDREWS: things like this</p> <p>CD: yeah and the drug company that designed uhm Viagra were looking for like an anti-anginal medication like a nitrate like the spray that people put under their tongue and they found that all these men were coming back in saying well yeah my angina is alright but you know things have improved (laugh)</p> <p>MR. ANDREWS: (laugh)</p> <p>CD: and they weren't working for a while you know</p> <p>MRS. ANDREWS: yes yeah</p> <p>CD: you know so uhm so then they thought obviously they thought we could make some money out of this because it wasn't a very effective</p>	
--	--	--

	<p>anti-anginal medication anyway  uhm so that was the route they  went down  MR. ANDREWS: it was an off shoot  sort of thing  CD: yeah  MR. ANDREWS: I can see that  there's another bit  CD: yes there's something in it  that's going to it was more unusual  because up to that point there was  nothing in terms of tablets that you  could take  MR. ANDREWS: no  CD: and there was no they didn't  find anything that worked on the  specific receptors in that artery so  yeah the day they realised that they  must have been thinking wow we've  we are millionaires Rodney (laugh)  MR. ANDREWS: (laugh)  MRS. ANDREWS: yes definitely  CD: it's one of those subjects that I  am getting a bit desensitised to it  now you know when you well you  spend all day reading research  articles about erectile dysfunction  and then you go to clinic and you do  your ED clinic you forget how  personal it is you know  MRS. ANDREWS: yes  CD: my poor father god love him  the numbers of times I have sat  there and he has gone good day at  work yeah you wouldn't believe and  he's like oh Catherine (laugh)  MR. ANDREWS: (laugh)  MRS. ANDREWS: sit there Dad let  me ask you some questions (laugh)  oh god  CD: bless him he has had a  prostatectomy so he has you know  kind of had all of this education so  he is like I don't really want to be  you are the last person I want to be  talking to about it you know so even  when you get someone sat in the  room who is you know pretty well  versed in it you don't necessarily  want to speak to them about it</p>	
--	---	--

MRS. ANDREWS: no no when he was going into hospital to have it straightened sort of thing he didn't want me to tell the girls

CD: right

MRS. ANDREWS: and I said we have I said because you know God forbid if anything did go wrong and they are going to wonder

CD: to say what exactly are you doing in the hospital

MRS. ANDREWS: exactly and you know you are there over-night what am I going to say

CD: yes yeah

MRS. ANDREWS: cos they talk to him every day and I said no we have to tell them

CD: yeah

MRS. ANDREWS: so I just said something and that was fine its never been brought up since has it

CD: there is a big generation thing though

MRS. ANDREWS: oh yes

CD: I was reading some research yesterday on uhm patients disclosing to GP's they were talking to the GP's about you know who gets most disclosures in their practice and whatever and the GP's were saying well I am happy talking to patients who are sort of my age maybe a bit younger but I don't really want to talk to the patients who are in their sort of 80's and 90's about it and that's what makes me feel uncomfortable and then the younger GP's were saying oh I don't think I would be wanting to talk to anyone over 50.

MR. ANDREWS: (laugh)

MRS. ANDREWS: (laugh)

CD: I think they put themselves as that bench mark and all of a sudden like ten years maybe was fine but after that good grief people aren't doing it after ten years so young GP's were really thinking that when you got to forty that was the end of

	<p>games yeah</p> <p>MRS. ANDREWS: (laugh)</p> <p>CD: but it shifts as they go along it will shift with their own age (laugh)</p> <p>MR. ANDREWS: we all learn by experience</p> <p>MRS. ANDREWS: well we all have to learn these things everybody yes</p> <p>CD: and I think if it was more kind of especially at medical students learned about it and the other embarrassing maybe sort of things they would be more comfortable talking about it as they go along but even</p> <p>MRS. ANDREWS: yes</p> <p>MR. ANDREWS: yeah well</p> <p>CD: they don't get any sort of formal education or training and then they sort of panic then when someone does say something</p> <p>MR. ANDREWS: yeah but at least you know if they discussed it or they know about it</p> <p>CD: yeah</p> <p>MR. ANDREWS: then if anything happens or somebody says anything then its sort of it'll sort of ring a bell</p> <p>CD: yes</p> <p>MR. ANDREWS: and they'll think oh perhaps oh we can sort it out you know as long as they have got maybe not know a lot about it but know that it is there because obviously years and years and years ago nobody knew anything about it anyway</p> <p>CD: yeah</p> <p>MR. ANDREWS: because it is not a thing that you talk about</p> <p>CD: no</p> <p>MR. ANDREWS: you know we don't know how long its been going on</p> <p>CD: yeah</p> <p>MRS. ANDREWS: or how many people have got it</p> <p>CD: yes these statistics that come up that say you know rest assured you are not unusual but really they</p>	
--	--	--

	<p>are very difficult to establish because a lot</p> <p>MR. ANDREWS: you know they say well</p> <p>CD: a lot of people say well I'm just getting older that's to be expected</p> <p>MRS. ANDREWS: exactly put it down to age</p> <p>MR. ANDREWS: an age thing</p> <p>CD: uhm yeah</p> <p>MRS. ANDREWS: yeah</p> <p>MR. ANDREWS: it's not you know as you as perhaps it's the old furring up of the arteries or whatever kind of</p> <p>CD: which comes you know which comes as you are getting older but it's not necessarily a direct consequence of getting older you know there's people just do assume that you get it</p> <p>MR. ANDREWS: I say not everybody gets it so</p> <p>CD: yes exactly</p> <p>MR. ANDREWS: but the ones who do is it an early warning signal for whatever to do with the way you live, the way you eat</p> <p>MRS. ANDREWS: that's the way they are going at the moment isn't it?</p> <p>CD: yeah</p> <p>MR. ANDREWS: so the way you live, to what you eat what you do and everything else you can see the logic of it whether or no the only thing they have got to do is prove it now</p> <p>CD: yes yeah exactly and trying to prove it by taking out all the other variables is quite difficult but yeah I mean it is something that it's a very powerful tool really isn't it in terms of if someone says to you well if you start sorting out your diet and losing a bit of weight and doing these things you know it's one of the main motivators for men isn't it is even if we say to them your erectile function will improve</p>	
--	---	--

	<p>MRS. ANDREWS: no  CD: no (laugh)  MRS. ANDREWS: no (laugh) I've tried for years  MR. ANDREWS: (laugh)  MRS. ANDREWS: I mean he didn't smoke at home cos he knew I didn't like it  CD: right  MRS. ANDREWS: but he smoked in work he smoked when he went to golf and I used to say to him you know give it up and he was being very sly with it then no I don't smoke  MR. ANDREWS: as we do (laugh)  CD: (laugh)  MRS. ANDREWS: oh yes you do you know and no way would he give it up there was no way he just carried on so  CD: I went to a presentation the other day by one of the uhm cardiologists from Swansea and he reckons that everyone's tablets should be covered in nicotine cos then they would all take their tablets religiously he said it's the only way  MR. ANDREWS: (laugh)  MRS. ANDREWS: yeah  CD: completely on their drug regime because if they crave nicotine then they will  MRS. ANDREWS: because they poo pooped the subject now its nothing to do with cigarettes now it's not that that's causing it well it could be a furring up it could be this that no so of course this is how he ends up now but its I definitely think and you know they have said yes it can be a factor  CD: yeah as can multiple things but also the other thing is that all the research on genetics and whether things are related to family history we are never going to really know if ED is you know back in your family because who the heck is going to ask the previous generation (laugh)</p>	
--	--	--

	<p>MRS. ANDREWS: (laugh) exactly  no no one will ever ask their father  CD: exactly and your kids aren't  going to ask you  MR. ANDREWS: have you got  problems Dad (laugh)  CD: yeah no exactly its not  something that research ain't ever  going to get done is it  MRS. ANDREWS: its so much  easier being a woman because we  are so much more open  CD: yeah  MR. ANDREWS (laugh)  MRS. ANDREWS: cos that's how  we are with everything aren't we  CD: yeah and if you've got a little  worry you say to someone have you  ever had  MRS. ANDREWS: yes exactly you  talk about it and you know you are  straight to the doctors  CD: yeah  MRS. ANDREWS: you find a lump  then you go to the doctors men find  a lump and they leave it and you  think how stupid are you? Well  CD: yeah men (laugh)  MR. ANDREWS: it's a man thing  isn't it its well  MRS. ANDREWS: its not good  MR. ANDREWS: it's a mental thing  you have got to get over that's you  know I am the man  CD: yeah there is a lot of you know  I'm in control I'm  MR. ANDREWS: it doesn't happen  to me its fine  MRS. ANDREWS: it becomes  arrogant in the end doesn't it you  know  CD: I suppose once you have said it  once I am fine you kind of then get  yourself into more of a trench then  don't you I AM absolutely fine I  really am fine I am fine  MRS. ANDREWS: yeah  MR. ANDREWS: until it goes wack  and you are down and then that's it  but there we are that's just blokes</p>	
--	--	--

	<p>really isn't it</p> <p>CD: yeah I don't think we are going to change blokes as a whole are we</p> <p>MR. ANDREWS: no</p> <p>MRS. ANDREWS: no</p> <p>MR. ANDREWS: as I say as long as with the ED as long as the more people know about it not that they are going to do anything about it but</p> <p>CD: and they don't have to put their hand up and go yeah I've got it do they but</p> <p>MR. ANDREWS: it's just to think it's worth going to get it checked out</p> <p>MRS. ANDREWS: so maybe when you go to the golf club now tomorrow you need to talk about it (laugh) and say boys I've got something to ask you</p> <p>CD: that'll be your membership card ripped up (laugh)</p> <p>MR. ANDREWS: (laugh) banned from the club house</p> <p>MRS. ANDREWS: has anybody got this problem</p> <p>CD: cos there is that programme on the television isn't there embarrassing bodies have you seen that one</p> <p>MRS. ANDREWS: yes</p> <p>CD: that one amazes me that people they get on there describing all sorts</p> <p>MRS. ANDREWS: and what they show as well</p> <p>CD: yes</p> <p>MRS. ANDREWS: yes</p> <p>CD: yeah they were out in the some high street somewhere in the North of England shouting has anyone got ED and I just thought as if anybody is going to stand in Queen Street and say yeah yeah</p> <p>MRS. ANDREWS: but men were coming forward for certain things and they were showing certain bits as well and you know mostly the younger ones though not your older generation the younger ones</p> <p>MR. ANDREWS: no its entrenched</p>	
--	---	--



	<p>isn't it now young is more receptive  and more I would say open to more  information and everything else and  all that  CD: right yeah  MR. ANDREWS: there was one  when they had all the rugby team  sat there you know how to check  yourself because nobody  CD: nobody would  MR. ANDREWS: they didn't know  how to  CD: yeah  MR. ANDREWS: and why and then  they eventually they did and I think  they were one or two they had to  check out  CD: oh gosh  MR. ANDREWS: for some reason  but they were ok looking for the  lumps  MRS. ANDREWS: and they did  blood tests on them as well to see  whether they had picked up any  diseases because of you know not  using anything and no it was very  good there were about ten of them  yeah really good  MR. ANDREWS: yeah they were  prepared to go and you know they  were sat there with the towels  around them  CD: can you imagine though on the  telly, I saw you on the telly last night  oh really (laugh)  MR. ANDREWS: (laugh) they had  some firemen as well doing it as  well so it was up another age group  so they had them on as well same  thing because blokes just don't do  that until they get a kick in it or  whatever and then they think about  it  CD: yeah they just ignore it don't  they up to that point yeah  MR. ANDREWS: yeah  MRS. ANDREWS: hoping it will go  away  CD: yeah miraculously  MRS. ANDREWS: yes</p>	
--	---	--

	<p>CD: right well that's brilliant thank you very much for my coffee MRS. ANDREWS: oh you are welcome CD: that's lovely excellent</p> <p>Thirty one minutes and forty seven seconds</p>	
--	---	--

Themes:

**Funnelling:**

Reducing tension

Power/ status

Participant closing down discussions

Me managing difficult statement- changing subject

Connection ie putting me in to context

**How life changes with age:**

Language- negative and medical

Previous self (MI was life changing)

Current self (impact of age)

**ED and what it means personally:**

Language- "it" euphemism

Shared understanding

Maleness

Sense of self "alone"- not discussed with other people

Context- determines level of importance

Acceptance ? contradicting thoughts

**ED and what it means in terms of disclosure:**

Language- need for medical language

Shared understanding

Knowledge of treatment Mr. Andrews causes required in advance-looking for a medical cause

Description of disclosures- highlights risk

Delay from onset to disclosure

Personal feelings after disclosure

Trust in HCP- stronger in relation to MI than ED

## Appendix Thirteen

### Themes

#### What does erectile dysfunction mean personally

##### Mr. Andrews

<b>This is a very personal issue</b>
<b>ED impacts on your male identity</b>
<b>You would not choose to discuss ED with your friends, it affects you alone, “taboo subject”</b>
<b>The context of your life determines whether you will be motivated to seek help</b>
<b>Contradictions in relation to acceptance or degree of bother</b>
<b>Disclosing is not always helpful and effects can be long lasting</b>

##### Mr. Collins

<b>Contradicting of degree of bother, accepting and fatalistic “at my age, I am 58 now well OK” but seeking help</b>
<b>It is embarrassing</b>
<b>Unable to connect with media images of people older than himself, wants more positive images of sexual health problems</b>
<b>“Yes it is hard because it is a man thing isn’t it you know that is what boys talk about from that age up and then your prowess has ended for Christ sake””</b>

##### Mr. Bridges

<b>Due to personal circumstances he has no need to seek help</b>
<b>Having unsuccessful sex was the “lowest moment of his life”</b>
<b>Feels alone and isolated, when compared to previous “riotous” sex life</b>
<b>Felt a connection with the DVD</b>

##### Mr. Davies

<b>The current situation he describes as “surviving”</b>
<b>A sense of hope that there may be a treatment</b>
<b>With age, things which used to facilitate sex have come to hinder it</b>
<b>“is it just me?”</b>
<b>Would now talk to friends because he has the knowledge that ED and CVD are linked</b>
<b>“I do feel that I should still be functional”</b>

**Mr. Evans**

<b>Sex is not purely a physical thing “it’s a mental thing”</b>
<b>“It is not a manly thing to talk about because you lose your manhood”</b>
<b>“frustrating”</b>
<b>Has an effect on his wife “my wife was taking it a bit personal was well like”</b>
<b>“It is not a very nice thing to cope with”</b>
<b>“I stopped functioning”</b>
<b>“I virtually accepted the fact because there is no point discussing it really”</b>
<b>“my wife was taking it a bit personal like as well which, it was nothing to do with her really but I knew the problem was with me like”</b>

**Mr. Franks**

<b>Did not seek help because he found ED embarrassing and was scared</b>
<b>He cannot talk to his wife</b>
<b>Knowing that other Asian men can talk about ED he now does not feel as embarrassed</b>

**Mr. Groves**

<b>Did not talk about ED being related to him “men won’t admit they have got a problem”</b>
---

**Did not feel a connection with the DVD so thought it was a “waste of time”**

**“all men want sex and think about it a lot”**

**Mr. Hobbs**

**Rather accepting, “it’s natural”, “older men are not that bothered”**

**To be expected at his age (72)**

**Not seeking help as it is not a significant issue- motivated to take part to pay back the healthcare professionals**

**“it is not a great part of my life now really” “”it affects men differently at my age now, if I was 29 it would be different”**

**Mr. Innes**

**Has made several attempts to seek help, but has now given up seeking help**

**Loss – “those days have gone”**

**Sex is natural**

## Disclosures

### Mr. Andrews

<b>Has disclosed ED to several healthcare professionals</b>
<b>Has sought information privately prior to disclosing</b>
<b>Sought help following discussion with wife</b>
<b>Delay from onset of ED to first disclosure</b>
<b>Disclosures have not resulted in satisfactory answers</b>
<b>Would rather disclose to a man "it is a man to man thing"</b>

### Mr. Collins

<b>Has disclosed ED to a practice nurse who asked about "erectiles"</b>
<b>Would need to be asked and this would not cause offence</b>
<b>Needs to feel a connection with any materials used as information ie DVD</b>
<b>Would talk to a healthcare professional, based on the individual rather than gender or age although would be disinclined to pick up a Viagra prescription from a "pretty young girl" at the pharmacy</b>
<b>Has sought information on the internet "privately" before disclosing</b>
<b>Was critical of a doctor who prescribed Viagra but never revisited the subject to assess its use and so its failure has never been addressed</b>

### Mr. Bridges

<b>Has not disclosed ED because of personal circumstances</b>
<b>Would only disclose to a healthcare professional</b>
<b>Disclosure may be a threat to sense of self</b>

### Mr. Davies

<b>Has never disclosed ED to anyone</b>
<b>Sought information during the interview</b>
<b>Has not sought help before because of home life, age and "having no-one to</b>

<b>practice with”</b>
<b>Decided to be interviewed because of like with CVD, that is “when I turned”</b>
<b>Would talk to his GP, but this would be as an aside “I’ll try and have a word”</b>
<b>Age and gender of healthcare professional not an issue but “would not buy condoms from a young girl in the chemist”</b>
<b>Sense of self has changed with age therefore more likely to disclose and talk about sex at his current age than before</b>

**Mr. Evans**

<b>Has spoken to GP once but did not find the conversation useful “didn’t have much joy”</b>
<b>Does not trust the GP</b>
<b>Has taken alternative remedies which were more successful</b>
<b>“you can’t talk to my wife very much on that subject like”</b>
<b>“who is this person going to share my business with”</b>

**Mr. Franks**

<b>Had not disclosed ED to any healthcare professionals but having watched the DVD feels that he now would</b>
<b>Had not previously disclosed because of embarrassment, which was due to culture</b>

**Mr. Groves**

<b>Has not disclosed ED to a healthcare professional</b>
<b>Feels he can talk to any healthcare professionals, leaving his pride at the door of the hospital</b>
<b>Would prefer to talk to a man</b>

**Mr. Hobbs**

<b>Had not disclosed ED</b>
-----------------------------



**Had attributed ED to age, “natural aging”, a lack of bother and because he was unaware that it was a marker of cardiovascular disease**

**Sexual intercourse is not a “significant issue” in his life**

**Mr. Innes**

**Had made several disclosures over the years**

**Had been met with pitiful comments “I am sorry”**

**Has not liked the treatment options given to him, cost spontaneity etc**

### **What does society think about sex**

#### **Mr. Andrews**

People do not talk about sex

"The whole place (the golf club) would be in uproar if I broached the subject"

#### **Mr. Collins**

Other people may lie when asked about ED

Society needs to "open up" the subject

People will take risks when taking illicit and prescribed drugs, an indication of the hidden nature of the problem

People expect with age that they will have less of a sex life

"men" would like to have sex with a younger woman

Generations do not talk to each other about sex

Society would benefit from more positive images of men with ED

#### **Mr. Bridges**

Society's acceptability of sex changes with time

Erectile dysfunction remains a secret

Society behaves in particular ways because of embarrassment

Men think about sex a lot

People expect their sex lives to change with increasing age

#### **Mr. Davies**

Other people seek illicit treatment in the pub and toilets "oh I have had offers, if you are getting into trouble take these"

The media portray this as a problem of people older than himself

People do not normally talk about sexual problems

**Mr. Evans**

“now I mean today you can talk about virtually anything”

“it depends on the generation you were brought up in”

“oh yeah a man can do it if he has got a young woman”

“bring it up in a conversation? Most men are not inclined to do that I don’t think no”

“they can make your life hell”

**Mr. Franks**

In his culture sex is not talked about, between people of the same generation and people from different generations

Sex is powerful and can significantly influence people’s behaviour

People in other cultures find it easier to talk about sex

**Mr. Groves**

Men giggle like boys when they are in a group talking about sex

All men want sex and think about it a lot

Men won’t admit they have a problem

**Mr. Hobbs**

If people knew that ED was related to CVD they would be “a fool not to go” to get help

“yeah that’s what they (men) do its jokey jokes about the place”

“it affects men differently, the degree that they are worried about it, doesn’t really I mean at my age now if I was 29 it would be”

**Mr. Innes**

Aware of public health campaigns
----------------------------------

Rationalising of provision of services, ED should be prioritised to the younger men
---

Society does accept light hearted discussion, because sex is natural
--

## Language

### **Mr. Andrews**

Lots of medical language "peyronies disease" "Nesbitts procedure"
Colloquial language in relation to ED "it" "brewers droop" "a rather personal part of your body"
Negative language to describe having erectile dysfunction "you are not a man and you can't do it" "it goes wack and you are down"

### **Mr. Collins**

Fatalistic use of language "once it has come upon you" "it has just gone gradually down since that"
The use of "it" - "who specialises in it"
"Your prowess has ended"
"my doctor the one I generally see he said everything OK and we'll have a chat about your legs hurting everything else OK yeah fine Al yeah and you know it's been 12 years and not mentioned that"

### **Mr. Bridges**

Very open language "riotous sex life", "wank", "sordid details", "masterbates"
Did check what I was willing to hear

### **Mr. Davies**

Lots of euphemism and humour, to try and avoid answering a question he said "excuse me I have just got a couple of phone calls I have got to make no sorry I am only joking"
Loss- "now you have had your good times"
In describing his sex life he said "things weren't completely right, to put it like that"
"getting into trouble"

Euphemism- "it's time to stop and put your key in your pocket"

"I do work it's just other things that don't work" "I am collapsing now"

### Mr. Evans

Negative language about ED "didn't have much joy", "zilch", "no point", "frustrated", "it has taken its toll"

"it" used a lot

"the opportunity has arose now" to talk about ED

"didn't have the energy and strength to carry on"

### Mr. Franks

Very negative language "flops", "wrong" "deal with it"

The use of "it" a lot

Sex is not talked about it is "hush hush"

Has to have a "sneaky watch"

### Mr. Groves

Language changes through the interview, becoming more euphemistic and less formal- love life "down the drain" "reared its ugly head"- euphemism

Indirect language "we done what we done" ie having sexual intercourse

Direct language "to watch porn"

### Mr. Hobbs

Positive in relation to hospital care for MI "glad to be here"

In relation to ED more negative "trying to control the demise"

Language was stunted because of the shared understanding, which limited the flow

### Mr. Innes

Language becomes more colloquial during the interview

Used direct language describing himself as “impotent” and euphemism “those days are gone”

Rehabilitation talk was socially acceptable “a light hearted discussion”

Healthcare professionals

Professional self

Rebecca (interview 2)
Lots of training and cardiac experience over 15 years but none related to erectile dysfunction
Did not want to build into clinical practice routinely asking about ED
Did not think that professional colleagues would want to know about ED

Jeremy (interview 4)
Professional self not discussed in terms of training- shared understanding
Men do not disclose because of his professional role
Happier to discuss in terms of research “clinical phenomenon”
Is it rehab’s job?

Alison (interview 6)
Experienced cardiac nurse who had undertaken much education and was seeking education in ED
Runs her own clinic where the patients will inevitably have a high risk of ED
Uses her personal self to justify her professional actions throughout the interview
Has built in a routine to ask as many men as she feels comfortable doing
Her comfort seems to be routed in her personal self

Anna (interview 8)
Has undertaken lots of post-registration training but has never had any related to erectile dysfunction.
When she does receive a disclosure “I don’t tend to go into more information than we have a clinic”
Seems to believe that other members of her team (cardiac rehabilitation) receive more



disclosures “on a personal level I wouldn’t say that frequently”

Uses professional judgement “you have go with how they are a bit haven’t you”

Angie (interview 11)

Lots of funnelling and discussion around professional qualifications, or lack of. Lots of cardiac experience.

When taking one particular clinic Angie has a tick box pathway which has ED on it and she feels professional pressure to complete this element “you have to ask the question because it’s on the piece of paper and there is a tick”

Angie commented on the BHF video which she uses as part of the cardiac rehabilitation course “nothing no just a crappy two minutes, have you seen the BHF video the sex one? The nurse she really puts you off, there is a pump on the table, honestly it is terrible”, this seems to cause her some professional embarrassment.

She worries about how to talk about ED “you are not sure what you are going to say, as a nurse you are going to be a bit scientific”, “you could really tread on someone’s personal life couldn’t you”

Angie does not like this part of her job “I have got to be honest haven’t I, I think I would rather them not ask me, I am pushing that it is nothing to do with me aren’t I in a way

Ceri (interview 15)

Ceri works in a long term monitoring clinic and felt that patients would disclose to her because they had built up a relationship.

Disclosures are rare

Ceri uses a questionnaire to monitor symptoms and feels this is a way of opening up this conversation “I just say oh you know you have left this bit blank, is there any particular reason”

Ceri says that she does not directly ask “but have never directly asked the question, we should I suppose”

Thomas (interview 18)

Thomas did not ask about ED but understood the link between cardiovascular disease and ED. He described why he did not ask “you are under time pressure and do you want to open that can of worms”, he went to explain that he did not ask because “it’s

slightly embarrassing so it is not something I would actively seek out”
He felt that his role prevented men from telling him but understood why some men may choose to tell him “I am the heart doctor who started the pills but I suspect far more discuss it with their GP, hospital doctors are probably less approachable than GP’s”
He felt that patients and healthcare professionals would be limited by embarrassment “the patient is too embarrassed, the doctor is too embarrassed or the doctor is just too busy”

Steve (interview 20)
Steve does not ask about erectile dysfunction, although he knew of the link “we don’t actively pursue it as a symptom”
The Minnesota quality of life tool gives an indication of whether there are issue, however sometimes “they leave it blank or they sort of homogenise it”

Sian (interview 26)
Sian believes that her male colleagues probably have more disclosures than she does and describes ED as “it’s not my little area”
The infrequency of disclosures makes her feel unsure in treating ED “so you feel you are not as competent on it because you just don’t see the patients really”
The information in the practice waiting area is kept to a minimum to prevent cross infection
During her medical training ED was not addressed “it’s not something in medical school, if someone has IHD think ED”

Experience of Disclosure

Rebecca (interview 2)
One experience in whole career, disclosure initiated by wife of patient
Had asked for some detail, but not “in detail” from the patient in order to make the referral
Had referred on to ED clinic

Jeremy (interview 4)
Very little because of position
Despite understanding of evidence does not ask
Has a fear of being misinterpreted
"it needs to be taken seriously, it needs to be dealt with"
You have to be careful how you ask
Contradictions in relation to asking and evidence
Language "it" and medical language
"I would see erectile dysfunction as a medical term"

Alison (interview 6)
Asks as a matter of course therefore recalls many more disclosures
Recognises barriers (culture, age, relatives)
Uses a rehearsed patter although has not had any training
Leaves patients with contact details, should they change their minds
Acknowledges that people "psych themselves up" to disclosing

Anna (interview 8)
Feels that people do not disclose frequently
Patients have asked and are seeking a treatment "some patients ask in uhm you know saying that they have got problems and if there is anything available"
Does not seek disclosures but refers on if she does receive a disclosure
Has identified situations where she would not ask "I don't tend to say if they are older blokes (laugh) which is probably a bit bad" "if someone is widowed I never know whether to talk about it or not"
Has identified a change in herself which helps "it is not so bad now I am older but the younger girls"

Angie (interview 11)
----------------------

Angie feels that barriers to disclosure are confidentiality (environment) and other people being within ear shot. She described a scenario where several assessments were taking place in one room and she witnessed one man, as he worked his way around several professionals in the room to be assessed, having to tell each one what the prescription for sildenafil was.

Angie had a bad experience where she was in a patients home and his discussion about his sex life made her feel very uncomfortable “they are just testing you out sometimes, I couldn’t get out fast enough, horrible man”

Angie also used her own thoughts and experience to influence her thoughts “my mum and dad would fall off their chair if someone mentioned it”

“it’s embarrassment on both sides, the nurse and the patient”

Ceri (interview 15)

Disclosures have always come from a married couple in the room together, never the man on his own and always where they have know Ceri for some time.

Humour is used “they make a bit of a joke about it”

Ceri believes it is important to revisit symptoms “if they had oedematous legs, are you taking your diuretics? So why shouldn’t you if it has been highlighted?”

Ceri reflected on her own behaviour and feels that she is getting to be more comfortable with disclosures “I have become quite aware of how I am, I sort of try and oh well it is a normal function, the first few times I sort of just documented and trying not to and that’s wrong, I shouldn’t have done that in that way”

Thomas (interview 18)

People who have started a conversation with him have been “slightly embarrassed you can tell from the body language”

Thomas used his own thoughts to rationalise who men might prefer to talk to about ED “I have got a very old senior GP, I could probably tell her anything”

His thoughts on the treatments available were quite negative describing them as “pretty horrific”

He also expressed negative opinions of men who he considered to be too old to be having sex “randy eighty year old”

He talked about people’s language “normal people use some kind of euphemism and I find myself using slightly bizarre euphemisms”

Steve (interview 20)

One experience of having a patient disclose peyronies disease “scarred me quite considerably”

Disclosure is very rare

Sian (interview 26)

Sian did not use herself or her personal life to rationalise her practice but she did identify that as a relatively young female GP she may not be the doctor that men would choose to talk to

Sian felt that the disclosures she had received came from men who she had known for a while and who may have initially described another symptom “they are sussing you out first and getting the courage to talk to you”

When she has asked or been asked about ED she believes that language is important “so quite direct, no farting around otherwise they don’t know what you are talking about”

## **Appendix Fourteen**

### **Idiographic Experience**

#### **Interview Nine**

##### **Who**

Mr. Andrews was a sixty nine year old man who had, until recently worked as an electrician, he was married and his two grown-up children lived nearby in a suburban, middle class area of the city. He had originally arranged to be interviewed within the university but had cancelled the appointment and had rearranged, inviting me to his house. He had been recruited via the cardiac rehabilitation team and had, at the time of the interview, completed the six week course.

##### **How did the interview go**

Mrs Andrews was present during the interview and she contributed to the conversation. The reflective diary taken at the time described how her presence was “nice” and “contributed to the discussion”. I did note that “the patient’s wife was trying not to say too much or speak for her husband”. However from the transcript it become apparent that Mr and Mrs Andrews had clearly engaged in a dialogue about Mr Andrews erectile dysfunction and that they were telling me what they, as a dyad, believed. A similar dynamic was only present in the interview with Mr Groves and his wife, all other participants being interviewed on their own.

This was the first interview that I had undertaken with a man with erectile dysfunction, I recognise within the reflective diary that I was “apprehensive” and I may have made a more proficient attempt of interviewing a dyad if I had more experience before undertaking this interview. Assisting the man to think about the topic is complex enough, without managing the complexity when the wife is also present.

Reviewing the interview transcript it become clear that there was an element of funnelling on my behalf, discussion about where to place the recorder and emphasising the importance of the participants’ voice over my own were all used to lead the participants into the discussion. This funnelling differed from most of the other interviews by using very little discussion of the previous experience of the heart attack, and although Mr Andrews did refer to the myocardial infarction his discussion of the incident was minimal in comparison to the other men.

### **What points were made**

Mr Andrews had made several attempts to seek help from healthcare professionals for his erectile dysfunction. His general sense over the issue was one of despondency and a lack of any hope. Originally he had approached the General Practitioner who he remembers telling him “oh it’s a bit of trauma and basically hard luck”. This meeting had been several years ago and Mr Andrews was still upset at this response.

Subsequently Mr Andrews had approached another healthcare professional because he was “fed up with waiting” and he was then who referred for surgery to address a fibrous plaque within his penis. Having undergone surgery Mr Andrews was the only participant who had received any invasive treatment to his penis, but this did not address his erectile dysfunction and he seemed upset that he still experienced problems with his erections.

### **What were the main issues**

Mr Andrews and his wife discussed his previous attempts to seek help or answers from healthcare professionals. The impact of these discussions was evident in the dismissive language used by Mr Andrews, particularly “well that was a waste of time”.

Mr Andrews described the effect of erectile dysfunction on himself as a “falling to bits” and the reflective diary describes how “at one point we were discussing what stops men from discussing ED and Mr Andrews described a problem that is “right there”, putting a clenched fist to his chest, indicating his heart or at the centre of his being”.

### **Golden Nuggets**

Mr Andrews had discussed his erectile dysfunction and his Peyronies disease (the fibrous plaque), with several healthcare professionals over the years. Although other participants had also disclosed erectile dysfunction to healthcare professionals Mr Andrews had been the most persistent in seeking answers, when he felt he had waited for too long, or was not happy with the response from a professional he sought answers with others or from other sources such as the newspapers, the library and the internet.

### **Reflecting back how did the interview go**

Reflecting back on the interview, it is clear that the depth of questioning and resultant thinking by the participants was limited, probably due to a lack of experience on my part. Mr Andrews remains, despite a considerable time span, negative about some of the interactions he has had with healthcare professionals in relation to discussing erectile dysfunction. This was juxtaposed with his trusting discussion around the treatment of his heart

condition, he takes the medication he is prescribed to minimise the risk of having another heart attack and did not discuss any negative interactions with healthcare professionals in relation to this health concern.



## **Interview Thirteen**

### **Who**

Mr Collins was a fifty eight year old gentleman who was interviewed in his home, on his own. He was married with two grown up children and worked as a managing director of a company, describing himself as “I sit down most of the day, I used to go out a lot but I don’t do that anymore lots of other people do that for me”. Despite this statement about his lack of activity he had completed the cardiac rehabilitation course and was actively trying to keep up some activity in the gym.

### **How did the interview go**

The interview was very relaxed, taking place in Mr Collins’ living room. During the interview there were interruptions from the dogs, which were in the room with us and the gardener who was working outside. These interruptions did not seem to bother Mr Collins and the conversation quickly returned to the topic that we had been focusing on.

This interview did have a significant amount of funnelling and there were four pages of dialogue which focused on Mr. Collins’ previous medical history and his relatively recent myocardial infarction. He was keen to demonstrate his surprise at this event “I collapsed in work, just collapsed like that, didn’t feel any pain whatsoever I just went down. Came home in the afternoon, went to bed for a few hours, went out. Came back home and said I am going to bed now and Mrs Collins came twenty minutes later or so. She said I was looking straight through her, rather than at her and a bit incoherent in my speech, so she called the paramedics and was told then after blood tests that I had a heart attack.” Mr Collins regularly attended clinics to monitor his diabetes and was aware that he was at greater risk of atherosclerotic disease, but he was still not anticipated the situation.

### **What points were made**

Mr. Collins discussed how he had been asked by the nurse at his general practice about his “erectiles” and how this question had not offended him in any way. This was the first time he had been asked in a healthcare setting other than the diabetic clinic and again, he seemed surprised at this. “you know what, for the first time last week, when I went to the not to the clinic with the health practitioner who sees me now, because it has only been the last 3 or 4 years that I do a yearly health check at my GP. She put it as a side issue as part of my examination, we were doing blood pressure and all this chit chat and she said, as part of this now I have got to ask you how is your erectiles or ED, yeah she said ED I am sure she did”.

When Mr Collins was talking about whom else he may have a discussion with about sexual problems he said he would not speak to his older sisters, or his children “because they would be horrified if they thought their parents were having sex”, he had however spoken to a close friend, which was unusual within this group of men.

Age and culture did appear to influence Mr Collins’ thinking in relation to the topic in several ways. He was particularly overt in his views of the image portrayed of men with ED in the media and he had particular issues with the characterisations used within the educational video used by the cardiac rehabilitation team. “the DVD annoyed me to be honest, now this is not an ethnic thing, they had an Asian couple on there, which is fine, I am not prejudice, but these guys can’t speak English, and the subtitles come up and I felt affronted, I felt there is enough people out there they could have chosen.... that annoyed me a bit uhm education wise yes it opens it up but what it did also (laugh) again and I know it does affect a lot of people this, is stigma, it affects people of age, it is a stigma and you will probably tell me different and I am sure that this is the case that a lot of people are a lot younger than me probably still have the same problem, but this DVD had old people, sorry. I know my kids think it is disgusting that they found that their mother and I were still having sex, but so that DVD did give you that impression. It is outdated. If you look at any advert on the web they are young couples.... it gives you that sort of feel good factor”.

### **Reflecting back how did the interview go**

Reflecting back on this interview I felt that this was a very open discussion and that Mr Collins had given the points that he wanted to make quite considerable consideration. Reading the transcripts there is a significant amount of funnelling on my part, but this was only the second interview that I had conducted and it did result in Mr Collins feeling able to provide his thoughts, even when he may have thought them to be “politically incorrect”. After the interview Mr Collins phoned to tell me that he had given the topic further thought and that he would be uncomfortable collecting a prescription for Viagra from the chemist if the assistant was a young, pretty girl. The fact that he had continued to think about our discussion and had taken the time to contact me again, made me think that the interview had gone well.

## **Interview Fourteen**

### **Who**

Mr Bridges was a sixty eight year old man who had worked as a social worker. He lived with his wife, who had also worked in a similar role and this was his second marriage. On the telephone when we were arranging a date for the interview he explained that his wife would be present and in response to me explaining that he could have whoever he wished present, he explained that he wanted to make sure that I felt comfortable, because I was visiting their home and he had professional experience of being in people's homes. Mr Bridges was, at the time of the interview half way through his cardiac rehabilitation course.

### **How did the interview go**

Mr Bridges' wife was at home when we conducted the interview, but Mr Bridges told me that she was upstairs having a lie in and "reading the guardian". During the interview Mr Bridges told me about his wife's current state of health, she was receiving treatment for a female cancer. Mr Bridges was the only carer for his wife and this obviously provided important context for some of his later discussion.

Mr Bridges was exceptionally open in his discussion, his use of language was highlighted as direct and during the discussion I asked him about whether he felt embarrassment whilst having this discussion. When this was put to him he thought that he would only have such discussions with a healthcare professional and that this was probably as a result of his previous profession where he had "been right up against life in the raw".

This was the second interview that I had conducted and on reviewing the transcript it would appear that there was more discussion from the participant than myself, a change from the previous interview. This may have been related to my previous reflection or it may have been because of Mr Bridges confidence and willingness to talk. On reviewing the transcript there were only twelve lines of funnelling discussion prior to starting to talk about the sex DVD in the cardiac rehabilitation class.

### **What were the main issues**

All of Mr Bridges' discussion and rationalisations about his own sex life were contextualised with discussion of his wife's current state of health and this was clearly an emotional topic for him. At one point he said "I thought this was the lowest moment of my life, I am making love to my cancer ridden bald wife". His current role as her carer and the impact of her current health condition were unique to his story and illustrated how the health of the man may not be the only factor which influences the priority they afford their own sex life.

Mr Bridges was disinclined to consider any other cause for his erectile dysfunction other than the beta-blocker that he had been prescribed when he had been admitted to hospital. He had considered himself fit and was categorical in his belief that the beta-blockers had caused his problems with erections. He had not sought information from any sources other than healthcare professionals and the information leaflets which came with the medication

### **Reflecting back how did the interview go**

This interview felt easier from my perspective and I think that was because Mr Bridges had worked in healthcare and therefore from the outset there was a shared understanding about what and how it was appropriate to talk about the subject. That said Mr Bridges did check with me during the interview what it was appropriate to tell me and what level of detail I was requiring.

## **Interview Seventeen**

### **Who**

Mr Davies was a gentleman who did not give me his actual age, but told me he was in his late sixties. He had worked as an electrician and had in fact worked within the clinical setting that we were in, when it was being built. Mr Davies agreed to be interviewed within the hospital outpatient department, following his out-patient appointment. Mr Davies was married with grown up children, one of whom was still living at home. This was the first time Mr Davies had disclosed erectile dysfunction to a healthcare professional and this accompanied with the setting and following his clinic appointment may have resulted in this interview looking more like a consultation than an unstructured interview.

### **How did the interview go**

This interview was quite short although Mr Davies appeared very honest and happy to answer any questions. There was not much funnelling and Mr Davies seemed less comfortable, in the early stages of the interview, talking about his recent heart attack. He was keen to put it behind him “one it is gone it is gone for me”. Once we had talked about erectile dysfunction he returned to talking about his heart attack, and seemed more relaxed in doing so, knowing that the discussion of his sexual health was over.

### **What points were made**

Mr Davies had not disclosed erectile dysfunction to a healthcare professional before. This seemed to be heavily influenced by the context of his love life, describing his home life as “the wife and myself now, we don’t live a sort of life together now completely, so that’s all gone now”. This lack of intimacy was cited as the main reason that he had not sought help, but when he had received the recruitment information he describes it as “that’s what made me turn”, and therefore arrange an interview. During the interview it became obvious that this “turn” was a decision to seek help and Mr Davies sought reassurance and signposting from me as to who he should speak to about his erectile dysfunction.

Mr Davies used a lot of humour and at times diverted the conversation away from the topic, momentarily when he did not feel comfortable. This use of language was similar to the other men, but at times more obvious, for example when we began to talk about the onset of erectile dysfunction he said “uhm I have got a couple of phone calls to make (laugh)” and then he immediately brought the conversation back with “sorry about that, no uhm, I don’t know really I think probably slowly”.

### **Reflecting back how did the interview go**

Reflecting upon this interview it was clear that Mr Davies was motivated to take part in the study so that he could gain some information in relation to his condition. He had not previously sought help and therefore his thoughts and rationalisations in relation to the barriers to disclosure were very real and current for him. This interview was relatively short, however it provided information from the perspective of someone having such a conversation for the first time and the fears, concerns and coping mechanisms expressed during the interview.

## **Interview Twenty Two**

### **Who**

Mr Evans was a retired painter and decorator in his 70's who was interviewed in the out-patient department of the hospital after a follow-up appointment. He lived with his wife of fifty years and one of their adult children. Mr Evans came to the interview and his hospital appointment alone. At the time of the interview he had completed the cardiac rehabilitation course and he was continuing to go to the local leisure centre.

### **How did the interview go**

The interview seemed at the time to be brief, but on looking at the transcript it took 21 minutes, not dissimilar to the other interviews, the conversation seemed to flow more easily than in previous interviews. There was far less funnelling in this interview and Mr Evans was the only participant who initiated the conversation about erectile dysfunction. He said

"I had a heart attack in March uhm did a bit of rehab, they uhm they used to give us lectures prior to us going to the gym, right one of the lectures that came up was about erectile dysfunction like, relationships er they said do you want to purse it like, take it further ... and basically the opportunity have arose now".

Mr Evans discussion of his heart attack was minimal early on in the interview, which was opposed to the other men who had initially discussed their heart attack, however having moved on from the discussion quickly, it was returned to later in the interview.

### **What points were made**

Mr Evans was keen to discuss his concerns over confidentiality and before the interview began he asked who would have access to the data. This issue was discussed again, within the interview when we talked about who he might feel he could disclose erectile dysfunction to and he replied

"I suppose it depends on the person you are doing the interview with, who are you going to talk to like, you know, I think one of the main things with me is who is that person going to discuss my business with"

Mr Evans was the only man to identify confidentiality as a particular issue of concern.

### **What were the main issues**

Mr Evans had disclosed erectile dysfunction to his General Practitioner and did not feel that this had been a helpful experience

“so basically like I said he put me on a course of tablets like I say having nobody to work it out with I suppose I didn’t really give it much of a chance, nothing was happening like anyway”, and chance he described himself as having “stopped going there” (the General Practice).

Despite this Mr Evans sought alternative help from a Chinese therapist, which he believed

“out of all of them they did me more good than the ones prescribed by the doctor”

He was the only participant who disclosed the use of any alternative therapies and was happy to report their success.

The initial discussions before the interview took place about issues of confidentiality did concern me, however with the reassurances that were documented within the project information leaflet it would seem that Mr Evans was happy to talk and in my reflective diary I describe the discussion as “very open”. Mr Evans’ motivation to participate seemingly stemmed from the hope of being referred to an erectile dysfunction clinic and to seek reassurances about the treatment that he was currently taking. He did not appear to have a sense of duty to the cardiac rehabilitation team, although he was happy with the rehabilitation course.



## **Interview Twenty Three**

### **Who**

Mr Franks was a man in his 60's who was working in a health care setting, but at the time of the interview had not returned to work following his heart attack, he had completed the cardiac rehabilitation course and was about to undertake further rehabilitation classes . He lived with his wife and two adult daughters and we conducted the interview in the family home, although no-one else was at home at the time. Mr Franks described how he had grown up locally and that his parents had moved from Asia, which he felt had influenced his upbringing and subsequently his understanding of some of the issues we went on to discuss.

### **How did the interview go**

The interview was seemingly easy to conduct, Mr Franks was happy to talk about a variety of things relating to his heart attack and to his sex life, although he described himself as "shy", it appeared that he felt comfortable enough to discuss his thoughts and understandings in detail; so much so that the interview took forty minutes. Much of this was, on reflection, funnelling by both Mr Franks and myself, because he had described himself as "shy" and I knew that I may have not had the insight into his culture in the same way as I may have the other men, so there was a significant amount of talking around other issues before discussing erectile dysfunction. However the resulting transcript was an open discussion of many issues surrounding sexual intercourse, not just erectile dysfunction.

### **What points were made**

The DVD used by the cardiac rehabilitation team had been discussed by other participants however Mr Franks was the only person to describe how it changed his perspective

"the DVD they put in, done by the British Heart Foundation and they more or less interviewed the majority of different types and different age people that's where I found myself thinking oh right!... but now I feel after watching that video that I don't feel embarrassed any more ... there was an Indian chap and uhm there was he was talking about it and he said about it how I am scared to do it in case I overdo it with my heart and then they said no there is nothing to worry about just be normal... so I am not shy anymore about why to seek help... because on the video it was an Indian chap and I thought well if he can be on in front of the camera"

Mr Franks was the only man who describes feeling connected with the people in the DVD and this seemingly affected his sense of understanding of the issue

and where he as an individual, but also as a member of a particular culture, fitted.

### **What were the main issues**

Much of Mr Franks' thoughts were anchored in his understanding of his culture and the British culture. He felt that it was difficult for him to talk about sexual issues and that it is easier for British people because

“British people are more open they even walk naked in the street they don't worry about it, but in Indian culture the woman are shy they always cover their bodies, they don't show, but modern day they do that's why the older generation feel embarrassed”

This interview was enlightening from the perspective of someone with an innate understanding of another culture. The other men who were interviewed were all British with British parents and had lived locally for their whole lives. Mr Franks provided a perspective from another culture, although he had experienced the same healthcare and education system as the other men he was able to talk about the influence of culture in a way that neither I nor the other men could do.

## **Interview Twenty Four**

### **Who**

Mr Groves was the youngest participant at forty seven years old, he had not been working having been medically retired. He was interviewed at home with his wife and at times during the interview other members of the family did walk in. When interviewed Mr Groves was undertaking the cardiac rehabilitation course and had experienced his heart attack two months previously.

### **How did the interview go**

Although members of the family came in and out during the interview this did not seem to disrupt either Mr or Mrs Groves' thoughts and neither of them asked the other family members to leave, so I continued as I saw appropriate! Mr. Groves spent a long time (10 pages) telling me about his experience of having a heart attack and what had happened to him on the day it happened and subsequently. His father before him had experienced several heart attacks and he used these experiences to make sense of what had recently happened to him. More so than the other men Mr Groves seemed to need to talk about the experience of having a heart attack, this may have been as he had experienced this most recently, describing his thought during the incident as

“I am dying here”

Or because at his age he was surprised, describing himself in the cardiac rehabilitation class as

“well I am the youngest obviously”

During the interview Mrs Groves made several comments akin to those of Mrs Andrews, in relation to the behaviour of men as a whole, and typifying male behaviours. Although this was a marital dyad there was less talking for each other than there had been in the interview with the Andrews.

### **What points were made**

Mr Groves provided a perspective of a younger man, who had not disclosed erectile dysfunction to a health care professional and despite this relatively unique perspective his thoughts were mainly congruent with those of the other men. He talked about how “fantastic” the emergency services were and how he had volunteered to be interviewed because the cardiac rehabilitation team had asked him, along with the rest of the attendees.

He did not allude to having ever disclosed erectile dysfunction to a healthcare professional and discussed his sex life quite openly, talking about the practical difficulties of having so many adults living in one house and the current issue of not having a door on his bedroom. At no point did he discuss erectile

dysfunction treatments and he would quite often talk about erectile dysfunction in the third person, as if it were a problem for other men. Reading the transcript back it is at times unclear whether Mr Groves has erectile dysfunction and if he does whether it is a persistent condition.

## **Interview Twenty Five**

### **Who**

Mr Hobbs was a seventy two year old gentleman who was interviewed in his home. His wife was at home but after introducing herself and making me a cup of tea she went out to the kitchen to leave us to conduct the interview. Mr Hobbs' living room was surrounded with photographs of family members and what I assumed to be grandchildren. He did speak of family but only in terms of a relative who had previously had a heart attack, the result of which had informed his actions on the day that he had experienced the same thing.

### **How did the interview go**

This interview was difficult to initiate. Mr Hobbs gave me one word answers to the first four questions I had asked him and these were not in relation to erectile dysfunction. Looking at the transcript it may have been that in anticipation of the topic he was surprised by the questions about his general health and therefore was a little taken aback by them. Once we started discussing the cardiac rehabilitation session on sex he seemed to give more rounded answers.

### **What points were made**

Mr Hobbs had never disclosed his erectile dysfunction to a health care professional and had decided to participate because of a sense of debt to the healthcare professionals in the cardiac rehabilitation team

"I am talking to you now because I feel that er I can put some input into you and you know may be of assistance to you I am trying to pay back the system that have er done so much for me"

He did not want to pursue any treatment, declining any further referrals with

"it doesn't bother me, it's not a great part of my life now really"

The interview covered many of the thoughts expressed by the other men and by the end of this interview I was having difficulty in identifying any new concepts or thoughts. Mr Hobbs, although rare, in that he was speaking to me as the first healthcare professional about his erectile dysfunction, had experienced many of the same thoughts as the other men. He did not have experience of discussing erectile dysfunction but he was in a position to express the thoughts and cognitions of a man with the condition who had considered the potential outcomes of a disclosure.

## **Interview Twenty Seven**

### **Who**

Mr Innes was a 78 year old gentleman who was interviewed at his home, his wife had gone out shopping but had offered to stay for the interview, he had told her that he would be able to conduct the interview alone. Mr Innes had three grown up children and several grandchildren who all lived locally, and of whom he was obviously proud. Much of the funnelling in the build up to his interview discussed his family and his previous career in the media.

### **How did the interview go**

The interview went well and I was offered a second cup of coffee. Mr. Innes had undertaken the cardiac rehabilitation course with enthusiasm and was keen to tell me about the two incidents when he had recently been hospitalised with a myocardial infarction. Similar to Mr Hodges he was keen to pay back something to the cardiac rehabilitation service and hence he volunteered for the interview.

Mr Innes had discussed his erectile dysfunction with several healthcare professionals over a period of about 15 years. These discussions had been met with a variety of responses, similar to those described by the other men, however he had reached a sense of acceptance with the situation and was not seeking any further help.

Mr Innes described a severe erectile dysfunction which he had noticed to be a problem for some time. He told me that he and his wife “still have a loving relationship”, he had tried medications but they had discussed the fact that “sex has been spontaneous” and that having to “wait for you to get a bottle out or whatever”, was not something that they felt was conducive to their love life.

At the end of this interview I was left with a feeling that Mr Innes was telling me similar thoughts to the men I had already interviewed and on further analysis of the transcript it became clearer that for most of Mr Innes’ discussions, I had had previous similar discussions with the other men.

## **The Idiographic Experience Healthcare Professionals**

### **Interview Two**

#### **Who**

Rebecca was a clinical nurse specialist who had worked for the previous fifteen years within the cardiology department of a large university hospital. Her current role involved managing a case load of patients with a specific cardiac problem, working specifically with one consultant cardiologist who specialised in treating this particular pathology.

Rebecca was one of a team of three and on the day of the interview her office was quiet because she was the only member of the team who was in work, this however made her more busy than usual and during the interview she had to answer the telephone several times. I had previously been based in Rebecca's office when I was working within the department and it was this familiarity with the environment that I have stated in the reflective notes as helping me to feel more comfortable in this interview. Rebecca knew me from my time in this previous role and because she had referred a patient to the erectile dysfunction clinic, hence there were two things which I noted in relation to this interview; Rebecca's honesty in discussing her clinical practice and her need to seek advice or guidance from me in relation to whether she had appropriately managed the patient that she had referred.

In relation to the interview there was some funnelling and discussion about Rebecca's professional experience and training, she had undertaken several courses since qualifying and had not been aware of any educational input in relation to erectile dysfunction. She described herself as having

"no major awareness, only that through common knowledge, friends and colleagues"

Rebecca focused on the one disclosure that she had received in her whole career, which had been in a clinic situation where a wife was present with her husband and Rebecca described the man, who was her patient as "puce", as his wife told her that "he was having troubles in the bedroom". Rebecca then went on to discuss how

"I think I appreciated that she actually approached the subject"

Rebecca was unique in this comment, in demonstrating her own appreciation of the wife initiating the conversation. Despite acknowledging how difficult it must have been to initiate this conversation Rebecca was reluctant to be initiating any conversations of a similar nature with any other patients, saying that

"I won't routinely bring it up (laugh) cos they are not so much cardiology patients I suppose with chest pain and atheroma and things like that"

Rebecca worked within a team of three nurses and her perception was that another member of the team regularly received disclosures of erectile dysfunction,

"it's funny cos there are three of us and it is always M that they approach"

This had become a joke within the team and Rebecca had joked with M that the patients only phoned to speak to her if they had a problem with their sex life!



## Interview Four

### Who

This interview was with a senior academic medical professional whose current role involved clinical practice as well as a significant research and teaching component. I had previously worked within the same department as Jeremy and he had invited me to his office to conduct the interview. It is probably because of our previous working relationship that we both felt comfortable enough to conduct the interview in a much less directed format that I had undertaken before, my questioning became far more open and less structured because I had confidence in knowing that he would be comfortable in leading the discussion.

The topic of erectile dysfunction was discussed within the opening sentences of the interview, there was no funnelling evident in the interview transcript and my reflective notes at the time comment on the fact that on arrival I said something to him about interviewing experts and opinion leaders, to which he belittled himself, saying he was neither! During the interview it became clear that he had an in depth understanding of the research which supports the erectile dysfunction and cardiovascular link, he had also published several papers which related to the theories of endothelial dysfunction. Therefore the early self-deprecating comments were unfounded and likely to have been used for my benefit.

Jeremy clearly felt comfortable talking about research and the use of data to inform clinical practice. None of the other participants used research in such detail to support their clinical decision making, many alluded to supporting data, but Jeremy could quote authors and rather than providing single sentences in relation to this, he had large monologues.

“how strong do I think the link is right OK well there have been a number there have been a number of studies that have looked at that and I think there have been I mean I think there have been a couple of systematic reviews I am not so uhm well up on the systematic reviews but there are a large number of population studies that have shown in the general population and also in people with cardiovascular disease that erectile dysfunction is a marker of ischaemia and also coronary and cardiovascular risk in general so in terms of epidemiological association the data are very strong so you know showing that its independent of other sort of standard markers of cardiovascular risk and cardiovascular disease that actually seems to be associated with the additional risk and it's probably a marker not just of the atherosclerotic burden but also the vascular function and that's in line with uhm with other evidence so there's linked endothelial function to prognosis because obviously the erectile function is in large part due to the coro, the pudendal vascular endothelial function and so that's of particular importance you know beyond the actual atherosclerotic disease burden you know you can have a lot of disease or you know a moderate amount of disease and in two groups of patients and if one group has endothelial dysfunction and the other has relatively well preserved endothelial function despite the same sort of burden of atheroma then the people with the endothelial dysfunction are more likely to have an acute event and so its s sort of a clinical marker of endothelial function as well as marker of fixed disease so it gives you a number of other inferences and then

of course there is also the psychological element as well that might be linking uhm endo erectile function to risk so we know from other large studies in lots of different settings and general populations in acute coronary syndrome stable coronary disease that people with depression anxiety and you know that sort of adverse constellation of psychological symptoms or factors are more likely to have cardiovascular events or if they have a cardiovascular event are more likely to do badly after their cardiovascular event so and that's associated with all sorts of things and again the psychological elements either causing or consequence of erectile dysfunction may also be influencing the adverse outcome so I think it is multi-factorial but the data connecting the presence and a bad cardiovascular outcome are really pretty strong exactly what the causal pathway is isn't you know firmly known whether its endothelial function a marker of disease burden marker of sort of the psychological elements and other co-morbidities that also link into bad outcome so the data are very good obviously what we need to do is to look at whether intervening on erectile function independently of the way that you would intervene in someone just on the basis of their cardiovascular risk factors whether that changes outcome at all or whether you just intervene more intensively on the risk factors and that's sort of the way that people are more sort of proceeding at the moment that if you have got someone with erectile dysfunction that you might I mean certainly this is far from wide spread approach but there are the people who are in the know as it were and the expert recommendations are that if people do have erectile dysfunction that is not due to sort of a urological or neurological cause that it is likely to be due to a vascular cause and that person should have their risk factors more intensively managed than they might do otherwise"

Despite knowing of the link between erectile dysfunction and cardiovascular disease and providing a robust and considered defence of the science supporting it, he did not routinely ask patients whether they had erectile dysfunction and he did not feel that cardiologists should necessarily be the healthcare professionals to which patients should turn for treatment. He did state that cardiologists had a responsibility to ask, so that they had useful clinical information, but that they were not ideally placed to treat. As he was discussing this it became obvious that the lack of clarity in his discussion was because he was considering this possibly for the first time.

"it is not something that is considered primarily our responsibility, but it is something we take responsibility to ask"

Jeremy was unique as the only male doctor who did not seem to use his own personal beliefs to guide his practice. He did recognise the sensitivity required but did not overtly put himself in the position of being a patient in order to rationalise his own practice.

## Interview Six

### Who

Interview six was with Alison a nurse practitioner with over twenty years experience in cardiac nursing. Her current role primarily focuses on seeing patients in a nurse led clinic for follow-up after revascularisation; by angioplasty or coronary artery bypass grafting. Alison and I had worked closely together in years prior to this interview and she had expressed an interest in becoming a member of the erectile dysfunction clinic team. Despite this existing relationship there is a significant amount of funnelling at the beginning of the interview and this may be because of an over familiarity between us, or because I was about to ask her about her consultation with patients, which I had never directly witnessed. The time spent in the initial stages of this interview appears to have facilitated very honest responses to questions and at times it is clear that Alison is beginning to think about how or why she makes the decisions she does.

Alison is the only healthcare professional who routinely asks her patients about erectile dysfunction, although she does add a contextual caveat of not asking in particular situations, such as if the man has a relative present, they are from a particular culture or if she feels too embarrassed to ask because they are old

“barriers to me asking you say? I do feel a bit if it’s like I said if its relatives we get a lot of people who can’t speak English that well so they will bring a relative in so I wouldn’t go there and also I do feel a bit funny asking Indian men I don’t know why (laugh) uhm I make a point of doing it with the younger people with the older people it depends how old they are because sometimes I do get a bit embarrassed if they are like eighty because I don’t think my father would like to talk about it if I was there (laugh) and I wouldn’t like to know what my father was up to either”

Alison rationalised many of her decisions, such as not asking in the presence of a relative with her perception of what her father would want, but in thinking about why she would not ask Indian men she provides no rational.

Alison had developed a routine for broaching the subject which involved telling the patient that they could talk to her if they wanted to, that erectile dysfunction is common in the group of patients that she sees, there are treatments available and then leaving the man with contact details so that they could seek help after taking time to consider what she had told them

“no I think sometimes you just sort of offer I try and do it with the majority of patients I say any problems with sexual activity you don’t have to talk about it if you don’t want to but the option is there because there is help available and a lot of people suffer from it and uhm accept it without doing anything about it so a lot of people will say no problem and a lot of people will say there is, some people will I offer them to refer them to Nick some patients will accept it and some patients will say they will think about it so I write his name down and say to them your GP can refer at a later time if you change your mind”

## **The Idiographic Experience Interview 8**

### **Who**

Anna was a cardiac rehabilitation nurse who had undertaken many post-registration courses, most recently having completed a degree. Since qualifying twenty years ago she had worked in various roles within cardiology and cardiac surgery settings. This was discussed within the early stages of the interview and there was a sense of nervousness during the interview which Anna was trying to overcome by talking about all of the courses she had undertaken. My notes from the reflective diary say that

“I found this quite a difficult interview as she was not as keen to talk as the other professionals had been and is quite a shy person naturally so she gave short and polished answers, I got the impression that she might have been a little nervous”

Interestingly there is some discussion in the introductory funnelling about Anna’s age and I express surprise at her being older than me because she looks significantly younger. Although this was not identified as a factor by Anna, it may be a reason as to why she receives, what she believes to be, fewer disclosures than her colleagues.

Within Anna’s current role she is responsible for giving the talk on sexual intercourse as part of the cardiac rehabilitation course, but during the interview she was clear that she did not like this aspect of her job and even identified scenarios where she would deviate from the routine practice and not discuss the topic.

“I don’t tend to say it if they are older blokes (laugh) which is probably bad and if someone is widowed I never know whether to talk about it or not”

Anna’s laugh is not one of finding what she is saying funny, but an expression of discomfort in talking about her practice. With further reflection on this type of practice she did conclude that such conversations were getting easier with age and she had sympathy for younger colleagues.

“it’s not so bad now I am older but the younger girls”

## **The Idiographic Experience Interview 11**

Angie is a cardiac rehabilitation nurse who worked in the same department as Anna and would be ten years older than her. Her role is the same as Anna's but in addition she infrequently stands in for another colleague and takes an outpatient clinic to follow up after angioplasty. In this clinic Angie described how she felt a professional responsibility to ask about erectile dysfunction because it was on a clinic pro forma and she did not want to let her colleague down by not asking.

“you have to ask the question because it is on the piece of paper and there is a tick”

Despite feeling this obligation she describes how she does not like this aspect of her job, finding it no easier with the proforma.

“I have got to be honest haven't I think I would rather them not ask me, I am pushing that it is nothing to do with me aren't I in a way”

Angie was the only member of staff to discuss the British Heart Foundation video, which she and the team use in the rehabilitation talk. Her thoughts were as negative as some of the men about the video but she found it troubling for different reasons.

“nothing no just a crappy two minutes, have you seen the BHF video the sex one? The nurse she really puts you off, there is a pump on the table, honestly it's terrible”

Angie is clearly bothered by the portrayal of her profession in the video and the men are more concerned with the portrayal of men in the video.

The third thing that Angie was unique in discussing was the one situation she had been in where a discussion of sexual intercourse with a patient had made her feel uncomfortable; she had been visiting a patient at home and he had started a discussion about his sex life, which Angie felt was unnecessary and not relevant to her assessment of him. The result of this conversation left her feeling uncomfortable and less willing to engage in such conversations with other patients

“they are just testing you out sometimes, I couldn't get out of there fast enough, horrible man”

Angie then went on to say that she feels more comfortable having such conversations with

“a nice sensible older couple” although she contradicted herself by saying that

“my Mum and Dad would fall off their chair if someone mentioned it”, basing this on her rationalisation that her parents would be an older couple.

### **The Idiographic Experience Interview 15**

Ceri worked in the cardiology out-patient department where there was a large notice board dedicated to erectile dysfunction being a marker of cardiovascular disease and she said that she had seen many people reading it but none had come to her to discuss erectile dysfunction.

“she had cleared some time in her diary to conduct the interview and she had given the topic some consideration prior to the interview”

“Once the interview had come to what I considered to be a natural end she asked me a lot of questions about ED and what happens to the patients when they attend, it appeared to be a genuine interest”

As part of this role she was responsible for running a drug monitoring clinic and this was where she had received disclosures of erectile dysfunction. This treatment is used to relieve symptoms and as a result much of Ceri’s work focused on assessing the patients’ symptoms and whether they had improved or declined on treatment. As part of the assessment Ceri used a standardised questionnaire and she described how she could use this to start a conversation with patients.

“I just say oh you know you have left this bit blank, is there any particular reason?”

This use of a formalised questionnaire to begin a conversation was unique to Ceri and she said that she could use the revisiting of the questionnaire after six months of treatment to revisit the topic.

### **The Idiographic Experience interview 18**

Thomas is a consultant cardiologist who specialises in interventional cardiology and with whom I had previously worked. This existing relationship may account for his very candid approach to the interview and his willingness to demonstrate views which were clearly personal and not his professional take on this subject. My notes from the interview comment on the lack of any preparation by this participant "he had not really given the interview any prior thought and had not prepared any answers for me!" I also commented on my surprise at his openness and the language that he was prepared to use.

The interview was conducted in his office; he was late arriving on his bike and wearing his cycling shorts. I was waiting outside his office so when he arrived he did seem a little flustered or rushed and apologised several times. We had a cup of tea whilst conducting the interview and although the transcript reads as though this was a stilted conversation this was not the feeling that I had at the time.

Thomas understood the link between cardiovascular disease and erectile dysfunction but admitted that he finds asking about peoples' sex lives embarrassing, so he does not routinely ask, however he has received disclosures from his patients. Apart from the relatively uncensored use of language Thomas did not demonstrate any unique thoughts on the subject and his experience of disclosures and professional behaviour appears akin to the other participants.

## **The idiographic Experience interview 20**

Steve was a senior registrar who had over ten years' experience in cardiology and was about to start his first consultant post. We met to conduct the interview in his coffee break and because he did not have an office he suggested that we meet in the hospital canteen. This was the only interview that I conducted within earshot of other people, this may have impacted upon the depth achieved, however Steve was very honest in his responses and I did not have the impression that the location impacted on what he was willing to discuss. The fact that he was on his coffee break resulted in a time constraint and I was conscious of this, the interview was brought to a close with me saying

“no that's great I won't take any more of your time”

Steve had a limited number of experiences to draw on but he did recall a consultation where a patient had disclosed Peyronies disease. This is a fibrous plaque, usually on one side of the shaft of the penis, which in an erect state causes the penis to be bent. The patient had felt unable to describe this to a doctor so had taken a photo of his penis in an erect state as evidence. The photo was shown to Steve and he described the experience as having “scarred me quite considerably”, he then shook his head and made a shivering motion at the recall of the event.

Steve was the only healthcare professional who would routinely see patients in an acute phase of their disease, none of the other healthcare professionals would be involved in care whilst in the accident and emergency department. Steve said that he had only ever received a disclosure of erectile dysfunction when he had seen patients in the outpatient department and that in an acute setting he would only establish if the patient had erectile dysfunction if there was a PDE5 inhibitor on the patients repeat prescription. As part of his routine questioning in the acute setting he would only ask about five risk factors “previous stroke, smoking, hypertension, diabetes and high cholesterol”.



### **The Idiographic Experience Interview 26**

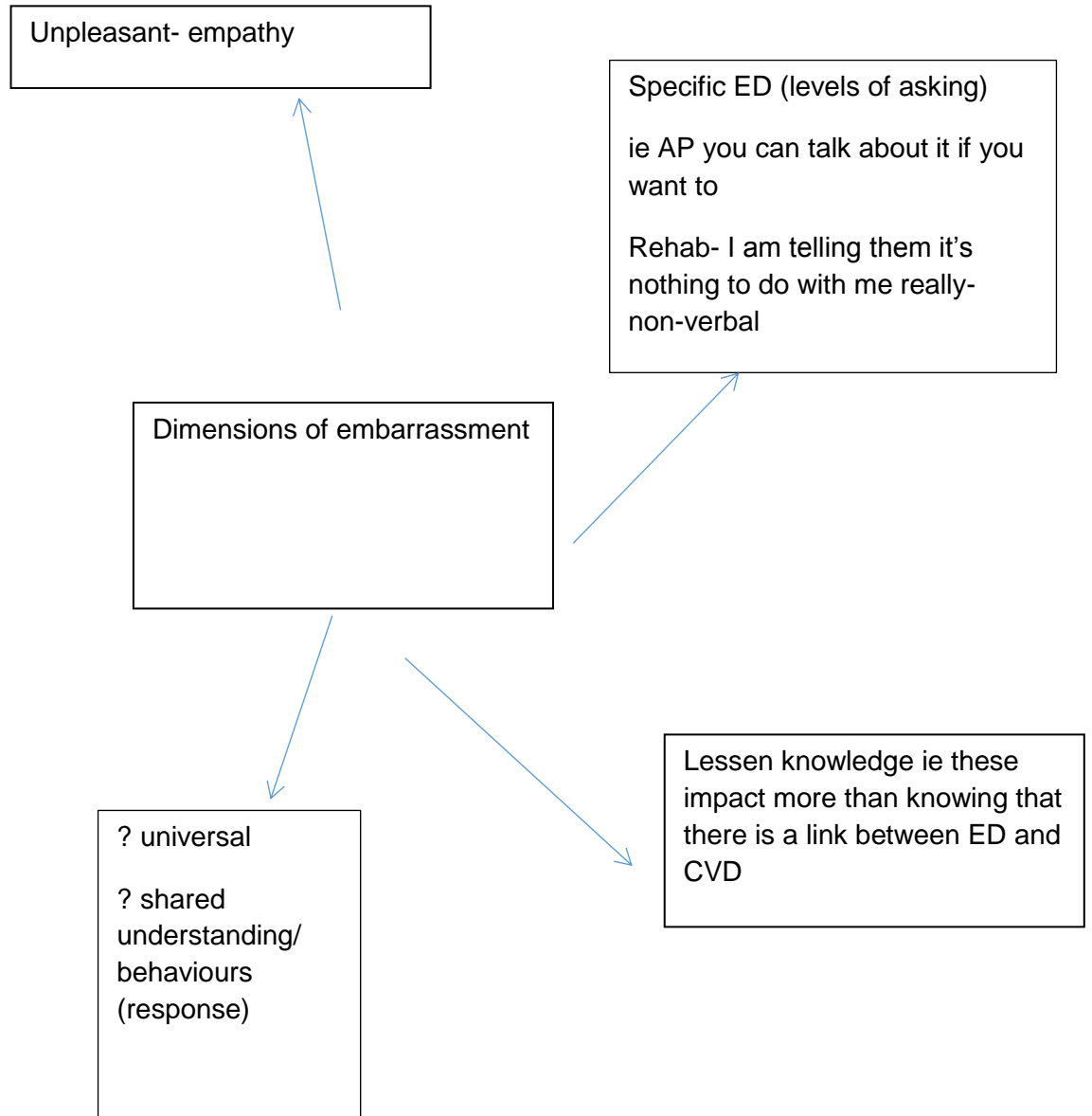
Interview 26 was with Sian a thirty eight year old General Practitioner, who invited me to her house because she felt that she would be interrupted at work. Sian had been working in her current practice for the previous ten years and had developed a specialist interest in minor surgery. As the only female doctor being interviewed for this project her perspective would be unique, however her thoughts were congruent with her male colleagues. Notably however she did not do was use her own thoughts or beliefs to rationalise her behaviour, there were no references from her to her parents or husband for example.

Sian stated that she did not receive many disclosures of erectile dysfunction, believing that her male colleagues “probably got more” and rationalising this to be because of her perceived age and that she is female. She felt that given a choice the patients at her practice, which is large, would choose to speak to a male doctor. Sian said that she had discussed the frequency of disclosures with her colleagues and that their experience was that the male doctors felt that they received disclosures frequently, although they could not quantify this, and the more senior female partner felt that she had been receiving more disclosures the older she had got. Sian felt that this may have coincided with the increasing popularity of PDE5 inhibitor use and therefore could not categorically relate this to her colleagues age.

Sian was the only healthcare professional to work in a non-hospital setting and provided a unique perspective on information giving. Within the practice notice boards and information leaflets had been phased out over recent years due to infection control issues and therefore she gave information to patients in the form of leaflets which she printed out as required; she recognised that this could be prohibitive in relation to erectile dysfunction as she would need to have received a disclosure before she would be prompted to print the relevant information.

## Appendix Fifteen

### Mind Map of Embarrassment



Mind Map of Real World

Gender impact (ED  
menopause)

Holistic psychological  
impact and  
consequences

Theorists:  
  
Goffmann, Gross, Stones  
  
Sex and sexuality is the most  
embarrassing topic- Lawler

Social impact/ public personal  
? not alone ? shared emotion  
(Lawler)

Empathy as people

Superordinate- life changer ie  
ED does not just result in the  
emotion of embarrassment it is  
a change in self

Context of Self-selecting men  
so were these men  
embarrassed?

Embarrassment (body object/  
body subject) (Julia Downing)

Professional rules/ norms  
(medicalisation)

Lawler- Nurses break social  
rules but does medicalisation  
mean that the social rules are  
changing?