



Cardiff University/ Prifysgol Caerdydd

A Critical Exploration of the Individual Quality of Life of Adult Home Mechanically
Ventilated Patients.

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This thesis is submitted in part for the candidature for the degree of Doctor of
Philosophy

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Summary

This thesis joins wider social sciences discourses about disability and quality of life, focusing on individuals who are mechanically ventilated in their own homes. It is about the struggle of Home Mechanically Ventilated (HMV) individuals in living a normal life. Using a qualitative approach to explore the relationship between HMV and the *individual's* perceived Quality of Life (iQoL), discourses around iQoL were analysed to identify the impact of, practices used to promote and enabling and disabling factors of iQoL.

In Wales, seven participants, via semi-structured interviews, shared their views. Fairclough's (2015) Critical Discourse Analysis (CDA) framework was adapted. This enabled exploration of how discourse is shaped by micro situations, meso level institutions and macro structures, and, conversely, how discourse shapes these factors.

The findings reveal individualised struggles, hidden conflicts and discourses. The text reveals the discourses of Being Normal and Seeking Independence. Interpretation and explanation of the findings are considered against the political rhetoric and policy surrounding the expansion of care within the community and closer to home. Such political drivers aim to provide increased independence and control over individual circumstances. However, the findings reveal a different reality. The HMV population's reliance on technical equipment and personnel to support and sustain life undermines independence, whilst tacitly accepting interdependence.

This thesis exposes the discourses surrounding policies on integrated care and how the social theory of disability can be applied to HMV individuals. It provides evidence to guide healthcare policy and care provision, adding to the limited UK evidence on the iQoL of HMV individuals. It proposes exploration of the impact of attitudes towards HMV individuals, the psychological issues such individuals face, and the experiences of carers, service providers and commissioners, to provide a clearer picture of what affects the quality of life of HMV individuals across the UK.

Prologue

This study is about the day-to-day lives of individuals who are home mechanically ventilated (HMV). The focus is on the individual's quality of life (iQoL).

This study began from my interest in what happens to the HMV population following discharge from Critical Care Units. As I nursed these patients and observed an increasing number being discharged to their own homes, I began to think about their quality of life (QoL) and how this was affected by HMV. I wondered how these individuals maximise their QoL, and what factors hinder or help them resume their life in the community and in their own home. There was a drive amongst the medical staff with whom I worked at the time to create a long-term weaning¹ unit that would accept patients from wider afield, either to wean from mechanical ventilation, or prepare the patient for discharge home with a ventilator. I was surprised at the lack of appreciation by the medical staff of the stress, for both patients and relatives, arising from being critically ill and separated from their family, or having a sick loved one being cared for far from home. What I sensed was a lack of understanding of the emotional and psychological issues related to critical care and the enormous effort required to overcome the hurdles to getting well and going home. I reflected on these different perspectives, as well as how extended care provision is resourced, and whether home is the best place to care for patients requiring long-term mechanical ventilation, from both the patient and medical perspective.

Government drivers assume that care is best (and more economically) delivered at home, reflected in both the Welsh and UK governments' drive for Care Closer to Home (UK Government 2015a). However, there are no Welsh and few UK studies on patient perspectives on HMV health and social care services: where they would like to 'be', how they would like their care delivered and how it feels to be on the receiving end of the care and changes imposed upon them. There is a difference between the provision of fundamental (basic) prescribed treatment and the associated required services, and individually tailored care. Personalised care and support planning facilitates an improved

¹ Weaning from mechanical ventilation involves teaching and training the patient to breathe again on their own, without the support of the ventilator.

dialogue between patient and health and social care services. The aim of personalised care planning is to recognise what is important to each individual, to enable them to achieve a good life and maximise their immediate well-being and long-term health. Care planning should ensure that the support these individuals receive is co-created and co-ordinated around their preferred outcomes, which may transcend treating the disease. It draws on current discourses in relation to specific diseases, such as cancer, about living well with disease versus surviving disease.

The fact that the HMV population depends upon ventilation to breathe and maintain their lives makes them a unique community. There are other individuals in society who rely on healthcare technology; for example, those who require renal dialysis several times weekly. Those who are HMV however, require continuous technical and medical intervention via a ventilator. Typically, this requires constant individualised care delivered by specially trained carers. As a result of this dependence, the individuals who are HMV must adapt their lives and homes, as must those with chronic illness, to enable a meaningful life and a level of well-being to continue. The adaptation involves the following:

- The acceptance of life-saving (maintaining) equipment in every aspect of their lives;
- The introduction of care teams delivering care of differing levels of intensity and regularity in their homes;
- Mental and psychological adaptation to the physical changes, including accepting the need for ventilation to prolong and maintain life.

There is a shift from the criticality of the conditions and situations to a more chronic perspective. HMV individuals become chronically critically ill. They strive to achieve a normality that is life-affirming whilst being ventilated by technological means. This sets them apart from societal norms. Persons who are HMV search for meaning in their existence and position in the family and more broadly, in society. Yet the reality remains that without a ventilator, these individuals would not survive. Their dependence is unique – their treatment is not regular, but constant. The HMV population's dependence is not only on medical and care staff, but on fully functioning equipment. Any malfunction in equipment with a change in their physical status or breakdown in communication between

patient and carer could result in catastrophic outcomes. This is the fundamental difference between the chronically ill population, and the chronically critically ill.

As my thinking progressed, questions around the relationships between individuals who are home mechanically ventilated and their carers, the healthcare staff, the institutions and government involved began to develop. Does the involvement of such a wide range of individuals and institutions hinder or help the HMV population in relation to their iQoL and if so, how? Are there elements of power and control in the relationships formed? The HMV population is dependent on equipment and technology as well as nursing and social care, which presents an alternative angle of power and control. Power is seen as dynamic in this study, shifting between social groups and organisations, from participants to carers and institutions and back again. Power (and control) filters through each of the discourses HMV individuals identify.

The HMV population inhabit a world of interdependence, and strive for normality. Individual struggles around normality and dependence/ independence/ interdependence were, however, inconsistent with current theories of disability and normality. For example, the bio-medical model views disability as a biological problem that needs 'fixing', whilst the social model views disability as a social problem due to unequal access to resources. This study suggests that applying the social theory of disability could influence the care and iQoL of the HMV population, supported by a more holistic, nursing approach to the care of these individuals. The study adds to the evidence base of individual quality of life of home mechanically ventilated individuals, specifically in the UK.

A Critical Exploration of the Individual Quality of Life of Adult Home

Mechanically Ventilated Patients

CHAPTER 1

1. Introduction

This thesis focuses on the effects of home mechanical ventilation (HMV) on the individual quality of life (iQoL) of disabled people in Wales. It explores discourses around iQoL and the factors that enable and disable it, using a qualitative approach. The study presupposes that iQoL in the HMV population differs from that in the general population and from other quantitative QoL measures. The measurement of iQoL enables a subjective view of factors that are important to participants and are not predefined.

The rationale for the choice of topic is having cared for ventilated patients on Critical Care units during my clinical career and observing an increasing number of ventilated patients discharged to their own homes. This raised questions about how their QoL has been affected, how it can be maximised and what factors hinder or help patients resume their lives in the community and in their own home. Further, how is extended care provision resourced and is home the best place to care for patients who require long-term mechanical ventilation?

1.1 The Aim and Research Questions

The aim of this thesis is to explore critically the iQoL of individuals requiring HMV. Exploring the relationship between HMV and perceived iQoL of patient participants, the following questions clarify and define the scope of the study:

From the HMV participants' perspective:

1. What is the impact of HMV on their iQoL?
2. What practices do HMV individuals use to sustain and enhance iQoL?
3. In the discourses surrounding iQoL, what facilitates and hinders iQoL?

1.2 Background

Patients who need to be ventilated are regarded as critically ill, and are normally cared for in critical care settings, such as intensive care units, in hospitals. Such patients are increasingly

surviving critical illnesses previously associated with high morbidity and mortality. This is due to an increase in health care technology, treatments and a continuously evolving evidence base (The Welsh NHS Confederation 2015; Deloitte UK 2017; National Audit Office 2017). This increase in knowledge and sophistication of treatment and the ensuing increase in survival rates have increased pressure and demand for critical care services. Owing to their specialist nature, critical care services are expensive. Demand for such specialist services is expected to rise by 4 to 5% per annum, as a result of a growing and ageing population and its associated co-morbidities (The Welsh NHS Confederation 2015; WG 2017). In conjunction with increased survival rates of patients in critical care, from 79% in 2011-12 to 83% in 2015-16 (WG 2017), this places an additional burden on finite healthcare resources. Enabling discharge from Critical Care areas can therefore decrease the pressure on and cost to the health service. For discharge, however, most patients need to be weaned from mechanical ventilation (Boles et al 2007), which involves training the patient to breathe again on their own. This normally happens when the patient is stable and well enough to breathe independently, and, importantly, as soon as possible, to limit the risk of respiratory infections (Boles et al. 2007). However, some patients are unable to wean, whilst others, through a deterioration in their disease process or condition, require long-term ventilation. These patients are otherwise clinically stable, and do not require the advanced treatment and care a critical care setting provides, other than ventilation. This presents a challenge of where these patients should be cared for, to optimise their quality of life, and reduce costs to the NHS.

Consistent with political drivers, the focus of care delivery has in the past 20 years switched from formal healthcare settings, such as hospitals and long-term care institutions, to the patients' own homes (WG 2018c; 2016; 2014). This move towards increased community-based care embraces **all** patients, including those who require permanent and invasive² ventilatory support (HMOV). The iQoL of these patients in the UK and specifically in Wales however has been inadequately explored, despite increasing numbers of HMOV patients,

² Invasive ventilation involves the insertion of a tube into the patients' trachea, either via the mouth or via a procedure called a tracheostomy, where an opening is made in the trachea from the outside of the patient's neck. In either case, a tube is inserted into the trachea, which is then connected to a ventilator.

with very few studies based in the UK (Maclaren et al. 2018; Lone and Walsh 2011; Lloyd-Owen et al 2005).

This drive to increase care provision in the community (WG 2018c; 2016; 2014) requires a vast amount of preparation in the case of ventilated patients. Safe discharge home is managed by transferring the individual to a longer-term weaning unit, where packages of care are developed to fit individual needs. These packages of care include home adaptations and agreements of the level, extent and cost of care services required (NHS CHC 2018a). The cost is further complicated by separate and shared health and social care budgets (NHS CHC 2018b). Moving patients to longer-stay units, critical care outcome measures, such as length of stay (LOS), continue to be applied. The change in care environment does however reduce the cost of care: in critical care (Level 3 care) environments (Nuffield Trust 2014), the cost per bed per night is approximately £1932 (WG 2013). By comparison, a ward bed costs on average £413 per night, whilst a Level 2 High Dependency bed costs on average £857 per night (WG 2013). With extended LOS, risk of infection and other complications increase, adding to the cost of care. Transfer out of critical care is therefore crucial for all patients who do not absolutely require it. The personal cost of an admission to critical care, however, is lost in the financially driven health service. QoL remains a secondary concern.

The timely agreement of the care package required must be agreed upon before discharge, as delayed discharge of patients who require HMV to their own homes results in an increased cost to the health board. According to Hirano et al. (2006), there are fewer social difficulties when the patient lives at home, reducing the emotional and psychological cost for patient and family. Patient flow is key, ensuring that discharge is enabled and critical care bed occupancy managed efficiently. The number of critical care bed hours lost between 2015 to 2016 was 148,424 hours, due to delayed discharges and transfers of care (DToC): patients continuing to occupy beds when critical care services were no longer required. This equates to 51% (4860) of patients discharged. A conservative estimate of the cost is £9.1m (WG 2017). The Critically Ill Implementation Group (WG 2017 p. 1) undertook to:

‘work with local hospitals, Welsh Government and the wider systems to address this as a priority, looking to new, innovative ideas to help repatriation and community based care’.

The recently announced increased funding of £15m to Critical Care Services in Wales should help realise the above statement in due course, through a reconfiguration of current services (WG 2018a). However, QoL and well-being have only recently been explicitly recognised in relation to patients requiring critical care services, in the outcome measures of the 2013a and 2017 Welsh Government (WG) Delivery Plan for the Critically Ill. There was a brief reference only to quality of life and well-being in the 5-year NHS Plan and Achieving Excellence: The Quality Delivery Plan (2012-16). The Outcomes Framework of 2016-17 (WG 2016a) does not reference quality of life. However, dignified and individualised care, where people's specific needs are recognised is outlined. The locality of care, and ensuring that care is delivered as close to home as possible is another domain. Yet, health and social care remain as separate entities, both feeding in to the Well-Being of Future Generations (Wales) Bill of 2015.

The concepts of QoL and well-being are now nonetheless firmly positioned in the wider political agenda, with numerous documents, policies and measures implemented to increase QoL for all citizens (Care Act 2014; Social Services and Well-Being (Wales) Act 2014). The government's drive to increase QoL and well-being is in contrast to the current widespread mind-set of dependence on services, and places the onus for maximising and maintaining a QoL and well-being on individuals. This need for a change in how healthcare is viewed, with individuals taking responsibility for their own health, is due partly to finite resources. NHS and Social Care funding and resources are stretched, with health boards and NHS Trusts across Wales recording a £163m deficit in budget over the past year (WG 2018b). In conjunction with financial difficulties and limited resources, demographic changes are becoming increasingly apparent, as previously mentioned, with an ageing population who have multiple co-morbidities, and an increase in acute illness in patients who live and are cared for in the community setting. All of these factors have prompted a change in the way funding and care are managed (WG 2018b).

Patients who live in the community rely increasingly on care to support their daily living, however the demarcation between health care and social care is, at times, unclear (Health and Social Care Act 2008; Care Act 2014). Owing to the range of conditions leading to HMV, this patient population will continue to require medical care and treatment. However, with a shift in how health and social care services are delivered and managed, a paradox

emerges: HMV individuals who require continuing medical support and funding also fall under the remit of social care. To support the changes in how care is delivered, a shift in how society views healthcare is needed, away from the medical model focus on illness, disease and cure. Individual expectations need to be managed, the onus shifting to individuals to maintain their own health and well-being (WG 2018c). Drawing on the Prudent model of healthcare, the right care should be delivered through co-production and in partnership with patients, in the right place at the right time (WG & NHS Wales 2018 and 2016). This way of thinking should encourage individuals who are HMV to actively participate in their care, and retain control over decisions made, remaining in their own homes, surrounded by their families and carers. This transformation and transition to fully embracing self-management may not be entirely possible in this population, owing to (increasing) dependence on HMV and deteriorating medical conditions. However, some changes to care provision are possible in this context. These are being implemented with the integration of social care and with health care practitioners (qualified, registered nurses) being replaced by social (unqualified, unregistered) carers.

The Bevan Commission (2011 and 2018) reported that technology is increasingly used to promote and sustain QoL. This increases expenses for a health service already facing sobering financial challenges (NHS Finance Wales Act 2014). Current funding structures mean that individuals with continuing healthcare needs are funded in part by the Continuing Health Care budget. Transferring care to the community and to patient's homes reduces the cost to hospitals and healthcare institutions. It does, however, increase the health and social care budget in the community setting. Amalgamating the health and social care budgets means the cost of care could be shared. Ideally, appropriate care would be delivered by the appropriate service to individuals in the community who require individualised care and support, in line with the Prudent model of care (WG & NHS Wales 2018 and 2016).

Thus far, the "seamless whole systems approach" (WG 2018d p. 1) to the amalgamation of the health and social care budgets has yet to be realised at an individual, care delivery level, with no evidence in the current study or literature being available of its successful integration. The 'A Healthier Wales' (WG 2018d p. 1) document, recognises that:

‘services from different providers should be seamlessly co-ordinated, and we should go beyond services to make a difference to the social and economic factors which influence health, wellbeing and life chances’.

The wellbeing and life chances of all individuals and the wider social and economic influences in society are thus acknowledged. The terms well-being and QoL are often used interchangeably (Larsen 2019; Lubkin and Larsen 2013; ONS 2012; Zeigler and Schwanen 2011; Scott et al. 2004; Peplau 1994; Meeburg 1993; Siegrist and Junge 1989). The recognition of well-being reflects the concept as defined in the Care Act of 2014. However, there is no clear acknowledgement of specific QoL and life chances of HMV patients in such statements or in the critical care related literature. Only generic outcome measures of QoL and well-being have been developed.

The majority of literature on HMV is biomedical in nature, based on an outsider’s perspective (Lindahl et al. 2005). This objectifies a subjective position. To develop sensitive outcome measures specific to the HMV population, the evidence base of patient perspectives needs to be expanded. Based on the 2009 report by The Commission on the Measurement of Economic Performance and Social Progress (Stiglitz et al. 2009), a recommendation was that national statistics agencies collect data on subjective wellbeing. A comprehensive QoL measure would better elucidate the determinants of quality of life (Stiglitz et al. 2009). A person-centred, individualised method of measuring QoL would mean care and treatment could be tailored to the HMV population, maximising subjective patient outcomes. Quality of life as a specific measured outcome in the care and treatment of HMV patients has yet to be realised. It would contribute significantly to the evaluation and development of services provided to this unique population.

Despite the proliferation of policies by Welsh and UK government, however, QoL remained a secondary concern until recently. The Social Services and Well-Being (Wales) Act 2014 underpins Welsh political drivers, which document outcome measures for QoL and well-being. This is reflected in the English Government’s Care Act 2014. The Social Services and Well-Being (Wales) Act 2014 defines well-being, frequently referred to in QoL discourses. A statutory requirement of The (Wales) Act 2014 is that a definition of well-being is provided, and that outcomes are measured. To this end, WG (2016) published a Measuring Wellbeing

National Outcomes Framework for individuals who need care and support, and their carers. Its aim was to track and monitor the transformation of care and support services at a local and national level: to describe outcomes, generate data to guide and set the direction of travel of services and develop greater transparency by using consistent, comparable indicators of whether services are improving the well-being of individuals (WG 2016b).

Developing services for and improving the well-being of the HMV population will require individually tailored outcome measures. Health and social service needs differ depending on individual, chronic or life-limiting diagnoses. The one element that brings this population together as a group is their need for ventilation. However, the well-being of HMV individuals is currently classed alongside those with chronic illness. As time progresses and policies and understanding develop, care planning for individuals with chronic illness are increasingly recognised. For example, with the publication of 'My Health in My Hands' by the WG in 2015, there is specific mention of the QoL of individuals with chronic illness. Additionally, in the 2018e Welsh Government policy document, 'A Healthier Wales: our Plan for Health and Social Care', well-being measurement is clearly outlined, and The Office for National Statistics (ONS) has, since 2010, published statistics on personal well-being. From January to December 2017, an increasing proportion of Welsh citizens reported lower life satisfaction, worthwhileness and happiness than people in the rest of the UK (ONS 2018a and 2018b). It is noted that indicators unique to the HMV population are not included, however, in either the ONS or in the current 'A Healthier Wales: our Plan for Health and Social Care' (WG 2018d). This perpetuates the centralisation of services and care, which remain financially driven and medically orientated, rather than individual and condition focused.

1.3 Statement of the Problem and Justification of the Study

The QoL literature is dominated by Health-Related Quality of Life (HRQoL); particularly in relation to HMV, which drives current healthcare policy and treatment (Sandstedt et al. 2016; MacIntyre et al. 2016; Huttman et al. 2015; Bach and Tilton 1994; Bach et al 1991). HRQoL is based on a biomedical model of care, and is financially driven, constructed from an objective perspective (Lindahl et al 2005). It objectifies a subjective and highly personal situation for individuals requiring HMV. In contrast to HRQoL, individual quality of life offers a personal perspective on the daily QoL of those relying on medical and technical support to

sustain life. Both perspectives are found in the literature; the body of evidence around iQoL those with HMV and their carers is however, limited but growing (Dyrstad et al. 2012; Martinsen and Dreyer 2012; Lindahl 2010; Lindahl 2011; Ballungrud et al. 2009). This iQoL evidence base requires expansion to inform care and treatment.

It is presumed for the purpose of this study that iQoL embraces a broader remit than health, consistent with the increasing focus on well-being (ONS 2012). There is uncertainty as to whether the mainly health-related, medically focused discourse surrounding QoL enables or hinders individuals requiring HMV, and their reliance on healthcare and technology to support their wellbeing, to live a full and meaningful life.

The challenge is to develop a body of knowledge and patient reported outcome measurements (PROMs) of what iQoL means for the HMV population. Developing this evidence base would provide a stronger voice for HMV individuals, as well as guide healthcare policy and care provision. Measuring and assessing individual iQoL should allow care and treatment to be tailored to this population, maximising outcomes. This will accurately capture the essence of individual quality of life and well-being.

Wider issues noted are that the number of patients requiring some form of ventilation (invasive or non-invasive) in Wales and the UK are not recorded and remains unknown, in contrast to Norway, for example (Markussen et al. 2017). Disease registers maintained as part of the Quality and Outcomes Framework for Wales for 2017/18 (NHS 2016) do not include HMV patients. They do, however, reference patient experience, however these reports are non-specific. In the current study, the need to survey the number of invasively HMV patients in Wales and to develop a database or national patient/service is acknowledged. This is, however, beyond the scope of the current study. A database or register would enable audit to be conducted, allowing comparison and benchmarking of clinical practice and outcomes (WG, 2011a). Benchmarking of practice and outcomes would enhance quality of care and iQoL and facilitate accurate assessment and allocation of funds (Nonoyama et al. 2018). Developing and benchmarking service provision and evaluating patient well-being would elucidate the Wales (and UK) wide HMV picture. The literature reveals that the level, quality and equity of health and social care remains unexplored for this population in Wales. A previously noted, there is also a gap in the broader UK literature in relation to iQoL: the majority is medically based, focused on the HRQoL of the HMV

population (Sandstedt et al. 2016; MacIntyre et al. 2016; Huttman et al. 2015; Bach and Tilton 1994; Bach et al 1991).

1.4 Scope of the Study

The study scope was to explore the iQoL of HMV patients in Wales, through semi-structured interviews, using the Schedule for Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW (O’Boyle et al. 1993a)). The Welsh HMV population is small, consisting of individuals with diverse diseases and conditions. There were various barriers to sampling. From an initial sample of 18 HMV individuals, seven individuals consented and were interviewed. Barriers included illness, death, lack of mental capacity, lack of access to patients and refusal to participate. Access to the population was through medical consultants for ventilatory care and treatment. They acted as gatekeepers (Shoemaker and VOS, 2009) and access was granted via the Wales Research Ethics Committee to interview patients in both South and North Wales. Interviews were, however, only conducted in South Wales, owing to the barriers above. Owing to communication difficulties associated with ventilation, it was necessary to include carers in the interviews. Most interviews were therefore conducted as dyads. The findings reveal numerous concepts that affect the QoL of these individuals.

1.5 Conceptual Definition of Quality of Life

Quality of life has long been a topic of philosophical debate. Discussion of what constituted a “good life” is noted as far back as the fifth century BC (Michalos 2015, p. 1). Hippocrates, the father of medicine, recognised that individuals’ constitutions, humours, diet and seasonal climates affected well-being (Michalos 2015). Social indicators research can be traced back to the 17th and 18th centuries in the organisation of national, social, demographic and economic data (Rapley 2003), all of which feed into the measurement of QoL. Such research converged on the term ‘quality of life’ in the 1960s. Definitions of this term in the current literature vary widely, demonstrating its multidimensional nature.

Differing meanings attributed by different populations make QoL a fluid concept. Quality of life encompasses concepts such as well-being, satisfaction and happiness (Larsen 2019; Lubkin and Larsen 2013; Scott et al. 2004; Peplau 1994, Meeburg 1993, Siegrist and Junge 1989), as recognised by Hippocrates. Indeed, Peplau (1994, p.10) suggests that quality of life

"is synonymous with well-being". This is reflected in current policies; the Care Act of 2014 recognising well-being and quality of life as one and the same, and literature using the terms interchangeably (Larsen 2019; Lubkin and Larsen 2013; ONS 2012; Zeigler and Schwanen 2011; Scott et al. 2004; Peplau 1994; Meeburg 1993; Siegrist and Junge 1989).

Different QoL sub-categories are recognised, including HRQoL (Sandstedt et al. 2016; MacIntyre et al. 2016; Huttman et al. 2015; Bach and Tilton 1994; Bach et al 1991). The relationship between health and QoL is weighty enough to have been segregated by researchers and merit its own 'label': health-related quality of life (HRQoL) (Michalos 2004). Health is broadly defined as physical well-being, as well as emotional and mental health (NCCDPHP 2011). For some authors, HRQoL implies reference to the presence or absence of disease or illness (Lubkin and Larsen 2013), however, its definition is broader and includes such factors as social functioning and role limitations due to emotional as well as physical health issues (Jenkinson et al. 2011b). As a term, it is used interchangeably with quality of life (Jenkinson et al. 2011a). Despite researchers assuming that health is integral to QoL (Low and Molzahn 2007a, Low and Molzahn 2007b), study participants with certain conditions however rarely identify health as the most important aspect of their lives (O'Boyle et al. 1993a). Other participants refer to their health as being of a good level or standard, despite suffering from chronic conditions and diseases indicating a degree of shifting responses to their specific situations (Schwartz, 2010; Rees et al. 2004; Sprangers and Schwartz 1999); HRQoL is therefore viewed differently by differing authors and researchers. As HRQoL is frequently used to guide and develop patient-centred policies, guidelines and outcomes and the use of PROMs (Patients Reported Outcome Measures) (Jenkinson et al. 2011a) the importance of individual, subjective assessment becomes clear, along with more distinctly defined constituent concepts and synonyms, essential to formulating (i)QoL outcome measures.

Attempts at providing a definition include that of The World Health Organisation (WHOQOL Group (WHO) 1999, p. 3), defining QoL as follows, taking into account its subjective and multidimensional nature:

'[A]n individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, values and concerns...incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features in the environment...Quality of life refers to a

subjective evaluation which is embedded in a cultural, social and environmental context...quality of life cannot simply be equated with the terms 'health status', 'life satisfaction', 'mental state', or 'well-being'. Rather it is a multidimensional concept'.

This recognises the broadness of the construct, contradicting the interchangeable use of wellbeing to encapsulate QoL.

1.6 What is Individual Quality of Life?

According to the literature, individuals consider QoL multidimensional, and it is subjective and open to interpretation (WHO 2018; Michalos 2004; Hickey et al. 1996). In its broadest sense, elements such as physical environment (housing, area and water quality) also contribute to general happiness and well-being (WG 2018c; Michalos 2004). Individuals with diverse circumstances, resources and limitations to different elements of their lives will apply different combinations of factors to determine how satisfied they are (Masefield et al. 2017; Lamas et al. 2017; Lindahl et al 2005; Lindahl 2010; Lindahl 2011; Dreyer and Pederson 2009; Michalos 2004).

Self-perception changes with chronic illness; living with and perception of the symptoms of diseases and conditions affects how people respond to the illness (Lubkin and Larsen 2013) and gauge their QoL. Cultural and social influences also impact individual attitudes towards illness and belief systems around them. Strauss (1975) noted a culture of chronic illness, whereby time and coping strategies are reordered to create an environment that normalises the situations chronic illness creates. For those with chronic illness, a 'new normal' develops (Lubkin and Larsen 2013, p11). Assessing and exploring iQoL is therefore fundamental to understanding the impact chronic illness and, in this case, disability and HMV has on patients. The aim is to understand how a new normal is created.

Subjective iQoL is the gap between individuals' hopes and expectations, and what they are currently experiencing (Calman 1984). Exploring this gap will allow us to identify individual concerns related to QoL, as opposed to those presumed to affect individuals. Participants may have different perspectives entering the new phase of their lives brought about by chronic illness or disability. For example, patients suffering from chronic conditions may be more accepting of changes resulting from chronic illness and the need for ventilation, whilst for a previously well and active individual, being ventilated may result in different reactions. Using iQoL, which is more flexible than HRQoL, takes into account risks, burdens and the need for

resources, effectively becoming a measure of intervention efficacy and whether treatment improves the patient and their carer QoL (Larsen 2019).

Despite the lack of clarity in defining QoL, an operational definition of iQoL was required for this study, to guide ethical review and stakeholder engagement:

‘The subjective, personal evaluation of satisfaction with areas of life that are important to him/her’ (adapted from Scott et al. 2004, p. 248).

1.7 Measurement of Quality of Life

1.7.1 Taxonomy of quality of life

The breadth and nature of the term QoL, and its lack of clear definition, make measuring it difficult (Farquhar 1995). QoL has positive connotations: of being a “positive state rather than simply ‘a state’” (Farquhar 1995, p. 22). A taxonomy of QoL definitions provides some clarification of its origins:

- Type I Global definitions
- Type II Component definition
- Type III Focused definitions
- Type IV Combination definitions

Each of these is influenced by cultural and weighting factors (Farquhar 1995). Definitions reinforce the judgemental approach, potentially influencing the participant views of QoL and thus, by providing guidance as to how it is defined, could affect its measurement. Nevertheless, the combination definitions provide a relatively holistic overview of areas that could contribute to QoL. The operational definition above fits this category. The difficulty in defining this construct highlights how subjective individuals’ perspectives are in relation to QoL ratings. The subjective nature of the individual scoring tools raises reservations on their generalizability; this is beyond the scope of this study.

There are different approaches to measure QoL. In medicine, a broadly quantitative approach is applied to the measurement of quality of life, while the sociological and philosophical fields interpret QoL through a qualitative lens (Rapley 2003). Owing to the plethora of QoL definitions (Rapley 2003), a conceptual model or theory unsurprisingly does not exist, nor is there a standardised form of measurement as stated previously

(Pennacchini et al. 2011). Rather, there is a broad array of tools (Taillefer 2003). Examples range from the SEIQoL-DW (O'Boyle et al. 1993a) to those that focus on quantitative measurement; for example, SF-36 (RAND 2018), quality-adjusted life year or quality-adjusted life-year (QALY³), disability-adjusted life years (DALY⁴) and EuroQOL EQ-5D (Euroqol 2018 and 2011) and others that are disease specific, some of questionable quality (Fava 1990).

The perspective from which QoL is viewed, its definition and the measurement tool used will affect its measurement of QoL. For example, measures and interpretations of health-related QoL are explained variously (Michalos 2004). If the WHO (2018) definition of health - which includes all elements (physical, mental and social well-being, and not simply the absence of disease (WHO 2018)) - is accepted, then one's QoL may be excellent, and its measurement will be accurate. However, if any of its aspects, physical, mental and/or social, are compromised, the HRQoL measurement will be inaccurate (Michalos 2004). Measuring HRQoL only within this study, would be limiting; only one QoL domain would be explored. Assuming that HRQoL provides a subjective perspective on objectively measured elements of the lives of HMV patients, this would provide a limited view (Michalos 2004). Equating only physiological QoL (self-perceived health status) in the HMV population through, for example, a lack of ventilator-acquired pneumonia or respiratory infection, with a good quality of life, would be remiss.

Measuring the QoL of 'average' individuals living in different social circumstances excludes specific populations, who may view life differently. Ingersoll (1991) noted that the psychosocial aspect of quality of life is a vital facet of overall QoL. Applying this to HMV patients, and in combination with physical and social problems, it may provide a clearer explanation of their iQoL of life. However, it is difficult to remove the objective aspect of measurement from this subjective experience entirely (Michalos, 2004). The SEIQoL-DW (O'Boyle et al. 1993a) is, nevertheless, a good starting point for subjective assessment in this context, and has proven a valid and reliable data collection tool, providing a platform for the measurement of individual quality of life in this study (Wettergren et al. 2009).

³ A QALY is a generic measure of disease burden. It includes the quantity and quality of the life lived.

⁴ A DALY is a disability-adjusted life year. It measures overall disease burden, and is presented as the number of years lost by individuals owing to ill-health, disability or early death.

1.8 An Historical Overview of Ventilation

At the core of this study's development is ventilation. It defines the population being studied, extending their lives. The fascination with ensuring health and prolonging life throughout history is well documented (Michalos 2015). Mechanical ventilation as a means of prolonging life has progressed significantly over the last hundred years. Its foundations, however, lie far further back in history. Documented histories of ventilation can be traced to Chinese, Egyptian and Greek writings (Koupparis 2010; Kotur 2004). The Bible references ventilation in the Old Testament, when the Prophet Elisha (Kings 4:34-35) produces pressure by breathing into the mouth of a dying child from his own. Further evidence is noted in 'Treatise on Air' by Hippocrates (460-375 BC), with the first written documentation of endotracheal intubation (Kotur 2004).

Mechanical ventilation itself dates back to the 16th Century (1550) with the first study documenting mechanical ventilation by Paracelsus (1493-1541). He documented the use of 'Fire Bellows' in assisted ventilation, in which a tube placed in the patient's mouth was attached to the 'bellows'. John Fothergill (1744) wrote about mouth-to-mouth resuscitation, which resulted in the development of the Humane Society (Dutch Society for the Rescue of Drowned Persons), founded in 1767. These techniques form the basis of today's ICU treatments (Kotur, 2004). The 1800's however, heralded a new era, during which the body was considered a machine that also contained a spiritual being: the ancient Greek concept of Cartesian Dualism. This interaction between mind and (physical) body strengthens the need to recognise the holistic needs of the individual.

The evolution of medical treatment for individuals with respiratory failure however has focused on the physiological elements, and progress in the early 20th century gave rise to the development of mechanical ventilation. The creation of commercial companies such as Dräger (Bahns, 2007) has continued the development over the past 100 years, from the original Pulmotor ventilator in 1911 to the current advanced technologies that are responsive and sensitive to the patient's respiratory status. Normal ventilation in well individuals occurs via a negative pressure system, and early developments in mechanical ventilation included negative pressure appliances that exerted pressure to the body, specifically the thoracic region; these were known as 'Iron Lungs' (Drinker and Shaw tanks)

(Kotur 2004). These machines successfully ventilated patients at home for periods of 25 to 30 years. Two forms are most familiar: the Chest Cuirass, in which only the patient's thoracic region is encased, and the whole body system, in which the patient's entire body is encased in a cylinder or box (Iron Lung), with his or her head protruding (Kotur 2004).

The poliomyelitis epidemic in Copenhagen between mid-July and early December 1952 claimed hundreds of lives, but also transformed ventilation and launched a new era of treatment (Ibsen, 1954). In the epidemic, 2711 patients were diagnosed, of whom 315 required ventilatory support in the Community Disease Hospital, requiring the first mass use of Iron Lung ventilators. In contrast to the negative pressure ventilation of the early 20th century, positive-pressure ventilation (PPV) was developed, which increases the patient's airway pressure (in the lungs) via an endotracheal or tracheostomy tube. The increase in positive pressure allows air to flow into the airway and lungs, creating a tidal volume of air, until the breath is terminated by the ventilator. The airway pressure then drops to zero, and with the elastic recoil of the chest wall and lungs, the breath and air is pushed out through passive exhalation (Kotur, 2004). Until the 1960s, negative pressure ventilation was the most widespread mode of artificial ventilation; however, it was limited (it was difficult to handle and to observe the patient closely enough) and it fell into disuse when PPV was developed (Linton 2005). The advent of PPV led to modern critical care units, and manual ventilation was superseded by the precursors of modern day ventilators (Berthelsen and Cronqvist 2003). In the late 1960s and early 1970s, the development of Positive End Expiratory Pressure (PEEP), a pressure provided by the ventilator that holds open the alveoli in the lungs to maximise respiratory gas exchange, also influenced current practice (Mora Carpio and Mora 2017).

Technological advances have improved the experience of ventilation for the patient, as well as for healthcare professionals, allowing the healthcare professional to focus on and optimise other care and treatments (Bahns 2007). These developments have allowed patients to move from hospital based, institutionalised care to their own homes. This marries with the direction that policy is now taking.

1.9 Policy Drivers

An overview of the key healthcare policies and papers that have shaped the care of the chronically ill in Wales since Welsh Government devolution in 1997, is presented below.

There is notable overlap between the English and Welsh policies, resulting at times in a lack of clarity and direction of political drivers.

In 2000, a Command Paper was published by the UK Government. The Department of Health released the NHS Plan, a programme of modernisation and investment over a ten-year period, formalised in 2001 by the Health and Social Care Act. This has been superseded by the 2014 Care Act and the 2018 NHS ten year plan (The Kings Fund 2018). The NHS Plan (2000) was supplemented by WAG's ten year plan, 'Designed for Life' (2005), which envisaged the creation of a world-leading health and social care service for Wales, fit for the 21st Century and with a focus on managing chronic conditions. Designed for Life, like most other political drivers, does not specify the care and treatment of HMC patients, as they do not precisely fit the definition of chronic conditions. Furthermore, no reference to quality of life is made. The National Health Service (Wales) Act 2006 further defined the Welsh Government's responsibility to promote a comprehensive health service that would improve the people of Wales' mental and physical health, and improve the prevention, diagnosis and treatment of disease. It did not define any specific provision for continuing healthcare or social care.

Other WG developments such as 'Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework' in 2007, has been published. In addition, four Chronic Conditions Directives were released by the Welsh Assembly Government, including a chronic respiratory conditions directive (WG 2010). The HMC population do not benefit from such directives, as respiratory failure is a secondary symptom of their primary diagnosis. Nevertheless, the Chronic Conditions Directives do play a role in the care of chronically ill individuals and, with the systematic structure and guidance of the National Service Frameworks (NSFs), improve healthcare quality and standards.

In attempting to develop a more coherent service, healthcare and social care was defined in the UK Government Health and Social Care Act 2008 as:

all forms of health care provided for individuals, whether relating to physical or mental health, and also includes procedures that are similar to forms of medical or surgical care but are not provided in connection with a medical condition. “Social care” includes all forms of personal care and other practical assistance provided for individuals who by reason of age, illness, disability, pregnancy, childbirth, dependence on alcohol or drugs, or any other similar circumstances, are in need of such care or other assistance. “Health or social care” means health care or social care (p. 4).

This definition is significant to the development of HNV patient services, as there is a drive to employ non-qualified, trained care staff in the care of HNV patients, to lower costs. This was reiterated by the WG in its Prudent Healthcare drive in 2016 (updated 2018). However, the patient’s preferences have not been recognised in the proposed changes. Following the publication of the Health and Social Care Act 2008, a UK-wide document, ‘Thanks for the Petunias: A guide to Developing and Commissioning Non-Traditional Providers to Support Self-Management of People with Long-Term Conditions (LTC)’, encouraged a more cohesive and integrated approach to healthcare, through recognising the subjective experiences of individuals rather than focusing on their condition or disease (NHS 2011b). It also emphasised the increased blurring of the pathway between medical and social models of health for people with LTCs. This is visible in the current political notion of joint social and healthcare budgets and new models of care delivery (WG 2018b; Cameron et al. 2017).

Changes in the way health and social care are provided are currently highly visible politically (WG 2018d). Further devolution in 2011 provided the Welsh Government (WG) with law making powers that include health. Numerous Welsh Government and NHS published documents prior to and post devolution (WAG 2003a and WAG 2003b; WG 2007; WG 2009; WG 2010; WG 2011a and WG 2011b; WG 2012; WG 2013; WG 2015) outline the programme of development of healthcare and services from 2003 to 2016 and beyond. These focus on health for all, patient experience and access to services, and service safety and quality. All of these benefit health outcomes. Yet again, there are no specific measurement indicators and outcomes related to QoL in the government documents, despite reference to patient experience. There is no mention of chronic long-term

mechanical ventilation: these populations remain subsumed under other categories. There is however, an increased drive to include patient and carer perspectives on QoL.

In more recent publications (WG 2014, 2015, 2018d, 2018e), the term 'well-being' is used, in contrast to a multidimensional QoL definition encompassing life satisfaction (WHO 1999). The WG publications reflect the work of the ONS, who established the Measuring National Wellbeing (MNW) programme in 2010 (UK Government 2010), offering a six-monthly comparison across the four countries of the UK. Four measures of well-being are assessed: life satisfaction, feeling that what one does in life is worthwhile, happiness and anxiety. However, in 2014-2015, the only country to report a life satisfaction significantly lower than the other three UK countries was Wales, with a score of 7.55 compared to 7.61 (ONS 2015). Numerous factors contributed to this lowered score, ranging from social issues and environment to finance and health. The four measures of well-being have since been incorporated into numerous government, academic and third and business sector surveys (ONS 2015). As general indicators, they provide a useful guide. However, they do not accurately indicate the well-being of individuals in the population under study, and the gap between their lived reality and their hopes and expectations. Interestingly, other countries consider happiness and general wellbeing an important aspect of life, and they are incorporated into economic and social policy, including traditional areas of socio-economic interest alongside cultural and psychological wellbeing (Oxford Poverty and Human Development Initiative 2018).

The Measuring Wellbeing National Outcomes Framework (WG 2016a) includes a well-being statement that complements and builds on the original definition of well-being in the Social Services and Well-Being (Wales) Act 2014. This statement describes national well-being outcomes that relate to each and every area of a person's life⁵ (WG 2016b). The 41 indicator measures include both objective data (for example, unemployment rate) and subjective data (for example, satisfaction with job) to provide a more complete view of the nation's

⁵From the Social Services and Well-Being Act 2016, the 8 aspects of an individuals' life that are included are: physical and mental health and emotional well-being; protection from abuse and neglect; education, training and recreation; domestic, family and personal relationships; contribution made to society; securing rights and having a social life and enough money to live healthily; and having a good home.

progress than economic measures such as gross domestic product (GDP) can do alone. It documents individuals' thoughts and feelings on QoL and is a measure of the concerns of the population as identified by the ONS (2015). However, the outcomes indicators are quantitative in nature, yielding statistical comparators to evaluate the general well-being of the Welsh nation, rather than an individual and condition-specific approach. Each of these strategies and The Act 2014 are complemented by other laws, such as the broader Well-Being of Future Generations (Wales) Act 2015, which documents well-being duty and goals that may influence ONS statistics.

Quantitative measures of life satisfaction provide some guidance for the development of healthcare services, but do not capture individual qualitative perspectives on QoL. WG currently advocates for specific mention of QoL alongside partnership, engagement and responsibility for and with their own care (2003a and 2003b; 2018d). The Social Services and Well-Being (Wales) Act 2014 and 'Our health, our health service' (WG 2015) recognise the centrality of the patient in any decisions that affect their care. The Social Services and Well-Being (Wales) Act 2014 focuses on social services, however there is recognition of the multi-agency approach required to deliver care and support. It reflects the emphasis given to quality of life by the earlier Wanless (WG 2003a) report and the 'Review of Health and Social Care in Wales' (WAG 2003a), which warned of escalating health care costs owing in part to chronic conditions and an ageing population (WG 2003a and 2018). The increased costs have come to fruition and are fuelling the politically dominated, financially-driven medical model of disability and approach to changes in health and social care provision in relation to care of individuals with long-term chronic conditions.

Another generic measure of health and well-being is the annual National Health Survey for Wales. The National Health Survey provides overall satisfaction scores with health, social care and support, and noted that, for the year 2016/17, satisfaction rating was lower in comparison to the 2014/5 data (Welsh Health Survey 2017). This demonstrates a drop in satisfaction from 2014/15, in relation to those receiving care and their carers, with a drop in perceived QoL as a result of the care they received. To demonstrate a true decrease in satisfaction scores, however, data trends over a greater period of time are required. Furthermore, scores are only a general indicator of satisfaction, and are not specific to individual populations. There is also a need to recognise the individual status of the HMV

population and other social indicators such as their social class, and to look beyond health issues, which an individual QoL evaluation provides. There is value in considering the link between social class and issues such as financial security and poverty. In Wales, poverty remains an intractable problem. According to the Joseph Rowntree Foundation, approximately 23% of the population (700,000 individuals) lived in poverty in 2015. The impact of poverty is felt across the well-being spectrum, through physical and mental health and well-being, and on the individual's ability to provide for their own health and well-being needs. Individual quality of life should therefore present a broader perspective, by including specific factors and recognising discriminatory structures such as ethnicity, gender and culture.

As is gleaned from the background information, specific mention of HMV is lacking in all the Welsh (and English) Government drivers and documents reviewed. Development of critical care services is documented in the somewhat dated document 'Designed for Life: Quality Requirements for Adult Critical Care in Wales' (WAG 2006). Yet, there is no mention of discharge to the community from critical care in the document, or of the complex needs of this specific patient population, despite the home ventilation of patients for a number of years prior to the document being published. Similarly, NICE Guidance on Rehabilitation in Critical Care (2009 and 2017) lists nine functional assessment points, none of which refers to QoL or well-being, although the psychological elements of care are recognised in the assessment. There is no further recognition or development of critical care services outside the hospital environment, contradicting the nature and focus of rehabilitation: to return individuals to their previous level of functioning.

Owing to the complexity of care required for this niche population, funding provision falls to the NHS, as opposed to social care. Continuing Healthcare (CHC) (WG 2014), the government policies that guide NHS processes and responsibilities surrounding financial support in Wales, offers financial support to individuals who require continuing care from registered and qualified nursing and medical staff. However, the move towards a combined health and social care budget (WG 2018a and 2018b) is slowly being realised, and there is a lack of detail available regarding how this will affect CHC funding. Movement towards employing unqualified care staff to care for HMV patients is nevertheless emerging in local practice. How these changes are implemented is questionable, with affected individuals

commenting on a lack of communication, which demonstrates a lack of adherence to policy and guidance in documents such as 'No Decision about Me without Me' (DoH 2012). More specifically, there is increased emphasis in current policies and guidance on the services provided by GP practices, stressing co-production and partnership among patients, public and professionals (WG 2018d; Royal Pharmaceutical Society 2016, The Welsh NHS Confederation 2015 and 2016; WG 2015). This is consistent with recognition of the increasing complexity of the health and care needs of the general population, support for whom could partially be met by primary and community care services (The Welsh NHS Confederation 2015 and 2016). How the changes affect the HMV population, and how effective they are, have yet to be evidenced.

1.10 Current Home Mechanical Ventilation (HMV) Evidence Base

As a result of developments discussed, ventilatory support can today be delivered in hospitals, institutions or at home, to prevent the respiratory failure that occurs as a result of a myriad conditions. This study includes patients with respiratory muscle failure and acute-on-chronic respiratory failure. The Eurovent study (Lloyd-Owen et al. 2005) identified 21,526 HMV patients across Europe who required HMV between June 2001 and June 2002, equating to 6.6% per 100,000 persons who required ventilation. In 2002, UK-wide estimates of chronically ventilator dependent individuals were 2400, although it was recognised that this could be an underestimation (NHS 2002). In Wales, statistics indicated that 92 adults required and received invasive and non-invasive HMV and associated care between 2006 and 2008 (SEWNMLC 2008). As there is no UK- or Wales-wide register of the HMV population to provide accurate figures of how many individuals are ventilated at home, and with long-term complex care becoming increasingly common in the UK as medical treatment and technology progresses rapidly, these figures will have increased (Maclaren et al 2018; NHS 2011b; Lone and Walsh 2011; Simonds 2006).

Not all patients with respiratory failure require invasive ventilation. There is an extensive body of literature on non-invasively ventilated HMV patients (Windisch 2008; Simonds 2006; Simonds 2003). There is, however, a growing body of qualitative evidence on the quality of life of invasively ventilated (HMV) patients, emerging predominantly from Scandinavia (Lamas et al. 2016; Briscoe and Woodgate 2010; Lindahl 2010; Lindahl 2011; Dreyer and Pederson

2009; Ballangrud et al. 2009; Lindahl et al 2005). Non-invasive and invasive ventilation are frequently grouped together in studies, making it difficult to extract data relevant to invasive HMV (Masefield et al. 2017; Markussen et al. 2017; Cazzoli and Oppenheimer 1996). There is a wealth of literature on HMV children and adolescents (Noyes et al. 2006, Gatford 2004, Kirk and Glendinning 2004). However, only two studies were found on the QoL of HMV patients based in the UK (Maclaren et al. 2018; Lone and Walsh 2011), and none relating specifically to patients in Wales. There is therefore a gap in the UK and Welsh literature of the QoL, treatment and care of invasively HMV patients.

1.11 Summary of Chapter

Current practice reveals a move towards primary care and away from secondary, hospitalised care. This affects all patient populations, including the HMV population. The individual quality of life of this specific population has not been adequately explored in the UK, particularly how the political discourse surrounding their reality affects their ability to pursue a 'normal' life. The emphasis of Government drivers on wellbeing is far greater in the more recent and current publications and policies, stressing co-production and partnership among all individuals. However, the HMV population is not well recognised. Long-term conditions are clearly recognised in their complexity, but acknowledgement of and data on the iQoL of the chronic critically ill population, with their diverse needs, remains sparse.

CHAPTER TWO

2. Literature Review

The purpose of this study is critically to explore and gain a greater understanding of the perceived iQoL of home mechanically (invasively) ventilated (HMV) participants. The exploration of the relationship between HMV and perceived iQoL of patient participants will be guided by the following questions, which clarify and define the scope of the study:

From the participants' perspective:

1. What is the impact of HMV on their iQoL?
2. What practices do HMV individuals use to sustain and enhance iQoL?
3. In discourses on iQoL, what facilitates and hinders individuals in maximising their iQoL?

2.1 Search strategy

To answer the research questions, a comprehensive and systematic approach to reviewing the literature was taken. Owing to the qualitative approach, qualitative literature was searched. Quantitative literature was also used, to supplement critical discussion. To formulate and define key elements of the literature review questions, an appraisal of the tools available was undertaken. The PICO framework (Richardson et al. 1995), which is most effectively applied to structure study questions that have planned interventions and comparisons, was rejected. Other frameworks reviewed included: PICOC (Center for Evidence-Based Management 2018), PICOT (Fineout-Overholt and Johnson 2006) and ECLIPSE (Wildridge and Bell, 2002). These, too, were rejected, as they provide a structure more suited to quantitative studies, such as interventions and health service management. SPIDER, which is used in qualitative evidence synthesis, was also reviewed and rejected as it continues to require further refining and testing (Cooke et al. 2012).

An adapted version of the SPICE framework (Booth 2004) was applied, as it has a greater affinity with social science. However, application of such a specific and formal framework to define the search terms was not entirely suitable. In Table 1, below, is the adapted SPICE framework (Booth 2004). As qualitative literature does not generally include comparisons, the framework has been adapted by removing the comparative element.

Table 1. SPICE framework:

Setting	Perspective	Intervention	Comparison	Evaluation
Home	Patient	Artificial respiration	N/A	Individual Quality of life
Community	Quality of life (NOT Health related QoL)	Mechanical ventilation (ventilat*)		
Primary Care	Experience or perspective	Invasive ventilation (ventilat*)		
	Patient's perspective	Ventilation or mechanical ventilation		
	Wellbeing or well being or well-being	Assisted ventilation		
	Wellness	Home mechanical ventilation		
	Satisfaction / life satisfaction	Chronic ventilation		
	Happiness	Long term ventilation or long term home ventilation		
	Dependent	Transition to long term ventilation		
	Lived experience			

The key words and Medical Sub-Headings (MeSH) terms used to define the scope of this initial qualitative literature search and review are listed in Box 1, below. Truncation was applied, to retrieve terms which have a common root, e.g. ventilation/ ventilated/ ventilator = ventilat*. The Boolean operators 'AND' and 'OR' were used in combination with 'N2', to find terms within 2 words proximity to one another, to ensure accuracy and depth of review. MeSH terms searched were: Artificial respiration.

Box 1 Search terms

<p>Ventilation:</p> <ul style="list-style-type: none"> • Artificial respiration (MeSH) • Ventilation • Home mechanical ventilation • Mechanical* N2 ventilat* • Invasive* N2 ventilat* • Home N2 ventilat* • Community N2 ventilat* • Primary care N2 ventilat* • Transition to long term ventilation • Long term ventilation • Long term home ventilation • Chronic ventilation • Neuromuscular disorders • Amyotrophic lateral sclerosis • Assisted ventilation • Duchenne’s muscular dystrophy 	<ul style="list-style-type: none"> • Quality of life: • (MH “Quality of life”) • (MH “Human Needs (Psychology)+”) • (MH “Human Needs (Physiology)”) • Lived experience* • Wellbeing • Well being • Wellness • (MH “Life Experiences”) • Life satisfaction • Happiness • Long term effects • Individual quality of life • Experiences of living with chronic illness • Patients’ perspectives • Decision making • Patients’ perspectives on use of mechanical ventilation • User satisfaction and mechanical ventilation • Dependent/ dependen* • Experience • Experience of perspective
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Owing to the breadth of the topic and numerous methods of measurement of QoL, a large body of quantitative evidence addressing the topic was found, which informs the field and was retained and used to deepen the discussion. Numerous citations excluded from the review were retained for reference in the discussion. As stated, there is a paucity of qualitative literature on the QoL of HMV individuals, specifically related to the UK; few UK based qualitative studies were found during the search. An abundance late 1990’s and 2000’s US literature was found, and a body of qualitative evidence from Scandinavian countries, from the mid-2000’s onwards. The focus of the Scandinavian research literature is on individuals who have transitioned to the community setting, and require treatment and care related to their need for mechanical ventilation. Additionally, a body of European evidence was located, written mainly in German, along with Japanese citations that do not have an English translation.

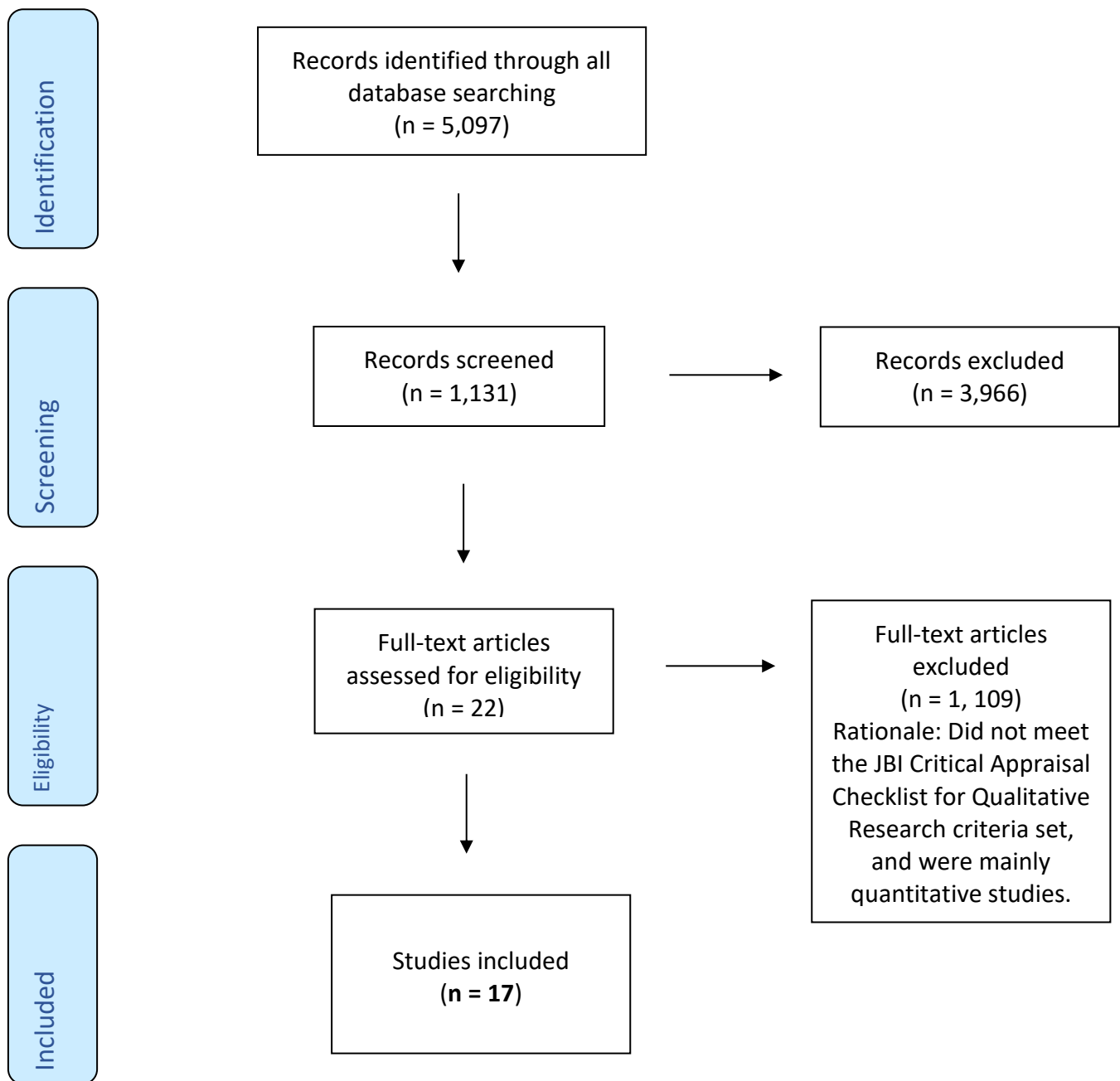
All citations used in the literature review were required to meet inclusion criteria. It is assumed for this study that iQoL embraces a broader range of factors than health, and as such, health-related QoL (HRQoL) has been excluded from the formal appraisal in the literature review. However, studies that refer to HRQoL have been retained for the discussion. The majority of health-related status measurement tools and instruments were created for and validated on populations that did not require invasive ventilation (Bach and Tilton 1994; Bach et al. 1991), which limits their generalisability to the population studied.

Box 2 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Types of Study: Primary qualitative, research studies Phenomenological Grounded theory Ethnographic Descriptive studies Narrative studies	Quantitative studies
Research published in the English language	Health-Related Quality of Life (HRQoL)
Invasive ventilation	Paediatrics
Tracheostomy	Non-Invasive Ventilation
Patient’s perspectives	Discussion papers
English language papers	Literature reviews
	Letters and commentaries

No date restrictions were applied to the year of publication, to enable a comprehensive review of perspectives of home mechanically invasively ventilated individual’s QoL to be constructed. Further concepts and areas of investigation identified during analysis of the study data have been searched separately and are presented in chapter 7 and applied in the discussion. The final numbers of citations included in the systematic review of the qualitative literature are presented using a PRISMA diagram (Diagram 1). However, evidence shows that when papers from a systematic review of complex evidence are sourced via an audit of primary sources, only 30% are generated through the defined protocol (Greenhalgh and Peacock 2005). Other strategies such as ‘snowballing’ (back chaining) and individual knowledge or contacts in the specialist area made up the majority of search citations, and librarian support was sought in conducting the search. All searches can be found in Appendix 1 and 2.

Diagram 1 PRISMA Diagram of the sourcing of citations



Each database has its own architecture, and in sourcing the necessary studies using CINAHL and MEDLINE via a combined search, it required the application of a combination of search terms drawn from the set research questions and wider reading. A total of 57 separate searches were conducted to exhaust combinations of search terms applied. The search of CINAHL & MEDLINE resulted in an initial 1563 citations using combinations of the MeSH and specific search terms listed in Box 2. Following an initial review of the title and abstract search of CINAHL and MEDLINE, 78 articles were drawn for further review prior to critical

appraisal, and 21 were drawn for critical appraisal. Seventeen studies were included in the final review.

Additional searches included one of the Joanna Briggs Institute (JBI) Evidence Based Practice (EBP) database with the term 'quality of life'. This revealed 1525 citations of general QoL issues. A further search of the JBI database exposed two systematic reviews using the search terms 'home mechanical ventilation' (two citations found (Mu et al. 2008 and 2010)); in combination with 'quality of life', using the command 'AND', no additional sources were revealed. Both citations had the same author and appeared as updated versions of the same review. Neither was included in the main review, as the studies were quantitative and QoL was not explicitly mentioned. However, they were retained for background information and possible application in the discussion. A search of Google Scholar (30th July 2018) using the search terms 'home mechanical ventilation in adults' and 'Quality of Life in the UK' resulted in 32,300 citations, an increase from the 16,700 found in the previous search (18th August 2017). It was impossible fully to review this volume of citations. A brief review, however, reveals that numerous of the studies and articles fall outside the inclusion criteria set, and refer to quantitative, intensive care based and child-focused literature.

The National Institute for Health and Care Excellence (NICE) website and repository was searched using the following search terms: 'mechanical ventilation' (54 citations), with a filter of three years, to ensure that results from a clinical guidance perspective were current. This yielded 14 citations. A further search of this repository, using the search term 'respiratory', revealed non-specific guidance that did not refer to mechanical, invasive and long-term ventilation. What was returned was guidance specific to disease processes and conditions, e.g., Motor Neurone Disease (MND), which refers to non-invasive ventilatory support guidance (NICE 2016 NG42).

A document on Rehabilitation after Critical Illness in Adults (NICE 2009 & 2017) was also found, providing some background information. Further searches of the NICE Pathways documentation resulted in 119 citations being located, none of which have any clear relevance to long-term invasive ventilation. The search identified and drew on previously identified documents, e.g., NICE MND (NG42) from February 2016. A further search using

'invasive ventilation' identified 45 citations, specific to disease processes and did not refer to the long-term invasive ventilation of any of the populations included in the study sample.

On searching the NICE website using the search terms 'quality of life' (accessed 20th July 2018), an initial 1716 documents were identified. With the application of filters (all guidance), this reduced the search to 941 documents. A detailed search of these citations did identify some alternative documents; however, most were duplicates and of limited value to this literature review. A search for wellbeing resulted in 585 citations, and 16 citations were found using the search terms, 'ventilation' and 'wellbeing'. No documents specific related to long-term ventilation were found.

Alerts were set up on specific journals and search engines such as Google Scholar, which retrieved only quantitative literature, background material, or studies that did not meet inclusion criteria. OpenGrey was not accessed, owing to the volume of evidence related to general, non-specific QoL literature. AMED was not accessed, as it is relevant to allied health professionals, complementary medicine and palliative care. Table 2 below lists the searches conducted and the number of citations sourced from each database. The final number of citations used in the review are also listed in Table 2.

Table 2 Citation search

Database searched	Initial citations found	Citations for full text analysis	Citations selected for critical appraisal	Duplications	Back-chained citations	Citations for literature review
CINAHL and MEDLINE (combined search)	1563	78	21	0	4	17
TRIP Database Plus	378	24	1	1	0	0
BNI	325	4	0	0	0	0
EMCARE	7	1	0	0	0	0
Scopus	46	4	0	0	0	0
NICE	2519	1016	0	0	0	0
JBI	2	0	0	0	0	0
Cochrane	53 reviews 204 trials	0 reviews 4 trials	0 0	0 0	0 0	0 0
Total number of sources	5097	1131	22	1 (removed)	4	17

2.2 Critical Appraisal

Following a review of the numerous available critical appraisals and data extraction tools, including the JBI and the Scottish Intercollegiate Guidelines Network (SIGN), the JBI Critical Appraisal Checklist for Qualitative Research was applied (see Appendix 3). This a familiar tool and provides a detailed focus on qualitative research. From the ten questions listed on the JBI Critical Appraisal Checklist for Qualitative Research, five were deemed essential prior to progressing to the data extraction stage. From the themes identified, a narrative review incorporating reference to quantitative studies to support discussion is presented. Table 3 provides details of the qualitative studies used in the review. Appendix 4 provides a detailed summary of the studies.

2.3 Emerging Themes

The themes identified at the critical appraisal stage were:

Decision making, adaptation, quality of life (QoL), relationships, dependence/independence, future/optimism, demands on family/carer, verbalisation/communication, physical impairment and trust and confidence/competence in healthcare personnel.

These have been further condensed, to enable greater depth of discussion and to make the literature more manageable to read. The following themes provide the structure of the literature review:

- Decision making
- Future/optimism
- Adaptation
- Relationships

Table 3 Qualitative citations following critical appraisal

Author	Date	JBICATool Score minimum score=7	Title
Briscoe, W.P., & Woodgate, R.L.	2010	10	Sustaining self: the lived experience of transition to long-term ventilation. <i>Qualitative Health Research</i> . 20 (1): 57-67
Ballungrud, R., Bogsti, W.B., & Johanson I.S.	2009	9	Clients' experiences of living at home with a mechanical ventilator <i>Journal of Advanced Nursing</i> . 65 (2): 425-434
Brooks. D., King, A., Tonack.M., Simson., Gould, M. and Goldstein, R.	2004	8	User perspectives on issues the influence the quality of daily life of ventilator-assisted individuals with neuromuscular disorders. <i>Canadian Respiratory Journal</i> . 11 (8): 547- 554
Dale, C.M., King, J., Nonoyama M., Carbone S., McKim D., Road J., & Rose L.	2018	8	Transitions to home mechanical ventilation: the experiences of Canadian ventilator-assisted adults and their family caregivers <i>Ann Am Thorac Soc</i> . 5, No 3, pp 357–364, Mar
Dreyer, P.S., Steffenson, B.F., and Pedersen, B.D.	2010a	9	Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation <i>International Journal of Qualitative Studies on Health and Well-Being</i> . 5 (3): 5388
Dreyer, P.S., Steffenson, B.F., and Pedersen, B.D.	2010b	9	Life with home mechanical ventilation for young men with Duchenne muscular dystrophy. <i>Journal of Advanced Nursing</i> . 66 (4): 753-762.

Author	Date	JBICATool Score	Title
Dreyer, P.S., & Pedersen, B.D.	2009	9	Distanciation in Ricoeur's theory of interpretation: narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. <i>Nursing Inquiry</i> . 16 (1): 64-73
Dyrstad, D.N., Hansen, B. S. and Gundersen, E.M. 2013.	2012	8	Factors that influence user satisfaction: tracheotomised home mechanical ventilations users' experiences. <i>Journal of Clinical Nursing</i> 22, 331-338
Finkelstein & Marcus	2018	8	Realizing autonomy: the phenomenology of independence and interdependence while living with Duchenne muscular <i>Disability & Society</i> , 33:3, 433-453, DOI: 10.1080/09687599.2018.1427049
Lemoignan, J., & Ells, C.	2010	7	Amyotrophic lateral sclerosis and assisted ventilation: how patients decide. <i>Palliative and Supportive Care</i> 8: 207-213
Lindahl B.	2010	10	Patients' suggestions about how to make life at home easier when dependent on ventilator treatment – a secondary analysis. <i>Scandinavian Journal of Caring Sciences</i> . 24: 684-692.
Lindahl B.	2011	9	Experiences of exclusion when living on a ventilator: reflections based on the application of Julia Kristeva's philosophy of caring science. <i>Nursing Philosophy</i> . 12: 12-21.
Lindahl B., Sandman, P-I., & Rasmussen, B.H.	2005	8	On becoming dependent on home mechanical ventilation. <i>Journal of Advanced Practice</i> 39 (1): 33-42
Martinsen, B., & Dreyer, P.	2012	8	Dependence on care experienced by people living with Duchenne muscular dystrophy and spinal cord injury. <i>Journal of Neuroscience Nursing</i> 44(2): 82-90.
Schaepe, C. and Ewers, M.	2017	8	'I need complete trust in nurses' – home mechanical ventilated patients' perceptions of safety' <i>Scandinavian Journal of Caring Sciences</i> . 31; 948–956

Author	Date	JBI CA Tool Score	Title
Young, J.M., Marshall, C.L. & Anderson E.J.	1994	7	Amyotrophic lateral sclerosis patients' perspectives on use of mechanical ventilation <i>Health and Social Work</i> 19 (4): 253-260
Van Huijzen, S., & van Staa, A.	2013	9	Chronic ventilation and social participation: experiences of men with neuromuscular disorders. <i>Scandinavian Journal of Occupational Therapy</i> . 20: 209-216

2.4 Overview of Studies and Themes

The main studies are qualitative in nature, with most identifying clear qualitative methodologies. QoL is identified through its composite concepts and individual issues raised by study participants, as opposed to being overtly labelled as 'quality of life'. The studies included applied mainly semi-structured interviews as the method of data collection. Findings are discussed using a thematic approach, supported by excerpts, thereby recognising the voice of the participants in the data transcribed from the interviews. The conclusions drawn are linked to the analysis of participant responses. The trustworthiness and authenticity of the findings are, for the most part, demonstrated by the input of a second and third researcher, to ensure that data codes and themes reflect participant statements. Credibility in the studies is enhanced because the authors are experts in the field of research and/or the care of HMV individuals, and have first-hand experience of the topic.

Some limitations exist. One of the mixed methods studies (Young et al. 1994) is dated, and there is less congruity between the research methodology and analysis/representation and interpretation of the findings of the data in this study. However, there was enough strength to include the study in the review (see Table 3 and Appendix 4). Other limitations include varying degrees of transparency of justification by the authors for the chosen methodology. However, reliability is reinforced by stepwise discussion of the data analysis process. Generalisability is possible for the niche population under study, with recognised themes reflected in the findings of my own study. The populations do, however, differ in terms of the disease process requiring participants to be ventilated, which may limit transferability (van Huijzen and van Staa 2013; Dreyer et al. 2010a and 2010b; Lemoignan and Ells 2010; Lindahl 2010). Dependability varies, and different levels of detail are provided across studies; further exploration with the original authors would have enhanced dependability. Confirmability, and the degree of bias is, for the most part, identified through recognising the author's potential influence on the data. Some studies demonstrate clearly how this has been taken into account (Ballungrud et al. 2009; Dreyer et al. 2010a).

The findings of the included studies focus more on the issue of disability per se, as opposed to dependence on HMV, with HMV seen as a key contributor to the renewed energy and vitality of the patient population (Briscoe and Woodgate 2010; Ballungrud et al. 2009;

Dreyer et al. 2010a; Lindahl 2010; Lindahl et al. 2005; Martinsen and Dreyer 2012). Quality of life issues also focus on areas other than HMV, such as healthcare provision, conceptual topics, decision making and family/relationships.

This literature review is not a true systematic review, but takes a systematic approach. Some quantitative studies have been referenced to facilitate the discussion. Caution is thus required when interpreting these studies, as interview questions and measurement scales were often designed specifically for some quantitative studies (Hirano et al. 2006), limiting generalisability. Comparisons are also made across populations (Huttmann et al. 2015), negating the individual and disease-specific circumstances each disease process and treatment brings. No study has been identified that applies a questionnaire or tool specific to HMV, a fact recognised by Markussen et al. (2017). Comparison with qualitative studies are also limited owing to the focus on HRQoL in the quantitative literature. Caution is also needed in application of the results of studies using validated, reliable data collection tools to questions of individual, person-centred care (Sandstedt et al. 2016).

2.5 Decision Making

Decision making was a recurrent theme in seven of the qualitative studies (Lindahl et al. 2005; Ballangrud et al. 2009; Dreyer et al. 2010b; Briscoe & Woodgate 2010; Dyrstad et al. 2012; Martinsen and Dreyer 2012; van Huijzen and van Staa 2013), and recognised in the quantitative literature (Israelsson-Skogsberg et al. 2018; Goldstein 1998; Miller et al. 1990). Two main threads can be found within this theme:

1. Decision making around accepting ventilation
2. Decision making as part of everyday life

2.5.1 Decision Making Around Accepting Ventilation

In their narrative approach, Lindahl et al. (2005) studied the meaning of becoming dependent on mechanical ventilation. Clear documentation of the data analysis process through naïve interpretation, structural analysis and comprehensive interpretation yielded well-defined themes, further developed into composite stories of 'to get one's breath' and 'to hold one's breath'. These provide a detailed narrative of the meaning of becoming dependent on mechanical ventilation. One clear theme is decision making, with the composite story of 'to get one's breath' beginning with the comment that the decision to

accept ventilation was a simple one (Lindahl et al. 2005, p. 38). This is echoed by Dreyer et al. (2010b, p.757), a study in which participants with Duchenne Muscular Dystrophy state that their wish to prolong their lives meant accepting ventilation was a necessity, not a decision. It relates to acceptance of ventilation when the work of breathing becomes too great for the participant. As documented by Brook et al. (2004), ventilation was welcomed, enabling life to be re-captured, leaving behind their previous “sleepy ‘half-life’” existence captured by Lindahl et al. (2005, p. 38) and expanded upon by Briscoe and Woodgate (2010), Dale et al. (2018) and Ballungrud et al. (2008), manifesting in physical symptoms such as feeling disembodied, with headaches, memory loss, mental cloudiness, reduced alertness and weariness.

Briscoe and Woodgate (2010) outline a broader perspective on decision making around ventilation, demonstrating its complexity. While they identify self-determination and autonomy as concepts, Ballungrud et al. (2008) note that empowerment and control influence QoL and decision making in this regard. These concepts are discussed under the theme of Adaptation. Studies show that participants are highly knowledgeable about their illnesses or conditions, the equipment they use, and their rights (Ballungrud et al. 2008; Dale et al. 2018). This level of knowledge allows patients to participate and make decisions about their situations, limiting the historically paternalistic stance of healthcare practitioners towards HMV patients (Dreyer and Pederson 2009).

Making decisions about ventilation can nevertheless be highly distressing for patients and some delayed accepting the need for ventilation (Dreyer et al. 2010b; Dreyer and Pederson 2009; Lindahl et al. 2005). On being asked to make a decision about accepting ventilation, participants in various studies understood that their life was indeed in peril, and that their options were limited to two: to accept ventilation or to die (Dale et al. 2018; Dreyer et al. 2010b; Lindahl et al. 2005; Briscoe and Woodgate 2010). Lindahl et al. (2005) write of conflicting emotions and a loss of control alongside losing the ability to breathe independently. One participant recognised the broader issues involved in the decision-making process, and considered refusing treatment; however, he recognised this would shorten his life, and concluded that to be ventilated was an active choice (Lindahl et al. 2005). Similarly, the responsibility for decisions and choices was sought-after by participants, in numerous other studies (van Huijzen and van Staa 2013; Brook et al. 2004;

Goldstein 1998), aiding the transition to HMV. Decision making was also identified as maintaining optimism and risk-taking. Participants defined risk-taking as making decisions around maintaining social participation by going out and travelling on their own; they recognised that the risk was theirs, providing they had been briefed by healthcare providers of the risks associated with their actions (van Huijzen and van Staa 2013).

Recognising their own participation in the decision-making process of accepting ventilation was, for some, difficult, relying on healthcare staff to make decisions. Some participants, struggling to find meaning and “wholeness” (Lindahl et al. 2005, p. 39) considering the progression of their condition, the necessity of ventilation, and the weight of responsibility for making decisions while unwell, consider it a relief to have others overseeing these decisions (Dreyer et al. 2010b; Lindahl et al. 2005). Nonetheless, once ventilation was commenced, participants emphasised the importance of participating actively in making decisions about treatment planning and living at home (Lindahl 2010; Brook et al. 2004). This is consistent with Lemoignan and Ells (2010), who identified self-determination and autonomy as integral to making decisions about treatment and recognising the involvement of carers and families in such discussions, whilst recognising that ultimately the decision is the patient’s own.

2.5.2 Decision Making as Part of Everyday Life.

The importance of patient involvement in decision making, and in their being taken seriously as part of a collaborative approach to ensure day-to-day issues are resolved, has been noted elsewhere (Dyrstad et al. 2012; Brook et al. 2004). Collaboration was with a wide variety of professional staff and carers. Decisions involved numerous individual and personal issues; for example, equipment choices, modes of ventilation, employing care assistants, when the participants chose to take a shower and the clothes they wore. Martinsen and Dreyer (2012), Ballangrud et al. (2009) and Lindahl et al. (2005) note that participants continued to make decisions, but that some outcomes were reliant on healthcare staff and carers actioning these. As one participant stated, “it is still me who is the brain” (Martinsen and Dreyer 2012, p. 87). Some patients were not credited for their abilities, with care staff assuming they were incapable of making decisions about equipment and financial issues, disregarding their previous experience and ability (Lindahl 2010).

Contrastingly, Dale et al. (2018) focused on how the prior knowledge of patients helped the carers understand the ventilator and treatment.

As healthcare staff developed a greater understanding of the participant's need for independence, the participants could be involved more in decisions (Lindahl 2010). In a limited quantitative study, Gelinas et al. (1998) noted that adjustment to the new reality following HMV depended on the relationship between carer and patient. A strong relationship empowered the patient, helping them recover their autonomy and envision their future; creating a partnership around their care (Lindahl 2010). This is however not always the case: there is often conflict between among care givers, patients and family (Dale et al. 2018).

2.6 Thoughts of the Future

Young et al. (1994) and Dale et al. (2018) identified a balance between negativity and positivity about the future. Participants articulated a difference between physical and mental freedom: how HMV can liberate them mentally contrasting to their physical deterioration. Playing a role in and contributing to other's lives was also important to their quality of life (Young et al. 1994). Rabkin et al. (2006) established that the choice of accepting HMV was often associated with feeling that life is worthwhile. Negatively, Young et al.'s (1994) study of patients with Amyotrophic Lateral Sclerosis (ALS), noted that with the trajectory of the disease, the participants recognised that, should they commence with ventilation, their life span would be lengthened, and would be associated with further deterioration in physical disability, which was intolerable for some. However, it is important to note that the study was conducted in 1994. HMV technology has developed rapidly over the past 25 years, vastly improving the treatment modalities and understanding of the issues associated with HMV. Quality of life may perceived and also defined differently by the current HMV generation, who may experience better QoL, with this access to improved technology and therapies.

Alternative perspectives of the future and optimism are recorded by Dreyer et al. (2010) who describe the need to lead a 'normal' life and to enjoy every moment. In their study of individuals with numerous differing diagnoses, Briscoe and Woodgate (2010) describe uncertainty, worry and fear about the future, exacerbated by disease trajectory and the need for HMV. Participants whose cognitive abilities and energy were restored with HMV

expressed a feeling that life continued to move forwards, and a focus on re-building a home and a life for themselves. Successful adjustment requires forward-looking perspectives (Gelinas et al. 1998). This involved understanding that a change in perspective was required, and that there was a need to develop new skills (living with the equipment and technology), providing a sense of control over the changed physical and psychosocial circumstances (Briscoe and Woodgate 2010; Brook et al. 2004).

2.7 Adaptation

This theme encompasses numerous sub-themes: physical impairment and adjustment (adaptation), changes to home and environment, changes to QoL, empowerment, control, dependence and independence, normalisation, communication and relationships, all of which influence adapting to a new life with mechanical ventilation.

2.7.1 The Process of Commencing HMV, and Building Confidence in Technology and Staff

Commencing HMV touches on the theme of decision-making. Participants recognised that there is limited, if any, time for consideration when respiratory function deteriorates, and ventilation is required, describing it as a “crisis event” (Lindahl 2010, p. 686). This, however, may not be every HMV individual’s experience of the beginnings of HMV, with some experiencing a longer, more difficult journey or battle with breathlessness and fatigue (Dale et al. 2018; Briscoe and Woodgate 2010; Ballungrud et al. 2009; Lindahl 2005). Ultimately however, it resulted in a decision being made to accept ventilation, or not (Dreyer et al. 2010b; Briscoe and Woodgate 2010). Participants in the study by Dreyer et al. (2010b) stated that it was a conscious effort for them to breathe prior to being invasively mechanically ventilated. HMV often leads to a good QoL (Dreyer et al. 2010a and 2010b; Dale et al 2018; Lindahl et al. 2003, 2005 and 2006; Ballangrud et al. 2009), and that mechanical ventilation removed the conscious effort of breathing. This is consistent with quantitative sources, in which HRQoL is reported as good (Markussen et al. 2017; McDonald et al. 1996; Bach and Tilton 1994).

Some participants view ventilation as being dominated and contaminated by a machine, with fears about its use, its stigma, life being a burden and HMV signifying loss of different aspects of life (Lindahl et al. 2005; Brook et al. 2004; Goldstein 1998). Briscoe and Woodgate (2010) noted a loss of self. These concepts are explored further below. For others, adaptation involved coming to terms with technology being incorporated into the home and

seeking knowledge and understanding, to continue life with some semblance of normality (Dale et al. 2018; Goldstein 1998). Technology (the ventilator) was seen as converting the home environment into a clinical environment, with recognition that the equipment was identical to that used in critical care environments, to care for critically ill patients. The alarms associated with the equipment, signalling deviation from set ventilation limits or disconnection from the ventilator, were associated with critical and intensive care environments. Alarms were also associated with safety and with security, and were viewed as important when being ventilated; participants expressed a need to trust the equipment (Lindahl 2010). Some participants noted that they had set up the home environment to mirror that of the hospital setting, to maintain a level of control and to cope (Dale et al. 2018). Invasive ventilation was perceived by participants as offering more security than non-invasive ventilation, making the patients feel safer. Failure of the equipment and also human failure was recognised by participants in studies by Dreyer et al. (2010b) and Hirano et al. (2006).

Frustration was exacerbated by an inability to communicate easily, as a result of ventilation (Brook et al. 2004). Communication issues for both patient and carer were also reported in the quantitative literature (Masefield et al. 2017; Huttmann et al. 2015; Hirano et al. 2006). Lindahl (2010), Ballangrud et al. (2009) and Schaepe and Ewers (2017) reported that participants' need for trust and safety extended beyond the physical equipment to relationships with carers. Participants expected nurses to be intuitive to their needs, preventing continual explanation (Schaepe and Ewers 2017). Participants believed a relationship of trust was developed over time, and that with new carers, it was difficult to judge competence and whether the carer could be relied upon in a crisis (Schaepe and Ewers 2017). Gelinis et al. (1998), echoes this finding, reporting that developing a relationship with one's carer was key to accepting the change in situation and adjusting successfully to the new reality. Schaepe and Ewers (2017) noted that the nurse is seen as providing a sense of safety. Only when this secured, could the participants relax and feel safe.

2.7.1.1 Normalisation

Normalisation is identified as a theme (van Huijzen and van Skaa 2013; Lindahl 2011; Lindahl et al 2011; Ballangrud et al. 2009; Brook et al. 2004) with individuals wanting to restore and

live a 'normal' life alongside the ventilator. This adaptation is both psychological and physical and required some thought around the additional care required with invasive ventilation (Brook et al. 2004). Some participants tried to camouflage the equipment, to make it look less technical by disguising the tubing under clothes; others began developing HMV technology, to develop less physically imposing equipment (Dreyer et al. 2010b; Lindahl 2010; Brook et al. 2004). In contrast to the participants who hid their equipment, Dale et al (2018) provided evidence of integration of their equipment into their homes, mirroring the hospital environment. This approach to the organisation of the physical equipment provided a safety mechanism for these participants (Dale et al. 2018). Despite the additional workload associated with mechanical ventilation, participants reported that it allowed them to live with renewed vigour and energy (Brook et al. 2004). Participants with Duchenne's muscular dystrophy could live a 'normal' life, and saw HMV as life-saving and as increasing QoL (Dreyer et al. 2010b p758). These findings might not, however, be transferable to other HMV populations, as the study was based on a homogenous group of individuals. All participants had the same condition and were from a Westernised, European context. Caution should be applied when considering application to heterogeneous populations.

In the studies by van Huijzen and van Skaa's (2013) and Dreyer et al. (2010a), normalisation is linked to optimism and thoughts of the future. Participants who suffered from neuromuscular disorders (van Huijzen and van Skaa 2013) and male participants with DMD (Dreyer et al, 2010a) compared themselves to those without the disorder and viewed themselves as "just like others" (van Huijzen and van Skaa 2013, p. 213). This highlights societal influence and the perceptions of others in relation to how diseases and conditions are perceived (Thomas and Sakellariou 2018). Humour and a strong, supportive network of individuals were reported as key to quality of life (Gelinas et al. 1998). They also disclosed that not feeling bitter or expressing self-pity was a reason for life going well and being enjoyable (Dreyer et al. 2010a). By contrast, Lamas et al. (2016) found that, in a mixed methods study of individuals defined as chronically critically ill (MacIntyre 2012; Nelson et al. 2005; Higgins and Daly 1999), participants refused to face reality, believing that to discuss setbacks was negative (Lamas et al. 2016). However, this study has limited applicability to the HMV population, as participants lived in long-term institutional settings

as opposed to in their own homes. Nevertheless, it provides a useful contrast to the views of those who are HMV in their own homes, which are mainly positive (Lindahl 2011; Lindahl et al 2011; Dreyer et al. 2010b; Lindahl 2010; Lindahl et al 2005).

In their quest for normalisation, participants often question their existence (Briscoe and Woodgate 2010). Autonomy, empowerment, dependence/independence, self-advocacy, vulnerability, isolation, diminished sense of self, freedom and imprisonment and a wish to maintain control are also central (Lemoignan and Ells 2010; Lindahl et al. 2005; Lindahl 2010; Dreyer and Pedersen 2009). Participants generally adapted physically before they did so emotionally and psychologically, owing to the loss of freedom, control, independence and sense of self (Briscoe and Woodgate 2010). In contrast, participants in a study by Dale et al. (2018), noted an improvement in life and increase in independence from ventilation. Part of the loss of self-involved a struggle to maintain independence and identity in the healthcare culture, emphasising independence and dependence. Participants perceived that they lived independently, despite relying on carers for care and treatment to sustain normality and day-to-day function (Dale et al. 2018). The definition of independence, as with quality of life, is individual, and is linked to purpose, described as the difference between living and existing (Briscoe and Woodgate 2010).

2.7.2 Dependence/ Independence

This is a common topic and influences all main themes in the review. Definitions and perceptions of dependence and independence vary, not only across studies but throughout the literature (Secker 2003). The independence or dependence of HMV and disabled individuals can be viewed twofold: most commonly, it is referred to by Secker (2003) as relating to physical dependence and to requiring support for everyday tasks. Alternatively, it can be perceived in relation to an individuals' ability to make decisions (Leece and Peace 2010). Recognising the individual interpretation of independence is therefore vital.

In the studies included in the review, some participants view their position positively (Dale et al. 2018) and others negatively (Young et al. 1994). Those with a positive outlook believe independence is linked to creating a social network (Dale et al. 2018; van Huijzen and van Skaa 2013; Brook et al. 2004; Gelinis et al. 1998;) for support and decision making, therefore suggesting that physical dependence can be managed or even overcome (van Huijzen and van Skaa 2013). This is consistent with Martinsen and Dreyer (2012), who

reported that dependence on care was seldom perceived as constraining participant's actions, provided that carers delivered a high standard of care/support. Freedom is associated with carers' ability to help participants maintain control over their lives (Ballangrud et al. 2009), through daily routine. This normalises everyday life (Ballangrud et al. 2009 p429).

Individuals with negative views feared the dependency associated with HMV: the lack of control and ability to action their own wishes and in relation to overall quality of life (Young et al. 1994). Other participants did not identify with being physically disabled and thus dependant, as mentally they did not *feel* disabled, even though they recognised and could see that they were physically unable, for example, to eat and dress themselves (Dreyer et al. 2010a; Secker 2003). This introduces the conundrum of what 'normality' is and what 'normal' means. The reality experienced by some HMV individuals differs from societal expectations of disabled persons, through their participation in sports, as spectators or players, studying and through travelling, which are all indicators of autonomy, successful adjustment, independence and quality of life (Dreyer et al. 2010a; Hirano et al. 2006; Gelinas et al. 1998). That they are dependent upon others to meet their physical needs is transcended by engagement and involvement in life, in seeking to live as 'normal' a life as possible, developing coping mechanisms to deal with their dependency (Dreyer and Pedersen 2009; Dreyer et al. 2010a). This view is not shared by all participants however. In the Young et al. (1994) study, some participants recognising carer burden and the impact of HMV on the lives of their families. A tentative conclusion can be drawn that dependence or independence thus appears largely a function of the degree of acceptance of HMV and its necessary restrictions.

2.8 Loss of Self and Freedom

Loss of independence (and therefore increased dependence) can result in a loss of self and control, over situations and circumstances, and in a loss of relationships. For some participants in Briscoe and Woodgate's study (2010), the new and altered reality that HMV brings, requires partners to be brave in facing the changing landscape, placing a burden on partners and family. Lemoignan and Ells (2010) study revealed a wish on the part of participants to protect their family from caregiving responsibilities, while Brook et al. (2004) report on the sense of purpose relationships provide, consistent with the meaning of

existence discussed by Briscoe and Woodgate (2010). Lindahl et al. (2005) identified two factors important to becoming dependent on a ventilator: the unburdening and burdening of the participant's body and of the world that they inhabit. Translating these factors to the theme of the 'Existential Thoughts' described by Lindahl et al. (2005), 'unburdening' relates to being overwhelmed by gratitude and thanks, allowing the individuals to re-establish their lives and seek enjoyment. 'Burdening' however, related to the realisation of the enormity of their position and the despair and uncertainty associated with being overwhelmed.

Participants viewed their position with sadness, resulting in existential loneliness. This study sample identified individuals with a wide variation in disease process/ conditions that required HMV, and so the findings may have wider transferability, and mirror the struggle with loneliness reported by Dreyer et al. (2010a) in their study of individuals with Duchenne's Muscular Dystrophy. Burden was also identified by Young et al. (1994) and Lemoignan and Ells (2010), who noted that participants were aware of the pressures HMV exerts on family members and carers, and the negative impact it has on their QoL, being viewed as enslaving caregivers who participants respected (Young et al. 1994). Participants witnessed how difficult it was for their families (mothers, in particular) to relinquish the responsibility of care to professional, paid carers in light of the knowledge that they have of individual preferences and care needs, along with the emotional difficulties that this results in (Dreyer et al. 2010). Lemoignan and Ells (2010) report a wish to protect family who were caregivers from the pressures of delivering daily care. Recognising caregiver support is interwoven with the sub-theme of relationships.

In support of these findings, a secondary analysis study of a heterogeneous group of HMV individuals reported isolation and stemming from this, existential loneliness (Lindahl 2011). The study documents individuals feeling like 'strangers to themselves' (Lindahl 2011, p16), compounding feelings of isolation and loss of meaning to life. This perceived social rejection in conjunction with feelings of being unclean due to the need for suctioning, and damage to the body as a physical phenomenon, exacerbate the feelings of rejection, resulting in a loss of identity and self-understanding (Lindahl 2011).

Similarly, physical accessibility affected the realisation of self and ambitions. Modern technology bestows freedom and with it a degree of independence (Martinsen and Dreyer 2012; Dreyer et al. 2010a; Brook et al. 2004), allowing individuals to develop relationships

through playing electronic games with friends from across the globe on-line, for example, This experience is somewhat of a paradox and is in stark contrast to the physical difficulties they encountered accessing social spaces that support a social life, such as friends' homes, cinemas and restaurants. The same physical equipment that improves QoL for HMV individuals can thus impede it (Martinsen and Dreyer 2012, Dreyer et al. 2010a; Brook et al. 2004). Others reported that requiring a member of staff to be present to support them at all times violated their privacy, and was a restricting factor, owing to the inflexibility of care(r) routines, as identified by van Huijzen and van Skaa (2013) and Brook et al. (2004). Dale et al. (2018) and Dreyer et al. (2010a) noted that the attitudes of individual participants or others that the participants encountered, affected whether individuals felt socially isolated. Individual personalities and attitudes dictated whether participants chose to expend energy on attempting to change and overcome restrictions to physical accessibility issues, by changing their environment or their attitude (Martinsen and Dreyer 2012).

The transition to home was a significant factor. Home was perceived as a refuge (Dale et al. 2018; Schaepe and Ewers 2017), whilst Lindahl (2010) noted that normality was restored by integrating technology. Home was perceived as a comfort associated with well-being (quality of life), despite the changes to the physical environment that HMV required (Lindahl et al. 2005). Home as a place of refuge was perceived in relation both to burdening and unburdening (Lindahl et al. 2005); the uncertainty for those who viewed HMV as a burden related to risk and safety issues stemming from ventilation.

2.9 Relationships

Relationships are viewed both positively and negatively (Lindahl et al. 2005). For those who regarded relationships as positive, it related to the experience of competent care and the concept of trust, as well as the pleasure and purpose derived from relationships (Dale et al. 2018; Schaepe and Ewers 2017; Lemoignan and Ells 2010; Lindahl et al. 2011; Brook et al. 2004). According to Lindahl et al. (2005), relationships can offer hope and an opportunity to heal, whereas those who view relationships negatively, associate them with humiliation and exclusion (social isolation), and a longing for healing relationships. Dreyer et al. (2010a) identified emotional and sexual aspirations, recognising the influence of technology and the Internet (social media) in developing personal relationships. This influence is also felt in the experience of freedom, physically, emotionally and metaphorically. Consideration is given to

‘what ifs’ and recognising but not railing against the control of institutions (healthcare services) in terms of personal choices (Dreyer et al. 2010a; Brook et al. 2004). Dreyer et al. (2010a) also recognise the joy of being part of a (sexual) partnership, with intimacy and shared interests.

Relationships were also identified between participant and carer, with positive relationships enabling a greater level of decision making, independence for the participant and advocacy (Schaepe and Ewers 2017; Ballangrud et al. 2009; Brook et al. 2004; Gelinias et al. 1998). Martinsen and Dreyer 2012 noted that HMV individuals were able to realise their ideas through their carers, while Ballungrud et al. (2008) observed that to develop and sustain good working relationships, caregiver continuity was essential. Similarly, communicating with carers was key to building a relationship (Schaepe and Ewers 2017). Providing services to meet these standards and expectations was not always realised, with concerns raised around poor organisation of services, lack of continuity and time allocated to care, and lack of competence in care delivery (Dale et al. 2018; Ballangrud et al. 2009; Brook et al. 2004). Of further importance is that a high level of dependency requires that the right individual who can cope with a high level of physical and mental dependence is employed as a carer, to meet this demand (Dreyer et al. 2010; Brook et al. 2004).

2.10 Summary of Chapter

Despite requiring HMV, being dependent on mechanical ventilation and others to maintain normal, everyday living, ventilation was perceived as improving QoL overall. Individual quality of life encompasses myriad definitions and interpretations, realised through the main themes of decision making, future and hope, adaptation, and relationships. Different disease processes and conditions affect individual’s perspective on QoL, as well as on related concepts. No one specific data collection tool related to individual quality of life in HMV patients has been identified, and additionally, no studies that used the Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL – DW) were identified (O’Boyle et al. 1993b). Most of the qualitative studies included were methodologically sound, rendering the findings transferable to the HMV population being studied, and will be applied in the discussion. The quantitative literature supports the qualitative findings. Its focus on HRQoL, however, makes it ungeneralisable to the HMV population. The lack of definition and conceptual clarity of HRQoL, as well as the limited number of standardised,

valid and reliable measurement tools used also make the results of the qualitative data difficult to generalise. In the following chapter, an overview of the methodological and theoretical considerations of the study are provided.

CHAPTER THREE

3. Methodological and Theoretical Considerations - Ontology and Epistemology of Critical Realism

3.1 The Ontological Self and Epistemology

This study seeks to explore the quality of life of individuals who are mechanically ventilated in their own homes. It aims to uncover the discourses that influence the QoL of HMV patients on a daily basis. The discourses stem partly from the current political agendas that underpin health and social care and their delivery. These discourses and agendas are based largely on a biomedical, reductionist model of care, with an emphasis placed on classifying, diagnosing and treating conditions, rather than on adopting an holistic approach to the care of, and recognising the HMV individual's needs.

On commencing this study, it was necessary for me to reconcile my worldview and my positioning in relation to my clinical background of intensive and critical care nursing, with its scientific, empirical, and evidence-based focus. From my worldview, I see HMV individuals as persons, with personalities and characters. They, like everyone, are a combination of their physiological, pathophysiological, psychological and social qualities. Acknowledging the assumptions that underpin medicine, I recognise that HMV individuals experience reality subjectively, as they are at the centre of their experience, and partially construct it.

I regard both the observable and experiential phenomena of HMV individuals as the result of biochemical and physiological changes resulting from the diseases or conditions affecting them. The requirement for mechanical ventilation distinguishes the study sample from the wider population. In recognising the HMV individuals constructed reality, I recognise that my professional background anchors me in the reality of critical care and the evidence-based practice of mechanical ventilation, which cannot be explained and explored adequately through social constructionism. Reflexively recognising the co-relationship between ontological and epistemological perspectives has been important in situating myself as a researcher. By reflexively exploring the appropriateness of a constructionist (relativist) ontological approach and social constructionism as epistemology, I realised that adopting this approach would have resulted in an 'honourable fudge' or 'epistemological eclecticism' (Michael, 1999, p54 -55). Assuming a critical realist position, however, allows

me to recognise the scientific, empirical and physiological basis upon which the participants' existence through ventilation is possible, whilst acknowledging the subjective reality of their worlds.

Critical realism as an approach to the philosophy of social science was developed by Bhaskar (1989) and others (Archer et al. 2017; Archer 2002 and 2016; Archer et al. 1998; Collier 1994). According to Bhaskar (1989), social science or sociology can uncover the causal and underlying powers possessed by social entities, structures and systems. This approach is anti-reductionist and anti-positivist (Little 2013). It is anti-positivist in that it rejects the positivist theory that knowledge is based on empirical data, and adopts a different epistemological stance. This requires that researchers are, or become aware of the effects of language, concepts and ideas on their perceptions of the social sphere they are investigating (MacLionis and Plummer 2012). The approach reflects how invisible social causal mechanisms can often influence and cause social change (Gorski 2013). Bhaskar (1989) further describes the differences between intransitive and transitive dimensions: intransitive dimensions are those that perceive the natural world as it really is, and transitive dimensions recognise how conceptualisation of the natural world changes. In recognising the changes in how we perceive the world, critical realism constantly reflects upon its own categories and the ontology itself is provisional and fallible (Gorski 2013).

Critical realism provides a means of describing the process of knowing ('realism'), and that knowledge is derived from exposing causal structures and systems. The approach recognises that reality for HMV individuals is only accessible through discourse that connects the knower (HNV individuals) and the topic (iQoL). In accessing this reality, individuals begin by organising the world around them into distinct structures, such as social networks. The relationships between or properties of these structures (social networks) can change through interaction (discourse), resulting in new structures or social forms (Little 2013). All other elements, including temporal, spatial and cultural possibilities are then evaluated in relation to the system. The final part is where we as individuals understand the implications of our thoughts and actions within the system and realise that we have some power to become agents of change (Gorski 2013). Dialectic critical realism recognises that the macro

systems or factors can affect the micro levels and vice versa, and that change occurs in both directions, offering a foundation for exploring individual quality of life.

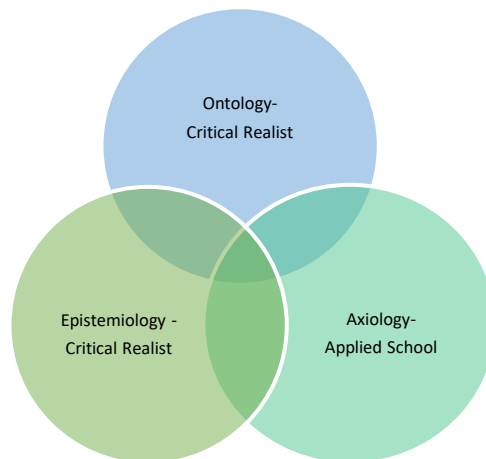
Critical realism, as a meta-theory, occupies a position between the relativist, constructivist and interpretive approaches and the realist, positivist (and post-positivist) approaches (Durant-Law 2005). Critical realism positions the study both ontologically and epistemologically. Critical reality, ontologically, recognises a single reality, but that multiple interpretations of this reality can exist (Fleetwood 2013). In epistemological terms, critical realism recognises that knowledge is fallible and fragile (Bergene 2007), and that knowledge is derived from revealing causal mechanisms. This then smooths the connection between ontology and epistemology, blending the evidence base of pathophysiology and the necessary ventilation of the HMV population with the recognition that within this one reality, there will be multiple, individual interpretations and understandings. Every individual participant constructed their own QoL reality, which encompassed mechanical ventilation, through discourse. Discourse took the form of spoken or written communication, guided by the conventions of the social sphere HMV individuals occupy.

The above positioning therefore points towards a methodological assumption which reflects the context-bound nature of data collection through a flexible design, searching for patterns, with an emphasis on qualitative analysis (Polit and Hungler 1999).

Methodologically, to fit with the overarching ontological and epistemological perspectives, Critical Discourse Analysis (CDA) (Fairclough 2015) has been used, with the objective of exploring and uncovering power-knowledge and socio-political agendas. This uncovers the voice of the powerless, exposing power relations and struggles, as discourse links the relativist, subjective experience of iQoL with the objective state of the individuals (Willig 1999).

The approach recognises the tensions and influences of reconciliation of an evidence-based background with critical realist ontology. The point at which all circles in Diagram 2 intersect, denotes the philosophical stance adopted here (Durant-Law 2005). CDA occupies the central point of the intersecting circles, realising the co-relationship among elements:

Diagram 2 The Philosophical Stance of the Study



The study is subjective and has value-laden content, reinforcing its ontological and epistemological positioning (Polit and Hungler 1999). However, it is essential that the role of values is questioned, and that I concede that researcher bias is unavoidable. The implications of this are that, as a researcher, I should openly discuss these biases and values to help form the narrative. Reflexivity is fundamental and I also need to recognise my novice status in research. I have experience of the topic, but am learning the methods and processes involved in research. The contrary perspectives of the 'insider' and the 'outsider' to research (Clancy 2013) - drawing on prior experience as an 'insider' or being completely new to the arena being researched - are not binary opposites and should be recognised in the discussion. The narrative should include the personal interpretations of the researcher alongside those of the participants (Creswell 2007). The use of CDA as a method facilitates personal interpretation and recognises the influence of values by recognising Member Resources (MR)⁶ in interpreting data. However, it is important to acknowledge the impositions of my own values and assumptions, taking precautions not to limit the study by fixating on subjective perspectives. Through the elements of interdiscursivity and intertextuality, CDA enables a wider contextual appreciation (Fairclough 2015; Clancy 2013; Holloway and Biley 2011).

⁶ Member resources refer to what the researcher brings to the analysis and interpretation of text. They are referred to as background knowledge, which may be a misleading term, as member resources are commonly ideological rather than knowledge-based. Each interpretation of the text will be different owing to individual interpretation and different MR perspectives (Fairclough 2015).

Undertaking this study, I am aware that the questions developed were founded on an assumption that HMV as a medical intervention impacts iQoL. The existence of iQoL is also assumed. Despite providing a definition as a guide in this study, the concept of iQoL should be just that: satisfaction related to individual and personal elements of life. In attempting to categorise and analyse the discourse(s) generated in the interviews, there is a possibility that the meaning of the discourse(s) could be changed, and, in turn, the meaning could be altered by the discourse, a premise of CDA. Further assumptions are that iQoL includes more than just health-related quality of life concerns, and that quantitative research on the general population provides sufficient data for social and political change to be effected. This fails to take account of iQoL and the complexities involved in living in the multifaceted society of today.

3.2 Theoretical Framework - Critical Discourse Analysis (CDA)

3.2.1 What is Discourse?

Discourse or discursive practice is a term used to describe all aspects of written or spoken communication. Fairclough (2015) views discursive practice as including all types of discourse and labels these as “text”, e.g., verbal conversation, signed language, transcribed text, written text, pictorial and diagrammatic representation, and advertising material. Discourses, set in their specific social contexts, are types of social action and interaction (van Dijk 1998). When participating in discursive practice, individuals, known as social actors, are members of groups and specific cultures. As such, they are more than simply readers and hearers, or speakers and writers of discourse. They share a discourse structure guided by social and cultural convention. Discourse in turn constructs, validates, normalises and evaluates social practice, allowing individuals to use and change social practice. Individuals in turn construct discourses and influence social practices. The functions and conditions, and ultimately the effects of discourse and discursive practice, are all social in nature; as individuals, our ability to participate in discourse is learned socially (van Dijk 1998).

3.2.2 Orders of Discourse and Social Orders

Texts are composed of amalgamations of different discourses and genres. Both terms are explained below. Discourses as a means of representing can be defined both as an abstract and a count noun. As an abstract noun, it refers to the use of language as a social practice;

whereas as a count noun, it describes an experience from a specific perspective (Fairclough 2015). Both apply in this study. Particular social activities draw on certain types of language, known as genres and are defined by Fairclough (2015) as “ways of (inter)acting” (p17). In the case of this study, these ways of (inter)acting are uncovered in the participant interviews.

The way in which individuals experience society and the institutions that constitute society are experienced are separated into different situation types, social practice and domains of action. These situation types and areas have associated types of discourse practice, which are guided by social and cultural convention. Different practices exist, which depend upon the situations and scope of action considered possible through the structures and practices society and social institutions impose. The social spaces that cover and provide structure for these discourse practices are known as social orders. The research interview as a discourse type is an example of how a social “space” has been split into situation types and specific areas (Fairclough 2015, p. 61). The research interview should therefore adhere to the convention of research interviews, drawing on orders of discourse and social orders associated with interviewing (Fairclough 2015). More importantly, the discourses exposed in the data reveal different types of social spaces and social orders.

To study social orders from the specific perspective of the discourse, the entire “production, distribution and consumption of text” (Fairclough, 2010 p. 95) and the associations and interactions among them must be considered. The study should illustrate discourse(s) through the description, interpretation and explanation of discourse in the text. Challenging the power and control effected through discourse through the description, interpretation and explanation of the discourse used by the participants is, although extremely challenging, a potential outcome.

3.2.3 What is Discourse Analysis?

Discourse analysis is the study of the use of language (Gee 2011a and 2011b). Discourse analysis contrasts with the analysis of modern linguistics, in that it looks to analyse larger pieces of text, rather than focusing on individual words and sentences (Tannen 2012; Wodak 1996). Discourse analysis facilitates the critique of language and its use, uncovers its

influence on social practice, and in turn, reveals how social practice influences language and its use.

3.2.4 What is Critical Discourse Analysis?

CDA is a general theory and method that includes numerous approaches, each drawing on a particular theoretical context (Titscher et al. 2000 and 2003). As a theory, it provides a series of principles upon which to base analysis; as a method, it also provides the framework or tools to conduct CDA. The CDA framework developed by Fairclough (2015) has been adapted as a method for the needs of this study. It has three fundamental properties:

- it is relational, in that its focus is on social relations
- it is dialectical, in that it recognises that the elements explored do not exist as distinct, individual elements, but rely upon other elements, in a bi-directional relationship
- it is transdisciplinary rather than multidisciplinary, in that it draws on varying disciplines, theories and frameworks, crossing boundaries to make use of the theories available to analyse discourse (Fairclough 2015).

The critical element is derived from critical theory, with its emphasis on power and how constructs such as religion, race, class and economy influence social systems. The influence of such constructs on social systems can be neutral, merely reproducing and reinforcing social positions and systems, or it can result in change and transform the social structure and system (Fairclough 2015; Mogashoa 2014). The critical element challenges the reductionist and dogmatic approach of biomedicine and reveals power relations and ideologies present in social struggles. Fairclough (2015) views discourse as twofold: being involved in social struggles, whilst also being the setting and scene of social struggles.

3.3 Theoretical/ methodological fit

The importance of QoL in the management of patients who are mechanically ventilated and chronically critically ill patients cannot be underestimated (MacIntyre 2012; Nelson et al. 2005; Higgins and Daly 1999). In this study, a qualitative cross-sectional design was applied, to explore the perception of individual's requiring HMV of their overall iQoL, as opposed to their HRQoL. It was also important to ensure a 'fit' with the study methodology, by recognising the ontological and epistemological stance and analytical framework adopted,

to capture the iQoL of such a specific population. CDA is well suited to the ontological and epistemological stance, as it offers the opportunity to explore how discursive practice shapes and is shaped by:

- micro situations; in this case, individual ideologies, mechanical ventilation in the home environment, and physical and psychological care
- meso level institutions, which can be defined as hospitals, healthcare settings and care provision
- macro structures, such as society and government policies.

CDA attempts to expose power-knowledge and socio-political agendas and presents an opportunity to challenge these agendas by exposing discourses, giving a voice to the powerless. CDA explores the intertextual focus of text and the presence of voices other than those of the authors of the texts, in discourses implied in but outside the text being analysed. These unspoken discourses are recognised and are drawn upon to create meaning and shape social practice.

Relationships, knowledge, situations and social identities all shape discussion, which help alter the social position (Wodak and Meyer 2009). This can be applied to the situation individuals requiring HMV and their families face, as they partially create their own realities, informing the broader social picture of care of the individuals with complex long-term conditions. The participants differ in their knowledge, experiences, situations and social identities.

3.4 Variations in CDA

Fairclough (2010 and 2015) identifies three variants of CDA:

1. Ideological
2. Neo-liberal
3. Political discourse analysis.

In this study, the focus is neo-liberal, using the critique of discourse as a mechanism of social change. In a top-down approach, the neo-liberal agenda incorporates efforts to impose socio-economic restructuring. This emphasises the control, power and influences imposed on individuals in society.

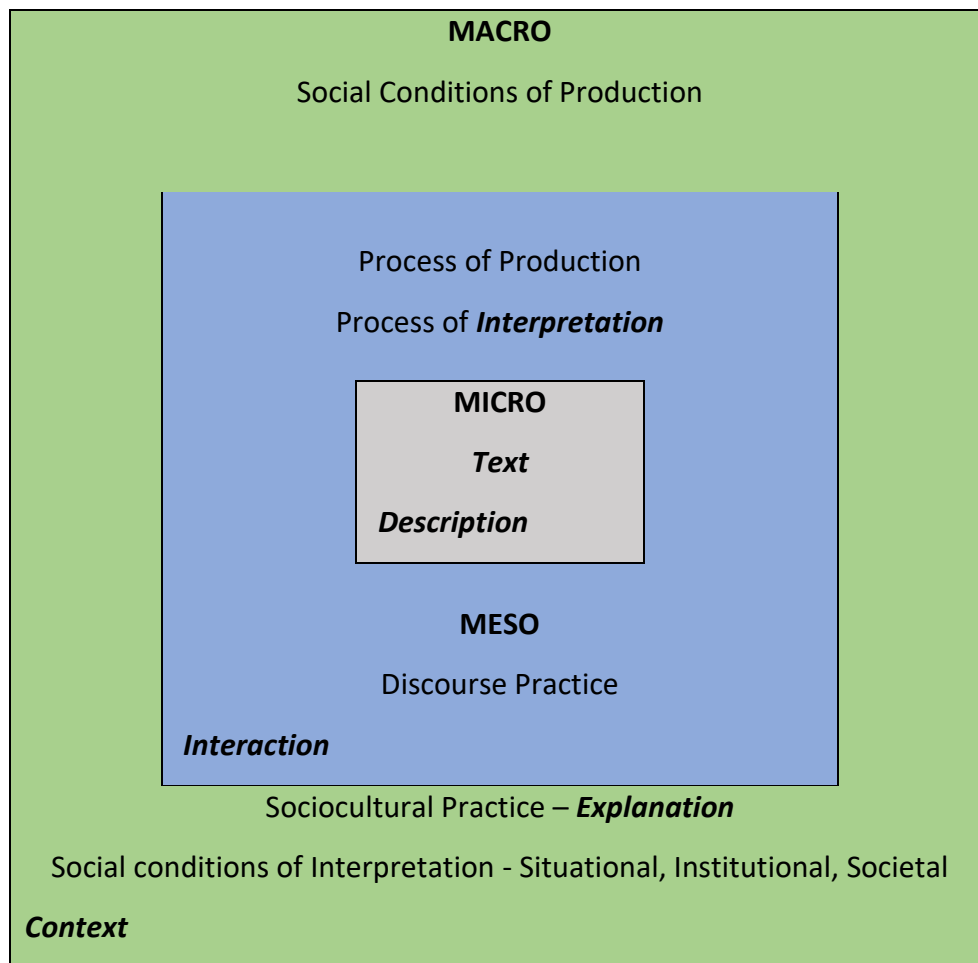
The adapted three-dimensional CDA framework (Fairclough 1993 and 2015) plots three individual levels of analysis:

1. Micro level (**description**): analysis of text
2. Meso level (**description/ interpretation**): analysis at the level of discourse practice, forming part of processing analysis and interpretation. This involves the processes of text production, its distribution, dissemination and its consumption. It involves interpreting the power relations involved, how power relations are enacted and
3. Macro level (**explanation**): this is the analysis of discourse practice to develop inter-textual understanding, to understand the wider situational, institutional and societal elements affecting text.

Member resources (MR) (Fairclough 2015) are applied to CDA, and MR is what the researcher brings to the analysis and interpretation of text. MR are referred to as background knowledge, which may be a misleading term, as member resources are commonly ideological rather than knowledge based. Each interpretation of the text differs owing to individual interpretation and MR perspectives applied from both a researcher and participant perspective. Cues in the text prompt the application of MR, and there is a “dialectic interplay” (Fairclough 2015 p. 155) between the two.

From the three levels of analysis (micro, meso and macro) identified above, the framework allows the *description* of linguistic properties, the *interpretation* of the relationship between text and the productive and interpretative processes, and the *explanation* of the relationship concerning discursive, social practice at a personal and situational level (Titscher et al. 2003). In addition, Fairclough’s intertextual analysis has a greater level of interpretation compared to descriptive linguistic analysis, connecting social and cultural elements, linking text and discursive practice (Titscher et al. 2003). This study is at the micro level, reflecting individual and personal situations, and drawing on the macro explanatory level, to partially reveal institutional and socio-political influences. The levels of analysis can be visualised using Diagram 3:

Diagram 3 The Three-Dimensional CDA Framework – Levels of Analysis



(Adapted from Fairclough 2015, p. 58; Titscher et al. 2003, p. 152)

Analysis at a text and descriptive (micro) level provide an entry point to the text. However, only certain elements of the descriptive level of analysis have been retained in the adapted CDA framework applied to this study. These are the use of pronouns, the experiential, expressive and relational values of words, and presuppositions. This allows a focus on the interpretation (explanation) of situational struggles influenced by the institution (meso level) and sociocultural/political (macro) structures affecting HMV participants (Mogashoa 2014).

To interpret the text from the interviews, I have again adapted Fairclough’s (2015) framework of the interpretive processes (see Diagram 4). Each of the outer circles denotes the interpretive procedures and what was searched for in the interview text. The central circle denotes the interpretation of the interview context, and the situational context and

intertextual elements explored. A key to the meaning of each of the points is provided in Box 3.

Diagram 4 Interpretive Processes



Box 3 Interpretation of Meaning

Interpreting statement meaning:	Interpreting procedure linked to the interpreting statement:
<p>Surface of utterance:</p> <p>This uses the interpreter’s knowledge of language and their MR i.e. it draws on the understanding of how sounds are joined together to form recognisable words, sentences and phrases.</p>	<p>Phonology, grammar and vocabulary:</p> <p>The study makes limited reference to the phonology, grammar and vocabulary of the text produced during the interviews. <i>As the study has not focused on this, this has been greyed out in diagram 4.</i></p>
<p>Meaning of utterance:</p> <p>This involves giving meaning to the ‘utterances’ which are for example, sentences. Again, the interpreter’s MR is used to understand and combine grammatical elements and word meanings. These individual meanings are then combined to provide an overall meaning to the entire sentence/ group of words. It also involves recognising which speech acts are used.</p>	<p>Semantics and pragmatics:</p> <p>The study looks more so at sentence construction in combination with the local coherence and the text structure and point (see below*), rather than the meaning of individual sentences. <i>Again, as the study has not focused on this, this has been greyed out in diagram 4.</i></p>
<p>Local coherence*:</p> <p>Local coherence encompasses looking for meaning across sections of conversation/ text rather than the whole. It involves applying understanding of the ‘local context’ and interpretation of ‘utterances’ that may not follow a logical pattern. It involves knowledge of assumptions around the text, which can be ideological.</p>	<p>Cohesion and pragmatics:</p> <p>The study makes use of local coherence and assumptions that the participants (and that I as a researcher) make during the interview, which is possible by drawing on MR and a partially shared background and understanding of health services and ventilation. A more specific example is the assumption that as a researcher, I had an understanding of the religions and practices, the consequences of which affected iQoL for some participants.</p>
<p>Text structure and ‘point’:</p> <p>This involves looking at the whole rather than the constituent parts of a text. It consists of working out how the whole text fits together and its ‘global’ coherence as opposed to local coherence. This lends information in deciding what the overall point or focus of the text is, from the perspective of the interpreter.</p>	<p>Schemata:</p> <p>In a similar fashion to pattern recognition used in decision making, using the text structure allows the interpreter to match the text to a catalogue of previously recognised and understood types of discourse. In this instance, reference to the health services and changes to the provision of care was a frequently cited schemata.</p>

Situational and individual cues are used to interpret the overall context of the interviews. To interpret the situational context of what is happening at a local level, the physical environment must be understood, from knowledge of previous discourse, and also by applying MR. All cues generated, which represent social and institutional social orders, were interpreted in relation to the individual participant's particular situation. Interpreting and explaining the intertextual context also involved recognising the discourses outside of the text and recognising that these influenced the direction of the main (dominated) discourse. There may have been assumptions on the part of the participant that I, as a researcher, would understand the intertextual context and of the history of the previous and possibly ongoing discourses, outside the interview. I appreciate that not being aware of, and not having a clear understanding of, the intertextual context could result in assumption, and influence the analysis.

The textual structures and functional elements of discourse at a textual level have also been given less consideration for pragmatic reasons. Because the study population is invasively HMV, speech and the textual structures such as interruption, turn taking, pauses and hesitations are altered and obscured by the breathing patterns and physical conditions of the participants. In the HMV study population, one of the participants was diagnosed with locked-in syndrome, and her responses are gathered through the use of a communication board. Another participant required that her responses were lip-read. For most participants, however, who relied on a ventilator to breathe, this interfered with the actual discourse, as the breath generated by the ventilator interfered with speech pattern(s), masking the textual structures identified above. Analysis therefore primarily focused on describing, interpreting and explaining the text at a situational level.

3.5 Description

To describe text, the vocabulary and grammar is examined, and textual structures can be identified. This results in a list of questions to ask about the text (see Appendix 5). The dimensions of meaning (what constitutes meaning) are the contents, relations and subjects of a text (discourse). The contents, relations and subjects are then reflected at the interpretation stage. The values of the features include:

- Experiential – this relates to the text producers’ experiences of the social world and are reflected in the text
- Relational - this is to do with social relationships and relations
- Expressive - the text producers’ evaluation elements.

These are exposed during the analysis of the textual (micro) level in terms of the grammar and language participants use. The structural effects, which refer to how they ‘fit’ with each of the dimensions, are outlined in Table 4:

Table 4 Dimensions of Meaning

Dimensions of Meaning	Values of Features	Structural Effects
Contents	Experiential	Knowledge/ Beliefs
Relations	Relational	Social Relations
Subjects	Expressive	Social Identities

3.6 Interpretation - Situational Level

As the focus of the study is at the situational level, interviews revealed the struggles (and discourses) participants encountered on a daily and subjective level, related to their individual, social, and familial circumstances. The elements used as part of the adapted framework are explained below.

3.6.1 Text Interpretation

Interpreting text begins with the schemata, structure and ‘point’ of the text (Fairclough 2015) (Upper green circle in Diagram 4). The schemata are the modes of social behaviour and relate to the activity taking place. The topic provides the experiential aspect of the ‘point’ or purpose of a text, an interpreted summary of the text. This interpreted summary draws on MR and incorporates participant perspective, for interpretation. There are experiential, expressive and relational elements to the point of a text, and to its overall topic. This enabled me to draw on the descriptive elements of the data and text, to inform the analysis.

Relationships exist between the situational context and the interview text. Analysing the text at the level of the individual, the interpretation identified larger-scale structures and presuppositions that existed outside the text, informing the discourse and providing the interactional history and context of the text (Fairclough 2015). Interdiscursivity, which is

based on and includes intertextuality, demonstrates the typical heterogeneity of text. These features provided a foundation upon which to interpret quality of life at the situational level of individual participants.

3.6.2 Speech Acts

To interpret a discourse, I drew on my MR to interpret the context. These are informal interpretations of the pragmatic properties or meanings of a text. As part of this interpretation, I characterised the speech acts, which involved deciding whether the producer was, for example, asking a question, making a statement, providing instructions, issuing a warning, or making a promise. Various speech were included in the text. To determine the value of the speech act, the contextual nature of the text had to be considered. The situational and intertextual contexts were broad and included the MR of the participants as well as my own. The speech acts revealed some of the ideological representations of the different subjects/ individuals and discourse(s) and also the social relationships among them (Fairclough 2015).

3.6.3 Schema, Frames and Scripts

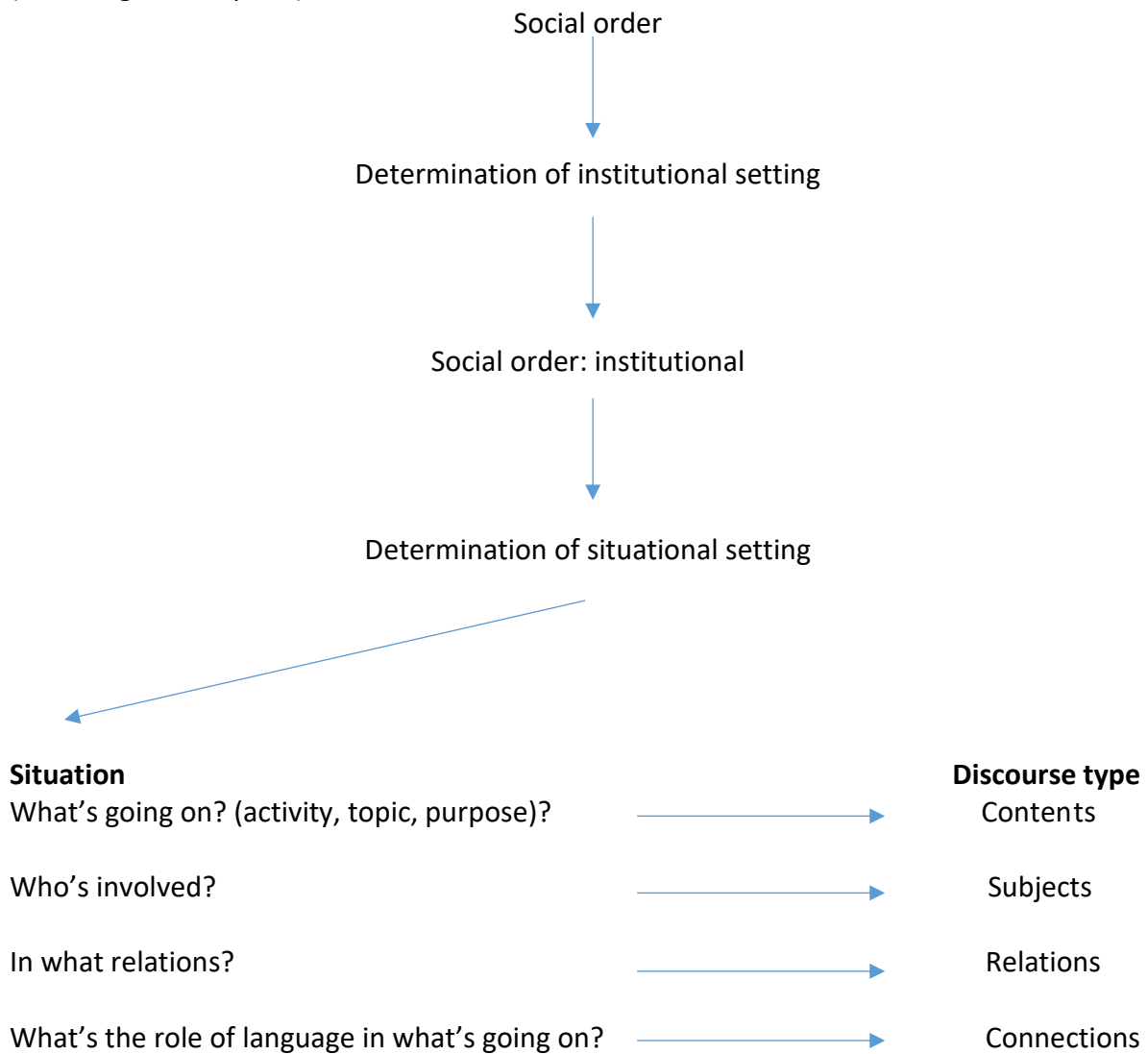
Schema, frames and scripts were all used to interpret text, providing a mental representation of participants' worldviews. A brief description of each is as follows:

- Schema: this refers to the activity at hand for example, a schema provides a mental representation of the conversation with healthcare professionals
- Frames: this refers to the topic or subject matter which for example, could be the delivery of care for the HMV individual
- Scripts: this refers to the individuals involved in the frames and scripts and their relationships; for example, the participant and healthcare professional or patient/carer, son/mother. Scripts indicate how subjects behave and conduct relationships with one another.

Frames can be animate (individuals) or inanimate objects, processes or concepts (Fairclough 2015). Other frames (contents) were woven into the overall topic area, and uncovered during interviews and interpretation of the data. The overall schema, frames and scripts intertwined in the interpretation of the text. The concepts described above are applied in

the discussion, however reference to the actual terminology used is limited, to allow ease of reading.

Diagram 5 Process of Analysis
(Fairclough 2015, p159):



For the purposes of analysis, as depicted in diagram 5 above, the following questions were posed, adapted from Fairclough (2015). Further information is listed below the questions, to provide context and to act as a further guide:

1. What is the text structure and 'point'? What is the topic?
This forms the basis of interpretation and focuses the interview. For the purposes of this study, the overall focus is iQoL.
2. What activity is going on, and its purpose (drawing on point 1 above)?

The activity is an interview, drawing on the individual perspectives of participants of their QoL. Other activities may be discernible in the interview itself through an intertextual context for example, interactions between the HMV individual and healthcare practitioners.

3. Who is involved?

This will, of course, include the researcher and participant. In addition, all persons mentioned during the interview, in an intertextual context, are involved; for example, carers or healthcare professionals. By referring to the CDA framework, it is important to reflexively recognise my position as a researcher and any effect that MR might have on interpreting who is involved.

4. What is the relationship among participants?

The relationships outlined in the interview can be explored in relation to their influence on the iQoL of participants. Some relationships may be self-evident; however, relationships are complex social constructions and affect the discourse itself, which warrant and require exploration. Again, by applying my own MR, it is important that I remain attuned to how I as a researcher may affect the interpretation.

5. What role does language play in the activity and what is the intertextual context?

Are presuppositions evident?

The text is explored for interdiscursivity; that is, whether influence from discourses outside the text are apparent. It has also been interpreted as questioning whether an understanding of their meaning and inclusion in the current discourse is assumed. The use of language to convey these meanings is analysed. MR is again applied and, as a researcher, I must be cognisant of this.

6. What speech acts are identifiable?

Are there any identifiable speech acts; that is, can the following be identified in the text: does the participant use questions, make statements, state warnings or make promises?

7. Identification of the schema, frames and scripts in relation to interpreting a point.

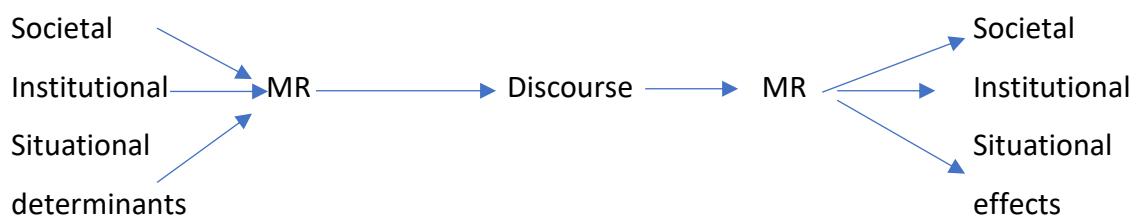
Schema, frames and scripts offer a personal worldview, and can vary ideologically.

3.7 Explanation

The reproduction of a text, for example, during a conversation, draws on the interpreter's MR. During the conversation, MR is employed, and interpretation occurs. This is taken a step further during explanation, and changes to an individual's MR may occur during the reproduction of the text; that is, during the conversation, the thoughts, beliefs and ideologies of the individual can change (Fairclough 2015). Through the explanation, discourse can therefore be maintained or altered as part of a social process or practice. The explanation demonstrates how discourse affects social structures, by either sustaining or changing them. Change can occur both to MR and/or social structures, as social structures influence MR and vice versa. This results in a cyclical process (Fairclough 2015).

This is illustrated in Diagram 6 (taken from Fairclough 2015, p. 173):

Diagram 6 The Process of Explanation:



The focus of the interpretation and explanation centre on the individual struggles at a situational level. As part of the explanatory level of analysis, the three questions asked of the text that were framed by Fairclough (2015) have been modified, to identify what shapes discourse:

1. What (power) relations influence the discourse?
2. What ideologies (belief systems) are revealed?
3. What is the effect of the discourse on HMV iQoL?
4. How are the struggles at a situational (personal) level reflected in and through the discourse?
5. Are the struggles the individuals face hidden or evident/visible?
6. Does the discourse perpetuate existing power relations, or change them?

3.8 Summary of Chapter

This chapter offers an insight into the ontological and epistemological approach adopted here, that of critical realism. A background that locates me as researcher is provided, and the framework for analysis, CDA is presented. CDA can yield insights into the way discourse reproduces (or resists) social and political inequality, domination or abuse of power. Using the framework, it has been possible to expose the discourses around the wider social and political (macro) and institutional (meso) elements and how these affect those living with HMV, as well as how individual, personal (micro) and institutional elements influence the institutional (and societal and political levels). How this is applied to the research design is discussed in the coming chapter.

CHAPTER FOUR

4. Research Design

4.1 Ethical Approval

Following scientific and ethical scrutiny and approval through the School of Healthcare Sciences at Cardiff University, and agreement of sponsorship by Cardiff University, ethical approval for the project was sought and granted by the Research Ethics Committee (Wales REC 6) in 2014 (Appendix 6). This was subject to site-specific Research and Development (R&D) approval (Appendix 7 & 8) and Cardiff University sponsorship (Appendix 9). The project was also granted pathway to portfolio via the Cardiff and Vale University Health Board Critical Care Directorate.

4.2 Methods

The need for an individualised, patient-centred approach to care and QoL measures and recognition of outcomes has recently seen a fundamental change, with a greater emphasis on patient involvement in all aspects of care (NIHR et al. 2018; DH 2012; DH 2010; Department of Health 2008). There is an ever-increasing focus on patient involvement in decision making (DH 2012; The Health Foundation, 2014; Coulter & Collins, 2011), with the DH (2012) recognising patients should be more involved in care planning. This involves patients being more involved in the management of their care, and they should be afforded greater recognition of their own role in the self-management of their health and social care. Quality metrics are increasingly applied to evaluate the efficacy of patient care, which are reflected in outcomes frameworks (WG 2012). These include self-evaluation of individuals' health status and QoL (DH 2012; Ahmed et al 2005). Patient reported outcome measures (PROMs) are being used to report on health and specifically on the effects of treatment, with numerous tools being devised to support this measurement (Meadows 2011). However, the use of iQoL assessments as outcome measures need to be applied with caution, as the meaning of QoL is dynamic. Changes over time to individual meanings of QoL (response shifts) could result in misguided and inappropriate outcome measures (Ahmed et al 2005; Allison et al 1997). Response shifts denote changes in the meaning of an individual's self-evaluation of quality of life as a result of 3 potential elements:

1. Scale recalibration, which infers changes to the individual's internal standards of measurement;
2. Reprioritisation, related to changes to the individual's values related to iQoL; or
3. Reconceptualization, which infers a redefinition of the quality of life (Michalos 2018).

In addition, the classification of symptoms that lead to the diagnosis of conditions that affect HMV individuals has biological roots, governed by chemical and physical laws. These empirical, scientific chemical and physical laws, influence the assumptions that guide current healthcare agendas. Crucially, these assumptions are not routinely critically explored, exposed or opposed. This affects the measurement of QoL, as most general approaches are derived from assumptions that stem from empirical laws. It is therefore crucial to keep in mind that using such measurement tools reinforces the above assumptions (Thomas et al. 2012).

To measure iQoL, a data collection tool that captures the individual responses of participants was needed. A range of tools is available. The majority focus on HRQoL (Sandstedt et al. 2016; MacIntyre et al. 2016; Huttman et al. 2015; Bach and Tilton 1994; Bach et al 1991), or are quantitative in nature (RAND 2018, EuroQoL 2018 and 2011), while others were developed to measure QoL in specific populations. The validity and reliability of some of these disease specific tools has been questioned, having not been comprehensively tested (Page et al 2017; Ware et al 2016; Jenkinson et al. 2011b). Prior to focusing on the data collection tool chosen, the conceptual background of the assessment (and evaluation) of quality of life is outlined. The main approaches identified in the literature are the standard needs assessment and the psychological processes approach.

The standard needs assessment of QoL measures how well particular universal needs have been met, whilst the psychological processes approach takes an alternative stance and evaluates QoL in relation to areas of life significant to the individual (Browne et al. 1997). Standard needs assessment offers a more objective perspective than an individually constructed evaluation. Standard assessment is evaluative, with judgements being made on the individual's behalf. For example, intrinsic weightings are allocated for those with greater levels of physical, psychological and social ability and contact (Browne et al. 1997; Jenkins

1992). There is also the assumption that 'needs' incur a higher value in determination of QoL than do 'wants', reflected in the findings of this study. Once needs are met, however, wants become the norm in shaping views on QoL. These needs can be transposed onto Maslow's hierarchy of needs (Maslow 1968), and also draw on the adaptation and response shift effect, where individual quality of life assessment is adjusted consistent with changes to circumstance (Michalos 2018; Rees et al. 2004; Sprangers & Schwartz 1999; Browne et al. 1997; Howard et al. 1979). This involves individuals' responding and adapting to, and accepting their own personal circumstances, without comparing their QoL to that of others. Response shifts which result in this type of adaptation are important in relation to the analysis in this study and reflect the psychological-type of needs assessment (Sprangers & Schwartz 1999; Allison et al. 1997; Howard 1979; Golembiewski et al. 1976). The response shift highlights the dynamic nature of QoL.

In standard needs assessment, QoL domains are selected, usually by an expert in the field being researched. The selection includes criteria to assess these life domains, which are weighted. The weightings denote areas of significance, be they greater or poorer (Browne et al. 1997). This method is less responsive to changes in perception of day to day QoL, as it relies upon updating domain assessment and weighting, by experts in the field, rather than offering a method of capturing present day views. The standard needs assessment contrasts with the SEIQoL-DW (O'Boyle et al. 1993b) as a data collection tool, where domains are chosen by participants.

Standard needs assessment data collection tools evaluating or assessing QoL, and, more specifically, HRQoL are abundant and include the Sickness Impact Profile (Bergner et al. 1981), the patient generated Index (PGI) (Ruta et al. 1994) and the World Health Organisation Quality of Life-100 and WHOQOL-BREF (WHO 1997 and 1996). Further tools that measure health status include: the Short Form 36 (McHorney et al. 1994) and the EuroQol EQ-5D, a health-related generic measure (EuroQol 2011). This is by no means a definitive list. Specific wellbeing measures have also been developed; for example, the Beck Depression Inventory (Beck et al. 1961) and the Hospital Anxiety and Depression Scale (Zigmond 1983). With the current focus on wellbeing at a government level (WG 2018c and 2018d; 2014), a proliferation of scales now exists, including the simplistic tools used by the

ONS, such as their six-monthly assessment of the well-being of the UK population (ONS 2018a and 2018b), and numerous condition-specific tools (Chow et al 2013; Wells et al 2011). The aim of this study is to measure individual views on QoL, and therefore requires a specific tool to measure individual quality of life. As such, it is important to recognise that patients may view health and QoL as distinct concepts, and in disclosing their views around quality of life, HRQoL may not be referred to (LeVasseur et al. 2005).

4.2.1 Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (DW)

To capture the views of individual HMV participants, and consistent with the psychological processes approach to iQoL evaluation, data for this study was collected using the SEIQoL-DW (O’Boyle et al. 1993b), which provided the framework for semi-structured interviews. SEIQoL-DW falls under the psychological processes approach to QoL evaluation, as it is related to decision-making assessment methods (Browne et al. 1997). SEIQoL-DW is derived from Social Judgement Theory (SJT), a comparison of current attitudes against the individual’s perceptions and evaluation of ideas, thoughts, beliefs and opinions. It involves sifting and sorting these ideas the moment they are perceived. The individual weighs up the ideas against what their current views are and positions this weighting on an attitude scale (Griffin 2012). SEIQoL-DW can therefore be used as a patient reported outcome measure for iQoL.

Ease of use for the population being investigated was also a factor in choosing a data collection tool. Logistic and pragmatic considerations had to be considered, in terms of the tool’s acceptability, length and relevance, its ease of completion and scoring and whether an instruction manual was available (Meadows, 2011). The original SEIQoL (O’Boyle et al. 1993a) takes a substantial amount of time to complete, and the authors note its limitations: its judgement analysis does not link well with its theoretical basis. The SEIQoL-DW is better suited, demanding less of participants with reduced cognitive function. This factor was derived from psychometric information obtained from healthy adult respondents (O’Boyle et al. 1993b). It is hoped that choosing SEIQoL-DW provided an opportunity for HMV individuals to paint a more accurate picture of the issues and factors affecting their iQoL, irrespective of cognitive function. Yet, certain study limitations are recognised. As a cross-sectional study, this will only provide a snap-shot of the issues affecting iQoL for these

individuals at one point in time. Furthermore, issues important to individuals change over time. Comparisons of scores over two time periods is impossible in the current study design and, should the study be repeated, it is likely to record changes to iQoL (Macduff 2000). If participants are asked to re-evaluate their quality of life using previously defined domains, these may have changed. However, if we attempt to evaluate the 'here and now', asking a participant to create more or different domains may result in different results. The comparison of such results becomes difficult, if not impossible. Response shifts as indicated above can therefore affect the validity and reliability of the findings and results obtained with the SEIQoL-DW. Nevertheless, the tool enabled data collection, offering an insight into the perceptions of HMV and their iQoL. Following is a synopsis of SEIQoL-DW and its application.

4.2.2 Stages of SEIQoL-DW

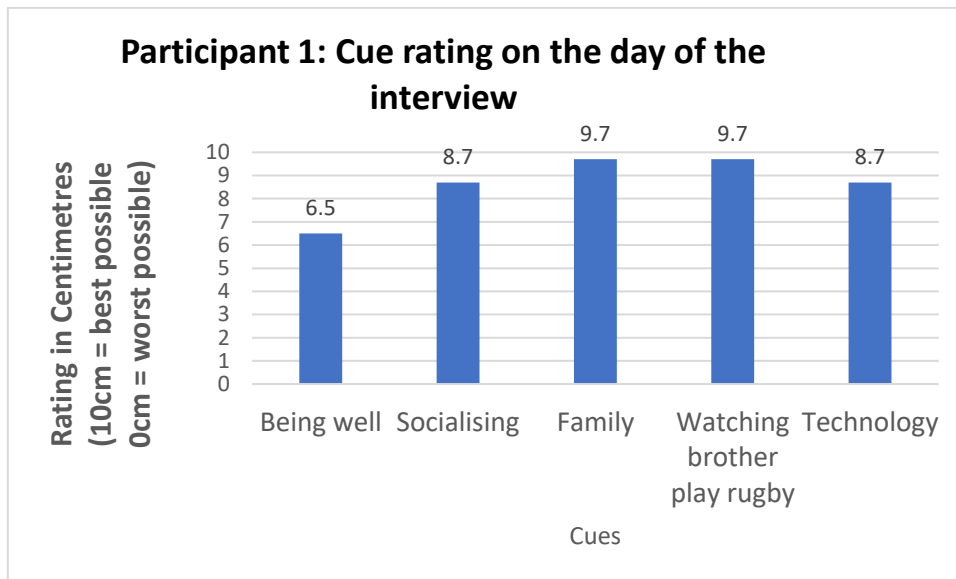
SEIQoL-DW (O'Boyle et al. 1993a) is a tool to evaluate factors that individuals identify as important to their own QoL. It measures three elements:

1. Those factors fundamental to iQoL
2. Satisfaction with each of the identified cues (see Table 5)
3. Relative importance of each of the cues.

Stage 1

From Stage 1, above, the minimum number of cues elicited is three to a maximum of five. Participants are encouraged to introduce further cues should the initial number be too small, and all participants in this study identified five cues.

Stage 2
Graph 1



To indicate the level of satisfaction of each cue, participants are asked to draw a line/ mark on a graph corresponding to each cue. This allows participants to assess their own status relative to each domain/cue (Macduff 2000). An example is provided above in Graph 1.

Stage 3

The relative importance of each of the cues are then given a weighting by the participant. This is done by manipulating a disk of moveable coloured segments labelled with the cues identified by each participant. See Diagram 7 below:

Diagram 7 SEIQoL –DW Tool



Individual quality of life scores are calculated from the sum of the cue weighting and rating (Joyce et al. 2003). Overall iQoL score was calculated by multiplying the level assigned to the cue (very poor to very good), to yield a score. Scores are then totalled to yield an overall SEIQoL-DW Index Score. The overall SEIQoL-DW Index is scored on a scale of 0 to 100, with 100 indicating the highest iQoL score. The overall SEIQoL-DW Index scores generated for all participants in this study are available in Appendix 10 and an example is provided above in Diagram 7 and below in Table 5 in the scores Participant 1 generated:

Table 5 Participant 1’s Identified Cues:

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 1				
Being Well	65mm	25% (0.25)	16.25	}
Socialising	87mm	20% (0.2)	17.4	}
Family	97mm	40% (0.4)	38.8	} 86.5
Watching Brother Play Rugby	97mm	10% (0.1)	9.7	}
Technology	87mm	5% (0.05)	4.35	}

According to Farquhar et al. (2010), the SEIQoL-DW is reductionist, limiting participants through the identification of only five cues. Limitations include whether the five identified cues accurately correspond to the most important areas related to iQoL, and, indeed, whether five cues are sufficient to capture participant perspectives. Its validity is therefore questionable, reducing iQoL as it does to five cues and deconstructing iQoL without a global appraisal of QoL as a construct (Farquhar et al. 2010). Nevertheless, iQoL is just that – *individual*. A global appraisal of QoL could result in judgements being imposed on an individually perceived construct.

4.2.3 Validity and Reliability

Despite the study’s qualitative approach, the SEIQoL-DW provides an additional quantitative measure of quality of life, yielding an overall index of iQoL. As such, some narrative is required on the matter of validity and reliability of quantitatively measuring iQoL, alongside discussion of the trustworthiness of the study.

The aim and intention of true experimental design is to rule out threats, strengthening validity and reliability (Robson 2002). However, threats to validity in qualitative research, for example, selection bias, are impossible to control. Alternative terms as opposed to validity are thus applied to qualitative studies, including credibility, transferability, dependability and confirmability (Parahoo 1997). However, as this study uses a measurement tool, the internal validity of QoL measurement tools needs somehow to be addressed and this has long been subject to discussion and debate. The validity and reliability of SEIQoL-DW has been reported across numerous specialities (Farrand and Woodford 2013; Sundberg et al 2010; Frei-Rhein & Hantikainen 2009; Crang and Muncey 2008; LeVasseur et al 2005; Lhussier et al. 2005; Wettergren et al 2005; Mountain et al. 2004; Prince and Gerber 2001; Lintern et al. 2001; Cheyne and Kinn 2001; Schuurbiens et al 2000; Broadhead et al 1998; Bayle et al 1997; Hunt 1997). Nevertheless, achieving true validity is questionable, owing to the shifting nature of iQoL as a subjective and individual construct that alters in response to changes over time (Ahmed et al 2005; Allison et al 1997).

In a review of two respondent-generated tools, Macduff (2000) notes the versatility of SEIQoL-DW, and its suitability for use in healthy and non-healthy populations. It can be used to customise care plans related to health promotion for patients. This application to health promotion is, however, questionable: shifting individual perceptions of quality of life will affect the trajectory of care planned. The review offered by Macduff (2000) however, was based on a review of tools that measured different elements of QoL as a concept, namely measurement of overall QoL (O'Boyle et al. 1993b) and the more specific HRQoL (Ruta et al 1994). The usual limitations that apply to small sample sizes, typical of qualitative research, relate here, and high rates of attrition further limit generalisability of the study results (Ferrans, 1990). There is debate in the literature as to whether SEIQoL-DW measures the determinants of QoL or actual QoL when a definition is not set (Hall et al. 2011; Farquhar et al. 2010; Moons et al. 2004). In response to this criticism however, correlations between SEIQoL-DW overall index and single QoL ratings indicate that the construct being measured is the same (Hall et al. 2011). Setting a definition also conflicts with the principle of attempting to define iQoL, introducing a preconception of what iQoL 'should' be, steering the participant and research to search for the defined elements, rather than allow the

individual to define the concept themselves; setting a definition may indeed, influence both participants and researcher.

Established and standard psychometrics do not apply to the SEIQoL–DW as external criteria are not applied. Instead, it is the individual’s internal reliability and validity that is important. High correlation and/or consistency with current scales traditionally yield a validity score. Owing to the individual nature of patient reported outcome measures, however, low or zero correlations can provide greater insight into factors affecting quality of life (Joyce et al., 2003). SEIQoL-DW has other advantages. It does not require the participant to be able to read. It also does not require participants to interpret questionnaire items, which requires a degree of conceptual interpretation and therefore a certain level of cognitive ability (Prince and Gerber 2001). Understanding the unique situation of each participant is central to the study (Joyce et al. 2003), and the SEIQoL-DW facilitates this, sampling each individual’s cue profile and elucidating their inner world.

How the researcher affects the reliability and validity of the tool is an important consideration. In this case, the researcher ensured participants were focused and understood the questions being asked. Additional issues, such as prompting participants to provide cues, raised questions about influencing participants. However, it is a recognised part of the use of SEIQoL-DW and pointers and guidance have been produced by the original authors. There is a possibility that similar cues will be identified, and how these should then be grouped and analysed, is also an issue (Joyce et al. 2003). Sometimes the researcher must assist with manipulating the SEIQoL-DW disc, which similarly impacts on the reliability and validity of the tool and measurement.

In the current study, manipulating the disk to indicate the participants’ levels of satisfaction with identified cues did require my involvement. However, there was consistency across the cohort, in that I manipulated the disc for all participants, and the levels set were checked with each of the participants before final agreement was reached. O’Boyle et al. (1993b) recognise that participants may not usually think about the areas under discussion, and asking them to focus might have been sufficiently challenging without introducing new methods and tool of data collection that were complex and unwieldy. In the current study,

some participants required support to draw the of levels of cues. However, presenting paper and pen to do this was not new or difficult for these participants. The pilot study with SEIQoL-DW supported this approach. To further ensure a standardised, reliable and valid measurement, the scale of the paper needed to be exact; data extracted to produce results might otherwise be inaccurate (Streiner and Norman 2014). The scale I used was exact for each participant, but I did note, when photocopying the paper scales, that there was a discrepancy between the height of the x-axis listed by the authors of the scale and the actual scale used. In the current study, this was remedied, rendering values that are reliable and valid for the dynamic nature of iQoL.

4.2.4 Trustworthiness

Certain disciplines in the humanities employ criteria such as elegance, coherence and consistency as evaluative criteria (Altheide and Johnson 1994). Reference to coherence and consistency are included here in the explanation of trustworthiness, congruent with the study design.

To ensure trustworthiness, the theory underpinning the research as opposed to the methods or data generated is fundamental in explaining reality (Robson 2002). The ontological and epistemological approach is that of Critical Realism. Critical Realism recognises that knowledge is fallible, consistent with the purpose of the study: to explore and identify factors that facilitate and hinder iQoL, recognising that participant perspectives may change. Each participant offered a different perspective on QoL, captured at a specific point in time. This is a recognised limitation of this study and the fallibility of the knowledge generated could stem from a shift in responses over time. The data generated during the current study would be superseded by the reconceptualised perspectives, reinforcing the fallibility of the knowledge generated. In longitudinal studies, response shifts happen because participants learn between interviews, and because their perceptions on how discourse influences social situations and vice versa, changes. A response shift in terms of what the researcher acknowledges and looks for in the data is also a possibility, skewing the data. The purpose of an interview schedule and a valid, reliable data collection tool is to guard against potential researcher influence.

My influence as a researcher could affect the data collection and interpretation stages. It is therefore important that I recognise the potential as a researcher of pre-conceptions (member resources) I may bring to the interview and analysis of the data. Researcher qualities as outlined below were foremost in my mind as the interviews and analysis progressed, respecting and being open to the views expressed, in an attempt to suspend researcher bias. However, the thoughts and beliefs are recognised in the analysis of the data. Heightened awareness of qualities and of skills honed in my career as a nurse and lecturer were employed, such as sensitivity and responsiveness to potentially contradictory evidence; being adaptive and flexible to changes and open to enquiry; being a good listener, unbiased and non-judgemental to enhance trustworthiness, as the lack of rigid rules to guide the research can add complexity to qualitative, flexible design (Robson 2002). In addition, self-reflexivity is fundamental to trustworthiness (Andrew and Halcomb 2009) which was supported through supervision and the recording of a reflective diary documenting the decision trail. The use of supervision to debrief was also used to reduce the threat of bias (Robson 2002).

An iterative process was not entered into with participants, owing to potential changes to the perception of QoL over time (response shift), time constraints and logistical difficulties in arranging further meetings. To prevent a threat to trustworthiness and validity, each step of the interpretive process was captured and demonstrated using a carefully adapted version of Fairclough's (2015) CDA framework, to prevent the use of a framework imposing meaning on the data (Robson 2002). The adaptation provides a degree of safeguarding in that meanings will not be imposed on the data, and that alternative meanings or explanation will be considered. The decision-making trail is clearly documented on the transcripts of how the interpretation (and explanation) has occurred, evidencing the approach to preventing a threat to validity. Previously recognised assumptions recognise the influences and views I brought with me to the study, in the form of assumptions related to my background in critical care nursing and the care of long-term ventilated patients.

The cross-sectional study design offers the opportunity to focus on potential relationships between and amongst findings in a single group. Patterns of findings may be interesting in their own rights, or there may be cause for establishing causal links with wider social, macro

elements related to QoL. Anastas and MacDonald (1994) note that findings from flexible qualitative research are as legitimate as those from any other study design. In reporting the data, I was also aware of my obligation to prevent researcher bias by not quoting from one participant over another (Robson 2002). I have thus offered a balanced perspective of the data generated and its interpretation and explanation. Internal transferability/generalisability of the findings and recommendations is possible to the wider HMV population. However, transferability of the findings to a broader audience would require caution owing to the specific nature of the population sampled. Some level of transferability outside the population should not be precluded, as the theoretical insights may prove valuable to other populations.

4.2.5 Response-Shift and 'Gap' Theory

Threats to the validity of respondent-directed QoL evaluations can stem from a response shift (Rees et al. 2004; Howard et al. 1979). A response shift refers to a change in the individual's view of a domain of QoL over a period of time. Golembiewski et al. (1976) explored the dynamic nature of constructs, noting three types of change that occur when measuring a response to a construct: alpha, beta and gamma. Alpha is a conventional change that may be recorded in taking blood pressure measurements and assumes that the construct is stable; it involves recalibration or instrumentation (Howard et al. 1979). Beta involves changes to an existential state, in which recalibration has occurred, e.g., changes in pain perception over time. Gamma refers to reconceptualization: a change in perspective (Ahmed et al 2005). Gamma change is the most difficult to control. It is questionable whether it is at all possible to measure changes in constructs such as quality of life (Allison et al. 1997). The terms of reference for each individual may alter over time, with changes to the domains (cues) that influence individual evaluations. There are also changes to the relative significance and weighting of these domains (Allison et al. 1997).

A response shift related to QoL can occur as a result of one of two elements (Golembiewski et al. 1976):

1. Alteration in participant values (beta change)
2. Reconceptualization (gamma change)

Recalibration or a change in perspective is the result of a change in the participants' own standards of measurement, whereas alteration in participant values refers to a modification of participant values. An example of an alteration (beta change) would be a change in the importance of domains the individual associates with QoL, while reconceptualization (gamma change) would be the result of re-defining their perception of QoL (Sprangers and Schwartz 1999). Ahmed et al (2005) suggests that reconceptualization (gamma change) should be ruled out before beginning to explore recalibration (beta change) and alpha changes.

Response shift mechanisms have resulted in the need to factor illness and disease trajectories into assessing and evaluating QoL as documented by Sprangers and Schwartz (1999). Larsen (2019) notes similar response shifts by referring to the 'new normal' when dealing with individuals with chronic illness. Examples of such response shifts include reports that patients with chronic illnesses report an iQoL similar to healthy subjects (Larsen 2019; Breetvelt and Van Dam 1991). Response shifts have also been recorded when using proxy-raters for quality of life, with the proxy-raters underestimating the patients' QoL. These underestimations have occurred between physician and patient as well as carer and patient (Sprangers and Aaronson 1992).

Calman's (1984) gap theory refers to the discrepancy between what the participant views as their quality of life, and their hopes and aspirations. However, with the changes that occur to individual perceptions over time, the 'gap' between reality and hopes and aspirations would also likely change. Recognition of individual awareness of hopes and aspirations was important to this study, as being asked to consider QoL could potentially have raised concerns, resulting in distress, had the participants not previously considered these issues. It was vital to ensure that support mechanisms were in place to support any unintended harmful effects (Macduff 2000). As such, participants were encouraged to contact their General Practitioners (GPs) should they need to. A letter was sent to the GP's informing them of their patients' participation in the study (Appendix 11). The participant information sheet (see Appendix 12) also included information that the researcher would contact the lead respiratory consultant if issues were identified.

4.2.6 Consensus on Quality of Life Criteria and Operational Definition

The importance of exploring iQoL with patients themselves, as opposed to vicariously interviewing carers or healthcare professionals, is acknowledged in the literature: patients perceive their QoL very differently when compared to their carers or medical team (Sprangers and Aaronson 1992). It has been noted that carers record lower quality of life scores on behalf of patients, than patient participants themselves (Spitzer et al. 1981; Epstein et al. 1989). Variations between physician and patient, with frequent under-estimations by medical staff, are also consistently noted across a broad span of time by Levy et al. (2014), Kremenutzky and Walt (2013), Miravittles et al. (2013), Sprangers and Aaronson (1992), Slevin et al. (1988) and Spitzer et al. (1981). Interpretations by carers and healthcare professionals of patients' interests and expectations were recorded by Browne et al (1997) as being biased toward the carer or healthcare professional's perspectives. The lowest concordance between patient and proxy was found with the most subjective elements; for example, with concepts such as satisfaction, which equates with QoL (Epstein et al. 1989).

Defining QoL nullifies the individual perceptions of what this entails. However, having previously provided a rationale for the use of and an operational definition for QoL in the context of this study, participants were informed of the operational definition in the letter inviting them to participate. The operational definition aided medical colleagues' understanding of the study, particularly when approached to access potential participants, as gatekeepers, as their focus leaned towards health related quality of life. The operational definition was also helpful during the Wales Research Ethics Committee meeting, when discussing the elements of QoL that the study intended to explore study.

4.3 Research Procedure

4.3.1 Sample

A self-selecting sampling technique was used to recruit participants to the study. At the time of commencing the study, 18 participants throughout Wales met the NHS Modernisation Agency (2002 p6) definition of ventilation:

‘Chronic ventilatory dependence: This includes dependence upon all forms of positive and negative pressure ventilation, but CPAP (Continuous Positive Airway Pressure) provided by a nasal or face mask is excluded. Ventilation may be provided either invasively or non-invasively, but the retention of a tracheostomy without any mechanical ventilatory support is not regarded as inferring ventilatory dependence. Patients who require ventilatory support regularly each day or night, irrespective of how many hours it is used for, are deemed to be ventilatory dependent if the duration of treatment exceeds one month. Ventilatory support is usually received in the home rather than hospital. The weaning process ceases when the patient’s condition is stable, medical treatment has been optimized and the requirements for ventilatory support minimized’.

Inclusion and exclusion criteria for the study

Inclusion criteria

- Participants were individuals receiving HMV, according to the operational definition of ventilation above
- Adult participants over the age of 18 years
- No upper age limit was imposed to ensure that the sample was of sufficient size
- Participants understood and could communicate in English or Welsh
- Had capacity to take part (all participants were assessed by the lead clinicians for their care)

Exclusion criteria:

- Individuals requiring HMV who were residents of institutional facilities and not resident in their own homes
- Individuals requiring HMV who resided outside of Wales

As HMV individuals require a level of healthcare, their care is funded by NHS Continuing HealthCare (CHC). Permission was therefore requested from the individual health boards Research and Development departments across Wales, to access the patient population. Possible participants were identified by contacting three lead clinicians for HMV individuals in South and North Wales. Recruitment occurred across Wales, with contact being made with appropriate participants by the respiratory care consultants as the gatekeepers of access to the potential participants. The respiratory care consultants made the decision as to whether to contact the potential participants. From a potential sample of 18, seven individuals consented to be interviewed, or were able to take part in the study. Potential

participants were sent a participant information sheet (PIS) (see Appendix 12) by the respiratory care consultants, outlining the study and inviting them to participate. When a participant agreed to take part, I was given their contact details by the respiratory care consultants, and contacted them to arrange an interview. A scripted approach was used to explain the project, providing a foundation for informed consent, and reinforcing the trustworthiness of the study.

The aim was to schedule the interview with participants within two weeks of initial agreement, which occurred in all cases. The two-week period allowed the participants' time to consider their decision without feeling under duress to complete the interview. Mental capacity (Mental Capacity Act 2005 c.9) was assessed by the respiratory care consultants. Had any concerns been raised around mental capacity, a decision of whether to continue with the interview would have been taken at the time of the interview in collaboration and discussion with the carer/family and lead clinician. Additionally, had any of the participants lost the capacity to consent at any point during the study, the non-identifiable data related to that participant would have continued to be used (Mental Capacity Act 2005 c.9). Written and/or verbal consent from participants was required prior to conducting the interviews, and each participant was asked to provide consent on the day of the interview (see Appendix 13 for consent form). Verbal consent was audio recorded as part of the interview process. Consent could be withdrawn at any point during the study, which was highlighted on the information sheet and repeated on the day of the interview.

There was a potential for causing participants distress while discussing their iQoL. Advice was sought from and guidance provided by a consultant clinical psychologist for a local healthcare provider, to ensure the psychological wellbeing of participants. Screening for psychological wellbeing, in tandem with screening for capacity was conducted by respiratory care consultants prior to the interview, to ensure that participants were psychologically well and able to undertake the interview. The consent form included a section that informed participants that they should contact their own GP should any psychological issues be identified during the interview. With the permission of participants, I would inform the respiratory care consultants of any additional concerns. Exploring the available psychological support of participants has led to a future research question being generated,

which is whether the psychological needs of this population are being met, as there are no clinical psychologists linked to the care of the H MV patient population in Wales.

Final Sample

Of an initial total population of 18 and working within the relatively small community within Wales, hopes were high of recruiting most if not all of the H MV population. Sadly, recruitment was exhausted without full population recruitment due to the reasons detailed below. However, seven participants were identified and interviewed over a 12-month period, from a total of 18 who had regular contact with the respiratory care consultants.

Those who did not participate were noted to:

- have difficulty communicating due to their specific disease process (x 1)
- have died (x 1)
- be too ill to take part (x 1)
- have declined to be interviewed following my initial approach (x 1)
- not have responded to the consultant's approach (x 6)
- not been in regular contact with the lead clinician and respiratory services (x 1)

The recruitment process minimised recruitment bias and respected the health professional's duty of care, safeguarding participants. Gatekeeping is linked to the control (and power) of respiratory care consultants in allowing access to the patient population. The concept of control (and power) at this early point in the recruitment of participants was recognised, in an attempt to limit recruitment bias, which could limit the conclusions drawn from the work. However, duty of care to the participants was the overriding mechanism for the recruitment decisions made.

As the recruitment process unfolded, I spoke with the respiratory care consultant of a potential participant who declined the interview. The consultant commented that they would speak with the participant and inform them that they would need to take part in the study. I felt extremely uncomfortable with this and discussed it with my supervisors. We agreed that contacting this participant was ethically and morally difficult, and that, by not responding to my invitation, the potential participant had possibly decided to decline. Being cognisant of the Mental Capacity Act (2005 c.9) in the Continuing NHS Healthcare framework (WG 2014), the presumption of capacity was respected, whereby:

‘[E]very adult has the right to make his or her own decisions and must be presumed to have capacity to do so, unless it is proved otherwise (WG 2014)’.

The potential participant was free to decide in this case, shaping the outcome of the situation. A shift in control (and power) from the lead clinician to the potential participant is apparent, through their lack of response to the invitation. However, the need for medical support ultimately underpins the potential participant and respiratory care consultant (WG, 2014), as the existence of the individual in the community depends upon the consultant’s care and support. Opposing views were thus evident early in the study, revealing the pull and push of power relationships at a situational level.

Reflexively, my neutral positioning here as a researcher lead to a lack of power to influence the situation, and I felt to some extent that I was being used as a pawn in a ‘bigger battle’ of power between the potential participant and the doctor. Alternately, it could be viewed that the decision, having been taken from my hands, and not being required to interview the participant, was a positive one, with the participant unwittingly providing me with the data to analyse the situation, and ultimately to present a discussion of power relationships. The situation was also a learning opportunity about respecting choice, and how participants may be influenced to take part, which could result in participant bias.

Sample diversity

The sample had a relatively equal gender distribution (4 female (57%); 3 males (43%)). The data has been anonymised however, to protect the participants, and reference to gender has been removed. Race distribution was four White, one Asian and two mixed race participants. A range of diagnoses resulting in respiratory failure were included and the biographical details of participants presented in Table 6 below. Participant anonymity was ensured by referring to participants by number, as opposed to pseudonyms, as the sample is small and potentially identifiable. There was no attrition from the final sample.

Table 6 Sample Diversity

Participant Pseudonym	Age Group	Diagnosis	Level of Disability	Length of time fully ventilated
Participant 1	20-30 yrs	Neuromuscular Disorder	Tetraplegia	6 months
Participant 2	20-30 yrs	Neuromuscular Disorder	Paraplegia	20+ yrs
Participant 3	40-60 yrs	Neuromuscular Disorder	Tetraplegia	20 yrs
Participant 4	40-60 yrs	Neuromuscular Disorder	Tetraplegia	Approx.20 yrs
Participant 5	20-30 yrs	Disability due to Road Traffic Collision	Tetraplegia	20 +yrs
Participant 6	60-80yrs	Neuromuscular Disorder	Paraplegia	20 yrs
Participant 7	20-30 yrs	Disability due to Road Traffic Collision	Tetraplegia	10 yrs

All of the conditions above resulted in either an immediate requirement for full ventilatory support, or a deterioration of respiratory capacity and ability, which then required ventilation. All participants required differing degrees (modes) of ventilatory support, but all required night ventilation via tracheostomy, meeting the inclusion criteria for the study. Physical ability had also deteriorated in all participants, and all required wheelchairs to mobilise.

4.4 The Interview Process

Owing to the nature of the study population, all interviews were held in the participant's own homes, providing a space that was non-threatening and private (Dearnley 2005). This did however limit control over the location, in that it was not possible to ensure that the interviews were uninterrupted and that there would be minimal distraction. Following initial contact and agreement to be interviewed, I negotiated an appropriate date and time for the interview. Once agreed, I travelled to the participant's home, allowing time to travel and find the location. Consistent with the lone worker policy at Cardiff University (2015), I ensured that one of my supervisors was aware of the interview date and time, and I contacted them prior to entering the property and on leaving. Once at the participants home, to create an appropriate atmosphere and to set participants at ease, there followed

general introductions and conversation. With the agreement of the participant, the interviews were audio-recorded and transcribed verbatim following the interview. Field notes were taken during the interviews and written up as soon as practicable post-interview. These facilitated an understanding of the patient and carer experience. However, data analysis includes only interview content; field notes are not referenced.

Participants were informed of the purpose of the study, and the participant information sheet was read to them again, if they requested clarification. Informed consent to undertake the interview was sought, and consent forms were signed, by the participant themselves, if possible, or by proxy (the carer or family member present). Participants were informed that they were not obliged to answer any questions they did not wish to, and that they could withdraw from the study or terminate the interview at any point. Participants were asked whether they felt well enough to conduct the interview and were told that, should they feel tired at any point, they should indicate this and that we would discuss rescheduling a second interview for data collection. As previously mentioned, contact with the GP would be suggested to the participant should they feel distressed by any points raised during the interview, and that I would contact the respiratory care consultant to inform them. Participants were reassured that, should they have further queries or questions in the following few days or weeks, they could contact me. My contact details were made available.

4.4.1 Speech and Communication

Speech and communication differed across the study population. Care was taken to ensure that participants did not tire too much during the interview. As a clinician, I was cognisant of the body language and responses of participants, observing lack of focus and inattentiveness, and body language, such as yawning and fidgeting. Interviews were therefore conducted in several parts for some participants, with breaks allowed for tracheal suctioning, comfort breaks and to allow for any interruptions, such as dealing with pets.

Some participants were interviewed in the presence of their carers, owing to communication difficulties or the need for carer presence at all times due to ventilation. This constitutes a limitation of the study, as it may have affected the openness and honesty

of participants in their responses. Interviews lasted approximately 70 minutes; however, I allowed 1.5 hours for each, given the health status of participants. Interview timings taken from a previous study of elderly patients indicated the need to allow up to 100 minutes for completion (Mountain et al. 2004). Interview lengths however, ranged from 70 minutes to two hours. One participant had locked-in syndrome and required the use of a communication board; this lengthened the interview, and resulted in the participant becoming tired, requiring a second interview to be arranged. Another participant relied upon lip reading as a form of communication. Lip reading was carried out by myself and the participants' carer, and was captured as part of the transcription. All other participants could verbalise without the need for translation or a communication board, and none required the use of a speaking valve⁷ on their tracheostomies to enable speech. Time was allowed for each participant to speak and articulate their views, as the breaths triggered by the ventilator can impact speech patterns. This necessitated patience on both the participants' and my part, but proved worthwhile as participants were keen to share their experiences and thoughts, despite the time and physical and mental effort it took them to explain and make themselves understood.

As my background is critical care, I have experience using communication boards and lip reading, which were the method of communication of two of the participants. I was aided in using the bespoke communication board, developed specifically for the HMV individuals, and in lip reading both by carers and family, who were more familiar with the participants' mode of communication. I am fluent in both Welsh and English and it was therefore possible to conduct interviews in either language (WG 2011b and 2012). One interview was conducted in Welsh.

⁷ The Passy-Muir speaking valve, to help patients with tracheostomies speak, is a one-way valve which attaches to the outside opening of the tracheostomy tube. The valve allows air to flow in to the tracheostomy. It does not allow air to flow back out through the valve. When the patient breathes in, the valve opens and on expiration, the valve closes. The air then flows around the tracheostomy tube, and up through the vocal cords. This enables sounds to be made (John Hopkins University 2018).

4.4.2 Interview Schedule

A semi-structured interview format was used and a guide to the questions can be found in Appendix 14. The questions were adapted during the interview, to reflect individual circumstances and ensure that relevant data was captured.

4.4.3 Pilot: An Account of the Involvement of a 'Lay' Individual in the Piloting of Data Collection: a Confessional Tale.

I wanted to present a realist approach to the writing up of the project. According to Smith (2006), participant's accounts of their experiences are included in realist tales; the researcher's voice, however, is typically held back and seldom heard in confessional tales. Confessional tales relate to the actual fieldwork journey and difficulties rather than the findings, requiring recognition of and transparent exploration of researcher bias, character flaws, concerns and weaknesses. This allows the reader to develop a representation of the researcher with which readers can connect (Smith, 2006). I hope that the following section goes some way towards explaining my fieldwork journey to this point, and learning how to position myself in the research, creating more of a confessional tale.

Reflection is interconnected with and relates to thinking (Doyle 2013, p. 251): cognition and metacognition occur, providing meaning. Mezirow (1990) defines learning as the practice of reworking and adjusting meaning that stems from experience. By revising the meaning of the experience, consequent understanding and further actions can be adapted. I have attempted to find meaning in the experience of involving lay people in my research, in the hope that this will alter my understanding, and support how I approach the recruitment and participation of lay persons in future studies.

The organisation Involving People (involving members of the public in research) was contacted, and an advert posted in the October 2013 Involving People newsletter to recruit a lay person to trial the data collection tool (NIHR 2018). I hoped that this would help me learn from alternative views and develop the study design. I was subsequently contacted by a gentleman (pseudonym, Bob (Nursing and Midwifery Council (NMC) 2018)) who offered his support in trialling the data collection tool. He lived some distance from my work base, however due to other commitments, he frequently travelled to the area and we thus

arranged to meet to discuss the project. I was grateful that I had a respondent to support the study development. I was excited at the prospect of gaining some experience of data collection and that I had managed to involve patient representatives. It would hopefully help me gain a broader perspective and confer greater credibility to my work.

A mutually convenient time and venue was agreed upon, in a busy area of the University. Having met with Bob, we started the conversation, providing an overview of my clinical and professional history and moving on to discussion of his background, in nursing. He stated that he had a PhD and sat on numerous healthcare panels as a lay member. Gerstl-Pepin and Patrizio (2009) note that the researcher should recognise the effect they have on the situation/participant and on the research itself. As the interview progressed, I explained the study and the data collection tool. There are several parts to the data collection process, as previously detailed. We progressed to a 'trial run' of the tool, which involved asking the individual what he considered the five areas integral to his iQoL.

The points Bob identified as affecting his iQoL were:

1. Health (accepting health limitations, boredom, lack of sex)
2. Reason for living (post-retirement, focus, reason for existing, seeing the positive in a situation)
3. Work (importance of sitting on committees, having opinions/voice about health structures, frustrations)
4. Lack of sex (lost skill)
5. Happiness of children (family).

To make sense of this encounter, Savin-Baden (2004) recommends using biographical and narrative accounts to contextualise the individual and interpret the data in relation to this. I recognise that the data collection tool does allow a narrative account to be presented to some extent. In my interpretation of the meaning of this encounter (Mezirow 1990), I now wonder whether Bob was making sense of his iQoL issues, drawing on his own thoughts and beliefs, his member resources, as we were speaking. This struck a chord for me, having read a question raised by Savin- Baden (2004, p. 365): "What is being realised through this research, by whom, for whom?"

I have gained an alternative perspective on what is being realised through this study in terms of my own personal and professional development, but also in the wider remit of how this could truly influence patient and carer lives. Reading the question from Savin-Baden (2004), what has appeared is an alternative agenda, a smaller schema than the overall research project, when viewed (reflexively) from a different angle: that of the participant. Questions now arise as to how many alternative voices this study offers, not only to provide the actual participants with a 'voice' which was recognised while writing the proposal, but whether individuals who seek exposure through involvement with bodies such as Involving People, have individual agendas. I had not considered encountering such alternative agendas during the initial phases of the project. I learned from the reflection, experiencing as noted by Denzin (1989), an illuminative epiphany where an encounter or event presents insights, resulting in transformational learning (Savin-Baden 2004).

Returning to the meeting, the data collection tool subsequently prompted me to ask Bob to identify on a graph his satisfaction with each of the identified areas. Despite his being articulate and cognitively able, SEIQoL-DW proved confusing for Bob, and I deliberated on my ability to phrase the question and explain clearly. Despite having read about and understanding the background to the creation of the tool and testing it on my family, this was my first time using it in context. Having revised the tool the evening prior to the meeting, I was confident in my ability to present a coherent explanation of how the tool worked and what the participant would need to do. I was disappointed. I had understood what was required, but my explanation did not translate well.

The experience was, in this sense, extremely worthwhile. I reflected on all aspects in relation to how this information was presented and factors that could have affected the delivery of information. Numerous thoughts as to why this stage of data collection failed were raised. Was my explanation poor? Had I misunderstood the tool? What was the extent of Bob's cognitive ability? Was it related to the environment, the timing or not having provided sufficient information beforehand? Was I flustered because it was midday and the middle of my working day, having trouble switching between lecturer to researcher? This was a useful experience, resulting in numerous ideas as to how to present this information, trialled with varying degrees of success. Have I truly accounted for Bob's honest account,

and was I empathic (Cutcliffe, 2003)? Was I sensitive to his feelings and the meanings of the discourse, and were my responses true and conveyed empathetically? I recollect 'being professional', using silence and offering discursive space (Öhlén et al. 2008) throughout sections of the discourse that seemed appropriate. Did the fact that Bob continued to disclose personal things to me indicate that I was empathetic and 'getting it right'? Were my communication skills such that he felt enabled to disclose? Reviewing the thesis to this point, I have achieved a moment of illuminative epiphany, transforming my perspective of the situation (Savin-Baden 2004).

Returning to the pilot study, and having completed the first two elements of data collection, I proceeded to ask Bob to divide the SEIQoL-DW disc, allocating a percentage to each cue identified to reflect his quality of life. Bob found the physical manipulation of the tool difficult, and his suggestion of an electronic version resonated with me. This made me deliberate whether the tool would work for ventilated individuals, how much support they would require to use it. I researched the use of electronic formats, and did produce an electronic version with the support of a learning technologist (Ring et al. 2006). The continued use of the original manual disc was eventually decided upon, as introducing a 'new' tool as well as asking participants to reflect on areas of potentially distressing issues may have caused further upset.

On concluding the meeting an hour later, Bob offered further support for the project. In light of the identification of a different agenda that is, the agenda of the lay person, it continues to raise concerns as to how to deal with such situations, and on how vulnerable the lone worker is (Cardiff University, 2015). I frequently wonder how someone else would have dealt with the situation, and how individuals find their way into such positions. This is partly answered by the contextual information gained in the initial part of the interview and the power and control involved (importance of sitting on committees, having opinions/voice about health structures, frustrations). It has made me question whether this was a one-off situation, and whether other researchers have had similar experiences. It opens the debate as to whether participants arrive with their own agenda's, rather than offering to share their views from an open and altruistic viewpoint; what are the motivations behind lay individuals

wanting to support research? I replied formally to the email from Bob, thanking him for his input into the trial run of the data collection tool.

I have, to this point, explored the situation and hopefully demonstrated reflection on action, and possibly in-action (Schon 1983) and reflexivity. I understand that reflexivity is the act of monitoring and affecting action *in situ* (Iedema 2011). However, reflexivity in the context of research is about the positioning of the researcher in, and the effect that they have on the research itself. Cutcliffe (2003) argues whether we truly know ourselves or are truly self-aware. Reflexivity is a way to achieve this, albeit partially. The use of reflexivity in quantitative research introduces epistemological questions, however, it is well suited to qualitative research (Walker et al. 2013).

Smith (2006) further emphasised the importance of reflection in research, teaching, learning and praxis, as well as the advantages of writing in the first person, something I have not done in several years. This I have applied to the remainder of the thesis with varying degrees of success. According to Savin-Baden (2004, p. 374), it helps the researcher engage and 'speak for themselves', removing the barrier of 'voicelessness' as a researcher. It relates to how each of us position ourselves as researchers and how to present data, and that what we are presenting is an interpretation of the participants' views, tinged with our own interpretations (MR) and personal stance. True reflexive research includes sharing information about one's personal stance. This separates the research from the experience of the researcher, with processes and formalities such as methodologies and findings on one side, and my own experience on the other (Savin-Baden 2004).

Power relationships, such as the one detailed in the pilot, are inherent to research processes and scientific research reports (Smith, 2006) and correspond with power relationships in society (Titscher 2000; Fairclough 2003). Reflecting on the discourse and situation and my position therein, although I used the research process and guided the interview, Bob had his own agenda. This reflected the political and power relationships in society more than my fieldwork. Gender, class, disability and age influenced this example of fieldwork, which should be taken into account alongside QoL and how participants construct knowledge, which is then represented in the text (Smith 2006). Saven-Baden (2004) states that the

outcome of reflexivity should be an appreciation and understanding of how participants view themselves in relation to their contexts. This parallels CDA, and how social and personal situations affect individuals' lives and vice versa (Fairclough 2003; Titscher 2000).

4.5 Transcription

All interviews were transcribed verbatim. The one interview conducted in Welsh was transcribed in Welsh and translated into English before being analysed. Both Welsh and English transcripts were re-read and checked for accuracy in translation, to ensure that meaning was maintained to the best possible standard. The English translation of the Welsh language interview was back-translated to ensure accuracy. Consistent with transcription guidance for qualitative research studies, all spoken words, pauses, laughter and speech characteristics were transcribed (Bailey 2008). It was not possible to identify and transcribe all spoken words owing to the speech difficulties HMV causes, as well as to communication issues with two participants. All transcripts were line-numbered to facilitate analysis and direct quotations. An example of an analysed transcript is included in Appendix 15. Field notes recorded after the interviews were revisited during the transcription to assist with re-engaging with the situation and with participants but were not used in the analysis itself. The explanations for the keywords used is below:

Table 7 Transcription Notation:

Notation or symbol used within the text	Meaning
...	To indicate a pause. The length of the pause is also indicated in the text
(inaudible/unclear)	To indicate speech that was inaudible
[name]	To anonymise an individual person or place
(action)	To indicate some form of action e.g. laughter, coughing etc.
Bold	To emphasise spoken speech
[spoken by researcher/ carer]	To indicate speech lip-read by either researcher or carer

4.6 Summary of Chapter

This chapter provides insight into the research design, including an overview of the potential data collection tools available, and the rationale for choosing the SEIQoL-DW (O'Boyle et al. 1993b) as a measurement tool. Differences between standard and psychological processes assessments are articulated. The stages of SEIQoL-DW (O'Boyle et al. 1993b) are outlined and its validity and reliability explored, recognising the importance of response shifts. The chapter details participant recruitment, and how the interview process was conducted, taking into account special difficulties in interviewing this specific population. I hope that I have provided an insight into my learning as a novice researcher by including information about the pilot study of the data collection tool, which informs the overall study. In the following two chapters, the findings are presented.

CHAPTER FIVE

5. Qualitative Findings and Analysis

Based on Fairclough's (2015) CDA framework, the following chapters provide description, interpretation and explanation of the qualitative data collected across seven interviews. This chapter will present the findings from each of the seven interviews, focusing on the interpretive elements and drawing on the text analysis at points. Each case will be presented in turn, providing context for each case, cues identified and cue ratings on the day of the interview. This is followed by excerpts of text and a brief interpretive narrative. The subsequent chapter will focus on the explanation of the discourses that emerge from the interpretation.

5.1 Interpretation

In the adapted form of CDA (Fairclough 2015) applied here, there are three platforms of analysis: Text Analysis, Interpretation and Explanation. The focus of this chapter is contextual interpretation and some explanation, as the two concepts cannot be fully segregated. According to Fairclough (2015), interpretation involves the interpretation of the text and context. This involves identifying the different situations in which we find ourselves, and the different discourse(s) embedded in these. It also includes identifying the individuals involved (subjects) and how they are related. Wider interpretation of the context encompasses identifying social orders, which are the individual representations of how social space is organised. Social orders in turn, draw on three elements:

- schema - the different types of behaviour noted
- frames - the subject matter
- scripts - the subjects involved

Interpretation relies on the researcher drawing on their MR. These MR are the thoughts and beliefs an individual brings to each situation, and are described by Fairclough (2015) as what is "in" the individual (p155). As I interpret the data, I am mindful that I draw on my own MR, the thoughts and beliefs I bring to each situation. I reflexively recognise that my own MR may influence both interpretation and explanation and therefore might influence the findings.

5.2 Data Collection and Style of Presentation

Using SEIQoL-DW (O’Boyle et al. 1993b) each interview resulted in the generation of cues, which captured the participants’ individual views of factors that affect their individual quality of life. The cues initially covered a vast array of domains, including independence, a loss of freedom, socialising and social life, religion, technology and changes to key relationships in their lives. These are detailed in Table 8 below. The participant’s explanation of the cues is provided following the interview context for each participant interview.

Table 8 Categories of Cues

Family/ Relationships	Health	Concepts	Social Life	Equipment/ Finance	Religion
Family/ Friends x1	Dexterity/ Mobility x1	Independence x3	Socialising x1	Technology x1	Religion x1
Family x6	Health x2	Freedom x1	Social Life x3	IT, Wheelchair, Adaptations x1	Spirituality x1
Watching Brother Play Rugby x1	Being Well x1	Loss of Freedom x1	Social Activities x2	Finance x2	
Patient x2	Tiredness x1	Not Being Heard x1	Loss of Friendship/ Socialising x1		
Relationships x3	Home x1	Music x1	Education x1		
Nurses/carers x2		Travelling x1	Home x1		

The explanation provided by each participant of the chosen cues enabled the cues to be condensed into two main categories, Seeking Independence and Being Normal, based on their individual definitions and also as a result of the elements of cross-over and connection between each of the identified cues. This provided a broad structure for interpretation (and explanation) and identification of discourses. Instances of cues which are inter-related (cues that have intertextual elements and discourses) (Fairclough 2015) can be found throughout the data. For example, there are similarities between family and relationship cues, and how they form intertextual associations with social life. There is no clear segregation of the cues to either of the two main categories identified. The two categories are described in Table 9:

Table 9 Categories of Cues

Seeking Independence	Being Normal
Concepts	Social Life
Health	Family
	Religion
	Equipment/ Finance

SEIQoL-DW also generates a quantitative score of individuals' global quality of life⁸ (see Appendix 10). It provides a guide to overall iQoL at that point in time. However, I recognise that this view may change over time, as circumstance and individual perception change (Ahmed et al 2005; Sprangers and Schwartz 1999; Allison et al 1998). A vast range of scores were documented and are listed in Table 10 below. The scores are reflected in the text generated in the interviews.

Age, diagnosis, and level of disability varied among the seven participants. To protect anonymity, disabilities have been grouped into broad categories. The participant's level of disability influenced the way in which they communicated, and vocalisation was difficult for some patients due to tracheostomy and ventilation. Carers were thus required to translate speech or lip-reading in some interviews. Where this occurred, it has been identified. The

⁸ The overall SEIQoL index is calculated using the sum of the values attributed to the five cues identified, multiplied by the rating of the cues, and is scored on a scale of 0-100, with 100 indicating the highest individual quality of life score (see Appendix 10)

participant is identified using 'P', the carer is referred to as 'C' and I am identified as 'A', the interviewer. The participant details and overall SEIQoL Index Scores are listed in Table 9 below:

Table 10 Participant Details and SEIQoL-DW Scores

Participant Pseudonym	Age Group	Diagnosis	Level of Disability	Overall SEIQoL Index Score
Participant 1	20-30 yrs	Neuromuscular Disorder	Tetraplegia	86.5
Participant 2	20-30 yrs	Neuromuscular Disorder	Paraplegia	44.05
Participant 3	40-60 yrs	Neuromuscular Disorder	Tetraplegia	70.8
Participant 4	40-60 yrs	Neuromuscular Disorder	Tetraplegia	82.88
Participant 5	20-30 yrs	Disability due to Road Traffic Collision	Tetraplegia	81.5
Participant 6	60-80yrs	Neuromuscular Disorder	Paraplegia	25
Participant 7	20-30 yrs	Disability due to Road Traffic Collision	Tetraplegia	53.5

The interpretation of each interview is structured as follows: a brief biographical account of the participant, to contextualise the data, and the cues presented using the data, enabling interpretation. The cues merge in the individual interviews, creating intertextual contexts across interviews. Not all categories will be evident in each interview. As noted in Table 10 above, despite the extent of injuries/ limitations due to the clinical conditions of the participants, the SEIQoL-DW score for several of the participants was relatively high: 3 participants scored above 80/100, with one other scoring 70/100. The remaining 3 participant's scores varied, at 25/100, 44/100 and 53/100. Further discussion of the variation in scores and high scoring of some of the participants will be included in Chapters 6 and 8.

5.3.1 Interview 1 - Participant 1

Interview Context

Participant 1 was an individual with a Neuromuscular disorder. Participant 1 lived at home with their parents who were the main carers. Participant 1 commenced Non-Invasive Positive Pressure Ventilation (NIPPV)⁹ at 18 years of age which Participant 1 required intermittently for approximately ten years. However, as the disorder progressed, and their breathing deteriorated, Participant 1 ultimately required the use of NIPPV throughout the day. Participant 1 had become embarrassed to go out as their dependency on NIPPV increased and Participant 1 stated that they did not have any quality of life at that time. A tracheostomy was then inserted, and invasive mechanical ventilation was commenced.

The financial agreements for and introduction of a package of care to support Participant 1 at home took 12 months to put in place. Participant 1 was discharged home six months *prior* to instigation of the care package. This resulted in Participant 1's parents taking on the role of carers, who had to use the medical equipment necessary to support invasive ventilation without training. However, Participant 1 stated that their quality of life had increased since full ventilation was instigated, potentially indicating a response shift. This is reflected in participant 1's overall SEIQoL score of 86.5, despite a poor prognosis and increasing disability as a result of a deterioration in the participant's physical condition. The care package at the time of the interview included 'sitters' for four nights a week, and two four-hour sessions during the day, per week. The family provided all other care. In the interpretation below, several of Participant 1's responses are expanded upon by Participant 1's mother, who was present owing to the participant's ventilatory needs. Her presence is apparent in the responses.

Participant 1 identified the following cues, which are listed alongside their meaning to the participant:

1. Being well – this meant being free from (respiratory) infection, and also being mentally well. It indicated an overarching wellbeing, and being free from the pain

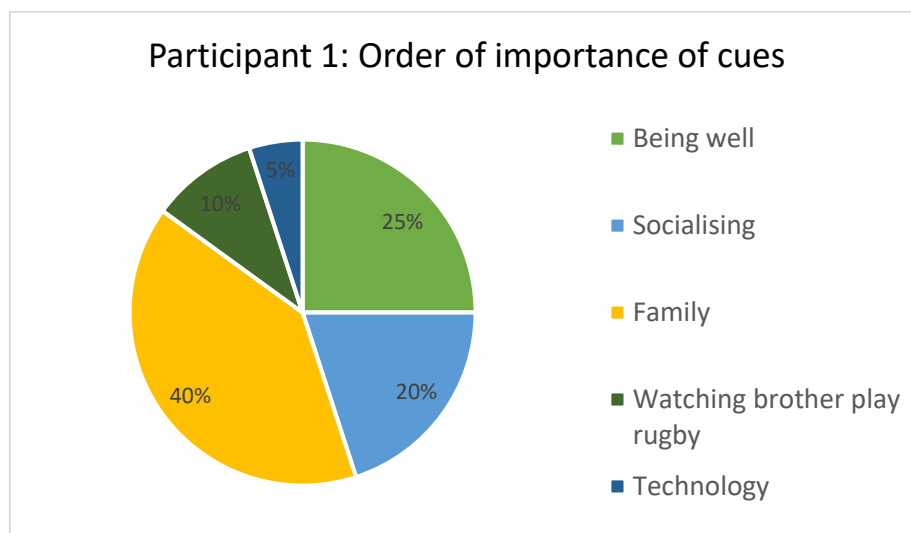
⁹ Non-invasive positive pressure ventilation (NIPPV) requires the use of a nasal or face mask attached to a ventilator. NIPPV provides ventilatory support of differing levels, and is used by individuals without tracheostomies. Invasive ventilation is delivered via an endotracheal or percutaneous tracheal tube.

participant 1 suffered in their legs. It also referred to a lessening of the worry around not being able to breathe, which HMV had resulted in.

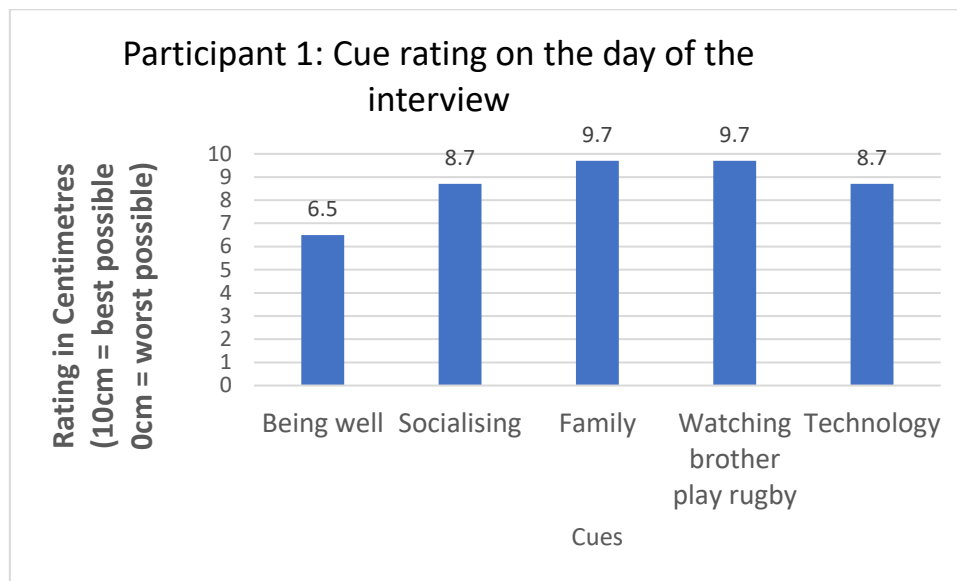
2. Socialising- being able to get out and about was important to the participant. It meant that they were able to 'escape' to see friends and family, and get some 'fresh air'.
3. Family - this involved the participant's entire family, from a newborn nephew, to older nephews and nieces, brother and parents.
4. Watching the participant's brother play rugby – this linked with the participants' need to socialise, and it allowed the participant to indulge their passion for watching rugby. It required the participants' parents to be able to transport the family, and therefore an adapted car had been purchased by the participants' uncle to support the family.
5. Technology – this enabled the participant to widen their world, and to indulge their interest in history as well as sport. The participant also used the internet and relied on their laptop when researching cold and warm water exotic fish, and to maintain the fish tank.

Cues

Pie Chart 1 Participant 1's Order of Importance of Cues



Graph 2 Participant 1's Cue Rating



Interpretation

Participant 1's overall SEIQoL score was 86.5%, the highest of all participants. This was despite the difficulties that the participant faced in relation to a deteriorating neuromuscular condition, and was possibly a result of the mechanisms used to increase iQoL. Family was identified as the most important of the five cues identified by Participant 1 (Pie chart 1 and Graph 2) and was weighted at 40%. The participant listed watching their brother play rugby as another cue, which is both family and socially orientated, creating an intertextual element. Participant 1 did refer to the negative effects of HMV and concerns around losing their voice; however, HMV enabled Participant 1 to live at home. Its positive effect on their ability to socialise is reflected below, and the participant recognised their own need to socialise:

P (P26 Lines 15 – 23): "I'm not stuck in here being bored", "not listening to the telly or machines", "[a need for] socialising ...seeing other people..."

Ironically, being fully ventilated and unable to breathe without the ventilator, Participant 1 stated that they needed **(P26 L23)** "...sunshine and fresh air". Participant 1 expressed frustration at their situation and condition and compared them self to a cousin, also a wheelchair user, following a car accident. Participant 1 recognised that their own level of disability was far greater than their cousin's, and felt that their cousin did not make the most of his situation **(P38 L25-30)**:

C: "...and he can drive a car, he can travel, and like Participant 1 said, most of the things 'that I would love to be able to do'

P: ...a frustrated feeling. I would like to be where he is".

Participant 1 was not, however, wholly negative about their condition and prognosis, as reflected in the overall SEIQoL-DW index score, preferring to look at the more positive aspects of life, and the joy that they brought. In terms of their family and socialising, Participant 1 delighted in their nephew and the normality of having a child sit in their lap:

(P40 L1-22):

A: "Yeah ok, your family, your nephew...obviously the joy of your life. So, when you think about your nephew, what are you looking forward to?

P: Well, seeing him, like and spending time with him...spending time with him, all day and all night

C: Jumping on the chair...

P: Yeah

C: He is the only one out of all of them that have ever got on Participant 1's seat

P: Climbed up it!

C: Climbed up it and sits on [participant 1]'s lap...yeah. I got a photo when he climbed up Participant 1's legs and sat on [participant 1]'s lap, whereas all the others have been a bit... um... less curious, but he just had to have a go and climb up

A: How did that make you feel?

P: I liked that! Yeah I like having [nephew] climb up my chair".

The joy that Participant 1 felt for their family and sport is apparent stating that they were "proud" (P p41 L15) when they watched their brother play rugby. This again reflects the overall SEIQoL score.

(P41 L19 – p42 L5):

P: "I love rugby

C: Although Participant 1's brother plays rugby...he don't half watch as much rugby as Participant 1

P: Yeah, I can watch rugby, shouting!

A: Are you an armchair referee?

P: Yeah! Shouting... I can't be calm!

C: For Participant 1, the first time, well not the first time we went to watch him [Participant 1's brother], we went a couple of weeks ago, didn't we, Participant 1?

P: Yeah we escaped".

Watching sport enabled Participant 1 to socialise, and it also enabled further integration into their own social world through their knowledge and understanding of the game, increasing the overall SEIQoL score:

(P43 L23-26):

C: "if Participant 1's father is having a competition with somebody about football or rugby

P: and they can't remember

C: and they can't remember a name of a person, they will either go or ask Participant 1 or phone and would say 'go and ask Participant 1 who so and so is' and Participant 1 will remember".

However, Participant 1 recognised the restrictions that their health requirements due to the muscular-skeletal disorder imposed on their life, curtailing their freedom to watch rugby, for example. Participant 1 did not refer directly to health but to "being well", which in rating the cue, scored 6.7cm on the day of the interview. They defined being well as "not having chest infections" (p37 L5) and, more broadly, "being happy in yourself" (p37 L10), recognising both their physical and mental health. Participant 1 referred to the use of non-invasive ventilation and its effect on iQoL, indicating a shift in response over time, related to the positive effect of HMV:

(P5 L4-23):

C: "Participant 1 stopped going out 'cos [they] didn't like to go out with the mask on.

P: I didn't like the mask on my face

C: [Participant 1] didn't like the mask on [their] face. Didn't like people to see [Participant 1] with it on [Participant 1]'s face

P: Going out then, I was moving all the time, I'd be rocking back and forth

A: Just to breathe?

P: Yeah! (Laughed)

C: ...just to try and get air in [Participant 1]'s lungs

P: it was bad...don't go anywhere

C: yeah, so basically [Participant 1] quality of life then was nothing really...[Participant 1] would avoid it...[Participant 1] didn't want to...'cos Participant 1 had always been a big rugby fan...Always liked going down the rugby club, and hearing different things

P: Yeah

C: Watching [Participant 1] brother play rugby, but everything came a big struggle... so in the end um...we talked to them [medical staff] and [Participant 1] decided to have this done [tracheostomy]. [Participant 1] was asked to have this [tracheostomy] done quite a few years ago, but Participant 1 was adamant then...

P: Didn't want it at that time".

Participant 1 had worried about the insertion of the tracheostomy, and identified their fear of not being able to speak and be heard following the insertion of the tracheostomy.

Participant 1 stated that, in relation to their overall level of physical disability:

P (p39 L6): "it's not the worst you can be; that's when you can't talk".

This fear was realised following the insertion of the tracheostomy: the participant became very unwell, and it took several weeks to stabilise their ventilation:

(P7 L17 – P8 1-31):

C: "...they [medical team] said then that they didn't have to put [Participant 1] in intensive care, it went really well, and that [Participant 1] could come straight to the ward. They fetched [transferred] [Participant 1] to the ward, within half hour of...being on the ward, [Participant 1] had haemorrhaged. And that basically then it was a big scare for the nurses on the ward 'cos they didn't know the machine [ventilator]....They were trying to get people who could come and sort it out, then the blood started coming out through [the tracheostomy]...they had to then call for the crash team...It was a very scary time wasn't it, Participant 1?

P: yes it was

C: so for the hour basically, it was a (sic) hour but it felt like a day...they had to stabilise Participant 1 then and I have to thank the doctor...and all the staff on the ward. They were brilliant, and the crash team...there were all brilliant. They were really good. It took them a long time then to stabilise Participant 1 enough to get [Participant 1] from there down to ITU ...nobody come and tinkered around with the machine [ventilator] on him. Participant 1 was left with the machine on... which...meant [Participant 1] couldn't speak at all. So Participant 1 couldn't tell you what was going on. Only I knew that [Participant 1] wasn't right from the way [Participant 1] was breathing, and basically [HNV specialist nurse] came the one time, and he...said he didn't know anything about it [the ventilator]...

P: he [HNV specialist nurse] said it was so new, that nobody knew anything about this machine

C: nobody knew the machine like, and it was horrendous...Another doctor was actually doing a round but he wasn't Participant 1's doctor, but the machine was actually beeping as he was doing the round. He introduced himself and he asked 'do you mind, I know I'm not Participant 1's doctor, but do you mind if I take a look?'... He went to Participant 1 and...He done something to the machine, and all of a sudden, Participant 1's breathing just went 'sshhh' like that, and Participant 1 mouthed me 'a lot better'

P: Yeah it was really hard work. For days, gagging I was

C: for days, [Participant 1] couldn't breathe. [Participant 1] was struggling...
A: how did you feel?
P: I just felt awful at that time I wished I never had it done at that time. Yes, it was really hard...it was really hard".

The insertion of the tracheostomy and recognition of the progression of the condition and prognosis of the condition had initially left Participant 1 feeling low, but Participant 1 had "started picking up" (P p37 L16). This again highlights a shift in response to the commencement of HMV. The text below highlights the struggles with breathing and the physical disabilities that accompany the condition, which affected the participant's mobility and ability to operate their electric wheelchair.

(P14 L34- 25 & P 15 P L1-24):

A: "Were you thinking about your breathing?
P: Yeah, it was always there in my head...where now it's just...I don't even have to think about it
A: So it's more natural?
P: Yeah, more natural...yeah, it has helped
A: So all in all, after a very rough year, how is it now?
P: Much better now, I am....I can go out and sit down. I don't have to worry about rocking back and fore, moving my chair and knocking someone
C: Whereas before, when [Participant 1] went down the pub, [Participant 1] always had to keep the chair on and go [rock] back and fore to breathe. Either that, or we would take the [breathing machine]...
P: Rocking back and fore all the time...
C: Then [Participant 1] would be worried...about people pushing into [their] hand... because then Participant 1 hadn't really got a bit of muscle in [their] thumb, and [they] would worry about that as well. So in the end, [Participant 1] used to say, 'I'm not coming. I don't want to come', and of course, it meant if Participant 1 didn't go, we couldn't go, so... but like now, like [Participant 1] said, [Participant 1] can go to a place, knock the chair off, and not worry about anyone touching.

The instigation of invasive ventilation required the organisation of a package of care delivered by non-registered nursing staff. Agreeing the funding of the package had been a complex and lengthy process, involving numerous agencies and institutions.

(P6 L1-7):

C:" it was a 12 month before that [insertion of tracheostomy and commencement of invasive ventilation], that [Participant 1] actually decided that they wanted it done then. But it took a 12 month to actually...get everything sorted, all down to

funding...who was paying for it, who was paying for the machines...who was going to service the machines....big funding issue for over a 12 month, it was ridiculous...”

However, despite the issues, concerns and limitations of the health service in delivering the care required, Participant 1 had benefitted from the establishment of mechanical ventilation. This is captured by the participants’ positivity, response shift from a negative outlook to positive, and is reflected in the overall SEIQoL score:

(P15 L5-10 & L20-24):

C: “yeah it’s a lot better now innit?

P: yeah it has helped

C: yeah it has

A: so, all in all, after a very rough year how’s it now?

P: much better now I am...I can go out and sit down I don’t have to worry about rocking back and fore moving my chair and knocking someone...

A: so life is better?

P: yeah

C: much better

P: yeah that’s right, so now I am more positive”.

Interview 1 Summary

The issues faced by Participant 1 highlight their struggles with the effects of their condition, deteriorating health, and dependence on HMV and on others. Their enjoyment of family and relationships are identified, promoting a greater iQoL. This is reflected in the overall SEIQoL score of 86.5/100 and demonstrates a shift in responses. Their lack of power and vulnerability are also highlighted. Participant 1 did not mention health as a cue, but health influences all of the cues identified, as HMV is central to Participant 1’s reality and the interview. The discourses and influence of political drivers for health and social care and how they affect service provision are visible in the text. The schema and frames described by Participant 1 revolve around their health needs, both in hospital and at home. There are numerous subjects (frames) involved, with interactions and intertextual discourses woven between the following subjects:

- patient/carers and medical and nursing staff
- patient and parents
- relationships with wider family members
- institutions and care agencies

5.3.2 Interview 2 - Participant 2

Interview Context

The second interview was of Participant 2, who was diagnosed with a neuromuscular condition as a child. Following initial diagnosis, Participant 2's life expectancy was predicted to be short, yet the participant had survived. However, the condition had left significant physical disabilities and respiratory failure, requiring ventilatory support. The participant was hospitalised as a child for a period before being discharged home with a full package of care, and registered nurse support 24 hours a day. This had been reduced, and, at the time of the interview, Participant 2 received registered nurse support overnight (9pm – 9am) and carer support three times a day. Participant 2 lived in an adapted bungalow on their own. The participant was able to perform their own tracheal suction and manage some fundamental care, and prepare straightforward meals.

Participant 2's parent's relationship had broken down when they were a child. The participant's mother left the family home when Participant 2 was 12 years old, and the participant's father and partner cared for Participant 2 and sisters. Following schooling, Participant 2 had undertaken several courses at college, and worked in the voluntary sector for several years. This had become too difficult, and, at the time of the interview, Participant 2 worked as a volunteer one day per week. The challenges faced in everyday life, limitations imposed by the condition and participant's attitude and well-being are reflected in the overall SEIQoL score, which is 44.05/100. In comparison to other participants, the score is relatively low.

Participant 2 identified the following cues, which are listed alongside their meaning to the participant:

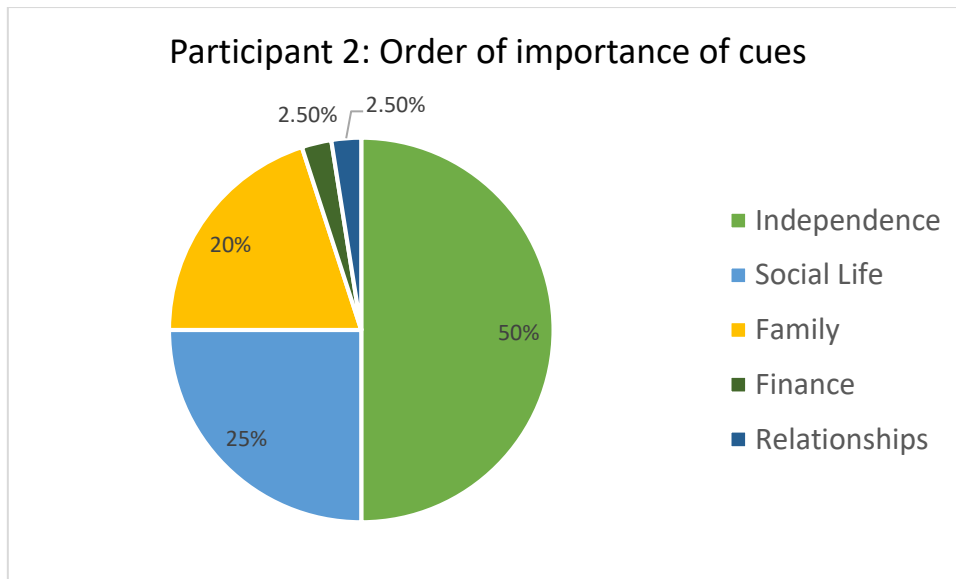
1. Independence – the participant felt that they had quite a good level of independence, being able to carry out a lot of their own care, however they noted a dependence on carers for physical care. The participant did not link their independence with their dependence on carers, or perceive it as affecting their independence.

2. Social life – Participant 2 felt that their social life was limited, as friends did not call, and that the weather and seasons limited their ability to socialise. The participant found that winter and the need for more clothing/ coats made life difficult when attempting to get dressed to go out. Poor weather also limited the participant’s ability to get out, as they relied on public transport. The onus was on the participant to travel to see friends, rather than friends calling to see the participant.
3. Family – the participant noted that they had limited involvement with their family, yet they listed family as a cue, and suggested a 20% level of importance. The concept of ‘family’ was important to the participant, despite limited contact.
4. Finance – this cue offered insight into the participants’ views on debt and disability. The participant was aware of their level of debt but also that as a disabled, ventilated individual, their disability would likely not lead to incarceration and therefore they chose to ignore their debt. The limitations of the finance available to the participant was a restriction on their life.
5. Relationships – this cue is linked to the first, second and third cues identified. It offered an insight into the perceptions of the participant of how the world viewed disabled individuals. It exposed difficulties with sexual health and how empowering a relationship can be.

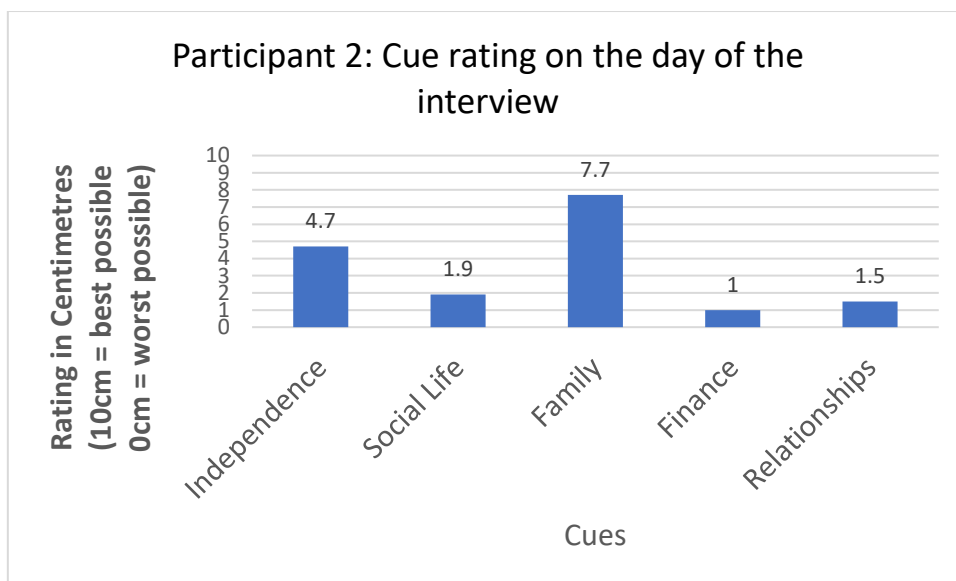
The influences above offer insight into the overall SEIQoL score, and the individual perspective of the participant as to how their life was affected by the challenges faced.

Cues

Pie Chart 2 Participant 2’s Order of Importance of Cues



Graph 3 Participant 2's Cue Rating



Interpretation

Independence was the most important cue identified by Participant 2, at 50%. Participant 2 rated their independence on the scale as 'bad', which equated with a measurement of 4.7cm on the day of the interview. This was echoed in the overall SEIQoL score. Participant 2 identified how the weather and dependence on carers affected their independence:

(P31 L10-26 & P32 1-9):

P: "Well it's definitely not best possible...Shall I put neither good not.....? Oohhh....what does that mean? I'm really stuck in a rut...not going anywhere, so....yeah...."

C: In the summer it'll be different because then, you're out and about a lot, innit?

P: Yes, and weather

A: So seasons affect you, do they?

P: Massively...And the fact that in the winter, it's harder for me as in like, I need to put layers on, so I need help with, with putting coats on...carers put my coat on...half past eleven and if I come back, I've got to sit with that coat on 'til somebody comes...I'm stuck right now...but in the summer it's easier to do".

The intertextual nature of the cues is apparent as Participant 2 who was single, described their previous relationship and how it enabled them to be and feel more independent. The participant allocated an overall score of 2.5% to relationships and scored this as 'very bad' (1.5cm) on the date of the interview, again reflected in the overall SEIQoL score.

(P38 L26 & P39 1-26 & P40 L1-40):

P: "...having independence....

A: What does that mean?...

P: Like being able to think on my own...not being stuck in, not being tied to anyone...like if want to jump on a on a bus and go to [Name of Town]...which is about all I go anyway, does that make sense?

A: Yes, absolutely

P: Like going to the firework display...to not to answer to anyone,

A: What would make that better for you?

Silence while the participant thinks

P: I don't know, um...I don't really know, it is hard...God...I suppose there is things like ...you know, I don't want a carer tied to me 24/7, ...if right now, if I want to go out, I got to have my jacket put on, on a certain time...or like...if I want to go to bed in the afternoon I can't, 'cos I got no-one here...So.....it's not so much having a carer tied to me but maybe having....

C: Somebody there when you need it...

P: Yeah...

A: Is that tied...in any way to your relationship? ...

P: ...Oh loads...loads, yes...it did increase my independence loads...When I was with [ex-partner], we could just go some-place overnight, 'cos [ex-partner] does look after me overnight...um....[ex-partner] could do all the vent [ventilator], [ex-partner] could do all my care...so we'd even planned to go on holiday so ..but [ex-partner] could do all that...and I know Mam's not going to like what I got to say, but it's true.....so yeah that was a massive thing that I do miss from my relationship...".

Participant 2 also highlights how an intimate relationship resulted in a more equal footing and how a relationship had broadened their social life. A response shift from a greater

degree of independence when part of a relationship, to a lower level of independence when single, was discernible.

P (p62 L11-17): “Well, like I said, I could go out. If me and my ex wanted to...go somewhere, we’d...go...I suppose it was a lot easier....And it wasn’t a carer. It was a partner”.

Participant 2 viewed the provision of the package of care as restrictive, tying them to their home, as the care package did not allow for payment of carers/qualified nursing staff in an overnight stay away from her home.

P (p42 L3-4): “Like if I wanted to go away for the night, to be able to go then that's not an option”.

The participant grudgingly accepted this but referred to the situation as “NHS rules...God, don’t I know about that” (**p41 L21-23**). Participant 2 felt their social life was poor. Their social activities were restricted by the weather and care regime and they noted that:

“I don’t really go anywhere do I? Friends don’t come here” (**P p32 L25**).

The participant’s social life had become more restricted over winter and was limited to visiting a friend at the post office, influencing their perspective of their individual and overall quality of life:

P (P43 L17-20):“... I've got a friend who works down town, in the Post Office, I go and see them but apart from that I don't really do much... kind of stuck in a rut at the moment, I don't really go anywhere....”.

Despite stating that they felt independent, Participant 2 offered insight into the level of care that they needed.

(P9 L9-25 & P10 L10-11):

A: “...and in terms of re-positioning in bed...?”

P: My night...staff help me with that

A:...And to get you up and sorted out in the morning, personal care, the staff, they help you with stuff like that?

P: Yes, they help me with that then I have...carers come in at, at 10 that helps me shower...the night staff just get me up and get me dressed...and then the carers come in and help me shower...and get me dressed ...

C: [Participant 2] likes to go out and all that, [participant] goes into town and [participant]'ll have carers right through the day and it means [participant]'s limited, [participant]’s got to be back here then for them to be here”.

At an individual, situational level, poor family relationships dominated Participant 2's life. However, Participant 2 identified family as an important cue. The participant had once been estranged from their mother and at the time of the interview was estranged from their father. Participant 2 did not have a strong bond with their sisters. Participant 2 regarded their family as selfish. Yet, in contrast to this opinion, the participant viewed family as a cue as the most positive (7.7cm), while allocating its importance at 20%. The participant stated that they did not see their family frequently:

P (p53 L24 & p54 L1-5): "Don't get me wrong, I love my family to bits, but they...Can be selfish. I don't see my sisters, unless they want something, ...I know Mam got something to do, but some days I don't see them, I hardly see my Dad...".

However, Participant 2 became animated when discussing their voluntary work, expressing their 'worth' to the community. Individual issues affected Participant 2's ability as a disabled individual to contribute to society. Nevertheless, the participant took pride in their work with the elderly, young and disabled. This did not appear to influence the overall, individual quality of life score:

(P13 L21 – 26 & P14 L1-11):

P: "I've done most of my voluntary work I've done since I moved here, ummm...I done the play schemes...I've gone into schools and taught young kids about sex... I've worked with the elderly...and I currently do...um....voluntary work on a Wednesday, working in a radio station...it's a radio station that promotes independence for people with disabilities, so I do that on a Wednesday. So that's it.... it was getting that I was out every day.

A: And you were tired?

P: Yeah, it's like with play schemes... it was five days a week and I wasn't getting home 'til like ...half past six, seven,

C: Exhausting.

P: Yeah".

The normality and worth the participant sought through voluntary work was offset by the way they coveted attention, through their attitude and use of language. This is exemplified by an instance in which the participant's wheelchair was jammed outside their home, on a rainy day:

P (p19 L1-6): "...and I got stuck on the pebbles. Mam wasn't around....luckily enough they were still building the houses over the fence...so I was screaming, the dog was going mad. This builder looked over, he said 'you alright love?'. So then, excuse my

French, I said 'do I fucking look alright?' and he went 'Oh, I'll come and help you now'".

Participant 2's challenging attitude towards authority is further exemplified in their attitude towards debt. The tensions that exist between regulation and maintaining control in society, and the situational, individual push-back against social norms were apparent. The participant believed authorities would and should treat them differently to people without disability. Participant 2 believed they could win sympathy because of their disability and thereby avoid sanction such as jail:

P (p61 L10-17): "Yeah, I've got debt collectors after me, but I don't care....What they going to do, put me in jail?...You know, are they seriously going to wanna put a [person] in a wheelchair in jail, with a vent?Probably cost them more. I'm not stupid, I know how to put in for sympathy.....do you know what I mean?"

Descriptions of relationships with healthcare staff were couched by a general mistrust of healthcare services. The respiratory care consultant in charge of Participant 2's care, John, was, however, spoken of fondly, on a personal level and using his first name. The participant's attitude towards John was positive and separate to their negative attitude towards the GP and other general healthcare practitioners and services.

(P24 L1-7):

P: "And ummm... the doctors down here don't seem to know their arse from their elbow...they put me...on antibiotics a month ago and not even for my infection...and then when John saw me after that, he was like, oh yeah,...[participant] needs to be on these [antibiotics]".

(P97 L19-21):

P: "Now, they haven't given me any scans, I was hoping to get...I spoke to John again, and he spoke to Dr. [Name withheld] about maybe getting' a scan, cos like I said to John, I feel that they are 'fobbing' me off".

On closing the interview, Participant 2 identified reproductive system problems as an issue. The participant had been investigated for pain whilst having sex and referred for psychosexual counselling. Participant 2 maintained that it was a 'mechanical' problem owing to anatomical deformities, rather than a psychological problem. The participant referred to their physical appearance in attending the clinic, contrasting this with non-physically disabled individuals stating that "people don't look like me go there" (p99 L13), offering

insight into a low overall individual quality of life score. The location of the clinic on the top floor of a hospital building that did not have lift access resulted in further difficulties for Participant 2 in accessing care and treatment, along with the discrimination of staff, and the requirement to fit in with the 'normal' rules of the clinic:

P (P97 L6-8): "...this stupid woman, basically said to me, well why are we even having sex...That I should be on contraception, 'cos I'm disabled..."

The participant further disclosed in discussion the effect of reproductive system problems, again potentially revealing its influence on overall individual quality of life score:

(P98 L 12-26 & P99 L1-9):

P: "...[it's] affecting me massively

C: ...but the impression I get with [participant] which makes [participant] feel worse is...what's the point? [Participant]'s in a wheelchair...You know, just disregard [participant]...it's like this psychotherapy thing...[participant]'s going to go to, but personally, even John said, he don't see why [participant] needs to go to it, it's stupid, cos all they're going to do is talk, plus they told [participant], that [participant] can't go to it, unless [participant] got a partner..

P: I go to the initial assessment on my own...But I can't go to psychosexual therapy without a partner

C: Which is stupid because, who's to say [participant] might not get a partner in the future? Why does [participant] need a partner...?

P: I'm not being funny, you meet someone, you don't say right, you're lovely and all that, but you got to come to psychosexual therapy with me!"

Interview 2 Summary

In relation to the research questions set, the impact of disability as opposed to HMV on Participant 2 is apparent through, for example, the restrictions that the disability imposed on the participant, and identifiable in the overall, individual quality of life SEIQoL score of 44.05/ 100. The cues identified demonstrate Participant 2's struggles at an individual, situational level. These are intertextually related to struggles at an institutional level and can be related to the wider societal landscape of discrimination against disabled individuals, specifically the need for a care package, which depends upon governmental CHC budgets. The care package does enable the maintenance of a degree of independence, but is a double-edged sword, in that it also curtails of Participant 2's social life and relationships. Promoting Participant 2's iQoL is mainly via institutional level mechanisms such as provision of carers and financial benefits to maintain their standard of living. Strategies used by

Participant 2 to promote their iQoL revolve around their social life, and involvement in third sector community work. The potential positive effects of this however, were not visible in the overall SEIQoL score.

The schema and frames described by Participant 2 focused on their experiences in healthcare and socially, and the influence of the participant's outspoken nature. As with Participant 1, there were several subjects (frames) involved, and interactions and intertextual discourse(s) were woven between the following individuals:

- Participant 2 and family/ carers
- Medical staff
- Friends and partners

5.3.3 Interview 3 - Participant 3

Interview Context

Participant 3 was a middle-aged individual with a neuromuscular disorder, which affected the participant's arms, hands and respiratory muscle function. The participant's parents were no longer able to deliver the care required due to their own deteriorating health, and care was provided 24 hours daily via the NHS funded CHC budget. None of Participant 3's carers were qualified nurses.

From diagnosis at 11 years of age, Participant 3's deterioration had been gradual. Key stages in the deterioration noted by Participant 3 were the diagnosis of sleep apnoea and subsequent tracheostomy insertion at 33 years of age, and a move to full ventilation at 49 years of age. The deterioration in the participant's health had resulted in a gradual withdrawal from social life. A response shift is visible; Participant 3 was a musician and the disease progression had resulted in the participant no longer being able to sing or teach children to play the piano, and in having to stop playing the organ at the local chapel. This was a source of great sadness for the participant. However, the general loss expressed in the interview itself was not reflected in the overall, individual quality of life score of 70.8/100.

Because of losing their voice due to tracheostomy and ventilation, I interviewed Participant 3 in the presence of their main carer. Participant 3's words were lip read and relayed either by the carer or by me, resulting in the use of the third person in the text. The frequent use of 'you' as a pronoun is therefore evident and is used to substitute the word 'I'. The interview was conducted in Welsh and the transcription translated back into English. It was re-reviewed (back translation) to ensure accuracy of meaning.

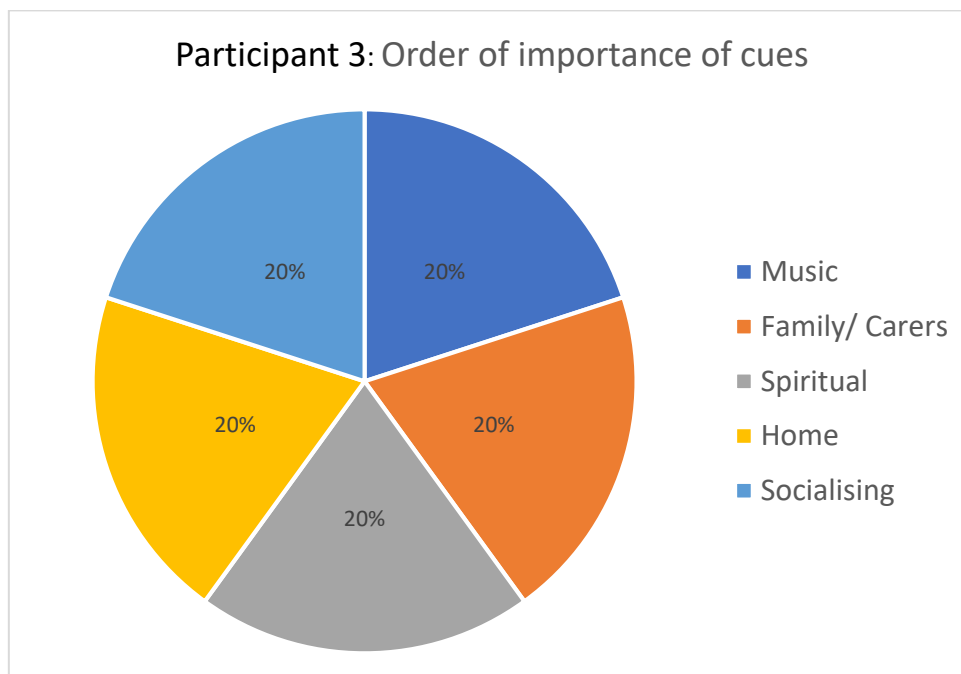
Participant 3 identified the following cues, which are listed alongside their meaning to the participant:

1. Music - this cue covered a multitude of related points, such as losing the ability to sing, play the piano and organ, teaching music to school children and composition. The cue was broad and brought both joy and sadness; the sadness was reflected in the loss of ability and joy in the pleasure that music in whatever form, continued to bring.
2. Family/ carers – the participant referred to sharing their life with their family and carers and how important this was to them. It incorporated the participants' cats, who shared the participant's bed and offered comfort.
3. Spiritual – references to how religion could be practiced anywhere were masked by unhappiness about how the participant's condition had limited their ability to share in the joy of religion and prayer, through attending chapel. The discussion offered insight into the participant's mental health and wellbeing. The increasing bouts of depression affected the participants' enjoyment of life, but reassurance was sought and found in a belief in God.
4. Home – the participant revealed the extent of their world: the bedroom. This is where all of the ventilatory equipment to maintain their life was stored. Home was secure and important. The participant saw that their life was restricted, linking with the above cues, and indicating a shift in response and reconceptualization of their iQoL.
5. Socialising - this cue involved the joy that seeing old school friends brought, tempered by the participant's current inability to travel to see them. Socialising involved friends and family calling in, and again, a sadness that the local religious

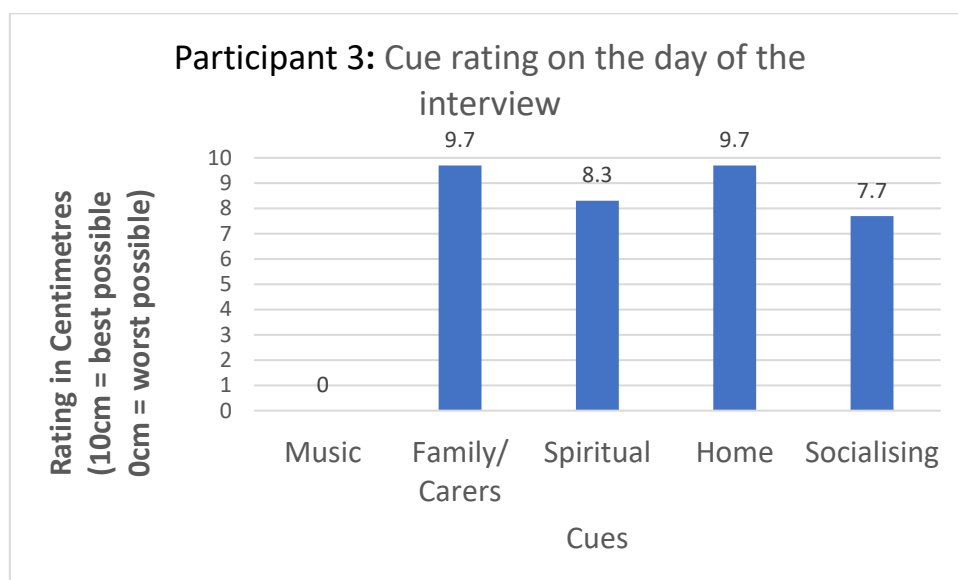
leader and congregation did not call to visit Participant 3. The participant was very aware of how the condition limited their ability to socialise.

Cues

Pie Chart 3 Participant 3's Order of Importance of Cues



Graph 4 Participant 3's Cue Rating



Interpretation

Despite their deteriorating condition, Participant 3's overall SEIQoL score was 70.8.

Participant 3 rated four of the five cue levels as between good and the best possible. The

participant rated music at 0, and considered all of the cues identified to be equal in terms of order of importance:

(P27 L22-24): “20% each....They’re all important”.

Music was the first cue identified by Participant 3 and included the participant’s joy of music, composition and playing piano, competing at national festivals and competitions, their role as a music teacher and as the organist and member at the local chapel. The limitations brought on by the participant’s illness of their ability to take part and socialise within their community via the medium of music brought to light the intertextual aspects, reflected in the cue rating, and indicating a shift in response.

P (P9 L1-17):

P (C speaks): “You have a diploma in piano playing...You taught children to play the piano...25 children a week

A: goodness, that’s a handful, that’s a lot to do

P (C speaks): That’s why you have such patience today, you think!

A: I can believe! (all laughed)...Did you gain a lot of pleasure from it? Yes, yes..

P (C speaks): you’ve missed a lot of things.....Because you’re musical.....

A: ...so you still enjoy music...?

P (A speaks): Yes....So after that...you then came home, and you haven’t worked...things have deteriorated since then...yes

P (C speaks): Once the trachy came that was the end of it....”

The participant did not identify health as a cue, although this does appear in an intertextual context throughout, exemplified below when identifying cues from provided prompts:

P (P15 L20-21) (C speaks):

“Not one of those...money doesn’t bother you....money doesn’t buy health”.

P (P38 L24-256) (C speaks):

“Health. That’s what you’d say. If you haven’t got health, you got nothing...You’re rich if you have health”.

The participant’s poor mental health was recognised, and they expressed their low mood and fatigue with life and their situation, contrasting with their overall individual quality of life score, and a response shift:

A (P14 L 3-10): “ ...do you have any pleasure from watching the Eisteddfodau [National Welsh music and dance festivals]...Yes

P (C speaks): With tears on occasions....That's where you'd beshould you have had your health....everything went slowly [abilities/ health]....You're quite low at the moment".

Sharing the participant's life with their family and carers had increased in importance to Participant 3. The participant included carers alongside family as a cue. The participant clarified, nevertheless, that despite the strength of the personal bonds between themselves and carers, professional boundaries existed as part of their relationships. This was exposed as Participant 3 discussed difficulties with one carer in particular:

P (C speaks) (P41 L4-8):

"...things are going on in her [carer's] life...Tipping over into work. Can't separate the two...because you've become so close, they think that they have the right to talk to you as they want... you're the boss, and you don't want to put up with any more nonsense..."

The angst and blame are blatant in Participant 3's description of their relationships with the health board and individuals, as the health board tried to outsource the participant's care to an agency.

P (P9 L24-25 & P10 1-4):

(C speaks): "two years ago, you went in [to hospital].....there's been a falling out between you and the health board...they want to give you to an agency.....no chance.....when you went in to intensive care.....you'd been 18 years with carers.....[participant] wasn't allowed to go home until all the carers were trained....that was one of the worst days in your life...With John's [respiratory care consultant] help.....they've backed off...."

P (P30 L18-25, & P311-24):

(C speaks): Not a lot can change...because of the bodythe body is going, but the brain is right....

A:the carers' package...is that worrying you at the moment?

P (A speaks): That has helped you...deteriorate....because of stress.....falling out with the health board.....trying to give you to an agency...You had a hard time with it....the lies that they were saying was terrible...Trying to pull John [respiratory care consultant] into the middle of it....with John on your side....trying to pull your GPs into it....she [GP] walked out of the meeting.....she [GP] said she wasn't going to be involved with red tape....she [GP] said 'I'm here to care for Participant 3'.....

A: How did that make you feel?

P (A speaks): Felt good...Someone on your side...A full room of people...a big circle...chest nurse from a different hospital...everyone there...And only you...and a

couple of carers...And you had to listen to, excuse me, shit.....how could people be present in this meeting without seeing you for years...the chest nurse walked out... before the end of the meeting...She wasn't happy that you'd said [mentioned some facts about the poor standard of care received]....she knew that the cap fitted...it doesn't matter how weak nobody dictates how you live...you had to fight to have the bed.....the bed £3,500.....that cost Muscular Dystrophy Society paid..."

Battle lines are drawn as Participant 3 questions 'their' [health board and staff] allegiance to themselves as a patient, specifically the family care officer, who was employed to act as an advocate:

(P31 L25-26; P32 L1-27 & P33 L1-14):

P (C speaks): you've got a family care officer Participant 3's sister is ill too with [neuromuscular condition]...you haven't heard anything from her [family care officer]...polite words...you went up to the [Welsh National] Assembly...with your family care officer...they get paid by the health board.....which side are they onthe side of the health board.....you had slight words.....there was a meeting in the Assembly.....you haven't heard from the Assembly.....[family care officer] spoke on your behalf.....so, the family care officer, don't they support the family.....There wouldn't have been a problem...with the health board...wanting you to go with the agency...it would have been all right.....but she tried to lie to you, [said that] she was on your side.....once you arrived at the meeting, she was sitting on the other side....You've coped with the lot...there's no doubt that your health....you've worsened since then....you emailed your social worker....to say to carry on.....with as you are now.... you had a letter saying you had to go to agency....out of the blue.... advocacy.....if you want anything now.....go through the advocate in London.....

P (C & A speak): You haven't heard anything from anyone [Healthboard or family care officer]...John [respiratory care consultant] saying...they've probably given up.....they're probably scratching their heads....Yes...it's easier for them to shove it in the drawer than think about it and help rather than put things in the way....it hasn't been easy has it? And all you wanted was to stay at home....You didn't want agency.....don't fix something that's not broken.....you've been doing [staff] rotas.....with help now....it all comes from you....yes, yes....you're a strong [person]... you're not as strong as you were....once some stress comes, you then decline.....can't cope."

Despite Participant 3's feelings that there had been a deterioration in their health owing to stress because of the disagreement with the health board, the participant asserted their continued strength to fight to live at home and be cared for by carers who had been

supporting the participant for 18 years. This highlighted the intertextual relationship with health, despite not listing this as a cue:

P (P31 L19): “It doesn’t matter how weak, nobody dictates how you live”.

Participant 3’s social life included the occasional evening with both friends, and a weekly visit from the participant’s sister who “comes over every Sunday” (P16 L4). Participant 3 spoke of their two oldest friends, and how they “have been friends for...49 years” (P24 L1). The participant’s parents were elderly and, with Participant 3’s mother’s advancing dementia, Participant 3 recognised the importance of social contact and support and how “socialising is important” (P29 L5). Yet, the participant’s own social interaction was limited, which saddened the participant, reducing their iQoL, particularly in relation to Participant 3’s great-niece, who, at five years of age, could not lip read:

P (P16 L13-14) (C speaks): “She doesn’t talk to me...it’s heart-breaking...you like interacting with the children.”

The concept of loss was raised again, as Participant 3 identified spirituality as a cue. The participant referred directly to religion. This was important to the participant, and they spoke of their relationship with a previous chapel minister who had developed motor neuron disease, and how he was “special...he was so good to you” (P18 L5). Participant 3 stated that the minister felt that the participant was “...an inspiration for him to carry on” (P18 L7). The current minister did not call as often, and Participant 3 expressed sadness at the loss of this relationship, and that the participant missed attending chapel and playing the organ. Participant 3 recognised the restrictions to their social life which revolved around their faith, and was dismayed that the chapel community did not make the time to call to see them, indicating a shift in response:

P (P21 L14-16): “You only need 5 minutes to call with someone...Call in and out...Too busy”.

However, the participant’s faith in God was strong. Participant 3 viewed their life as hopeless re-defining their perception of iQoL. By contrast, their faith provided hope in an afterlife:

P (P17 L10-14) (C speaks): “You speak to Him oftenyou don’t want to be here anymore...Sometimes...you do believe...strongly believe”.

P (P20 L6-8): “Doesn’t make a difference where you are.....you don’t have to go to chapel [to pray]...God is with you wherever you are...”.

Participant 3 recognised that death was the ultimate outcome of the neuromuscular condition, and they reverted to the lyrics of a Welsh hymn to express their feelings around the future:

P (P29 L17-19): “To a world that’s better to live in....That’s better than this...To smile....on all the storms...”.

Participant 3 included their home as a cue and part of their iQoL, influencing their SEIQoL score. On probing, a broader intertextual component was identified, as the participant’s home and bedroom had become the breadth of their social life, because of all of the equipment needed to maintain the participant’s breathing and life were contained within it. This was where the participant spent their days, interacting with the participant’s parents, carers, family and cats; it was where they socialised, prayed and listened to their passion: music. This was reflected on constantly throughout the interview, with death being the other constant referent, and captures the re-definition and reconceptualization of their iQoL:

P (P21 L20-21) (C speaks): “...this is where you are now...you don’t want to leave here....this is where you want to befrom here to the graveyard....”.

Interview 3 Summary

Participant 3’s cues, in contrast to the overall SEIQoL score, point to a re-defining of their iQoL and to loss: of music as their main love in life, the participant’s social life and, indirectly, how their illness rather than HMV had affected all aspects of their life. The participant recognised that with the insertion of a tracheostomy and full mechanical ventilation, their health had rapidly deteriorated. The participant’s focus was at an individual, situational level but also recognised the institutional involvement in her care. The power relations were apparent and are exemplified in the struggles Participant 3 had in maintaining the carers they had for 18 years, rather than be moved to agency-based care provision. Participant 3 clearly identified issues at a meso level that affected the participant on an individual, situational level. The subjects (frames) identified by Participant 3 revolved around the participant’s different roles as patient, daughter, sister, friend, organist, member of the chapel congregation and respected music teacher. The other subjects involved are

the healthcare staff, carers, family, muscular dystrophy society and Welsh Government. The schema and frames revolve around Participant 3's situational and institutional concerns. These relationships were positive and negative in turn, depending on the effect that the decisions made had on Participant 3 at an individual level. Strategies to promote a greater iQoL were limited, with breaks and trips to see friends becoming increasingly difficult, however faith was a central focus, potentially influencing the overall iQoL score. Informal (intertextual) support networks were apparent throughout the interviews, through carers, family and friends, and faith and religion.

5.3.4 Interview 4 - Participant 4

Interview Context

In a similar picture to Participant 1, Participant 4 was diagnosed with a neuromuscular disorder at the age of four. Participant 4 lived with their mother and sister who provided care and support. There was a genetic history of the neuromuscular disorder in the family. The participant's grandmother had recognised the weakness in the participant's legs as a symptom of the condition. Participant 4 attended mainstream school, but was bullied as their health deteriorated:

P (P16 L18-23): "I used to like... walk on my toes. It's one of the signs of [the neuromuscular condition] when you walk on your toes...and basically, I couldn't balance like that, so I used to fall. So, when kids used to go past, they would push me on purpose".

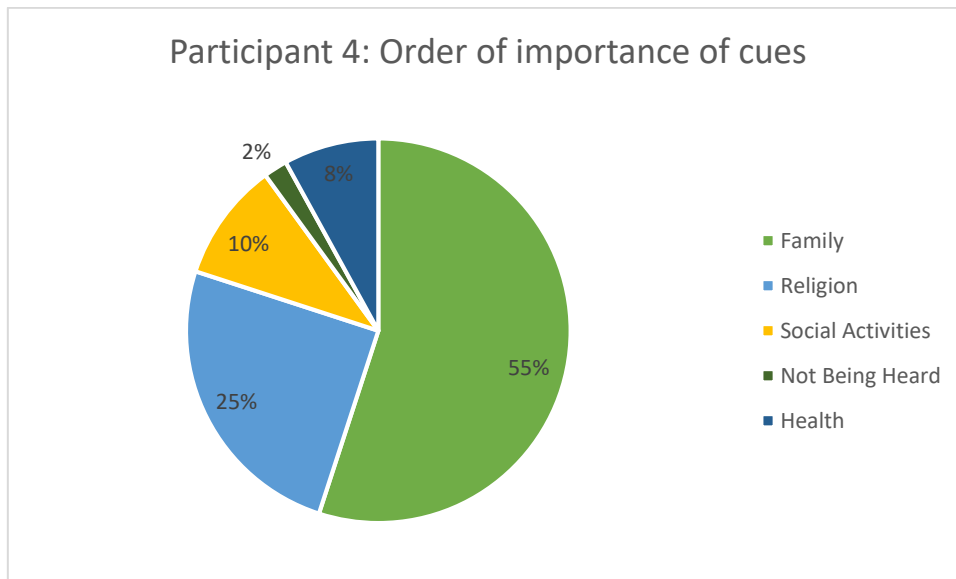
As the participant's respiratory failure worsened, Participant 4 had a tracheostomy inserted and was fully ventilated at 26 years of age. At the time of the interview, the participant had outlived the prognosis for the neuromuscular disorder, living approximately 20 years from the insertion of a tracheostomy. This was viewed positively, indicating a re-conceptualisation of iQoL. The participant had regular carers, which had recently changed from registered nursing staff to an agency supplying non-registered carers (physical assistants (PAs)) alongside some district nursing (DN) input. The PA role was limited, with family continuing to provide care from 6pm to 11pm daily, alongside additional personal care when required. The participant's sibling was present during the interview owing to issues with the participant's tracheostomy. Participant 4's mother was away celebrating the wedding of another of her children.

Participant 4 identified the following cues, which are listed alongside their meaning to the participant, and their overall SEIQoL score was 82.88/ 100:

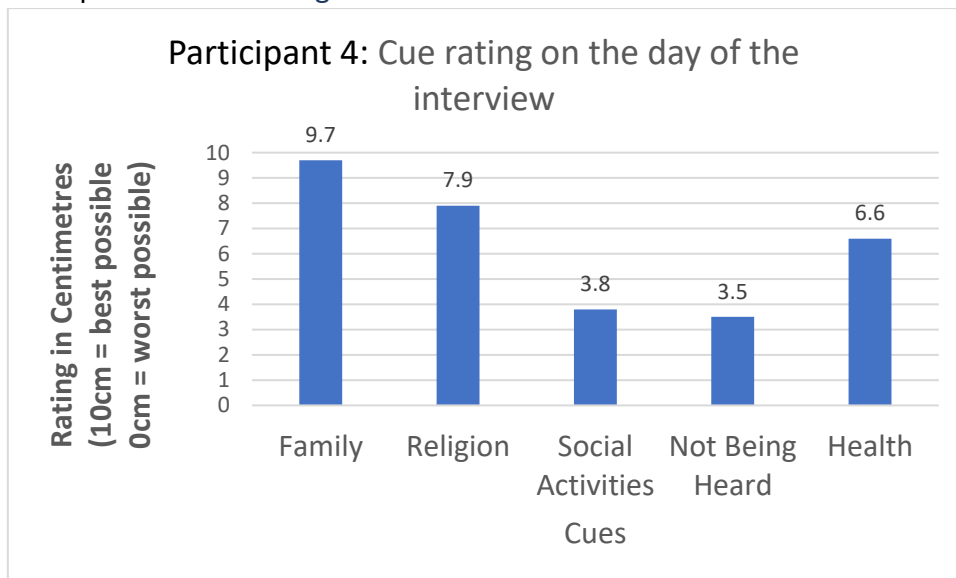
1. Family – Participant 4 listed family as very important, in that the participant was appreciative of the caring role the family took on, and how the family looked after the participant. Family meant that the participant was happier, which is reflected in the overall SEIQoL score. The participant liked being around family and spending time with them, making the participant feel important and fulfilled. A shift in response is evident.
2. Religion – Having been diagnosed with a progressive neuromuscular condition as a child, the participant had experienced anger as a young person, and found that they had become depressed. Religion and faith had offered purpose to their life, and that they felt more content, indicating a reconceptualization in iQoL. The religious leader had been instrumental in this, enabling the participant to ‘do the best’ they could, which is reflective of the overall iQoL score.
3. Social activities – for the participant, this involved family, and nights out at the cinema and at the homes of family. The participant expanded their meaning, expressing their joy at attending football matches, although this was tempered by limits imposed due to a lack of money. The deteriorating condition left the participant feeling frustrated due to the restrictions it imposed; attending football matches and social events resulted in the participant feeling more normal and more a part of society.
4. Not being heard – Participant 4 noted a frustration when not listened to by the carers/ nursing staff. It resulted in anger which was directed at the family. This intimated a lack of involvement in decision making alongside not having views and needs recognised.
5. Health – The participant noted that their health was of a good standard. The focus was less about the long-term condition and more about how the participant felt ‘in themselves’, their current wellbeing. This is reflected in the participants’ overall SEIQoL score, and reflects a shift in response. There were links made between this cue and religion, with recognition of the anger that the participant felt as a young person, in dealing with the diagnosis.

Cues

Pie Chart 4 Participant 4's Order of Importance of Cues



Graph 5 Participant 4's Cue Rating



Interpretation

Participant 4 identified family as the most important cue, according to a 55% weighting. Family also rated highest of all cues on the day of the interview. Family formed the main relationships in the participant's life and were interconnected with the participant's social life. Participant 4 noted:

P (P36 L24): "So I think the most important thing actually, is like, family".

The participant's family made Participant 4 feel included, providing the participant with a reason for being, reflecting a shift in response and redefinition of their iQoL:

(P50 L 6-8):

P: "I think my family is my purpose.....I think I am here like, for them, that's what I think".

(P42 L26-29):

P: "...my family is a lot of fun. Like sometimes my aunties and my cousins come over and I feel quite..... I quite enjoy spending time together.

A: ...how does that make you feel?

P: (silence) Important".

Participant 4 refers to their position and significance in the family circle, and pleasure that they gain from being with their family. The participant reflected on their search for significant relationships and normality and purpose in all aspects of his life. Significantly, Participant 4 accepted the limitations that the neuromuscular condition and lack of money, have imposed on them, as reflected in the overall iQoL score of 82.88/100. It also indicated a shift in their response to iQoL:

(P43 L1-6):

P:"You know I do sometimes feel... well...like normal people and get married and things....I would have loved to have done that – but I have accepted the fact...that it's not meant to be like...I would have loved to have had kids".

P (P50 L16 – 34; P51 L1-13):

A: "...a day trip...how important is that to your quality of life?

P: well, it is important because I love to, if could I would go around the world...to see different cultures, and I'd love to go to America, that's my ambition...I'd love to go to New York. I feel like that one day I will do that. I just have to find the way...'cos the last time I went away, abroad was when I went to [country name] in about '92...and that's the last time I ever went abroad...I do miss the options to go places...That's why, when I win the lottery, hire a jet and that just go around the world! (Laughs)

A: yeah, yeah....so is finance important then?

P: I would say it is really in that aspect of it...so I could have a bit more independence...its obvious money does give me independence really..... the more I can do...so that does restrict me a bit...because obviously I need a lot more...finance, to allow me to do things more and more that I could do, you know because of my special needs...".

(P 49 L4-33 &P50 L1-4):

P: “Well, I lose some independence, like I used to feed myself, and...I stopped feeding...it's things like that, it hits you...You lose the ability and you think, that's another thing I can't do anymore. I think that's when I really get frustrated...slowly lose the ability to do certain things....I think that used to get to me as well.

A: Yeah.....so do you think a lot about your prognosis now? Or do you take every day as it comes?

P: do you know what, I don't...no I don't, I'm here... every day is a bonus...'Cos I feel that I wouldn't have been here...when I was 27 when I had my tracheostomy...so I've had nearly 16 years, I feel that I should be grateful that I am still here... Yeah that's what I feel. Obviously I'd like to live another twenty years! (Laughed)...I still feel that I have a purpose in this life...to be with my family...there is still a purpose there. For some reason I...I am still here, maybe for my family, I don't know...they all say that ... because I am here, they feel... my cousins love me (laughs) my cousins... think that it's not so bad, that there is purpose in everything”.

Drawing on Participant 4's recognition of their deteriorating abilities, the participant accorded health a score of 6.6cm (8% overall importance), noting:

P (P39 L26): “ Health is...I think I would say...I think it's good actually”.

The participant noted a good level of health despite numerous issues surrounding their physical and mental wellbeing, mirroring the overall SEIQoL score of 82.88/100. An alteration in their view of their health, recalibrating their perspective is discernible. They listed physical complaints such as friable skin and potential pressure sores (**P10 L30**), contractures (**P12 L18**), aspiration of food (**P13 L15**) and refashioning of his tracheostomy (**P6 L11**). The participant matter-of-factly noted that they had previously “respiratory arrested and that was it” (**P4 L30**). Having been critically ill, Participant 4 viewed their current condition as stable, and in accepting this condition, felt well. This highlights the intertextual context of health, relationship and family cues, and suggests the influence of these aspects in relation to a shift in response to, which is observable on the iQoL score.

Participant 4 focused on the changing and developing relationships with the recently employed PAs and medical and nursing teams, highlighting personal, situational struggles. The change from registered nursing staff to agency and non-qualified carers centred on the minutiae of day-to-day living, such as the need to be repositioned and the trust developed

between patients and carer over years, influencing his individual quality of life. A shift in response to a more negative perspective was visible.

(P22 L5-34 & P23 L1-21):

P: the thing is with my other team, I was with them some of them, they were with me for ten, fifteen years, so you get that...what's that called?....what's that word?... you get that?

C: ...you build a rapport and trust and [participant] trusted them

P: yeah...because if anything happened, they would notice straight away...so if my vent [ventilator] come off or a different noise on it. So, I was really reluctant to go to agency. So, all those years I...was having to start from scratch again...

C: because sometimes, if [participant] needs suction, you can hear [participant] gargling...so you can tell if you have been with [participant] long enough, oh hang on, so without [participant] even...saying it, they used to give it [suctioning] to [participant]

P: I wasn't really happy about them going really...but I had no choice

C: yeah, but it's like one of them, some of them are youngsters, and they have...no life experience, and to them it's just a job you know...and why she [carer] was suspended was because [participant] was calling her, and she didn't hear [participant]...she doesn't like nights and it was a night shift and...we don't know whether she dosed off, which we think she might, I don't know, but it was only when the vent alarm went off

P: I needed suction! (Laughed)

C: that she got up because there was...

P: high pressure on it....

C: so much gunk there [secretions in his airway], because [participant] didn't have the suction, couldn't breathe, so the ventilator had no air going in, so it went off. She got up.... the others would have done it straight away, in the fifteen years or so that has never ever happened. You know [participant] will call, ok fine, after about the fifth or fourth time, extreme, they will get up and do it, but she didn't...

Participant 4 raised the issue of awareness of cultural norms, and identified the need for education to facilitate a higher quality of care delivery.

P23 L25 – 37 & P24 L1-8):

C:you know personal hygiene, in our culture, religion we've got to clean ourselves down there, you know, we've got to wash ourselves? But then um...pubic hair, you've got to shave it, but I don't think they do it to you, do they?

P: no

C: there used to be one nurse

P: my mum does it sometimes

C: there used to be one nurse who used to do it, around...you know, genitalia, you know, shave [participant] and everything but [name withheld]...used to do it...?

P: yes [name withheld], she's retired

C: she's left, but she has retired and the district nurses, you can't even get them to do normal things, so there is no way they are going to do that, and it's uncomfortable for them...number one it's in our religion, we have to do it

P: yes, because we pray and that so....

C: you have to be clean.... and um...and now it's like, no one does it".

Participant 4's total dependence on their carers and family for this and other care elements and day-to-day issues were also apparent:

(P23 L1-21):

C: "....I buy [participant]'s clothes...

P: Basically, you do everything...everything that I need, really need

C: ...like when I went to hospital with him. I had to do everything: wash [participant] as well um....give [participant] a wee, which is a bit awkward as I am [participant]'s sister, so I have to go in blind, and...[participant]'s like left, right, up, down...and it's like hard, it's hard doing that... (Carer cried)".

Participant 4's personal struggles with carers came to the fore, as the participant recognised frustration and anger with the carer's lack of attention to his needs, and not being heard, and the ramifications of this for the participant's family:

(P37 L17-35):

C: I think one of the ones for [participant] is um... being heard. If there is something that is goingwrong and they don't listen to [participant] or they think.. because ..they are professionals, doctors, trained, they think they know better. So I think that frustrates [participant] the most sometimes when... they don't listen to [participant], and [participant] has been in tears sometimes...especially in the morning when district nurses...[participant] used to be really angry

P: yeah I am angry with them aren't I?

C: and then [participant] takes it...and...we get it then...[participant]'s bashing [the] wheelchair against doors

P: (laughs)

C:then just....cascades and then [participant]'s like 'I am not eating', and then we go to death all of a sudden

P: (laughing) yes that....!

C: (effecting an impression of Participant 4) 'Fine, I will leave, I will die, it will be better if I died' and then my mum will be like, 'well I might die before you'...

P: (laughing) make me feel bad then".

The participant was reticent to ask for help, and felt that, once they had asked once, the request should be actioned:

P (P58 L6-9): “If something’s not right I try to...manage but I know I can’t. I think if I ask once, then I ask twice, I feel like I can’t ask a third time, and I don’t like asking”.

This dependency extended to Participant 4’s social life. The participant recognised the implications of their dependency on others to enable the participant to socialise. Participant 4’s condition made it difficult to communicate at times, as crowds made it difficult for the participant to concentrate and hear. Participant 4 also recognised the struggle to live, and a need to make the most of life, which is visible in the overall iQoL score. The participant’s need to break out of the routine of the home environment had, however, previously resulted in injury:

(P52 L20-34 & P53 L1-20):

P: “you know, I do enjoy going out...it’s difficult for me sometimes...a lot of people have lots of things to do, and even though they’re not straightforward [communication at social gatherings], I still enjoy them, and I’ve had to go through all the difficult times to get to here

A: too many people?

P: yeah. To be around....I don’t talk to them, but I am still sitting there with them

A:at a social event?

P: yeah. It’s just um...I miss it more and more

A: ...social contact?

P: yeah. I think it’s important...being inside your room...you do get a bit frustrated...you know sometimes I feel like that I am in prison...just in the house and that’s what it’s like innit?

A: Yeah. So, you feel...restricted?

P: yeah (silence)

A: so, does it get to a point where you say, right, I have to go out, I need to go out?

P: yeah...once, once, it was a bad idea but there was like snow, on the ground, outside...so I said to my mother, no offence, I need to get out of the house...she goes like, I don’t think you should go...because of the weather, but I said I’m going...I just need to get out the house. So, I went, came back and I fell off my ramp...because it was icy and....

A: did you hurt yourself?

P: I hurt my shoulder and banged my head on the ground (laughed), but my brother hurt himself...I landed on his leg (laughed)”.

Participant 4 tried to normalise their life through their love of sport and in their attendance at football matches:

P (P37 L10-12):

“going to football matches.....things like that, trying to be as normal as I can”.

P (P51 L18-33 & P52 L1-17):

A: so how do you feel when...you go to these football matches? How does that make you feel?

P: it makes me feel more normal...you know, that I am just the same.....you know, I feel more like part of society and not just someone who stays in the house all the time (laughs)...’Cos I went to a match before and.... It was actually about three years ago when Cardiff played Liverpool...when Liverpool scored I was like, yes!

A: what was the atmosphere like?

P: yeah an amazing...you know it gave you goose bumps...It was an amazing feeling, I just love it...so you know, I do get quite passionate about it”.

In gaining a sense of normality, religion featured clearly for Participant 4. The participant found peace and contentment in prayer, helping them accept their condition, and found that religion provided:

P (P37 L3-4): “... a satisfaction from it and I feel calm and I feel...like you know just, at peace, so that’s fine”.

Participant 4 felt as and after he prayed, “...I feel content” (**P p44 L8**). Participant 4 reflected on his personal and situational conflict in accepting his diagnosis. This signifies a shift in response, and the participants’ overall SEIQoL score is indicative of this. The participant commented on how their relationship with the local religious leader, a “sensible...chap” (**P46 L15**), had supported them, intertextually drawing on relationship as a cue:

P (P43 L28-32): “I never had no religion in my life...I used to be quite angry...really angry... why me and all that stuff...and I feel religion has calmed me down”.

Receiving care at home however affected the practice of their faith, restricting how and when the participant socialised. Prayer time coincided with the carers scheduled time to deliver care. Participant 4’s condition also means their focus on prayer could not be maintained owing to tiredness. If the participant’s carers were late arriving to get the participant up in the morning, the participant found that they felt sleepy, and could not focus on prayer:

P (P43 L1-3): “when I’m in bed, you know like I’m doing it [praying], then all of a sudden you drop off, then...you wake up,...so then it get so difficult that I can’t...”

This resulted in individual, personal struggles for Participant 4 who stated that “[life] it’s hard” (P44 L32).

Interview 4 Summary

Participant 4 weighted family heavily, at 50%, forming the bedrock of their iQoL. Despite the poor prognosis, Participant 4’s overall SEIQoL-DW index score indicates a relatively high iQoL at 82.88. Participant 4’s focus was their purpose in life, which revolved around their family. A shift in their conceptualisation of, and a re-definition of their iQoL is demonstrable. The participant’s struggles were individual, drawing on wider factors that influence their individual situation. Power is exerted through institutional involvement in health and care provision, and wider discourses such as religion and faith are visible. Their influence and impact on Participant 4’s situation are viewed both positively and negatively. These discourses define the frames, including family, carers, Imam and healthcare staff, and schema.

5.3.5 Interview 5 - Participant 5

Interview context

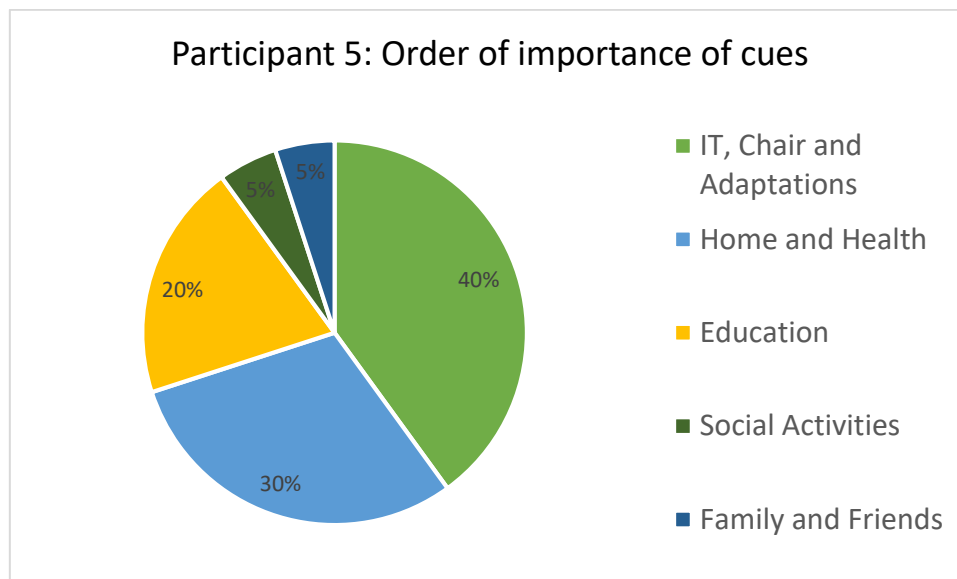
Participant 5, a young student, was involved in a road traffic collision (RTC) at 18 months of age. The participant was removed from the care of their birth mother and became a ‘cared-for’ child until they reached 18 years of age, with both healthcare and social service involvement. Participant 5 had lived in a series of foster homes. The participant was fully ventilated and tetraplegic as a result of the RTC. At the time of the interview, Participant 5 lived with carer support in the participant’s own ground floor flat; the participant was supported by two qualified nurses per shift on 12-hour shift patterns, seven days a week. The participant had an advocate who had worked with them for four years. The advocate had previously been employed as a carer for Participant 5, when under the guardianship of both social and healthcare services as a minor.

Participant 5 scored 81.5/ 100 in terms of the overall iQoL score, and identified the following cues, which are listed alongside their meaning to the participant:

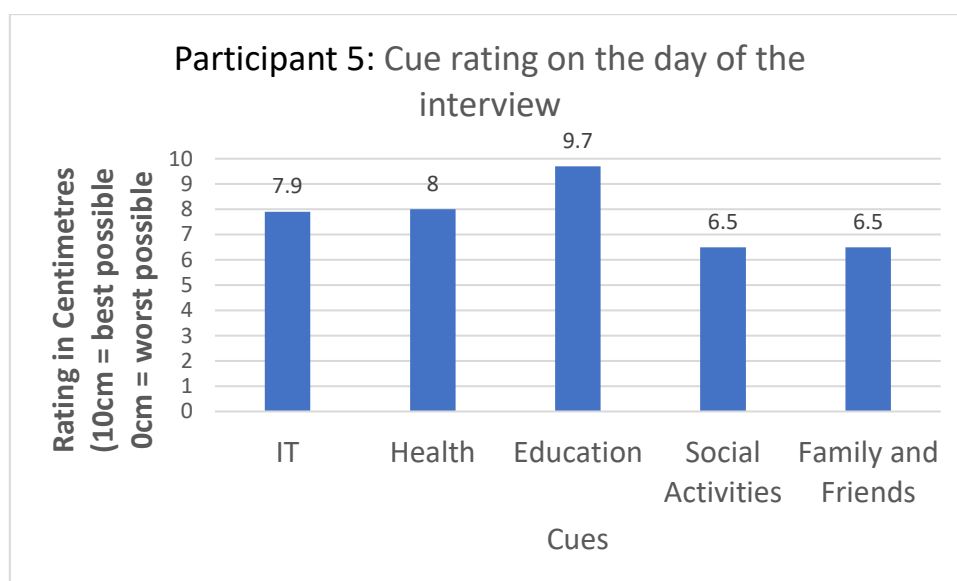
1. IT, Wheelchair and Adaptations – this cue identified a number of connected elements that affected the participant’s life and ultimately their quality of life. The focus was on functioning equipment, and how any breakdown affected the participant. There was also a focus on communication, as the participant was reliant on IT to communicate, and how this enabled the participant to control their life.
2. Home and Health – Participant 5’s health and home were intertwined with the first cue, as the participant’s home was adapted to support their everyday needs. Neuromuscular issues affected everyday living, and health impacted on the participant’s education and ability to socialise.
3. Education – again, there is a direct link to the first cue above. The reliance on technology to support the participant’s education is clear. The participant identified that they required additional time to complete assignments and projects, requiring educational programmes to be adapted to their specific needs. The participant recognised their additional learning needs, and that socialising with other students was difficult.
4. Social Activities – the participant identified that since moving to adult services, they were less dependent on services to make decisions, increasing their independence in decision making. A shift in response and re-defining of their perspective was visible. It enabled the participant, through the support of an advocate, to be more independent, indicated by the overall SEIQoL score of 81.5/100.
5. Family – The participant identified their increased contact with family over the past few years, which had increased their quality of life, and is reflected in the overall iQoL score, and hinted at a shift in response. The discussion however is dichotomous; the participant stated that their quality of life had improved through increased contact, however this was tempered by the account that contact with the participant’s family was sporadic.

Cues

Pie Chart 5 Participant 5's Order of Importance of Cues



Graph 6 Participant 5's Cue Rating



Interpretation

Participant 5's overall iQoL index was relatively high, at 81.5. Participant 5 struggled to identify cues, and constantly reinforced their dependence on technology to support their life. The participant identified family as a cue and rated this at 6.5cm, with an importance of 5%. Having transitioned from child and young person to adult health and care services, Participant 5 had freedom to contact their birth parents following a forced estrangement of several years. Participant 5 believed that

“...seeing family and stuff like that sometimes, it is quite important” (P28 L9-10).

However, the reality of the situation was that contact with both the participant's parents was infrequent.

(P29 L21-22 & P30 L16):

A: "that's a big family... How often you see them?"

P: again, I would say it's only this year that I have got back in contact with mum, my brothers and my sister. ...I was in contact with dad when I was like 16-18...he is the one I get on better with, because we have better interests...but he hasn't been to this house for about...four years at least...it might...be even five years that he hasn't seen me...like I said, it's not a big issue really because...I talk with him on-line and stuff...

A: How often do you talk to your dad on-line?

P: very rare now, to be honest".

The participant continually returned to discussing their desire to develop an (on-line) relationship with their father, but was contradictory and dismissive, demonstrating a level of mistrust and uncertainty:

P (P40 L9-13):

P: "...either it would benefit, it would improve..., with regards to...maybe having more contact with...perhaps...dad a little bit. Again, dad is not on-line much...active much but again, I am not too bothered either".

Participant 5 tried to make sense of their estranged relationships with both parents, expressing that having a relationship was an improvement and benefit. The participant did not indicate that this brought them joy or happiness. It did not appear to influence the overall iQoL score, but potentially indicated a re-definition in their response and iQoL:

(P28 L13-21 and P29 L1-17):

P: "again, it's more so my dad I have got on better with than my mum until now...he's also going back to [overseas country] back and forth...so he has relatives there...he prefers staying there you see, so when he does come over, I try my best to get him over, but it's mainly my mum that I have got back into contact this year which is a big benefit...and even though it's not regular, it's a big improvement to what it was like ten years ago.

A: you didn't see much of her ten years ago?

P: yeah, well, I haven't seen her in the last ten years...last year I started on-line contact...I think she...felt like shy to come again you know, because I have had different, you know, authorities in my life like social services and health and things like that, but now, now it's...she feels more confident to come...I have tried to initiate for a while and then I stopped then because she wasn't making much of an

effort, again that was partly because of, of, you know, the different people involved in life...she comes in now like a normal guest you know, she comes with the family you know, with my other brothers and sisters”.

Participant 5 recognised the depth of involvement of social and healthcare services in their life, and how their level of control had increased following the transition to adult services. A positive shift in response to iQoL was revealed. Participant 5 was aware that they needed support with their decision making through the participant’s advocate and commented:

(P46 L7-8):

P: “even little things that I can’t always judge, but sometimes other people can”.

P (P48 L3-24 & P49 1-15):

A: “Was that transition hard from everybody making decisions for you, and then you being responsible?

P: I think some decisions I still struggle with now, if I am honest... the transition between being able to do, make more decisions myself. I am able to do activity more within my interests, maybe with a little of prompting at times...I can’t always think about what I want to do at certain times

A: yeah. But you feel you’re getting there?

P:...but even little things like deciding when I want to eat, little things like that like...when I was young...I had a set time because I had a set routine. Because I was in school every day and college every day...little things like that, and even some activities that social services provide me. Yes I do, because you know, they were alright activities, but some activities I’ll be honest, I didn’t like necessarily doing on that certain day or what not. Um... so little things like that, even if I, for say example, doing an activity with social services but on a different day.... the only main day they picked and then obviously I didn’t want to cancel it, just because I didn’t want to do it then. But again, I was under the age of 18 then, and I didn’t feel that confident speaking up because, as I had loads of people in my life as well...before I was eighteen, I used to have three to four members of adults here without including me... sometimes there were interferences, I would be honest about that.

A: hmm. So...Life is better?

P: it is better by far, like I said...its better now at least I don’t have to...I know my boundaries and I am sensible with boundaries as well, you know, little things like that. But you know, I have more control over life that’s the main thing, main thing that’s better, even if it’s just managing my finances, or you know, or talking to people on line or what not”.

Participant 5 previously had teams of carers, with at least four staff present in their home prior to transfer to adult services: two staff from social services and two nurses. At a

situational, personal level, Participant 5 had learned to rely on staff for friendship, developing distant, personal relationships with them and contacting them on-line:

P (P28 L5-7): "...with some friends because I play chess with them [on-line], like a carer that used to work with me before".

Participant 5 understood that they had difficulty communicating, and that they relied on social media and electronic formats rather than face-to-face communication. Participant 5 felt more confident regulating relationships and situations on-line, which was reflected in their contact with their estranged parents.

P (P13 L19-21): "...sometimes I speak better on-line to people you see, that's why I get on well with the laptop quite well,...so that's...probably a benefit to me as well".

P (P24 L13 & 16-17): "...most of my friends are on Facebook"... "We end up, having a good chat on-line, quite often because that is the main thing I can control";

(P40 L9-21 & P41 L1-6):

P: "...I socialise on-line to them [family] mostly...either it would benefit, it would improve...maybe having more contact with...perhaps...dad a little bit. Again, dad is not on much on...active much, but again I am not too bothered either...at least I know it has improved from the last ten years isn't it?...ten years ago there was no contact at all....

A: did you find that hard Participant 5?

P: then I would have said it was as low as possible [scoring on SEIQoL score] but as it has improved over the ten years, I'd say it's good, especially getting back in contact with my mum and my other brothers and sisters as well."

P (P51 L11): "I again communicate easy on email".

Participant 5 was hospitalised for the first four years following the RTC, and subsequently placed with three different sets of foster parents. This may provide some context in relation to the participant's lack of social skills and reliance on social media to maintain relationships. The participant stated that they "will just have fun with the staff" (**P69 L7**), rather than identifying friends or peers:

(P27 L8-21):

A: ...What do you do, when you go out?

P: again, you know, certain things I prefer to do rather than other things. I like the cinema...I went to quite a bit. I go sometimes outside to places like [Town]...or I have done long trips before like go to um...watch a show...Last year, I went to [Safari Park]

last year. That was different, the safari park there, so that was a nice long day out...umm...just to vary my activities really but the majority, I do like to chill out and spend time on-line and things like that”.

The interface between health and social care needs was particularly blurred in Participant 5’s case. Participant 5 regularly needed to be hospitalised but not for health reasons; whenever their home needed any adaptations, and as there were no respite services available to cater for the participant’s needs, the participant had a “hospital trip while this house was adapted, putting the hoist tracking in” **(P50 L6-7)**.

P (P18 L13-15): “the last few years, it’s been when I have had house adaptations. It’s just been the hospital main area, mainly because of safety reasons, I think it was”.

The participant accepted this as part of their day-to-day struggles, and does not appear to influence the overall iQoL score. This highlights how social care cannot accommodate specialist healthcare requirements. Participant 5 identified health as a cue, which they rated as good, again contrasting with the overall SEIQoL score. The participant suffered from autonomic dysreflexia, a syndrome resulting in a sudden onset of extremely high blood pressure. This results in symptoms such as anxiety and apprehension, irregular or racing heartbeat, pounding headache, flushing of the skin and profuse sweating. It results from spinal damage and can be triggered by stress or poor positioning in his chair.

P (P25 L8-15):

P: “Health yeah, one minute I can be fine...and the next minute I’m not, and for some reason I can’t be in you know, Uni...It’s not really my fault, it’s you know, it’s sometimes, sometimes, I can’t do no work like at...at home...and it depends on how, what health need has gone wrong you know, if it’s a small thing with the chair that’s gone wrong...then I can perhaps carry on with the work or tasks they are doing. It is just a case of whether I understand it [University work] really”.

Information Technology (IT) and the equipment he required were integral to and had intertextual influences on the other health cues Participant 5 identified.

(P43 L9-13):

P: “IT is partly with the education...that is why it is so high, you know what I mean?...if the IT doesn’t work for me, then the education doesn’t work for me as well”.

Illness resulted in time away from university, and Participant 5 struggled to keep up with the workload and their development. The participant recognised that they required additional

academic support and that, “sometimes asking for help is a bit different to other students” (P23 L15-16). Participant 5 accepted that health affected their ability to work and learn. The participant’s health status had wider intertextual implications, from an educational perspective, including an extension to the length of the course, and additional one-on-one teaching. These enabled the participant to maintain a level of normality, and to continue their learning, offering a mechanism to increase iQoL, reflecting in the SEIQoL score. Participant 5 recognised the difficulty they had with communicating and continually referred to their additional learning needs:

P (P23 L17-19): “which is why I prefer to go in alone... because the students are, you know, not there, and you can ask whatever you want then, and spend more time with the lecturers.”

P (P26 L5): “I liked this course as long as I can do it at a slower pace”.

The participant clearly stated their reliance on IT to maintain relationships, to communicate and continue their education.

P (P14 L11-14): “...if I am, say, for example, needing to go to the University and the chair is out for a long time, it makes me need to catch up on more work when I’m in university, and not always I can catch up the work at home, because sometimes I don’t understand all the work”.

Participant 5’s dependence on IT and support from carers, lecturers and the larger institutions; that is, university and health care, highlight the participant’s struggles with everyday life.

[Interview 5 Summary](#)

The case highlights Participant 5’s dependence on their carers, equipment and services to maintain iQoL, on which Participant 5 scores relatively highly at 81.5/100. The impact of the participant’s disability on their iQoL is more apparent than that of HMV, however it is not as visible in the overall iQoL score. The participant clearly identified the link between functioning equipment and everyday life: if the participant’s wheelchair malfunctioned, or if the IT infrastructure did not work, it affected the participant’s iQoL. Participant 5 had been surrounded by institutional level services their entire life, of which they were aware, and how this had enabled them to live as independently as possible in the community, which is

mirrored in the SEIQoL score. The move to being cared for by adult services implied a shift in response and re-definition of their perception of their iQoL. The presence of an advocate to support the participant was a significant strategy to promote their iQoL, reducing the stress associated with decision making, and offered an alternative functional subject and frame.

5.3.6 Interview 6 - Participant 6

Interview context

This interview was different to the others, in that its tone was primarily negative. The negativity was mirrored in the overall SEIQoL score of 25, and revealed a reconceptualising of their iQoL. Participant 6 was an older lady with a neuromuscular diagnosis. The disease signs and symptoms result in a gradual deterioration in ability, dexterity and respiratory function. Participant 6 had been diagnosed 20 years previously, and the participant's health and physical abilities had deteriorated gradually. The participant lived in the same house and relied on a partner to manage the equipment needed such as the ventilator, ventilator tubing and tracheostomy tubes. The participant's partner however had been diagnosed with an aggressive form of cancer two years prior to the interview, and was undergoing treatment. Prior to the diagnosis of cancer, the partner had been the sole carer for Participant 6 for 20 years. The care package in place for Participant 6 had since been increased, as their partner was no longer able to provide the physical and emotional care the participant required.

Participant 4 identified the following cues, which are listed alongside their meaning to the participant:

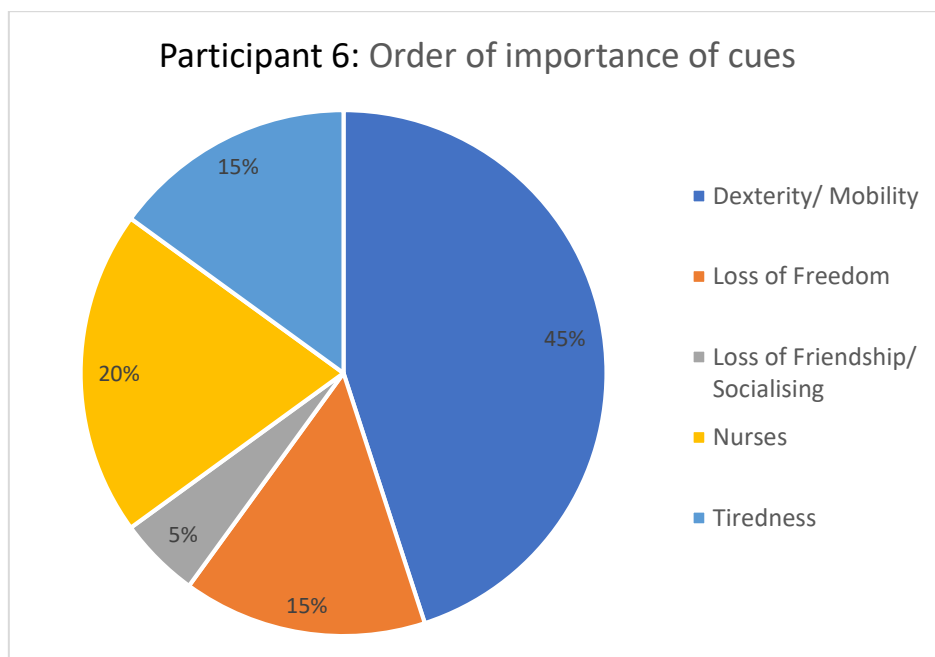
1. Mobility and dexterity – Participant 6 focused on the losses to their quality of life, mirrored in the overall low iQoL score, indicating a shift in response, The inability to walk and complete handicrafts was a great loss to the participant. The participants' limited dexterity affected day to day tasks such as eating and drinking, lowering iQoL.
2. Independence – the participant related an increased reliance on others to maintain their independence, in the same instance, emphasising a dependence on their carers. This limited iQoL and the freedom that the participant had previously had,

prior to the deterioration in the disease process, signifying a change in perspective and shift in response.

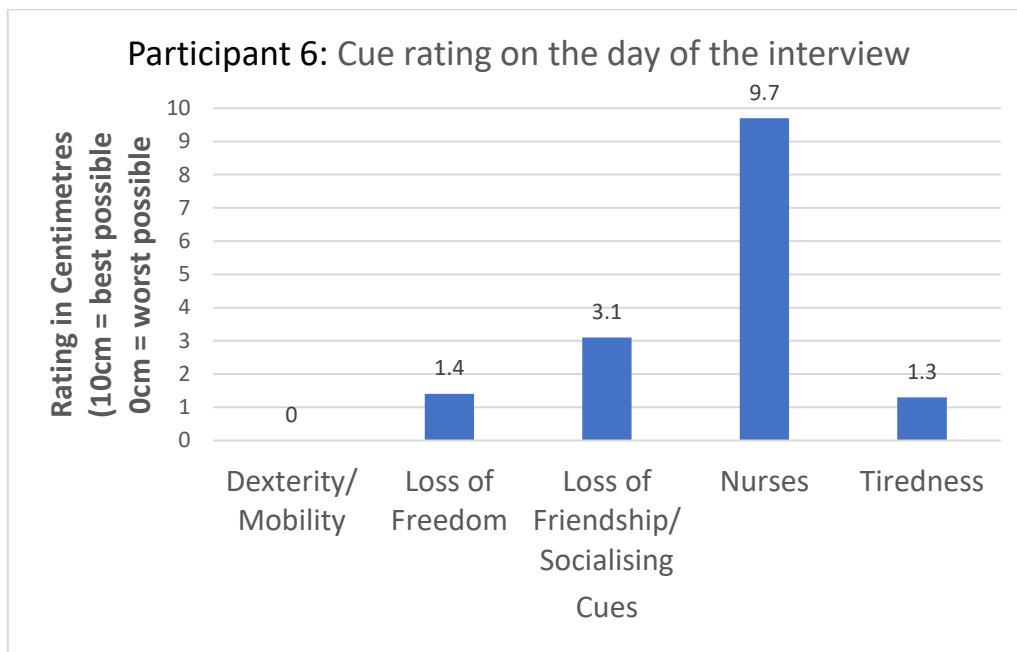
3. Loss of Friendship and Socialising – Participant 6 noted that the condition and ventilation limited their quality of life through preventing them from socialising and in turn, relaxing. The theme of loss was continuous throughout the interview, with little positivity noted, and continuous shift in perception.
4. Nurses – this was the only point that Participant 6 raised that was positive in relation to their iQoL. The importance of nurses/ carers in the participant’s everyday life was key to their quality of life through the relationships developed and care delivered.
5. Tiredness – this cue points towards health and how it affected all aspects of the participant’s life. The participant related how they had to adjust their lifestyle and daily activities to accommodate tiredness, and how they had learned to live and adjust to their limitations.

Cues

Pie Chart 6 Participant 6’s Order of Importance of Cues



Graph 7 Participant 6's Cue Rating



Interpretation

Participant 6 scored the lowest global iQoL score at 25 of all participants. The participant was direct and focused on the losses to their life because of their illness. The need for HMV was identified as restrictive however, health was not identified as a cue. It was, nevertheless, an intertextual feature of all of the cues identified. The cue allocated the greatest weighting (45%) was the participant's loss of dexterity and mobility. Participant 6 stated that this had affected all aspects of their life, from their ability to take part in and enjoy handicrafts, to eating and to their social life. It also drew on the loss of friendship/socialisation cue, and revealed a change in perception of their iQoL:

(P3 25-33 & P4 L1-7):

P: "...my diaphragm is paralysed, it's pushed my stomach up to here (indicates on her chest) um...I still get cramp...and now...I can't walk at all....I did try the other day, holding onto the commode, but it was no...I took 3 small steps, and that was it....so I guess I won't be able to do it now. I daren't hold anything, cup, that's why I've always got a straw...because I just can't hold anything...I'm very reliant on my nurses, 'cos sometimes.....when I'm really bad, they've got to feed me...or else I'll pick it up with my hands. More often than not, I'll eat with my hands. I try not to have anything that's got too much juice".

P (P31 L19-20):

“Not being able to use my hands and do my own cooking and my handicrafts that is what I miss the most”.

(P14 L14-26):

P: “But I can’t do...I can’t do my crocheting and I can’t do my knitting and I used to do a lot of making cards and I could make um....pictures out of.... I used to get them cd’s...put them in...I used to do a lot of that because they were useful, and they were handy for placemats. All sorts of things...and I have given them as presents...and I use to crochet little baskets and stiffen them with sugar... I’ve got a big crocheted hat that I designed myself and I was going to wear it to my son’s wedding...”.

There was little reference to family and Participant 6 did not identify family as a cue, but did identify the nurses who cared for them, and their relationships with the nurses, as the only positive cue. The rating of nurses as a cue on the day of the interview was the highest, at 9.7cm. Participant 6 claimed a form of ownership over the nursing team, stating “I rely on my nurses and I am very fond of my nurses” (P24 L1-2), and that, “my nurses are most important, very important they are” (P34 L17). In the participant’s relationships with the nurses, Participant 6 relied on humour to deal with a loss of ability, independence and dignity:

P (18 L22-23): “I can’t wash by myself ... um I think [nurse] has seen my bum more often than he has seen my face! (Laughed)”.

Not all references to healthcare were complementary, and the involvement of the local health boards and agency as a body supplying staff for Participant 6’s care package, were viewed negatively. Participant 6 viewed the nurses as completely distinct from the agency that employed them. There were numerous intertextual facets within this element, identifying wider institutional and governmental influences on care delivery. The participant did not praise the agency involved in the care package delivery:

P: (P24 L1-4): “What does annoy me...the agency I’m with, are not very good...they... they haven’t got enough staff basically to cover”.

Participant 6’s reliance on others, is again highlighted, alongside the participant’s forthright attitude. Participant 6 had refused to allow some nursing staff from the agency to care for them, and recognised that they, as a patient, were at times straight-talking:

P (P5 L9): “He hadn’t nursed anybody like me. I’m very direct”.

The participant linked their loss of freedom to the loss of ability to use their hands, and drew examples related to fundamental care, denoting a shift in response:

(P18 L1-2):

P: "I have lost my freedom in what I want to do, and the other thing is because I can't use my hands. I used to do a tremendous amount of handicrafts."

P (P18 L22-23):

"I can no longer do my make-up, do my own nails, I can't wash by myself ...".

The participant's loss of independence and freedom was linked to a loss of social life, including going out for a meal. Participant 6 insisted that they were unable to leave the house because they depended upon a humidified (wet) ventilatory circuit, which is not portable:

(P2 L11-19 & P3 1-18):

P: "lost my independence..."

A: lost your independence. Are they two separate things (loss of mobility/ dexterity and independence) or are they part of the same thing?

P: hmmm...I think they are separate...Because I have to rely on other people...I can't go out...because I'm [airways are] too dry on the dry machine [portable ventilator]...I miss going out for, for a meal, we used to go out to the local pub...We use to go early to miss the crowds. Um....some people were very rude if they saw me on my machine and they'd asked to be moved.....one woman said that shouldn't be allowed here. You get it. There is some horrible people about but there are also some very nice people.

A: is that part of the reason you don't go out and don't want to go out?

P: no, I can't because of the dryness...I would go out, it wouldn't stop me because I would turn around and tell.... Well, I did, I turned around to this one woman and I said to her "Pardon me for breathing" and her husband just put his hand on her. I thought well, that little cow (sound of Participant 6's laughter)".

Participant 6 referred to their image and appearance. The participant placed great emphasis on their figure in their younger days, which linked to their previous comments about not being able to put on their make-up and 'do' their own nails:

P (P4 L9-15): "...I had a very thin waist. I was a 23" waist in those days...I was 34" 23" 33" I was very shapely. Ahhh! Now I am just lumps...and bumps".

Participant 6 reported how being tired limited all aspects of their life, affecting their quality of life:

(P25 L20-21):

A: "So your tiredness affects you...?"

P: Terribly, and it effects everything"

(P2 L11-12):

P "...and I try and have a shower...well, at least once a week. This is my limit because it, it exhausts me".

The effort and exertion of washing and dressing emphasised the participant's personal struggle coming to terms with the condition, and losing their freedom and independence, where they noted: "you get to learn your limitations" (P7 L30). This evidences a shift in response and re-definition of their individual quality of life.

Interview 6 Summary

Participant 6 focused on their illness and its effects on them as an individual rather than on the fact that they were mechanically ventilated. At 25, the participant's overall iQoL score was the lowest of all the participants, which was reflected in their negative attitude to most of the cues that were identified. A distinct shift in response and reconceptualization of their iQoL was revealed. The presence of nurses, and the care they delivered was the only positive cue, and the participant recognised that this attributed to their iQoL. Identifying nurses as a cue was weighted at 20% and rated at 9.7cm on the day of the interview. Participant 6 focused on the negative elements and the loss associated with the deterioration of their health. There were no clear practices applied to promote the participant's iQoL and they perceived both their illness and ventilation as having reduced their quality of life.

5.3.7 Interview 7 - Participant 7

Interview context

The interview with Participant 7 was the most technically difficult of the population interviewed. Participant 7 was tetraplegic due to incomplete fractures of their cervical spine at levels 1 & 2 (c-spine) following a road traffic collision (RTC). The participant communicated via a communication board. Participant 7's words were spoken either by the

participant's mother or by me as words were spelt out letter by letter. Part of the interview was conducted with Participant 7's mother present.

Participant 7 lived in their own home. Following the RTC, the participant initially spent 30 months in numerous hospitals and was eventually discharged to an adapted home in the community. The RTC was a hit-and-run incident and the driver, who did not have neither car insurance nor a driving licence and was under the influence of drugs at the time of the crash, served seven months of a 14-month sentence. Family paid for the cost of the participant's home, but compensation had been secured following the court case. The interview spanned two sessions, owing to Participant 7's tiredness. The participant was supported by one qualified and one unqualified nurse per shift, 24 hours a day. Participant 7's care package was long established and worked effectively for the most part. The participant's mother continued to input into the individual's care and was on occasion required to 'step-in' and care for Participant 7, when healthcare services were unable to provide the necessary care.

In the interpretation below, pauses to spell out words are captured in terms of their approximate length, to illustrate how challenging this made the interview. The actual spelling of words is kept to a minimum, but highlighted in some places, where Participant 7 revealed an important emotion or element. Participant 7 was able to blink 'yes' and 'no' as responses and shrug to a certain degree, which were also used to capture the data and convey their thoughts. These are indicated in the text in italics and in brackets. I have also split up the larger sections of text, for ease of reading.

Participant 7 identified the following cues, which are listed alongside their meaning to the participant:

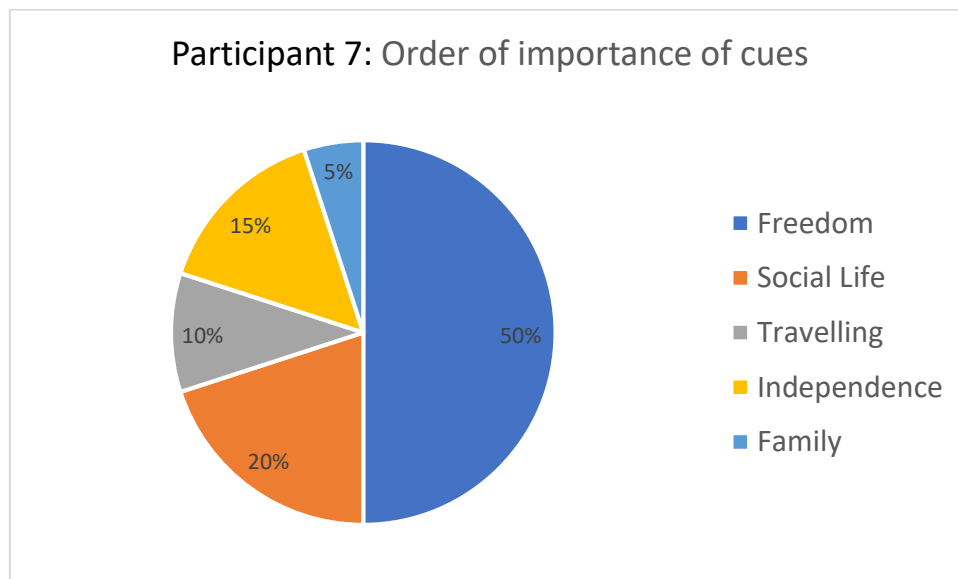
1. Freedom – This differed to independence for the participant. The participant referred to the conceptual definition and linked with a freedom to think and to make decisions about their life. They stated that it was to 'be themselves'. The ability of Participant 7 to explain was limited by the involvement of the participant's carer, who explained on the participant's behalf. The participant explained that their freedom had been lost due to their condition, and that it was linked to their social

life. There is an indication here of a change in perspective and reconceptualisation of their iQoL, and is reflected throughout the cues identified.

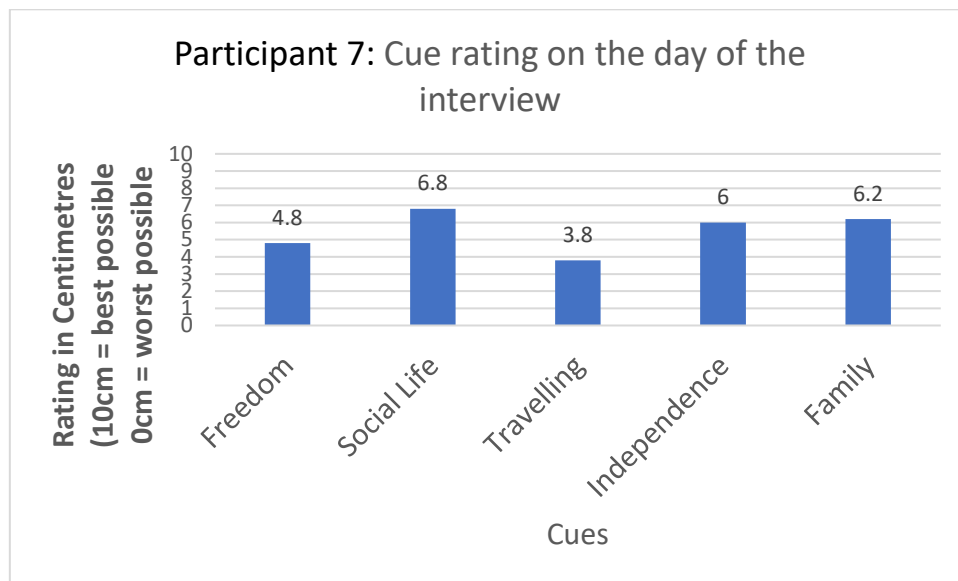
2. Social Life – Participant 7 noted a loss of their social life, which they missed their friends who lived some distance away, and that they missed chatting to their friends about everyday issues. The participants’ social life prior to their ventilation included skateboarding and smoking, which were again noted as losses.
3. Travelling – Again, the participant noted a lowering of their iQoL due to their inability to travel. This is reflected in their overall iQoL, and demonstrated a shift in response. The participant related how they had previously travelled, and how they felt limited by not having the freedom to travel.
4. Independence – Participant 7 noted that they were not independent; that they relied on carers for every need, and had no control over decisions such as finance. They revealed that they were due to start an education course/programme, however they felt that this would not increase their independence.
5. Family – The participant noted family as part of their quality of life, however contradictorily noted that their main carer, their mother, did not understand their needs and wants.

Cues

Pie Chart 7 Participant 7’s Order of Importance of Cues



Graph 8 Participant 7's Cue Rating



Interpretation

Participant 7 scored their overall iQoL as 53.5. The participant identified their loss of freedom as a cue and accorded the greatest weighting to this cue (50%). This determined a change in response and recalibration of iQoL. The measurement of their iQoL took place on the day of the second interview, and the participant's rating of freedom as a cue was relatively low, at 4.8cm. The following points related to freedom were identified in the presence of Participant 7's mother, who verbalised her own and Participant 7's comments:

(P59 L13-17):

A: "Does freedom and independence...do they co-exist?... (short pause – time taken to consider)

C: (offering her own opinion) freedom is both...both physical and spiritual, isn't it? Independence is more physical isn't it, rather than relying, depending on other people..."

(P60 L2-5):

C: (offering her own opinion) "Freedom it's...really like **completely** free to decide or do things, feeling or not feeling trapped isn't it, all that and being free to decide, make decisions, to go where you want to go, when you want to go, to say what you want to say...It's a complete, sort of overall isn't it?"

Later, without the participant's mother being present, Participant 7 clarified that freedom was:

(P62 L7-10): “To do what you want (long pause)...that is your freedom...(long pause) both physically and mentally”,

(P66 L16): “...just being you (short pause)...Freedom just to be yourself”.

This demonstrated the participant’s struggle to make themselves heard and to have their thoughts and views recognised. Participant 7 continued to discuss their freedom, and linked this to their social life, and manifests in the overall iQoL score of 53.5/100:

(P69 L4-13):

“I’m...(long pause)...not a positive person...Generally you’re not a positive person...Social life...So tell me about your social life...(very long pause)...not in [name of local town where the participant lived]. Social life is...(long pause) no good...(long pause) your social life is not in [name of local town where she lived]...is it elsewhere? Yes, ok...So where is your social life? (long pause) [names of towns]. Yeah, further away (very long pause)...So your friends still live away, or live in [name of town]...and you are here...Do you see them at all? (very long pause) Yes, but not as often as you’d like.”

The conversation around loss of freedom and lack of social life developed to identify a sense of loneliness, establishing a re-definition of their iQoL:

(P69 L19 – 27 & P70 L1-31 & P71 L1-24):

A: “(very long pause) L...O...N...Being...L...O...N...E...L...lonely? So being here means you’re lonely. Yeah....does not having a relationship have a part of that as well?(short pause)...Yes (blinked response), and you miss that part too, yes (blinked response)...it’s the whole social life, friendship, partnership that you miss...That must be hard...(blinked agreement)... I understand. So, do you think that going to college is going to help? (short pause)...No...Is the loneliness that you are describing different?...or the lack of friendship differ to what you are going to college for? (pause but no clear response). Is that [college] just a kind of social event, rather than having friendships and a proper social life do you think?...(long pause) Yeah. So, tell me a bit more about...your loneliness with your social life. Um...What do you miss most about not having as much of a social life? (very long pause) Talking. Yeah...Is that talking to friends about how you are feeling? (blinked positive response) Yeah. And do you find that even though you have a really good communication tool here, that it’s restricted?...(blinked positive response) Yeah...do your friends use this with you? (blinked positive response) Yeah”.

“...So, what would you talk to your friends about, what bits of that talking has it affected? (Very long pause)...usual stuff, day to day things...(very long pause)

shopping, TV, clothes...that sort of things. (very long pause) Relationships...carers...(very long pause) Whatever's going on...Yeah, that's a big part of your life isn't it. How hard has that been for you to have carers in your life all of the time? (very long pause)...Is it really hard for you? Yeah (blinked positive response and long pause)...very hard. Do they affect or do they help your social life?... (very long pause) [affect] a little bit maybe...any words you want to add? (shoulder shrug and negative eye blink) No, ok."

"Ummm...did you use to go out much, before the accident...or did you do any activities or anything like that? (blinked positive response). Yeah, what did you use to do? (long pause) Skateboarding - you were a skateboarder! Did you belong to a club or did you just skate with friends?... (long pause) Just friends...So you miss the physical as well as the social part of skateboarding? (blinked positive response) Yes...yes...Did you have many boards, or just the one skateboard? One? No? More, yeah...Two? Hang on (eye contact)...You are having to count (eye contact and shrug) (Participant 7 laughs)...(short pause)...Seven boards!...(eye contact and shrugs)...(long pause)...Roughly, that you can think of!...Did you (take part in) any competitions? (blinked positive response)...Yes? Did you ever hurt yourself?...Yeah, (long pause)...no broken bones just bumps and bruises. And you were still doing that at the time of the accident? (positive blinked response)...Yeah...ok so that's part of your social life that...you miss. Is there anything else that you used to do, that you miss?" (sound of communication board being wiped clean ready for next words)

"Ready? (long pause)S...M...O....K....I think I know what's coming – smoking? (blinked positive response). You used to smoke. How many a day did you used to smoke? (short pause) Depends (blinked positive response). Yeah. What did it depend on? Whether you were having a good or bad day...(shrugged response). Did you smoke from a young age?... (short pause)...Teenager...(long pause) from 13 years old...Did you enjoy it or was it the social part? (positive blinked response). Ah yes, you enjoyed it as well, having a cigarette in your hand. Were your friends' smokers? (blinked positive response)...Yeah...Were you still smoking when you had the accident? (blinked positive response). Yeah. So everything stopped at that point...(long pause) everything you enjoyed...yeah (long pause)...it was a big wrench".

The participant's personal struggles and the need to reconceptualise their iQoL are visible in the extract above, providing insight into the enormity of the changes to all aspects of the participant's life following the RTC. It is exhibited in the lower overall SEIQoL score generated during the interview. Participant 7's disability, and not HMV specifically limited her opportunities and interaction with friends through the physical and logistical limitations it imposed, including where the participant lived.

The changes to the participant's life were reflected in their responses regarding family, which Participant 7 identified as a cue, and weighted at 20%. When asked whether their family brought quality to their life, Participant 7 did not truly answer but stated that they felt their relationship with their mother had changed since the accident. This indicated a change in response and re-definition of their position. The participant's mother did not understand their perspective. Participant 7 expressed jealousy of their mother's relationship with the participant's carers and believed that their mother favoured the carers, treating the participant differently:

A (P73 L30 – 31 & P74 L1-6):

P:“...(very long pause as Participant 7 spells out the sentence on the communication board) oh, your mum doesn't get you? Doesn't get what you want or need, or doesn't get you as a person?...She gives more help...oh, gives more help to carers than you.”

The difference between wants and needs are highlighted, and wants are left 'wanting'. Independence, weighted at 15%, as part of the iQoL was explained by Participant 7 in response to a question:

(P72 L26 – 31 & P73 L1-22):

A: “In terms of your quality of life, how does your independence fit it?... ready? (short pause)...G...O...N...E...your independence has gone. Completely? (blinked agreement). Yeah, so the fact that you have carers here to support you, um...even though are you're in your own home, you don't have a level of independence. Is that right? (blinked agreement)...Yeah...just to think about it a bit more, do you run your finances? Are you independent in looking at your finances? (negative blinked response) No....(long pause)...Somebody helps with those, yeah. What else does your independence mean to you? (long pause)...A...L...O...S...T...Lost? No...(inaudible). What else does your independence mean? (long pause)...A...L...O...T...your independence means a lot.....Do you shop and go out and buy clothes for yourself? (positive blinked response) Yes. But it's the fact that you have to have someone with you to do that...(positive blinked response). Yeah...(long pause)...that's the way your independence is affected...Is there any (thing)...else it's effected?... (very long pause) E...V...E...R...Y...W...A...Y”.

“So, what about when you think about treatment and things like that from the hospital...do you have any say in that or control over that? (negative blinked response) No...Is that hard? (blinked response) Yes. Do you sometimes feel that you would like to have more say in what goes on? (very long pause with no clear response but clear from body language that it was being given thought)...difficult

question...Do you feel you have gained more independence coming back home to live on your own? We will call it on your own although you have carers here. Do you feel you have gained more independence from doing that or does independence mean something different? (very long pause)...Means something different...ok. So you see you being here as being dependent on the carers.....”

Participant 7 did not believe they had any independence, living in the community supported by and depending on carers. The participant believed they had lost all aspects of their independence. Participant 7 viewed the concept negatively, as a loss and highlights a change in perception. Travelling as a cue was viewed both negatively and positively, with previous experiences highlighted, but the participant closed the interview when asked about their current ability to travel:

(P71 L27-29 & P72 L1-23):

A: “So how does travelling affect your quality of life?...Did you travel a lot before the accident? (positive blinked response) Yeah. Did you travel all over the world?...No, but you have been a few places. Tell me where you have been...have you been to Japan? (blinked positive responses and long pause).....Because of your mum. You have family there, haven't you? (blinked positive response). What's it like? (long pause)...stunning...Where are your family based? (long pause)...Fukushima. Ah....Is it beautiful? (positive blinked response). Yes...So where else have you travelled? (long pause)...Morocco, ah, hence the influences around the house. What was Morocco like? Was it beautiful? (positive blinked response) Yes...so did you just go to Morocco, just to see, or go on an adventure holiday... (long pause)...Ah with your parents. Ah, ok...And you miss that now? (blinked positive response) Do you travel at all now?... (blinked negative response) No...Do people, do family come to you? (positive blinked response). Yes, yes. How often do you see your friends, when they come to you?...Not sure...ok”.

Interview 7 Summary

This case differs from the others, in that the cues of freedom and independence are more conceptual in nature, and Participant 7 felt their loss greatly. Subjects are varied and range from the participant's mothers' understanding of them as a person, to carer, nurse, medical staff, parents, cousins and friends. Health is not directly referenced, although the overall impact of disability rather than HMV specifically was apparent in its effects on independence and freedom. Re-definition of the participant's perception of their iQoL is discernible. Each schema and frame are different and the relationships within them differ. Each relationship influences and encourages strategies to promote individual quality of life.

The participant's promotion of their iQoL included beginning to study again, but this was tempered by their reliance on a Personal Assistant (PA) to support them with this. The promotion of the individual QoL is not reflected in the overall SEIQoL score, however.

5.4 Summary of Chapter

Referring to the research questions, the impact of home mechanical ventilation on each participant is individual. The participants in most cases do not refer to ventilation *per se* as affecting their individual quality of life, and there were only two direct references to health. It is the sequelae of their conditions as opposed to HMV that impacts participants, affecting their iQoL. The frames and schema identified are similar across interviews:

- patient and parents
- relationships with wider family members
- relationships with institutions and care agencies, carers, advocates and medical and nursing staff

From an individual quality of life perspective, each participant employs different strategies to promote or deal with their iQoL, be it faith, anger, control over carers, education, use of the Internet or their social lives. Not all are identified directly as cues, but are raised over the course of the interviews as intertextual factors. Major changes in resourcing from qualified to unqualified care were highlighted by numerous participants. Thus, the cases identify individual struggles influenced at an institutional level, with few references to higher levels of power and control, such as political and government forces. There is direct reference by several participants as to how their perspectives have changed over the course of the trajectory of their condition, linking clearly with the literature related to response shifts.

In the next chapter, explanations of the personal, individual and situational aspects of these struggles are provided and explored; how views and beliefs change, and the link to response shifts, by exposing the main discourses.

Table 11 Categories of Cues

Seeking Independence	Being Normal
Concepts	Social Life
Health	Family
	Religion
	Equipment/ Finance

During analysis, it became apparent that none of the cues and categories existed in isolation, and each influenced some, if not all of the other cues and categories raised by the participants. However, there were broad foci/ categories visible within the data, which married with the literature explored within the literature review. These were Seeking Independence and Being Normal. Within the analysis (interpretation and explanation), reference is made to the individual cues within the discussion. The main cues (categories) identified above are on occasion referred to intertextually by participants other than those who identified the categories and cues during the interviews. There is frequent fusing of categories within and across the data, as participants discussed the factors that affected their individual quality of life.

Nevertheless, the broad categories of Seeking Independence and Being Normal that encompass Family and Relationships, Concepts, Religion, Health, Social Life and Equipment and Finance enabled the exposition of discourses that facilitated or limited the individual quality of life of home mechanically ventilated individuals. The categories of Seeking Independence and Being Normal also provide an overarching structure for the discussion of the findings drawing on the literature critiqued in the literature review that frames the thesis. Further literature was sourced and presented as a focused literature review, in a narrative format to expand and further explore the cues, concepts and topics identified in the analysis. All of the categories that comprise the overarching categories of Seeking Independence and Being Normal, have power and control as underpinning influences as a result of individual, institutional and governmental involvement.

CHAPTER 6

6.1 A Guide to the Explanation

From the interpretation of the findings and cues presented in Chapter 5, the overarching concepts of 'seeking independence' and 'being normal' were identified and will guide the explanation of the data. The discourses embedded in 'seeking independence' and 'being normal' have two sides: one personal and one social. This chapter attempts to explain both sides: how the views and beliefs of participants (personal) and social structures influence discourse, and vice versa. For example, during a conversation, the text is changed as it is reproduced (spoken) by those involved. This may result in a change in the views of those who are part of the discourse, which in turn, influence and change social structures and practice.

The reproduction of the text links the CDA steps of interpretation (Chapter 5) and explanation. Interpretation is concerned with how the values and beliefs are used in discourse, whereas explanation is concerned with how reproduction alters views and beliefs. Explaining how discourse influences the social reality of HMV individuals provides a foundation from which to challenge the discourse. The outcome of a successful challenge and alteration to social and personal views would represent a change in the iQoL of HMV individuals.

Broad questions based on Fairclough's (2015) framework were used to explore the discourses that drive the explanation:

1. What (power) relations influence the discourse?
2. What ideologies (belief systems) are revealed?
3. What is the effect of the discourse on HMV iQoL?
4. How are the struggles at a situational (personal) level reflected in and through the discourse?
5. Are the struggles the individual's face hidden or visible?
6. Does the discourse contribute to sustaining existing power relations, or alter these?

Control and power are inextricably linked, and are embedded in the explanation as each of the participants provided descriptions of individual struggles around 'seeking independence'

and 'being normal'. 'Seeking independence' and 'being normal' are interrelated, as ***being normal depends on*** the support and input of carers, health and social services. This implies a power dynamic between the HMV individual and carer, and also health and social care service. This exposes the power that exists 'in' and behind discourse'.

Power and control ebbed and flowed through the interviews and discourses. Participants were aware of this to different degrees and reacted differently, with differing levels of recognition, understanding, appreciation of and push-back against the exposed sources of power and control. Control over the participants lives and choices were influenced and dictated by differing sources such as healthcare professions and services, and individual family members. Small gains in the struggle for independence at a personal level appeared to reinforce the feeling of control for numerous participants. However, larger shifts in control imposed by the healthcare system exposed the influence of the health board and government (meso and macro), and this was rarely challenged. For example, changes in care teams were generally not openly challenged, despite participants feeling angry and bitter at the loss of established caring relationships and trust. However, discourses around 'seeking independence' and 'being normal' exposed control and power influences not imposed at a meso, institutional level; some participants identified divisions between themselves and family and carers. Whatever the root cause of the exposed power and control, it was generally left unchallenged. Nevertheless, exposing discourses between participants, healthcare services (meso level institutions) and society and government (macro level) should allow discourses to be challenged.

Participants referred to and identified discourses outside the text (intertextual references), and occasionally assumed a degree of common knowledge between themselves and myself as the researcher. These intertextual references and presupposed 'common ground' assumptions influenced the text. The views, assumptions, beliefs and values I impose on the explanation as a researcher should be recognised, as they influence the discourses. Nevertheless, as is the nature of discourse, other discourses in the text will not have been exposed, and there is a large degree of overlap among discourses.

Using the concepts 'being normal' and 'seeking independence' as a basis for the explanation, the purpose of this chapter is to identify the hidden factors affecting how participants cope with and manage the effects of HMV, and how this influences iQoL. The

explanatory critique will expose problematic discourses, allowing them to be challenged and hopefully contribute to changes in policy where appropriate, as well as understanding and improving individual quality of life in this population.

6.2 Broad Categories of Identified Discourses:

- Seeking independence:
 - Being involved in decision making
 - Having a voice
- Being normal:
 - Integration into society and striving to maintain a social life
 - Family

6.3 Seeking Independence

As each participant relies upon care and support to live in their own homes, definitions of dependence and independence were unclear. Participant 7 was clear that they were not independent, that their independence had been lost following the RTC, reflected in a lower iQoL score. A re-definition of their iQoL was visible. By contrast, Participant 2 considered them self “quite independent” (**P10 L7**), both physically and in their ability to make decisions, despite requiring carers to support their physical needs on a daily basis. Nonetheless, participant 2’s iQoL score was lower at 44.05%.

Other participants saw decision making as important to their independence. Participant 3 made a stand for equality for individuals who, despite a weakening physical condition, retain their mental capacity and can be actively involved in making decisions, bolstering their independence. Participant 5 reported increased independence and control over choices since moving from Children and Young Adult Services to Adult Services care, corresponding with the overall SEIQoL score, and a shift in response to iQoL. Ostensibly, living at home and in a community with which they were familiar, motivated participants to seek independence, to whatever level that this was possible, and decision making was key to this independence. However, ‘seeking independence’ was influenced by other discourses; some visible, whilst others remained hidden.

6.3.1 Being Involved in Decision Making

Making decisions included when to eat a meal, accepting medical interventions or being part of decisions around changes to care teams, and participants experienced these differently. The latter was evidenced by revealing limitations to the care packages, the timings of care provision and a reduction in qualified nursing personnel by numerous participants. This recognises the discourses around NHS commissioning and funding, and how care is delivered as a result of reduced healthcare budgets. For example, changes resulted in new and different staff being employed to care for HMV individuals. The new care teams were composed of unqualified (non-registered) staff, changes typically introduced to the participant and families without a shared decision making process. This is illustrated by Participant 4's case, with decisions relating to funding made at a government level, resulting in changes to the participant's care team. Participant 4 expressed their anger at the 'new' care teams' inability to recognise their physical needs and how they needed to rebuild the trust and rapport developed over a number of years with the previous care team. Being excluded from the decision to change the participant's care team negatively affected Participant 4's decision making, control, independence and individual quality of life, rendering the participant powerless. This exposes patient involvement and shared decision making and contradicts the rhetoric that the patient is placed at the centre of all decisions.

Further hidden discourses are exposed: dignity, respect, rapport, trust and empowerment in relation to decision making. The issues of rapport and trust were uncovered in Participant 4's interview, during which they disclosed that one of the PAs was dismissed due to neglecting the participant's physical care. Actioning care and treatment is a fundamental part of the carer role. For this to work effectively, there needs to be trust between patient and carer. Similarly, Participant 3 describes a struggle between themselves and a carer, exposing how the carer abused her position, trying to dictate to Participant 3 rather than discuss the care issues with the participant. This situation impacted Participant 3's decision making, independence and iQoL, revealing how protecting vulnerable adults and advocacy and empowerment of the patient is unsupported.

In a reversal of the discourse around dignity and respect for patients, Participant 6's attitude differed to that of all other participants. The participant aggressively ensured they were involved in all decisions around their care. Participant 6's view was that, ideologically, the

medical profession is perceived to 'know best'. The participant did not accept this belief, and was derogatory about medical staff, challenging doctor's behaviours, stating that they were "not afraid of them" (P5 L13). Similarly, Participant 2 readily articulated their concerns and expressed a mistrust of medical staff: "the doctors down here don't seem to know their arse from their elbow", (P24 L1-7) and "they are 'fobbing' me off" (p97 L19-21). However, despite discussing the issues and, therefore, reproducing the text, a change in the discourse was not realised at a personal level for either Participant 2 or Participant 6. Nevertheless, exposure offers further opportunity to influence the discourse. As with Participant 6, Participant 2's forthright attitude demonstrated an attempt to increase their independence through decision making. They both used an informal style of speech that presupposed an understanding of their situation. In so doing, they disclosed their own perceptions, understanding and experience of the healthcare system. What was not apparent however, were the explicit thoughts of the healthcare staff with which both Participant 2 and Participant 6 dealt, but were alluded to by the intertextual context. This was exemplified by difficulties in staffing, observed by Participant 6.

All participants used the pronouns 'they' and 'them' to refer to individuals and organisations with whom they had encountered difficulties, including carers and the faceless NHS, revealing how care can be depersonalised. Additionally, for both Participant 6 and Participant 2, the experiential and expressive values in their choice of words indicate their frustration and dissatisfaction with the healthcare service at the level of the health board and not at a personal level with their carers and nurses. Participant 3's experiences of decision making are also negatively phrased and argumentative in tone. The intertextual contexts points towards the continuing difficult financial healthcare funding situation, and patients who are HMV and/or have long-term chronic illnesses. It also uncovers the current tension around respect and dignity for healthcare staff. Recognising these discourses, the possibility of change is presented. Participant 6 was vocal about their concerns regarding alterations to their care team and attempted to change the discourse by raising their concerns with the nursing agency and staff. As with Participant 4, Participant 3's carers had looked after the participant for a number of years, building trust and respect. However, the discourse around independence in decision making in Participant 3's experiences was negative and argumentative. The phrase Participant 3 used, "to give you to an agency" (P9

L25), illustrated the participant's view that they were seen as an object, owned and controlled by the health board. It demonstrated a loss of involvement in the participant's own care and a breakdown of relationships, with a lack of appreciation of the foundation of trust and care between Participant 3 and their carers, established over 18 years of care provision. This again reflected Participant 4's experience, and signals a re-definition of their perceptions.

Other intertextual factors that influenced the situation were the delegation of care to an external nursing agency employed by the NHS, funded by the CHC budget. Staffing resources were therefore underpinned by a broader political basis. The NHS ideology is far from realised, with care rationed in line with Prudent Healthcare principles (WG & NHS Wales 2018 and 2016). However, the power of illness itself and its consequences also limited iQoL, with an overall score noted of 25, the lowest of the entire sample; this is apparent in the decisions Participant 6 made surrounding their social life. Participant 6 believed their freedom was curtailed by their deteriorating mobility and dexterity, and that their dependence on humidified ventilatory support meant the loss of "...freedom in what I want to do..." (**P18 L1**). It is indicative of a reconceptualisation of their iQoL.

Participant 3 spoke of a lack of advocacy in fighting to keep their carers, the stress of which led to further physical deterioration. Despite the participant's physical weaknesses, their mind remained alert and active. The participant's physical deterioration is not absolutely reflected in the overall SEIQoL score, at 70.5%. However, this speaks to how physical disability is viewed in society, and how decisions are made on behalf of disabled individuals (paternalism). Participant 3 revealed their loss of control over decision making and the lack of advocacy available to them despite the involvement of a named advocate (family care officer), who should have empowered the participant to maximise their independence in decision making. Correspondingly, Participant 4 recognised their dependency on healthcare staff and a lack of advocacy in relation to religion and prayer. The participant's dependence on carers and the timing of care affected their ability to pray at certain times of the day, a situation the participant accepted rather than challenged. Discourses around religion and cultural awareness, alongside the ability of healthcare staff and services to deliver holistic care related to dependency are raised.

Thus far, the struggles around seeking independence and being normal have been viewed from a negative perspective. However, Participant 5's interview rebalances this view, promoting empowerment and advocacy. Participant 5's interview uncovered how their reliance and dependency on their advocate and care team empowered them, enabling the participant to achieve their goals and make decisions. Participant 5 saw the change from child and young person care services to adult services as positive. A reconceptualisation of their iQoL to account for a greater level of independence (interdependence) is exposed. Having moved from a team of four to two carers per shift, the participant believed that they had more autonomy and was empowered to decide more. The participant viewed their care team as supportive and enabling.

From Participant 5's perspective, the discourses exposed are those that enable a greater degree of independence in decision making: positive and supportive carer attitudes, team working and shared decision making, while still protecting a vulnerable adult. Participant 5's choice of wording to describe the relations with their carers prior to moving to adult care services ("interferences" **P49 L9**) implied conflict and control. For Participant 5, the interview further revealed how control experienced at a personal level stemmed from the principle of protection of a vulnerable individual (adult) (POVA). The experiential elements of the interview text describe and expose how social and healthcare services had controlled Participant 5's social life, from choices about mealtimes to when they socialised. The societally imposed legal age of consent was also recognised in the transition of services and in the fewer staff required to care for Participant 5. The participant described how their choices had expanded now that they lived in their own home, having reached the socially determined age of consent.

Nevertheless, the text demonstrates an interdependence rather than independence, with Participant 5 receiving guidance and support to enable a degree of independent living, whilst being fully dependent for all aspects of his physical care. The participant stated clearly that they had more control over life choices, and recognised their need for support in relation, for example, to finances, exposing advocacy as a discourse. However, in the same way that Participant 2, Participant 3 and Participant 4's mental health and wellbeing needs were not recognised, neither were Participant 5's, suggesting the presence of a hidden discourse, not being addressed by health and social care services.

The discourses around advocacy and empowerment (or lack thereof) by healthcare staff and taking an active role in decision making are further reflected by Participant 7's position.

Participant 7 appreciated and recognised their level of involvement and was uncertain of whether they wanted to be more involved in making decisions. The ideology that 'doctors know best' becomes visible in the text, which reveals a degree of institutional paternalism. This could have influenced Participant 7's response here. The struggles Participant 7 faced in playing a greater part in their own treatment and care are also reflected in the relationship with the participant's mother, contributing to a further paternalistic approach to care.

Participant 7's use of a communication board and minimal body language did limit communication and potentially limit the development of relationships, which may have played a part in the lack of shared decision making and Participant 7's central role in this.

The discourse of independence through decision making identified a lack of individual choice and shared decision making. This is reflected in numerous interviews, such as Participant 1 and Participant 2. In Participant 2's case, they identified how their social life was ruled by the decisions taken by the health and social care services about the timing of care delivery. There was a lack of shared decision making and an appreciation of Participant 2's individual needs. This exposes discourses around prudent healthcare, and new models of care. The extent of dependency of the participants was assessed and decided by the health board, further dictating what type of care was required. In a move away from person-centred care and individualised care packages, the timing of care was routinised and was mainly structured around staff availability. This reflects the financial drive that underpins the NHS as opposed to person-centred care, the ethos of the health service.

Participant 3 challenged the hierarchical (power) relationships between the participant and the healthcare services. Participant 3's independence was demonstrated by their active role in making decisions about their own care. The participant challenged the decision to change their care team, and the health board retracted the proposed changes, based on financial constraints, allowing Participant 3 to keep their established care team. The reductionist biomedical approach is revealed: biomedicine reduced Participant 3 to a patient with a series of care needs, rather than an individual requiring individualised care. This challenges the holistic approach of nursing; this was not challenged by the nursing care team, nor was the participant enabled and empowered. However, Participant 3's self-empowerment

challenged these decisions. The conversation (reproduction) resulted in a change at a personal level, exposing the practise and discourse of prudent healthcare to a wider audience, inviting further change.

All participants raised the issue of expectations about who should deliver care. This is exemplified by Participant 4's interview. The participant's sister (and main carer) described her discomfort in providing personal care. Participant 4's sister carried out the participant's toileting and personal ablutions alongside buying the participant's clothes. She found carrying out toileting and personal care upsetting and cried during the interview, calling into question social norms and expectations of family roles. It uncovered how disability can influence and cause her role as a sister to be replaced by that of a carer, affecting her own iQoL. By emphasising the intimate nature of personal (hygiene) care, it also exposes discourses around privacy and dignity. Neither privacy nor dignity were afforded to neither Participant 4 nor their sister in this case, partly as a result of a health service that is financially stretched. It calls into question whether the nursing care provided was holistic, or reduced to a series of tasks, distributed to a wider, non-qualified, non-registered nursing team. It raised questions of whether the principal model of care, the medical model, effectively supported the participants, and how a more nursing-focused and holistic model of care was not visible. Further debates are exposed around accountability and responsibility for care delivered, and whether carers should be required to deliver this care, given an overburdened, cash-strapped NHS.

The impact on Participant 4's mental wellbeing as a result of their sister delivering care nonetheless remained hidden. The participant did not engage in the text around family delivery of care; only their sister's experiences and emotional distress was revealed. Nevertheless, this exposure does offer some insight into the (power) dynamics of the situation, as Participant 4 did not respond to the distress of their sister. It demonstrates Participant 4's powerlessness to change the situation, as the dependence on others for the participant's care is absolute. A number of the participants and their families/carers expressed concern with institutional level decisions that dictated that the family should provide some of the care. Participant 1's interview typifies this, with their carer referring to the discussions concerning who was responsible for funding the care required, whilst in the meantime, the family continued to, and was expected to provide the care the participant

required. Here, the extent of dependency of the NHS on informal and unpaid carers is uncovered. The recognition of additional services provided by unpaid carers identifies the need for change and again questions the lack of influence of nursing. It challenges the health and social care services to provide assistance to meet the need of both patient and families/informal carers, to enable them to maximise their QoL.

Limited care funding affects the decision making power of these individuals, making them dependent on government decisions and health board actions. The concept of shared decision making nevertheless remains part of the healthcare agenda, revealing an inconsistency between what was delivered at an individual level and the political rhetoric around shared decision making. The struggles of the individuals are revealed here, offering an opportunity to challenge such decisions.

6.3.2 Having a Voice

In maintaining independence, another dimension exposed by Participant 1 and Participant 4 was their need for a voice. Participant 1 acknowledged their fear of losing their voice following the insertion of the tracheostomy, stating that the inability to express them self was worse than any physical disability. This would have resulted in further loss of independence over their care and life, as the participant used their voice to promote their iQoL through their independence in decision making. Participant 4 in comparison, experienced their loss of voice as more metaphysical, with a lack of their carer's ability to understand their needs, highlighting their vulnerability as a patient. The discourses around autonomy, advocacy, patient-centred care and shared decision making are again exposed. Both Participant 4 and Participant 1 scored high SEIQoL scores of 82.88/100 and 86.5/100 respectively. This was despite their deteriorating health and need for additional respiratory support. Both also indicate a reconceptualisation of their iQoL, through acceptance of HMV and their deteriorating condition.

Participant 1's delayed decision to consent to HMV was partially driven by their fear of losing their ability to speak and express their needs. Participant 3 similarly expressed their sadness at not being able to converse with nieces and family following the tracheostomy insertion, requiring a carer to lip read and translate their speech. Participant 3 referred to their feelings of loss and the companionship and relationships that speech brought. Talk and speech were equally important to Participant 1, something they enjoyed and engaged in

willingly. It uncovered the discourses of paternalism and autonomy, and implied a hidden fear of the participant's wishes not being addressed in their treatment. These fears were overcome after the tracheostomy: Participant 1 maintained their ability to speak, retaining a level of independence and enabling the participant to achieve a greater iQoL, recalibrating their view of ventilation. Participant 4 spoke about how their voice was not heard by their paid carers. The participant's sister acknowledged a degree of paternalism reminiscent of that in Participant 7's interview. Paternalism limited Participant 4's iQoL through a lack of control, and decreased their independence and role in decision making. Not being heard resulted in the participant's carers taking a paternalistic view of Participant 4's care and treatment, as the newly enforced care team were not able to 'read' the participant's needs. The skill and intuitive response to 'knowing' their patient had not been established by the new care team. The previous registered nursing care team had, over a period of years, developed an understanding of Participant 4's needs, resulting in trust and understanding. The value of nursing and the profession's holistic view of care was emphasised by the lack of attention to detail, understanding and knowledge of the participant's needs by the paid, unregistered care staff.

Autonomy is exposed and echoed in Participant 2's interview. Despite being extremely vocal during the interview about their lack of respect for authority, Participant 2's voice was not clearly heard by the carers. Participant 2's interview revealed a lack of understanding and appreciation of the participant's dependency and need by the health and social services. For example, Participant 2's need for physical help resulted in the participant sitting in their coat for long periods of time, waiting for carers to arrive, and in the participant's inability to free themselves when their wheelchair became wedged in a doorway. However, Participant 2 was contradictory; the participant believed them self to be "quite independent" (P10 L7), and that they did not want a carer tied to them 24/7, but the participant recognised that they needed support. The participant complained about depending on carers and how their life revolved around the carers' allocated time slots. This provides insight into the effects of disability due to HMV on individual quality of life, highlighting autonomy and interdependence.

In contrast to Participant 1, Participant 2, Participant 3 and Participant 6 were extremely vocal in relation to their care. Participant 3 required a carer to lip read their speech, whilst

Participant 2 and Participant 6 retained the ability to vocalise. Each identified similar scenarios that exposed an intertextual element of lack of awareness and time afforded to listening to their concerns. From this lack of appreciation of the individual's needs, paternalistic attitudes and discrimination are revealed, with the lack of inclusion of the participants in decision making. This highlights a limited independence.

Paternalism of a different form was apparent in Participant 1's interview. The participant's mother responded frequently on the participant's behalf, and the participant's mother's influence may have affected the exposure of other discourses that directly affected Participant 1. In analysing the text, Participant 1 appears to accept this situation as the norm. Discourses of paternalism and autonomy can also be identified in Participant 7's interview, and again in reference to a familial relationship. Participant 7 described their struggle with making themselves heard, and in getting others to recognise their thoughts and views, as the participant's mother answered on their behalf. During the interview, Participant 7 did express themselves once their mother had left the interview, for example in clarifying what freedom meant to the participant; that freedom was mental and physical, and that it involves "...just being you...Freedom just to be yourself" (P66 L16). The paternalism ironically did not allow the participant to be them self.

This emphasises how carers can influence situations for disabled people by influencing their responses, rather than allowing the disabled individual the autonomy to explain what they mean. A level of dependence was created by the carer - in this case, Participant 7's mother - with health and social care staff relying on Participant 7's mother's interpretation of Participant 7's needs. Participant 7 also expressed their jealousy of their mother's relationship with the carers and believed that their mother favoured the carers, treating the participant differently. This highlighted an intertextual dynamic of favouritism that Participant 7 believed existed between the participant's mother and their carers. It identified the personal struggles the participant faced in expressing them self and being heard as an individual, and the dependence in their relationships. Exploring this with the participant, they stated that the participant's mother "didn't get" them (P74 L1). This highlighted how Participant 7's mother misinterpreted the participant's wishes, and assumed that she knew the participants (and child's) needs and wants. Yet, Participant 7 had not tackled this concern, and, although the discourses around paternalism and a lack of

autonomy are visible in the text, they remain hidden and contained in the dynamic of the participant's relationship with their mother. It reveals how the daily lives of disabled individuals are affected by the sequelae of HMV.

In addition to the broader, dominant discourses, such as equality and discrimination, the intertextual context illustrated the small scale politics surrounding the lives and care of HMV participant, and how their voices were heard. For example, there were disagreements between families and the care teams in terms of what care and treatment should be delivered by whom, and how it was being delivered. For example, despite raising their concerns with the care team, this had not lead to any changes to Participant 4's care. Both the participant and sister drew comparisons between the 'new' care team and their experiences of the original nursing team. The comparison exposed the new team's lack of understanding of Participant 4's religious and cultural needs, exposing religious and cultural awareness and sensitivities. As the local, small-scale political game played out, this affected Participant 4 as the participant recognised their own anger at their lack of voice and not being heard, and lack of recognition of their needs and wishes. This had repercussions which influenced the participant family's QoL, as Participant 4 directed their anger at their family. The ability of nursing as a profession to provide holistic, tailored care is again exemplified in its absence, demonstrated through comparisons drawn between the 'new' teams of unregistered carers, and 'old' nursing teams.

The words Participant 4 used to describe the effects of not being heard are powerful: "...I am not eating...it will be better if I died" (P37 L33 & 34). This is in contrast to Participant 4's beliefs that their reason for being was to support their family. However, Participant 4's family used humour to offset the participant's anger, exposing the family dynamics. It demonstrates the influence of Participant 4's family on the participant's wellbeing and once more, the hidden discourse around the mental wellbeing and care of HMV patients.

6.4 Being Normal

Being normal encompassed participant's attempts at retaining and creating a sense of normality, recognising and coming to terms with differences between their personal situations and what they saw and experienced in society. This involved integrating into society and socialising, families, partners, marriage; all elements that constitute relationships. The dominant discourse is that of equality. However, there are other, hidden

discourses of ability and disability, empowerment and advocacy and identity alongside the ideologies and beliefs of the participants and of society.

6.4.1 Society, Integration and Social Lives

Being 'normal' was mentioned specifically by Participant 4, Participant 2 and Participant 1. Each described ways in which they integrated into society. They all compared their own situations and abilities with society's notion of 'normal', and referred to how they viewed able bodied individuals. Participant 1 referred to a cousin who also used a wheelchair, but was less physically disabled than the participant. A hidden discourse of jealousy or envy was exposed, as the participant described how they would like to be in their cousins' position rather than their own. The frustrations of disability were uncovered, yet Participant 1 viewed the advent of HMV as positive, and had accepted it, as it had restored their ability to socialise. A response shift is visible here, as views and perceptions have changed with an acceptance on the part of the participant.

Participant 4 also viewed ventilation as positive. As ventilation had stabilised the participant's health, it allowed Participant 1 to focus on their own 'wants', rather than their immediate 'needs', contrasting with society's view of only providing fundamental care. This exposes the dominant discourse of equality. However, Participant 4 did not challenge the health services focus on their fundamental as opposed to holistic needs. By contrast, Participant 2 did not accept the health services and society's views, challenging the norm through their attitude, use of language and lack of deference to authority. Participant 2 did, however, refer directly to their physical appearance, contrasting this with non-physically disabled individuals and stating that "people who look like me don't go there" (**P99 L13**), when they attended a sexual health clinic. This touched on society's perceptions of (the importance of) physical appearance, body image and blending into society. Participant 2's recognition of their physical appearance is echoed by Participant 6 through their perceptions of a deterioration in their own physical appearance. Both Participant 2 and Participant 6's direct reference to how they viewed their physical appearance provides an intertextual insight of how physical appearance and body image may have affected their integration into society. Participant 2 did not comply with societal views of disability and altered physical appearances, and explicitly challenged perceptions. By contrast, Participant

6 was negative about changes to their physical appearance and how this had changed during the course of their illness. The participant described all changes to their physical health and appearance as a loss, and how they had learned to accept their disabilities and limitations. This is indicative of a reconceptualisation of their iQoL. For example, when referring to the loss of their figure, this culminated in a revealing question around the importance the participant attached to physical appearance, and the ideal that society sets for individuals:

(P25 17): P: "...I am ten and a half stone I might even be eleven. I'm not heavy, am I?"

Similarly to Participant 2, Participant 6 referred to their body image, as the participant felt that their body now resembled 'lumps and bumps' **(P18 L11-13)** revealing their sense of loss and a change to their body image as the condition progressed. Participant 6's need for reassurance hinted towards the intertextual discourse of loss of empowerment and a lack of self-assurance, in direct contrast to other sections of the interview text, where the participant asserted them self. The intertextual insight into their concerns and insecurities around their body image revealed the importance of appearance to their iQoL. It also reveals the societal influences surrounding acceptance of physical (and psychological) differences. Judgemental attitudes, discrimination and lack of acceptance of society of the physical effects of disability that both Participant 6 and Participant 2 faced, had affected their integration into society. Participant 6 did not want to appear in public with a changed body image, and hid behind the HMV equipment that maintained their life, stating that they could not socialise because of their reliance on a humidified ventilator circuit. Participant 6's self-enforced seclusion appeared to stem from the pressures in society to 'look normal' and fit in.

Participant 6's responses and statements around their physical appearance were in contrast to Participant 2, who had lived with physical deformity all of their life. Despite Participant 2's recognition that they looked different, the participant did not seek reassurance or confirmation of their attractiveness, whereas Participant 6 did. Age was an intertextual factor which may have influenced both their attitudes to challenging societal norms, with Participant 6 being 30 years Participant 2's senior. However, achieving normality for both

Participant 2 and Participant 6 involved how they looked, and it highlighted how physical disability is viewed by society.

Participant 5 had a contrasting view. The participant enjoyed a day out and socialising, and did not comment on the public's perception of disability when discussing their social activities. The care required by Participant 5 extended to all of their needs, be they health or social care, and therefore they required healthcare staff to be with the participant at all times, including when the participant was involved in social activities. Participant 5 did allude to a shyness or embarrassment about attending University, stating that they preferred to do this when the other students were not there, which provides an intertextual representation of the effects of disability on the individual and public perception.

Participant 2 also challenged society's perceptions, discrimination and stereotyping of physical disability and 'looks' through her attitude and integration into their local organisations and community. The participant expressed incredulity that their physical disability should affect the way they were treated; this exposed a positive discourse around self-empowerment and 'being normal' along with revealing the negative discourses of discrimination and judgemental attitudes of individual healthcare staff. Participant 2 continued to push for further treatment and challenged the NHS to offer equal access to all patients. Participant 2 recognised their physical deformities and disabilities, the participant's appearance and the use of their wheelchair. The participant did not, however, allow these factors to define them as a person, positively reinforcing the discourse around ability and not disability. The participant promoted them self and did not shy away from sensitive topics, raising the profile of the value and worth of disabled individuals to society, which may slowly change perceptions. This would offer a mechanism of re-definition of societies' views of disability.

The social ideology is that every individual must have a purpose and contribute to life, imposing a certain requirement on individuals in society to behave in certain ways, and to meet normal social conventions. This assumption has different implications for the HMV population and their dependence on support to maintain a level of normality. At a personal and situational level, the ability to contribute and to socialise depends upon the perspective of society on recognising the value of disabled individuals. The discourse around equality and the focus on ability is revealed. However, the ability to contribute is also controlled by

individual financial situations, driven by the welfare state. To contribute to society and work requires society to offer the same opportunities for all individuals; however, the ideological view that all individuals within society should have the same access and opportunities is flawed. This ideology does not recognise the differing social backgrounds and financial status of individuals, or the limitations imposed by society on those who have a disability. The discourses around dependence and independence are therefore re-emphasised. Recognising the discourses is an opportunity to challenge the situation.

Through Participant 2's involvement in the local communities, the intertextual context is that they contributed to the community, and added value. However, this was tempered by the participant's ability to physically 'keep up' with the working environment, and how they tired when they were out at work five days a week, not returning until 6pm most evenings. The discourse around the social model of disability emerges, offering an opportunity for society to change, rather than expecting Participant 2 as a disabled individual to fit into an able person's world. No other participant was in paid employment, although Participant 6 and Participant 3 drew on memories from their previous working life and abilities.

Participant 6, Participant 3 and Participant 4 craved the normality of being able to do things for themselves and to still have the skills they had lost, be they handicrafts or playing a musical instrument. Participant 4 referred to lost skills in terms of physical dependence, for example, the participant was no longer able to feed them self. The discourse of dependency is revealed, and there was sadness and loss around the acceptance of no longer being able to do something for themselves. However, Participant 4 and Participant 6 recognise that they have come to accept elements of life affected by their conditions, and as such, have identified a potential response shift that has occurred over a number of year. Participant 6 recognises their limitations, and Participant 4 has learned that their life will not resemble the hopes, dreams and aspirations that they had in their younger years.

Attempting to integrate into society, the dominant discourse of equality and discrimination was again highlighted by Participant 2 and Participant 4. Participant 4 recognised and accepted that, to attend football matches, they were required to apply for a limited number of tickets allocated to disabled fans, exposing the discourses of equality and discrimination that hide the control and power of the masses. Participant 4 also recognised that to travel,

they would need more money to accommodate their equipment, "...because of my special needs..." (P51 L13).

Physical access to buildings proved difficult for Participant 2 when referred to a psychosexual counselling service, as the clinic was located on the top floor of a hospital building without lift access. This emphasises the divide between the reality of everyday life for individuals with disabilities, and the rhetoric of society around integration of disabled individuals into society. It exposes the societal and health services perceptions of who would normally access the clinic, and demonstrates a lack of appreciation of their disabled client's requirements. Participant 2, like Participant 4, accepted the issues related to access: intertextually, Participant 2 implied this was a regular and normal aspect of their life. However, Participant 2 vocalised their disdain at the attitude of staff. This revealed the dominant discourse of equality and those of prejudice and discrimination by an individual member of healthcare staff, who told the participant that they should be prescribed contraception and should not be having sex, because they were disabled. This conflicts with the ethos and philosophy of nursing, and Participant 2 challenged society's view of disability by exposing the discourses interwoven with equality. By so doing, the participant created an opportunity to change the discourse and society's beliefs of disabled individuals. It is debatable however, how visible these discourses and challenges are to the wider public, with changes slowly to be seen, and services slow to respond. Participant 2's voluntary work partly enabled this challenge, as they confronted stereotypical images and perceptions of disabled people, enabling them to achieve a greater iQoL.

Sport provided both Participant 4 and Participant 1 with a voice to express themselves as individuals, and an opportunity to integrate into society, widening their social lives, something they both appreciated. Both interviews reflected and referred to the wider discourse of inclusivity and equality through engagement with sport. As sport draws in individuals, it displaces the loss of ability that a chronic critical illness and diagnosis of a life-limiting disease imposes, levelling the playing field, so to speak. Participant 4 acknowledged and stated that attending sporting events, mainly football games in his case, brought with it a level of normality. The experiential, expressive and relational words used provided insight into the value of the experience for Participant 4. The use of the metaphor 'goose bumps' (P52 L2) to describe the participant's emotions and feelings provided insight into the effect

sport can have, regardless of the individual's ability to participate physically. The dominant discourse is that of equality, and stereotypical images of disabled individuals are challenged through their engagement with sport. However, the intertextual context alludes to continued discrimination and control, with the limited numbers of tickets and spaces for disabled individuals being exposed.

Participant 7 was similarly involved in sport: skateboarding. The participants expressed their sadness and loss, and the loneliness that followed the participant's accident, which had brought to an end their physical enjoyment of skateboarding, a key part of their social life. Unlike Participant 4 and Participant 1, Participant 7 did not refer to watching sport, only how Participant 7's physical disability had restricted their social contact and how their freedom had been lost; it resulted in a recalibration of the participant's iQoL. Participant 7 exposed the discourse around loss of ability, as did Participant 6 and Participant 4. In contrast to Participant 7, the positive effect of sport on Participant 4 was clear, engaging the participant in the atmosphere and wider culture and discourse that surrounds football. In attending football games, the participant engaged with society and therefore actively challenged views of disability. This promotes the breakdown of stereotypical views of disabled individuals. However, it was tempered by the limited availability of disabled seating at sporting and other events as highlighted above. This uncovers intertextual discourses around the continued repression of disabled individuals in society through only partial integration and inclusivity. Government influences on transforming these power relations are laid down in law, through the anti-discriminatory laws (Equality Act 2010) that require bodies to provide equal access to all, and to engage with all members of society.

Participant 1 similarly enthused about their love of rugby, and how it enabled the participant to regain some freedom and 'escape' (**P42 L5**) from their home. This was a sentiment echoed by both Participant 4, when he referred to their home as a 'prison' (**P52 L3**), and by Participant 7, who recognised their loss of freedom and social life which centred on skateboarding prior to their accident. Participant 1, like Participant 4, became animated when describing how watching rugby and sport on the television made them feel. The experiential values the participants' words evoke yet again provide an intertextual insight into how sport engages individuals, disabled or able. The expressive elements of the text show how Participant 1 loved rugby and shouted when they watched a game, recognising

how sport was part of their social and individual identity. Sport drew Participant 1 out from their home, to socialise more. Participant 1's mother described how the participant's love of sport enabled them to take part in a pub quiz, for example, as their friends and family would always turn to the participant for an answer, boosting the participants' self-esteem.

In contrast to Participant 1 and Participant 4 and their yearning to socialise, Participant 5 revealed that their social life was mostly on-line, reflecting how much of modern life is now lived through social media. Participant 5 felt that interacting on-line brought them an element of independence in managing their own relationships. Participant 5 revealed that they would "just have fun with the staff" (**P69 L7**), rather than socialising with their friends, providing an intertextual insight into the lack of contact with and peer relationships. It exposed the discourse around vulnerable adults and developing relationships. It suggested a naivety, uncertainty and mistrust within relationships, and demonstrated his personal struggles forming bonds and relating to family and friends.

Participant 7 indicated that their social life was extremely limited, as their friends did not live locally, whilst Participant 3 identified discourses around how the local community and religion and the social aspect that is incorporated played a role in maintaining the participant's iQoL. Participant 3 felt let down by their friends and fellow members of the religious congregation, as they did not visit the participant. The friends and congregation members held respected positions of responsibility and authority in society, which exposes the rhetoric that society and religion embraces care and compassion through neighbourly behaviour. In Participant 3's interview, the participant presupposed an appreciation of the intertextual context of different religious denominations, and the hierarchical structures embedded within them. The intertextual discourses in Participant 3's interview revealed judgemental attitudes, and Christian beliefs, morals and values. Participant 3 held a negative view of the individuals who did not call to see them, revealing once again the discourse of loss associated with increasing disability and dependency and its influence on iQoL.

Participant 6 likewise exposed the loss of their social life, but in contrast to Participant 3, Participant 4 and Participant 1, for instance, they were partly responsible by refusing to go out socially, because of their own perceived and stated reliance on humidified ventilation. This reveals the complexities of maintaining a social life, and the discourse surrounding

discriminatory behaviour and equality that affect disabled individuals. In an effort to retain a level of normality in the participant's life by going out for a meal, Participant 6 was exposed to discrimination and in tackling discrimination head-on, they attempted to retain a level of control over their life. In analysing the discourses revealed around Participant 6's reticence to socialise, the intertextual context exposes discourses around how discriminatory behaviour may have influenced Participant 6's behaviour and willingness to socialise, along with changes to their body image, directly affecting their individual quality of life. Public attitudes and perceptions of disability and body image limited the participant's attempts to maintain a social life.

6.4.2 Relationships

The discourses revealed through relationships are closely associated with those around decision making, having a voice and social lives. However, in focusing on relationships, further insights are revealed.

Relationships between the participants and their carers took numerous forms, and differed in the level of familiarity and understanding. In Participant 4's case, as with Participant 3, trust and rapport had developed over a period of years, and it was a blow to Participant 4 when the care team was dissolved and a different team introduced. The introduction of the newly-sourced care team meant Participant 4 had to develop new relationships, rapport and trust, as well as a shared understanding of their level of physical dependence with the participant's new carers. Participant 4 explained their level of trust in the previous qualified carers, as any changes to their health and well-being were identified quickly, maximising their ability to maintain independence. It exemplifies the effects of education that professional nursing brings to patient care and emergency situations. The established care team and qualified nurses 'knew' Participant 4, which offered the participant security. Participant 4 commented that having a new team was like "having to start from scratch again" (P22 L16). Participant 4 further stated that they "...wasn't really happy about them going really...but I had no choice" (P22 L22). A lack of respect for Participant 4's views is visible, and their dignity compromised, as the carer is in a position of power. If the patient feels safe and cared for, (power) relationships between patient and carer are balanced, as the carers empower the patient through the trust that they develop.

Participant 7's relationship with their mother exposed paternalism and a struggle to make the participant's voice heard. The discourse of advocacy and those of dependence and independence and their meaning to Participant 7 were uncovered. As the participant's advocate, Participant 7's mother did not recognise her child's needs. By contrast, Participant 5 relied on their advocate, and demonstrated a close relationship that conveyed and exposed discourses around trust, dignity and respect. However, a further perspective was presented by Participant 5, as they talked of their anxiety in developing their relationship with their parents. Participant 5 having been forcibly estranged from their parents until the age of 18, had contacted their parents following the transition of their care from child and young adult services to adult services. Participant 5 tried to emphasise that their relationships with their family were normal and that they was not troubled by this. The intertextual context, however, revealed a dysfunctional family, ambivalence, alienation and estrangement. Discourses around safeguarding and POVA dominate Participant 5's individual struggles and their attempts to change the relations between their siblings, parents and them self. The participant's success was limited. The participants' parents visited only sporadically.

A further perspective on relationships is exposed by Participant 6. The participant revealed a level of intimacy related to depending on carers, and used humour to describe how the carers had seen more of the participants' body than their face. The participant attempted to lighten the loss of independence and reflected on how they depended on the relationships with "my nurses" (**P24 L1**) to care for them. Participant 6 alluded to dignity and respect, recognising they can no longer apply their own make-up, or wash them self, requiring assistance with fundamental care. The participant was also aware of their limitations and how they had learned over time, to understand how much they were physically able to do. A re-definition of the participant's view of iQoL and their situation was evident.

Intimate and personal relationships were discussed by Participant 2 and Participant 4. Participant 4 explained how they had learned to accept their disability, resulting in the participant leading a different life to that which they had imagined. The participant had envisaged a life journey where they would marry and have a family, fitting societal norms. The intertextual discourses revealed are those of the medical model versus the social model

of disability, emphasising the changes disabled individuals are required to make to their outlook, rather than society altering its view of disability, but also of a change in their own perceptions and a shift in responses. Participant 4 was accepting of their situation, and at the loss of an imagined life; this does highlight the discourse surrounding society's ideology of families and stereotyping of disabilities, and how individuals are forced to adapt their own views. Society's views of traditional families has and is changing, and this discourse offers further opportunity to challenge social norms, to enable disabled individuals to integrate fully into society. Similarly, Participant 2 talked of their previous relationship with their partner, and how this had afforded them a greater level of independence and widened their social life. Participant 2 differentiated between having a carer deliver their care and how having a partner to champion their care and needs differed, exposing and presupposing the intertextual discourses around intimacy and interdependence as part of a couple: "...and it wasn't a carer. It was a partner" (P62 L17). Participant 2 challenged society's view of disability and intimate relationships by forming and being a part of a couple, and as indicated previously, by accessing sexual health services. Participant 2 recognised the difference that the presence of a partner made in their iQoL, enabling a greater degree of freedom, independence, and lack of dependence on services.

In contrast to the poor relationships participants had fostered with healthcare staff, and revealed through discourse, the extent of the trust and rapport participants had developed with John, the respiratory care consultant, was clear. It demonstrated a more level playing field in terms of independence in decision making. Each of the participants commented on an equality in their relationship with John, with Participant 2 discussing their lack of faith in and respect for doctors with John, as though with a friend. The participants noted that John responded to their queries on a personal level, and they each had a personal relationship with him. This reveals a re-balancing of the hierarchical relationships between patients and healthcare staff and shows that decisions can be shared. This changed the discourse and began a move away from the societal view of a hierarchical and medically-dominated healthcare service, to one that reflected and respected patient's views.

Ideally, the NHS as an institution should advocate on behalf of all patients. However, there is a fundamental disparity between the advocacy the health service should deliver and that

which Participant 3, Participant 4 and other participants experienced. The hidden discourses of discrimination, lack of advocacy and empowerment are visible in both Participant 3 and Participant 4's interviews, but are also visible in the text from other participant's interviews, such as Participant 2 struggling against individual prejudices, exposing individual NHS staff prejudices and the dominant discourse of equality.

The relationship between participant and ventilation is also visible in the text. Participant 3 viewed their declining health negatively, particularly from the point of insertion of the tracheostomy. This however, contrasted with Participant 3's overall SEIQoL score of 70.8/100 which was relatively high in comparison to others. The insertion of the tracheostomy for Participant 3 was perceived as a turning point, and that their social life had waned from this point onwards, requiring a redefinition of their iQoL. Participant 6's view compared with Participant 3's in that they viewed ventilation as a reason for their withdrawal from social life and integration into society. However, their SEIQoL scores differ dramatically, with Participant 3 scoring 70.8 overall, whereas Participant 6 scored the lowest of all of the participants with 25. The discourses revolve around loss of their previous life (and of control); however, control over health was enabled for some through ventilation. For example, Participant 1's health had stabilised, and their social life expanded with the introduction of full mechanical ventilation. The consequence of this was that the participants' parents and family's social life and their own independence had ultimately improved, collectively improving their iQoL. Participant 1 recognised that their relationship with ventilation was positive, reflective of a positive reconceptualisation of their iQoL. The overall SEIQoL score reflected this at 86.5./100.

Comparatively, Participant 4's SEIQoL score was also high at 82.88/100 and they also stated that being ventilated was a positive factor, and that, despite a difficult time prior to the insertion of the tracheostomy and commencement of ventilation, they had a good quality of life. In recognising that the participant had survived, Participant 4 acknowledged that the tracheostomy and ventilation were allowing the participant to live "a decent life" **(P5 L30)**. Re-definition of their iQoL had occurred. The tracheostomy allowed Participant 4 to continue living and find a reason for their life, to support their family.

Relationships with, and discourses and ideologies around, beliefs and religion were also revealed. Participant 4 revealed how religion had helped them cope with their diagnosis and

deteriorating health. The participant's faith and the religious leader as its physical representative, were supportive and maintained contact to support Participant 4. By contrast, Participant 3 disclosed how they felt abandoned by the physical representation of their religion; the participant did however believe that they had a close relationship with God, to whom they prayed regularly. Here, the effect of religion in supporting individuals became apparent, improving iQoL. Participant 4 recognised how faith had enabled the participant to accept their disability and deteriorating illness, whereas Participant 3 sought sanctuary in their belief in God. For Participant 3, attendance at religious services demonstrated the link between social life and relationships and how the participant's loss of skills and deteriorating health had brought to an end their physical prowess in playing the piano. However, the text revealed that the actual need to attend a religious service to renew and sustain their faith were less necessary. The discourse around the power of religion to maintain faith and to provide a reason for being is exposed.

6.5 Summary of Chapter

This chapter has provided an explanation through identifying the discourses that affect HMV individuals, with intertextual elements further illuminating the situations and discourses that affect iQoL. My own interpretations (MR) are evident, and may have influenced the conclusions drawn and the discourses identified. The dominant discourse is that of equality, which recognises inclusivity, disability/ability, empowerment and advocacy. How individuals' changing views and responses to their diseases and conditions over time are affected influences the discourses at a situational level. These discourses are mediated through and are recognised in the intertextual and competing discourses of NHS Funding, Prudent Healthcare, joint commissioning and person-centred care. The ideologies or beliefs around social norms and roles relate to contributing to society and purpose, structure and agency, religion/faith, and how the ideology of the NHS is compromised, alongside a change to the value of nursing, which is pushed aside in favour of a medical model of care. Chapter 7 will present a brief additional, targeted and narrative literature review to complement the additional findings and original literature review, and support the discussion of the findings, drawing on the literature and enabling conclusions and recommendations to be made are presented in Chapters 8 and 9.

CHAPTER 7

7.1 Focused literature review

Having provided an interpretation in Chapter 5 and an explanation of the findings in chapter 6, the key findings exposed are how power and control are enacted through discourses that frame the overarching concepts of seeking independence and being normal. To enable a fuller discussion and further inform any conclusions drawn, a secondary, targeted search of the literature was conducted, including the terms: equality, inclusivity, disability/ability and interdependence, judgemental attitudes, discrimination and body image alongside the social and medical models of disability, structure and agency, and social norms and roles. The intertextual and competing discourses of NHS Funding, Prudent Healthcare, joint commissioning and person-centred care were also included. Power and control are embedded in these discourses.

This focused literature review is presented in a narrative format, and differs from the systematic approach taken for the initial literature review. The aim was to provide some bridge-building between the data found and the evidence base, providing an opportunity to further support my theoretical position, the methodologic critical approach taken along with developing the discussion of the discourses exposed in the text. The literature covered is representative as opposed to exhaustive, and provides a basis on which to further the analysis. It also offers an additional lens to policy makers and clinicians, recognising the ongoing changes to occurring within practice, at a micro and situational level, due to meso and macro level changes. Please note that, as the writing of this thesis progressed, the use of terms has changed, reflected in the use of the terms 'being normal' (Chapter 6).

Returning to the literature, several terms are used, including 'normality', 'normalisation' and 'normalcy', which have been included in the review. Additional information on 'being normal' has been included to support the discussion. No literature specific to home mechanical ventilation was found on a broad search of judgemental attitudes, and discrimination. However, there is plentiful literature on a range of disabilities in relation to these concepts.

For the purpose of this chapter, the above concepts have been collapsed and the following overarching concepts and discourses will guide the brief literature review:

- Equality and Normality

- Interdependence
- Social and Medical Models of Disability
- Social Norms and Roles, Structure and Agency
- Integrated Care

7.2 Equality

Searching for literature on equality, a vast number of characteristics were found. Equality today is governed by law through the Equality Act 2010, an umbrella act for various acts and anti-discrimination laws, including the Disability Discrimination Act of 1995, the Race Relations Act and the Employment Equality (Religion and Belief) Regulations of 2003. To protect disabled individuals requiring access to healthcare services from disadvantage and discrimination, the UK Equality Act 2010 obliges healthcare providers to make reasonable adjustments to their services and practices. The literature suggests that, despite legislation, health services do not always deliver or offer reasonable adjustments for disabled people (Read et al. 2018). Indeed, evidence and discourse around normality highlights a ‘them and us’ polarity between institutions and service users, which does not dictate equality, inclusivity and integration. To enable a greater degree of inclusivity and integration, Read et al. (2018) recommended a culture change in the NHS, to support individuals with disabilities, including changing the values or attitudes of staff through education and taking time to listen to disabled individual’s needs.

In contrast to the control imposed by the medical model of care, in a secondary analysis of the narratives of people with severe functional disabilities receiving of personal care, Wadensten and Ahlström (2009) report that, rather than forcing the individual to adapt, it is the environment that should change. This perspective reflects the Swedish ideology that all people are of equal worth and is captured in a law: the Act Concerning Support and Service for Persons with Certain Functional Impairments and the Assistance Benefit (Swedish Code of Statutes SFS 1993:387 & 1993: 389). The Act encompasses four ethical principles: autonomy, integrity, influence and participation. Wadensten and Ahlström (2009) focused on the participants’ experience of receiving care. They were empowered by being understood, which involved experiences with the care provider (institution) (poor and good experiences), and with carers, which were mostly positive. The focus of narratives of

experiences with the carer underpinned the importance of being listened to, which led to a greater level of satisfaction, respect and empowerment. In support of this view, Gibson et al. (2014) note that it is important that the perception of individuals with disabilities of what they consider to be a good quality of life is recognised, offering a degree of parity with able individuals.

Equality signifies a level of equivalence and parity in how individuals are treated. Normality is seen as representing and being part of individuals' inclusion and integration into society. In a systematic review of the literature between 1966 and 1997, Deatrick et al. (1999) attempted to clarify the concept of being normal. The studies in the review focused on families and children/young adults and on developing a revised table of conceptual components or attributes of being normal. The attributes include: acknowledging the individuals' condition and its potential to threaten their lifestyle, how the family adopts a 'normalcy' lens to define the child and family, family and parenting behaviours and routines are consistent with the 'normalcy lens', treatment routines are developed to tie in with the 'normalcy lens' and view the family and child as normal, and how they interact with others as though this is so. This review yielded a reductionist approach to defining the attributes of normalcy, with each of the above attributes focusing on specific areas as opposed to an overall holistic view. The reductionist view reflects the biomedical approach to care and disability, where individuals are required to 'fit into' the treatment routines of healthcare providers, as they strive to create a 'normal' life for themselves. There are clear links with the social and medical model discourses of disability.

The elements of normalcy identified by Deatrick et al. (1999) were furthered by Morse et al. (2000), who studied the concept of normalisation from the perspective of the individual with a disability. They identified two *worlds* that families with disabled children inhabited: the everyday-as-normal world, and that of the disabled-as-normal. The everyday-as-normal world comprises values, beliefs and customs in the wider community, outside the normal sphere of individuals with disabilities. The disabled-as-normal world ("like me" (Morse et al. 2000, p. 665)) is one in which customs, beliefs and values are imposed on the individual with a disability and their families, owing to the disability. Social interaction, such as schooling, led to the child and family interacting with the wider community, and further integration resulted in adaptive behaviours to 'fit in' to the reference group (Morse et al. 2000), such as

excelling at a skill that belonged in the everyday-as-normal world, relocating them from the disabled-as-normal to the everyday-as-normal world. Developing their own and maximising their capabilities moved children towards an everyday-as-normal world; children with disabilities were treated as normal at home, yet disabled in the everyday-as-normal world (Morse et al. 2000). Doubt and McColl (2003) noted that social integration is a key element in normalisation. Barriers to social integration resulted in social isolation due to the need to use equipment, for example. Attributes indicating normalisation included:

- Comparison of self with a target reference group
- A desire to fit into this targeted reference group
- An emphasis on the similarities and not on the differences of the child to the target reference group
- 'Fitting in' – strategies used to enable this (Morse et al. 2000).

Using a phenomenological approach, Doubt and McColl (2003) explored the perceptions and experiences of teenagers with physical disabilities who attended mainstream secondary schools, and concluded that individuals did not fully integrate, despite using numerous strategies to do so, and that they accepted this limited degree of integration (Doubt and McColl 2003).

Best practices (and discourses), such as empowerment, self-determination and choice, have, over time, become embedded in the normalisation principle. Further foci and discourses are those of inclusion, autonomy, social integration and reimagining. Nirje (1970) developed the idea of the Normalisation Principle (Nirje 1970), which is tied to social relationships and integration into society. The principle was based on individuals with learning disabilities. The normalisation principle was retitled Social Role Valorisation (SRV) by Wolfensberger (2011), and refers to integration and provision of comparable situations, settings and patterns of living that are encountered in life and society by able-bodied individuals for disabled or indeed, any individual. The focus of SRV is providing direction on achieving 'good things in life' through the use of best practices (Thomas and Sakellariou 2018; Wolfensberger 2011). Nirje (1970) also proposed that self-determination should be part of the lives of individuals with intellectual disabilities. The normalisation principle designates equivalence in terms of choice for individuals with or without intellectual disability. This echoes the Independent

Living Movement, according to which dependence is viewed as choice over the care delivered (Gibson et al. 2009).

Robinson (1993) conducted a secondary analysis of two previous studies on the narrative of normalisation for adults and children. This revealed two factors: maintaining perspective on chronic illness, and reframing viewpoints. Discourse would enable a reframing of perspectives and change in meaning for individuals and societies. The reconceptualization of individual perspectives included the level of ability and how this affected their 'normal'. Individuals reconceptualise and alter their perspectives over time, changing how they view their lived reality and their hopes and expectations, exposing the discourses of the effects of disability. However, in reflecting on the literature presented in chapter four, it is worth asking whether it is possible to measure changes in constructs such as quality of life (Ahmed et al 2005; Allison et al 1997)

Perez et al. (2015) explored the attitudes of individuals with disabilities towards their ability to work. This offered insight into how organisations and families support individuals with disabilities, influencing job satisfaction and providing an indicator of their intention to leave their jobs. Several valid and reliable tools were used to measure support and satisfaction, although the study is limited by sample size. Organisations that took positive action to improve the well-being of individuals with disabilities, resulted in the promotion of job satisfaction.

Galli et al. (2015) in contrast explored the implicit and explicit attitudes towards wheelchair users. Patients with spinal cord injury (SCI) had negative implicit attitudes, and positive explicit attitudes towards their fellow-SCI individuals. The attitudes of healthcare staff were influenced by the amount of experience they had with wheelchair users and in interacting with wheelchair users with SCI who contradict prejudices. This mediated the implicit negative attitudes of those without SCI.

Similarly, Buljevac et al. (2012) reported that disabled participants experience stigma of disability through intrinsic and extrinsic factors. This contrasts to implicit and explicit factors. Intrinsic elements were those that made participants feel different owing to negative attitudes, prejudice and stereotyping. Extrinsic factors are those that include broader societal level discrimination and labelling. The stigma of disability is exhibited through the

powerlessness of participants in making decisions, and in that society viewed the disability as the main characteristic of the individual. A degree of overprotection, associated with paternalism, was also noted, reducing QoL, independence and participation in society and leading to social exclusion. Galli et al. (2015) also reported that society's perception of the use of a wheelchair affects how the individual is viewed. Yet, when healthcare staff interact with individuals with disabilities, it cultivated positive attitudes, increasing acceptance and reduced (personal) bias.

However, these behaviours could be due to uncertainty about how to behave when in the presence of a wheelchair user or disabled individual, rather than implicit attitudes towards visible differences being viewed negatively (Stock et al. 2013; Roberts et al. 2017; Roberts 2014). Compassion and kindness are socialised behaviours; however, explicit behaviours may reflect more negative affective reactions (Houston and Bull 1994). Physical differences owing to disability present the public with a struggle, as there are no explicit social codes of behaviour around responding to individuals with visible differences. This results in awkwardness, potentially owing to a lack of awareness regarding how to respond to visible differences in social circumstances (Roberts and Gierasch 2013).

7.3 Interdependence

Despite of the existence of numerous Acts, policies and guidelines - for example, the Well-being of Future Generations (Wales) Act 2015 and the Equality Act 2010 - such laws and policies have failed fully to integrate individuals with disabilities into society, when considered from the perspective of the social model of disability. The Care Act 2014 recognises living independently as a core element of wellbeing, identifying the requirement to support individuals to live as independently as possible, for as long as possible. What, therefore is dependency? Defining independence provides a comparator and according to Morris (1997),

“Independence is not about doing everything for yourself, but about having control over how help is provided” (p. 56).

The continuum that spans dependence, independence and interdependence is well recognised in nursing (Roper et al. 2000). Independence is linked to autonomy, particularly the autonomy of decision making, whilst interdependence exists between the individual with a disability, their carer(s)/health care institutions and family members who provide

care. Physically disabled individuals rely on their mental authority to make decisions and retain a level of autonomy, whilst relying on carers to provide for their physical needs, effecting a level of interdependence. The social view of autonomy and, therefore, independence is built on a conceptual and abstract self, recognising the participant's fundamental humanity and isolation to others (Mackenzie 2008). It therefore does not reflect the interpersonal and social relationships around which life is fashioned. The nature of these interpersonal and social relationships signifies values such as trust and caring, as identified by Finkelstein and Marcus (2018). Major life decisions usually involve others; therefore self-determination, choice, autonomy or control could be viewed as conditional as opposed to fixed states (Burton Smith et al. 2005). In a study by Meyer et al. (2007), participants sought assistance and facilitation of their personal autonomy when they received care and support; personal autonomy was perceived as relating to choice, in recognising and enacting the choices of the individual with a disability. Wadensten and Ahlström (2009) further categorised feelings of dependence or independence within the dimensions of autonomy, whilst autonomy, by exercising personal control through stating views and making decisions were deemed important factors that increased quality of life according to Steffanson et al. (2016).

However, interdependence recognises the roles individuals play in supporting one another in everyday living, developing meaningful relationships with others (Mackenzie 2008). This creates happiness in life, and includes developing relationships with carers and others in the same position. The development of meaningful relationships was recognised as a key element of nursing, as Henderson (1978) noted, whilst partnership working is advocated by the NMC (2018); nurses provide a care to support individuals with essential daily activities at times when the individuals may lack the strength, knowledge, or will, to carry out the activities themselves. Nursing care is required when independence has been lost, and a degree of interdependence exists. Nursing through autonomous, collaborative care and advocacy, aims to support individuals function and work towards healthy independence (ICN 2019). Nursing can provide intimate and person-centred care which the NMC (2018) advocate, and Henderson noted as being a universal element of the concept of nursing. Carper (1978) and the Fundamental Patterns of Nursing, breaks down the work of nursing into 4 categories: Empirical, Aesthetic, Ethical (moral) and personal knowledge. These four

categories should be woven through all aspects of care, to enable individuals who access nursing care to receive care of the highest standard.

In one study, a participant highlighted developing relationships between themselves and their carers: “I’m an 18-year-old guy living here. On my own. With ten PCA’s [Personal Care Assistants]”. (Israelsson-Skogsberg et al. 2018, p. 14). Similarly, one participant in the study by Finkelstein and Marcus (2018) viewed himself as independent, recognising that the carers viewed him as dependent. The participant’s perception was that the carers did not realise that, as patients, disabled individuals were the driving force of decision making, and that depending on physical care did not reflect his views of his independence (Finkelstein and Marcus 2018).

Wadensten and Ahlström (2009) reported that dependence and independence indicate how participants related these concepts and discourses to whether they were in control of their situation. Independence indicated a greater level of control, and thus a greater level of equality with non-disabled individuals was achieved. A disabled individual may therefore interpret independence as freedom in terms of decision making, whereas carers may interpret independence as the ability to care for oneself (Mackenzie 2008; Reindal 1999). Only by exposing the influence of the carer on and in the relationship is the norm challenged, facilitating a relationship based on caring, empathy and mutual respect (Gibson et al. 2009). Dependent individuals thus negotiate independence; the concepts are interlinked (Finkelstein and Marcus 2018). This restores control to the patient, enabling a greater degree of dependent-independence (or interdependence and control). Living between dependence and independence, and recognising the facilitative role of carers in increasing the independence of patients, while drawing attention to interdependence was reported by Israelsson-Skogsberg et al. (2018). Disabled individuals can be said to live between power and vulnerability and between dependence and independence (Israelsson-Skogsberg et al. 2018). This particularly applies to the HMV population, due to their dependence on equipment. This acknowledges that living with technology can present a series of additional challenges, requiring extensive planning to gain and maintain independence and normality.

Patronising and paternalistic attitudes were evident in the literature (Somerset et al. 2002). These affect the QoL of individuals by influencing decision making and participation. Care is ultimately imposed, and challenges and affects autonomy and also freedom. Powerlessness, disempowerment and humiliation are centred on patronising attitudes and exclusion from making decisions (Israelsson-Skogsberg et al. 2018; van Huijzen and van Staa 2013; Dyrstad et al. 2012; Martinsen and Dreyer 2012; Briscoe and Woodgate 2010; Dreyer et al. 2010b; Ballangrud et al. 2009; Lindahl et al. 2005; Miller et al. 1990; Goldstein 1998). This highlights a lack of understanding of carers of the need to involve disabled individuals in their own care.

Institutionalisation and the perception that disabled individuals are passive recipients of care, undermines the potential for individuals to live independently. Care is thus a highly political, socially and individually constructed concept. Social care and healthcare disempowers disabled individuals, as the ideology of the practice of caring involves loss of power (Gibson et al. 2009). There is a loss of individualised care, through the interpretation of need being viewed according to the medical model, applying a task-based approach to highly personal needs, and indeed 'wants'.

Privacy and choice were elements of living independently that directly affected how healthcare staff, qualified (registered) or un-qualified carers, integrated into the home (Finkelstein and Marcus 2018; Wadensten and Ahlström 2009). The importance of boundaries between participants and carers relates to a need for respect, confidentiality and sensitivity, a need echoed by several participants. The need for privacy, as carers could be present 24 hours a day, and independence away from carers, is recognised in the literature, as some carers interfered in all aspects of participant's lives, when it was not required or requested (Wadensten and Ahlström 2009). Laakso et al. (2011) reported that participants found a lack of privacy difficult when depending on a carer to support communication, which often led to feelings of being controlled. Strong relationships with carers and nursing staff through open communication are key to supporting disabled and chronically ill individuals, reducing vulnerability, fear and loneliness, worries and suffering (Hofhuis et al. 2008; Johnson 2004).

Communication is fundamental to developing and maintaining relationships that facilitate equality in service delivery and access. Communication is highly important when mobility is restricted, as communication is a means of maintaining independence and control (Laakso et al. 2011). The use of technology facilitated communication, as speech loss can lead to social exclusion and fear of loss of control. Participants stated that having a voice meant they could make themselves heard, be “in charge” (Laakso et al. 2011, p. 692). Despite a relatively small sample, in a secondary analysis of communication during ventilation, Guttormson et al. (2015) found that participants were frustrated by failed communication and a lack of information. This is mirrored by numerous studies and with participants who could not communicate, associating voicelessness with feeling helpless, panicked and frustrated (Guttormson et al. 2015; Engstrom 2013; Karlsson et al. 2012, Laakso et al. 2011; Johnson 2004). The use of technology and equipment present a less than ‘real’ world requiring adaptation on behalf of the individual requiring ventilation, as the equipment amplified the sense of frustration due to a loss of means of communication. Johnson’s (2004) study, conducted in an intensive care unit, reported that some participants describe what means to reclaim the everyday world, whilst existing in the ‘uneveryday’ world of critical care, with its unique use of technology and high intensity treatments and nursing care, in order to reclaim and reassert themselves (Johnson 2004). Despite the different study settings, the issues and findings remain relevant to all ventilated individuals as they learn to make sense of their lives and existence, as their dependence is absolute.

7.4 Social and Medical Models of Disability

The social and medical models of disability vie for supremacy across the care and healthcare services. The social model of disability considers disability an issue for society, based on unequal access to resources. By contrast, the medical model of disability believes that disability is perceived as a biological problem that requires treating and curing the problem (Thomas and Sakellariou 2018). Alternative models, such as the critical disability theory, have been proposed to overcome the dichotomy between the social and medical models (Horkheimer 1972), however further discussion is beyond the scope of this literature review.

Recognising the differences in perspectives of the social and medical models exposes the discourse around equality: reframing social perspectives around disability and chronic illness

requires that individuals are recognised as people with decision making powers, regardless of their level of ability or disability. Medicine sees a 'patient', not an individual who exists in a family or society (Wellard 1998), limiting the holistic approach to care and treatment delivery, as the social context in which the illness is experienced is not recognised (Tesh 1990). As the neoliberal government and society continues to focus on health and wellness, being a disabled or chronically ill individual requires that the individual learns the politics of their disability and illness. Discourses around powerlessness, autonomy, paternalism and competing discourses such as those of NHS Funding, Prudent Healthcare and joint commissioning come to the fore, and the reality contrast with the emphasis on health and wellbeing (WG & NHS Wales 2018 and 2016; Cameron et al 2017; Hughes 2017; Dickinson et al. 2013a; Gibson et al. 2009). These dominant discourses are involved in the political game playing at a local and individual level. Merging health and social care services, and the likely discord of the disparate social and medical models of disability, can result in a loss of understanding and meaning of what care is required and desired (the 'needs' and 'wants') by individual disabled populations.

The concept of care is perceived as being under the control of medicine, with discourses that fit with the medical model attempting to 'fix' those who are ill and disabled, resulting in normalising the individual. With care being controlled by and through a medical model, and being delivered in the home environment, it is possible to transpose Foucault's suggestion that control (and power) is institutionalised through surveillance via social structures for example, prisons and schools, to the community and home environment. By providing care in disabled individual's homes, the individuals remain under observation. This enforces control and the individuals under surveillance become docile bodies, offering less opposition to the institutions (Taylor 2013; Forbat et al. 2009; Faubion et al. 2000; Gutting 2015; Foucault 1975/1995).

7.5 Agency and Structure, and Social Norms and Roles.

7.5.1 Agency and Structure

Structure is concerned with how society, culture and family shapes individuals. It is focused on social institutions at a meso level. Agency, by contrast, is related to how individuals create society through their actions and behaviours. The focus on agency is on how individuals develop, sustain and reproduce the sense of social structure; for example, their

relationships in the family and at school. Individuals influence social structures through their actions, and vice versa. There are therefore mutual influences between individuals and social structure and society, resulting in a need to understand the nature of both (Burke and Stets 2012). Agents are actors (individuals, persons) in society, and are the objects that act in the theories that have been constructed to explain behaviour and patterns of interaction. Agents have a variety of features, which may assist understanding of the different types of agents and their actions (Burke and Stets 2012). This can be likened to the subjects and relations that Fairclough (2015) emphasises through the use of frames and scripts in the interpretation of text. However, the effectiveness of agents is offset by the inequalities and barriers implicit in the social structure and its norms, rules and beliefs (about age, gender, class and cultural identity, for example).

7.5.2 Roles and Norms

Identities or frames (Fairclough 2015) are formed by roles in society, such as daughter, brother, carer or healthcare professional. One person can have numerous roles, and these identities relate to one another, influencing individuals' thoughts, beliefs, feelings and behaviours, and binding them to society as a structure. Social roles are played out in society, with behaviours and actions that correspond to the role being played, meeting the expectations of the role. The expected behaviours or social norms and roles influence attitudes and behaviours and any deviation from these can result in exclusion and stigma.

As a result of disability or illness, the suggestion is that individuals become exempt from their normal roles, accepting that (medical) healthcare staff will make decisions on their behalf, and thus be deferential to the greater level of knowledge (and power and control) that educated and trained, healthcare staff (doctors) hold. Passive acceptance of changes, be it acceptance of treatment suggested by clinicians was described by Parsons (1951) as the sick role. Family dynamics also change as a result of illness and disability. Individuals transition from socially and culturally established roles to new, different roles, as do their caregivers. Plank et al (2012) reported that family caregivers recognised a core concept of 'being responsible for everything' and that balancing their many obligations and fulfilling different social roles alongside being a carer was of concern. This highlighted the carers' need for hope, confidence and safety, recognising the effect of disability of loved ones and a

change in roles. Safeguarding as a mechanism of protection of vulnerable adults is key and is enshrined in law (Social Services and Well-Being Act (Wales) 2014).

Roles within societal discourses, and their relation to control, can be separated into feminine and masculine forms. The archetypal model of masculinity is that of control and independence. It infers physical strength and control of social relationships (Gibson et al. 2007). Illness and disability disrupts this image and the display of control. Care, in comparison, is perceived as a feminine characteristic, and is typified by social and economic roles. The work of caring is done mainly by women in health and social care, as well as in families, most of which remains hidden, despite government recognition of unpaid carers in the UK (Carers Trust 2018; Watson et al. 2004). This hidden influence undermines the control of the situations around care provision; it is estimated that the contribution made by unpaid carers in the UK to the economy is £132bn a year and that there are approximately 370,230 carers in Wales (Carers Trust 2018).

In relation to DMD, specifically, it distorts the masculine concept, as this disease affects only males, altering perspectives of control and independence, and requiring adaptation to depending on others and technology for support. Dreyer et al. (2010a and 2010b) reported that it resulted in 'independent-dependency' as individuals with DMD did not view themselves as different to others. By contrast, Yamaguchi and Suzuki (2013) reported that individuals with DMD struggled with dependence and independence as a result of the disease, and viewed themselves as different, despite attempting to achieve normality. Furthermore, Kohler et al. (2005) reported that individuals diagnosed with DMD early in their lives, in comparison to those who become disabled as a result of an accident for example, tend to adapt to the limitations that are set by the condition. Diagnosis at an early point in their lives allows time for adaptation, drawing on the support available to them via their parents and carers. This allows roles to establish over time. However, as previously recognised, a change in roles can result such as when the care of DMD individuals is handed over to formal carers from mothers, for example. Mothers as carers have great insight into the particular needs and wants of individual DMD sufferers, and participants acknowledged the emotional difficulty of surrendering the responsibility of care to paid carers (Dreyer et al. 2010a and 2010b).

Social norms are challenged by disability, and stigma and social exclusion can also result from differences in appearance as well as behaviours and attitudes. Visible differences, such as appearance, have over the past few years, owing to socio-cultural changes, resulted in the increased visibility of individuals with a visible difference or disability (Roberts and Gierasch 2013). Rumsey and Harcourt (2005) define visible differences as “a difference from a culturally defined norm which is visible to others” (p. 88). With social media increasingly emphasising bodily and physical appearance, negative effects on individuals with visible differences are increased (Hamlet and Harcourt, 2015).

7.6 Integrated Care

In attempting to improve patient outcomes and satisfaction, including their QoL, along with ensuring that funds are most effectively spent, the role of the NHS in society is also key. The integration of health and social care services at a local level is promoted by governments across the UK (NAO 2017; European Social Network 2017; Scottish Government 2017; Wodchis et al. 2015; WG 2014). The NHS Constitution (2011a) captures the ethos and principles of the health service. Changes instigated through joint commissioning are captured in the constitution, with the NHS committed to joint and collaborative working with other agencies to deliver a high standard of care (National Audit Office (NAO) 2017; European Social Network 2017; Scottish Government 2017; Wodchis et al. 2015; WG 2014; NHS 2011b).

According to its founding principles, the NHS is free at the point of contact. However, provision of services to individuals with greater needs and limited means is only provided for by local health (and social care) bodies once assessed and deemed necessary. Assessment and funding is a broad church, with services paid for mainly through CHC budgets (WG 2014) for the HMO population, although, during this study, the terrain was beginning to change, with the inclusion of social care. The neoliberal marketization of services, as visible in the current health and social care systems, has increased joint commissioning. Joint commissioning involves both social and healthcare services reaching a decision around the assessment of need, as well as allocating resources, purchasing, monitoring and reviewing services (Smith, et al. 2010). This has changed yet again, with the

inclusion of another body - local councils – in assessing need and allocation of monies through the Independent Living Grant (UK Government 2015b). Outcomes however will need to be defined and evaluations that are responsive to individual needs developed. Joint commissioning is intended to make best use of a limited pool of resources, whilst improving outcomes (Humphries and Wenzel 2015). However, limited evidence exists regarding the benefits and value of marketization in terms of reducing costs and improving the quality of services (Dickinson et al. 2013b). In addition, Wye et al. (2015) noted that commissioning involves the management of power relationships, competing agency and personal agendas and demands, whilst integrated care policies act as a discourse only to control funding pressures as opposed to effectively lowering hospital admissions (Hughes 2017).

Supporting care in the home environment, as dictated by policies such as Care Closer to Home (UK Government 2015a), offers an opportunity to lower hospital based costs, however individuals who require HMV are, in Western communities, treated and live according to a biomedical model of care (Gibson et al. 2009). All elements of the service are driven by medicine and finance. Maclaren et al. (2018) noted that care as a whole is influenced by how service is provided, and that tension exists through its implementation via separate services. Government-led attempts to unite health and social care to enable a more holistic service, have yielded limited success (WG 2014; NAO 2017; European Social Network 2017; Scottish Government 2017). Of the £2.1 billion NHS Sustainability and Transformation (Better Care) Fund for 2016-17 for England, £1.8 billion was allocated to covering NHS deficits, rather than to transforming and integrating services (NAO 2017).

The complexities of health and social care, and attempted integration of patients into service design and delivery, with its reliance on numerous services, organisations and professions, results in conflicting professional perspectives (NAO 2017). Daykin and Clarke (2000) identify this clash between qualified (registered) and unqualified, healthcare assistants, pointing towards a reproduction of hierarchical models applied to the organisation of work. These professional perspectives are highlighted specifically through discourses around integrated care and NHS Funding, Prudent Healthcare, joint commissioning and person-centred care in this study (WG & NHS Wales 2018 and 2016). Cameron et al. (2017) propose three discourses of joint commissioning (Dickinson et al. 2013a):

- Prevention, as a means of reducing inequalities and improving service delivery;
- Empowerment, in developing services that are reflective of the needs of those who access them; and
- Efficiency, through eradicating service duplication and improving performance.

Cameron et al (2017) reported that prevention by inputting services early in the patient's journey improved outcomes and reduced cost, whereas the discourse around empowerment established that patients were not listened to, resulting in frustration for the patient. Managing expectations is an issue, and how patients are involved in decision making in care is crucial in identifying issues and problems. Again, Cameron et al (2017) note that cross-organisational commissioning makes the resolution of such issues increasingly possible, and offering standardised approaches to care are either more expensive or cost-cutting, but not cost-neutral. By offering services that include the patient at the centre of the care and that are sensitive to their needs, services can be commissioned that save money. They are "person-shaped" (Cameron et al. 2017, p. 68) as opposed to standardised solutions. Through empowerment, efficiency savings were made, drawing on the third discourse identified above. Again, by placing the patient or service user at the centre of the discussion, it was possible to identify overlap in services, reducing cost.

This highlights the difficulties the health service faces in delivering an increasingly costly healthcare provision with reduced funding. With approximately 23% of the population of Wales living in poverty, a factor felt more keenly in the South Wales valleys, poverty impacts on physical and mental health and well-being, affecting individuals' ability to provide for their own health needs (Joseph Rowntree Foundation 2015). Poverty-stricken individuals therefore rely more on service provision, both social and healthcare. In addition, the financial restrictions imposed on and by the NHS have resulted in patients having to fit into a healthcare system driven to ensure financial savings and cost containment (Wenzl et al. 2015). This depersonalises care and results in a fragmented as opposed to a person-centred, cost-effective service (Hughes 2017). Steffanson et al. (2016) report a significant positive association with the effectiveness of care services: freedom of choice in relation to service provision and its association with the perceived effectiveness of services - for example, choosing meals and scheduling care delivery times - were key to how individuals viewed the service. Decision making in such circumstances is underpinned by freedom of choice, or self-

determination, and is linked to autonomy and thus control (Rabiee 2013; Burton Smith et al. 2005).

As part of effective care delivery, patients' freedom is increased by technology that is fully functioning, fitting and comfortable. The use of technology leaves the user vulnerable in terms of breakdown of equipment that essentially maintains life, whilst it also increases dependency on services to maintain the functioning of the equipment (Laakso et al. 2011). The dependency of the participants on the differing agencies that support care to also maintain the equipment is therefore essential.

7.7 Summary of Chapter

The chapter has provided additional literature to support the discussion in light of the findings. In the following chapter, a discussion of the main findings and discourses that influence the quality of life of home mechanically ventilated patients is presented.

CHAPTER EIGHT

8.1 Discussion

This broad aim of this study was to critically explore the individual quality of life of home mechanically ventilated persons. To frame the discussion, the research questions established, to be answered from the participants' perspective were:

1. What is the impact of HMV on their iQoL?
2. What practices do HMV patients use to sustain and enhance iQoL?
3. Within the discourses surrounding iQoL, what factors facilitate and limit iQoL?

The target audience of this research is academics studying HMV, and practitioners and policy makers working with HMV individuals and their carers. The research will add to the body of qualitative evidence and research in the UK and Wales, specifically around the quality of life of HMV adults. This chapter discusses the findings of this study in relation to the literature. It outlines their significance in relation to how the main discourses identified could change or be changed by their reproduction and resistance to enforced changes by, of and for participants. The purpose of this chapter is to summarise and discuss the main discourses, to enable conclusions to be drawn around iQoL, without necessarily restating or incorporating all of the findings. The discourses intertwine and are difficult to separate, and as such, the overarching discourses of Seeking Independence and Being Normal are used to guide the discussion. The individual concepts and cues identified are further explored and debated, drawing on the literature to inform the critical discussion. The influence of structure and agency, and power and control will be woven throughout the discussion, and the resistance of participants, where identified, will be acknowledged.

Authority and therefore control are pre-defined in the structure of society, with social class characterising and distinguishing which classes, professions and individuals have control (and power) over others. In what could be perceived as the 'hidden hand of the state', conformity to rules and regulations, whether disabled or able bodied, is the norm. Government policies and laws set out expectations, and societal norms and roles to a certain extent, whilst advocating that control - for example, in the instance of health and social care - should be jointly afforded to both the patient and the health and social care

practitioners, setting the expectations of those receiving the service. The control handed to those with disabilities enabled by the Equality Act 2010, is, in itself, controlled. This is illustrated through offering HMV individuals the choice of whether they would like to, and enabling them to live at home; however this reality is controlled through care provision and the opportunities afforded these individuals.

Consequently, the question of whether iQoL is a genuine concern is introduced, if these HMV individuals' lives are controlled by societal structures and agencies, with little individual agency to change matters. In response to this, I return to the ontological and epistemological underpinnings of this study, where I recognise my critical realist positioning and the scientific and rational elements of the HMV individual's existence, alongside that of the reality participants themselves create. The reality that the HMV individuals create themselves is the crux of the issue, and is the reason for exploring the iQoL of this population. As Gibson et al. (2014) noted, individual perceptions need to be considered, improving the parity in comparison to able bodied individuals. The quality of life of these individuals is of importance and concern, and the opportunity to explore and expose the struggles and tensions that are a part of their lives may allow identification of and change of societal structures and agencies, thus in turn, changing factors that underpin their iQoL.

New and emerging discourses are identified alongside findings that are consistent with the literature in terms of QoL and practices to sustain and enhance iQoL (Dale et al. 2018; Lamas et al. 2016; Dyrstad et al. 2012; Martinsen and Dreyer 2012; Briscoe and Woodgate 2010; Lindahl 2010; Lindahl et al. 2011; Dreyer and Pederson 2009; Ballangrud et al. 2009; Rabkin et al 2006; Lindahl et al. 2005; Brook et al. 2004; Gelinas et al. 1998; Young et al. 1994). The emerging discourses revolve around the discourses of new models of care delivery and integrated care (Hughes 2017; Cameron et al. 2017), which negate patient-centred care and contradicts the political rhetoric of including patients in their care (WG and NHS Wales 2015; Coulter & Collins 2011), and the philosophy of nursing.

The implications for nursing as a profession, with the implementation of a medical model of care and the influences that the medical model wields, are that there is a lack of emphasis on tailored, patient-centred care; this impacts participants through a lack of holistic care

and loss of individuality. The International Council of Nurses definition of nursing as broadly embracing care that is collaborative and autonomous, delivered across all settings, to all ages of individuals, to families, and groups and communities, whether they are sick or well, includes advocacy (ICN, 2019). The Nursing and Midwifery Council (NMC 2018) Code stipulates Prioritising People, listening to their concerns and preferences, and responding to their needs. Participants offered views on how these elements were not met. Advocacy by nurses of the patients' needs was missing for the most part from the broad categories of discourses identified, be it seeking independence or being normal. There was an acceptance of the introduction of the medical model, and a withdrawal of registered nursing care, replaced by unregistered and unqualified carers.

Henderson (1978) noted that the role of the nurse is to care for individuals, and to assist them if unable to perform activities unaided, that contribute to their health, enabling the individual to gain or regain as much independence as possible, as quickly as possible. Within the discourses identified, maintaining the level of independence (interdependence), and also promoting the dignity of participants was key (NMC 2018). This would support a good individual quality of life. Nursing shares this responsibility with other professions, however with the advent of integrated care, and a move towards financial prudence and less costly services, the role of the registered nurse is eroded, to the detriment of patient-centred and holistic care. It also highlights the level of control enforced on HMV individuals by the financially struggling health and social service sectors.

Participants reported a focus on meeting their fundamental needs, rather than their wants, fitting in with the time limitations imposed on the carers that stem from the new models of care delivery. A lack of attention to the holistic nature of their needs was apparent; understanding and appreciation of the subtleties of meeting cultural requirements and how care impacted on their abilities to socialise was negligible. For patterns of care to change, the discourse needs to reflect the voice of the HMV individual, which is currently unheard and the impact of 'wants' over 'needs' is not recognised. The problem reflects the medical model of care, and its reductionist approach, and influences a number of discourses including but not limited to autonomy (of decision making), empowerment, powerlessness and paternalism. Macro level policy and law ought to empower individuals, for example the Equality Act 2010 should enable all individuals to access equal care. However, this was not

apparent in the interview text. Participants reported difficulty accessing services and the establishment of reasonable adjustments to enable participation in society was not realised for most, despite legislation obliging public bodies and commercial companies to conform (Read et al 2018). This made it a struggle to maintain a level of 'being normal'. This however was not reflected in the overall SEIQoL-DW score of a number of participants. Despite all participants reporting an element of lack of adjustment, however, there were instances of action on behalf of public bodies to enable integration and participation in education, for example. Yet, it fell to the individual to adapt for the most part.

Factors that facilitate or hinder HMV individuals' lives can be seen in the conflict between agency and structure and the resistance with which imposed changes are met. The majority of resistance was at a local and individual level and for the most part, was passive. Little resistance was identified that resulted in change. Participant 5, for example, identifies the elements of power and control by recognising the "interferences" (P49 L9) to which he was subjected as a minor, with both social and healthcare services involved in his care. The structure of the health and social care services influenced the delivery of his care and Participant 5 demonstrated a limited ability to control this as the agent. However, resistance was manifested in small ways; for example, in how Participant 5 refused to attend social events arranged by social services. Integration is therefore limited (Doubt and McColl 2003).

Yet there were differences in the individual participants' resistance. Participant 5 demonstrated very little resistance compared to Participant 2 and Participant 3. Participant 2 specifically challenged the (NHS) system in numerous ways, presenting resistance to enforced changes. Despite being accepting of some actions and approaches, both Participant 2 and Participant 6 actively challenged others' attitudes and behaviours. Participant 2 specifically resisted control by actively challenging the structure and systems in place in society through their financial position as a debtor, disrespecting structure, agency and the medical profession as a whole. Participant 2 for example, swore to communicate their point, demonstrating individual resistance at a situational and personal level. Struggles such as these offer insight into the continued inequalities in society that disabled individuals face. The discourses in these instances however remain unchanged. Small scale transformations and a (re-)balancing of power (and control) are seen specifically in relationships with the respiratory care consultant, however this is unusual rather than the

norm. These will be discussed in further depth in the following discussion, which is framed by 'Seeking Independence' and 'Being Normal'.

8.2 Seeking Independence

8.2.1 New Models of Service Delivery

In discussing the health and social care delivered, it is impossible to ignore the structure within which this is delivered. The translation of questions around healthcare values to economic discourse and language has transformed care. Health and social care have been central to the wider changes imposed by government in what is a neoliberal approach to policy making. The focus is on reduction of costs, (benefits) and efficiency. As a political economic theory, neoliberalism is captured specifically through the discourse around funding, and joint models of health and social care. Its principle is to develop and enhance well-being by liberating entrepreneurialism via a free market within an institutional framework. However, the neoliberal policies have resulted in fragmentation of health and social care services, resulting in the privatisation of services, and paternalism from an increasingly corporate perspective, with the possible unintended consequences of integrating care services leading to loss of personalised care. This was evident in the study, with the change in care teams resulting in a loss of personalised care and knowledge of individuals' needs and wants. Cultural and religious needs, previously respected, were not recognised by the 'new' care team, perpetuating health inequalities in a health and social care system based on neoliberal policies. In some instances, with the more general 'needs' of the participants having been met, the 'wants' had surfaced as more pressing issues. There was a general recognition of how money affected lifestyle choices. Some participants recognised the cost of services, yet, verbalised 'wants' such as greater freedom to come and go on a daily basis; it thus turns full circle to the recognition of the limitations set by the health and social care system. The discourse, hidden for the most part, demonstrates acceptance of the situation by the participants. One noted no fear of repercussions from accrued debts, as they recognised that their disability would likely result in a more lenient and compassionate outcome. The participant adopted discursive strategies that appealed to human compassion. Nevertheless, there was recognition of the limitations imposed on their independence, as a result of a reduction in and a joint commissioning and sharing of services.

Joint commissioning is perceived as beneficial and as promoting positive outcomes and QoL (Cameron et al. 2017). However, discourse can also be a mechanism to manage struggles related to funding, rather than an intervention to reduce inappropriate hospital admissions (Hughes 2017). The discursive strategies employed by government have nevertheless provided legitimacy for imposed changes. It restrains the transformation of services through ensuring that the issues are viewed via a neoliberal perspective.

The free market is ideologically portrayed as one in which competition is fostered and innovation embraced. In reality, it is often a means to maintain the monopoly of power and control of services, and incidentally, service users. With a neoliberal approach, power and control is concentrated at meso and macro levels. The micro level 'wants' and 'needs' are side-lined to some extent, and patients and carers are little involved, reflected in the discourses here. Political rhetoric around involving the patient in care decisions (WG 2018c and 2018d; Coulter and Collins 2011) appears to be just that: rhetoric. The government maintains power by controlling funding, and developing policies and Acts (Health and Social Care Act 2001; Health and Social Care Act 2008; Health and Social Care Act 2012; Health and Social Care Act 2014). The NHS Constitution (2011a) declares it is committed to providing the most effective and sustainable use of resources ensuring the best use of public money, however CDA reveals the contradiction in political rhetoric and policy making on the one hand, and the care patients actually receive, on the other. The intrinsic value of care has been eroded and is now commercialised. This is reflected in the discourses identified by the participants. The 'needs' of some participants are not met, with religious and cultural issues disregarded as care teams move towards joint working between social and health care. Thus, the recognition of and auctioning of 'wants' become even more distant, and are not managed in the care planning of such individuals. Policy development represents an ideological force in social reproduction, reinforcing capitalist ideals and political hegemony. This risks the lack of recognition of, or the meeting of the 'wants' of HMV individuals becoming entrenched (and silent/ hidden) through social reproduction and policy. Health and social care services policies and guidelines and the discourse surrounding these provides nothing more than symbolic reassurance. Prudent healthcare (WG/NHS Wales 2016 and 2018) as the chosen approach to health and social care, and the focus on involving patients in their own care, are not actually solving the issues in the system. Disabled or

chronically ill individuals are forced to involve themselves in the politics of their specific condition at a local and individual level. This may offer a way forward in drawing attention to the situation that HMV individuals face. However, their disabilities and the affect that this can have on their ability to vocalise their 'wants', not only through a physical voice, would need to be supported. Those in control dictate the dominant social ideologies, and these are exerted as economic power.

A key concern for participants was the funding of services and care. The literature emphasises the complexities that the health and social care services face in delivering an increasingly costly service with reduced funding (WG 2018a and 2018b; WG 2014). The Bevan Commission (2011 and 2018) noted the increased cost of developing technology which will add to the financial burden. Discourses around empowerment, efficiency and prevention (Cameron et al. 2017; Dickinson et al. 2013a) and how the merger of services through joint commissioning has improved patient empowerment and efficiency and prevented poor outcomes, are, as the study reveals, yet to be realised in Wales. Findings reveal a lack of choice, decision making, and trust in the carers and participants' voices being heard. This is reflected in the literature (Maclaren et al 2018). Physical access to services along with public spaces, which requires money to make adjustments, is also far from equal. This exposes the lack of attention given meeting the 'wants' as opposed to the needs of the HMV individuals, to enable them to engage fully and actively in society. Thus, the discourses of empowerment and efficiency appear as paradoxical and impossible to achieve. The lack of parity is reflected in some participant's interviews, however it does not appear to influence the overall iQoL of all participants. Discrimination in terms of lack of equality of physical access was emphasised by the participants, with a passive acceptance that this was the case. No resistance was reported, perpetuating the situation for all disabled individuals. The discourse remains hidden to a certain extent amongst the HMV population and a degree of acceptance amongst the participants noted. Increasing awareness of rights, exposing the discourse, could redress the balance.

Prudent healthcare resulted in the participants having to fit into a health and social care system driven by political ideology and rhetoric, and financial restrictions regardless of the likely inequalities in health (and social opportunities, and often case, the 'wants' of participants) this perpetuates (Wenzl et al. 2015). Medicine views the HMV individual as a

'patient' and not a person who lives within a family or society; the social context is not recognised, as opposed to a nursing approach, which embodies a broader, more holistic perspective when viewing HMV individuals' lives (Tesh 1990; Wellard 1998). Participants identified the limitations to the services they received, through time-limited care and a focus on tasks related to physical care, as opposed to holistic care. 'Wants' are opposed to the 'needs' of participants. The health board and CHC budget, and in addition, local councils now control these services, with formal needs assessments determining the level of care required. Nevertheless, the mutual influences of both social structures and individuals needs to be understood and appreciated, to ensure that the centrality of individuals is respected (Burke and Stets 2012). The reframing of perspectives through the application of a social model of disability, alongside the application of a philosophical approach more closely aligned to nursing, would enable the respect of individuals to be maintained. The planning of care could thus recognise the fundamental aspects of care required, alongside the aspirational wants of participants, in an attempt to reach self-actualisation (Maslow 1968).

However, recognising only fundamental 'needs' as dictated by the medical model, makes it difficult to address what patients 'want'. The most basic of Maslow's hierarchy of needs (1968), safety and physiological requirements are recognised, while the higher needs of friendship, family, intimacy, self-esteem and self-actualisation are neglected. It proves the assumption that 'needs' incur a higher value than 'wants'. This situation promotes dependence and limits the development of independence and a creative interdependence between patient and carer. It has implications for trust and rapport, with participants specifically identifying issues arising from a lack of trust and rapport with newly established care teams. An emotional and personal component is identified in the participants responses, contrasting with the business and marketization approach (discourse) taken by health and social services. The changes to services forced the participants into making mental adjustments to and redefining their situation, both to the change in carer teams and more broadly, at the lack of shared decision making. A response shift was recognised, with the perceptions of participants of support, rapport, and trust altering as services were reconfigured. The changes imposed resulted in turmoil, instability and uncertainty,

challenging the schemas constructed around their conditions and reality. The dynamic state of iQoL was visible (Ahmed et al 2005; Sprangers & Schwartz 1999; Allison et al 1997).

Developing relationships with new carers requires time, as trust and rapport must be developed between participant and carer. The need for trust in relationships with carers was emphasised by Schaepe and Ewers (2017), Lindahl (2010), Ballangrud et al. (2009) and Mackenzie (2008). The relationships that had developed over time between this study's participants and their carer's encompassed trust and respect, with carers 'knowing' their patient's needs without explanation. This is reflected in the theory of nursing, and specifically Carper's Fundamental Patterns of Knowing (1978), across all 4 elements: the empirical, scientific factors, the aesthetic elements; personal knowledge; and moral understanding. It offers an alternative approach, to meeting the 'needs' and 'wants' of the participants, with recognition of their individuality, and specific requirements. To prevent the repeated frustration of articulation their 'needs', participants expected their carers to be intuitive to their needs (Schaepe and Ewers 2017). However, the change to unregistered nursing staff (carers) in the current study may have been responsible for the lack of understanding of staff; of not 'knowing' the participants in their care. Unregistered and non-nurse carers would not have the depth of knowledge and education to fully understand the needs of the HMV individuals across all 4 types of knowing in nursing. Due to Prudent healthcare and the new agenda for shared services and commissioning, the likelihood is that unregistered carers will continue to be employed in place of qualified and registered nurses. This may have implications for nursing as a profession; the watering-down of the knowledge, understanding and skills that nurse education provides, through the introduction of a trained, non-registered workforce may dismantle the strength, advocacy and understanding that nursing as a profession bring (Henderson 1978). The longer-term implications for iQoL as a result of the change in staffing are as yet unknown and unproven, and will need to be monitored over time. The discourses of the new models of care, specifically empowerment and efficiency, as diametrically opposed concepts, will develop over time. Measurement of the iQoL of HMV individuals, and being cognisant of the potential of response shifts will be necessary.

As with the current study, Schaepe and Ewers (2017) noted that, with the establishment of a new care team, it was difficult to judge whether the carer was competent and could be

relied on in a crisis, and that participants needed to feel safe when being cared for. The discourse around competence and the employment of unregistered carers to meet the tightening budgets of health and social services is uncovered. Measuring competence of registered staff occurs as part of education and training; how this is effectively managed and ensured in the unregistered carer population is unclear. Local level governance, as opposed to macro regulation via professional bodies and the discourse is beginning to take shape. The voice of the HMV individual in how this discourse develops would be key in its development, necessitating use of currently available, such as SEIQoL- DW, or development of specific PROM's. Using SEIQoL-DW would offer a means of measuring iQoL; there is however a need to be cognisant of potential re-definition of the individual's perception of iQoL.

Returning to the need to develop rapport and trust, the erosion of an established level of trust had occurred for one participant, with a 'new' carer being investigated and dismissed, having been negligent in their care of the individual. Despite the issue being dealt with by the health and social care services, with the discourse being bared, there is little resistance demonstrated by the participant in the text. The effectiveness of the agent, in this case the participant, to change the situation is offset by the barriers that social structure puts in place. However, the power of the organisation, that is, the health and social care systems is demonstrated, further representing control over the care and service delivered. The carer did not conform to the corresponding behaviours and actions that social norms dictate, and was excluded from further carer roles; the iQoL of the participant was, however, affected. Where the medical model of care is adopted, offsetting a holistic, patient-centred nursing approach, the offering of education to and consequentially facilitating the development of relationships with those who care for disabled individuals is essential. This may aid in the process of HMV individuals accepting circumstantial changes that the new reality of disability bring (Gelinas et al. 1998). This in turn may affect the response shift, providing an alternative discourse of how acceptance of situations and circumstances influence iQoL.

The dignity and respect expressed towards the participant was also identified as lacking on occasion, with elements of care related to religious beliefs, for example, being neglected. This could be due to a lack of understanding and education on the part of the carer. However, the care service should be cognisant of patient's religious needs, which should be

documented. There is a discourse around new models of care as an intervention, and differing types of professional/ carer delivering care, however they are proving more useful to guide and manage the tensions linked to funding (Cameron et al 2017) as opposed to meeting the individual needs of the service user. The lack of understanding of carers as opposed to that which is typified by the profession of nursing, exposes the hidden discourse around the philosophy of nursing. A lack of appreciation of the need for holistic care, drawing out the wants as well as needs of the individuals through the 4 patterns of knowing, for example, is apparent (Carper 1978). There is no demonstration of empowerment of the participant through meeting their individual religious needs in this study, and a conflict of professional perspectives was revealed, through local political struggles. This is an indication of how power and control are used by service providers, evidenced in the wider literature (Cameron et al. 2017; NAO 2017; Daykin and Clarke 2000), but sadly, the philosophy of nursing and advocacy in particular (Henderson 1978), are shrouded in the move to create a more prudent service.

Similarly, there was a hidden discourse around the dignity and respect afforded to care staff by participants and their families. Some participants were vocal in their praise and their level of dependence on care staff; however, structural barriers to care delivery at an institutional level resulted in what Participant 5 referred to as “interferences” (P49 L9) at the situational and personal level, for participants. The participants as agents were ineffective in instigating changes, as the care was dictated by laws, governance policies and funding. However, the agents affecting and providing the care (health and social care services) perpetuated the situation, as they were also restrained and regulated by the social structures in place. The resulting position is one of an impasse; neither the participant nor carer/ service provider offered a means of changing the direction of the discourse. Transformation will require further attention to and reproduction of the discourse.

8.2.2 Decision Making and Roles

According to the findings, being part of decision making was key to the control HMV participants exerted over their care. This included involvement in decisions on where and when to socialise, which was a key finding across all participants; making decisions and changes to care teams was also a key finding, as the funding transitioned to joint commissioning across the health and social care services. Control on a personal level for

disabled and chronically ill individuals is a key element of QoL, and decision making is integral to self-determination (Maclaren et al 2018; Israelsson-Skogsberg et al. 2018; van Huijzen and van Staa 2013; Dyrstad et al. 2012; Martinsen and Dreyer 2012; Briscoe and Woodgate 2010; Dreyer et al. 2010b; Ballangrud et al. 2009; Lindahl et al. 2005; Somerset et al. 2002; Nirje 1970). This contrasts with the sick role described by Parsons (1951), where deference to medical authority is observed, and disregarding subjective, individual involvement in decision making. Partial or passive acceptance of medical decision making and paternalism was reported by some participants. However, others demonstrated complete rejection of decisions made by doctors around changes to care services, clearly resisting change. Variation in response to decision making and thus attitude, could be explained by differences in personality. It was noted that the two participants who scored lower iQoL scores offered greater resistance to social and healthcare services. However, the authority that is conferred on medical doctors by society through roles and norms, strengthens their position of power and was captured in the study by one instance that demonstrated the level of individual struggle and resistance by the phrase: "I'm not afraid of them". The challenge to the discourse here offers a potential alternative to the norm: that of equality of status. Class structures however perpetuate the norms revealed above, nevertheless, they are being challenged in society, with a recognition of the need to widen access to education.

This resistance to the power and authority of medicine, empowered participants in believing that they retained control of their care. However, the importance of the involvement of others in decision making should not be underestimated. Burton Smith et al (2005) noted that major life decisions usually involve others. This reimagines concepts such as self-determination, choice, autonomy or control as being conditional as opposed to being fixed states. There are parallels to be drawn with the measurement of iQoL here, as a dynamic concept; it is not a discrete measurement but a fluid concept that should be viewed across a continuum of time and (patient) experience. The importance of potential shifts in responses of participants who have been ventilated for a long period of time should not be underestimated (Ahmed, 2005; Sprangers and Schwartz 1999; Allison 1997). The shift in response is visible for example, in Participants 4 and 6. Participant 4 noted how they had accepted their position, and that life would not play out as imagined, whilst Participant 6

noted changes to abilities and how they had become accustomed to their now physical limitations. Both reconceptualised their perspectives of their quality of life, as a result of their conditions (Ahmed, 2005; Sprangers and Schwartz 1999; Allison 1997); one to a positive acceptance, and the other to a more negative conclusion. These conclusions were reflective of the overall iQoL scores. A tentative conclusion would be that all concepts and similarly, discourses that revolve around iQoL are in conditional, changing as they are reproduced and affected by social structures and individual influences.

Closely related to control and decision making, independence was viewed by some as their ability to make decisions. Therefore, having decisions made around, for example, changes in their care teams, without negotiation or shared decision making, diminished their control. Yet, participants viewed independence differently. For others, there was an acceptance that their part in decision making was surrendered to medical staff. Choice was limited (Gibson et al 2009). Some resistance to the control imposed by the CHC services through a lack of shared decision making was found in a number of situations, with some success. However, for the most part, resistance was passive and did not result in change. This alludes to an element of disempowerment and powerlessness of the participants, with few voices and advocates in the interview text to support their wishes and views. The evidence similarly catalogues concerns of powerlessness, disempowerment and humiliation, focused on decision making and patronising attitudes (Israelsson-Skogsberg et al. 2018; Maclaren et al 2018; van Huijzen and van Staa 2013; Dyrstad et al. 2012; Martinsen and Dreyer 2012; Briscoe and Woodgate 2010; Dreyer et al. 2010b; Ballangrud et al. 2009; Lindahl et al. 2005; Miller et al. 1990; Goldstein 1998).

Some participants recognised a lack of appreciation of the respect and dignity by healthcare staff and inclusion of participants in decision making. There are elements of resistance, however. Making changes to care without prior consultation with the individual receiving care contradicts the principle that the NHS should place every patient at the heart of everything it does, through the promotion and management of their own health, care and wellbeing, and that patients will be consulted on decisions related to their care (NHS 2011). It documents that:

‘NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers’. (NHS 2011a, p. 3)

This has implications for all patients and service users, particularly those with low income, as changes to the service due to financial constraints reduces the capacity to provide holistic care, with discourses around power and control, dependence and (a lack of) independence continuing to manifest. These struggles by individuals with disabilities to attain and maintain a level of well-being and normality in light of these imposed changes is apparent. This is despite numerous Acts, policies and guidelines. For example, the Well-being of Future Generations (Wales) Act 2015, fails to fully integrate individuals with disabilities into society. As government and society continues to focus on health and wellness, being a disabled or chronically ill individual requires that the individual learns the politics surrounding their disability and illness. These discourses involve political game playing at a local and individual level, as their illness and disability and dependency on care, in opposition to the emphasis on health and wellness, sets them apart in society (Gibson et al. 2009).

This is exemplified in Participant 2's interview, and the participant's attitude towards authority. Participant 2 played a political game with the authorities, flaunting their situation and inability to pay debts; the participant used their individual power and control of the situation, and disability, to evade penalty and punishment, relying on compassion and sympathy. Other participants identified a level of political savvy, with a high level of working knowledge of the health and social care services, ensuring that their voices were heard and their views and wishes realised. Some relied on carers to enable a physical voice to be heard, whilst others had the physical ability and mental determination to do this for themselves. Interdependency is apparent: regardless of the will of the participant in making their voice heard, they depended on others (carers/healthcare staff) to do so; in some cases, literally - to give them a voice and translate their communication.

Others relied on their carers to carry out the 'political fight' on their behalf. The implications and repercussions of decisions made at societal (governmental, macro) level were visible and had a ripple effect down to the individual (micro) level, mirroring the framework employed to analyse the data (CDA). Political battles, those with a 'small p', were won and lost by participants, with care being shifted from established teams to new, more social-care focused teams at the behest of the institutions. This was as a result of the lack of, and change of funding from purely healthcare (CHC) to a means- and disability-assessed level of service, consistent with the current trend towards a joint health and social care service.

There is an onus on the meso level services to review their practise, and to evaluate the influences and outcomes of such changes.

This returns the discussion to the concept of independence and the interdependence that participants illustrated. Despite being in the hands of carers (Finkelstein and Marcus 2018), participants relied on their carers to carry out their wishes and to vocalise their concerns. An appreciation of where the control lies within the relationship between carer and HMV individuals is unclear. Carers potentially and likely believe that the power and control rests with them; however evidence of resistance demonstrates participants have a different mind-set. The participants 'wants' and 'needs' should be paramount. Education of carers is thus the key, enabling participants to realise their wishes, creating a greater level of integration into society and exposing the discourse and voice of HMV individuals to a wider audience. This would develop acceptance of all individuals within society. Exploration of the views of carers however is necessary to enable conclusions to be drawn. Evidence could be used to develop the education of carers and services delivered; iQoL of HMV individuals could therefore be improved.

8.2.3 Control and Power

The concepts of control and power are difficult to disentangle. The concepts of powerlessness, disempowerment and empowerment are embedded in power, but also merge with independence. Each participant referred to power and control as intertextual influences, in relation to micro, individual and situational struggles with the health services at a meso level, which in turn, allude to governmental and societal, macro involvement. Control was important in how independent they felt. Small scale, micro level 'wins' in the struggle with the health board were negligible. By supplying care and support at home, at specified times and with specified limits, these services institutionalised participants in their own homes to a degree. There is an imposition of discipline through adherence to what could be termed social and health care services demand. These demands expose elements of Foucault (1975/1995)'s description of the institutionalisation of power through surveillance of the individual (Taylor 2013; Forbat et al. 2009; Faubion et al. 2000; Gutting 2015). It could be suggested that integrating health and social care into individuals' homes imposes a similar mechanism of surveillance. It imposes a level of discipline, with individuals who are disabled having to adapt to the medical model of care and accept treatment and

care according to when the institution deems it appropriate. It imposes a level of control, whilst removing the control and power of individuals over everyday choices. Returning to a nursing perspective, placing the patient at the centre of care as ideologically espoused by the NHS (2011a) would promote advocacy and empowerment of the patient, returning the control to the HMV individual.

This leads to the resistance seen in the study. Participant 3, for example, refused to allow changes to their care team, and thus new rules to control the timing and delivery of their care. Participant 3 openly regarded this situation as a fight, disclosing their beliefs and views around the services and institutions, and the individuals, including an advocate, who dispensed and actioned the consequences of policy changes. This, for the participant, resulted in a poorer individual quality of life, both physically and mentally. Macro influences of politically enforced changes at a meso level, impacted directly on the participant's care and (micro) iQoL. A lack of advocacy was highlighted in this and other cases, with elements of paternalism exposed. In two of the interviews, formal advocates were acknowledged. Yet, the principle of advocacy was not realised in both cases. One advocate identified closely with the formal definition of advocacy, supporting and upholding the views and wishes of the participant, through a sound working and personal relationship, enhancing empowerment and interdependence around advice suggested as part of decision making. This is reflected in the literature, with positive relationships enhancing decision making, independence and advocacy (Schaepe and Ewers 2017; Ballangrud et al. 2009; Brook et al. 2004; Gelinis et al. 1998). The other participant's advocate however, advocated on behalf of the continuing care services, not communicating with the participant, and not defending the participant's wishes and thus, wants. This led to a lack of empowerment and expenditure of energy by the participant in fighting to retain their care package. Revealing the discourse of lack of advocacy should raise its relevance and importance with respect of individuals who are vulnerable and require care (Social Services and Well-Being Act (Wales) 2014). It should also highlight the issues to the nursing services within healthcare, identifying circumstances and conditions where advocacy by nursing staff are essential.

However, there is a tension here between the expectations of the individual and the actual policy and guidance around advocacy, and how situations are negotiated through communication. Communication is therefore an important determinant of the struggle for

control, and could be perceived as a capital resource, used to negotiate control in (power) relationships. The study revealed that communication itself was a struggle for some participants, owing to their dependence on ventilation and their condition. If communication is a capital resource, participants with difficulties communicating would be at a disadvantage, and lack power. The study disclosed participant's fears and struggles with communication, from a loss of physical and metaphysical voice. Voicelessness is associated with feelings of helplessness, panic and frustration, which infers a lack of control (Guttormson et al. 2015; Engstrom 2013; Karlsson et al. 2012, Laakso et al. 2011; Johnson 2004). In this study, voicelessness was felt in negotiations, decisions and, ultimately, control over the situation. Nonetheless, this voicelessness for the most part, was not reflected in participant's overall iQoL scores. For the two participants who articulated concerns about voicelessness, their iQoL scores were two of the highest across the sample. Consistent with Laakso et al. (2011), communication and retaining their own voices that were heard was perceived as a means of maintaining control over decision making and thus independence. The potential for social exclusion was a real threat: participants stated that having a voice meant they could make themselves heard, and be in charge of their decision making and care (Laasko et al. 2011).

Adding further complications to the tensions around communication, struggles were also identified between participants who *did* have a physical voice but whose carers failed to 'hear' them and recognise their voice and wishes. Talking over participants or not recognising their worries and concerns, because of judgemental attitudes and blatant discrimination against their disability, emphasised the control carers affect, and how attitudes can affect the iQoL of the participant, both positively and negatively. The social exclusion felt by participants, both in and as a result of the situations, negatively influenced their experiences. Discrimination and stigma were found, through intrinsic and extrinsic factors. Intrinsic discrimination was evident in the negative attitudes, prejudice and stereotyping of participants. Extrinsic discrimination was acknowledged at a societal level, reducing iQoL. Discrimination was a response to the appearance and disability of the participants; a partially socialised response. Awkwardness in response to disabled individuals may be caused by a lack of exposure to disability and a lack of awareness about *how* to respond to disability in social settings. In some cases, participants tried to protect

themselves from the distress of social exposure by limiting venturing into society. As socialising was a key cue identified by all participants, the effect of limiting a strategy that enabled iQoL cannot be taken too lightly. The effect on some of the participants was to not socialise, whilst others noted a decrease in their mental well-being due to a lack of socialising. Galli et al (2015) report that discriminatory responses and attitudes significantly influenced social exclusion. Social awkwardness owing to pre-established social norms results in a lack of social behaviour codes to guide the public (Roberts and Gierasch 2013; Roberts et al. 2017). Recognition of the discourse and exposure of both the discourse and disabled individuals within and to society, could influence changes. The transformation would result in a more equitable arena, reinforcing and empowering HMV individuals, and improving iQoL.

Dale et al. (2018), Schaepe and Ewers (2017), Lemoignan and Ells (2010) and Brook et al. (2004) reported negative attitudes and conflict in relationships. This they noted together with and in contrast to, positive relationship outcomes in the context of competent care delivery and when sense of purpose and value of relationships was recognised. However, one participant sadly noted explicit judgmental attitudes, dispensed by a healthcare professional. This resulted in a lack of respect and willingness to participate in further treatment. It potentially hindered iQoL; the participants' overall iQoL score was the second lowest. Nevertheless, the positivity of relationships was substantiated in all of the participant relationships with the lead respiratory consultant, who surmounted professional and social barriers to offer support and advocacy to his patients, restoring the balance of power (and control) between patient and medical profession. This disregard for authority (and control) and the balance established on behalf of the doctor was unusual. Some participants had developed fractious relationships with other healthcare staff and carers, influencing their views and beliefs of healthcare staff and carers as a whole. Significantly, the lead respiratory consultant was not seen as belonging to the medical profession, but was perceived as a friend. The participants spoke of him on first-name terms, illustrating familiarity and intimacy. Both participants and the respiratory consultant were motivated to work collaboratively. The HMV individual and the lead respiratory consultant were united and shared a common purpose, and resulted in a positive experience for the participant. Whether this affected the overall iQoL of participants is difficult to ascertain however, it did

nevertheless, provide a mechanism of support for the HMV individuals, and potentially facilitated their iQoL.

The structure and agency equilibrium here is splintered, to the benefit of participant autonomy. Strong relationships built on trust, empowerment and partnership, increase autonomy (Lindahl 2010; Gelinis et al. 1998). The discourse around partnership in care is positive in this instance, although that was not always the case. Participants touched on the ideology that 'doctors know best', and resistance and challenges to this ideology are presented. The text offers an insight into how patient experiences of the health service and doctors specifically are shaped, resulting in animosity towards most medical staff. Only one participant referred directly to nurses; the discourse around the views of and role of registered nurses remains hidden. Further studies into the perceptions of the health and social care staff, and specifically nurses, may disclose other hidden discourses that could reshape the landscape around partnership in care for HMV individuals. Clinicians should be aware of and endeavour to balance the level of involvement that the HMV individual seeks whilst delivering evidence based medicine, tailoring the treatment and care. This would complement the newer discourses of prevention, empowerment and efficiency that joint commissioning and new models of care have identified. Developing services that engage service users and reflect their needs is thought to increase empowerment (WG & NHS Wales 2018 and 2016; Cameron et al 2017; Hughes 2017; Dickinson et al. 2013a). Evaluation of joint services will be required to determine the level of success.

8.2.4 Reframing Perspectives

Degrees of independence were observed and reflected in the discourses identified. Not all participants identified with independence; some said theirs was lost, owing to their condition and need for continuous physical support reflecting a negative response shift; others viewed their lives as relatively independent or interdependent on and with others, more positively recognising and reconceptualising their iQoL with their current situation. Participants in the current study accepted that to live as independently as possible required negotiated dependence in relation to the delivery of physical care, evidenced in the literature around interdependence and autonomy (Finkelstein and Marcus 2018; Israelsson-Skogsberg et al. 2018; Wadensten and Alström 2009; Meyer 2007). Of the two participants

with a diagnosis of the same neuro-muscular condition, both understood their dependence on others and that they were visibly different to the general population. This is consistent with Yamaguchi and Suzuki (2013), but contradicts Dreyer et al. (2010a and 2010b), in which those with a similar disorder did not view themselves as different, but recognised their 'independent-dependency'.

Ahmed et al (2005) and Robinson (1993) recognised adaptation, changes and reconceptualization of individual situations over time. These discourses were captured as direct and intertextual references in the current study. Participant 4 and 6 referred directly to how they had reconceptualised their outlook, due to the deterioration in their conditions. However, participants generally did not identify health as a cue to their iQoL. For those who did choose health as a cue, participants noted a combination of views: those who appraised their health status as good, and those who felt that they did not have any quality of health. Interestingly, participants did refer to a deterioration in their physical condition and increasing limitations to their abilities, despite assessing their health as good. The concept of health was viewed separately to their physical condition. Participants attempts at making sense of their condition schema through recognising deterioration from a depreciation of physical and psychomotor skills without directly linking this to their health and condition may have influenced and shaped their emotional responses and attitudes, be they positive or negative. Of interest is the SEIQoL-DW scores; for those participants with degenerative conditions and limited life-spans, these were of the highest across the population studied. It offers insight into a potential reconceptualization of their situation and understanding and acceptance of their condition. The intertextual context of a continuum of deterioration and adjustment to their condition may have made the appreciation of, and referral of any deterioration to the healthcare team less of a priority. Focus tended to be on other health issues, not directly related to HMV, which occurred as a consequence of their condition. This highlights the subjectivity of individuals in defining their concerns, and reconceptualization of their position (Ahmed, 2005; Sprangers and Schwartz 1999; Allison 1997). Participants established their own schema, drawing on their own specific contextual positions. Medical intervention and social investigation and support were only requested where the individual had decided, having mapped against their own criteria and hierarchy of needs and prioritised their concerns, that intervention and thus potential change, was required.

Reconceptualisation and an acceptance of the changes that respiratory failure brought was thus visible in the population (Ahmed et al 2005; Sprangers and Schwartz 1999). However, change to the domains identified (recalibration) and considered important to the individuals was not recorded, due to the nature of the study. The reconceptualization however, did not extend to exposing acceptance of changes to the long-term sequelae of introducing HMV into the participant's lives.

Dependence on technology reinforced the control of services over the HMV individual. However, the term technology spanned a range of resources such as the ventilator and equipment, laptops and computers that enabled communication, to social media and IT. Ventilators and clinical equipment presented challenges in 'making the technology work' for the participants in the study. That it was fully functioning was all important: ultimately, should the ventilator fail, then the life of the participant would be in danger (Lindahl 2010). Here, the change in focus from quality of life to maintaining life is evident. There was also a reliance on carers to ensure that the equipment (technology) functioned effectively. Levels of trust in carers abilities to diagnose and remedy any issues were reported, as evidenced in other studies (Schaepe and Ewers 2017; Lindahl 2010; Ballangrud et al. 2009). This had implications for both maintenance of life and on iQoL. The discourses suggest that living with technology is stressful, a factor that could affect the overall wellbeing and iQoL of participants. Promotion of the overall wellbeing and care of this population is suggested.

Ventilation was both a facilitator and an inhibitor of social life; it increased iQoL and likely decreased it for differing participants. However, a reliance on ventilation was only one element of technology. All participants were wheelchair users, with all relying on technology to mobilise. One participant recognised that if their wheelchair did not work, it would affect their overall iQoL. Additionally, as the participant relied on IT, if this did not work, it would affect a number of domains in their life such as education and communication, directly affecting the overall iQoL.

Technology was also relied on in terms of communication, and social media was a method of communication for some participants, offering a mode of 'speech' that facilitated control over relationships. Similarly to ventilator equipment, the uncertainty of whether equipment and technology would work and empower the individual to communicate existed.

Participants did not mention adaptation to living with ventilation and technology as

evidenced in the literature; all participants appeared to have adapted and were comfortable in using technology to enhance and maintain their iQoL (Dale et al. 2018; Briscoe and Woodgate 2010; Brook et al 2004; Goldstein 1998). However, the sequelae of being HMV did influence iQoL, and response shifts are clear in the text, as participants adapted to the reality of life as a HMV individual. Ventilation was noted as being an inhibitor and facilitator in relation to its effect for example on the participants' social life. It is highly likely that the discourses that influence technology and how technology influences care and treatment will extend. The Bevan Commission (2018) advice of rising costs associated with the developments that Prudent healthcare and new models of care will need to be cognisant of. The discourse around and debate of how the environment should change to accommodate disabled individuals as opposed to the individual adapting continues (Wadensten and Ahlström 2009). This reflects a social model of disability approach to the care of individuals, as opposed to a medical approach.

The recognition of other discourses and domains that influence each individual's situation, the contextual data, reflects the differing foci of patients in comparison to healthcare practitioners. From the study, HMV individuals take a holistic stance to their needs, reflective of a nursing approach, whereas the clinical approach is condition and problem focused; more in tune with a medical model of care. A paradox is thus presented, that is mirrored in the way the service is driven via a reductionist, medical approach. By prioritising their concerns, participants may have been purposely selecting the issues that they shared, resulting in less expenditure of emotional and physical energy and power on their part. Clinicians should thus be cognisant of the HMV individuals own appraisal of their condition or issues, and the overall implications of the progression of the condition on the individuals' well-being, and impact of separate issues. Professions should be cognisant of their philosophical stance, and approach, the loss of which should be guarded against in the drive for prudent healthcare. The influence of nursing in recognising the 'wants' and 'needs' of patients could be a major influencing factor and enabler of iQoL. Again, the overall well-being of those individuals who are HMV should be recognised, and support offered to help individuals adjust to their limitations and physical deterioration.

Coming to terms with the reality of being mechanically ventilated, participants reframed their understanding of their situation and life and had, for the most part, accepted the 'new'

normal (Larsen 2019). Some had been disabled for most of their lives and had passively accepted the changes as their conditions deteriorated. For others, disability and HMV had come at a later point in their lives. They had lived an able and 'normal' life, and felt their loss deeply.

This finding was echoed in the SEIQoL-DW scores for those who had become disabled at a later point in their lives. For the majority of participants who had been diagnosed at an early age, their SEIQoL-DW scores were relatively high (86.5/100; 70.8/100; 82.88/100; 81.5/100). Whilst comparison of the individual situations is not possible, the recalibration of the outlook of these individuals is likely, establishing a response shift to a more positive frame of mind. However, this did not occur in all cases, and some participants were more negative, noting losses rather than gains in their iQoL. There was evidence of recalibration of iQoL within sections of participant's lives, moving from a negative to positive and back to negative outlook. Most, though not all, had accepted ventilation, as it offered an opportunity to re-establish their social lives and to further their education and lead fulfilling lives. As such, they had also reconceptualised their situation and perspectives. Increases in dependency and consequently decreasing independence as conditions progressed however, manifested as distress for some participants. The discourse around loss was dominant, and mirrored in the overall SEIQoL-DW scores. Some reflected that the commencement of ventilation was the beginning of a gradual loss of ability to self-care and the loss of a social life. For others, the potential loss of metaphorical voice was a concern.

The current study participants were required to adjust emotionally and mentally to the major changes, losses and gains, as well as accommodate and acclimatise to the physical implications of HMV. Again, as reflected in the literature, some participants of the current study noted a protracted journey to full ventilation, and on commencing HMV, that it renewed their vigour for life, regenerating their social lives (Dale et al. 2018; Briscoe and Woodgate 2010; Ballungrud et al. 2009; Lindahl et al. 2005; Rabkin et al 2006). Some participants explicitly expressed their gratefulness at the commencement of ventilation; it offered freedom from worry around breathing and empowered them to resume their social lives. It enabled iQoL. The discourses exposes the effect that the individuals decision to accept ventilation has on individuals with respiratory failure. Healthcare practitioners

should be aware of the significance of this decision for their patients; the need for the patients to be fully informed of all factors, and be part of a shared decision is key. In addition, the availability of nursing support could be crucial in making such life changing decisions, through provision of advocacy and a holistic perspective.

The magnitude of support for overall well-being evaluated through an holistic lens cannot be underestimated. The ethos of the NHS is captured in the NHS Constitution (NHS 2011a). It is based on three founding principles: that it should meet the needs of everyone, be free at the point of delivery and that the service should be based on clinical need and not on the ability of the individual accessing the service to pay. Based on the findings of this study, however, the NHS constitution has failed to deliver on a number of the principles. Significantly, there is limited evidence of, or reference to, the well-being support available to the HMT population. Mental health care was only briefly mentioned by two participants and was conspicuous in its absence from the majority of interviews. This highlights a deficit in the holistic care of the study population. Physical wellbeing and mental health problems are thus not treated equally, with an erosion of social duty specifically of nursing care, to promote equal access to services, due to paternalism, discrimination and stereotyping.

8.2.5 Paternalism, Discrimination and Stereotyping

Paternalism on the part of staff and family carers was visible, and reduced the iQoL of patients, who were excluded from decision making and therefore lacked control. Discrimination and stereotyping, in direct contradiction to the Equality Act 2010, were clearly evident, in the form of paternalism and lack of involvement, or through lack of access to physical environments or opportunities. All of this limited iQoL, although some participants saw the introduction of ventilation as positive. There was a genuine acceptance that with disability would come some form of discrimination, and that society's view of disability was sometimes critical and segregating. The sample included a broad cross-section of conditions and illnesses, and demographic factors, therefore presented a breadth of presentation of disability. Discourses around attitudes towards visible physical disability differences, however, were similar and negative. Participants were able to narrate their experience of judgemental attitudes and discrimination, which contrasts with the findings of Roberts et al. (2017), who report that attitudes to visible differences were less negative, and

related to a lack of understanding of how to behave towards an individual with a disability. It was discomforting to hear that nurses were responsible for some of the discriminatory attitudes experienced. The continued negative attitudes towards, and discrimination and stigmatisation of disabled individuals, as identified of HMV individuals, impacts wellbeing and iQoL.

Most participants demonstrated a propensity to adapt to their changing situations, through acceptance over a number of years of being increasingly disabled and passively or actively resisting the changes imposed by CHC, or finding acceptance through faith or religion. This reflects the response shift as previously discussed. The power of prayer and faith was used to reclaim individual quality of life, despite the tension between the HMV individuals and how provision, or religious representative's care influenced its practice. This impacted on iQoL. The discourse of respect for others' faith is highlighted, and education to deepen understanding of how this impacts on individuals would raise the profile of the discourse. Similarly, if the discourse around faith was promoted then an increase in education may result in societal changes to attitudes and respect.

8.3 Being Normal

Normalcy and being normal can be viewed through different lenses; those of the disabled individual and of society in general. The participants strove to fit into the social structures that society imposes (Deatrick et al. 1999; Morse et al. 2000). Imposed beliefs and values required HMV participants to conform to the social norms of society. At home they were treated as 'normal' individuals, only to be confronted with different views, prejudice and discrimination and viewed as disabled in the 'outside' world. The participant's experiences outside of their homes described discourses of paternalism, discrimination and stereotyping. However, inside the home, when viewed as 'normal', participants had defined roles as part of the family, increasing their iQoL and offering them a positive function in the lives of their family. HMV individuals struggled to create a 'normal' life, where they did not have to 'fit in' to society and healthcare demands. Despite their disabilities, families tried to create routine that normalised the situation, equating with the findings of Deatrick et al (1999). A reductionist approach to normalcy or 'being normal', in breaking down the attributes of being normal was reflected in the study; by defining the components of what is

normal however moves away from the subjectivity and holistic view of the topic to a more objective approach, echoing the medical model of care. This effects a paternalistic style of care management that influenced the iQoL of participants.

The participants compared their physical appearance, opportunities and abilities to those of others in society, with a shift of views to accommodate their disabilities and appearances, emphasising their similarities and not differences, to enable social integration and normalisation (Robinson 1993). Attitudes of participants towards their disability was expressed as an overall feeling of loss; of a life imagined, of psychomotor skills and abilities, and of the pleasure that they drew from socialising. This compares with evidence of negative implicit attitudes in wheelchair users towards self, and positive explicit attitudes towards other disabled persons (Galli et al 2015). However, it was not possible to evaluate the participant's explicit attitudes toward other HMV individuals and disabled persons. Further study of attitudes of HMV individuals towards one another and the influence of discourse and social structures is suggested. This may reveal further hidden discourses of the perception of disability of individuals who are HMV.

The study found that extrinsic factors influenced the confidence and attitudes of participants; it hindered their iQoL. Discrimination and prejudice were reflected in participant's statements around body image, of how society should not be exposed to home mechanically ventilated individuals, and that disability did not entitle HMV individuals to partake in 'normal' aspects of life such as intimate and sexual relationships. Social media increases the definition of differences, and through its focus on physical appearance has negative effects (Hamlet and Harcourt 2015; Rumsey and Harcourt 2005). Disability was viewed as the main characteristic of the participant, as exposed by Buljevac et al (2012). Evidence of discrimination on a larger scale was apparent through limitations imposed on access to sporting venues. Greater exposure of society to those with disabilities would encourage a better understanding of the subjectivity of 'being normal' and enable a greater iQoL for the HMV individuals. Integration and education are key, beginning at the start of life for all of society, for both able bodied and disabled individuals.

Reframing perspectives to accommodate social norms and the medical model of disability was apparent. The application of the social model of disability would reverse this reframing, requiring society to do likewise, drawing on the normalisation principles proposed by Nirje (1970) and developed by Wolfensburger (2011). The struggles to realise integration offer insight into how the views of society control and affect iQoL for these individuals. The experiences of one participant in their communication with a sexual healthcare worker clearly evidences discrimination, impacting on iQoL. Despite legislation, integration and provision of comparable situations and patterns of living, appropriate care was not offered to the participant. This conflicts with the philosophy of nursing as a holistic view of the participant as an individual was not visible in the uncovered discourse.

The medical model of disability is evident in the delivery and underlying healthcare policies and ideologies relating to disability and the HMV population. In attempting to normalise the individual - attempting to 'fix' them - the medical model directly contrasts to the social model of disability, where the onus is on society to adapt. It also conflicts with the view of nursing, where individuals are accepted and supported to maximise their health, abilities and contributions to their own health, wellbeing, and society. This should enable individuals to maximise their iQoL. The reality of the HMV population is generated by the individual themselves; disability is part of their everyday life. Normality and reality for HMV individuals includes their equipment; their need for and dependency on ventilation is absolute. Should their normality be dictated by or seen as normal for their disability, as opposed to being compared to that of able bodied individuals? Participant 2 attempted to integrate into society through their work for charitable organisations. However, the participant was restricted by their physical ability to 'keep up' with able bodied individuals. Whether Participant 2's motivation was purely altruistic, or whether their motivation was to promote their own situation, or both, is open to debate. However, Participant 2's self-confidence and iQoL was boosted by the motivation to be wanted and a part of a community. Well-being is evidenced as being linked to job satisfaction, providing that organisations are supportive (Perez et al. 2015).

Participant 4 also recognised that their physical disability and need for ventilation restricted their wish (want) to socialise and integrate into society, recognising the financial

implications of care that “special needs” requires **(P51 L13)**. Changes to social perceptions of disability would require adaptation of environments alongside the much more difficult and greater work of changing attitudes towards disability. Individuals with visible disabilities are discriminated against (Roberts 2014), reflecting the experiences of some of the HMV population through exposure to judgemental attitudes of the general public as well as healthcare staff. Despite the creation and enactment of the Equality Act 2010, the enormity of the task of changing society’s attitude towards disability is clear. The social model of disability promotes such change but will, like all change, take time. I return to the biomedical approach and model of disability, and its focus on and attempt to fix the disability and thus normalise the disabled individual. Care of these individuals is perceived as being under medical control, and the view that disabled individuals are passive recipients of care contradicts the possibility for individuals to live independently. There needs to be a greater nursing voice within the discourse, to promote individuals’ wishes, and maximise individual quality of life. However, to enable this, there is a need to explore the view of the registered nursing workforce on the direction of care. Whether care reduces the empowerment of disabled individuals as a therefore highly political and socially constructed concept, is debatable (Gibson et al. 2009).

8.3.1 Sport

The iQoL of HMV individuals who enjoy sport was supported by inclusivity as promoted by the Equality Act 2010, and was empowering for participants, although control of the degree of integration was visible; for example, in the number of tickets available for disabled individuals. There is a contradiction in society and politics: the idea that disabled individuals be included in all aspects of society is championed, while there are factors that limit this. The power of sport to make participants feel included and a part of social spheres was clear, empowering and encouraging autonomy (Dreyer et al. 2010a; Hirano et al. 2006; Gelinias et al. 1998). This bolstered participant and carer iQoL, and was used as a coping mechanism in dealing with the social reality of HMV. For the participants who voiced their love of sport, their individual SEIQoL-DW scores were high; a tentative conclusion drawn is that sport played a part in this, as both participants recorded sport as specific cues. The higher SEIQoL-DW scores were recorded despite a continued deterioration in their physical condition, and poor prognosis resultant from their degenerative illness.

8.3.2 Relationships

Discourses around and struggles with and about intimate relationships and partners, children and families resonated with several participants. Tensions between services and within families were exposed, with the broader discourse of class and financial security demonstrating how finance hindered iQoL. There was a general recognition that lack of power was influenced by the participant's financial situations, although resistance on a personal level was evident. Current political influence on finance is unlikely to change the situation, and so finance will remain a disabler of iQoL for this population, unless discourse alters the landscape. Current changes towards different methods of awarding (and naming) disability allowance has further complicated a contentious issue that highlights the strata within society. Social schema are drawn from reference to social class, and poverty, particularly amongst the population studied was an issue (Joseph Rowntree Foundation 2015).

All participants identified financial pressures, which were both hidden and visible. The micro influences of the meso and macro decisions around funding and benefits were visible, as limited monies curtailed the expression of the 'wants' of the participants. Independence to travel, as a distinct 'want' of participants, be it for one night or a longer holiday were linked at a micro level to a lack of monies. The reliance on services and relationships with care staff did not extend to overnight stay or trips out to dinner; thus the freedom that personal relationships embraced had offered participants a glimpse of normality and greater social integration. A lack of a personal, intimate relationship had changed the world view and perspective of one participant in particular, although they had reconceptualised their role within their own family. Reconceptualisation had resulted in the participant offering less of a physical influence, and more mental and emotional guidance and support. Nevertheless, the participant was aware of the pressure exerted on their family in attempting to maintain a social life for the participant and also as a family. This compares to another individual who verbalised a reconceptualisation in their position when part of a couple. A greater level of freedom resulted from being part of a couple, and individual QoL was improved as freedom widened the participant's social life.

Further complications, in smaller scale tensions within families were revealed by all, identifying dysfunction and paternalism, and how ventilation influenced the wider family experience and quality of life. Norms and roles were affected by the individual's disability rather than the initiation of ventilation, with families having to adjust their social lives which therefore affected their own, broader iQoL, as a result of the participant's condition. Evidence suggests that carers often feel responsible for all elements of care (Plank et al. 2012), and that the carer role is only one of several that each and every individual occupies (Fairclough 2015). Nevertheless, social expectations in terms of family roles were superseded by roles that met the physical and emotional care requirements of participants and crossed boundaries of a personal and intimate nature that some found uncomfortable and difficult. Where the roles and responsibilities of the health and social care services end and those of the family begin is ill-defined and can affect the iQoL of patients and carers. This returns to the discourses revolving around commissioning of care and the empowerment of service users. It also emphasises the hidden discourse around the presence and influence of nursing as a profession, and how the remit of nursing is changing. It remains to be seen whether the changes instigated will result in an improved individual quality of life for either the HMV individual or their family carer.

Intimacy was a discourse, both in terms of physical care and sexual relations. Participants referred to how they had adjusted and recognised they would not live a 'normal' life, marrying and having children. One participant recognised the change to their situation that came with the intimacy of a personal and sexual relationship. Here, the care differed and restrictions that came with the need for and dependency on continuing care staff became dispensable; exploding the evidence that relationships increase iQoL (Dreyer et al. 2010a). The participant in this study, through their intimate relationship, challenged the social norms, system and structure by struggling against discrimination to ensure their sexual health and promote their individual quality of life. The discourse of the effect of physical care on dignity and respect, and learning to adapt to and live within physical limitations was another feature of discourses involving relationships. Reliance on others to carry out fundamental care changed the view of participants; it created a dependency and relied on trust as evidenced by Schaepe and Ewers (2017), Lindahl (2010), Ballangrud et al. (2009). Trust is a fundamental element of the profession of nursing. A positive and reciprocal

relationship with carers enabled trust and rapport to be developed. However, with the changes to carer teams, this trust had been eroded. Policy needs to reflect the individual in amongst the changes that are being made and recommended; the participants' and also nursing's voice is key to challenging the discourse and changing practice to ensure a high quality service is delivered to safeguard iQoL.

The above provides discussion on the discourses identified in the study, across the broad categories of Seeking Independence and Being Normal. The independently identified cues offer insight into the explicit and hidden discourses that influence the iQoL of HMV individuals both positively and negatively. The importance of individual 'wants' and 'needs' have been emphasised, along with the response shift and reconceptualisation of some of the participant's perceptions of their iQoL. It identifies similarities in cues across the HMV population, and in the challenges that they face at a situational and personal level from changes instigated by health institutions through the appraisal of and implementation of policies. Recommendations are drawn below. Firstly however, the methodological, conceptual and practical issues are presented.

8.4 Methodological Contribution: Application of CDA

The research makes an innovative methodological contribution by applying CDA to the qualitative exploration of the iQoL of HMV patients. This study highlights the potential contribution of CDA in an area outside the traditional foci of gender and identity. The potential of CDA for exploring iQoL is considerable, as it enables the identification of visible and hidden discourses that affect individuals receiving health and social care within a financially limited and politically driven system.

8.5 Conceptual, Methodological and Practical Limitations

8.5.1 Assumptions

On reflecting on the assumptions compiled at the beginning of the study, I now return to discuss these in light of the findings. One assumption was that a biomedical and reductionist model of care existed in this context. This was evidenced by the findings, substantiated by

the changes to care funding and commissioning, reducing the care delivered to a series of tasks as opposed to viewing the individual's care holistically.

The research questions revealed the assumption that HMV as an intervention influences individual quality of life. HMV as an intervention has less impact. Rather, it is the sequelae of and concerns associated with HMV and the participant's condition that impact iQoL. Having stated this, it is important to remember that some participants saw ventilation in either a positive or negative light, but all were accepting of the need for ventilation.

I assumed that iQoL would include broader concerns than only HRQoL. This proved true, with only two participants identifying health-related issues as cues. There was also a methodological assumption that the flexible design used to collect the data recognised the context-bound nature of iQoL. The data did reveal individual concerns, defending the assumption. A further assumption was that quantitative, statistical research is sufficient upon which to base social and political change. However, in conducting a qualitative study, individual experiences and QoL were clearly not reflected by quantitative data. Such data fails to capture the complex issues HMV and disabled individuals face.

8.5.2 Limitations

This small sample study was designed qualitatively to explore the iQoL of HMV individuals in Wales. As such, the study was not designed to represent the quality of life of those with other disabilities, or to be compared with quantitative evidence on HMV. There may be some transferability and generalisability to similar populations across the UK. However, variants of HMV and the health and social care and support operate across the UK. Wider aspects of practice and progress have not been considered in this thesis.

In terms of the reliability and validity of the interviews, I had limited the interview time to a maximum of 120 minutes to ensure participants did not tire and that their focus was maintained. Only one interviewee required a second interview, owing to tiredness. Their views on iQoL may have changed during the elapsed time, influencing the findings, as the study was cross-sectional, capturing the views of participants at one point in time. The same participant had 'Locked-In' syndrome, and therefore I had to learn how to communicate,

and identify the body language (blinks and shrugs) that feature in her communication strategy. The participant also took time to formulate her responses and communicate these through a communication board. This was exhausting for both the participant and me, and I am fully aware that I may have missed nuances and discourses here. A potential further criticism is the length time that it took to arrange and conduct all participant interviews. As the study measured iQoL, it is difficult to compare and contrast the quality of life of one individual against another. The study measured iQoL at one specific point in time, and not longitudinally; this identifies further potential research, to monitor iQoL over time, however the difficulties inherent in this should be recognised.

The study population was physically disabled, with few able to write and hold a pen, requiring a carer or advocate to respond on their behalf. During data collection, it was necessary to manually adjust the data collection tool. This involved my carrying out the manipulation of the tool on their behalf, and amounts to a limitation of the study. The participants' meaning in relation to the cues chosen was checked and confirmed, as were their scores on the tool, but the limitation should be considered when reviewing the study findings and transferability.

CDA allowed me to apply my own thoughts, feelings and beliefs to the analysis (MR in interpreting findings (Fairclough 2015)). This, too, might have influenced the findings. Condensing the findings for the purposes of the thesis also has implications, in that only a section of the actual findings has been reported.

The study sought to respect participants and their carers, and remain sensitive to the difficulties and challenges HMV individuals face. Upholding this professional and ethical principle, contact was not sought from HMV individuals who did not respond to the invitation to participate. Likewise, participants were not pressured to discuss aspects of their lives or quality of life and experiences they found upsetting. In so doing, it is possible that an incomplete picture of iQoL is presented. Despite these limitations, the study findings will be of relevance to a wide range of readers, including clinicians, health and social care commissioners, academics and policy makers.

8.5.3 SEIQoL-DW

As it is associated with the psychological processes approach to the evaluation of quality of life, SEIQoL-DW (O'Boyle et al. 1993b) was an appropriate choice of data collection tool. SEIQoL-DW offers a means of comparing the individual's current attitudes against their perceptions of and evaluation of ideas, opinions, thoughts and beliefs. The individual participants were required to sift and sort these ideas and opinions during the interview. Having completed this element, the participants then evaluated their ideas, and compared these to their current views. The weighting of these views and ideas were then positioned on an attitude scale (Griffin 2012).

SEIQoL-DW as a PROM and data collection tool was effective in capturing the views of the HMV participants. It offered a mechanism to capture both qualitative and quantitative data that enabled a broad picture of the participant's worldviews to be described and analysed. It enabled identification of and discussion around the exposed discourses of that stemmed from the participants' individual wants and needs. Farquhar et al. (2010) argue that SEIQoL-DW is reductionist in only allowing participants to identify 5 cues as opposed to a more comprehensive catalogue of factors that affect their quality of life. This argument was challenged in this study, as participants did not identify more than 5 cues, despite suggestions being offered to the participants, as advocated by O'Boyle et al (1993a). A contra-argument could be raised in that as the participants had possibly not previously considered their own iQoL, then they would not be able to generate possible cues. However, some participants had clear views of the factors both positive and negative, which influenced their iQoL.

The physical manipulation of the tool itself resulted in difficulties; none of the individuals were physically able to handle the tool. This resulted in the disk being manipulated by me as the researcher, and offering it back to the participants to member-check and validate their views. This worked well, with participants for the most part holding strong views as to the importance of the cues in relation to one another. These views and measurements (percentages) offered further insight into the complexity of iQoL, and its influences, when balanced against the narrative. Some conflict in opinion was noted however, the overall tool

offered a mechanism to gather a richness of data through the description and discussion of the factors that influenced iQoL.

SEIQoL-DW can be used as a patient reported outcome measure tool (PROM) for iQoL for the HMV population, as it is generic in nature. SEIQoL-DW could be used to replicate the study, and to pursue a longitudinal study to explore the response shift of the individuals. It would offer insight into the changes to recalibration, reprioritisation and reconceptualization of the HMV individuals over time. It presents an opportunity to use a tool that offers some quantitative insight, alongside a greater level of focus on the qualitative issues that influence the individual quality of life of HMV individuals.

8.6 Summary of Chapter

The chapter considers and debates the impact of HMV on iQoL. The sequelae of HMV and the underlying condition requiring HMV emerge as the main limiting factors for participants. HMV individuals maintain and boost their iQoL via numerous avenues, including faith and religion, socialising and education. The literature on disability can be applied to the discussion of the HMV population: the physical ability of most of the participants was in decline, but mechanical ventilation stabilised their respiratory system status. Recognising how HMV had alleviated or impeded the march of their deteriorating respiratory condition was part of accepting a new normality for these individuals.

Numerous discourses identified facilitated or hindered the iQoL of this specific population: equality, independence/dependence including shared decision making, social norms and roles, and integrated and new models of care delivery. However, there is a need to look beyond HMV to the broader context and structures such as social class, poverty and education to identify the influences and discourses that affect HMV individuals. The broader context of disability and ability, and the dominant discourse of equality, are clearly visible in the study findings. Interestingly, reproduction of the discourses at this situational and personal level did not result in recognition of the struggles faced or changes, however pockets of resistance to the discourse at a personal level were found. Ideological principles of the health service were not met in relation to HMV individuals, and changes are required

to attitudes across society and in health and social care, to better serve the HMV population.

CHAPTER NINE

9.1 Summary of the Study

As the final chapter of my thesis, I present a summary of the overall findings of the research. In order to explore the individual quality of life of home mechanically ventilated adults, this study considered the impact of HMV on iQoL; what practices HMV patients use to sustain and enhance iQoL and which factors facilitate and hinder iQoL. This chapter draws together the findings, offering recommendations and suggestions for enhancing the iQoL of HMV individuals.

The research questions were answered as follows:

What is the impact of HMV on their iQoL?

For the most part, composite factors impacted on iQoL. As previously indicated, the impact of HMV is individual to each participant, and scores differed across the sample. As a result, the influence of a response shift cannot be discounted. Within their responses, the majority of participants do not refer to ventilation per se as affecting their individual quality of life, and health was only referred to directly by 2 participants. It is the sequelae of the individual conditions and HMV that affects the iQoL of participants and how their condition influenced their iQoL due to requiring a greater level of support, be it physical care or financial assistance.

The initial cues identified by the participants were clustered into 6 distinct groups and reflected the individual factors that impacted on the individual's quality of life. The range of cues were broad, and the labels assigned to the groups offer an interpretation of the findings and discourses that they revealed. The groups included family/ relationships; health; conceptual factors; social life; equipment/ finance; and religion. The breadth of cues identified offered insight into the individuals' views of their QoL, their individual 'wants' and 'needs', and how, if at all, HMV impacted on their iQoL. Technology in the form of ventilation enabled life, which for some was viewed negatively however for others, HMV was a positive element to their life, which empowered other aspects of their lives.

However, the impact of HMV on iQoL was for some, negative. Participants noted a loss of their previous life and skills, and linked this to the commencement of and use of HMV.

Participants who linked the commencement of HMV with a deterioration in iQoL clearly saw an increased dependency on HMV as a marker that their physical (and for some, their mental) health was deteriorating. Their 'needs' were prioritised above their 'wants', influencing their iQoL. However, others viewed HMV as positive, enabling participants to re-engage with their social lives and maintain contact with family. HMV enabled participants to integrate with society and re-establish friendships, offering a mechanism to overcome feelings of being 'in prison'; it helped them 'escape'. It offered some participant's longevity of life, and for one, enabled them to offer their family a form of emotional support. Changes to societal views that surround disability and a move towards adopting a holistic nursing approach, and a social model of disability may enhance the experience of HMV individuals and consequently, their individual quality of life.

What practices do HMV individuals use to sustain and enhance iQoL?

To enhance their individual quality of life, numerous strategies were used. The practices and strategies invariably were reliant on carers/ families to enable the participants to achieve and enhance their iQoL. A level of interdependence was therefore evident. The practices included, but were not limited to the following: socialising; involving and being involved with their family; personal relationships, partners and marriage; being present in sport as a spectator; the use of technology and equipment to widen their worlds; maintaining their independence mainly through decision making; using their knowledge of social and healthcare systems to achieve the outcomes they had established and set for themselves; music; spirituality or religion; recognising the comfort of their home; education; and reliance on carers/ nursing staff. Participants, in reflecting on their situation, recognised their own limitations, and altered their lifestyle to retain a level of quality of life.

A consistent strategy for most participants was being involved with and involving their families in their lives. This extended to nurses and care staff in some cases. This offered participants a way to socialise in addition to meeting their 'wants' as well as their 'needs'. Family members/ carers offered physical as well as emotional support, and enabled a wider social circle; they were more adept in recognising the participants' physical needs and concerns. There was an element of 'knowing' the participant by the carer family member, facilitating a faster response and demonstrating a more attuned ability in recognising

distress, anxiety or disquiet. Family and carers were engaged to support participants, who needed support to resist imposed changes, renew and maintain relationships with friends, and re-establish social lives. This influenced the iQoL of participants.

Socialising was also a recurring cue, with numerous intertextual discourses revealed. Sport was used to broaden social inclusion and to 'escape' the home. Being a spectator of sport enabled a more equal standing between disabled participants and those in society who are able bodied. Participants described how sport gave rise to passion and emotional responses, increasing their iQoL. Technology made socialising and participation in sporting events possible, with electric wheelchairs being key to mobility and independence for the participants. More widely, technology influenced iQoL positively, through its use in education, and connecting individuals through social media. Socialisation was also intertextually related with music and religion/ spirituality. Religion/ spirituality despite being linked to a loss of socialisation for one participant, still offered comfort and was used to influence iQoL positively.

Decision making as a strategy to retain control was a focus for many. Participants perceived a continued independence through retaining decision making capacity, and dependent on whether it was retained or lost, influenced iQoL positively or negatively. Decision making by the healthboards and clinicians was questioned by some participants. A deep-rooted understanding of the healthcare system offered some participants a means of influencing decision making related to their care and treatment. This impacted on their iQoL, as they realised control over the situation.

Recognition of and tailoring of services to meet individual requirements would benefit those who are home mechanically ventilated. Returning to an holistic (nursing) model of care would empower participants, offering a method of recognising their individual 'wants'. This is a change that needs to occur at a situational, individual level, driven by nursing as a profession at a meso level. Changes to the philosophy of care would require the influence of nursing as a profession. Improved education and training of staff to better understand cultural and individual requirements and needs, along with the recognition of wants would result in greater equality for this population. The subjective experience of H MV individuals

needs to be recognised; use of PROM's would facilitate this. The use of a PROM such as SEIQoL-DW that captures the iQoL of HMV individuals is therefore necessary. HMV individuals should be encouraged to share their views and thus actively partake in the reproduction of text and discourse as continued reproduction and exposure should enable change, enhancing the iQoL of individuals.

In the discourses surrounding iQoL, what facilitates and hinders iQoL?

Facilitative and hindering influences (and discourses) are intrinsically linked to the strategies that HMV individuals use to enrich their quality of life. The dominant discourse revealed that should facilitate iQoL was that of equality. However, further hidden discourses of ability and disability, empowerment and advocacy and identity alongside the ideologies and beliefs of the participants and of society were visible influencers of iQoL. Factors identifiable within these discourses that facilitated and hindered iQoL were numerous, some stemmed from hierarchical sources at societal and governmental levels, which were then enacted at a meso or institutional level. The discourses, such as inclusion in sport and changes to staffing, affected the individual and situational quality of life of participants both positively and negatively.

However, there were other situational, individual factors and hidden discourses that influenced iQoL. A common facilitator of iQoL was the ability to socialise and retain a social life. This originate from an acceptance and ability to integrate within society, and to have the infrastructure in place to enable the individual to do this. There was a reliance on carers to enable the HMV individual to socialise, and to achieve the 'wants' of the participants; in tandem, there was a reliance on services to support the individual through either financial support or provision of care. Both facilitated or were perceived as hindering the iQoL of HMV individuals. Thus family life and relationships, and social life are inextricably linked when exploring iQoL for the HMV population.

The discourses that surround conceptual factors such as freedom and independence were found to be linked to iQoL. The enabling of choices and decision making, and promotion of interdependence offered another means of facilitating iQoL. However, freedom for most

participants was perceived as lost due to their condition and the sequelae of HMV. This draws on the discourses of joint commissioning, and the reliance of the participants on social and health care, influencing their iQoL. Broader financial factors, through needing increased amounts of money to offset the cost of travel hindered iQoL, although participants were reconciled to this. Other disablers of iQoL were the financially driven policies, laws and governance that controlled the inclusion and equal treatment of HMV individuals, and complex intertextual discourses reveal the multiplicity of social norms and rules that govern life.

A lack of holistic care, evidenced through the hidden discourse of nursing care, and highlighted by numerous participants, hindered iQoL. Drawing on the need for improved communication, a lack of attention to individual participant 'wants' was found to hinder iQoL; a greater level of attention to individual 'wants', through the application of a more holistic approach would further facilitate iQoL. Improved communication had the potential to empower HMV individuals and reduce resistance to change, reflecting the current discourses of new models of care. Involvement includes listening and hearing the voice of the participants, and encouraging and engaging them in discussion of policy and guidance changes led by government at macro level. Thus, more local changes implemented by health and social services, could be influenced and would consequently influence a change in discourse.

Religion as a cue offered insight into how exposed and hidden discourses of how intrinsically linked religion is to socialising and integration. It offered a means to facilitate and also to hinder iQoL, viewed from differing perspectives, in one instance by the same individual. The emotional adjustment alongside the physical adjustment to HMV was not recognised, hindering iQoL. A lack of recognised emotional and mental health support was identified by its absence. Services should recognise the particular needs of this population and offer support which may further improve communication and the overall individual quality of life of HMV individuals.

Critical Discourse Analysis was chosen as an appropriate theoretical and methodological approach, underpinned by the ontological and epistemological positioning of a critical

realist approach. CDA has enabled the exposition of discourses, both hidden and visible, through describing, interpreting and explaining representations and the formation of relationships, processes and structures that affect iQoL. The interview format was that of semi-structured interviews, of a purposive sample of HMV individuals across Wales. A major challenge was the recruitment of individuals; the final sample was smaller than initially expected. On reflection however, the data collected and analysed was rich and any further recruitment may have resulted in a more superficial level of analysis. The participant's contribution varied, due to their conditions; all data is however valuable and a strength of the study is that it included HMV individuals who do not communicate with ease. It offered a voice to those who may feel unheard.

With ever increasing developments in medicine, care and technology, this research sits at the crest of and develops the dialogue of growing research into the iQoL and well-being of individuals who are chronically ill, specifically those who are HMV. This study aims to contribute understanding of the needs of HMV patients, and exposes a need to understand the needs of their carers. The study has hopefully exposed both visible and hidden discourses and will encourage debate around these, to further inform policy and enrich the iQoL and well-being of HMV individuals. There may also be transferability of some of the implications to the wider disabled populations.

9.2 Practical Application

The research aimed to set the stage following exposition of the discourses that surround iQoL and well-being for further discussion, and to enhance the understanding of service providers and policy makers, to consider the consequences, unintended or otherwise, of the dominant and dominated discourses. However, regardless of practical applications, the findings emphasise how government policy contradicts the reality for patients, furthering awareness of HMV individuals and those who are chronically ill. By exposing such discourses, the reality of these individuals can be discussed, discourses challenged, and social and individual change effected.

9.3 Recommendations and Future Research

- The study has identified that there are no specific Patient Reported Outcome Measures for the iQoL and well-being of HMV individuals. However, SEIQoL-DW has proved effective as a PROM, and could be used in future research of the HMV population, and the wider population with chronic illnesses. This could be used to inform the development of (Welsh) government frameworks that accurately capture the essence of iQoL and well-being of individuals with chronic illness. This would enable evidence unique to HMV and not only data that is disease or system specific, to be developed to inform the Critical Care Delivery Plan and more widely applied across chronic illness pathways and plans;
- In tandem with the above recommendation, to focus on the individual wants and needs of HMV individuals, using SEIQoL-DW as a PROM. This could expose differing discourses to inform on how policy development and its implementation ultimately effects the iQoL at a situational level;
- To address disparities in and limited opportunities of HMV individuals, an exploration of the impact that attitudes toward HMV individuals is needed, to inform strategic and targeted intervention approaches;
- To refocus on applying a more holistic nursing approach to the care of HMV individuals, encouraging a professional culture based on the influence of a social model of disability to incorporate HMV individuals, to focus on the capabilities of individuals who are HMV as opposed to their inabilities;
- To explore the mental as well as physical issues faced by HMV individuals and their carers, as this was less visible in participant responses;
- Recognising the needs of HMV individuals also exposes carer needs. Consistent with the increased focus on unpaid carers in the UK, further research on the specific HMV carer population, both paid and unpaid is required, to fully understand the needs of carers of those with HMV;
- Service commissioner perspectives in light of developments in joint commissioning and the delivery of social and health care need to be explored, to inform services and explain to HMV individuals the rationale for changes to services;

- The experiences and views of the medical teams involved in the care of HMV individuals should be explored, to add to the knowledge base and assist with the development of policies and services;
- A longitudinal study should be conducted, to capture the views of HMV participants over time and document changes in their perception of iQoL over time.

9.4 Reflection

The process and journey of reaching this point, as with most PhDs I know of, has been eventful. Every journey is different and I reflect on mine and value what I have learned. I have glimpsed healthcare from a myriad different perspectives, and particularly through the participants' eyes. I cannot truly say I understand all of these views, as I have not experienced life through their eyes. However, I have attempted to understand and respect the different positions, opinions and perspectives. It has enabled me to, using a phrase from the body of work itself, reconceptualise how I view quality of life, and indeed individual quality of life. This has enabled me to grow and learn as an academic, recognising my mind-set, my position as a nurse and a clinician, as a tutor, daughter, sister and aunt.

At the start of the PhD, I had personal and professional experience of healthcare services, from a patient perspective. However, this broadened unintentionally as a result of physically sitting in the same position in my 'free' time as well as work time, which resulted in increased back problems necessitating investigation. The overwhelming panic I felt on being fed through the MRI scanner was a shock. I am not the type of person to panic, as I usually just get on with whatever is at hand. However, having been 'talked down' by the expert radiographers and reassured that I was not the only one who felt claustrophobic taught me a valuable lesson; what it feels like to have things 'done' to me and things being outside my control. This made me recognise the degree of control I have over whatever many aspects of my life, to complete things, and how I then compared this to the participants who had kindly let me into their lives and the limitations that I interpret of their situation. I also compared this to the matter at hand: my thesis. The control I have exerted over its completion has had varying degrees of success.

Adding further complications, as a daughter, I had the previous experience of being a relative when critical illness struck. The situation reared its head again with my mother becoming increasingly disabled and ill, with a diagnosis of cancer given as an incidental finding from a CT scan. The trauma of a cancer diagnosis and the ramifications of an inoperable tumour weighed heavily. Both parents required increasing support. In terms of the diagnosis and innumerable hospital visits, treatment and missed referral targets, communication was extremely poor between the surgical team, my mother as a patient and us a family. The importance of clear and unambiguous communication resonated when carrying out the interviews and in writing the thesis, adding a personal perspective.

My coping strategy with all such situations is to work: to fall headlong into whatever is thrown at me. This I did, and what followed was several years of long trips to keep my parents afloat. The balance between work, study and downtime became increasingly blurred. It has only been during the past year, as my mother's condition has stabilised and both my parents' health worries have calmed somewhat, that I feel more in control, and able to complete this journey.

My understanding of peoples' difficulties has altered. I further appreciate that a small issue can be enormous in someone else's world, depending on whatever else is going on, and that there are usually numerous concerns. Objectivity in terms of just getting the job done was hampered by my emotional fragility. Nevertheless, I have used criticism and experience constructively and wisely, engaging and responding, I hope, to other's needs and concerns positively and with full support.

I have also learned from and about the research process. I am more realistic about how research ambitions and how objectives translate into achievements. Compromise in terms of what I set out to achieve has been difficult, and the challenges that were faced have taught me much. Initially wanting to produce a mixed methods study, a compromise was necessary: the data collection tool and method did offer both qualitative and quantitative measurement, however it became apparent that the qualitative evidence was extensive and that with such a small sample, the quantitative data did not allow comparison. In itself, comparison would have been difficult, as measuring individual quality of life is so subjective. The data revealed a large social influence, which dictated the analysis. The influences of

power and control integral to CDA were applied as power and control are apparent in the text. The focus is on how appreciation of discourses that reveal structure, agency and resistance and the differing approaches towards disability could improve iQoL.

The pilot study resulted in a deepening of understanding of what lone working can entail, and experiences that researchers are sometimes subjected to. My own morals and nursing experience have taught me to respect individuals and ensure that dignity is preserved. However, it did not occur to me that I would be met with individual attitudes that did not correspond with my own standards of practice. This particularly resonated as the individual involved was from the same profession! The recognition that persons who offer their support bring their individual agendas to the table, rather than acting from an altruistic standpoint opened my eyes to how research can be influenced.

My learning encompasses a greater understanding of the influences that I bring to the research: my own MR. I have become increasingly aware of this over the course of the journey and writing the thesis. The nature of my relationship with the participants, and a greater appreciation of the differences in relationships and roles, from nurse, to nurse lecturer to researcher, has been a large part of my learning. I am very grateful to the participants and their carers. Their time and honesty in sharing their views opened a wider window into their lives; how they view health and social care services, the intrusions inflicted by the services they need to live as independently as possible, and how they just get on with their lives. It was a luxury to spend time with them and explore their views fully; this is something that healthcare practitioners rarely have time for. I greatly appreciate my own life and have much respect for all who live with the burden of chronic disease, my parents included. Translating the findings into information, guidance and recommendations for clinicians, policy makers and academics was challenging but extremely valuable.

To conclude, in terms of reality, norms and beliefs, I have returned to the reason and 'place' I entered nursing in the first place – to listen and make a difference, be it to even one rather than many lives.

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APPENDICES

Appendix 1 OVID EMCARE/ NICE/ BNI/ Scopus Searches

OVID EMCARE Database Search 31st July 2018

<input type="checkbox"/> 45 from 41 keep 37, 55, 140, 165, 201, 278...	8	Advanced	Display Results More
<input type="checkbox"/> 44 from 38 keep 32, 46	2	Advanced	Display Results More
<input type="checkbox"/> 43 from 30 keep 2	1	Advanced	Display Results More
<input type="checkbox"/> 42 6 and 8 and 10 and 12 and 18	67	Advanced	Display Results More
<input type="checkbox"/> 41 17 and 26	372	Advanced	Display Results More
<input type="checkbox"/> 40 26 and 30	0	Advanced	Save More
<input type="checkbox"/> 39 24 and 25 and 26 and 30	0	Advanced	Save

					More
					Display Results
<input type="checkbox"/> 38 28 and 33	51	Advanced			More
					Save
<input type="checkbox"/> 37 30 and 33	0	Advanced			More
					Save
<input type="checkbox"/> 36 30 and 33 and 34	0	Advanced			More
					Save
<input type="checkbox"/> 35 25 and 26 and 28 and 29 and 30 and 33 and 34	0	Advanced			More
					Display Results
<input type="checkbox"/> 34 experience/ or personal experience/	29005	Advanced			More
					Display Results
<input type="checkbox"/> 33 duchenne muscular dystrophy.mp. or Duchenne muscular dystrophy/	2142	Advanced			More
					Display Results
<input type="checkbox"/> 32 dependency.mp.	11758	Advanced			More

<input type="checkbox"/>	31 assisted ventilation.mp. or assisted ventilation/	6356	Advanced	Display Results More
<input type="checkbox"/>	30 (user satisfaction and mechanical ventilation).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	3	Advanced	Display Results More
<input type="checkbox"/>	29 patient/ or human/ or qualitative research/	3982905	Advanced	Display Results More
<input type="checkbox"/>	28 decision making.mp. or decision making/	149003	Advanced	Display Results More
<input type="checkbox"/>	27 human/ or patient/	3975510	Advanced	Display Results More
<input type="checkbox"/>	26 amyotrophic lateral sclerosis.mp. or amyotrophic lateral sclerosis/	5596	Advanced	Display Results More
<input type="checkbox"/>	25 neuromuscular disorders.mp. or neuromuscular disease/	3993	Advanced	Display Results

			More
			Display Results
<input type="checkbox"/> 24 lived experience.mp. or personal experience/	22415	Advanced	More
			Display Results
<input type="checkbox"/> 23 interview/ or human/ or chronic disease/ or qualitative analysis/ or personal experience/ or social support/	3837449	Advanced	More
			Display Results
<input type="checkbox"/> 22 artificial ventilation/ or human/	3792121	Advanced	More
			Display Results
<input type="checkbox"/> 21 observational study/ or rehabilitation patient/ or human/ or artificial ventilation/ or home care/ or breathing/	3805600	Advanced	More
			Display Results
<input type="checkbox"/> 20 human/ or artificial ventilation/	3792121	Advanced	More
			Display Results
<input type="checkbox"/> 19 adult/ or human/ or assisted ventilation/ or artificial ventilation/ or long term care/	3876146	Advanced	More

<input type="checkbox"/> 18 adult/ or human/ or assisted ventilation/ or artificial ventilation/ or long term care/	3876146 Advanced Display Results More
<input type="checkbox"/> 17 ventilation.mp.	69946 Advanced Display Results More
<input type="checkbox"/> 16 14 and 15	3 Advanced Display Results More
<input type="checkbox"/> 15 wellness.mp. or wellbeing/	46343 Advanced Display Results More
<input type="checkbox"/> 14 5 and 8 and 12	7 Advanced Display Results More
<input type="checkbox"/> 13 9 and 10 and 11 and 12	0 Advanced Save More
<input type="checkbox"/> 12 well being.mp. or wellbeing/	60222 Advanced Display Results More

<input type="checkbox"/> 11 happiness.mp. or happiness/	5035	Advanced	Display Results More
<input type="checkbox"/> 10 life satisfaction.mp. or life satisfaction/	6976	Advanced	Display Results More
<input type="checkbox"/> 9 7 and 8	256	Advanced	Display Results More
<input type="checkbox"/> 8 quality of life.mp. or "quality of life"/	155637	Advanced	Display Results More
<input type="checkbox"/> 7 5 and 6	14431	Advanced	Display Results More
<input type="checkbox"/> 6 patient/ or artificial ventilation/ or home care/	713995	Advanced	Display Results More
<input type="checkbox"/> 5 1 and 3	15141	Advanced	Display Results

<input type="checkbox"/> 4 limit 3 to (full text and abstracts and human and english language)	9219 Advanced More Display Results
<input type="checkbox"/> 3 mechanical ventilation.mp. or artificial ventilation/	More 44239 Advanced Display Results
<input type="checkbox"/> 2 limit 1 to (full text and human and english language)	More 318311 Advanced Display Results
<input type="checkbox"/> 1 adult/	More 1386212 Advanced Display Results More

NICE website search

Last run on 31st July 2018:

QOL:

1716 results – no filter applied.

Filter applied – guidance = 947 citations

Filter refined – guidance (all boxes checked ✓) = 941 citations

Relevant docs:

- [Community engagement: improving health and wellbeing \(QS148\)](#)
- [Motor neurone disease: assessment and management \(NG42\)](#)
- [Multiple sclerosis \(QS108\)](#)

Wellbeing:

- [Community engagement: improving health and wellbeing and reducing health inequalities \(NG44\)](#)
- [Maintaining health and wellbeing](#)
- [Social and emotional wellbeing tool: beta version](#)
- [Looked-after children and young people \(QS31\)](#)
- [Effectiveness and cost effectiveness:- Are particular components of community engagement approaches more effective and cost effective at improving health and wellbeing and reducing health inequalities than other components?](#)
- [Collaborations and partnerships:- What are the components of collaborations and partnerships between people, local communities \(including community representatives, such as peers\) and organisations that lead to improved health and wellbeing?](#)
- [Housing: planning to improve health and wellbeing](#)

Wellbeing and ventilation – 16 results and none relevant.

British Nursing Index (BNI) search

Last run on 31st July 2018:

Search	Databases	Results	Actions
<input type="checkbox"/> Select item 5	S5 (quality of life) AND (home mechanical ventilation) AND (well being) Limits applied	British Nursing Index	325 Actions
<input type="checkbox"/> Select item 4	S4 (quality of life) AND (home mechanical ventilation) AND (well being) Limits applied	British Nursing Index	626 Actions
<input type="checkbox"/> Select item 3	S3 (quality of life) AND (home mechanical ventilation) AND (well being)	British Nursing Index	709 Actions
<input type="checkbox"/> Select item 2	S2 (quality of life) AND (home mechanical ventilation) AND (well being) Limits applied	British Nursing Index	0 Actions
<input type="checkbox"/> Select item 1	S1 (quality of life) AND (home mechanical ventilation) AND (well being)	British Nursing Index	709 Actions

SCOPUS Search history

Last run on 31st July 2018:

16 (home AND mechanical AND ventilation OR long AND term AND ventilation OR chronic AND ventilation) AND ((individual AND quality AND of AND life AND not AND health AND related AND quality AND of AND life) AND ((quality AND of AND life OR wellbeing OR well AND being OR well-being OR satisfaction) AND (home AND mechanical AND ventilation))) AND (LIMIT-TO (SRCTYPE , "j")) AND (LIMIT-TO (LANGUAGE , "English")) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "NURS")) AND (LIMIT-TO (EXACTKEYWORD , "Human") OR LIMIT-TO (EXACTKEYWORD , "Humans") OR LIMIT-TO (EXACTKEYWORD , "Article") OR LIMIT-TO (EXACTKEYWORD , "Adult") OR LIMIT-TO (EXACTKEYWORD , "Quality Of Life") OR LIMIT-TO (EXACTKEYWORD , "Artificial Ventilation")) ... **46 document results**

15 home AND mechanical AND ventilation OR long AND term AND ventilation OR chronic AND ventilation **8,777 document results**

14 (individual AND quality AND of AND life AND not AND health AND related AND quality AND of AND life) AND ((quality AND of AND life OR wellbeing OR well AND being OR well-being OR satisfaction) AND (home AND mechanical AND ventilation)) AND (LIMIT-TO (SRCTYPE , "j")) AND (LIMIT-TO (LANGUAGE , "English")) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "NURS")) AND (LIMIT-TO (EXACTKEYWORD , "Human") OR LIMIT-TO (EXACTKEYWORD , "Humans") OR LIMIT-TO (EXACTKEYWORD , "Article") OR LIMIT-TO (EXACTKEYWORD , "Adult") OR LIMIT-TO (EXACTKEYWORD , "Quality Of Life") OR LIMIT-TO (EXACTKEYWORD , "Artificial Ventilation")) ... **61 document results**

13 individual AND quality AND of AND life AND not AND health AND related AND quality AND of AND life **120,335 document results**

12 (quality AND of AND life OR wellbeing OR well AND being OR well-being OR satisfaction) AND (home AND mechanical AND ventilation) AND (LIMIT-TO (SRCTYPE , "j")) AND (LIMIT-TO (LANGUAGE , "English")) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "NURS")) AND (LIMIT-TO (EXACTKEYWORD , "Human") OR LIMIT-TO (EXACTKEYWORD , "Humans") OR LIMIT-TO (EXACTKEYWORD , "Article") OR LIMIT-TO (EXACTKEYWORD , "Adult") OR LIMIT-TO (EXACTKEYWORD , "Quality Of Life") OR LIMIT-TO (EXACTKEYWORD , "Artificial Ventilation")) ... **452 document results**

Appendix 2 CINAHL and MEDLINE Search History

Last run on 31st July 2018

Each title and abstract from the combined searches (e.g. S54 and S56 = S57) was reviewed and appropriate citations drawn for critical appraisal.

#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S57	S54 AND S56	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	26	Martinsen & Dreyer 2012 Dependence on care experienced by people living with Duchenne muscular dystrophy and spinal cord injury. Finkelstein & Marcus 2018 Realizing autonomy: the phenomenology of independence and interdependence while living with Duchenne muscular dystrophy.
S56	experience or perspective	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,282,821	
S55	experience	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	968,864	
S54	S50 AND S52	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	759	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used

S53	S51 AND S52	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	6	<p>Lindahl et al 2006; On becoming dependent on home mechanical ventilation: depictions of patients' experiences over time</p> <p>Lindahl 2011 Experiences of exclusion when living on a ventilator: reflections based on the application of Julia Kristeva's philosophy of caring science.</p> <p>Lindahl et al 2005 On becoming dependent on home mechanical ventilation.</p> <p>Schaepe & Ewers 2017 'I need complete trust in nurses' – HM Ventilated patients perceptions of safety.</p>
S52	dependen*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,695,250	
S51	S18 AND S50	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	42	No relevant citations found
Query	Limiters/Expanders	Last Run Via	Results	Citations Used	Query

S50	duchenne muscular dystrophy	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	12,372	
S49	S18 AND S47	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	90	1 citation found: Young et al 1994 Amyotrophic lateral sclerosis patients' perspectives on use of mechanical ventilation
S48	S22 AND S47	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	16	No relevant citations found
S47	dependent	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,425,358	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S46	S35 AND S45	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	61	1 citation found:

			Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE		Lemoignan & Ells 2010 Amyotrophic lateral sclerosis and assisted ventilation: how patients decide.
S45	assisted ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	3,506	
S44	user satisfaction and mechanical ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	7	1 citation found: Dyrstad et al 2012 Factors that influence user satisfaction: tracheotomised home mechanical ventilations users' experiences.
S43	patients' perspectives on use of mechanical ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	2	No relevant citations found
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S42	S7 AND S26 AND S41	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	14	No relevant citations found

			Database - CINAHL Plus with Full Text;MEDLINE		
S41	decision making	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	300,233	
S40	S35 AND S39	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	39	
S39	patient's perspective	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	16,987	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S38	S26 AND S35	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	55	

S37	S32 AND S35	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	0	
S35	amyotrophic lateral sclerosis	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	27,442	
S34	AML	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	32,716	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S33	S18 AND S32	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	4	Dreyer et al 2010 Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation Dreyer et al 2010 Life with home mechanical ventilation for young men with Duchenne muscular dystrophy.

S32	experiences of living with chronic illness	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	224	No relevant citations found
S31	S29 AND S30	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	47	1 citation found: Van Huijzen & van Staa 2013 Chronic ventilation and social participation: experiences of men with neuromuscular disorders
S30	neuromuscular disorders	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	7,520	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S29	chronic ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,808	
S28	S3 AND S27	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	0	

			Database - CINAHL Plus with Full Text;MEDLINE		
S27	long term home ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	146	No relevant citations found
S26	long term ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,754	
S25	transition to long term ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	6	No relevant citations found
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S24	S18 AND S23	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	5	Ballungrud et al 2009 Clients' experiences of living at home with a mechanical ventilator Brooks et al 2004 User perspectives on issues the influence the quality of daily life of ventilator-assisted individuals with neuromuscular disorders.

					Rwakonda Munuaradzi 2017 PhD Thesis – unavailable. Dale et al 2018 Transitions to Home Mechanical Ventilation: The Experiences of Canadian Ventilator-Assisted Adults and Their Family Caregivers.
S23	individual quality of life	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	5,985	
S22	home mechanical ventilation and quality of life	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	169	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S21	S3 AND S18	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	4	No relevant citations found
S20	S3	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	6,842	

			Database - CINAHL Plus with Full Text;MEDLINE		
S19	S16 AND S18	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	0	
S18	home mechanical ventilation	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	808	
S17	S4 AND S16	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	8	Lindah1 2010 Patients' suggestions about how to make life at home easier when dependent on ventilator treatment – a secondary analysis.
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S16	life satisfaction or happiness or well being	Limiters - Full Text Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	15,024	

S15	Wellness; (MH "Life Experiences")	Limiters - Full Text Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	11	No relevant citations found
S14	Lived experience*	Limiters - Full Text Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,507	
S13	S4 AND S10	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	0	
S12	S7 AND S8	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	66	No relevant citations found
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S11	S7 AND S8 AND S9 AND S10	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	0	

S10	Long term effect*; (MH "Quality of Life+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	3,402	
S9	• (MH "Human Needs (Physiology)")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	515	No relevant citations found
S8	(MH "Human Needs (Psychology)+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	1,661	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S7	MH "Quality of life"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	248,409	
S6		Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	0	

	(Quality of life and long-term effects) AND MH “Human Needs (Physiology)” AND MH “Human Needs (Psychology)+” AND MH “Quality of life”		Database - CINAHL Plus with Full Text;MEDLINE		
S5	S1 AND S4	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	936	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S4	artificial respiration or ventilation or mechanical ventilation	Limiters - Full Text; References Available; Abstract Available Expanders - Apply related words; Also search within the full text of the articles Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	4,566	

S3	quality of life or well being or well-being	Limiters - Full Text; References Available; Abstract Available Expanders - Apply related words; Also search within the full text of the articles Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	33,487	
#	Query	Limiters/Expanders	Last Run Via	Results	Citations Used
S2	TX quality of life or well being or well-being	Limiters - Full Text; References Available; Abstract Available Expanders - Apply related words; Also search within the full text of the articles Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	33,487	

S1	artificial respiration or ventilation or mechanical ventilation (spelling error embedded in EBSCO not typographical error)	Limiters - Full Text; References Available; Abstract Available Expanders - Apply related words; Also search within the full text of the articles Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text;MEDLINE	4,566	
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Appendix 3 JBI CA Checklist

Essential inclusion points listed in bold text

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info
 Comments (Including reason for exclusion)

Appendix 4 Data Extraction

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Briscoe, W.P., & Woodgate, R.L. 2010 Sustaining self: the lived experience of transition to long-term ventilation. <i>Qualitative Health Research</i> 20 (1): 57-67	To explore the subjective meaning of the experience of transition from spontaneous breathing to reliance on LTMV.	Hermeneutic phenomenological study	Canadian study. Recruited from a respiratory unit at a long-term facility 11 participants recruited (no details, but it is termed 'selection') 5 lived in long term care and the other 6 lived in houses or apartments . 9 women and 2 men	Not noted where data was collected. Semi-structured in-depth interviews. Audio recorded. One participant opted to be interviewed on numerous occasions due to inability to articulate clearly. (Five times for 20 minutes). Interviews conducted by primary author.	None indicated.	Ethical consent obtained.	Analysis – van Manen 1990. Hermeneutic cycle Meaning units aggregated into working themes, reflection used and reduction. Rigour mentioned but not trustworthiness. Authors experience recognised.	Recruitment strategy hazy. Potential bias if relationship between participants and researcher. Overrepresentation of females Study funded by Canadian lung association and a Scientist Award. Findings: The essence of ventilator users experiences of transition – sustaining self. Tyranny of symptoms Self in peril: being in the ICU and making a decision, being ventilated Awakening to a paradox Struggling for autonomy Life goes on with a reclaimed self Gaining perspective Living with uncertainty.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Ballungrud, R., Bogsti, W.B., & Johanson I.S. 2009 Clients experiences of living at home with a mechanical ventilator. <i>JAN</i> 65 (2): 425-434	To study how clients experience living with home mechanical ventilation and how they experience care and supervision of healthcare personnel.	Inductive qualitative approach.	Invitation by regional staff working at a Norwegian centre for HMV. Information mailed to potential participants . 20 invited – 10 recruited. 3 women and 7 men.	Interviews. Piloted. Interviews conducted in the participants own homes.	None declared.	Ethical approval gained.	Content analysis – manifest and latent content. Manifest = what the text says Latent = what the text talks about, what the reader understands by it. Rigour commented upon	Bias potential in recruitment by healthcare staff, in identifying those who were likely to agree. Rigour commented upon rather than trustworthiness. No full listing of all sub-categories presented. Limited to Norwegian participants and those well enough to participate. Participants became tired and therefore may have limited data collection. Findings: 3 main themes – 5 categories and 10 sub-categories. Main theme 1 – the home ventilator enhances quality of life – life worth living. 3 categories in main theme: Significance of respirator for person’s strength and wellbeing; control of own life situation; to live a normal and active life. Main theme 2- Competence and continuity of healthcare personnel as factors for success 2 categories: Varied competence among and follow-up by healthcare personnel; significance of teaching and information giving.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Brooks. D., King, A., Tonack., Simson., Gould., M. and Goldstein, R. 2004 User perspectives on issues that influence the quality of daily life of ventilator-assisted individuals with neuromuscular disorders. <i>Canadian Respiratory Journal</i> . 11 (8): 547- 554.	To identify user perspectives on the issues that impact the quality of the daily lives of ventilator-assisted individuals living in the community.	Grounded theory – inductive reasoning to build knowledge from ground up of the day to day experiences of individuals.	Advertising in magazines from organisations for disabled individuals, contacts with medical and service agencies (resp home companies and equipment pools). No further detail and no	Semi-structured face-to-face interviews in participant's homes or community centres. 26 ventilated participants. 23-60 yrs. Ventilated 3-53 yrs. Neuromuscular conditions. Interviews recorded and transcribed verbatim. 30 individuals contacted and 26 interviewed	Unclear. Recruitment would potentially indicate no conflict, however none are declared. Interviewers – background in education and experience with working with disabled individuals.	Ethics agreed by University and health service. No concerns raised at accessing patient contact through health services. Funding – acknowledged.	Analysis of 3 interviews at a time, increased to 5 and then 7 until data saturation. No indication of who carried out the analysis.	26 interviewed - ? data saturation <ul style="list-style-type: none"> Identified adjustment to ventilation period Integrating ventilation into routine Positive outcomes – less sick Acceptance Participating in daily life – contribute to society. Quality of life influenced by satisfaction of successes or frustration associated with barriers: housing, income, transport, and self-managed attendant programmes. General satisfaction – increased energy, education, employment, advocacy, successful health management, supportive relationships, positive attitudes. Barriers: <ul style="list-style-type: none"> Increased care requirements, increased personal attendant requirements and public embarrassment. Government and service bureaucracies. Co-ordination of multiple services. Positive health related QOL. No information provided of when data saturation was achieved.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Dale, C.M., King, J., Nonoyama, M., Carbone, S., McKim, D., Road, J., and Rose, L. 2018 Transitions to Home Mechanical Ventilation. The Experiences of Canadian Ventilator-Assisted Adults and their Family Caregivers. <i>Ann Am Thoracic Society</i> 15 (3): pp 357- 364. Doi: 10.1513/AnnalsATS.201708-6630C	To explore the experiences of individuals as they transition from a hospital setting to the home environment, and to identify how this process could be optimised.	Descriptive, qualitative study. Ecological framework (not expanded on).	Ventilator assisted individual requiring 6hrs per day tracheostomy or NIV indefinitely. Participant will in last 2 yrs: Transitioned to HMV without admission to acute care setting; Mode of vent changed (NIV to invasive); Transition from acute care (vent) to HMV. Exclusion: obstructive sleep apnoea requiring NIPPV. Recruited through HM programme, Outreach programme, Rehab centre, Chronic Vent programme. Clinical staff approached participants.	Semi-structured individual and ventilator assisted individual – family caregiver dyad interviews. 33 individuals – 19 HMV and 14 family caregivers. 10 participants interviewed side by side with carers. Interview length 54 minutes. (24-106 mins). 58% male, age 55yrs (21-77yrs). 40% needed continuous HMV. All caregivers female. Interview guide produced. Piloted with participants (over phone and f-2-f). Interview guide sent out in advance. Audio recorded and transcribed verbatim.	No rel. with participants and were experts in mech vent.	Research ethics board of Uni of Toronto, British Columbia, Saskatchewan, Regina and Regina Qu'appelle Health Region, and Uni of Calgary. Written consent.	Deductive content analysis methods and application of ecological framework - including validated domains relevant to health service transition for young adults with complex chronic health issues. Limitation: what of age range of sample? NVivo coding using applied ecological domains to meet established definitional agreement. Instructions generated for coders to enable assignment of category labels. 2 authors present throughout data analysis, & team meetings. Reflexivity incorporated. 3 rd analyst to ensure dependability and confirmability.	Findings: Facilitators: Health status – improved health status after transition to HMV. Knowledge: respiratory therapists and nurses main sources of knowledge and patient education, and development of skills. Expectations/ self-efficacy: Capacity to manage equipment issues/ malfunctioning Relationships/ psychosocial: range of supportive individuals from family to church, clinicians. Positive relationships. Home/ equipment access: home adaptation. Health insurance issues, grants, donations, facilities etc. Barriers: Individual knowledge and skills Social relationships: threatened feelings. Discord between ICU team and family/ patient. Challenging attitudes of community providers Access/ support: 'fight' for patient-centred care. Knowledge/ policy: incomplete understanding of policy by family/ patient – led to surprise at lack of support workers with HMV experience. Caregivers may have imposed views, and therefore not truly representative of HMV individuals. Lack of carers with HMV resulted in potential continuing leaning on main providers. Multiple conditions across wide geographical area. Female dominated care group (similar across other studies).

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Dreyer, P.S., Steffenson, B.F., and Pedersen, B.D. 2010a Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation. <i>International Journal of Qualitative Studies on Health and Well-Being</i> . 5 (3) : 5388	To study life experiences of people living with Duchenne's muscular dystrophy home mechanical ventilation and physical impairment from a patients perspective with special emphasis on living with a physical impairment.	Part of larger study. No clarity over reference of larger study. Phenomenological hermeneutic approach inspired by Ricoeur's theory of interpretation.	21 participants chosen randomly from 60 treated by an outpatient nurse. 2 excluded/refused. OPD nurse facilitated contact.	Narrative interviews. 19 participants with DMD and HMV interviewed at home.	Author conducted interviews, but no clarity around any relationships with participants.	Ethics agreed but ? by whom. Not clear. Paid carer teams in Denmark conditional on leading an active life. Study funded by ICU and Anaesthesia Depts – potential bias.	Naïve reading, structural analysis and critical analysis.	The meaning of being physically impaired Dependency and independency -and interdependence. 'Independent dependent' Importance of friends and family Emotional and sexual aspirations Positive outlook on life NORMALITY a goal. Normalisation – Deatrick et all 1999. Cultural transferability may be an issue.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Dreyer, P.S., Steffenson, B.F., and Pedersen, B.D. 2010b Life with home mechanical ventilation for young men with Duchenne muscular dystrophy <i>Journal of Advanced Nursing</i> . 66 (4): 753-762.	To describe the life experiences from a patient perspective, with mechanical ventilation among young men with Duchenne muscular dystrophy.	Phenomenological hermeneutic approach based on Ricoeur's interpretation theory	National register maintained in Denmark of HMV patients. 21 men chosen from 2 centres randomly selected from group of 60 patients by an OPD nurse.	Open narrative interviews of 19 men by 1 st author conducted in participant's homes. 21-40 yrs and HMV 3-18 yrs.	Not clarified (similar to the other studies in this group).	Ethics agreed, but no further detail of by whom.	Naïve reading Structural analysis Critical analysis.	Themes: <ul style="list-style-type: none"> • Decision making • Conscious breathing • Care rules • Failure • Ventilator adapting. Participants all had same diagnosis, cultural issues (Westernised context).

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Dreyer, P.S., & Pedersen, B.D. 2009 Distanciation in Ricouer's theory of interpretation: narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. <i>Nursing Inquiry</i> 16 (1): 64-73.	A phenomenological hermeneutic study of life experiences living with HMV	Phenomenological hermeneutic study	20 participants . No details of recruitment included,	Open narrative interviews – 40 to 2 hours duration.	None declared.	None included as this is an interpretation of the experiences .	Ricouer's theory of interpretation used. Naïve reading Structural analysis: Interpretation of what the text says across the data, interpretation of what the text speaks about, interpretation of the themes related to both what the text says and to what the short story speaks about.	Insufficient data available to comment on the trustworthiness of the study. However the authors comment on trustworthiness in the discussion. It's merged with other studies and 3 articles were found by the same authors analysing different elements of the same study. No ethics reported One theme and several sub themes noted: Theme: Decision making Subthemes: ethics between autonomy and paternalism, Independency-dependency, Vulnerability. Plurality and multiplicity of interpretation.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Dyrstad et al 2012 Factors influencing user satisfaction – HMV patients. Journ Clin Nurs 22, 33-338. Back chained Israelsson-Skogsberg 2016.	Describe self-reported life situations of HMV and user satisfaction.	Descriptive, explorative design using interviews – no depth or detail provided	6 HMV users. Recruited through physician. 3 males/ 3 females. 37-78 yrs, 2-10+yrs HMV. Differing diagnoses. Use of communication aids.	1-to-1 interviews. 30 – 50 minutes	Researcher conducted interviews. Experienced ICU nurse so therefore could have been known to the patient participants.	Recognised and approved.	Qual. content analysis. Sub-themes and themes created by abstraction.	Findings: Need to be included in early stages of decision making, difference individual needs require range of approaches, resulting in 3 sub themes: 1. Tailored information, 2. Sensitivity in decision making, 3. Building trust and confidence. Need for strategies to improve satisfaction identified. Experiences varied depending on age, where they lived, who they encountered in the healthcare system and level of family support. Data important for generation of new knowledge. Relate to own study in terms of decision making and timings – Participant 4, Participant 2 and Participant 3 specifically. Trust and confidence – relate to Participant 4. Limitations: findings limited and not sufficient use of quotations – feels a little 'light'. Discussion lengthy in light of short findings section. No direct mention of QOL but all findings echo own study findings. 'normal' highlighted and respect & time One mention of QOL – p 335. All other findings are implied within QOL. Vulnerability and HMV. Powerlessness of individuals with chronic disabilities.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Finkelstein, A. & Marcus E-L., 2018 Realizing autonomy: the phenomenology of independence and interdependence while living with Duchenne muscular dystrophy <i>Disability & Society</i> , 33:3, 433-453, DOI: 10.1080/09687599.2018.1427049	Exploration of daily life and world view of patient with DMD.	Case study of one individual. Qualitative phenomenological approach (interpretive approach). Reference to first author as ethnographer.	Request to all (?) residents at a rehab centre approached (no numbers included). 'Almost none' responded. Unclear what that means. No clear recruitment strategy included. Conducted in a rehabilitation centre for young adults aged 18 yrs or over with neuromuscular disorders requiring daily care. Required 24/ 7 HMV via tracheostomy. One patient agreed to be interviewed.	Interviews. Unclear how relationship influenced this. 13 90 minute interviews conducted, recorded and transcribed professionally (unclear what this means). Speech – issues due to HMV and therefore unclear in parts. Sections repeated by interviewer where unclear for the purposes of the interview. Member checking introduced to ensure accuracy. Iterative process.	Relationship through interviews turned into a long-term relationship, resulting in informal discussion as well as formal interviews. Unclear how this affects the data. Researcher and participant have continued to keep in touch. Honest explanation however may introduce bias. Other researcher/ author is clinician responsible for participants care. 2 nd researcher was not involved in interviews and has not read transcripts.	As previously noted – potential of bias. Ethics – 'relevant institutional committee' – no further detail. Informed consent form signed via stamp of participant's signature. Participants own name used in study with his agreement.	Continuous dialogic process, Returning to the text revealed further layers of meaning. Reflexive interviews. Interpretive approach. Findings reported in 1 st person. Not clear what the process was.	Guiding new volunteer carers – privacy and intimacy with strangers. Constant exposure fundamental to living with condition. Intimate care part of everyday life. Routine of dependency. Volunteers view dependency differently, but participant sees himself as independent due to decision making powers. Staff carry out wishes. Respect of safety, comfort and autonomy. Formation of relationships - 'touch' emotionally and become significant in other's lives. Investment in relationships. Boundaries between carers and friendship roles Understanding between participant and carer – trust. EOL – DMD. Longing for intimacy. Struggle to accept deteriorating health and EOL. Being at the mercy of carers responses in relation to receiving care (e.g. suction). Participant's choice not to respond to questions. Fragile position as patient. Loneliness and boredom 'I would love to be like everyone else'. Morris: 2004: need to amend legislative framework to enable disabled to integrate...denied full human and civil rights (p.427)

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Lemoignan, J., & Ellis, C. 2010 Amyotrophic lateral sclerosis and assisted ventilation: how patients decide <i>Palliative and Supportive Care</i> 8: 207-213	To explore the experience of decision-making about assisted ventilation for ALS patients.	Qualitative study. Phenomenological approach	Variation sampling strategy applied. No details of how the participants were approached or by whom. Diversity of age, gender, ALS type, speed of progression, choice of strategy to manage respiratory symptoms used as part of sampling.	Semi-structured, in-depth interviews. Tape recorded and transcribed.	Potential bias as the researcher also treated/cared for the participants. This is recognised by the researcher. May have added to the study, as the researcher was aware of the participant deficits and could accommodate for these.	Ethics approval sought and gained. Caregivers present at some interviews – paternalism could be an issue.	Thematic analysis (although not clearly stated) - categories of significant statements were grouped together.	Six themes: <ol style="list-style-type: none"> 1. The meaning of the intervention 2. The importance of context 3. The importance of values 4. The effect of fears 5. The need for information and 6. Adaptation to or acceptance of the intervention. From 1: LTMV – choice between life and death. Invasiveness of LTMV deterrent, as was their perception that the machine would take over their breathing. Importance of control emphasised, fears of dependency and deterioration of ALS 2. Context – assisted ventilation limited functional status. 3. Values affecting decision making – Communication, relationships, autonomy life and QOL 4. Fears – imminence of death, being a burden, disease progression, running out of air, 5. Need for information – 6. Adaptation – lengthy process involving gradual familiarisation with equipment

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Lindahl, B. 2010 Patients suggestions about how to make life at home easier when dependent on ventilator treatment – a secondary analysis. Scandinavian Journal of Caring Sciences. 24: 684-692.	The aim was to present patient views and suggestions about how to improve the HMV care regimen.	Secondary analysis of 3 studies: Lindahl, Sandman & Rasmussen 2005, 2006 and 2003. Qualitative content analysis. Phenomenological-hermeneutic method.	As per initial studies which is not outlined in this study reporting.	35 initial interviews 9 participants who had long term experience of HMV and 13 participants who were about to start or had just started treatment – narration of experiences. 2 separate interviews per participant.	Author collected data – possible bias.	Ethics agreed by university and informed consent sought for initial studies.	Qualitative content analysis. Phenomenological-hermeneutic method. Categories and sub-categories identified	<p>Findings:</p> <ul style="list-style-type: none"> • The start-up process • Self and the ventilator • To experience home as a shelter • To seek knowledge and understanding • To build up confidence in technology • The need to have people to relate and depend on. <p>Freedom and imprisonment in using the ventilator. To be involved in decision making. To be like everybody else Feelings of at-homeness. Access to technology. Confidence and trust in carers – communication and relationships.</p> <p>Grants supplied - ? bias as its unclear from where and what the nature of the funding body is/ was.</p> <p>Secondary analysis – may look for specific areas/ findings. Any flaws in the initial studies would be continued into the secondary analysis.</p>

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Lindahl, B. 2011 Experiences of exclusion when living on a ventilator: reflections based on the application of Julia Kristeva's philosophy to caring science. <i>Nursing Philosophy</i> . 12: 12-21.	No clear aim set. It states 'Reflections in the light of Kristeva's philosophy concerning empirical data drawn from research describing everyday life of people dependent on ventilators.	Secondary analysis of narratives collected from a phenomenological-hermeneutic approach study (Lindseth and Norberg 2004) of everyday life of adults living with HMV. Narratives retold in form of composite story and imaginary first person. Narrative methodological approach from a person-centred perspective.	Secondary analysis of primary study.	Interviews for initial study conducted in participant's homes; most ventilated at night, and some during the day, Few 24 hours.	Unknown. Not clarified.	Ethics agreed for primary study through University.	Narratives retold in form of composite story and imaginary first person based on Kristeva's philosophy to caring science.	Existential loneliness – isolation People as strangers to themselves. Unclean and loss of meaning affecting mood Abjection Physical body experience Caring as gift 'Difference' – cultural, social, ethical, religious, physical and or psychological. – exclusion.

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Lindahl B., Sandman, P-I., & Rasmussen, B.H., 2005 On becoming dependent on HMV <i>Journal of Advanced Practice</i> 39 (1): 33-42 CINAHL	Illuminate meanings of becoming dependent on home mechanical ventilator treatment	Narrative approach – analysis of narratives and narrative analysis. Phenomenological – hermeneutic approach influenced by Ricoeur’s philosophy. Reflexive diary used.	13 participants about to or just started HMV. Invited by healthcare staff working in respiratory centres across Sweden. No random selection – selected to ensure variation of disease and reason for HMV, age & gender.	Interviews at home, in hospital or in work. Interviews recorded. 52-81 yrs. 5 employed others retired. Not all HMV 24hrs a day. Some via face/ nasal mask.	Not indicated. Potential bias if researcher and participant known to one another.	Ethics granted from University, No written consent required in Sweden.	Naïve interpretation, structural analysis and Critical analysis. Use of composite stories.	Initial categories from structural analysis: <ul style="list-style-type: none"> • Framing/ Situating yourself and your story; Experiences of illness • Decision making; Relations to ventilator; Relationship; My home and leaving my home; Existential thoughts; The future; Themes: <p>Unburdening means:</p> <ul style="list-style-type: none"> • Taken for granted choice or being taken by surprise • Existing in a welcoming relation to the ventilator • Maintaining a creative relationship with others • Feeling that home signifies well-being and comfort and that the ventilator is part of the home • To be overwhelmed by thankfulness • To recapture a purpose in life. <p>Burdening means:</p> <ul style="list-style-type: none"> • To be uncertain and to consider refusing treatment despite still have a desire to live • Being dominated by a contaminating machine or fears of life and being a burden • Experiencing in a wounding/ distressing relationship with other. • Feeling that home represented well-being but also uncertainty and fragility • Being overwhelmed by despair and uncertainty • Uncertainty that the future is going to be enjoyable. Limitations: use of non-invasive HMV,

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Martinsen, B., & Dreyer, P. 2012 Dependence on Care Experienced by People Living with Duchenne Muscular Dystrophy and Spinal Cord Injury <i>Journal of Neuroscience Nursing</i> 44(2): 82-90.	To describe the meaning of dependence on care in a private home setting among people living with help requirements for all aspects of daily life.	Phenomenological hermeneutic approach – Ricouer’s philosophy of interpretation. Based on 2 previous empirical studies – secondary analysis.	As per previous studies, but not made explicit	Interviews – audio recorded and transcribed. No further data provided.	Not explicit. Unclear whether authors collected data and therefore not possible to discern bias from this paper. Review of previous papers documenting original studies reveals:	Ethics agreed for initial studies. None raised for secondary analysis. Denmark – paid care is conditional on the individual continuing to participate in life, therefore participants could be forced into engaging due to fear of loss of carers. Cultural norms may differ in other countries/ contexts.	Naïve reading, structural analysis and then critical Reanalysis.	<ul style="list-style-type: none"> • The helper as liberating • The paramount verbalisation of own need • The creative engagement in life • Accessibility as an issue in everyday life <p>Care time was not dictated, and therefore potentially contributed to increased autonomy Powerlessness or loss of control NOT reported in this study, or carers talking over their heads. Dependence on care and readiness of helpers to follow instruction – unregistered carers better than registered. Dependence/ independence recognised and independence seen as a subjectively self-assessed life experience. <i>Draws on:</i> <i>Benner’s theory of ontological care – people live in a world dependent on care reliance on others. It is interwoven and taken for granted. Loss in the form of disability may change lifeworld’s but caring sets up a possibility for acting under new conditions (adaptation?)</i></p> <p>Technology enabled communication and contact.</p>

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Schaepe, C. and Ewers, M. 2017 'I need complete trust in nurses' – home mechanical ventilated patients' perceptions of safety' <i>Scandinavian Journal of Caring Sciences</i> . 31; 948–956	To examine how HMV patients perceive their situation and what makes them feel safe or unsafe.	Explorative qualitative study. elected empirical methods based on grounded theory methodology (34) were applied for sampling, data collection and data analysis	Inc. criteria: HMV Participants HMV, older than 18 years of age & able to communicate. Sampling strategy maximum variation in relation to age, disease and hours of ventilator use. Participants recruited mainly via staff of different outpatient nursing care providers. Further participants recruited via hospital-based specialised respiratory care centres, personal contacts and organisations such as the German Association for Muscular Dystrophy and patient advocacy groups.	Data were collected in two regions in Germany between April-December 2014. Iterative process. Semi-structured interviews. 15 interviews were initially planned, but subject recruitment continued until saturation was reached after 21. The qualitative interviews, 13–107 min in length, were audiotaped and conducted in accordance with a semi-structured interview guide. Guide piloted. Verbatim data transcription and coding were performed in German and managed using MAXQDA 11.	None disclosed but reference to personal contacts in recruitment strategy may indicated level of recruitment bias.	Limited ethical details included. No ethical approval noted. Informed consent stated.	Thematic analysis. Coding, categorisation and analytic reflection to identify relevant themes. Concurrent thematic analysis and data collection. Some difficulties due to recruitment. Open coding: multiple readings of transcripts and in-vivo coding continued until first themes emerged. Portioned interview transcript into parts, data categorised, using constant comparison method. Themes linked with subthemes during axial coding. Reflexive memo writing. Findings integrated, refined and condensed.	3 themes emerged: Being familiar, having trust - The meaning of an interpersonal relationship between the nurse and HMV patient Being able to communicate and be noticed -The importance of the attentiveness of nurses for the patients' feeling of safety Experiencing continuity – Feeling presence points to the organisational dimension of HMV care provision. Questionable whether bias present in recruitment. Provision of semi structure interview guide would be helpful. Nurses caring for patients used as interpreters – bias?

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
<p>Young, J.M., Marshall, C.L. & Anderson E.J. 1994 Amyotrophic lateral sclerosis patients' perspectives on use of mechanical ventilation. <i>Health and Social Work</i> 19 (4): 253-260</p>	<p>To determine the factors involved in making a decision whether to use mechanical ventilatory support.</p>	<p>Qualitative design. No further details. However, there is reference to the ALS Severity Scale (Quantitative) in the methodology section.</p>	<p>Not stated. 16 participants selected in non-random manner (no details given) from 65 registered individuals. No details of male/female split. Differing carers noted. 4 using HMV,</p>	<p>One hour, semi structured interviews</p>	<p>Not stated.</p>	<p>Not stated</p>	<p>Not stated, but refer to a mean score and standard deviation.</p>	<p>Potential for mixed methods approach but unclear in the text. ALS Severity Scale used. Several participants did not have an understanding of ventilation and so the physician met with them prior to the interview. This may have resulted in bias. Recruitment strategy unclear.</p> <p>Four factors identified most frequently in support to HMV: Quality of life Availability of ventilation by means of a nasal mask, The ability to control discontinuation of mech vent Desire to live.</p> <p>4 factors against: Possible admission to long-term care facilities Quality of life Concerns about care demands on family Concern for emotional health of family</p> <p>Quality of life cannot be determined by severity of disability.</p>

Author, Date, Title, Journal, Database	Aims	Research Design	Recruitment Strategy	Data Collection	Researcher/ Participants Relationship	Ethical Issues	Data Analysis	Findings & comments
Van Huijzen, S., & van Staa, A. 2013 Chronic ventilation and social participation: experiences of men with neuromuscular disorders. <i>Scandinavian Journal of Occupational Therapy</i> . 20: 209-216	To investigate how mechanical dependent adults with NM disorders experience their occupational and social participation.	Qualitative design. No further information	Convenience sampling of individuals who lived in a 'care hamlet' – purpose built accommodation providing 24/7 care. Identification by care coordinators. 10 individuals identified. Potential bias. 6 agreed to participate.	Focus groups. Piloted focus group discussion with 3 adults in a nursing home. 2 successive focus groups conducted, lasting approx. 2 hours.	No relationship declared.	Ethical approval given.	Trustworthiness demonstrated. Four central themes and 4 overarching themes identified.	Potential bias in identifying individuals during recruitment by identifying those who were likely to agree. Lack of clarity over research design. Narrow recruitment strategy from one care facility – no wider recruitment. Discussion guide developed from pilot may have not been appropriate as the sample for the pilot was elderly. Findings: focused on social participation. Identified that participants wanted to be taken seriously, to be seen as responsible, autonomous adults who can decision make, have self-determination in risk-taking and be engaged in meaningful pursuits (work and leisure). Others: Influence of dependency, being treated as an employee (activities not meaningful), maintaining optimism. Normalisation.

Appendix 5 CDA Questions Asked of a Text

Critical Discourse Analysis (CDA) (Fairclough 2015 p129-131) Description of a text

Questions asked of the text:

Vocabulary

1. What experiential values do words have?
 - i. What classification schemes are drawn upon?
 - ii. Are there words which are ideologically contested?
 - iii. Is there *rewording or over-wording*?
 - iv. What ideologically significant meaning relations (*synonymy, hyponymy, and antonymy*) are there between words?
2. What *relational* values do words have?
 - i. Are there euphemistic expressions?
 - ii. Are there markedly formal or informal words?
3. What *expressive* values for words have?
4. What metaphors are used?

Grammar

5. What experiential values do grammatical features have?
 - i. What types of *process and participant* predominate?
 - ii. Is agency clear?
 - iii. Are processes what they seem?
 - iv. Are *nominalisations* used?
 - v. Are sentences active or passive?
 - vi. Are sentences positive or negative?
6. What relational values do grammatical features have?
 - i. What modes (*declarative, grammatical question, imperative*) are used?
 - ii. Are there important features of *relational modality*?
 - iii. Are the pronouns, *we and you* used, and if so, how?
7. What expressive values do grammatical features have?
 - i. Are they important features of *expressive modality*?
8. How are (simple) sentences linked together?
 - i. What logical connectors are used?
 - ii. Are complex sentences characterised by *coordination or subordination*?
 - iii. What means are used for referring inside and outside of the text?

Textual structures

9. What interactional conventions are used?
 - i. Are there ways in which one participant controls the turns of others?
10. What larger-scale structures does the text have?

Appendix 6 NISCHR RES Approval

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.

Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



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Website : www.nres.nhs.uk

Wales REC 6

Floor 8

36 Orchard Street Swansea

SA1 5AQ

Fax : 01792 607533

07 May 2014

Miss Anna Jones
Room 610 Eastgate House,
Newport Road
Caerdydd
CF24 0AB

Dear Miss Jones

Study title: Home Mechanical Ventilation (HMV): A critical exploration of the quality of life of adult patients and their families.
REC reference: 14/WA/0134
Protocol number: SPON 1247-13
IRAS project ID: 136193

Thank you for your letter of 07 May 2014, 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 [Chairman](#).

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Participant 3 Beresford, Participant 3.beresford@wales.nhs.uk.

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

NHS 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).

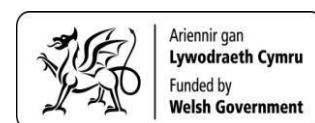
Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys



The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

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 organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity

e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	HMV Newsletter V.2	05 September 2013
Evidence of insurance or indemnity		26 July 2013
GP/Consultant Information Sheets	2	07 February 2014
Investigator CV		07 February 2014

Letter from Sponsor		25 September 2013
Letter of invitation to participant	4	25 January 2014
Other: CV	Jane Hopkinson	
Other: CV	Jane Harden	01 April 2014
Other: PR Invalidation letter		24 March 2014
Participant Consent Form: patient	5	28 April 2014
Participant Consent Form: carer	5	28 April 2014
Participant Information Sheet: Welsh version	1	25 January 2014
Participant Information Sheet: patient	5	28 April 2014
Participant Information Sheet: carer	5	28 April 2014
Protocol	6	28 April 2014
REC application		12 March 2014
Referees or other scientific critique report	Matt Wise letter	
Referees or other scientific critique report	Claire Edgeworth letter	28 June 2013
Referees or other scientific critique report	Roselmary Williams letter	12 June 2013
Response to Request for Further Information		07 May 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review


14/WA/0134

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



pp Roy

L.

Evans

Chairman

Email: Participant 3.beresford@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: *Helen Falconer, Cardiff University*
Mrs Lee Hathaway, Cardiff and Vale University Health Board



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Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

**Panel Arolygu Mewnol Y&D
R&D Internal Review Panel**

Betsi Cadwaladr University Health Board
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Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk

Tel/Fax: 01248 384 877

04 July 2014

Dear Miss Jones,

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	Home Mechanical Ventilation (HMV): A critical exploration of the quality of life of adult patients and their families
R&D reference	136193

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The R&D office considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Documents Reviewed:	Version	Date
R&D Form	-	10/05/2014
SSI Form	-	18/05/2014
Protocol	5	28/04/2014
Patient Information Sheet – Patient	5	28/04/2014
Consent Form – Patient	5	28/04/2014
Carer/Relative Information Sheet	5	28/04/2014
Consent Form – Family/carers	5	28/04/2014
GP Letter	2	02/07/2014
Newsletter Synopsis	2	05/09/2014
REC Favourable Opinion Letter	-	07/05/2014
Funding Letter	-	03/07/2013
Anna Jones CV	-	07/02/2014

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009).

An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found

at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact wendy.scrase2@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Academic Supervisor: Dr Jane Harden
Eastgate House
35-43 Newport Road
Cardiff
CF24 0AB

hardenj@cf.ac.uk

Academic Supervisor: Dr Jane Hopkinson
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hopkinsonjb@cf.ac.uk



Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board
Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park, Parc Y Mynydd
Bychan,
Cardiff, CF14 4XW Caerdydd, CF14
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7747
Fax 029 2074 3838 Ffacs 029
20743838
Iviiniccm 029 2074 3632 Minicom 029
2074 3632

From: Professor C Fegan
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF144XW

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

Ms Anna Jones
Cardiff University
Room 610, 6th Floor Eastgate House
34-43 Newport Road
Cardiff CF24 OAB

08 July 2014

Dear Ms Jones

Cardiff and Vale UHB Ref and study Title : 13/CLC/5790 : Home Mechanical
Ventilation (HMV): A Critical Exploration of the Quality Of Life Of adult Patients
And Their Families.

IRAS Project ID: 136193

The above project was forwarded to Cardiff and Vale University Health Board R&D Office by the NISCHR Permissions Coordinating Unit. A Governance Review has now been completed on the project.

Documents approved for use in this study are:


Document	Version	Date of document
NHS R&D Form	3.5	Received 27/05/2014
SSI Form	3.5	Received 27/05/2014
Protocol	5	28/04/2014
Participant Information Sheet: Patient	6	05/07/2014
Participant Information Sheet: Carer/Relative	6	05/07/2014
Newsletter: Stud S no sis	2	05/09/2013
GP Letter	2	07/02/2014
Participant Consent Form: Family member/Carer	5	28/04/2014
Participant Consent Form: Patient	5	28/04/2014

I am pleased to inform you that the UHB has no objection to your proposal and that this study has been classed as pathway-to-portfolio. You have informed us that Cardiff University is willing to act as Sponsor under the Research Governance Framework for Health and Social Care.

Please accept this letter as confirmation of permission for the project to begin within this UHB. May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the R&D Office if this project has not opened within 12 months of the date of this letter. Failure to do so may invalidate R&D approval.
- Inform NISCHR PCU and the UHB R&D Office if any external or additional funding is awarded for this project in the future
- Submit any substantial amendments relating to the study to NISCHR PCU in order that they can be reviewed and approved prior to implementation
- Ensure NISCHR PCU is notified of the study's closure
- Ensure that the study is conducted in accordance with all relevant policies, procedures and legislation
- Provide information on the project to the UI-IB R&D Office as requested from time to time, to include participant recruitment figures

Yours sincerely,



Professor Christopher Fegan

R&D Director | Chair of the Cardiff and Vale Research Review Service (CaRRS)

Lead Dr Matthew Wise

Sponsor: Chris Shaw, Research Innovation Enterprise Services, Cardiff University

Academic Supervisor: Dr Jane Harden

Academic Supervisor: Professor Jane Hopkinson Page 2 of 2 Version 2.0 8-7-13



Research and Commercial Division
Director Geraint W Jones
Adran Ymchwil a Masnach Cyfarwyddwr Geraint W Jones

Dr Jane Harden
School of Healthcare Sciences

Cardiff University

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Casnewydd
Caerdydd CF24 ODE
Cymru Y Deyrnas
Gyfunol

September 25th 2013

Dear Dr Harden

Home mechanical ventilation (HMV): A critical exploration of the quality of life of adult patients and their family.

I understand that you are acting as Academic Supervisor for the above PhD project to be conducted by Anna Jones.

I confirm that Cardiff University agrees in principle to act as Sponsor for the above project, as required by the Research Governance Framework for Health and Social Care.

Scientific Review

I can also confirm that Scientific Review has been obtained from the School of Nursing and Midwifery Studies Research Review and Ethics Screening Committee.

Insurance

The necessary insurance provisions will be in place prior to the project commencement. Cardiff University is insured with UMAL. Copies of the insurance certificate are attached to this letter.

Approvals

On completion of your IRAS form (for NHS REC and NHS R&D approvals), you will be required to obtain signature from the Sponsor Declaration by the Sponsor Representative').

Please then submit the project to the following organisations for approval:

- the appropriate Research Ethics Committee(s);
- National Institute for Social Care Health Research Permissions Coordinating Unit (NISCHR PCU to arrange host organisation R&D approval);

Once Research, Innovation & Enterprise Services has received evidence of the above approvals, the University is considered to have accepted Sponsorship and your project may commence.

Roles and Responsibilities

As Chief Investigator you have signed a Declaration with the Sponsor to confirm that you will adhere to the standard responsibilities as set out by the Research Governance Framework for Health and Social Care. In accordance with the University's Research Governance Framework, the Chief Investigator is also responsible for ensuring that each research team member is qualified and experienced to fulfill his/her delegated roles including ensuring adequate supervision, support and training.

Roles and responsibilities are adequately detailed in the research protocol.

Cardiff University is a registered charity, no.
1136855
Mae Prifysgol Caerdydd yn elusen gofrestredig,
rhif 1136855

THE QUEEN'S
ANNIVERSARY
PRIZES



2007
&
2009

- May I take this opportunity to remind you that, as Chief Investigator, you are required to:
- ensure you are familiar with your responsibilities under the Research Governance Framework for Health and Social Care;
- undertake the study in accordance with Cardiff University's Research Governance Framework and the principles of Good Clinical Practice;
- ensure the Research complies with the Data Protection Act 1998;

- inform Research, Innovation & Enterprise Services of any amendments to the protocol or study design, including changes to start end dates;
- co-operate with any audit inspection of the project files or any requests from Research, Innovation & Enterprise Services for further information.

You should quote the following unique reference number in any correspondence relating to sponsorship for the above project:

SPON 1247-13

This reference number should be quoted on all documentation associated with this project,

Yours sincerely



Dr K J Pittard Davies
Head of Research Governance and Contracts
Direct line: +44 (0) 29208
79274 Email:
resgov@cardiff.ac.uk

cc: Anna Jones
Hasilwood House
60 Bishopsgate
London EC2N 4AW Tel: 020 7847 8670
Fax: 020 7847 8689



TO WHOM IT MAY CONCERN

26th July 2013

Dear Sir/Madam

CARDIFF UNIVERSITY AND ALL ITS SUBSIDIARY COMPANIES

Clinical Trials Coverage

We confirm that the above Institution is a Member of I-J.M. Association Limited, and that the following cover is currently in place in respect Clinical Trials undertaken within the United Kingdom subject to the cover terms, conditions and exceptions.

Certificate of Entry No.	UM165/13
Period of Cover	1st August 2013 to 31st July 2014
Limit of Indemnity	£30,000,000 any one claim and in the aggregate including claims costs and expenses

Basis of Cover	Legal Liability or No Fault cover
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited
Main Cover Exclusions	<ul style="list-style-type: none"> i) Trials involving subjects under 5 years of age ii) Trials assisting with or altering in any way the process of conception iii) Trials investigating or participation in methods of contraception iv) Trials involving genetic engineering other than for preventing and diagnosing disease v) Trials involving drugs or surgery or nutrients vi) Trials involving persons known to be pregnant vii) Trials involving products manufactured by the University

Yours faithfully



Susan Wilkinson
For I-J.M. Association Limited



I-J.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW

Registered in England and Wales No. 2731799

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London EC2N 4AW Tel: 020 7847 8670
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Website: www.umal.co.uk



TO WHOM IT MAY CONCERN
26th July 2013

Dear Sir/Madam

CARDIFF UNIVERSITY
AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of I-J.M. Association Limited, and that the following covers are currently in place:-

PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No. UM165/13

Period of Cover 1st August 2013 to 31st July 2014

Includes Indemnity to Principals and includes cover whilst University employees and its students are engaged in Health and Social Care activities world-wide — excluding Medical Malpractice claims except as under

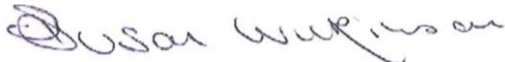
Includes Medical Malpractice (mis-treatment) claims against the University and its employees and its students providing the latter are working under the supervision of a Medically Qualified person

Limit of Indemnity a) £50,000,000 any one event and in the aggregate in respect of Products Liability and Unlimited in the aggregate in respect of Public Liability

b) Medical Malpractice — £10,000,000 any one event and in the aggregate

Cover provided by U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Ltd

Yours faithfully



Susan Wilkinson for I-J.M. Association Limited



I-J.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London EC2N 4AW
Registered in England and Wales No. 2731799

Appendix 10 SEIQoL-DW Quantitative Results

In the table below are listed the cues identified by each participant. The data lists:

- Level: the elicited rating of present life – the rating of the 5 most important areas of life, drawn as a bar chart;
- Weight: the importance (weighting) of the 5 areas of life in relation to one another;
- Score: Individual quality of life score for each cue;
- Overall SEIQoL Index Score: Individual overall measure of quality of life, on a scale of 0-100.

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 1				
Being Well	65mm	25% (0.25)	16.25	}
Socialising	87mm	20% (0.2)	17.4	}
Family	97mm	40% (0.4)	38.8	} 86.5
Watching Brother Play Rugby	97mm	10% (0.1)	9.7	}
Technology	87mm	5% (0.05)	4.35	}

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 2				
Independence	47mm	50% (0.5)	23.5	}
Social Life	19mm	25% (0.25)	4.75	}
Family	77mm	20% (0.2)	15.4	} 44.05
Finance	1mm	2.5% (0.025)	0.025	}
Relationships	15mm	2.5% (0.025)	0.375	}

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 3				
Music	0mm	20% (0.2)	0	}
Family/ Carers	97mm	20% (0.2)	19.4	}
Spiritual	83mm	20% (0.2)	16.6	} 70.8
Home	97mm	20% (0.2)	19.4	}
Socialising	77mm	20% (0.2)	15.4	}

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 4				
Family	97mm	55% (0.55)	53.35	}
Religion	79mm	25% (0.25)	19.75	}
Social Activities	38mm	10% (0.1)	3.8	} 82.88
Not Being Heard	35mm	2% (0.02)	0.7	}
Health	66mm	8% (0.08)	5.28	}

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 5				
IT, Chair and Adaptations	79mm	40% (0.4)	31.6	}
Home and Health	80mm	30% (0.3)	24	}
Education	97mm	20% (0.2)	19.4	} 81.5
Social Activities	65mm	5% (0.05)	3.25	}
Family and Friends	65mm	5% (0.05)	3.25	}

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 6				
Dexterity/ Mobility	0mm	45% (0.45)	0	}
Loss of Freedom	2.1mm	15% (0.15)	2.1	}
Loss of Friendship/ Socialising	31mm	5% (0.05)	1.55	} 25
Nurses	97mm	20% (0.2)	19.4	}
Tiredness	13mm	15% (0.15)	1.95	}

Identified Cues	Level	Weights	Score	Overall SEIQoL Index Score
Participant 7				
Freedom	48mm	50% (0.5)	24	}
Social Life	68mm	20% (0.2)	13.6	}
Travelling	38mm	10% (0.1)	3.8	} 53.5
Independence	60mm	15% (0.15)	9	}
Family	62mm	5% (0.05)	3.1	}

Levels ranged from 0 to 98mm. It has been noted that there is a variation in the length of the weighting scoring tool, which has resulted in a shorter scale being used with each participant i.e. 98mm in total length as opposed to 100mm from the original form. However, an indication of the overall level is presented, to support the qualitative data.

Weightings ranged from 2% to 50%.

Overall Quality of Life scores ranged from 25 to 86.5

A common cue was relationships, mentioned by 6 participants. However, exploration of the concept of relationship during the interviews revealed differing perceptions and individual definitions of relationship/s.

Appendix 11 Information Sheet to Participant's GP

School of Healthcare Sciences
Head of School and Dean Professor Sheila Hunt



Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila
Hunt

Our Ref: PhDAJGP
07 June 2019

School of Healthcare Sciences, Cardiff
University
Ystafell/ Room 610 Ty Eastgate House
35-42 Heol Casnewydd/ Newport Road
Caerdydd/ Cardiff
CF24 0AB
Tel: 029 2091 7769

email/ ebost: jonesa23@cf.ac.uk

Twitter: @cardiffsonms

Cardiff University is a registered Charity No:
1136855

Dear *(insert GP's name)*:

I have contacted your patient (insert name) and their main family member/ carer (insert name) in relation to a PhD study which I am conducting on Home Mechanical Ventilation (HMV): a critical exploration of the quality of life of adult patients and their family.

To outline the project for you: I am an intensive/ critical care nurse by background, and now lecture at the School of Healthcare Sciences at Cardiff University. I am keen not to let my clinical background 'drop' as so often happens when staff move into the School, and so along with my interest in Quality of Life, and how services and treatment/care and technology are changing, the PhD offers me a route of maintaining my interests. The title of the project is: Home Mechanical Ventilation (HMV): A Critical Exploration of the Quality of Life of Adult Patients and their Family

I aim to interview all home mechanically ventilated patients in Wales and one of their primary carers, using Schedule for the Evaluation of Individual Quality of Life: a Direct Weighting procedure for Quality of Life Domains (SEIQoL-DW)(O'Boyle, 1993) which will provide the focus for semi-structured interview as a data collection tool. A lack of exploration of the level, quality and equity of healthcare for this specific population within

Wales is apparent in the dearth of literature. This study thus offers a prime opportunity to survey the number of invasively HMV patients within Wales and to generate a database or service register to include such information as trigger for HMV, modes of ventilation, and specific service user requirements; this would enable audit to be conducted, allowing comparison of clinical practice and outcomes, to ultimately develop quality of care, and add to the global picture of the issues affecting HMV patients, their main carer and/or family.

I would like to understand how being mechanically ventilated has impacted on your patient and their family, and to measure their general quality of life, rather than health related quality of life. They have agreed to be interviewed by me, and this has been facilitated by the lead clinician (*insert clinicians name*) for their ventilatory care. There are approximately 18 patients across Wales who require HMV, and I will be inviting all of these patients and their main carer to participate in my study. Participation in this study is voluntary. I will ask the participant to sign a consent form prior to being interviewed and they are free to withdraw at any time, without giving reason.

It will involve an interview of approximately *45 minutes* in length to take place at the patient/ carer's home. If they get tired, I may need to interview them twice. I will ask them to identify up to 5 areas that describe their own quality of life, in order of importance to them. I will then ask the participant to give a weighting (score) to each of the areas using a disk on which sections labelled with the areas that they identified are moved to show their levels of satisfaction. The participants' quality of life scores can then be worked out from the total of the areas weighting and how important they considered their rating. If they need help to move the disk, I can help with this. I will then ask some questions on the areas that have been identified. The participant can refuse to answer any of the questions and with the participant's permission I will audio record the interview to help with the collection of information, to be transcribed.

This study will offer the participant (patient and carer) the opportunity to talk about their feelings and concerns. I may however, touch upon personal and sensitive issues. With the participant's permission, the critical care/ anaesthetic consultant who is involved in their care will carry out a brief discussion with them in the weeks prior to the interview to ensure

that they are well and able to undertake the interview. If I identify any issues or concerns during the interview, I will suggest that they contact you as their GP and with their permission, I will inform the critical care/ anaesthetic consultant involved in their care.

I hope that the results of my study will ultimately be of benefit to your patient and service. If you have a concern about any aspect of this study, I would ask that you initially contact me. If you remain unhappy and wish to complain formally, you can do this by contacting my supervisors in the first instance. If you feel that the issue has not been dealt with in a satisfactory way, you could then submit a complaint via the NHS complaints procedure.

I would like to assure you that this study has been reviewed and received ethical consent through the School of Healthcare Sciences at Cardiff University. This study has also been reviewed and given **(favourable)** opinion by **(yet to complete) Research Ethics Committee**. All of the information which is collected during the course of the research will be kept strictly confidential, and your patients' name will not appear in any thesis or report resulting from this study, however, with the participants' permission I will use anonymous quotations. Information collected during my study will be kept for 15 years on a secure computer system and in a locked office at the School of Healthcare Sciences at Cardiff University. Only I will have access to this information. I hope to publish the results of the study, and they will be made available to your patient/ carer on completion of the study. You will not be identified in any report or publication.

Further information and contact details:

If you have any questions or concerns about my study, or would like more information, please contact me on: 029 2091 7769 or by email at: jonesa23@cf.ac.uk.

With thanks in anticipation and kind regards/ Diolch yn fawr iawn a cofion gorau

Anna Jones Student Investigator,

School of Healthcare Sciences, Cardiff University
Ystafell/ Room 610 Ty Eastgate House
35-42 Heol Casnewydd/ Newport Road
Caerdydd/ Cardiff

CF24 0AB

Tel: 029 2091 7769

email/ ebost: jonesa23@cf.ac.uk

Twitter: @cardiffsonms

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Appendix 12 Participant Information Sheet

School of Health Care Sciences
Head of School and Dean Professor Sheila Hunt

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



Participant Information Sheet:

Dear *(insert participant's name)*:

I would like to invite you to consider taking part in my study. Before you decide I would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?

This study is aimed towards gaining a PhD. I would like to understand how being mechanically ventilated has impacted on you and your family, and to measure your quality of life. Quality of life is your personal evaluation of satisfaction with areas of your life that you feel are important to you. I would like to measure and discuss your quality of life, and how mechanical ventilation has affected you emotionally.

Why have you been invited?

As you need home mechanical ventilation (HMV), I would like to understand how this has impacted on you and your family, and to measure your quality of life. There are about 18 patients across Wales who need HMV, and I will be inviting all of these patients and their main carer to participate in my study.

Do I have to take part?

Participation in this study is voluntary. It is up to you to decide to join the study. I will describe the study and go through the information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

It will involve an interview of approximately *45 -60 minutes* in length to take place at your home. If you get tired, I may need to interview you again, which could mean that I will visit you twice. I will ask you to identify up to 5 areas that describe your own quality of life, in order of importance to you. I will then ask you to give a weighting (score) to each of the areas using a disk on which sections labelled with the areas you identified are moved to show your levels of satisfaction.

Your quality of life scores can then be worked out from the total of the areas weighting and how important you considered their rating. If you need help to move the disk, I can help with this. I will then ask you some questions on the areas that you identified. You can refuse to answer any of the questions.

With your permission, I will audio record the interview to help with the collection of information, which I will later write out (transcribe).

What are the possible disadvantages and risks of taking part?

This study will offer you the opportunity to talk about your feelings and concerns. I may however, touch upon personal and sensitive issues. With your permission, the consultant who is involved in your care will carry out a brief discussion with you in the weeks prior to the interview to ensure that you are well and able to undertake the interview. If I identify any issues or concerns during the interview, I will suggest that you contact your own GP and with your permission, I will inform your GP and the consultant involved in your care.

What are the possible benefits of taking part?

With the support of the doctors involved in your care, and with your permission, the information could be shared which could improve service provision/ treatment and care. I hope that the results of my study will ultimately be of benefit to you. My study may provide a resource to develop of a register of patients like yourself and family (HIV (invasive) patients) throughout Wales, and possibly the UK.

What if there is a problem?

If you have a concern about any aspect of this study, you could speak to me, and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting my supervisors in the first instance. If you feel that the issue has not been dealt with in a satisfactory way, you could then submit a complaint via the NHS complaints procedure.

Will my taking part in this study be kept confidential?

All of the information which is collected about you during the course of the research will be kept strictly confidential, and your name will not appear in any thesis or report resulting from this study, however, with your permission I will use anonymous quotations.

Information collected during my study will be kept for 15 years on a secure computer system and in a locked office at the School of Healthcare Sciences at Cardiff University. Only I will have access to this information.

What will happen to the results of the study?

I hope to publish the results of the study, and they will be made available to you on completion of the study. You will not be identified in any report or publication.

Who has reviewed the study?

All research in the NHS is looked at by independent groups of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Wales Research Ethics Committee 6.

Further information and contact details:

If you have any questions or concerns about my study, or would like more information to help you in reaching a decision about taking part, please contact me on: 029 2091 7769 or by email at: jonesa23@cf.ac.uk.

I would like to assure you that this study has been reviewed and received ethical consent through the School of Healthcare Sciences at Cardiff University. However, the final decision about taking part is yours. I very much look forward to speaking with you and thank you in advance for your help with this project.

Yours Sincerely,

Anna Jones Student Investigator

Appendix 13 Consent Form

School of Healthcare Sciences
Head of School and Dean Professor Sheila Hunt

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



CONSENT FORM (Patient Participant)

Participant Identifier:

Title of project: Home Mechanical Ventilation (HMV): A Critical Exploration of the Quality of Life of Adult Patients and their Family.

Name of researcher: Anna Jones

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Anna Jones of the School of Healthcare Sciences at Cardiff University.

Please initial box

I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

I was informed that should any emotional issues be identified during the interview, I should contact my own GP and my GP and the consultant involved in my care will be informed by the researcher.

This project has been reviewed by, and received ethical clearance through the School of Healthcare Sciences at Cardiff University. The study has been granted ethical approval through review by Wales Research Ethics Committee 6.

I was informed that if I have any comments or concerns resulting from my participation in this study, I may initially contact Anna Jones or her supervisors, Dr. Jane Harden or Professor Jane Hopkinson.

With full knowledge of all of the above, I agree, of my own free will, to participate in this study.

_____	_____	_____
Name of Participant (Please print)	Date	Signature
_____	_____	_____
Person undertaking interview		
_____	_____	_____
Name	Date	Signature

When completed: 1 (Original) to be kept in care record, 1 for consultee, 1 for researcher file

Appendix 14 Interview Question Guide

- What does quality of life mean to you?
Prompts: If the participant is unable to provide an answer, remind the participant of the study's definition of quality of life.
- Do you think about your own quality of life?
Prompts: Is this something that you do routinely? What factors may trigger you to think about your quality of life?
- What do you feel is important to your quality of life?
Prompts: The CASPER acronym can be applied to ensure that a diverse range of factors are identified: C – Cognitive, A – Affective, S – Social, P – Physical, E – Ecological, R – Religious. What factors affect your own quality of life?
- How has your partner/ husband/ wife/ parent's illness and HMV affected your own quality of life?
Prompts: How long has your partner received HMV for? What type of impact has this had on your life/ lives?
- What do you do to help with ensuring/ improve your own quality of life?
Prompts: Draw on points identified in question 3. Additional points may include:
- Do you have friends and family support and/ or groups/ networks of carers? Formal mechanisms/ systems of support – how do these help? What are your expectations of these? What concerns do you have (now and future)? What challenges need to be overcome to ensure your quality of life? (based on O'Boyle et al. 1993b).

TOAC = Religion, prayer + coming point = "find something", prayer, religion, for vent, "bad", anger, illness, "couldn't breathe", independence - loss, "shadows", care is 24/7.

1 P: those two years I was just, I don't know...that's when I went through religion then *exp + exp*

2 A: mmm

3 P: to find something, how to pray and that. *exp + exp* *synonymous with peace/relaxing?*

4 A: mmm

5 P: and I felt better after that, *exp + exp* *Need for meaning/search for meaning*

6 A: mmmmm, mmmmm

7 P: But before that I was, I was bad. (laughs) *exp + exp* *expressive + experiential*

8 A: mmm

9 P: I used to be so angry (inaudible) *exp + exp* *expressive + experiential* *(10) Lack of individual power.*

10 A: It's brought you some peace? *tab tab* *Reliance on healthcare services for support.*

11 P: I don't know, maybe it's like um like, before I had my trachy I was like... less

12 (inaudible) I was ill and I couldn't breathe *exp + exp* *experiential + expressive*

13 A: mmm *(10) Need for healthcare.* *relational (to illness)*

14 P: but before that I used to go out on my own *exp + exp* *experiential, expressive* *(collates/conspires to use)*

15 A: mmm

16 P: I used to go to town, and meet my friends, ummm but then with this vent, I have to *careers* *have someone with me all the time* *tab tab* *Reliance on care.* *Loss of independence.*

17 A: mmmmm *loss of independence* *(10) Phases of independence.*

18 P: I think that got to me? *exp + exp* *expressive*

19 A: you lost your independence?

20 P: yeah, I think that's probably what it was *exp + exp* *expressive*

21 A: mmmmm *(10) Caring concept.* *Need for 24/7 support.*

22 P: going to 24/7 having someone with you all the time. *exp + exp* *expressive, KTR*

23 C: a shadow *relational*

24 P: Yeah, I think that's... I think that's why I was like that. *exp + exp* *expressive*

25 A: mmmmm

26 P: But I feel that religion helped me

27 A: mmmmm...do you want your tea whilst it's hot?

28 P: that's ok, I can drink it after.

29 C: It's too hot

30 A: too hot?! (laughs)

31 P: I can multi task (laughing)

(3ab) (3c) Society - ? awareness or blindness? *social context.* *experiential.* *Power to bespoke services but little understanding of situational impact.*

Contradictions - was it before vent, but independence *lost for many ventilation - double-edged sword - found meaning in life through religion & prayer but losses along the way.*

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