CARDIFF UNIVERSITY

Understanding the Lack of Equality and Diversity in the Parenting Population

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Thesis Summary

Despite great advances in the acceptability of diverse family forms, strong social norms that parents are typically nondisabled opposite-sex couples still prevail. Parenthood rates are low among those who deviate from this social norm, including disabled people, gay men and lesbians. These individuals are referred to collectively as non-normative groups. Parenthood rates are also low among those who cannot take the normative route to parenthood and require medically assisted reproduction, such as cancer survivors. These individuals were also classified as non-normative groups. Little is known about the reproductive decisions of these populations. The five studies presented in this thesis aimed to explore the causes and consequences of the lack of diversity in the parenting population.

Current parenthood rates in the UK at age 42 were assessed using a large representative dataset. Non-normative groups were at least twice as likely to be childless as the rest of the sample. Being childless was also found to have a negative impact on life satisfaction at age 42 regardless of whether participants belonged to a non-normative group. Current discourse on equality and diversity should tackle the question of whether steps should be taken to reduce the inequality in parenthood opportunities.

A systematic review and a study focusing on disabled people highlighted several barriers to parenthood that affect most non-normative groups. These include negative societal attitudes, poor perceived parenting skills and financial problems. One potential reason for the low parenthood rates among cancer survivors was explored further, that physicians may be less likely to discuss options to safeguard fertility with patients who are gay or single. However, the intentions of medical students were found to be unaffected by patient characteristics, although traditional family values were associated with self-reported bias.

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Glossary of Abbreviations

BCS	British Cohort Study
CI	
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
IAT	Implicit association test
IVF	In vitro fertilisation
MAR	Medically assisted reproduction
NHS	National Health Service
SD	Standard deviation
TDIB	Traits Desires Intentions Behaviour framework
TPB	Theory of Planned Behaviour

Chapter 1: General Introduction and Thesis Overview

General Introduction

Data published by the Office for National Statistics (2014a) suggests that in 2013 only 0.1% of live births in the UK were registered to same-sex couples. While 84% of births were registered to married or cohabiting couples only 6% of births were registered solely to the mother. Together these figures suggest that parents in the UK are very unlikely to be anything other than opposite-sex married/cohabiting couples, at least at the time at which the child is born. In a climate where diversity is encouraged, it might be considered timely to investigate the lack of diversity in the parenting population. There may be social norms associated with being a parent and people who do not fit these are less likely to have children. These individuals will hereafter be referred to as non-normative groups.

Clearly same-sex couples and single people cannot conceive spontaneously through sexual intercourse, and this may contribute to their low parenthood rates. However, over the past two decades, assisted reproductive technologies (ART) and adoption have become more readily available and can now be accessed by everyone in the UK, unless there is evidence of a serious risk of harm to the child (Boivin & Pennings, 2005). Hypothetically, single people and same-sex couples can use ART to have biological children. Whether these services are accessed is of course dependent on people wanting to have children and financial means if the ART required is not funded by the NHS.

What are Non-Normative Groups?

Two types of non-normative groups were identified for the purposes of this thesis: people who do not fit the social norms associated with being a parent and people who are not able to become parents via the normative route (i.e., unaided conception with an opposite-sex partner).

People who do not meet the social norms.

The nine characteristics protected under the Equality Act 2010 can serve as a starting point for identifying marginalised populations: age, disability, gender reassignment, marriage/civil partnership, pregnancy/maternity, race, religion/belief,

sex, and sexual orientation. It is illegal to discriminate based on these characteristics in many situations, such as in the workplace and in the provision of public services. It may or may not be reasons related to discrimination that cause low parenthood rates among certain protected groups, but having the option to become a parent is considered a basic human right (Article 12 of the Human Rights Act).

A recent study from the United States of America (USA) suggests that parenthood rates among lesbians aged 20-44 years are 23%, compared to 68% among heterosexual women (Brewster, Tillman, & Jokinen-Gordon, 2014). This study also found that 56% of bisexual women age 20-44 were mothers, a parenthood rate that is closer to that of heterosexual than lesbian women. Recent statistics from the Labour Force Survey, a representative household survey in the UK, show that 38% of married opposite sex couples have dependent children (defined as children currently living with their parents), as do 41% of opposite sex cohabiting couples. In comparison, only 13% of civil partnered (same-sex) couples and 6% of same-sex cohabiting couples had dependent children (percentages were calculated by the author based on the numbers of households with dependent children, Office for National Statistics, 2013a).

However, evidence also exists showing that childless gay men and lesbians report the desire for children less often than their heterosexual equivalents, but the number is still reasonably high (54% of childless gay men and 37% of childless lesbians want children, compared to 75% of heterosexual men and 68% of heterosexual women, Riskind & Patterson, 2010). These reduced desires are likely to have contributed to the low parenthood rates among gay men and lesbians but cannot fully account for them.

Research on parenthood rates in transgender individuals is minimal. One study found that 22% (n=11) of a sample of 50 transgender men in Belgium aged 22-52 (mean=37) had children (Wierckx et al., 2012). Eight of the 11 fathers (73%) became parents with a female partner using donor sperm, but the remaining three fathers had given birth before undergoing gender reassignment. A further study on parenthood rates among 412 transgender men and women aged 14-71 (mean = 32) in Belgium found that 25% had children (De Cuypere et al., 2007). It is clear that these parenthood rates are lower than in the general population, where approximately 80% of women in the UK have children by age 45 (Office for National Statistics, 2013b).

The British Household Panel Survey has allowed researchers to study parenthood patterns over 14 years among people with a long-term illness that limited their daily activities (1991-2005). These individuals were over 50% less likely to have children than the rest of the sample (Clarke & McKay, 2014). Data from a separate cross-sectional British dataset shows that 49% of disabled people in their 30s had dependent children in their household, compared to 63% of nondisabled people of the same age. Similarly, 52% of disabled people in their 40s had dependent children, which was the case for 61% of nondisabled people. At ages below 30 and over 49, the gap was much smaller (Clarke & McKay, 2014; also note that disabled people is currently the preferred term to use to refer to this group, Department for Work and Pensions & Office for Disability Issues, 2014a).

Not all populations protected under the Equality Act 2010 have reduced parenthood rates, however. Non-White race (e.g., Myers, 1997) and marriage (e.g., Liefbroer, 2005) have been shown to increase the likelihood of becoming a parent, and religion has not been found to influence parenthood rates (e.g., Testa & Toulemon, 2006).

Age is also a protected characteristic, and there are strong age-related norms regarding childbearing. Most people in Great Britain perceive the ideal age for becoming a parent to be 25, with ages below 19 or above 43 being regarded as too young or old (van Bavel & Nitsche, 2013). In particular, the public view of women becoming mothers beyond the average age of menopause (age 50-51) is that it is unnatural and dangerous, even though reproductive technologies exist to achieve a live birth at that age (implantation of frozen eggs). Men, on the other hand are congratulated on having children at ages as old as 70 (Campbell, 2011). Similarly, 19,694 children were born to men aged 45 and over in the UK in 2013, while 1,241 children were born to women of the same age (Office for National Statistics, 2014a). Given the availability of technology that allows women at these ages to have children using their own frozen eggs or donor eggs, women aged over 50 may be considered a non-normative group in future research.

Overall, evidence suggests a lack of diversity in the parenting population, with few people becoming parents who are not able-bodied, heterosexual and in couples. However, research to date is marred by methodological problems that may weaken this conclusion. First, statistics on parenthood among same-sex couples in the UK do not take unpartnered lesbian, gay and bisexual individuals into account or individuals

with children living elsewhere. Second, it is not known how many of the children being raised by gay men and lesbians were born within a same-sex relationship; it is likely that many were conceived during a previous opposite sex relationship. Third, it is not known how many of the children being raised by parents with disabilities were born prior to the parent becoming disabled, for example because of an accident. Additionally, end of life fertility rates among disabled people need to be established to assess how many never have children. Altogether these methodological issues mean that greater precision in research comparing parenthood rates would provide a more conclusive profile of the parenthood population.

People who require non-normative routes to parenthood.

Several other groups can be classified as non-normative because they cannot become parents via the normative route, i.e., by conceiving spontaneously via sexual intercourse. These individuals require some form of fertility treatment or reproductive technology in order to have a biological child, and consist of survivors of health conditions for which the treatment affected reproductive function (e.g., cancer) and people with transmissible conditions (e.g., genetic conditions, HIV) who do not want to risk passing the condition onto a potential child. Same-sex couples, single people, and transgender people who have undergone full gender re-assignment surgery also have to take non-normative routes to parenthood.

A population-based study of 25,784 cancer survivors in Finland found that men and women who were diagnosed before age 34 were approximately half as likely to have a first child as their healthy siblings (Madanat et al., 2008). This may be partly because, despite current guidelines stating that all cancer patients in their reproductive years should be offered fertility preservation before treatment (Loren et al., 2013), evidence suggests that this is not happening in practice. Among female cancer survivors 34%-61% of female cancer survivors recall having fertility discussed with them prior to treatment. The equivalent figure among male cancer survivors is 8.7-60% (Boyd, McCallum, Lewis, & Terris, 2006; Duffy, Allen, & Clark, 2005; Letourneau et al., 2012; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). The most common methods of fertility preservation for cancer patients are sperm, egg or embryo freezing.

People who carry genetic conditions for which the responsible gene is known can avoid the risk of passing it on to their children by using preimplantation genetic

diagnosis (available in the UK since approximately 1994, Harper & Handyside, 1994) or prenatal testing with followed by termination of affected pregnancies (which was available considerably earlier, e.g., Modell & Modell, 1990). However, a study of 451 individuals who were tested for Huntington's disease across several European cities found that those who tested positive were half as likely to have subsequent pregnancies as to those who tested negative (Evers-Kiebooms et al., 2002). Despite the availability of the technologies that could ensure Huntington's disease is not passed on, carriers seem to be frequently deterred from parenthood.

Infertile people are the final group who must also pursue a non-normative route if they want to have a biological child. However, these individuals are generally otherwise healthy and in opposite-sex relationships, so do not fit with the aim to investigate issues related to equality and diversity in parenthood opportunities. Therefore, people with medical infertility, who are already well-studied, will not be examined further in this thesis.

Medically Assisted Reproduction

Although all non-normative groups have the option of exploring parenthood through adoption, this does not allow the possibility for one or both parents to be genetically related to the child. The reproductive options that do allow the child to be genetically related to at least one parent differ between groups and are presented in Table 1.1. To define the terms used in Table 1.1, medically assisted reproduction (MAR) includes all in vitro procedures involving gametes, and a genetic surrogate is a woman who carries a child on the behalf of another individual/couple/co-parents and is also its genetic mother. MAR with cryopreserved gametes involves freezing oocytes or sperm, which can then be used in vitro fertilisation (IVF) at a later date. Alternatively, oocytes can be fertilised through IVF prior to freezing, allowing the embryo to be frozen. Semen retrieval refers to a collection of medical procedures that extract sperm when unassisted ejaculation is not possible.

Highly active antiretroviral therapy (HAART) suppresses HIV and stops the disease progressing. Sperm washing is a procedure that separates healthy sperm from the seminal fluid, thereby removing dead sperm, white blood cells, and bacteria which can reduce the likelihood of successful fertilisation. Consequently, it is used for procedures such as inter-uterine insemination and in vitro fertilisation. Further, because the HIV virus is present in the seminal fluid rather than the sperm itself,

sperm washing has been effectively used to prevent transmission within serodiscordant couples with male HIV infection. Although no randomised controlled trials on the efficacy of sperm washing in the case of male HIV infection have been conducted to date, a recent systematic review reports rates of seroconversion for the mother and child at zero (Savasi, Mandia, Laoreti, & Cetin, 2013). Sperm washing is also used to prevent transmission of hepatitis C when the prospective father is infected (Garrido, Meseguer, Remohí, Simón, & Pellicer, 2005).

Pre-exposure prophylaxis and timed intercourse is a more recently established alternative to sperm washing that can prevent transmission in serodiscordant couples when the man is infected with HIV. Firstly, the man undergoes HAART for at least six months, and providing an undetectable viral load is achieved, the woman then takes an oral or topical antiretroviral agent prior to exposure. Sexual intercourse is timed to coincide with ovulation to maximise the chances of conception (Savasi et al., 2013; Vernazza, Graf, Sonnenberg-Schwan, Geit, & Meurer, 2011). Antiviral therapies are drugs that help suppress the virus in question by minimising reproduction of the virus within the body. Finally, preimplantation genetic diagnosis involves checking embryos for affected genes prior to implantation.

As shown in Table 1.1, most non-normative groups are conceptualised as presumed fertile in order to acknowledge the possibility of unknown medical infertility. The exceptions are cancer survivors and transgendered individuals, who are presumed infertile but are defined as non-normative as a non-normative route to parenthood, namely MAR, is still required.

Table 1.1

The non-normative groups, presumed fertility status, and type of medical intervention required to become parents

NT /	D 1.C ('11')	N 1' 1 4'		
Non-normative group	Presumed fertility status	Medical options		
Lesbians	Fertile	MAR with donor sperm		
Bisexual women	Fertile	MAR with donor sperm if in		
		a relationship with a women		
Single women	Fertile	MAR with donor sperm		
Gay men	Fertile	Genetic surrogate mother		
Single men	Fertile	Genetic surrogate mother		
Transgendered men or	Infertile, non-transgender	MAR with donor sperm or		
women ^a	partner fertile	genetic surrogate mother ^b		
Cancer survivors	Infertile, unaffected	MAR with cryopreserved		
	partner fertile	gametes or embryos; donor		
		sperm or oocyte		
Disabled people	Fertile (men with spinal	For men with spinal cord		
	cord injuries, infertile)	injuries: semen retrieval then		
		MAR		
People with				
transmissible viral				
conditions				
HIV positive, mother	Fertile	HAART		
infected				
HIV positive, father		Sperm washing then MAR;		
infected		pre-exposure prophylaxis and		
		timed intercourse		
Hepatitis B, mother		Immunise the child at birth;		
infected		antiviral therapy		
Hepatitis C, father		Sperm washing		
infected				
Hepatitis C, mother		No known interventions		
infected		- · · · · ·		
People diagnosed with	Fertile	Preimplantation genetic		
genetic disease		diagnosis then MAR; Prenatal		
		diagnosis with the option of		
		terminating an affected		
		pregnancy		
Note: HIV = human immunodeficiency virus: MAR = medically assisted				

Note: HIV = human immunodeficiency virus; MAR = medically assisted reproduction, HAART = highly active antiretroviral therapy. ^a with the exception of those who have retained their original reproductive organs and have a partner with the opposite gametes. ^bDepending on gender.

Legal Rights for Non-Normative Groups

Reproductive options have been made available to lesbian couples with the Human Fertilisation and Embryology Act 1990, and same-sex couples gained full

adoption rights in England and Wales under the Adoption and Children Act 2002. However, legal barriers to genetic parenthood were not completely removed until 2008 due to an ambiguous clause in the Human Fertilisation and Embryology Act 1990. This clause allowed fertility clinics to refuse to treat gay couples and single women if it was perceived that these prospective parents could not meet the potential child's "need for a father" (p. 14). This clause was removed in the Human Fertilisation and Embryology Act 2008, which also extended surrogacy law to allow both members of a same-sex couple to apply for parental rights. Therefore, in principle non-normative groups should now be able to access MAR to conceive providing they have the financial means.

Psychosocial Theories of Reproductive Decision-Making

Four psychosocial theories have been applied to reproductive decision-making. Firstly, Life Course Theory (Elder, 1994, 1998) proposes that the complex interplay between the multiple pathways within each individual's life determines the life course. These trajectories partially result from changing societies and are often age-graded (Elder, 1994). Four main principles reflect the central premises of Life Course Theory: historical time and place, timing, interdependent lives, and agency.

Historical time and place are central to the life course in that they partially determine the events to which the individual is exposed. The principle named timing of lives refers to the age-related expectations and characteristics of social roles experienced by the individual (Elder, 1994). The principle of interdependent lives reflects the importance of the social relationships within which human lives are embedded, and through which social regulation takes place (Elder, 1994). The principle of human agency proposes that individuals make choices within available options and constraints, creating their life course. Behaviour is the result of an interaction between human agency and the changing social context (Elder, 1994).

The Theory of Planned Behaviour (TPB) (Ajzen, 1991) proposes that intentions to carry out behaviours can be explained by attitudes, subjective norms and perceived behavioural control. The behaviour itself can be predicted from intentions and perceived behavioural control. Subjective norms arise from beliefs about social pressures, and perceived behavioural control concerns the perceived ability to successfully carry out the behaviour. Applied to the domain of childbearing (Barber, 2001), attitudes are the result of the costs and benefits associated with parenthood and

the competing alternatives, such as career investment. Perceived behavioural control concerns the extent to which an individual believes they are capable of carrying out a behaviour, which also directly influences behaviour through the variable named actual behavioural control, since certain obstacles may be insurmountable (Ajzen, 1991)

The merits of the application of the TPB to the domain of reproductive decision-making have been extensively debated in the literature. It has been argued that the use of the TPB in fertility research is problematic as it may not be appropriate to assume that conscious intentions are formed prior to conception, given that pregnancies are frequently unplanned (Morgan & Bachrach, 2011). However, this has been disputed and said to reflect a misunderstanding of intentions in the TPB, as intentions relate to the behaviour which would lead to becoming pregnant or not, such as contraceptive behaviour, rather than to pregnancy itself. Therefore, although the pregnancy was unplanned, the behaviour that led to it is often planned on some level, and the high frequency of unplanned pregnancies does not negate the utility of the TPB (Ajzen, 2011).

Part of this uncertainty concerning the centrality of intentions in reproductive decision-making stems from the need for clarification of the concept of intentions, as it is unclear whether intentions are necessarily deliberative or if they can exist at a subconscious level (Bachrach & Morgan, 2011). Regardless of the precise nature of intentions, proponents of the TPB acknowledge that there are circumstances in which intentions are not realised (Ajzen, 2011; Barber, 2011), arguing that one of the benefits of the TPB is that it allows the assessment of the extent to which intentions predict behaviour, and provides a starting point for establishing the reasons for discrepancies, which may include the limits imposed by actual behavioural control (Liefbroer, 2011) or situational forces such as alcohol (Ajzen, 2011).

Multiple intentions can also be in competition with each other. For example, the affiliative drive, which promotes bonding behaviours and sexual intercourse, can occur in competition to contraceptive intentions (Barber, 2011). When a man wants to have sex but a woman does not, the woman's intention to keep and please her partner may override her intention to contracept effectively. This does not suggest that the TPB should be disregarded, rather the circumstances in which certain intentions override others need to be established. Ideally, TPB models of the most important competing intentions concerning any given behaviour should be formulated by collecting the corresponding data (Ajzen, 2011; Philipov, 2011).

Research using the TPB has generally conceptualised the behaviour variable as a single outcome: the birth of a child. However, in reality a myriad of decisions are involved, including the use of contraception and whether to abort a pregnancy (Morgan & Bachrach, 2011). This is not a problem with the TPB per se, but pertains to the need to reformulate intentions based on the most crucial behaviours involved in becoming a parent (Philipov, 2011).

The TPB has been criticised for modelling the associations between factors at a given time point, whereas a comprehensive model needs to account for the dynamic nature of the process (Morgan & Bachrach, 2011) given that many factors cause childbearing expectations to change over time, such as age, partnership, and having a first child (Iacovou & Tavares, 2011). However, Ajzen (2011) argues that this criticism is based on an over-simplified version of the model, and that the complete TPB model includes feedback arrows highlighting the mechanisms through which behaviour can alter beliefs. Therefore, it has been argued that the TPB is not a static model, but the issue is simply one of data collection due to the difficulties associated with collecting data frequently enough to model the recursive relationships between the TPB factors (Ajzen, 2011; Barber, 2011).

The TPB has been highly criticised for being a model that focuses on the individual, underestimating the importance of the social context in which people are embedded (Morgan & Bachrach, 2011). However, proponents of the TPB hold that the theory provides a complete account of the influence of the social context on behaviour through its influence on the unspecified beliefs that underlie all constructs in the model (Ajzen, 2011; Philipov, 2011). For example, changes in the preconditions for family formation, such as financial security, are likely to be reflected in changes in perceived and actual behavioural control (Liefbroer, 2011). Furthermore, reproductive decision-making is, for the majority of people, a process undertaken in tandem with a partner. Whether the TPB's mechanisms for incorporating influences beyond the individual can account for dyadic decision making is debatable.

The Traits Desires Intentions Behaviour (TDIB) framework (Miller & Pasta, 1995) is a fertility-specific theory and is less parsimonious than the TPB. As shown in Figure 1.1, it includes some of the TPB concepts, specifically intentions and attitudes. It differs from the TPB in its inclusion of motivational traits and childbearing desires, its exclusion of perceived and actual behavioural control, and that the TDIB constructs were designed to be measured in both members of the couple.

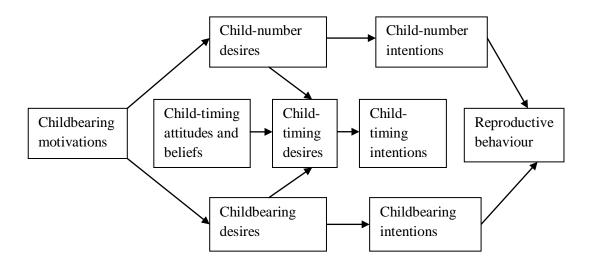


Figure 1.1. Miller and Pasta's (1995) Traits Desires Intentions Behaviour (TDIB) framework.

Although both the TPB and the TDIB present intentions as the precursor to behaviour, the construct is conceptualised differently in the two theories. In the TDIB women can fall into one of three categories: those who intend to contracept, those who intend to procept, and those who have no intentions either way. TPB research has generally measured intentions using a single bipolar scale from positive to negative, but this does not account well for women who have no intentions to either contracept or procept. In these individuals, resulting pregnancies may be guided by unconscious processes, and conscious attention only comes into play after the act to allow sense to be made of behaviour retrospectively (Miller, 2011a).

Motivational traits in the TDIB consist of bonding schemas, which are neurologically based structures that pertain to our perceptions of our social contexts, and how we think about and interact with the people within them. Such schemas have evolved to encourage social bonding and the schema most central to childbearing is the nurturance schema, which drives the affection for offspring as well as the drive to ensure their safety (Miller, 2011a).

Desires, as defined in the TDIB, can take three forms: childbearing, child-number, and child-timing desires (Miller, 2011a). The most similar TPB concept is attitudes, which differs in that it is concerned with the favourability of a behaviour, which in the case of childbearing might be, for example, the favourability of giving birth or stopping contraception (Miller, 2011a). Desires differ from intentions in terms of the underlying motive systems (Miller, 2011b). The TDIB represents two

separate motive systems involved in human reproduction. The first system is the more primitive of the two and involves the automatic and biological drives stemming from the bonding schemas (a form of motivational trait). This system is thought to be present in all mammals. The second system is a human specific system that operates at a cognitive level. It involves intentions and planning and is represented by the TPB. Research suggests that desires operate based on both systems, whereas intentions operate based on the second system only: a study of approximately 3000 related individuals has shown that child-number desires but not child number intentions are heritable (Miller, Bard, Pasta, & Rodgers, 2010). Similar supporting evidence comes in the form of the finding that child-number desires, but not child-number intentions, can be predicted from the variation at the neurotransmitter level (Miller, Pasta, MacMurray, Muhleman, & Comings, 2000).

The previously described criticism of the TPB, relating to lack of focus on the social context, is developed by the TDIB where the individual is conceptualised as part of the larger social system, as well as part of a partnership. Measuring the traits, desires, and intentions of both partners is the optimal way of modelling decision-making in the TDIB (Miller, 2011a).

The action-phase model of developmental regulation (Heckhausen, 1999; Heckhausen, Wrosch, & Fleeson, 2001; Wrosch & Heckhausen, 1999) has also has been applied to reproductive decision-making. This theory posits that as people approach deadlines for goals, their motivation to achieve the goal increases. According to the life-span theory of control, at this stage individuals enter a phase of goal-striving based on primary control: the control exerted when an individual attempts to adapt the world to meet their needs (Heckausen & Schulz, 1993, 1995; Schulz & Heckausen, 1996), Once the deadline has passed, regulatory processes dictate an expected shift to goal disengagement. At this point primary control is no longer adaptive, and the individual must apply their goals to fit into the environment as it stands, referred to as secondary control. In the case of reproductive decisionmaking, women experience a concrete biological deadline, and research has shown that women approaching the deadline tend to actively pursue parenthood whereas disengagement is apparent in those for whom the window of opportunity has passed (Heckhausen et al., 2001). Furthermore, women approaching the deadline were found to conceptualise childbearing as a central life goal, whereas alternative life goals were central to those who had passed the deadline (Heckhausen, et al, 2001). This implies

that the action-phase model of developmental regulation and the life-span theory of control posit that age is an important predictor of childbearing intentions.

Theoretical themes.

The four theories discussed were synthesised with the aim of identifying their points of convergence and divergence, and the results are presented in Table 1.2. A visual representation of the resulting five themes is presented in Figure 1.2, demonstrating how the themes might be grouped conceptually and including the interlinks between them.

Table 1.2.

Themes derived from four psychosocial theories

Theme	Definition	Theories it applies to	How it applies
Time	This theme incorporates two social constructs related to time: a) normative issues, and b) timing in relation to the individuals' life trajectory	All theories	Child-timing intentions, desires, attitudes and beliefs (TDIB) Timing of lives (transitions, LCT) Perceived norms concerning timing (e.g., age, stage of life) (TPB) Increased goal engagement as developmental deadline approaches (Heckhausen)
Agency	Freedom and ability to make choices within the available options.	LCT, TPB, Heckhausen	Biological deadline (Heckhausen, TPB through perceived/actual behavioural control) Capacity to have a child for other reasons, TPB through perceived/actual behavioural control, and agency from LCT.
Planning	Preparing for parenthood, readiness to become a parent	LCT, TPB, TDIB	 Childbearing intentions (Miller) Intentions (TPB) Timing of lives (LCT), other life transitions lead to readiness for parenthood
Motivation	Value attached to parenthood	TPB, TDIB	- Childbearing desires and motivation (TDIB) - Attitudes (TPB)
Population norms	Societal norms concerning whether, when, and with whom to have children.	TPB, TDIB, LCT	Perceived norms (TPB)Historical Time and place (as determines perceived norms, LCT)
Negotiated norms	The impact of the expectations and opinions of close others, such as partner, family and close friends.	TPB, TDIB, LCT	 TDIB: ideally predict decision-making by a couple at the dyadic level, so model all constructs of the partner. Interdependent lives (LCT)

Note. LCT = Life Course Theory, TPB = Theory of Planned Behaviour, TDIB = Traits, desires, intentions, behaviour framework. Heckhausen = the action-phase model of developmental regulation

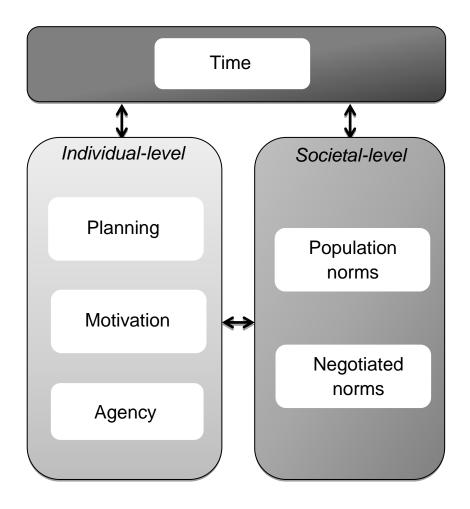


Figure 1.2. Links between the theoretical themes resulting from four psychosocial theories.

Empirical Evidence on Reproductive Decision-Making

Existing evidence supports the theoretical themes proposed in Table 1.2. The results of a systematic review and synthesis on the predictors of the postponement of childbearing have highlighted the factors that influence reproductive decision-making in the general population (Mills et al. 2011). The increased availability of effective contraception has contributed to the postponement trend, supporting the important role of agency. Changes in values and norms support the themes of timing and population norms. Increased education in women and labour market participation were also found to be contributory factors, which is consistent with the themes of planning, motivation, and population norms. Housing conditions, economic uncertainty, changes in partnership characteristics, and an absence of governmental policies that support childbearing were influential factors which highlight the relevance of the planning theme.

However, Mills et al.'s (2011) review did not seek to identify the literature on non-normative groups. To the author's knowledge, two systematic reviews on reproductive decision-making in a non-normative group have been published, both of which focused on HIV positive individuals and reviewed the factors influencing fertility desires (Berhan & Berhan, 2013) and intentions (Nattabi, Li, Thompson, Orach, & Earnest, 2009). Younger age was linked to increased fertility desires and intentions (Berhan & Berhan, 2013; Nattabi et al., 2009), supporting the importance of the timing theme. Accessible antiretroviral therapy and prevention of mother-to-child transmission programs were associated with increased fertility desires and intentions, while concerns about own health and survival had a negative effect (Nattabi et al., 2009). With the exception of the finding that actual experience of antiretroviral therapy had no significant effect (Berhan & Berhan, 2013) these findings are consistent with the principles underlying the theme of agency. Negative attitudes of health professionals towards parenthood among individuals with HIV and similar stigma from the community had negative effects on desires and intentions, reflecting the impact of population norms (Nattabi et al., 2009).

Although these studies provided valuable insight into the factors influencing childbearing amongst individuals living with HIV, the findings were not specific to the decision to become a parent because the results referred to individuals having not only their first, but also higher parity children. Research shows that the first and subsequent births are influenced by different factors (Hank & Kreyenfel, 2003; Kravdal, 1996) which could compound the findings of these reviews. A further limitation of the primary studies available for review was that the overwhelming majority were cross-sectional, preventing causal inferences from being drawn from the results (Berhan & Berhan, 2013; Nattabi et al, 2009).

The small number of existing empirical studies that have focused on other non-normative groups often suffer from similar methodological limitations. For example, a qualitative survey using a sample of 397 lesbians asked what the most difficult issue for lesbians considering parenthood was (Wall, 2011). The main themes were the practicalities of having a child (agency), the financial demands of pregnancy or adoption (planning), lack of social and familial support (agency, planning, and negotiated norms), fear of societal discrimination (population norms), and hindering laws and politics (population norms).

The main methodological limitation of Wall's (2011) study is that just under half of the sample were already parents at the time of the study and their responses may have been influenced by their parenting experiences. Retrospective designs are particularly problematic for studies on reproductive decision-making because longitudinal research has shown that attitudes towards children change significantly once an individual has had their first child (Abbey, Andrews, & Halman, 1994).

Overall, findings presented thus far highlight that the four psychological theories applied to childbearing account for the known barriers to parenthood in non-normative groups. However, poor methodological quality is prevalent in the literature, especially concerning lack of separation by parity, and a stronger review of the evidence is needed.

The Wellbeing of the Child

In considering whether attempts should be made to facilitate parenthood for non-normative groups, evidence on the wellbeing of the potential child must first be considered. Substantial evidence has accumulated showing that the wellbeing of children is not compromised by being raised within non-traditional families. Children parented from birth by single women or same-sex couples are just as well adjusted as the children of opposite-sex couples, with many reviews supporting this view (e.g., Anderssen, Amlie, & Ytterøy, 2002; Bos, Van Balen, Van Den Boom, & Sandfort, 2004; Fedewa, Black, & Ahn, 2015; Golombok & Badger, 2010). Research on the children of transgender individuals is scarce, but a recent study suggests that the children of transgender men develop typically and do not experience major difficulties (Chiland, Clouet, Golse, Guinot, & Wolf, 2013).

Studies have found that children with a parent with a spinal cord injury are not disadvantaged (Alexander, Hwang, & Sipski, 2002; Buck & Hohmann, 1981). Minimal research has looked at the impact of any other physical disability on child adjustment, but that which is available suggests that the children were not affected. In a cross-sectional study, Olkin, Abrams, Preston, and Kirshbaum (2006) examined large samples of parents with and without disabilities, all of whom had teenage children. Three quarters of the disabled parents in their sample had physical disabilities, and the remaining quarter had sensory (blind/deaf), psychiatric or cognitive disabilities. The self-reported family functioning was not found to significantly differ according to whether the parent had a disability or not. Although

self-report measures may be limited by factors such as reluctance to admit to problems, this evidence suggests that disabled people need not be deterred from parenthood by concerns for the child's wellbeing.

In terms of parents who have intellectual disabilities, when IQ is above 60 there is no consistent association between intellectual disability and parenting abilities or child adjustment (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). It has been recommended that parenting capacity is assessed on an individual basis taking into account the factors known to increase the likelihood of successful parenting (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). These include community involvement (Aunos, Goupil, & Feldman, 2003), absence of comorbid mental illness (McGaw, Shaw, & Beckley, 2007), and presence of a nondisabled partner (Tymchuk, 1992).

In terms of heritable genetic conditions, Huntington's disease is used as an example. Current recommendations state that carriers should not automatically be denied the opportunity to have children (de Die-Smulders, de Wert, Liebaers, Tibben, & Evers-Kiebooms, 2013). Counselling focused on the potential impact of parental illness on the child should be undertaken, taking into account the specific situation (MacLeod et al., 2013) and the age of the carrier. The average age of onset is 47 (Orth & Schwenk, 2011) and the older children are at this critical point the more likely they are to form a secure attachment style, an indication of adjustment that predicts healthy relationships later in life (de Die-Smulders et al., 2013; Van der Meer et al., 2006). Altogether these studies show no evidence of there being child welfare issues associated with increasing parenthood rates amongst non-normative groups.

Thesis Overview

This thesis comprised five empirical chapters including a range of designs. Specifically, a longitudinal study (Chapter 2), two cross-sectional designs (Chapters 4 & 6) and an experimental design (Chapter 5). Two secondary analyses were conducted, one which involved a large-scale representative dataset (Chapter 2) and the other consisted of a systematic review of quantitative and qualitative studies (Chapter 3). In addition, three cross-sectional primary datasets were collected and analysed (Chapters 4, 5 and 6). The first of these three datasets (Chapter 4) made use of an Implicit Association Test (IAT) to assess participants' beliefs indirectly to avoid

limitations stemming from socially desirable responding. The other two cross-sectional datasets both consisted of an experimental design (Chapters 5 & 6) and also incorporated a qualitative component (Chapter 6).

Chapter 2: The Extent and Consequences of the Lack of Diversity in the British Parenting Population.

Although existing evidence suggests that non-normative groups are less likely to become parents than the rest of the population, current end of life parenthood rates in the UK are yet to be established. For example, the only UK statistics available on parenthood rates among same-sex couples are those previously described which were calculated by the author based on the numbers of households with dependent children (Office for National Statistics, 2013a). These figures are limited in that they only take cohabiting or civil partnered couples into account. Given that cohabitation or being married increase the likelihood of having a first child in the general population (Hank, 2003; Jokela, Kivimaki, Elovainio, & Keltikangas-Jarvinen., 2009) these figures are likely to over-estimate the proportion of gay men and lesbians who are parents. Furthermore, it is not known how many of the dependent children were from previous heterosexual relationships.

Research has also compared the percentage of childless disabled and nondisabled people of various ages who go on to have children over a 15 year period (Clarke & McKay, 2014). Ideally end of life parenthood rates should be calculated to identify the proportion of disabled people who have children at any point in their lives, regardless of the age at which they had their child(ren).

A substantial body of literature has investigated the impact of being childless on wellbeing, but most non-normative groups are yet to be investigated in this regard. Cancer survivors constitute the one exception. For example, one study found that cancer survivors who desired a child post-treatment but did not conceive reported higher levels of infertility-related distress in comparison to those who did conceive, and higher levels than those who did not want a child (Canada & Schover, 2012). In the general population being childless only appears to become detrimental to wellbeing once people are aged over 40 (Margolis & Myrskylä, 2011). Whether this finding can be generalised to non-normative groups is unknown.

The aim of the Chapter 2 was to estimate parenthood rates and the impact of being childless on wellbeing at the end of the reproductive years among non-

normative groups in the UK. Data was taken from the British Cohort Study with the most recent wave being at age 42. When examining the impact of parenthood and childlessness on life satisfaction at age 42, life satisfaction data from the age 29 wave was used to control for selection effects.

Chapter 3 Part 1: Review of Quantitative and Qualitative Systematic Review Methods

Researchers undertaking systematic reviews frequently conduct meta-analyses of quantitative studies in order to statistically combine the results. However, this approach requires excluding qualitative studies that answer the same research question, resulting in a potential loss of valuable information. Therefore, the aim of Chapter 3 Part 1 was to discuss available methods for the synthesis component of systematic reviews of qualitative and quantitative primary studies. The most underdeveloped area for mixed-method reviews is how to integrate the results of a meta-analysis with the results of a synthesis of qualitative primary studies. A new method for achieving this was proposed and demonstrated in Part 2.

Chapter 3 Part 2: Systematic Review of Reproductive Decision-Making among Non-Normative Groups

Although extensive research has focused on the factors that influence the likelihood and timing of parenthood, the literature is strongly biased towards couples that fit the social norm associated with a parent (i.e., in a heterosexual cohabiting partnership or marriage, and in good health). Research on non-normative groups is comparatively scarce. Chapter 3 Part 2 aimed to identify the main reasons for the low parenthood rates among non-normative groups by investigating the barriers and facilitators of parenthood. A systematic review of reproductive decision-making in all populations was conducted, followed by a sub-search relevant to non-normative groups. Eligible studies used quantitative or qualitative methods to examine the factors associated with a relevant measure of outcome such as first birth, childbearing intentions, or childbearing desires. The systematic review undertaken in this chapter required the results of a meta-analysis to be combined with the results of a synthesis of the primary qualitative studies, which was achieved using the methods proposed in Part 1.

Chapter 4: Implicit Attitudes towards Disabled Parents: Consequences for Parenthood Intentions

The systematic review conducted in Chapter 3 highlighted that no research existed on reproductive decision-making among disabled people. Chapter 3 also demonstrated that age and perceived parenting skills were among the factors that influenced the likelihood of parenthood among other non-normative groups. The role of internalised stigma was less clear because the quantitative and qualitative studies reported inconsistent results (nonsignificant and significant associations respectively, Rabun & Oswald, 2009; Solomon, 1991). One possible explanation for this discrepancy is that the quantitative measures were not specific to parenthood. Alternatively, participants may have been unwilling to report that they held negative beliefs concerning their own group. Implicit measures that do not rely on self-report overcome this limitation whereby participants do not honestly report socially undesirable cognitions. Of these, the most established is the Implicit Association Test (IAT).

Chapter 4 aimed to investigate whether internalised stigma is associated with the intention to have a first child among disabled people. Additionally, the study aimed to assess whether disabled and able-bodied people differ on how capable of raising children they perceive themselves to be and the degree of social pressure to have children they experience. Internalised stigma was operationalised as negative attitudes towards disabled parents, measured using an IAT and a self-report measure. Disabled people and a control group of nondisabled people were recruited into the study. Participants had to be currently residing in the UK, aged 18-28 and childless.

Chapter 5: Don't Ask, Don't Get: A Randomised Vignette-Based Study of Biases in Oncofertility Provision among Medical Students

As previously described, cancer survivors are classified as a non-normative group because many cancer treatments, including chemotherapy, frequently cause fertility problems. Therefore, cancer survivors require a non-normative route to parenthood, and one option is freezing oocytes/sperm or embryos so that they can be implanted at a later point when the person wishes to have a child.

According to current national guidelines, all cancer patients should be told about the risk to their fertility prior to treatment (Loren et al., 2013; National Institute

for Clinical Excellence, 2013; Peccatori et al., 2013). However, only 34% to 61% of cancer survivors recall being informed about the possibility of infertility before they underwent treatment (Duffy et al, 2005; Letourneau et al., 2012).

Physicians have been previously found to admit to being less likely to offer certain cancer patients fertility preservation, including patients who are gay (Forman, Anders, & Behera, 2010; Gilbert, Adams, Mehanna, Harrison, & Hartshorne, 2011; Schover et al., 2002) those who are unmarried or not in a relationship (Forman et al., 2010; Gilbert et al., 2011), and those with a poor prognosis or who need treatment urgently (Forman et al., 2010; Gilbert et al., 2011; King et al., 2008; Quinn et al., 2007; Schover et al., 2002). This can potentially prevent parenthood post-cancer.

However, physicians have also reported being less likely to treat patients who do not bring up the topic of infertility (King et al., 2008; Quinn et al., 2007; Quinn et al., 2009b; Schover et al., 2002). Therefore, one possible reason for the reported biases against certain patients is that those patients are less likely to request fertility information.

The first aim of Chapter 5 was to assess whether medical students are biased by the characteristics of the patient when deciding whether to discuss fertility options prior to cancer treatment. The second was to investigate the extent to which any bias could be accounted for by patients with certain characteristics being less likely to request fertility information. Medical students were randomly assigned to one of six conditions where hypothetical clinical vignettes designed to elicit the known biases were presented: older age, same-sex partner, being unpartnered, poor prognosis, fertility information requested/unrequested, and a control condition. In the first wave the cases involved childless hypothetical patients who requested fertility information. In the second wave the patients did not request fertility information and their parity was not mentioned.

Chapter 6: What Makes Medical Students Biased? The Predictors of Prejudice in Oncofertility Provision.

In Chapter 5 it was established that the characteristics of a hypothetical patient (sexual orientation, marital status, prognosis and age) had no influence on medical students' intentions to discuss fertility prior to the patient's treatment. It was only when the hypothetical patient requested fertility information that intentions to provide this information increased among medical students. Despite the lack of bias at the

group level, there was variation in intentions, which could indicate that individual difference variables influenced the decision-making process and potentially the presence of bias in some medical students.

Research investigating the effect that physicians' beliefs and values have on whether they discuss fertility options with cancer patients is lacking. A small number of studies suggest that influential factors include attitudes towards fertility preservation (Quinn et al., 2009b) and level of comfort discussing the topic of fertility (King et al., 2008; Quinn et al., 2009a).

The aim of Chapter 6 was to explore the beliefs that underlie the bias reported by some medical students, as well as the extent to which the TPB variables can explain intentions. As in Chapter 5, medical students completed a survey containing measures of intentions to initiate fertility discussions or referrals with a hypothetical female breast cancer patient. However, in the present chapter additional measures were analysed, including self-reported bias against referring certain patients (gay, unmarried, poor prognosis, and the patient requesting fertility information), beliefs related to fertility preservation, and traditional family values.

Chapter 2: The Extent and Consequences of the Lack of Diversity in the British Parenting Population

Introduction

Convincing evidence suggests that non-normative groups have lower parenthood rates than the rest of the population, but research that allows the extent of the current discrepancy in the UK to be assessed is lacking. The strongest UK research on parenthood rates among any non-normative groups focused on disabled people. Clarke and McKay (2014) compared the percentage of childless disabled and nondisabled people of various ages who went on to have children in the next 15 years, and found that disabled people were approximately half as likely as nondisabled people to become parents. This is compelling evidence from a large representative dataset that disabled people have low parenthood rates, but it does not show end of life parenthood rates, i.e., the proportion of disabled people who have at least one child during their lifetime, regardless of the age at which they had their child.

The only UK statistics available on parenthood rates among same-sex couples are those described in Chapter 1 which were the proportion of same-sex and opposite-sex partner households with dependent children (Office for National Statistics, 2013a, proportion calculated by the author). These figures only take the dependent of cohabiting or civil partnered couples, which further limits the conclusions that can be drawn. In the general population, cohabiting or being married strongly predict the likelihood of a first child (e.g., Hank, 2003; Jokela et al., 2009), so these figures may over-estimate the frequency of parenthood among people who identify as lesbian or gay. Additionally, if gay men and lesbians are more or less likely to be living with a partner/spouse than heterosexual people, as research suggests is the case (Brown & Keel, 2015; Cochran, Sullivan & Mays, 2003), and if gay men and lesbians are more or less likely to have children that do not live with them, these figures will provide inaccurate indications of the difference in parenthood rates. Furthermore, it is not known how many of the dependent children in these figures were from previous opposite-sex relationships.

Interpretation of the figures is further complicated by the use of relationship status to infer sexual orientation. It is likely that a proportion of the people in

same-sex relationships identify as bisexual or sexual orientations other than lesbian or gay. Furthermore, research suggests that in the USA parenthood rates among bisexual women (56%) are substantially higher than those among lesbians (23%, Brewster et al., 2014), so people who identify as bisexual should be treated as a separate group to gay men and lesbians. In the present study, these limitations were addressed by assessing parenthood rates among lesbian, gay and bisexual individuals using self-reported sexual orientation and inferring whether these children were had within the context of a same-sex or opposite-sex partnership. Parenthood rates among people with disabilities only examined people who reported having a disability before they had children. End of life parenthood rates were estimated that took into account whether people had ever had a child and not just whether they had a currently dependent child in their household.

Gay men and lesbians report wanting children less often than their heterosexual equivalents, but the number is still reasonably high and cannot fully account for the low parenthood rates. Specifically, 54% of childless gay men and 37% of childless lesbians aged 15-44 in the USA want children, according to a large scale representative dataset collected in 2002. In comparison, 75% of childless heterosexual men and 68% of childless heterosexual women expressed parenthood desires (Riskind & Patterson, 2010).

Overall, despite the availability of ART and at least moderate desire for children, non-normative groups are less likely to become parents than the rest of the population. The aim of the present study was to establish parenthood rates, as well as the reasons for and consequences of being childless, among non-normative groups

The Wellbeing of Adults with and without Children

The low parenthood rates among non-normative groups may present a quality of life concern. There is research on the impact of being childless on wellbeing, but this literature is yet to investigate diverse family forms as represented by the non-normative groups described. The one exception concerns cancer survivors. A study of 240 female cancer survivors showed higher infertility-related distress in those who wanted a child post-treatment but did not have one, compared to those who had successfully conceived or did not want a child (Canada

& Schover, 2012). No studies have looked at the impact of having children among male cancer survivors, however.

The general research on the relationship between parental status and wellbeing presents a complex picture: parenthood comes with costs and benefits, and the relative influence of each depends on the social context of the individual. Studies have found that having children increases (e.g., Hansen, Slagsvold, & Moum, 2009; Nelson, Kushlev, English, Dunn, & Lyubomirsky, 2013) and decreases (e.g., Stanca, 2012) life satisfaction. The context of the lives of nonnormative groups is central to understanding the impact of having children among these groups.

Life Course Theory (Elder, 1994, 1998) is a commonly used framework for interpreting the literature on parental status and well-being (e.g., Umberson, Pudrovska, & Reczek, 2010). As stated in Chapter 1, the framework emphasises the importance of considering the many facets of the social context when explaining human development. It consists of four main principles which can be used to help map the possible impact of parenthood on non-normative groups.

The principle of timing highlights that the many trajectories in an individual's life (e.g., financial security, parenthood) are influenced by each other. For example, a large scale study across 94 countries found that parenthood negatively affected financial satisfaction (Stanca, 2012). Consequently overall life satisfaction was reduced for the majority of the sample because it is related to financial satisfaction. However, when a measure of life satisfaction that excluded financial satisfaction was used as the outcome measure, parenthood was found to significantly improve life satisfaction (Stanca, 2012).

The impact of having children is further illustrated by evidence showing that parents live longer than childless individuals, even after confounding variables such as relationship status are controlled (e.g., Martikainen, 1995; Ringbäck Weitoft, Burström, & Rosén, 2004). It is conceivable that parenthood would be a more stressful experience and would have a more negative effect on life satisfaction for some non-normative groups. For example, for same-sex couples societal stigma may render parenthood more stressful, or in the case of people with certain disabilities, health limitations may make raising children a lot more demanding. Studies highlight the social and practical difficulties involved with bringing up children as a disabled parent (e.g., Duvdevany, Buchbinder, & Yaacov, 2008;

Preston & Jakobson, 1997), suggesting that a life trajectory that involves being a member of a non-normative group strongly influences the trajectory that parenthood experiences take.

The principle of linked lives highlights that each individual's life course is profoundly influenced by the lives of those around them. This suggests that the nature of a parent's relationship with their child influences the quality of life of the parent. The consensus of the literature is that the stress of parenting young children is temporarily detrimental to the wellbeing of most parents (e.g., Evenson & Simon, 2005; Umberson et al., 2010). However, a study on individuals over 55 suggested parenthood can be beneficial if the relationship with their child(ren) is strong. Parents with close relationships with their children reported higher life satisfaction and happiness than individuals who wanted to have children but never did. Those with distant relationships with their children experience experienced poorer happiness and life satisfaction than parents with close relationships (Connidis & McMullin, 1993). Overall, given the previously described evidence that diverse families function as well as traditional families, there is no reason to expect that parent-child relationship quality would differ by family type. All individuals with strong relationships with their older children are likely to benefit from parenthood, suggesting that the well-being of non-normative parents will not differ to that of the rest of the population.

The principle of agency highlights that people make choices within the available opportunities and constraints. Few studies have taken into account whether it was the individual's choice to remain childless. However, the previously mentioned study of people over the age of 55 found that the happiness and life satisfaction of people who were childless by choice did not significantly differ from parents who had close relationships with their children. Those who were involuntarily childless, however, reported significantly lower life satisfaction than parents with close relationships to their children. Men but not women who were involuntarily childless also reported significantly lower happiness than parents with close relationships with their children (Connidis & McMullin, 1993). To the authors' knowledge there are not any studies on younger people that take voluntary childlessness into account. As non-normative groups experience more constraints to becoming parents, more of those who wanted children may perceive that their situation prevented them from having children. This perceived lack of control may

cause a similar negative impact on wellbeing to that experienced by the involuntary childless people in Connidis & McMullin's (1993) study.

The final principle of Life Course Theory is that historical time and the geographical location in which the individual's life takes place will influence their life course. For example, a large scale survey of over 200,000 individuals from 86 countries found that the welfare regimes of different countries influenced the association between parenthood and happiness in complex ways (Margolis & Myrskylä, 2011). Specifically, parenthood was found to be associated with lower happiness scores among young adults, and this effect was the strongest in countries with poor public support available for parenthood, including former socialist and Southern European countries. However, after the age of 40, parenthood became associated with higher happiness scores, and this finding was strongest in countries where family members typically assume responsibility for supporting people through old age, including many developing countries. This suggests that nonnormative parents will cope better with the stress of childrearing when they live in places with supportive social attitudes.

Methodological Issues in Assessing the Consequences of Being Childless

One of the methodological difficulties in research on the impact of having children on life satisfaction is controlling for selection effects. It is possible that any differences between parents and nonparents may be because happier people are more likely to have children. Some of the studies described attempt to control for these selection effects using measures such as inpatient stays in hospital in the four year period prior to the study (Ringbäck Weitoft et al., 2004). However, by the authors' own acknowledgement, although those with inpatient stays are likely to be less happy, controlling for inpatient stays does not entirely control for happiness levels. The use of a longitudinal design would better control for selections effects with participants completing the same measure of life satisfaction in early adulthood and once they are no longer of reproductive age.

One of the main difficulties in analysing data from minority groups is that the optimal sampling methodology, probability sampling (when the entire population has equal probability of selection and are selected randomly), typically results in small numbers of minority group members. Nonprobability sampling (when participants are not picked randomly, usually based on convenience) introduces bias due to the often unknown differences between selected and unselected participants. Nonprobability samples can be used to test for associations between variables, but as they are not representative they cannot be used for estimating population-level parameters like prevalence (Meyer & Wilson, 2009). Therefore, in order to achieve the aim of estimating parenthood rates among nonnormative groups in the UK, a probability sample was required. The main disadvantage of using a probability sample in the current context, was that particularly rare groups, such as transgender individuals, were likely to be too scarce in the sample to allow analysis. Sampling strategies to recruit representative samples of such individuals need to be developed to accurately establish their parenthood rates.

The Present Study

The first aim of the present study was to establish parenthood rates at the end of the reproductive years among non-normative groups in a representative UK sample. The second aim was to compare the reasons given for remaining childless across groups. The third aim was to compare the impact of having children on life satisfaction at the end of the reproductive years between non-normative groups and the rest of the sample.

Based on the existing evidence, the parenthood rates in the non-normative groups were hypothesised to be lower than in the rest of the sample. The previously described principles of Life Course Theory support the null hypothesis that the impact of having children on life satisfaction would not differ between the non-normative groups and the rest of the population, and that having children would be associated with higher life satisfaction for all at the end of the reproductive years. It was also hypothesised that people with disabilities or transmissible conditions would give more health-related reasons for not having children than controls, and other groups would give more societal reasons than controls.

The British Cohort Study (BCS) was the most suitable dataset because the most recent wave took place recently in 2012 when participants were age 42.

Although age 42 years is two years younger than the conventional definition of end

of reproductive years for women (Dietz et al., 2011), and some men will have children at older ages than this, this dataset was deemed the most suitable as it is the only one that measured sexual identity and provides the longitudinal data required to control for selection effects. The BCS aimed to recruit everyone born in the UK in a particular week in 1970.

The impact of parental status on life satisfaction was examined because evidence suggests that parenthood/having children may influence cognitive factors such as life satisfaction more strongly than affective wellbeing, such as depressive symptoms (Hansen et al., 2009). Based on the previously described studies, financial difficulties and not wanting to have children also influence the impact of parental status so were controlled in these analyses. Selection effects were controlled using life satisfaction at age 29.

Methods

Participants

The British Cohort Study aimed to recruit all children born in the UK in a single week in 1970. In wave one (at birth) there were 16,571 participants, which was the result of a response rate of 95.9%. Parents gave informed consent on behalf of the participants, who were followed up with their parents at the ages of five, 10, and 16. Participants gave informed consent themselves for the adult follow up interviews at ages 26, 30, 34, 38, and 42. Of the 12,198 participants who could be traced and were invited to participants in the age 42 wave, 9,841 participated giving a response rate of 74.6%. Of the original sample, 58.6% completed the age 42 interview. Participants were assigned to a non-normative group or the control group, i.e., the normative group.

As shown in Table 2.1, five non-normative groups within the sample were identified: gay men/lesbians, bisexual people, cancer survivors, disabled people, and a control group. Participants had to have been present at the age 42 wave of the survey to be eligible for inclusion. If a group did not meet the criteria for a non-normative group then they were assigned to the control group.

Table 2.1.

The inclusion criteria for each of the five groups of participants.

Group	Inclusion criteria
Gay/lesbian	Present at age 42 wave
	Self-identified as gay or lesbian at the age 42 wave
Bisexual	Present at age 42 wave
	Self-identified as bisexual at the age 42 wave
Cancer	Present at age 42 wave
	Had any type of cancer while childless at any age
Disability	Present at age 42 wave
	Reported a long term medical condition/disability while childless at
	any age
Control	Present at age 42 wave
	Self-identified as heterosexual at the age 42 wave
	Did not report experiencing cancer or a disability while childless

Information on HIV and hepatitis was not obtained in the age 42 wave, but at age 38 three participants reported HIV and none reported any form of hepatitis. Additionally, no information on carrier status for genetic conditions was obtained during the study so individuals with transmissible conditions could not be studied from this dataset. Two participants indicated that they had undergone gender reassignment at age 42, which also precluded analysis of this group. Single men and women who could be classified as non-normative group could not be assessed because whether participants had met the right person to have children with or not is subjective, and few individuals would have been unpartnered for their entire lives. As shown in Table 2.2, individuals who identified as gay or bisexual constituted less than 4% of the sample. Less than 1% were cancer survivors. The largest group was disabled people (approximately 20%). The control group comprised individuals who identified as heterosexual, never reported a disability or cancer, or reported experiencing disability or cancer after the birth of their first child.

Table 2.2.

The percentages of the 1970 cohort that identified as gay/lesbian or bisexual, or had experienced cancer or a disability while childless, according to gender (N=9841).

Characteristic	Men (<i>n</i> =4724)	Women (<i>n</i> =5117)
	% (<i>n</i>)	% (n)
Gay/lesbian	2.4% (112)	1.3% (67)
Bisexual	0.7% (31)	1.0% (50)
Cancer	0.5% (22)	0.4 (22)
Disabled	20.0 (946)	18.4% (943)
Control group	77.1% (3644)	78.9 (4038)

Some participants belonged to more than one non-normative group, as many gay men and lesbians also had disabilities. Specifically, of the 112 gay men, 50 (44.6%) reported a disability. Of the 67 lesbians, 29 (43.3%) reported a disability. Rates of disability were also high but to a lesser degree among bisexual people. Of the 31 bisexual men, 10 (32.3%) reported disabilities and 18 of the 50 bisexual women (36.0%) reported disabilities. No gay or bisexual participants were also cancer survivors.

The majority of cancer survivors also reported being disabled. Of the 22 men who were cancer survivors, 14 reported being disabled (63.6%), as was the case for 16 of the 22 woman cancer survivors (72.7%).

Materials

The following describes how questions from the BCS were used in the present set of analyses.

Parenthood.

Participants were coded as having at least one child, biological, adopted, fostered or a step-child. If participants had at least one biological child, they were coded as biological parents. Participants who had at least one step-child were coded as step-parents regardless of whether they also had any foster/adopted children, primarily because there was no variable specifically to indicate that participants had adopted or fostered at any point in their lives. The only participants who were coded as foster/adoptive parents were people who reported

having at least one child but not biological or step-children. Parenthood status was assessed at every wave of the study in order to determine if participants who had experienced disability or cancer did so before becoming parents.

Participants were coded as either being childless at age 42, being parents by age 29, or childless at age 29 but parents by age 42. This was because life satisfaction at age 29 was controlled for, as described in more detail in the subsequent section. Being a parent was defined as having at least one biological or nonbiological child.

Life satisfaction.

Life satisfaction was measured using a single item: 'Here is a scale from 0 to 10, where '0' means that you are completely dissatisfied and '10' means that you are completely satisfied. Please select the number which corresponds with how satisfied or dissatisfied you are with the way life has turned out so far.' Life satisfaction at age 29 was used to control for selection effects because age 29 represents an age where participants would have contemplated or would be contemplating their childbearing goals. Specifically, average age at first birth for women in the UK is currently 28.3 (Office for National Statistics, 2014a).

One way of assessing the reliability of single-item measures is to use longitudinal data. An autoregression model is used, predicting life satisfaction scores on a given wave from the life satisfaction scores on previous waves. The proportion of variance accounted for by previous life satisfaction is interpreted as an indicator of reliability. Using an enhanced version of this method that takes into account the variation in life satisfaction that is due to specific events that occur close to the time of measurement, Lucas and Donnellan (2012) found that a single-item measure of life satisfaction, similar that used in the BCS, had moderate reliability. The consensus is that adequate reliability is indicated by a coefficient of 0.7, and the single-item measure was found to have coefficients of 0.74, 0.74, 0.73 and 0.68 in four separate longitudinal datasets (Lucan & Donnellan, 2012).

Measure of sexual identity.

Participants were asked: 'Which of the following options best describes how you think of yourself?' Five response options were provided: 'Heterosexual / Straight',

'Gay / Lesbian', 'Bisexual', 'Other' or 'Prefer not to say'. Questions of this type measure participants' sexual identity, which is an aspect of the self-concept and concerns how participants view themselves (Ridolfo, Miller, & Maitland, 2012). Sexual identity was of greater interest in the present study than measures related to sexual attraction or behaviour. Participants who indicated 'prefer not to say' or did not answer the question were excluded. Additionally participants who indicated 'other' were excluded as they are likely to be a heterogeneous group.

Disability.

People were classified into the disability group if they reported being disabled at any point in their lives while childless. Under the Equality Act 2010 disability is defined as having lasted 12 months and substantially affecting daily life.

In the BCS, disability at age 16 was assessed via participants' parents' response to 'Does your teenager have an impairment, a disability or a handicap? (By 'impairment' we mean a physical or mental abnormality-illness. By 'Disability' we mean difficulty in doing one or more mental or physical activities that average 16 year olds can do. By 'Handicap' we mean a disability which interferes with the opportunities that others take for granted. E.g. problems with access/facilities in public buildings; not being considered for jobs he or she could manage if given a chance; other people are put off without even knowing what he or she is like).' Five response options were provided: no, yes, an impairment, yes, a disability, yes, a handicap, and not known. Participants whose parents checked the response option 'not known' were marked as not having a disability, because if they were still disabled at a subsequent wave they would be classified into the disability group anyway.

At age 21 participants were asked 'Do you suffer from any long term health problem, long standing illness, infirmity or disability, including problems due to depression or emotional problems?'. Yes/no/don't know. At age 26 participants were asked 'Do you suffer from any long term health problem, long standing illness, infirmity or disability of any kind?' Yes/no/don't know. Disability questions at other ages were similar. There was no feasible way of assessing what type of disabilities participants had as this was not measured in all waves.

There was no data to allow duration of disability to be assessed at any age apart from disability reported at age 42. At age 42 participants were asked 'Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?' Yes/no. If yes they were asked 'Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities? Would you say: Yes a lot, yes a little or, Not at all'. If the answer is yes a lot or yes a little, then participants were asked 'For how long has your ability to carry out day-to-day activities been reduced? Would you say less than six months, between six months and 12 months, or, 12 months or more'. For this age participants who reported a condition that affected their ability to carry out daily activities (a lot or a little) that had lasted 12 months or more were classified as disabled.

Cancer.

The first age at which participants were asked whether they had ever had cancer was at age 29. The question text read: 'Have you ever had or been told you had cancer?' and the response options were yes/no. Participants were also asked 'How old were you when you first had cancer?'. If they had experienced cancer before their first child was born then they were classified into the cancer group. Experience of cancer was also measured at ages 34, 38 and 42. Age at which cancer was diagnosed was not measured in these waves so only participants who were childless at the point of each wave were classified into the cancer group. Participants who were already parents at the time of cancer diagnosis were placed in the control group because they did not belong to a non-normative group at the time of decided whether or not to have a first child.

Questions on reasons for not having children.

In the age 42 wave, participants who were childless were asked the following question: 'Are there any particular reasons why you have not [yet] had any children? Please select all that apply' The list of 15 options presented to participants by the interviewer was: 1) infertility problem (personal), 2) infertility problem (partner), 3) my partner has been sterilised or had a vasectomy / hysterectomy, 4) other health reason, 5) I have not wanted to have children, 6) I have wanted to have children but have not got round to it, 7) my spouse/partner has

not wanted to have children, 8) my spouse/partner already has children and has not wanted any more, 9) I have never met the right person to have children with, 10) my financial situation would have made it difficult, 11) my housing situation would have made it difficult, 12) I have not wanted to compromise my relationship with my partner, 13) I have been focused on my career, 14) no particular reason, 15) other reason (specify).

The first three options were combined and described as 'infertility or sterilisation' and the two options related to financial and housing situations were combined to form 'financial reasons'. Relational options 7, 8, 12 were grouped to form 'relational reasons'. The final list of reasons was therefore 'infertility or sterilisation', 'financial reasons', and 'relational reasons'.

Employment.

Employment was measured using a derived variable created by the Centre for Longitudinal Studies (Hancock & Brown, 2014), whereby if participants provided their employment status at their last interview and indicated that their status had not changed, this was coded as their employment status. Those who did not provide information on their employment status at the last interview were asked 'Which of the things on this card best describes what you were doing [in 'year of last interview' or on 1st January 2000].' The following response options were provided: full-time paid employee (30 or more hours a week), part-time paid employee (under 30 hours a week), full-time self-employed, part-time self-employed, unemployed and seeking work, full-time education, part-time education, on a government scheme for employment training, temporarily sick/disabled, permanently sick/disabled, looking after home/family, other.

Participants who indicated that their employment status had changed since the last interview provided a chronological account of the changes that took place until current employment status was reported. The same response options were provided. For the present study, the employment variable was dichotomised such that participants who selected any of the first four points were classified as employed. All other responses were classified as unemployed.

Partnership status.

Participants reported all members of their household, and their relationship to each member. From this information, those living with a partner/spouse could be identified. Participants who were not living with a partner were asked the following question: 'Are you in a relationship with someone at the moment?' (yes/no). Participants who responded 'yes' were coded as having a noncohabiting relationship.

Ethnicity.

Ethnicity was not measured at age 42, so data from the age 29 dataset were used. The percentage of participants who reported their ethnicity as anything other than White was too low to allow subgroup analysis by different non-White ethnicities, such as Asian or Black. Therefore, participants were broadly classified as either 'White' or 'non-White'.

Income.

Participants were asked 'What was your take-home pay the last time you were paid, that is after any deductions were made for tax, National Insurance, pension, union dues and so on?' Participants provided a figure to the nearest £ and indicated the period of time that payment covered. Participants were then asked 'Is this your usual take-home pay?' (yes/no). Participants who responded no indicated their usual take-home pay. Appropriate multiplications were conducted to convert all responses into a figure for annual income.

Self-employed individuals were asked the following question: 'I know that it is sometimes difficult for self-employed people to give an exact figure for their income, but could you please think about your take home income in the last 12 months. That is, the amount you personally took out of the business after all taxes and costs. About how much is this?' Participants responded to the nearest £. An overall annual income variable was constructed by combining participants' usual take-home pay per annum with the annual take-home pay reported by self-employed individuals.

Education.

The Centre for Longitudinal Studies classified academic and National Vocational Qualification (NVQ) levels of education into five levels: No qualifications, NVQ level 1, bad O-levels or CSE grades 2-5, NVQ level 2, good O-levels, 2+ A levels or 1 A level, NVQ level 3, >1 A level, NVQ level 4, diploma, degree or PGCE, NVQ level 5, higher degree. The measure was dichotomised for use in the present study such that participants were classified based on whether they had been educated to diploma/degree level or not.

Religion.

Participants were asked: 'Do you see yourself as belonging to any particular religion? If so, please select which one.' Due to the low prevalence of religions other than Christianity, in the present study responses were coded according to whether they saw themselves as belonging to any religion or not.

Financial difficulties scale.

Financial difficulties were measured using the following question: 'How well would you say you personally are managing financially these days?' A five point response scale was provided (1 'living comfortably' to 5 'finding it very difficult').

Future parenting.

Future childbearing expectations and the value of having children were measured and reported separated by parenthood status because evidence shows that attitudes towards children change once people have had their first child (Abbey et al., 1994). Childbearing expectations were assessed with: 'How likely is it that you will have a/another child?' A four point response scale was provided, 1=very likely, 4=not at all likely. In order to assess the value having of children, participants were asked: 'Below is a list of things that people value. For each one we'd like to know on a scale from 1 to 10 how important each one is to you, where '1' equals 'Not important at all', and '10' equals 'Very important'.' One of the items

in the list was 'having children', and responses to this item represented the value of having children.

Desire for children was also measured using the responses to the previously described questions on not having children. Childless participants that indicated that one of the reasons why they were not parents was because they had no desire for children were classified as not wanting children. Not specifying that lack of desire was one of their reasons for not having children was taken to indicate that they did experience parenthood desires.

Data Analysis

In order to determine whether socio-demographic characteristics varied by group, dummy variables for each group were created. For example, the dummy variable for cancer survivors was coded one if the individuals reported a diagnosis of cancer and zero if they had not. This was regardless of their potential membership of other non-normative groups, for example if they also identified as gay or lesbian. To assess whether relationship status significantly differed according to cancer survivorship, a chi-square was conducted: experience of cancer by relationship status. The reason for looking at whether any demographic variables differed by group was to ensure that there were no confounders in any of the regression models.

A logistic regression was used to assess the association between being a member of a non-normative group and being childless at age 42. In the first step the dummy variables previously described representing the non-normative groups (to which participants could belong to more than one) were entered. In the second step any demographic variables were entered which significantly differed by group and were associated with parenthood status with at least a medium effect size. Prior to conducting the logistic regression it was checked that no more than 20% of cells had expected counts of less than five.

Prior to conducting the regression model with life satisfaction as the dependent variable, data screening was undertaken. Frequency counts of all dichotomous variables were computed to check for variables in which 90% or more of the responses fell into the same category. This creates not only univariate outliers, but also the correlation coefficients representing associations with other

variables are reduced in size (Rummel, 1988). Given that gay men/lesbians, bisexual individuals and cancer survivors each represented <10% of the sample, robust linear regression was the appropriate method to use because it is not biased by outliers or extreme splits. Using the R package robust, M-S estimators were used as these are currently the optimal robust method for multiple regression involving categorical predictors (Wang et al., 2014).

A hierarchical robust multiple regression was run, comprising four steps within which forced-entry was used to enter variables. In the first step the dummy variables comprising the non-normative group in question (i.e., whether participants were gay, bisexual, disabled, or a cancer survivor) were entered, in order to assess the impact of belonging to one of the non-normative groups on life satisfaction. The reference group was the control group. The second step added parental status to the model.

In the third step of the model the covariates that could account for other influences on life satisfaction were added. These were life satisfaction at age 29, financial difficulties, whether the participant was childless because they did not want children, gender, and any demographic variables that significantly differed by group and correlated with life satisfaction at age 42 such that r>.03. It was necessary to separate between people who became parents before and after age 29 because controlling for life satisfaction at age 29 results in the beta coefficients signifying the change in life satisfaction between the age of 29 and 42. The life satisfaction of people who already had children by the age of 29 would most likely be influenced by the stresses of parenting young children. Therefore the change in life satisfaction between ages 29 and 42 would reflect the change associated with their children growing older rather than the impact of having children.

In the fourth step interaction terms were added to investigate whether the influence of having children on life satisfaction was moderated by gender or membership of the non-normative group in question (e.g., cancer survivor). The three-way interactions 'characteristic x gender x parental status' were included, along with all possible two-way interactions based on the same three variables. The interactions between parenthood status and life satisfaction at age 29 were also included to assess whether there were any differences in the relationship between life satisfaction at age 29 and 42 in the three parenthood status groups (parent by 29, parent after 29, childless).

Power calculations were run using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009). As there are no power calculators available for robust linear regression, conventional linear regression calculations were used as a guide. The multiple regression model described would have involved 32 independent variables if no demographic covariates were used. A minimum sample size of 193 participants (overall, i.e., including the non-normative and control groups) would be required to achieve adequate power to detect medium effect sizes. Clearly the overall sample size is well above that but the small size of some of the non-normative groups may still negatively affect power.

Results

Socio-Demographic Characteristics

The demographic characteristics of the sample are presented in Table 2.3 and Table 2.4, the latter of which separates by gender. Relationship status significantly differed by sexual orientation (gay/bisexual/heterosexual by relationship status, χ^2 (6) = 239.65, p<.001), cancer survivorship (χ^2 (3) = 11.0, p=0.013) and disability status (χ^2 (3) = 192.79, p<.001). Bonferroni post hoc tests revealed that people in any non-normative group were less likely to be in a relationship than those not in that group. Therefore, gay men/lesbians and bisexual people were more likely to be single that heterosexual people, cancer survivors were more likely to be single than people who had not had cancer, and disabled people were more likely to be single than nondisabled people. Divorce rates were significantly higher among bisexual individuals (χ^2 (1) = 12.16, p=0.001) than people who identified as heterosexual. Additionally, divorce rates were significantly lower among people with disabilities (χ^2 (1) = 6.87, p=0.010) than the rest of the sample. No other non-normative groups had an increased likelihood of divorce.

Significance testing revealed that income was significantly higher among people who identified as gay or lesbian compared to people who identified as heterosexual (Kruskal Wallis Test conducted due to income being skewed, $\chi^2(1) = 15.71$, p < 0.001). Income was significantly lower among people who identified as

bisexual compared to heterosexual (χ^2 (1) = 10.50, p=0.001), cancer survivors compared to people who had never had cancer (Spearman's rho = -0.021, p=0.038) and disabled people compared to nondisabled people (Spearman's rho = -0.027, p=0.008).

The majority of the sample was employed, although people with disabilities were significantly more likely to be unemployed than full-time employed, compared to nondisabled people (χ^2 (1) = 32.94, p<.001), and bisexual people were significantly less likely to be full-time employed than heterosexual people (χ^2 (1) = 12.64, p=.001) Approximately half of the sample had degree-level education, but more individuals who identified as gay reported having done a degree than heterosexual people (χ^2 (1) = 14.91, p<.001).

Ethnicity did not significantly differ by group, with the vast majority of the sample being British. Around half of the sample reported no religion, and gay men and lesbians were significantly less likely to be religious than heterosexual people (χ^2 (1) = 11.80, p=.001). Of the demographic characteristics that differed by group, the only one that was correlated with life satisfaction to the degree that would warrant inclusion in the regression model (r > .3) was relationship status.

The value of having children was significantly lower among childless gay men/lesbians than among childless people who identified as heterosexual or bisexual (Spearman's rho = -0.17, p<.001). Similarly, the value of children reported by gay/lesbian parents was significantly lower than that reported by bisexual or heterosexual parents (Spearman's rho = -0.026, p=0.035). Parents with disabilities also reported lower value of children (Spearman's rho = -0.043, p<.001) compared to parents who did not have disabilities. Similarly, childless gay men and lesbians were more likely to report no desire for children (χ^2 (1) = 14.96, p<.001), while childless cancer survivors reported wanting children more frequently than those who had not experienced cancer (χ^2 (1) = 5.87, p=0.021).

Table 2.3.

Sample characteristics by group.

	Gay (<i>n</i> =179)	Bisexual (<i>n</i> =81)	Disabled (n=1,889)	Cancer survivors (<i>n</i> =44)	Control group (n=7682)
In a relationship % (n)	58.7 (81)	64.1 (50)	75.4 (1257)	77.3 (34)	87.1 (6689)
Mean income (SD)	22,355 (15,939)	14,541 (21,066)	18,095 (21,054)	13,375 (13,665)	20,052 (52,866)
Employed % (n)	88.3 (158)	71.6 (58)	80.3 (1511)	70.5 (31)	86.7 (6641)
Education to diploma or degree level % (n)	54.7 (98)	42.0 (34)	46.0 (867)	43.2 (19)	40.3 (3098)
British ethnicity % (n)	95.3 (143)	91.4 (53)	94.6 (1,602)	89.7 (35)	95.0 (6204)
No religion % (n)	63.0 (104)	55.2 (37)	51.2 (855)	52.5 (21)	49.1 (3271)
Mean value of having children (SD) nonparents	2.26 (1.98)	3.26 (2.7)	3.81 (2.92)	4.42 (2.65)	3.82 (2.85)
Mean value of having children (SD) parents	7.16 (3.48)	8.17 (2.3)	8.39 (2.42)	8.38 (1.96)	8.73 (2.08)
Want to have children (SD) nonparents	52.4 (75)	59.1 (13)	68.4 (563)	88.9 (24)	67.0 (599)

Note. SD = standard deviation. Participants were all aged 42 at the time of completing all measures apart from ethnicity

Table 2.4. *Sample characteristics by group and gender.*

_	Gay		Bisexual Disa		Disabled	isabled		vivors	Control group	
	Men (n=112)	Women (<i>n</i> =67)	Men (<i>n</i> =31)	Women (n=50)	Men (<i>n</i> =946)	Women (<i>n</i> =943)	Men (<i>n</i> =22)	Women (n=22)	Men (<i>n</i> =3644)	Women (n=4038)
In a relationship % (n)	48.3 (43)	77.6 (38)	61.3 (19)	66.0 (31)	72.2 (675)	78.6 (732)	81.8 (18)	72.7 (16)	89.1 (3245)	85.2 (3437)
Mean income (SD)	24,640 (16,896)	18,569 (13,498)	13,007 (10,840)	15,531 (25,669)	22,186 (24,746)	14,060 (15,627)	15,655 (15,644)	11,094 (11,256)	27,420 (30,518)	13,505 (66,031)
Employed % (n)	90.2 (101)	85.1 (57)	67.7 (21)	74.0 (37)	82.7 (777)	77.9 (734)	77.3 (17)	63.6 (14)	92.8 (3374)	81.1 (3267)
Education to diploma or degree level % (n)	55.4 (62)	53.7 (36)	41.9 (13)	42.0 (21)	41.2 (389)	50.8 (478)	27.3 (6)	59.1 (13)	40.3 (1466)	40.4 (1632)
British ethnicity % (n)	95.6 (87)	94.9 (56)	96.0 (24)	87.9 (29)	94.9 (780)	94.4 (822)	100 (18)	81.0 (17)	94.3 (2837)	95.5 (3367)
No religion % (n)	59.8 (61)	68.3 (43)	39.3 (11)	51.3 (20)	59.2 (481)	43.6 (374)	59.1 (13)	40.0 (8)	56.4 (1754)	42.7 (1517)
Mean value of having children (SD) nonparents	2.12 (1.74)	2.55 (2.41)	2.73 (2.65)	4.00 (2.88)	3.67 (2.62)	3.96 (3.18)	4.92 (2.47)	3.92 (2.84)	4.02 (2.89)	3.56 (2.77)
Mean value of having children (SD) parents	5.67 (3.50)	8.05 (3.24)	7.12 (2.52)	8.74 (1.98)	8.01 (2.57)	8.74 (2.21)	8.71 (1.70)	8.11 (2.21)	8.38 (2.24)	9.02 (1.88)
Want to have children (SD) nonparents	57.6 (57)	40.9 (18)	41.7 (5)	80.0 (0)	68.3 (282)	68.5 (281)	92.9 (13)	84.6 (11)	69.8 (344)	63.6 (255)

Note. SD = standard deviation. Participants were all aged 42 at the time of completing all measures apart from ethnicity

Parenthood Rates

As shown in Figure 2.1, 11.6% of gay men and 34.4% of lesbians were biological or non-biological parents at age 42, compared to 86.5% of control men and 90.1% of control women. Parenthood rates among bisexual men were 61.3% and 80.0% among bisexual women. Among cancer survivors, 36.4% of men and 40.9% of women were parents. Of the individuals who had disabilities, 53.6% of men and 55.2% of women had children.

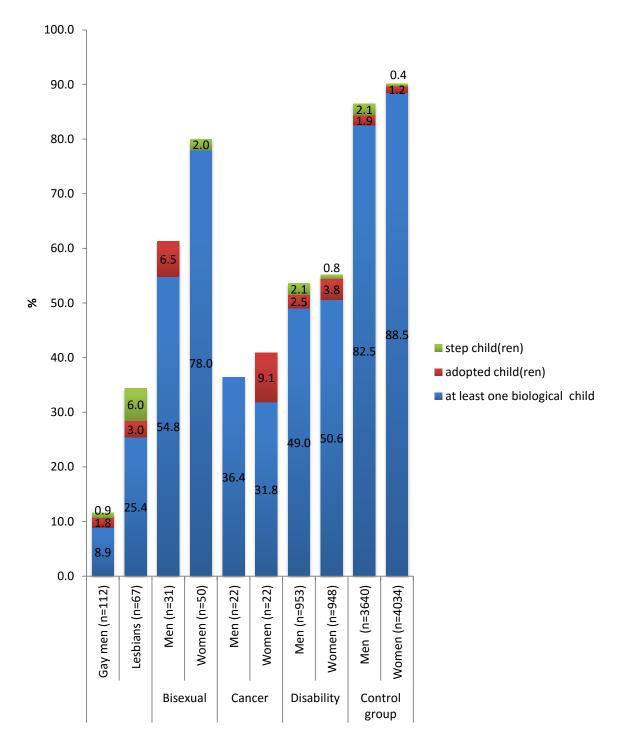


Figure 2.1. Parenthood rates by group. The sample sizes presented on the horizontal axis refer to the total number of participants in each group, regardless of whether they were parents or not. Data labels on the bars are percentages.

A logistic regression was conducted to assess the association between all non-normative groups and parenthood (χ^2 (4) = 1076.33, p<.001). 82.5% of the variance was explained. As shown in Table 2.5, all non-normative groups apart from bisexual people were significantly less likely to be parents than controls, controlling for

membership of more non-normative group. Gay men and lesbians were 16 times and cancer survivors were four times more likely to be childless than the control group. Similarly, individuals with disabilities were 5.5 times more likely to be childless than the control group.

The second step of the model added relationship status because this factor significantly differed by group (as mentioned previously) and was associated with parenthood with an effect size (Cramer's V) of greater than 0.3 (χ^2 (3) = 1319.43, p<.001), indicating that people in cohabiting relationships or married people were more likely to be parents. Accounting for relationship status significantly increased the amount of the variance explained by the model (χ^2 (3) = 889.59, p<.001), and the overall model allowed 85.0% of participants to be correctly classified (χ^2 (7) = 1965.91, p<.001). Controlling for relationship status caused the odds of being childless to nearly halve for gay men and lesbians, but little change was observed for the other group.

In the third step of the model gender and interactions between group and gender were added. This significantly increased the variance explained (χ^2 (5) = 65.46, p<.001). The percentage of participants correctly classified did not change from 85%, despite the step being significant (χ^2 (12) = 2031.37, p<.001). Overall, men were more likely to be childless than women. The interactions between gender and two of the groups were significant: the gay/lesbian group and the disabled group. Simple slope analyses were conducted to assess the impact of being in one of these non-normative groups for men and women separately. This revealed that gay men were 14.09 times more likely to be childless than control men, while lesbians were 4.66 times more likely to be childless than control women. Similarly, disabled men were 3.78 times more likely to be childless than control men, while disabled women were 7.50 times more likely to be childless than control women. All simple slope analyses were significant at the p<.001 level.

Table 2.5.

The relationship between non-normative groups and the likelihood of being childless.

	Step 1		Step 2		Step 3	
	Beta	Odds ratio [Lower CI, Upper CI]	Beta	Odds ratio [CI]	Beta	Odds ratio [CI]
Sexual identity:		Opper Cij		[CI]		[CI]
Gay/lesbian ^a	2.78***	16.11 [10.52, 24.67]	2.15***	8.60 [5.52, 13.40]		
Bisexual ^a	.31	1.37 [.80, 2.35]	-0.24	0.79 [0.44, 1.40]		
Cancer survivors ^b	1.42***	4.13 [2.10, 8.13]	1.44***	4.22 [2.05, 8.69]		
Individuals with disabilities ^c	1.71***	5.51 [4.90, 6.19]	1.67***	5.30 [4.67, 6.02]		
Relationship status Cohabiting ^d			1.06***	2.88 [2.46, 3.38]		
Non-cohabiting relationship ^d			1.44***	4.21 [3.44, 5.15]		
Not in a relationship ^d			2.13***	8.42 [7.27, 9.76]		
Gender ^e					-0.51***	0.60 [0.52, 0.70]
Gay*gender					-1.11*	0.33 [0.13, 0.86]
Bisexual*gender					-0.98	0.37 [0.12, 1.21]
Cancer*gender					-0.89	0.41 [0.10, 1.73]
Disability*gender					0.68***	1.98 [1.54, 2.56]

Note: CI = 95% confidence interval ^a reference group = heterosexual ^b reference group = people who never had cancer or had cancer after they had their first child ^c reference group = people who never had a disability or people who only reported having a disability after they had their first child. ^d reference group = married or in a civil partnership. ^e 0 = men, 1 = women.

Reasons for Remaining Childless

As shown in Table 2.6, infertility was cited as a reason for remaining childless more often by cancer survivors than controls. Relational factors were cited more often by lesbian and bisexual women than control women, and bisexual women cited financial reasons more often than controls. Female cancer survivors and men and women with disabilities cited health reasons more often than controls. Gay and bisexual men and lesbians cited lack of desire for children more often than controls, but bisexual women cited it less frequently than control women. Not meeting the right person and career focus were not cited more frequently by any particular group. Being in a same-sex relationship was cited as a reason for being childless by 15% of gay men, 5% of lesbians and no bisexual individuals.

Table 2.6.

The percentage of childless participants that gave each reason for not having had children (n).

	Infertility	Relational	Financial	Health	Did not want children	Did not meet right person	Career focus	Same-sex relationship
Gay men	1 (1)	8.1 (8)	4 (4)	2 (2)	42.4 (42)	7.1 (7)	3 (3)	15.2 (15)
(n=99)								
Lesbians	6.8 (3)	20.5 (9)	2.3 (1)	4.5 (2)	59.1 (26)	2.3 (1)	0(0)	4.5 (2)
(n=13)								
Bisexual men ($n=12$)	0 (0)	8.3 (1)	8.3 (1)	8.3 (1)	58.3 (7)	33.3 (4)	8.3 (1)	0
Bisexual women ($n=10$)	20(2)	20(2)	20 (2)	10(1)	20(2)	30 (3)	10(1)	0
Male cancer survivors	21.4 (3)	7.1(1)	14.3 (2)	0	7.1(1)	21.4 (3)	7.1(1)	0
(n=14)								
Female cancer survivors	30.8 (4)	0	7.7 (1)	53.8 (7)	15.4(2)	30.8 (4)	0	0
(n=13)								
Men with disabilities	8.9 (39)	11.6 (51)	7.3 (32)	4.8 (20)	31.7 (131)	25.7 (106)	5.1 (21)	1.5 (6)
(n=438)								
Women with disabilities	20.6 (87)	9.2 (39)	7.1 (30)	11.5 (47)	31.5 (129)	22.2 (91)	6.8 (28)	0.2(1)
(n=422)								
Control men (<i>n</i> =495)	9.7 (48)	10.3 (51)	6.1 (30)	2.2 (11)	30.2 (149)	27.2 (134)	5.5 (27)	0
Control women (<i>n</i> =402)	17.7 (71)	10.7 (43)	4.7 (19)	1.7 (7)	36.4 (146)	24.2 (97)	7.2 (29)	0

Impact on Life Satisfaction

A robust multiple linear regression was used to examine the effect of having children on life satisfaction by group. Summary statistics are presented in Table 2.7, which shows that step 1 of the model was significant and that life satisfaction was significantly lower among all groups apart from cancer survivors. The inclusion of parental status in step 2 explained significantly more variance and childless individuals reported significantly lower life satisfaction than parents. Identifying as gay or lesbian was no longer associated with reduced life satisfaction. The inclusion of financial difficulties, whether childless participants wanted children, life satisfaction at age 29, gender and relationship status in step 3 significantly increased the variance accounted for. All five new variables were significant, but two results from step 2 changed. Being bisexual was no longer significantly associated with life satisfaction, and life satisfaction among childless individuals no longer significantly differed to the life satisfaction of people who had children before the age of 29. People who became parents after age 29, however, were still found to have significantly higher life satisfaction than childless individuals. The addition of the interaction terms in step 4 was insignificant.

Table 2.7.

Robust linear regression with life satisfaction as the dependent variable (unstandardised coefficients, n=8158)

	Step					
Predictor	1	2	3	4		
Sexual orientation						
Gay ^a	-0.34*	-0.094	0.19			
Bisexual ^a	-0.72**	-0.61**	-0.17			
Cancer ^b	0.13	0.22	0.18			
Disabled ^c	-0.32***	-0.27***	-0.14**			
Parenthood status ^d						
Parent by 29		0.29***	0.11			
Parent after 29		0.56***	0.21**			
Life satisfaction (age 29)		0.00	0.57***			
Financial difficulties			-0.56***			
Did not want children ^e			0.24**			
Female gender ^f			0.14***			
Relationship status ^g			0.14			
Cohabiting			-0.17***			
			-0.17			
Noncohabiting relationship			-1.17***			
Not in a relationship			-1.1/*****	0.15		
Gay x gender				0.15		
Bisexual x gender				-1.55		
Cancer x gender				-0.56		
Disabled x gender				-0.25		
Gay x parent by 29				0.23		
Gay x parent after 29				0.077		
Bisexual x parent by 29				-0.61		
Bisexual x parent after 29				-1.11		
Cancer x parent by 29				2.035		
Cancer x parent after 29				0.90		
Disabled x parent by 29				-0.086		
Disabled x parent after 29				-0.33		
Gay x gender x parent by 29				-0.79		
Gay x gender x parent after 29				-0.36		
Bisexual x gender x parent by 29				2.09		
Bisexual x gender x parent after 29				1.85		
Cancer x gender x parent by 29				-6.34		
Cancer x gender x parent after 29				0.76		
Disabled x gender x parent by 29				0.29		
Disabled x gender x parent after 29				0.39		
Life satisfaction (age 29) x parent by 29				-0.17		
Life satisfaction (age 29) x parent after 29				-0.31		
Overall significance	F(4,	F(6,	F (13,	F (35,		
-	8153) =	8151) =	8144) =	8122) =		
	12.80**	22.93***	211.47***	79.60***		
Overall R^2	0.0050	0.014	0.23	0.23		
Step change significance		F (2,	F (7, 8150)	F (22,		
1 0 0		8155) =	=373.61**	8145) =		
		44.10***	*	2.14		

Note: reference groups: ^a heterosexual ^b people who never had cancer or had cancer after they had their first child ^c people who never had a disability or people who only reported having a disability after they had their first child. ^d no biological, adopted, fostered or step children ^e all parents and people who were childless but did not agree with a statement about not wanting children. ^f male ^g married or in a civil partnership

Table 2.8 shows the standardised coefficients for the same regression model to allow the relative contribution of each predictor to be assessed. In steps two and three it is apparent that not having children was more strongly associated with poorer life satisfaction than experience of disability. Step three also shows that life satisfaction at age 29, financial difficulties and not being in a relationship were stronger predictors of life satisfaction at age 42 than being childless. Step four is not included in Table 2.8 because all coefficients were insignificant.

Table 2.8.

Robust linear regression with life satisfaction as the dependent variable (standardised coefficients)

	Step		
Predictor	1	2	3
Sexual orientation			
Gay ^a	-0.021*	-0.0058	0.012
Bisexual ^a	-0.030**	-0.026**	-0.0071
Cancer b	0.0044	0.0074	0.0061
Disabled ^c	-0.011***	-0.0091***	-0.0047**
Parenthood status d			
Parent by 29		0.074***	0.028
Parent after 29		0.13***	0.047**
Life satisfaction (age			0.29***
29)			
Financial difficulties			-0.27***
Did not want children ^e			0.029**
Female gender ^f			0.036***
Relationship status ^g			
Cohabiting			-0.032***
Noncohabiting			-0.074***
relationship			-0.0/4****
Not in a relationship			-0.21***

Note: reference groups: ^a heterosexual ^b people who never had cancer or had cancer after they had their first child ^c people who never had a disability or people who only reported having a disability after they had their first child. ^d no biological, adopted, fostered or step children ^e all parents and people who were childless but did not agree with a statement about not wanting children. ^f male ^g married or in a civil partnership

Discussion

All non-normative groups had much lower parenthood rates than the rest of the sample. The relationship between parental status and life satisfaction was the same among all men and women, regardless of whether they belonged to a non-normative group or not. However, the lower rates of parenthood among non-normative groups imply that a larger proportion would be affected by the poorer life satisfaction reported by childless individuals at age 42.

These low parenthood rates may be the result of parenthood being more accessible for some people than others. We propose that the lack of diversity in the parenting population should be discussed in a similar manner to the lack of diversity in the workplace. In the interest of providing equal life opportunities for all, it might be justifiable to provide the financial and practical support that would enable more non-normative group members to have children.

Parenthood Rates among Non-Normative Groups

Parenthood rates among non-normative groups ranged between 12 and 80%, compared to approximately 90% of the control group. The groups with the lowest rates were gay men who were 14 times more likely to be childless than the control group once relationship status had been taken into account.

To put this finding into context, few sociodemographic characteristics are such strong predictors of parenthood. For example, people who have high level professional careers are twice as likely to remain childless throughout their lives compared to people who have never worked (Shkolnikov, Andreev, Houle & Vaupel, 2004). This highlights that membership of any non-normative group (with the exception of bisexual individuals) provides a much stronger predictor of remaining childless than occupation. In the present study, people who were not in a relationship were 8.4 times more likely to be childless than people who were married, an effect of a similar magnitude to identifying as gay or lesbian (when both genders are combined).

People who identified as bisexual were the only non-normative group that was not significantly less likely to be a parent than the control group. This may have been because a large proportion of the bisexual people in the sample had opposite-sex partners, but this possibility requires investigation.

Reasons for Rates

Some barriers to parenthood were shared across the entire sample regardless of whether people belonged to a non-normative group or the control group (e.g., relational, financial), while others were unique to specific groups (e.g., reporting having a same-sex partner as the reason for not having children). Other reasons for not having children were shared by non-normative groups and the control group, but were clearly more problematic for certain non-normative groups. For example, health reasons were cited by all groups, including the control group, but were reported much more frequently by female cancer survivors and disabled women. The finding that more disabled women than disabled men viewed their health as a barrier to parenthood may reflect societal expectations that women should undertake the majority of childcare.

More gay men, lesbians and bisexual men reported that they never wanted children than in other groups. This finding is consistent with previous studies that show fewer childbearing desires among gay men and lesbians than heterosexual individuals (Riskind & Patterson, 2010). It is hard to speculate on what might stop lesbians and gay men from wanting children other than societal resistance and the expense of surrogacy or insemination with donor sperm. However, gay men and lesbians cited financial reasons less frequently than controls, so the latter seems unlikely. The perceived difficulties of being a gay/lesbian parent may put these individuals off, or some other aspect of having a gay/lesbian/bisexual identity or same-sex partner. Future research is needed to further explore these questions.

Many cancer survivors are unable to have biological children because of the effects of treatments such as chemotherapy. Evidence suggests that many cancer patients do not preserve their fertility prior to treatment (Armuand et al., 2012; Letourneau et al., 2012). This was reflected in the higher rates of infertility reported by this group. Notably, 10% of female cancer survivors had adopted children, compared to no male cancer survivors and 1% of the control women. This may reflect the greater convenience and lower expense of fertility preservation for men than women.

Controlling for relationship status substantially reduced the odds of gay men and lesbians being childless. This appears to suggest that not being in a relationship may have been a reason for being childless for some, but this is not supported by the data: fewer childless gay men and lesbians than controls said the reason was not

having met the right person. Since causality cannot be inferred, it is also possible that those without children were less likely to be in a relationship at age 42, simply because they were childless. Alternatively, some gay men and lesbians may have made the decision to stay single and childless at age 42 because of their values or competing priorities. The relationship between relationship status and parental status among gay men and lesbians requires further exploration.

Another finding that may partially account for the low parenthood rates among gay men and lesbians is that just under half also reported a disability. It is well established that gay men and lesbians suffer from higher rates of physical and mental health problems (e.g., Sandfort, Bakker, Schellivis, & Vanwesenbeeck, 2006), and so some may be deterred from parenthood due to their health problems. Lesbians were over twice as likely as control women to report health, although the actual figures were small: 1.7% of childless controls compared to 4.5% of lesbians. Gay men, on the other hand, the proportion of gay men and controls that reported health as a reason for not having children was the same. This is consistent with the finding that disabled women were more likely than disabled men to report health reasons for being childless. Future research should further investigate the impact the high rates of disability among gay men and lesbians have on their reproductive decisions.

Consequences of Being Childless

One of the most concerning consequences of the low parenthood rates among non-normative groups is the risk of a reduced quality of life for those who wanted to have children. The present study suggests that quality of life was improved by age 42 among those who had children after the age of 29. The reasons for this are unclear, but it is possible that, due to controlling for financial satisfaction, having children improved life satisfaction regardless of the age of the children. Therefore people who already had children before the age of 29 did not experience any further increase in life satisfaction by age 42. The consequence of being childless is slightly lower life satisfaction at age 42, although the magnitude was small at 0.2 on an 11 point scale.

Childless individuals were found to report poorer life satisfaction than people who had children after the age of 29, regardless of whether participants belonged to a non-normative group or not. Given that parenthood rates are low in non-normative groups, the negative effect of being childless at age 42 onwards will affect a higher proportion of these populations.

However, the greater consequence of the low parenthood rates among nonnormative groups might be seen as a lack of equally accessible life opportunities for all. Despite great steps forward in terms of social attitudes and legal support, alternative family forms are rare in the UK. We propose that the topic of parenthood should be brought into the discourse surrounding diversity, and the issue of whether it should be facilitated should be considered. Perhaps equality and diversity in parenthood should be encouraged in a similar way to that of equality and diversity in the workplace.

Limitations

As previously described, small sample sizes are an inherent problem with using probability sampling to assess populations that form a small minority. Although adequate power was achieved to detect medium effect sizes, the small numbers of cancer survivors and bisexual people are a reason for caution, and replication in larger samples is needed. This was a particular problem for making inferences about the reasons given for not having children, as for example, only 10 bisexual women were childless. Consequently, significance testing could not be carried out on this aspect of the data. Additionally, some of the interaction terms included in the regression model may have been underpowered and replication in a sample with larger numbers of nonnormative groups is recommended.

The demographic characteristics of the sample suggest that it was representative, for example fewer disabled people were employed than controls (Office for National Statistics, 2014b). Nonetheless the dropout rate was around 40%, and it is likely that people with severe disabilities may have been more likely to dropout due to the greater inconvenience of completing an interview. Therefore, the disability group may not have been representative.

The other limitation of the dataset was that certain populations were too rare to be investigated: there only two transgender individuals, two people with spinal cord injuries and three people who reported having HIV in the sample. Furthermore, no information was available on whether participants were known carriers of genetic conditions. Future research should focus on collecting representative datasets from these populations to allow parenthood rates in the UK to be estimated.

Measures of sexual identity are always limited by some individuals being unwilling to report their gay or lesbian identity, who may lie or decline to answer the

question. People who are uncomfortable making this disclosure may also be particularly unlikely to have had children with a same-sex partner, so the percentages of gay people who had children with a same-sex partner reported in the present study may be slight over-estimations.

The multiple choice questions used to ascertain the reasons for remaining childless will not have covered all possible reasons. For example, some disabled people may not have had children because of fear of experiencing stigma from family, friends or society in general.

The measures of disability varied by wave, and some waves did not ask participants to report how long the disability had lasted. Others only gained information about a long-term health condition and did not establish whether daily activities were affected. As the closest proxy to disability had to be used, in the present analysis some participants with mild health conditions that did not disrupt daily life or had been present for under a year would have been classified as disabled. This may have caused the parenthood rates among people with disability to be overestimated. Furthermore, some disabled people would have been socialised as disabled whereas others acquired disabilities later in life. Parenthood rates may be lower in the former than if stigma is internalised during childhood, but data to establish age of disability onset was not available.

Ways to Address Problems

In other domains efforts have been made to improve participation opportunities for disadvantaged individuals, for example access to work funding is available to help people with disabilities gain employment. This can cover things such as equipment, support workers, and disability awareness training for colleagues (gov.uk, 2016). Whether the same commitment to providing equal opportunities to become parents should be made is a complex question, but arguably one that should be present in discourse surrounding diversity.

One strategy to facilitate parenthood among same-sex couples (men and women) might be to alleviate the financial burden of achieving biological parenthood for one member of the couple. Currently, in the UK lesbians have to self-fund artificial insemination six times before they are considered for NHS funded fertility treatment (National Institute for Clinical Excellence, 2013, Stonewall, 2014), which would typically cost £795 per natural cycle of intrauterine insemination (i.e.,

insemination without hormonal stimulation), plus an extra £850 per treatment cycle for donor sperm (prices taken from London Women's Clinic, n.d.). Six self-funded cycles with donor sperm would therefore cost £9870. It is illegal to pay for surrogacy in the UK but the prospective parents are generally expected to reimburse the surrogate's expenses which reportedly usually come to £7,000-£15,000 (Surrogacy UK, n.d.). These costs are likely to be prohibitive for many same-sex couples who wish to have children. However, there is insufficient evidence to conclude that financial barriers are the reason for the low parenthood rates, especially as the present study suggests that lack of desire to have children is a more common reason for being childless than financial difficulties.

Among cancer survivors the solution is more straightforward. Evidence suggests that many patients are not offered fertility preservation options prior to treatment (Duffy et al, 2005; Letourneau et al., 2012), despite it being already funded by the NHS. Ensuring all patients who might want to have children post-treatment freeze their sperm or an embryo (egg freezing is not currently funded) would likely increase parenthood rates.

The majority of people with disabilities will not experience fertility problems, but yet few become parents. Based on comparing the reasons given by disabled people to those given by the control group in the present study, the main barrier to parenthood for disabled people appears to be their health concerns. Consequently, providing more practical support to these individuals might make parenthood more accessible. Data on the role played by societal attitudes and/or stigma is not available from the British Cohort Study data, but qualitative evidence suggests that this is something encountered by parents with disabilities (Duvdevany et al., 2008). Further research on this issue is required.

Conclusions

Despite diverse family forms becoming increasingly accepted in the UK, very few gay men, lesbians, disabled people, and cancer survivors have children. This is concerning because the present study provides evidence suggesting that being childless at age 42 is associated with poorer life satisfaction. This was found to be the case for all groups, i.e., regardless of sexual identity, disability or cancer survivorship. Further research is needed to confirm that the complex effects of having children on wellbeing do not differ by non-normative group membership at other ages.

Consideration of whether measures should be taken to render parenthood more accessible for non-normative groups is needed. Such steps might include increased practical support to help disabled people raise children, and increased provision of fertility preservation services to cancer patients.

Chapter 3 Part 1:

Review of Quantitative and Qualitative Systematic Review Methods

Introduction

Systematic reviews of social research topics frequently result in a variety of different types of evidence. However, examination of the last 10 systematic reviews published in Social Science and Medicine revealed that only four included qualitative and quantitative studies. Of the other six, two explicitly excluded qualitative studies. The remaining four did not explicitly address the reasons for the exclusion of qualitative studies, but some had research questions that could only be addressed with one design, for example one review topic was related to survival analysis, a quantitative analytic approach. These 10 studies are detailed in Appendix A. This illustration shows that reviews tend to be biased toward particular types of designs. Multiple reasons could explain this bias but a primary one is likely to be a lack of satisfactory and accessible procedures for conducting integrated qualitative and quantitative reviews.

Failing to include qualitative or quantitative evidence in a review without good reason can result in the loss of important information. For example, Padmanathan and De Silva (2013) reviewed the acceptability and feasibility of the provision of mental health care by people who are not specialists. The quantitative and qualitative studies they included provided slightly different information, for example, a quantitative study found that treatment by less specialised professionals did not significantly influence patient attitudes towards treatment received. A qualitative study, however, revealed that the acceptability of less specialised professionals to patients with schizophrenia depended on the characteristics of the professional including their education, experience and gender. Failing to include particular types of designs is also counter to the principles of a systematic review which is expected to be comprehensive. Studies relevant to the research question should not be excluded purely on the grounds of the perceived difficulty of combining results from qualitative and quantitative studies.

The aims of Part 1 of this chapter were to discuss issues related to integrated qualitative and quantitative reviews and introduce available review procedures. The goal was to inform the choice of synthesis methods for a systematic review on

reproductive decision-making among non-normative groups, which is presented in Part 2 of this chapter. A further goal was to provide future researchers with a guide to their options when it comes to the synthesis stage of a mixed-method systematic review.

How to Synthesise Qualitative and Quantitative Primary Results

Figure 3.1 presents a decision tree highlighting the different approaches to mixed-method synthesis and when to use them. The first decision to be made by researchers who wish to synthesise primary results from qualitative and quantitative studies is determining how primary results from each will be represented in the review. In single metric approaches data from all studies is first converted to a common single metric (textual or numeric) and the review carried out on this single metric. In dual metric approaches data are retained in their original form (textual or numeric) and a separate synthesis for each type of data is conducted. Findings from both are then integrated using a further integrative synthesis, or by juxtaposing the results of the qualitative and quantitative syntheses in the discussion. These approaches will be described in the subsequent sections.

The choice of single or dual metric approaches depends on the weight applied to the type of data (textual or numeric) and how important it is to the research question to amalgamate all the results together regardless of type of study. Arguably one of the first questions researchers should ask themselves should be whether it would be useful to analyse the exact size of effects found by the primary quantitative studies. In quantitative research, the effect size indicates either the size of the difference between two or more groups, or the strength of the association between two variables. There are many reasons why effect sizes should be analysed when they are available, including the ability to assess the magnitude of an effect rather than just its presence, and also the ability to take sample sizes and consequently the power to detect significant results into account.

In most cases researchers will opt to conduct two separate syntheses, one numerically combining the effect sizes and the other a textual synthesis of the qualitative data. Other than the use of effect sizes, this approach benefits from the in depth textual analysis of the results of the primary qualitative studies. Research questions that would benefit from a thorough qualitative synthesis of this type alongside the numeric component are those where an understanding of the lived

experiences of participants would be informative, or in new research areas where quantitative studies may not have yet measured all the most important factors.

For some research questions, however, effect sizes are not of interest and the amalgamation of quantitative and quantative primary study results is more important. Research questions that might benefit from this approach, referred to as a single metric synthesis, include those that aim to establish the strength of a very specific effect. For example, in a systematic review examining whether high levels of career investment deter women from having children, qualitative primary results could feasibly be coded numerically. Specifically, effect sizes could be calculated based on the proportion of women who reported career investment as a barrier to parenthood in each sample.

Research questions that are not concerned with the sizes of effects can benefit from the use of a single metric synthesis that is textual rather than numeric. This involves presenting the quantitative results in textual form rather than estimating numerical effect sizes based on the qualitative primary results. Research questions that might benefit from a single metric approach include those that are broad and exploratory. If there are few quantitative studies, or few of high quality, effect size information in of limited use. Rather, in depth textual analysis of the results of the primary qualitative studies is likely to be much more informative in highlighting the main factors for consideration in a new domain. Findings from any quantitative studies can be incorporated into the textual synthesis through contributing to the overall themes that are identified.

Single Metric Synthesis

A numeric single metric synthesis involves analysis of data in numeric form, which can be derived from primary quantitative and (when available) qualitative studies. A textual single metric synthesis involves analysing data that is in textual form, and again this data can originate from primary studies that are quantitative or (when available) qualitative.

Numeric Methods

Converting textual primary results to numeric data.

In order to use a numeric method, textual data must first be converted into numeric estimates. One approach involves calculating the approximate proportion of

participants associated with an effect implied in the authors' descriptors of 'few' and 'many' (see Voils et al., 2009 for further information on how this is done). The limitation of this approach is that qualitative studies often do not provide sufficient information on the percentage of participants to which a descriptor like 'few' is applied so estimations are unlikely to be precise.

Alternatively, textual and numeric data can be represented in the same numeric metric by assigning values to the qualitative and quantitative studies based solely on the direction of effects. For some analyses the values assigned are arbitrary, whereas for others specific values are needed, e.g., one for significant positive associations, 0.5 for nonsignificant findings, and zero for significantly negative associations (Crandell, Voils, Chang, & Sandelowski, 2011). Although this approach avoids inferring unreliable effect sizes from primary qualitative results, any precise effect sizes reported in the quantitative studies are lost.

Numeric synthesis methods.

Once all data have been converted to a numeric form, the synthesis method can be applied. The different numeric methods for a single metric synthesis are displayed in Figure 3.1. The single metric effect sizes from the quantitative and qualitative studies are combined using a Bayesian (Voils et al., 2009) or frequentist meta-analysis. In a meta-analysis (Bayesian or frequentist) the original effect sizes from the quantitative primary studies are combined with the estimated effect sizes from the qualitative primary studies.

It is frequently the case that some quantitative studies do not report effect sizes, and/or that effect sizes cannot be derived from available data. Researchers can deal with this by excluding these studies, but this introduces bias to the data because exclusion tends not to be random as non-significant findings are more often excluded. For this reason, Wang and Bushman (1999) developed a method for combining primary results without effect sizes within a meta-analysis. The results without effect sizes are entered as vote-counts. A vote-count means coding the study as having a positive, negative or absent relation. Conventional vote-counting methods simply take the most common finding across included studies as the result, in other words, the result with the most 'votes' wins. This approach is problematic because the sample sizes determine the likelihood of a statistically significant result being found, with significant effects being more likely to be detected in larger samples. Wang and

Bushman's (1999) vote-counting method overcomes this limitation by taking sample size into account. Although not as precise as effect sizes, this method is less biased than excluding studies without effect sizes altogether (for further information see Wang & Bushman, 1999).

Bayesian data augmentation can also be used. Augmentation involves creating a matrix where each primary study is a row and each predictor a column. The effect sizes for quantitative and qualitative studies are inserted according to coded values. The authors recommend that positive associations are coded one, negative associations are coded zero, and no association 0.5. Specific effect sizes reported by the quantitative primary studies are not used. There are usually empty cells in this matrix because only a subset of the primary studies will have investigated each predictor relationship. This data set is augmented by filling in the missing cells with estimated values using algorithms applied to the data that exist. The mean effect size and confidence intervals are then calculated for each predictor variable based on this augmented data set (for further information see Crandell et al., 2011).

Qualitative primary results can also be incorporated into a numeric synthesis by using them to devise the prior probabilities in Bayesian meta-analysis (Roberts, Dixon-Woods, Fitzpatrick, Abrams, & Jones, 2002). Prior probabilities are researchers' estimates of the probability of the hypothesis being true, based on what they know prior to undertaking the statistical analysis, and are what differentiates a Bayesian meta-analysis from a frequentist meta-analysis. In Bayesian meta-analysis, the prior probability is conditioned on the data entered into the analysis. In this method, the qualitative evidence contributes through prior probabilities on which the main part of the analysis (i.e., meta-analysis of quantitative data) is conditioned.

Conditioning a probability on observed data means that the probability is adjusted in light of the observed data. To give a simple example, if there are four scratch cards (scratch cards A, B, C, and D) and only one must be a winner, the probability of scratch card C being a winner is 0.25 (one in four). However, if one observes scratch card A being scratched and it turns out not to be a winner, the probability of scratch card C being a winner is conditioned on that new knowledge. Therefore the conditional probability of scratch card C being a winner given that scratch card A is not is 0.33 (one in three). For example, in a Bayesian meta-analysis of the factors affecting adherence to the recommended childhood immunisations, qualitative studies combined with the subjective beliefs of five reviewers informed the

prior probabilities (Roberts et al., 2002). However, this method has been criticised for giving greater weight to the quantitative than qualitative studies (Voils et al., 2009).

Textual Methods

Converting numeric primary data to textual form.

Figure 3.1 also shows the textual approaches to a single metric synthesis. For these methods, numeric data is first converted into or extracted as textual data, and then combined with existing qualitative primary data which is not converted. The method by which the quantitative primary results are converted into textual form is not clear as few authors specify how this was done. One exception is Popay et al. (2006) who reported "For example the variable labels included in survey research may be extracted as 'themes' in the same way as conceptual themes are extracted from qualitative research reports" (p. 18).

Textual synthesis methods.

Once conversion has been done, all results are considered equivalent, and themes are identified using whichever textual synthesis method has been selected. There are four main textual single metric synthesis methods presented in Figure 3.1 which are closely related to those used in analysis of primary qualitative data. Much has been written on the difficult task of selecting a method of analysis when conducting primary qualitative research, because unlike quantitative research, there are no rules to follow in how to approach data analysis (Spencer, Richie, & O'Connor, 2003). Which analysis method is used should be chosen based on it having suitable epistemological assumptions and the optimal fit between the review question and what the synthesis method aims to achieve (Harper, 2011, Spencer et al., 2003).

Meta-narrative review is used to synthesise large numbers of studies on topics that have been examined over time using different methods (Greenhalgh et al., 2005). A separate meta-narrative for each discipline is constructed, which map the trajectory of topic understanding over time. A realist synthesis is used solely for intervention studies and aims to identify which interventions work for whom, under what circumstances, and why (Pawson, Greenhalgh, Harvey, & Walshe, 2005). A final approach is a critical interpretive synthesis, which aims to develop concepts and theory rather than aggregate data. It differs from other textual approaches in its

emphasis on critiquing the primary studies, in terms of the ways in which the results were derived and the assumptions made (Dixon-Woods et al., 2006).

The final textual synthesis method that has been proposed for synthesising quantitative and qualitative primary studies is narrative synthesis, which aims to describe and explain study results using three main elements: a preliminary synthesis which describes the primary results, an exploration of the relationships within and between studies, and an assessment of the robustness of the synthesis results (Popay et al., 2006).

Popay et al. (2006) recommend a number of methods that can be used for conducting the preliminary synthesis. Thematic analysis involves converting numeric data into textual form. Popay et al. (2006) suggest that this is achieved by extracting conceptual themes from the variables included in the quantitative studies. Thomas and Harden (2008) develop further the methods for the thematic synthesis the results of primary qualitative studies. Content analysis can also be used, which involves coding the qualitative and quantitative findings and organising these codes into categories. The number of included studies within each category is counted and these frequencies are reported in the results (see Dixon-Woods, Shaw, Agarwal, & Smith, 2004 for further information).

Although Popay et al. (2006) describe their narrative synthesis approach as primarily a textual method, their guidance suggests one numeric method that can be useful for conducting the preliminary synthesis of primary quantitative and qualitative studies (if both are present in the review). This method is vote-counting, which as previously described, involves coding the primary results of all studies as positive or negative direction of effects, or an absent effect. Although vote-counting is problematic when used instead of a meta-analysis for reasons detailed previously, for the purposes of describing primary study results in a succinct way in the first stage of a narrative synthesis it can be a useful method.

Following the preliminary synthesis, the next stage of a narrative synthesis is to explore the relationships within and between studies. This involves an in depth examination of the differences in the characteristics of the primary studies (e.g., those related to methodology, sample, measure of outcome) and consideration of the ways in which they might have influenced the results (Popay et al., 2006). Finally, the robustness of the synthesis results is assessed, which involves evaluating the quality

and quantity of the primary studies and the trustworthiness of the methods used in the synthesis.

Dual Metric Syntheses

A dual metric approach involving two separate syntheses can be employed when a review would benefit from numeric synthesis of the quantitative studies and separately from textual synthesis of the qualitative studies. A dual metric synthesis might be needed, for example, when a precise estimation of the size and significance of effect sizes from the quantitative studies is desired while at the same time having a need for a textual synthesis to portray lived experiences from qualitative studies. The use of a separate textual synthesis of qualitative primary study results can also be used to shed light on when and why any numeric effects might occur. The methods available for a dual metric synthesis are outlined in Figure 3.1.

Numeric Methods

The same methods used for the numeric single metric synthesis can also be employed for the numeric part of a dual metric synthesis. Meta-analysis (frequentist or Bayesian) is the optimal method because it allows the statistical amalgamation of results through estimation of the pooled effect size and of heterogeneity around the mean of that effect size. For example, Thomas et al. (2004) conducted a meta-analysis of interventions to promote healthy eating before analysing qualitative evidence investigating participants' views on the same topic. As in relation to numeric single metric syntheses, sometimes quantitative studies do not report the effect size, so cannot be included in a meta-analysis in the conventional way. This can be dealt with by entering the direction and significance of effects from the studies into a vote-count analysis, which can be combined with the meta-analysis using Wang and Bushman's (1999) method. Alternatively, Bayesian data augmentation could be used, but this suffers from the limitation that effect sizes are disregarded so should only be considered when none of the quantitative studies report effect sizes.

Textual Methods

Figure 3.1 presents the textual methods available for the synthesis of qualitative studies. The four methods that have been proposed for conducting textual single metric syntheses of quantitative and qualitative studies can also be used for the

textual synthesis within a dual metric approach. Additional techniques are described in the following sections. The guidance previously given for selecting a textual analysis method for a single metric synthesis also applies here.

Meta-synthesis is one of the most commonly used textual synthesis methods and involves the identification of first order constructs (quotations from participants), second order constructs (interpretations of quotations made by the authors of the primary studies included in the review), and third order constructs (higher order themes that go above and beyond the primary studies, Noblit & Hare, 1988). Third order constructs serve as the main results for a meta-synthesis, in the same way as the themes from a thematic analysis.

The metastudy method consists of three phases. The metatheory phase involves consideration of the theories that informed the primary studies. The metamethod phase involves evaluating the ways in which the methodological characteristics of each primary study may have influenced its findings. The final stage, meta-data-analysis, consists of critically evaluating the interpretations made by authors of the primary studies, comparing this across studies and ultimately synthesising the main findings of the primary studies (Thorne et al., 2002).

Meta-summary was developed for systematic reviews where meta-synthesis could not be conducted because some of the primary studies reported summarised rather than synthesised results. For example, in Sandelowski and Barroso's (2003) meta-summary investigating motherhood among HIV positive women, some of the primary studies consisted of lists of common responses to survey questionnaires, and sometimes also the frequency with which these responses were reported. When data are reported in this form rather than as a conventional qualitative results section, conducting a meta-synthesis can be challenging due to the lack of quotations and textual descriptions. A meta-summary is created by extracting thematic statements from the primary studies and reducing these to a smaller number of overarching themes (referred to as statements in this context). Related statements are then grouped together and the frequency of occurrence in the data is assessed (Sandelowski & Barroso, 2003).

The final textual method is a framework synthesis, which again involves identifying recurring themes from the data in the primary studies. This method is similar to a thematic analysis, with the main difference being that it involves a deductive approach. In a deductive approach the synthesis is conducted starting from

themes derived from theories that existed in the literature prior to beginning the systematic review, and the data is coded according to these themes (Carroll et al., 2013). This top down approach contrasts to the bottom up approach of generating themes that are entirely driven by the primary data.

Integrative Synthesis Methods

After individual syntheses have been generated for the textual and numeric data the method to bring the findings together must be decided. A third synthesis can be conducted where the results from the numeric and textual syntheses are combined, or the findings from the two syntheses can be juxtaposed in the discussion (Noyes & Lewin, 2011). Which is most appropriate depends on whether the aim is to combine or compare the results. If the decision is to integrate using a third synthesis, several options exist on how best to achieve this.

For researchers who wish to combine the results of the numeric and textual syntheses, few examples of integrative syntheses exist. A research group in the Evidence for Policy and Practice Information and Co-ordinating (EPPI) Centre devised a matrix approach that comprised a numeric synthesis of quantitative studies on the effectiveness of interventions and a textual synthesis of qualitative studies on participants' views and recommendations for such interventions (Thomas et al, 2004). The results of the two syntheses were put into a matrix which allowed participants' recommendations for interventions to be mapped to the interventions evaluated in the quantitative studies. This matrix revealed any recommended interventions which had not yet been implemented. For example, Thomas et al. (2004) numerically assessed the efficacy of interventions to increase children's fruit and vegetable intake. Qualitative analysis of children's views, however, revealed that they viewed fruit and vegetables quite differently. Interventions that separated fruit and vegetables were noted to be absent in the Thomas et al. (2004) review, thus served as a recommendation to be implemented by future interventions.

The integration of qualitative and quantitative analysis results is also a crucial component of mixed-method studies, but integration is frequently omitted in such studies, as highlighted by O'Cathain, Murphy, & Nicholl (2010). Although infrequently used, several integration methods integrating the quantitative and qualitative findings from mixed-methods studies have been proposed, and it may be possible to use these to integrate qualitative and quantitative findings in a mixed-

methods systematic review. The 'triangulation protocol' involves presenting the quantitative and qualitative results simultaneously in a matrix, grouped by conceptual themes so that the degree of agreement between the two can be easily examined (Farmer, Robinson, Elliott, & Eyles, 2006). An alternative approach is 'following-a-thread', which involves identifying a theme in either the quantitative or qualitative data, and examining to what extent the other type of data is consistent with it (Moran-Ellis et al., 2006). The triangulation protocol and following-a-thread techniques could be adapted for the purpose of integrating textual and numeric data in syntheses.

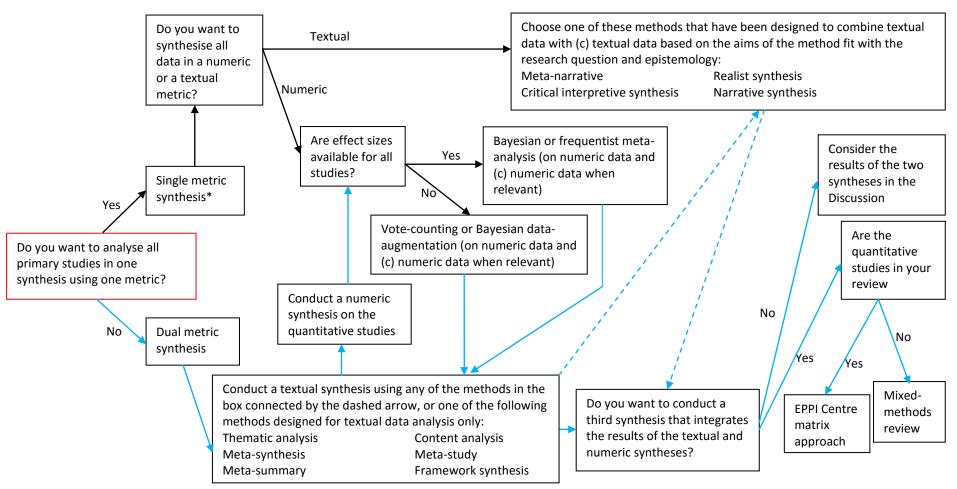


Figure 3.1 Decision tree to help choose between syntheses which group studies according to their use of qualitative or quantitative methods, and those which do not.

Note: Black arrows indicate the route to take for a single metric synthesis and blue arrows show the route for a dual metric synthesis.

^{*}For single metric syntheses, pages 63-64 and page 66 explain how to convert textual primary study results into a numeric metric and vice versa. (c) data = data that has been converted from numeric to textual form, or vice versa. Thematic and content analysis refers to analysis of primary study results.

Conclusions

Failing to include either qualitative or quantitative primary studies in a systematic review without good reason can bias the results of the review. However, researchers who wish to include both types of design face a number of decisions that must be made. The qualitative results can be converted into numeric form and combined with the numeric results of the quantitative studies, or vice versa, the quantitative results can be converted into textual form and combined with the results of the qualitative studies. These approaches frequently result in a loss of information and are not ideal for many review topics. For researchers who wish to conduct a dual metric synthesis, i.e., keeping the quantitative results in numerical form and the qualitative in textual form, few examples of frameworks exist to integrate two separate syntheses. The options available are summarised in the decision tree (Figure 3.1) to provide a quick way for future systematic reviewers to assess the available methods and decide which to read into in more detail.

The main challenge faced in conducting this review of the literature of mixedmethod syntheses was that, although there are lots of good papers on single metric synthesis methods that can be used for reviews including qualitative and quantative studies (e.g., Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Kastner et al., 2012; Mays, Pope, & Popay, 2005; Sandelowski, Voils, Leeman, & Crandell, 2012), the final integrative synthesis has had little attention. Although a number of papers mention that qualitative and quantitative studies can be synthesised separately and then subsequently integrated (Grant & Booth, 2009; Mays et al., 2005; Noyes et al., 2011), very little has been written on how to achieve this. Most papers cite the EPPI Centre matrix approach as an example, which is ideal for systematic reviews where the quantitative studies are interventions. However, to the author's knowledge no other methods for integrating numeric and textual syntheses have been proposed, so researchers reviewing non-intervention studies (or other topics for which the EPPI Centre matrix approach is unsuitable) have no methods available. In this part of Chapter 3, it was suggested that the approaches used to integrate quantitative and qualitative results in mixed-methods primary research could be adapted for this purpose. In Part 2 of this chapter, a systematic review conducted using this method is presented.

Chapter 3 Part 2:

Systematic Review of Reproductive Decision-Making among Non-Normative Groups

Introduction

The first step towards improving equality and diversity among the parenting population is to understand how non-normative groups make reproductive decisions about whether or not to start a family. While there is a plethora of research on the decision to have a first child in the general population, very few studies have investigated reproductive decision-making among non-normative groups.

Theoretical Approaches to Reproductive Decisions

The four main psychosocial theories that have been applied to reproductive decision-making were discussed in Chapter 1 and six themes were identified that capture the main elements of these theories. The barriers to parenthood highlighted by the six themes are likely to apply to non-normative groups as well as the general population, but in non-normative groups the same barriers may be more prevalent or take a different form.

For example, the theme of population norms, that highlights the influence of societal-level beliefs and attitudes, appears to influence reproductive decision-making for most people, as demonstrated by the average age at first birth in the general population increasing as the age considered ideal to have children became older (Mills et al., 2011). The population norms affecting non-normative groups may differ slightly in that they could be more related to social stigma, as suggested by qualitative studies of disabled and gay parents that highlight experiences of negative social attitudes (Duvdevany et al., 2008; Preston & Jakobson, 1997; Wall, 2011).

Similarly, when contraceptives became readily available reproductive decisions among the general population changed and the average age at first birth increased (Mills et al., 2011), highlighting the importance of the theme of agency. This theme proposes that the sense of being capable of being a parent (or conversely being able to choose to not get pregnant) is a strong factor determining the likelihood of the first birth. Compared to people in opposite-sex relationships, gay men and lesbians' sense of agency concerning being able to conceive a biological child may be

more dependent on financial factors, as they generally need to fund their own reproductive technologies in the UK unless they have a fertility problem (National Institute for Clinical Excellence, 2013; Stonewall, 2014).

The small amount of research that has examined reproductive decision-making among non-normative groups further supports the notions that the four psychosocial theories are applicable. As described in Chapter 1, to the author's knowledge there are two existing systematic reviews on reproductive decision-making among non-normative groups. Both of these reviews investigated the factors influencing reproductive decisions for individuals who are HIV positive. Measures which would be expected to increase agency for these individuals, specifically the availability of services to prevent mother to child transmission, were found to increase parenthood desires and intentions to have children (Nattabi et al., 2009). Similarly, desires and intentions were stronger among younger people (Berhan & Berhan, 2013; Nattabi et al., 2009), highlighting the relevance of the timing theme (because of social expectations concerning the time of life at which one should have children) and the agency theme (because women are constrained to having biological children within their reproductive years, with the exception of those who freeze their eggs).

The theme of population norms was also evident in the results of these two systematic reviews as the attitudes of healthcare professionals and the community in general were found to influence parenthood desires and intentions (Nattabi et al., 2009). However, it should be noted that discrepancies in the evidence base regarding the role of population norms are apparent in the literature identified by this review. For example negative attitudes amongst healthcare workers were found to influence reproductive decision-making in America by Sowell and Misener (1997) but not by Craft, Delaney, Bautista, and Serovich (2007). Although this discrepancy may be partially due to the decrease in negative social attitudes towards parenthood among individuals with HIV over time, further research is needed to form stronger conclusions.

Although these findings are consistent with the general themes gleaned from the psychosocial theories in Chapter 1, there is an exception. Educational attainment had a non-significant effect (Berhan & Berhan, 2012), despite being a factor that might be expected to decrease motivations to have children because of higher levels of career investment (the motivation theme holds that motivations to have children,

which are reduced by competing alternatives such as career investment, influence reproductive decisions). However, the nonsignificant effect of education may have been because all included studies were conducted in Africa or Brazil, and education may genuinely not be a barrier to parenthood for people with HIV residing in developing countries. Alternatively, since the measure of education was dichotomous, i.e., primary or no education compared to secondary and above, the nonsignificant effect may have been because it is only tertiary education that hinders parenthood in the populations in question.

It should also be noted that the factors identified by these two reviews cannot be interpreted as reflecting the decision to become a parent because the included studies did not require participants to be childless. The decisions being modelled frequently pertained to having a second, third or higher parity child. Research examining reproductive decisions in the general population has shown that the decision to have a first child is influenced by different factors to the decision to have subsequent children (Hank & Kreyenfeld, 2003; Kravdal, 1996), so results concerning subsequent parities cannot be generalised to the decision to have a first child.

Overall, these two existing systematic reviews highlight that the four psychological theories applied to childbearing account for the known barriers to parenthood in non-normative groups. However, poor methodological quality is prevalent in the literature, especially concerning lack of separation by parity, and a review specific to the decision to have a first child that also encompasses non-normative groups other than individuals who are HIV positive is needed.

The Present Study

The aim of the present study was to identify the barriers contributing to the low parenthood rates observed in non-normative groups. Additionally, factors that facilitate parenthood among these populations were identified. This was achieved by synthesising the findings of quantitative and qualitative studies of the decision to have a first child in non-normative groups. The hypotheses were derived directly from six theoretical themes identified in Chapter 1, and are presented in Table 3.1.

Table 3.1.

Hypotheses arising from the six themes summarising the four psychosocial theories that have been applied to the domain of reproductive decisions.

Theme	Definition	Hypotheses
Time	Social constructs	Child-timing intentions, desires, attitudes and beliefs will
Time	related to time:	predict the age at first birth
	normative issues,	The timing of adult life transitions (e.g., job stability, own
	timing in relation	house, long-term partnership) will be related to the first birth
	to the	Societal norms concerning age at first birth and the stage of
	individual's life	life that should be achieved before becoming a parent will
	trajectory	influence the first birth
Agency	Freedom and	Although obvious, in women age younger than the
	ability to make	biological deadline (approx. 45) will be a predictor
	choices within	Other capacity limitations will be a barrier to becoming a
	the available	parent (e.g., access to required medical interventions,
	options	concerns over physical capacity for parenting if chronic
		disease is present or imminent)
		People who perceive themselves as capable of being a good
		parent will be more likely to have a first child. Lack of a partner and financial difficulties may pose barriers to
		parenthood if they cause people to feel they do not have the
		resources required to raise a child successfully are in place.
Planning	Preparing for	Childbearing intentions will predict first births
C	parenthood,	Readiness to parent will predict first births, and is defined as
	readiness to	having completed the life transitions that typically precede
	become a parent	parenthood. For example, having a stable relationship and
		financial and career security
Motivation	Value attached to	Desires and positive attitudes will facilitate parenthood.
	parenthood	Childbearing motivations (defined as positive feelings evoked by caring for children, Miller et al., 2004) will have
		positive effects. The factors that underpin motivations
		include satisfaction associated with childcare, feeling
		needed and connected, and fears and worries about
		parenthood (Miller et al., 1995)
Population	Societal norms	Societal norms concerning the age at first birth and the
norms	concerning when	preconditions for parenthood will have predictive value: In
	to have children	developed countries, perceived norms dictate that the
	and who should	acceptable ages to have children are approximately 19-43
	be parents	(van Bavel & Nitsche, 2013). Furthermore, it is likely that
		population norms dictate that one should be in a relationship
		at the time of the first birth. Therefore, being between 19 & 43 years old and being in a relationship were expected to be
		predictors
		Negative societal attitudes towards non-normative groups
		will reduce the likelihood of having a first child
Negotiated	The impact of the	Positive partner attitudes and motivations toward
norms	expectations and	parenthood will have facilitator effects
	opinions of close	Presence of absence of support from close family and
	others, such as	friends will influence the likelihood of parenthood
	partner, family	
	and close friends	

Few studies have examined the decision to have a first child among non-normative groups, so excluding either the qualitative or quantitative studies would cause substantial information loss. The review of the available methods for synthesis of quantitative and qualitative studies (Chapter 3 Part 1) showed that there are multiple approaches that can be taken. In the present study a dual metric synthesis was used because the statistical amalgamation of the effect sizes from the quantitative studies would be useful to show the relative importance of the barriers to and facilitators of parenthood. In addition, the in depth information provided by the qualitative studies was expected to be useful in identifying any potential important factors not assessed by the quantitative studies, or to shed light on why certain factors had a strong influence on reproductive decisions.

Methods

Search Strategy and Selection Criteria

The present study was part of a broader systematic review not specific to non-normative groups. The broader review aimed to identify all studies on the biological, psychological and social factors that influence the decision to have a first child. The search terms incorporated factors related to the decision-making process and outcomes related to the first birth (see Appendix B for search terms).

Fourteen electronic databases were searched: Medline, Medline in Process, Embase, PsychInfo, Psych Articles, HMIC, EBM, ASSIA, The British Humanities Index, Sociological abstracts, Social Services Abstracts, Studies on Women and Gender Abstracts, OpenSIGLE, and Proquest (Dissertation and Theses). The initial search was performed on 2nd and 3rd March 2009 and a final update on 20th March 2013. Two databases, EBM and Studies on Women and Gender Abstracts, were no longer accessible when the review was updated. Studies published prior to 1990 were excluded and date restrictions were set to 1990 onwards when possible.

A sub-search was applied to the resulting database of records to identify studies relevant to non-normative groups (see Appendix C for search terms). MeSH searches were used to assist in the compilation of search terms.

The author identified eligible studies and 20% were independently cross-validated for eligibility by another researcher with 100% agreement. Studies were eligible if they investigated reproductive decision-making among non-normative groups and when at least 90% of the study respondents were childless. Quantitative studies had to examine the relationship between driving factors and a measure of outcome such as childbearing desires, intentions, or first live birth.

Studies were excluded if they involved teenage pregnancies, abortion or reported the same data as another paper. Retrospective studies, quantitative studies without significance values, and papers in languages other than English were also excluded.

Data Extraction

In accordance with the Cochrane Handbook (Higgins & Green, 2011) and the guidance published by the Centre for Reviews and Dissemination (2009), from the

quantitative studies data were extracted on the aim/hypothesis, measures of outcome, predictor variables, study design, year of data collection, sample size, sampling procedure, country, eligibility criteria, urban or rural location, gender, age, socioeconomic status, ethnicity, method of data analysis/statistical test, confounders, response rate, significance and direction of results, and the conclusions drawn in the paper.

The qualitative data extraction forms were based on those constructed by Munro et al. (2007). The complete list of variables extracted is similar to the quantitative list, with the main additions being theoretical background, sampling approach, data collection methods, data analysis approach, key themes identified in the study, explanations of the key themes, and recommendations.

Quality Assessment

The critical appraisal tools for quantitative and qualitative studies published by Weightman, Mann, Sander, & Turley (2004) were used, but the quantitative tool was combined with that of Zaza et al. (2000) to increase its specificity. Most items were related to methodological quality (e.g., Did the study achieve a good response rate?), with some assessing reporting quality (e.g., Did the authors specify the screening criteria for study eligibility?).

The scoring system developed by Dixon-Woods et al. (2007) for qualitative studies was adopted. Rather than purely using the checklist score, qualitative studies were judged to be conceptually rich key papers, satisfactory, or fatally flawed. For 20% of the included studies there was independent cross-validation with moderate agreement found for the quantitative (80% agreement, κ = .50, P < 0.01) and qualitative (89% agreement, κ = .61, P < 0.05) primary studies. Discrepancies were resolved through discussion.

Synthesis Methods

The structure of the three syntheses is presented in Figure 3.2. As shown by panel 1a, the first stage involved extracting effect sizes from the data and undertaking meta-analysis and vote-counting procedures that were based on the guidelines in Wang and Bushman (1999). When studies did not report sufficient information for

effect sizes to be extracted, the direction and significance of the result was entered into the analysis as a vote count. The syntax used was that provided by Wang and Bushman (1999) adapted for the present study (See Appendix D for the syntax). Meta-analyses and vote-counting were conducted using SAS software (version 9.3, SAS Institute, Inc., Cary, NC, USA). The measure of heterogeneity, I², was calculated using the R package MAc (Del Re & Hoyt, 2012). Due to the heterogeneity in outcome measures, random effect meta-analyses were conducted.

Panel 1b in Figure 3.2 shows that the second stage of meta-analysis was to conduct sensitivity analyses by measure of outcome, sample representativeness, and mean age. Subgroup analyses were conducted by year of study as societal attitudes have changed over time.

The qualitative meta-synthesis (panels 2a to 2d in Figure 3.2) was conducted according to Britten et al. (2002)'s adaptation for health research. Panel 2a shows that the first step was to identity the first and second order constructs, as previously defined. As indicated by the panel 2b in Figure 3.2, the second step involved evaluating how the second order constructs in the different studies related to each other, and identifying those that were conceptually similar. The third stage (panel 2c) consisted of translating the second order constructs into one another to bring together conceptually equivalent second order constructs from different studies. For example, if three different studies include the same second order construct, bringing the perspectives of all three studies together can inform an overarching definition of the construct.

Panel 2d in Figure 3.2 shows that the final stage consisted of a thematic analysis, which was used because it is one of the most frequent qualitative methods of synthesis of health-related evidence. Further, Thomas and Harden (2008) have published guidelines on the use of thematic analysis in the context of a health-related systematic review. Thematic analysis was applied to the first and second order constructs with the aim of identifying the overarching themes, referred to as third order constructs. Thematic analysis can be data- or theory-driven, and was data-driven in the present study as the aim was not to refute or affirm a specific theory.

When conducting a thematic analysis to synthesise qualitative studies, the researcher must consider the three ways in which studies can relate to one other. When the results of the primary studies are very similar the synthesis is referred to as

reciprocal translation, whereas refutational translations are undertaken when studies oppose each other. Finally, studies that together can be used to go beyond the individual studies to form inferences about the general phenomenon in question are synthesised with the aim of constructing a line of argument (Noblit & Hare, 1988).

To maximise the reliability of the thematic analysis, two researchers independently applied the coding system to the data and identified the third order constructs. Any points of disagreement were resolved through discussion. Extra information to make the meaning of quotations clear to the reader is provided in brackets within quotations in the results section.

Panel 3 in Figure 3.2 shows that next stage was to carry out the integrative synthesis. The procedure was based on the triangulation protocol (Farmer et al., 2006) primarily because it provided a basis for adapting the EPPI Centre matrix approach used to integrate numeric and textual synthesis findings as described in Chapter 3 Part 1. An adaption was proposed which involved producing a matrix with each qualitative theme as a column header (see Figure 3.2 panel 3a). The conceptually related quantitative results were listed in the cells below each qualitative theme.

As shown by panel 3b in Figure 3.2, this allowed the qualitative and quantitative results to be easily evaluated for agreement or dissonance. Agreement refers to situations where the same results were found by the qualitative and quantitative studies and dissonance occurs when the results are inconsistent with each other. When the qualitative and quantitative results are inconsistent, strategies intended for mixed-method designs can be drawn upon for the synthesis. One strategy is reconciliation that refers to situations where the divergent results have a logical explanation, possibly leading to new understandings of the phenomenon. A second strategy is exclusion of one result, used when results diverge because of incomplete/inadequate data or validity problems (Pluye, Grad, Levine, & Nicolau, 2009).

Figure 3.2. The process of undertaking a quantitative meta-analysis, a qualitative meta-synthesis, and integrating the findings.

3b. Evaluation of agreement between results

Results

Description of Included Studies

Overall, a total of 50,775 records were identified from searching the electronic databases, excluding duplicates, and 11 studies were eligible for inclusion (see Figure 3.3). Seven of the eligible studies were published in academic journals and there were four unpublished PhD theses. All seven of the quantitative studies were on lesbians or gay men, including the eligible quantitative section of the mixed-method study by Solomon (1991). The five qualitative studies, including the qualitative sections of the two mixed-method studies, included individuals with heritable conditions, cancer survivors, lesbians, and gay men (see Appendix E for full details on the included studies).

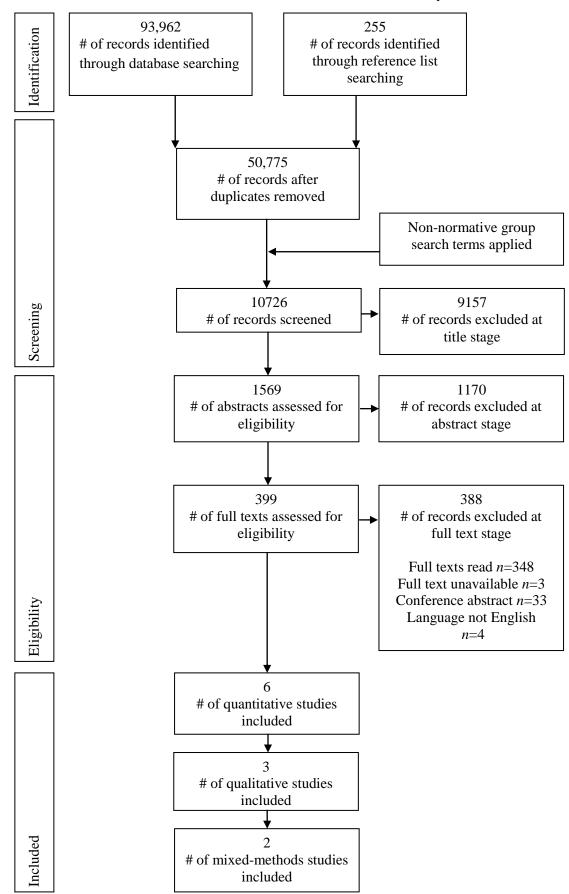


Figure 3.3. Flow chart of the results of the identification and selection procedures

All but two studies used self-selecting samples, defined as participants opting to take part. All but one study involved participants living in the United States of America (USA) and Canada. Response rates ranged from 24-97% and sample sizes ranged from 10 to 294; when only a subsample of participants was eligible for inclusion, the size of the subsample was reported as the sample size. The mean age of the majority of samples was early 30s, and the most common measure of outcome was parenting intentions (see Appendix E for further information on the sample and design characteristics of the included studies).

All seven quantitative studies or sections of studies were rated as high quality and four of the five qualitative studies or sections were rated as key papers, with one rated as satisfactory (see Appendix F for further information).

Meta-Analysis

Enough information for a meta-analysis to be conducted was present for three predictors, i.e., at least two studies that examined these factors reported effect sizes: age, education and relationship status. As previously described, random effects meta-analyses had been planned for all predictors, but a fixed analysis was conducted for relationship status because I^2 was 0%.

Lack of effect size information meant that vote-counting procedures had to be carried out for the remaining 10 factors, either because no studies reported effect sizes or only one did. Wang and Bushman's (1999) procedure for combining vote-counts and meta-analysis does not allow a single effect size to be combined with a single vote-count, so in these cases the effect size was converted to a vote-count and included in the vote-counting procedure. Five factors could not be synthesised using Wang and Bushman's (1999) vote-counting procedure because all the votes were the same, which prevents the algorithm from running. In these situations, given all studies found the same result, that result was taken as the pooled result.

The direction of scoring for each variable is indicated by its name, for example younger age \$\psi\$ indicates that younger age was associated with a reduced likelihood of having a first child. To summarise Tables 3.2 to 3.4, four demographic variables were examined by at least two studies, and results showed that increasing age hindered childbearing in gay men and lesbians. All other demographic predictors, the two relational variables, the five factors related to sexual identity, parenting attitudes and

self-esteem were not significant predictors of having a first child. Having good perceived parenting skills facilitated parenthood in gay men and lesbians, however.

Table 3.2. The effect sizes and vote-counts from each study, and the aggregated results for the demographic factors.

Factor			Demographic			
Study	Younger age		Lower level of education		Low	Non-white
					income	race/ethnicity
	r^{a}	VC	r^{b}	VC	VC	VC
Solomon	0.25		0.064			
(1991)						
McCrohan	0.34					
(1996)						
Sbordone	0.29			NS	NS	NS
(1993)						
Shenkman et	0.13		-0.090			
al. (2011)						
Eisenberg		↑		↑	↑	
(2004)		NIC			NG	NG
D'Augelli et		NS			NS	NS
al. (2007) Riskind et al.		^				NIC
(2010)		↑				NS
women						
Riskind et al.		↑				↑
(2010) men		ı				ı
Total	0.25*	0.046	-0.043	0.035	-0.101	-0.045
[95% CI]	[0.11,	[-0.069,	[-0.14,	[-0.13,	[-0.13,	[-0.17,
	0.38]	0.16]	0.052]	0.20]	0.11]	0.082]
Combined	0.13*	,	-0.023	_	,	,
result	[0.046,		[-0.11,			
[95% CI]	0.22]		0.06]			

Note. Factors that have no column headed 'r' did not provide sufficient information on effect sizes to run a meta-analysis. * indicates that the result was significant, as indicated by the confidence intervals not crossing zero (the procedure does not generate exact p values). VC = vote counts ${}^{a}I^{2} = 33.00\%$ ${}^{b}I^{2} = 22.95\%$

Table 3.3.

The effect sizes and vote-counts from each study, and the aggregated results for the sexual identity factors.

Factor Sexual identity					
Study	Longer time out to others	Internalised homophobia	Comfort with sexual orientation	Age first identified as gay	Sexual orientation
	VC	VC	VC	VC	VC
Solomon (1991) McCrohan (1996)				NS	NS
Sbordone (1993) Shenkman et al. (2011)	NS	NS	NS		NS
Eisenberg (2004)	↑	NS			
D'Augelli et al. (2007) Riskind et al. (2010) women Riskind et al.		NS	NS	NS	
(2010) men Total [95% CI]	0.035 [-0.13, 0.20]	NS	NS	NS	NS

Note. Factors that have no column headed 'r' did not provide sufficient information on effect sizes to run a meta-analysis. * indicates that the result was significant, as indicated by the confidence intervals not crossing zero (the procedure does not generate exact p values). VC = vote counts

Table 3.4.

The effect sizes and vote-counts from each study, and the aggregated results for the self-perception, relational and parenting factors.

Factors	Self- perceptions	Relational		Parenting		
Study	Self esteem	Relationship status	Shorter relationship duration	Good perceived parenting skills	Positive attitudes toward parenting	
	VC	<u>r</u> ^c	VC	VC	VC	
Solomon (1991)	NS	0.076		↑		
McCrohan (1996)			NS		↑	
Sbordone (1993)	NS					
Shenkman et al. (2011)		-0.020				
Eisenberg (2004) D'Augelli et al.			↑	↑	NS	
(2007) Riskind et al. (2010)						
women Riskind et al. (2010)						
men Total [95% CI]	NS	0.008 [-0.11, 0.13]	0.012 [-0.12, 0.15]	↑	0.0071 [-0.13, 0.14]	

Note. Factors that have no column headed 'r' did not provide sufficient information on effect sizes to run a meta-analysis. * indicates that the result was significant, as indicated by the confidence intervals not crossing zero (the procedure does not generate exact p values). VC = vote counts $^{\rm c}I^2=0.00\%$

Qualitative Meta-Synthesis

The included studies approached reproductive decision-making from different angles, so a line of argument was constructed (Noblit & Hare, 2008), which means that general inferences about reproductive decision-making beyond the primary studies were made. Four third order constructs were identified and are presented in

the following sections: Value of parenthood and intentions, preferred routes to parenthood, psychology barriers to parenthood, and practical impediments.

Value of parenthood and intentions.

The qualitative results showed that among lesbians, cancer survivors, and individuals with heritable conditions, greater value of parenthood and stronger intentions increased the likelihood of having a first child. Cancer survivors found the prospect of infertility distressing, suggesting they valued biological parenthood highly (Gorman, Bailey, Pierce, & Su, 2012). "...maybe I don't have time to deal with that right now or don't have the emotional energy to deal with that right now in case it's bad news [i.e., would not be able to conceive]" (26 year old cancer survivor, Gorman et al., 2012, p. 202).

Among Fragile X carriers, "many of the study participants reported that knowing their genetic risk status had no effect on their desire for children" (McConkie-Rosell, Heise, & Spiridigliozzi, 2012, p. 63). However, desire for children lessened in some and increased in others: "It's made me think about it [having children], you know, a lot deeper, and it's made me actually want it more" (Carrier, 22 years, McConkie-Rosell et al., 2012, p. 63). Some lesbians reported prioritising career investment over motherhood: "I feel a sense of loss about my decision [to prioritise my career over parenthood] but also feel it was the right one for me to make" (Solomon, 1991, p. 91).

Preferred routes to parenthood.

Cancer survivors, individuals carrying Fragile X syndrome, and gay men were open to considering alternative routes to parenthood. For example, cancer survivors were "open to the option of adoption if they were unable to have a biological child" (Gorman et al., 2012, p. 202), and most gay men "challenged the idea that fathers need to be biologically related to their children by discussing adoption as socially responsible parenthood" (Rabun & Oswald, 2009, p. 277). Reproductive technologies were endorsed by about half of the Fragile X syndrome carriers in the study, and most also held positive attitudes towards adoption although some reported "they would adopt if it were the only way to become a mother" (McConkie-Rossell et al., 2012, p. 66).

Psychological barriers to parenthood.

Subtheme 1: Concerns over own or child's health.

Many cancer survivors and individuals at risk of Huntington's disease were deterred from parenthood by health concerns. Cancer survivors were concerned about pregnancy causing their cancer to return or worsen (Gorman et al., 2012), as well as the effects that their long-term health and possible early death could have on a child: "...I'm worried about how it's [history of cancer] going to affect family structure, how it's going to affect morale or their emotional development, things like that..." (Age 23, adolescent cancer survivor, Gorman et al., 2012, p. 206).

Many people at risk of Huntington's disease had seen their family members suffer with the illness, which often lead to high levels of opposition to having biological children: "It was not like I had to sit there and think about it and think about it and struggle with it. It was like I'm just not gonna have kids" (Woman at risk for Huntington's disease, Quaid et al., 2010, p. 613).

Subtheme 2: Relationship problems.

Difficulties with relationships presented a barrier to parenthood among people at risk of Huntington's disease and cancer survivors. Some cancer survivors had had relationships end once they disclosed their situation, as a 23 year old survivor explained: "The last person I dated, like that was kind of what broke it [disclosing their possible infertility]. Even though you're only a month in that just was the final straw discussing children and options" (Gorman et al., 2012, p. 205).

Some people at risk of Huntington's disease avoided relationships to protect others from the devastating effects of the disease: "I've lived my life as if I'm going to be alone for the rest of my life because I don't know [when I will die]" (Male at risk of Huntington's disease, Quaid et al., 2012, p. 614).

Subtheme 3: Societal issues.

It was evident that, among the sample of gay men, increasing societal acceptance facilitated parenthood. Most individuals were able to reconcile being a gay man and the desire to be a father: "...the idea of family that has always been traditionally placed into your consciousness will have to be modified...it is something

that you are gonna have to work around and kinda redefine for yourself" (Carson, age 22, Rabun & Oswald, 2009, p. 277).

Despite this, most gay men stated that their biggest concern about future parenting was the potential for the children to suffer socially or be bullied for having gay parents (Rabun & Oswald, 2009). The data on the lesbian sample, published 24 years ago, showed that some were deterred from parenthood because they lacked support because they "had no family nearby and they couldn't find a place in the lesbian community" (Solomon, 1991, p. 91).

Practical impediments.

Cancer survivors, lesbians, and gay men reported financial concerns as a practical barrier to parenthood (Gorman et al., 2012; Rabun & Oswald, 2009; Solomon, 1991). Some cancer survivors were unable to have biological children because their health care providers had failed to offer them the option to preserve their fertility prior to undergoing treatment. The perceived reasons included "providers were uncomfortable talking about it and did not think it was important" (Gorman et al., 2012, p. 203). Others were told that their cancer stage was too advanced to delay treatment to undergo the oocyte retrieval required to preserve their fertility (Gorman et al., 2012).

Synthesis of the Qualitative and Quantitative Results

The matrix in Table 3.5 presents the qualitative themes in the top row of each column with the corresponding quantitative results listed below them.

Table 3.5. *Matrix of qualitative themes and corresponding quantitative results*

Value of	Preferred routes to parenthood	Emotional barriers to parenthood			Practical barriers
parenthood and intentions		Concerns over own or child's health	Relationship problems	Societal issues	to parenthood
Positive attitudes toward parenting	No relevant quantitative results	Good perceived parenting skills	In a relationship	Internalised homophobia	High income
			Longer duration of relationship	Self esteem	
			•	Comfort with sexual orientation	
				Self-report sexual orientation scale	
				Longer time out to others	
				Age first identified as gay	

Note. Column headers refer to the qualitative themes. The corresponding quantitative results are listed in the column under each theme. Self esteem was classified as a societal issue as it is likely to be affected by social experiences such as homophobia. However, it is acknowledged that self-esteem can be related to numerous factors.

Points of convergence.

Both syntheses found that not feeling capable of being a good parent (whether due to poor health or poor perceived parenting skills) was a barrier to parenthood (Table 3.5, 'Concerns over own or child's health'). The only barrier measured by the quantitative studies was income which was not significantly associated with the likelihood of parenthood. This may be because both exceptionally high and low income can pose barriers to parenthood, advertently causing the association to go undetected by linear statistical tests. The qualitative findings suggest that practical barriers can be posed by high levels of career investment and financial difficulties (Table 3.5, 'Practical barriers to parenthood'). This would suggest a curvilinear relationship between income and the likelihood of having a first child.

Points of divergence.

Three quantitative findings (related to age, education, and race/ethnicity) did not correspond to any of the qualitative themes. Additionally, the numeric and textual synthesis results were not in agreement about the influence of parenthood motivations. Although the textual results suggest that valuing parenthood facilitated having a first child, in the numeric results positive parenting attitudes had no significant effect (Table 3.5, 'Value of parenthood and intentions'). The reason for this discrepancy may be due to the attitudes scale used by Eisenberg (2004), which measured the perceived costs and benefits of having a child, some of which were specifically related to lesbian identity, and this measure unrelated to intentions. The other quantitative study, McCrohan (1996) measured attitudes towards children in a way that was not specific to lesbian identity, and this measure was associated with intentions. It may be that it is not issues related to parenthood and lesbian identity which influence parenthood, but rather more general attitudes towards parenthood.

The qualitative results suggested that relationship difficulties due to being a carrier of Huntington's disease or cancer survivor posed a barrier to parenthood. However, the quantitative synthesis found relational factors not to be significant in gay men and lesbians (Table 3.5, 'Relationship problems'). This discrepancy in relational effects is confounded. It could be that it is due to the method difference between studies (e.g., qualitative methods may be better able to tap into relational problems), or it could be due to the different populations (e.g., the relational

difficulties typically encountered by gay people and people with health conditions are very different). It is not possible to disentangle this effect because the quantitative studies only investigated gay men and lesbians and the qualitative studies only examined people with health conditions.

The qualitative data highlight that social stigma is a barrier to parenthood while increased social acceptance facilitates it. However, the quantitative measures of stigma were nonsignificant (see Table 3.5, 'Societal issues') which may have been because none of these measures specifically related to parenthood, rather they measured participants' acceptance of their sexual identity in a more general sense.

Discussion

There is a concerning scarcity of research on the decision to have a first child among non-normative groups. Existing studies provided too little evidence to support or refute specific hypotheses but general patterns could be observed in the results, especially that age and perceiving oneself to be capable of being a good parent appear to be the most important determinants of parenthood intentions.

It was evident from the results that some barriers are common to all nonnormative groups despite being expressed in different ways across studies (e.g., low
perceived parenting skills, which were due to health limitations among cancer
survivors but appeared to be more general among lesbians, none of the studies on gay
men assessed this construct). Other barriers were unique to the specific group (e.g.,
concerns over disease transmission among individuals with Huntington's disease).
There were also clear differences between the quantitative and qualitative study
results, especially concerning stigma-related factors which were frequently cited as
barriers in the qualitative findings but were nonsignificant in the quantitative results.

Theoretical Implications

The results of the syntheses lent support to the six themes derived from the psychosocial theories outlined in Chapter 1 in a variety of ways. The first theme, time (that hold that the trajectories of different areas of life influence each other), was supported by the financial barriers cited in the qualitative studies, which highlight the need to have reached the right stage of life. Financial barriers may be a greater problem for non-normative groups than for most people for a variety of reasons.

Outside of the UK, high medical bills may be faced by people with cancer or other health conditions. To add to this, disabled people are known to be less likely to be employed than nondisabled people (Office for National Statistics, 2014b) so are more likely to be living on a limited income.

However, neither being in a relationship nor duration of relationship had significant effects on the intentions of lesbians or gay men. This appears to contradict the principle of Life Course Theory that the timings of major life transitions influence subsequent decisions, and evidence suggests that cohabitation or marriage are important stages to reach before having children, as they strongly predict the first birth in the general population (e.g., Hank, 2003; Jokela et al., 2009). It is possible that transition to a cohabiting relationship/marriage/civil partnership is less important to the reproductive decisions of gay men and lesbians. A stable relationship may not contribute to the feeling of achieving the right stage of life to have children among same-sex couples to the same degree as opposite-sex couples. This might be because same-sex couples face many other barriers to parenthood which prevent them from feeling ready to have children to the same extent as their opposite-sex couple equivalents, possibly including concerns about societal stigma and the practical and financial efforts involved in pursuing biological parenthood (e.g., surrogacy, insemination, or selection of donor sperm/eggs).

The finding that older age decreased the likelihood of parenthood, and that cancer survivors were concerned about having a shortened reproductive window, also demonstrate the overall importance of time in the decision-making process. All women are constrained by their reproductive years, but the results show that cancer survivors have to factor in even greater time pressures to their reproductive decisions.

These age effects are also related to the agency theme, as women are constrained to having biological children within their reproductive years. Cancer survivors also reported concerns about the impact their health problems might have on a child deterring them from parenthood, possibly by reducing their sense of agency i.e., feeling capable of raising a child successfully. The predictive value of having good perceived parenting skills and the barrier posed by financial difficulties also highlight that the perceived ability to raise a child successfully increases the likelihood of parenthood. However, it is not known whether perceived parenting skills and financial difficulties influenced parenthood decisions among gay men and lesbians

more commonly than in the general population. In order to provide more informative data on the role of these issues, the studies should employ comparison groups of people who do not belong to a non-normative group.

The finding that partnership status was not significant among gay men and lesbians suggests that having a partner had less of an effect on agency than among people who identify as heterosexual, perhaps partly because of the role having an opposite-sex partner plays in the ability to conceive. However, relationship concerns reported by people who were at risk of being a carrier of Huntington's Disease seemed to deter them from parenthood, so relational factors may be more important to the sense of parenthood-related agency among people at risk of a transmissible condition.

The influence of a lacking sense of agency was also evident in the concerns people reported about transmitting a condition to a potential child, who may have perceived themselves as unable to have a child who is likely to have a good quality of life. A further loss of agency was evident among the cancer survivors who had not been offered fertility preservation prior to treatment, or those who were told about fertility preservation but were not able to undergo the procedure due to cancer type of advanced stage.

The importance of the planning theme (which proposes that people have plans for what they want to achieve before they have children) was supported by the finding that financial difficulties were a barrier among cancer survivors, but again the insignificance of the relationship-related factors in lesbians and gay men was unexpected. There was evidence that cancer survivors and individuals with Huntington's disease had strong relationship concerns, and consistently with the planning theme, it was implied that this hinders parenthood plans. As previously described, most people in the general population are cohabiting or married before having children (Hank, 2003; Jokela et al., 2009), implying that most people's plans to prepare for parenthood involve finding a stable partner.

Motivations to have children (one of the six themes) featured strongly in the results, represented by the qualitative theme 'Value of parenthood and intentions' as well as the generally positive attitudes toward assisted reproductive technologies and adoption under the 'preferred routes to parenthood' theme. These results primarily related to cancer survivors and people with genetic conditions, and it appears that these individuals were highly motivated to have children. Whether this level of

motivation differed to that of the general population is not known, and future studies should use comparison groups to establish whether motivation to have children differs between cancer survivors and people with genetic conditions and those without either.

However, of the two primary studies that employed a quantitative measure of attitudes (both used lesbian samples), only one found a significant association between more positive attitudes and an increased likelihood of having a first child. The nonsignificant finding (Eisenberg, 2002) may have been due to the use of a slightly different measure of attitudes, which was constructed to measure the perceived costs and benefits of motherhood specifically for lesbians. For example, it included items related to the impact of motherhood on participants' sexual identity and whether they thought they would feel isolated as a lesbian mother. It may be the case that the specific perceived costs and benefits that are related to how motherhood might impact on someone's identity as a lesbian women are less important for reproductive decisions than general attitudes towards children.

Some evidence of high levels of career investment deterring lesbians from parenthood was present, from the qualitative results. It is possible that, in general, gay men and lesbians have fewer parenthood motivations than heterosexual people. This is supported by existing evidence which suggests that fewer childless lesbians report the desire for children than the equivalent heterosexual women (Riskind & Patterson, 2010), although research is yet to examine the reasons for this. It is possible that gay men and lesbians tend to have specific social experiences that make them less interested in being parents, for example exposure to prejudice against same-sex parents. It is consistent with the premises of the Traits Desires Intentions Behaviour framework (TDIB) and the Theory of Planned Behaviour (TPB) that people who are less motivated to have children would be less likely to become parents, and low motivations are likely to be a factor that contributes to the low parenthood rates among gay men and lesbians.

Evidence for the influence of population norms (a theme holding that social norms held at the societal-level impact decisions) was prevalent in the qualitative interviews with gay men and lesbians as concerns about negative social attitudes were reported. However, the five quantitative variables related to sexual identity and internalised homophobia were nonsignificant. This may have been because none of

the quantitative measures assessed attitudes specific to parenting as a gay man or lesbian, something which should be addressed by future research.

Life Course Theory emphasises the importance of social experiences over individuals' psychological processes, which is consistent with the finding from the qualitative results that some gay men and lesbians were affected by negative social attitudes towards same-sex couples being parents. The TPB is not specific to reproductive decisions so does not offer any guidance on which aspects of stigma would be expected to influence reproductive decisions. Although the TDIB is a fertility model, it is not specific to non-normative groups so again does not include guidance on the role of stigma. Future research should conduct more comprehensive assessments of the role of stigma, which would also have the benefit of showing how factors that apply to non-normative groups that would not be experienced by other people fit into the TPB and the TDIB.

No factors present in the systematic review related to the final theme, negotiated norms, which proposes that the beliefs held by close others, such as family, friends and partners, influence decision-making. This is an important area for future research because for people in relationships, reproductive decisions are generally a dyadic process.

Limitations

A potential limitation of the synthesis methods is that the author's position in relation to the data was that of a nonparent not actively engaged in reproductive decision-making, which may introduce particular biases to the results of the textual synthesis. However, an independent researcher also analysed the data and any points of discrepancy were discussed in order to minimise any such bias.

The limitations of the primary studies also constrain the conclusions that can be drawn from the synthesis. One such limitation is that none of the included studies use first live birth as a measure of outcome and most used intentions, as is frequently the case in demographic studies of fertility (Philipov, 2011). Consequently, the results should be interpreted bearing in mind that childbearing expectations, attitudes, and intentions do not always get translated into behaviour. It is widely accepted that there are situations in which intentions are not realised (Azjen, 2011; Barber, 2011), and reasons may include the limits imposed by actual behavioural control (Liefbroer,

2011) or wide-ranging situational factors such as alcohol (Ajzen, 2011). Individuals can also experience multiple intentions that compete with one another, and childbearing intentions may not be realised due to being overridden by another intention (Barber, 2011).

Furthermore, of the six quantitative studies to which a response rate was applicable, only one could be classified as good (97.1%, Shenkman, 2012) based on the generally accepted response rate threshold of 80% (Boivin, Griffiths, & Venetis, 2011). Only one of the included studies was deemed to have employed a representative sample during the critical appraisal process (Riskind & Patterson, 2010), limiting the generalisability of the results. Longitudinal designs were absent from the quantitative studies, preventing causal conclusions from being drawn. The main limitation of the four qualitative studies was that two failed to specify a formal method of analysis, necessitating caution in interpreting the results. Furthermore, to fully explain the low parenthood rates among non-normative groups, future research needs to employ comparison groups. This would allow the assessment of whether barriers to parenthood that can affect all potential parents apply to non-normative groups to a greater degree (e.g., financial difficulties and poor perceived parenting abilities).

Finally, the following non-normative groups were absent from the included studies: people with HIV, hepatitis B or C, spinal cord injuries, transgender individuals, disabled people, single women and single men. Further research is needed to investigate the barriers in these groups.

Conclusions

In conclusion, the combined syntheses identified a range of demographic, psychological, health, and stigma-related factors which influence reproductive decision-making in non-normative groups. The results suggest that the four main psychosocial theories that have been applied to childbearing offer adequate explanations of the decision-making among these populations. However, one of the six theoretical themes, negotiated norms, was not investigated by any of the primary studies. Future research is likely to show that negotiation with a partner influences reproductive decisions among many people belonging to non-normative groups.

Limitations of both the quality and quantity of existing research limited the findings of the present review. Fewer barriers emerged from the quantitative studies than from the qualitative studies, suggesting that quantitative studies to date have not manage to isolate all the factors that contribute to the low parenthood rates among non-normative groups. Furthermore, research was entirely absent on several previously specified groups, which requires urgent rectification given the finding that barriers differ across groups. Interventions are required to meet the needs of these individuals and to generate more equality and diversity in the parenting population, which might include public anti-stigma campaigns and parenthood decision aids aiming to optimise quality of life.

Conducting a dual metric synthesis in the present study allowed the effect sizes from the quantitative studies to be statistically combined and the qualitative data to be analysed in depth. The use of the triangulation protocol to integrate the results of the numeric and textual syntheses provided an intuitive, transparent and time-efficient method for reflecting on the extent to which the qualitative and quantitative results were in agreement and highlighting areas where existing evidence is inconclusive. There are few available methods for integrating numeric and textual syntheses, and the present paper provides a new approach that is likely to be useful for non-intervention reviews for which the EPPI Centre matrix approach is not suitable.

Chapter 4:

Implicit Attitudes towards Disabled Parents: Consequences for Parenthood Intentions

Introduction

Although extensive research has investigated reproductive decision-making, the literature is strongly biased towards participants that fit the social norms associated with being a parent, i.e., heterosexual couples in good health. Research on individuals who do not meet these social norms (i.e., non-normative potential parents) is comparatively scarce. Furthermore, as highlighted by the systematic review in Chapter 2, to the author's knowledge not a single study has examined reproductive decision-making among childless disabled people. Given recent evidence showing that disabled adults in the UK are approximately half as likely to have children as nondisabled adults (Clarke & McKay, 2014), the reasons for the low parenthood rates need to be identified to assess what intervention is required, if any.

There are many possible barriers to parenthood that might affect disabled people. One important reason might be social stigma, but research is yet to assess its impact in the domain of disability. In Chapter 2, qualitative primary studies included in the systematic review suggested that societal stigma might deter some gay men and lesbians from parenthood. However, the quantitative self-report measures of internalised homophobia (defined as a gay/lesbian person holding negative attitudes towards gay/lesbian people) were found not to influence parenthood intentions (also in Chapter 2). This evidence suggests that negative social attitudes towards same-sex parents may be having an impact of some description but its exact nature is unclear.

The present chapter aimed to investigate further the ways in which societal stigma might contribute to the low parenthood rates among disabled people. The decision to focus on this specific non-normative group was made because of the absence of any existing research on childless disabled people's decisions. Specifically, the association between internalised stigma and intentions to have a first child was examined. Intentions were used as the outcome measure because they are the closest available proxy to actually having a first child. Internalised stigma is defined as the consequence of individuals taking on board negative societal attitudes towards their group, and consequently adopting those negative attitudes themselves.

So in the present study, disabled people who hold negative attitudes towards disabled people having children are said to have high levels of internalised stigma.

Internalised stigma was measured explicitly using a self-report questionnaire, but also implicitly to minimise the effects of participants not wanting to admit to holding negative attitudes towards their own group. The most established implicit measure of attitudes is the Implicit Association Test (IAT), which assessed attitudes based on the extent to which it is easier to categorise objects alongside good or bad words. Consequently, the secondary aim of the study was to develop an IAT that measures attitudes towards disabled parents.

Theoretical Perspectives on Internalised Stigma

The ways in which internalised stigma might contribute to the low parenthood rates among disabled people are best captured by the psychosocial theories that have been applied to reproductive decision-making. The first of these is the Theory of Planned Behaviour (TPB, Ajzen, 1991). Evidence supporting the predictive value of the TPB concerning the decision to have a first child has been found in the general population (Sobotka, 2011) and also in a sample of lesbians (McCrohan, 1996).

In relation to the TPB, there are two ways in which internalised stigma might influence behaviour. The first is that internalised stigma might contribute to the individual's attitudes. Disabled people who hold negative attitudes towards disabled parents may, as a result, hold more negative attitudes about having children themselves. Figure 4.1 shows how this would fit into the TPB model as a behavioural belief, one of numerous potential behavioural beliefs that underlie attitudes. Similarly, internalised stigma may also serve as a normative or control belief, influencing subjective norms or perceived behavioural control. These are also shown in Figure 4.1.

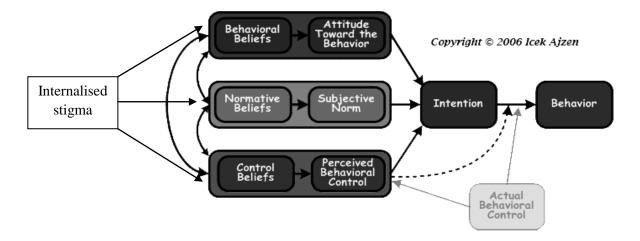


Figure 4.1. The role of behavioural, normative and control beliefs in the TPB, with the potential role of internalised stigma added in by the author.

Alternatively, the influence of internalised stigma may be unaccounted for by the TPB. As shown in Figure 4.2, it may operate directly on intentions without influencing attitudes, norms or perceived behavioural control.

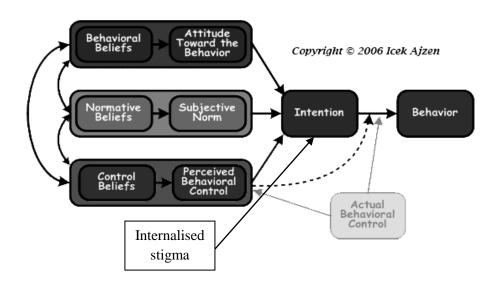


Figure 4.2. A direct relationship between internalised stigma and intentions, unaccounted for by the TPB.

The Traits Desires Intentions Behaviour Framework (TDIB, Miller & Pasta, 1995) is an extension of the TPB, as described in Chapter 1. Therefore the same two possibilities apply, internalised stigma may influence the motivations for having children, which in turn influence childbearing desires and intentions. However, this may not be the case and internalised stigma may act directly on intentions.

Life Course Theory (Elder, 1994, 1998) holds that human behaviour is largely determined by the social context. One of its main principles is referred to as interdependent lives, and posits that the behaviour of close others has a strong influence on an individual's life choices. Consequently, if family and friends express negative attitudes about disabled parenting, this would be expected to deter disabled people from becoming parents. Another principle of Life Course Theory is that the historical time and place are major determinants of decisions. This notion suggests that negative attitudes at the societal-level could also contribute to behaviour, regardless of the behaviour of close others. For example, negative depictions of disabled parents in the media, or witnessing/experiencing prejudice from strangers might be ways in which societal stigma is experienced. However, with its emphasis on social context, Life Course Theory does not provide much insight into why people who are exposed to the same negative societal attitudes vary in the degree to which they internalise those attitudes. In a sense, it does not account for the step between social experiences and behaviour, which is the internalisation of those experiences.

Evidence on Internalised Stigma and Reproductive Decisions

As demonstrated in Chapter 3, the only existing quantitative evidence on the decision to become a parent among any non-normative group has focused on gay men and lesbians. No studies have examined the impact of internalised stigma specific to parenthood, but internalised homophobia has been examined by a small number of studies. Internalised homophobia is not specifically about parenthood, it assesses the degree to which gay/lesbian/bisexual people hold homophobic attitudes in general. However, it may be related to internalised negative attitudes towards same-sex couples being parents so can be interpreted in a similar way.

Of the small number of studies that have investigated the impact of internalised stigma on the reproductive decisions of gay men and lesbians, one investigated the relationship between internalised homophobia and motivations for having children. The parenting motivation construct was derived from questions about motivations including improvement of well-being (i.e., believing that having a child will make life and romantic relationships complete), social expectations (i.e., avoiding feeling like an outsider when others have children), and continuity (i.e., to continue the family and to avoid being alone in old age). In a sample of 164 childless gay and bisexual men residing in the USA, it was found that higher levels of

internalised homophobia were significantly associated with reduced parenthood motivations (Robinson & Brewster, 2014). However, three other studies on gay men and lesbians also in the USA found no effect of internalised homophobia on intentions to have children (D'Augelli, Rendina, Sinclair, & Grossman, 2007, Eisenberg, 2004; Sbordone, 2002). Inconsistency in this literature may be due to the differences in the outcome measure, because Robinson & Brewster (2014) looked at parenthood motivations while the other studies examined intentions. Given that parenthood motivations are conceptually similar to attitudes, this evidence that internalised homophobia influences attitudes but not intentions fits with the idea that internalised homophobia might serve as a behavioural belief (that underlies attitudes) within the TPB.

All of the studies that examined the impact of internalised homophobia in the context of reproductive decision-making suffer from social desirability effects, which may have deterred some people from reporting homophobic attitudes. Additionally, some people may not have been fully aware of their attitudes. Although this cannot explain the differing results from these studies, research using implicit measures that do not rely on self-report may find stronger or more consistent effects of internalised stigma.

The qualitative studies with childless gay and lesbian participants in Chapter 3 found that they reported lacking social support (Solomon, 1991) and that they would be concerned about their children being bullied for having same-sex parents (Rabun & Oswald, 2009). This evidence suggests that social stigma does have an impact on the reproductive decisions of non-normative groups in some way. It may be that the quantitative measures that would detect the effects of internalised stigma have not yet been used in research. Internalised stigma specific to parenthood may prove more influential for intention formation than internalised stigma concerning the group in general.

Although research is yet to examine the reproductive decisions of childless disabled people, evidence suggests that stigma may be influential. The National Survey of Parents with Disabilities, comprising a sample of 1200 disabled parents, found that 32% had experienced discrimination. Furthermore, 14% had experienced pressure to have a tubal ligation so prevent them from having children, and 13% had experienced pressure to have an abortion (Preston & Jakobson, 1997). Duvdevany et

al. (2008) interviewed 12 fathers with spinal cord injuries about their experience of parenting, many of whom reported encountering negative attitudes. For example: And then the kindergarten teacher asked, "Say, isn't [your son's problem] to do with the fact that you are in a wheelchair?" She immediately made the connection: The kid is venting his frustration over the fact that his dad is in a wheelchair. I said, "I don't think so. My behavior is not like that. But I'm not a psychologist." In retrospect, we learned that it was an isolated incident. (Interviewee 4, Duvdevany et al., 2008, p. 1024)

Implicit Measures of Attitudes

The IAT is based on the premise that the time it takes to perform a task is a reflection on its difficulty. The task involves classifying stimuli into one of four categories. In the present study the categories were 'disabled', 'able-bodied', 'good' and 'bad'. The stimuli can be all words, all images, or a mixture of the two and are sorted into categories using only two response keys (usually the 'e' key for the left hand and the 'i' key for the right). This means that two categories are assigned to each key. The stronger the association between the two categories assigned to a given key, the easier the task should be to perform. Ease of performance is measured by recording the time between being shown each stimulus and pressing the response key, as well as the accuracy of each response. Easier tasks should result in faster and more accurate responses. The categories assigned to each key are switched during the IAT, for example if the right hand key 'i' was initially pressed to indicate a 'good' word or an 'able-bodied' photograph, later on it would be used to indicate a 'bad' word or a photograph of a disabled parent (Lane, Banaji, Nosek, & Greenwald, 2007).

A meta-analysis examining the association between IAT scores and explicit self-report measures found a mean effect size of r = 0.24 (Hofmann, Gawronski, Gschwendner, Le, & Schmitt, 2005), which is considered small to medium. One potential theoretical reason for weak associations between implicit and explicit measures is the unwillingness to report socially undesirable attitudes. However, Hofmann et al. (2005) examined this and found that the social desirability of the topic was not significantly associated with the effect size of the implicit-explicit correlation. In other words, the degree of socially desirable responding did not moderate the relationship between the IAT and self-report measures. In contrast, Greenwald, Poehlman, Uhlmann, and Banaji (2009) conducted a separate meta-analysis and found

that socially sensitive topics rendered the association between implicit and explicit measures weaker. Further research is required to clarify the moderating effect of socially undesirable topics.

Another theoretical explanation for weak explicit-implicit correlations is conceptual differences between the constructs assessed by the implicit and explicit scales. Hofmann et al. (2005) also examined the characteristics of the self-report measure, and found that use of self-report questionnaires resulted in significantly weaker associations than alternative explicit measures such as adjective ratings and feeling thermometers. In order to explore potential reasons for this, Hofmann et al. (2005) investigated the hypothesis that affective self-report measures would be more strongly associated with IAT scores than cognitive ones. This is because IATs are generally assumed to measure affective rather than cognitive associations. The hypothesis was confirmed, explaining the finding that questionnaires resulted in weaker associations, as these measures are more cognitively based than the other types of measures (e.g., feeling thermometers).

Additionally, explicit measures were coded as being either absolute or relative. If people were simply asked to evaluate a group, the measure was coded as absolute. A relative measure was defined as a measure that was worded such that participants were asked to evaluate one category in comparison to the other (e.g., Black people in comparison to White people). Alternatively, a relative measure could consist of the difference between two absolute measures, one concerning each group (i.e., the difference between evaluations of Black and White people). IATs are by nature relative, so as expected relative explicit measures were found to correspond significantly more closely with IAT scores than absolute explicit measures (Hofmann et al., 2005).

A further theoretical reason for differences between self-report and IAT scores is that people may not be fully aware of their own attitudes towards the target (Hofmann et al., 2005). However, this hypothesis has not yet been researched, and it is hard to imagine what methods would allow you to assess each individual's level of insight on an explicit measure, other than discrepancies with an IAT score.

Implicit and explicit attitudes have been found to generally have small to medium associations with behaviour. For example, a meta-analysis by Greenwald, Poehlman, Uhlmann, & Banaji (2009) found that across 184 independent samples, self-report measures were more strongly associated with behaviour (including

physiological responses and judgements, r=0.36) than IAT scores (r=0.24). For example, Jajodia and Earleywine (2003) conducted multivariate analyses examining the relationship between IAT scores (positive and negative associations with alcohol), a self-report measure of attitudes towards alcohol, and self-reporting drinking behaviour over the past 30 days. Although standardised beta coefficients in the regression model indicated that explicit measures were a stronger predictor of drinking than IAT scores, IAT scores remained significant even when explicit attitudes were controlled for. This indicates that the implicit and explicit measures each explained variance in the dependent variable that the other did not. Therefore, using implicit measures in conjunction with self-report measures can add to the predictive value of attitudes.

In Greenwald et al.'s (2009) meta-analysis, the social sensitivity of the topic was found to explain 24.5% of the variance in the association between explicit measures and behaviour, whereas it only explains 3.4% of the variance in the implicit-behaviour association effect sizes. This is consistent with the idea previously described that explicit measures are likely to be more affected by socially desirable responding than implicit measures.

Perceived Parenting Skills

Another important potential reason for the low parenthood rates among people with disabilities is the practicalities of caring for a child. Clearly this will vary greatly depending on the type of disability, but many disabled people required support in managing the practical side of child care. From the National Survey of Parents with Disabilities, which comprised a sample of 1200 disabled parents, 79% reported difficulties using transport with their children, 43% required assistance in playing with their children and 33% needed help to life or carry a child. Further, 58% used personal assistant services to help with parenting (Preston & Jakobson, 1997). Such practical difficulties are likely to contribute to low parenting self-efficacy, i.e., the perceived ability to raise a child successfully among disabled people. Although the predictive value of perceived parenting skills has not been studied among disabled people, studies on gay men and lesbians have examined the link. For example, Robinson and Brewster (2014) found a significant association between higher parenting self-efficacy and stronger motivations to have children among 164 childless gay and bisexual men. This association was significantly stronger for people with

high levels of internalised homophobia. Similarly, Eisenberg (2004) and Solomon (1991) both found significant associations between higher perceived parenting skills and stronger intentions to have children among childless lesbians.

Parenting self-efficacy is similar conceptually to the TPB construct perceived behavioural control. The small number of studies that have measured perceived behavioural control in the general population have asked participants how much their decision to have children would depend on factors such as financial situation and housing conditions (Dommermuth, Klobas, & Lappegård, 2011). Another study additionally asked participants how much control they felt they would have over those factors (Billari, Philipov, & Testa, 2009). These aspects of control clearly pertain more to the ability to raise a child than the ability to conceive one.

The Present Study

The primary aim of the present study was to assess whether implicit and explicit attitudes towards disabled parents are associated with the intention to become a parent among childless disabled people in the UK. The second aim was investigate whether there are any differences in how capable of parenting disabled people perceive themselves to be, and other people's expectations about whether they should have children (norms from the TPB), in comparison to nondisabled individuals.

Based on Life Course Theory, the first hypothesis was that negative attitudes towards disabled parents would be associated with reduced parenting intentions among disabled participants. Although, as previously described, existing evidence about the role of internalised stigma is largely nonsignificant, this may be because the measures of internalised stigma used were not specific to parenthood. Based on the premises of the TPB, it was also hypothesised that internalised stigma would influence intentions via norms, perceived behavioural control or attitudes.

Given the qualitative evidence in which fathers with spinal cord injuries report people questioning their ability to raise a child (Duvdevany et al., 2008), the second hypothesis was that disabled participants would report more negative subjective norms than nondisabled people, due to decreased social pressure to have children. Due the additional practical challenges faced by many disabled parents, it was also hypothesised that they would feel less capable of bringing up children than nondisabled people.

Intentions to have a first child were used as a proxy to behaviour (i.e., actually becoming a parent) as the study was cross-sectional. There is a gap between intentions and behaviour with a meta-analysis of meta-analyses finding intentions explain only 28% of future behaviour (Sheeran, 2002). A large-scale study has examined the realisation of intentions to have a first child in the next three years among childless people in France, Hungary, Bulgaria and Georgia (Spéder & Kapitány, 2014). It was found that across the four countries, of people who intended to their first child within three years, the proportion that did so ranged from 28% (Bulgaria) to 38% (Georgia). Despite this substantial gap, according to the TPB, intentions are the closest available proxy to measuring future behaviour.

Methods

Developing the IAT: Pilot Study 1

Introduction

The choice of images in an IAT is crucial to ensuring that the test measures the intended construct. If the images are not representative of the construct, then the results will not be valid. There is no established method for selecting images for use in IATs. However, when using photographs of people, authors have conducted pilot work in which participants rate the attractiveness of the people in each photograph. Photos with similar attractiveness ratings were then selected for use in the IAT (e.g., Banse, Seise, & Zerbes, 2001; Snowden & Gray, 2013).

In the present study two types of images were used, families with children where one parent was in a wheelchair and families where neither parent appeared to be disabled. Given that the photos required contained at least three people, one of whom was a child, participants were not asked to rate attractiveness. Instead, the first pilot study aimed to assess whether any other characteristics of the images may influence attitudes towards the photos other than just the individuals depicted.

Consideration of the photographs lead to the identification of four characteristics that might confound the results and account for any differences in attitudes towards the control and disability photographs. The first two of these aspects were the emotions of the individuals in the photographs (happiness and anger), because parental conflict is known to influence child adjustment (Zimet & Jacob, 2001). Therefore parents who appeared to be unhappy might be assumed to negatively impact their children. Additionally, aspects of the photograph other than the family itself were considered. The photos varied in their background (some were outside and others indoors, for example) and the activity in which the family were engaging (some families were obviously engaged in an activity such as eating a meal, while others appeared to not be engaged in any activity at all). Consequently, participants rated the pleasantness of the background to each photo and the activity in which the family was engaging.

Methods

Participants

An advertisement outlining the aim of the study (that participants would be asked to rate 18 photographs of families on the intensities of emotion and the backgrounds) and a link to the online survey was posted on the Cardiff University Noticeboard from the 1st to the 3rd September 2015. Additionally, the study advertisement and link were emailed to all Cardiff University School of Psychology PhD students and posted in facebook groups for these same students on the 25th and 26th September. No payment or incentive for completing the study was offered. The survey was completed by 46 participants.

Materials

A pool of suitable images was identified from those available to purchase from shutterstock.com or available on flickr with a creative commons licence that allowed distribution for non-commercial use. Images were of a two parents with at least one child, but in some images one member of the couple was in a wheelchair. Further, two of the images which had licenses that allowed modifications were edited such that the disabled person appeared to be an amputee. Thirteen control photographs and five photographs of families where one parent was in a wheelchair were identified.

It is good practice to ensure images in different categories are equivalent in other aspects, e.g., race, gender and age (Pruett & Chan, 2006). Given the limited number of available images of disabled and same-sex couples, photos could not be matched exactly on these characteristics. However, it was ensured that the parents were an opposite-sex couple in all pictures, and the number of children in each of the final selection of images was matched as closely as possible.

Participants were also asked to rate the background of each photo and the activity the family in the photo were engaging in. The measures were based on the attitudes scales recommended by Ajzen (n.d.), but due to the large number of photographs to be rated by participants, only a single item was used for each. Therefore, participants were presented with the following items: 'The background in the photograph is: 1 (pleasant) – 7 (unpleasant)' and 'The activity the family in the photograph is engaging in is: 'Pleasant – unpleasant'.

The measures for emotion intensity ratings were taken from Matsumoto and Ekman (1989). Participants were asked 'Please rate the intensity of the following emotions in the photograph: 1) anger 2) happiness'. The response scale was from 0 (absent) -8 (strong). In order to assess how obvious it was to participants whether one of the parents was disabled or not, participants were also asked 'Would you assume any of the people in this photo have a disability?', yes/no.

The four categories used in the present IAT were good and bad words, disabled parents and able-bodied parents. The minimum number of images (or words, whichever was deemed most suitable) required for each category in an IAT is three. Using a larger number of images does not further increase the reliability/validity and it has been suggested that maximum construct validity is obtained by using fewer prototypical images rather than a large number of less representative images (Lane et al., 2007). Therefore, three or four pictures will be selected to represent each category in the IAT that do not vary by their other characteristics (happiness, anger, background and activity).

Procedure

Upon clicking on the survey link, participants were presented with a brief consent form explaining that they would be asked to rate 18 photographs on their backgrounds and intensity of emotions, and that their data would be stored anonymously. They indicated their consent by checking a box, and were instructed to close the window if they did not wish to complete the survey. They were also informed that they survey would take approximately 15 minute to complete. Participants were then presented with the photographs of disabled and nondisabled families in a mixed order (although not randomised across participants), and underneath each photo were the five questions: the pleasantness of the activity and background, the intensity of anger and happiness, and whether they assumed any of the people in the photo had a disability. Finally, participants were presented with a debrief form that explained more about how their data would be used to construct the IAT.

Results

As shown in Table 4.1, one of the 18 photos received a unanimously correct classification into the disabled/nondisabled category. All other photos ranged from

being 2.2-17.4% wrongly classified. All photographs that were mislabelled by over 5% of participants were dropped, which resulted in the removal of seven photographs (six control, one disability).

Table 4.1. Frequency and percentage of participants who assumed that one of the people in each photo was disabled (N=45).

Photo number	% who assumed disability (n)		
Control 1	2.2% (1)		
Control 2	10.9% (5)		
Control 3	17.4% (8)		
Control 4	4.3% (2)		
Control 5	13.0% (6)		
Control 6	6.5% (3)		
Control 7	4.3% (2)		
Control 8	4.3% (2)		
Control 9	4.3% (2)		
Control 10	2.2% (1)		
Control 11	6.7% (3)		
Control 12	10.9% (5)		
Control 13	2.2% (1)		
Disability 1	100% (46)		
Disability 2	93.5% (43)		
Disability 3	97.8% (45)		
Disability 4	95.7% (2)		
Disability 5	95.7% (2)		

The remaining seven control pictures were arranged into all possible combinations of four images, and the mean scores for happiness, anger, activity and background across the four photos were calculated for each participant. As there were only four disability photographs remaining, the average of these on each variable was also calculated.

Table 4.2 shows that the four disability photos were rated as having significantly less pleasant backgrounds and activities than the least pleasant combinations of control photographs. Similarly the combination of control photos that was rated as having the highest intensity of anger still scored lower on anger than the disability photos. The lowest scoring combination of control photos on intensity of happiness was not significantly different to the disability photos.

Table 4.2.

Mean ratings of the four disability photographs and the highest and lowest scoring combinations of four control photographs (standard deviation).

	Background pleasantness	Activity pleasantness	Intensity of anger	Intensity of happiness
Disability photos	4.32 (0.64)	4.84 (0.60)	1.65 (0.68)	7.03 (0.91)
Highest scoring control photos	4.91 (0.76)	5.31 (0.64)	1.35 (0.51)	
Lowest scoring control photos				7.22 (0.98)
T-test ⁺	t(45) = 7.25***	t(44) = 7.48***	<i>t</i> (45) = - 4.64***	t (45) = 1.69

Note: $^+$ within-subject t-test with 2000 bootstrapped samples because differences between each participant's scores were not normally distributed. ***= p<.001

Since there were no sets of four photos that could be matched across the disability and control conditions, scores on sets of three photos were assessed. Examination of scores on each of the four disability photos revealed that one photo was rated as having lower pleasantness scores, higher anger intensity and lower happiness intensity than the other three. This photo was subsequently dropped and the remaining three disability photos were compared to all combinations of three control photos.

Table 4.3 shows that at least one combination of control photos was identified that allowed each construct to match on the control and disability photographs. Further details of these analyses are available in Appendix G. However, there was no single combination for which all four constructs were nonsignificant. Specifically, three combinations of control images were matched to the disability images on activity, anger and happiness scores. However, none of these combinations also matched on background scores.

Table 4.3.

The mean ratings of the three disability photographs and the highest and lowest scoring combinations of three control photographs (standard deviation).

	Background pleasantness	Activity pleasantness	Intensity of anger	Intensity of happiness
Disability	4.59 (0.77)	5.27 (0.61)	1.25 (0.63)	7.95 (1.07)
Highest scoring control photos	4.68 (0.95)	5.23 (0.71)	1.44 (0.68)	
Lowest scoring control photos				7.02 (1.13)
T-test ⁺	t(45) = 0.76	t(45) = -0.59	t(45) = 2.61*	t(45) = -5.89***
	This was the	All control	All control	All control
	only	combinations	combinations	combinations
	combination that	scoring ≤ 5.41	scoring ≤ 1.32	scoring ≥ 7.68
	was NS	NS	NS	NS

^{*} within-subject t-test with 2000 bootstrapped samples because differences between each participant's scores were not normally distributed. NS = control photos did not significantly differ to the disability photos. *p<.05, *** p<.001

Discussion

In searching for photos that were licensed for non-commercial use, it became apparent that there were very few available where one of the two parents was in a wheelchair. This is likely to be a result of social norms that dictate that parents are rarely disabled. The photos of disabled parents that were available were rated as having less pleasant backgrounds and engaging in less pleasant activities than the control photos. Additionally, the disabled parents were rated as showing more intense anger than controls, but happiness levels were more comparable.

In order to maximise the chances of finding combinations that matched, all possible combinations of three control and disability photographs were compared. Three is the lowest number of photos required for each category (Lane et al., 2007). Three different combinations were found that matched on three of the four variables of interest: activity, anger and happiness. However, photos could not be matched on background ratings.

It is unclear why some participants reported assuming some photos contained a disabled person when there was no visible disability. The control photos for which more than 5% of participants reported assuming one of the people had a disability did not obviously differ to the photos which few participants reported as depicting a disabled person. A small number of participants may have been especially aware of

disabilities that cannot be seen in a photograph, and may have been responding partly based on that possibility. Similarly, it was surprising that despite the presence of a wheelchair, over 5% of participants reported not assuming that anyone in one of the disability condition photos was disabled. This may have been due to some participants being aware that the presence of a wheelchair does not necessarily indicate the presence of a disability. Other health conditions can require temporary use of a wheelchair.

Examination of the backgrounds in question revealed nothing obvious that would make some less pleasant that the others. The finding that the backgrounds to disabled families were rated as consistently less pleasant than the backgrounds to nondisabled families may be a carry-over effect from negative attitudes towards disabled parents. This possibility was further investigated in the second pilot study using four photos (two in the disability category and two in the control category) that matched on activity, anger and happiness.

Developing the IAT: Pilot Study 2

Introduction

The second pilot study was conducted to further explore the finding from the first pilot study that backgrounds were rated as less pleasant when one of the parents in the photograph was in a wheelchair. The aim was to investigate whether replacing the backgrounds in the photographs with plain white backdrops would eliminate the difference in ratings of the control and disability backgrounds.

Methods

Participants

Participants were recruited via the Cardiff University Noticeboard from the 25th to the 29th September 2015. The eligibility criteria were that they must not have completed the first pilot study. In total 34 participants, 14 men and 20 women, completed the study. Participants were randomly assigned to view the photographs with either blank or the original backgrounds. The blank background condition was completed by 14 participants and the original background condition by 20

participants. Demographic characteristics did not significantly differ by condition (gender, age, ethnic group and highest level of education, p<.05).

Materials

Four of the shortlisted photos from Pilot Study One were selected and the original backgrounds were replaced with plain white. This was done by a member of IT staff at Cardiff University. Participants were asked the same questions about each photo as in Pilot Study 1.

Unlike Pilot Study 1, Pilot Study 2 was a between-subjects design so some demographic information was obtained from participants to ensure this did not confound the results. Participants were asked their gender, age, ethnic group and highest level of education.

Procedure

The procedure was the same as that of the first pilot study with two changes. Firstly, participants only rated four photos, so the consent form stated that the survey would take approximately five minutes to complete. The other additional element was the demographic questions, which were presented between the final photo and the debrief form.

Results

One of the four photos was given a significantly less pleasant background rating when it was plain white compared to original (t(16.73) = 2.42, p=0.027). This photo was one of the photos that contained a disabled parent, and the mean pleasantness score for background was 5.32 for the blank background and 5.45 for the original background. Scores on the three other variables were not significantly affected by background in any of the photos (p>0.05).

Discussion

Changing the backgrounds in the photos to plain white did not significantly affect how pleasant they were rated to be for three out of the four photos. One of the disability photos was rated as having a significantly less pleasant background in the plain white condition than in the original background condition. Use of the blank

background version of this photo would therefore only exacerbate the pattern of the backgrounds being rated as less pleasant when there is a disabled parent in the photo.

Although it is unclear how participants judged the pleasantness of plain white backgrounds, they were the most neutral point of comparison for scenic backgrounds. These findings suggest that the original backgrounds were neutral enough as to be rated as minimally different to plain white backgrounds. Therefore, the finding from Pilot Study 1, that the backgrounds of photos were rated as less pleasant when there was a disabled parent in the foreground, may reflect more negative overall appraisals of photographs that contain a disabled parent. This is not an unexpected finding given that the IAT is hypothesised to find an association between disabled parents and negative words.

Main study: Methods

Participants

Recruitment took place from the 15th October until the 14th December 2015. Participants were recruited by contacting disability-related charities and organisations based in the UK. This was done via email, although sometimes an initial phone call was made to obtain the relevant email address. Eleven disability charities/organisations were contacted requesting their help with recruitment, along with six facebook pages/groups who were contacted via facebook message. Of these 17 requests, replies were received from six (35.3%) of which five agreed to distribute the survey via their social media channels and/or email (29.4%). The one reply declining to distribute the survey was because they worked with people primarily below the age of 18. Additionally, the advertisement was posted on four other online forums and facebook groups/pages which allowed members of the public to post research advertisements themselves. The control group was recruited by posting the study link on callforparticipants.com, a website aimed at recruiting participants into scientific studies.

The eligibility criteria were that participants must be currently residing in the UK and aged 18-28 as the latter is the average age of first birth in women residing in the UK (Office for National Statistics, 2014a). Participants also must not have had a known or diagnosed fertility problem or reproductive disease that affects fertility such

as endometriosis. Participants also had to be childless because attitudes towards children change following the birth of the first child (Abbey et al., 1994). Participants could not currently be pregnant or actively trying to conceive, adopt, or have a child through surrogacy. They also could not have ever tried to become a parent in any way. The reason for excluding those trying (or who had tried) to become a parent is that these individuals have already decided to have a child so the decision to have a first child cannot be examined.

Participants must also identify as heterosexual because people who identify as lesbian/gay are known to have low parenthood rates (Brewster et al., 2014), and the images used in the IATs were all of couples comprising a woman and a man. It was specified that the control group must not have a disability. Disability was defined according to the Equality Act 2010:

A person has a disability for the purposes of the Act if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities (Office for Disability Issues, 2011, p. 5)

A long-term effect is defined as lasting or being expected to last 12 months or more. Fluctuating conditions or conditions which recur sporadically are classified as long-term if the episodes have occurred or are expected to occur over a period of 12 months or more (Office for Disability Issues, 2011).

Participants were sent a £10 Amazon voucher in return for completing the survey. It can be beneficial to offer an incentive when recruiting hard to reach groups to maximise the response rate. The exact response rate is unknown for the present study because we are not aware of exactly which social media outlets organisations used to advertise the study, and current facebook algorithms mean that posts are not shown to all people who have 'liked' a page. Additionally, it is not known how many of the people who viewed the study advertisement would have fitted the eligibility criteria.

The intended analyses required a linear regression with 11 predictors, which would require a sample of 59 to detect large effect sizes, 123 to detect medium effects and 850 for small effects (Faul et al., 2009). An initial sample of 98 participants was obtained. However, eight participants did not report their date of birth and another five were aged over 28 on the 1st January 2015, so all 13 of these had to be dropped. One further participant reported identifying as gay and so was also removed from the

dataset. The final sample consisted of 84 participants, 47 with disabilities and 37 without. Two of the disabled participants did not report what type of disability they had. Of those who did, 41 (91.1%) reported having a physical disability, one reported that their disability was mental illness (3.7%) and another checked the 'other' option and specified that they had neurological multiple sclerosis (3.7%).

Materials

All materials used in the survey are presented in Appendix H.

The IAT.

The three images of disabled families and three images of nondisabled families selected following the pilot studies (images available in Appendix I) were used in the construction of the IAT to assess implicit attitudes towards disabled parents in comparison to able-bodied parents. These constitute the target concepts, and the attribute concepts were 'good' and 'bad'. Good and bad were selected as they have been extensively validated within an IAT assessing attitudes towards gay people and disabled people (e.g., Nosek, 2005; Nosek et al., 2007)

A typical seven block IAT was used according to the direction of Lane et al. (2007). In the first block participants indicated whether photos belong to the category of disabled parents (by pressing 'e' on the keyboard) or the category of able-bodied parents (by pressing 'i' on the keyboard). In the second block, four good and four bad words used in Nosek's (2005) IAT assessing homophobia were used to represent the categories 'bad' ('e') and 'good' ('i'). The words were beautiful, superb, joyful, lovely, agony, tragic, painful, and awful. The third block combined the previous two blocks, whereby 'e' was pressed in response to either a bad word or a photo of a disabled parent, and 'i' in response to good words or a photo of two able-bodied parents. The fourth block was the same as the third but contained 20 extra trials. Block five was a reversal of block 2, whereby participants classified 'good' words using 'e' and 'bad' words using 'i'. Blocks six and seven were a reversal of blocks three and four, such that 'e' indicated disabled parents and good words, and 'i' represented able-bodied parents and bad words.

Blocks one, two and three consisted of 20 trials, and block four involved 40 trials. Studies have found that increasing the number of trials above this point does not further improve the psychometric properties of the IAT (Lane et al., 2007; Nosek, 2005). Similarly, blocks five and six consisted of 20 trials and block seven 40. If participants incorrectly classified a word or photo, a red X was presented. Reaction times for incorrect trials were calculated as the mean latency for the correct trials plus 600 ms, as recommended by Greenwald et al. (2003).

For studies aiming to estimate the overall magnitude of the IAT effect, it is recommended that the order of blocks two to four, and five to seven is counterbalanced (Lane et al., 2007). This was done in the present study, but as suggested the order of presentation was controlled for in order to eliminate this additional source of variance when examining associations with IAT scores (Lane et al., 2007).

The currently recommended scoring algorithm for IATs is that of Greenwald et al. (2003), which produces a construct referred to as *D*. *D* is calculated as the difference in response times between the first part of the IAT and the second part where the categories paired together for each response key are reversed. This difference is then divided by the standard deviation of all blocks together.

The internal consistency of the IAT was calculated using the split-half method of Greenwald, Nosek, & Banaji (2003), which involved calculating d based on blocks 3 and 6, and then again using blocks 4 and 7. Then the correlation between these two measures was calculated, which resulted in r = 0.37. It is typical for reaction time-based measures to have lower internal consistency than self-report measures because if participants sneeze or blink this can affect their latency on that trial (Buchner & Wippich, 2000; Lane et al., 2007). However, given that a meta-analysis found that across 50 IATs, the mean reliability (internal consistency or split-half reliability) was 0.79, the reliability of the present IAT should still be interpreted as slightly low.

Demographic variables.

Participants were asked to report their highest qualification by checking one of five options: NVQ levels 1-5 or the equivalent academic qualifications, gender, relationship/marital status, duration of relationship, gender of partner, type of disability (physical, intellectual, sensory, mental illness, or other (please specify), date of birth and ethnicity (measured based on Office for National Statistics, n.d.). Sexual

identity was assessed using the method recommended by Haseldon and Joloza (2009): 'Which of the following options best describes how you think of yourself? 1) Heterosexual or straight, 2) gay/lesbian, 3) bisexual, 4) other, 5) prefer not to say'.

Participants were also asked to leave their email address at the end of the survey for the purposes of payment and being invited to complete a similar survey in two years' time. The purpose of the Time 2 study will be to examine whether intentions were translated into behaviour.

Explicit measures of attitudes.

To the author's knowledge, there are no existing measures of attitudes towards disabled parents. Hollekim, Slaatten, and Anderssen (2012) published a self-report questionnaire that contained 14 items measuring attitudes towards gay parents, but information on its reliability or validity is not available. Well-validated scales assessing attitudes towards people with disabilities (regardless of parental status) are available, but it was found that the equivalent scales on attitudes towards gay men and lesbians were generally of a style that was more readily adaptable to the topic of non-normative parents. For example, Findler, Vilchinsky, & Werner's (2007) multidimensional attitudes scale toward persons with disabilities focuses on people's affective, cognitive and behavioural reactions to a hypothetical situation that involved imagining inadvertently having to spend 15 minutes alone with a person in a wheelchair. A hypothetical scenario involving spending unplanned time alone with a disabled person and their children may have seemed unrealistic as it is not a situation that happens to many people.

Grey, Robinson, Coleman, and Bockting (2013) conducted a systematic review of measures of homophobia and internalised homophobia and identified 23. Herek's (1988) 20 item scale was identified as the best validated, but examination of the items revealed that it did not lend itself to ready adaptation to non-normative parenthood. The questions largely consist of evaluations of sexual orientation that do not make sense when applied to parenthood. For example, 'A woman's homosexuality should not be a cause for job discrimination in any situation', and 'Female homosexuality is detrimental to society because it breaks down the natural division between the sexes.' Similarly, Worthington, Dillon, and Becker-Schutte (2005) had the second most frequently validated scale, but omitting items that could not be adapted for non-normative parenthood (e.g., 'I am knowledgeable about the significance of the

Stonewall Riot to the Gay Liberation Movement') resulted in the five factor structure of the scale being lost. With certain factors missing or only measured by a single item, the validity of an adapted version of this measure would be questionable.

Ultimately, the Wright, Adams, & Bernat (1999) homophobia scale was identified as one that could keep its structure when modified for disabled parents. Exploratory factor analysis conducted by Wright et al. (1999) revealed three factors: Behaviour/negative affect, affect/behavioural aggression, and cognitive negativism. Concurrent validity in that study was indicated by a strong correlation with the Index of Homophobia, r = 0.66, p < .01 (Hudson & Ricketts, 1980). Overall the reliability coefficient alpha was 0.94 and the one week test-retest reliability coefficient was 0.96. For the present study only 15 of the original 25 items were retained because 10 items could not be readily adapted to disabled parents. An example item is 'Disabled parents make me nervous', with the response scale 1 (strongly agree) to 5 (strongly disagree). For this and all other self-report measures in the present study, the mean score was calculated across all items. Due to skewed items, Cronbach's alpha could not be computed for the scale in the present study, but ordinal alpha was calculated as 0.83 according to the method of Gadermann, Guhn, and Zumbo (2012) using the psych and GPArotation R packages (Bernaards & Jennrich, 2005; Revelle, 2013).

Subjective norms and perceived behavioural control.

Perceived behavioural control was measured using five items developed by Harrison (2012) which were originally found to have a Cronbach reliability coefficient of α =.71. In the present study Cronbach's alpha was found to be 0.30. This could not be adequately increased by the removal of items, so the item deemed to be the most conceptually relevant was selected as the sole measure of perceived behavioural control. The five items were 'It is easy for me to become a parent', 'The decision to become a parent is beyond my control', 'If I wanted I could become a parent', 'Whether I become a parent is entirely up to me', and 'Whether I become a parent is not entirely up to me'. The item selected was 'Whether I become a parent is entirely up to me' because it seemed to encompass the meaning of the other questions, apart from the question 'it is easy for me to become a parent'. However, perceived behavioural control should primarily focus on whether a behaviour could be achieved, rather than how much effort would be required to achieve it, so it was decided that that

aspect of the measure could be excluded without losing the overall meaning of the construct.

Similarly, an eight item scale measuring subjective norms also developed by Harrison (2012) was also included. This scale was previously found to have a Cronbach reliability coefficient of .82. Minor wording changes were implemented to adapt to the items to the topic of the present study, with an example item being 'Most people who are important to me would want me to become a parent'. Both norms and perceived behavioural control response scales were 1 (strongly disagree) to 7 (strongly agree). The ordinal alpha for the norms scale in the present study was 0.78.

Attitudes.

Attitudes were measured using the Attitude Toward Babies Scale (ABS) scale developed by Brase and Brase (2012) to measure 'baby fever', defined as a deeprooted and instinctive desire to have a baby. The measure consists of 34 statements which participants rate on a five point response scale from 1 (strongly agree) to 5 (strongly disagree). An example item is 'Dealing with the needs and wants of children is annoying'. Participants were told to be as honest as possible and to answer questions they do not have the experience to answer based on what their response would be. There are five subscales: positive exposure, negative exposure, trade-offs, nurturance, and female role beliefs. Ordinal alpha indicated that the reliability coefficient in the present study was 0.94.

Capable parent scale.

Most established measures of perceived parenting skills are designed for parents who already have children (e.g., Arnold, O'Leary, Wolff, & Acker, 1993). The only two measures suitable for use with childless individuals that were identified were the Capable Parent Scale (Eisenberg, 2002) and a scale constructed by Goldberg and Smith (2009). The Capable Parent Scale was selected because it assesses a broader range of parenting abilities. Devised by Eisenberg (2002), it is a 26 item scale that was designed to assess perceived parenting skills among lesbians in the USA. Eisenberg (2002) found it to have good internal consistency (Cronbach alpha = 0.85). It was modified for the present study by omitting three items that were only relevant to women who identified as lesbian. Also, the item 'I cannot afford insurance/healthcare for my child' was removed because it is not relevant to the UK. An example of an

included item is 'I feel I would be nurturing to a child', with a response scale of 1 (strongly disagree) to 6 (strongly agree). In calculating the ordinal alpha, it was found that all items that were reverse scores were negatively correlated with the total score. The most likely explanation is that some participants were not reading the items carefully so did not spot that some were reversed. Therefore all nine reversed scored items had to be dropped from the scale, leaving 13 remaining items with an ordinal alpha of 0.93.

Intentions.

Ajzen and Klobas (2013) highlight that the behavioural goal must be clearly defined before an intentions measure can be constructed. In the present study the behavioural goal is having a first child at any point, including biological, adopted or fostered children. Participants were asked 'Do you intend to have a child at any point? This includes biological, adopted and foster children.' A four point response scale was provided, where 1 = 'definitely not' and 4 = 'definitely yes'.

Manipulation checks.

At the end of the survey, participants were presented with the six photos of families and were asked the same five questions asked in both of the pilot studies.

Procedures

Participants who clicked on the study link viewed a consent form detailing the eligibility criteria and outlining what they would be asked to do should they choose to participate in the study. They were asked to tick a box to indicate consent, or to quit the page if they did not consent or did not want to take part.

Participants then completed the IAT which took approximately five to ten minutes. This was followed by the questionnaires that were expected to take approximately 30 to 45 minutes to complete. Finally, participants viewed a debrief form explaining the study's investigations. The consent and debrief forms are presented in Appendix J.

Data Analysis

The first step of data analysis was data screening all variables. The distribution of all continuous variables was checked for non-normality using the

skewness and kurtosis statistics divided by their standard errors. All variables were normally distributed apart from the measure of intentions, which was negatively skewed, and income, which was positively skewed. A logarithmic transformation rectified the skewness of intentions but transformation of income did not result in a normal distribution so nonparametric tests were used for this variable. Outliers beyond three standard deviations from the mean were also checked for, and none were present.

Next, whether any demographic variables differed between the groups with and without disabilities was checked for. Chi-square tests were used for the categorical and dichotomous variables, and Pearson's correlations for the continuous variables. Correlation analyses were used instead of t-tests despite disability being a dichotomous variable to avoid data screening each variable in two different ways, separately by group for the t-tests and with both groups combined for the regression models carried out later.

Following the demographic checks, descriptive statistics related to implicit and explicit attitudes towards disabled parents were calculated, checking for differences between the disabled and nondisabled groups. As well as means and standard deviations, the association between implicit and explicit measures was assessed, controlling for the counterbalancing of the order of blocks as recommended by Lane et al. (2007).

The next stage of descriptive statistics involved examining the TPB variables (attitudes, norms and perceived behavioural control) and the variable perceived parenting capabilities to see if any significantly differed by disability status. Pearson's correlation analyses were used for the same reason previously described, to avoid carrying out two types of data screening.

Univariate correlations were calculated next. The first step was to assess all correlations between demographic characteristics that differed by group and intentions, to assess whether any needed to be controlled for in the regression model predicting intentions. This involved Pearson's correlation analyses, although Spearman's correlations were computed for the skewed income measure as well as dichotomous variables with a split more extreme than 90/10%, which creates outliers and has an undue influence on coefficients (Rummel, 1988). The second step was to assess all the correlations between the predictor variables intended to go into the equation (implicit and explicitly measured internalised stigma, the TPB variables and

perceived parenting abilities) to ensure that collinearity would not be present in the regression model.

A hierarchical forced-entry linear regression with four steps was conducted. In the first step implicit attitudes, order of blocks in the IAT, explicit attitudes and the presence/absence of a disability were entered. In the second step, interactions between implicit attitudes and disability, and between explicit attitudes and disability, were entered. The third block added in the TPB variables (attitudes, perceived behavioural control and norms), and perceived parenting capability. The further block added two final interactions, between norms and disability, and perceived behavioural control and disability. The reason for adding the interactions in at different stages in this way was to assess whether any relationships between internalised stigma (i.e., implicit or explicit attitudes) influenced intentions directly or whether they operated through the other TPB constructs, norms, attitudes and perceived behavioural control. If a mediation of this type was present, any significant interactions between disability and internalised stigma would be expected to weaken in step 3 when the TPB variables are controlled for. Should this be the case, mediation analysis would be conducted using the PROCESS macro for SPSS (Hayes, 2013).

Results

Demographic Characteristics

As shown in Table 4.4, the majority of the sample were women, of White ethnicity, in a cohabiting relationship, in full time employment, had degree level education and were around 24 years of age. The demographic characteristics that significantly differed according to disability status were ethnicity, employment status, relationship status, relationship duration and income. The disabled group were more likely to have a non-White ethnicity, be unemployed and have report a lower income than the control group. Additionally, the disabled group were more likely to be single or in a noncohabiting relationship than the control group who were largely cohabiting with partners. Of the disabled people who were cohabiting or married, they on average reported a longer relationship duration than the control group.

Table 4.4.

Demographic characteristics of the sample by disability status.

Characteristic	Disabled group n=29 (% of disabled group)	Control group <i>n</i> =37 (% of control group)	χ ² or correlation ⁺ analyses
Gender	<u>U</u> 17	<u>U</u> 17	
Female	22 (46.8%)	23 (62.2%)	χ^{2} (1) = 1.96, Cramer's V = 0.15
Ethnicity			
White	27 (62.8%)	36 (97.3%)	$\chi^{2}(1) = 14.15***,$ Cramer's V = 0.42
Relationship status			2
Married	7 (14.9%)	7 (18.9%)	$\chi^{2}(2) = 38.70***,$ Cramer's V = 0.68
Cohabiting	6 (12.8%)	27 (73.0%)	
Single/in a noncohabiting relationship	34 (72.3%)	3 (8.1%)	
Employment status			
Full time employment	26 (55.3%)	33 (89.2%)	Fisher exact test = 11.46**, Cramer's V = 0.38
Part time employment	12 (25.5)	1 (2.7%)	
Full time student	3 (6.4%)	2 (5.4%)	
Unemployed	1 (2.1%)	0	
Highest qualification	, ,		χ^2 (1) = 0.29, Cramer's V = 0.059
Degree	30 (65.2%)	22 (59.5%)	
Relationship duration	4 years and 2	2 years and 2	r = 0.48**
among those in	months (3	months (10	
cohabiting	years and 2	months)	
relationships/married	months)		
people (mean (SD))	02.51 ****	22 90	0.000
Age (mean (SD))	23.51 years	23.89 years	r = 0.089
Income (mean	(2.47 years) £44,426	(1.61 years) £128,432	r = -0.69***
(SD))**	(£20,389)	(£138,307)	<i>i</i> – -0.0 <i>)</i>
(~2))	(320,20))	(32120,201)	

*** p<.001 ** p<.01, SD = standard deviation ⁺ correlation analyses were all Pearson's tests apart from for income for which a Spearman's test was used due to significant skewness.

Descriptive Statistics

Internalised stigma.

As shown in Table 4.5, the disability group and the control group did not significantly differ on their scores on the implicit or the explicit measures of attitudes

towards disabled people. A one sample t-test was conducted to assess whether implicitly measured attitudes significantly differed from neutral. A score of 0 represents implicit attitudes that do not favour either disabled or nondisabled parents, negative scores show a preference for nondisabled parents (i.e., stigma) and positive scores show a preference for disabled parents. It was found that participants showed a significant preference for nondisabled parents based on their implicit attitude scores (t(72) = -12.00, p < .001).

For explicit attitudes a score of three (on a scale on 1 to 5) indicated neutral, higher scores indicated stronger negative attitudes towards disabled parents and scores below three indicated positive attitudes towards disabled parents. A one-sample t-test showed that explicit attitude scores were significantly more positive than neutral (t(67) = 6.76, p<0.001). Given the trend-level difference between the disabled and control groups on attitude scores, the one-sample t-test was repeated separately by group as factorial analysis of variance tests cannot incorporate a one-sample test. The alpha value was halved to compensate for multiple comparisons, and both were still significant (disability group: t (34) = -3.40, p=0.002, control group: t (32) = -6.68, p<0.001).

Table 4.5.

Means (and standard deviations) of the disabled and control groups on implicit and explicit attitudes.

Measure	Disabled	Control group	Pearson's correlation
	group		coefficients (r)
Implicit attitudes towards	-0.49 (0.31)	-0.39 (0.31)	-0.167
disabled parents			
Explicit attitudes towards	2.69 (0.54)	2.46 (0.46)	-0.224+
disabled parents			

Note: Explicit scale was 1 to 5. p<0.01. Implicit attitudes scores are in the D metric as previously defined

A linear regression was computed examining the association between implicit and explicit attitudes in the first step, with explicit attitudes as the dependent variable. In total 5.7% of the variance in explicit attitudes was predicted by implicit attitudes, which was insignificant (F(1,56) = 0.21, p=0.21), $R^2 = 0.060$. In the second step counterbalancing was controlled for, which did not significantly increase the amount

of variance explained (F change (1,55) = 1.49, p=0.23, R^2 change = 0.026). Summary statistics are presented in Table 4.6.

Table 4.6.

Regression model examining the association between IAT scores and explicit attitudes towards disabled parents (step 1), controlling for counterbalancing (step 2).

	Step 1		Step 2	
Predictor	Unstandardised	Standardised	Unstandardised	Standardised
	coefficient (CI]	coefficient	coefficient (CI]	coefficient
IAT score	0.10 [-0.35,	0.60	0.20 [-0.28,	0.12
	$0.55]^{+}$		0.67]	
Order			-0.018 [-0.48,	-0.17
			0.12]	

Note: IAT = implicit association test, n = 58 due to missing data, CI = 95% confidence intervals

TPB variables.

As shown in Table 4.7, the only predictors to significantly differ by disability status were norms, perceived behavioural control and the capable parent scale, with disabled participants reporting significantly lower subjective norms, higher perceived behavioural control, and lower perceived parenting abilities than the control group. Overall, mean scores on all variables were moderately positive for both groups.

Table 4.7.

Means (and standard deviations) of the disabled and control groups on implicit and explicit attitudes.

Measure	Disabled group	Control group	Pearson's correlation coefficients (<i>r</i>)
Intentions	5.28 (1.35)	5.59 (0.73)	0.034
Attitudes towards children	3.62 (0.51)	3.74 (0.65)	-0.11
Norms	4.82 (0.84)	5.34 (0.44)	-0.36**
Single item PBC: 'Whether I become a parent is entirely up to me'	4.83 (1.46)	4.05 (1.03)	0.29**
Capable parent scale	4.36 (0.57)	4.81 (0.63)	-0.35**

^{**} p<.01 PBC = perceived behavioural control, capable parent scale was 1 to 6. Norms, intentions and PBC scales were 1 to 7. Attitudes scale was 1 to 5.

Predictors of Intentions

Univariate analyses.

Firstly, all demographic variables that significantly differed by disability had their correlations with intentions calculated. As relationship status had three categories, a linear regression was conducted with intentions as the dependent variable and two dummy variables as predictors. As shown in Table 4.8, none of the demographic characteristics that significantly varied by disability status were significantly related to intentions (r<0.3, p>.05). Therefore, these did not need to be controlled in the regression predicting intentions.

Table 4.8.

Associations between the demographic variables that significantly differed by disability status and parenthood intentions.

Demographic variable	Association with intentions
Relationship status	
Married (ref)	
Cohabiting	0.114 (unstandardised beta)
Single	0.015 (unstandardised beta)
Employment status ⁺	r = 0.047
Ethnicity	r = 0.15
Relationship duration	r = -0.084
Income	r = 0.090

⁺ due to low numbers of students, unemployed people and part-time workers, this variable was dichotomised into full time employment (coded 1) versus everything else (coded 0) for the purposes of this correlation analysis

Table 4.9 shows the univariate correlations between all the variables that might be used to predict intentions in the regression model. Initially it was intended that all three TPB variables, the Capable Parent Scale, implicit and explicit attitudes towards disabled parents would be included in the model. However, collinearity was present between subjective norms, the Capable Parent Scale and attitudes towards children. This meant that only one of these three variables could be included. Norms was selected as this was the most relevant to the present study's research question related to societal stigma.

It is also evident in Table 4.9 that neither implicit nor explicit internalised stigma were significantly associated with intentions. However, higher scores on all

three TPB variables (attitudes, norms and perceived behavioural control) and the Capable Parenting Scale were significantly associated with stronger intentions.

Table 4.9. *Univariate correlations between all predictor variables and intentions.*

Pearson's r	Intentions	Explicit attitudes	Implicit attitudes	Order of blocks	Attitudes towards children	Subjective norms	Perceived behavioural control	Capable Parenting Scale
Explicit attitudes	-0.20							
Implicit attitudes	-0.04	-0.060						
Order of blocks	-0.017	0.13	0.30**					
Attitudes towards children	0.48**	-0.15	0.046	0.029				
Subjective norms	0.45**	-0.13	-0.13	0.025	0.66**			
Perceived behavioural control	0.25**	-0.36**	-0.081	0.096	0.21	0.25*		
Capable Parenting Scale	0.45**	-0.010	0.010	-0.009	0.77**	0.65**	0.14	
Disability status	-0.034	0.22	-0.17	-0.067	-0.11	-0.36**	0.29**	0.35**

Note. **p<0.01, *p<.05

Multivariate analyses.

The first step of the hierarchical model, containing implicit and explicit attitudes, disability status, and controlled counterbalancing from the IAT, was found to be nonsignificant (summary statistics for all steps are presented in Tables 4.10 and 4.11). The addition of the interactions in the second step significantly increased the amount of variance explained, with the interaction between explicit attitudes and disability status being significant. Simple slope analysis revealed a significant association between more negative explicit attitudes towards disabled parents and intentions in the control groups (unstandardised beta = 0.088, lower 95% confidence interval (CI) = 0.023, upper CI = 0.15, p=0.009), but in the disability group stronger negative attitudes towards disabled parents were significantly associated with poorer intentions (unstandardised beta = -0.12, lower CI = -0.18, upper CI = -0.066, p<0.001).

Inclusion of the TPB variables in step three did not significantly improve the fit of the model, and neither did the interactions between the TPB variables and disability status in step 4.

Table 4.10.

Regression model predicting intentions based on attitudes towards disabled parents, disability status, subjective norms and perceived behavioural control.

Unstandardised coefficients [95% confidence intervals].

Predictor	Step1	Step 2	Step 3	Step 4
IAT score	-0.29		0.001	
	[-0.082,		[-0.064, 0.065]	
	0.024]			
Order of tasks	0.052		0.058	
	[-0.065, 0.17]		[-0.046, 0.16]	
Explicit score	-0.029		0.065	
•	[-0.082,		[-0.005, 0.14]	
	0.024]		. , .	
Disability	0.001		0.029	
ř	[-0.11, 0.11]		[-0.090, 0.15]	
IAT score x	, ,	-0.063	-0.042	
disability		[-0.15,	[-0.14, 0.052]	
•		0.028]	. , .	
Explicit score x		-0.21***	-0.18***	
disability		[-0.30, -0.13]	[-0.28, -0.087]	
Norms		, ,	0.052^{+}	
			[-0.009, 0.11]	
PBC			-0.017	
			[-0.079, 0.046]	
Norms x				0.014
disability				(-0.13, 0.16]
PBC x disability				0.085
·				(-0.040, 0.21]
Step significance	NA	F(2,48) =	F(2, 46) = 1.46	F(2,44) =
1 6		12.73***	, ,	1.34
Model	F(4,50) =	F(6,48) =	F(8,46) =	F(10,44) =
significance	0.57	4.80**	4.03**	3.47**
R ² change	NA	0.33	0.037	0.029
Model R ²	0.043	0.38	0.41	0.44

Note. NA = not applicable, n=55 due to missing data, IAT = implicit association test, PBC = perceived behavioural control *trend level significance, p<0.1 **p<0.01***p<0.001

Table 4.11.

Regression model predicting intentions based on attitudes towards disabled parents, disability status, subjective norms and perceived behavioural control. Standardised coefficients.

Predictor	Step1	Step 2	Step 3	Step 4
IAT score	-0.15		0.003	_
Order of tasks	0.13		0.15	
Explicit score	-0.16		0.35	
Disability	-0.003		0.074	
IAT score x		-0.22	-0.15	
disability				
Explicit score x		-0.83***	-0.72***	
disability				
Norms			0.25^{+}	
PBC			-0.084	
Norms x				0.055
disability				
PBC x disability				0.33
•				0.33

Note. NA = not applicable, n=55 due to missing data, IAT = implicit association test, PBC = perceived behavioural control ⁺trend level significance, p<0.1 **p<0.01

Mediation analysis.

Since the univariate analyses showed that explicit attitudes and perceived behavioural control were significantly associated, and the coefficient of the explicit x disability interaction term reduced once perceived behavioural control was added into the model, a mediation analysis was carried out. Among the disabled participants, a significant effect of explicit attitudes on intentions via perceived behavioural control was found, b = -0.047, bootstrapped confidence intervals [-0.10, -0.0040]. Kappasquared = 0.20 [0.031, 0.37], indicating that the indirect effect was approximately 20% of the maximum possible, i.e., a complete mediation. Mediation via norms or attitudes towards children was not tested because univariate analyses revealed that these variables were not significantly associated with explicit attitudes towards disabled parents.

Manipulation Checks

Within-subject t-tests were performed with bootstrapping due to non-normally distributed differences between scores on all four variables. The disability photos did not significantly differ from the control photos with regards to intensity of anger (*t*

(82) = -1.39 p=0.18), happiness (t (83) = 1.78 p=0.076) and pleasantness of activity (activity t(83) = -1.13, p=0.27). However, the photos of disabled families were rated as having significantly less pleasant backgrounds than the control photos (t(83) = 2.91, p=0.010), with the mean for the control photos being 6.20 and the mean for the disability photos being 5.96.

Discussion

Evidence from the present study suggests that negative societal attitudes towards disabled parents contribute to the low parenthood rates. Specifically, higher levels of internalised stigma, when measured explicitly, were associated with reduced parenthood intentions among childless disabled people. Perceived parenting abilities and perceived social pressure to have children were also reported as significantly lower by disabled people than nondisabled people. Overall these findings suggest that, in a variety of ways, negative societal attitudes influence the reproductive decisions of disabled people.

Internalised Stigma

The IAT identified a preference for nondisabled parents over disabled parents, which did not differ between participants with and without disabilities. Attitudes towards disabled parents measured using the explicit self-report measure, on the other hand, were significantly more positive towards disabled parents than neutral, and were more positive in the control group than the disabled group. However, the magnitude of this was small with, on a five point scale, the mean scores for disabled participants being 0.31 below neutral (high scores indicated greater prejudice), and the control group mean was 0.54 below neutral. This discrepancy between the implicit and explicit measures may be partly due to people's hesitancy to report negative attitudes about such a socially sensitive topic as disabled parenting.

IAT scores were not significantly associated with intentions to have children, while self-reported internalised stigma was. This might be due to the suboptimal reliability of the IAT or the small sample size. However, it might also be a genuine effect whereby the social desirability effects captured by the explicit but not the implicit measure have an impact on reproductive decisions. In other words, some disabled people may have shown an implicit preference for nondisabled parents in the

IAT, but may also have strong principles regarding equal opportunities, so would explicitly report that disabled people should be able to be parents if they wish. Such a belief may have made some individuals reluctant to report negative attitudes about disabled parents, and also intend to have children themselves. Alternatively, the causality could be in the opposite direction. Disabled people who intended to have children may have been less willing to admit to holding negative attitudes towards disabled parents.

The significant association between explicitly measured internalised stigma and parenthood intentions differs from the findings of existing studies that examined the effect of stigma on parenting intentions among childless gay men and lesbians. With one exception (Robinson & Brewster, 2014), self-report measures of internalised homophobia have been found to be unrelated to parenting intentions (e.g., D'Augelli et al., 2007). There are a number of possible reasons why the present study found a link when others did not. Internalised stigma may simply have a stronger effect on intentions among disabled people than among gay men and lesbians. Alternatively, the use of a measure that assessed internalised stigma specific to parenthood, rather than attitudes towards the group in general (previously studies used internalised homophobia), may explain the significant association found in the present study.

The explicit measure of attitudes towards disabled parents was uncorrelated with IAT scores. Typically, correlations between implicit and explicit measures are found to be low to moderate (Hofmann et al., 2005) and certain characteristics of the present study are known to reduce the association further.

Firstly, the explicit measure used in the present study was a self-report questionnaire, a cognitive measure. In contrast, IATs are considered an affective measure, and are more strongly associated with affective than cognitive self-report measures (Hofmann et al., 2005). Similarly, the explicit measure used in the present study was an absolute rather than a comparative measure. This means that it measured attitudes towards disabled parents, rather than the difference in attitudes towards disabled and nondisabled parents. An absolute measure was selected because there was no established and validated comparative measure available for the domain in question. Also it was not important for the research question to have correlated explicit and implicit measures, but on the other hand it was crucial to have a reliable and valid explicit measure. For these reasons the lack of correlation between the implicit and explicit measures was to be expected and should not be interpreted as

suggesting either one failed to measure the correct construct. It is more likely that in the present sample there was no association between implicit and explicit measures of a large enough effect size to be detected given the power available, or they were simply uncorrelated.

Evidence from the pilot studies.

While developing the IAT, two challenges were encountered that are likely to be a result of negative societal attitudes towards disabled parents. The first was that, in searching for photos of families that were licensed for non-commercial use, it became quickly obvious that there were not many available where one parent was in a wheelchair. This in and of itself is likely to reflect the low parenthood rates among disabled people and societal expectations that they will not be parents. Having a small pool of photographs reduced the likelihood of being able to identify at least three that did not significantly differ to the control photographs on any of the dimensions of interest (pleasantness of background and activity, intensity of anger and happiness).

Despite the small number of photographs of disabled families to choose from, disabled and control photos were identified that did not significantly differ by anger, happiness or activity ratings. However, participants rated the pleasantness of the backgrounds to the disability photos as consistently less pleasant than the backgrounds to the control photos. There was only one combination of photographs that did not significantly differ, but this combination did not match on the other three constructs. In the second pilot study it was established that substituting the backgrounds for plain white backgrounds had a minimal effect on the ratings of the backgrounds. This strongly suggests that the backgrounds to photos with one parent in a wheelchair were rated as less pleasant because attitudes towards the whole photograph were more negative.

Theoretical Implications

The effects of negative societal attitudes towards disabled parents were also evident in the finding that disabled participants reported, on average, lower subjective norms than the control group. This indicates that the disabled people in the study felt less social pressure to have children, from family, friends and society in general. According to Life Course Theory, the social context in which an individual is embedded is the primary determinant of behaviour. The theory posits that people

have linked lives, and that people's behaviour is affected by the behavioural of the people around them. It follows that childless disabled people who are less pressured by others to become parents would be less likely to have children. Also, disabled people who notice that other disabled people they know rarely have children may be influenced by that, and so become less likely to become parents themselves.

Translating intentions into behaviour.

Given that a previous study found that disabled parents were approximately half as likely to have children as their able-bodied counterparts (Clarke & McKay, 2014), it was unexpected that intentions did not significantly differ between disabled people and the control group. One possibility is that this is due to the young age of the sample (aged 18-28) so differences in intentions may not emerge until older ages. For example, a longitudinal study found that after the age of 30 women adjust their expectations to be more realistic (Iacovou & Tavares, 2011).

Alternatively, it may be that disabled people in the general population intend to have children just as often as people with disabilities, and it is in attempting to realise their intentions that disabled people encounter barriers to parenthood. According to the TPB, actual behavioural control moderates the relationship between intentions and behaviour. Actual behavioural control cannot be readily measured in a self-report setting, because if participants are aware of limits on their control then what is being measured is perceived behavioural control.

In considering what factors may prevent disabled people from realising their childbearing intentions, one factor which may limit actual behavioural is infertility. However, most disabilities do not cause fertility problems, so infertility is unlikely to explain the low parenthood rates. It may be that that despite intending to have children at some point, disabled people are less able to achieve the preconditions that many people want to have in place before they have their first child. For example, having a partner/being married (e.g., Jokela et al., 2009) is a strong predictor of having a first child among the general population. It is unclear why relationship status was unrelated to intentions in the present study, but it may have been that the effect was too small to be detected with the present sample size. Assuming that partnership status will have an affect, albeit small, on reproductive decision among disabled people, the finding that many more are unpartnered may explain why some are deterred from parenthood.

The finding that the disabled group reported on average higher perceived behavioural control than the control group suggest that some barriers to parenthood may not have been anticipated by the disabled people in the sample. Perceived behavioural control may have been higher among disabled people because they reported less social pressure to have children, so felt that whether they have children or not is entirely their choice. Future research should further investigate perceived behavioural control and the process of translating parenting intentions into behaviour among disabled people.

Internalised stigma and the TPB.

Previously, two possible routes through which internalised stigma might influence intentions were outlined. The first was that internalised stigma would influence intentions via attitudes, norms or perceived behavioural control, as predicted by the TPB. The second route was that internalised stigma would have a direct influence on intentions that could not be accounted for by the TPB variables. The results supported both of these models to a degree, because the influence of explicit attitudes on intentions was found to be partially mediated by perceived behavioural control. Specifically, 20% of the relationship between explicit attitudes and intentions could be explained by perceived behavioural control. However, the remaining 80% of the effects of explicit attitudes appeared to be influencing intentions directly.

Limitations

Firstly, the control group may not be very representative of the general population due to being recruited through a website designed to facilitate recruitment of participants into scientific studies. The control group may have been unusually interested in scientific research, which likely contributed to the high levels of education in the sample. Evidence shows that the higher people's levels of education, the more likely they are to remain childless throughout their lives. For example, in a large representative dataset, women (but not men) residing in the USA who were childless at age 70 had significantly more years of education than parents of the same age (Zhang & Hayward, 2001). Another nationally representative USA sample found that childless men and women aged 35-74 had higher levels of education than parents (Rothrauff & Cooney, 2008). Therefore, it is possible that the sample in the present

study had lower parenthood intentions than the general population due to their high levels of education.

Similarly, despite the advertisement being distributed to a large (albeit unknown) number of disabled people through social media, the small number of participants indicates that the response rate must have been very low and recruitment was a very time-consuming process considering the small sample size obtained. It is possible that those who responded had less severe disabilities than those who did not. If parenting intentions decrease with severity of disability, then it may be that the disabled group in the present study reported stronger intentions than a representative sample of disabled people would. Although the sample was similar to that of the UK population in that the most common type of disability was physical (Department for Work and Pensions & Office for Disability Issues, 2014b), nothing is known about the severity.

The results of the present study should also be interpreted bearing in mind that it is not known how long ago disabled participants' conditions onset or became severe enough to fit the definition of a disability. Future research should investigate how the age at which someone becomes disabled affects the reproductive decision-making process.

Due to the financial incentive, some participants may have completed the survey as quickly as possible with minimal thought. Although there were no obvious instances of participants repeatedly clicking the same response option or other response patterns, there is also no way of telling if some participants were responding randomly. The IAT scoring system deals with this to some extent by dropping exceptionally fast or slow reaction times, but all other noise in the data remains. Given the extensive piloting of the images used in the IAT, its low split-half reliability may be at least partly due to some participants not giving the survey their full attention. It might seem conceivable that running IATs online may lead to people concentrating less than in a lab setting, but many studies have run IATs online and achieved good reliability. For example, Nosek (2005) ran 57 different IATs online which resulted in a split-half reliability of 0.68. However, these studies were voluntary and did not offer an incentive, so presumably their participants were genuinely interested in IATs and were motivated to complete it to the best of their ability. It appears to be that use of the internet is not the problem, but motivational factors might be. Further piloting of the disabled parents IAT should assess the

internal consistency and split-half reliability (often used interchangeably in the context of IAT research) in a situation where participants are more motivated to apply full concentration.

Furthermore, the perceived parenting abilities construct showed low reliability when reverse items were included, but this was not the case for two other scales which contained several reversed items (explicit attitudes towards disabled parents and attitudes towards children). Given that the perceived parenting abilities construct was the first of the explicit measures, it cannot have been that participants' attention reduced over the course of the survey. However, participants' may have had reduced concentration at that point due to having just completed the IAT.

Reported income was unrealistically high, and two participants reported their income in dollars. Although these were converted into pounds, it suggests that some participants may have been residing outside the UK. The income question did not require participants to specify the currency because of the eligibility criteria that participants should be currently residing in the UK, so it was assumed that all would report income in pounds. There is no way of knowing how many participants were residing outside of the UK and reported their income in other currencies.

It should also be noted that that the regression model was underpowered. Although a sample of 98 was originally obtained, once missing data had been taken into account and participants that did not fit the eligibility criteria removed, the final regression model only contained 55 participants. This means that only large effect sizes could have been detected, so replication with a larger sample is required to examine smaller associations in these populations.

Another limitation is that the two groups were recruited from different places. Disabled people were recruited via charities while the control group were recruited from callforparticipants.com. This means that the two groups may differ in ways not captured by the demographic variables, for example, people on callforparticipants.com may have been more motivated by money and less invested in the research topic than the disabled participants. However, recruiting the control group from disability charities would not have solved this problem. It would have resulted in highly unrepresentative controls with very high levels of interest of disabilities, probably mainly care-givers and people working in the disability-related fields. Similarly, attempting to recruit disabled participants from callforparticipants.com would have been unlikely to yield enough participants given the low prevalence of disability in

young adults. Given that in the UK currently 6% of children and 16% of working age adults are disabled (Department of Work and Pensions & Office for Disability Issues, 2014b), the prevalence of disability among 18-28 year olds (the eligibility criteria for the present study) can be expected to fall between those two figures.

An important anomaly was the collinearity between norms and attitudes towards children. A key feature of the TPB is that these variables should be distinct. This finding might be explicable by the use of slightly different target behaviours. The target behaviour for norms and perceived behavioural control was the act of having a first child. The attitudes measure, on the other hand, was a construct designed to measure desire for children, i.e., attitudes towards raising a child, rather than the act of having a baby or adopting/fostering.

Conclusions

Disabled people who explicitly reported internalised stigma were less likely to intend to have children. Furthermore, disabled participants experienced less social pressure to have children than nondisabled participants. Although larger-scale research is required before any definitive conclusions can be drawn, these results suggest that internalised stigma may contribute to the low parenthood rates among disabled people.

Should the findings of the present study be replicated in larger samples, reducing societal stigma would appear to be an important step in improving the extent to which disabled people are represented in the parenting population. Anti-stigma campaigns might be an effective means of achieving this. Exposing the public to evidence that the wellbeing of children with disabled parents is rarely compromised (Alexander et al., 2002) and normalising the experience of being raised by a parent with a disability, might lead to improved public attitudes.

Chapter 5:

Don't Ask, Don't Get:

A Randomised Vignette-Based Study of Biases in Intentions for Oncofertility Provision among Medical Students

Introduction

Infertility resulting from cancer treatment is a pressing quality of life issue for cancer survivors (Canada & Schover, 2012; Carter et al., 2005). Current clinical guidelines for the UK, Europe, and the United State of America (USA) state that all patients should be informed about the risk of infertility prior to treatment (Loren et al., 2013; National Institute for Clinical Excellence, 2013; Peccatori et al., 2013). Studies suggest that approximately half of oncologists refer cancer patients in their reproductive years to a reproductive specialist as standard practice (Quinn et al., 2009b; Forman et al., 2010), and the percentage of oncologists who report routinely discussing fertility issues has been found to range between 61% (Forman et al., 2010) to 97% (Adams, Hill, & Watson, 2013).

There are many reasons that contribute to why doctors may fail to discuss fertility with patients, including lack of knowledge (Adams et al., 2013; Forman et al., 2010; Quinn et al., 2009a), negative attitudes towards fertility preservation (FP) (i.e., not thinking preserving fertility is important or justified at the time of a cancer diagnosis, Adams et al., 2013; Quinn et al., 2007), lack of convenient access to and knowledge of the required facilities (Forman et al., 2010; King, Davies, Roche, Abraham, & Jones, 2012; Quinn et al., 2007; Schover et al., 2002; Vadaparampil et al., 2007; Vadaparampil, Quinn, King, Wilson, & Nieder, 2008; Yee, Buckett, Campbell, Yanofsky, & Barr, 2012) and being biased against parenthood for certain patients (Forman et al., 2010, Schover et al., 2002). The latter is the focus of the present study.

Clinical guidelines specifically state that discussions of fertility risk and options to preserve fertility should take place regardless of age, parity, socioeconomic status, and prognosis (Loren et al., 2013). In self-report studies, physicians have indicated that these factors and many others irrelevant to the success of FP would make them less likely to discuss fertility, including the patient being gay (Forman et al., 2010; Gilbert et al., 2011; King et al., 2012; Schover et al., 2002), already having a

child (Adams et al., 2013; Forman et al., 2010; Gilbert et al., 2011; Quinn et al., 2007), being unmarried or single (Forman et al., 2010; Gilbert et al., 2011; King et al., 2012; Vadaparampil et al., 2007), being HIV positive (Quinn et al., 2007; Schover et al., 2002), and being older (Adams et al., 2013; Gilbert et al., 2011; King et al., 2008, 2012). Physicians are also less likely to discuss fertility with patients with a poor prognosis/urgent need for cancer treatment (Adams et al., 2013; Forman et al., 2010; Gilbert et al., 2011; King et al., 2008, 2012; Quinn et al., 2007; Schover et al., 2002; Vadaparampil et al., 2008), which appears to be largely driven by physicians not feeling uncomfortable discussing fertility with patients whose chances of survival are low (Quinn et al., 2009a). Further, many physicians feel uncomfortable discussing any fertility topics (King et al., 2008, Quinn et al., 2009a; Vadaparampil et al., 2007, 2008). These findings are striking as social desirability would be expected to cause doctors to underreport bias that shows disregard for clinical guidelines.

The literature reviewed provides valuable insight into the factors affecting oncofertility provision, but the results are potentially limited by recall bias; doctors may not always have accurate perceptions of the factors that influence their clinical practice. An audit study of actual referral overcame this limitation and found results inconsistent with those of previous studies: older age increased the likelihood of being referred for FP and being childless at the time of diagnosis was not significant (Lee, Heytens, Moy, Ozkavukcu, & Oktay, 2011). None of the other previously mentioned factors were measured, but this evidence suggests that methodological characteristics could impact results.

The reasons for any bias on the part of the physician, if it exists, remain unclear. One possibility is that physician behaviour is determined by their values and beliefs about which patients should have children, which is what has been suggested thus far. Another possibility is related to the consultation being a dyadic exchange between the doctor and patient, with each influencing the other. It is well established that physicians are much more likely to discuss fertility with patients who ask for information (King et al., 2008; Quinn et al., 2009b; Schover et al., 2002; Vadaparampil et al., 2007) or appear interested in having children post-cancer (King et al., 2008). Research has shown that breast cancer patients who are older, non-White or less educated are less likely to ask their oncologist questions in general at the initial consultation (Siminoff, Graham, & Gordon, 2006). If certain patients (such as

people who are single, gay or have a poor prognosis) are less likely to request fertility information, doctors may discuss it less frequently with these individuals.

The present study aimed to clarify whether biases were present using a randomised vignette design. The presence of bias was assessed by comparing intentions to initiate fertility discussions and referrals across hypothetical patients with different characteristics. Based on the previously described evidence, it was hypothesised that the following patient characteristics would reduce the likelihood of intending to initiate fertility discussions or referrals with the hypothetical female patient: being gay compared to heterosexual, being age 40 compared to 32, being unpartnered compared to married, having a poor prognosis compared to a good prognosis, and not mentioning fertility compared to requesting fertility information.

The secondary aim was to explore the nature of any bias. This was achieved by conducting the study in two waves, one where the patient in the vignette requested fertility information (the Prompt Wave) and one where they did not (the No Prompt Wave). In the Prompt Wave the control condition was designed to maximise the likelihood of medical students intending to discuss fertility with the hypothetical female patient and make a relevant fertility referral. The patient described was young, in a heterosexual relationship, had a good prognosis, and requested fertility information. In each of the five experimental conditions one patient characteristic was manipulated such that bias would be expected to occur. It is possible that hypothetical patients requesting information would prompt high intentions to provide the information (as shown in earlier results, e.g., Quinn et al., 2009b). This would lead to high intentions in all conditions in the Prompt Wave and causing possible biases to be obscured. Therefore, the No Prompt Wave aimed to assess the influence of patient characteristics when the hypothetical patient did not request fertility information. This design allowed exploration of the possibility that patients with certain characteristics are less likely to receive fertility information because they are less likely to request the information. This pattern is referred to as 'prompting bias' for the purposes of the present study.

Medical students were recruited to ascertain the quantity and quality of bias present in the early stages of medical training, on the assumption that the personality traits and attitudes that are associated with bias (e.g., the personality factors Openness to Experience and Agreeableness) are relatively stable over time (Caspi & Roberts, 2001; Ekehammar & Akrami, 2003; Pratto, Sidanius, Stallworth, & Malle, 1994).

Examination of the literature revealed comparable bias between medical students and doctors in many domains, including obesity (Phelan et al., 2014; Sabin, Marini, & Nosek, 2012), mental illness (Mukherjee, Fialho, Wijetunge, Checinski, & Surgenor, 2002), and gender (Berger, 2008; Torres et al., 2013). In order to minimise social desirability effects, medical students were not aware that the aim of the study was to investigate the effect of patient characteristics on fertility referrals and discussions.

Methods

Participants

For the Prompt Wave Medical Schools in the United Kingdom were contacted and invited to help with the study by the author and three undergraduate students (see acknowledgements). The information they received explained that they would need to distribute the survey link to their medical students via email. As there were not enough remaining UK medical schools to allow us to reach our desired sample size in the No Prompt Wave, recruitment was broadened to the United Kingdom, Republic of Ireland, USA, Canada, Australia, New Zealand, Denmark (translated), and the Netherlands. Universities were contacted by email, or phone if a suitable email address could not be found, requesting their help with the survey. All universities in the UK were contacted for one of the two waves (but never both to ensure the same students would not complete both surveys). All medical schools in Canada (apart from those in French speaking regions), USA (apart from a small minority for which a suitable email address could not be obtained via phone) the Republic of Ireland, Australia, Denmark were contacted. Only one university in the Netherlands was contacted due to time constraints, which was chosen because of a contact there. The only inclusion criterion was that participants had to be an undergraduate or postgraduate medical student. For the No Prompt Wave, the survey was also advertised via Facebook.

Table 5.1 shows the demographic information for the sample in each wave. In the Prompt Wave, 143 medical students completed the survey whereas the final sample size for the No Prompt Wave was 162. The two waves significantly differed in terms of country of residence, and participants in the No Prompt Wave were significantly older than those in the Prompt Wave, but the year of medical school was not significantly different. Additionally, more of the Prompt Wave sample had

experience with cancer patients than the No Prompt Wave sample. Since the two waves were not compared statistically, these differences did not need to be controlled for.

The majority of participants were in their early twenties and their third year of medical school and few were married or had children. Most participants had previously worked with cancer patients, but less than 25% of these had been exposed to FP topics during this work. Fewer participants had previously worked in fertility, and of these about 25% had covered FP in relation to cancer patients in their medical education. Less than a fifth of the sample were intending to specialise in fertility or oncology. No demographic variables significantly differed by condition with the exception of marriage in the Prompt Wave and experience with cancer patients in the No Prompt Wave (see Table 5.1), but these variables were uncorrelated with all four measures of intentions.

Table 5.1.

Demographic and professional characteristics of the sample

Variable	Prompt Wave $(N = 143)$		No Promp	Between waves	
	Mean (SD)	Between conditions comparison test	Mean (SD)	Between conditions comparison test	comparison test
Mean age (SD)	21.97 (2.42)	<i>F</i> (5,137) = 0.233	23.6 (3.32)	<i>F</i> (5, 153) = 0.87	t (295.48) = 4.75*
Mean year of medical school (SD)	3.34 (1.29)	F(5, 132) = 0.708	3.01 (1.165)	F (5, 152) = 0.10	t (290.53) = -1.92
(/	% (n)		% (n)	-	
Female gender		_	66.5 (107)	$\chi^2(5) = 2.10$	
Marital status		Fisher's exact	, ,	Fisher's exact	
Married/civil partnered	2.1 (3)	test = 8.34*	6.8 (11)	test = 4.59	$\chi^2(1) = 3.82$
Cohabiting	-		20.4 (33)		
Neither married nor cohabiting	-		72.8 (118)		
Has children	1.4 (2)	Fisher's exact $test = 6.087$	3.1 (5)	Fisher's exact $test = 4.39$	Fisher's exact $test = 0.98$
Country of residence				$\chi^2 (20) = 20.98$	$\chi^{2}(4) = 113.56***$
UK	100 (143)	-	44.1 (71)		
US	-	-	6.2 (10)		
Denmark	-	-	29.2 (47)		
Canada	-	-	10.6 (16)		
Australia Desired specialisation	-	-	9.9 (16)		
Fertility	17.5 (25)	$\chi^2(5) = 3.76$	8.1 (13)	Fisher's exact test = 4.075	$\chi^{2}(1) = 6.13$
Oncology	11.9 (17)	$\chi^2(5) = 5.29$	13.0 (21)	Fisher's exact $test = 4.51$	$\chi^2(1) = 0.092$
Covered FP in relation to cancer patients in medical education to date	-	-	26.7 (43)	$\chi^2(5) = 3.80$	-
Previously worked with CANCER	75.5 (108)	$\chi^2(5) = 2.23$	58.6 (95)	$\chi^2(5) = 12.85*$	$\chi^{2}(1) = 7.05**$
patients If yes, was FP mentioned during	-	-	23.2 (22)	$\chi^{2}(5) = 0.76$	-
this work Previously worked with FERTILITY patients	43.7 (62)	$\chi^2(5) = 3.11*$	23.5 (38)	$\chi^2(5) = 6.89$	$\chi^2(1) = 16.20***$

^{***}p<0.001 **p<0.01 *p<0.05

Materials

All measures used in the two waves of this study are presented in Appendices K and L.

Vignettes used for experimental manipulation.

Intentions elicited via vignettes for medical decision-making have been demonstrated to be accurate predictors of physician behaviour when compared to standardised patients (actors trained to behave as patients, the gold standard but costly tool) and actual practice (Dresselhaus, Peabody, Luck, & Bertenthal, 2004; Peabody, Luck, Glassman, Dresselhaus, & Lee, 2000; Peabody et al., 2004; Sandvik, 1995). All vignettes were constructed based on the guidelines provided by the British Medical Journal for submission of case reports (British Medical Journal Case Reports, 2011), but were simplified to retain the key information only. One vignette was a control condition and the other five vignettes each contained a manipulation of one of the patient characteristics from the control vignette. In the Prompt Wave all six vignettes highlighted that the patient was childless, and started with the following sentence:

"Please imagine that you are about to have a consultation with Miss/Mrs Smith (as appropriate to condition) who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals."

The following text constitutes the clinical vignettes, with the manipulated text presented in brackets and the text for the control condition being presented outside brackets. Mrs [unpartnered condition: Miss] Emily Smith is a 32 [older condition: 40] year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery [poor prognosis condition: stage three metastatic breast cancer, she has poor prognosis for recovery]. Her treatment plan involves surgery, chemotherapy and radiotherapy. Mrs Smith lives with her husband [gay condition: wife; single condition: Miss Smith lives with friends] and has no children [fertility information unrequested condition vignette ends here], but would like children in the future and has queried whether her fertility may be affected by her treatment.

The manipulation in which the patient was presented as gay was achieved by specifying a wife instead of a husband so that gay and heterosexual married/civil partnered individuals could be directly compared without relationship status presenting a confounding variable.

In the No Prompt Wave none of the six vignettes specified whether the patient had any children in order to avoid priming participants with any information related to parenthood status. In this wave, fertility information was only requested in one experimental condition to replicate findings in the first wave. Otherwise, all other aspects of the vignettes were as in the Prompt Wave. Throughout this chapter, the methods used in the No Prompt Wave were the same as the Prompt Wave, unless otherwise specified.

Intentions.

Two questions with open-ended text response boxes were used and specified: 'What should be discussed with Miss/Mrs Smith?' (as required by condition) and 'It is your responsibility to ensure that Miss/Mrs Smith is referred to all relevant specialists. Which would you refer her to?' The open-text responses were coded to derive three outcome measures. The author and an independent coder coded the textual responses, with a code of one indicating that fertility discussion intentions (defined as indicating that they would discuss fertility in any form, and a code of zero indicating that they were not) or referral intentions (defined as intentions to refer to a fertility specialist, gynaecologist, or any speciality related to reproductive health) were present. Cohen's kappa was computed to evaluate the level of agreement in coding for fertility discussions in the Prompt Wave (kappa = 0.96, p < 0.001), and referrals (kappa = 1.00, p < 0.001) in the Prompt Wave. Due to this extremely high level of agreement, interrater reliability was not computed for the No Prompt Wave. The first open-ended question, 'What should be discussed with Miss/Mrs Smith?', was additionally coded for specific reference to FP (present = 1, absent = 0). Altogether coding provided three measures of intentions, intentions concerning fertility discussions, FP discussions, and referrals to fertility specialists.

A quantitative (closed-ended) measure of intentions was obtained using five items (e.g., 'I would offer fertility preservation options to Emily Smith or refer her to someone who could') that were rated on seven-point scales of agreement (1= 'definitely not' to 7= 'definitely'). The mean score of the five items was calculated with higher scores indicating stronger intentions to discuss fertility with the patient. Internal consistency was good (Prompt Wave ordinal alpha = 0.86, No Prompt Wave ordinal alpha = 0.96).

Demographic and professional data.

Medical students indicated their desired speciality by ticking one of the following five options: fertility, oncology, general practitioner, undecided or other. Participants were also asked 'Have you worked with patients with cancer on placement?' and 'Have you worked with patients with fertility problems on placement? Both questions were answered on three-point scales ('none', 'some' or 'a lot'), which were dichotomised for the purposes of analysis ('none' or 'some'). In the No Prompt Wave, participants were presented with the following two questions: 'Was fertility preservation mentioned while you were working with cancer patients?' and 'In your medical education to date, has fertility preservation in relation to cancer patients been covered?' Yes/no response options were provided. Participants also indicated their age, year of medical school, marital status, and parental status.

Fertility preservation knowledge.

In the Prompt Wave, participants were asked to indicate whether they were aware of the following FP methods: freezing embryos, egg cells, ovarian tissue, and immature egg cells, as well as in vitro maturation of immature egg cells, organ preserving surgery and hormonal protection of ovaries. The response options provided were yes or no. These options were summed to provide an overall awareness score ranging from 0 (no awareness) to 7 (high level of awareness). Internal consistency was good (ordinal alpha = 0.75). For each of these seven methods, participants were also presented with the statement: 'I am confident of my knowledge about this method', followed by a five point response scale (1 = 'not at all' to 5 = 'extremely').

Manipulation check.

In order to evaluate whether medical students could recall the vignette at the end of the survey, in the Prompt Wave they were asked to report the hypothetical patient's age, marital status, sexual orientation, prognosis and any other topics (if any) she raised. For example: 'How old was Mrs/Miss Smith?' Open-ended text boxes were provided, and a 'don't know' check box was also available for each item.

Procedures

The Prompt Wave survey took approximately 15 minutes to complete, and data collection was carried out during February and March 2012. After indicating their agreement to the consent form, medical students were randomly assigned to one of the six conditions. They were then instructed to read the vignette and complete the openended intentions questions followed by the closed-ended intentions measure. The open-ended questions were placed first to avoid the patient being prompted by the more specific quantitative questions (i.e., 'I would offer fertility preservation options to Emily Smith or refer her to someone who could'). Several measures of individual differences were then completed (reported elsewhere), and finally, medical students provided their demographic and professional information. On the final page of the survey, participants were provided with a debrief form that explained the true purpose of the study and invited them to contact the researcher with any questions about the need for deception. None of the participants made this request.

The No Prompt Wave was shortened to five minutes through the omission of individual difference questionnaires (presented in Chapter 6), to facilitate the recruitment of larger numbers of medical students. Data collection was carried out between March and October 2013. The survey was constructed and piloted in English and the shortened version professionally translated into Danish. A Danish fertility expert cross-checked the Danish translation with the English and made adjustments where necessary. Students in the Netherlands were provided with the English version.

Data Analysis

One participant in the Prompt Wave was excluded due to only completing the first half of the survey. Three cases in the No Prompt Wave were deleted: one participant who had already graduated, one who submitted a blank survey, and one who started one condition of the survey, did not submit but returned at a later date and submitted a different condition. Data screening was carried out prior to analyses, during which outliers, defined as data points above or below three standard deviations from the mean, were replaced with the value of three standard deviations (Field, 2013). The closed-ended measure of intentions was negatively skewed in both waves. In the No Prompt Wave a square root transformation satisfied the normality assumption required by multiple regression and a log transformation was used for the Prompt Wave (Field, 2013). Chi-square, Fisher's exact test, and one-way between

subjects analysis of variance, as appropriate, were employed to assess whether demographic characteristics differed across condition. These tests were conducted using IBM SPSS Statistics Version 20.

Ordinal alpha was employed to determine the reliability of the skewed Likert scales according to the method of Gadermann et al. (2012). For this, the R Core Package version 3.0.3 (R Core Team, 2014) and the psych and GPArotation packages (Bernaards & Jennrich, 2005; Revelle, 2013) were employed.

For the experimental manipulation check, the associations between condition and recalled characteristics of the hypothetical patient were assessed using between-subject t-tests, chi-square tests and Fisher's exact tests as appropriate.

Logistic regressions were used to establish the influence of condition on the three dichotomous measures of intentions, and dummy variables were constructed for the five experimental conditions, with the control as the reference category. When sparse data rendered logistic regression unstable, exact logistic regressions were conducted according to Derr's (2009) guidelines using SAS software (version 9.3, SAS Institute, Inc., Cary, NC, USA). When multiple empty cells resulted in the exact distributions consisting of a single value (Zorn, 2005), Firth logistic regressions were conducted according to the guidelines provided by Heinze and Ploner (2004). For this the R Core Package version 3.0.3 (2014) using the R package logistif (Heinze, Ploner, Dunkler, Southworth, 2013) was used. Forced-entry multiple regression was used for closed-ended intentions with IBM SPSS Statistics Version 20. All statistical tests were two-tailed.

Power calculations for exact and Firth logistic regressions are not available (Ryan, 2013), but there should be at least 10 participants per predictor for conventional logistic regression (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996; Vittinghoff and McCulloch, 2007). Taking this as a guideline, adequate power was achieved.

Thematic analysis of medical students' responses to the two open-ended questions was carried out blind to condition in order to explore any qualitative differences between the content of proposed discussions or referrals between conditions that could indicate bias. Thematic analysis was conducted according to Braun and Clarke's (2006) guidelines. Thematic analysis was used because it can be readily applied to large datasets (Braun & Clark, 2006), and the sample size of the present study was larger than is typical of qualitative studies.

Prior to extracting the themes, the data was coded by the author. Morse, Barrett, Mayan, Olson, & Spiers (2002) report that a crucial aspect of maximising the trustworthiness of qualitative results is an iterative process: when a new idea was discovered, all previously analysed data was re-examined and coded for the presence of the new idea. Saturation was reached after the first 126 of the discussion responses and the first 123 of the referral responses in the Prompt Wave. No new codes were identified after this point.

Themes were constructed, reviewed, and revised until the essence of the data was accurately portrayed. The author derived the themes that were then validated by another researcher. There is no established method for calculating a statistical measure of the extent to which agreement was reached in the derivation of themes, but the researchers only disagreed on a few minor points, which were resolved by discussion.

Results

Fifteen medical schools were contacted during recruitment for the Prompt Wave, and five agreed to distribute the survey. Of the 10 who did not agree to participate, eight did not reply, one did not want to participate due to overloading students, and the reason for the 10th not agreeing is unknown. During recruitment for the No Prompt Wave, 119 medical schools were contacted and 11 participated. The majority of universities (60.5%) did not respond to emails, and of those that responded but did not agree to distribute the survey, the most common reason given was desire to avoid overloading students. No universities from the Netherlands, Republic of Ireland, or New Zealand agreed to distribute the survey, and no students from these countries responded to facebook advertisements.

Table 5.2 shows that the majority of the sample (Prompt Wave only) was aware of methods involving freezing embryos and egg cells, but fewer were aware of other FP methods. Confidence in knowledge of FP methods ranged between 1.25 and 2.17 on a five point scale. Significant correlations were present between awareness scores and FP discussion intentions (r=0.21, p =0.017) and fertility referral intentions (r=0.19, p =0.029), but not with fertility discussion intentions (r=-.034, p=0.70) or closed-ended intentions (r=-.076, p =0.39).

Table 5.2. Self-reported knowledge of fertility preservation methods among the sample for the prompt wave (n=143)

Method	% Aware of the method (n)	Between condition comparison test	Mean confidence in knowledge (SD)	Between condition comparison test
Freezing embryos	74.8 (107)	$\chi^2(5) =$	1.95 (0.94)	F(5, 104) =
		3.94		0.35
Freezing egg cells	76.8 (106)	$\chi^2(5) =$	2.17 (1.05)	F(5, 104) =
		3.86		1.49
Freezing ovarian	12.9 (18)	$\chi^{2}(5) =$	1.22 (0.49)	Fisher's
tissue		7.10		exact test =
		2		4.33
Freezing immature	34.3 (47)	$\chi^{2}(5) =$	1.36 (0.65)	Fisher's
egg cells		4.16		exact test =
		2		2.96
In vitro maturation of	31.9 (45)	$\chi^{2}(5) =$	1.46 (0.80)	$\chi^{2}(5) =$
immature egg cells		6.79		4.22
Organ preserving	34.3 (48)	$\chi^{2}(5) =$	1.54 (0.84)	$\chi^{2}(5) =$
surgery		3.23		3.015
Hormonal protection	19.7 (28)	$\chi^{2}(5) =$	1.25 (0.54)	Fisher's
of the ovaries during		0.78		exact test =
cancer treatment				1.72

Note: The response scale for confidence is 1 = 'not at all' to 5 = 'extremely'. p>0.05 for all comparison tests.

Manipulation Checks

Respondents in the older age condition recalled the hypothetical patient to be significantly older than those in the other five conditions, t (124) = -12.74, p < 0.001, r = 0.57. Medical students in the unpartnered condition were more likely to recall that the patient was unmarried (χ^2 (1)= 94.64, p < 0.001, Cramer's V = 0.88). 100% of medical students in the poor prognosis group reported the patient's prognosis as poor, and 100% of those in the same sex- partner condition recalled sexual orientation as homosexual, lesbian, or nonheterosexual etc. Finally, medical students were 11.58 times more likely to recall that the patient mentioned fertility in the conditions when this was true (Fisher's exact test, p <0.001).

Intentions

The means/frequencies for each measure of intentions by condition and wave are presented in Table 5.3, and show that rates of fertility discussion and referral

intentions were lower in the fertility information unrequested condition (Prompt Wave) and, conversely, higher in the fertility information requested condition (No Prompt Wave). FP discussion intentions were zero in the older age condition in both waves. Scores on the closed-ended measure ranged between 5.71 and 6.36.

Table 5.3.

Frequencies and means for the four measures of intentions according to condition for each wave of the study

Wave	Condition	n	Ope	n-ended intent	ions	Closed-
			Fertility	FP	Fertility	ended
			discussion	discussion	referral	intentions
			% (<i>n</i>)	% (<i>n</i>)	% (<i>n</i>)	to discuss
						fertility and
						refer
						Mean (SD)
Prompt	Control	22	81.8 (18)	18.2 (4)	27.3 (6)	6.09 (0.80)
	Older	11	81.8 (9)	0	54.5 (6)	6.36 (0.55)
	Single	41	92.7 (38)	12.2 (5)	51.2 (21)	6.40 (0.68)
	Poor prognosis	24	100 (24)	4.2 (1)	66.7 (16)	6.02 (0.81)
	Gay	21	85.7 (18)	33.3 (7)	57.1 (12)	6.35 (0.62)
	Fertility information	24	20.8 (5)	0	12.5 (3)	6.33 (0.73)
	unrequested					
No Prompt	Control	21	4.8 (1)	0	4.8 (1)	6.01 (1.03)
-	Older	28	0	0	0	5.98 (1.16)
	Single	23	13.0 (3)	13.0 (3)	8.7 (2)	5.97 (0.95)
	Poor prognosis	24	4.8 (1)	4.8 (1)	5.0(1)	5.71 (1.23)
	Gay	39	2.6(1)	2.6(1)	8.3 (3)	5.77 (1.16)
	Fertility	27	66.7 (18)	7.4(2)	59.3 (16)	6.20 (1.11)
	information requested					

Note. SD = standard deviation. FP = Fertility preservation. In the Prompt Wave all conditions request fertility information except for 'fertility information unrequested'. In the No Prompt Wave the reverse was true: fertility information was only requested in the 'fertility information requested' condition.

The response scale is 1= 'definitely not' to 7= 'definitely'.

The effect of condition on intentions was examined in a series of regressions. Summary statistics for the Prompt Wave are presented in Table 5.4. In the Prompt Wave all conditions explicitly request information except the 'fertility information unrequested' condition. As shown by the odds ratios in Table 5.4 most conditions (being older, single or gay) were not significantly related to intentions. The poor prognosis condition was associated with a higher intention to refer to a fertility specialist (but not general fertility or fertility preservation discussions). The condition 'fertility information unrequested' was significantly associated with a reduced chance of general or fertility preservation discussion. Closed-ended intentions were not significantly predicted by any condition.

Table 5.4. Summary statistics for the logistic regressions showing effect of each condition on four types of intentions in the Prompt Wave

			Ope	n-ended intention	ons		Closed-ended intentions to discuss	
Condition ^a	intentions (N=143) ^b disc		discuss	Fertility preservation discussion intentions (<i>N</i> =143) ^c		y referral ons (<i>N</i> =143) ^d	fertility and refer ^e (<i>N</i> =143)	
	OR	CI	OR	CI	OR	CI	Unstandardised beta	CI
Older	1.00	0.12, 13.04	0.18	0.0013, 1.93	3.08	0.55, 18.79	0.059	-0.063, 0.18
Single	2.77	0.42, 20.91	0.62	0.16, 2.56	2.76	0.82, 10.41	0.079	-0.008, 0.17
Gay	1.32	0.19, 10.37	2.12	0.56, 8.85	3.45	0.85, 15.59	0.059	-0.41, 0.16
Poor prognosis	6.55	1.054, infinity	0.26	0.025, 1.58	5.12*	1.29, 23.07	-0.013	-0.11, 0.085
Fertility information unrequested	0.064***	0.010, 0.30	0.08*	0.00062, 0.86	0.39	0.054, 2.16	-0.058	-0.16, 0.039

^{*} indicates significance at the p < 0.05 level. *** indicates significance at the p < 0.001 level.

Note. OR = Odds ratio, CI = 95% confidence intervals

^a Reference group is the control condition ^b Exact logistic regression, joint score statistic = 58.84, p<.001 ^c Firth logistic regression, penalised likelihood ratio test (5) = 13.53, p =0.019 ^d Exact logistic regression, joint score statistic = 19.76, p =.0.0010 ^e Linear regression, F(5, 138) = 1.31, p=0.26, R² = .046

Table 5.5 shows the summary statistics for the logistic regressions in the No Prompt Wave. In the No Prompt Wave none of the conditions explicitly requested fertility information, except for the 'fertility information requested' condition. As was the case for the Prompt Wave, most conditions were not significantly associated with intentions (older, single, gay, poor prognosis). However, the condition where the hypothetical patient requested fertility information was significantly associated with a higher level of all intentions apart from FP discussion intentions. Further, closed-ended intentions were significantly higher when the patient had a same-sex partner.

Table 5.5. Summary statistics for the regression models showing effect of each condition on four types of intentions in the No Prompt Wave

			Closed-ended intentions to discuss					
Condition ^a	Fertility discussion intentions (<i>n</i> =158) ^b		Fertility preservation discussion intentions (<i>n</i> =158) ^c		Fertility referral intentions $(n=155)^d$		— fertility and refer (<i>n</i> =160) ^e	
	OR	CI	OR	CI	OR	CI	Unstandardised beta	CI
Older	0.75	0.00, 14.25	0.76	0.004, 141.88	0.75	0.00, 14.25	-0.061	-0.65, 0.53
Single	2.93	0.007, 44.53	0.91	0.0049, 172.43	1.80	0.091, 117.90	.20	-0.42, 0.82
Gay	0.55	0.007, 44.53	1.72	0.088, 254.68	1.88	0.13, 100.15	.071*	0.003, 1.10
Poor prognosis	1.00	0.012, 82.37	3.15	0.16, 468.72	1.05	0.013, 86.71	.55	-0.54, 0.68
Fertility information requested	36.67***	4.53, >1000	4.22	0.32, 595.86	27.09***	3.38, >1000	.87**	0.28, 1.46

^{*} indicates significance at the p < 0.05 level. ** indicates significance at the p < 0.01 level. *** indicates significance at the p < 0.001 level. Note. OR = Odds ratio, CI = 95% confidence intervals

^a Reference group is the control condition

^b Exact logistic regression, joint score statistic = 68.40, p < .001

^c Firth logistic regression, penalised likelihood ratio test (5) = 2.65, p = 0.75

d Exact logistic regression, joint score statistic = 51.81, p < .001 e Linear regression, F(5, 155) = 3.45, p = 0.006, $R^2 = 0.10$

Thematic Analysis

Four overarching fertility themes emerged from the thematic analysis of responses to the question 'What should be discussed with Miss/Mrs Smith?': fertility solutions, FP-specific solutions, fertility risks and generic treatment side effects. The theme 'fertility solutions' referred to responses that considered the use of fertility options but did not explicitly mention FP, for example, discussing methods such as the use of a donor gamete in the future or minimising the risk to fertility. 'FP-specific solutions' referred to intentions to explicitly discuss FP, what would be involved, and the likelihood of success: "In particular, her query on fertility should be focussed on and egg harvesting and storage should be explained as the chemo could affect fertility" (participant in the control condition). The theme 'fertility risks' was used for generic fertility discussions that raised the possibility of infertility to the patient, discussed their future childbearing wishes, and/or offered patients fertility counselling. These discussions were not specific with regard to fertility solutions or preservation, for example "risks of the treatment especially in relation to current and future fertility" (participant in the single condition). The theme 'generic treatment side effects' referred to generic discussion of the general harms of cancer treatment without explicitly highlighting fertility among them. No other aspects of reproductive health (e.g., contraception or body image concerns) were present in the data. Three fertility themes were derived from responses to the question 'It is your responsibility to ensure that Miss/Mrs Smith is referred to all relevant specialists. Which would you refer her to?' These consisted of referrals to fertility services, non-specific referrals that may incorporate fertility-related care, and referrals to geneticists. Referrals to fertility services included fertility specialists, reproductive medicine, FP, gynaecology, obstetrics, and IVF clinics. Non-specific referrals that may have incorporated fertilityrelated care included multidisciplinary teams, general support services, or stating that the oncologist would make further referrals. Finally, some medical students referred to a geneticist, which may reflect a level of awareness that reproductive decisionmaking may be relevant to the patient. No qualitative differences in the fertility themes were apparent across conditions.

In the No Prompt Wave there were three or fewer participants in each condition (with the exception of the fertility information requested condition) who reported fertility discussion or referral intentions in response to the open ended questions. Therefore, fertility-specific thematic analysis was not conducted.

Discussion

There was no evidence of bias against hypothetical patients who were unpartnered, older, had a poor prognosis or were in same-sex relationships. However, there was prompting bias, with medical students much more likely to intend to discuss fertility and refer to a fertility specialist when they had been prompted about fertility. These results suggest that the reported bias in oncofertility could be due to the effect of person characteristics (e.g., poor prognosis, being gay) on patients' own behaviour (i.e., not requesting fertility information) with a knock on effect on the doctors' behaviour (i.e., not providing fertility information). This explanation of bias is consistent with our proposition that an unmeasured confound may account for the biases reported by oncologists in past research (e.g., Forman et al., 2010). If certain patients are less likely to ask about the risk to their fertility, this may further reinforce the social norm that patients interested in fertility (and therefore potential candidates for FP) are mainly young heterosexual married couples, possibly leading some physicians to assume that patients who do not have these characteristics are not interested in parenting. In reality, people who are gay, unpartnered, older or have a poor prognosis may have many other reasons for not asking about their fertility, for example perceived physician attitudes or lack of knowledge of options to conceive given their circumstances.

The findings indicating a lack of bias for person characteristics contradict the many studies previously described that found that some physicians reported being less likely to discuss fertility with certain patients. None of the previous studies on bias report whether the disadvantaged patients requested fertility information (e.g., Forman et al., 2010; Quinn et al., 2009a, 2009b; Schover et al., 2002). Therefore, a possible explanation is that the disadvantaged patients were less likely to receive fertility information because they were less likely to request it. The present study only provides indirect evidence for this explanation, but further support from outside of the oncofertility domain is available. For example, Siminoff et al. (2006) recorded initial consultations between oncologists and breast cancer patients. Patients who were younger, White, more educated or higher earning were significantly more likely to ask their physician questions. Future research in a similar vein should focus on which patients are most likely to ask questions related to fertility in the initial consultation,

and should also investigate other alternative explanations for the results of the present study.

The other key factor which may account for a difference in results between this and other studies is the use of medical students rather than medical doctors who have been the target sample to date. The most fundamental difference between medical students and physicians is likely to be knowledge. Some (e.g., Forman et al., 2010; King et al., 2008, Quinn et al., 2009a) but not all (e.g., Quinn et al., 2009b; Schover et al., 2002) studies have found evidence that knowledge influences the likelihood of discussions or referrals. In the present study, the majority of students (~75% in Prompt Wave) were aware of embryo and oocyte cryopreservation, and knowledge was weakly and inconsistently associated with fertility discussion and referral intentions. Together these findings would argue against low knowledge being an explanation for lower referrals rates in the present study compared to other studies (Forman et al., 2010; Adams et al., 2013).

Medical students were not confident about their fertility knowledge. However, this seems an unlikely explanation for the difference in results between students and doctors, and the fact that medical doctors are accustomed to referring patients to specialists for consultation is a more plausible reason. Other factors that covary with being a doctor (e.g., being less risk averse) could also explain between study differences.

The scope of the present study was limited to assessing group-level biases. Previous studies have shown that physician characteristics including knowledge, attitudes and gender influence decision-making in an oncofertility context (e.g., Quinn et al., 2009a, 2009b). Further replication among diverse medical doctors (oncologists, fertility specialists) is required, taking into account oncofertility knowledge.

In contrast to these null results there was multiple evidence for a prompting bias. First, if hypothetical patients asked for fertility information 78% of medical students reported that they would discuss fertility but when patients did not this percentage was much lower, 5%. This discrepancy was obtained when the parity of the patient was mentioned (the Prompt Wave used a childless hypothetical patient) and replicated when the parity of the patient was not mentioned (in the No Prompt Wave the parity of the hypothetical patient was not mentioned). However, as per previous studies (e.g., Quinn et al., 2007), intentions were found to be stronger when the patient was specified to be childless. The specification of parental status may have

formed a cue if it alerted participants to the topic of parenthood, hence this may be another form of prompting bias. Finally, intentions to discuss fertility or refer to a fertility specialist were much stronger in response to questions that primed fertility ("I would offer fertility preservation options to Emily Smith or refer her to someone who could") than in response to open-ended questions that did not ("What should be discussed with Miss/Mrs Smith?"). This pattern of results clearly indicates that when patients don't ask for fertility information they don't get fertility information or are much less likely to get it (from medical students).

Providing information only when asked would seem to be an example of failing to identify the needs of the individual and to provide patient-centred care. Standardised fertility information needs to be available to all patients, who should all be directly asked whether they would like to receive it. A previous study has shown that the use of a standardised fertility education brochure for cancer patients increased referrals by 9 times (Quinn et al., 2011). Previous interventions aiming to standardise procedures in other domains have been shown to improve patient outcomes (e.g., Pronovost et al., 2006) but have been met with resistance and have not been routinely implemented in practice (Mahajan, 2011). Clearly clinical guidelines that make this recommendation are not fully implemented. The results suggest a need to better educate doctors that all patients of childbearing age should be offered the opportunity to address their fertility needs, regardless of whether or not they know to raise this topic.

Limitations

The results of the present study require replication among oncologists. For example, an oncologist is likely to incorporate many factors in their decision-making that medical students would not, for example, what a doctor thinks has or has not benefited patients in their past clinical experience may lead them to prioritise some patients over others. Barriers that hinder the translation of intentions into behaviour in clinical practice may also be encountered, such as time constraints and limited resources.

Some questions and elements of the experimental design would need to be further fine-tuned. For example, closed-ended intentions were higher when the patient had a same-sex partner, but this is unlikely to be due to socially desirable responding because there was no significant effect of sexual orientation on any other measures of

intentions. The reasons for this and the finding that referral intentions were increased for patients with a poor prognosis in the Prompt Wave are unknown. Future research needs to consider the impact of extraneous variables that may influence responses to certain patient characteristics.

Due to not knowing how many students received the study advertisement via email or how much exposure the Facebook advertisements gained, response rates could not be calculated but are estimated to be low (if 500 students from each of the 16 universities saw the advertisement, the response rate would be approximately 4%). Despite the fact that responders may have been particularly interested in oncology, it is unlikely that they differed from non-responders in terms of bias because the advertisement did not specify that the study was investigating the influence of patient characteristics.

Two psychologists coded the qualitative data so discipline bias could have been introduced. Although inter-rater reliability was very good, future research might be improved through the use of a multidisciplinary coding team. A further limitation is that although knowledge of FP methods was assessed, future research should also measure knowledge of the treatment types associated with fertility risk to give a clearer picture of participants' level of understanding.

Conclusions

In conclusion, medical students were not biased by sexual orientation, age, partnership status or prognosis. The only influential factor was the patient requesting fertility information, which raises the possibility that the well-documented biases in the provision of fertility information may not result from physician prejudice. Instead, certain patients may be less likely to receive fertility information because they are less likely to request it, but these findings require replication in oncologists.

Current guidelines emphasize the physician's responsibility to inform patients about their fertility options (Loren et al., 2013), and clearly there is an urgent need for interventions to ensure all eligible patients receive timely fertility information. During the wait for these interventions to be implemented, awareness campaigns run by healthcare providers, relevant charities, and patient advocacy groups encouraging cancer patients to request fertility information may be a possible short-term strategy to minimise unnecessary loss of parenthood opportunities.

Chapter 6:

What Makes Medical Students Biased? The Predictors of Prejudice in Oncofertility Provision

Introduction

Despite current recommendations stating that all patients should be informed about the risk to their fertility and fertility preservation (FP) options prior to cancer treatment (Loren et al., 2013), and evidence showing that cancer-related infertility presents a pressing quality of life issue (Canada & Schover, 2012), cancer survivors frequently fail to recall having fertility discussed with them prior to treatment. Studies have found varying figures: for example, 34-61% of female cancer survivors in the United States of America (USA) recalled being informed about the effects of treatment on fertility (Duffy et al., 2005; Letourneau et al., 2012).

A substantial body of evidence suggests that cancer patients with certain characteristics are less likely to have fertility discussed with them, for example gay patients (Forman, Anders, & Behera, 2010; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002) and patients who do not request fertility information (Schover et al., 2002). Clinical guidelines explicitly state that patient characteristics such as prognosis should not prevent FP discussions from taking place (Loren et al., 2013). Using a randomised design involving vignettes describing hypothetical female breast cancer patients, in Chapter 5 the impact of the patient's characteristics on intentions to initiate fertility discussions and referrals was investigated. The results showed that among two samples of medical students, intentions were not affected by sexual orientation, age, prognosis or marital status. The only influential factor was whether the patient specifically requested fertility information. When they did, medical students' intentions to discuss fertility with the patient or refer them to a fertility specialist strongly increased.

Although it is reassuring that the characteristics of the patient did not influence medical students' intentions at the group level, there are still likely to be individual differences that warrant further exploration. Minimal research has looked at the impact of the views and beliefs held by the physician on their decision-making in oncofertility. That which does exists suggests that attitudes towards FP (Quinn et al., 2009b) and comfort with discussing fertility (King et al., 2008; Quinn et al., 2009a)

might be important. Other constructs which might be expected to contribute to bias include beliefs about who should and should not have children and the tendency to discriminate against certain social groups. An established measure of the latter is social dominance orientation, which has been found to predict many forms of bias including racism, sexism, and homophobia (Pratto et al., 2000; Pratto et al., 1994).

The first aim of the present study was to establish whether The Theory of Planned Behaviour (TPB) (Ajzen, 1991) can predict intentions to initiate fertility discussions or referrals with a hypothetical patient described in a vignette. Vignettes have been well-validated and are a cost-effective method for assessing clinical practice (Peabody et al., 2000; Peabody et al., 2004). The TPB posits that intentions to carry out a behaviour can be predicted from attitudes towards the behaviour, subjective norms (perceptions of how favourably others view the behaviour), and perceived behavioural control (perceived ability to carry out the behaviour). Attitudes, subjective norms and perceived behavioural control are constructs that stem from relevant beliefs held by the individual (Ajzen, 1991).

According to the TPB, attitudes, subjective norms and perceived behavioural control are underpinned by certain beliefs, and these differ according to the behaviour in question (Ajzen, 1991). Therefore, the present study also aimed to identify the beliefs that underpin these constructs in the context of oncofertility, and assessed a range of beliefs that were hypothesised to contribute to the attitudes, norms and perceived behavioural control that underlie the intention to discuss fertility with a patient. The identification of beliefs that contribute to preventing physicians from discussing fertility with patients may provide a possible basis for intervention, and those measured in the present study included positive and negative feelings towards FP, the willingness to discuss FP with patients, and the extent to which parenthood is viewed as a burden.

The second aim of the study was to establish the personality traits and beliefs associated with self-reported bias. Self-reported bias refers to the extent to which medical students report that patient characteristics would influence whether they would discuss fertility. It was hypothesised that strong tendencies to be prejudiced and negative views of non-traditional family forms would be associated with higher levels of self-reported bias.

The sample employed to answer these questions was the first of the two samples of medical students described in Chapter 5, who completed a detailed survey

measuring the TPB constructs, views on FP and beliefs related to prejudice. Medical students were recruited to ascertain the factors that influence decision-making and bias in the early years of training before strong habits have been formed. In many medical domains the predictors of attitudes towards and biases against certain patients have been found to be similar, although not identical, in both medical students and doctors. Examples include obesity (Phelan et al., 2014; Sabin et al., 2012), mental illness (Arvaniti et al., 2009; Mukherjee et al., 2002), and race (Rathore et al., 2000; Sabin, Nosek, Greenwald, & Rivara, 2009).

Methods

Participants

Medical Schools in the United Kingdom were invited to distribute the survey link to their medical students via email. The only inclusion criterion was that participants had to be an undergraduate or postgraduate medical student. The survey was completed by 143 medical students whose mean age was 22.0 and mean year of study was 3.3. 75.5% (n=108) of the sample had some previous experience with cancer patients and 43.7% (n=62) had experience with fertility patients. Most medical students were aware of methods involving freezing embryos (74.8%, n=107) and freezing egg cells (74.6%, n=106).

The Cardiff University School of Psychology Research Ethics Committee approved this study. Certain Schools of Medicine also chose to have the study approved by their own ethical committees.

Materials

All materials discussed in this section are presented in Appendix K.

The TPB.

After indicating their consent, medical students were randomly assigned to one of six vignettes describing a hypothetical female breast cancer patient. Next, two open-ended questions were presented to ascertain intentions before medical students became aware that fertility was the focus of the study. These questions are not used in analysis of the present study because they were measured before attitudes, norms and

control. Factors that are used to predict outcomes must be measured before the outcome to avoid the risk of order effects, i.e., responses on the predictors may be influenced by the experience of previously responding to the measure of outcome. See Chapter 5 for details of the vignettes and open-ended questions.

The measures of the TPB variables were constructed according to the available guidelines (Ajzen, n.d.). The attitudes measure consisted of eight items. Two questions were presented ('Discussing fertility with Mrs Smith is:' and 'Discussing fertility with every patient is:'), and each question was followed by four response scales (1 = 'not important' to 7 = 'important', 1 = 'bad' to 7 'good', 1 = 'unnecessary' to 7 'necessary', 1 = 'uncomfortable' to 7 = 'comfortable'). The internal consistency for the measure was good (ordinal alpha = 0.88).

Five norms items were presented (e.g., 'Most doctors would discuss fertility preservation with patients whose fertility may be affected by their cancer treatment'). Responses were indicated on seven point response scales (1 = 'agree' to 7 = 'disagree') and the internal consistency was good (ordinal alpha = 0.80).

The measure of perceived behavioural control originally comprised six items but due to low internal consistency the only item used in the analyses was that which was judged to assess the construct most accurately: 'How much control do you feel you have over whether this patient will have the opportunity to undergo fertility preservation?' (1 = low') to 7 = high'.

Five items ascertained intentions concerning fertility discussion and referrals (e.g., 'I would offer fertility preservation options to Emily Smith or refer her to someone who could'). Seven-point scales were provided (1= 'definitely not' to 7 = 'definitely'), all with high scores indicating strong intentions. Internal consistency was good (ordinal alpha = 0.86).

Beliefs related to FP and parenthood.

Four measures were adapted from those developed for a previous study (Tschudin et al., 2010): Knowledge of FP, willingness to discuss FP despite risks, and positive and negative feelings towards FP. The knowledge of FP measure assessed awareness of seven methods (e.g., freezing embryos). For each, participants were presented with 'Aware of method' and a 'yes/no' response option. The mean score across items for each participant was calculated and the internal consistency of the measure was good (ordinal alpha = 0.75).

Willingness to discuss FP despite risks was measured by four items (e.g., 'How likely would you be to discuss fertility preservation if there is a small risk of reimplantation of cancer cells due to fertility preservation?'). The response scales ranged from 1 = 'not at all' to 5 = 'extremely'. The internal consistency was good (ordinal alpha = 0.82).

Positive feelings towards FP were measured using six items (e.g., 'The possibilities of fertility preservation are beneficial'), and the measure of negative feelings towards FP comprised seven items (e.g., 'I have ethical reservations with regard to fertility preservation'). The response scale for both measures ranged from 1 = 'strongly agree' to 5 = 'strongly disagree'. The internal consistency of positive feelings towards FP was good (ordinal alpha = 0.78), but the negative feelings towards FP scale had to be reduced to three items in order to achieve adequate internal consistency (final ordinal alpha = 0.75).

The perceived burden of children measure comprised six items (e.g., 'Children are a financial burden on their parents', ISSP Research Group, 2016). The response scales consisted of 1 = 'strongly agree' to 7 = 'strongly disagree'. Due to low internal consistency, two items were removed which resulted in adequate reliability (ordinal alpha = 0.65).

Beliefs related to prejudice.

Traditional family values were measured using seven questions (e.g., 'People who want children ought to get married') (ISSP Research Group, 2016). The response scale ranged from 1= 'strongly agree' to 7 = 'strongly disagree' and ordinal alpha = 0.90.

The 16-item version of the social dominance orientations scale (Pratto et al., 1994) was used to assess participants' general tendency towards prejudice (e.g., 'Some groups of people are simply inferior to other groups'). The response scales ranged from 1 = 'very negative' to 7 = 'very positive', and internal consistency was good (ordinal alpha = 0.94).

Conscientious objection to FP was assessed by adapting a one-item measure previously used in the context of medication dispensing by pharmacists (Davidson, Pettis, Joiner, Cook, & Klugman, 2010): 'Mark the option that best describes your level of comfort in discussion or offering fertility preservation options to cancer patients prior to treatment on personal or moral grounds (not medical or legal)'. Four

response options were provided: 'Discuss and/or offer without moral objection', Discuss and/or offer but morally object', 'refuse to discuss or offer on moral grounds but transfer', and 'refuse to discuss or offer on moral grounds and refuse to transfer'.

Self-reported bias.

Medical students reported the extent to which they thought certain patient characteristics would affect their behaviour by answering five statements, each concerning one of the manipulated patient characteristics (e.g., 'The sexual orientation of a patient would affect whether I would make referrals concerning fertility preservation'). The response scales ranged from 1 ='strongly agree' to 7 ='strongly disagree'. The mean of three of these questions was calculated for each participant in order to provide an indication of the influence of bias. Specifically these were the effects of a patient's sexual orientation, marital status and prognosis. The two questions which were not included in the measure related to requesting fertility information and the age of the patient. Requesting fertility information was not taken as an indication of bias because strong group effects were observed when patients requested fertility information (see Chapter 5), so individual differences were not relevant. Additionally, the question asking whether the age of the patient would influence referrals was not taken as an indicator of bias because patients beyond their reproductive years would not be referred. The internal consistency of the three-item measure was good (ordinal alpha= 0.77).

Background information.

The following demographic information was requested: year of medical school, age, marital status, and parental status. Gender was inadvertently omitted from the survey. Medical students also indicated the extent of their previous experience with cancer patients and patients with fertility problems on three-point scales ('none', 'some' or 'a lot'), which were later dichotomised ('some' or 'none'). Intended speciality was indicated by ticking one of the following five options: 'fertility', 'oncology', 'general practitioner', 'undecided' or 'other'.

Data Analysis

One participant was excluded due to only completing half of the survey. Ordinal alpha was employed to assess the internal consistency of measures with skewed items (Gadermann, et al., 2012) using the R Core Package version 3.0.3 and the psych and GPArotation packages (Bernaards & Jennrich, 2005; Revelle, 2013). All other analyses were carried out using IBM SPSS Statistics Version 20.

Data screening was carried out prior to analyses, during which outliers were winsorised to three standard deviations. Skewed variables were transformed in order to achieve normality, and log transformations were applied to intentions and subjective norms and attitudes, perceived behavioural control, positive and negative value of parenthood, and square root transformation were used to normalise traditional family values and social dominance orientations.

The TPB.

Forced-entry multiple regression was used to identify the extent to which norms, attitudes and perceived behavioural control predicted intentions. Since the measure of intentions did not differ by condition (effects of the manipulation were found in open-ended questions only, see Chapter 5), condition did not need to be controlled for in the models. All power calculations were conducted using G*power (Faul et al., 2009), which for this multiple regression model indicated that a sample size of 77 would be required to detect medium effect sizes.

Univariate correlational analyses were performed to establish which measures of beliefs, prejudice, and sociodemographic variables were associated with any of the three dependent variables: attitudes, subjective norms and perceived behavioural control. Three multiple regressions were run, one for each of the dependent variables, and all measures of individual differences that were significantly correlated with the dependent variable in question were entered as predictors. Although it was not known prior to these analyses how many predictors would be entered into each model, an estimation of 10 was made. Power calculations indicated that a total sample size of 118 would be required to allow medium effect sizes to be detected.

Self-reported bias.

Friedman's two-way analysis of variance by ranks was used as the nonparametric alternative to a within-subjects analysis of variance to compare the scores across the four questions on the influence of bias, as the differences between scores were not normally distributed for each participants. Next, in order to assess whether the mean for each question significantly differed from one, one-sample t-tests

were run for each question. The comparison point was set at one because it was the lowest point on the Likert scale, representing no bias. Power calculations indicated that a sample size of 34 would allow medium effect sizes to be detected in the one-sample t-tests.

Univariate correlation analyses were conducted and all measures of individual differences and demographic variables that were significantly associated with the influence of bias were entered into a multiple regression. As in the previous section, for the purposes of a priori power calculations, it was estimated that 10 predictors would be included in the model, so at least 118 participants were need to ensure that medium effect sizes could be detected.

Results

Five of the 15 medical schools contacted agreed to circulate the survey to their medical students. The means and standard deviations for the individual difference and demographic variables are presented in Table 6.1. Mean attitude scores were more positive than neutral and the subjective norms and perceived behavioural control means were more negative than neutral. On average, willingness to make FP referrals despite risks was neutral, as was positive feelings towards FP. Participants generally had low scores on negative feelings towards fertility preservation, burden of children, conscientious objection, social dominance orientation, and awareness of FP methods. Scores for traditional family values were slightly below neutral.

Table 6.1.

Sample characteristics (means and standard deviations for continuous variables)

Variable	Mean (SD)
Intentions ^a	6.27 (0.72)
Attitudes ^a	6.02(0.74)
Norms ^a	3.69 (0.86)
Perceived behavioural control ^a	3.69(1.59)
Burden of children ^a	2.34(1.03)
Willingness to refer for FP b	3.99(0.62)
Positive feelings towards FP b	4.32 (0.50)
Negative feelings towards FP ^b	2.15(0.99)
Conscientious objection ^c	1.22 (0.50)
Awareness of FP methods ^d	2.81(1.67)
Traditional family values ^a	3.61(1.53)
Social dominance orientation ^a	1.84(0.73)

Note. SD = standard deviation, FP = fertility preservation. ^a response options were 1-7, ^b response options were 1-5, ^c response options were 1-4, ^d maximum possible score = 7. Means and standard deviations were calculated post-winsorisation.

Predicting Intentions using the TPB

Table 6.2 shows that higher scores on subjective norms, attitudes and perceived behavioural control significantly predicted higher intention scores. The model accounted for 20.6% of the variance, F(36, 131) = 11.33, p<.001, $R^2 = 0.206$.

Identifying the Beliefs that Underpin the TPB Variables

The multiple regression model comprising the variables associated with attitudes in univariate analyses explained 20.4% of the variance, F(4, 124) = 8.94, p<.001, $R^2 = 0.204$. Higher scores on willingness to refer for FP, positive value of FP, and older age remained significantly associated with more positive attitudes (see Table 6.2). Social dominance orientation became nonsignificant (p=0.078). The regression model for norms explained 7.7% of the variance, F(2, 134) = 5.56, p=.005, $R^2 = .077$. As shown in Table 6.2, the positive value associated with FP was significant while willingness to discuss FP was not. In univariate analyses, perceived behavioural control was found to only be significantly associated with the positive value associated with FP (r = 0.20, p=.019).

The Influence of Bias

Figure 6.1 shows that, on average, participants reported that marital status and sexual orientation would not strongly influence their referrals, but that most would be

influenced by a patient's prognosis and whether they requested fertility information. Friedman's test showed that the differences were significant, $F_r(3) = 230.20$, p<.001. Pairwise comparisons revealed that medical students reported being significantly more strongly influenced by the patient requesting fertility information than by sexual orientation (p<.001) or marital status (p<.001). Similarly, medical students reported a significantly stronger influence of poor prognosis compared to sexual orientation (p<.001) or marital status (p<.001).

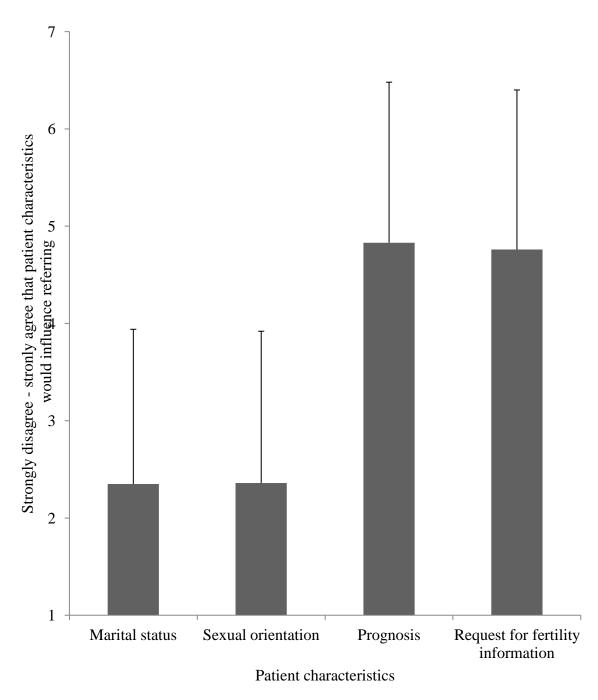


Figure 6.1. The extent to which medical students reported that the likelihood of referring would be influenced by four patient characteristics. Error bars are ± 1 standard deviation.

One-sample t-tests were conducted on each of the four questions separately in order to assess whether the means significantly differed from the scores that would indicated no bias. Since the scale ranged from one (strongly disagree) to seven (strongly agree) a score of one represented no bias. The results showed that the means for all four questions were significantly higher than one: marital status, t (141) =

10.13, p<.001, sexual orientation, t (142) = 10.45, p<.001, prognosis, t (142) = 27.72, p<.001, and requesting fertility information, t (142) = 27.44, p<.001.

The regression model containing all the variables significantly correlated with the influence of bias measure explained 42.0% of the variance, F(8, 118) = 10.69, p < .001, $R^2 = 0.42$. As shown in Table 6.2, the significant predictors were traditional family values and being undecided on one's future speciality.

Table 6.2.

Multiple regression model of the predictors of the Theory of Planned Behaviour constructs

	Standardised beta coefficients					
Variable	Intentions ^a	Attitudes b	Subjective norms ^c	Self-reported bias ^d		
Attitudes	0.17*		понна	087		
Subjective norms	0.32***			.007		
Perceived	0.22**					
behavioural control	0.22					
Willingness to		0.19*	0.086	-0.14		
discuss FP		0.17	0.000	0.1		
Positive value of FP		0.19*	0.23*	-0.076		
Social dominance		-0.15		0.13		
orientation						
Age		0.19*				
Negative value				0.14		
of FP						
Moral objection				0.080		
Traditional family				0.32**		
values						
Undecided about				-0.15*		
future speciality						

Note. Due to missing data: a n=135, b n=129, c n=137, d n=127. FP=fertility preservation.

Discussion

On average, medical students reported that the marital status, sexual orientation and prognosis of a cancer patient would be likely to influence the likelihood of them making a FP referral, which contradicts current guidelines (Loren et al., 2013). Higher levels of self-reported bias against certain patients were associated with strong traditional family values. Medical students who were undecided about their future speciality reported significantly lower levels of bias,

^{*}p<.05, **p<.01, ***p<.001

which may have been due to these students being on average less rigid thinkers or another personality trait.

The TPB model fit relatively well, with high scores on the attitudes, norms and perceived behavioural control measures all being significantly associated with stronger intentions, and together accounting for 21% of the variance. The most common predictor of high scores on attitudes, norms and perceived behavioural control was attributing more positive value to FP. Although it is likely that other unmeasured beliefs also underlie these constructs, this finding suggests that the value placed on FP is an important factor in the decision-making process.

Self-Reported Bias

The strongest determinant of self-reported bias against gay patients, single patients, and patients with a poor prognosis was traditional family values. Participants' general tendency to hold prejudiced views, as measured using the social dominance orientation scale, was nonsignificant. This might be considered surprising because social dominance orientation is known to predict homophobia (Pratto et al., 1994), but it should be noted that in the univariate analyses it was significantly associated with self-reported bias. One explanation for social dominance orientation becoming nonsignificant in the multivariate model is that there may not have been enough power to detect small effect sizes. Alternatively, social dominance orientation may not have explained any additional variance in intentions once traditional family values was controlled for. Both of these explanations may also account for why moral objection was significantly correlated with intentions but became insignificant in the multivariate analyses.

Overall, these exploratory results suggest that traditional family values are the main determinant of self-reported bias, indicating that beliefs about who should and should not raise children may influence FP referrals. Future research needs to establish whether the same association exists in oncologists, but if so this may be an area that future interventions could target. Possibilities might include encouraging doctors to be aware of their own beliefs about the ideal family structure and to make a conscious effort to prevent these from influencing their practice. Alternatively, a system that prompts doctors to discuss fertility preservation with all eligible patients might reduce the impact of the individual physician's beliefs in the decision-making process.

The Beliefs Underlying the TPB Constructs

Of the TPB constructs (attitudes, norms and perceived behavioural control), attitudes was the best predicted by the explanatory variables included in the model, with approximately one fifth of the variance being accounted for. More favourable attitudes were associated with the attribution of positive value to FP and willingness to discuss FP, suggesting that medical students' individual beliefs about FP and the extent to which they were comfortable talking about it were central to the decision-making process.

Older age was also associated with more favourable attitudes. It is unclear why the association between age and attitudes exists, as the likely confounders such as year of medical school and experience with cancer/fertility patients were unrelated to attitudes. One possible reason is that medical students who were older were closer to considering becoming parents themselves given that the average age of women at the first birth in the UK is 28.3 (Office for National Statistics, 2014a). Being more engaged in the reproductive decision-making process themselves may have caused some of the older medical students to have a greater awareness of how much people value parenthood, causing their attitudes to be more positive.

Subjective norms and perceived behavioural control, on the other hand, were poorly predicted by the explanatory variables measured in the present study as less than 10% of the variance in norms and less than 5% of the variance in perceived behavioural control was explained. The only variable significantly associated with either norms or perceived behavioural control was the positive value of FP, such that attributions of more positive value of FP were related to more positive subjective norms and greater perceived behavioural control. This was unexpected because, conceptually speaking, social pressures to offer FP (subjective norms) and anticipated barriers to offering FP (perceived behavioural control) should not be determined by the value the individual participant places on FP. In contrast, the value of FP fits closely with the definition of attitudes, i.e., the perceived costs and benefits of the behaviour (Ajzen, 1991), so attitudes would be expected to be influenced by the value of FP.

One possible explanation for these unexpected findings is the use of medical students, the vast majority of whom had little or no experience of oncofertility.

Subjective norms relate to the social pressure to behave in certain ways (Ajzen, 1991),

but without experience of that area of medicine, it is not clear what the subjective norms medical students reported would have been based on. Similarly, with little or no experience of a real life oncofertility context, it is unclear how medical students would have estimated how easy it would be to offer the patient fertility options (the definition of perceived behavioural control, Ajzen, 1991). One possibility is that they may have drawn on their experiences in other areas of medicine. In summary, subjective norms and perceived behavioural control may not be very meaningful constructs when measured in medical students with no experience of oncofertility, as they would not have had the opportunity to acquire perceptions of subjective norms and perceived behavioural control. A sample of oncologists would be needed to more accurately identify the beliefs that underlie the TPB constructs in this domain.

Overall, in this exploratory study involving medical students the positive value of FP was the main factor associated with the TPB constructs, suggesting it plays a strong role in decision-making. Should this finding be replicated in qualified physicians, it would suggest that an effective approach to improving fertility provision might be educational interventions that aim to ensure that oncologists fully appreciate the value of FP. In future research with oncologists, a wider range of beliefs might also be measured to help explain norms and perceived behavioural control better. These might include beliefs about whether most doctors working in oncofertility hold traditional family values and how many of these allow their prejudices to affect their clinical practice. Additionally, beliefs relevant to perceived behavioural control that should be measured might include those related to whether the physical felt the facilities available would allow them to offer a fertility referral to all cancer patients in their reproductive years.

Limitations

The accuracy of the self-report measure of individual-level bias depends on participants' level of insight into their decision-making processes. Future research should employ techniques which assess bias using indirect methods, such as a within-subject design where multiple hypothetical patients with varying characteristics were presented to each participant. This would allow FP referral intentions to be compared, but the disadvantage would be that participants may be likely to guess that the study was assessing their responses to diverse patients. This may prompt them to hide their bias. Implicit association tests aim to measure unconscious cognitive processes

(Greenwald, McGhee, & Schwartz, 1998), so may provide a useful tool for assessing attitudes towards different types of cancer patients without being affected by socially desirable responding. Additionally, the present study was limited by not assessing gender differences, which should be incorporated into future studies.

Conclusions

Medical students reported that their FP referrals would be influenced by patient characteristics irrelevant to the success of the procedure and that directly contradict guidelines. The most important predictor of bias was traditional family values, suggesting that beliefs about who should have children underlie biased behaviour. The TPB accounts for approximately one fifth of the variance in intentions to initiate fertility discussions and referrals, and the main belief driving the TPB constructs was found to be the positive value attributed to FP.

The finding that students also reported that a patient requesting fertility information would influence their decision-making suggests that patients who are perceived to be interested in fertility are more likely to be offered a referral. This might contribute to explaining why some medical students reported bias again people who are gay, unmarried or had a poor prognosis. If medical students assumed that these individuals would not be interested in having children, then they might not think to offer them fertility options.

Should the findings of this exploratory study be replicated among oncologists, a number of possible approaches to improve the provision of FP would be indicated. These include training physicians to counteract the influence of their personal beliefs about the ideal family form, and education to ensure the value of FP is fully understood.

Chapter 7:

General Discussion

The research presented in this thesis aimed to investigate reproductive decision-making among non-normative groups. In a domain with little existing research, these studies have shed some light on the reasons for the low parenthood rates among these populations. Clarification of the current parenthood rates in the UK revealed that non-normative groups were at least twice as likely to be childless as the rest of the population at age 42. These low parenthood rates had negative consequences, in that childless people who wanted children had lower life satisfaction than parents and voluntarily childless people. This finding was consistent regardless of whether people belonged to a non-normative group or not but affected a greater proportion of non-normative groups because more were childless.

A range of quantitative designs were used in the thesis, including a longitudinal study (Chapter 2) an experimental design (Chapter 5) and a cross-sectional design (Chapter 4). Three primary datasets were collected (Chapters 4, 5 and 6), a secondary dataset was used when a large representative sample was required (Chapter 2) and a systematic review was conducted (Chapter 3). An implicit approach to quantitative attitude measurement was taken in Chapter 4 to overcome some of the limitations associated with self-report measures in socially sensitive domains. Furthermore, two chapters incorporated qualitative methods to gain the additional depth of understanding that such approaches can offer (Chapters 3 and 5).

The present chapter provides an overview and integration of the five preceding chapters. The relevance of the findings for the psychosocial theories presented in Chapter 1 are considered and the methodological limitations discussed.

Theoretical Considerations

In Chapter 1 (p. 8-15), the four psychosocial theories that have been applied to reproductive decision-making were synthesised into six themes which capture the main factors emphasised by each. The theories were Life Course Theory (Elder, 1994; 1998), the Theory of Planned Behaviour (TPB, Ajzen, 1991), The Traits Desires Intentions Behaviour model (TDIB, Miller & Pasta, 1995), and the action-phase model of developmental regulation (Heckhausen, 1999; Heckhausen et al., 2001;

Wrosch & Heckhausen, 1999). Each theme is considered in turn in relation to the findings from the studies presented in this thesis.

Time

The time theme proposes that social constructs that relate to the time of life at which people should have children are important for reproductive decisions, as is the timing of other adult life transitions. The importance of this theme was supported by association between older age and the reduced likelihood of parenthood among childless gay men and lesbians in the systematic review (Chapter 3). In the same chapter, cancer survivors reported concerns about having a shortened reproductive window. These findings highlight that time of life is a major determinant of parenthood among non-normative groups.

According to Life Course Theory, the timing of major life transitions influences other areas of adult development. In the domain of reproductive decision-making, entering into a partnership might be expected to be a transition that helps people feel ready for parenthood. Numerous studies have found that in the general population people are much more likely to have a first child if they are cohabiting or married (Hank, 2003; Jokela et al., 2009). However, neither being in a relationship nor duration of relationship was found to have significant effects on parenthood intentions among lesbians or gay men in the systematic review (Chapter 3). This was unexpected but it is possible that lesbians and gay men were less concerned with finding a stable partner with whom to have children, perhaps because compared to opposite-sex couples they face many additional issues when considering biological parenthood (e.g., donor sperm/oocytes need to be chosen, and gay men need to find a surrogate mother).

Agency

This theme relates to the freedom and ability to make choices within the available options. The importance of age (although previously mentioned in this chapter under the 'Time' theme) may be strongly related to agency for women, as their reproductive years are generally considered to end at around the age of 45. For cancer survivors, the sense of agency in relation to parenthood was strongly influenced by their concerns about the impact their health problems might have on the child, based on

qualitative primary studies included in the systematic review (Chapter 3). A further loss of agency was evident among cancer survivors who had not been offered fertility preservation prior to treatment, or those who were told about fertility preservation but were not able to undergo the procedure due to their condition being too advanced (Chapter 3). Among some people with genetic conditions, concerns over a child inheriting the disease deterred them from parenthood (Chapter 3). These findings all emphasised the strong impact physical limitations, be it health or fertility, have on people's concept of agency when it comes to having children.

The perceived ability to bring up a child successfully also seems to be a strong determinant of parenthood. This was evident from the finding that gay men, lesbians and disabled people with good perceived parenting skills had stronger intentions to have children (Chapters 3 and 4) and that the qualitative synthesis found that financial difficulties deterred cancer survivors, lesbians, and gay men from parenthood (Chapter 3). Although relationship status was not found to be significantly associated with parenthood intentions in the quantitative studies on gay men and lesbians in Chapter 3, nor the disabled people in Chapter 4, not having a partner would be expected to reduce many people's sense of agency. This could be in terms of feeling they do not have the time or resources to be a good parent by themselves, and for people who want a partner of the opposite sex, conceiving a biological child without a partner may be perceived as more difficult. Similarly, financial difficulties may affect people's sense of agency about being able to raise children successfully.

Furthermore, perceived behavioural control was found to be a significant predictor of intentions among disabled people, as predicted by the TPB (Chapter 4). In the same chapter, disabled people with high levels of self-reported internalised stigma were found to have lower perceived behavioural control, suggesting that people's sense of agency can be reduced by negative societal attitudes towards non-normative parents.

Planning

The planning theme highlights the importance of being prepared for parenthood in the decision-making process. In Chapters 3 and 4, income was not found to be significantly associated with intentions to have children, suggesting that for gay men, lesbians and disabled people achieving financial security may not be an important part of planning for having children. However, this may have been because

both high and low income can pose barriers to parenthood, so linear statistical tests would have failed to detect a relationship. Moreover, the primary qualitative studies in Chapter 3 found career investment and financial difficulties to hinder parenthood cancer survivors, lesbians, and gay men.

The nonsignificance of the relationship-related factors in Chapter 3 previously described in relation to the 'Time' theme, suggests that partnerships may not be an important part of planning for parenthood among gay men and lesbians. The qualitative primary studies included in the systematic review (Chapter 3) revealed major relationship concerns among some cancer survivors and individuals with Huntington's disease, and it was implied that this presented a barrier to reproductive planning. These relationship concerns were focused on the health effects of having had cancer or potentially suffering from Huntington's disease in the future. The different role partnership status plays in reproductive decisions seems to differ between the different non-normative groups, but this finding requires further investigation and replication in larger more representative samples before any conclusions can be drawn.

Motivation

In this context, motivations for parenthood primarily pertain to the value attached to parenthood. Analysis of the reasons participants in the British Cohort Study gave for being childless at age 42 revealed that disproportionately high numbers of gay men and lesbians had chosen not to have children because they did not want to be parents (Chapter 2). This finding is consistent with another study that used data from a USA sample in 2002, which found that childless gay men and lesbians were less likely to report the desire to have children than heterosexual people (Riskind & Patterson, 2010). The reasons for these reduced parenthood desires are unknown, but are likely to be related to the challenges faced by gay and lesbian individuals in the process of becoming biological parents and raising children as a same-sex couple.

In the same analysis, it was found that similar proportions of childless disabled people and childless controls reported not being parents because they did not want children. The difficulties associated with parenting with a disability do not seem to deter disabled people from parenthood in the same way that gay men and lesbians appear to be deterred. This may be because the definition of disability included onset

at any age, so many of the disabled people in the study may have wanted children since before the onset of their disability. Similarly, cancer survivors were less likely than the control group to be childless because of a lack of desire for parenthood. Again, presumably many of these individuals had the desire for children before they experienced cancer. For some having cancer may have increased their desire for children, possibly by forcing them to think about their reproductive options in a similar way to that reported by people with genetic conditions in the qualitative primary studies form the systematic review (Chapter 3).

Consistent with one of the central premises of the TPB, disabled and nondisabled people with positive attitudes towards children were found to be more likely to have them (Chapter 4). However, of the two primary studies that employed a quantitative measure of attitudes in the systematic review (Chapter 3), only one found a significant association. As discussed in Chapter 3, the study that found the nonsignificant results measured attitudes as the perceived costs and benefits of motherhood specifically for lesbians, in terms of the impact on their identity among other issues. It may be the case that it is general attitudes towards children that are important, and that this result was insignificant because of one of the two primary studies that measured it operationalising the attitudes construct somewhat differently.

Motivations to have children featured strongly in the results of the qualitative component of the systematic review (Chapter 3) as a major predictor of parenthood. People with genetic conditions reported a range of effects on their motivations. Some people were deterred from having children because of the risk of passing on the condition they carried, whereas others found that being forced to think about parenthood due to being a carrier actually increased their desire for children. Attitudes towards adoption and reproductive technologies that avoid the risk of transmission were generally positive. There was also some evidence of high levels of career investment reducing the likelihood of having a first child in the qualitative findings from a lesbian sample (Chapter 2). Competing career motivations may reduce motivation to have children if the two are incompatible.

Population Norms

Population norms are defined societal-level beliefs and attitudes about who should be parents and at what point in life people should have their first child. The study presented in Chapter 4 found that, among childless disabled adults, internalised stigma was associated with reduced parenthood intentions when measured explicitly. This effect operated partly through perceived behavioural control, but the majority of the influence of internalised stigma on intentions was a direct effect. This raises the possibility that the TPB may not provide a complete model of reproductive decision-making for disabled people, but further research is needed to establish whether this is a genuine effect or some artefact of the methods (as described in detail in Chapter 4).

Evidence disputing the influential role of internalised stigma was also identified in this thesis. The three primary quantitative studies that assessed the influence of internalised homophobia on parenthood intentions in Chapter 3 found a nonsignificant association (D'Augelli et al., 2007 Eisenberg, 2004; Sbordone, 2002). This may have been because internalised stigma was operationalised as negative attitudes towards gay and lesbian people, not specifically gay and lesbian parents. It is also possible that internalised stigma influences intentions among disabled people but not gay men and lesbians. To clarify the role of internalised stigma for the reproductive decisions of gay men and lesbians, internalised stigma specific to parenthood, in other words, attitudes towards gay and lesbian parents, need to be assessed. This should be done implicitly, as well as explicitly through self-report, because some people may be reluctant to report negative attitudes towards their own group.

A further nonsignificant effect was that the implicit measure of internalised stigma was not found to predict intentions among disabled people in Chapter 4. This may have been because the split-half reliability of the IAT was slightly lower than hoped, so there may have been noise in the data that obscured any associations with other variables. It is also possible that the use of online testing affected the data, because as previously noted, there were some signs of poor concentration on the self-report measures (discussed fully in Chapter 4). However, IATs have been conducted online in numerous other studies (e.g., Nosek, 2005), so it may be that there is a genuine lack of association between implicitly measured internalised stigma and parenthood intentions among disabled people.

In Chapter 5 it was found that medical students were no less likely to discuss fertility options with cancer patients who belonged to non-normative groups (i.e., were single or gay) or those who were older or had a poor prognosis. However, patients who requested fertility information were much more likely to be offered it. Should this finding be replicated in a sample of oncologists, it would suggest that certain cancer patients (those who are single, gay, older or with a poor prognosis) were less likely to request fertility information than other patients. Internalised social norms may account for this, causing these people to not see themselves as parents and therefore not even consider that they might be entitled to services that would safeguard their fertility for the future. Physicians need to ensure all cancer patients are offered fertility information in a standardised way to ensure everyone has the opportunity to undergo fertility preservation if desired.

Negotiated Norms

The negotiated norms theme is concerned with the impact of the expectations and opinions of close others, such as partner, family and close friends. No studies modelled the decision-making process as a dyadic one, taking the beliefs of both partners into account (for people who were in relationships). Subjective norms (discussed subsequently under the heading 'Population and negotiated norms) reflected the pressure to have children participants perceived from close others, but their perceptions may not have been accurate. Factors such as the desire for children, perceived behavioural control and perceived parenting abilities of the partner may have an important influence on joint decisions about parenthood. Examining partner's views might help develop a more complete understanding of the factors that deter non-normative groups from parenthood.

The dyadic relationship between doctor and patient might be considered another setting where negotiated norms come into play. Medical students reported that the likelihood of them making a fertility referral for a cancer patient would be influenced by the patient belonging to a non-normative group (gay and single patients were the two non-normative groups covered by the study), or if the patient had a poor prognosis or requested fertility information. The main predictor of medical students being biased against certain patients was traditional family values, the measure of which encompassed beliefs such as unmarried people and same-sex couples should

not be parents (ISSP Research Group, 2016). Should this finding be replicated in qualified oncologists, it would indicate that some doctors with especially traditional beliefs may be consciously or unconsciously denying certain cancer patients the opportunity to have biological children after treatment.

Population and negotiated norms.

In Chapter 4, which consisted of a sample of disabled people and a sample of nondisabled people, subjective norms (a component of the TPB) were measured by asking questions about four types of people: participants' partners (if they were not single), family, friends, and 'most people'. As recommended by Ajzen (n.d.), the mean of all items was calculated for each, so scores did not distinguish between the social pressures experienced from the four different types of people. However, the ordinal alpha (0.78) indicated high internal consistency, indicated that in general, most people perceived similar levels of social pressure from their friends, family, partners and society. Due to this, subjective norms can be interpreted as reflecting the influence of two of the theoretical themes, population norms and negotiated norms.

Subjective norms scores were found to be significantly lower in the disabled group than the control group. This is likely to be a consequence of negative social attitudes, highlighting that disabled people experienced less social pressure to have children than the control group.

The Problem of What to Call the Groups

The overall aim of the study was to investigate the lack of equality and diversity in the parenthood population. One of the biggest challenges encountered in bringing these highly heterogeneous groups that have low parenthood rates together was to identify a term that could be used to collectively refer to them. This issue was discussed extensively throughout the author's studentship and several different names were considered.

Initially the term 'people who cannot conceive spontaneously (CCS)' was adopted for a period of time because the focus was on populations who require reproductive technologies to conceive, which is all non-normative groups apart from (most) disabled people. This term was problematic because in fact the majority of disabled people can conceive spontaneously but are still underrepresented in the

parenthood population (Clarke & McKay, 2014). The other problem was that people who are infertile also often cannot conceive spontaneously, but including infertile people as one of the groups would not have fit with the overall aim because most infertile people are otherwise healthy heterosexual couples and not considered 'diverse'.

The second name given to the groups was low parenthood groups (LPGs). However, this suffered from the same problem as the name 'people who cannot conceive spontaneously', in that the definition by default included infertile people as their parenthood rates are likely to be lower than those of the general population, given that evidence suggests that only approximately half of people with fertility problems seek medical help (Boivin, Bunting, Collins, & Nygren, 2007).

The name that was eventually settled on, non-normative groups, is not without problems. Perhaps the most obvious difficulty is that it might seem to suggest some people are not normal. To counteract this issue as much as possible the definition in Chapter 1 emphasised that 'normative' in this context strictly only refers to social norms and the normative route to parenthood (i.e., the route most commonly taken).

Additionally there is something inherently uncomfortable about placing unpartnered people, transgender people, gay men and lesbians in the same category as disabled people, people with transmissible conditions and cancer survivors. This is because the later groups all have medical conditions, so the concern was that grouping them together would inadvertently seem to imply that identifying as a gay men or a lesbian is similar to having a medical condition. However, in equality and diversity research it is important that all underrepresented groups should be included in order to avoid further marginalising any populations. The decision to bring the groups together was made largely because they have been bough together before in the Equality Act 2010, under which disability and sexual orientation are both deemed protected characteristics.

Key Methodological Issues

Sampling Issues

The biggest barriers to methodological quality in the present thesis stemmed from recruitment difficulties. Three of the five empirical chapters (Chapters 4, 5, and 6) involved primary data collection rather than secondary analysis, and in all of these

response rates could not be calculated. The two samples of medical students were recruited via emails circulated on the author's behalf by their universities, but the size of the mailing list was not known. Disabled people were recruited via disability charities and organisations, through both mailing lists and social media. Again, the sizes of the mailing lists were not known, and the algorithms of facebook are such that not all people who are group members or 'like' a page will see posts. However, it is likely that response rates were very low for all three samples and therefore likely to be highly unrepresentative.

Given that a generous financial incentive was used for recruitment in Chapter 4, but response rates among disabled people remained very low, it is suggested that recruitment in the future employs other types of motivations. For example, researchers could network with disabled people who are very politically active, so who are likely to be keen to assist with research. A financial incentive may have helped with medical students, as although they are very busy, they do not have an income so financial incentives may work better as a motivational factor.

Another time-consuming challenge for recruitment was finding medical schools and organisations for disabled people that were happy to distribute the study advertisements. Only a small proportion of those contacted agreed to help with the study. A number of medical schools responded saying they could not assist because they did not want to overload their students with requests. The reasons why so many organisations for disabled people failed to respond is unknown, but is possibly due to their already high workloads. To reduce the time needed for future recruitment of this nature, it is recommended that researchers focus on organisations they already have connections with. Rather than contacting new organisations out of the blue, it may help to identify specific people working within each organisation who have an interest in research and attempt to build a mutually beneficial relationship before requesting help with recruitment.

It is possible that the organisations that were happy to help differed in certain ways to those that could not or did not respond to the emails. For example, the medical schools that agreed to distribute the survey may have placed an especially high importance on research. It seems unlikely that students of such organisations would significantly differ to those of other organisations in terms of their responses to hypothetical cancer patients, but this cannot be known for certain.

Intentions as a Proxy for Behaviour

Typically intentions only explain 28% of the variance in behaviour, according to a meta-analysis of studies across many domains (Sheeran, 2002). Similar results have been found in the domain of reproductive decisions (Spéder & Kapitány, 2014), indicating that intentions are a poor predictor of future parenthood. The finding in Chapter 4, that parenthood intentions did not significantly differ between the disability and control groups, suggests that some of the inequalities in intentions arise because disabled people are less likely to realise their intentions than nondisabled people. This may be due to factors such as not being able to afford to look after a child, or not having enough support to feel able to raise a child while in poor health. Another possible explanation is that many disabled people intend to have children at one point, but change their mind. Factors that might contribute to disabled people changing their parenthood intentions might include internalised stigma, the lack of social pressure to have children, financial and health concerns.

Longitudinal designs are needed to examine the causes of changes in intentions over time among all non-normative groups, as well as the factors that can prevent intentions from being realised. The intentions-behaviour relationship among non-normative groups will also differ to that of controls because people who require medically assisted reproduction to have biological children will have low or nonexistent rates of unintended pregnancy.

Future Research

The biggest challenge for future research to address is sampling. Large representative longitudinal datasets are needed in order to detect small effect sizes and to infer the causal relationships between constructs. However, even large scale datasets such as the British Cohort Study (used in Chapter 3) are not sufficiently large to contain adequate numbers of all non-normative groups. For example, in Chapter 3, only two transgender individuals were available for analysis out of the sample of 9,841 participants. In a research domain that aims to address inequalities it is essential that no marginalised groups are excluded, even if they are hard to reach. It may be that transgender people have to be recruited through relevant charities and organisations, even though a sample recruited this way would not be representative of all transgender individuals. With lesbians, gay men and cancer survivors, larger

numbers than were available in the British Cohort Study would be beneficial to allow higher power analyses to be run to ensure small effect sizes were detected. One solution to this might be to recruit a large sample of lesbians and gay men from relevant charities and organisations, recognising that these would not be representative of gay and lesbian populations. Then the same analyses could be repeated in smaller representative samples, paying more attention to effect sizes than significance values, to see if the same patterns emerge.

One non-normative group that was not investigated at all in this thesis was single men and women. Exploring the reproductive decisions of people who only belong to a non-normative group when they are unpartnered is difficult. Studies have been conducted that consist of interviews with single mothers by choice (Bock, 2000; Mannis, 1999), but suffer from the limitation that participants are recalling their decision-making processes retrospectively. One approach might be to conduct a cross-sectional study and recruit childless women who have been single for a substantial period of time and who are nearing the end of their reproductive years. In such a sample, it would be expected that most women will have considered the pros and cons of being a single mother by choice as their opportunities to have a biological child are limited time-wise. The equivalent research on single men would be harder to design as their opportunities for biological parenthood are less constrained by age. Single men in their 40s or 50s may still intend to have a child with a partner in the future.

A separate area for future research to focus on is the implicitly measured internalised stigma in all other non-normative groups, as this thesis was only able to examine it in disabled people. Due to explicit measures being limited by social desirability effects, the use of implicit measures would be expected to increase understanding of the influence of negative societal attitudes on reproductive decisions.

Conclusions

The research in this thesis confirmed that current parenthood rates among nonnormative groups in the UK are very low and that the parenting population is lacking in equality and diversity. The impact of being childless on life satisfaction at age 42 was examined, and was found to be equally negative among non-normative groups and the rest of the populations. Given the much lower parenthood rates among nonnormative groups, a higher proportion are likely to suffer negative consequences to their wellbeing.

Given the evidence that the children brought up by non-normative individuals are not disadvantaged (e.g., Alexander et al., 2002; Fedewa, et al., 2015; Golombok & Badger, 2010; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008), the lack of equality and diversity in the parenting populations should be brought into the discourse surrounding equal opportunities. Huge advancements have been made in improving workplace opportunities for protected minorities, and arguably parenthood is something that is at least as important to many people as their careers. Whether steps should be taken to make it easier for non-normative groups to achieve parenthood should be discussed.

If discussion should lead to the decision that equal parenthood opportunities for all should be promoted, there are several factors which the studies presented in this thesis suggest are likely to be major contributors to the low parenthood rates among non-normative groups. Many of these barriers to parenthood were found to apply to most non-normative groups despite the huge heterogeneity between the groups, primarily internalised stigma, poor perceived parenting abilities, low subjective norms and financial difficulties. An additional barrier was faced by the groups characterised by health problems (disabled people, cancer survivors and people with transmissible conditions), which was concerns about the impact of one's own poor health on a potential child. Attempts to reduce these barriers might enable more non-normative individuals to achieve their parenthood goals.

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- *indicates primary studies included in the systematic review (Chapter 3 Part 2)
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Appendices

Appendix A: The Past 10 Systematic Reviews in Social Science and Medicine

Table A.1.

The designs included in the last 10 systematic reviews published in Social Science and Medicine. Search carried out on 16.08.2015, search term was "systematic review" present in title, abstract or key words of articles.

Study	Eligible designs	Reason
Klein & Knesebeck (2015)	Quantitative	Aim of the study was to review survival analyses, which are by
		definition quantitative
Tsai & Burns (2015)	Quantitative	Excluded qualitative studies because a meta-synthesis was beyond the scope of their review.
Bancroft et al. (2015)	Quantitative	Outcome measure was objective physical activity
De Goeij et al. (2015)	Qualitative and quantitative	
Aitken et al. (2015)	Qualitative and quantitative	
Agampodi et al. (2015)	Qualitative and quantitative	
Ludolph et al. (2015)	Quantitative	Designed were quasi-experimental or experimental to ensure causality could be inferred
Perkins et al. (2015)	Quantitative	Inclusion criteria was "used quantitative data collected via censusbased inclusion of participants"
Hunter et al. (2015)	Quantitative	Did not explicitly exclude qualitative studies but primary outcome measure had to be physical activity, which may
		have excluded qualitative designs. No qualitative evidence described in
		results section so assumed all studies were quantitative.
Roy et al. (2014)	Qualitative and	1
• , ,	quantitative	

Appendix B: Full Search Strategy

Medline

#

Searches

((parenthood or fatherhood or motherhood) adj2 (intent\$ or start\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$
or reason\$ or costs or benefits or barrier\$ or choos\$ or choice\$ or beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$ or optimal condition\$1).tw.

(Childbearing adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)

- (childbearing adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1)).ti,ab.
- (Childless\$ adj2 (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$ or costs or benefit\$ or barrier\$ or choose or choice)).ti,ab.
- (childless\$ adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1 or costs or benefit\$ or barrier\$ or choose or choice\$)).ti,ab.
- (becom\$ pregnant adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)
- (Reproductive behavior/ or pregnancy/px) and (marriage/ or time factors/ or maternal age/ or paternal age/ or religion/ or career choice/ or "Costs and Cost Analysis"/)
- (Reproductive behavio?r and (marriage or time factors or maternal age or paternal age or religion or career choice or Costs)).ti,ab.
- reproductive behavior/ and (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$).tw.
- 20 reproductive decision\$.ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$

or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/) 21 (voluntary childlessness or emerging adulthood).ti,ab. intended childlessness.ti,ab. 22 23 conceiving time.ti,ab. 24 Intention to conceive.ti,ab. Childbearing decision\$.ti,ab. Fertility timing.ti,ab. 26 27 ((future or pursu\$) adj parenthood).ti,ab. 28 ((future or pursu\$) adj motherhood).ti,ab. 29 ((future or pursu\$) adj fatherhood).ti,ab. 30 reproductive intention\$.ti,ab. 31 Start\$ a family.ti,ab. 32 ((child\$ or motherhood or fatherhood or parenthood) adj1 timing).ti,ab. 33 attaining motherhood.ti,ab. 34 attaining fatherhood.ti,ab. 35 attaining parenthood.ti,ab. want\$ children.ti,ab. 36 37 *reproductive behavior/ planning a family.ti,ab. 38 39 child planning.ti,ab. Fertility decision making.ti,ab. 40 41 Try\$ to get pregnant.ti,ab. 42 (try\$ adj2 conceiv\$).tw.

43

or/11-42

^{44 (}infertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or

common or frequen\$)).ti,ab.

- (fertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- (fecundity adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- 47 (fertil\$ adj1 (problem\$ or difficult\$)).tw.
- 48 (infertil\$ adj1 (problem\$ or difficult\$)).tw.
- 49 (ability to conceive or fail\$3 to conceive).ti,ab.
- 50 able to conceive.tw.
- 51 conceiving time.ti,ab.
- 52 time to conception.tw.
- 53 time to pregnancy.tw.
- 54 childbearing ability.tw.
- 55 (try\$ adj2 conceiv\$).tw.
- 56 Try\$ to get pregnant.tw.
- 57 or/44-56
- 58 ((consult\$ adj2 doctor\$1) or (consult\$ adj2 GP\$1)).tw.
- (helpseek\$ or help seek\$ or health seek\$ or advice seek\$ or decision\$ or seek\$ medic\$ or consult\$ doctor\$1 or consult\$ GP\$1 or treatment\$ seek\$).tw.
- 60 ((detect\$ or diagnose or diagnosis) adj2 (self or able or ability)).tw.
- 61 (Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$).ti,ab.
- 62 Complementary Therapies/
- 63 ((complementary or alternative) adj therap\$).tw.
- 64 (fertilit\$ adj2 kit\$1).ti,ab.
- 65 58 or 59 or 60 or 61 or 62 or 63 or 64
- 66 57 and 65

Fertility Decision-Making.ti,ab. 67 inFertility Decision-Making.ti,ab. 68 (fertility/ or infertility/) and (attitudes/ or awareness/) and (pregnancy/ or reproduction/ or parents/) 69 70 (fertility/ or infertility/ or reproductive medicine/) and patient acceptance of healthcare/ 66 or 67 or 68 or 69 or 70 71 (fertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormon\$ remed\$ or hormon\$ 72 therap\$)).ti,ab. (infertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormonal remedies)).ti,ab. 73 74 alternative parenting.ti,ab. 75 IVF.ti,ab. ICSI.ti,ab. 76 77 IUI.ti,ab. 78 assisted reprod\$ technolog\$.ti,ab. 79 (assist\$ adj2 (conceive or conception)).ti,ab. 80 in vitro fertilisation.ti,ab. 81 in vitro fertilization.ti,ab. 82 infertility investigat\$.ti,ab. ((fertil\$ or infertil\$) adj3 kit\$1).ti,ab. 83 Infertility/th, rh, su [Therapy, Rehabilitation, Surgery] 84 85 or/72-84 86 Attitudes/ or attitude\$.ti,ab. 87 beliefs.ti,ab. 88 Aware\$.ti,ab. 89 knowledg\$.ti,ab. 90 attitude\$.ti,ab.

91	perception\$.ti,ab.
92	religio\$.ti,ab.
93	ethnic\$.ti,ab.
94	attribution.ti,ab.
95	stigma\$.ti,ab.
96	faith.ti,ab.
97	norms.ti,ab.
98	social represent\$.ti,ab.
99	social influenc\$.ti,ab.
100	Decision making/
101	deliberat\$.ti,ab.
102	cues to action.ti,ab.
103	optimal condition\$.ti,ab.
104	(advice adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or communic\$ or source\$)).ti,ab.
105	(information adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or communic\$ or source\$)).ti,ab.
106	Consumer Health Information/
107	or/86-106
108	107 and 85
109	43 or 71 or 108
110	limit 109 to (humans and yr="1990 - 2009")
111	((retrospective\$ adj2 review\$) or (case\$ adj2 review\$) or (patient\$ adj2 review\$) or (patient\$ adj2 review\$) or (patient\$ adj2 review\$) or (case\$ adj2 report\$) or (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep)).ti,ab,sh. or editorial.pt. or letter.pt.

112 110 not 111

Medline in Process

1

((parenthood or fatherhood or motherhood) adj2 (intent\$ or start\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or costs or benefits or barrier\$ or choos\$ or choice\$ or beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$ or optimal condition\$1)).tw.

(Childbearing adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)

(childbearing adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1).ti,ab.

(Childless\$ adj2 (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$ or costs or benefit\$ or barrier\$ or choose or choice)).ti,ab.

(childless\$ adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1 or costs or benefit\$ or barrier\$ or choose or choice\$)).ti,ab.

((becom\$ pregnant adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)) and (reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$)).ti,ab.

Reproductive behavio?r and (marriage or time factors or maternal age or paternal age or religion or career choice or Costs)).ti,ab.

(reproductive decision\$ and (reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$)).ti,ab.

10 intended childlessness.ti,ab. 11 conceiving time.ti,ab. 12 Intention to conceive.ti,ab. 13 Childbearing decision\$.ti,ab. 14 Fertility timing.ti,ab. 15 ((future or pursu\$) adj parenthood).ti,ab. 16 ((future or pursu\$) adj motherhood).ti,ab. 17 ((future or pursu\$) adj fatherhood).ti,ab. 18 reproductive intention\$.ti,ab. 19 Start\$ a family.ti,ab. 20 ((child\$ or motherhood or fatherhood or parenthood) adj1 timing).ti,ab. 21 attaining motherhood.ti,ab. 22 attaining fatherhood.ti,ab. 23 attaining parenthood.ti,ab. 24 want\$ children.ti,ab. 25 planning a family.ti,ab. 26 child planning.ti,ab. 27 Fertility decision making.ti,ab. 28 Try\$ to get pregnant.ti,ab. 29 (try\$ adj2 conceiv\$).tw. 30 or/1-29 (infertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or 31 status\$ or concern\$ or common or frequen\$)).ti,ab. (fertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ 32 or concern\$ or common or frequen\$)).ti,ab.

(voluntary childlessness or emerging adulthood).ti,ab.

9

(fecundity adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or 33 status\$ or concern\$ or common or frequen\$)).ti,ab. 34 (fertil\$ adj1 (problem\$ or difficult\$)).tw. 35 (infertil\$ adj1 (problem\$ or difficult\$)).tw. 36 (ability to conceive or fail\$3 to conceive).ti,ab. 37 able to conceive.tw. 38 conceiving time.ti,ab. 39 time to conception.tw. 40 time to pregnancy.tw. 41 childbearing ability.tw. 42 (try\$ adj2 conceiv\$).tw. 43 Try\$ to get pregnant.tw. 44 or/31-43 45 ((consult\$ adj2 doctor\$1) or (consult\$ adj2 GP\$1)).tw. (helpseek\$ or help seek\$ or health seek\$ or advice seek\$ or decision\$ or seek\$ 46 medic\$ or consult\$ doctor\$1 or consult\$ GP\$1 or treatment\$ seek\$).tw. 47 ((detect\$ or diagnose or diagnosis) adj2 (self or able or ability)).tw. (Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ 48 or expectation\$ or believ\$).ti,ab. 49 ((complementary or alternative) adj therap\$).tw. 50 (fertilit\$ adj2 kit\$1).ti,ab. 51 or/45-50 52 44 and 51 53 Fertility Decision-Making.ti,ab. 54 inFertility Decision-Making.ti,ab.

55

52 or 53 or 54

56	(fertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormon\$ remed\$ or hormon\$ therap\$)).ti,ab.
57	(infertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormonal remedies)).ti,ab.
58	alternative parenting.ti,ab.
59	IVF.ti,ab.
60	ICSI.ti,ab.
61	IUI.ti,ab.
62	assisted reprod\$ technolog\$.ti,ab.
63	(assist\$ adj2 (conceive or conception)).ti,ab.
64	in vitro fertilisation.ti,ab.
65	in vitro fertilization.ti,ab.
66	infertility investigat\$.ti,ab.
67	((fertil\$ or infertil\$) adj3 kit\$1).ti,ab.
68	or/56-67
69	attitude\$.ti,ab.
70	beliefs.ti,ab.
71	Aware\$.ti,ab.
72	knowledg\$.ti,ab.
73	attitude\$.ti,ab.
74	perception\$.ti,ab.
75	religio\$.ti,ab.
76	ethnic\$.ti,ab.
77	attribution.ti,ab.
78	stigma\$.ti,ab.
79	faith.ti,ab.

- 80 norms.ti,ab.
- 81 social represent\$.ti,ab.
- 82 social influenc\$.ti,ab.
- 83 deliberat\$.ti.ab.
- 84 cues to action.ti,ab.
- 85 optimal condition\$.ti,ab.
- 86 (advice adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or communic\$ or source\$)).ti,ab.
- 87 (information adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or communic\$ or source\$)).ti,ab.
- 88 or/69-87
- 89 68 and 88
- ((retrospective\$ adj2 review\$) or (case\$ adj2 review\$) or (patient\$ adj2 review\$) or (patient\$ adj2 chart\$) or (peer adj2 review\$) or (chart adj2 review\$) or (case\$ adj2 report\$) or (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep)).ti,ab,sh. or editorial.pt. or letter.pt.
- 91 30 or 55 or 89
- 92 91 not 90
- 93 from 92 keep 1-115

All EBM Cochrane Database of Systematic Reviews, CENTRAL, DARE, ACP)

((parenthood or fatherhood or motherhood) adj2 (intent\$ or start\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or costs or benefits or barrier\$ or choos\$ or choice\$ or beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$ or optimal condition\$1)).tw.

(Childbearing adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or

constraint\$).ti,ab. or attitudes/)

- (childbearing adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or
 religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1)).ti,ab.
- (Childless\$ adj2 (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$ or costs or benefit\$ or barrier\$ or choose or choice)).ti,ab.
- (childless\$ adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$
 or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1 or costs or benefit\$ or barrier\$ or choose or choice\$)).ti,ab.
 - (becom\$ pregnant adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)
- Reproductive behavior/ or pregnancy/px) and (marriage/ or time factors/ or maternal age/ or paternal age/ or religion/ or career choice/ or "Costs and Cost Analysis"/)
- 8 (Reproductive behavio?r and (marriage or time factors or maternal age or paternal age or religion or career choice or Costs)).ti,ab.
- reproductive behavior/ and (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$).tw.
- reproductive decision\$.ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)
- 11 (voluntary childlessness or emerging adulthood).ti,ab.
- 12 intended childlessness.ti,ab.
- 13 conceiving time.ti,ab.

6

- 14 Intention to conceive.ti,ab.
- 15 Childbearing decision\$.ti,ab.
- 16 Fertility timing.ti,ab.

- 17 ((future or pursu\$) adj parenthood).ti,ab.
- 18 ((future or pursu\$) adj motherhood).ti,ab.
- 19 ((future or pursu\$) adj fatherhood).ti,ab.
- 20 reproductive intention\$.ti,ab.
- 21 Start\$ a family.ti,ab.
- 22 ((child\$ or motherhood or fatherhood or parenthood) adj1 timing).ti,ab.
- 23 attaining motherhood.ti,ab.
- 24 attaining fatherhood.ti,ab.
- 25 attaining parenthood.ti,ab.
- 26 want\$ children.ti,ab.
- 27 *reproductive behavior/
- 28 planning a family.ti,ab.
- 29 child planning.ti,ab.
- 30 Fertility decision making.ti,ab.
- 31 Try\$ to get pregnant.ti,ab.
- 32 (try\$ adj2 conceiv\$).tw.
- 33 or/1-32
- (infertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- 35 (fertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- 36 (fecundity adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- 37 (fertil\$ adj1 (problem\$ or difficult\$)).tw.
- 38 (infertil\$ adj1 (problem\$ or difficult\$)).tw.
- 39 (ability to conceive or fail\$3 to conceive).ti,ab.

40 able to conceive.tw. 41 conceiving time.ti,ab. 42 time to conception.tw. time to pregnancy.tw. 43 44 childbearing ability.tw. 45 (try\$ adj2 conceiv\$).tw. Try\$ to get pregnant.tw. 46 47 or/34-46 ((consult\$ adj2 doctor\$1) or (consult\$ adj2 GP\$1)).tw. 48 (helpseek\$ or help seek\$ or health seek\$ or advice seek\$ or decision\$ or seek\$ medic\$ 49 or consult\$ doctor\$1 or consult\$ GP\$1 or treatment\$ seek\$).tw. 50 ((detect\$ or diagnose or diagnosis) adj2 (self or able or ability)).tw. (Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or 51 expectation\$ or believ\$).ti,ab. Complementary Therapies/ 52 53 ((complementary or alternative) adj therap\$).tw. 54 (fertilit\$ adj2 kit\$1).ti,ab. 48 or 49 or 50 or 51 or 52 or 53 or 54 55 56 47 and 55 57 Fertility Decision-Making.ti,ab. 58 inFertility Decision-Making.ti,ab. (fertility/ or infertility/) and (attitudes/ or awareness/) and (pregnancy/ or reproduction/ 59 or parents/) 60 (fertility/ or infertility/ or reproductive medicine/) and patient acceptance of healthcare/ 56 or 57 or 58 or 59 or 60 61

(fertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormon\$ remed\$

62

or hormon\$ therap\$)).ti,ab.

63	(infertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormonal remedies)).ti,ab.
64	alternative parenting.ti,ab.
65	IVF.ti,ab.
66	ICSI.ti,ab.
67	IUI.ti,ab.
68	assisted reprod\$ technolog\$.ti,ab.
69	(assist\$ adj2 (conceive or conception)).ti,ab.
70	in vitro fertilisation.ti,ab.
71	in vitro fertilization.ti,ab.
72	infertility investigat\$.ti,ab.
73	((fertil\$ or infertil\$) adj3 kit\$1).ti,ab.
74	Infertility/th, rh, su [Therapy, Rehabilitation, Surgery]
75	or/62-74
76	Attitudes/ or attitude\$.ti,ab.
77	beliefs.ti,ab.
78	Aware\$.ti,ab.
79	knowledg\$.ti,ab.
80	attitude\$.ti,ab.
81	perception\$.ti,ab.
82	religio\$.ti,ab.
83	ethnic\$.ti,ab.
84	attribution.ti,ab.
85	stigma\$.ti,ab.
86	faith.ti,ab.

- 87 norms.ti,ab. 88 social represent\$.ti,ab. 89 social influenc\$.ti,ab. Decision making/ 90 91 deliberat\$.ti,ab. 92 cues to action.ti,ab. 93 optimal condition\$.ti,ab. (advice adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or 94 communic\$ or source\$)).ti,ab. (information adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or 95 helpseek\$ or communic\$ or source\$)).ti,ab. Consumer Health Information/ 97 or/76-96 98 97 and 75 99 33 or 61 or 98 limit 99 to (humans and yr="1990 - 2009") [Limit not valid in CDSR,ACP Journal 100 Club, DARE, CCTR, CLCMR; records were retained]
- ((retrospective\$ adj2 review\$) or (case\$ adj2 review\$) or (patient\$ adj2 review\$) or (patient\$ adj2 chart\$) or (peer adj2 review\$) or (chart adj2 review\$) or (case\$ adj2
- (patient\$ adj2 chart\$) or (peer adj2 review\$) or (chart adj2 review\$) or (case\$ adj2 report\$) or (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep)).ti,ab,sh. or editorial.pt. or letter.pt.
- 102 100 not 101
- 103 from 102 keep 1-122

HMIC

((parenthood or fatherhood or motherhood) adj2 (intent\$ or start\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or costs or benefits or barrier\$ or choos\$ or choice\$ or beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$ or optimal condition\$1)).tw.

(Childbearing adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)

(childbearing adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or
 religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1)).ti,ab.

(Childless\$ adj2 (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$ or costs or benefit\$ or barrier\$ or choose or choice)).ti,ab.

(childless\$ adj2 (beliefs or Aware\$ or knowledg\$ or values or perception\$ or religio\$
 or ethnic\$ or attribution or stigma\$ or faith or norms or social represent\$ or social influenc\$ or attitude\$1 or costs or benefit\$ or barrier\$ or choose or choice\$)).ti,ab.

(becom\$ pregnant adj2 (optimal condition\$1 or costs or benefit\$ or barrier\$ or choose or choice\$ or intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$)).ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)

- 7 (family planning/ or pregnancy/) and (marriage/ or maternal age/ or religion/ or occupations/ or costs/)
- 8 (Reproductive behavio?r and (marriage or time factors or maternal age or paternal age or religion or career choice or Costs)).ti,ab.
- family planning/ and (intent\$ or start\$ or plan\$ or intend\$ or achiev\$ or attempt\$ or pursu\$ or desir\$3 or need\$3 or wish\$3 or motivation\$1 or postpon\$ or delay\$ or defer\$ or timing or decision\$ or reason\$ or preference\$).tw.

reproductive decision\$.ti,ab. and ((reason\$ or Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or expectation\$ or believ\$ or religio\$ or ethnic\$ or attribution or stigma\$ or faith or norms\$ or preference\$ or influenc\$ or constraint\$).ti,ab. or attitudes/)

- 11 (voluntary childlessness or emerging adulthood).ti,ab.
- 12 intended childlessness.ti,ab.
- 13 conceiving time.ti,ab.

2

6

- 14 Intention to conceive.ti,ab. Childbearing decision\$.ti,ab. 15 Fertility timing.ti,ab. 16 ((future or pursu\$) adj parenthood).ti,ab. 17 18 ((future or pursu\$) adj motherhood).ti,ab. 19 ((future or pursu\$) adj fatherhood).ti,ab. reproductive intention\$.ti,ab. 20 Start\$ a family.ti,ab. 21 ((child\$ or motherhood or fatherhood or parenthood) adj1 timing).ti,ab. 22 attaining motherhood.ti,ab. 23 24 attaining fatherhood.ti,ab. attaining parenthood.ti,ab. 25 want\$ children.ti,ab. 26 27 family planning/ 28 planning a family.ti,ab. 29 child planning.ti,ab. 30 Fertility decision making.ti,ab. Try\$ to get pregnant.ti,ab. 31 (try\$ adj2 conceiv\$).tw. 32 or/1-32 33
- (infertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- (fertil\$ adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.
- 36 (fecundity adj2 (myths or risk factor\$ or cause\$ or prevalence\$ or incidence\$ or status\$ or concern\$ or common or frequen\$)).ti,ab.

(fertil\$ adj1 (problem\$ or difficult\$)).tw. 37 (infertil\$ adj1 (problem\$ or difficult\$)).tw. 38 (ability to conceive or fail\$3 to conceive).ti,ab. 39 40 able to conceive.tw. 41 conceiving time.ti,ab. 42 time to conception.tw. 43 time to pregnancy.tw. childbearing ability.tw. 44 (try\$ adj2 conceiv\$).tw. 45 Try\$ to get pregnant.tw. 46 47 or/34-46 ((consult\$ adj2 doctor\$1) or (consult\$ adj2 GP\$1)).tw. 48 (helpseek\$ or help seek\$ or health seek\$ or advice seek\$ or decision\$ or seek\$ medic\$ 49 or consult\$ doctor\$1 or consult\$ GP\$1 or treatment\$ seek\$).tw. 50 ((detect\$ or diagnose or diagnosis) adj2 (self or able or ability)).tw. (Attitude\$ or belief\$ or Aware\$ or knowledge or values or perception\$ or perceive\$ or 51 expectation\$ or believ\$).ti,ab. alternative medicine/ 52 53 ((complementary or alternative) adj therap\$).tw. 54 (fertilit\$ adj2 kit\$1).ti,ab. 55 48 or 49 or 50 or 51 or 52 or 53 or 54 47 and 55 56 Fertility Decision-Making.ti,ab. 57 inFertility Decision-Making.ti,ab. 58

(human fertility/ or infertility/) and (attitudes/ or awareness/) and (pregnancy/ or family

59

planning/ or parents/)

60	(human fertility/ or infertility/ or reproductive technology/) and Health Care Seeking Behavior/
61	56 or 57 or 58 or 59 or 60
62	(fertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormon\$ remed\$ or hormon\$ therap\$)).ti,ab.
63	(infertil\$ adj2 (treat\$ or therapies or therapy or medical monitoring or hormonal remedies)).ti,ab.
64	alternative parenting.ti,ab.
65	IVF.ti,ab.
66	ICSI.ti,ab.
67	IUI.ti,ab.
68	assisted reprod\$ technolog\$.ti,ab.
69	(assist\$ adj2 (conceive or conception)).ti,ab.
70	in vitro fertilisation.ti,ab.
71	in vitro fertilization.ti,ab.
72	infertility investigat\$.ti,ab.
73	((fertil\$ or infertil\$) adj3 kit\$1).ti,ab.
74	Infertility/
75	or/62-74
76	Attitudes/ or attitude\$.ti,ab.
77	beliefs.ti,ab.
78	Aware\$.ti,ab.
79	knowledg\$.ti,ab.
80	attitude\$.ti,ab.
81	perception\$.ti,ab.
82	religio\$.ti,ab.

83	ethnic\$.ti,ab.
84	attribution.ti,ab.
85	stigma\$.ti,ab.
86	faith.ti,ab.
87	norms.ti,ab.
88	social represent\$.ti,ab.
89	social influenc\$.ti,ab.
90	Decision making/
91	deliberat\$.ti,ab.
92	cues to action.ti,ab.
93	optimal condition\$.ti,ab.
94	(advice adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or communic\$ or source\$)).ti,ab.
95	(information adj2 (avail\$ or access\$3 or seek\$ or find\$3 or locat\$ or identif\$ or helpseek\$ or communic\$ or source\$)).ti,ab.
96	consumer health information/
97	or/76-96
98	97 and 75
99	33 or 61 or 98
100	limit 99 to (humans and yr="1990 - 2009") [Limit not valid; records were retained]
101	((retrospective\$ adj2 review\$) or (case\$ adj2 review\$) or (patient\$ adj2 review\$) or (patient\$ adj2 chart\$) or (peer adj2 review\$) or (chart adj2 review\$) or (case\$ adj2 report\$) or (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep)).ti,ab,sh. or editorial.pt. or letter.pt.
102	100 not 101

IBSS

infertil* or fertile* or fecundity

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myths or risk factor* or cause* or prevalence* or incidence* or status* or concern* or common or
frequen*
s1 and s2
fertil* N1 problem*
fertil* N1 difficult*
infertil* N1 problem*
infertil* N1 difficult*
"ability to conceive"
"fail* to conceive"
"able to conceive"
"conceiving time"
"time to conception"
"time to pregnancy"
"childbearing ability"
try* N2 conceiv*
"Try* to get pregnant"
s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13 or s14 or s15 or s16
consult* N2 doctor*
consult* N2 GP*
helpseek* or help seek* or health seek* or advice seek* or decision* or seek* medic* or consult*
doctor* or consult* GP* or treatment* seek*
detect* or diagnose or diagnosis
Attitude* or belief* or Aware* or knowledge or values or perception* or perceive* or expectation* or
believ*
Complementary therap*
Alternative therap*
fertilit* N2 kit*
s18 or s19 or s20 or s21 or s22 or s23 or s24 or s25
s17 and s26
Fertility Decision-Making
inFertility Decision-Making
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(ZU "FERTILITY AND FAMILY") or (ZU "FERTILITY AND MARRIAGE") or (ZU "FERTILITY AND RELIGION") or (ZU "FERTILITY ATTITUDES")

For All other search engines the following was used:

(((("fatherhood" or "motherhood" or "parenthood")) and(("attitudes" or "attributions" or "awareness" or "barriers" or "beliefs" or "choice" or "costs benefits" or "decision making" or "delay" or "desire" or "ethnicity" or "faith" or "intention" or "knowledge" or "motivation" or "norms" or "perception" or "postponement" or "reasons" or "religions" or "social influence" or "social representation" or "timing" or "values"))) or(("childbearing") and(("barriers" or "choice" or "costs benefits" or "decision making" or "delay" or "desire" or "motivation" or "planned pregnancy" or "postponement" or "timing")) and(("attitudes" or "attributions" or "awareness" or "beliefs" or "ethnicity" or "expectations" or "faith" or "knowledge" or "norms" or "perception" or "preferences" or "reasons" or "religions" or "social influence" or "values"))) or(("childlessness") and(("choice" or "barriers" or "costs benefits" or "decision making" or "delay" or "desire" or "intention" or "motivation" or "planned pregnancy" or "planning" or "postponement" or "preferences" or "reasons" or "timing"))) or((("attitudes" or "attributions" or "awareness" or "beliefs" or "ethnicity" or "expectations" or "faith" or "knowledge" or "norms" or "perception" or "preferences" or "reasons" or "religions" or "social influence" or "values")) and("childlessness")) or(("pregnancy" and "becoming")) or((("attitudes" or "attributions" or "awareness" or "barriers" or "beliefs" or "choice" or "costs benefits" or "decision making" or "delay" or "desire" or "ethnicity" or "faith" or "intention" or "knowledge" or "motivation" or "norms" or "perception" or "postponement" or "reasons" or "religions" or "social influence" or "social representation" or "timing" or "values")) and(("attitudes" or "attributions" or "awareness" or "beliefs" or "ethnicity" or "expectations" or "faith" or "knowledge" or "norms" or "perception" or "preferences" or "reasons" or "religions" or "social influence" or "values")) and("pregnancy")) or((("pregnancy" or "reproductive behaviour")) and(("costs benefits" or "age" or "career choice" or "cost analysis" or "fatherhood" or "marriage" or "motherhood" or "parenthood" or "religions" or "time"))) or((("attitudes" or "attributions" or "awareness" or "barriers" or "beliefs" or "choice" or "costs benefits" or "decision making" or "delay" or "desire" or "ethnicity" or "faith" or "intention" or "knowledge" or "motivation" or "norms" or "perception" or "postponement" or "reasons" or "religions" or "social influence" or "social representation" or "timing" or "values")) and(("pregnancy" or "reproductive behaviour"))) or((("attitudes" or "attributions" or "awareness" or "beliefs" or "ethnicity" or "expectations" or "faith" or "knowledge" or "norms" or "perception" or "preferences" or "reasons" or "religions" or "social influence" or "values")) and(("decision making" and "reproduction"))) or(("childlessness" and "voluntary")) or(("timing" and "fertility")) or(("parenthood" and "future")) or(("parenthood" and "pursuit")) or(("motherhood") and(("pursuit" or "future"))) or((("pursuit" or "future")) and("fatherhood")) or((("parenthood" or "children" or "fatherhood" or "motherhood")) and("timing")) or((("parenthood" or "children" or "fatherhood" or "motherhood")) and("achievement")) or(("decision making" and "fertility"))) or((("decision making" and "fertility")) or(((("infertility") and(("causes" or "concerns" or "incidence" or "myths" or "prevalence" or "risk factors" or "status"))) or((("causes" or "concerns" or "incidence" or "myths" or "prevalence" or "risk factors" or "status")) and("fertility")) or(("fertility") and(("difficult" or "difficulty" or "problems"))) or(("infertility") and(("difficult" or "difficulty" or "problems"))) or(("timing") and("conception")) or(("timing") and("pregnancy")) or(("childbearing") and("ability"))) and((("treatment" or "advice" or "decision making" or "health" or "helpseeking")) or ((("diagnosis" or "detection")) and (("ability" or "self"))) or(("beliefs" or "attitudes" or "awareness" or "expectations" or "knowledge" or "perception" or "perceptions" or "values")) or ("alternative medicine") or (("alternative medicine") and ("therapy")))) or(("infertility" and "decision making")) or((("fertility" or "infertility")) and(("awareness" or "attitudes")) and(("parents" or "pregnancy" or "reproduction"))) or(("health") and((("fertility" or

"infertility")) or(("reproduction" and "medicine"))))) or(((("fertility") and(("hormones" or "monitoring" or "therapy" or "treatment"))) or((("hormones" or "monitoring" or "therapy" or "treatment")) and("infertility")) or(("parenting" and "alternative")) or("reproductive technologies") or("in vitro fertilization") or(("investigations" and "infertility")) or(("surgery" and "infertility" and "rehabilitation" and "therapy"))) and(("attitudes") or("beliefs") or("awareness") or("knowledge") or("perceptions") or("religions") or("ethnicity") or(("attributes" or "attributions")) or("faith") or("norms") or("social representation") or("social influence") or("decision making") or(("action" and "cues")) or(("advice") and(("sources" or "access" or "availability" or "communication" or "helpseeking" or "identification" or "identity" or "location"))) or(("sources" or "access" or "availability" or "communication" or "helpseeking" or "identification" or "identity" or "location"))) and("information"))))

Appendix C: The Search Terms for Non-Normative Groups

Genetic conditions search terms

genetic

hyperplasia

alagille

antitrypsin

anemia

elliptocytosis

glucosephosphate dehydrogenase

hemoglobin

spherocytosis

thalassemia

angioedemas

ataxia telangiectasia

lymphoproliferative

blood coagulation

activated protein c resistance

afibrinogenemia

antithrombin iii deficiency

bernard-soulier syndrome

factor v deficiency

factor vii deficiency

factor x deficiency

factor xi deficiency

factor xii deficiency

factor xiii deficiency

gray platelet syndrome

hemophilia

hermanski-pudlak syndrome

hypoprothrombinemias

protein c deficiency

thrombasthenia

von willebrand

wiskott-aldrich syndrome

brugada syndrome

cadasil

camurati-engelmann syndrome

cardiomyopathy

charge syndrome

cherubism

chromosome disorder

22q11 deletion syndrome

angelman syndrome

beckwith-wiedemann syndrome

branchio-oto-renal syndrome

cri-du-chat syndrome

de lange syndrome

down syndrome holoprosencephaly jacobsen distal 11q deletion syndrome prader-willi syndrome

rubinstein-taybi syndrome sex chromosome disorders silver-russell syndrome smith-magenis syndrome sotos syndrome wagr sundrome williams syndrome wolf-hirschhorn syndrome costello syndrome donohue syndrome dwarfism achondroplasia cockayne syndrome congenital hypothyroidism laron syndrome mulibrey nanism silver-russell syndrome eye disease aicardi syndrome albin aniridia choroideremia corneal dystroph duane retraction syndrome gyrate atrophy optic atroph retinal dysplasia retinitis pigmentosa vitelliform macular dystrophy weill-marchesani syndrome frasier syndrome x-linked aicardi syndrome androgen-insensitivity syndrome barth syndrome bulbo-spinal atrophy choroideremia dent disease dyskeratosis congenita ectodermal dysplasia fabry disease focal dermal hypoplasia glycogen storage disease granulomatous disease

hemophilia b

hyper-igm immunodeficiency syndrome

hypophosphatemic rickets

ichthyosis

isolated noncompaction of the ventricular myocardium

mental retardation

muscular dystroph

oculocerebrorenal syndrome

ornithine carbamoyltransferase deficiency disease

pelizaeus-merzbacher disease

wiskott-aldrich syndrome

combined immunodeficiency disease

y-linked

hajdu-cheney syndrome

hemoglobinopathies

autoinflammatory disease

cryopyrin-associated periodic syndromes (titles and abstracts, 0)

familial mediterranean fever

mevalonate kinase deficiency

heredodegenerative disorders

alexander disease

amyloid neuropath

canavan disease

cockayne syndrome

dystonia musculorum deformans

gerstmann-straussler-scheinker disease

hepatolenticular degeneration

hereditary central nervous system demyelinating diseases

sensory neuropath

autonomic neuropath

motor neuropath

huntington disease

lafora disease

lesch-nyhan syndrome

menkes kinky hair syndrome

myotonia congenita

myotonic dystroph

neuroacanthocytosis

neurofibromatos

neuronal ceroid-lipofuscinos

pantothenate kinase-associated neurodegeneration

rett syndrome

spinal muscular atroph

spinocerebellar degeneration

tourette syndrome

tuberous sclerosis

unverricht-lundborg syndrome

hyperthyroxinemia

kallmann syndrome

kartagener syndrome

loeys-dietz syndrome

marfan syndrome

metabol

amino acid transport disorder

amyloidosis

cytochrome-c oxidase deficiency

hyperbilirubinemia

lysosomal storage disease

peroxisomal disorder

porphyrias

progeria

renal tubular transport

distal myopathies

glycogen storage disease type vii

walker-warburg syndrome

myasthenic syndrome

nail-patella syndrome

neoplastic syndrome

adenomatous polyposis coli

basal cell nevus syndrome

birt-hogg-dube syndrome

colorectal neoplasms

dysplastic nevus syndrome

exostos

hamartoma syndrome

hereditary breast and ovarian cancer syndrome

li-fraumeni syndrome

multiple endocrine neoplasia

peutz-jeghers syndrome

wilms tumor

osteogenesis imperfecta

pain insensitivity

pelger-huet anomaly

polycystic kidney

polycystic kidney

pycnodysostosis

skin disease

cutis laxa

darier disease

dermatitis

dyskeratosis congenita

ectodermal dysplasia

ehlers-danlos syndrome

epidermolysis bullosa

erythrokeratodermia variabilis

hyalinosis

ichthyosiform erythroderma

ichthyosis bullosa of siemens

ichthyosis vulgaris

ichthyosis

incontinentia pigmenti keratoderma leukokeratosis lipoid proteinosis of urbach and wiethe monilethrix netherton syndrome pemphigus porokeratosis porphyria prolidase deficiency pseudoxanthoma elasticum rothmund-thomson syndrome sjogren-larsson syndrome trichothiodystrophy syndrome xeroderma pigmentosum werner syndrome yellow nail syndrome

Disability search terms

disabilit paralys paralyz spinal cord pelvic inflammatory quadriplegi paraplegi tetraplegi spasticity hypokalemia cordotomy subarachnoid hemorrhage cystic fibrosis spina bifida myelomeningocele multiple sclerosis rheumatoid arthritis plegia pals

Cancer search terms

cancer

HIV search terms

aids
hiv
human immunodeficiency virus
acquired immunodeficiency syndrome

Lesbian, gay, bisexual and transgender search terms lesbian

gay transgender bisexual homosexual same-sex

Single mother search terms single mother solo mother

Appendix D: SAS Syntax for Combining a Random Effects Meta-Analysis with Vote-Counting

- If you do not have a SAS licence a free version is available to academics at http://www.sas.com/en_us/software/university-edition.html
- This syntax must be run in the order presented
- It is strongly recommended that you purchase a copy of Wang and Bushman (1999) where all the syntax referenced below is explained.
- This syntax has been checked for accuracy by Prof M. Wang (personal communication, August 25, 2015)

Step 1: Enter the data

- Create a SAS dataset containing your effect sizes and the variance.
- An example of the syntax to achieve this is available at http://www-personal.umich.edu/~bbushman/software/ch7/
- data72.sas contains syntax that creates the dataset required to calculated population correlation coefficients, as used in the present review.
- If you need to estimate the population standardized mean difference then you will need to refer to data71.sas
- You will see in these datasets that effects sizes are included for the studies that did not report them. It is necessary to include effect size data for these studies because an interative numerical procedure is run that requires initial values. Data72.sas enters the following effect sizes for the studies that did not report effect sizes: half are the effect sizes as the lowest value from the effects sizes that were reported, and half as the highest.
- For some cases uses the lowest and highest effect sizes will not work, and the iterative procedure will not converge (M. Wang, personal communication, August 28,2014). In these cases you will need to experiment with entering different initial values until you find some that allow the procedure to converge.
- The syntax used to create the dataset for the analysis involving age in the present review is given below. Using the lowest and highest effect sizes as initial values did not lead to convergence in this instance, but reflecting the highest from positive to negative solved this problem.
- Also note that the vote-counting procedure assumes that all significant effects were in the positive direction. Therefore, if your analysis aims to pool negative and insignificant associations, all effect sizes need to be reflected from negative to positive. As explained in the present paper, Wang and Bushman's (1999) procedure does not allow positive, negative and insignificant results to be combined.

```
options nodate nocenter pagesize=54 linesize=80 pageno=1;
libname Age "/folders/myfolders/Age";
/* Studies with effect size estimates */
data age.ageESdata;
   input study nn rr;
cards;
1
      81
               0.2540
2
      163
               0.3400
               0.2894
      80
               0.1300
      183
data age.agevotesdata;
   input nn rr sig;
cards;
181
       -0.34
                     1
       -0.34
225
                     0
45
       0.1300
                     1
       0.1300
102
                     1
proc print data=age.ageESdata;
  title;
proc print data=age.agevotesdata;
run;
```

Step 2: Initial macros

- Run seven initial macros described in Wang and Bushman (1999), also available via http://www.sas.com/store/prodBK_55810_en.html and clicking 'Example Code and Data" at the bottom of the page. The execptions are wavgmeta and covtefst, which can be found here: http://www-personal.umich.edu/~bbushman/software/ch5/
- 1. Votecdf1
- 2. Votea
- 3. Voteb
- 4. Voterun
- 5. Compeff
- 6. Wavgmeta
- 7. Covtefst

Step 3: Calculate the random-effects variance component

- 1. Run a random-effects meta-analysis using PROC MIXED as described in van Houwelingen, Arends and Stijnen (2002).
- 2. The four numbers in brackets (.01094) (.00483) (.01063) (.00531) are the variances of each of the primary studies. You will need to replace these with the variances of your own primary studies.

```
PROC MIXED cl method = REML DATA=age.ageesdata; CLASS study; MODEL rr= / s cl; RANDOM int/ subject=study s; REPEATED / GROUP = study; PARMS (0.01 to 2.00 by 0.01) (.01094) (.00483) (.01063) (.00531) / EQCONS=2 to 5; make 'Parms' out=Parmsml; RUN;
```

3. Make a note of the estimate for the intercept from the output, this is the random-effects variance component

Covariance Parameter Estimates										
Cov Parm	Subject	Group	Estimate	Alpha	Lower	Upper				
Intercept	study		0.004471	0.05	0.000706	419.86				
Residual		study 1	0.01094		-					
Residual		study 2	0.004830		-					
Residual		study 3	0.01063		-					
Residual		study 4	0.005310							

Step 4: Modify the maxcorr macro

- Copy and paste the maxcorr macro syntax (available via http://www.sas.com/store/prodBK_55810_en.html) into SAS
- 2. Locate the following line in the syntax:

```
variance = (1-xnew*xnew) * (1-xnew*xnew) / sum(nn);
```

3. Modify this one line of syntax so that variance = the variance of the random-effects variance component calculated in step 2. For example, when the variance of the random effects is 0.004471 the syntax should be the following:

```
variance = 0.004471;
```

4. Run the maxcorr macro with this modification.

Step 5: Run the meta-analysis and vote-counting procedure

- Because the example in this paper used only correlation coefficients, the syntax for Example 7.2 was used (available via http://www.sas.com/store/prodBK_55810_en.html). However, Example 7.1 provides equivalent syntax for the meta-analysis of other types of effect size.
- 2. In the present review, all the studies that did not report effect sizes reported whether the results were significant or not. Therefore the section of Example 7.2 that deals with studies that did not report significance was removed. This was the final syntax for the meta-analysis and vote-counting procedure looking at the association between older age and likelihood of having a first child:

```
options nodate nocenter pagesize=54 linesize=80 pageno=1;
libname ch6 "/folders/myfolders/metabook/ch6/dataset";
libname ch7 "/folders/myfolders/metabook/ch7/dataset";
libname Age "/folders/myfolders/Age";
/**********************
/* Meta-analysis for studies that reported enough
                                              */
   information to calculate Pearson product-moment
                                              * /
   correlations
                                              * /
/***********************
proc iml;
  reset nolog;
  reset storage=aa.imlrout;
  load module=(maxcorr);
  use age.ageESdata;
  read all;
  level=0.05;
  run maxcorr(nn,rr,level);
run;
data combine1;
  method="MLE
  study = 4;
  set mcorrout;
/**********************
/* Meta-analysis for studies that only reported the
   significance and direction of sample correlations
%voterun(age.agevotesdata, "corr", 0.05, 0.95);
data combine2;
```

```
method="Vote-count (SIG)";
  study=4;
  set votebout;
  estimate = rho;
  variance = vrho;
  keep method study estimate variance lower upper;
/* The combined procedure
data temp;
  set combine1 combine2;
  eff = estimate / variance;
  veff = 1 / variance;
  keep eff veff;
proc means data = temp noprint;
  var eff veff;
  output out = tempout sum = s1 s2;
data combine4;
  set tempout;
  method="Combined";
  study=8;
  estimate = s1 / s2;
  variance = 1 / s2;
  lower = estimate + probit(0.025) * sqrt(variance);
  upper = estimate + probit(0.975) * sqrt(variance);
  keep method study estimate variance lower upper;
data result; set combine4 combine1 combine2;
proc print data = result noobs;
  var method study estimate lower upper;
  title;
  format estimate 5.3 lower upper 5.3;
run;
```

Morgan C. Wang and Brad J. Bushman, 'Integrating Results through Meta-Analytic Review Using SAS(R) Software.' Copyright® 1998, SAS Institute Inc., Cary, NC, USA. All Rights Reserved. Reproduced with permission of SAS Institute Inc., Cary, NC

Solution for Fixed Effects									
Effect	Estimate	Standard Error	DF	t Value	Pr > t	Alpha	Lower	Upper	
Intercept	0.2508	0.05416	3	4.63	0.0190	0.05	0.07844	0.4232	

method	study	estimate	lower	upper
Combined	8	0.133	0.046	0.220
MLE	4	0.245	0.113	0.376
Vote-count (SIG)	4	0.046	069	0.162

References

van Houwelingen, H. C., Arends, L. R., & Stijnen, T. (2002). Advanced methods in metaanalysis: multivariate approach and meta-regression. *Statistics in Medicine*, 21, 589-624.

Wang, M. C., & Bushman, B. J. (1999). *Integrating results through meta-analytic review using SAS software*. Cary, NC: SAS Institute.

Appendix E: Sample and Design Characteristics of the Included Studies

Table E.1.

Sample Characteristics of the Included Studies

Authors	Year of data collection	Population	Country	Sample size ^a	Mean age
D'Augelli et al. (2006/2007)	2001-2004	Lesbians and gay youth	USA	133	19.25
Eisenberg (2002)	2002	Lesbians	USA	181	31
Gorman et al. (2012)	2011	Cancer survivors		22	NR
McConkie-Rosell et al. (2012)	NR	Heritable condition: Fragile X syndrome	USA	35	18.35
McCrohan (1996)	1995	Lesbians	USA	163	34
Quaid et al. (2010)	NR	Heritable condition: Huntington's disease	USA	10	42
Rabun & Oswald (2009)	NR	Gay men	USA	14	NR
Riskind & Patterson (2010)	2002	Gay men and lesbians	USA	294	Women=31.1, men=32.0
Sbordone (1993)	1991	Gay men	USA	80	35.4
Shenkman (2012)	2008	Gay men	Israel	155	32.92
Solomon (1991)	NR	Lesbians	USA and Canada	81	33

Note. ^awhen only a subsample of participants was eligible for inclusion, the size of the subsample was reported as the sample size. NR = not reported, USA = United States of America.

Table E.2.

Design characteristics of the included studies.

Authors	Quantitative/qualitative	Sampling procedure	Response rate (quantitative studies only)	Measure of outcome (quantitative studies only)
D'Augelli et al. (2006/2007)	Quantitative	Self-selecting	NR	Child-rearing expectations
Eisenberg (2002)	Quantitative	Self-selecting	24.4%	Intention to parent
Gorman et al. (2012)	Qualitative	Self-selecting	N/A	N/A
McConkie-Rosell et al. (2012)	Mixed-methods (quantitative component excluded)	Self-selecting	N/A (as quant section not eligible)	N/A
McCrohan (1996)	Quantitative	Self-selecting	46.9%	Intention to parent
Quaid et al. (2010)	Qualitative	Purposive sample	N/A	N/A
Rabun & Oswald (2009)	Qualitative	Self-selecting	N/A	N/A
Riskind & Patterson (2010)	Quantitative	Representative sample	N/A	Parenting desires, intentions and attitudes
Sbordone (1993)	Quantitative	Self-selecting	64%	Desire for a child
Shenkman (2012)	Quantitative	Self-selecting	97.1%	Likelihood estimations of becoming a parent
Solomon (1991)	Mixed-methods	Self-selecting	27.4%	Voluntarily childless vs. considering motherhood

Note. NR = not reported, N/A = non-applicable, USA = United States of America

Appendix F: Quality Assessment of the Included Studies

Table F.1. Quality assessment of quantitative studies: Methodological quality criteria

Study	Outcome variable	Outcome variable	Representative sample ^c	Response rate	Predictor variable	Predictor variable
	validity ^a	reliability ^b	1	$\geq 80\%$	validity? ^a	reliability? ^b
D'Augelli et al. (2006/2007)	1	0	0	N/R	1	0
Eisenberg (2002)	1	0	0	0	1	1
McCrohan (1996)	1	1	0	0	1	1
Riskind & Patterson (2010)	1	0	1	N/A	1	1
Sbordone (1993)	1	0	0	0	1	1
Shenkman (2012)	1	0	0	1	1	0
Solomon (1991)	1	0	0	0	1	1

Note. N/A = Non applicable, N/R = Not relevant

a Clear definition/ Measurement in different ways/Citations or discussion as to why the use of these measures is valid.

^b Internal consistency/ Measurement in different ways/Interrater reliability/Agreement between measures/ Considered how setting and sampling of study population might affect reliability/ Citations or discussion as to why the use of these measures is reliable.

^c Yes = entire eligible population or probability sample. No = convenience or self-selected sample.

Table F.2. Quality assessment of quantitative studies: Reporting quality criteria

Study	Description of study population ^a	Screening criteria specified	Aims of the investigation clearly stated	Choice of study method appropriate	Identified and stated how potential confounders and biases assessed.	Tables/graphs labelled and understandable	Confident in use of statistics?	Results applicable to the local situation? ^c	All important outcomes/ results considered?
D'Augelli et al. (2006/2007)	1	1	1	1	1	N/A	1	0	N/A
Eisenberg (2002)	1	1	1	1	1	1	0	0	N/A
McCrohan (1996)	1	1	1	1	1	1	1	0	1
Riskind & Patterson (2010)	1	1	1	1	1	1	1	1	1
Sbordone (1993)	1	1	1	1	1	1	0	0	N/A
Shenkman (2012)	1	1	1	1	1	1	1	0	N/A
Solomon (1991)	1	1	1	1	1	1	0	0	N/A

Note. N/A = Non applicable, N/R = Not relevant

a Location, population density, age, gender, socioeconomic factors, and ethnicity reported.

b Consider differences between the local and study populations (e.g., cultural, geographical, ethical) which could affect the relevance of the study.

Table F.3.

Quality assessment of quantitative studies: Total scores (maximum 15)

Study	Total score
D'Augelli et al. (2006/2007)	10
Eisenberg (2002)	10
McCrohan (1996)	12
Riskind & Patterson (2010)	14
Sbordone (1993)	10
Shenkman (2012)	11
Solomon (1991)	10

Note. Totals of 0-4 classified as a low quality score, 5-9 as a medium quality score, and 10-15 as a high quality score.

Table F.4. Critical appraisal of qualitative studies

			Reporti	ng quality crit	Methodological quality criteria				
	The	Authors' position	Sampling strategy	Method of data collection	Procedures for data analysis	Credibility of results? ^b	Applicable to local situation ^c	All important outcomes considered	Appropriate choice of method
Gorman et al. (2012)*	Y	N	Y	Y	Y	Y	N	Y	Y
McConkie-Rossell et al. (2012)*	Y	N	Y	Y	Y	Y	Y	Y	Y
Rubin & Oswald (2009)*	Y	Y	Y	Y	Y	Y	N	Y	Y
Quaid et al. (2010)*	Y	N	Y	Y	N	Y	N	Y	Y
Solomon (1991)	Y	N	Y	Y	N	Y	N	Y	Y

Note. * indicates a key paper

^a Description and justification reported

^b Presentation of quotes, availability of data for independent assessment, plausibility and coherence of explanations, comparison of results with other studies.

^c Consider differences between the local and study populations which could affect the relevance of the study.

Appendix G: Further Information on the Analyses to Identify Matching Photographs

The control combination of three photos with the least pleasant rated background did not significantly differ to the three disability photos. However, all other combinations of control photos significantly differed to the disability photos in terms of background (p<.05).

The one set of three control photos that matched on background scores was rated as portraying a significantly less pleasant activity than the disability photos (t (45) = -2.56, p<.05). However all control combinations scoring below 5.41 did not significantly differ on pleasantness of activity (p>.05). There were 11 control combinations that scored below this threshold.

With regards to the anger scores, only the highest scoring control combination significantly differed to the disability photos, and this was in the direction of the control photos being rated as significantly more angry. All other control combinations scored between 1.32 and 1.04 and did not significantly differ to the disability photos.

All combinations of control photos with happiness scores of 7.68 or above were found not to significantly differ to the disability photos. This left 12 control combinations that did not significantly differ to the disability group on this variable.

Appendix H: The Survey Accompanying the Implicit Association Test

Demographic questions

What is your gender?

- o Male
- o Female

What is your current relationship status?

- o Single
- o In a noncohabiting relationship
- Cohabiting
- o Married or in a civil partnership

If you are in a relationship, how long have you been with your current partner?

- Months
- o Years

If you are in a relationship, what is the gender of your current partner?

- o Male
- o Female

Which of the following options best describes how you think of yourself?

- Heterosexual or straight
- o Gay or lesbian
- o Bisexual
- o Other
- o Prefer not to say

Do you fit the following definition of disability taken from the Equality Act 2010: A physical or mental impairment that has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities. A long-term effect is defined as lasting or being expected to last 12 months or more. Fluctuating conditions or conditions which recur sporadically are classified as long-term if the episodes have occurred or are expected to occur over a period of 12 months or more.

- o Yes
- o No

Are you registered as disabled i.e. do you received a disability allowance?

- o Yes
- o No

If you have a disability, which of the following best describes it? (tick all that apply)

- o Physical
- o Intellectual disability
- Sensory
- Mental illness
- Other (please describe in box below)
- o Disability_other

What is your date of birth?

What is your ethnic group? (dropdown menu:)

- 1. English/Welsh/Scottish/Northern Irish/British
- 2. Irish
- 3. Gypsy and Irish Traveller
- 4. Any other White background, please describe
- 5. White and Black Caribbean
- 6. White and Black African
- 7. White and Asian
- 8. Any other Mixed/multiple ethnic background, please describe
- 9. Indian
- 10. Pakistani
- 11. Bangladeshi
- 12. Chinese
- 13. Any other Asian background, please describe
- 14. African
- 15. Caribbean
- 16. Any other black/African/Caribbean background, please describe
- 17. Arab
- 18. Any other ethnic group, please describe

Please describe	your ethnic	c group	here if	you :	selected	an	option	above	that	requests	you
to do so:											

What is the highest qualification you have achieved?

- No qualifications
- o NVQ level 1, GCSE grades D to E
- o NVQ level 2, GCSE grades A-C, 2+ AS levels or 1 A level
- o NVQ level 3, >1 A level
- o NVQ level 4, diploma, degree or PGCE
- o NVQ level 5, higher degree

What is your employment status? (dropdown menu:)

- 1. Full-time paid employee (30 or more hours a week)
- 2. Part-time paid employee (under 30 hours a week)
- 3. Full-time self-employed
- 4. Part-time self-employed
- 5. Unemployed and seeking work
- 6. Full-time education
- 7. Part-time education
- 8. On a government scheme for employment training
- 9. Temporarily sick/disabled
- 10. Permanently sick/disabled
- 11. Looking after home/family
- 12. Other (SPECIFY)

Other			

Please estimate how much income you took home over the past 12 months, that is after any deductions were made for tax, National Insurance, pension, union dues and so on.

Capable Parent Scale

We are interested in your perceptions of yourself as a good parent. This scale does not measure your competence as a parent nor does it equate capable parenting to one's sexual orientation. This scale measures your own thoughts about your attitudes toward parenting and being a good parent.

I think that I could provide well for a child

- o Strongly disagree
- o Moderately disagree
- o Slightly disagree
- o Slightly agree
- o Moderately agree
- o Strongly agree

(Women only) I am concerned at how my body will feel during pregnancy (same response scale for all subsequent items)

I feel I would be able to spend enough time with my child

I have the resources (financial/family/friends) to help with daycare/babysitting

I think that I would make a good mother/father

I did not have good parental role models when I was a child

I can provide good role models for my child

I am concerned that the child will have unclear ideas of gender roles

(Women only) I am afraid of childbirth

I feel I would be nurturing to a child

I can afford the costs associated with getting pregnant or adopting a child

If I have a child, I would love my child unconditionally

I do not feel I could handle the responsibility of having a child

I feel capable of handling problems that may arise for my child

I feel that I have good communication skills to be able to communicate well with my child

I have the skills to be a good mother/father

If there were problems in my relationship, I might take it out on my child

I feel that I can control my anger appropriately with my child

I feel that I would be a good role model to my child

(Women only) I am concerned that I would not be able to physically recover from pregnancy or childbirth

I do not feel I could handle the stress of having a child

I cannot afford to provide my child with food, clothing and shelter

Attitudes towards babies scale

The following questions are designed to measure your attitudes towards babies. Please be as honest as possible. If there are any questions that you do not have the experience to answer, please indicate what you think your response would be. Answer each item by marking the number after each question that reflects your level of agreement or disagreement with each statement.

After holding and cuddling someone else's baby, I want a baby of my own.

Strongly disagree

0

0

Strongly agree

Looking after other people's babies makes me want to have a baby of my own. (Same response scale for all subsequent items)

Looking at baby clothes and baby toys makes me want to have a baby.

Seeing a small baby, peacefully sleeping, makes me want a baby of my own.

Seeing children growing up and becoming independent makes me want to have a baby.

Seeing family members who have babies makes me want to have a baby myself.

Seeing pregnant women makes me want to have a baby.

The smells of a baby (baby powder/baby wash) make me want to have a baby of my own.

Watching babies on TV makes me want to have a baby in real life

When I see children playing and laughing, I want a child of my own.

Dealing with the needs and wants of children is annoying.

I generally do not feel protective and nurturing toward children.

Looking after other people's babies or children makes me want to never have children of my own.

The disgusting aspects of babies (dirty diapers, spit-up, etc.) make me not want to have a baby.

When I see a child having a tantrum, I want to get as far away from the noise as possible.

When I see an infant crying, I want to get as far away from the noise as possible.

When I see babies having a tantrum and crying, I know I will never have children of my own.

I do not like looking after children

Having a baby of my own would be too damaging to my career/educational goals.

Having a baby of my own would cost too much money.

Having a baby would cut into my own personal time too much.

Having a baby would destroy my freedom to do whatever I want, when I want.

Having a baby would destroy my social life.

I do not have the time or energy to take care of a baby.

I sometimes feel as though I would give my own life just to ensure the safety of my children.

Seeing parents shout at their children makes me want to protect the children somehow.

When I see a child about to do something that will cause them harm, my gut impulse is to intervene and stop them.

When I see a child having a tantrum, I want to comfort them.

When I see an infant crying, I want to comfort them.

When I see upset children and their mothers who cannot cope, I want to help.

It is the social duty of women to have children.

The primary purpose of women is to produce children.

The proper place for women is in the home, raising children.

Women need to have children to feel fulfilled.

Attitudes towards parenting by people with disabilities

This questionnaire is designed to measure your thoughts, feelings, and behaviour with regard to gay fathers. These statements reflect diverse views on parenting. It is not a test, so there are no right or wrong answers. Answer each item by marking the response option that reflects your level of agreement or disagreement with each statement. If you do not know any disabled parents please respond how you think you would if you did.

Disabled parents make me nervous

- o Strongly agree
- o Agree
- Neither agree nor disagree
- o Disagree
- o Strongly disagree

Disabled parents deserve what they get (Same response scale for all subsequent items)

Disabled people raising children is acceptable to me

I would not be friends with a disabled parent

I make derogatory comments about disabled parents

I enjoy the company of disabled parents

Disabled parents are acceptable

Disabled parents raising children is immoral

I tease and make jokes about disabled parents

I feel you cannot trust a disabled parent

Organisations which promote rights for disabled parents are necessary

I have damaged property of disabled parents, such as "keying" their cars

It should not be against the law for disabled people to have children.

I avoid disabled parents

It does not bother me to see disabled parents and their child(ren) together in public

Norms and perceived behavioural control

Below are a number of factors that may influence an individual's decision to become a parent.

Please indicate to what extent you agree or disagree with the following statements using the response scale: strongly disagree to strongly agree with statement.

It is easy for me to become a parent

- Strongly agree

The decision to become a parent is beyond my control (Same response scale for all subsequent items)

If I wanted I could become a parent Whether I become a parent is entirely up to me Whether I become a parent is not entirely up to me

Most people who are important to me would want me to become a parent

Generally speaking I want to do what most people who are close to me think I should do I think my partner would want me to become a parent (if you do not have a partner please respond in the way you think you would if you did)

Generally speaking I want to do what my partner thinks is best (if you do not have a partner please respond in the way you think you would if you did)

I think my family and/or in-laws would want me to become a parent

Generally speaking I want to do what my family and/or in-laws think is best

I think my friends would want me to become a parent

Generally speaking I want to do what my friends think is best

Parenting intentions

Do you intend to have a child in the future? This includes biological, adopted and foster children.

- o Definitely not
- 0
- 0
- 0
- 0
- Definitely yes

How important to you is it that your child is genetically related to you? If this is not applicable to you because you do not intend to have children please tick the checkbox labelled N/A below

- Not important
- 0
- 0

O O
Extremely important
What would be the best age for you to have children?
In Box 1 below please state the age before which you consider it to be 'too early' for you to have your first child. In Box 2, state the age that you think is the 'ideal or right time' for you to have your first child. In Box 3, state the age after which you would consider it to be 'too late' for you to have your first child.
In each case the age might be your current age, younger than your current age or older than your current age.
If you do not intend to have children please tick the checkbox below
Box 1: Too early Box 2: Ideal time Box 3: Too late
☐ I do not intend to have children
How strong is your intention to have a child within the next 2 years? By intention we mean the behaviour of actually trying to get pregnant, father a child, or adopt/foster a child.
Please indicate on the response scale where 0 means no intention at all and 10 means a very strong intention.
 0 No intention at all 1 2 3 4 5 6 7 8 9

If you have a partner how strong do you believe their intention is to have a child within the next 2 years?

Please indicate on the response scale where 0 means no intention at all and 10 means a very strong intention. Leave the response scale blank and tick the box below if you do not have a partner.

0	0 No intention at all
0	1
0	2
0	3
0	4
0	5
0	6
0	7
0	8
0	9
0	10 Very strong intentions
	I do not have a partner

How strong is your intention to have a child within the next 5 years? Please indicate on the response scale where 0 means no intention at all and 10 means a very strong intention.

If you have a partner how strong do you believe their intention is to have a child within the next 5 years?

Please indicate on the response scale where 0 means no intention at all and 10 means a very strong intention. Leave the response scale blank and tick the box below if you do not have a partner.

0	0 No intention at all
0	1
0	2
0	3
0	4
0	5
0	6
0	7
\circ	8

910 Very strong intentions
☐ I do not have a partner
When do you plan to actively start trying to have/adopt/foster your first child? Please state in years and months from today By actively trying we mean not just planning on having a child at some point but actually trying to get pregnant/father/adopt/foster a child. If you don't intend to have children please tick the checkbox below. Years
Months
☐ I do not intend to have children
Please provide your name and email address below if you would like to be emailed a 210 Amazon voucher to thank you for your time. Please double check that you have entered your email address correctly. Name
Email address
Confirm email address
Please tick the box below if you are happy to be contacted requesting that you complete he second part of this study in two years' time. We can only contact you again if you have provided your name and email ddress in the boxes above.

Appendix I: Photographs used in the Implicit Association Test













Appendix J: The Consent and Debrief Forms

This Consent Form has four parts.

Part 1: What is the survey about?

Thank you for considering participating in this study. This survey will involve categorising images of families and words as quickly as possible. You will then be asked to complete questions about your attitudes and intentions concerning parenthood, and will be required to report your sexual orientation, whether you have a disability or not, and your social situation (e.g., whether or not you are living with a partner).

This will take approximately one hour of your time, in return for which you will be sent a £10 Amazon youcher.

Please be aware that participation in this study will involve you being asked to indicate the extent to which you agree or disagree with statements reflecting diverse views on parenting. Please be aware that reading some of these statements may elicit strong emotions.

This project has received ethical approval from the Cardiff University School of Psychology Research Ethics Committee.

Consent Form Part 2: Are you eligible?

If you meet the following criteria you are eligible to participate in this study:

- You must not have a disability. Disability is defined as a physical or mental impairment that has lasted or is expected to last at least 12 months that has a substantial effect on your ability to carry out normal day-to-day activities.
- You must be currently residing in the UK
- You must be aged between 18 and 28
- You must not have any children, including adopted, fostered and stepchildren
- You must not be currently pregnant or trying to get you or your partner pregnant
- You must not be in the process of adopting, fostering or arranging a surrogate mother
- You must not have any known fertility problems or diagnosed reproductive diseases that affect fertility e.g. endometriosis
- You must be identify as heterosexual and be willing to disclose this information

If you meet these eligibility criteria please continue to find out more about the study.

Consent Form Part 3: Giving us your email address

If you participate in this study and wish to receive a £10 Amazon voucher, you will need to provide us with your email address. Additionally, you will be asked whether you would be happy to be contacted in two years' time to complete the second part of the

survey. In order for us to contact you, you will have to provide your name and email address.

If you provide your name and/or email address the information provided by you will be held confidentially and will only be accessible to Christine Pinkard (PhD student) and Prof Jacky Boivin. The information will be retained for up to 10 years when it will be deleted/destroyed. You can ask for the information you provide to be deleted/destroyed at any time and you can have access to the information at any time. If you complete the second part of the survey my data will then be linked and anonymised.

Consent Form Part 4: Declaration of consent *

□ Yes

I understand that participation is entirely voluntary and I am free to withdraw at any point without giving a reason, or to discuss my concerns with Prof Jacky Boivin. I understand that if I wish to be sent a £10 Amazon voucher I will need to provide my email address. If I click out of the survey before pressing submit at the end my responses will not be saved so the researchers will not have my email address to send payment to. I can however leave blank any questions I do not wish to answer without loss of payment.

I understand that if I do not opt to provide my email address, I will not be able to withdraw once I have submitted the survey. This is because my information will be anonymous so the researchers will not be able to identify which is mine. I understand that my data will be retained indefinitely.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study. Tick 'yes' to consent to participate in the study conducted by Christine Pinkard, School of Psychology, Cardiff University with the supervision of Prof. J. Boivin.

Debrief form: Attitudes towards disabled parents and parenthood goals

Thank you for participating in this study. Although attitudes towards disabled people have been extensively studied by social scientists, minimal evidence exists on on attitudes towards parenting by these individuals. The goal of the present study was to investigate attitudes towards parenting by disabled people people among disabled and able-bodied people. Parenting desires and intentions were also assessed in order to compare the parenthood goals of disabled and able-bodied people.

Data will be held confidentially or anonymously depending on whether or not you have agreed to complete the survey again in two years' time. If you have agreed to participate again in two years' time, then your name and email will be retained confidentially. Confidential means that only the research team (lead by Professor J Boivin) can access this information. In two years we will contact you at which time you will again have the opportunity to participate or not in the survey. If you complete the

second part of the survey your data will then be linked and anonymised. You can also ask to withdraw your data without explanation at any time by emailing Boivin@cardiff.ac.uk.

If you do not opt to provide your email address to participate in the study in two years' time, you will not be able to withdraw once you have submitted the survey. This is because your data will be anonymous so we will not be able to identify which is yours.

If any of the issues raised in the present study have distressed you at all, there are helplines available from many disability charities and organisations. We particularly recommend the following:

http://www.scope.org.uk/about-us/contact-us/helpline Thank you for your participation.

For more online psychology studies visit www.onlinepsychresearch.co.uk

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Prof Jacky Boivin School of Psychology Cardiff University Tower Building Park Place Cardiff CF10 3AT Tel: 02920875289

Tel: 02920875289 boivin@cardiff.ac.uk

If you wish to make a complaint, please contact:
Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT

Tel: 029 2087 0360

Email: psychethics@cardiff.ac.uk

Appendix K: Wave One of the Oncofertility Survey

Correlates of referral patterns in consultations with patients with cancer

I understand that my participation in this study will involve reading a hypothetical case study about a patient with cancer and making a medical judgment about issues to be discussed in the consultation and referral. I will then be asked to complete questions about my views regarding referral options (e.g., knowledge, attitudes and perceived norms and efficacy of different options). I understand that this will take approximately 15 minutes of my time.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason. Since this study consists solely of an online survey, 'no-fault liability' insurance cover is not required.

I understand that I am free to withdraw or discuss my concerns with Professor J. Boivin.

I understand that the information provided by me will be held totally anonymously, so that it is impossible to trace this information back to the individual. I understand that this information may be retained indefinitely.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

Tick 'yes' to consent to participate in the study, conducted by Sarah Sherratt and Christine Pinkard, School of Psychology, Cardiff University, with the supervision of Prof. J. Boivin.

o Yes

Poor prognosis

Please imagine that you are about to have a consultation with Mrs Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Mrs Emily Smith is a 32 year old woman with stage three metastatic breast cancer, she has poor prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Mrs Smith lives with her husband and has no children, but would like children in the future and has queried whether her fertility may be affected by her treatment.

o I have read the case study fully and carefully

Topic not mentioned by patient

Please imagine that you are about to have a consultation with Mrs Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Mrs Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Mrs Smith lives with her husband and has no children.

o I have read the case study fully and carefully

Control

Please imagine that you are about to have a consultation with Mrs Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Mrs Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Mrs Smith lives with her husband and has no children, but would like children in the future and has queried whether her fertility may be affected by her treatment.

o I have read the case study fully and carefully

Age

Please imagine that you are about to have a consultation with Mrs Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Mrs Emily Smith is a 40 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Mrs Smith lives with her husband and has no children, but would like children in the future and has queried whether her fertility may be affected by her treatment.

o I have read the case study fully and carefully

Marital status

Please imagine that you are about to have a consultation with Miss Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Miss Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Miss Smith lives with friends and has no children, but would like children in the future and has queried whether her fertility may be affected by her treatment.

o I have read the case study fully and carefully

Sexual orientation

Please imagine that you are about to have a consultation with Mrs Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Mrs Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer,

she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Mrs Smith lives with her wife and has no children, but would like children in the future and has queried whether her fertility may be affected by her treatment. O I have read the case study fully and carefully
What should be discussed with Mrs/Miss [appropriate title displayed depending on condition] Smith?
It is your responsibility to ensure that Mrs Smith is referred to all relevant specialists. Which would you refer her to?
Attitudes Discussing fertility with Mrs Smith is:
Not important Important
Bad Good
Unnecessary Necessary
Uncomfortable Comfortable
Discussing fertility with every patient whose fertility may be affected by their cancer treatment is:
Not important Important
C C C C C C Good
Unnecessary Necessary
Uncomfortable Comfortable
Subjective norms Most doctors would discuss fertility preservation with any patient whose fertility may be affected by their cancer treatment.

Agree D

Disagree

Most doctors would discuss fertility preservation with Mrs Smith (from the case study). (same response scale as above for all subsequent questions)

Most patients would want the opportunity to have children after cancer treatment. Patients like Mrs Smith would want the opportunity to have children after cancer treatment.

It is normal for Mrs Smith to want the opportunity to undergo fertility preservation.

Perceived behavioural control

I feel I have the expertise to discuss fertility preservation with Mrs Smith.

Agree						Disag	gree
0	0	0	\circ	0	\circ	0	

I feel I have sufficient knowledge and information to discuss fertility preservation with Mrs Smith.

(same response scale as above for all subsequent questions)

If appropriate, I would know who to refer Mrs Smith to for fertility preservation. Mrs Smith is likely to live long enough to benefit from undergoing fertility preservation.

The risk for Mrs Smith to undergo fertility preservation is:

Lo	W					Hig	h
0	0	0	•	0	0	0	

How much control do you feel you have over whether Mrs Smith will have the opportunity to undergo fertility preservation?

Lo	W					High	h
0	0	\circ	\odot	0	\circ	\circ	

Intentions

I would discuss fertility preservation options with Mrs Smith.

Definitel			D	efin	itely		
0	0	0	0	\circ	\circ	\circ	

I would offer fertility preservation options to Mrs Smith, or refer her to someone who could.

(same response scale for subsequent questions)

I would recommend that Mrs Smith explored fertility preservation options. I would take steps towards helping Mrs Smith learn more about fertility preservation.

If necessary, I would ask a colleague to provide me with more information so I could better advise Mrs Smith.

Knowledge

Please indicate in this section whether you know about the technique listed, and for each technique you know about, please indicate whether you think it is established (available for patients and used with some success) or still experimental, whether you think it might be harmful in any way to the patient or the patient's offspring, and how confident you are of your knowledge.

you are of your knowledge.
You will be taken through questions concerning seven different techniques.
Technique 1: Freezing embryos I am aware of methods involving freezing embryos. O Yes O No
If yes: This method is
This method might harm: ☐ The patient ☐ The patient's future child ☐ No one ☐ Don't know
(same questions repeated for six other techniques) Technique 2: Freezing egg cells Technique 3: Freezing ovarian tissue Technique 4: Freezing immature egg cells Technique 5: In vitro maturation of immature egg cells Technique 6: Organ preserving surgery Technique 7: Hormonal protection of the ovaries during cancer treatment
Willingness to discuss FP About your opinion and concerns with regard to fertility preservation: How likely would you be to discuss fertility preservation if
there is a small risk of re-implantation of cancer cells due to fertility preservation? O Not at all O O

o Extremely

...there is a delay of the start of the patient's cancer treatment for stimulation and egg cell retrieval?

(same response scale for all subsequent questions)

...there is a high chance of fertility preservation leading to a future pregnancy? ...the method is still experimental?

Value of FP

To what extent do you agree with the following statements?

The possibilities of fertility preservation are beneficial.

- o Strongly agree
- o Somewhat agree
- o Neither agree nor disagree
- o Somewhat disagree
- o Strongly disagree

0

Every cancer patient undergoing a treatment that might harm fertility should have the possibility to preserve fertility.

(same response scale for all subsequent questions)

Fertility preservation should be covered by the National Health Service or other insurance.

The cost for fertility preservation will limit its availability.

The existence of all these options is a real achievement.

I have ethical reservations with regard to fertility preservation.

I have religious reservations with regard to fertility preservation.

The existence of all these options to preserve fertility would be a burden to patients.

The existence of all these options to preserve fertility would give patients hope.

Fertility preservation should only be offered if there is a real chance that it will be successful.

Having to think about future fertility issues when absorbed by the cancer treatment would be difficult for patients.

Preserving embryos / egg cells / ovarian tissue prior to cancer treatment does not imply that patients have to make use of the stored tissue afterwards.

Not knowing what would happen to stored tissue that patients could not or would not use would bother patients.

Conscientious objection

Mark the option that best describes your level of comfort in discussing and/or offering fertility preservation options to cancer patients prior to treatment on personal or moral grounds (not medical or legal).

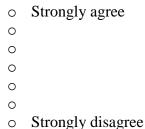
- o Discuss and/or offer without moral objection
- o Discuss and/or offer but morally object
- o Refuse to discuss or offer on moral grounds, but transfer

o Refuse to discuss or offer on moral grounds, and refuse to transfer

Traditional family values

To what extent do you agree with the following statements?

Married people are generally happier than unmarried people.



People who want children ought to get married.

It is alright for a couple to live together without intending to get married.

Divorce is usually the best solution when a couple can't seem to work out their marriage problems.

One parent can bring up a child as well as two parents together.

A same-sex female couple can bring up a child as well as a male-female couple.

A same-sex male couple can bring up a child as well as a male-female couple.

All in all, what do you think is the *ideal* number of children for a family to have?

Burden of children scale

To what extent do you agree with the following statements?

Watching children grow up is life's greatest joy.

0	Strongly agree
0	
0	
0	
0	
0	
0	Strongly disagree

Having children interferes too much with the freedom of parents.

(same response scale for subsequent items)

Adult children are an important source of help for elderly parents.

Children are a financial burden on their parents.

Having children restricts the employment and career chances of one or both parents.

Having children increases people's social standing in society.

Social dominance orientation

Which of the following objects or statements do you have a positive or negative feeling towards? Beside each object or statement indicate the degree of your positive or negative feeling.

Some groups of people are simply inferior to other groups.

In getting what you want, it is sometimes necessary to use force against other groups.

- Very negative
- 0
- 0
- 0
- Very positive

It's OK if some groups have more of a chance in life than others. (same response scale for subsequent items)

To get ahead in life, it is sometimes necessary to step on other groups.

If certain groups stayed in their place, we would have fewer problems.

It's probably a good thing that certain groups are at the top and other groups are at the bottom.

Inferior groups should stay in their place.

Sometimes other groups must be kept in their place. It would be good if groups could be equal.

Group equality should be our ideal.

All groups should be given an equal chance in life.

We should do what we can to equalise conditions for different groups.

Increased social equality.

We would have fewer problems if we treated people more equally.

Demographic questions

What year are you in?

- o First year
- Second year
- Third year
- o Fourth year
- Fifth year
- Sixth year
- Intercalating

How old ar	e you?
------------	--------

Have you worked with patients with cancer on placement?		
o Yes, a lot		
o Yes, a little		
o No		
Have you worked with patients with fertility problems on placement?		
o Yes, a lot		
o Yes, a little		
o No		
What speciality or specialties are you considering pursuing?		
□ Oncology		
□ Fertility		
\Box GP		
□ Undecided		
□ Other		
Are you married?		
o Yes		
o No		
Do you have any children?		
o Yes		
o No		
Manipulation checks		
Finally, please recall some information about Mrs Smith from the hypothetical case		
study you read at the start of the survey.		
How old was Mrs Smith?		
o Don't know		
What was Mrs Smith's marital status?		
(subsequent questions have the same response options as above)		
What was Mrs Smith's sexual orientation?		
What was Mrs Smith's prognosis?		
What other topics, if any, did Mrs Smith bring up?		

Self-reported bias

To what extent do you agree with the following statements?

The age of a patient would affect whether I would make referrals concerning fertility preservation options.

o Strongly agree
o
o
o
o
o
o
Strongly disagree

The marital status of a patient would affect whether I would make referrals concerning fertility preservation options.

(same response options)

The sexual orientation of a patient would affect whether I would make referrals concerning fertility preservation options.

Whether I would make referrals concerning fertility preservation options would be affected by a patient bringing up the topic of fertility and their desire to have children in the future.

A patient's prognosis would affect whether I would make referrals concerning fertility preservation options.

Please leave any comments or thoughts about the survey here, as well as any ideas improvement.	for

Please make sure you click the submit button at the bottom of this page.

Debrief

Correlates of referral patterns in consultations with patients with cancer.

Thank you for participating in this study. This study explored the correlates of referral patterns with cancer patients, specifically what factors are related to whether or not the patient is referred to fertility preservation services.

In this study you read a hypothetical case study of a woman with breast cancer, and asked what should be discussed with the patient and to whom the patient should be referred. Patient characteristics such as prognosis, sexual orientation, marital status and age were varied across participants in the study to examine whether these influence referral patterns. You also completed measures assessing family values, knowledge of fertility preservation options and conscientious objection to fertility preservation to determine whether these affected referral. Additionally, you completed a measure of an individual difference variable called social dominance orientation, which gives an indication of your general tendency towards viewing groups in a hierarchical manner. Finally, you completed a manipulation check which involved you recalling various characteristics from the case study, as well as questions concerning whether you think these patient characteristics would influence your clinical practice. Your personal status on three of the patient variables was also measured: your age, your marital status, and whether you have children already.

Based on previous research, it was hypothesised that patient characteristics (e.g. prognosis) and individual difference variables (e.g. attitudes towards fertility preservation) would both affect whether fertility preservation options were offered to cancer patients.

More information about fertility in cancer patients can be found on the Fertile Hope website: http://www.fertilehope.org/

Your data will be held anonymously. As data is stored anonymously, it is not possible to withdraw your data once it has been submitted.

If you are interested in this area, we recommend reading:

Schover, L. R., Brey, K., Lichten, A., Lipshultz, L. L. & Jeha, S. 2002. Oncologists' attitudes and practices regarding banking sperm before cancer treatment. Journal of Clinical Oncology, 20, 1890-1897.

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Appendix L: Wave Two of the Oncofertility Survey

Correlates of referral patterns in consultations with patients with cancer.

This survey can be completed in English or Danish, please select your preferred language in the box in the top right corner.

Please note that only medical students are eligible to participate in this study. If you have completed this survey previously please do not complete it again.

I understand that my participation in this project will involve reading a hypothetical case study about a cancer patient and making a medical judgement about issues to be discussed in the consultation and referral. I will then be asked to complete questions about my views regarding referral options (e.g., knowledge, attitudes, perceived norms and efficacy of different options). I understand that this will take approximately five minutes of my time.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason.

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with Professor J. Boivin (<u>cardifffertilitystudies@cardiff.ac.uk</u>).

I understand that the information provided by me will be held totally anonymously, so that it is impossible to trace this information back to me individually. I understand that this information may be retained indefinitely.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

If you do not wish to continue with the survey please close the window.

Tick 'yes' to consent to participate in the study conducted by Christine Pinkard, School of Psychology, Cardiff University with the supervision of Prof. J. Boivin.

Yes

[Control condition]

Please imagine that you are about to have a consultation with Emily Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Emily Smith's husband, Jack, has attended previous appointments with her.

o I have read the case study fully and carefully

[Age condition]

Please imagine that you are about to have a consultation with Emily Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Emily Smith is a 40 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Emily Smith's husband, Jack, has attended previous appointments with her.

o I have read the case study fully and carefully

[Single condition]

Please imagine that you are about to have a consultation with Emily Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals. Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Emily Smith does not have a partner and has attended previous appointments alone.

o I have read the case study fully and carefully

[Poor prognosis condition]

Please imagine that you are about to have a consultation with Emily Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Emily Smith is a 32 year old woman with stage three metastatic breast cancer, she has poor prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Emily Smith's husband, Jack, has attended previous appointments with her.

o I have read the case study fully and carefully

[Gay condition]

Please imagine that you are about to have a consultation with Emily Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Emily Smith's wife, Julie, has attended previous appointments with her.

I have read the case study fully and carefully

[Patient mentioned topic condition]

Please imagine that you are about to have a consultation with Emily Smith who was diagnosed with breast cancer and is attending to receive information about the next steps in her treatment. Referrals have not yet been made to other professionals.

Emily Smith is a 32 year old woman with stage two non-metastatic breast cancer, she has good prognosis for recovery. Her treatment plan involves surgery, chemotherapy and radiotherapy. Emily Smith would like children in the future and has queried whether her fertility may be affected by her treatment. Emily Smith's husband, Jack, has attended previous appointments with her.

o I have read the case study fully and carefully

What should be discussed with Emily Smith?
It is your responsibility to ensure that Emily Smith is referred to all relevant specialists.
Which would you refer her to?
We are particularly interested in fertility preservation. Please answer the following questions about fertility preservation.
I would discuss fertility preservation options with Emily Smith.
Definitely not
OOODefinitely
I would offer fertility preservation options to Emily Smith or refer her to someone who could.
(Same response scale for all subsequent questions)
I would recommend that Emily Smith explored fertility preservation options.
I would take steps towards helping Emily Smith learn more about fertility preservation.
If necessary, I would ask a colleague to provide me with more information so I could better advise Emily Smith.
To discuss fertility with Emily Smith is:

o Not important

0	
0	
0	
0	
0	
0	Important
0	Bad
0	
0	
0	
0	
0	
0	Good
dia	avec fartility with avery nations whose fartility may be affected by their and

To discuss fertility with every patient whose fertility may be affected by their cancer treatment is:

(same two response scales presented as for the previous question)

Subjective norms

Most doctors would discuss fertility preservation with any patient whose fertility may be affected by their cancer treatment.

- o Agree
- 0 2
- 0 3
- 0 4
- 0 5
- 0 6
- o Disagree

Most doctors would discuss fertility preservation with Emily Smith (from the case study).

(same response scale as for the subsequent question)

Patients like Emily Smith would want the opportunity to have children after cancer treatment.

It is normal for Emily Smith to want the opportunity to undergo fertility preservation

Perceived behavioural control

How much control do you feel you have over whether Emily Smith will have the opportunity to undergo fertility preservation?

- o Low
- 0 2
- 0 3
- 0 4
- 0 5
- 0 6
- o High

Traditional family values

To what extent do you agree or disagree with the following statements?

It is alright for a couple to live together without intending to get married.

- o Strongly agree
- 0 2
- 0 3
- 0 4
- 0 5
- 0 6
- Strongly disagree

One parent can bring up a child as well as two parents together.

A same-sex female couple can bring up a child as well as a male-female couple.

A same-sex male couple can bring up a child as well as a male-female couple.

Demographic variables

Next, please tell us some information about yourself.

What year of medical school are you in?

- o First year
- Second year
- o Third year
- o Fourth year
- o Fifth year
- o Sixth year
- o Intercalating

Have you worked with patients with cancer?

o Yes, a lot

0	Yes, a little
0	No
Was fertilit	y preservation mentioned while you were working with cancer patients?
0	Yes
0	No
Have you v	vorked with patients with fertility problems?
0	Yes, a lot
0	Yes, a little
0	No
In your med	dical education to date, has fertility preservation in relation to cancer patients ed?
0	Yes
0	No
What speci	ality or specialties are you considering pursuing?
□ Onc	cology
□ Fert	
☐ GP	
□ Unc	lecided
☐ Oth	er
Which univ	versity do you attend?
What is you	ar country of residence?
, ,	
If America,	which state do you reside in?
Are you:	
	Mala
	Male Female
O .	i Cinaic
How old ar	e you?

any ideas

Please make sure you click the button at the bottom of this page to submit your survey.

Debrief

Correlates of referral patterns in consultations with patients with cancer

Thank you for participating in this study. This study explored the correlates of referral patterns with cancer patients, specifically what factors are related to whether or not the patient is referred to fertility preservation services.

In this study you read a hypothetical case study of a woman with breast cancer, and asked what should be discussed with the patient and to whom the patient should be referred. Patient characteristics such as prognosis, sexual orientation, marital status and age were varied across participants in the study to examine whether these affected referral patterns. You also completed measures assessing attitudes, subjective norms, and perceived behavioural control concerning the discussion of fertility preservation, as well as a measure of family values. Your personal status on two of the patient variables was also measured: age and marital status.

Based on previous research it was hypothesised that patient characteristics (e.g. prognosis) and individual difference variables (e.g. attitudes to fertility preservation) would both affect whether fertility preservation options were offered to cancer patients.

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If you wish to make a complaint, please contact:

Secretary of the Ethics Committee School of Psychology Cardiff University Tower Building Park Place Cardiff CF10 3AT

Tel: (+44)29 2087 0360

Email: psychethics@cardiff.ac.uk

Please make sure you click the button at the bottom of this page to submit your survey.