THE UNIVERSITY OF HULL

An exploration of the motherhood decision

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull,

by

Hannah Marklew BSc. (Hons) Psychology

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Acknowledgements

Firstly and foremost, my sincerest gratitude goes to the women who volunteered their time and experiences to this study. Their openness and honesty are what made this piece of research and it was truly a privilege to hear their stories.

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Thanks also to Dr. Tim Alexander, who answered many questions along the way.

To my parents, who themselves decided to have children in the midst of MS, thank you. Your lifelong guidance and support has always proved invaluable. And to my brother, a sincere friend in whom I have been able to share many highs and lows.

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Last but not least, to Chris, for your belief in me, your patience and most importantly, your humour throughout times of immense pressure and high emotion.
A. Overview

The portfolio thesis is separated into three parts: a meta-synthesis of qualitative research, an empirical study and appendices.

Part one is a meta-synthesis reviewing the published qualitative literature regarding the decision to remain childfree in women. The aim of the synthesis was to provide healthcare professionals with an in depth insight into the influences and consequences of the decision in order to inform aspects of their practice when working with childfree women, alongside infertile women and those contemplating the motherhood decision. Five broad themes were discovered from six papers eliciting that the childfree decision is multifaceted and individual. The findings are discussed in relation to clinical implications and potential future research.

Part two is an empirical study that explores the experience of the motherhood decision in women diagnosed with Multiple Sclerosis. Eleven women were interviewed, and data was analysed using Interpretative Phenomenological Analysis (IPA). Though the study involved both women who had children and women who did not have children following diagnosis, several themes occurred across interviews with participants. Key implications for the aid of the decision making process within health care services are discussed.

Part three consists of appendices supporting both the meta-synthesis and the empirical study. It also includes a reflective statement detailing the process of the research from beginning to end.

Total word count: 26,874

(including tables, figures & references, excluding appendices)
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Part One:

Remaining childfree: A qualitative meta-synthesis
Remaining childfree: A qualitative meta-synthesis

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Short running heading: Remaining Childfree

Key words (not in title): voluntary childlessness, decision, choice, female identity

This paper is written in the format ready for submission to The *Journal of Biosocial Science*. Please see Appendix A for instructions for contributors.

Word count (inclusive of tables, figures & references): 10,831
Abstract

An increasing number of women have remained childfree within the UK since the 1970’s (Gillespie, 1999) despite this contradicting societal norms. This qualitative meta-synthesis aimed to provide a descriptive understanding of women’s childfree decision. Descriptive meta-synthesis was employed to synthesise findings from single qualitative studies which were identified through the systematic searching of electronic databases. Six articles were synthesised yielding five superordinate themes and seven subthemes: (i) Rigidity of the decision (persistent, fluid), (ii) The push and pull (desirability of voluntary childlessness, undesirable nature of motherhood), (iii) Stigmatisation (experienced, internal, counteracting), (iv) Femininity is maintained, (v) The potential for regret. Findings suggest that the decision to remain childfree is a multifaceted and individual experience influenced by childhood and adulthood circumstances, the societal environment and embodiment. Implications for the care of childfree women, infertile women and women considering whether or not to have children are discussed in terms of a health and mental health context.
Introduction

Within a pronatalist society, the words ‘woman’ and ‘mother’ are relatively synonymous and traditional perspectives would see the two as inextricable (Balmer, 1994). Pronatalism encourages the increase of birth rates and reinforces the societal expectation that individuals should not only have children, but should want to do so as well (Veevers, 1975).

Despite this, trends have occurred related to having fewer children and delaying motherhood (Gillespie, 2003). Over the past 50 years, fertility patterns within the UK have fallen and it was found that between 1970 and 1992 the average number of children per mother fell from 2.4 to 1.8 (Gillespie, 1999). Although a slight increase was noted in 2010 indicating that birth rates may be increasing again, with an average of 2 children being born per woman (Office for National Statistics, 2011), this still does not exceed the replacement level of fertility of 2.07. Interestingly, an increasing number of women have remained completely childfree since the 1970’s (Gillespie, 1999) and figures from 2012 report that 1 in 5 women within England and Wales who have reached the end of their childbearing years (defined as aged 45) have never had children (Office for National Statistics, 2013). Discourses surrounding women who are not mothers have often employed terms such as ‘childless’ or ‘infertility’ which suggest an absence or deficiency of motherhood (Gillespie, 2003). More recently the term ‘childfree’ has been used in order to highlight the choice in the decision (Bartlett, 1996). As a consequence it is this term that will be used throughout this review.

Accompanying the trend in those remaining childfree has come a trend in research attempting to understand it. So far, most studies have been survey based or at a societal level (Shaw, 2011), focusing on predicting the reasons for a woman’s choice to remain
childfree. Such research has identified the following causes: higher levels of education, increasing female participation in the labour force, monetary advantages, introduction and use of birth control, later marriage and marital breakdown, disinterest in children, partner’s wishes, the emotional strain, responsibility, and concern regarding the environment and state of society (Dalphonse, 1997; Houseknecht, 1987; Kiernan, 1989; Heaton & Jacobson, 1991; Langdridge et al., 2005). Further research has begun to explore the experiences of heterosexual couples who decide to remain childfree (Letherby, 1994; Carmichael & Whittaker, 2007). Whilst it is acknowledged that men are an important component in the fertility decision making process within such a relationship (Testa et al., 2012), it cannot be ignored that due to the historic and traditional discourses surrounding the identity of a woman as also a mother, that the lived experience of the decision making process is different for the woman in the relationship due to different role expectations and socialisations. Not only this, but different reactions can be experienced from the wider society in response to their decision. For women, failure to conform to the expectations of femininity can result in questions, suspicion and doubt, and even abhorrence from society (Letherby & Williams, 1999). Research into the perceptions of childfree women has revealed negative stereotypes, with childfree women labelled abnormal, selfish, immature and child haters (Houseknecht, 1987; Letherby, 2002; Rich et al., 2011).

With respect to ontology, the reproductive capacity of the female body is what has differentiated and categorised apart ‘woman’ from ‘man’ in societal knowledge (Malson and Swann, 2003). As a consequence, the concept of motherhood has been reduced to the maternal drives or instincts considered the norm for every woman (Raymond, 1993). Feminist literature has argued against such essentialist views, suggesting that they support ideas which propose that women are genetically predisposed to mother, nurture
and tend to their young (Hird, 2007). This categorisation of ‘woman’ determined by biology, not only differentiates her from ‘man’, but also creates divides between women. If motherhood and nurturance is perceived as the ‘norm’, then the rejection of motherhood, consequently, will be supposed ‘abnormal’ (Rich et al., 2011).

It is acknowledged that the expected norms of society discussed herein will persist throughout professional bodies too and therefore counsellors, psychologists and other health care staff may carry particular judgements or assumptions about women who decide to remain childfree. Many developmental models that healthcare staff are familiar with profess that parenthood and childrearing are normal aspects of lifespan development (Mollen, 2006).

The criticism endured by individuals who actively choose not to have children, is also felt by those who wish to have children, but who cannot conceive. Whiteford and Gonzalez (1995) discuss the failure felt by women who cannot bear children which appears to have increased due to the introduction of medicalised interventions. Distress is common in such women, due to the internalisation of societal norms and gender roles which they cannot meet (Whiteford & Gonzalez, 1995). Whilst the medical story of infertility is often one of new possibilities, new treatments and hope, the lived experience of infertility often highlights unsuccessful treatment, failure and sadness.

Similarly, stigmatization is felt by those who are disabled (but can bear children) and for whom motherhood is therefore potentially more challenging. Societal stigma directed at this population suggests that disabled mothers are receivers of care, rather than givers of care (Grue & Tafjord Laerum, 2002) and consequently, should not parent.

At present there appears to be a lack of research which examines the contribution of published qualitative research exploring the reasons for remaining childfree from the
perspective of women. Due to much of the research about childlessness to date focusing on more quantitative measures (Graham et al, 2013), rather than the reasons that a woman may have for not becoming a mother, it appeared more interesting and imperative to the researcher to gain in depth, qualitative understanding of women’s reasons for remaining childfree. This appeared particularly important given the pronatalist attitudes that exist within western culture and the potential for stigmatisation. The current review therefore aimed to conduct a meta-synthesis of qualitative studies to provide a descriptive understanding of such reasons. The question to be answered therefore was:

- What are the influences on and consequences of remaining childfree in women as described or interpreted through methods of qualitative analysis?

It was hoped that by sourcing this information, healthcare professionals might have a deeper understanding of the reasons behind remaining childfree and could use this knowledge to inform several aspects of their practice. Firstly, they may become more aware of their own prejudices or judgements towards individuals who decide not to have children, challenge assumptions made toward such women and help them develop their identity and voice regarding their decision. Secondly, the information may inform their work with women who have not yet made the decision to have children or not (perhaps due to disability) and help them to explore their options from a more informed and objective standpoint. Thirdly, by gaining a more in-depth understanding of this choice, healthcare professionals may be able to help those individuals facing the consequences of infertility. Additionally, by carrying out this review, it was hoped that a direction for future research, in order to further our understanding of the decision, may be identified.
Method

Method of meta-synthesis

‘Meta-synthesis’ is a term created by Stern and Harris (1985) to define the technique of examining and amalgamating a collection of similar qualitative studies. The main aim of a meta-synthesis is “…to produce a new and integrative interpretation of findings that is more substantive than those resulting from individual investigation…” (Finfgeld, 2003; pp. 893). It is suggested that qualitative literature could face marginalisation from both clinicians and policy makers if it remains isolated (Silverman, 1997). Therefore these ‘islands of knowledge’ (Glaser & Strauss, 1971; pp. 181) created through qualitative data, must situate themselves within a larger interpretative context in order to provide informed bases for health care practice (Sandelowski et al., 1997).

Epistemological Issues

The idea of synthesising tentative qualitative data that has been produced through varying qualitative methods and which have been informed by several epistemological positions has been criticised (Walsh & Downe, 2005). In opposition to positivist approaches which believe there is an objective ‘truth’, constructivist-interpretivists who often carry out qualitative research maintain a subjectivist stance, believing that reality is socially constructed (Ponterotto, 2005). Thus, suspicion is created when the method of meta-synthesis attempts to generate a comprehensive understanding of one coherent theory of a particular human phenomenon (Walsh & Downe, 2005). Walsh and Downe (2005) however, argue that because within a qualitative paradigm knowledge is constructed and there are multiple truths, the inclusion or exclusion of particular qualitative research within a meta-synthesis is void and it may therefore be justifiable to include a variety of qualitative approaches. In addition to concerns about whether it is
possible to synthesise multiple approaches though, there is also contention about exactly how to do it.

Within this review, the identified papers all describe attempts to understand or explore the voluntarily childless decision suggesting an exploration of human experience according to the individuals lived world, which is how Finlay (2009) describes phenomenology. Therefore, despite some of the studies not explicitly reporting their underpinning approaches, it was considered that the data collected could be synthesised due to the inferences of a similar approach.

*Descriptive Meta-synthesis*

The included studies were synthesised using descriptive meta-synthesis. Meta-synthesis considers phenomena more broadly and results in a comprehensive analysis of the phenomena (Schreiber et al., 1997). Following the descriptive intent of this kind of meta-synthesis, findings are not deconstructed. Alternatively, texts of the research findings supply data for translation across studies (Schreiber et al., 1997). Noblit & Hare’s (1988) work on meta-ethnography provided some direction for procedure of the synthesis as it has been used to derive substantive interpretations in both ethnographic and interpretative studies (Bondas & Hall, 2007). This method involved finding a specific research question to address, and searching for and identifying relevant papers that answered the chosen question. The papers were then read carefully in order for the quality assessment to take place, to identify key aspects of each study (e.g. the sample and setting) but more importantly, to identify the main concepts that arose in each paper, and the researcher interpretations. Once each paper had been read individually, recurring and common concepts and interpretations identified in the papers were established and this allowed for themes and subthemes across the papers to be
generated. The results of the synthesis were then written up in a coherent narrative, using extracts from the papers to provide supporting evidence of the themes and subthemes identified.

**Literature Search Strategy**

Searching occurred within five electronic computer databases (PsycINFO, PsycARTICLES, MEDLINE, CINAHL Plus with Full Text, Web of Science). Due to the topic area of the review being broad, it was considered that many disciplines may have potentially conducted research in the area and therefore databases were selected that represented research from several different disciplines.

The following search terms were employed:

(i) wom?n OR fem*

AND

(ii) “voluntary childlessness” OR “voluntarily childless” OR childless* OR “childfree” OR “child-free” OR “child free” OR “without children” OR “not wanting children” OR “do not have children” OR “not having children” OR “no children” OR “reproductiveW1intention*” OR “pregnancyW1intention*”

**Inclusion/Exclusion Criteria**

Inclusion Criteria:

- Articles that had been published in peer review journals
• Articles that included women who had made an active decision or choice not to have children
• Articles using qualitative methodology in order to explore the reasons for remaining childfree
• Only articles written in English

Exclusion Criteria:

• Articles using quantitative methodology or mixed methodologies
• Articles which were systematic, literature or book reviews or case studies
• Articles that aimed to explore the views of both men and women, or couples

Articles involving couples were excluded from the review as it was felt that the decision to have a child holds different meanings for women and men due to society gendered norms. It was also considered that women may respond differently to questions should a partner be present. This review therefore acknowledged the importance of exploring the experiences of women and their decision to remain childfree.

A total of 7017 articles were found using the above search terms (Figure 1). Following the removal of articles that were not peer reviewed, alongside the removal of duplicates, 4488 articles remained. Article titles were examined to ascertain whether each study met inclusion or exclusion criteria and abstracts were viewed if the focus of the article could not be established from the title. After the application of the inclusion/exclusion criteria seven articles remained. These were later reduced to five once the full text articles had been retrieved. A majority of these papers were excluded due to them being of a quantitative nature. Though several qualitative papers exploring the experience of childfree individuals were found throughout the search, many were rejected due the
inclusion of couples or male participants. Further studies were rejected as they looked at the life experiences of women who were childfree, such as the consequential stigmatisation or regret in later life, rather than the reasons for and the decision of becoming childfree.

**Hand searching**

Reference sections of the five remaining articles were viewed and three papers were selected for review. One of these papers was added to the meta-synthesis, and two were removed following inclusion/exclusion criteria screening.

**Final Studies included in the Review**

Six articles were included in the review representing five studies (see Table 1).
Figure 1. A flow chart illustrating the article selection process for the meta-synthesis
Quality Assessment

For qualitative research, there is extensive debate considering what constitutes as good quality research, or whether there should be any concern over quality at all (Harden et al., 2004). As a consequence, the use of generic quality checklists to assess quality remains controversial (Murphy et al., 1998). Walsh and Downe (2005) however, argue that the use of quality markers to decipher the quality of qualitative articles is imperative if the method of meta-synthesis is to be recognised as valuable within the research community. As a consequence, an adapted version of the NICE qualitative research assessment tool (National Institute for Health and Clinical Excellence, 2009) was used to assess the quality of each article included in the review (Appendix B). This tool was selected as it represents the amalgamation of 4 other quality checklists that assess scientific rigour and quality of qualitative research. For each criterion within the checklist, a score of 0 (not reported/unsure) to 3 (excellent) was awarded. A score was granted for each article, with 63 being the highest total a paper could achieve. Independent ratings were made for each study by two researchers and in the case of any difference, discussions occurred until a consensus was reached (Appendix C).

Results

Data Extraction

A summary of the characteristics of the included papers along with their quality rating can be seen in Table 1. The studies had been carried out between 1999 and 2013, three of which took place in the UK, one in America, one in Australia and one in Sweden. All the authors were female. The number of participants across all studies summated to 77, though sample sizes in the individual articles varied between three and 30 participants. Age of participants ranged between 21 and 64 years old, though Gillespie (1999) did not
specify the age of the participants within her study. Four of the studies reported participants’ ethnicity, whilst two did not (Doyle et al., 2012; Peterson & Engwall, 2013). Two studies reported the women’s educational background (Mollen, 2006; Doyle et al., 2012) and three discussed their employment (Gillespie, 2003; Mollen, 2006; Doyle, et al., 2012), though only one discussed this in terms of annual salary (Mollen, 2006). All studies but one used semi-structured interviews for their data collection (some of which occurred via telephone), whereas Doyle et al. (2012) opted for an unstructured interview technique. Alongside semi-structured interviews, Mollen (2006) also used journal entries and a focus group to collect data. Only three of the studies reported the type of data analysis that they used to interpret data (Mollen, 2006; Shaw, 2011; Doyle et al., 2012) and these consisted of Grounded Theory, Interpretative Phenomenological Analysis and Reflective Thematic Analysis.
Table 1. Description of articles included in the meta-synthesis

<table>
<thead>
<tr>
<th>Author(s), Date, Country of origin</th>
<th>Gender and discipline of Author(s)</th>
<th>Scope/aims</th>
<th>Sampling</th>
<th>Participant Characteristics</th>
<th>Data Collection</th>
<th>Analytic Approach</th>
<th>Quality Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gillespie (1999); UK</td>
<td>Female Discipline not reported</td>
<td>To explore from women why more women are remaining childless. To assess the ways in which childlessness has been understood in relation to motherhood and femininity.</td>
<td>Participants recruited from among women attending a family planning session at a clinic. All were invited to participate and fill in a questionnaire. Those who stated they were childless were then invited to interview via letter or telephone.</td>
<td>N = 25; white; 2 lesbians, 23 heterosexual</td>
<td>In depth semi-structured interviews lasting 1.5-2 hours. Questions focused on how each woman had come to be childless and what childless meant for later life.</td>
<td>Not reported</td>
<td>37/63 59 %</td>
</tr>
<tr>
<td>Gillespie (2003); UK</td>
<td>Female School of Social and Historical Studies</td>
<td>To explore why individual women choose to remain childfree and consider how this informs broader understandings of gender identity.</td>
<td>Participants were self-selected - recruited from an initial survey carried out on the childbearing intentions of 269 attendees at a family planning clinic. Those who stated that they were</td>
<td>N = 25; aged 21-50; white; 23 heterosexual; 16 in relationships; 20 employed, 4 students, 1 economically inactive</td>
<td>Semi-structured Interviews lasting 1.5-2 hours. 23 in participant’s home, 1 at researchers home, 1 at a university. Participants were asked how they had come to be childfree and to describe their childfree lives</td>
<td>Not reported</td>
<td>36/63 57 %</td>
</tr>
</tbody>
</table>
Childfree were later invited to interview.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Study Design</th>
<th>Sample Details</th>
<th>Data Collection</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mollen (2006); USA</td>
<td>Female Dept. of Psychology and Philosophy at Texas Woman’s University</td>
<td>To understand women’s reasons for the voluntarily childfree choice, their experience’s of others reactions to their choice, and to provide guidelines to clinicians as a consequence of their experiences.</td>
<td>Participants identified by key informants. N = 9; aged 32-51; 8 European American, 1 Multiracial (European, African and Native American); 2 completed high school, 1 associate’s degree, 1 bachelor’s degree, 2 master’s degrees, 3 doctoral degrees. Personal annual income = $18,000-$84,000</td>
<td>Semi-structured interviews lasting 60-90 minutes, semi-structured journal entries and a focus group. Interviews took place at the researcher’s home, home of the participant or workplace of the participant.</td>
<td>Grounded theory 57/63 90 %</td>
</tr>
<tr>
<td>Shaw (2011); UK</td>
<td>Female School of Life and Health Sciences</td>
<td>To explore the journey towards voluntary childlessness.</td>
<td>Recruited via UK-wide electronic mailing lists</td>
<td>N = 3; white; aged 28-47</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Doyle et al. (2012); Australia</td>
<td>Females Disciplines not reported</td>
<td>Implement a phenomenological approach to understanding the choices and resulting experiences of</td>
<td>Snowball Sampling Method</td>
<td>N = 10; aged 32-53 (M = 43.7, SD = 5.93); heterosexual; 7 in relationships (married or de facto); half of the</td>
<td>Unstructured, using open ended questions, 1-2 hours in duration.</td>
</tr>
</tbody>
</table>
Peterson & Engwall (2013); Sweden

<table>
<thead>
<tr>
<th>Females</th>
<th>Disciplines not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explore the claims childfree women make about their bodies when they talk about their childfree experiences and to capture how childfree women make sense of their childfreeness.</td>
<td>Not reported</td>
</tr>
<tr>
<td>N=30; aged 29-64; heterosexual; 15 single, 2 married, 9 cohabiting, 4 in long term relationships but not cohabiting.</td>
<td>Semi-structured interviews. 27 oral interviews (some as telephone interviews), 3 participants answered the interview questions through writing. Questions concerned motives for the decision to remain childfree, attitudes towards them as childfree, relationships with partners, friends, parents and children, contraception and sterilisation.</td>
</tr>
</tbody>
</table>

Women had obtained undergraduate or postgraduate degree, others had completed year 10 or above in high school; all women employed; 8 had no religious affiliation, but 7 of these 8 expressed spiritual beliefs.

Voluntarily childless women
Methodological Quality

The articles included within the meta-synthesis varied in quality on the quality assessment checklist, gaining a range of scores between 38% and 90% with a mean of 66%. It was decided however that no articles would be excluded from the review due to few articles being identified from the original search. It is also acknowledged here however that a larger sample of articles, in comparison to the 6 included in this meta-synthesis, may have impeded the analysis and consequently threatened the interpretative validity of the findings (Sandelowski et al. 1997). All of the studies demonstrated relatively clear aims and questions, seeking to understand subjective experience, best met with a qualitative approach. The criteria for recruitment and data collection were not met by several of the studies with many not specifying how samples were recruited and others giving very little information regarding data collection. Nonetheless the data collection methods were considered appropriate for qualitative research. Despite many of the studies discussing the participant demographics in detail, several lost points on the quality assessment checklist for the lack of representativeness of their sample to the population under study. As a NICE qualitative research assessment tool was being used which included a question on representativeness, the representativeness of the samples within the studies were considered. It is acknowledged however, that within qualitative research, the purpose of research is to understand participants individually and understand their specific experiences, knowledge, perspectives and beliefs, rather than gaining a generalised understanding of the sample experiences, knowledge, perspectives and beliefs. A substantial limitation for three of the studies (Gillespie, 1999; Gillespie, 2003; Peterson & Engwall, 2013) was that they did not provide information of the data analysis used and it was not reported as to how many individuals themed or coded transcripts. Findings and conclusions were reported by all studies and the conclusions related to the aims or questions at hand. Limitations of the studies were only discussed
in detail within two of the articles (Mollen, 2006; Doyle et al., 2012) and the role of the researcher within the studies was also only considered and discussed within two articles (Shaw, 2011; Doyle et al., 2012). A further limitation of some of the studies was the consideration of ethics. Only three out of the six studies explicitly referred to gained ethical approval (Mollen, 2006; Shaw, 2011; Doyle et al., 2012), though several others did discuss the consideration of ethical issues such as consent.

Synthesis

A descriptive meta-synthesis of the findings from all six articles identified five superordinate themes, and seven subthemes as illustrated in Table 2.
<table>
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<tr>
<th>First consideration of themes</th>
<th>Summarised themes</th>
<th>Relevant papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zero desire/early rejection of maternal role/never experienced maternal instinct/no biological signals/something is missing/escaping gender fate of motherhood</td>
<td><strong>Rigidity of the decision</strong>&lt;br&gt;Persistent</td>
<td>Gillespie, 1999&lt;br&gt;Mollen, 2006&lt;br&gt;Shaw, 2011&lt;br&gt;Doyle et al., 2012&lt;br&gt;Peterson &amp; Engwall, 2013</td>
</tr>
<tr>
<td>Never said no/circumstantial/gradual occurrence of decision/ongoing process</td>
<td>Fluid</td>
<td></td>
</tr>
<tr>
<td>Hard work/loss of energy, free time, money, identity, personality/mothers are undervalued/repulsion of pregnancy/poor family relations</td>
<td>Undesirable nature of motherhood</td>
<td></td>
</tr>
<tr>
<td>You’re not a real woman until you give birth/selfish/pressure from family/discrimination/social exclusion</td>
<td><strong>Stigmatisation</strong>&lt;br&gt;Experienced</td>
<td>Gillespie, 1999&lt;br&gt;Gillespie, 2003&lt;br&gt;Mollen, 2006&lt;br&gt;Shaw, 2011&lt;br&gt;Doyle et al., 2012&lt;br&gt;Peterson &amp; Engwall, 2013</td>
</tr>
<tr>
<td>Am I weird/?hope I change my mind/I don’t fit in</td>
<td>Internal</td>
<td></td>
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<tr>
<td>Healthy relationships with other children/ voluntary work/coping strategies</td>
<td>Counteracting</td>
<td></td>
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<tr>
<td>Femininity linked to sexuality/more time to look after myself/motherhood transforms the body to be less female/womanhood not compromised</td>
<td><strong>Femininity is maintained</strong></td>
<td>Gillespie, 1999&lt;br&gt;Shaw, 2011&lt;br&gt;Peterson &amp; Engwall, 2013</td>
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<tr>
<td>Later life regret/apprehension/guilt/sadness/possibility of wanting a child in the future</td>
<td><strong>The potential for regret</strong></td>
<td>Shaw, 2011&lt;br&gt;Doyle et al., 2012&lt;br&gt;Peterson &amp; Engwall, 2013</td>
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Superordinate Theme 1: Rigidity of the decision

Whilst some of the participants described feelings of not wanting children being ever present since childhood or a natural occurrence that was innate within them, others described the process of deciding to not have children as ongoing, influenced by circumstances and the potential to change their mind.

Subtheme: Persistent - Never wanted children

For some women within the studies, reports of simply never wanting to have children or never having a maternal urge for children were expressed.

“I never ever really wanted kids.” (Doyle et al., 2012; pp. 400)

Knowing this at a young age was something that some of the women discussed.

“Even when I was a young girl, I sort of knew then I wasn’t going to have children.”

(Doyle et al., 2012; pp. 400)

Several of these accounts appeared to stem from early rejection of gender roles, with women describing themselves as ‘tom boys’, refusing to play with dolls (Mollen, 2006). Similarly, but later into early adulthood, women spoke more rebelliously regarding feminism, equality and escaping prescribed traditions.

“If you’d asked me this question in my twenties I’d have talked about all the sort of feminist things and wanting to be independent and have a career. [...] in my thirties I was so adamant that I wasn’t going to have children that I’ve been sterilised so I can’t have children.” (Shaw, 2011; pp. 154)

Some of the women in the study by Peterson & Engwall (2013) agreed with the idea of never wanting children, but perceived it slightly differently in terms of a ‘natural’ occurrence within their body - one of embodiment - and therefore positioned themselves
as ‘naturally childfree’. In comparison to women within the other studies included in this meta-synthesis who experienced or described being aware of their ‘abnormality’ and deviance from societal norms, the women in the study by Peterson & Engwall (2013) discussed their ‘childfreeness’ in a very ‘laissez faire’ manner – appearing completely unperturbed by it.

“It goes without saying. I should not have kids. It’s not a problem or a crisis.” (Peterson & Engwall, 2013; pp. 380)

Rather than making an active decision to not have a child, these women described it as something that resides within the body.

“It’s not something you choose. I think it’s genetic.” (Peterson & Engwall, 2013 pp. 381)

“I just feel it so strongly within me.” (Peterson & Engwall, 2013; pp. 381)

In comparison to ideas of agency, the embodied experiences of these women reduce being childfree to a non-decision. They discussed that there is simply no connection between a female biological body and the emotional yearning for a child.

Following the idea of being ‘naturally childfree’, the termination of a pregnancy was also discussed within a discourse of being ‘natural’, once again, with some individuals reporting an unperturbed reaction to the process of a termination, simply because they felt that remaining childfree was situated within them.

“It was perfectly natural.” (Peterson & Engwall, 2013; pp. 384)

**Subtheme: Fluid - An ongoing process**

Whilst some participants, as above, described the decision as a natural one, or one that occurred early in life, others had a far more steady journey to remaining childfree within
life. Participants described a very gradual process, rather than a distinct moment in time where they decided that motherhood was not for them.

“I always imagined I’d probably have children [...] but never really sort of got round to it.” (Shaw, 2011; pp. 154)

“I don’t think there was any particular point in my life where I sat down and thought, “Right. I’m just not going to have children.” I think it was something...it was very gradual...” (Gillespie, 1999; pp. 47)

Whilst some individuals passively didn’t want children, there was a sense of openness to the possibility that this may change in the future, suggesting the continuous rather than finite boundaries of the decision.

“It wasn’t really a firm decision, but it was...a sort of...well, I don’t really want them, but who knows what I’m going to feel like...” (Gillespie, 1999; pp. 47).

Some participants discussed personal circumstances that occurred throughout their life which perhaps halted them from entering motherhood.

“I don’t think I would have been strong enough to have been a single parent...[and] I didn’t get married until I was 40, because I had very bad health. I realised that I could not cope with looking after a child at the time. It was a choice that I made because I wanted to be responsible and hated the thought of bringing a child into the world and have it go into care...” (Gillespie, 1999; pp. 46)

“I didn’t want to bring a child into that marriage and so it wasn’t meant to be, I’m afraid.” (Gillespie, 1999; pp. 46)

One particular individual attempted motherhood, only to find out that her husband was infertile. No attempts could be taken in order to become pregnant via technological
methods and the consideration of adoption was rejected. The individual therefore considered herself to be childfree by choice despite attempts and a desire to have children.

“It’s a voluntary choice not to adopt and actually that makes me feel a bit more in control of the whole situation.” (Shaw, 2011; pp. 155)

A further individual within the paper by Doyle et al. (2012) implied that she had attempted to follow societal norms whilst gradually becoming aware over time that doing so didn’t feel particularly right.

“I think back then I was trying to fit into society by doing the right thing, so getting married, having children, getting a career were all part of that structure, but there’s a slow realisation as I got a bit older, that I never fitted that mould.” (Doyle et al., 2012; pp. 402)

**Superordinate Theme 2: The Push and Pull**

Whilst one paper suggested that women found it difficult to describe why they had become childfree (Peterson & Engwall, 2013), participants within all other papers were able express a wide variety of reasons for remaining childless. What was striking was that not only was there a pull towards becoming childfree, but a push away from the existence of motherhood too.

**Subtheme: Desirability of remaining childfree**

Within the considerations of remaining childfree, ideas of independence and freedom were of great importance (Gillespie, 1999; Gillespie, 2003; Mollen, 2006; Shaw, 2011, Peterson & Engwall, 2013). Participants discussed the spontaneity of being able to travel when wanted and making plans easily without the consideration of others or the
consideration of childcare responsibilities. It was made clear that these opportunities simply would not be available if a child were involved.

“\textquote{I want to travel a lot more. I like a lot of time to myself. I like to read. I like to sew. I design my own clothes. You can’t do that when you’ve got children. Yes, it’s time to myself...It means having the freedom, within certain restrictions, to say I am going to do that now; I am going to do that tomorrow; the next year; and know that I can.}”

(Gillespie, 2003; pp. 127)

Without the ability to have one’s freedom, some participants identified that they may feel resentful.

“\textquote{It means that I am me, not someone’s mother. It means having freedom. I think I would feel resentful.}” (Gillespie, 1999; pp. 48)

Of imperative importance within the desirability of remaining childfree, was having the extra time to commit to marriage and friendships which was perceived as not being able to coexist with having a child (Gillespie, 1999; Gillespie 2003; Mollen, 2006; Shaw, 2011).

“\textquote{It also means being able to give a lot more time to other relationships like my marriage, friendships. These are the things that make me happy, and I don’t want to give them up.}” (Gillespie, 2003; pp. 129)

It also gave participant’s more time which could be devoted to their own development in terms of their careers, hobbies, leisure activities, interests and community involvement (Mollen, 2006; Doyle et al., 2012)

“\textquote{I can go and do anything I want to do and be anything I want to be because I don’t have kids.}” (Doyle et al., 2012; pp. 402)
Along similar lines, the opportunity to have a career, rather than just a job and to be able
to engage in work commitments without the strain of other burdens related to
motherhood was important (Gillespie, 2003; Mollen, 2006; Doyle et al., 2012)

“I always wanted to work and have a career, and even as a seven - or – eight-year-old,
that was what I wanted to do.” (Gillespie, 1999; pp. 48)

Several articles discussed the advantages of having a two income household (Gillespie,
1999; Gillespie, 2003; Mollen, 2006)

“We are better off. (Erm), we don’t have the money worries that obviously people with
children have.” (Gillespie, 2003; pp. 128)

Additionally, having some control, rather than the potential unpredictability that a child
can bring was mentioned.

“I think it means I have the house the way I like it. I don’t have somebody going around
wrecking it. I have peace and quiet.” (Gillespie, 1999; pp. 48)

Subtheme: Undesirable nature of motherhood

Whilst participants expressed the many positives that remaining childfree allowed, their
discourses around being childfree within all articles also contained discussion that
alluded to the rejection of motherhood and the changes in their lives that motherhood
would bring.

“To be honest, the biggest thing that comes to mind is sacrifice. And it just seems
sacrifice of your own personal identity and all of your own wishes or desires, you have
to give those up for someone else. It just seems a terrible, terrible burden. It obviously
changes everything...every aspect of your life...” (Gillespie, 2003; pp. 131).
Participant responses to questions on the rejection of motherhood involved discussions around losses; losses of time, energy, money, and identity.

“Expense, effort, no free time...you have to spend all your time, that is if you adopt a responsible approach...But for me, I just would not want to do that.” (Gillespie, 2003; pp. 130)

Motherhood was also discussed in terms of the dreary domestic activities and activities of homemaking that come with motherhood (Gillespie, 1999; Gillespie, 2003; Mollen, 2006)

“My best friend Riah has 3 children. She says Monday is the worst day of the week because she rushes home and spends all evening karting her kids to clubs and fetching them home again; weekends are a nightmare. You think, where’s the time for you, what about your life?” (Gillespie, 2003; pp.132)

There was an acknowledgement by the participants that parenthood comes with immense responsibility, that some individuals did just not feel ready for.

“I take the role very seriously, I think it’s very, the most important [role] that anyone ever does is to raise a child, you have lots of responsibilities, I don’t think I was prepared to take on that responsibility.” (Doyle et al., 2012; pp. 401)

The fear of responsibility within motherhood could also be seen in specific external concerns that participants had regarding child bearing (Mollen, 2006). These involved bringing a child into a world where conditions are detrimental to the raising of that child and the possibility of the child inheriting genetic conditions or diseases. Such considerations contradict the stereotypical view that women without children are selfish (Gillespie, 1999)
In the study by Shaw (2011), despite one participant engaging in feminist ideologies, she alluded to the fact that with the rise of feminism, came a shift to the ‘autonomous mother’ in comparison to previous tight knit communities which helped and guided one another in their mothering roles. A single responsibility, rather than that of a collective responsibility, could therefore be seen as off putting for potential mothers.

The rejection of a maternal role appeared to start early in life for some participants, having experiences of ‘caring’ for other individuals at a young age, and not finding the duties involved very appealing (Mollen, 2006)

Early experiences of relationships with parents appeared to also be a pivotal consideration as to why an individual would neglect a mothering role. Several described having difficult relationships with their parents and therefore did not wish to re-enact similar circumstances.

“because I didn’t like the way my mother behaved with me and my sister, a really strong part of my identity forming was about not being like her.” (Shaw, 2011; pp. 158)

“I just didn’t think it was fair to bring a life, a whole fresh new life, into the world and beat the crap out of it emotionally and physically.” (Doyle et al., 2012; pp. 401)

Alongside this, one participant described an experience of realising that their mother was undervalued and therefore did not wish to become undervalued also.

“realised that my mother was less valued than my dad because she didn’t work outside the family home.” (Mollen, 2006; pp. 274)

Finally, though much discussion involved that of motherhood, one participant who fell pregnant implied that simply being pregnant was undesirable.
“My mood was terrible. I felt really bad. It was like if I had an alien...it was something that had invaded my body...it was horrible.” (Peterson & Engwall, 2013; pp. 384)

**Superordinate Theme 3: Stigmatisation**

Despite two studies (Mollen, 2006; Doyle et al., 2012) briefly describing experiences of support for the childfree decision, all of the articles portrayed the stigmatisation that participants were subject to from family, friends and workplaces due to their rejection of conforming to pronatalist ideals. Further explanations described how they internalised the experienced stigmatisation or attempted to counteract it (Shaw, 2011; Doyle et al., 2012)

**Subtheme: Experienced Stigmatisation**

Women found themselves being judged negatively as a consequence of their decision and assumed deviation from societal norms. Whilst some were described as ‘hard’ or ‘selfish’, (Gillespie, 1999; pp. 46) one participant repeated many comments she had faced.

“You’re not the same, you’re different, you’re weird, you don’t make the same choices, you’re not natural, you’re not normal.” (Doyle et al., 2012; pp. 403)

Other instances of stigmatisation strongly represented the expectations of gender roles within society.

“You’re not a real woman until you’ve given birth.” (Peterson & Engwall, 2013; pp. 384)

Participants experienced pressures from family members, particularly those who had children and who struggled to understand anything but a powerful pronatalist mandate.
“Education was not considered a priority by my father, you’re just female. You’re just female! All you’re going to do with your life is grow up, get married, and have children. That’s all you’re going to do.” (Doyle et al., 2012; pp. 402)

For others, their decision was simply dismissed as a potential ‘phase’ and it was assumed that they would change their mind (Doyle et al., 2012). This ultimately was experienced as patronising as any sense of choice or agency was unacknowledged.

Participants within two studies (Mollen, 2006; Doyle et al., 2012) experienced discrimination within the workplace due to their decision, finding themselves being expected to work longer hours, at weekends or within school holidays.

**Subtheme: Internal Stigmatisation**

Despite the rejection from many women of society gendered norms, some of the participants discussed their own surprise at their lack of wanting a child, suggesting that the norms and following stigmatisation had been internalised.

“I do think that it’s a bit weird that I’ve never worried about not having children, I have thought a few times perhaps that’s a bit weird.” (Shaw, 2011; pp. 157)

“It does make me feel like a bit of a freak [...] because you’re the odd one out [...] you just feel like the person who doesn’t fit it, the person who’s life isn’t as fulfilled.” (Shaw, 2011; pp. 157)

Another participant’s experiences and internalisations of societal norms caused her to hope that one day she would experience a longing for a child. This suggests that despite no innate want or need for a child, pronatalist ideals still penetrate her thoughts.

“No I haven’t sterilized myself, because I’ve hoped that I’d change my mind.” (Peterson & Engwall, 2013; pp. 383)
Subtheme: Counteracting Stigmatisation

Some of the women within the studies had or were prepared to have meaningful relationships with other children, for example step children or nieces and nephews (Gillespie, 1999) which offsets the negative stereotypical view of childfree women. Though women did not see these relationships as a substitute for mothering in any way, one woman described allowing her niece to be assumed her daughter when shopping together in order to avoid stigmatisation (Doyle et al., 2012)

Despite not feeling a maternal urge, or being considered capable of nurturing through stigmatisation, some of the participants explained that they find this outlet in areas of their lives other than mothering. For example, some participants described a sense of nurturance for their pets or within their workplace.

“I guess working in teams, one of the things I enjoy is being in a position where I can actually create an environment where someone can grow, learn, deal with something, feel safe, feel nurtured.” (Doyle et al., 2012; pp. 404)

Women within the studies, considered that although not a mother, they contributed to society elsewhere for example within their jobs, through voluntary work and within their extended families. The statement below suggests that although this individual carried out voluntary work for other reasons, the predominant reason may have been in order to counteract stigmatisation being experienced.

“I felt I had to give something back because I didn’t want to be seen as selfish. I did volunteer work for other reasons as well.” (Doyle et al., 2012; pp. 404)

By not being a mother, it was felt that women could give more of their energy and time to such means.
Superordinate Theme 4: Femininity is maintained

For those studies that discussed the consequences of remaining childfree on a women’s sense of female identity (Gillespie, 1999; Shaw, 2011; Peterson & Engwall, 2013) it was reported that women still maintain a strong connection to their femininity, and do not feel that their womanhood has been compromised. Unlike society gendered norms, the women within these studies believed that their femininity was constructed of things other than mothering and went on to suggest that motherhood can decrease femininity.

“I don’t feel any less feminine because I am not a mother. I see women as women, not as mothers. I do not see the two bound together, although lots of people do.” (Gillespie, 1999; pp. 50)

In two studies (Gillespie, 1999; Peterson & Engwall, 2013), it was suggested that being feminine is linked to your sexuality, rather than motherhood and childbearing.

“more related to sexuality [and] the sexual encounter with a man.” (Peterson & Engwall, 2013; pp. 385)

“To me, being feminine is wearing beautiful underwear, nice clothes and painted nails. It’s all part of the parcel and if you’ve got a baby, one, two, three or four, it doesn’t matter, you haven’t got the time or energy.” (Gillespie, 1999; pp. 50)

Similar to the statement above, it was discussed that being childfree actually provided women with the opportunity to be more feminine.

“You picture a mother in her 40s being a little bit rotund and having let herself go because she’s been looking after the kids, and I think, because I’ve only had myself to think about, I take better care of myself.” (Gillespie, 1999; pp. 50)
The idea of becoming less feminine was not only related to motherhood, but to pregnancy too. Within one of the studies, a woman, on realising that she had fallen pregnant was concerned about the transformation that may occur within her body,

“Oh my God! My body! I don’t want to be ruined.” (Peterson & Engwall, 2013; pp. 385)

This suggests that although a biologically functioning female body is considered to inform gender norms and construct feminine identity, for some having the ideal female body is more important.

**Superordinate Theme 5: The potential for regret**

Despite one paper explicitly concluding that the women within their study viewed their decision to remain childfree positively (Doyle et al., 2012), suggesting that a finite decision can be made within some women, some papers also alluded to potential sense of regret, or apprehension regarding their childfree situation.

For the participants within the Peterson & Engwall (2013) study, the idea that they had a female body, biologically designed and able to give birth provided them with a sense of unrest. Women described guilt over not using a perfectly able, fertile body, and sadness over not allowing the body to be used for what it was made for.

“It’s my duty as a woman to use the uterus for what it was made for.” (Peterson & Engwall, 2013, pp. 384)

Within the same study, participants discussed how their ‘silent body’ which had so far not produced any maternal feelings, may begin to ‘speak’ to the women, providing them with an innate instinct to reproduce.
“I have considered it...but the thought has been there: ‘What if I change my mind?’...if I suddenly in 10 years time will feel: ‘Wow, now I want to have a baby!’” (Peterson & Engwall, 2013; pp. 384)

This was supported with a quote from the study by Shaw (2011) which alluded to the fact that a participant may have regrets over her decision to be sterilised.

“I don’t say so much cheated, but I felt a sense of loss that that door wasn’t open anymore.” (Shaw, 2011; pp. 154)

In contemplating the future, discussions had occurred in apprehension regarding leading a life without children and therefore potentially having no care in later life (Doyle et al., 2012). Whilst some had planned ahead, setting up arrangements to suit their needs, that this idea was considered within the interview process suggests the potential for regret.

**Discussion**

The current review explored the experiences of women who have remained childfree in terms of how they came to be childfree and the consequences of their childfree position. The themes reported within this meta-synthesis present opportunities for healthcare professionals that are involved in the care of such women, alongside women facing infertility and those whose motherhood decision is uncertain, perhaps as a consequence of disability.

Findings from the current review suggest that deciding to remain childfree is an individual and multifaceted experience which can be shaped by childhood, the environment and adulthood circumstances. Whilst within the theme of ‘Rigidity of the decision’ some women discussed knowing that they never wanted children from a young age, others described never falling into motherhood due to life circumstances, or steadily realising throughout adulthood that they did not wish to pursue motherhood.
The idea that women may never want to have a child or that their body does not ‘speak’ to them in this way (Peterson & Engwall, 2013) runs contrary to social norms or ideals about women (Gillespie, 1999). In its exploration of the embodied experiences of childfree women however, the study conducted by Peterson & Engwall (2013) brings new and interesting findings and understandings to the research on remaining childfree which other research has not yet acknowledge. Finlay (2006) suggests that within phenomenological research, the body should be considered just as important as the words in transcripts. It has been argued that whilst the body connects us to the world, it also allows us to understand the world, ourselves and others (Finlay, 2006). In a majority of phenomenological research however, there is an absence of consideration of the body.

The different experiences of the timing of the childfree decision however, have previously been articulated (Callan, 1984; Cannold, 2004). Callan (1984) discussed ‘early articulators’ and ‘postponers’, separating those who make a decision not to have children prior to marriage from those who become childfree due to a succession of temporary postponements to parenthood. Additionally, Cannold (2004) suggested that women are either ‘childless by choice’ or ‘childless by circumstance’ and went on to separate the latter group into two further categories – ‘thwarted mothers’ and ‘waiters and watchers’. The term ‘thwarted mother’ refers to those who invest in plans to have children and who would resist any revisions to those plans even when faced with significant difficulties or obstacles. ‘Waiters and watchers’ however, refers to those who are ambivalent or passive regarding motherhood, depending on external circumstances such as finding a partner and financial stability to consider procreation. This review highlights that the process of remaining childfree is therefore different for each individual. Though some may simply know that they are not to be, or do not wish to be mothers, others may encounter life circumstances that cause postponement or careful
consideration of whether to become a mother or not. It appears important for healthcare professionals who may come across these individuals, such as GP’s or nurses in terms of contraceptive practices, or psychologists in terms of any psychological difficulties encountered as a consequence of the individual’s decision, to gain an understanding of the individual’s route to a childfree existence so that a client centred approach can exist.

Despite some women within the articles in the current review expressing an absence of the need or want for a child, the superordinate theme of ‘the potential for regret’ suggests that even an unequivocal decision can potentially waver. Consequently, it is important for healthcare professionals to remain mindful of the fact that life is unpredictable – circumstances quite often change and as a consequence, decisions can change too. Although women within the review appeared irritated by those who suggested their childfree decision was temporary (Doyle et al., 2013), it would be unethical of any medical practitioner to abandon conversing with an individual about the potential for regret, particularly if the practitioner is a surgeon or counsellor and sterilisation is being considered. Counselling is recommended prior to sterilisation surgery (NHS, 2013).

Interestingly, one woman in the study by Doyle et al. (2012) within the meta-synthesis expressed potential regret in terms of apprehension regarding her old age and consideration over how she would cope in later life without a child to take care of her. Indeed, theories of family lifecycles (Carter & McGoldrick, 1999) often suggest that adult children in the family take a central role within family maintenance and allow their elderly parents to relinquish this role. The increasing number of childfree individuals has implications for health care systems at a national level as service provision will be required to change and expand in order to supply care to an ever increasing elderly population who do not have children.
The consequences of the tension between acknowledging a woman’s choice regarding remaining childfree whilst making sure she is aware of the consequences of her choice could create difficulties for health care staff. Again, what appears important from this review is healthcare professionals’ understanding of the many routes to remaining childfree and of the need to be considerate and non-judgemental of a woman’s decision.

Despite the potential for regret, the superordinate theme of ‘the push and pull’ identified within the review makes explicit that there are multiple reasons that attract women to their childfree position, alongside reasons that dissuade them from motherhood. The factors involved in this decision to remain childfree may therefore inform practice when working with individuals who are infertile or who are currently in the midst of making a decision regarding whether to have a child or not because there is such limited literature exploring motherhood decision making in general. Mollen (2006) has made suggestions for counsellors working with such women, expressing the need to explore and embrace the many lifestyles that can be experienced other than parenthood, whilst maintaining an awareness of many other options for parenting that women have in today’s world, such as adoption, surrogacy and fostering.

The stigma experienced by childfree women that was revealed within this meta-synthesis is also of importance in terms of implications for health care professionals. Women experienced negative responses from family, friends and society in reaction to their decision and as a consequence felt socially excluded. In some instances, women were considered ‘unwomanly’ as a consequence of their decision and as not “contributing to the betterment of others” (Doyle et al. 2012; pp. 404). These reactions support the ever present pervasiveness of pronatalist attitudes and gender norms within society. Though it is difficult to weaken societal discourses, such women should be able
to discuss their decision with healthcare professionals, such as GP’s or nurses, in a trusting and non-judgemental environment.

Within the seventh stage of Erikson’s model of personality development (Erikson, 1959), Erikson described a tension between generativity and stagnation. Erikson explained that in this stage, individuals become productive within their workplace and within their families by raising their children, or otherwise attending to the needs of young individuals. Erikson expressed that an individual’s culture defines these standards of generativity that one should meet. For those who are unwilling or unable to meet such standards, Erikson proposed that they become stagnant and self-centred.

Although the women within the current meta-synthesis did not have children of their own, they expressed achieving generativity within their workplace, within volunteering opportunities and through the care of children within their family (Gillespie, 1999; Doyle et al., 2012).

In light of the stigmatisation that childfree women face, increasing their social support from trusted others, (e.g. peers who are also childfree) may create a sense of belonging (Goffman, 1963) and may also allow for experiences of stigmatisation to be mediated. Through the use of the internet, childfree individuals now have easy access to the support and company of other childfree individuals. The ‘meet up’ website is an example of a source that can be utilised by the childfree to connect with others in a similar geographical area who have made the same decision.

Despite criticism from families, peers and society regarding their lack of womanhood, women within this review strongly expressed that they did not perceive their femininity to be compromised as a consequence of remaining childfree within the superordinate theme ‘femininity is maintained’. This attitude reflects the overall transformations that have occurred for women in society in the second half of the twentieth century and early
in the twenty-first century (Gillespie, 1999). New possibilities have been provided which have enabled women to shape a fulfilling gender identity, in comparison to following the hegemonic traditions that prevailed beforehand. With the increasing trend to remain childfree being ever present in society and with more literature representing women’s articulations of their reasons for doing so, the idea of remaining childfree may steadily become more accepted. This can be aided by healthcare professionals who work with such individuals by challenging the assumptions of others in relation to this population.

Limitations

The articles included in this meta-synthesis varied in their quality significantly. Three of the articles did not include detail regarding data analysis. It has been argued that it is unfeasible to synthesise results carried out in different contexts and that doing so disregards the rich data gained which in turn compromises sound qualitative research (Britten et al., 2002). It is therefore imperative for future research within this area to explicitly define and explain data analysis methods so that readers and individuals who may potentially involve the study within a meta-synthesis have a clear understanding of the methods used and the underpinning epistemological perspectives.

Currently, the methods used to create qualitative meta-syntheses are indistinct and assessing the quality of qualitative research remains controversial. The controversy surrounding quality assessments, alongside differences in methodological approaches, causes difficulties in the replication of meta-syntheses. In order to try and limit these difficulties, this review undertook a broad search of potential papers in order to prevent excluding potentially valuable data. The review also made explicit the inclusion and exclusion criteria. Alongside this, two raters independently assessed the quality of papers and discussed any differences until consensus was reached. Individuals who
have decided to remain childfree may be in the best position to assess the interpretations made of the studies within the review, however, a session for peer-review of the analysed data was not conducted.

Interestingly, all of the authors who conducted the studies included in this meta-synthesis were female. They are therefore all susceptible to pronatalist societal views and therefore hold an insider perspective on the gendered norms expected of women. Only the study by Doyle et al. (2012) however, expressed their own fertility decisions and discussed this in terms of reflexivity. Others did not acknowledge or discuss this at all.

**Future Research**

Given the interesting findings reported in the Peterson & Engwall (2013) study, future research could elaborate on the embodied experiences of individuals who remain childfree. In consideration of the potential cultural influences on the embodied experience, questions on the embodiment of remaining childfree should be incorporated into any further exploratory qualitative studies carried out with women worldwide in relation to their decision to remain childfree. Results from a similar study conducted with men could also yield fascinating results and many of the studies included in this review also expressed this as an area for future research too (Gillespie, 1999; Gillespie, 2002; Mollen, 2006; Shaw, 2011; Doyle et al., 2012).

Similarly, given that this review discusses the pronatalist ideals based within the UK, further research should be conducted with women worldwide, in order to discover what value those societies and cultures place on motherhood, what influences the women to remain childfree, and what consequences women experience as a result.
In light of the potential for regret, longitudinal qualitative studies exploring any changes in the childfree decision over time would also elicit important information that will aid the work of healthcare professionals when discussing the options of remaining childfree or becoming a mother with women.

Conclusion

In conclusion, the current meta-synthesis has contributed to a greater understanding of the childfree decision. By identifying themes, this meta-synthesis has not only discovered many reasons as to why individuals remain childfree but some of the consequences of doing so as well. As a consequence, health care professionals can be more informed in terms of their practice with such individuals. There is evidence to suggest that there are similarities in the way that women experience remaining childfree, however, further knowledge on the embodiment of the experience, alongside knowledge regarding how women in other countries and cultures explain their experience would be of great benefit to the literature.
References


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1 Asterisk (*) indicates papers included in meta-synthesis.


Part Two:

Multiple Sclerosis and the motherhood decision: A qualitative study
Multiple Sclerosis and the motherhood decision: A qualitative study

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Abstract

Purpose

This qualitative study aimed to explore the decision to have or not have children in women diagnosed with Multiple Sclerosis (MS).

Method

Semi-structured interviews were employed to elicit narrative accounts from eleven women diagnosed with MS and data was analysed using Interpretative Phenomenological Analysis (IPA).

Results

Four superordinate themes and eight subthemes were identified: (i) “Nobody knows for sure” (Subthemes: hope, despair), (ii) Identity (Subthemes: the female body, the disabled body), (iii) Social Context (Subthemes: support, isolation), (iv) The Balancing Act (Subthemes: practicalities and adaptations, “you have to get answers”).

Conclusion

Findings suggest that the decision to have or not have a child for women with MS is multi-factorial and complicated by the unpredictable nature of MS. Though both women who decided to have children as well as women who decided to not have children were involved in the study, commonalities were found in the decision making process. Key implications for the aid of the decision making process within health care services are discussed.
Introduction

Multiple Sclerosis (MS) is a currently incurable, chronic and degenerative disease affecting the central nervous system (CNS) (Hennessey & Rumrill, 2008). The vast array of symptoms are different in nature, severity and duration for each individual (e.g. mobility, fatigue, pain, incontinence; MS Trust, 2011), however, some patterns of symptoms have been monitored and observed and four categories of the disease have been named: Relapsing Remitting MS (RRMS), Primary Progressive MS (PPMS), Secondary Progressive MS (SPMS) and Benign MS (MS Trust, 2011). Roughly 85% of the 100,000 individuals estimated to be living with MS in the UK have RRMS (MS Trust, 2011). This is characterised by a series of unpredictable relapses where the MS becomes active with previous symptoms being exacerbated and/or new symptoms arising, followed by complete or partial recovery, often referred to as remission (Leary, Porter & Thompson, 2005).

Diagnosis of MS affects the individual’s personal life, their family, their employment, and their self confidence and self esteem (Murray, 1995). Though the symptoms experienced by each individual vary, the unpredictable nature of the disease is universal, meaning that those affected by it have to adjust to living with uncertainty everyday and this can be a great challenge (Kroencke, Denney & Lynch, 2001).

Twice as many women are diagnosed with MS in comparison to men and the majority of diagnoses occur between the ages of 20 and 30 years (Prunty, Sharpe, Butow & Fulcher, 2008), when family planning is at the forefront of many individuals minds. With an estimated 20,000 women of childbearing age living with MS in the UK at any one time (Lee & O’Brien, 2008), it seems likely that one of the main dilemmas that they can face is whether to become a mother or not. Concern over how the disease may
affect pregnancy and how pregnancy may affect the disease, alongside many other pregnancy related and family orientated issues is usual (MS Trust, 2011). Historically, disabled women, including those with MS were encouraged by both professionals and family not to have children, to terminate any pregnancies that did occur and consider sterilisation (Birk & Rudick, 1986). More recently, women with MS were discouraged from becoming pregnant due to the assumption that having children could hasten the progression of the disease (Lee & O’Brien, 2008). A wealth of current research however, has demonstrated that the overall course of MS is unaffected by pregnancy. The risk of relapse decreases during pregnancy (Birk & Rudick, 1986) and research has suggested that MS causes little if any, difficulties throughout labour and delivery (Argyriou & Makris, 2008). What has been found however is that there is a specific increase in the chance of experiencing a relapse in the six post partum months (Birk & Rudick, 1986).

Despite current research establishing that pregnancy in women with MS is safe for both mother and baby (Wates, 1997; Confavreux, Hutchinson, Hours, Cortinovis-Tourniaire & Moreau, 1998), studies suggest that there are fewer births and more terminations of pregnancy amongst women with MS in comparison to women without MS (Poser & Poser, 1983). Possible reasons behind these figures involve the consideration of a potential increased need for support during the post partum period. Individuals may not wish to have the help of another, or simply may not have a social network or finances to support this requirement. Additionally, women must be prepared to discontinue their medication in order to conceive. Despite medication for MS resulting in decreased relapse rates and a delay in new lesion formation (Lezak, Howieson, Loring, Hannay & Fischer, 2004) little data is available on long term outcomes and women are therefore advised to withdraw use throughout pregnancy (Hellwig, Haghkia, & Gold, 2011). Alongside this, women have to contend with the stigma of being a disabled mother and
the idea that they may never live up to the standards or ideals of what is expected from a ‘perfect mother’ within society. Despite many illnesses interfering with a woman’s ability to mother, research has shown that disabled women are invested in their identity as a mother and their mothering role (Vallido, Wilkes, Carter & Jackson, 2010). The same piece of research also found that disabled women feel unsupported in their mothering role by healthcare professionals, and believe that they are perceived as receivers of care rather than givers of care.

Due to the consequential obstacles that can stand in the way of being a mother for women with MS, the concept of a ‘decision’ and therefore ‘choice’ is interesting. When interviewing fertile women who had never had children about their fertility decision making, based on their responses, Cannold (2004) categorised them into two groups. The first group were considered ‘childless by choice’ and were committed to a life without children. The second group, named ‘childless by circumstance’ were subsequently split into two further groups entitled ‘thwarted mothers’ and ‘waiters and watchers’. Whilst ‘waiters and watchers’ were ambivalent in their decision to have children and dependent on circumstances, ‘thwarted mothers’ were committed to having children, and would hesitate to revise such plans even in the face of obstacles. Such similarities may be replicated within those facing the circumstances of disability. For those previously ambivalent to motherhood, MS may be a factor that influences a decision to forgo motherhood. For those who have always wanted and planned children however, MS may not weaken their desire and motherhood may still be sought after. Such women would only then become ‘thwarted’ should symptoms become so severe, that the decision or choice was taken away.

Further research considering the reproduction intentions of individuals without a disability has been carried out and a significant theoretical framework has been
developed for studying fertility decision making: the Theory of Planned Behaviour (TPB) (Ajzen, 1991). TPB is theory applied to the prediction of psychological and behavioural phenomena across many behavioural domains (Miller, 2011) including the domain of fertility decision making (Dommermuth, Klobas & Lappegard, 2011). It proposes that reproductive intentions precede subsequent behaviour, but suggests that intentions are created under the influence of three factors. The first factor, involves both the positive and negative attitudes towards the behaviour e.g. having a child; the second factor is subjective norms e.g. social pressure to engage or not engage in the behaviour; and the third factor is perceived behavioural control, which in the case of having a child, may depend on the resources available.

Alongside this, Langridge, Sheeran and Connolly (2005) carried out a study looking into the specific reasons which underlie individual’s intentions to have or not to have children. Their study suggested that the reason used by individuals wanting to have children that best separated them from those who do not intend to have children is the belief that having children would bring fulfilment. The results also suggested that becoming a family and having an individual that was biologically related to both members of the couple in question were also strong reasons underlying the intention to conceive. For those not wishing to conceive, the underlying reason consisted of having other more important things in their life and feeling that having a child would hinder freedom and career progression.

There is a small existing body of research that has started to explore fertility decision making in women with MS (Smeltzer, 1994; McNary, 1999; Smeltzer, 2002; Prunty et al., 2008; Payne & McPherson, 2010; Kosmala-Anderson & Wallace, 2013).

Themes amongst these papers suggested that despite current research and knowledge, for women with MS, concerns regarding the effect of MS on pregnancy and
motherhood and the effects of pregnancy on MS and its progression are still present (Prunty et al., 2008). Within the study by Kosmala-Anderson and Wallace (2013) it was discovered that women attempting to find relevant and reliable information found this very difficult. Similarly, Smeltzer (1994) found that any concerns women had were heightened further when little credible and consistent information could be obtained from healthcare professionals.

The studies suggested that the type of information women were attempting to gain, were answers to concerns regarding their own well-being alongside those of their unborn child, as might be expected. In terms of their own wellbeing, women were curious about the effect of coming off their medication in order to conceive (Smeltzer, 1994; Kosmala-Anderson & Wallace, 2013) as well as the potential for relapse in the postpartum months and how this would affect their ability to care for their child (Smeltzer, 1994; McNary, 1999; Prunty et al., 2008; Kosmala-Anderson & Wallace, 2013). They also discussed concerns for their child in terms of medication and whether medication consumption prior to conception, throughout pregnancy and after birth would affect the child in any way (Smeltzer, 1994; Prunty et al., 2008; Payne & McPherson, 2010). Several studies discovered that women also had concerns for their children regarding the heritability of MS (Smeltzer, 1994; Kosmala-Anderson & Wallace, 2013).

Consistent with research suggesting that a woman is most vulnerable to relapse within the six post partum months, the research suggested that enlisting practical support was of particular importance, particularly in the immediate post-natal period (Smeltzer, 1994; McNary, 1999; Smeltzer, 2002; Prunty et al., 2008; Payne & McPherson, 2010; Kosmala-Anderson & Wallace, 2013).
Importantly, these studies have provided several suggestions aimed at the work of healthcare professionals involved in the care of women with MS. They have suggested that clinicians should have access to and be aware of up to date knowledge about MS and pregnancy so that they can share this with patients in order to support decision making (Smeltzer, 1994; Kosmala-Anderson & Wallace, 2013). They have also stressed the importance of understanding the need for women to voice their concerns and allowing them to do so, whether on an individual basis or within a group setting (McNary, 1999).

In spite of such profound knowledge, there remains a lack of qualitative literature attempting to understand the experiences of women with MS and the decision that they face. It is imperative that women’s experiences are understood, so that the care they receive from health care professionals can be client centred and shaped to their specific needs. To date, only one study has been carried out in the UK exploring the decision with those who were considering pregnancy, those who were pregnant and those who had recently had children. To add to the literature, the current study therefore aimed to explore the experience of the motherhood decision within women with MS by interviewing those who had decided to have children after diagnosis and those who had decided not to have children after diagnosis. This was to ensure that any influences distinguishing the two groups from one another have not been missed. In order to do this, the study employed the qualitative methodology of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). More specifically, this study aimed to use IPA in order to explore the following questions:

- How do women make a decision to have a child or not after they have been diagnosed with MS?
• What factors and resources influence the way women experience making this decision?

• What meanings do these decisions carry for women diagnosed with MS?

Method

Design

A qualitative methodological design using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was employed to retrospectively explore the experience of making a decision about motherhood in women diagnosed with MS and the factors that might influence their decision about whether or not to have a child (Appendix F).

Participants

Participants were eligible to partake in the study providing they met the following criteria:

• Female

• Aged 18 or over

• Self reported diagnosis of MS made by a neurologist

• English speaking as there was not a sufficient budget for interpretation

• Had actively made a decision to have or not to have a child after diagnosis of MS – including women who have decided to have children and/or already have children, women who have decided not to have children, and women who have had a termination.

• Ability to give informed consent
Recruitment took place between August and November 2013 and eleven participants were identified through purposive sampling (table 1).

Participants described themselves as White British (n=6), English (n=1), White (n=1) British (n=2). One participant did not respond to this question. All participants were married. The number of completed years of education of participants varied between 11 and 20 years. Six participants reported being employed, four participants reported being unemployed, and one participant reported being employed but currently not working. Nine of the participants reported the use of medication specifically for their MS, whereas two participants did not. Only two participants within the study (Anica and Amanda) had no children at all, whilst 8 of the participants (Josie, Lisa, Elizabeth, Jenny, Katy, Jane, Michelle and Laura) had decided to have children after a diagnosis of MS. Claire had one child prior to diagnosis but had decided to have no more since her diagnosis. Michelle had three children prior to diagnosis, and decided to have another following diagnosis. Laura was diagnosed with MS simultaneously to conceiving her first child. She later went on to have a second child despite diagnosis. Jenny had previously decided not to have children, but changes to her physical ability due to medication gave her the opportunity to have a child. Katy had one child after diagnosis, and subsequently terminated the pregnancy of a second child due to poor physical ability.
Table 1. Demographic information obtained from participants including assigned pseudonym, age, number of years since diagnosis, MS type and number of children

<table>
<thead>
<tr>
<th>Participant Pseudonym</th>
<th>Age</th>
<th>Years Diagnosed</th>
<th>Type of MS</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Josie</td>
<td>27</td>
<td>1</td>
<td>RRMS</td>
<td>1</td>
</tr>
<tr>
<td>Lisa</td>
<td>33</td>
<td>7</td>
<td>PPMS</td>
<td>1</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>39</td>
<td>9</td>
<td>RRMS</td>
<td>3</td>
</tr>
<tr>
<td>Claire</td>
<td>34</td>
<td>&gt;1</td>
<td>RRMS</td>
<td>1</td>
</tr>
<tr>
<td>Anica</td>
<td>38</td>
<td>5</td>
<td>Not specified</td>
<td>0</td>
</tr>
<tr>
<td>Amanda</td>
<td>32</td>
<td>3</td>
<td>RRMS</td>
<td>0</td>
</tr>
<tr>
<td>Jenny</td>
<td>39</td>
<td>8</td>
<td>RRMS</td>
<td>1</td>
</tr>
<tr>
<td>Katy</td>
<td>38</td>
<td>14</td>
<td>SPMS</td>
<td>1</td>
</tr>
<tr>
<td>Jane</td>
<td>45</td>
<td>28</td>
<td>SPMS</td>
<td>2</td>
</tr>
<tr>
<td>Michelle</td>
<td>33</td>
<td>4</td>
<td>RRMS</td>
<td>4</td>
</tr>
<tr>
<td>Laura</td>
<td>33</td>
<td>6</td>
<td>RRMS</td>
<td>2</td>
</tr>
</tbody>
</table>

Procedure

Two pathways for recruitment were devised.

The first pathway of recruitment was via MS nurses from one NHS site in the North of England. Invitation letters (Appendix G) accompanied by information sheets (Appendix H) were sent to potential participants who had been identified by the MS nurses within their caseloads as meeting inclusion criteria. Interested participants were asked to contact the researcher for further information or to arrange an interview date. MS nurses also told potential participants about the study in their clinics. In this instance,
interested participants were asked to fill in a contact form (Appendix I), giving permission for the researcher to contact them. Research posters (Appendix J) advertising the study were also placed in waiting rooms. Eight participants were recruited via this method, all of whom contacted the researcher after being sent an invitation letter.

The second method of recruitment was via the MS society and involved an advertisement posted on to the MS society website (Appendix K), alongside an advertisement (the same as the poster displayed in waiting rooms and clinics, as above) being posted within the newsletter of an MS society branch in central England. In both instances, interested participants were invited to contact the researcher for further information and to arrange an interview date. Three participants were recruited via this route.

Data Collection

All but one of the women, chose to be interviewed within their homes. The receiving of consent (Appendix L) from the participant was preceded by an ethical and research discussion which included confidentiality, anonymity, the right to withdraw, use of participant data and storage of data. Participants were also asked to complete a short demographic questionnaire (Appendix M) prior to the interview, gathered in order to give some context to the accounts. A semi-structured interview technique was employed so that participants could flexibly discuss their experience of the decision making process, as suggested by Smith et al. (2009) (See Appendix N for interview schedule). The interview schedule was developed after reading other qualitative papers within the area of study and identifying the key issues that had been raised by past participants. The interview schedule was then piloted when the researcher attended an MS support group and asked members to view the interview schedule and make suggestions for any
omissions or alterations. All interviews were audio recorded so that transcription could occur. The lengths of the eleven interviews ranged from between 25 and 75 minutes.

**Data Analysis**

The analytic process of IPA detailed by Smith et al. (2009) was followed closely, commencing with the digital recording and subsequent verbatim transcription of the interviews that took place with participants. Immersion within the data then followed, by reading and re-reading each transcript in order to ensure that the participant was the focus of the analysis. Initial coding of the data then occurred through the researcher noting anything of interest in terms of the descriptive comments that participants used, alongside language use and any conceptual comments. Emergent themes were later developed through thorough consideration of any connections and interrelations between the notes made. This process was then replicated for each transcript. Lastly, following the analysis of each individual transcript, patterns between emergent themes in the transcripts were detected, creating superordinate themes (see Appendix O for an example of data analysis). Consistent with methods of interpretative qualitative research, and therefore IPA, a reflexive attitude was adopted throughout the whole research process, and particularly during analysis. It was imperative to be aware of any beliefs or suppositions held in order to fully appreciate the aims of the study and questions that were being explored, as well as having a greater understanding of the role of the researcher in relation to the world of those whom data is gained from (Shaw, 2010). Despite being a women and therefore having an understanding of the potential innate want for a child, having not yet had children, the researcher occupied an outsider perspective on the phenomenon of having children. Alongside this, the researcher held an outsider perspective on the phenomenon of living with MS but held some insight due to being the daughter of a woman with MS. It was important to recognise these
perspectives when interpreting the women’s stories, as they may have influenced how the participants interacted with the researcher or how the researcher interacted with participants (Dwyer, & Buckle, 2009).

**Validity and Quality**

By following Yardley’s (2000) principles for assessing the quality of qualitative research, attempts to maintain the validity and quality of the study were taken throughout. Sensitivity to context was established by obtaining data of quality through a thorough understanding of the interview process and by immersive analysis of the data. Commitment was demonstrated by maintaining attentiveness to the participants in both data collection and data analysis. Rigour was established through appropriate sampling of participants, interview quality and idiographic analysis which involves an iterative process. Transparency of the study occurred through the definition of clear research stages and coherence was established by ensuring that the study was carried out in a way that implemented the underlying principles of IPA methodology. Alongside this, a reflective diary was kept in order to be attentive of how preconceptions and biases may have an effect on what is trying to be understood. A credibility check of themes and interpretations was also carried out by a researcher familiar with IPA methodology to ensure that themes were grounded within the data.

**Ethics**

Ethical approval was granted for the commencement of the study by the Proportionate Review Sub Committee of the National Research Ethics Service (NRES) Committee, North of Scotland 2, UK (Research Ethics Committee; REC reference number: 13/NS/0040). Further approval was granted for an amendment of the study at a later date by the same Proportionate Review Sub Committee. A request for amendment was made by the researcher as the original protocol for the study suggested that 12-20
participants would be recruited for the study, consisting of 6-10 participants who had decided to have a child after a diagnosis of MS, alongside 6-10 participants who had decided not to have a child after a diagnosis of MS. On further reflection, and due to a suggestion made by a university lecturer, it was decided that the study aimed to look at the decision making process, rather than the outcome, and therefore an amendment was requested for the overall sample size for the study to be reduced to 6-12 participants.

Original approval and approval for the amendment was also received from three research and development departments within three local NHS Trusts in the North of England. Alongside this, the MS Society approved the commencement of the research, and therefore the recruitment of willing participants from any of their branches throughout Britain.

Results

Following analysis, four superordinate themes and eight subthemes emerged from the data (table 2).

Table 2. Superordinate themes and subthemes regarding the motherhood decision in women with MS following IPA analysis

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Nobody knows for sure”</td>
<td>Hope</td>
</tr>
<tr>
<td></td>
<td>Despair</td>
</tr>
<tr>
<td>Dual Identity</td>
<td>The Female Body</td>
</tr>
<tr>
<td></td>
<td>The Disabled Body</td>
</tr>
<tr>
<td>Social Context</td>
<td>Support</td>
</tr>
<tr>
<td></td>
<td>Isolation</td>
</tr>
</tbody>
</table>
Superordinate Theme 1: “Nobody knows for sure”

Throughout all of the participant interviews, the unpredictability of MS and the reality of an uncertain future was a prevalent theme. This was discussed in relation to their life in general as a result of their MS diagnosis, as well as in relation to their decision to have a child or not. The unpredictable nature of MS was often discussed as the worst thing about the disease.

“It’s just the unknown...I hate it. I’ve said many a time, you know, take my leg off, take both legs off! I know what I’m getting up every morning to sort of thing, whereas, MS, you can’t, you just don’t know. It’s horrible for that reason.” (Lisa)

“...the worst thing is that someone can’t say to you, in 10 years this is where you’ll be, in 20 years this is where you’ll be because there’s just no way of knowing like...it could be that actually I’ll get to 70 and I get pretty tired...but it could be that in 10 years time I’m completely wheelchair bound and it’s the not knowing is the really hard thing...” (Josie)

The unpredictability of the symptoms of MS was not only discussed in terms of a long term impact, but in relation to their impact on a day to day basis too.

“MS is the type of condition as well where you can’t say “oh yeah, we’ll go out partying a week on whatever”...it all depended on the day before or the day itself, whether you’d be, have the energy to do it.” (Jenny)
A further source of uncertainty appeared to be the huge individual variation in MS. Participants would compare themselves with others with MS, which highlighted the differences in each individual’s journey and in turn amplified the unpredictability of the disease.

“I met a lady not long after I’d had (name of child) who’d also erm, had MS for so many years and she had erm, a daughter and it left her, erm, with one side really badly sort of damaged. Erm…and I remember looking at her thinking God, well I’ve had a lucky escape.” (Laura)

It was evident throughout the interviews that the unpredictability of MS caused great difficulty when making plans in life and for the future. This was especially true when considering motherhood. The experience of perceiving an uncertain future clearly resulted in uncertainty in terms of becoming pregnant and being unsure of what affect pregnancy could have on their MS.

“It’s all potential isn’t it? Because nobody knows for sure.” (Katy)

As a consequence of the unpredictable nature of MS, the participants described experiencing feelings of both hope and despair within their interviews which ultimately had an impact upon their motherhood decision. Josie portrayed the tension between the two very coherently, whilst discussing the decision to have a child or not.

“I guess that goes one of two ways doesn’t it? It either means that you kind of shut yourself off completely and go well, I’m never going to be able to do it so there’s no point trying, or you just go with it and do as much as you can while you can and like…you know, so yeah.” (Josie).

Subtheme: Hope
It appeared that the lack of certainty within participants’ lives and in relation to their future allowed room for hope. This appeared to be particularly important when considering whether or not to have a child.

“But this isn’t, this isn’t a kind of terminal diagnosis and so like, it erm…it’s a, it’s a maybe diagnosis isn’t it? It’s kind of, these are all the possible outcomes like on a massive scale that you’ll fall somewhere in, like, so yeah.” (Josie)

Participants discussed ways in which they actively strove to maintain hope and employed a number of strategies in order to do this. In one instance, hope was instilled through remaining positive and adopting a healthier lifestyle.

“When they told me, I start living better, eating better food and try healthy living, yoga.” (Anica)

For some, one way of maintaining hope was the use of humour. This appeared to allow them to cope with their diagnosis and potentially alleviate the seriousness of their condition.

“Because it was a bit of a joke, cause we used to have this, whoever got there first and hooked up with AIV, it was sorta like a bit of a…race you know, to see who’d get it off? ...And then when we decided we was gona have children it was like, who’s gona get pregnant first?” (Jenny)

For others, hope was firmly grounded in the reality of the condition and a ‘matter of fact’ approach of facing and accepting the diagnosis appeared central to some participant’s sense of hope.

“I kept thinking “well, it is what it is and you can’t change it and it won’t kill you.” (Claire)
Some of the participants expressed that being able to compare themselves to others allowed them to feel more hopeful. One of the participants in particular was a child of a woman with MS herself, and expressed that gaining information on the different types of MS allowed her to understand the differences in individual experiences.

“So knowing that it was different was quite important, quite nice, erm...because it gave me a bit more kind of hope...that it might not be kind of the same.” (Josie)

The hope generated from the unpredictable nature of the disease, for some, appeared enough to outweigh any potential concerns or risks when considering having children.

“It wasn’t going to stop me, you know, it’s what I wanted and I’d be devastated if I never had a child, you know, so that to me was worth...any risk.” (Katy)

“But then again, you don’t know, anything could happen anytime, so it was worth the risk.” (Jenny)

**Subtheme: Despair**

In stark contrast to the hope generated by the unpredictability of the disease, the theme of despair revolved around the impact and potential impact that MS can have on the individual who has been diagnosed, on relatives and on any potential future children.

Several of the women interviewed, expressed difficulties in coming to terms with their diagnosis, and in coping with the impact that it was having on their lives. In some cases, the participants were diagnosed with particular mental health difficulties.

“So they put me on to the anti-depressant, which I still take now, which is fine.” (Laura)

MS appeared not to be an individual condition however, it affected the whole family and participants explicitly expressed their concerns about the impact of their diagnosis on their immediate relatives.
“It didn’t just affect me, it affected everybody else, it affected my husband, it affected everybody else around me.” (Katy)

Poignantly, Katy also discussed the termination of her second child as a consequence of strong recommendations from healthcare professionals and pressure from family members. Although Katy understood the reasons for the termination, in that she possibly wasn’t in the best physical position to carry and raise a child, the decision was understandably very difficult. She expressed that she had the termination as a consequence of the impact that it would have on her family.

“When I did it, I did it for the right reasons and I did it for everybody else. I didn’t do it for myself, I did it for everybody else. Erm...(long pause)...I, I was, I was mortified, because it wasn’t what I wanted.” (Katy)

Participants shared concerns regarding the uncertainty of or the possibility of inflicting themselves on relatives if their physical ability were to worsen after having a child.

“And it’s, I cannot do this to my husband, I’ll be in wheelchair, kid will be screaming like bloody peacock somewhere, you know, it’s just...no.” (Anica)

Josie, a daughter of a woman with MS herself, described considering whether she should give a child a similar, potentially challenging upbringing occurred.

“I dunno, maybe in my head that feeling of guilt...of...like...is it fair to inflict upon (name of child) what I had when I was younger growing up and things like that.” (Josie)

Similarly, all of the participants interviewed discussed concerns regarding the heritability of MS and whether they could potentially ‘pass’ MS onto their child.
“I was wondering whether I could pass it on to them, because I wouldn’t have had children if I could have passed it on to them.” (Jane)

The uncertainty surrounding their ability to take care of the child in the future as their MS progressed was also a concern shared by all participants.

“I still stand by it wouldn’t be fair for me to have a child. To bring it in to this world when I’m not going to be able to look after it, when I’m not going to be able to provide for it. That’s not why you have kids.” (Amanda)

Despite wanting a child, prior to certain medication, Jenny felt that she would have struggled physically with looking after a child and subsequently decided against attempting.

“It would have been selfish of me to do that to a child and to do that to my husband as well, because he works full time and he’s my main carer, so it would have been unfair for him to…expect him to have her.” (Jenny)

When considering the unpredictability of the disease, Claire expressed concern that if her disease were to progress if she were to have a child, she could resent it.

“I’m quite a selfish person as well, and I think it would be a case of…I’d be afraid that I’d resent that…extra pull on the, whatever resources that I have.” (Claire)

This appeared to be preceded by difficulty in raising a child prior to diagnosis. Claire discussed how raising her son was the most stressful and tiring thing she’s ever done.

“Then on top of that you get fatigue from the MS, imagine that and a small baby…I don’t want to and it’s not fair.” (Claire)

Similarly, Amanda was able to reflect on her experience of helping to raise her nephew, which she found difficult, and allowed her to reason that raising her own child,
alongside having MS was an experience she didn’t want, nor feel she would be able to cope with.

“So I’ve done the requirements if you like of being a parent without actually being a parent. And nah, I’d rather have dogs.” (Amanda)

**Superordinate Theme 2: Dual identity**

The superordinate theme of ‘dual identity’ represents the two sub themes of the female body and the disabled body. It captures the tension between many of the participants’ longing and considered right to be a mother and their acceptance of their diagnosis and the impact it has on their physical ability to be a mother. Many of the women spoke about this perceived inconsistency in identity.

**Subtheme: The female body**

The sub theme of the female body encapsulates the maternal desire of women. For many participants within the study, MS was not going to get in the way of having a child and could not overshadow the desire to parent.

“I always wanted children and having MS wouldn’t change that.” (Josie)

“I was having one no matter what.” (Lisa)

Additionally, for those who did wish to have children, or those who had children, some of the participants discussed how they had always wanted to be a mother, or had always wanted to parent, which gave extra weight to the idea that they were not going to let the MS get in the way of doing that.

“I never aspired to have a massive career, I never, you know, my brother went to university and did his you know, doctorate stuff and I was never that type of person I
always wanted to be a wife and a mum, and a…that’s, that’s all I ever wanted out of life.” (Katy)

In comparison, for some of the participants who did not wish to have children however, there was a rejection of the maternal instinct.

“I’m not the strongest maternal person in the universe so I’m certainly not the kind of person who, who had the massive desire to have a football team of children, if any, to be fair.” (Claire)

Despite there being an indication that motherhood was something some of the participants wanted to do, and felt they had a right to do, there was a continual comparison to ‘the norm’ that suggested that these participants had separated themselves away from the rest of society due to their disability, and therefore they had an acceptance that they were ‘different’. Continuing on from previous conversation however, they did not feel that this should change anything in terms of having a child.

“But as long as they did what they were told to do you know, with their medication and things like that, I think can go on to have an absolutely completely lovely pregnancy, normal pregnancy, same as everybody else.” (Katy).

Many stated that their MS wasn’t the issue, but that pregnancy and motherhood have their own issues that can run the risk of complications.

“And most…health…they look at it is that it can be dangerous for you to have a child and basically it’s dangerous anyway. There’s always complications…why not be able to have a child?” (Michelle)

Similarly, others felt that women can contend with far worse in life, and therefore a woman with MS should not be treated differently to any other.
“...and then another part of me thinks, well, again, it’s not cancer, it’s not...there are worse things.” (Claire)

**Subtheme: The disabled body**

In contrast to this, the disabled body was a theme in which many of the participants identified with in terms of having a disability. They identified that MS had an impact on their working and social lives and therefore could potentially have an impact on their ability to carry a child and to parent. This was particularly the case for those who chose not to have children.

“To me, a parent should be like that, should be active, should be always taking them to school, stuff like that, when they’re at primary school. And like I say, having MS, you’re not going to be able to do that all the time.” (Amanda)

Concerns predominantly referred to difficulties in motherhood, rather than in pregnancy. Claire had a child prior to diagnosis and reported finding raising her child difficult. Her MS has therefore influenced her decision not to have another child as she felt that her MS would make motherhood even more difficult.

“Pregnancy was fine, I had an easy pregnancy with (name of child) and that was all fine so I never sort of worried about the idea of being pregnant but erm, maybe because...having a baby...was one of the hardest times in our relationship, was, was difficult, that was difficult for us to adapt to. So maybe I, I now look at babies like that. Like this big difficult thing.” (Claire)

Claire also expressed that she had other health issues alongside her MS influencing her decision.
“...and I’m overweight which is not really good for carrying a baby with any, without any type of disease and erm...I’m a smoker er, not great, and yeah, there’s just a huge other amount of aspects that I would need to get into place realistically to do that without even considering having MS so...yeah.” (Claire)

Many compared themselves to others without a disability, suggesting that they have added concerns, and motherhood would be more difficult due to their MS.

“It may be different because they are not tired like me, even they said “yeah we are tired of kids”...just if they, they said they are tired, I’m tired a hundred times more.” (Anica)

The disabled body appeared to be a deciding factor in the motherhood decision for several of the participants. For some, being physically able at the time of conception allowed the consideration of children.

“Because I was fit and able bodied, erm, I didn’t think it would erm...spring up and like affect me. Yes it probably could have done, but it didn’t to me.” (Jane).

For others, due to the lack of physical health, raising a child simply didn’t appear to be an option.

“Just because of how ill I was, just because I couldn’t cope, I couldn’t even get up the stairs on my own, you know. I was totally reliant on my husband and erm, there was, there was just no way that I would have been able to bring a child into the equation with my health the way it was.” (Jenny).

**Superordinate Theme 3: Social context**

The theme of social context accounts for the inconsistency of support provided to the participants. Whilst positive experiences of encouragement and support from friends,
family and healthcare professionals were reported, experiences of isolation were also discussed. These experiences of support and isolation appeared unique for all individuals, though many of the participants appeared to have encountered both whilst living with MS.

**Subtheme: Support**

The subtheme of support represents the participants’ discussions of the support and encouragement that they received from family, friends and healthcare professionals which aided them in their motherhood decision making.

“For me to miss out on having a child would be damn right cruel, you know, and nobody wanted that for me, they wanted, they knew how much it meant to me, so everybody was really, you know, encouraging.” (Katy)

Many spoke of how important a support network was in terms of their decision. The knowledge that friends and family would support them and be able to help them in the event of a relapse or consequence of symptoms of MS appeared to make the decision far more viable.

“And yes if I had a relapse I’d got family that would come and help.” (Jane)

“He’s here to help and if he’s not, friends are and if they’re not, family are.” (Laura)

Others derived comfort and support from individuals who had MS themselves, and therefore had a true understanding of the decision that was facing them. For Jenny, talking to a friend who also had MS, allowed her to optimistically discuss the possibility of motherhood, despite any potential risks.
“Whereas speaking with (name of friend), she was in the same boat you know, exactly the same reason, she did see positive as well. You know, all the same sort of reasons not to have children, but she also was that voice that said ‘but why not?’” (Jenny)

Several of the participants considered the support and knowledge of healthcare staff very important and influential in their decision and journey to motherhood too.

“...the guy I was seeing at the hospital knew everything. He knew from my MS nurse, who she was, to what actually goes off, and how I could feel. So really good, and that really put my mind at ease, knowing that there was someone there who’s gona be able to support me if need be, that knew it all.” (Michelle).

This is also demonstrated by Laura, who believed, up until a conversation with her MS nurse, that having a second child could severely disable her. It was that one conversation that encouraged her to have a second child.

“And I said, well I can’t. She said why can’t you? I says well, cause I’ll get real poorly. And she said where you got that from? So I explained about me talking to another lady. She went no, everyone’s individual, she went, you know, it can happen and...she took me through it all.” (Laura)

**Subtheme: Isolation**

In contrast to the theme of ‘support’, a theme running through a majority of the interviews was that of isolation. This appeared to relate the lack of care, understanding and support that participants experienced from friends, family, and healthcare professionals, alongside stigmatisation that individuals with a disability can endure from the wider society. Participants spoke about feelings of isolation arising as a result of experiences of living with MS, alongside feeling isolated within their fertility decision making. Additionally, women discussed feeling isolated in pregnancy and motherhood.
Laura discussed a lack of support and understanding, alongside a loss of friends, in the context of the unpredictability, stress and experienced embarrassment of her MS, suggesting that MS itself can be isolating.

“Erm, and you do sorta start to lose people that you thought were friends because they kinda get fed up.” (Laura)

In terms of healthcare, some of the participants expressed a lack of support that they received from services leaving them feeling isolated.

“But the problem is, like I say, the support in this area, isn’t really good. I kinda feel tossed on the rubbish here.” (Amanda)

Despite feeling relatively content with the care that she had so far received from healthcare professionals, Claire described feelings of isolation in that she had not yet been given the opportunity to discuss the general consequences of her disease with a professional.

“So...I’m at the point now where I’ve got, the drugs are set up, I’ve got contact numbers for various things and I know when the clinics are and all the different pieces, but I still feel like I could do to see somebody to have a proper chat about...stuff...bits and pieces of stuff, erm, really.” (Claire)

She later expanded on this, by suggesting that there may simply not be enough health care professionals to deliver an adequate service.

“I don’t like the idea of complaining about them as if they...erm, as if they’re, you know, as if they’re no good or anything like that, or they can’t be bothered or they don’t care, I don’t think that’s it, I just think...there’s, there’s not enough really.” (Claire)
There were discussions surrounding the feeling of burdening staff from several of the participants suggesting that healthcare professionals can be unapproachable and individuals with MS can feel isolated as a consequence.

“And I really felt like I was bothering the staff when I went.” (Laura)

Considering the motherhood decision more specifically, a lack of support was felt by Katy from a combination of friends, family and healthcare professionals regarding a second pregnancy that she consequentially terminated as a result of being isolated in her decision. Although Katy could consider the attitudes of family and healthcare professionals in the context of her current physical ability, she felt that this decision was taken away from her and was unable to discuss her options with anyone.

“You know, more or less, you must have a termination. Erm, so as much as I wanted everybody to say, “oh that’s fantastic you know, got another one and whatever happens we’ll be there for you” and it wasn’t like that at all. It was “oh my god, you can’t, you know you can’t keep it don’t ya?” and there wasn’t one person that, that said to me, listen if you decide, it’s your decision, if you decide to keep it erm, then we’ll support you.” (Katy)

In opposition to this, other participants described a lack of acknowledgement from their healthcare professionals regarding their pregnancy.

“And we didn’t...get any comment from erm...well not, not that they would comment really, but the fertility people or the MS people...didn’t flag it up, bring it up, nobody batted an eyelid really.” (Elizabeth)

Participants made comments regarding the potential responsibilities of midwives in having a brief understanding of certain diseases so that individuals felt less isolated by their MS.
“But I believe there should be a bit more support and people should know, especially people like...when you are pregnant your midwife should know...just the basic facts about MS and what can happen.” (Michelle).

This was of particular concern to Michelle who experienced differing views from different healthcare professionals.

“...and you've got one from one end and one from another and you’re like eurrghhh, no I'm not breastfeeding.” (Michelle)

A lack of support was also felt by a few participants following the birth of a child leaving them feeling isolated in motherhood.

“Well, they know what MS is and they know that I had it cause it was on my notes, so why would they leave a woman whose a mum for the first time, in a room on her own without tending to her, knowing full well that she could drop the baby, you know?” (Laura).

Alongside this, many discussed the still prevailing stigmatisation of women with a disability and motherhood which contributes to the isolation of women with MS in society.

“What I didn’t like is...and made me feel like they was going to be “oh, she’s pregnant again” because I’ve already got three kids and having another one and having MS. People look at you differently and you think “mmm, but I’m the same as you”. Yes, fair enough I have got MS and I have got a disability and it can cause major problems but...get on with life. It’s up to me what I do with my body, nobody else. At the end of the day, I know I can manage.” (Michelle).
Superordinate Theme 4: The balancing act

Living in the context of uncertainty allowed for both hope and despair when making a decision about motherhood. As a consequence, many of the women appeared to ‘weigh up’ their options, and considered the practicalities of having a child alongside MS in their current circumstances or gathered further information to inform their choice. There was a sense of tension, and discussions surrounding attempts to juggle the influences on their decision.

Subtheme: Practicalities and adaptations

Discussions regarding practicalities and adaptations predominantly involved considerations over the timing of having a child, the compensation or management of their disability and sacrificing their own wants or needs in order to have a healthy pregnancy and child. The women spoke of these strategies in a very ‘matter of a fact’ way, suggesting that in order to have a child, certain things would have to be done.

Of those who had children, many discussed the considerations in the decision making phase regarding any planning that was required or adaptations that would need to be made in order to compensate for their MS symptoms and look after a child safely.

“So everything was adapted for me, erm, so that when I was left on my own in the house with the bairn, everything was always brought downstairs, so everything was like, so I didn’t have to, to do the stairs.” (Laura)

Michelle had contemplated the fatigue that would be associated not only with being a mother, but with MS too and decided on strategies to compensate for this fatigue.

“I’ve got to think about when she is asleep, to sleep myself.” (Michelle)
A few others considered the hiring of aid in order to help with the physical difficulties and demands of having MS and bringing up a child.

“Because they were, you know they were all over the place and it’s quite hard work really. So we did, after, before, before I had the twins when I was about nine months pregnant, we, we got a nanny who comes everyday erm, and she’s brilliant. So without her now...erm, you know I would be fairly lost.” (Elizabeth)

Jenny discussed cutting down her hours at work despite enjoying her job in order to compensate for the fatigue of both the MS and being a mother.

“I’ve just started doing three days a week, cause I was doing five days a week and that was actually more tiring.” (Jenny)

For those who had children, the timing of the decision appeared to be a particularly important practical decision to make and it was something that a lot of the women commented on within the interviews. For Josie, parenthood was something she decided to accomplish sooner rather than later as a consequence of her diagnosis.

“...so, if it changed anything it was how soon we had children, so that I could do more with them and kind of...just in case my physical time is limited.” (Josie)

Similarly, Katy had her child at a younger age than perhaps previously planned due to the advice from healthcare professionals.

“I was told by...by him that you know, having a child is not ideal, but if you are going to have one then you must have one before you’re 30.” (Katy)

Lisa also reflected on her missed opportunity of having children at a younger age, suggesting that her son could have had a sister or brother, had she done so.
“But he might have a brother, he might have a sister. Whereas now, there’s no chance.”

(Lisa)

Dissimilarly, Jenny’s opportunity and decision to have a child only came later in life as a consequence of a particular medication that enhanced her physical ability.

“...even if I’d have talked about it, dreamt about it, whatever, in the situation I was in those times before tsabri, it was never going to happen.” (Jenny)

Medication was discussed by many of the participants in terms of not commencing medication if becoming a mother was a future aspiration or in terms of the termination of its use in order to have a child. Lisa was certain that she wanted to have children, and therefore she did not commence medication until after she had her son. This was a huge practical decision to make.

“I always said that I would have a child, so they didn’t put me on it straight away.”

(Lisa)

For some, considering the discontinuation of medication and the potential for relapse was difficult and this contributed towards their decision not to have a child.

“If I’d have fallen pregnant I would have to stop taking the re-biff and there is a very good chance that if you stop taking that medication it can bring on a relapse, so, again, it’s a double edged thing isn’t it? You need to stop taking the medication for the sake of the baby, but then it’s going to mess you up...so...” (Amanda)

Contrastingly, Jenny’s medication had such a profound effect on improving her physical abilities that it was recommended by her consultant to remain on her medication until she had a positive pregnancy test.
"I stopped taking all of my drugs apart from the tsabri, cause there, there are very different erm...er, things that the doctors, people would say about you know, people that have been on the drug." (Jenny)

Despite this, some of the participants discussed following the recommendations of healthcare professionals, even when it went against their wishes, as they believed that it would give them the best chance of having a safe pregnancy and birth and a healthy child.

"I feared if I, if I didn’t go with the, with what was sort of said and erm, I, I and I, I owed it to my husband and to my family and my child to be as well as I possibly could, to keep myself as well as I possibly could be at the time so...I didn’t question anything, I just...just did it. Just did what I was told to do.” (Katy)

A final consideration discussed by several of the participants was the financial aspect of raising children. It was alluded to that having more children would be more viable should finances not be an issue.

"I think if I won a load of money...I’d do it.” (Jenny).

Subtheme: “You have to get answers”

It was evident throughout the interviews that many of the participants searched for information on MS themselves. General information was sought regarding MS, its symptoms and prognosis, alongside information regarding the impact of MS on pregnancy and pregnancy on MS in order to inform their decision. This seemed to be the consequence of a general interest in the disease that they had been diagnosed with, but also a lack of information and support from healthcare professionals. These attempts to understand were often met by difficulties however, which lead many of the
interviewees to hope that information and clarity can be provided to future generations of women in the same population so that similar experiences do not occur.

Claire described how she received very little information from healthcare professionals at the time of her diagnosis and therefore sought information elsewhere.

“‘I’ve had some leaflets and that’s kind of what it...you’re just kind of fumbling along with it really, so you have to get answers from other people.’ (Claire)

Josie explained how at the beginning of her diagnosis, she searched for information in order to determine a prognosis.

“‘Desperately looking, I think when you’re first diagnosed you’re desperately looking for a where will I be? What does this mean for me?’ (Josie)

This appeared to be consistent with the view from many of the interviewees that it was very unlikely to have the opportunity to discuss matters regarding their MS with healthcare professionals. In particular, two interviewees mentioned that healthcare professionals that they had seen would lead sessions and not allow time for what the appointment had been made for by the individuals with MS themselves.

“‘Let’s talk about the things that I wanted to talk about with whatever small time we have to talk about stuff.” (Claire)

Others described how even when searching for information, they often felt like the expert.

“‘Well, I...the doctor’s actually asked me at one time, can you tell me about this, they didn’t know, erm...so they were asking me erm...what and asking all these different things about MS.” (Jane)

Some women found the internet and other resources useful to guide their research.
“I will have read and realised that having a baby...you’re quite more likely to have a relapse after, after that, in the first however many months.” (Elizabeth).

“I was looking on the forums for the people who were on the same drug, the tsabri. Erm, I’m also part of erm, there’s a Facebook one, erm...that I know, erm, mums with MS, erm, on Facebook and I’m part of that.” (Jenny)

However, it was acknowledged by some of the participants that there is no censoring on the internet, and it can provide information that understandably, can be distressing to read.

“I kind of read a few bits on like forums and things erm...but they tended to upset me because again there’s a lot of people on there kind of saying about like, how they’ve had to put their wives in like care homes and things like that and it’s just not really helpful.” (Josie)

Individuals also mentioned this of MS groups that are in place in order to provide information.

“When I first went, it was quite frightening, because it was sort of like a waiting room for God, you know?” (Jenny)

It was therefore mentioned by several of the interviewees, that information regarding MS, particularly of the nature of motherhood and MS should be readily available to women alongside the opportunity to openly discuss these issues. One participant in particular, felt very strongly about this, and wished that she could have experienced such support whilst considering whether or not to continue with a pregnancy.

“Maybe just seeing that...little bit of hope...might have made it harder for me, I don’t know. But at the time that’s what I was looking for and there was none. There wasn’t
any at all anywhere. Erm, and, or even just, just speak to somebody that had been in a similar situation to me, or having any sort of information erm...even say from my MS nurses or...somebody there that...that would erm...look into on behalf of me, and the positive rather than negative. Then maybe we wouldn’t feel so trapped into making that decision, I don’t know.” (Katy)

Discussion

The current study has provided an insight into the lived experiences of women with MS and their motherhood decision which appears to be complex and multi-factorial. This study lends support to the use of qualitative methods such as IPA when studying human phenomena, due to it being an approach that commits to exploring how people make sense of significant life experiences. At present, there are very few pieces of qualitative research exploring the phenomenon of fertility decision making in this population, and only one other study has been carried out in the UK (Kosmala-Anderson & Wallace, 2013). The current study aimed to increase information within this area by exploring the decision of both women who have decided to have children and women that have decided not to have children.

Findings from this study suggest that MS has a significant impact on the lives of those affected. The presence of the disease appeared to impinge on their ability to make both long term and short term decisions and therefore had an influence on day to day plans as well as lifelong aspirations, including the motherhood decision.

The findings of this study relate to the categorisations of women without children established by Cannold (2004) who separated women into ‘childless by choice’ and ‘childless by circumstance’. The category ‘childless by circumstance’ was subsequently separated into two additional categories; ‘thwarted mothers’ and ‘waiters and watchers’. For most of those within the current study who always wanted children, the decision
remained very clear and such participants, although having concerns about their MS, were willing to overcome any difficulties in order to have children. This therefore encapsulates the idea of a woman who potentially could have become a ‘thwarted mother’ but who overcame any obstacles of MS that lay in her way in order to mother. This suggests a sense of agency and choice in the motherhood decision within women with MS. For others, physical ability was a significant contributing factor that led to a decision not to have a child, despite the want of a child. In such cases, these participants would be considered a ‘thwarted mother’ suggesting that the decision can potentially be taken away by severity or perceived severity of the disease. Other participants however, appeared to have a weaker maternal urge for a child, discussing other reasons for not having children, rather than solely the potential consequences of MS. Rather than being thwarted by their MS, within the categorisations created by Cannold (2004), such women could be described as ‘childless by choice’ or ‘waiters and watchers’.

The most significant effect that MS had on the participants’ lives arose from its unpredictability, as represented in the superordinate theme ‘nobody knows for sure’. Individuals with MS have to cope with unpredictability on a day to day basis, in terms of deteriorating health, increasing support needs and ever changing intimate and social relationships (McCabe, McKern & McDonald, 2004). The fact that MS affects each individual differently also creates uncertainty. Within the subtheme ‘hope’ however, participants spoke of how the unpredictability of their illness creates leeway for hope; hope that having a baby and being a mother is still a possibility despite having a potentially disabling disease. Hope is an essential part of life, embodying our visions of the future and the direction that our lives may take (Morgante, 2000). Hope has been explored as a mechanism for coping with chronic illness and it has been suggested that existence of hope for someone facing a chronic illness can provide the energy necessary for maintaining health and improving well-being (Morgante, 2000). In a study which
attempted to understand hope in patients with MS (Soundy et al., 2012) the authors found a paradox within participants’ responses, explaining that although accepting of their illness, participants would strive to defy the illness. They found that participants defied their illness by maintaining or retaining aspects of their life that were important to them and also found that hope was generated by gaining a sense of purpose in life following a diagnosis of MS. In the current study some participants described defying their illness by becoming a parent, or retaining their decision to become a parent in spite of MS. For some women living with MS, becoming a parent may create hope by giving them a purpose in life.

Positive psychology, which studies the processes and conditions that contribute to the optimal functioning of individuals or groups (Gable & Haidt, 2005) may be of interest in future research in this area, given that some of the participants in the current study discussed attempts to think and live positively. As an example, several participants discussed using humour as a way of actively striving to maintain hope despite illness. On several occasions within the current study, participants would refer to the fact that they could be ‘worse off’. Hinds and Martin (1988) found that this was also a strategy used by adolescent cancer patients in order to banish despair.

These strategies employed by the participants represent ways of coping and dealing with difficult or stressful situations associated with their MS. In contrast to previous research which suggests that individuals with MS are more likely to use emotion focused styles of coping and more specifically, detached styles of coping (avoidance), rather than problem focused coping (seeking social support, focusing on the positives) when compared to a group of individuals from the general population (McCabe et al., 2004) many of the participants within this study used problem focused strategies in order to avoid despair. This discrepancy may be explained in terms of the potential
strength and resilience of modern women in the face of a chronic disability. As such, other positive psychology constructs such as resilience (Ong, Bergeman, Bisconti & Wallace, 2006) and optimism (Norem & Chang, 2002) maybe worthy of future research.

Hope was often present alongside feelings of despair. The subtheme ‘despair’ was discussed in terms of participants being affected physically by their MS and the uncertain possibility of this worsening if they were to have a child. Participants spoke of not wanting to burden family members or any potential children. For some women these feelings of despair about their MS and their uncertain future resulted in the decision not to have children. All participants also discussed the potential for despair in terms of whether MS was heritable and therefore whether or not they could ‘pass MS on’ to any child that they decided to have. With this in mind, some participants discussed further use of problem focused strategies such as seeking information in order to gain knowledge regarding any uncertainty of having a child, alongside the implementation of compensation strategies in order to overcome any potential difficulties that child bearing may bring (as represented within ‘The Balancing Act’ superordinate theme), so that they could have a child. Alternatively, individuals made a conscious and active decision not to have a child which could also be considered a problem focused strategy.

The superordinate theme of ‘dual identity’ captures some of the participant’s desire to mother a child (‘The Female Body’) challenged by the acceptance of their disability and the fact that they may struggle to take care of a child (‘The Disabled Body’). The women within the study expressed their ideas of a ‘good mother’ in terms of being active, being able to cook, run, play and carry their child. They were all aware that they were not able to do such things, or at some point in the future, may not be able to do such things. Currently, societal norms offer very few options to women in terms of
motherhood; women are expected to become mothers and be ever nurturing and available to their offspring (Choi, Henshaw, Baker & Tree, 2005). It is therefore unsurprising that many of the participants within this study who decided to have children reported always having wanted to. The difficulty arose for such women when they decided to be a mother who has a disability. In complete contrast to the ideals of a ‘good mother’ participants expressed concern that they would not be able to take care of a child properly, in terms of feeding it or changing it, and others discussed the possibility of not being able to walk their child to school or play with them in the park. Interestingly, participants focused on the physical aspects of MS in relation to caring for a child and no participants discussed any cognitive difficulties. This is in line with the fact that MS is considered predominantly a physical disease and therefore cognitive deficits are often overlooked (MS Trust, 2011). A woman with a disability is considered by society to be a patient and receiver of care, rather than a woman capable of childbirth and parenting (Grue & Tafjord Laerum, 2002). Such societal discourses are unhelpful to women with a diagnosis of MS. Alongside the stress of MS due to the unpredictability of the disease, women can experience fear, guilt and a loss of self-worth (Maybury & Brewin, 1984). Societal stigma therefore only magnifies these feelings and could lead to further complications within the motherhood decision, or a woman forgoing motherhood all together. If motherhood were to be abandoned, the women could miss any psychological benefits that being a parent can bring, such as a sense of self or hope. Although participants within this study reported wanting to be treated the same as others, and not stigmatised for being a mother with a disability, the acknowledgement of potentially providing inadequate care was a concern highlighted by all participants whether they chose to have a child or not.

Within the superordinate theme of ‘social context’ both the subthemes of ‘support’ and ‘isolation’ that participants felt from friends, family and healthcare professionals in
relation to not only the decision making process but their experiences of living with MS were discussed. The support of a spouse or partner appeared imperative. Without the support of friends, family and healthcare professionals, it appears that many of the participants within this study would not have considered motherhood. For those who decided not to have children, this was a contributing factor. This was often spoken of in the context of a potential relapse and the support that an individual would need from others in order to provide for a child during such times. It was also discussed in relation to the support of those around them in terms of views of ‘suitability’ of motherhood. Participants spoke of either the encouragement or discouragement that they received from family, friends and health care professionals in relation to having a child. These contributions to the decision have already been highlighted in previous literature on the motherhood decision within those with MS, particularly in the study by McNary (1999) who found that her participants discussed MS as a ‘family disease’. Prunty et al. (2008) found that women in their study were unwilling to have children if they didn’t think they would be able to cope, and discovered that those who didn’t have children often did not have relatives living nearby. Smeltzer (2002) also identified social support as a factor that influenced her participant’s decision to have a child or not, including the level of encouragement they received from their partner and friends in relation to their decision and the availability of family and friends should severe symptoms of MS occur within the postpartum period.

Though participants felt that support from healthcare professionals was an influential and important factor within their experience of MS and fertility decision making process they found that it was not always available. Many felt isolated from their healthcare professionals or had experienced feeling a burden to staff, and therefore felt apprehensive about approaching a MS nurse or midwife in regards to their decision.
In relation to the feelings of isolation, the subtheme ‘you have to get answers’ within the superordinate theme ‘the balancing act’ was identified within the data. This subtheme symbolised the information that needed to be accessed in an attempt to make a decision regarding parenthood. Many participants within the study discussed having researched information for their own benefit, which is consistent with views that this knowledge is not readily available from health care professionals, or that this knowledge can be inconsistent between healthcare professionals (Kosmala-Anderson & Wallace, 2013). The independent research of participants is a representation of the increase in access to professional information that lay people now have (Sarangi & Clarke, 2002). The rise of access to such information, alongside their own experience reportedly left some of the participants in the role of expert. This role appeared to be considered undesirable by participants though, considering that they were attempting to seek rather than provide information. The role of expert that some of the participants had to undertake, is also inconsistent with some of the participant’s demonstrated compliance with healthcare professional’s advice. Harrison, Kushner, Benzies, Rempel and Kimak (2003) looked into the involvement of women with high risk pregnancies in their health care decisions and found that some women prefer to take a passive role in this decision making, trusting the professionals to use their expert knowledge to do what they believe is best.

What appeared important throughout the interviews though, was that the simple provision of information and the acknowledgment or opportunity of a discussion regarding motherhood would have given the participants a greater sense of control over their decision, no matter what choice they decided upon.

‘The balancing act’ superordinate theme which contains the ‘you have to get answers’ subtheme represented the ‘weighing up process’ that women attended to, in order to
decipher whether any potential benefits to having a child outweighed any potential risks. Although several of the women discussed knowing that they wanted to have children, and refused to allow MS to get in the way, it appears that this balancing process was effortful and well-considered, with the participants, including those who had decided not to have children, still revisiting their choice in hindsight. At the time of decision making, in light of the unpredictability of the disease, the discrepancy in identity of their female and disabled bodies, and in consideration of the support and knowledge available to them, not only did women seek information, but also considered the implementation of strategies in order to help them with their decision making. The subtheme ‘practicalities and adaptations’ represents the considered practical strategies that would need to be implemented in the event of deciding to have a child. These factors related to a range of vocational, financial and physical factors and particularly for those who went on to have children, were often discussed in terms of adaptations that had to be made in order to have and bring up a child safely. This subtheme supports the theme of ‘Concerns about baby’s well-being, Child Care, and Parenting’ identified in a previous paper by Smeltzer (1994) which studied the concerns of pregnant women with MS. Within this theme, participants discussed the household changes and arrangements required to take care of their infant. It also supports the theme ‘Conserving energy’ discussed by Payne and McPherson (2010) in their study which explored motherhood and MS.

Despite the decision being complicated by factors relating to their MS, the fertility decision making of women with MS can still be considered in terms of the Theory of Planned Behaviour (Ajzen, 1991). The TPB suggests that behaviours are preceded by intentions, but that intentions are influenced by three groups of factors. The first factor includes the positive and negative attitudes felt by individuals towards having a child. Within the current study, themes of both hope and despair were identified in terms of
the decision to have a child or not, which appropriately represent the positive and negative attitudes in the TPB. The second group of factors that influences the intentions of fertility decision making within the TPB is that of subjective norms which have a strong link to the ‘dual identity’ superordinate theme within the current study and the societal norms of motherhood and stigmatisation of disabled motherhood. There is also a link here, to the ‘social context’ superordinate theme and the attitudes of family members, friends and health care professionals, in terms of their views of how ‘appropriate’ the pregnancy and motherhood would be. The superordinate theme of ‘social context’ alongside the superordinate theme of ‘the balancing act’ also map onto the third group of factors that influence intentions of fertility decision making: perceived behavioural control. This encapsulates the support of others, the knowledge regarding motherhood in MS and the adaptations made.

Interestingly, Ajzen (2010) himself acknowledged, that his TPB does not involve the intentions of a partner in regard to fertility decision making, which was an important component of the decision making process for the women in this study. Further research has taken place which has also supported the importance of the partner’s intentions within fertility decision making (Barrett & Wellings, 2002). Ajzen (2010) therefore clarified that the close relationship between intentions and consequent behaviour only remains true if the behaviour is specified in its four elements: the context, the time, the target, and the action (Ajzen, 2010). In the specific domain of fertility, the context would be the couple, the time would be the timeframe in which they wish to conceive, the target would be a child and the action would be to give birth. For the women within this study, several discussed the timing of having a child in the midst of MS, and how this changed due to their diagnosis.
Strengths, Limitations and Future Research

A strength of the current study is that the participants were involved in different services and therefore have not all encountered the same care teams and professionals. The relatively small sample size within this exploratory study could be considered a limitation, however the in depth material produced from the interviews provides imperative insight into the experiences of women with MS and their motherhood decision. IPA places importance on the homogeneity of a sample so that convergence and divergence can be examined in detail (Smith, Flowers & Larkin, 2009) and all women within this study did have a diagnosis of MS, and discussed the impact of this diagnosis on their decision to have a child or not. Although data was collected on the type of MS that the women had and some women discussed their own perceptions of their disability throughout the interview, it may have been useful to have collected some individual, subjective data on the severity of their condition, to examine whether this had an impact on their decision to have a child or not. It is acknowledged however, that due to the progressive nature of the disease and the retrospective approach of the study that an individual’s disability and therefore perception of their disability may have changed since making their decision. With the methodology of IPA suggesting that no one ‘true’ form of reality exists though (Smith & Osborne, 2003), it is unlikely that this would be problematic. Despite this, future studies may choose to use a sample that are in the midst of their decision making process, or may conduct longitudinal studies to assess whether the decision changes with time and circumstance.

Additionally, further information from participants within the study suggested that, due to the unpredictability of the disease, women have prospective concerns about their future parenthood. As a consequence, research could consider exploring the lived experiences of mothers with MS.
A specific limitation of this study involves the method of recruitment and sampling bias. All participants were recruited via invitations sent in the post, or advertisements and posters on websites, in newsletters, in MS centres and in waiting rooms and clinics. The sample within this current study therefore ‘opted in’ to the opportunity to participate suggesting that they were willing to discuss their MS and motherhood decision. This study may therefore have neglected the experiences of a population of individuals with MS who are more isolated in their disease or unwilling to discuss their experiences.

This study also only involved women who were Caucasian and therefore did not explore the motherhood decision within an ethnically diverse population. Future research looking into the cross cultural differences may therefore be considered, as the result of stigma surrounding disability within other cultures may provide contrasting findings (Becker & Arnold, 1986).

Similarly, to adhere to the homogenous principle of IPA, this study only interviewed women, though it appears that men have been neglected within such research. Interviewing males with MS to gather information on their experience of the decision to have children or not following a diagnosis would therefore add to the literature about this population. Alternatively, due to the importance of the spouse or partner within the fertility making decision, couples could be interviewed together.

Additionally, despite the current study having a sampling bias towards women who had children, it sheds light on the complexity of the population. Whilst some women in this population may never have wanted children, others may have many children. Whilst one woman may have had all of her children after a diagnosis, another may have had one before and one after. Another woman may have chosen to terminate a pregnancy in order to avoid motherhood. It is therefore important within future research that all of
these subgroups are considered so that any factors influencing the decision are not ignored.

Considering that MS is predominantly diagnosed during the childbearing years and considering the influence of MS on time of first birth that several women within this current study discussed, the need for a discussion about the motherhood decision must occur relatively soon after diagnosis. As this is a potentially sensitive topic however, research could be carried out with women with MS in regards to their motherhood decision, and how long it took after a diagnosis for them to consider parenthood.

Interestingly, women employed several different coping strategies and incorporated compensatory strategies into their lives to aid their disability when facing motherhood. Further research could look into not only the emotional aspects of coping that help women with MS when considering or participating in parenthood, but also the practical strategies employed too, given the potential clinical benefits that such an understanding might add.

A final consideration of this research regarding limitations is that despite being a woman, the corresponding author has never had children and therefore occupied an outsider perspective on the phenomenon of having a child or making the decision to have children. This may have had an influence on how the stories and accounts of the participants were interpreted. A credibility check of themes and interpretations was carried out by a female researcher who has a child to allow for the opportunity to draw on other insights.
Clinical Implications

For women who are considering motherhood, key clinical implications relate to the information available to them alongside educating healthcare professionals and the community surrounding women with MS.

Though the sample was small and therefore it is difficult to make generalisations, the current study highlights how the fertility making decision for women with MS is a complex one and one that is often revisited. Though very little regret was spoken of within the interviews, the decision appears to continually be reviewed as a consequence of the constant unpredictability of the disease, ever changing ability and social support.

It is therefore important that motherhood within MS is not a taboo topic. Though it cannot be assumed that every woman wishes to mother, it also cannot be assumed that a disabled woman does not wish to and the importance of allowing such conversations to occur, alongside the provision of knowledge cannot be underestimated. Though unethical to discuss this at point of diagnosis, this study has highlighted that women perceive having children at a younger age as beneficial due to the symptoms of MS. It is suggested that such a topic should therefore be raised as soon as felt morally possibly. MS nurses are in the best position to provide such information and can liaise with neurologists and midwives in order to provide maternity care tailored to the specific individual. Partners or family members and friends should also be encouraged to attend such discussions as the current study has indicated that the decision is influenced and encouraged or discouraged by those around the individual with MS.

It is noted that a large number of women quickly accepted the opportunity to take part in this research which could be a reflection of their willingness, but also need, to discuss their decision and the difficulties that they face. Despite 20 years having passed since the first piece of qualitative research explored the motherhood decision in women with
MS, it still appears that some of the concerns that this population has regarding pregnancy and motherhood are being neglected. In order to address this, training about MS and any potential issues that can arise when considering motherhood could be provided to those who could possibly work with women with MS, but who do not have specific training on MS. Such training may create confidence of knowledge within these professionals which will in turn facilitate the discussions described above and consequently ensure that consistency of information and care is perceived by the recipients. Although the women in the current study highlighted different experiences of care, for many, this appeared to be lacking.

There also appears to be a need for peer support as several of the women within the current study discussed the use and benefits of talking to another individual with MS in order to aid their decision, or discussed how helpful the opportunity would have been. Although MS groups are available, they were discussed with fear by some of the participants within the current study due to the level of disability encountered and therefore such groups may not be suitable for a younger generation with sufficient ability to consider parenthood.

For those who do not pursue motherhood, implications still apply to healthcare professionals in terms of whether these women later revisit their decision. As has been discovered within the current study, the motherhood decision for women with MS is complex and may be re-considered due to ever changing circumstances. In this instance, it would be important to have a discussion with the woman regarding her wishes, and her potential options.

**Conclusion**

This study provides valuable insight into the experiences of women with MS and their motherhood decision. Whilst both women who decided to have children, alongside
women who decided not to have children were involved within the research, several themes occurred across interviews with participants. This suggests that despite two opposing outcomes, there are some commonalities within the experience of making the decision. Suggestions are provided to aid this decision making process both for the women themselves, alongside the systems providing care around them.

**Declarations of Interests**

This research was funded by the University of Hull, UK, as part of fulfilling a Doctorate in Clinical Psychology qualification. No other interests are declared.
References


Part Three:

Appendices
Appendix A

Instructions for contributors

Journal of Biosocial Science

Subject areas

The *Journal of Biosocial Science* publishes original papers, short reports, reviews, lectures and debates dealing with social aspects of human biology, including reproduction and its control, gerontology, ecology, genetics and applied psychology, with biological aspects of the social sciences, including sociology, social anthropology, and education, with social and biological elements of nutrition, growth and development, health and epidemiology, and with biosocial aspects of demography. Preference is given to material that is clearly interdisciplinary.

Submissions

Manuscripts should be submitted as email attachments to the Editor at cmg26@cam.ac.uk. Please send a PDF of the complete paper with line numbers added along with a copy of the text and tables in Word, and press-quality figures prepared according to the instructions given in the section *Guidelines for the Preparation of Manuscripts*.

Papers are considered for publication on the understanding that they have not been, nor will be, published elsewhere in whole or in part, and that they, where customary, have been approved for publication by the relevant Head of Department. The Editor’s decision on all editorial matters is final. The Editor reserves the right to make minor literary emendations but manuscripts will not be substantially altered without consultation with the author. The author is responsible for the accuracy of quotations, tabular matter and references.
Guidelines for the Preparation of Manuscripts

General information

Papers should be written in English using British spelling (as in the Oxford Concise Dictionary), except for quotations, which should follow the original. Note that the following are not used in the journal:

Personal pronouns (I, we, our etc.).

Endnotes.

Footnotes.

There is no word limit for full papers in the journal, but these should be succinct, and verbosity is strongly discouraged.

Arrangement of papers

Manuscripts should bear the title of the paper, authors’ names, a brief address (not full postal address) for each co-author, name and email address of the corresponding author and a short running heading (maximum 50 characters and spaces).

A short summary should precede the text. It should consist of one unnumbered paragraph. Subsequent text is then generally divided into Introduction, Methods, Results, Discussion and Reference sections, but deviations from this format are acceptable.

Acknowledgments should be made a separate section at the end of the text.

Tables

Tables should preferably be constructed in Word* using the ‘Tables’ facility. Each Table should not exceed in size the equivalent of one Journal page\(^2\). Tables should be referred to in the text by Arabic numerals, e.g. Table 3. Each Table should have its own self-explanatory title.

\(^{2}\) Please note that for ease of reading the size of Table 1 within the meta-synthesis exceeds the journal page limit. This will be amended upon submission.
*Tables constructed in Word should have a new row of cells for each line of data: do not separate data within columns with paragraph returns.

**Figures**

Simple charts can be constructed in Excel, PowerPoint or SPSS, although Excel is preferred. On acceptance, these will be edited by the Journal office to produce a consistent style within the Journal. Other figures can be sent as high-quality graphic files (minimum 300dpi) or PDFs with embedded fonts. Note that the journal does not use colour, and figures are printed in black/white/grey tones.

Note that Figures should not be enclosed by boxes. Do not use gridlines or upper and right-hand axes. The font for legends and labels should be san-serif (such as Arial) and the font size chosen such that this is approximately 9-point when reduced to the size when printed in the Journal. Any shading should be homogeneous; stippling should be avoided as this does not reproduce well.

Figure legends are re-set by the printers: do not incorporate these within the figures, but include with the text Word file.

**Equations**

Simple mathematical equations should be set by inserting special symbols in the text in Word. Complex equations should be set using Microsoft Equations Editor. Please ensure that single-letter variables are in italics.

**References**

References in the text should be given by author(s)’ name(s) and date in parentheses. Where several references are given together they should be in chronological order, separated by semicolons. When a paper written by two authors is cited, both names are given; for three or more authors only the first name is given, followed by ‘et al.’. An alphabetical list of references should be given at the end of the text. Each journal
article entry should include, in order: author(s)’ name(s) (in regular case [not upper case], bold typeface), initials, year of publication in parentheses, article title, journal name in full (not abbreviated), volume number and first and last page numbers:

**Kleinman, J. C., Pierre, M. B., Madans, J. H., Land, G. H. & Schramm, W. F.**


If the paper is not yet assigned to a specific issue (incremental publishing) and the Digital Object Identifier (DOI) is known, it can be given at the end of the citation entry:


10.1017/S0021932003001615.

For books and conference proceedings (try to avoid citing the latter in the main text: cite peer-reviewed primary publications instead), editor(s)’ names, publisher and place of publication should be included:


Unpublished material may be referred to sparingly in the text, by giving the authors’ initials and names followed by ‘unpublished observations’ or ‘personal communication’.

**Short Reports**

Manuscripts for publication as Short Reports should be of an overall maximum length of 2000 words, including summary and references. This is equivalent to approximately four printed pages of the Journal.

If Tables and/or Figures are included (maximum of one page), the text should be limited to 1500 words.

The report should have a short summary, followed by a single text section that is not divided into introduction, results and discussion sections etc. (as in full papers). These should be submitted to the Journal in the same way as full papers (see Submissions).

**Debates**

A section is reserved for publishing comments (maximum 500 words) on papers appearing in previous issues. Authors whose papers are involved will be given the opportunity for simultaneous response.

These should be submitted to the Journal in the same way as full papers (see Submissions).

**Proofs**

Proofs will be sent by email to the corresponding author (unless we receive instructions otherwise) for minor corrections and should be returned to the Editor within 3 days of receipt. Major alterations to the text will be accepted only at the author’s expense.

**Offprints**

An electronic, PDF version of each article will be supplied free of charge to the
corresponding author, or to a co-author upon request.

**Online publication**

Accepted articles are published online on the *Cambridge University Press* journals website in *FirstView* prior to assignment to an issue. These are accessible to journal subscribers at:

http://journals.cambridge.org/jbs

3rd December 2013
Appendix B

Qualitative Research Assessment Tool

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### Theoretical Approach

- Clearly focused question(s) which seek to understand subjective experiences. Clearly focused aims/objectives
- Aims appear justified based on background literature
- Qualitative methodology most appropriate
- Underpinning assumptions and values discussed

### Recruitment and Data Collection

- Sampling strategy reported
- Data collection methods reported
- Method used to collect data appropriate for the research question(s)

### Participants

- Characteristics of participants reported
- Sample is representative of the population studied
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<th><strong>Main Findings</strong></th>
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| **Main conclusions relate to the**    |  |
| **questions**                         |  |

| **Implications of research reported** |  |

| **Limitations of research reported**  |  |

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| **Role of researcher clearly**        |  |
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| **Further Comments**                  |  |
## Appendix C - Independent Quality Assessments - Researcher HM

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Appendix D

Guidelines for Authors: Disability and Rehabilitation

Disability and Rehabilitation

Instructions for Authors

*Disability and Rehabilitation* is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

*Disability and Rehabilitation* is organised into sections: Reviews; Research Papers; Case Studies; Perspectives on Rehabilitation; reports on Rehabilitation in Practice, Education and Training and Correspondence. Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Submissions and Peer-Review

All submissions should be made online at *Disability and Rehabilitation*’s ScholarOne Manuscripts site: http://mc.manuscriptcentral.com/dandr

Authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is ‘Anonymous’ or ‘Not Anonymous’ during manuscript submission, and should pay particular attention to the below:

Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the “Main
Document” and will be sent to the referees. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.

**Authors who wish to be indentified** should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the “Main Document”.

**All submissions** should include a separate title page that contains contact information for the authors(s). This should be uploaded as a “Title Page” and will not be sent to referees.

If a paper is deemed to be acceptable for publication pending minor revision, the author(s) names may be disclosed to the referees when the Editor’s decision is made, irrespective of whether the authors names(s) were included as part of the original submission. Every effort will be made to keep the author(s) name(s) anonymous, if required, should the paper require extensive revision and further peer-review. If authors wish to remain anonymous throughout the second round of peer-review, they are reminded not to include identifying information in the “Authors Response” section during the upload of their revised paper.

Every paper that is revised and resubmitted must clearly indicate the parts of the manuscript that contain amendments, by highlighting the revised text in a different colour or by using ‘Track Changes’(for minor revisions).

Systematic Reviews should be submitted as a “Review” and Narrative Reviews should be submitted as “Perspectives in Rehabilitation”. All Systematic Reviews will be automatically submitted for the annual Best Review Paper competition.
**Education and Training**

This is a new section for the journal. It will publish papers relating to the education and professional training of those working in the field of rehabilitation. Papers are encouraged which develop innovatory approaches to this process and provide multidisciplinary and international comparisons for those working in the field. Through this new section it is intended to contribute towards the development of education and training within these professional groupings.

Papers should be submitted with any tables, figures, or photographs, all of which should be of high quality suitable for reproduction. Submissions should be in English presented in double line spacing.

Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given. Photographs of patients should be avoided, but if essential, patients' consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patients’ eyes.

**Word Limit**

There is no stated word limit to papers submitted to *Disability and Rehabilitation*. It should however be noted that space is at a premium and therefore succinct and well-constructed papers are more likely to be reviewed positively. However, the key to evaluating a paper will be the quality of the work along with the methodology adopted particularly for qualitative studies which do tend to be longer.

*Disability and Rehabilitation* considers all manuscripts at the Editor’s discretion; the Editor’s decision is final. Please see below for information on the Journal’s Appeal Procedure.
Disability and Rehabilitation considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to Disability and Rehabilitation, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which Disability and Rehabilitation incurs, and their papers will not be published. Copyright will be transferred to Disability and Rehabilitation and Informa UK Ltd., if the paper is accepted.

IMPLICATIONS FOR REHABILITATION

A feature of the Journal is a boxed insert on “Implications for Rehabilitation”. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature. This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission.

Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy

• Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.

• Reconstructive surgery is a technique available to this group.

• In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis
• Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).

• People with MS have complex reasons for choosing to exercise or not.

• Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Example 3: Community Based Rehabilitation

• Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.

• CBR needs to be “owned” by those involved and subject to re-interpretation to be effective in other cultures.

Standardised Reporting Guidelines

We encourage Authors to be aware of, and to take into account standardised reporting guidelines when preparing their manuscripts.

The table below provides information about guidelines for different study types:

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Name</th>
<th>Source</th>
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<tr>
<td>Case Reports</td>
<td>CARE</td>
<td><a href="http://www.care-statement.org/">www.care-statement.org/</a></td>
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<tr>
<td>Diagnostic Accuracy</td>
<td>STARD</td>
<td><a href="http://www.stard-statement.org/">www.stard-statement.org/</a></td>
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<tr>
<td>Observational Studies</td>
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<tr>
<td>Randomised Controlled trial</td>
<td>CONSORT</td>
<td><a href="http://www.consort-statement.org/">www.consort-statement.org/</a></td>
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<tr>
<td>Systematic Reviews, meta-analyses</td>
<td>PRISMA</td>
<td><a href="http://www.prisma-statement.org/">www.prisma-statement.org/</a></td>
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</tbody>
</table>

Whilst the use of such guidelines is supported, given the multi-disciplinary nature of the Journal, it is not compulsory.
Manuscript Preparation

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. These should be submitted as ‘Image’ files during submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Structure of Paper

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files).

An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

Title Page

A title page should be provided comprising the manuscript title plus the full names and
affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as “title page” on ScholarOne Manuscripts. This will not get sent to referees.

**Abstracts**

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title page, preceding the main text.

**Purpose** State the main aims and objectives of the paper.

**Method** Describe the design, and methodological procedures adopted.

**Results** Present the main results.

**Conclusions** State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.

The abstract should not exceed 200 words.

**Nomenclature and Units**

All abbreviations and units should conform to SI practice. Drugs should be referred to by generic names; trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

**Copyright Permission**

Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than fifty word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa UK Ltd or the contributor. This applies both to direct reproduction or 'derivative reproduction' - when the contributor
has created a new figure or table which derives substantially from a copyrighted source.

**Code of Experimental Ethics and Practice**

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

**Tables, figures and illustrations**

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written $10.0 \pm 0.25$ indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written $10.0 \text{ SD } 2.65$.

Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4+; a group aged 3.50 to 4.49 years 4± and a group all precisely 4.0 years, 4.0.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case.

'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

*Insert table 2 about here*\(^3\)

Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic,

\(^3\) For ease of reading, tables and figures were embedded in the main body of the text.
Tables

Tables should be used only when they can present information more efficiently than running text.

Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text.

Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible.

Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher.

Please note that it is in the author's interest to provide the highest quality figure format possible.

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose.

The Acknowledgments section details special thanks, personal assistance, and
dedications.
Contributions from individuals who do not qualify for authorship should also be acknowledged here.
Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/freelance writer), grant support and numbers, and statements of employment, if applicable.

**Acknowledgments section**
Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

**Declaration of Interest section**
All declarations of interest must be outlined under the subheading “Declaration of interest”. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: The authors report no declarations of interest. When submitting a paper via ScholarOne Manuscripts, the “Declaration of interest” field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

**Mathematics**
*Click for more information on the presentation of mathematical text.*
References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

Examples are provided as follows:


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4 For ease of reading, the American Psychological Association (APA) reference style was adopted instead of the Council of Science Editors (CSE) citation and sequence format.


**APPEAL PROCEDURE**

*Disability and Rehabilitation and Disability and Rehabilitation: Assistive Technology*

The Editors of both Journals will respond to appeals from Authors relating to papers which have been rejected.

The Author(s) should email the Editor outlining the concerns and making a case for why their paper should not have been rejected. The Editor will undertake one of two courses of action:

1: The Editor Accepts the Appeal

I. In this case the Editor will secure a further review making available confidentially the relevant information for the reviewer

II. The Editor on receiving the review will either accept the appeal and therefore invite a resubmission for further review; or reject the appeal and no further action will be taken.

III. If an appeal is rejected there will be no further right of appeal within the jurisdiction of the Journal.

2: The Editor does not uphold the Appeal

I. If the Editor does not accept the appeal and is not prepared to secure further review
the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of Disability and Rehabilitation, the Editor of Disability and Rehabilitation: Assistive Technology will be contacted, and if an appeal is not upheld by the Editor of Disability and Rehabilitation: Assistive Technology, the Editor of Disability and Rehabilitation will be consulted.

II. The Editor will either confirm the decision or recommend that a further review be obtained.

III. Therefore, if both Editors agree that the appeal should not be upheld there will be no further right of appeal within the jurisdiction of the Journal.

Dave Muller, Editor in Chief, *Disability and Rehabilitation*

Marcia Scherer, Editor, *Disability and Rehabilitation: Assistive Technology*
Appendix E

Implications for Rehabilitation: A Feature for the journal Disability & Rehabilitation

“A feature of the Journal is a boxed insert on ‘Implications for Rehabilitation’. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature. This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission.”

Multiple Sclerosis and the motherhood decision

- MS is an unpredictable disease and therefore can hinder the ability of an individual affected by it to make concrete plans.
- As a consequence, the motherhood decision for women with MS is complex and multi-factorial.
- Common themes occur in the decision for both those who decide to have children and those who decide not to have children after diagnosis.
- The provision of consistent information and support is required from health care professionals to aid women with MS in their decision making process.
Appendix F

Epistemological Statement

The way in which we, as researchers, conduct research, is inevitably influenced by the way in which we experience the world. The choice of methodology within research therefore requires careful consideration in terms of the researcher’s epistemological and ontological position. Whilst there is not one ‘correct’ position within research, different positions inform different approaches to research, and consequently, different knowledge is gained.

Epistemological assumptions define how we come to know about reality (Doucet, Letourneau & Stoppard, 2010) and concern the relationship between the individual being researched and the researchers themselves (Ponterotto, 2005). Ontological assumptions are connected to the nature of reality (Doucet, Letourneau & Stoppard, 2010) and attempt to answer questions regarding what entities are real within the world.

As the question at hand within the current study regarded an exploration of the motherhood decision within women with MS, a positivist stance was instantly rejected. Positivism, which underlies most quantitative research, adheres to scientific methods of research: systematically observing and describing phenomena within the constraints of a model or theory, using tightly controlled experiments to test hypotheses, and interpreting statistical results in the context of the original theory (Ponterotto, 2005). As a consequence, positivists believe that one true form of reality exists which is not only identifiable, but measurable also. From a positivist position, dualism and objectivism are emphasised, whereby the researcher and participant are independent of one another, and the researcher can study the participant without bias influencing the results in anyway.
In contrast to a positivist paradigm, constructivism, which underlies most qualitative research, adheres to a relativist position in which multiple forms of reality can exist (Ponterotto, 2005). Constructivism believes that reality is influenced by the participant’s social environment, their experience and perceptions of their world and the interaction between themselves and the research. Reality from the view of constructionists is therefore subjective and influenced by the situational context. With this in mind, it was considered that whilst some similarities may exist across individuals with MS in their decision of whether to have a child or not, the decision will also be influenced by their individual social context and as a consequence, qualitative methodology was employed for the current study.

The author considered four different qualitative approaches in order to understand the experience of women with MS and their motherhood decision. These were: discourse analysis, content analysis, grounded theory and interpretative phenomenological analysis (IPA). After examining each approach, it was decided that IPA would provide the most appropriate form of analysis for the research questions at hand. The four methodologies are discussed below.

*Discourse analysis*

Discourse analysis attempts to identify the ways in which meaning is constructed through language and how this varies depending upon context (Willig, 2001). The current study aimed to understand the motherhood decision through the lived experience however, and not just through language and therefore this method of analysis was rejected.
Content Analysis

Within content analysis, researchers examine artifacts of social communication in order to make systematic and objective inferences regarding a particular phenomenon (Pope & Mays, 1995). They do this by grouping themes and developing categories from the data. The aim of content analysis is therefore to categorise phenomena, rather than exploring phenomena, which could be considered reductionist. As a consequence, this method of analysis was rejected.

Grounded Theory

The main aim of grounded theory is to develop new theories which are grounded within analysed data (Strauss & Corbin, 1994). It does this by drawing on themes generated from an initial source of data and compares these with similar or opposing themes that arise within further sources of data (Willig, 2001). Grounded theory contains both positivist and interpretative elements; whilst maintaining the use of systematic techniques to study the world is consistent with a positivist approach, its emphasis on how people construct meanings and actions is pivotal to an interpretative stance (Smith, 2008). Despite its inclusion of interpretative principles, the author was not hoping to create theory, but explore the motherhood decision within women with MS and therefore this method was considered inappropriate for the current study.

IPA

IPA was considered the most appropriate method of analysis for exploring the lived experience of the motherhood decision within women with MS, as it examines how individuals make sense of such major life experiences without attempting to draw conclusions or create theory (Smith, Flowers & Larkin, 2009). IPA is informed by three theoretical underpinnings: phenomenology, hermeneutics and idiography (Smith,
Flowers & Larkin, 2009). Phenomenology refers to the study of experience, considering what it is like to be human and what things within our world matter to us as human beings. Hermeneutics is the theory of interpretation, considering the purposes and methods of interpretation, the potential ability to discover the original meaning of the articulated phenomena and the relation between the original text and its meaning at the time of production in comparison to its interpretation in present day context. Within IPA, the researcher is considered to be engaged in a double hermeneutic as they attempt to make sense of how participants make sense of the phenomena being explored. The third influence within IPA is that of idiography which is concerned with the particular. Idiographic research emphasises that the experiences of the individual are unique and complex and therefore attempts should be made to explain phenomena through individual in-depth understanding, rather than by prediction and explanation of phenomena (Ponterotto, 2005).

As a consequence of the above, IPA was considered the most appropriate methodology for the current study. The ideologies of IPA, in terms of understanding individual experiences, felt appropriate in terms of the phenomenon being explored. It therefore appeared imperative to the researcher to pay attention to these individualities as they are considered important, rather than making attempts to generalise. It was also felt that the decision to have a child or not will be individual to each participant as it will influenced by the world around them. This not only supports the idea of relativism, but also the researcher’s belief that reality is socially constructed.
References for Appendix F: Epistemological Statement


Appendix G

Participant Invitation

Dear

I am writing to you as a research study is currently being conducted in the local area exploring the experiences of women living with MS and we would like to give all of our female patients the opportunity to take part if they wish to. The study involves talking to women about their motherhood decision after a diagnosis of MS, whether they decided to have children or not and how they made this decision.

The aim of this study is to improve our understanding of the support and information needed by such women when deciding to have a child or not so that we can use this knowledge to help our patients in the future. The information sheet enclosed provides more detail about the study and what taking part would involve.

Your participation in this research is entirely voluntary. Whether or not you decide to take part will have no implications whatsoever for your current or future medical treatment. All responses provided within the interview will be completely anonymous.

If you wish to take part in this study, or have any queries, please do not hesitate to contact the researcher using the telephone number or email address below.

Researcher Name: Hannah Marklew
Researcher Telephone Number: XXXXX XXXXXX
Researcher email address: h.marklew@2008.XXXX.ac.uk

Yours sincerely

MS Nurses
Neurology Department

V1. Participant Invitation 01/02/2013
Appendix H

Participant Information Sheet

Information Sheet

You are being invited to take part in a research study. Before you decide whether you would like to take part or not, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and feel free to discuss it with friends or relatives if you wish. Please do not hesitate to contact the researcher if something is not clear or if you would like more information, the contact details are given at the end of the document.

What is the title of the research?

Multiple Sclerosis (MS) and the motherhood decision.

What is the purpose of the study?

Twice as many women are diagnosed with MS in comparison to men and the majority of diagnoses occur between the ages of 20 and 30 years, when many would consider starting a family. Despite current research suggesting that pregnancy in women with MS is both safe for mother and baby, studies suggest that there are fewer births and more abortions amongst women with MS in comparison to women without MS. Despite such profound knowledge, there is a lack of qualitative literature attempting to understand the experiences of such women and their decision to have or not to have a child after diagnosis.

The main purpose of this study is to explore the experiences of women with MS regarding their decision making process. This will hopefully increase the quality of services and information given to women during this process.

Can I take part?

You may take part if:

- You are female
- Over the age of 18
- Have a diagnosis of MS made by a neurologist
- Have made a decision to have, or not to have children after being given a diagnosis of MS.
Do I have to take part?
It is completely your decision to take part. If you decide to take part, you will be asked to sign a consent form. You will be free to change your mind at any point throughout the study, up until the completion of the transcription of the interview and the deletion of the interview from the Dictaphone. You may do this without having to give a reason.

What will I have to do?
You will be contacted by the researcher to arrange a suitable time and place to meet in order for an interview to take place which will last around 1 hour. There are no right or wrong answers to the questions you will be asked – the study is seeking for you to discuss your own personal experiences. Prior to the interview, you will be asked to fill in a consent form to say that you agree to take part in the interview and that you are happy to have the interview recorded. You will also be asked to fill in a form containing some basic information about yourself. All information collected during the study will be kept anonymous and confidential.

What are the possible disadvantages of taking part?
The questions asked will require you to think about and discuss your personal experience of MS and your decision making process regarding having a child or not after diagnosis. If you feel that this may be upsetting then you do not have to take part in the study. If you become uncomfortable at any point throughout the interview you are free to withdraw from it at any time.

What are the possible benefits of taking part?
We cannot promise that they study will help you. However many people feel that they have contributed something of great importance by taking part in research. We hope that the information gained from you and other participants may provide an understanding of how women with MS can be better supported by services through their motherhood decision making in the future.

What happens if I don’t want to carry on with the study?
You can stop taking part in the study at any time throughout the interview if you become uncomfortable. You can also have your data withdrawn from the study and destroyed at any point prior to the transcription of the interview and deletion of the audio recording of the interview. You will not have to give a reason for withdrawing from the study.
Will my taking part in the study be kept confidential?

Yes. Ethical and legal practice will be followed and all information gained throughout the study will be kept strictly confidential. The interviews will be recorded by the researcher and kept securely on an encrypted memory stick. All other information will be securely stored by the researcher at the University of XXXX. Additionally, all data collected will be made anonymous and therefore no individual will be identifiable.

In the event that you as a participant discuss any information throughout the interview which suggests some form of risk, either to yourself, or to another individual, the researcher will have to discuss this information with another individual.

What will happen to the results of the research study?

The results of the study will be written in a report and will be submitted for publication in a scientific journal and in a thesis at the University of XXXX. This is so that other professionals and students can read the report. You will not be personally identified in any publication or report. If you wish to receive a copy of the report once it is complete, please make this known to the researcher.

Who is organising the research?

The research has been organised by the researcher, Hannah Marklew and has primarily been developed to meet the requirements for a Doctorate in Clinical Psychology.

Who has reviewed the study?

Every stage of the study's development has been reviewed and commented upon by the Chief Investigator's academic and field supervisors. The final research proposal has also been independently peer reviewed by the research group within the Department of Clinical Psychology and Psychological Therapies at the University of XXXX and has received a favourable review.

If you have any complaints or concerns regarding the research:

If you are taking part in this research project through the XXXX NHS Trust, please direct any complaints or concerns to:

XXXX NHS Trust Patient Advice and Liaison Service (PALS) Telephone Number: XXXXX

Email: pals@XXX.nhs.uk
If you are taking part in this research project through XXXX NHS Foundation Trust, please direct any complaints or concerns to:

XXXX PALS Telephone Number: XXXXX XXXXXX

Email: pals@XXXX.nhs.uk

Address: PALS, XXXX NHS Foundation Trust, Freepost, XXXX, XXXX, XXXX, XXXX.

If you are taking part in the research project through the MS society, please direct any complaints or concerns to:

Dr XXXXX XXXXXXXX

Telephone Number: XXXXX XXXXXX

Email: XXXXX @XXXX.ac.uk

Address: Department of XXXXX, XXXX, University of XXXX, XXXXXX, XXXX, XXX XXX.

If you have any further questions, or require further details on this project, please do not hesitate to contact the researcher.

Researcher details:

Name: Hannah Marklew

Telephone Number: XXXXX XXXXXX

Email address: h.marklew@2008.XXXX.ac.uk
Appendix I

Contact Form

Contact Form

Thank you for expressing an interest in taking part in the study entitled ‘Multiple Sclerosis and the motherhood decision: a qualitative study.’ It will be necessary for the researcher to contact you to discuss this further. Please enter appropriate contact details and sign to indicate that you agree to being contacted.

I agree to give my telephone number/email address and to be contacted by the researcher.

Telephone number: ________________________________

Email address: ________________________________

_________________________  __________________________  __________________________
Name                    Date                      Signature

V1. Contact Form 01.02.2013
Poster/Advertisement

Motherhood and MS

Did your diagnosis influence your decision?
Whether you have children or not, your story is invaluable to this piece research.

We are looking for women diagnosed with MS who are willing to talk about their decision to have or not have a child after their diagnosis, and what influenced their decision. Little research has been carried out so far to understand the experience. We hope that by gaining this information healthcare professionals will be better informed of the experience women go through when making their decision, and what we can do to help.

If you would be interested in taking part in this piece of research, please contact the research using the contact details below:

Researcher Name: Hannah Marklew
Telephone Number: XXXXX XXXXXX
Email Address: h.marklew@2008.xxxxxxxxx.ac.uk
Appendix K

Screenshot of advertisement on MS website

MS and Motherhood

What's this study about?

MS is commonly diagnosed between the ages of 20 and 50, when many women may consider starting a family. Despite pregnancy being found to be safe for both mother and child, many women with MS are choosing not to have children.

This study aims to improve our understanding of the experiences of women with MS and how they make decisions about whether or not to have a child.

How will this help people affected by MS?

By improving our understanding of women's experiences, services could be altered to provide women with the support and information needed to make an informed decision about having a child.

What will participants be asked to do?

You will be asked to complete a web-based questionnaire and invite four friends to do the same. The interview will last for roughly an hour and will consist of questions regarding your decision making process over whether to have a child or not after a diagnosis of MS.

Who can take part?

You can take part in this study if you meet the following criteria:

- You are female
- Over the age of 18
- Have a diagnosis of MS made by a neurologist
- Have made a decision to have, or not to have children after being given a diagnosis of MS
- Able to speak English

Who is conducting the research?

Miss Ioana Manolea - Trainee Clinical Psychologist (Principal Investigator), supervised by Dr Emma Volkmer - Clinical Psychologist

When can I take part in this study?

June 2013 - October 2013

Where is the research taking place?

The research is being conducted online and within your home. The interviews can take place at a venue of the participant's choosing.

Who has reviewed this study?

Interested?

If you would like to find out more about this study and would like to receive a participation information sheet, please contact Ioana Manolea at

Please note that engaging in this project does not commit you in any way.
Appendix L

Consent Form

CONSENT FORM

Title of Project: Multiple Sclerosis and the motherhood decision: A qualitative study

Name of Researcher: Hannah Markiew

1. I confirm that I have read and understand the information sheet dated 01/02/2013 (Version Number 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time prior to transcription of the interview and deletion of the audio recording, without giving any reason, without my medical care or legal rights being affected.

3. I agree to being audio recorded.

4. I agree to take part in the above study.

__________________________________________________________________________
Name of Participant                                             Date                                           Signature

__________________________________________________________________________
Name of Person Taking consent  (if different from researcher)   Date                                           Signature

__________________________________________________________________________
Name of Researcher                                              Date                                           Signature

I for patient: 1 for researcher

V2. Consent Form 01.05.2013

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DEMographic Form

Please could you tell us some more information about yourself?
This information will be anonymised and is treated confidentially.

What is your date of birth?
__________________________________________________

How would you describe your ethnicity?
__________________________________________________

Are you...?
Single [ ]
Married [ ]
Divorced [ ]
Cohabiting [ ]
Other, please specify ____________________________________________

How many years were you in education for?
__________________________________________________

Please tick the box showing the highest qualification you have

No qualifications [ ]
O-level/G.C.S.E’s [ ]
A-levels [ ]
Diploma [ ]
Degree/professional qualification [ ]
Postgraduate degree [ ]
What is your current employment status?
Unemployed [ ]
Employed [ ]
Job Title ____________________________________________________________

When were you diagnosed with MS?
____________________________________________________

What type of MS do you have?
Benign MS [ ] Primary Progressive MS [ ]
Relapsing Remitting MS [ ] Secondary Progressive MS [ ]

Do you take medication for your MS?
No [ ]
Yes [ ]

Do you have any children?
No [ ]
Yes [ ]
If yes, how many and how old are your children?
____________________________________________________

Did you have your children before or after diagnosis?
Before [ ]
After [ ]
Before and After [ ]

Do you intend on having any more children?
Yes [ ]
No [ ]
Appendix N

Interview Schedule

Questions for study on MS and the motherhood decision

1. As you are aware, this study is about a woman’s decision making process as to whether to have a child or not after a diagnosis of MS. Can I please just confirm that you have/have not had a child after diagnosis?

2. As this study is about your experience of living with MS, I was wondering if it would be ok to start with you telling me about how you came to be diagnosed with MS?
   - What were your feelings and thoughts at this time?

3. Obviously my study is about motherhood and the decision to have a baby – had you every thought about being a mum before diagnosis?
   - What did you imagine it to be like?

4. I would be interested to hear about whether your diagnosis of MS influenced your decision to have a baby or not?
   - What factors influenced your decision?
   - What sources of information were important when thinking about having a baby or not?
   - Did you involve other people in your decision?

5. How do you think other people perceived your decision to have/not have a child?

6. Did you have any concerns about the impact of MS on motherhood?
   - On your ability to mother?
   - The effect on your health?
   - The effect on the baby’s health?

7. Looking back over the decision you’ve made, have your feelings changed now?

8. Is there anything else that you would like to tell me about that we haven’t yet covered or discussed?
## Appendix O

### Example of Data Analysis - Michelle, Lines 136-164

<table>
<thead>
<tr>
<th>Initial Comments</th>
<th>Transcript</th>
<th>Emergent Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>R</strong>: Erm, so I was just wondering, about if you had any concerns about your MS on motherhood? I’m wondering if you had any concerns about your ability to mother er...and like your diagnosis of MS?</td>
<td><strong>Social Context</strong></td>
<td></td>
</tr>
<tr>
<td><strong>M</strong>: The concerns...I had few concerns...if I didn’t have support would...if I had a relapse what would happen then and things like that. But I also thought I’ve got to get on and do this. I’m bringing a new baby into the world, I’ve got to think about when she is asleep to...if I can’t do it all, a babies not going to tell you what to...that you’re doing it wrong or nothing. You just learn to adapt. You have to, that’s the only thing you can do, so...</td>
<td><strong>Hope</strong> <strong>Practicalities</strong></td>
<td></td>
</tr>
</tbody>
</table>

#### Needing the support of others/dependence

- Defiance and positivity
- Compensatory strategies
- Adapting to your situation
- No choice in the matter – going to be/want to be a mother
R: And erm...did you have any concerns about erm, the pregnancy or motherhood on your health at all?

M: No, no. Since being diagnosed I’ve only had one major relapse and...I knew if I tried my best and kept myself healthy and just things like that I would get through it and get straight back on my medication. Since (name of child) was born I’ve not had a relapse so I’ve...although it’s been hard work and it’s tiring and man, I try to just do things slowly, don’t care about what anyone says and do it at my own pace, not worry about anybody else. Really...

R: And did you have any worries about erm...the effect it would have on (name of child) and her health all?
<table>
<thead>
<tr>
<th>Worries of ‘passing on’ MS</th>
<th>M: I do worry because I know the fact is it isn’t proven hereditary, but there is a lot of families out there that you’ve read about, I’ve read about and the mother or the son has got it but...I believe with it not being hereditary it does not mean the end of the world for (name of child). She might or my other kids, they might not get it. If they do, just got to be supportive. Life’s a vicious circle; you do not know what’s around the corner. Something else major could come more. But just get on with it and enjoy it while you’ve got the chance.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading information – trying to understand</td>
<td>Despair</td>
</tr>
<tr>
<td>Positive attitude</td>
<td>Attempts to understand</td>
</tr>
<tr>
<td>Unknown future</td>
<td>Hope</td>
</tr>
<tr>
<td>Unknown future</td>
<td>Uncertainty</td>
</tr>
<tr>
<td>Positivity</td>
<td>Uncertainty</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>R And just looking back over the decision that you made now to have (name of child), would you change it at all or...?</td>
<td>Hope</td>
</tr>
<tr>
<td>It’s worth it</td>
<td>M: No, I would never change having her. I find having children keeps you going, keeps you from thinking about “oh, I’ve got MS” and I feel like having them, I ain’t got time to think about my MS and let it worry and get me down. I enjoy them and they, they understand and (name of child) when she’s older will understand about my MS and we just carry on, get on with life. That’s the main thing.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Being a mother is a distraction</td>
<td>Female body vs. Disabled body</td>
</tr>
<tr>
<td>Shared understanding</td>
<td>Social Context</td>
</tr>
<tr>
<td>Positivity</td>
<td>Hope</td>
</tr>
</tbody>
</table>
Appendix P

Reflective Statement

Throughout this research process which started over two years ago, I have gained a wealth of experience and knowledge. In this statement, I will reflect on the major stages of my research journey, attempting to capture the thoughts I had, emotions I experienced, my sense of achievement and the many challenges that I encountered. I will then conclude with some final reflections.

Developing the study

Choosing the research area

Choosing the correct topic for my study was imperative to me. Not only did I want it to be something that interested me clinically and within a research capacity but I also wanted it to mean something more to me than just a hurdle to overcome in order to qualify as a Clinical Psychologist. My predominant interest lies within health psychology and I have always been fascinated by individuals who show strength in the face of adverse life events such as the diagnosis of a life threatening or debilitating illness. My own mother was diagnosed with MS at a young age and therefore I have grown up being aware of her disability, the effects it has on her and those that it has on my family unit. One thing that I had never really considered prior to this project however, was whether my mother’s diagnosis influenced my parents’ decision to have children in any way. A literature search within the area suggested that very little research had been carried out exploring the motherhood decision of women with MS and at that point no research had been carried out in the UK. As a consequence, I concluded that it would be interesting to do this. My family connection to MS ensured me that my interest and motivation in the study would be maintained throughout the length of the process, however, I did have some concerns that my connection would
bias my interpretation of results in some way. I also considered that this study could be more sensitive than I at first anticipated and I could potentially become upset by my encounters. Despite this, I decided to proceed and luckily found that I was only inspired by the women that I met.

Choosing the design

Having chosen the topic of my research, I then had to decide on an appropriate design. After discussions with my supervisor, it was concluded that an exploratory qualitative study would be most appropriate. I wished to explore how people experienced their decision making and so the methodology of IPA appeared to be most suitable for discovering this information. Despite this, I was relatively apprehensive regarding the use of qualitative methods of research as any previous experience of research that I had, was of a quantitative nature. I was excited to be attempting something different however, and after reading further around the use of IPA and other explorative qualitative methodology, I was amazed at the wealth of information researchers received and astounded that it is only relatively recently that research has been conducted in this way. Giving voice to and listening to an individual’s subjective experience is such a dominant aspect of clinical psychology that it is difficult to imagine that research, at one time, did not take this in to account.

Recruitment

Despite IPA not having a prescriptive sample size and despite being aware that a relatively small sample size would be sufficient, the recruitment of participants was still an anxiety provoking occurrence. I frequently considered whether or not I had chosen a research area which was of significance to potential participants and in which they would be prepared to give up their time in order to participate and be interviewed. My methods of recruitment were of particular concern but I was luckily given the advice by
a colleague to recruit via letters, through which I gained a majority of my participants. I was also very fortunate in that many staff members, whether within a hospital setting or within the MS society were so helpful in terms of recruitment. My initial fears were not realised and within roughly three months I had recruited and interviewed all the participants required for the study. This was incredibly surprising yet immensely rewarding; the women willing to participate were clear about their perceptions of the importance of the study.

**Interviews**

Interviewing participants was by far the most enjoyable experience of the research process. All interviews bar one took place in participant’s homes which provided a more comfortable environment for them to discuss potentially sensitive topics. I have often wondered whether the women would have shared the same stories had the interviews had taken place within a more clinical environment. It was a privilege to hear the stories of the participants, though challenging at times. With some participants, I shared laughter, whereas with others, I could easily have cried. At these points, it was incredibly difficult to restrain my clinical psychology training and desire to intervene; it was important to remember that I was there as a researcher. Despite this, some of the participants expressed that simply discussing their experiences was helpful, which lead me to consider whether the semi structured interviews themselves facilitated some form of therapeutic process.

**Data analysis and Write-Up**

The analysis of the data that I had collected from participants was a lengthy and challenging, yet exciting process. It was easy to be immersed in and consumed by the data due to the iterative approach of reading and rereading. Similarly, it was easy to feel overwhelmed by the data, given it being so rich and descriptive and I occasionally felt
confused about potential themes. The analysis was not a linear process, and I consistently shifted between different transcripts, themes and quotes. In order to remain objective throughout, supervision was utilised and a reflective diary was kept, allowing me to take note of how I was feeling in regards to the data and to note down any comments or themes that popped into my head. This ensured that analysis was grounded in the data. Having done the interviews and having met the women whose data was creating the research, I reflected that any feelings that I was experiencing in terms of being overwhelmed, were perhaps a reflection of the pressure I was putting upon myself in order to do justice to their stories, and create a piece of research that was worthy of the time and honesty that they had given to the study. Once the analysis reached a stage where clear and defined themes had been sought, this pressure was alleviated, and contentedness replaced it.

The writing up phase posed further challenges however, in terms of selecting the quotes from participants that best supported the themes. In doing so though, it felt unjust to neglect the quotes and experiences of other participants. Through reflection on this, I came to the realisation that despite not explicitly quoting each individual’s experience within each theme, these experiences still made up the findings of the study and therefore will be embedded within each theme.

**Meta-synthesis**

The meta-synthesis that I carried out as part of this thesis portfolio was an incredibly challenging piece of work. I originally wanted to carry out a review looking into the experiences of motherhood in women with a disability or chronic health condition, however searches suggested that such reviews had already been carried out. Through further consideration within supervision, looking into the experience of becoming childfree became an interesting option and one that had not yet had its qualitative
studies reviewed. Due to the limited qualitative research within this area however, I considered whether the topic was relevant and feasible for review. Reassurance and enthusiasm from my supervisor however, particularly in regards to the clinical relevance of the topic area ensured me that it was. Synthesising the data posed a challenge, especially as there is little consistency in terms of methods of conducting a meta-synthesis. By reading other meta-syntheses however, and by examining literature on methods of synthesising data within meta-syntheses, I gained confidence in doing so. Ultimately, I am glad that I waded through any apprehension in regards to the topic area as I feel it has enriched my understanding of the overall motherhood decision.

**Final reflections**

Despite the process of developing, carrying out and writing up this research posing many challenges and difficulties, the overall sense of achievement in having done so, far outweighs any negatives. Having only carried out quantitative research prior to the conception of this thesis, I have a new found enthusiasm for research that takes into account the idiographic experiences of individuals, rather than reducing such experiences to numbers or general statements. Qualitative methodology would definitely be my methodology of choice when considering research in the future.

Most importantly however, despite growing up with a mother with MS, my knowledge of the lived experiences of those affected by MS, particularly in relation to motherhood, has substantially grown. Despite closing the door on this thesis, my mind will be forever aware of the admiration I experienced in relation to the resilience and strength that was shown by participants in the face of such an unpredictable disease.