Mothering and Self-Othering: The Impact of Uncertain Reproductive Capability in Young Women after Haematological Malignancy


Abstract
We explored the experience of uncertain fertility, pregnancy and motherhood in twelve young women treated for haematological malignancy during their reproductive years. It is demonstrated how, through interpretations of the women’s own words, these women lived and coped with a sense of “otherness” in relation to their peers. The concept of otherness is described and discussed in relation to relevant existing literature and it is concluded that, regardless of their cancer history, young women’s uncertainty in this context has a broad impact on their psychosocial health and requires sensitive and empathic information, discussion and support.

Keywords
Cancer, fertility/infertility, lived experience, mothers, mothering, phenomenology, pregnancy, reproduction, uncertainty, van Manen, women’s health
Martin & Bringelsen, 1999). It has also been suggested to compel a re-evaluation of generative identity and to force a woman to re-appraise her sense of self and her expectations for the future (Raphael-Leff, 2000). Thus, for women who desire a child, reproduction failure is believed to be a silent and internal loss of self (Elson, 2004), and a threat to dreams of having a perfect and complete family (Field & Marck, 1994). This can trigger many kinds of psychosocial distresses by directly threatening women’s societal and familial status (Thorn, 2009).

The threat of infertility because of chemo-radiotherapy for the treatment of cancer is therefore a critical issue (Boyes, Hodgkinson, Aldridge & Turner, 2009; Redig, Brannigan, Stryker, Woodruff & Jeruss, 2011). However, the possibility of (in)fertility following cancer is often shrouded in uncertainty (Halliday & Boughton, 2011), with a major characteristic of post cancer fertility being the relative unpredictability of outcomes from specific treatments, as well as the problems incurred when generalising from population data to individual women (Corbeil, Laizner, Hunter & Hutchinson, 2009; Lee, Schover, Partridge, Patrizio et al. 2006). This may in part reflect the lack of available data regarding rates of female infertility following cancer treatments, or the large number of patient factors (e.g. age, cancer and treatment type) that can influence outcomes (Greenberg & Urbach, 2006; Lee et al. 2006; Wallace & Barr, 2010). Fertility concerns and uncertainties may go beyond the impact of cancer treatment. For example some survivors may be uncertain about their ability to become pregnant, whereas others may be uncertain about the safety of pregnancy to themselves and their unborn child (Syse, Kravdal & Tretli, 2007; Zebrack, Casillas, Nohr, Adams & Zeltzer, 2004), or concerned about the health of future children, as well as have uncertainties about their own long term survival and parenting potential (Parry, 2003).

Infertility is often emotionally painful as an isolated health problem (Thorn, 2009). Likewise, the phenomenon of uncertainty has been linked to excessive stress and difficulties with coping (Lazarus & Folkman, 1984), and has also been reported to effect adjustment and adaptation to a diagnosis of cancer and is associated with higher levels of emotional distress, poor psychosocial outcomes and reduced quality of life (Shaha, Cox, Talman & Kelly, 2008). Therefore it is suggested that infertility, or uncertainties about fertility and reproductive capability after cancer can only magnify the distress, anxiety and life disruption when superimposed on to the cancer experience (Canada & Schover, 2010; Nieman et al. 2006). Carter and colleagues (2010) propose that more adjustment difficulties are experienced because of the double trauma effect.

We report in this article the findings of a qualitative research project and focus on “otherness” describing how the women who participated in this study shared a feeling of being different and felt they did not quite belong in relation to their peers who were following largely unconscious predetermined and easy pathways to motherhood. The women all acknowledged that because of their cancer histories, they had special needs and concerns that nurtured a sense of detachment and difference or alienation, isolation and sometimes marginalisation. This has been interpreted here as “self othering” (Canales, 2010) and led to the lived experience of “otherness”.

Introducing the Concept of Otherness
The notion of otherness has been recognised as a fundamental part of lived experience, and as an important perspective in the study of thought in the human and social sciences. Staszak (2008) suggested that otherness or othering is the process of categorising individuals into two groups- one that embodies the norm and whose identity is valued, and one that is devalued, defined by its faults and susceptible to discrimination. Otherness and identity are two inseparable sides of the same coin (Staszak, 2008). Through the process of othering, people identify what makes them either similar or
dissimilar from others based on (ideological) stereotypical attributes and societal norms, and subsequently categorise themselves as either the same or different. It is these categorisations or labels that define their identity and situate them in relation to the normative or prevailing ideals of the dominant majority (Canales, 2010). This ultimately constructs an identity of “other” with their perceived degree of otherness depending on how far they deviate from the norm (Mullin-Jackson, 2009). From a relational perspective, self-identity is only truly known through comparisons to the ordinary and typical attributes of others who are perceived as socially normal. However, once labelled as different from this prevailing norm individuals are stigmatised, and it is this sense of difference that constructs their identity as other or of an “alienated self” (Balibar, 2005).

Method
Phenomenology as a research method was chosen as it offered a means of exploring the lived experience, and when coupled with hermeneutics provided a way to uncover and describe through writing, the “essences” of the experience as it was lived (van Manen, 1990). This methodology is most appropriate in cases were little is known about a phenomena and the aim is to delve into the lived experience of an event or condition to determine what it is really like (Willig, 2001).

Ethical consent was granted by the university human research ethics committee. Recruitment through non-medical units was chosen because the aim of the research being to explore the women’s experiences after their primary treatment had finished and they were integrating back into their everyday lives. Participants were recruited purposively. In total four websites, one email “buddy list” and one on-line support group were used. Details of the study were provided by moderators/administrators who posted an outline of the research and contact details of the researcher. Interested women emailed for further information and were forwarded a participant information sheet and consent form. After reading through the recruitment information, they were requested to send through confirmation of their wish to participate, or any additional questions they may have had. At this point, arrangements for either face to face or telephone interviews were organised. Face to face interviews were carried out when feasible although on several occasions because of the inter-state locations of the participants and the financial constraints imposed by this, telephone interviews were necessary.

The exact number of participants needed for a qualitative enquiry and the number of interviews per participant depends on the goals and purpose of the study. While there are no set rules about how many participants to include in a study, there should be enough to provide rich data. In this project recruitment continued until data saturation was achieved to allow the “core essences” of the experience to be uncovered. In total, 12 Australian women were recruited, aged between 25-39 years and at least one year post diagnosis for a haematological malignancy. Two women already had children prior to diagnosis (one wished to extend her family but was unsure whether this was achievable), two had achieved pregnancy and given birth between diagnosis and the time of interview and another two were pregnant at time of interview (one has given birth to a healthy baby and the outcome of the other unknown). One was pregnant when diagnosed and advised to terminate (she is uncertain whether she is able to become pregnant in the future), and the remaining five were uncertain of their fertility status but were not in a position to attempt pregnancy.

Data were gathered through in depth phenomenological interviews. Phenomenological interviews do not attempt to explain, predict or generate theory, but to understand shared meanings by drawing from the participant a vivid picture of their lived experience complete with all the richness of detail and context that shape it. Interviews were undertaken during January 2010- March 2011. Regardless of
mode, all interviews were digitally recorded with each participant’s written consent. In keeping with an in-depth interview technique, the interviews lasted between 40 minutes and one and a half hours. Each woman was interviewed on a day and at a time that was convenient for her. The women were situated at home for all of the interviews. All participants spoke openly and extensively about their experiences and their fears, concerns and uncertainty about their fertility, ability to be a mother or ability to care for their existing children. The interviews were transcribed verbatim.

This research employed several recommended procedures to ensure trustworthiness and credibility including a clear and transparent audit trail, peer reviewing and member checking. Pseudonyms were assigned to protect participant’s identities as well as the removal of any potential identifiers from quotes.

The six research activities outlined by van Manen (1990) were used to uncover the essence or structure of the phenomenon of uncertainty. This involved turning to a phenomenon and investigating an experience as it is lived, reflecting on the essential themes, describing the phenomenon through writing and rewriting, maintaining an oriented relation to the phenomenon, and balancing the research context by considering the parts and the whole. Each transcript was read line by line multiple times, and words or comments that appeared important in capturing the women’s experiences were highlighted and colour coded. This has been referred to as de-contextualising the data (Sandelowski & Pollock, 1986). In addition, researcher notes (LH, MB) were written in the margins of each transcription to facilitate reflection and aid in later stages of the analysis. This process was repeated several times as further interviews were completed. Highlighted or colour coded sections of the transcripts were cut and pasted into a new document and grouped together to allow commonalities of the experience to be revealed. This helped with the development of themes and allowed phenomenological interpretation to occur (van Manen, 1990). Each theme was re-read several times to cross check attributes of the phenomena, and links between participants and context. The resulting categories (or essences) of the experience were uncovered after several themes were merged or refined as researcher consensus (LH, MB) was achieved.

Findings
The women in this study constantly compared themselves to other women and for the most part, categorised themselves as different. They described not fitting in or feeling “defective” and misunderstood. They often felt disconnected from their pregnant friends, and a sense of ‘otherness’ permeated existing relationships as well as when trying to form new relationships. The two major themes and related elements of experience that constructed the lived experience of “otherness” portrayed by the women’s accounts of living with uncertainty centre around the following (1) otherness as difference and (2) heightened temporal awareness. These are expanded and described below.

(1) Otherness as Difference
The concept of otherness for young infertile women has been described as synonymous with feeling very different from other women in the dominant culture of fertility (Sandelowski & Pollock, 1986). The women in this study described experiencing a kind of “alienated self” (Balibar, 2005), where they were placed on the periphery or borders of their peer group. They felt- not quite the same, but not totally different- uncertain and out of their comfort zone, in a lived space that was unfamiliar and held several challenges for them. They struggled with “internalised exclusion” (Balibar, 2005) because of their uncertainty surrounding whether or not they could get pregnant, give birth to a healthy child, or raise
their children long into the future in the same way as their friends and family. Otherness as difference is constructed of three sub themes: deviating from social norms and expectations, disconnecting from pregnant others, and minimising difference through making comparisons.

Deviating from social norms and expectations
While undertaking the analysis it became evident that an awareness of internalised social pressures, expectations and norms was unmistakable in the women’s descriptions of their experiences. As Rebecca clearly stated “you get engaged, you buy a house, you get married, you have kids”. Mel claimed “society says you can’t be as happy if you don’t have a child, or a husband, or a family”. This supports numerous studies that have indicated that most adults assume that love, marriage and parenthood go together in the “normal” adult lifestyle (Baker, 2004) and that “children provide existential meaning, identity, and status; they grant parents the traditional means of participating in the continuity of a family, a culture, and the human race” (Meyers et al. 1995). Amber reflected this belief when she stated:

“I mean it’s a very secure comfortable thing to do to have a family, it’s very accepted by society its very grounding in a way. You know you have your children, you look after your children, that is your number one pursuit so you are responsible to them and that’s wonderful and when you don’t have that it’s like well, well what’s(...)yes, it is freedom if anything, but what path do I take if I don’t have this biological clock if I don’t have a need to settle down by x age, if I’m not reproductive, if I don’t have the need, or I don’t have the possibility to procreate then do I need to have a life partner? You know, we are as human beings; we’re driven to have monogamous relationship in order to raise our children for their security. Do you need that if you aren’t gonna have children?”

Disconnecting from pregnant “others”
These women openly embraced the news of friends or family member’s pregnancies stating: “I felt nothing but joy for her”, but at the same time, they felt disconnected from the experience. Several comments described how they merely wanted to be the same as other women, to be “at that stage”, they “wished we were a bit like that” or felt sad or “jealous that it seems to come so easy for them, and it wasn’t gonna come easy for us, it wasn’t gonna be simple”. These women’s encounters with family and friends whose lives were following a predictive pathway and who were pregnant appeared to act as “contextual markers of difference” (Singer & Hunter, 1999) and tended to emphasise to them the challenges they had already faced and might face in the future, which magnified their sense of difference. Annabel stated “I can’t go through the same experiences as my friends or family”.

This awareness of what was potentially lost to them was only achieved through direct comparison with other women in their peer group. These encounters reinforced and exaggerated their sense of difference, lack of connection and feelings of exclusion. Natalie said “I went to a wedding and all these old friends that I hadn’t seen for ages were all pregnant or had babies and we weren’t in that position at that stage so I was sort of fairly upset”. Uncertainty for these women was doubly distressing as they had to acknowledge the threatened loss of not being able to conceive a child and the loss of the meaningful and significant ability to share in the common female experiences of pregnancy, childbirth, and motherhood.
For participants who had managed to achieve pregnancy a sense of “otherness” was still experienced suggesting that pregnancy after fertility challenges does not necessarily restore a sense of normalcy. This is consistent with past research (Greil, Slauson-Blevin, & McQuillan, 2010; Olshanksy, 2009). These women were typically placed in high-risk pregnancy categories and were therefore treated differently to “typical” pregnant women. They experienced routine appointments and procedures in a different way to “typical” pregnant women. This heightened their self-imposed sense of marginalisation and otherness. Molly stated:

“They have put me into a high risk category, so I can’t have a low risk birth at a low risk birthing facility cause I have to go to hospital, and it’s so confronting, and you know they have got five lines there for you to write down any operations that you have had on your form and then you sit there and have your interview, and that interview went for like an hour and a half because of my history, and the midwife just didn’t quite understand what I had had. So you know, so it still stays with you”.

Similarly, Natalie stated:

“That was sort of a big deal to be going through a pregnancy and other people talking about their births that they are going to have and their natural deliveries and how they are going to breast feed and this that and the other, and I did feel a bit juped. I suppose that those things weren’t an option for us”.

Minimising difference through making comparisons

The most common way the women attempted to minimise their sense of otherness and difference was by making downward social comparisons (Hogg & Vaughan, 2005). Downward comparison is a defensive tendency to evaluate against someone whose troubles are more serious and tends to occur when threatened people look to others who are less fortunate than themselves (Suls, Martin, & Wheeler, 2002). By making downward comparisons between themselves and others “there is always someone worse off” they diminished their feelings of victimization and enhanced their self-esteem and sense of self protection (Mok, Martinson, & Wong, 2004). In addition, this reduced the threat of infertility (Stanton, 1992) as this excerpt from Lynne demonstrates:

“I do have an amazing little girl [cries] and like I am very lucky in a lot of things and I do try and focus on the good things you know which I have a lot of (...) I just sort of distract myself from it and focus on them, remind myself of the good things that I have and you know there is a lot of people worse off than me”.

Upward comparisons emphasised their difference in relation to the taken-for-grantedness of fertility enjoyed by other women, which made them gain a sense of being an “other” non-normative being and often left them feeling bitter and angry (Sandelowski & Pollock, 1986). Upward comparisons also led to a sense of unfairness that some women have babies easily, and often they felt undeservedly.

“I get really annoyed at her as well because she has got a 3 year old and she had all sorts of problems when she had the 3 year old with post natal depression and
stuff and now she is pregnant with this one and I don’t think she really wants it, like she is not happy about it… and she’s you know always complaining and it’s a big hassle and when you are around that, cause I work with her and am around her all the time, it just…. half the time I want to hit her and say just stop your whinging you have got a beautiful three year old at home and you’re going to have another baby soon and you know you don’t know how lucky you are sort of thing” (Mel)

(2) Heightened temporal awareness
The temporal dimension to the lived experience of uncertainty related to their consciousness of time and time limits including their awareness of limited timeframes for having children, and the sense of urgency they experienced. Others felt restraints were placed on their time, they were held back from moving forward, or conversely felt they had “plenty of time”. This heightened time awareness was infused with uncertainty because the women never knew how much time it would take, or even if they would ever succeed in achieving or actually experiencing biological motherhood. Heightened temporal awareness was constructed from three main elements: awareness of biological clocks; pressure from time constraints; being on-time.

Awareness of biological clocks
Prior to their diagnosis, the women had taken for granted their ability to have a child if they chose to and had given little thought to the capabilities of their bodies. However, the cancer experience had heightened their awareness of their bodily limitations, and the majority of women were aware that their “biological clocks were ticking”. The metaphor of a biological clock is a common one (Earle & Letherby, 2007). Most spoke of their biological clocks as an internal system outside of their control that activated hormones at a certain point, which took over and led them to get the “motherly instinct” or “maternal thoughts”. This decline in corporeal mastery (Warren & Brewis, 2004) is elaborated in Molly’s response:

“Before I was diagnosed I was 28 and I didn’t really have thoughts, those maternal thoughts. You know, I would be around kids but wouldn’t be fascinated with that, yeah, but I found that that was starting to happen you know in my early thirties, and I guess that the biological clock and the different hormones that you get in your 30s kicking in really changed my thought patterns”.

As Ettorre (Ettore, 2004) noted “rather than a source of energy, time becomes somewhat of a burden for those whose biological clocks are perceived as not synchronised with their reproductive ones” (p316). Uncertainty had disrupted their assumptions and expectations, especially the assumption of their fertility and control over the reproductive powers of their body (Slepickova, 2010). This heightened their awareness of limited physical ability to reproduce, which was largely out of their control and reinforced their sense of difference to other women- a sense of otherness.

Pressure from time constraints
Because of the awareness of potential difficulties with conception and child birth plus concerns about premature menopause, several of the women were inadvertently hurried along the reproductive pathway. They were warned not to leave it too late and were inadvertently reminded of the threat that potentially hung over their ability to be mothers. These time constraints were additional pressures because of their uncertainty but “enabled us to I guess prioritise and take it serious within a certain time
frame.” Women who were in this phase of trying for a child stated having babies was “constantly on their mind”.

Time restrictions were imposed on them in several ways, either through knowing they had “to do things as soon as possible” or had to wait because of advised guidelines for conception after the use of particular treatments. For example, Rebecca’s doctor had advised her try for a baby straight away as after 30, he felt “there would not be a lot of options” and her chances of having a baby would be limited. In contrast to the sense of being rushed, Christine felt restricted. She held back after being advised to wait several months to allow her body to recover from the drugs she had been given. She stated “you can’t kind of get on with having kids...you want to have more kids but you just can’t”.

**Being on time**

Being in synchrony or being “on-time” with their friends helped to minimise their sense of otherness and helped them to feel “normal”. It also afforded them the opportunity to ignore the uncertainty surrounding their reproductive capabilities. Although some said their friends were slowly beginning to settle down after being in stable relationships for a while, they still felt that “kids are probably a couple of years away”. This led to a sense that they were still in line with peers, “I am still living like a lot of my other friends are living” and therefore fertility was something that they did not have to address immediately. Karen’s comment clearly showed the importance of feeling in synchrony with friends, but at the same time acknowledged the potential problems that might occur in the future:

> “Because I am not at the age where all my friends are having kids, it may be why it is not such a big deal for me yet- maybe if I was 10 years older I might be struggling with it more, but I am just not at that stage”.

Amber also acknowledged that there comes a point in the experience when fertility challenges can no longer be pushed aside or ignored. This occurs when a sense of being normal is eroded through their feelings of uncertainty and the recognition that the usual and often expected pathways in life are potentially closed. She said:

> “The older I get and the more I see my friends having babies, that’s when it starts to become a reality I suppose. There is a little bit of, am I ever gonna be able to experience that? That’s such a, you know, that’s such a human experience, such a real experience, and that makes me sad”.

**Discussion**

While much is known about the disruptive nature of a cancer diagnosis and likewise the impact of infertility in women, the actual experience of uncertain fertility for young women after treatment for haematological malignancy has not been previously described. The phenomenological descriptions reflected in these women’s own words about their everyday lived experiences of uncertain fertility, pregnancy and motherhood have served to illuminate previously unknown meaning and significance that can now be attributed to the unique situation in which they find themselves. The women in this study described their experiences in a comprehensive, emotional and compelling manner. Each woman’s experience varied by medical and personal situation, yet they shared a common experience- a connection- that of being diagnosed with cancer in young adulthood and consequently living with uncertainty in relation to becoming or being a mother as a consequence of this.
Regardless of personal circumstances, all the women shared concerns because of the effects of treatment they received. Although at times they felt certain in some aspect of their experience, they felt uncertain about others. Uncertainty for these women was multi-faceted and spanned a host of different issues— from wondering if pregnancy was a possibility or if it was safe for them to become pregnant, to worries about whether particular pregnancies would survive and result in healthy children. Even their ability to “mother” their children in the “normal” way was uncertain. Uncertainty dominated and altered the reproductive experience and the meanings inherent in it causing disruption and chaos, and fostered a sense of otherness.

Women are often expected as part of societal demands and norms to reproduce (Greil et al. 2010). Non-fulfilment of this expectation can for some women increase feelings of stigma and inadequacy and exclude them from cherished societal rituals (Thorn, 2009). Social norms theory first suggested by Perkins & Berkowitz in 1986, postulates that individuals adopt attitudes consistent with other members of their social group’s expectations and behaviours to fulfil affiliation needs and social comparison processes as well as to comply with group norms (Hogg & Vaughan, 2005). Thus, social norms provide feelings of connectedness because conforming to norms results in attaining a positive and valued social identity and leads to a sense of belonging (Smith & Mackie, 2007). In addition, our sense of self identity is formed by comparing ourselves to others and understanding sameness and difference—what we are and what we are not (Pullen & Simpson, 2009).

By self othering (Canales, 2010), these women categorised themselves as different. They made comparisons with their friends and family members who were having babies. They acknowledged that for them, their ability was uncertain and consequently through self-othering, took on an identity as different and non-normative in relation to their own and societal expectations. They could not enjoy the taken for grantedness of fertility enjoyed by other women, the absence of children in their lives was emphasised, as was their uncertain ability for motherhood.

Norms, the socially-imbedded unspoken guidelines for socially accepted age-appropriate behaviour, were explored by Neugarten and Hagestad in 1976. They found that age norms existed for many specific life course events such as marriage and childbirth (Hogg & Vaughan, 2005). They further suggested the existence of an inner "social clock", allowing people to gauge whether a life course event had occurred on-time or off-time (Degges-White & Myers, 2006). These age norms are used to evaluate individual experiences against normative standards (Pinhey & Pinhey, 2002). Individuals who fail to fulfil age related expectations or undertake these milestones off time are suggested to experience less psychosocial wellbeing (Degges-White & Myers, 2006). Because several of these women felt they were still in line with their peer group and therefore connected through common ground, they were shielded from the negative effects of developmental precociously and this minimised their sense of detachment and otherness. Nonetheless, they still experienced the uncertainty about whether this alignment with their peers would become problematic as they moved toward an uncertain future of reproductive ability.

There is a strong link between women’s roles, motherhood and femininity. Therefore, when motherhood was challenged, they experienced an identity crisis as their “real self” and “ideal self” were in conflict. In addition, when the ability to be a mother, extend a family or find a life partner was in doubt, the women’s social lives had to shift and alter. This usually occurred as female friends married, became mothers and changed their focus in life. This impacted on and influenced the quality of their friendships, with many infertile women losing contact or distancing themselves from friends who have
become mothers in an attempt to manage their emotional conflict (Thorn, 2009). These women described the stressful experience of “straddling two worlds” (Olshanksy, 2009) between the past experience of uncertain fertility and the future experience of uncertain childbirth and motherhood, resulting in a sense of disconnection, and loneliness. And even if they successfully moved forwards and took on the identity of “self as pregnant” (Olshanksy, 2009), they struggled to view themselves as “normal” pregnant women - they were different.

Their worlds were defined by new priorities and unique norms that created a sense of social distance from others who did not share their cancer histories or reproductive uncertainties. These women clearly articulated the lack of control they felt they had over their situation and reflects a common observation in qualitative studies that fertility challenges, particularly those requiring medical intervention foster a feeling of loss of control (Cina, 2007; Grinion, 2005; McCormick, 1980). Through their own and their doctors uncertainty, restricted choice of timing, and a sense of limited time, they felt obliged to move forward with conceiving or hold back even though they may have not done so if their situation had been different.

Limitations and suggestions for further research
It has been claimed that “there is no one true meaning produced by any interpretive study, but the meanings that are stated in the research findings must be logical and plausible within the study framework, and they must reflect the realities of the study participants” (Annels, 1996). The findings reported here are grounded in the data provided by the women themselves, with the women’s words used to authenticate or verify any interpretations made. However, the findings only relate to the women who were interviewed and therefore may not apply to all other young women diagnosed and treated for haematological malignancy, particularly as the women self-selected, and therefore may have had a personal interest in this issue because fertility was problematic for them, and therefore may have sought avenues to share their experiences. Saying that, many of the identified concepts discussed here may be applicable to other young women, particularly those aged between 25-39 years who receive treatment for various other types of cancer during their childbearing years.

It is also important to stress that interviews only provide a snapshot of frozen time in highly changeable trajectories (Weiner & Dodd, 1993). Therefore longitudinal studies are needed to follow women’s uncertainty as they progress through the reproductive trajectory, particularly those who are childless when diagnosed. In addition, expanding these findings by focusing on specific aspects of the reproductive experience would be beneficial in providing in depth knowledge of the many nuances and intricacies inherent in different reproductive phases.

Conclusion
As Schover (2009) stated, controlling cancer may be vital but it is not enough. While issues regarding fertility, pregnancy and motherhood uncertainties may be of less focus to healthcare professionals than the actual disease status, they remain a primary concern for women themselves. Fertility and the ability to be a mother have been identified as core elements of quality of life in young women after haematological cancer. Although when faced with a life threatening diagnosis fertility may be a secondary concern, the reality becomes apparent only when treatment ends. Fertility uncertainties surface and women are faced with the potential loss and realise the significant and radical impact this can possibly have on their quality of life.
Health professionals need to understand the myriad dimensions of uncertainty for young women related to post treatment fertility. Although life is paramount and a crucial concern when a diagnosis is made, the importance of being a mother to young women should not be underestimated or overlooked. Potential treatment effects on fertility capabilities should not be considered equivalent in importance to other side effects, particularly in light of knowledge of the impact of infertility on women’s lives (Greil et al. 2010). It is a specific, separate concern that has on going implications long after cancer treatment has been completed.

References


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