

Female relatives' experiences of testicular cancer

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Abstract

A qualitative descriptive study was undertaken using open-ended semi-structured interviews with 18 female relatives of men who had been diagnosed with testicular cancer to determine their experiences of coping with the illness and their support needs. Women were recruited from two Australian States. The impact on women whose partner or son had testicular cancer was described using the metaphor of attempting to navigate a small boat through a storm. The experiences of these women are captured by five themes: sensing atmospheric change, registering the swell, trying to ride the waves, balancing, and calmer waters – reconstructing health.

Findings indicate that women had multiple support needs and experienced profound loneliness in their search for support. Recommendations for clinical practice include the provision of disease specific information, emotional support and sensitive information disclosure, specifically around sexuality and fertility concerns from diagnosis onward.

Introduction

Testicular cancer is a disease of young men. It is the most common cancer in men aged 18-39 years and, despite the fact that approximately 95% of patients are considered cured, longer-term psychological and physical morbidity associated with treatment may persist^{1,2}.

At a time when young men diagnosed with testicular cancer may be developing intimate relationships or embarking upon fatherhood, the relationships and partners of these men become a relevant focus for study. The primary support person or partners of these men may play a particularly important role in helping the young men manage treatment and subsequent phases of adjustment.

Few studies have been conducted to examine the physical and psychological adjustment of testicular cancer on the lives of men, and even less research has been undertaken to document the impact of the disease on female partners or support people. Johansson and colleagues³ studied 39 relapse-free testicular cancer patients 1-6 years after completion of chemotherapy and found that 90% of the men indicated that their major source of support was family and friends.

Several studies have identified long-term problems with sexual function for the testicular cancer survivor^{4,5} as well as difficulties maintaining relationships^{6,7}. These studies report that testicular cancer survivors experience sexual and self-perception problems^{4,7}.

A meta-analysis of the literature on the topic of sexual function after treatment for testicular cancer published between 1975-2000 found wide variation in sexual morbidity and assessment methods used in the studies⁸. Retrospective studies reported more sexual dysfunction than did prospective studies. The authors reported that somatic consequences of disease and treatment may reduce ejaculation; however, other aspects of sexual functioning are not clearly related to disease or treatment-related factors and may instead refer to a psychological vulnerability caused by confrontation with a life-threatening disease such as testicular cancer. This meta-analysis did not focus specifically on the role of the relationships in the descriptions of sexual morbidity, nor was the female relatives' perspective the primary focus of the review.

Rudberg, Nilsson & Wikblad⁹ studied health-related quality of life of 277 survivors of testicular cancer (aged 18-83 years). They found that men treated with chemotherapy, either as a single therapy or in combination with other treatments, scored less favourably regarding quality of life. Perceived attractiveness, being fertile, having children, and living with a partner were the most important aspects of good health-related quality of life. The female partners' experiences were not explored.

Fossa and colleagues¹⁰ investigated the prevalence of chronic fatigue, levels of anxiety and depression, and the correlation between these conditions in long-term survivors of testicular cancer (n=791). They found that the prevalence of chronic

fatigue exceeds that of the general population and that anxiety is a larger problem than depression, particularly among the younger testicular cancer patients. Once again, the female partners of these men were not included in this study. Given the interactive nature of many of these issues, the perspectives of female support persons is relevant.

Only two studies were found that considered the female partners' experiences. Both these studies utilised small numbers of participants to elicit information about being the support person for a relative with testicular cancer. In 2002, Sanden & Hyden¹¹ involved 10 relatives of men diagnosed with testicular cancer, including three mothers, two fathers and five wives. They found that these relatives reported feelings of social isolation and that they attempted to normalise the situation in order to cope. Relatives expressed concerns regarding long-term consequences of the disease (e.g. fertility issues) and relied on their social network to initiate contact with them to provide help and support. Relatives reported that health professionals provided minimal information and support to them; they concluded that family members are a vulnerable group whose needs may be poorly met.

An earlier qualitative study by Gascoigne, Mason & Roberts¹² explored the ways that six men construed their symptoms of testicular cancer and the factors that influenced their decision to seek medical consultation. Four female relatives were also interviewed. They reported that providing men with information about testicular cancer might not guarantee early presentation. Factors that influenced the men's decision making processes were the extent to which the symptoms affected their lifestyle and reviewing their symptoms with other family members. Wives were reported to be extremely influential in persuading men to seek help.

These two studies provide beginning information about the support needs of female partners of men diagnosed with testicular cancer that include limited information about long-term consequences of the disease, minimal health care information and need for social support. In contrast, the experiences of female relatives of patients with other cancer diagnoses, in particular prostate cancer, reported generally unchanged or improved relationships¹³ and satisfaction with their social support¹⁴.

No previous research has described the experiences of female partners of men with testicular cancer from early treatment to survival, the impact on their relationships and their support needs. This study was undertaken to address this gap in knowledge.

The project aims were therefore to describe the experiences of female relatives of men who have testicular cancer at various stages of the illness trajectory (i.e. diagnosis, treatment and follow up) and identify support needs of these female relatives.

Research methods

A qualitative descriptive study was undertaken using open-ended semi-structured interviews with female relatives of men who had been diagnosed with testicular cancer to determine their support needs during the initial treatment and recovery phase for testicular cancer. Women had to be aged 16 years or

older, able to provide consent and able to read, understand and speak English. A total sample of 18 women was interviewed.

Because treatment protocols for testicular cancer vary according to stage, efforts were made to recruit female relatives of men at various stages of the treatment and illness trajectory. Time periods were chosen to allow for variation in treatment modalities, and were selected based on evidence from studies of other cancer populations that support needs may differ at various treatment stages. A detailed description of the treatment modalities can be found in another paper in this issue, *The impact and responses of men who have experienced testicular cancer*.

Accessing participants

The men who agreed to participate in the study were asked if they would nominate a female primary support who would also be interested in participating in the study. The women were asked to contact the chief investigator in each State directly if they would like more information and/or would like to be interviewed. A mutually agreeable time was arranged to interview those who were interested.

Data collection

An open-ended semi-structured interview was used to explore the experiences of the female relatives of men at each time period. Women were asked to focus on the impact that testicular cancer had on them. Participants were asked to describe the support that they needed during the illness episode and to describe strategies that helped or might have helped. Interviews were audiotaped and took approximately 60 minutes. Demographic information was obtained following the interview.

Data analysis

The audiotaped interviews were transcribed and entered into the Nu*Dist software (V4) program, which assisted with managing the data for content analysis, categorising and sorting of text. The data were analysed by three investigators in WA and two investigators in NSW. The texts were analysed for themes by the researchers using the process of constant comparative analysis¹⁵. The resulting preliminary analyses were then compared and discussed to determine the consistency of findings from the two sub-samples. Findings from the two sub-groups were extremely consistent and it was deemed appropriate to combine the data for the final analysis.

After completing several long days of data immersion and open coding, two researchers [LO, LK] were sailing in a small boat in open water when a sudden storm blew in across the river. The atmosphere changed quite suddenly from a warm, sunny afternoon, gentle waves lapping against the boat and a sense of enjoyment of life, to threatening storm clouds, strong wind, rain and a small boat awash from an increasingly turbulent river. The desire to trim the sails, stabilise the craft and head for the safety of calm water in the yacht club was instinctive.

After reaching the safety, the researchers reflected on the similarity of the impact of the sudden storm and their responses to what the participants were saying about their experiences

and their responses to having a relative diagnosed and treated for testicular cancer. The researchers could 'see' and 'feel' the various responses that the participants were describing; the storm, the wind and rain, the strong waves lashing against the boat and the sense of isolation and vulnerability became the metaphors that richly reflected the participants' voices about sudden change, coming to terms with the meaning of the symptoms, their emotional responses, coping and seeking normality.

A re-review of the transcripts by all the researchers to test this metaphor across the range of interviews indicated that the metaphor was appropriate. Analysis of the men's transcripts resulted in a description of their experiences as being like an "earthquake". It is also not unusual for an earthquake to be accompanied by a tidal wave. Therefore, the fact that the men described the "earth shaking" nature of the experience of testicular cancer and their female relatives experienced a related response of trying to navigate a small boat (their own lives) in the midst of this related storm fit the relationship between the two data sets. Although the researchers were unable to check with any of the female participants, this study has been presented at several conferences and delegates have confirmed that the metaphor had meaning for them.

Categories and themes that were most consistently reported and that demonstrated redundancy and density are reported here as the most trustworthy and consistent findings. Pseudonyms are used in the reporting of exemplars cited in the findings. Issues of trustworthiness of the data analysis process (i.e. truth-value, credibility, auditability and confirmability) were addressed using the following methods – audit trail, peer debriefing and use of multiple analysis teams to re-read and verify coding of data sets. Further information related to the data analysis process can be found in another articles in this issue, *The impact and responses of men who have experienced testicular cancer*.

Participants

Eighteen women who were the primary support person for men with testicular cancer agreed to be interviewed. The distribution of the women according to the time periods since their relative's diagnosis (see previous article) was: three in early treatment phase, three having completed treatment, three in transition phase and nine survivors. Participants included 12 wives or partners, five mothers and one aunt. Half the women were under 40 years of age. The majority of women were Australian or British. The participants described themselves as being professionals (7), health care workers (3), retail/clerical workers (6) or homemakers (2).

Findings: the impact of testicular cancer

The impact of testicular cancer on the female relatives interviewed and their responses to this health threat were best described using the metaphor of attempting to navigate a small boat through a storm with no prior experience. The impact of diagnosis and subsequent treatment had a profound and lasting effect on their relationships and family life.

Five themes were defined and described with accompanying exemplars below. These themes were sensing atmospheric change, registering the swell, trying to ride the waves, balancing, and calmer waters – reconstructing health.

Sensing atmospheric change

This theme was defined as the woman's awareness of changes in the man's health. This awareness was described in two ways – a sense of waiting and minimising warning signs.

Sense of waiting

A sense of waiting was described as sensing that something was wrong and perceiving the need for action. Excerpts from the transcripts that characterised this theme included:

I could tell myself. Instinct told me he really wasn't well, that's why we went off on our own bat to get another referral. I couldn't explain why [Jean].

A second woman recounted:

... then I took him back down again and I was forceful and said, "Right, do something about it now. I'm not going to wait any longer" [Elizabeth].

Minimising warning signs

Minimising warning signs was described as unclear symptoms that were perceived by the woman as being incongruent with her view of him as a healthy individual. The following exemplars reflect the thoughts of three young partners:

Initially he showed it to me and I thought it was an epidermal cyst. I said "Oh yeah and all the rest of it" [Jan].

... well as far as we knew, he just sort of had a sore groin (pause) ... and to be honest, I wasn't at all concerned because he went for the ultrasound and when they said, oh yes, they found a few (pause)... I was thinking in terms of cysts. It never once occurred to me that it could be cancer [Rosie].

... because he was 27 and I mean, I didn't ask him (pause), I would have liked to have a look [Lea].

It was apparent from these reports that, although the women sensed that something was not right with their relative's health, the youthfulness of the patients meant that the women tended to minimise the potential risks of early warning signs.

Registering the swell

This theme was defined as confirmation of the disease and coming to terms with the meaning of the symptoms. This theme was characterised by four responses – shock, disbelief, loneliness, and an impending sense of loss.

Shock

On being told the diagnosis, women recounted a feeling of shock and an immediate shattering of their world. These three young women recalled their feelings:

I was expecting him to come home with good news and he walked in the door looking like death, he was as white as a sheet and he said he'd had an ultrasound and all the rest of it and yeah, suddenly you feel like your whole world is falling apart [Jan].

I tend to think optimistic. I thought it's probably going to be fine. But I was shocked to find out it wasn't [Marilyn].

I felt terribly numb and really, I was speechless [Lea].

Disbelief

In a number of instances, women found it difficult to comprehend that a cancer diagnosis was possible in men so young and outwardly healthy:

I thought he's young. I wasn't prepared for the outcome [Ainsley].

At 27, I thought, well he's a month off 27 and I thought, that's an abscess, I really didn't think [Lea].

A mother recalled:

My head was going boom, boom... and this is an 18 year old who's only concern is having a good time on Saturday night [Elizabeth].

One wife of a patient stated:

You know you shouldn't really expect at 29 to be diagnosed with cancer [Becky].

Loneliness

Women described an overwhelming sense of loneliness on hearing the unexpected news of the diagnosis. Two young wives reflected on that time:

I was pregnant with our second child and I was just by myself at the hospital all day. I just cried all day [Brenda].

Jean remembered taking her husband to hospital within hours of the diagnosis and stated:

They got him straight upstairs... once I got home I just cried... it sank in then... I needed someone to tell me it was going to be OK [Jean].

Impending sense of loss

As women recognised and named the disease, they also confronted their awareness that the loss of their partner or adult son could occur. This young wife stated:

My main, only concern was that I was gonna lose Jerry [Anna].

One of the mothers recalled:

I hope he's not going to die... all that night... the uncertainty [Jenny].

This theme captured the vivid emotional responses that women experienced as they internalised the reality of the diagnosis.

Trying to ride the waves

Women experienced many emotional reactions in response to the patient's physical and emotional changes and to the effects of the treatment. The women responded to the effects of treatment on men such as threats to sexuality and fertility and their perceived shifts in roles and responsibilities.

The women also recounted the need to manage home and family in the midst of the treatment demands. These responses are described as encompassing sadness, fear, anger and self-doubt:

He had had two treatments and I always used to go in the morning and I would go and look and he is in bed and I thought you seem to be breathing, you know labouring, looking at him like that I felt so sad for him and then the phone rang... my sister-in-law... I spoke to her for a little bit then I hung up and I cried and cried and that is the first time that I sobbed and sobbed and never heard myself cry like that in my life [Helen].

The initial thing I guess was fear... the next thing was panic [Amy].

I don't know... sometimes I wonder how I survived it... it did lead to fights and problems [Marilyn].

It was very much internally. I mean many a time I could have really screamed and yelled at him [Lea].

We were trying for a family and everything like that, and being a young couple it was never suggested to us by the staff (hospital) that we do sperm banking. It was suggested by J's own GP and that is only because he knew we were trying [Anne].

... all I could think of was how I was going to face (my son) when he comes home knowing that he had cancer... how am I going to cope... how am I not going to cry? [Jenny].

This theme captured the range of very strong emotions, uncertainty and deep sadness that women experienced as they coped with various phases of the patient's illness. The anger that women reported captured anger toward the disease, the world in general, the unfairness of the situation and the health care system. Women's fears of how they would cope were notable.

Balancing

Balancing referred to the women's attempts to cope. This was described in three ways – seeking support, assembling illness information and relationship navigation.

Seeking support

Seeking support included two main strategies – reliance on work and the comfort of family and friends.

With regards to reliance on work, women described the importance of maintaining their work life as a way of helping them to cope with the illness and a way of creating a semblance of order in their lives. The women stated:

... going to work kept me sane, I wasn't sitting at home [Lea].

... where I work, I have been there a long time and I found my staff very supportive and although I am normally reserved, this has made me talk a lot [Rosie].

With regard to the comfort of family and friends, women reported the importance of understanding and support from friends and family who were able to acknowledge the concerns and needs that the women themselves were experiencing. As one wife of a patient recalled when her cousin arrived to support her:

I remember him sitting down and putting his arm around me and he said, "don't worry, if you ever want anything I'll be here for you" [Elizabeth].

Women also reported the importance of family and friends to provide them with the emotional support that they needed to maintain their balance in life and sustain a feeling of normalcy. Three women stated:

... we were lucky in this way because our daughter works in nuclear medicine and my husband had to have all these extra tests... and knowing the doctors that she works for... he did come out and he told us exactly what he had and he said that it is curable [Kerry].

... and I found that I unburdened a fair bit on friends and they were very good, they were interested and supportive [Rosie].

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I tried to keep the family routine as normal as possible... I didn't want the others to think that I was putting my husband's priority in front of their's. I kept everything up... soccer training, dancing... and all that... I suppose for my own sanity too... if I was busy I didn't have to think [Terri].

Assembling illness information

Assembling illness information was an essential determinant that defined how well women coped. This exchange of information was described in terms of communication tone, timing, amount and accuracy and source of information.

With regards to communication tone, the manner and language and approach used by health professionals in their communication exchanges with women was important and influenced the extent to which women received and understood the information provided:

... because you're a lay person, you hang on to what people say and how they say it. You try to piece information together [Rosie].

He (the doctor) speaks to you like a human being, he doesn't treat you like you are somebody else [Minnie].

With regards to information timing:

... my complaint was lack of communication... you just can't get that information... I wanted to know what had happened (in surgery) and I know there's a time factor... you have to wait for pathology... you have to wait for certain things... I found all that waiting horrifying. It was the most trying time [Rosie].

With regards to amount and accuracy:

... there was nobody that you could talk to, to find out what was happening was normal... something that you could ring up and say, well, is this what is supposed to happen? There just wasn't anybody [Lynley].

... then later on he had the second tumour removed and we were told that he may have to have chemotherapy. Now again, lack of knowledge, I thought there was a hierarchy of treatments and I always thought... ah, chemotherapy, that means it's terrible, this is when you die... cause it is just dreadful. I had no idea at the time that radiotherapy was a particular type and chemotherapy was another and there are all kinds of different sorts of chemotherapy. I thought there was just one and that he was on his last legs and it was an absolutely dreadful time [Rosie].

With regards to source of information:

She (nurse) was a contact person, that was wonderful, so I didn't flounder around in the dark [Minnie].

You speak to the nurses and they can tell you a certain amount, but they are not authorised I guess, to tell you anything much at all. And as helpful as they are, they can't tell you what the specialist knows [Rosie].

Women reported the importance of access to information that they could use to help them make sense of the illness. This information came from a variety of sources:

I got in touch with my cousin right away, the one who has been through cancer herself, she's a nurse. So I knew that for support the best person would be her because she's got the medical side as well [Becky].

The way in which information was shared, the specificity and clarity of the information and the timeliness of the discussions were all critical aspects of the information exchange that influenced how women coped. The combination of support and information were essential components that women relied upon to keep their balance amidst the illness storm.

Relationship navigation

The women also described their efforts to maintain their balance as a process of negotiating their relationship with the patient. This involved a need to stay strong, cry privately, reconcile sexuality uncertainties and address parenting concerns. One example of how women protected their partners was shown in the following example:

I never cried in front of him, not at the beginning [Brenda].

The reciprocal need for support also helped women maintain a façade of strength:

Because of having him be so strong, he kept me strong. I tried to keep the façade up for his sake... when I go home I'm in tears all the time [Helen].

Another woman stated:

I coped with great difficulty at first. With great difficulty, but I knew I had to stand up and be counted for my husband [Minnie].

Women described their capacity to cope by relying on their own personal resources and private approach to coping. Many reported that they needed to be strong for the patient:

I very much stick to myself. I don't talk to people about problems. I think basically I had a good cry in bed at night... but the next day at that time, very positive [Marilyn].

Another woman described how she maintained a matter-of-fact approach that allowed her to cope and at the same time protected the patient from her own concerns:

I just dealt with it the same way I deal with most problems which is to find out what I need to know and then just get on with it [Becky].

Women also described the ways in which they managed communication with their partners to help them cope:

Just listening to him... I had to learn not to get angry with him because he was going through something I had never experienced [Brenda].

I just had to try... so I would try to do silly things to make light of something... try not to make him feel that I resented the fact that he was going through these worries [Marilyn].

The wife of one patient who was diagnosed late in the illness and was not expected to survive confided:

I'm almost trying to grieve for him now to get the process over with. I know it's not going to work. It's going to be years before the hole starts to mend itself [Helen].

Questions about sexuality were mentioned by women in the study. Although this was not their primary concern, they did experience some worries and a need to reassure their partners about this aspect of their relationship. As one woman stated:

I felt a bit scared to have sex... not that you can catch cancer like that... but it was on my mind [Jeannie].

A related issue involved concerns about couples' abilities to be parents. One woman who had emigrated from Asia to marry her Australian husband stated:

Don't worry about that... if no baby. I can look after you. I can stay with you because I get married only one time in my life... not worry about baby [Amy].

Another described how she and her husband and reconciled themselves to the fact that they may not be able to have more children:

We were just so lucky for it to happen (pregnancy prior to diagnosis). I mean still even now, we don't know if we can have any more, but we are just so happy that we have our baby, we really aren't concerned [Anne].

This theme was richly described and demonstrated the three main coping strategies that women used to maintain their balance amidst the uncertainty of the disease and treatment effects – seeking support, illness information, and relationship negotiation.

Calmer waters – reconstructing health

This theme was defined as seeking normality. Normality is described as rearranging lifestyles and developing a plan to build a future.

Regarding rearranging lifestyles:

We decided we would slow down our life... we have a more relaxing and enjoyable life [Elizabeth].

It was good for him to go out... he's settled down in the last few years, he's got a girlfriend... he's relaxed a bit, he's past the eight year mark [Jenny, mother].

Regarding developing a plan to build a future:

I want to look to his future. I really do. I look to the future and see him better. I see him healthy and us starting a family, getting our own home... Just having a life. Not taking anything for granted any more. I want to grow old with my husband because I love him so much and my love has grown tenfold [Brenda].

Discussion

Findings from this study indicate that female relatives have multiple support needs that are ongoing from the early awareness of change in their partners' health to treatment and survival. The impact of testicular cancer on woman and their responses to their partners' health threat were best described using the metaphor of navigating a small boat through a storm with no prior experience. The impact of diagnosis and subsequent treatment had a profound and lasting effect on their relationships and family life.

Early literature has reported elevated distress for some female partners of male patients diagnosed with testicular cancer¹⁶

and other literature has indicated that wives of male cancer patients experience greater distress than do patients, both before and after the patient's¹⁷ surgery at four different stages of the illness¹⁸, and both cross-sectionally and longitudinally¹⁹.

However, other studies have not reported in detail the emotional burden and life changes that women experience in response to their male relatives' diagnosis and treatment of testicular cancer or the strategies that they used and found helpful. The stories of the women who participated in this study are particularly enlightening and may help to sensitise health professionals to the profoundly personal issues with which these women cope.

These findings also revealed the depth of loneliness experienced by the women and their search for support. It is notable that this support was usually found in the workplace and among family and friends, rarely from health professionals. Morse & Fife¹⁸ explored the psychosocial adjustment of partners/spouses of patients with cancer and found that female caregivers of cancer patients perceived a greater need for social support than male caregivers across the illness trajectory. This may result from financial concerns and problems related to women's dependence on their partners or, as in this study, the need to adjust to role changes and develop a script for living that will maintain the balance in their relationships.

This study has highlighted the un-met communication and information needs of this group. Northouse & Peters-Golden²⁰ describe the impact of a cancer diagnosis on the patient and family as an assault on the whole family unit. The authors note that the spouse is a partner in suffering and is equally in need of support and information. The females in this study have clearly described their needs to be considered partners in care and to be openly supported with information and sensitive communication throughout the illness.

It is possible, due to the relatively small number and the youth of this group, that the support needs of female relatives of men with testicular cancer may be overlooked. As a group, the female relatives of testicular cancer patients are unique in that they are often young and in early relationships that may not have had the time to develop or strengthen bonds of trust and supportive. In addition, concerns related to fertility and sexuality are more likely to be present than for partners of cancer patients with other diagnoses.

Recommendations

Caring for the female partners/relatives from diagnosis onward is essential to promoting quality of life for patients and their families. Four recommendations for clinical support to these women emerge from the findings.

- Given the fact that the women in this study were not well informed about the risk of testicular cancer, the possibility of a cancer diagnosis in young men, nor the signs and symptoms of this disease, information to help them be alert to this health risk is warranted. This could be offered through women's health clinics and general practitioners'

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surgeries in the form of brochures and pamphlets. Women play an active role in health protection for the whole family; therefore, information about testicular cancer targeted at women is appropriate.

- Female partners/mothers of men with testicular cancer have notable needs for information about the disease and the impact of the disease on the man's sexuality and fertility. Health professionals need to be alert to the importance of information disclosure with women and need to be attentive to their tone, pace of information, timing, and clarity of the messages given.
- Health professionals need to be able to assess relationship issues that may exist or develop between female partners/mothers of men with testicular cancer and be able to provide, or refer to, an appropriate resource.
- Female partners/mothers need to be offered emotional support throughout the duration of the disease treatment trajectory. Health professionals who are able to offer support to the female caregivers may facilitate the caregivers' abilities to be supportive of the patient and effective in coping with the illness.

Summary

In summary, the impact of testicular cancer on the lives of women whose relative/partner has this disease is considerable. The metaphor used to capture this experience helps to convey the destabilising nature of this event in their lives. Although women report that they find many ways to gain information and support and re-find a balance in their lives, the magnitude of the illness experience cannot be minimised. These findings also remind health professionals to be alert to both the obvious and more in-depth responses to this type of life trauma so that these women receive expert and attentive supportive care.

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