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ORIGINAL ARTICLE

Haematopoietic stem cell transplantation survivorship and quality of life: is it a small world after all?

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Abstract
Purpose The aim of this qualitative study was to gain a rich understanding of the impact that haematopoietic stem cell transplantation (HSCT) has on long-term survivor's quality of life (QoL).
Method Participants included 441 survivors who had undergone HSCT for a malignant or non-malignant disease. Data were obtained by a questionnaire positing a single open-ended question asking respondents to list the three issues of greatest importance to their QoL in survivorship. Responses were analysed and organised into QoL themes and subthemes.
Results Major themes identified included the following: the failing body and diminished physical effectiveness, the changed mind, the loss of social connectedness, the loss of the functional self and the patient for life. Each of these themes manifests different ways in which HSCT survivor's world and opportunities had diminished compared to the unhindered and expansive life that they enjoyed prior to the onset of disease and subsequent HSCT.
Conclusions HSCT has a profound and pervasive impact on the life of survivors—reducing their horizons and shrinking various parts of their worlds. While HSCT survivors can describe the ways in which their life has changed, many of their fears, anxieties, regrets and concerns are existential in nature and are ill-defined—making it exceeding unlikely that they would be adequately captured by *standard* psychometric measures of QoL post HSCT.

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Haematopoietic stem cell transplantation (HSCT) is a demanding therapeutic intervention used in the treatment of a range of life-threatening malignant and non-malignant diseases, with high treatment-related mortality. For those who survive, their lives are often complicated by a wide range of debilitating physical sequelae, with over 90 % of HSCT survivors experiencing at least one serious late adverse effect of treatment [1]. The coexistence of multiple late sequelae, particularly chronic graft-versus-host disease (cGVHD), is widely recognised as having a profound impact upon HSCT survivor's quality of life (QoL). Therefore, obtaining QoL information is a crucial part of the assessment of treatment success, as improved overall survival is no longer the only factor relevant to the evaluation of a *successful* medical outcome.

Recent reviews of QoL post HSCT have concluded that many aspects of the individual's physical, functional, social and psychological QoL improve despite high symptom burden [2–5]. Typical concerns of HSCT survivors include compromised fertility and sexual functioning, fatigue, cognitive declines and physical and emotional distress [2–4, 6, 7]. Fear of recurrence, the challenge of managing uncertainty and frustration at loss of control are also commonly cited psychological sequelae of post-HSCT survivorship [8, 9]. Inevitably, each of these challenges can compromise the survivor's social roles and identity and may have significant implications for their social interactions and relationships [10–13].

Previous research has highlighted the deleterious impact that late-onset and persistent adverse effects of HSCT may have on survivor's daily functioning and the intense frustration that survivors may feel as a consequence of these limitations and the intractable unpredictability of recovery [14]. Despite the challenges that HSCT survivorship brings, many survivors, however, are still able to reflect on the positive, transformative nature of HSCT and experience a renewed appreciation for life, a renegotiation of priorities, an enhanced spirituality, liberation from hospitals and the possibility of returning to study/work [15, 16]. While the experience of illness, survival and limitation may encourage many patients to reflect on their own lives and on the *human condition*, it remains the case that many survivors, particularly those dealing with the effects of chronic GVHD, struggle with the limitations on their lives and functioning as a consequence of the adverse sequelae of HSCT [17, 18]. Indeed, a review of the literature reveals how patients report being surprised by the severity and duration of distressing side effects particularly as it impacts on their ability to return to activities of daily living such as driving and returning to education or employment [14, 19].

While the concept of a 'shrinking life world' has been used to describe the patient's experience in a range of chronic illnesses, including the way in which illness may disrupt or diminish employment, restrict or limit social interactions and erode an individual's self-concept [20], this concept has yet to be explored in the context of HSCT survivorship. In part, this may be a consequence of what is known about long-term survival post HSCT, as the vast majority of studies reporting on the QoL of HSCT survivors are quantitative studies, and often retrospective registry reviews, and rely upon a limited range of measures to assess QoL. While such studies provide important and useful information about QoL, at the same time, they often fail to fully capture the ways in which survivor's lives have changed, including the existential and often ill-defined regrets, concerns, fears and anxieties that they experience. Although a number of important qualitative studies have provided some insights into the *everyday* challenges of survivorship [6, 14, 21, 22], there is also no doubt that more qualitative exploration of HSCT survivorship needs to be done in order to guide the development of models of care to improve symptom management, identify survivors at increased risk of poor QoL, provide opportunities for early intervention and help both health professionals and survivors with medical decision-making. This study describes the qualitative insights gained by asking a population of long-term survivors of HSCT a single open-ended question about the quality of their life post HSCT.

Methods

The study sample was selected from allogeneic haematopoietic stem cell transplantation databases of the four major adult metropolitan hospitals in New South Wales, Australia, that perform HSCT. Participants were eligible if they were ≥18 years of age and had undergone an allogeneic BMT between 1 January 2000 and 31 December 2012 and could read and write English. Consenting participants were given the option to self-complete the questionnaire or to complete a telephone interview with one of the researchers. A second round of telephone calls was made to consenting participants who had not returned the survey within a month. A total of 1475 allogeneic HSCT were performed in the study period. Of the 669 recipients known to be alive at study sampling, 583 were contactable and were sent study packs and 441 returned the completed survey. No respondent opted for a telephone interview. Three percent declined participation. Demographic characteristics of the study respondents are depicted in Table 1. The study was approved by the Northern Sydney Local Health District Human Research Ethics Committee (NSLHD Reference: 1207-217M).

In order to capture the diversity of responses and to avoid a positive or negative bias, data was obtained by positing a single open-ended question asking respondents to list the three issues of greatest importance to their QoL post HSCT. Responses to the QoL question were copied verbatim, maintaining confidentiality, into a word document. The analytical framework used for initial coding was guided by the model of QoL conceived by Ferrell et al. [23]. We further refined the thematic scheme through multiple readings and line-by-line coding. Initially 232 codes were identified. The codes were then grouped together with codes of similar meaning. The consolidated codes were further condensed to five common themes: the failing body and diminishing physical effectiveness, the changed mind, the loss of social connectedness, the loss of the functional self and the patient for life. The first and last authors performed the analysis, but final agreement on the themes was only reached after three other authors had independently read and provided commentary on both the codes and the characteristics of each category. Qualitative analysis was performed on NVivo software.

Table 1 Patient demographics and clinical characteristics

Characteristics	No. of patients (%)
Age group	
19–29	30 (6.8)
30–39	49 (11.1)
40–49	83 (18.7)
50–59	130 (29.5)
60–69	127 (28.7)
>70	22 (5.0)
Median; range	54; 19–79
Gender	
Male	250 (56.7)
Female	191 (43.3)
Culture, ethnicity	
Australian/European	323 (73.2)
Indigenous Australian	2 (0.5)
Asian	30 (6.8)
Middle Eastern	7 (1.6)
Other	10 (2.3)
Unknown	69 (15.6)
Years since transplant	
<2	58 (13.1)
2 to >6	204 (46.3)
6 to <10	117 (26.5)
≥10	62 (14.1)
Median; range	5; 1–14
Underlying diagnosis	
AML/ALL	226 (51.2)
CML/MDS/myelofibrosis	60 (13.6)
Other	137 (31.1)
Unknown	18 (4.1)
Remission status	
CR1/CR2	271 (61.4)
>CR2	22 (5.0)
Other	46 (10.4)
Chronic phase	18 (4.1)
Accelerated phase and blast crisis	3 (0.7)
Refractory	22 (5.0)
Partial remission	23 (5.2)
Unknown	36 (8.2)
Donor type	
Sibling	250 (56.7)
Haploidentical	10 (2.3)
Matched unrelated	158 (35.8)
Mismatched unrelated	21 (4.8)
Unknown	2 (0.4)
Stem cell source	
Bone marrow	48 (10.9)
PBSCT	381 (86.4)
Cord	12 (2.7)

Results

While some survivors experienced relatively good QoL post HSCT, many struggled with pervasive and unrelenting side effects. The overwhelming theme evident in the responses of those struggling with QoL was that their world and opportunities had become profoundly diminished compared to the life they enjoyed prior to disease and HSCT. (A selection of participant quotes exemplifying the themes are detailed in Table 2.)

The failing body and diminishing physical effectiveness

The majority of respondents reported that the toxicity and immunosuppression associated with HSCT resulted in a plethora of long-term impairments of survivor's physical, emotional and psychosocial function. A considerable number of survivors reflected on the impact of cGVHD. Reference to GVHD was frequently linked to comments highlighting the unrelenting implications for the individual's physical, social and psychological functioning. A large number of survivors reflected on the physical burden of transplant which was often associated with reduced emotional and social functioning including, inter alia, fatigue, employment, depression and declines in socialisation. Some respondents reflected that their social world had shrunk as a consequence of their physical restrictions and incapacity to regain fitness. Many reflected that the complications of transplant transformed their personal world and their intimate relationships, particularly their sexual identity, sexual functioning and fertility. A large number of women reported early onset of menopause, decreased sexual enjoyment, reduced fertility, vaginal dryness, irritation, pain and bleeding, while some men reported erectile dysfunction, lowered libido and decreased sexual enjoyment. Infertility and reports of sexual dysfunction were often linked to the survivor's low mood, poor self-esteem and relationship difficulties. The impact of HSCT on fertility, sexuality, identity and physical function led some respondents to reflect on the difficulty they faced in trying to secure future relationships. Despite many respondents reflecting on the persistence of significant medical complications and the functional limitations that compromised their QoL, the vast majority of respondents reported feeling a deep appreciation for life post HSCT.

The changed mind

Many survivors noted a range of mood changes post transplant including anger, frustration, anxiety and depression. Some survivors linked mood disturbances to social isolation. Several HSCT survivors also described cognitive changes following HSCT, including memory deficits, decreased concentration and attention, mental fatigue and reduced reaction times. Some survivors linked these cognitive impairments to

Table 2 A selection of participant responses to QoL question: What are the three things that have had the most impact on your quality of life since your transplant?

1. The failing body and diminishing physical effectiveness
"GVHD had the biggest impact on my QoL. In particular it attacked my tear glands and saliva glands – both no longer work. I have dry eyes and much discomfort regularly in my eyes. I can no longer drive, watch TV or read or go on the Internet because focusing my eyes hurts and my eyes are very sensitive to all forms of light. Earlier this year, my eyes really affected my mental health and it made me depressed."
"I just don't have the same amount of energy. I feel as if I only have 60 % of my energy since my SCT. This frustrates me…. It took me a long time to listen to my body and rest when I am tired, It does frustrate me as prior to the SCT I was always on the go. We don't plan things too often. I see how I feel when I wake up and if I have the energy, we go out for the day. I feel like my lack of energy rules my life."
"Prior to my transplant I was fit and healthy and now find I am unable to regain the fitness which means I can only do fitness activities including work, sport and leisure for short periods before tiring and requiring a rest. This lack of fitness makes it difficult to find suitable employment for my trade."
"My hormone levels are all over the place. My libido is very low. I've tried different things to help but nothing is helping and it is becoming a problem in my marriage. I am 28 and going through menopause. It is really hard and depressing. I wish I knew this before treatment."
"Finding a woman who will like me for who I am and not judge me for what I have been through…"
"I enjoy everyday. Some days I need to lie down for a few hours due to fatigue and body aches. But, I am so happy and live my life to the fullest. I have accepted that I will need ongoing health checks and I am very grateful for the opportunity to undergo the transplant."
2. The changed mind
"Anxiety & depression – I don't sleep, am always fearful, nervous and on-guard. I don't cope with little things. It's a big change to my personality. I withdraw from social situations."
"Feels like my memory is foggy. Sometimes unable to find the word or form a sentence properly. Unable to remember as well as I did prior to transplant. I feel I wouldn't be able to cope with a high pressure role. I find multi-tasking difficult and get stressed easier and am unable to juggle tasks and live like I used to."
"Fear of recurrence, further side effects and additional problems with health. This fear has restricted my social life and how I react with my family."
"I feel that my disease has set me back in my life so much for me and my family. We have lost 5 years of our lives and it has crippled our future plans and our dreams as a family. Everyone seems to be moving forward except for us. So much time lost…."
"It took quite a long time to rediscover my old self. Who I am? What am I supposed to do, act and feel? I felt like a non-entity and this was my main concern. Five years after BMT and I am only now coming to terms with my old/new self."
3. The loss of social connectedness
"The most important factor in my successful recovery was the love, support and encouragement of my wife, son and close friends. I cannot imagine how anyone would survive a BMT and the complications that follow it on their own."
"Feeling that I am a major drain on my wife's time and lifestyle, even though she does it all willingly and doesn't feel that way."
"Changes in family relationships – There is a distance between me and my wife and each of my 3 children…. I feel I have a disconnect."
"I am reliant on others. Losing my independence. Not knowing if I may have a dizzy turn means I am restricted as to what I do or try. Having been totally independent and self reliant prior to AML it is difficult to take a complete 180 turn around."
4. The loss of the functional self
"I've tried to work lasted one day put me back 3 months aggravated the GVHD. Working or not working is probably number 1 on the list. I won't go back to the position I held before the illness, or work again unless my mind gets better… It is killing me mentally and physically."
"I have reduced my workload in a limited way. I was formally the managing partner of my law firm – Now I have reduced responsibilities and I sometimes feel I have lost some respect. I also feel my firm has suffered from my new role and I could have done it better."
"Not being able to work. Less household income. Difficult to pay bills and medical expenses. Plus isolation, no longer having access to work, friendships and support. Loneliness and isolation."
"I have lost everything, my home, all my savings because it has been a very long treatment in and out of hospital for about 1 year for blood transfusions and had spleen removed, lots of costs for hospital parking and other things."
5. The patient for life—the unrelenting nature of follow-up
"Travel to the transplant unit sometimes monthly, fortnightly and at the moment twice weekly. I cannot work and my wife has had to stop work to become my full time carer. The large regime of medication I take to try and control GVHD and the side effects of medications are numerous and debilitating. I am always fatigued and cannot get motivated. I get over one thing and something else appears. There seems to be no end."
"I feel I need to be near my medical team and this restricts the distance I can travel from home. I am very wary as to where I go in case the communication with the team is not there, so I live in my safety zone."
"Running to doctors all the time, going to the hospital all the time, doctors in the country hospitals have no idea what's wrong, or what to do, even when told by the transplant team. They just don't care up here in the bush. One of the doctors was told by my team how to treat GVHD, but did nothing for 14 days."
"My local GP has caused me unnecessary anxiety due to his inability to cope with my situation. I feel he is lost and a bit afraid in dealing with me to the extent I have lost confidence in him. An example is my vaccination requirements where I had to fight to get the required vaccinations even though they were listed for him."
"I have a great relationship with my local doctor where I can have a conversation rather than just a consultation – this enables me to make health decisions that are supported an acknowledged."

SCT stem cell transplant, *BMT* blood and marrow transplant (these terms are synonymous with HSCT and can used interchangeably), *AML* acute myeloid leukaemia

problems with employment and relationships. One of the most dominant emotions expressed by many respondents was fear—the fear of disease recurrence, the fear of chronic GVHD and the fear of secondary malignancies occurring post HSCT. According to several subjects, this created enormous distress. For some subjects, this deep and pervasive fear made them reluctant to take risks or plan for the future, which further perpetuated shrinking opportunities in their life.

The loss of social connectedness

Perhaps unsurprisingly, family and friends featured prominently in respondents' descriptions of their QoL post HSCT,

with many emphasising the importance of both the physical and emotional support they received from significant others throughout both treatment and survivorship. At the same time, however, many subjects described the terrible impact that HSCT had had on their loved ones and the guilt that they felt about the way HSCT had changed not only their own lives but also the lives of those close to them. Some respondents also noted the degree to which they were dependent—physically, emotionally, socially and financially—upon others and the way that this made them feel.

The loss of the functional self

Many respondents reported an association between undergoing transplant and the loss of some of the certainties that most people take for granted—like health, stable relationships, sustained employment and financial security. For some, the loss of employment and the loss of capacity to work were linked to their sense of self-worth. Indeed for many subjects, work, while previously a central part of their lives, had become stressful and exhausting. Many survivors reported missing numerous workdays due to ill health, and some reported a loss of career momentum including the necessity to change their job or *downsize* to part-time job. Numerous subjects also reported that they were unable to return to work at all, with many describing how these changes caused them further distress including anxiety, depression and impairments in social functioning. A few survivors also reflected on the financial burden of HSCT including the loss of income. References to the financial burden of transplant were often linked to comments regarding the patient's sense of self-worth and financial security.

The patient for life—the unrelenting nature of follow-up

Many survivors described the burdensome requirement of life-long follow-up to prevent, identify and treat the myriad of late effects that complicate transplant survival. Some reported on the redirection of their attention from broader life issues to an intense focus on health and well-being. Some reflected on the restrictions in their life perpetuated by the unrelenting nature of follow-up including loss of productive function, social isolation and a diminished self-concept. Importantly, while many reflected on the fact that long-term follow-up (LTFU) was onerous, some respondents recognised how necessary it was and described how much they relied upon access to multidisciplinary long-term care and the expertise available through their transplant centre. Some survivors stated their desire to live within a safe distance from their transplant centre. This specification was often linked to the individual's anxiety about the uncertainties and dangers posed by the future.

A few survivors felt that the special expertise, knowledge and care provided by their haematologist and HSCT team were simply not available elsewhere. In many cases, this sense was heightened by adverse experiences that HSCT survivors had experienced before transplant and subsequent to it. This was particularly true for patients living in rural, regional or remote areas. Concerns regarding lack of expertise and knowledge were not, however, specific to those living in rural areas, with a few survivors expressing concerns regarding the lack of knowledge of their general practitioners. Importantly, however, even though some expressed concerns about their local doctor, others were very grateful for their relationship with them.

Conclusions

As survival following HSCT has improved, attention has increasingly turned to the impact of HSCT upon recipients' QoL and their experience of *survivorship*. Although a number of quantitative studies suggest that those who survive at least 1–2 years following HSCT have an acceptable QoL [2–5], it is clear that long-term survivors of HSCT face ongoing challenges and experience limitations in many domains of their life. By asking survivors one simple question—to describe the three complications of HSCT that have had the most impact upon their QoL—we were rewarded with a rich picture of the challenges of survivorship. What was clear from the accounts provided by HSCT survivors in this study was that QoL was most impacted by the physical burden of the failing body, the cognitive and mood changes, the diminished social connectedness, the loss of functionality and the burden of being a patient for life. These QoL challenges were shown to shrink various aspects of the HSCT survivor's world—restricting not only their capacities and function but also their identity and relationships. While existing literature has described the changes in self-concept and the loss of identity associated with reductions in HSCT survivor's ability to perform everyday functions of living, this is the first study to conceptualise these *losses* in terms of a shrinking life world [24, 25].

Many respondents to our study reported feeling a sense of dislocation and isolation in the years following their transplant—a sense heightened and perpetuated by their real or perceived fear of infection and GVHD. The functional impairments suffered as a result of overwhelming fatigue were also ubiquitous. Prior research has identified that GVHD and fatigue often compromise survivor's QoL for many years post transplant and are a frequent cause of mood disturbance [3, 4, 24]. For some survivors, this physical and psychological debility was so severe that they felt they had lost their sense of identity, independence and self-worth and were unable to fulfil the social, familial and professional roles that marked out 'who they were' before their HSCT. For others, fears about

their capacity to cope intensified their degree of dependence—binding them to their transplant centre and to the healthcare professionals that they trusted and preventing them from seeing a world beyond the geographical and emotional 'gaze' of their medical care. Not surprisingly, many survivors were distressed by their loss of function, particularly as it compromised those things that provide certainty and stability, like sustained employment and financial security. This is an important finding and is consistent with other recent studies that have highlighted the ongoing challenges associated with job insecurity, discrimination, career derailment and delayed goals, financial loss and instability and constraints on job mobility [19].

According to the literature, family and friends play an important function in providing social support. However, patients also worry that they may become a burden to others. One study concluded that some survivors felt their inability to contribute to the family and their lack of productivity made them feel useless [11]. These findings were consisted with the results of this study which highlighted both the importance of family to survivors and the guilt they experienced as a result of their physical, emotional, social and financial dependence. While prior to HSCT many haematologists and allied health professionals encourage survivors to consider the possibility that they may become 'a patient for life', in reality, it is difficult, if not impossible, to convey what this actually *means*, what impact transplantation may have on every aspect of a survivor's life, how unrelenting follow-up may feel and how difficult it may be for survivors to adapt to their post-HSCT challenges. Previous studies have concluded that while many survivors report adequate QoL, many do not believe they have returned to normal [25]. However, this is not to say that survivors of HSCT (particularly those that modify their expectations and accept that their lives are different post HSCT than they were beforehand) do not adapt, do not resume *normal activities*, do not cope with the uncertainty implicit in survival post HSCT or do not accommodate the need to cease or downsize their employment or modify their relationships and social roles [23]. Rather, it is to acknowledge that some survivors of HSCT will be more profoundly impacted upon than others by their failing body, impaired cognition, emotional distress and social isolation [3, 4].

Previous research has highlighted the important role that pre- and post-transplant education may play in improving the QoL of HSCT survivors and in enabling them to learn strategies to assist them cope with the changes in their lives [14]. As a result, it is now generally recognised that transplant centres should endeavour to incorporate education, counselling and support into every stage of the transplant recipient's journey [14]. But information in any form is very different to personal experience. It is one thing for a patient who is shortly to undergo a HSCT to be told by the transplant team that they have a 60 % chance of developing chronic GVHD but a very different thing to experience it. And it is one thing to record the frequency or numerical grade or extent of HSCT complications but another thing again to describe in one's own words what it is to experience them. While it is important to collective quantitative measures of QoL, it is also crucial to recognise the limitations of this form of data and supplement it with qualitative data that may reveal the full extent and meaning of the challenges to HSCT survivors' QoL.

The results of this study are important not simply because they contribute to the growing qualitative literature on post-HSCT survivorship but because it suggests that a single question may provide important insights into the experience of survival post HSCT. And this is important, because, unlike hour-long in-depth interviews, time could be found in the *routine* follow-up of HSCT survivors to ask them a question about how they are coping and what is of most concern to them. This study has some very clear limitations that caution against over-generalising the results to all HSCT survivors. Our analysis was based upon written responses to a single question about QoL, and we did not use other qualitative methods, such as in-depth interviews or ethnographic methods that would have undoubtedly provide a more nuanced account of the experience of survival post HSCT. But while other qualitative methodologies may have provided more detailed accounts of the experience of survivorship, the use of a single question prompt in this study to elicit qualitative descriptions of post-HSCT survivorship suggests other benefits. Firstly, our results suggest that asking a single, very specific question of HSCT survivors about their QoL may enrich and triangulate the quantitative description of survivorship provided by other psychometric measures of QoL commonly used in post-HSCT follow-up. And secondly, our results provide the possibility of translation, as unlike complex surveys or in-depth, unstructured interviews, regularly asking a patient to describe the main things that are having an adverse impact upon their QoL may be easily done, have clinical utility and have limited resource costs.

It is clear from the accounts provided by the respondents to this survey that while HSCT provides enormous benefits, it also is enormously challenging and may have a range of complex impacts upon the QoL of HSCT recipients and upon their experience of survivorship. While many will cope, and adapt, and continue to cherish the life they have, the vast majority will face challenges along the way. While better education of HSCT recipients may help the work that survivors need to do post HSCT, it is unlikely that it will ever be able to completely prepare HSCT recipients for what lies ahead. In these circumstances, what may be most important is for HSCT services to acknowledge and understand the pervasive impact of HSCT and offer reassurance that no matter what occurs, whether expected or unanticipated, they will always be available to provide care and support.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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