

Health-related quality of life in haematopoietic stem cell transplant survivors: a qualitative study on the role of psychosocial variables and response shifts

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Abstract

Purpose Psychosocial assessment prior to haematopoietic stem cell transplants (HSCT) can help to identify patients at risk of impaired health-related quality of life (HRQOL) post-transplant. According to the response-shift model, certain antecedents and mechanisms, along with changes in internal standards, values or conceptualisations of HRQOL, facilitate adjustment to changes in health circumstances. This study sought to explore the role of psychosocial variables in adjustment to compromised HRQOL following HSCT, from the theoretical basis of the response-shift model.

Methods Semi-structured interviews were conducted with 28 patients (15 women, 13 men; 22–71 years), post-HSCT. Time since transplant ranged from 1 month to 28 years. Verbatim transcripts were analysed using template analysis.

Results Patients provided narrative examples of changing their values and internal standards. Optimism, social support, social comparisons, changing expectations and setting goals were identified as important in managing threats to HRQOL.

Conclusions The response-shift model is a useful theoretical basis for exploring HRQOL in HSCT patients. Response shifts and psychosocial variables may help

patients to cope and enabling them to experience good HRQOL despite the negative effects of HSCT. Understanding the adjustment processes has implications for patient care.

Keywords Haematopoietic stem cell transplantation · Quality of life · Psychological adaptation · Psychosocial factors · Qualitative

Introduction

The use of haematopoietic stem cell transplants (HSCT) as a treatment for a variety of cancers and haematological disorders has increased substantially in recent years [1]. Medical and technological advances have increased both survival rates and relapse-free intervals. However, surviving recipients are at risk of a number of difficulties, which are likely to have a negative impact on their health-related quality of life (HRQOL). Difficulties include work-related problems, inability to resume social roles, sleep disturbance, infertility issues and physical and emotional distress [2]. Some may also develop post-traumatic stress disorder and/or mood disorders, including anxiety and depression [2, 3]. Compromised HRQOL has been reported after transplantation [4, 5], particularly in the physical domain. However, many studies have also found that recipients report good HRQOL, comparable to that of the general population [6, 7]. This suggests that many patients are able to adapt and cope with illness and treatment-related factors that continue to have a negative effect on life. However, this is not the case for all HSCT patients.

Certain psychosocial variables, including optimism and social support, may explain why some patients adjust better than others. It has been proposed that the assessment of

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such variables prior to transplant would be valuable to ensure optimal care for this patient group [8] and to facilitate early interventions when necessary [9]. In their guide to psychosocial assessment prior to HSCT, Blume and Amylon [8] list an extensive number of variables for inclusion, but such an extensive psychosocial assessment, in addition to necessary physical assessments, would be time consuming and exhausting for patients. Since few studies have explored the influence of psychosocial variables on HRQOL in this patient group, informed decisions on which variables should be assessed are not available.

Decisions about what to measure, and ultimately how to intervene to improve HRQOL, are likely to benefit from being theory driven. Theoretically guided work has the potential for more effective interventions and can improve our understanding of why HRQOL is compromised. The response-shift model [10] provides a theoretical framework for exploring adjustment and HRQOL within this patient group.

The response-shift model suggests that the perceptions of HRQOL are prompted by changes in health (*catalysts*, e.g. HSCT), initiating behavioural processes (*mechanisms*, e.g. seeking social support), which may lead to changes in internal standards, values or conceptualisations of HRQOL (*response shifts*). Furthermore, individual characteristics (*antecedents*) influence this process. The model suggests that these concepts are linked through “a dynamic feedback loop” that has the aim of maintaining or improving an individual’s perception of their HRQOL, regardless of any difficulties they may be experiencing [10]. An understanding of whether HSCT patients are engaging in response shifts, and which antecedents and mechanisms facilitate adjustment, will therefore help us to better understand the adjustment in this patient group, and in turn inform patient care.

The aims of the present study are to describe adjustment post-HSCT from the theoretical basis of the response-shift model, through (1) identifying the antecedents and mechanisms that patients find helpful for adjustment and (2) exploring whether patients report response shifts in describing their adjustment. Given the exploratory nature of this study, a qualitative design was felt to be most appropriate, enabling us to understand those antecedents and mechanisms that patients feel facilitate their adjustment and to provide narrative examples of the various elements of the response-shift theory.

Methods

Participants

Individual interviews were conducted with 28 HSCT patients aged 22–71 years. Patients were recruited from

the North Trent HSCT Programme, based in Sheffield. Eligible patients were identified from the HSCT database and selected from haematology clinics at Western Park and Royal Hallamshire hospitals. Patients were purposely selected to create a variation sample, stratified according to gender, age, time since transplant, diagnosis and treatment (see Table 1 for detailed sample characteristics).

Interview schedule

The interview schedule included open-ended questions, with interviewers trained to have minimal verbal input and prompt only when appropriate [11]. The schedule was piloted prior to the commencement of the study. The interviewing environment was set up so that interviewees were able to discuss HRQOL and their experience in their own way. The interview was structured to explore the following topics: patient background, HRQOL, coping and the future. Questions to explore the existence of response shift included the following:

Table 1 Demographic summary of participants

| | Number of participants (Total $n = 28$) |
|----------------------------------|---|
| Gender | |
| Men | 13 |
| Women | 15 |
| Age | |
| 20–30 years | 3 |
| 31–40 years | 0 |
| 41–50 years | 4 |
| 51–60 years | 9 |
| 61–70 years | 11 |
| 70+ | 2 |
| Diagnosis | |
| Multiple myeloma | 16 |
| Acute myeloid leukaemia | 4 |
| Chronic myeloid leukaemia | 2 |
| Hodgkin’s disease | 2 |
| Non-Hodgkin’s lymphoma | 1 |
| Mantle cell lymphoma | 1 |
| Waldenstrom’s macroglobulinaemia | 1 |
| Aplastic anaemia | 1 |
| Type of transplant | |
| Autograft | 16 |
| Allograft | 14 |
| Time since transplant | |
| <5 years | 19 |
| 5–10 years | 10 |
| >10 years | 1 |

- 1) What does HRQOL mean and how has it changed? (*reconceptualisation*).
- 2) How they would describe their current HRQOL, how this compared to their HRQOL pre-transplant, whether they would have viewed their HRQOL in the same way pre-transplant if asked at the time rather than in retrospect, whether a ‘good’ day (physically/socially/emotionally/cognitively) meant different things to them now as opposed to pre-transplant? (*recalibration*).
- 3) Whether different things were important to them now? (*changing values*).

Procedure

Ethics approval was obtained from the South Yorkshire National Health Service Research Ethics Committee. Eligible patients were contacted by letter or at a scheduled appointment by the clinic nurses, asking whether they would consent to take part in the study at their next clinic visit or at another convenient time. Patients were provided with an information sheet giving details of the study, who to contact for further information, what was involved and the anticipated benefits. Patients were given the opportunity to ask questions and, if they chose to participate, were then asked to sign an informed consent form. To our knowledge, all patients approached by the nurses agreed to take part. Following consent, semi-structured individual interviews were conducted by RB (PhD student, woman) and CE (Professor, woman) between April and October 2008. The timing of the interview in relation to other clinic appointments depended on the patient’s preference, and 3 patients were interviewed during inpatient stays. Neither interviewer had a clinical relationship with the patients. The interviews lasted between 30 and 120 min and took place in a private room at the hospital. No other persons were present during the interviews, with the exception of two patients who requested to have their partner present, and one patient whose mother was present.

Analysis

Interviews were tape-recorded and subsequently transcribed verbatim (maintaining anonymity) to a word document. Data were analysed according to the principles of template analysis [12] using QSR NVivo software. An initial template was therefore developed based on the response-shift model and the initial structure of the interviews. The reading and reflection of a small number of transcripts resulted in adaptation of this template and construction of a template of broad themes. All transcripts were then uploaded into the software and coded into more detailed sub-themes as data collection and analysis continued. When data saturation was

judged to have been reached, as no new themes were emerging, recruitment was stopped. The final template of 7 major themes (Appendix 1) was subject to check by the research team, and a second coder unrelated to the research project checked coding of each individual interview to minimise bias. Inter-rater reliability was generally high (>0.9), and any disagreements were resolved through discussion between the two coders. The results reported in this paper focus on themes 2 (HRQOL and response shift) and 7 (management post-transplant).

Results

Overall HRQOL

‘I would put the quality of life that I’ve got at the minute as quite high. Probably if I rate it on a one to ten basis, I would say I would be about seven and a half to eight.’ (P2)

Nine patients (32%) felt they had a good HRQOL that was comparable with their HRQOL previously. Thirteen patients (46%) reported their HRQOL to be reduced and more restricted compared with before treatment. However, all 13 had found ways to manage their problems and still described their HRQOL overall as ‘good’ or ‘ok’. Only 3 (11%) patients described their HRQOL to be much lower than previously.

Identifying the antecedents and mechanisms that patients find helpful for adjustment

Optimism Twenty-five patients (89%) identified optimism as important to adjustment. This involved feeling hopeful about life and positive that treatment would help. Two of the patients said they were hoping for a cure, whilst other patients hoped the treatment would ease symptoms and improve their HRQOL.

Patients highlighted the value of having the right attitude or frame of mind and also felt it was important to believe that you can survive, ‘*you’ve got to think it’s not the end of the road.*’ (P18)

Patients felt lucky to have survived this long, and this led them to make the most of the present and stay positive, ‘*no, I don’t worry about it getting worse because I always think it’s going to be maintained so I’ve been lucky enough now, at the minute, I’m fighting to get back to remission. And I always think of it that way rather than it getting worse.*’ (P26)

Others highlighted that although it was good to be optimistic, it was also important not to be unrealistic. A good balance of acceptance, and optimism, was felt to be

most beneficial for adjustment, *'don't go into it thinking oh it's going to work, it's going to solve the problem, I'm going to get better, you should be optimistic, I think you've got to be fairly up beat and go for it if you want to... but if you do go for it, you've got to be realistic and say if this goes wrong, it's going to go wrong.'* (P3)

Social support Twenty-five patients (89%) said they required some degree of support from other people to help them cope. They received support from friends and family and some a palliative care nurse. In addition, 7 patients (28% of 25) appreciated the support provided by fellow patients. Three (12% of 25) who did not benefit from such support expressed a desire to talk to other patients about their experiences, but were unaware of anyone in a similar situation.

Social support was described as beneficial as it not only provided physical and emotional aid, but also acted as a distraction, *"Family's been a great thing, yes, absolutely great. That's the biggest thing. When you have a lot of visitors and there's people coming to see you and do things for you, it's a big help. When you haven't got a big family and you don't see many people, you tend to ponder on things."* (P4)

Where families struggled to come to terms with the impact of their relation's illness and transplant, it was described as a hindrance to adjustment. For example, one patient described how her husband had found it difficult to cope with her illness and took it out on her *'he's angry with the myeloma but the anger comes out at me, do you see what I mean and he actually went to counselling about it... and they explained to him that he is angry with the illness but not with the person but he gets so frustrated with me sometimes.'* (P17)

Changing expectations Twenty-three patients (82%) identified changing expectations as important for coping. These patients felt that it was important to accept that things were different and adapt their expectations accordingly. Patients described how they came to accept that their lifespan may be shorter than normal, that their illness was incurable and that cancer was part of their identity. Thus, they changed their expectations to adapt to physical changes and to focus on the short term. Patients felt it was important to make the most of what they are able to do and be realistic about what the future might bring, *'rather than think I wish I could be doing this, I wish I could be doing that., I don't, I just say right, I'm not going to be able to do this, I'll shrink it...so you cope that way really.'* (P3)

Although these changes came easily to some, 4 (17% of 23) described finding it hard to lower their expectations and accept that things may not improve, which made adjustment more difficult *'you have to think oh well it doesn't matter as much, although it does really.'* (P17)

Social comparisons An additional mechanism that individuals engaged in as a way of coping was making social comparisons. Among 19 people (68%) who compared themselves with others, 11 found the comparisons helpful (58% of 19). Patients described making downwards comparisons with fellow patients or hypothetical others who were worse off than themselves. For 5 (26% of 19), this was upsetting, as it brought home their own mortality, but for 9 (47% of 19), it also made them appreciate their situation and see it more positively, *'I just count myself as being lucky that I had a perfect match with me brother. People I've known haven't had matches with their own brothers and they've got matches—in fact one from America. He died actually. I thought that were horrendous. He were doing really well and he suddenly went ... just gone, no time. I couldn't believe it. So I just count myself lucky, that's all.'* (P14)

How helpful comparisons were for adjustment depended on whether they were interpreted positively or negatively, regardless of whether they were upwards or downwards. The way in which comparisons were interpreted was at times described as being mood dependent, but individual differences were also important. Patients described how upward comparisons, with patients who had been through what they were going through and had recovered, gave them hope *'It's helpful because I know that okay these people, you know are different to me, but they're also leading a life and they've had the same sort of problems as I have and they've got over it, yeah it helps'* (P3). Those who interpreted comparisons negatively found it difficult to hear, when other patients were doing well, *'There is one person... I don't know whether I feel envious or want to give him a.... because he'll sit there quite adamant when we're having our treatment, I'm fine me, back to work, no side effects, I don't even know I've had a transplant'* (P21). Upward comparisons with friends who had better health could also make patients feel worse and more isolated and restricted, *'Terrible, compared to them... I just can't walk as far as them, I can't stay up at night like they can, I just haven't got the energy that they've got.'* (P14)

Avoidant coping Seventeen patients (61%) described doing things to avoid thinking about their illness. This can be described as a form of avoidant coping and included behaviours such as keeping busy, not analysing or thinking about the treatment, not talking about it, avoiding reading the myeloma magazine or things related to cancer and refusing to go into a hospice.

Patients felt there was very little they themselves could do to control the consequences of HSCT or possibility of recurrence. They therefore highlighted that it was unhelpful to focus or dwell on their illness. Instead, patients described the usefulness of distracting themselves through other

areas of their life, *‘I mean I did my degree while I got leukaemia so that took me through three years. I hadn’t it on my mind all the time—I was too busy at college to think about it really, so I thought that was a big help.’* (P14)

Setting goals The final mechanism described by 12 patients (43%) was setting goals. This gave patients a sense of achievement and purpose and also assisted their avoidant coping through acting as a distraction. In addition to activities such as completing qualifications, three patients mentioned their upcoming participation in the transplant games.

However, for most, setting smaller, realistic and achievable goals was just as important, *“I didn’t really think about goals perhaps five years ago, I just getting on with life, now I’ve got goals like I want to feel better, I want to feel less nauseous, I want to get some work done, I want to get out more.”* (P23)

Exploring whether patients report response shifts in describing their adjustment

Patients struggled to identify whether their understanding of HRQOL had changed since the illness, and only indirect evidence could be gleaned from those patients who defined their HRQOL in relation to their experience. However, there was stronger evidence that they changed both their standards and their values to help adjust to their illness and transplant.

Changing standards Fifteen patients (54%) indicated that they had engaged in a recalibration of what, for them, constitutes ‘good’ HRQOL. Patients described how previously they would not have evaluated their HRQOL in the same way, *‘I just don’t think you are aware at the time of the quality that you actually had. It’s only because it’s been taken away that you put it on a scale I suppose.’* (P22)

A number of patients justified their positive descriptions of their current HRQOL, stating that it was *‘good for their age’* or *‘considering what they’d been through’*, and described how ‘good’ meant different things since their illness, and now they were older. Their recalibrations linked in with their expectations being lower, *‘I enjoy the simple pleasures in life more, don’t expect too much, which is nice, it means you can be easily satisfied.’* (P13)

Changing values As with standards, there was also considerable evidence to suggest that patients had changed their values, with 16 patients (57%) indicating that what was important to their HRQOL was now different. Many discussed how work, money, physical appearance, and a ‘tidy’ home and garden were things that had been important prior to transplant. These became less important following the transplant, *‘I always said I would have money but I’m not bothered about it now. I used to save but I’m*

not bothered about things like that now. I just get on with it.’ (P24)

On the other hand, family and friends were seen to be more important than previously. For many, family and friends had played an important supportive role in their experience, and this had brought them closer; they therefore focused on this aspect of their lives rather than the domains that had been more compromised.

Patients also described ‘little things’ such as being in the garden, having visits from friends or simply feeling good throughout the day as important and current priorities, rather than focusing on things they could no longer do, *‘yeah I think because you’re limited and you know what the limits are, things you can do become important to you and you try and focus on.’* (P1)

Discussion

This study provides an in-depth exploration into HRQOL and adjustment following HSCT, from the theoretical perspective of the response-shift model of HRQOL. The findings suggest first that patients report relatively good HRQOL post-transplant, although they continue to experience illness and transplant-related difficulties. Secondly, a number of antecedents and mechanisms are helpful to adjustment post-HSCT, including optimism, social support, changing expectations, social comparisons, avoidant coping and goal setting. Finally, the majority of patients described engaging in a response shift involving a change in standards and/or values in their adjustment to difficulties experienced post-HSCT.

Both optimism and social support have previously been found to be related to better coping post-transplant and higher HRQOL following HSCT [9, 13–15] and in other patient groups [16–21]. Similarly, in an earlier qualitative study exploring the meaning of HRQOL for HSCT patients [22], seven themes were identified that positively influenced HRQOL, including social support, a positive attitude, and having goals, as identified in this study. Optimism is thought to be important to HRQOL as optimists, as well as having a positive outlook on life, use more effective coping strategies than pessimists, whose strategies are related to psychological distress and avoidance of good health practices [23]. In addition, availability of social support gives patients physical and emotional assistance, can act as a distraction and prevents feelings of isolation. As with social support, goal-orientated behaviour can also act as a distraction and gives patients a sense of control over their lives and enables them to feel productive. King’s [24] conceptual framework for nursing suggests that interactions between health care professionals and patients should help with goal setting and attainment as part of the process of enhancing health and HRQOL [25].

With regard to the mechanism of changing expectations, there is evidence that HRQOL can be enhanced by narrowing the gap between expectations and experience; individuals who have a better than expected experience also report higher overall HRQOL [26, 27]. Therefore, promoting realistic expectations before HSCT can potentially be beneficial to patients. There is evidence that people are more likely to make downward social comparisons (i.e. comparing themselves with others who were worse off) to enhance their self-image and positive affect when they are stressed or threatened [28]. In line with this, most patients described making downward comparisons as helpful to maintaining a positive outlook. Previous research has indicated that cancer patients are more likely to make downward comparisons [29] and that this is related to better HRQOL [20]. On the other hand, making unfavourable upward comparisons (comparing themselves with others that are better off) has been shown to be negatively associated with HRQOL in both patient and proxy reports [20, 30]. However, in this study, a small number of patients did report finding upward social comparisons helpful, which may be a result of these types of comparison giving hope [31].

Finally, the fact that avoidant coping was seen to be helpful for adjustment by patients is in some ways surprising. Coping research suggests that whilst avoidant coping may be beneficial in the short term, approach coping has more positive outcomes in the long run [32]. In contrast, when people cannot control their situation, approach coping is less helpful as it will only lead to frustration. In this context, avoidant coping may be the best approach and beneficial to HRQOL [33]. Given that the majority of patients did not feel they had control over their illness and/or side effects of treatment, this may explain why they cited avoidant coping as helpful for their adjustment, even for those patients more than 5 years post-transplant. This finding is also in line with that of a previous study looking at coping and HRQOL in patients on a waiting list for percutaneous transluminal coronary angioplasty (PTCA) [34]. Approach coping was found to be negatively associated with HRQOL, avoidant coping was positively associated with HRQOL and respondents were more likely to use avoidant coping.

In addition to highlighting a number of antecedents and mechanisms that patients use to help them cope, patients also provided narrative examples of engaging in response shifts. Patients described having lower standards for what constitutes 'good' HRQOL, as a result of the extreme lows they experienced during illness and treatment; i.e. a recalibration response shift. Patients also described changing their values following transplant; things that they were unable to do became less important to them, whereas domains of HRQOL that are readily available to them, such as family, became more important. These findings are in line with

previous research on response shift and HRQOL in other patient groups, including kidney and pancreas transplant patients [35]. However, evidence for reconceptualisation response shifts was difficult to assess in this study. Assumptions can be made concerning previous patient definitions of HRQOL; however, the majority of patients did not give clear indications as to whether their definition of HRQOL had changed following their experience of illness and treatment. Furthermore, at times it was difficult to distinguish between reconceptualisations and changing values. Reconceptualisations have not previously been explored in qualitative research, which is perhaps indicative of the difficulty in assessing this type of shift in this manner.

Some limitations of this study need to be considered. First, it is important to determine whether variables such as optimism and social support are predictors or outcomes of the experience of illness and transplant [36] by longitudinal pre/post-transplant designs. This design will also clarify the extent to which the response shifts described are responsible for HSCT patient reports of good HRQOL. Causality cannot be determined from our findings. Secondly, it is important to note that many of the effects observed were not a direct consequence of the transplant itself, but rather changes as a result of the illness or other treatments. Therefore, when taking these findings forward with regard to transplant care, future research should attempt to tease out the specific consequences of HSCT. Finally, it should be acknowledged that recall bias may have affected the accuracy of some of the patient recollections.

Despite the limitations, the results have clinical implications for patient care. They highlight the importance of antecedents and mechanisms to adjustment processes and suggest that variables such as optimism and social support help patients to cope and may act as a buffer, enabling patients to experience good HRQOL despite the negative effects of HSCT. It is therefore, important to consider these variables when designing pre-transplant psychosocial assessments such as that proposed by Blume and Amylon [8].

The variables identified also provide direction for the design of interventions to promote adjustment. Our findings suggest that interventions targeting expectations, social support and social comparisons may be particularly beneficial to patients with adjustment difficulties. Furthermore, the role of optimism may indicate that tailoring HRQOL interventions to suit individual personality types would be particularly useful, although this may be difficult when resources are limited.

Interventions may include pre-transplant educational programmes with the aim of providing patients with realistic information on the difficulties they will experience during the recovery process, which may help to bring patients expectations closer to reality [37]. Post-transplant education or counselling sessions could then reinforce what is 'normal'.

Interventions targeting the provision of social support may also prove to be fruitful. Support groups provide patients with a network of support from people who are going through or have gone through similar experiences. Alternatively, taking a family systems approach to psychotherapy may help families to understand how they can best support their loved one during this difficult time, in addition to providing family members with an outlet for discussing the difficulties they are likely to also be experiencing. Behavioural interventions such as cognitive behavioural therapy (which enables patients to identify, challenge and substitute problem behaviours such as making unhelpful social comparisons) or motivational enhancement therapy (which provides counselling to enhance a patients motivation to change problem behaviours by exploring and resolving ambience about change) may also prove to be effective. Finally, interventions could aim to ‘teach’ response shift through helping patients to change their values or internal standards within adaptation training programmes.

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Appendix 1: Final template of themes

1. Medical variables

- Initial diagnosis.
- Treatment.
- Time post-transplant.
- Frequency of appointments.
- Satisfaction with care.
- Additional complications.

2. HRQOL and Response shift

- Overall QOL.
- Change in values.
- Recalibration.
- Reconceptualisation.

3. Physical HRQOL

- Self care.
- Mobility.
- Strenuous activities.
- Differences.
- Fatigue.
- Sexual activity.

4. Social HRQOL

- Activities.
- Family.
- Friends.

- Relaxation.
- Differences.
- Confidence.

5. Emotional HRQOL

- Anxiety.
- Depression.
- Anger/bitterness.
- Differences.

6. Cognitive HRQOL

- Employment ability/status
- Employment satisfaction.
- Employment help.
- Concentration.
- Memory.
- Differences.

7. Management post-transplant

- Optimism.
- Social support.
- Social comparisons.
- Changing expectations.
- Setting goals.
- Avoidant coping.

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