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Quality of Life following Haematopoietic Stem Cell Transplant among recipients aged over 50 years:

An Interpretative Phenomenological Analysis

and

Clinical Research Portfolio

Volume I

(Volume II bound separately)

Rona Gilfillan

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Faculty of Medicine Graduate School

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CHAPTER ONE:

Systematic Review

The impact of Psychosocial Interventions on Quality of Life and Psychological well-being amongst Haematopoietic Stem Cell Transplant recipients: A Systematic Review

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Written in accordance to guidelines for submission to

Bone Marrow Transplantation (See Appendix 1.1)

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ABSTRACT

Objectives: Haematopoetic Stem Cell Transplant (HSCT) is a potentially curative treatment for haematological cancers and related disorders. However the treatment is extremely aggressive and potentially life threatening. HSCT impacts all aspects of recipients' lives due to its associated physical and psychosocial sequelae. Recipients of HSCT represent a unique group of individuals with cancer and interventions to maintain or improve quality of life and wellbeing has been limited. To date, interventions have mainly focused on the impact of exercise interventions, however, psychosocial interventions are increasingly being utilised with this population. Psychosocial interventions have demonstrated effectiveness among other groups of individuals with cancer. However, little is known regarding the impact of such interventions with HSCT recipients. This present review therefore aims to identify psychosocial intervention studies within this population and summarise the findings regarding the impact upon quality of life and psychosocial outcomes.

Methods: A systematic search was performed using Ovid; Medline & Embase, EBSCO; CINHAL, PsychINFO & SocINDEX and Cochrane Library databases to identify relevant studies. Eight studies were identified as meeting inclusion/exclusion criteria. Methodological quality of the eight studies was determined by using a specifically adapted checklist.

Results: Four studies were rated "good"; one study was rated as "moderate"; and three as being of "poor" methodological quality. The findings indicated that psychosocial interventions are highly heterogeneous making it difficult to compare findings. Emotional functioning is the most frequently investigated outcome to date and positive findings were identified in all eight studies for at least one QOL outcome parameter.

Conclusions: To date, there is insufficient evidence to suggest conclusive effectiveness of psychosocial interventions as improving QOL among HSCT recipients. However the positive effects identified in the studies suggest that there is a need to conduct more methodologically sound studies.

Keywords: haematopoietic stem cell transplant, psychosocial interventions, outcome, quality of life, systematic review.

INTRODUCTION

Haematopoietic stem cell transplantation (HSCT) is a potentially curative treatment for haematological cancers. For patients receiving autologous HSCT, stem cells are harvested from the patients themselves whereas in allogeneic HSCT, stem cells are harvested from a related or unrelated donor. Prior to receiving the transplant, many patients receive high-dose chemotherapy and possibly total body irradiation, leaving their immune system at its lowest point. The aggressive nature of HSCT means that patients spend significant periods of time in hospital, often in isolation, to protect against infection. As a result, normal life is put on hold during treatment and recovery. Although medical advances in HSCT procedures have improved resulting in the control of life-threatening diseases, about 40% of advanced cancer patients who undergo allogeneic HSCT die from transplant related complications.[1] This understandably results in fear and anxiety around the uncertainty of the procedure and its longer term recovery implications.

Regardless of transplant type, considerable physical, psychological and psychosocial distress before, during and after transplant is experienced by a majority of recipients.[2,3] A variety of such difficulties have been identified in empirical research as being; fatigue, loss of physical fitness as well as a number of unpleasant side effects including nausea and pain;[4] psychological distress such as PTSD;[5] persistent anxiety and depressive symptoms in a significant proportion.[2,6] Furthermore, recipients often experience some interruption in normal developmental tasks, for example, maintaining a career and establishing satisfactory marital and family relationships.[7,8] Distress and functioning in these areas tend to improve over time, however, long term impairment relative to non-cancer comparison groups is the norm.[9] Such associated morbidity has massive potential to threaten the overall quality of life and wellbeing of HSCT recipients and as a result of the overwhelming demands made on HSCT patients, it is recognised that recipients' ability to utilise normal coping strategies is compromised, particularly in the early stages of treatment and recovery.

Given the significant impact that HSCT can have on all aspects of lives of recipients and their families, research investigating interventions to improve QOL for HSCT recipients has increased. To date, the predominant focus of such interventions has been on the effects of exercise therapy. Recent reviews have found that exercise interventions in this field are still in their infancy and as such methodological quality is highly variable, with very few randomised controlled trials.[4,10] However, these reviews concluded that, methodological weaknesses notwithstanding, encouraging results were obtained for a diverse set of outcomes, such as physical fitness, health related QOL and psychological wellbeing, and recommendations were made for future studies on the effectiveness of exercise therapy for HSCT recipients.

As with exercise interventions, psychosocial interventions to improve the QOL and psychosocial functioning of HSCT recipients are also becoming more widespread. Psychosocial interventions use a variety of approaches such as behavioural and cognitive techniques, amongst others, and aim to relieve emotional distress and promote wellbeing and therefore seem well suited to use with HSCT recipients. Although psychosocial interventions with HSCT recipients are in their infancy, research has shown that such approaches are effective in improving wellbeing amongst other cancer populations. For example, a meta analysis of relaxation training among non-surgical cancer treatment patients, in reducing treatment related symptoms and improving emotional adjustment, found a significant effect on depression (medium effect size), anxiety and hostility (both small effect sizes).[11] This review did not focus on HSCT recipients but the findings were reported to suggest equal effectiveness in patients undergoing a variety of treatments, including HSCT. In addition, a systematic review of mindfulness approaches suggests such interventions may have a place in cancer care across the disease trajectory.[12] Furthermore, a meta analysis of the effectiveness of behavioural techniques on psychosocial functioning and health related QOL in breast cancer patients and survivors concluded effectiveness in improving fatigue, depression, anxiety and stress in this population.[13] Effect sizes were calculated using Cohen's rule of thumb and demonstrated smaller effect sizes for fatigue (ES -0.158) and stress (ES -0.159) as compared to depression (ES -0.336) and anxiety (ES -0.346) although all still fall within the small effect size range.

The effectiveness of psychosocial interventions with HSCT recipients, for whom treatment has a unique impact on QOL, is yet to be established. However, the value of conducting systematic reviews regarding the effectiveness of psychosocial interventions for individuals with cancer is demonstrated by Jacobson & Jim,[14] whose findings about the management of anxiety and depression facilitated the development of evidence based recommendations on a variety of psychosocial interventions for use with patients with cancer at different stages and undergoing different types of treatments (p.221). This type of information is invaluable to patients and clinicians.

Furthermore, Hoodin & Weber[15] conducted a systematic review of psychosocial factors affecting survival after HSCT. The reviewers' analysis of the methodologically sound studies suggested longer survival may be related to lower "anxious preoccupation", "higher fighting spirit" and better QOL ratings before and soon after transplant in adults (P. 181). This is important because effective psychosocial interventions can be used to address these factors and potentially facilitate not only improved wellbeing but also survival.

As far as the author of the present review is aware, no systematic reviews have been conducted regarding the evidence base for psychosocial interventions with HSCT recipients who face huge physical and psychosocial demands threatening their overall quality of life. Interventions within the HSCT population represent a developing area of research therefore it is important and timely to investigate the state of the literature and build our understanding of the most and least effective approaches since "psychosocial care that is ineffective may be worse than no care at all" (Jacobson & Jim, p. 214).[14]

Therefore, the objective of the following systematic review is:
To summarise the primary research findings obtained in psychosocial interventions aimed at improving quality of life or psychosocial wellbeing in HSCT patients, taking into account the methodological quality of the studies retrieved.
It will aim to answer the following question:

- How do psychosocial based interventions impact upon psychosocial and quality of life outcome following HSCT?

METHOD

Search strategy

The following electronic databases were used to identify suitable studies: Ovid; Medline & Embase, EBSCO; CINHAL, PsychINFO & SocINDEX and Cochrane Library.

These were searched using the following search terms including the Boolean operator “AND”:

[bone marrow transplant or hematopoietic stem cell transplant or peripheral blood stem cell transplant]

AND

[quality of life or psychosocial function or anxiety or depression]

AND

[outcome]

AND

[relaxation or psychoeducation or mindful or CBT or behavioural or psychosocial or art or cognitive or exercise]

AND

[therapy or intervention]

AND

[adult]

A multi database search was conducted using the above search terms, in addition the last 5 years (2006-2011) of the following journals were hand searched: Bone Marrow Transplantation, Psycho-Oncology and Journal of Psychosocial Oncology. The references of the most recent reviews/editorials/commentaries, n= 5 (Liu *et al*.,[10] Shennan *et al.*,[12] Schulz,[16] Somerfield & Rizzo[17], Wiskeman & Huber[18]) were examined to ensure that no appropriate studies had been missed.

Inclusion/exclusion criteria:

All papers retrieved by the database and journal searches were examined using the following inclusion criteria. Those not meeting the criteria below were excluded from the review.

- Published in peer reviewed journal
- Study examined data from original research
- Study is written in English
- Study uses quantitative methods and analysis
- Participants are adults, 18 years and over
- Participants have received or are undergoing a bone marrow transplant as defined by haematopoietic stem cell or peripheral blood stem cell transplant.
- Outcome measures include psychosocial or quality of life (e.g. depression, anxiety, quality of life dimensions)
- Established or standardised assessment measures are used
- Psycho-social intervention based study e.g. behavioural, cognitive behavioural, mindfulness, relaxation, art/music therapy etc.

Given the recent up to date reviews of the effectiveness of exercise interventions on improving QOL and psychosocial functioning, for the purpose of the current review, it was decided to exclude studies utilising a sole exercise intervention.

No restrictions were made regarding group size and the use of a control group. This was done to maximise the number of eligible studies.

Data extraction and quality rating:

Studies meeting the inclusion criteria were rated by the author using a quality rating form adapted from guidance outlined by the Scottish Intercollegiate Guidelines Network (SIGN 50 – Annex C)[19] and the Critical Appraisal Skills Programme (CASP)[20] (See Appendix 1.2). Studies were rated on 16 items in 4 main areas which were 1) Rationale 2) Participants 3) Confounding Factors and 4) Statistical Analysis yielding a possible total score of 25. Each paper's total score was converted into a percentage to define a quality rating description of 'Good' (>75%); 'Moderate' (50-74%); or 'Poor' (<50%).

An independent rater used the same quality rating scale to independently rate 50% percentage of studies randomly selected. Disagreement between raters was resolved by discussion. Table 1 (p.32) details the quality rating calculated for each study.

INSERT TABLE 1 HERE

RESULTS

The database and key journal search identified 148 papers. It was found that 112 papers were inappropriate to the current review, excluded on basis of title or duplicates. Abstracts and full text of the remaining 36 papers were examined using the full inclusion criteria, resulting in the further exclusion of a further 28 papers (Appendix 1.3). The final number of studies that were found to fully meet the inclusion criteria was 8. These were included in the review below (Bauer-Wu *et al.*,[21] Cassileth *et al.*,[22] DuHamel *et al.*,[23] Gaston-Johansson *et al*.,[24] Horton-Deutsch *et al*.,[25] Jarden *et al.*,[26] Kim & Kim[27], and Lounsberry *et al.*[28]). The aforementioned search strategy is outlined in a flow diagram (See Figure 1; p.33).

INSERT FIGURE 1 HERE

It was envisaged that studies would be too heterogeneous to be combined using a formal meta-analysis. Therefore, a narrative synthesis was performed. The results are summarised according to the type of intervention used and outcome measures assessed.

Description of included studies

Characteristics of the included studies are shown in summary Table 2 (pp34-44). Five studies used a randomisation procedure to allocate the psychosocial intervention.[22-24,26,27] The remaining 3 studies were uncontrolled pilot studies.

INSERT TABLE 2

Five studies were carried out in the United States of America.[21-25] The remaining three studies were carried out in Denmark[26], South Korea[27], and Canada.[28]

Sample characteristics

The 8 intervention studies were carried out on a total number of 365 participants aged between 18 – 74 years, with a treatment sample size ranging 13 to 110. Where reported, the haematological conditions were the following; Hodgkin & non-Hodgkin lymphoma, myeloma/amyloidosis, acute & chronic myeloid leukaemia, severe aplastic anemia, acute & chronic lymphocytic leukaemia, myelodysplastic syndrome, and myeloproliferative. Only one study reported using a non-haematological disease sample of breast cancer patients.[24] In terms of transplant type, 2 studies used solely autologous samples; n=110[24] and n=62[22]. Three used solely allogeneic samples; n=13,[28] n=35[27] and n=34.[26] The remaining three studies used samples comprised of both allogeneic and autologous recipients; Horton-Deutsch *et al.*[25] (n=15) and Bauer-Wu *et al.*[21] (n=15) neither of which reported frequencies. DuHamel *et al.*[23] reported 40 autologous, 35 allogenenic, and 6 “missing” transplant types.

Description of Psychosocial Interventions

A variety of interventions were utilised to measure the effect on quality of life and psychosocial functioning following HSCT. To summarise, two studies used mindfulness based approaches,[21,25] one study applied music therapy[22] and one study used a single Cognitive Behaviour Therapy (CBT) approach.[23]

Four studies evaluated a multi-modal approach[24,26-28] that included at least two different types of psychosocial interventions such as breathing/relaxation techniques, psychoeducation or CBT approach. Moreover, two of these studies evaluated a psychosocial intervention in combination with a physical exercise programme.[26,27]

Setting

Six interventions were conducted during hospitalisation.[21,22,24-27] Only 1 study reported the length of stay in hospital which was 21 days.[22] One psycho-educational support intervention used an outpatient community based video-conferencing approach for participants 0-3 years post transplant[28] and the remaining study utilised individual telephone cognitive-behavioural therapy sessions, also with outpatients 1-3 years post HSCT.[23]

Format of interventions

Six interventions were conducted with participants on an individual basis except for 2 group based studies.[27,28] All interventions were delivered by professionals trained in the specific intervention. 7 interventions were standardised and/or manualised with the exception of the music intervention[22] which was tailor-made to the needs and preferences of the patients.

Length of treatment

The length of treatment time varied across studies, with 3 interventions delivering programmes up to 6 weeks.[26-28] The music therapy[22] and Comprehensive Coping Strategy Program[24] studies were the shortest interventions at 5-15 days; and 11 days respectively. Mindfulness based interventions were carried out by Horton-Deutsch *et al.*[24] for 4 weeks and by Bauer-Wu *et al*.[21] for 9 weeks. The longest intervention study was delivered between 10-16 weeks.[23]

Outcome measures

Outcome measures to investigate the effects of the interventions were all questionnaire based except in one study,[23] which additionally used a structured diagnostic interview based on DSM-IV criteria for PTSD.

Outcome measures were highly heterogeneous across QOL and psychosocial domains. Emotional distress was measured across all eight studies. Measurement was highly heterogeneous with eight different measures of emotional distress reported across the studies. The Hospital and Anxiety Depression Scale[29] was most frequently used, by three studies.[21,25-26] The State-Trait Anxiety Inventory[30] and The Beck Depression Inventory[31] were the next most frequently used, by two studies.[24,27] The Profile of Mood States[32] was used in order to assess the effect of music therapy on mood.[22] One study[23] used 2 measures of emotional functioning which were The PTSD Checklist Civilian Version[33,34] and The Brief Symptom Inventory,[35] in addition to the Clinician – Administered PTSD Scale for DSM-IV.[36] The Positive and Negative Affect Scale[37] was used in one study,[25] and finally one study[28] used the Impact of Event Scale – Revised.[38]

Physical functioning was measured across four studies.[21,24-26] The Symptom Experience Scale[39] was used by two studies[21,25] to measure physical symptom frequency, intensity and distress. One study[26] measured fatigue using The Functional Assessment of Cancer Therapy – Anemia scale.[40] Finally, one study[24] assessed pain using The Gaston-Johansson Painometer[41] as well as nausea and fatigue, using The Visual Analogue Scale.[42]

Only two studies measured overall QOL[26,28] using 2 different global measures (Functional Assessment of Cancer Therapy – Bone Marrow Transplant;[43] and The European Organization for Research and Treatment Cancer Quality of Life Questionnaire,[44] respectively). In addition, Lounsberry *et al.*[28] measured the impact of the psychoeducational support group intervention on 2 further, more specific dimensions of QOL; participants' spiritual wellbeing, using The Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing[45] and also participants' perception of personal benefits that occur as a result of attempts to cope with treatment, using The Post-Traumatic Growth Inventory.[46]

Methodological quality of included studies

The rating tool identified that 4 of the randomised controlled trial design (RCT) studies were rated as good[22,23,27,27], one RCT was rated as moderate[24] and the remaining 3 (uncontrolled studies) were of weakest quality.[21,25,28] Scores ranged between 28% - 96%.

In the five RCTs, randomisation procedure was clearly described in all but one study,[24] which failed to report type of randomisation design and procedure utilised. Treatment allocation was adequately concealed to the researchers in two RCT studies.[22-23] The interventions in the remaining three RCT studies were delivered by the researchers thus preventing concealment. As with most psychosocial studies it was not possible to blind participants to the intervention in all eight studies.

In terms of baseline similarity in the RCT studies, two multimodal RCTs[26,27] explicitly reported conducting preliminary statistics (independent samples *t*-test of variance for continuous variables and Fisher's Exact test for categorical variables) to demonstrate no significant differences and showed similarity of groups at baseline with regard to the most important prognostic factors. One RCT investigating the impact of music therapy on mood reported groups as similar at baseline with regard to age and length of stay in hospital, however, no preliminary statistics were reported as being conducted.[22] One RCT[24] reported that groups were not similar at baseline, that is, patients in the intervention group using a Comprehensive Coping Strategy Program, found that 40% of the intervention group had used previous coping compared to 21% of the control group, representing a statistically significant difference in an important baseline factor. Finally, DuHamel *et al*[23]. did not report assessing baseline similarity and instead conducted later statistical analyses on the influence of demographic and medical factors.

All eight studies gave a clear and detailed description of the intervention. For RCT studies, four reported that the control groups received treatment as usual or standard care, apart from the outpatient based CBT intervention[23], whose control group received assessment only.

Seven of the eight studies utilised a standardised protocol intervention, apart from the music therapy intervention[22] which was delivered to meet the needs and preferences of the patients, ensuring the interventions were delivered as intended. Measurement of participant compliance, however, was reported as being an issue in two studies; In Gaston-Johansson *et al.*'s[24] Comprehensive Coping Strategy Program, participants were given a diary to record use of the taught techniques, however, it is not clear within the study whether or not participants made use of this diary and therefore the extent to which they utilised the techniques. In addition, a mindfulness based intervention, Bauer-Wu *et al.*[21] reported that participants did not reliably maintain listening logs of the mindfulness CD so the full extent of the intervention could not be determined.

Facilitator adherence was described in four studies.[21,23,25,26] Two of these studies utilised a 'monitoring logbook',[25,26] and two described receiving supervision from experienced clinicians or peers.[21,23] In the remaining studies, it was less clear how adherence and consistency to approach was monitored.

The withdrawal/dropout of participants was clearly described in only four studies.[21,23,26,27] Two RCTs described number and reasons for dropout for both intervention and control group[23,26] whereas one RCT,[27] reported the number and reasons for dropout in terms of the total sample. The uncontrolled study[21] clearly reported reasons for loss of 5 participants. These aforementioned studies reported that, in the majority of cases, the main reasons for withdrawal/dropout were as a result of patients being too ill or as having died during intervention. The remaining studies failed to report clearly reasons for attrition[22,25,28] and one study reported no attrition.[24]

A variety of statistical analyses were conducted across studies (e.g. ANOVA, MANOVA, ANCOVA) and there was variability in the level and detail of reported statistical methods and findings in the results sections. All studies reported using a *P*-value of 0.05 as the limit of statistical significance apart from one study.[25] This study reported using paired *t*-tests but failed to report any statistical results and commented on the findings without statistical values alongside. In terms of the RCT studies that did not fully and/or clearly report analysing baseline data for similarity,[22,23] they accounted for covariance in their data analyses. In the Comprehensive Coping Strategy Program by Gaston-Johansson *et al.*[24], which found statistically significant difference in the baseline factor of use of prior coping methods, they also reported controlling for covariates in their analyses. Four RCTs[22,24,26,27] reported that they based their sample size on power calculations, three of which resulted in final sample sizes being slightly underpowered.[22,26,27] DuHamel *et al.*[23] was the only RCT not to explicitly mention utilisation of power calculation. Only one study reported effect sizes following non-parametrical analyses on a sample size of 13 participants[28] and none of the studies calculated clinically significant change (Jacobson & Truax[47]). Four studies included a follow-up period[21,23,25,26] ranging from 30 days to 12 months.

Three RCT studies[22,23,26] explicitly stated that intention-to-treat analyses were conducted to deal with patients who were lost to follow-up. One RCT[27] study did not report using intention-to-treat framework therefore data from 7 participants lost to follow-up before completing the post-test were not in the final analyses. Finally, one RCT[24] study reported 100% retention of participants to follow-up, therefore not requiring consideration of intention-to-treat. The three uncontrolled studies[21,25,28] did not report using intention-to-treat analyses.

The five RCT studies were evaluated against a treatment as usual control group and therefore no comparisons can be made against other psychosocial interventions. Therefore the eight studies will be critically examined on the basis of their impact on quality of life, anxiety, depression and psychosocial functioning separately.

Effects on QOL and Psychosocial Functioning

Outcomes of studies aimed at improving one of the dimensions of patients' QOL or psychosocial functioning are summarised in Table 2 (pp34-44).

Emotional functioning – distress

Anxiety and depression as measures of emotional functioning were used in all eight studies. Statistically significant positive findings were reported in five of the included studies in terms of an emotional functioning variable; one study, utilising a relaxation breathing exercise[27] showed a statistically significant treatment effect for anxiety. In terms of depression, Kim and Kim[27] also showed a statistically significant treatment effect for depression. One other study,[23] using telephone-administered CBT, demonstrated a statistically significant difference in terms of fewer depressive symptoms in favour of the intervention group and results were consistent across three follow-up assessments. This study also found statistically significant improvements in PTSD symptoms of intrusive thoughts and avoidance as well as for global distress. One study using a mindfulness approach[21] demonstrated statistically significant improvement over time in combined anxiety and depression symptoms. The only other mindfulness study[25] reported statistically significantly lower scores in negative affect after intervention, however, the authors failed to report any statistical values. The authors of this same mindful study also reported anxiety and depression scores to have reduced post-intervention, however, these findings did not reach statistical significance. Finally, patients' total mood disturbance scores lowered significantly following a music therapy intervention[22].

In a multimodal study[26] using exercise, relaxation and psychoeducation, no significant differences were found between the intervention and control group in terms of anxiety or depression. However, notably, depression and anxiety scores were within the normal range for both groups at all test points including baseline. Lounsberry *et al.*[28] psychoeducational support group also failed to find any significant improvement within participants' levels of subjective distress post intervention. Finally, Gaston-Johnansson *et al*.[24] Comprehensive Coping Strategy Program found no significant treatment effect in terms of anxiety or depression.

Physical functioning

Positive effects were seen in two of the four studies[21,24-26] measuring physical functioning. One mindfulness study,[25] symptoms of nausea and appetite problems, as measured by the Symptom Experience Scale (SES),[39] significantly increased over the treatment period, although the authors failed to report the statistical values or the level of distress associated with these symptoms. Conversely, the other mindfulness study[21] demonstrated statistically significant improvement over time in physical symptom distress, also measured by the SES. The Comprehensive Coping Strategy Program[24] was found to be effective in significantly reducing nausea and fatigue, as measured by the Visual Analogue Scale (VAS).[42] Conversely, Jarden *et al.*[26] multimodal exercise, relaxation and psychoeducation study found no statistically significant effect for fatigue as measured by FACT-An,[40] although changes at all three test points following baseline favoured the multimodal intervention group but did not reach statistical significance.

QOL

No significant improvements were found in the two studies measuring overall QOL[26,28] as measured by the EORTC-QLQ–C30[44] and the FACT-BMT[43] respectively. However, Jarden *et al.*[26] did find a significant intervention pre-post effect for a specific QOL variable, reduction of diarrhoea. Furthermore, Jarden *et al.*[26] showed that changes at all three test points after baseline for overall QOL favoured the intervention group but did not reach statistical significance. The psychoeducational support group also failed to demonstrate any significant improvements in spirituality and meaning making or positive growth.[28] Although positive growth, as measured by the PTGI,[46] approached significance (P = 0.055), however the effect size was small (d = 0.17). In addition, The Appreciation of Life Subscale of the PTGI[46] showed significant change (P = 0.027) with a medium effect size (d = 0.46), indicating a better appreciation of life following the psychoeducational support group.

DISCUSSION

Main findings

Psychosocial interventions may be beneficial for HSCT recipients. All eight included studies showed positive effects on one of more indicators of QOL or psychosocial functioning, however, these effects are inconsistent across studies, regardless of quality rating.

In terms of effects on emotional functioning, five of the eight studies showed positive effects. However, these studies defined emotional functioning in different ways making comparisons and conclusions difficult. Some studies looked at depression alone, others combined depression and anxiety, and others evaluated emotional functioning and distress in more global terms. Although two of the higher rated quality papers reported no effect on anxiety or depression,[24,26] three other RCTs did report statistically significant improvement in terms of depression[23,27] and overall mood disturbance.[22] Furthermore, these findings are additionally complicated by Jarden *et al.*[26] sample which found depression scores within the normal range at baseline making it impossible to determine any potential positive or negative impact on anxiety and depression as a result of the multimodal intervention using exercise, relaxation and psychoeducation. The findings of the pilot mindfulness studies[21,25] suggest some possible consistency in terms of having a positive impact on anxiety and depression, however the poor methodological quality suggests caution when interpreting these results. In general, the high level of heterogeneity amongst outcome measures used increases the difficulty in interpreting the findings with regard to positive impact on emotional functioning.

In terms of physical functioning, inconsistent and contradictory findings were reported regardless of quality of study. Again, these findings are complicated by the use of heterogeneous outcome measures. Notably, in the two RCTs evaluating impact of intervention on fatigue, the multimodal study using relaxation, exercise and psychoeducation[26] that was unable to detect a statistically significant effect on fatigue was slightly underpowered. This is in contrast to the Comprehensive Coping Strategy Program[24] which did find a statistically significant improvement and was not underpowered. It may be that the Jarden *et al.*[26] findings reflect a Type II error due to being underpowered, when in fact a significant effect might have been found had the sample size reached power, particularly since changes in fatigue favoured the intervention group at all three follow-ups but did not reach statistical significance.

Overall QOL was the least frequently measured outcome.[26,28] However, as previously mentioned, the Jarden *et al.*[26] study was slightly underpowered and overall QOL favoured the intervention group at three follow-ups, possibly suggesting the same Type II error. Interestingly, the statistically significant improvement reported in the Lounsberry *et al.*[28] study on the variable *appreciation of life* may provide further evidence for post-traumatic growth theory.[46] However, effect size was small and furthermore, sample size was very small (n=13) and the study did not have a control group.

In terms of characteristics of the studies as described previously, the wide variation makes it impossible to ascertain the effect of variables such as duration of treatment or group vs. individual interventions or indeed the specific components of psychosocial interventions that may be having greatest impact on outcome.

The results show that psychosocial interventions enhance the QOL domain of emotional functioning most frequently amongst HSCT recipients. Physical functioning and overall QOL measures were less frequently used. No measures of social functioning or coping were used. Only one study[28] investigated variables concerning the spiritual and existential domain of QOL which is important as there is growing evidence to suggest positive growth following HSCT.[48] As part of a fuller evaluation of QOL amongst HSCT recipients, it is argued that both positive and negative sequelae should be assessed[48] and only one study[28] included such measures.

Limitations of the review

There are a number of limitations of the present review that must be taken into consideration. The systematic search attempted to be as extensive as possible however the heterogeneity of the studies required the adaptation of a quality criteria checklist. Although this was based on standardised guidelines, validity and reliability of scoring would likely have been greater had adaptation not been required. Furthermore, the inter-rater reliability was based on only 50% of the included studies thus reducing reliability somewhat.

The small number of included studies and the wide variability in design and quality requires that any conclusions should be treated with caution. Due to the heterogeneity of the studies, it is difficult to compare findings and as such this review can only perhaps suggest the feasibility of psychosocial interventions and recommend that efficacy is yet to be established through further research. This seems important as even studies that were underpowered demonstrated statistically significant findings, which possibly could have achieved the level of clear statistical and clinical significance when adequately powered.

Implications for clinical and research practice

More methodologically sound studies are recommended in this area. This could be achieved in a number of ways including the use of larger RCTs which involve treatment and control groups that are similar and comparable at baseline. This is particularly difficult when working within the field of cancer research given the inherent heterogeneity of individuals, however, studies could address this by utilising the most appropriate research designs and statistical analyses. Clearer inclusion and exclusion criteria such as the use of clinical cut-off scores would allow improved evaluation of the impact of the intervention on important prognostic factors. It would be ideal for studies to report not only statistically significant findings but also clinically significant findings. The use of follow-up designs would help achieve a better indication of clinical significance. It may be helpful to incorporate more qualitative aspects when evaluating the impact of psychosocial interventions. Pre-defined measures of QOL and psychosocial functioning are valuable in quantitative research and can demonstrate clinically significant change, however, they may fail to detect change as defined by the individual. Therefore, utilising satisfaction measures would be helpful to ascertain the value of intervention to individuals. The type of psychosocial intervention relevant and clinically significant to patients is likely to depend on their stage of recovery therefore, monitoring of patients' changing QOL at reviews would help identify potential psychosocial needs that could be met through the provision of appropriate interventions.

CONCLUSIONS

In summary, there is some preliminary evidence that psychosocial interventions using a variety of techniques are beneficial for the QOL and psychological wellbeing of HSCT recipients. However, evidence is limited as there have been few large methodologically strong trials. This is unsurprising in many ways given the challenges involved in conducting fully methodologically rigorous studies with populations such as HSCT recipients, who like many individuals with cancer, represent a highly heterogeneous population. Furthermore, HSCT recipients generally receive their transplants at regional cancer centres and have to travel long distances therefore gaining access to participants for follow-up, particularly as out-patients, can be very difficult. HSCT is a particularly toxic and aggressive treatment, associated with high mortality rates therefore attrition rates due to serious illness and mortality will be high.

Furthermore, the heterogeneity of outcome measures used indicate caution when interpreting findings as it has been demonstrated that, "Studies operationalising QOL from different conceptualisations frequently result in different findings even for the same group of people" (p. 614).[49]

Given the highly heterogeneous nature of the interventions and the fact that RCTs compared treatment groups to standard care or assessment only, it is not possible to draw any firm conclusions regarding the most effective specific psychosocial intervention approaches. However, this review highlights that research in this field is in its infancy and some of the positive findings demonstrated indicate that further investigation into psychosocial interventions is warranted.

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Table 1: Quality rating of studies included in systematic review

Study	Percentage %	Quality Rating
Bauer-Wu et al[21]	48	Poor
Cassileth et al[22]	92	Good
DuHamel et al[23]	96	Good
Gaston-Johansson et al[24]	52	Moderate
Horton-Deutsch et al[25]	28	Poor
Jarden et al[26]	92	Good
Kim & Kim[27]	88	Good
Lounsberry et al[28]	44	Poor

Figure 1 Flow Chart of systematic review study selection process

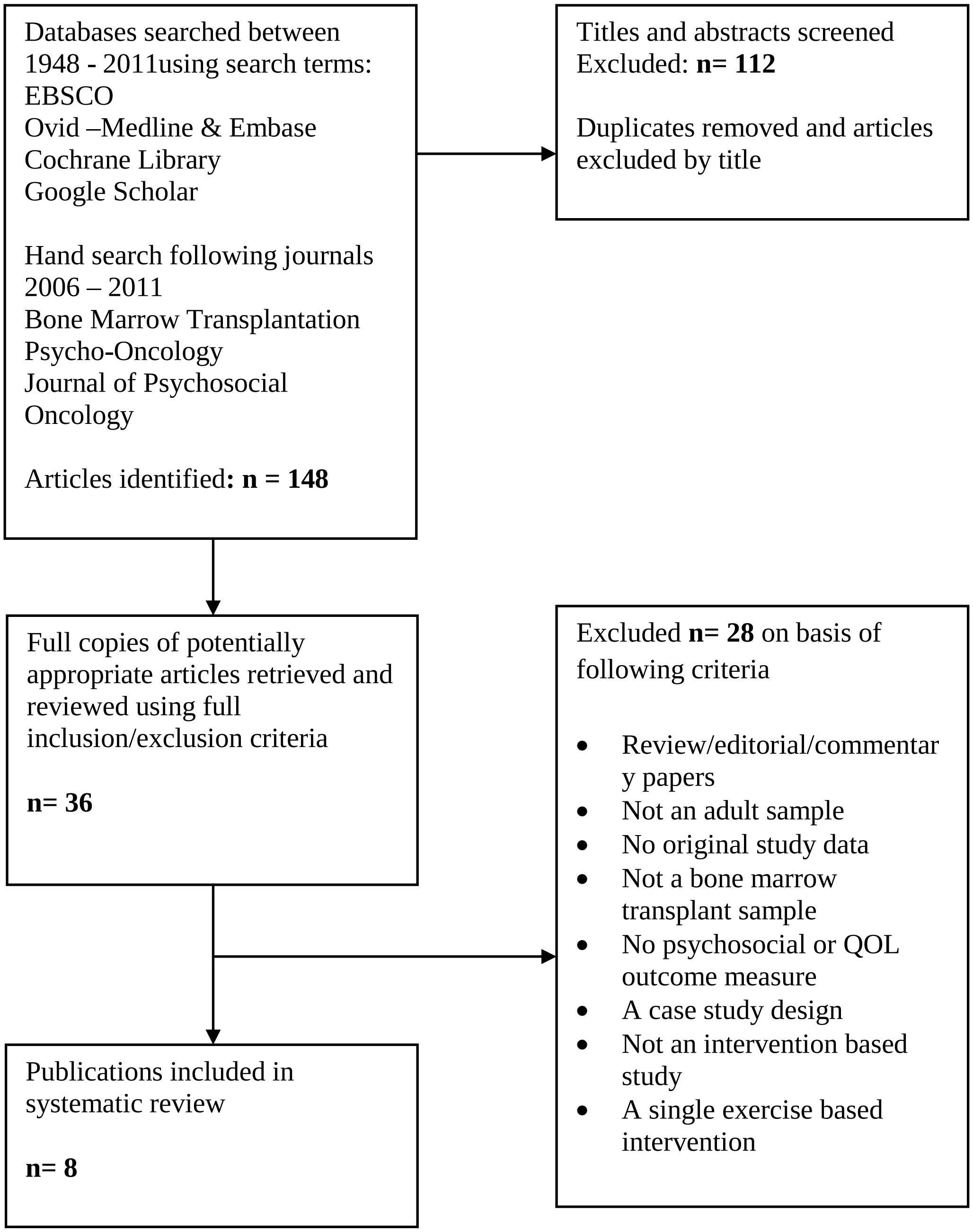

Table 2- Table summarizing studies included in systematic review

Study **Year** **Type of Design** **Quality Rating**	**Intervention**	**<u>Recruited Sample</u>** **Size** **Age** **Type of transplant recipients**	**Number Completed Treatment and followed up**	**Timing of Intervention**	**Outcomes Assessed**	**Outcome Measures**	**Significant Results / Main Findings**
Bauer-Wu et al. [21] (2008) Uncontrolled Pilot Study	Mindfulness Meditation	20 51 years Mixed HSCT	15 (79%)	Began 1-3 weeks pre hospitalization and continued throughout hospitalization, which typically lasted 3 weeks 6 fixed data collection points –	Psychological Distress Physical symptoms Distress	HADS SES	fixed effect of time was significant ($p < .0001$; $F = 7.93$, 5/80 *df).* fixed effect of time was significant ($p < .0001$; $F =$

48% - poor				before starting intervention, days 2, and 10 of admission, day of discharge, and 30 and 100 days after discharge			21.39, 5/79 *df).*
Cassileth et al.[22] (2003) RCT 92% - good	Music Therapy **vs.** Standard Care	69 Median range 51-53 years Autologous	62 (90%)	During inpatient stay i.e. received a median of 5 music therapy sessions during a median of 10 days 5-15 days	Mood	POMS	Music therapy > standard care (P = 0.014) on the Total mood disturbance score
DuHamel et al. [23]	Telephone - Cognitive	89	81 (91%)	Survivors of HSCT who had	PTSD	PCL-C	T-CBT > Control (t(80)

(2010) RCT 96% - Good	Behavioural Therapy **vs.** Assessment Only Control Group	Intervention = 52.19 (27-71) years; Control = 49.38 (19-74) years Intervention - Autologous = 28; Allogeneic = 17; missing = 2; Control – Autologous = 12; Allogeneic = 18; Missing = 4		undergone HSCT 1-3 years earlier Follow-up at 6, 9 and 12 months following baseline 10-16 weeks intervention 10 sessions	Distress Symptoms	(intrusive thoughts subscale) PCL-C (avoidance subscale) BSI (general distress)	= 2.60; *P* = 0.011) T-CBT > Control (t(80) = 3.95; *P* < 0.001) T-CBT > Control (F(4,80) = 4.05; *P* = .005)

					Depression	BSI (depressive symptoms)	T-CBT > Control (F(4,208) = 2.89; *P* =.023)
Gaston-Johansson et al. [24] (2000) RCT 52% - Moderate	Comprehensive Coping Strategy Program (CCSP) **vs.** Treatment as Usual (tau)	110 22-51 years Autologous	110 (100%)	During hospitalization CCSP taught to patients 2 weeks pre-admission and reinforced on 3 further occasions	Anxiety Depression Pain	STAI BDI POM	Non-significant Non-significant Non-significant

					Nausea Fatigue	VAS VAS	CCSP > tau (ß = -16.94; [beta] = 0.27; $p < 0.05$ CCSP > tau (ß = -26.23; [beta] = -.27; $p < 0.05$)
Horton-Deutsch et al. [25] (2007) Uncontrolled Pilot Study 28% - Poor	Mindfulness-Based Therapeutic Intervention	24 18-75 years Mixed Autologous and Allogeneic	15 (62.5%) followed up	During participants' hospital stay over course of 3 -4 weeks: twice weekly 20 – 40 minute individual patient sessions 6-8 bi-weekly sessions	Psychological and Emotional problems	PANAS	Significantly lower negative affect scores post intervention. Positive affect change non-significant

						HADS SES	Non-significant Nausea & appetite problems significantly increased
Jarden et al.[26] (2009) RCT 92% - Good	Multimodal intervention: exercise, relaxation and psycho education **vs.** usual care	42 39.1 years (mean) Allogeneic	Post = 34 (81%) 3months = 29 6months = 28	4-6 week program in hospital – took place 5 days weekly Four time points; baseline, post-intervention, 3- and 6- month follow up	QOL	EORTC QLC –C30 (global) EORTC QLC –C30 (diarrhea)	Non-significant Multimodal intervention > usual care ($P = 0.014$)

					Fatigue	FACT-an – fatigue	Non-significant
					Psychological wellbeing	HADS	Non-significant
Kim & Kim[27] (2005) RCT 88% - Good	Relaxation Breathing Exercise **vs.** Routine Care	42 RBE – 32.9 years (mean) Routine Care – 34.3 years (mean) Allogeneic	35 (83%)	Provided daily for 6 weeks during hospitalisation	Anxiety Depression	STAI BDI	RBE > routine care (P = .0001) RBE > routine care (P = .0001)

Lounsberry et al.[28] (2010) Uncontrolled Pilot Study 44% - Poor	Psycho-educational support group	19 Mean age = 45.8 years (range 19-66) Allogeneic	13 (68%)	Survivors 0 – 3 years post transplant 6 weekly, 1.5 hr group videoconference sessions	Quality of Life Spiritual Meaning Making Subjective Distress Perception of Personal Benefits that occur as a result of attempts to cope with treatment	FACT-BMT – Qol FACIT - Sp IES-R PTGI	Non-significant Non-significant Non-significant Non-significant but Appreciation of life subscale showed significant change ($Z = -2.21$, $P = 0.027$) with a medium effect size ($d = 0.46$)

<u>**Key:**</u>

SES – Symptom Experience Scale (Samarel et al., 1996) – consists of symptoms commonly experienced by cancer patients and describes symptoms frequency, intensity and distress, each rated on a 0-4 scale. Six subscales include nausea and appetite, fatigue and sleep, concentration, appearance, bowel function and pain;

HADS – Hospital and Anxiety Depression Scale (Zigmond & Snaith., 1983) – is a 14 item self-report measure with two 7-item subscales assessing anxiety and depression, or a combined total score of psychological distress. For use in investigations in patients with physical illness.

POMS – Profile of Mood States (McNaire et al., 1992) – widely used QOL measure. Self administered instrument combined of 65 adjective rating scales that assess transient mood states. The scale was developed for repeated use to measure change over time. Scores are obtained for six factorially derived mood or affective states: Tension-Anxiety; Depression-Dejection; Anger-Hostility; Vigor-Activity; Fatigue-Inertia; and Confusion-Bewilderment. A total mood disturbance score is obtained as the sum of all six factor scores after weighting Vigor negatively.

PCL-C – PTSD Checklist Civilian Version (DuHamel, Ostroff, Ashman et al., (2004); Weathers, Litz, Herman et al., (1993) – measure of illness-related PTSD symptoms previously used with HSCT survivors. Yields a total score and subscale scores for intrusive thoughts, avoidance, numbing and hyperarousal.

BSI – Brief Symptom Inventory (Derogatis, 1993) – is a questionnaire that assesses general psychological distress. Subscales include Global Severity Index and the depression subscale.

POM – Gaston-Johansson Painometer (Gaston-Johansson, 1996), designed to assess patients; overall pain intensity, the intensity of the sensory and affective components of pain, and the quality of pain.

VAS – Visual Analogue Scale (Gift, 1989), is a valid, reliable, and sensitive self-report tool for studying subjective symptoms.

STAI – The State-Trait Anxiety Inventory (Spielberger, Gorsuch & Lushene, 1971). Consists of two separate self-report scales for measuring state and trait anxiety. *State anxiety* is a transitory emotional response to a stressful situation. *Trait anxiety* reflects a stable predisposition to anxiety as determined by a personality pattern. Respondents rate themselves in relation to the statement on a Likert Scale from 1 to 4. The total score is the sum of all 20 responses and ranges from a minimum score of 20-39 (low anxiety) to 40-59 (moderate anxiety) to a maximum score of 60-80 (high anxiety)

BDI – The Beck Depression Inventory (Beck & Steer, 1993), consists of 21 items that describe particular symptoms of depression. Subjects respond to a Likert – type scale by rating each item 0 (no distress) to 3 (severe or persistent presence of the symptom). Scores range from 0-9 (normal) to 10-15 (mild depression) to 16-23 (moderate depression) to 24-63 (severe depression). The total score (range, 0-63) is obtained by summing the 21 responses.

PANAS – Positive and Negative Affect Scale (Watson, Clark & Tellegen, 1988) – is a 20-item self-report measure of positive and negative affect

EORTC –QLQ – C30 – The European Organization for Research and Treatment Cancer Quality of Life Questionnaire, Aaronson, Ahmedzai, Bergman et al., 1993). Comprises of 30 items to assess QOL in cancer patients

FACT – an – Functional Assessment of Cancer Therapy – Anemia scale (Yellen, Cella, Webster et al., 1997). Designed to measure the extent of fatigue.

FACT – BMT – Functional Assessment of Cancer Therapy – Bone Marrow Transplant (McQuellon, Russell, Cella et al., 1997). Measures five dimensions of QOL specific to HSCT population: Physical well-being; Social/Family wellbeing; Functional wellbeing; and additional concerns.

FACIT – Sp – Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing (Peterman, Fitchett, Brady et al., (2002). Used to assess impact of intervention on participant spirituality and meaning making. QOL measure.

IES-R – Impact of Event Scale – Revised (Weiss & Marmar, 1997) – used to measure subjective distress related to a particular event.

PTGI – Post-Traumatic Growth Inventory (Tedeschi & Calhoun, 1996) – used to evaluate the perception of personal benefits that occur as a result of attempts to cope with treatment.

CHAPTER TWO:

Major Research Project

Quality of Life following Haematopoietic Stem Cell Transplant among recipients aged over 50 years:

An Interpretative Phenomenological Analysis

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Prepared in accordance with submission guidelines for

Psycho-Oncology (See Appendix 2.1)

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Lay Summary

Blood cancers and related disorders are most commonly diagnosed in adults over fifty years old. However, until very recently adults over fifty were considered too high risk to receive a particular type of bone marrow transplant known as allogeneic haematopoietic stem cell transplant (HSCT), which has the potential to cure the disease. This is because HSCT is an extremely aggressive cancer treatment which means patients have to spend long periods in hospital and experience a lengthy recovery period. As a result normal life is often put on hold for a time. Research has shown that the treatment can have a significant impact on younger patients' quality of life. However, very little is known about what the experience of this transplant is like for older adults (50 years or more). Therefore, this study aims to explore the experience of QOL after HSCT for patients aged over fifty in order to help increase our knowledge and help to better inform potential patients of ways in which life may be impacted after transplant.

Abstract

Background: Allogeneic Haematopoietic stem cell transplant (HSCT) is a potentially curative treatment for haematological cancers however it is a particularly aggressive treatment that can impact individuals' quality of life (QOL) in multiple ways. Due to the toxicity of the transplant, adults aged over fifty years have only recently become eligible for this treatment following the development of a reduced intensity regimen. As a result, little is known regarding the experience of QOL among recipients aged over fifty years. QOL information is an essential part of assessing the success of medical treatments and can help prepare recipients for any ways in which their lives and those of their families may be impacted post-transplant.

Method

Potential participants were recruited through the Beatson West of Scotland Cancer Centre (BWSCC) and a purposive sample of eight participants volunteered to take part in the study. A qualitative approach, Interpretative Phenomenological Analysis was used to explore the experience of QOL among recipients.

Results

Four superordinate themes emerged from the data; 'Shifting sense of self and others', 'Adaptation and managing the impact', 'A new perspective on life and living', and 'Changing over time'. The findings helped highlight the challenges and gains experienced by HSCT recipients as well as the process of adaptation and adjustment which mediates the impact of HSCT on QOL.

Conclusions

The participants in this study demonstrated that there are a number of commonalities between younger and older recipients in terms of post transplant QOL when compared to the literature on younger recipients to date. However, increased age and stage of life was also shown to have a unique impact on the subjective experience of QOL after transplant. Increased age continues to represent a significant risk factor in terms of

QOL and survival post transplant. However, the findings from this study suggest that this small sample of recipients is adjusting well to the challenges of HSCT. Further research is required in this area. Limitations of this study are discussed.

Keywords: haematopoietic stem cell transplant, quality of life, allogeneic, qualitative

Introduction

Cancer and the treatment of cancer affect all aspects of patients' lives. For patients diagnosed with a haematological cancer, allogeneic haematopoietic stem cell transplantation (HSCT) is a treatment option with curative potential. Due to the highly toxic nature of the treatment, conventional allogeneic HSCT is contraindicated for people over the age of 55. Haematological cancers, however, are very common in people over this age, with the median ages of diagnosis ranging between 55 and 70 years [1]. In the late 1990s a reduced intensity conditioning (RIC) regimen was developed as an alternative to conventional HSCT [2]. This means that an increasing number of older adults are now able to receive allogeneic transplants.

The importance of evaluating quality of life (QOL) issues among survivors of cancer is now well recognised and a growing body of research has increased our knowledge of the impact of allogeneic HSCT on the lives of younger adult survivors [3,4]. Despite medical advancements contributing to improved outcomes for patients, allogeneic HSCT remains an aggressive and taxing treatment associated with physical and psychosocial sequelae such as fatigue, persistent anxiety and depressive symptoms, sexual dysfunction and fertility concerns [4]. As allogeneic HSCT uses healthy donor stem cells to restore blood cell production, this can result in graft-versus-host disease (GvHD). GvHD occurs when donor cells attack the patient's organs, precipitating a potentially life threatening condition. Furthermore, due to the often lengthy recovery, most adult recipients experience some interruption in normal developmental tasks, for example, maintaining a career and establishing satisfactory marital and family relationships [5]. Therefore, HSCT is a treatment which affects all aspects of individuals' lives.

Despite the many physical and psychosocial challenges presented by HSCT, a recent systematic review identified that some survivors report positive changes in QOL including an enhanced appreciation for life, different priorities, love and appreciation for family and friends, and greater religious or spiritual beliefs. These reported benefits are unrelated to physical functioning and other QOL indices [3].

It seems, therefore, that HSCT may impact both positively and negatively on both the recipient's life and that of their family and friends. It has been recommended that receiving HSCT should be conceptualised as a psychosocial transition period that offers the potential for growth [36]. Therefore in terms of research into the impact of HSCT on QOL, positive impact should also be explored. Qualitative measures have been invaluable in identifying such positive themes, changes and outcomes [6, 7]. It is recommended that more qualitative studies should be conducted within the field of HSCT, especially in the absence of good quantitative measures, and that these studies should ask about positive and negative outcomes [8]. Most QOL quantitative measures specific to HSCT are designed to detect negative changes in functioning and are consistent with the 'stress' paradigm.

Research in this field has tended to be quantitative studies using a variety of measures and methodological designs. However, the measurement of QOL among HSCT recipients remains a controversial issue due to the lack of agreement regarding the conceptual and operational definition of QOL. Furthermore, the lack of a gold standard for measuring QOL frequently translates into difficulty interpreting and synthesising research findings [9].

In response to some of the limitations of quantitative research investigating the impact of HSCT on recipients' lives, a small body of research has used qualitative approaches in order to gain a more in depth understanding of patients' experiences with HSCT [6, 7, 10, 11]. This research focused on exploring the QOL experienced by recipients following different types of HSCT and highlighted issues relevant to survival that were not particularly well covered or addressed in standardised questionnaires. Even this qualitative research, however, focused on younger adults (mean age at time of transplant 29, 32 and 31 years, respectively). These studies mentioned that the QOL implications for younger recipients may differ from those experienced by older recipients [10].

While the main domains of QOL identified in the literature are relevant to adults of all ages, these can vary in priority among people in different age groups [12].

Experts in the field of HSCT point out that although we are moving forward in our understanding of the impact of transplant on QOL in younger people, generally, little evidence exists to guide our understanding of the impact of HSCT on recipients aged 55 years or more [13, 14]. Researchers recommend caution in applying evidence in new populations such as those aged over 55 years [13]. Experts also argue that it is important to consider sub-groups of transplant recipients (i.e. allogeneic vs. autologous) due to the unique ways transplant can shape the symptom experience, functional status, psychosocial health, and QOL of recipients [15]. This is particularly relevant for adults over 55 receiving this new transplant who are not only at a higher risk of relapse but are also considered a high risk population due to the increased likelihood of GvHD, opportunistic infection, and transplant-related morbidities [16]. Research has shown that the patient experience with RIC HSCT is distinct in comparison with other transplant populations, due to the medical risks as well as the effects of physical ageing [17]. These factors may make this group of patients different to other transplant recipients.

With so many potential consequences in all areas of life, it is crucial to investigate older recipients' perceptions of their treatment and of themselves in order to identify any areas for intervention. Given some of the limitations of QOL quantitative methodologies which pre-define the construct and ask "what" has changed according to predefined categories, a qualitative approach using Interpretative Phenomenological Analysis (IPA) has been chosen as an alternative method as this allows people to describe their own perceptions of how life has been impacted and the personal, subjective meaning of any changes. By accessing underlying cognitions, such as beliefs and attitudes, this may help us shed light on a person's behaviour and experience [18]. This is important for the purpose of this study since it may be that individuals' perceptions and appraisals of any changes impact their experience of QOL. An in-depth understanding of the "objects of concern" in participants' worlds is required in order to build our knowledge of patients' experience with this newly developing treatment. IPA was chosen for this study, in preference to other qualitative approaches, due to its concern with the conducting a detailed examination of human lived experience, expressed in its own terms rather than according to predefined category systems [19]. This makes this approach particularly appropriate for investigating QOL after HSCT.

Qualitative studies in which survivors provide their own accounts of their experiences have been recognised as a valuable method for use with other sub-groups of younger recipients; however, the experiences of older recipients receiving a newly developed transplant procedure are lacking. The present study, therefore, attempts to elaborate the experience of QOL following HSCT and takes the lead from HSCT patients who have reported their dislike of aspects of standardized QOL questionnaires for reasons such as, they “did not address spiritual life, changes in perspective etc.”, “put words in mouth” “should be more in depth” and “asked specific questions with no place for explanation” [20 p. 152-153].

This study is interested in how older recipients experience the challenges of HSCT. Given that adults over 55 receiving RIC HSCT are considered to be a distinct recipient population with unique needs, it is essential to explore their subjective experiences of this life-changing event. Therefore, the present study aims to:

1. Explore participants’ personal meanings and experiences (positive and negative) of QOL following RIC HSCT.

2. Identify areas for intervention depending on experiences unique to older patients (55 + years) having this type of transplant.

This study comes at an exciting time in the field of HSCT, as advances in medical science have extended the use of transplant, allowing a much wider range of individuals to undergo this potentially curative treatment. Indeed, in their 2009 committee report Murphy *et al.* [16], stress the paucity of cancer research addressing the very unique needs of adults over 55 years undergoing allogeneic HSCT and argue that studies should investigate the effects of age on the experience of QOL. An understanding of patients' experience with HSCT within this changed context is critical in order to help prepare patients for ways in which life may change following transplant. This would allow for better informed consent. It would also help identify any areas for intervention depending on the worries, stresses or distress unique to patients having this type of transplant.

Method

Design

This qualitative study employed IPA which has its theoretical roots in phenomenology, hermeneutics and idiography [19]. IPA is concerned with the detailed examination of personal lived experience, the meaning of the experience to participants and how participants make sense of that experience [21]. IPA aims to explore the participant's experience from their perspective but the method recognises that the phenomenological analysis produced by the researcher is always as interpretation of the participant's experience [18]. This is referred to as the "double hermeneutic", whereby the researcher is trying to make sense of the participant making sense of what is happening to them [21 p. 10]. This makes the role of the researcher particularly significant in IPA therefore reflexivity is a meaningful part of write up, as will be elaborated upon within the method section.

IPA has become one of the best known and most commonly used qualitative methodologies in psychology and research investigating illness experience [21]. IPA was chosen as the preferred qualitative approach due to its focus on personal meaning and sense-making in a particular context, for individuals who share a particular experience. This is in contrast to other qualitative approaches such as Grounded Theory [39], for example, which aims to identify and explain in detail, contextualised social processes and factors which account for phenomena. IPA is instead concerned with gaining a better understanding of the quality of individual experiences; that is, it is interested in the nature or essence of phenomena [18; p.69].

Participants and recruitment method

The goal of qualitative studies is to capture the breadth of possible patient attitudes or experiences. In contrast to quantitative studies in which generalisability is critical, the goal of qualitative studies is not to obtain a statistically representative sample, but rather to achieve "symbolic representation" [22]. Therefore purposive sampling was used to recruit participants because they are the experts in the phenomenon being explored.

IPA is particularly suited to the analysis of small samples due to its focus on generating information-rich, in-depth knowledge of a particular phenomenon. For the purpose of conducting a Doctorate in Clinical Psychology (DClinPsy) thesis, Turpin *et al*. [23] state that a sample size of 8 is feasible and appropriate.

Participants were considered eligible to participate in the study if they had received a specific RIC HSCT from an unrelated donor at least 6 months prior to interview. Medical experts at the Beatson West of Scotland Cancer Centre (BWoSCC) advised this time frame as it would allow acute health problems to resolve and the normal recovery process to have begun. Eligibility criteria also specified that participants be aged 50 or more at time of transplant; that disease was controlled and no relapse of disease had occurred. As recommended by Smith, Flowers & Larkin [19], the participants in this study represented a reasonably homogenous, purposive sample.

Haemato-oncology medical staff working with patients undergoing RIC HSCT reviewed the database which revealed that approximately 30 individuals aged over 50 had received and survived an unrelated RIC HSCT within the last 6 years. Of this sample, 12 met inclusion criteria. Potential participants were then informed of the study by their Senior Nurse Specialist and given the information sheet. Participants interested in taking part were then invited to telephone the researcher directly. Eight participants expressed their interest in participating. During the data collection process it became apparent that 5 participants were being reviewed at the BWoSCC but that others were being reviewed by Consultants in their local geographical areas due to the significant distance from Glasgow. This is because the BWoSCC is the only centre in Scotland to perform RIC HSCTs, so often recipients only attend the BWoSCC annually and have more frequent review appointments within their local geographical area. Given participants' desire to be involved in the study, it was decided that conducting telephone interviews would be an appropriate alternative to conducting face to face interviews. Indeed, participants themselves suggested this alternative.

Participants were 5 males and 3 females. Their mean age at time of HSCT was 58 years (range = 52 – 63 years). Survival time since transplant to interview ranged from 10 months to 73 months (mean survival time = 33.9 months). Participants had undergone HSCT for a variety of haematological cancers and related life threatening blood disorders. All participants received allogeneic RIC HSCT from an unrelated donor. Table 1 gives a summary of participant characteristics and reported side-effects as a result of transplant. All participants have been allocated a gender appropriate pseudonym. Although one participant was receiving top-up lymphocytes to help control the disease and one participant had recently received a secondary diagnosis of breast cancer, it was decided that this would not affect the homogeneity of the sample as these individuals had both experienced HSCT which had controlled their original disease. Furthermore, receiving top-up lymphocytes is considered part of standard protocol following RIC HSCT and indeed a number of participants also received such follow-up treatment at various stages of recovery. The research question was therefore still important for these participants and it was decided that their inclusion would enrich the findings.

Table 1. Characteristics of participants

Name	Age at HSCT (years)	Time since HSCT (months)	Disease Type	Reported Adverse physical effects of HSCT	Type of Interview
James	55	11	Myelofibrosis	GvHD (L229) Reduced muscle mass (L115) Infections (L224) Taste buds and salivary glands affected (L151)	Face-to face
Helen	61	44	Acute Myeloid	None reported	Face-to

			Leukaemia (AML)	Recent secondary diagnosis of breast cancer (L51)	face
Mary	59	30	Myelodysplasia (MDS)	Fatigue (L370) Frequent infections (L257)	Face-to face
Paul	52	28	Chronic Myeloid Leukaemia (CML)	Pain (L701) Muscle weakness and aching (L714) No immune system (L964) *"there always seems to be something wrong. Ken, if it's not the cold I've got, it's – there's something" (L719)*	Face-to face
David	60	10	Myelodysplasia (MDS)	Fatigue (L294) Receiving venosections to remove excess iron (L323) Hearing and vision impairment (L325) Infections (L327) Balance and coordination problems (L337)	Face-to face
Geoff	61	18	B-cell chronic lymphocytic leukaemia (B-CLL)	Fatigue (L190) Reduced immune system (L271)	Telephone
Isobel	54	73	Lymphoma	Fatigue (L554) Slowed mobility (L262) Reduced muscle strength (L246) Chest cyst (L334) Still requiring venosections to reduce excess iron levels (L160)	Telephone
Harold	63	57	Myelofibrosis	Triggered Diabetes related problems (L126) Reduced physical capacity – balance, muscular tone and strength (L185) Impaired vision (L207) Impaired kidney function (L180).	Telephone

Procedure

Ethics

The study was carried out in accordance with the British Psychological Society's (BPS) Code of Ethics and Conduct [24]. Prior to commencement the study underwent a standard two-step process to receive organisational approval from the BWoSCC (see

Appendix 2.2). Full ethical approval was also obtained from the West of Scotland Research Ethics Committee (appendix 2.3) and management approval from Greater Glasgow and Clyde Research Development was received (see Appendix 2.4). Participants were fully informed (see Appendix 2.5 for information sheet) about the research aims and procedure and they gave their consent prior to data collection (see Appendix 2.6). Subsequent ethical approval was obtained to conduct telephone interviews for participants who could not travel to Glasgow for interview (Appendix 2.3 and 2.4). Written consent for participation, recording and transcribing of interviews as well as publishing of anonymised quotations was sought from all participants (see appendix 2.6). To ensure anonymity, each participant was given a gender appropriate pseudonym and all identifying information was removed.

Data collection

Data were collected through semi-structured interviews. The lengths of interviews ranged between 46 and 75 minutes (average 65mins) and were recorded for later transcription. Participants were encouraged to talk as widely as possible about their experiences of life after HSCT and the researcher made it clear that there were no right or wrong answers, simply a personal account of their own views and feelings. The researcher's clinical skills of active listening and empathy were given primacy on order to remain participant led as much as possible. The researcher kept a reflective diary throughout data collection in order to help facilitate questioning style for subsequent interviews but also to help retain the essence of the individual's account which would be later interconnected with others' experiences. All eight transcripts were then transcribed verbatim and included non-linguistic elements, for analysis.

Interview schedule

The interview schedule (Appendix 2.7) was developed based on a review of the relevant literature and current issues within the field of QOL among HSCT recipients. Research has shown that when asked about changes in general participants may be more likely to report more negative than positive changes out of habit or demand characteristics [25]. Therefore, the interview schedule included open-ended questions about both positive and negative outcomes as recommended by Bishop and Wingard [8].

Open-ended and non-directed questions were developed to encourage participants to talk as widely as possible about their experiences of life after transplant. The development of the schedule and interviewing style was influenced by the guidance provided in Smith, Flowers & Larkin's [19] text, which is particularly useful for IPA researchers. The interview schedule was not adhered to rigidly but rather used as a guide to help prompt deeper exploration of issues and was utilised in a flexible manner with participants. In order to try and give specific focus to the interviews and address the "objects of concern" within participants' experiences, a core question was asked of each participant, "what does the term QOL mean to you?" This was asked to help participants define their own meaning of the construct and then go on to consider their perceptions of any ways they felt life had changed since transplant. The researcher was then able to be led by participants in terms of following up on different domains pertinent to their QOL such as family life, social, ability to enjoy life, relationships with others etc. This allowed participants to retain the expert stance and describe their experiences on their own terms whilst ensuring the issues of interest were addressed.

Analysis

Analysis of the data was conducted according to the guidelines outlined by Smith, Flowers & Larkin [19] which are particularly valuable to novice IPA researchers and can help maximise rigour. This process was idiographic whereby one transcript was examined in detail before going on to examine others. The first stage was to become immersed in the data by reading and re-reading the data, initially listening to the audio recording simultaneously. The second stage involved producing a comprehensive and detailed set of notes focusing on descriptive, linguistic and conceptual comments. These were written on the right hand margin of the transcript. Emergent themes were then noted on the left hand margins which were expressed as phrases or words that were more conceptual in nature, for example, “using coping strategies” or “family life disrupted”. This process was repeated for each individual transcript. For each transcript, a full set of emergent themes was constructed and grounded in quotations from the text. Given the larger sample size, the researcher held off the search for patterns (as much as was possible) until examining all the cases together. In order to keep with IPA’s idiographic commitment, it was important to allow new themes to emerge with each new case, which is challenging, but the steps outlined help minimise being overly influenced by what has emerged so far. The last stage involved searching for patterns and connections across cases and emergent themes were then clustered together to produce a master list of superordinate themes. At this stage, measuring recurrence across cases is important. For the purpose of this study, recurrence of an emergent theme is defined as being present in at least half of participants’ interviews. Please see Appendix 2.9 for a summary table showing how themes were developed.

Reliability and Validity

In order to minimise interpretative bias, the first 3 transcripts were coded blindly by an experienced qualitative researcher who had no professional knowledge of this group of participants. This second researcher also found the same emergent themes from the data. Furthermore, emergent themes presented are supported by the participants’ actual quotes in order that the reader can assess the reliability and validity of the interpretations.

Reflexivity

Personal reflexivity is important when conducting IPA studies due to the potential for interpretative bias. I have not worked within a psycho-oncology setting but have had personal experience of family and friends who have had cancer. As such, I have been able to appreciate the complexity of experiences of life after treatment and the gains and losses inherent to survival. As a thirty year old woman who has been so fortunate to have never faced such life-threatening illness, I am acutely aware of my own stage of life priorities and concerns. However, having completed an older adults' specialist placement during my DClinPsy training, I hope that my understanding and awareness of ageing process involving both challenges and opportunities has helped me retain a balanced and open-minded approach to analysis.

Reflections upon interviews

Although the aim of my study was to gain an in-depth understanding of participants' perceptions of how HSCT had impacted their QOL, I found very quickly that participants would quite factually mention some of the things they felt they were doing less of in terms of hobbies and activities. Although they spent some time elaborating on the meaning of this changed physical existence, I found that they tended to then focus on how they cope and adapt to change. This seemed to represent a slight deviation from the research agenda but also provided information-rich and experiential data particularly amenable to IPA. As such, the research question slightly shifted from being an exploration of the meaning of the impact to include an exploration of their adaptation to the impact.

One other important experience encountered during the interviews was with one participant who felt it important to focus on her experiences of living with cancer for a number of years in an in-depth manner that produced much rich information for IPA but unfortunately produced very limited data in relation to the experience of life after HSCT. Her account was compelling and moving and perhaps best captured by the following recollection of being told the leukaemia was "winning" and that there was no further treatment that could be offered to her:

"Do you mean to say I'm going to die?" He said, "yes". [pause]. He said, I said, "And what happens now?" and he said, "oh…we're moving you to the hospice tomorrow" [pause] and that was that." Helen [L260].

This woman struggled to describe her experience of life after transplant and again is reflected in her statement:

"Well, I think what affected the bone marrow transplant is what went before." [L90].

As a result, this woman's experiences may appear less frequently within the results due to her desire to share her experiences of her journey towards finally being accepted for HSCT and her preference not to be guided by my research interests but her own most meaningful experiences of living with cancer:

"I'll leave the bone marrow transplant and go back to when I was diagnosed? If that's ok?" [Helen; L202]

Results

Setting the scene

Before participants began describing their perceptions of QOL and wellbeing following transplant, all spent some time describing their experiences of being diagnosed with a life-threatening illness that would result in loss of life without treatment. The majority of participants talked about the fact that they had been treated with different drug trials however these were unsuccessful in controlling the disease for any length of time. Four participants reported that they requested HSCT from their medical team. All but one participant reported their awareness of age as a possible precluding factor and described therefore having to go through a process of approval for HSCT. They all described being acutely aware of the risks of transplant but felt they had "no choice"; it would be "fatal" otherwise. For participants who had experienced longer histories of illness, they described being offered HSCT as meaning that there was finally "light at the end of the tunnel". All participants received a transplant using an unrelated donor's stem cells. For many, they described how lucky they felt that they had been able to find a match to permit the transplant. They also talked about their awareness of the rarity of this type of procedure being used with adults of their age. All but one participant described living with a variety of physical health impairments as a direct or indirect result of HSCT (See Table 1). These adverse physical effects were often described in a factual manner and not particularly amenable to IPA. Given the restrictions of the scope of this DClinPsy thesis, it was decided that analysis should focus on how participants make sense of their experiences. Although some of these scene-setting views and experiences are not directly related to answering the research question, they are essential to provide some background to these participants' experiences of transplant. This information places the data which has been subject to IPA in context.

The four superordinate themes that emerged from participants' accounts were 1) Altered QOL, 2) Protected QOL, 3) A new perspective and 4) Changing over time. The themes are presented in a linear fashion however full appreciation of a theme is maximised when interconnections with others are considered. The researcher has attempted to provide quotes that reflect the individually considered themes however the interconnected nature of the themes means that some individual quotes may reflect more than one theme.

Theme 1: Shifting sense of self and others

All participants described post-transplant experiences which underpinned a sense of alteration to various aspects of QOL and wellbeing including a ***changed sense of self***; ***changed family life***; and ***changed emotional wellbeing***.

Changed sense of self

Most participants reported that the resultant physical impairments of HSCT meant more than just an inability to do some of the things they used to do, but in fact impacted their self-concept (literally the way we view ourselves). Participants talked about living with a changed physical identity which in itself was challenging to their view of themselves as having been fit and healthy individuals. This transformed body felt unknown and represented a loss of individual identity requiring adjustment:

"*I went in to the transplant with a physical age maybe ten years younger than, eh, than my, sort of, normal age group. So, I, I think probably, probably one of the biggest shocks has been to age ten years in one [laughs]. Eh, cause that kind of takes quite a bit of adapting to in itself, y'know, just, em, so, I, I just have to suddenly I'm living within those kind of [inhales] limit, limits."* [Geoff; L184].

Recovering from HSCT often meant that family members were involved in caring for participants. David describes the way this experience was particularly difficult for him due to the direct challenge this made to his core beliefs and longstanding view of himself as independent:

"I: And what's that been like for you – your wife's role in your care and supporting you?

P: Well, I didn't find it easy cause I've been pretty independent all my life. Em, [pause] yeah, sort of [slight pause] it's been part of my definition of me that I do things, y'know, I do things. Em, and when you can't [laughing] it's, well, y'know, it's hard." [David; L582].

Physical impairments often meant that at times participants felt unable to do some things as well or as effectively as they used to do. For some participants, this meant that their view of themselves was changed. Such changes in perception of competency can potentially compromise self esteem and disrupt the stable sense of self, as described by David:

"I: And you were talking about something really important – the frustration about things that you used to do, and the meaning of I'm wondering, things like being able to do the fuel?

P: Well, it makes you feel yourself to be less than you were." [David; L628].

Although participants described living with various physical health impairments and side-effects as a result of transplant, these were not always appraised as being necessarily problematic in and of themselves. When these limitations interfered with participants' self-understanding, however, difficulties arose. For Harold, reading had a particular significance due to his lifelong profession and so the loss of his vision was felt deeply as it represented a loss of self. Physical impairments take on particular significance and meaning when the core sense of self-understanding is threatened and this can increase vulnerability to psychological distress at times, as made sense of by Harold:

"*But, what I find particularly frustrating is the loss of my vision. Em, because everything I like doing... I can't read a book for example, comfortably and I find that very frustrating. Because, that's been the basis of my whole life really.*

I: Yes, yeah. That must be really hard. And I'm just wondering how that affects you psychologically?

P: Well, it gets me depressed sometimes but I basically feel – the majority of the time, I feel, well, this is something I have to deal with and um, make the most of it. And, I'm generally, have a positive attitude toward life. Um, as I say, I'd rather be here than not [laughs]." [Harold; L206].

Participants often described the first year of life after transplant as particularly challenging due to reduced physical capacity and having to minimise risk of infection. This level of restriction often represented a significant change in existence for participants and a loss of continuity to life and self-concept. James described the impact this has on his sense of self and the loss of a familiar self. His use of language conveys a sense that this experience of poor health and reduced functioning represents a moving away from how he saw himself before transplant and a lack of continuity – the person he is today is not the busy, working person he was before transplant:

"I've had a pretty boring life for the last 10 months sitting at home doing very little and for somebody that did you know a pretty responsible job and uh had a very busy life, it was a complete turnaround." [James; L191].

Changed family life

Living with ongoing health problems as a result of transplant was perceived as altering family life by many participants. For many it meant that participants experienced disruption at times to normal family functioning, threatening the stability and continuity of the family unit.

James described the sense of disconnection, fragmentation and change in dynamic experienced within the family unit. His description indicates his feeling of separation from his family as his health prevents him from participating in family life to the same degree. His language also suggests a sense of burden as the normal family roles are altered. There is a shift in relationship equilibrium as a result of the loss of fitness as his wife takes on most of the responsibility of running the family home:

"Well, you end up eating at different times, you end up uh, um, uh, you know, just, just having almost well a completely different way of life really. You used to sit down and eat meals together you'd do different things that suit each other and the other thing is you can't, you're not fit enough to contribute to running the house so all the pressure goes onto your spouse to run the whole of the house and everything from cooking to ironing to gardening, to everything and that's very much a one way thing. I'm just not fit enough to do any of it." [James; L157].

For one participant, this transformation of family functioning has the potential to negatively influence relationships as families try to adjust to the changed physical capabilities of the individual following transplant. David makes sense of this process of recovery as creating tension in his marital relationship due to his wife's anxieties about his health and his trying to do more physically:

"It's distanced us a bit I think actually and that's basically because we tend to argue quite a lot about um, about what I can do and what I can't do. Em, but em, [pause] I think that's partly cause we're both learning. Both learning what I can and can't do y'know, so hopefully that'll go away." [David; L508].

However, positive effects on relationships were experienced by 2 participants who described *"feeling closer"* to her family [Mary; L355] and Paul described the way since his illness he sees *"them more now"* [736]. In general, however, changes in family relationships were not elaborated upon but these comments reflect the paradoxical way HSCT can impact family life.

Many participants described living with a compromised immune system. The consequences of this meant some of those participants' normal family life and family plans experienced interference. For example, Paul describes the guilt and frustration he feels about being unable to take his family on holiday. He perceives his compromised health status means that his family miss out on normal activities and pleasure:

"what really gets me is – I'm no, they'll no let me go on holiday. I cannae leave the country, right? Em, in case obviously I get an infection or anything like that. And, and, [wife's name] loves the sun, loves to get a tan em, and she's no had a holiday and I feel bad about that." [Paul; L297].

Participants described the way this experience of being unable to do things together to the same degree could feel upsetting at times. Geoff describes the way his fatigue imposes limits on doing things with his wife and that this creates a sense of isolation for them both as well as a concern for his wife's wellbeing:

"y'know, it's I, I slip off for an afternoon's snooze but that does limit the sort of things that we can do together as a couple. Em, so, that limits her as well y'know, I can, I'm just living with this, but those limitations have been extended to her as well in some, in some ways. Eh, so y'know, I've, I, I do try and get her to go off and do things by herself here and there y'know. But, that can be, it can be lonely eh, if you're not doing things with your partner and y'know, we are quite close [inhales]." [Geoff; L327].

For some, the impact on family functioning was experienced in terms of participants' ability to maintain their role within the family. Participants found it challenging to meet the needs of other family members at times and maintain previous family roles and responsibilities due to reduced physical functioning. Physical problems per se are not necessarily the issue until they interfere with family roles and responsibilities. Mary described the way her changed capacities take on particular significance when they interfere with her ability to maintain her valued role of caring for her mum. This results in her feeling conflicted and guilty. She also describes the way her attempts to maintain this role jeopardise her own vulnerable health:

"I find that quite difficult and really I should be going this weekend and I think – I'm not actually up to it and then who do you put first? Do I put her first or do I put me first? And I find that difficult whereas, if I hadn't been ill I know that I would have jumped in the car and gone and it wouldn't have been a problem. I suppose I was quite an active person...But I did gradually have to stop doing – I couldn't do lots of physical things in a day cause I would get tired. But em, I mean that's – it's not really a problem until I think, "Well, I should be going through and seeing my mum this weekend? So

I: And so, how do you deal with that? What's that like?

P: ...I brought her back cause I thought that would be easier and twice when I've had her to stay for the week – I've ended up at the doctor and got antibiotics the next day." [Mary; L531].

Changed emotional wellbeing

Many participants described their experience of HSCT in controlling their disease meant that their emotional wellbeing was enhanced and that participants felt more at "ease", which was thought to be extremely important to their overall sense of QOL. Despite living with uncertainty of disease recurrence, this did not seem to create any persistent, detrimental impact on their wellbeing. Rather, HSCT was described as an emotional benchmark or turning point; that they could allow themselves to relax and begin to think about a future no longer consumed by the fear and threat of illness and possible untimely mortality:

"*After the transplant I had total quality of life because it gave me back my health and my strength, back even probably better than I had before. But over and above that, and far more importantly for me, it gave me hope that maybe, just maybe, you know, everything was going to be alright. That is what was the main sort of quality of life for me and the transplant gave me that, it gave me my strength back and it gave me the mental hope that everything after all would be fine. You know, that I had finally closed this horrible chapter. Em, although there's no guarantees but within myself I felt [pause] more, em, how will we say, at peace with myself."* [Helen; L218].

They described being *"more positive about the future"* [Mary; L317] and feeling as though the potential risks of transplant were worth it for the sake of having less fear and anxiety about the disease recurring. The persistent anxiety and low mood associated with living with fear of relapse prior to HSCT was replaced with an alleviation of such worries:

"I was aware that y'know, yes I might, I might die going, going through the process but, em, it, there, it was a better chance than, than just sticking with the chemotherapy and permanently having that sort of black cloud, y'know, you're always looking over your shoulder and – is it coming back again? I think this is, this is a much better situation that I'm in." [Geoff; L557].

A new sense of hope and optimism replaced participants' prior inability to look towards the future with feelings of joy and happiness rather than sadness and grief:

"The way I see it now y'know, I'm hoping to be here to see my grandchildren get married and y'know, graduate. That type of thing y'know – I couldn't see y'know, when I was ill, I couldn't see that. I couldn't see that happening. But now, the like of that – I can see that happening. Y'know?" [Isobel; L464].

For some, the experience of surviving HSCT and life threatening illness had left them with an enhanced sense of hopefulness rather than any anxiety and depression about the future:

"I don't think I'm more pessimistic a person or more, if anything, I'm slightly more optimistic [laughs]. I think having been through something like this and come out the other end, relatively in one piece." [Harold; L280].

Although this was the predominant view held by most participants, one participant did describe living with significant emotional distress and fear of recurrence of disease, characterised by a feelings of pessimism and anxiety:

"*I get awfully emotional [pause] eh, a, a, and it could, I could be driving the car, I could be just sitting watching something on the telly and just burst oot and I... just hits me like that – I don't know why. I don't know what does it. Em, I mean, I know like, sometimes* *with the grandkids… I don't know, just y'know, things that I'll miss and that."* And later;

"But, every time I take a cold now, I worry, you know, I think, "Is this going to get worse?" [Paul; L150; L577].

This diverging view may be explained by Paul's circumstances. Paul was the only participant requiring top-up lymphocytes at the time of interview, in order to help control his disease. His disease had not relapsed and this process is considered part of standard care following the type of transplant received by these participants.

Theme 2: Adaptation and managing the impact

Most participants frequently moved on to describe ways in which the potential negative impact to various aspects of their wellbeing is buffered and protected by a number of factors. Participants' subjective meaning of the impact was influenced by a number of experiences – ***coping; age and stage of life; and social support*.**

Coping

Despite the challenges experienced by participants, most described simultaneously finding ways to adapt by using a variety of strategies in order to maintain or improve QOL. As a result, the meaning of the impact on their QOL and wellbeing is mediated by their experiences of coping with the challenges. For example, Harold described the importance of using compensatory methods to find meaning and pleasure in life. He also demonstrates the importance of attitudes and beliefs in terms of facilitating adjustment and adaptation. He acknowledges the sense of loss felt but rather than this meaning that he perceives his wellbeing to be destroyed, his experience of coping by finding other ways to enjoy life means that he feels QOL is upheld:

"the vision is the worst impairment – gives me the most em, it's the most disruptive and the most depressing – the loss of visual but, um, I can cope with that.

I: Sure. How do you cope? Just out of interest?

P: Well, I just find other things to do [laughs]. Uh, listen to music more, um, just I enjoy, I've always enjoyed just sitting outside em, and if I sit outside I enjoy with my eyes closed sometimes, it doesn't matter [laughs] if I sit – I'm quite happy just to breathe the fresh air and feel the wind in my face – that's ok. And, well, it's just life really – it just changes – you can't hold onto change and I feel quite ok with it. There's no point trying to be stuck – life is change and I feel that that's the way it is. I'm not, I don't feel uniquely em, eh, or, y'know, that I've been picked out to suffer. I think that's the important thing – I don't feel hard done by and if I felt hard done by, that all this darkness falls that they didn't give me the right sort of care and that's why I'm suffering now, I'd be a bit bitter I suppose. But, I definitely don't feel that. I think they did the best they could – they kept me alive and they cured the things – they've done what they could do. And I'm very happy with the treatment. I'm happy to be here as I say. I accept the consequences that are inevitable and predictable. And it's not a question of fair or not fair it's just the nature of life." [Harold; L365].

Coping styles varied among participants with attitudes being particularly important in mediating the perceived impact of the effects of the transplant on QOL. Geoff illustrates the way his proactive coping style and attitude allows him to feel as though his QOL is not restricted by his compromised immune system. Rather than avoiding social situations and withdrawing, he feels it important to stay involved in the world whilst being sensible about not putting his health at unnecessary risk:

"Well, you've just got to get a balance really. You can't lock yourself away as a, as a hermit thinking "Oh, god, y'know – it's dangerous is that world out there – I might catch something"..So, yeah, I'm living within those limitations but y'know they're not too, too onerous are they?" [Geoff; L529].

Participants described an incredible ability to cope at all stages of the recovery journey, demonstrating strength and resilience even in their most difficult periods. Participants described using strategies to help them hold on to their values in life. James describes the way his goal setting coping style allows him to work towards regaining QOL. His language conveys a sense of agency, control, achievement and hope for the future:

"Um, if uh, um, if things continue as they are then and I continue to make progress and I can stop having blips like this Graft versus Host Disease and the body starts to settle down then I'll get quality of life back and I intend to travel again and go round the world bird watching and do the things I really want to do. At least in the UK to start with and then um uh abroad again with my friends and family.

I: Yeah, so thinking about the future

P: Yeah, absolutely, that's my target and even just to get down, you know I set small targets just to get down the Ayrshire coast for a day out with my friends again uh, is my next target, you know for a few hours and have a coffee at a country park and things like that, they're my targets at the moment." [James; L276].

Positive thinking styles were used by many participants to help manage the psychological impact of the ways life had changed, such as living with physical health problems; being less active; losing ability to participate in previously enjoyed hobbies; and living with uncertainty. In this way, they made sense of the impact as being experiences to which they could adapt. Isobel describes the way she feels her coping style is important in helping maintain her psychological wellbeing which is potentially threatened as a result of her changed abilities. Her resilience is apparent in the way she actively chooses to protect her wellbeing from any negative impact by focusing on the here and now rather than ruminating on her losses:

"I feel that I can't do a lot of what I could do before. Eh,

I: And how does that make you feel?

P: [pause] Em, och, I never think about it actually [laughs]. I never – actually I don't, I never think, I never think of what I had before and what I have now because I'm just, I've just gotten to the stage – well, I've just got to accept what, what I've got now. Y'know? It's – there's no point in dwelling on what I had before, y'know what I mean – it's just what I've got now and I've just got to accept it. It's quite em, y'know, I think, I think if you go back to what you had and wishing that you could have that back – I think *that would play on your mind. You know? I think it would give you mixed feelings and everything. Mmmhmm."* [Isobel; L593].

Being able to adapt and utilise coping skills helped participants maintain and improve many aspects of their wellbeing threatened by the experience of HSCT including physical, emotional and ability to enjoy life. Coping allowed them to feel their values in life were preserved and upheld. Having the ability to adapt to their challenging experiences meant that their sense of competency and agency was maintained.

An optimistic coping style mediated the potential psychological impact of living with uncertainty for a number of participants:

"I mean, y'know, ok it's there, y'know ? It might fall over tomorrow and if that happens then obviously I'll have to deal with it but y'know, it isn't at the moment so I'm not worrying, I'm not going to worry about y'know, I'm not going to worry about it." [David; L489].

Although adaptive coping represented the predominant theme for participants, one man described his difficulty with this and described the way he copes with anxiety and uncertainty by avoidance and withdrawal which then has a knock on effect on other aspects of his wellbeing such as his relationships with his family and his own mood. This example seems to illustrate the relevance of the theme and the way coping mediates experience of QOL:

"I: And you say that you worry and again, I'm sorry for asking what seem like stupid questions but you know, how does that then, how do you notice that impacts you, when you're worrying like that? What's that experience like?

P: I just go quiet. I tend to keep myself to myself. I sit up in the room, watch the telly or I'm on the laptop. Em, dinnae do an awful lot.

I: Ok, so you kind of withdraw a bit? And then what happens then within the family and with your relationships?

P: They just leave me to it. They just leave me to it, until I get out of it [laughs]. Aye, I mean, [wife'sname] knows, she'll say, "what's wrong with you?" "nothing, fine", "no, it's not" [laughs] She knows but she just leaves me to it." [Paul; L582].

Age and stage of life

Many participants reflected on their age and stage of life when making sense of the multiple ways HSCT has impacted their lives. They described the experience of HSCT as occurring within the context of a particular stage of life characterised by change and transition. Participants' experience of this appeared to facilitate adjustment to and acceptance of a changed existence. For many, this meant that the impact to their wellbeing was buffered and threat minimised. As with coping, the subjective meaning of the impact of the HSCT on QOL is mediated by participants' experience of being at particular stage of life and their associated views. For example, Harold's experience of physical decline is normalised and transformed into part of the ageing process which seems to allow him to cope with the change and create less biographical disruption to his life:

"Well, I think it's, it's hard to separate the diminished things I can do uh, from being a consequence of the transplant or a consequence of just getting older. And I know people who haven't had transplants who are just older, getting old, getting on – experience diminished capacity and it's hard for them to cope with things the same as it is hard for me. And, clearly some of the difficult, eh, um, decline that I experienced is a consequence, albeit indirect, of the transplant – I don't, y'know, I don't, in my mind I don't say oh, that's because of the transplant and I, if I hadn't had the transplant that was a big mistake, I'd be better – because I wouldn't be better [laughs]. I wouldn't be, I wouldn't be complaining about it, I wouldn't be here. So, I think that, as I say, it's, I view it as y'know, that life, eh, is a journey and you go through it and your ability to live and do things, changes – it's quite different from when you're seventy compared to when you're twenty five." [Harold; L334].

All participants experienced change in their ability to be involved in previously enjoyed activities. For some, age related beliefs and expectations buffered the potential psychological impact of this loss. Isobel describes her feelings of loss in response to being no longer able to enjoy hill walking and like Harold, integrates this into her experience of growing older and expected changed abilities. As a result, emotional wellbeing is protected and acceptance and adjustment become possible. The meaning of the loss is thus changed slightly as a result of her views about the ageing process:

"I: Yes, mmhmmm. And you know, I'm just wondering to what extent you think that life or QOL has been what you expected it to be after the transplant? Has it been what you expected?

P: Em, [inhales] mmm – well, yes, I think so. At my age, yes. I think so. Em, because I was, well, near fifty-five when I went for it. Em, if I was a younger person, I would maybe hope to have more go. Em, [slight pause] y'know how, if I was maybe in my twenties and thirties y'know, like, being more physical with, y'know sports and that – I would feel y'know, that would affect me. But, now I'm older – no, I don't think so. The only, that's the only thing I miss is y'know – we used to walk a lot y'know in the country and that but I can walk just a wee bit but, y'know, it's just, I just suffer the next day. Because I'm so tired. See I still get a lot of like, fatigue. I think that's just because of the transplant. But, well

I: And how does that affect you?

P: Well I don't – it doesn't affect me so much because I think because I'm older. But, I think if I was thirty years younger – I think it would affect me.

I: Do you think it would be better or worse?

P: Em, it would be worse yes. But what I mean – the fatigue would be worse – y'know I couldn't do a lot of things, y'know? When you're older you don't expect to do a lot of things. Am I making sense? So, y'know, it's not like a big issue to me because I'm sixty, y'know? But, well, you just make the best of what you've got at sixty, you know what I mean?" [Isobel; L535].

Being of a stage of life where peers increasingly face health problems helped normalise the experience of living with ongoing physical health problems after transplant. This allowed participants to make positive social comparisons to age-similar peers and make sense of changed abilities as part of the normal ageing process. Mary's humorous and philosophical attitude towards the ageing process helps her feel less different from her peers, thereby protecting her view of herself and her abilities:

"I: And you mentioned about comparing yourself to your friends who are the same age and things – how do you compare yourself to them?

P: Em, [pause]. Och, favourably, I – em, em, [pause] I think everybody has their ups and downs. I don't feel that – sometimes I don't feel that I do as much as some of them but then I do more than others so em, it kind of evens out really...I've had a friend who's had her hip re done and she's really struggling, so from that point of view I can get about easier than her. Em, so we're getting to that age when we're all falling to bits, I think [laughs]." [Mary; L553].

For James, the impact of being unable to work as a result of the physical consequences of the transplant was buffered by his stage of life. Such major life changes have the potential to trigger serious biographical disruption for individuals however the psychological impact of this was buffered by the fact that that this was happening at a time in life where such transition was expected:

"I: I guess that must have been a big decision though to..

P: It was in a way but I was beginning to think of retiring in a year or so's time anyway, so it probably wasn't as big a decision as it really would have been a couple of years ago, um, so I was wanting to go early anyway. I've worked hard and had a long time, so." [James; L239].

Age and stage of life was also considered to protect QOL in terms of reducing the pressure for participants and their families, as they coped with the experience of life-threatening illness and treatment. Helen describes her belief that being at an older stage of life can reduce the burden of the experience due to facing less working life demands and priorities. She makes a downward social comparison to younger people and perceives her stage of life to help reduce the impact on overall wellbeing:

"[Husband's name] retired at the end of August, 2004...So, I mean, it was just a blessing as well that you know, in a way, that he didn't have a full time job, because, that would have been a real strain on him and myself...And, you know, youngsters that are, they're working and you know, with mortgages and things like that to worry about and my heart goes out to them because, em, money worries and, and family worries and things like that over and above having to face the sort if nightmare of the kind of [pause] cancer thing that people face. I mean, physically and mentally is bad enough without having face you know the other side of it". [Helen; L626].

Paradoxically, a number of participants commented on the way being older was also more likely to make physical recovery longer and harder:

"I would imagine that if you were younger – em, and whatever trauma you go through when you're younger – you pick up quicker than an older person." [Mary; L581]

The meaning of this was not elaborated upon in the data but seems to reflect complex beliefs participants hold when making sense of their experiences, perhaps reflecting the inherently contradictory nature of the human condition. The very factor that protects them to some degree has also made them more vulnerable.

Social support

All participants shared their view that they valued the support they received from their friends, families and others when recovering from HSCT. Those elaborating on the meaning of this described social support as a factor mediating their experience of wellbeing and QOL. Although variation existed in accounts, social support was described as protecting various aspects of wellbeing negatively impacted by transplant.

For example, James articulates the way contact from others helps improve mood. His language also conveys the sense of continuity to self concept and life that such support brings. His sense of isolation is reduced by support and he feels part of a wider, shared existence that he has been separated from during his recovery:

"The other thing that's very important I think is um I had a very good network of friends and a very good network of work colleagues that um uh kept coming and seeing me you

know once I was out of the um uh out of the job and on sick leave um I didn't lose touch with them, they still kept very much coming around and have done that the whole time and I think that's been pretty important to get that external contact as well.

I: Yes, yeah. What did that do for you?

P: Well it lifts you up definitely does and uh um it's good to know you've got that network of support." [James; L194].

Social support from others was considered an important means of providing a sense of normality when life after transplant had become focused on health care issues, hospitalisation and illness. Mary recalled being visited regularly when in hospital helped her feel less defined and consumed by her illness and allowed her to reconnect with her identity as a mum and a social being:

"..she was a church visitor and she used to go round and she used to sit and have a chat with you..And actually it was really quite nice to – she had 3 girls as well, funnily enough and she would speak about her girls. But she was really nice and that was nice to have somebody totally detached.

I: You were saying there was something about that that was good – do you know why it made a difference?

P: I think it made a difference because she wasn't involved in looking after me. She didn't know what I had or – she was just someone who came in and had a chat and went off again. And because she was – I don't know why it was nice – she just – it was just something not to do with your care or family or friends that knew that you were ill. She was just somebody that came in and had a chat." [Mary; L764].

In general, participants described valuing having their family there throughout their recovery to help them cope both practically and emotionally. They felt cared for and valued by others. Being part of a wider family network increased their sense of wellbeing, even when they were struggling during recovery. Paul describes the way having his family helps his motivation to keep fighting through the difficult times. His family helps his emotional wellbeing in tough times:

"And obviously having eh, [names of family members] and that there – eh, I'm happy – cause it keeps me going." [Paul; L740].

Theme 3: A new perspective on life and living

Regardless of the stage of recovery, all participants described the way their experiences had triggered a shift change in their perspective and represented a significant turning point in their life journey. This overarching theme is reflected by 3 sub-themes; ***personal growth and benefit; changed priorities***; and ***reappraising and accepting***.

Personal growth and benefit

All participants described ways in which their experiences with illness and transplant had triggered a sense of positive growth in their lives. It is not uncommon for positive change to co-exist with distress and this was reflected in the accounts of all participants. Although variation existed between participants, they all reported experiencing some personal growth or benefit, often in a seemingly paradoxical manner.

For example, Paul described a history of becoming aggressive when stressed yet living with the increased stress of illness has triggered a re-evaluation of his interpersonal style which allows him to have better relationships with others:

"*I used to get really angry at things – silly things, y'know? Em, and it was just a build up of stress. But, eh, now, well, I, I don't feel – although – I might have more stress because of the illness it's not the same. I've, I'm, I'd sit down and, and, and try to talk something through rather than lose the head.*

I: I wonder what that's about, how you make sense of that?

P: It's just totally different. I don't know, I don't know eh, what it is. Maybe, maybe things – life's more important, y'know, eh, em, and, you cannae just keep falling out with people [laughs] y'know?" [Paul; L405].

Coping with the challenges of illness and transplant often acted as a trigger for participants to become more appreciative of others and more outward looking. Participants often talked about the way they felt "lucky" and that some people have had much worse experiences with transplant. This tendency to make downward social comparisons prompted a positive change in perspective and outlook towards others:

"I think you're much more accepting. I think you're less judgemental and em, [pause] and I think you just appreciate em, what some people – you know I hate coming in here – em, what some people have to put up with and go through. Em, [pause]" [Mary; L496].

Most participants reported being more appreciative of being alive and often described having been given a "second chance at life". For one participant, the experience of surviving her illness and transplant and her belief that she "floated through transplant" (Helen; L722] meant that she experienced a profound sense of spiritual growth:

"before I was diagnosed away back in 2004, I had never given any kind of thought to – I didn't go to church, maybe I did when I was young, but I'd never given any thought to the spiritual or religious part of life really...Because, one thing I'm sure of is, there's more things that science can't explain just as many as things that can explain and em, there are miracles out there. There are miracles out there, I believe that. So there you go [laughs]." [Helen; L668].

Changed priorities - A time for re-evaluation & reconstitution

Many participants described the way their experiences of illness and transplant had influenced a changed view of QOL priorities. They described re-evaluating aspects of their definition of QOL following HSCT. Participants' previously held goals in terms of QOL were reconsidered and a new way of life was felt more worthwhile. This re-prioritising often reflected hopefulness felt by participants, that new or more meaningful experiences in life could be had in the present. Changed goals seemed to reflect a focus on achieving emotionally gratifying experiences.

The experience of spending long periods in hospital was often described by participants as difficult and was one of the reasons for Mary's change in priorities, from travel to spending time with her family. Her language also conveys her sense of the way her goals have become present focused and that she has a new appreciation for the joy of daily life experiences:

"I used to think that I would travel quite a lot – I don't now. Eh, funnily enough. I'm quite happy to be at home. I think it's because you spend so much time away from home, em, and from the grandchildren – em [pause] I've got no huge ambitions to do anything. Em, I sew – I still do embroidery and things like that. Em, so I'm still hoping to do a masterpiece but eh, everyday life – it's fine." [Mary; L292]

Changed priorities seemed to be reflective of a turning point in participants' lives. They described that having been through the experience of illness and transplant, they now wanted to reclaim QOL and define it on their own terms. This is apparent in James's reappraisal of the value he placed on work and his decision to retire. His focus on career planning and achievement has shifted and his language suggests a desire to pursue more emotionally gratifying activities:

"I put far too much over the years in [pause] personally into work really. I worked really long hours and um was a pretty committed person to the job I did here, so... I: Right. P: Um and uh I think uh I don't know whether that's a contributory factor to my illness or not but the amount of time I put in but it probably is not healthy so, to put that amount of time into your work... I've decided to take early retirement and I'm retiring in the next month or two and um going to try and get some quality of life back and uh, there's a lot more to life than working. [laughs]" [James; L86].

Some participants described wanting to give something back to society as a result of having survived HSCT. They often talked about feeling grateful that their transplant had given them a second chance at life. Geoff describes the way this prompted a new sense of priority to use his time more meaningfully. His language suggests he is redefining how he would like to spend his time which involves looking beyond himself towards a desire to contribute to society. This re-evaluation of the important aspects of QOL reflects feelings of optimism and positivity:

"I mean there is one aspect of all this, y'know, I feel, it has made me think, well, I'm, y'know, all these people have put all this into me, I've, I've really got to put something

back into society – I really owe society something, y'know, I can't just sort of sit back on this. Em, society has given my life back for a reason...I do feel that I shouldn't be wasting what time I've been given eh, eh, to eh, left on this earth really and I need to be doing something positive with it. So, I y'know, I've got that in the back of my mind. Don't just sort of twiddle your thumbs [participant's name], you've got to be, got to be doing something." [Geoff; L447].

Reappraising and accepting – the losses are worth it

Many participants described reappraising their losses and challenges. All participants described their physical health as transformed following HSCT. 7 participants described experiencing significant ongoing health problems as a direct or indirect result of the treatment. However, they also described being in the paradoxical situation of having experienced improvement in their physical health as a result of the success of the transplant in controlling the original life-threatening disease. This is perhaps best captured by Geoff's statement:

"The immune system is ineffective but at least the haemoglobin levels have recovered, so that's brilliant, y'know?" [Geoff; L196].

Despite life after transplant being challenging and disruptive to aspects of QOL, most participants shared their view that the losses are compensated by the gains. They acknowledge the losses but reconsider them as worth experiencing for the chance of being alive. Many described the way they felt accepting of a reduced level of functioning and an ability to cope with disruption for the sake of having a future. Mary describes the way she had to cancel social plans due to poor health but the meaning of this is mediated by her view that she now has a future life, which is much more important:

"So, regardless of missing – you know there were quite a few things this winter that I had to cancel – em, which was disappointing, but you know, at the end of the day, you know, there's still tomorrow." [Mary; L283].

Although this was the predominant view shared by participants, one participant was struggling to reconcile the losses and felt his overall QOL to be inferior to pre-transplant life.

"P: Yeah, I mean I worked right up – in fact – I even done the Glasgow to Edinburgh cycle. Just eh, in the September before I came in for my bone marrow. Did that in the September and I came in in the October. Aye, so I was still out and about. Up until I came in. It's only been post the bone marrow that I've – I don't really go out – I don't socialise much at all. So, aye, things have, things have changed. I wouldnae say anything's changed for the better. To be honest, because, physically – I'm worse. Eh, mentally, probably – so I don't and I don't, I don't really do anything [quieter] don't go out much." [Paul; L772].

Again given the unique situation Paul experienced in terms of the increased uncertainty associated with requiring lymphocytes to maintain control of the disease, this may help contextualise his diverging view. Indeed, when considering some of Paul's examples within other themes, a story emerges for this man which highlights the importance of the treating each individual HSCT recipient as a unique person and that one IPA narrative account cannot possibly fit the experiences of all.

Theme 4: Changing over time

Many participants described the impact on their QOL as changing over time in terms of the quality of their relationships with others; physical abilities; emotional wellbeing.

Mary described the way the sense of self is restored over time and how remission brings a resumption of normality. She describes the way time brings a restoration of the self:

"I think after a wee while, your relationship kind of goes back – with all of them I think goes back to what it was like before. I don't know if it's had a huge – I think they all knew that em, you know, hoped that everything would go ok. And then I think because it has – they then go back to you know – it's same old mum again.

I: Why do you think that is?

P: I don't know. I suppose because as each day goes on – the transplant, the hospital business is further away. It's time. And it's funny – one of the girls that was in when we were in the [hospital] [info omitted] and she was on the phone and she said, "isn't it funny, I'm feeling really grumpy and I'm annoyed about this – really it's ridiculous – same old person", she said "you forget how". I suppose you do lose that, "Oh, I'm in remission". Em, and you get back into normal life again. I think you have to." [Mary; L376].

Participants often recalled being extremely unwell immediately after transplant and reflected on how far they had come since then in terms of physical and emotional wellbeing. For example, Isobel reflects on being at her lowest in her early recovery period and feeling as though she was facing the prospect of death; however, she now feels this is a distant memory:

"after my transplant and that, when I was feeling really ill and down and that – you know, I said to my husband, look – I need to write letters and that...em, I just felt that [slight pause] I didn't say enough, y'know, before. So, y'know, I'd done all that on paper and that but [tails off]. But now, it's just – it seems a pinch of salt now [laughs]." [Isobel; L266].

Physical health and ability to do things and feel positive was also described as changing over time. In this way, QOL is described by participants as a dynamic experience. David describes the way the experience of change in itself helps protect wellbeing by increasing positivity:

"And, y'know, I've been able to get back to doing some things already so y'know, it's eh, I'm really quite positive about it." [David; L466].

The results have attempted to capture the dominant stories and experiences of the participants as a collective group, whilst striving to retain each individual's unique journey. Clearly a tension exists in this process and it is recognised that no one account will fully represent the full spectrum of each participant's experiences. Life after transplant seems to be full of inherent contradictions. However, it seems testament to participants' resilience that they find ways to reconcile their losses and adapt to a changed existence. This is not to underplay the significance of the challenges however and it is essential for transplant recipients to have access to supports when needed in order to help reinforce their resilience when required.

Perhaps the seemingly paradoxical nature of the results and the journey experienced by many participants is best made sense of by Harold:

"It's clearly been a mixed bag of emotions and experiences – it's not all horrible, it's not been y'know, all wonderful. And it hasn't been easy but uh, I'm happy I did it – I would have been happier if certain things hadn't happened like if my eyesight hadn't been affected. Em, but that's just the way it is. There's no point in me – what alternative is there? I can't go back and change things so the question is just to move forward and um, decide how you're going to cope with the situation as you find it." [Harold; L468].

Discussion

The purpose of the study was to explore recipients' experiences of life after HSCT and how they make sense of the impact on their QOL. Four emergent superordinate themes were identified.

The first theme 'Shifting sense of self and others' reflected the way QOL is impacted in multiple ways following HSCT, consistent with a biopsychosocial definition of the construct. The subordinate theme *'altered sense of self'* was reflective of participants' perceived change between their pre and post transplant self-concept. HSCT literature reviews refer to this as role functioning, that is, the way individuals define themselves in relation to their roles within family and community. It has been suggested that such decreases are transient as individuals resume prior roles over time [26]. However the theme as it emerged in this study seemed to reflect a more profound impact on identity and former self-image which is a topic less focused upon within the HSCT literature. To the researcher's knowledge, only one quantitative study has investigated this aspect and found that self-concept becomes increasingly defined as a 'HSCT patient' as cancer and its treatment impose increasing lifestyle disruptions [27]. Participants in the current study described that the extent to which they were resuming pre-transplant roles varied. Therefore, it may be interesting to explore the impact of HSCT on identity and how individuals experience and negotiate any loss of self, as conducted by Kathy Charmaz [28] among individuals with chronic illness.

In terms of '*altered family life'*, the study revealed both differences and commonalities in perceptions of the impact on family life when compared to the only other IPA literature on younger recipients [10]. Whereas older recipients discussed a disruption to normal family functioning and their ability to do things together, younger recipients described their primary fears as being related to not being able to have children and develop close relationships [10]. However, younger recipients also reflected similar family concerns about their ability to take care of their family and their sense of having "no life together" [10 p. 110]. As with the Holmes [10] study with younger adults, mixed findings were reported in terms of the impact on relationships with positive and negative changes reported (p110). Within this study, the theme '*altered family life'* emerged where participants' expressed views that their illness placed demands on their family members. This sometimes led to a sense of isolation and distance as well as tension at times as families tried to adjust post-transplant. Their accounts reflected a sense of concern over family well-being which has been documented as a source of stress for HSCT recipients [29]. Only one intervention study has been conducted to date with both the patient and their care-giver/family member to address their shared distress using a problem solving education intervention [30]. Results showed that participants found the intervention beneficial as it gave them the "opportunity to talk" and use "creative thinking" to help negotiate the challenges of adapting to the early recovery period following allogeneic HSCT (p.24). Although this theme is not new in terms of our understanding of how life is impacted after HSCT, given the predominant experiences of disruption to family life and participants' roles within that changed unit, it seems essential that efforts are directed towards working with both recipients and their families to help them adjust to any changes, transient or ongoing. This altered family existence also overlaps with the altered sense of self which helps us appreciate the importance of the interconnected nature of these themes.

The sub theme '*changed emotional wellbeing'* reflected the way participants reported an improvement in their mental wellbeing following transplant. Although one or two participants recalled their emotional health being jeopardised when their physical health was at its most vulnerable in the early recovery period, this resolved with improved health. No significant or persistent emotional experiences were reported by participants at the time of interview with the exception of one participant, who notably disclosed a history of mental health difficulties. These findings are in line with a recent systematic review by Mosher *et al*. [4], who found that HSCT survivors generally report decreased distress over time, with most research indicating that mean levels of distress are within normative limits at 3 or more years post-transplant. This finding is interesting considering the previous subthemes within this overarching 'Altered QOL' theme which highlighted potential threats to emotional wellbeing. However, when considered in light of the other superordinate themes emerging, it may be that these act as 'buffers' to the onset of perhaps of negative emotional wellbeing and boost resilience. Nonetheless, the experience of one participant highlights the importance of both assessing individual emotional wellbeing, and the having psychological services available to help meet the needs of recipients.

The second superordinate theme 'Adaptation and managing the impact' reflected participants' views and experiences of their QOL as being protected in some form or another. Participants showed a remarkable ability to use a variety of *coping* skills to help preserve their sense of wellbeing. Their accounts reflected a sense of determination, positivity and strength to overcome the challenges facing them post-transplant. This is important as lower levels of anxious preoccupation and higher levels of fighting spirit may be associated with longer survival post transplant [31]. The findings in relation to participants' ability to cope and the mediating impact this had on their appraisal of QOL also seems to provide support for Lazarus & Folkman's [32] Transactional Model and suggests that facilitating coping among HSCT recipients should remain a priority for professionals supporting recipients. Participants all described valuing '*social support'* with many describing the way it helped maintain their wellbeing, which would seem to add further support for the findings in the evidence base suggesting that poorer QOL is associated with reduced levels of social support [3]. The findings also suggest that assessing levels and quality of social support prior to HSCT would help identify individuals at increased risk for adjustment problems.

Whilst coping style and social support have both been found to be important predictors of QOL and survival post transplant, '*age and stage of life'* is a new emergent theme to this area as having a potential buffering effect on QOL. Previous research found older age as predictive of poorer post-HSCT QOL [3, 1]. However, the findings from this study suggest adults aged 50 years or more at time of transplant manage the challenges of HSCT extremely well and that their older stage of life actually facilitates adjustment and coping to maintain their QOL. There are many psychosocial and developmental theories of ageing which are likely to help contextualise the experiences of older HSCT recipients and their adaptation to post-transplant life however a full discussion of these is beyond the scope of this thesis. However, participants' descriptions of their stage of life and utilisation of coping strategies seem to fit well with theories such as Baltes & Baltes [33] theory of Selection, Optimisation and Compensation. This theory helps explain successful adaptation to the challenges of ageing which could also be applied to the older HSCT recipients facing the challenges of reduced physical functioning. Indeed, many participants seem to be naturally utilising such approaches by de-prioritising certain skills and tasks and selecting new ones that give their lives meaning. Their descriptions of using coping to hold onto valued goals also seems to fit with Ouwehand *et al.*'s [34] theory of proactive coping. Overall, given the findings relating to '*age and stage of life'* and the interconnected theme of '*coping'*, it seems that research pertaining to theories of successful adaptation to ageing may be a useful framework to consider when helping older HSCT recipients adapt but also as a useful additional conceptualisation for further research with older HSCT recipients.

The findings from the third superordinate theme, 'A new perspective on life and living' reflect issues that have been identified in the wider HSCT literature and add strength to some of the more preliminary findings. The findings from these 3 sub-themes generally reflect a focus on positive changes in quality of life after HSCT. Participants on the whole described the way their experiences of surviving illness and HSCT had triggered '*personal growth'* and '*changed priorities'* in their lives. They describe reinterpreting surviving the trauma of illness and HSCT as an opportunity for growth and benefit finding. They also describe their acknowledgement that some goals are no longer attainable and begin to formulate new goals. A number of current theories exist to help explain this apparent paradox following the experience of traumas including serious illness [35]. HSCT literature refers to this positive psychological and interpersonal growth as described by participants in this study as "post-traumatic growth" (Andrykowski et al. 1993) [36]. The findings of this study support this conceptualisation of HSCT as a "transitional event which creates the potential for both positive and negative change" [36, p. 261]. The experiences described by participants fit with Wingard & Bishop's [8] contention that in order to develop a comprehensive understanding of post HSCT QOL, both losses and gains should continue to be assessed (p.115).

In terms of the final sub-theme, ***'**Reappraising and accepting – the losses are worth it'*, participants' described that despite facing significant losses and challenges, they seemed to take a philosophical view that their life was still good and worthwhile. The previous themes of coping, social support, and stage of life as well as the aforementioned theories of adaptation may well account for the mechanisms facilitating adjustment in a paradoxical situation. However, a recent theoretical response shift model developed by Sprangers & Schwartz [37] was first utilised with a HSCT population in a qualitative study and found evidence of recipients engaging in response shifts such as lowering standards for what constitutes "good" QOL [38]. This theory would also fit with participants' accounts in this study as reported in this sub-theme. Overall, this superordinate theme seems to reflect adaptation and adjustment that could be explained by a number of relevant theories. Regardless of the mechanism used participants are describing their incredible ability to adjust.

This final superordinate theme **'**Changing over time' is not new in terms of HSCT research literature and conceptualisations of QOL as a dynamic construct. The majority of participants report positive change over time. It supports recent empirical evidence summarised in reviews regarding overall QOL after allogeneic HSCT as characterised by ongoing improvements reported from 6 months to 4 years post-transplant; and continued long term impairment relative to non-cancer comparison groups [26 p, 374]. This quantitative evidence is valuable to patients facing the decision to undergo transplant. However, this study highlights some of the mechanisms which might help explain such quantitative findings as a result of examining the experience in-depth. The 4 interconnected themes demonstrate the challenges facing recipients and also the interconnected processes of adaptation.

Conclusions

Overall, findings suggest that the sample of recipients who participated in this study are adjusting well to the challenges that this procedure presents. Many commonalities in experiences have been documented in the current literature relating to post allogeneic HSCT in younger patients. Participants describe living with various chronic symptoms and given their increased age these can be more difficult to manage. However, paradoxically they are simultaneously protected from this by various ‘stage of life’ factors and an increased acceptance of changing abilities. Chronological age has not been found to be an independent factor in psychological adaptation post HSCT in this study. This is a much more nuanced variable which is impacted and mediated by a number of important individual and interpersonal factors. Participants have demonstrated that they have the capacity to cope with the challenges of treatment and its resultant side-effects and value the treatment hugely. These individuals are adapting and reconstructing their QOL priorities to lead meaningful lives and have a desire to make valuable contributions to society. However, this population is characteristically heterogeneous, therefore pre-transplant assessment of variables such as coping style and social support seem crucial to consider with individuals and partners in order to help best discuss informed consent and ensure that support is delivered and targeted effectively. The remarkable adaptation described by participants should not deflect attention from the very significant physical and psychological challenges facing recipients as they negotiate their way through recovery. Hopefully, the findings of this study provide some unique insights into the experience of older adults' QOL after allogeneic HSCT that have important ramifications for their decision to undergo transplant and their adjustment to life after transplant.

Implications for Clinical Practice

Recipients' adjustment to life following HSCT could be facilitated through the application of research which has examined factors associated with successful ageing and adaptation to stressors. Psychologists, as part of a multidisciplinary team, have an important role to play in terms of their skills in formulating difficulties and developing strategies, in conjunction with the patient, to compensate for losses and bolstering resilience or 'post-traumatic growth'. Patients may also be helped to maximise their coping skills and peer support, possibly via haemato-oncology support groups. For patients requiring specific psychological intervention, Cognitive Behaviour Therapy and Acceptance and Commitment Therapy may be of value in helping recipients in recovery move forward in the context of change whilst holding onto their values in life. These psychological models may be particularly useful then for HSCT recipients requiring psychological intervention. In addition, it is important that interventions and support are offered to families and partners, where indicated.

When using standardised questionnaires, as part of QOL assessment, it is important to elaborate on responses by asking recipients how they are coping with change. It is also important to continue to conduct pre-assessments of coping styles, social support and psychological histories in order to identify individuals who are at increased risk of developing psychological difficulties and ensure that appropriate psychosocial supports are available. In addition, the use of ongoing assessment, for example, at yearly late effects clinic appointments would be helpful in monitoring patients' changing needs.

It is also important to continue to inform potential recipients of the possible changes to life that may be experienced (positive and negative) following transplant and help recipients feel as included in the process as possible. This could be done through the provision of information, signposting to relevant services, and facilitating contact with other transplant recipients. Finally, the findings from this research could form the basis for specific information provision for older patients considering RIC HSCT (e.g. through a leaflet) outlining what strategies other patients have reported facilitated the adjustment process.

Implications for Future Research

It would be useful to conduct further qualitative studies with homogenised groups in order to assess particular aspects of the experience of HSCT, for example, the impact of HSCT on identity and self-concept. This would allow a more in-depth exploration of how individuals restore their sense of self following major medical interventions such as HSCT.

Future research should focus on adaptation studies to identify holistic care needs. In addition, more studies are needed to assess the impact on carers and their QOL post-transplant.

Finally, more quantitative studies and longitudinal research designs are needed in order to assess the importance of predictors of quality of life, such as coping styles. Correlation study designs would likely add to our understanding of links between coping, support, age etc.

Limitations of Study

There are a number of limitations that must be taken into account when considering the conclusions and suggested implications of this study. Firstly, the participants were all at various stages of recovery and therefore QOL concerns will reflect these stages. It could be that those participants with longer duration post-transplant will naturally demonstrate increased adjustment however the findings suggest that this process of adaptation and adjustment is evident even in those most recently transplanted.

Since QOL is a dynamic and changing construct, homogeneity is reduced which is an important factor in IPA studies. However, homogeneity was considered in the development of the study and is reflected in the sample of participants who all received the same type of RIC HSCT from an unrelated donor.

Another issue to consider is the fact that the participants in this study all chose to take part and their disease had not relapsed. Undoubtedly, the QOL experiences of recipients for whom disease had not been successfully controlled post-transplant would be very different.

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CHAPTER THREE

ADVANCED PRACTICE I – REFLECTIVE CRITICAL ACCOUNT

Working with complex cases in a specialised multidisciplinary team: A Reflective Account.

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (DClinPsy)

ABSTRACT

The British Psychological Society requires that clinical psychologists be trained as competent reflective scientist-practitioners. Engaging in reflective practice allows clinical psychology trainees to critically appraise individual professional development in a constructive manner. Training placements provide environments full of learning experiences and opportunities however it can be challenging to incorporate those experiences into a meaningful and coherent narrative that is reflective of how we have progressed as trainees. The reflective account that follows therefore represents an attempt to articulate my understanding of how I have grown as a clinician as well as the limits of my competences as they currently stand. The account will use Rolfe et al.'s (2001) educational model to structure the reflexive process. It will also draw on other relevant psychological theories to deepen the reflection. This reflective account will consider the context of National Occupational Standards for Psychology to help link experiences to my perception of my clinical skills and competences. The account will focus on the experience of working with complex cases in a specialised multidisciplinary team.

CHAPTER FOUR

ADVANCED PRACTICE II – REFLECTIVE CRITICAL ACCOUNT

Improving access to psychological therapies and the role of the Clinical Psychologist: A Reflective Account

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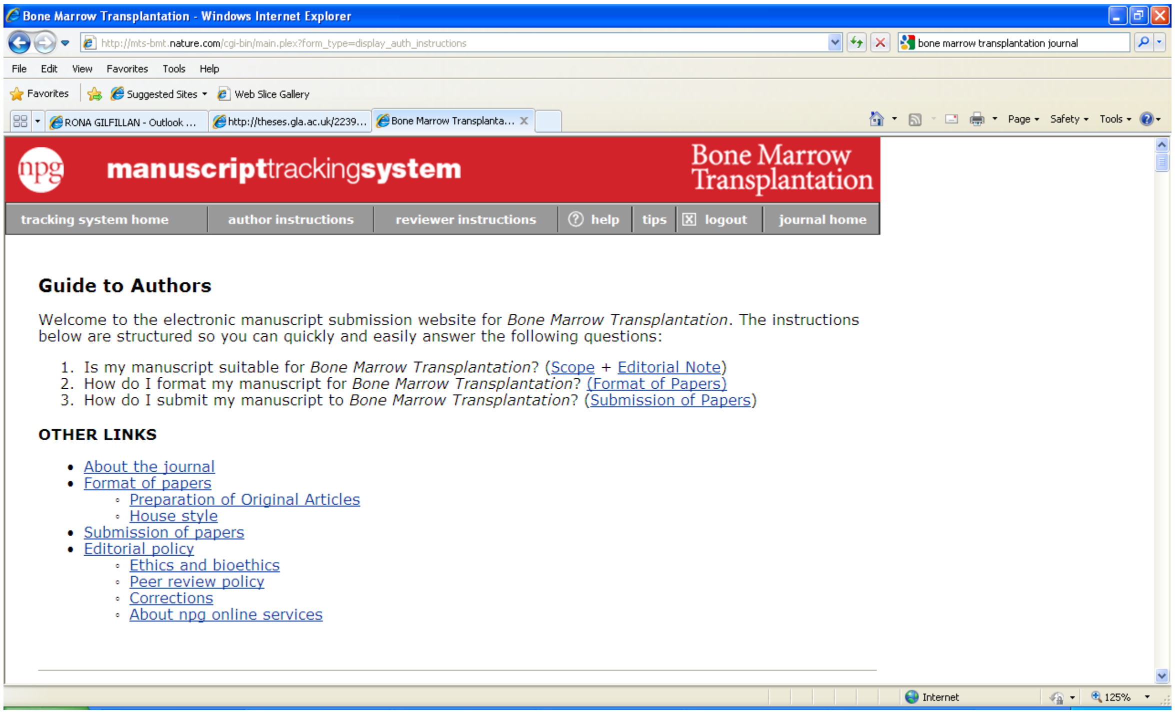
ABSTRACT

The National Occupational Standards for Psychology (NOS) help define the areas of expertise and common competencies associated with the roles of Clinical Psychologists. This reflective account focuses on Generic Key Role 6, defined as management of the provision of psychological systems, services and resources. The decision to focus on this role stemmed from an awareness of the current political and professional climate of change and an uncertainty as to the role of clinical psychologists within this context. Rolfe, Freshwater and Jasper’s (2001) Framework for Reflexive Practice, is used to provide structure to the reflective piece. The account attempts to demonstrate the strengths and limitations of my competencies as a clinical psychologist in training and the learning experiences that have shaped my understanding of my professional development. In addition, the regulatory body for clinical psychologists, the Health Professions Council, highlights that clinical psychologists must be able to use a reflective practitioner model when working with clients and so this piece of work is also an effort to demonstrate this required competency.

Appendix 1.1: Bone Marrow Transplantation Guide to Authors



Guide to Authors

Welcome to the electronic manuscript submission website for *Bone Marrow Transplantation*. The instructions below are structured so you can quickly and easily answer the following questions:

1. Is my manuscript suitable for *Bone Marrow Transplantation*? (Scope + Editorial Note)
2. How do I format my manuscript for *Bone Marrow Transplantation*? (Format of Papers)
3. How do I submit my manuscript to *Bone Marrow Transplantation*? (Submission of Papers)

OTHER LINKS

- About the journal
- Format of papers
  - Preparation of Original Articles
  - House style
- Submission of papers
- Editorial policy
  - Ethics and bioethics
  - Peer review policy
  - Corrections
  - About npg online services

For further details access

http://mts-bmt.nature.com/cgi-bin/main.plex?form_type=display_auth_instructions

Appendix 1.2: Quality Rating Form

QUALITY CRITERIA ASSESSMENT DATA COLLECTION SHEET		
Study ID (Author, title, year of publication, journal title, pages):		
Study Design:		
Checklist completed by:		
SECTION 1: RATIONALE		
1.1	The study addresses an appropriate and clearly focussed question.	1 Yes 0 No
1.2	Are the main objectives clearly stated?	1 Yes 0 No
TOTAL: SECTION 1		/2
SELECTION 2: PARTICIPANTS		
2.1	Participants are recruited in a scientifically appropriate manner and are representative of the defined population	2 Well covered 1 Adequately covered 0 Poorly addressed
2.2	The study has a control group	1 Yes 0 No
2.3	The assignment of participants to treatment groups are randomised	1 Yes 0 No
2.4	An adequate concealment method is used?	2 Well covered 1 Adequately covered 0 Poorly addressed
2.5	The treatment and control groups are similar at the start of the trial	2 Well Covered 1 Adequately addressed 0 Poorly addressed / Not Applicable
2.6	Are any inclusion/exclusion criteria stated?	1 Yes 0 No

2.7	Is the sample size stated?	1 Yes 0 No/not stated
2.8	The only difference between groups is the treatment under investigation	2 Well covered 1 Adequately covered 0 Poorly addressed/ Not Applicable
2.9	All relevant outcomes are measured in a standard, valid and reliable way for use with the sample population	2 Well covered 1 Adequately covered 0 Poorly addressed
2.10	Are intention to treat analysis carried out? (All subject data randomly allocated to group is analysed)	2 Well covered 1 Adequately covered 0 Poorly addressed
TOTAL SECTION 2:		/16
SECTION 3 CONFOUNDING FACTORS:		
3.1	The main potential confounders are identified and taken into account in the design and analysis where appropriate	2 Well covered 1 Adequately covered 0 Poorly addressed
TOTAL SECTION 3:		/2
SECTION 4 STATISTICAL ANALYSIS		
4.1	Is the analysis appropriate to the design and type of outcome measure?	1 Yes 0 No/not stated
4.2	Are the results clearly reported?	2 Well covered 1 Adequately covered 0 Poorly addressed
4.3	Have confidence intervals, effect sizes, p-values etc been provided where appropriate?	2 Well covered 1 Adequately covered 0 Poorly addressed
TOTAL SECTION 4:		/5
Quality scores OVERALL TOTAL: ____/25 PERCENTAGE: ____%		

QUALITY RATING: ____________________
Poor (<50%), Moderate (50-74%), Good (>75%)

DESCRIPTION OF STUDY

	How many patients are included in this study? *List the number in each group separately*	
	What are the main characteristics of the study population? *Include all relevant characteristics – e.g. age, sex, disease status, community/hospital based*	
	What environmental or prognostic factor is being investigated in this study? RCT - What intervention (treatment, procedure) is being investigated in this study?	
	What comparisons are made in the study? *Are comparisons made between treatments, or between treatment and placebo/no treatment*	
	For how long are patients followed-up in the study? *Length of time participants are followed from beginning participation in study. Note specified end-points used to decide end of follow-up*	
	What outcome measures are used in the study? *List all outcomes that are used to assess the impact of the chosen environmental or prognostic factor* *List all outcomes used to assess effectiveness of interventions used.*	

	What size of effect is identified in the study? *List all measures of effect in the units used in the study- e.g. absolute or relative risk. Include p-values and any confidence intervals that are provided.* **Note:** *be sure to include any adjustments made for confounding factors, differences in prevalence, etc.*	

Appendix 1.3: Excluded papers following inclusion/exclusion criteria

EXCLUDED PAPERS – n = 28

Review/Editorial/Commentary papers

Liu RDKS, Chinapaw MJM, Huijgens PC van Mechelen W. Physical exercise interventions in haematological cancer patients, feasible to conduct but effectiveness to be established: A systematic literature review. *Cancer Treat Rev* 2009; **35**: 185-192.

Shennan C, Payne S, Fenlon D. What is the evidence for the use of mindfulness-based interventions in cancer care? A review. Psychooncology 2011; **20**: 681-697.

Schulz KH. A comprehensive coping strategy programme reduced nausea and fatigue after autologous bone marrow transplantation for breast cancer. A commentary. *Evid Based Mental Health* 2001; **4**: 14-15.

Somerfield, MR, Rizzo, JD. Can a modest exercise program really improve physical functioning and quality of life among recipients of hematopoietic SCT? *Bone Marrow Transplantation* 2010; **45**: 217-218.

Wiskemann J, Huber, G. Physical exercise as adjuvant for patients undergoing hematopoietic stem cell transplantation. *Bone Marrow Transplantation* 2008; **41**: 321–329.

Children/adolescent/young adult mixed sample age group

Burns DS, Robb SL, Haase JE. Exploring the feasibility of a therapeutic music video intervention in adolescents and young adults during stem-cell transplantation. *Cancer Nurs* 2009; **32**: 8-16.

Non Haematopoietic SCT participant group

Duijts SFA, Faber MM, Oldenberg HSA, Van Beurden M Aaronson NK. Effectiveness of behavioral techniques and physical exercise on psychosocial functioning and health-related quality of life in breast cancer patients and survivors – a meta analysis. *Psychooncology* 2011; **20**: 115-126.

Luebbert K, Dahme B, Hasenbring M. The effectiveness of relaxation training in reducing treatment- related symptoms and improving emotional adjustment in acute non-surgical cancer treatment: A meta-analytic review. *Psychooncology* 2001; **10**: 490–502.

No psychosocial or Quality of Life outcome measures reported

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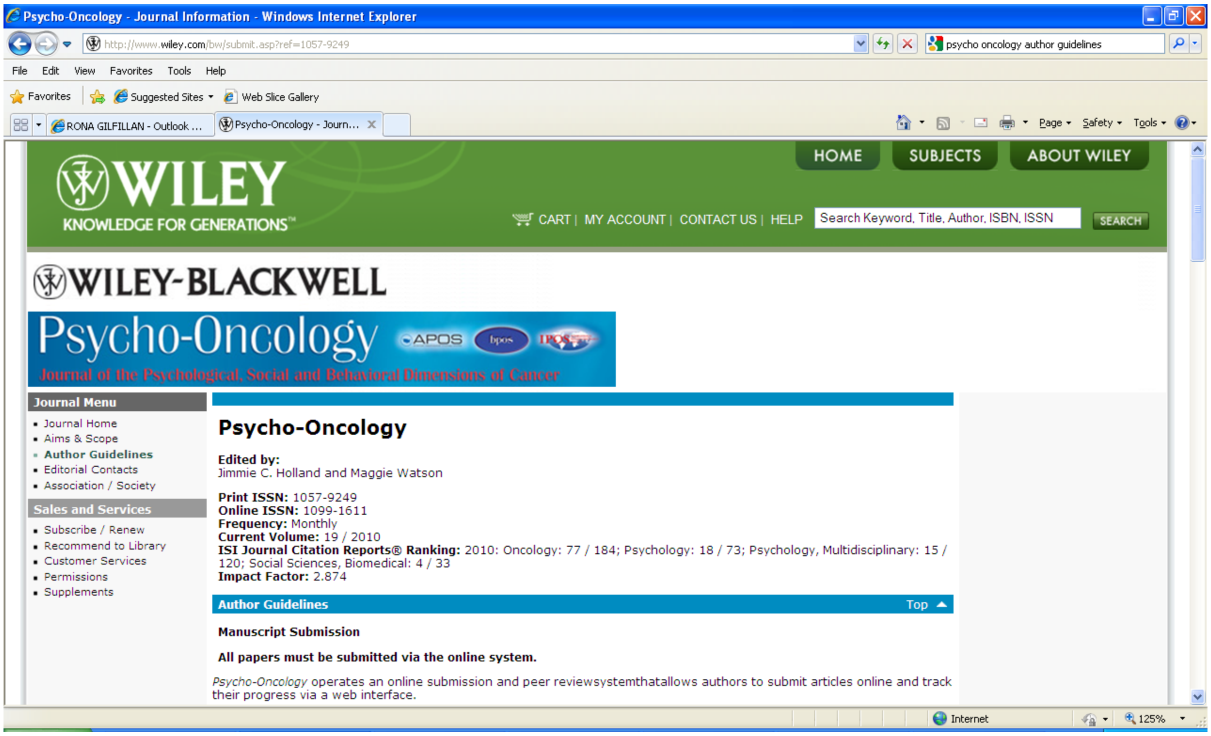
Appendix 2.1: Guidelines for submission to Psycho-Oncology



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Appendix 2.2 Beatson Approval

Our Ref: F:/Lynda/IHTAB/290910/rg/letter

Direct Line: ++44 (0)141 301 7185

Direct Fax: ++44 (0)141 301 7187

29 September 2010

Ms Rona Gilfillan

Trainee Clinical Psychologist

Dear Rona

Re: The impact of hematopoietic stem cell transplantation on quality of life among adults aged over 50 years: A qualitative investigation using semi-structured interview methods.

The outline proposal submitted to the In-House Trials Advisory Board on 20August 2010 was granted approval.

Following this, approval granted also at the Clinical Trials Executive Committee Meeting on 10 September 2010.

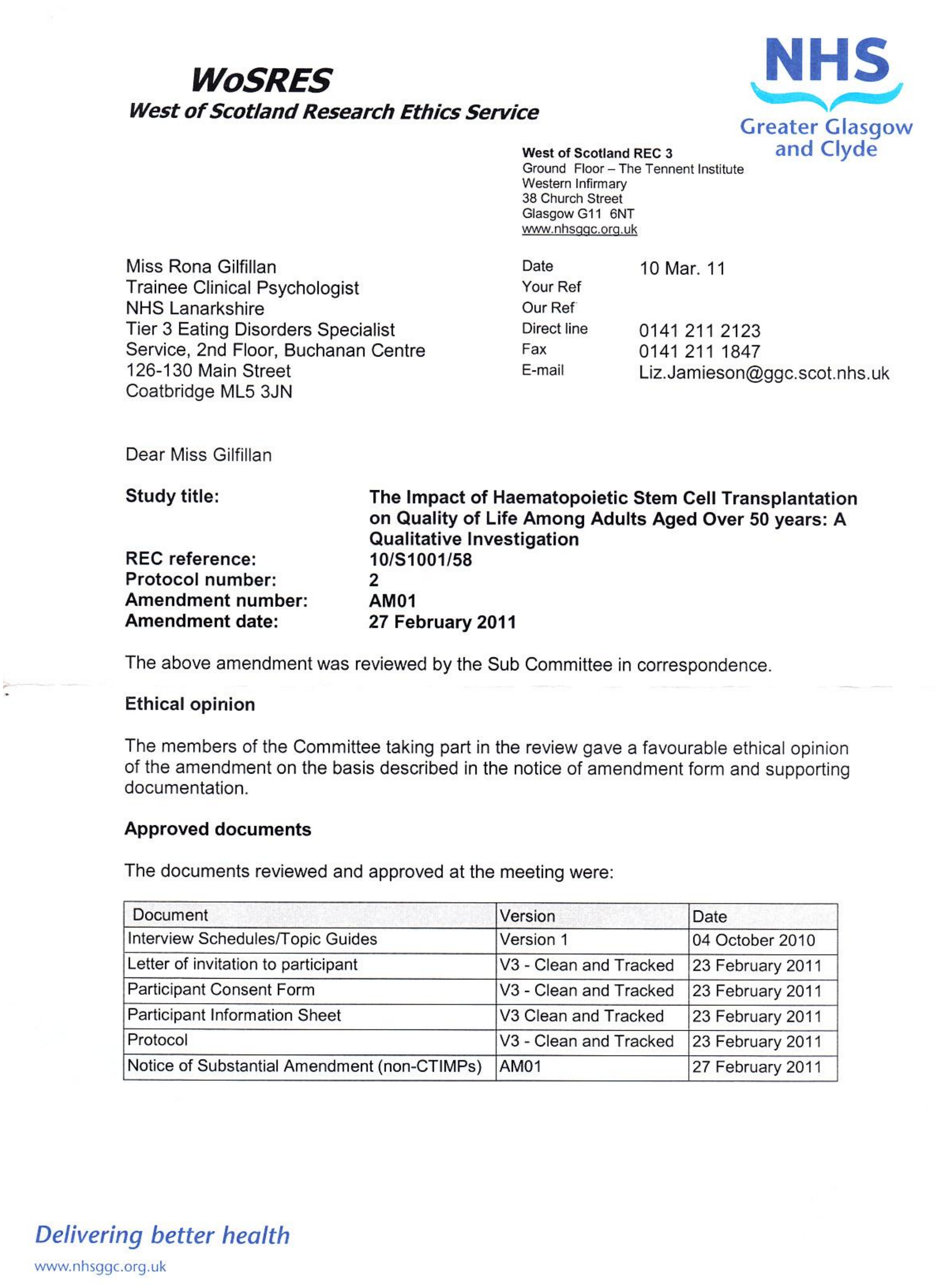
Please do not hesitate to contact me should you require any further information or help.

Yours sincerely

Lynda Harper

In-House Trials Administrator

Appendix 2.3. West of Scotland Research Ethics Approval



WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Miss Rona Gilfillan
Trainee Clinical Psychologist
NHS Lanarkshire
Tier 3 Eating Disorders Specialist
Service, 2nd Floor, Buchanan Centre
126-130 Main Street
Coatbridge ML5 3JN

Date	10 Mar. 11
Your Ref	
Our Ref	
Direct line	0141 211 2123
Fax	0141 211 1847
E-mail	Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss Gilfillan

Study title:	**The Impact of Haematopoietic Stem Cell Transplantation on Quality of Life Among Adults Aged Over 50 years: A Qualitative Investigation**
REC reference:	**10/S1001/58**
Protocol number:	**2**
Amendment number:	**AM01**
Amendment date:	**27 February 2011**

The above amendment was reviewed by the Sub Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	Version 1	04 October 2010
Letter of invitation to participant	V3 - Clean and Tracked	23 February 2011
Participant Consent Form	V3 - Clean and Tracked	23 February 2011
Participant Information Sheet	V3 Clean and Tracked	23 February 2011
Protocol	V3 - Clean and Tracked	23 February 2011
Notice of Substantial Amendment (non-CTIMPs)	AM01	27 February 2011

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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/S1001/58:	**Please quote this number on all correspondence**

Yours sincerely

Liz Jamieson

Mrs Liz Jamieson
Committee Co-ordinator

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Nathaniel Brittain, R&D NHS Greater Glasgow & Clyde

Appendix 2.4 Greater Glasgow and Clyde Research and Development Management Approval

Dear Ms Gilfillan,

R&D Ref: GN10ON408   **Ethics Ref**: 10/S1001/58
Investigator: Ms Rona Gilfillan
Project Title: The Impact of Haematopoietic Stem Cell Transplantation on Quality of Life Among Adults Aged Over 50 years: A Qualitative Investigation
Protocol Number: Version 3 dated 23/02/11
Amendment: Substantial Amendment 1(23/02/11)
Sponsor: NHS Greater Glasgow & Clyde

I am pleased to inform you that as Sponsor we have reviewed the above study's Amendment 1 (23/02/11) and can confirm that Management Approval is still valid for this study.

I wish you every success with this research project.

Yours sincerely,

Dr Nathaniel Brittain
Academic Research Co-ordinator

Dr Nathaniel Brittain
Academic Research Coordinator
Research and Development Directorate
NHS Greater Glasgow and Clyde
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Tennent Institute, 1st Floor
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Tel: +44 (0)141 211 8544

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Appendix 2.5 Covering letter and patient information sheet.

23.02.11 Version 3

Letter of Invitation to Participants

Dear Participant

Quality of Life Following Bone Marrow Transplant

Thank you for your interest in the above named study. My name is Rona Gilfillan and I am a Trainee Clinical Psychologist, studying at the University of Glasgow. As part of my training, I am currently carrying out a research study looking at the impact of transplant on people's quality of life.

As you will remember, your Senior Nurse asked you if you would mind being contacted about this study. I now enclose an information sheet and a consent form for you to read over.

If you decide you would like to take part in the study, I will meet with you at the Beatson West of Scotland Cancer Centre. If you decide that you would prefer to have a telephone interview, then we can arrange a suitable time for me to call you. Either option would involve a 90 minute interview to find out about your experience of quality of life since your transplant. In order to make sure that I fully understand your views about how transplant has impacted your quality of life, the interview will be tape-recorded. All information will be treated with the utmost confidentiality. However, you will understand that if something is revealed during the interview that suggests you or anyone else is at risk of harm, then it is my duty of care to share this information with other appropriate professionals.

If you would like more information, please do not hesitate to contact me by telephone on **01236 703 402**.

Yours Sincerely

Rona Gilfillan

Trainee Clinical Psychologist

23.02.11 Version 3

NHS
Greater Glasgow
and Clyde

University
of Glasgow

Quality of Life Following Bone Marrow Transplant

Participant Information Sheet

Thank you for reading this information sheet. I would like to invite you to take part in a research study. My name is Rona Gilfillan and I am a trainee Clinical Psychologist at the University of Glasgow. I am interested in learning about people's experiences of bone marrow transplantation and the impact this treatment has on quality of life. You have been given this sheet as you may be able to help me in this study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and feel free to discuss it with others if you wish.

Please ask me any questions you have. You can phone me on the following number (**07779 729 885**) or you can leave a message and I will get back to you as soon as possible.

What the study is about

I am interested in understanding your experiences of quality of life, such as physical and emotional well-being, since having your transplant. In particular, I would like to find out about the things that you think have changed in your life as a result of your treatment. This type of research might help to inform other people who are considering having a transplant about the kinds of things to expect after their treatment.

Why you are being asked to participate

We are asking adults aged 50 years or more who have undergone a bone marrow transplant to take part in this study.

Do I have to take part?

You do not have to take part in this study. It is up to you whether or not you wish to participate in the study. If you decide to take part you will be given this information sheet and be asked to sign a consent form. The consent form is a way of making sure that you know what you have agreed to. If you decide to take part you are still free to withdraw from the study at any point in time. If you decide to withdraw from the study at any time, this will not affect your ongoing medical care.

Taking part in the study – what will I have to do?

If you decide to take part I will arrange to meet with you at the Beatson West of Scotland Cancer Centre for approximately one hour. During this meeting I will ask you questions about your experience of quality of life since your transplant. I will ask you if the interview can be recorded (to make sure that I carefully understand your experiences and our conversation, and help me remember all the things we talked about). There are no right or wrong answers, the research just wants to find out about what you think and to learn more about your own experiences. If you would prefer to discuss your experiences in a telephone interview then I will arrange a suitable time to call you. The telephone conversation will be recorded using a telephone recording device.

If you are interested in taking part you can contact me to discuss more about what would be involved and I will answer any questions that you have.

Is there a down side to taking part?

It is possible that our meeting may cover topics that are difficult or distressing to talk about. However, if you do not want to continue you can end the interview, or have a break, at any time. If you feel distressed at all following the interview, I will be available to talk with you. Alternatively, the department's Consultant Clinical Psychologist, Dr Christopher Hewitt, will also be available to talk with you. For participants who decide to have a telephone interview, I will pass on the contact details of Dr Christopher Hewitt should you wish to seek further psychological support.

What are the possible advantages of taking part?

There are no direct benefits to you in taking part in this study. However, the information that we learn from the study will help us understand more about quality of life after bone marrow transplant. It will also help inform others who are deciding whether or not to have a transplant, and help medical staff better understand the experience of treatment so that they can provide the best support for people.

Will my taking part in this study be kept confidential?

The medical doctor responsible for your treatment, usually your Consultant at the Beatson will know that you are taking part in the study. However, everything that you say during our interviews will be kept strictly confidential and no-one but myself will have access to the recordings of the interviews. Your name, or other identifying information will not appear in any reports. With your permission, anonymous quotes of what you have said may be used in the report.

Are there any circumstances when information shared by me during the interview would not be kept confidential?

Everything you say during the interview will be kept private. However, if you tell me anything that suggests that you or anyone else is at risk of harm, then it is my duty to share this information with other appropriate professionals.

What will happen to the results of the research study?

I will provide you with a summary of the results of the study. The final results and conclusions of the study may be published in a scientific journal and will form part of my qualification in Clinical Psychology. Your identification will not be included in any publication.

Who is organising and funding the research?

The University of Glasgow

Who has reviewed the study?

The study has been reviewed by the Department of Psychological Medicine at Glasgow University to ensure that it meets important standards of scientific conduct and has been reviewed by the West of Scotland Research Ethics Committee to ensure that it meets important standards of ethical conduct. The study has also received organisational approval from the Beatson West of Scotland Cancer Centre and has been given management approval by Greater Glasgow and Clyde Research and Development.

Thank you very much for reading this and for any further involvement you may have with the study.

Appendix 2.6 Patient consent form

23.02.11 Version 3Cross reference to PIS 23.02.11 Version 3

Quality of Life Following Bone Marrow Transplant

Participant Consent Form

Please put your initials in each of the boxes to show that you have read and are in agreement with the statements:

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected ☐

I understand that the medical clinician who is involved in my care (Doctor or Nurse at the hospital) will be informed of my participation in the research ☐

I agree to my GP being informed of my participation in the above study ☐

I understand that as this is a telephone interview, a telephone recording device will be used to tape the interview solely for the purpose of the research study as described in the Participant Information Sheet and will be kept confidential ☐

I understand that quotations may be published but that all names, places and identifiers will be removed beforehand ☐

I agree to take part in the above study ☐

Name of Participant	Date	Signature
Researcher	Date	Signature

Thank you for taking part in this study

(1 copy for participant and researcher and 1 copy for medical notes)

Appendix 2.7: Semi-Structured Interview Schedule

NHS
Greater Glasgow
and Clyde

04.10.10 Version 1

University
of Glasgow

Quality of Life Following Bone Marrow Transplant

Interview Guide

The interview guide is based on relevant issues from the research literature.

1. Can you tell me what led up to you first seeking medical attention?

2. What does the term "quality of life" mean to you?

3. Can you tell me about what life has been like since your transplant?

4. What impact on your life (if any) do you think treatment has had?

5. How has life changed (if at all) since having your treatment?
   - Can you tell me about any negative changes?
   - Can you tell me about any positive changes?
   - Why do you think this is?

6. How do you view your quality of life now as compared with before you received the transplant?

7. What has been the biggest change in your life since having treatment? What do you think has caused this change?

8. What are your main concerns/worries?

9. Can you tell me about your expectations for the future?

10. Is there anything you wish you had known about before having the transplant?

11. If you could turn the clock back, would you undergo the transplant again?

12. Before we finish, is there anything about your experiences we have not covered that you would like to share?

Example Probes

- Can you tell me more about that?
- What does that mean for you?
- Could you give me an example of that?
- How does that make you feel?
- What do you think about that?
- What is that like for you?

Appendix 2.8: Major Research Project Proposal

Proposed title of project:

The impact of haematopoietic stem cell transplantation on quality of life among adults aged over 50 years: A qualitative investigation using semi-structured interview methods.

Student:

Rona Gilfillan

Matriculation Number:

9803726g

Academic Supervisor:

Dr. Kenneth Mullen

Field Supervisor:

Dr. Christopher Hewitt

Date of Submission:

23rd February 2011

Version Number:

3

Word Count:

3808

Abstract

- Background: Quality of life (QOL) research in the field of haematopoietic stem cell transplantation (HSCT) has added greatly to our understanding of the impact of this demanding medical procedure. However, little is known about the QOL experienced by recipients aged 50 years or more who undergo a reduced intensity conditioning treatment (RIC) prior to unrelated allogeneic HSCT.
- Aims: This study aims to add to the 3 existing quantitative studies that have looked at QOL among these RIC HSCT recipients and gain greater insight into the impact of treatment on QOL, which may be missed by standardised questionnaires.
- Methods: This study aims to use qualitative methods to investigate adults' perceptions of the impact that RIC HSCT has on their QOL, by developing a comprehensive list of themes through thematic analysis.
- Applications: HSCT is a life changing event and it is therefore essential that individuals are prepared as much as possible for the ways in which their QOL may alter. By identifying similarities and differences in the QOL experienced by this particular group of HSCT recipients, clinicians can be better informed as to how best support those individuals most likely to experience significant QOL issues post-HSCT.

Introduction:

There continues to be a lack of agreement regarding the conceptual definition of quality of life (QOL) and its subsequent operational definition (Hacker, 2003). However, most would agree that QOL is a multidimensional concept involving four core domains of functioning; psychological, social, occupational, and physical (Fallowfield, 1990). This definition reflects the influence of the biopsychosocial approach to the development of QOL as a construct (Moffat et al. 2009). QOL evaluation therefore requires a holistic view of the impact of illness and medical treatment. This approach is invaluable since survivors of diseases such as cancer report issues related to QOL as among their greatest concerns (Baker et al., 2005).

Haematopoietic stem cell transplantation (HSCT) is a treatment most often performed for individuals with certain types of haematological cancer. The number of HSCT survivors is rapidly increasing, as more than 45,000 people undergo the procedure annually throughout the world (Mosher et al., 2009). Although HSCT offers the potential of cure in 50% of patients who undergo the procedure, it is one of the most taxing cancer treatments to endure (Rusiewicz et al., 2008), generating serious QOL issues due to the potential for accompanying physical and emotional distress (Baker et al.,1999). HSCT involves the transplantation of haematopoietic stem cells derived from peripheral blood, cord blood, or bone marrow and the procedure varies depending on the type of transplant an individual is receiving. The different types of transplant are known as: autologous (i.e. the cells are taken from the patient and returned once chemotherapy has been given to eradicate malignant cells); sibling allogeneic (i.e. cells are transplanted from a matched sibling); or unrelated allogeneic (i.e. cells are transplanted from a voluntary donor (VUD) or cord blood). Allogeneic transplants, as well as autologous, involve aggressive pre-conditioning treatments prior to transplant, known as myeloablative conditioning. This involves the patient receiving high-dose chemotherapy and radiotherapy to “eradicate residual disease and recipient (host) immunity in preparation for healthy donor-derived haematopoietic stem cells (graft)” (Shelburne & Bevans, 2009, p. 120).

Regardless of the source of stem cells, HSCT is associated with a common set of biopsychosocial issues (Andrykowski & McQuellon, 2004). The treatment itself is life threatening and the uncertainty surrounding its outcome causes individuals significant stress (Thain & Gibbon, 1996). Due to the aggressive nature of the treatment, there are a number of side-effects including fatigue, nausea, mucositis and hair loss. Allogeneic HSCT is associated with graft-versus-host disease (GVHD), which involves attacks by donor marrow on the recipient’s organs and can result in serious complications which are significant threats to QOL (Neitzert et al., 2009a). Often, individuals remain in hospital for a period of time post-transplant and their progress is monitored. This is an anxiety provoking time as recipients wait to hear about the success of the treatment. There is evidence that the greatest psychosocial stressors facing individuals at this post-transplant stage are pain and thoughts about their survival or possible death (Haberman, 1988; Steeves, 1992). In short, HSCT recipients experience an array of taxing physical stressors within the context of psychological and social stressors associated with medical uncertainty and life threat (Andrykowski & McQuellon, 2004).

From the patient's perspective, a successful HSCT does not mean only that the patient survives. Patients also want a good QOL after transplant (Stewart, 2004). Ferrell et al., (1992a) were among the first to conceptualise QOL in HSCT patients. In a large sample (n = 119) of bone marrow transplant (BMT) survivors, these investigators collected qualitative data regarding the meaning of QOL to BMT survivors and the impact of the transplant on QOL. They developed a conceptual model depicting the impact of BMT on QOL involving four main areas: physical wellbeing and symptoms, psychological wellbeing, social wellbeing, and spiritual wellbeing. In the same study, the themes developed in relation to the meaning of QOL referred to being healthy, having a heightened appreciation for life, having family and relationships, being normal, being satisfied and fulfilled with life, being able to work and experience financial success, being independent, being alive, and having self-esteem and self-respect. In another study, Ferrell et al., (1992b) tried to discover individual perceptions of what makes QOL better or worse. The themes developed in this study were similar to those described in the previous work. However, experiencing physical losses, breaking relationships, having unfulfilled goals, and being financially distressed made QOL worse.

A large number of cross-sectional surveys have investigated QOL for HSCT patients from pre-transplant through approximately 10 years post-transplant. As a result, much is known about QOL outcomes of transplant over time for HSCT recipients within and across diagnoses (Syrjala, 2004). The central consistent findings of these studies are that:

1. physical function returns to pre-transplant level for approximately 75% of survivors by 1 year;
2. by 3 years, 80-90% of survivors are back to full time work;
3. the majority of patients manage the challenges of HSCT with good psychological health; and
4. a minority of patients will have major residual problems with a variety of QOL functions (Syrjala, 2004).

Despite positive reports of outcome studies, in terms of long-term recovery from HSCT, there is wide variability in the trajectory of recovery (McQuellon et al.,1998). Unfortunately some recipients never fully recover, both physically and psychosocially, from their HSCT experience, while for others, recovery requires a lengthy journey (Andrykowski & McQuellon, 2004). Returning to “normal” depends on each recipient’s perspective, however, even with the return of what they consider a normal lifestyle, few recipients are left unchanged by their HSCT experience (Stephens, 2005). Andrykowski and McQuellon (2004) summarise some of the late effects of HSCT. These include pulmonary problems, cataracts, sterility, endocrine dysfunction, chronic GVHD and weakness and fatigue. Even without late effects, most recipients experience some interruption in normal developmental tasks, for example, maintaining a career and establishing satisfactory marital and family relationships in the case of adult recipients. Psychosocial sequelae of HSCT such as anxiety, depression, strained interpersonal relationships, or even PTSD may persist for months or years after HSCT (Mosher et al., 2009; Andrykowski & McQuellon, 2004).

However, positive psychosocial changes can also stem from the HSCT experience, such as families being brought closer together (Holmes et al., 1997). A recent review of QOL post HSCT highlighted a number of studies that have identified benefits of the experience (Pidala et al., 2009b). Such studies report positive outcomes including an enhanced appreciation for life, greater feelings of love and appreciation for family and friends, improved self-esteem, new priorities in life and the perception of a new meaning in life (Pidala et al., 2009b; Andrykowski & McQuellon, 2004). This "post-traumatic growth" is theorised to result from adaptation to the trauma of HSCT (Pidala et al., 2009b). Therefore, recovery after HSCT involves the experience of both positive and negative outcomes.

Given the risks associated with HSCT, particularly a myeloablative conditioning regimen, the treatment has been preferentially used for younger patients as older age has been one of the most significant factors that adversely affect outcome. However, a more recent treatment approach using reduced intensity conditioning (RIC) regimens prior to HSCT is associated with a lower risk of transplant related mortality and therefore allows patients who are considered too high-risk for conventional myeloablative allogeneic HSCT, due to increased age or co-morbidities, to undergo potentially curative therapy for their disease. These new transplant strategies are now being used more widely with older patients who would have previously been considered unfit for HSCT (Shelburne & Bevans, 2009).

Although research has shown encouraging results for older patients undergoing RIC treatment in terms of survival (Shelburne & Bevans, 2009; Pidala et al., 2009a; Storb, 2007), little is known about the nature of that survival. Despite the large amount of research pertaining to QOL after HSCT, informing our understanding of recovery for the majority of recipients, inadequate data prevent any conclusions on QOL for patients over age 50 (Syrjala, 2004). Furthermore, since HSCT is recognised as a life changing event, causing interruption in normal developmental tasks (Andrykowski & McQuellon, 2004), our understanding of the meaning and impact of this for recipients aged over 50 years is far from clear. Just as little is known about older recipients' experience of HSCT, it is equally true that research is limited in terms of our understanding of the impact of RIC treatment itself on recipients' QOL (Shelburne & Bevans, 2009).

However, it may be the case that different treatment regimens are associated with distinctive physical and/or emotional side-effects impacting individuals' QOL (Neitzert et al., 1999). Therefore, the impact of RIC HSCT on the QOL of recipients aged 50 years and over remains inconclusive.

To date there have been only 3 quantitative studies looking specifically at recipient QOL following RIC HSCT (Diez-Campelo et al., 2004; Bevans et al., 2006; Andersson et al., 2009). These 3 prospective studies produced some mixed findings. For example, Diez Campelo et al., (2004) compared the QOL of 47 RIC recipients to 70 autologous HSCT recipients. Health related QOL was measured at seven points during the first year post transplant, with a questionnaire based on the Functional Assessment of Cancer Therapy (FACT) – BMT and items relating to GVHD. In terms of outcomes, this study found that the RIC recipients reported significantly better physical functioning compared with autologous recipients during the first year. No significant differences were found between either group of recipients for any of the functional, social/family, psychological distress items. Bevans et al., (2006) compared the QOL of 41 RIC recipients to 35 conventional allogeneic recipients. Health related QOL was measured using the Short Form – 36 Health Survey and the FACT – general and BMT at 6 points during the first 2 years post transplant. The results showed that both groups of patients experienced a similar improvement during early recovery and no significant differences were found between the groups across the various domains of QOL. These findings may indicate that RIC HSCT impacts QOL in a manner more similar to conventional allogeneic HSCT than autologous HSCT. However, the results of Andersson et al.'s (2009) study add further evidence making conclusions about this less clear. The authors compared the QOL of 32 RIC recipients to 25 conventional allogeneic recipients. Health related QOL was measured at 6 points during the first year post transplant using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC – QLC – C30 and the 19 item treatment-specific module High Dose Chemotherapy (HDC – 19). This study found that both groups reported most symptoms and worst functioning one month post transplant, but there were substantial differences, with the conventional allogeneic group doing worse than the RIC group. Overall, RIC recipients were found to regain health and QOL faster than the conventional group. However, no significant differences in global QOL were found at one year post transplant. Therefore, there is some contradictory evidence in terms of early recovery post transplant and it remains unclear whether QOL is significantly better during early recovery post RIC than conventional allogeneic transplant. In addition, the use of different measures in these studies may contribute to the mixed findings. Thus, it is not yet possible to be conclusive as to the impact of RIC HSCT on recipients' QOL.

The issue of measurement of QOL is highlighted by Hacker in her review of quantitative research, as she notes, "Studies operationalising QOL from different conceptualisations frequently result in different findings even for the same group of people" (Hacker, 2003, p. 614). Furthermore, no qualitative research has been conducted with this group, despite this methodology being particularly appropriate in addressing one of the major questions for outcomes research in this area, "What is the patient's experience with HSCT?" (Lee, 2004). Qualitative methods have been used in several studies to evaluate aspects of recovery following HSCT and these studies revealed several themes that are not particularly well covered in standardised instruments; for example, strategies that patients use to compensate for limitations, the multiple losses across various aspects of their lives and the greater appreciation for life brought about by the HSCT experience (Lee, 2004). Therefore, the use of standardised questionnaires may lead to a potentially incomplete picture of QOL (Fromm, Andrykowski & Hunt, 1996). Furthermore, patients themselves report their dislike of aspects of standardised questionnaires and report reasons such as, the questionnaire "did not address spiritual life, changes in perspective etc.", "put words in mouth" should be more in depth" and "asked specific questions with no place for explanation" (Byar, Eilers & Nuss, 2005, p. 152-153).

Given the lack of knowledge about the holistic experience of RIC HSCT recipients aged over 50 years, this study aims to add to the existing quantitative studies that have looked at QOL among these recipients and gain greater insight into the impact of treatment on QOL, which may be missed by standardised questionnaires.

Research Question

An exploration of the QOL experienced by adults aged 50 years or more following RIC HSCT.

Aims

The study aims to use qualitative methods to investigate adults' perceptions of the impact that RIC HSCT has on their QOL, by developing a comprehensive list of themes through qualitative analysis. The specific aims of the study are:

- To identify the impact RIC HSCT has on QOL from an adult recipient's perspective
- To identify age-specific concerns in relation to QOL

Plan of Investigation

Participants

Those individuals who have undergone RIC HSCT at different time points over the last 5 years, and are aged 50 years or more at the time of transplant. A review of the database held at the Beatson West of Scotland Cancer Centre (BWoSCC) indicated that approximately 20 patients would qualify as potential participants for this research. Potential participants will be outpatients who are attending the BWoSCC for review appointments.

Inclusion Criteria

RIC HSCT recipients aged 50 years or more at time of transplant who attend the BWoSCC for review appointments. Participants must be English speaking.

Exclusion Criteria

Substance misuse or dependency, or a learning disability. Those recipients identified by Medical staff as unsuitable for the study.

Recruitment Procedures

Prior to recruitment, a list of participants identified as meeting inclusion and exclusion criteria will be given to Medical Consultants who will be able to advise as to any reasons why they should not be contacted. Patients would be recruited through out-patient clinic and annual review meetings. For recipients attending the BWoSCC regularly, the primary medical staff involved in participants' care will advise recipients of the research and pass on information leaflets. Recipients will then be able to complete a consent form indicating their permission for the researcher to contact them about the study. For recipients who attend less frequently, at late effects clinics, information leaflets will be sent out with their appointment reminder letter. Again, interested recipients can return the consent form indicating their permission for the researcher to contact them about the study, in order to arrange a suitable time to meet. For those recipients who are unable to meet due to travel restrictions but wish to participate, a telephone interview will be arranged for a suitable time.

Design and Procedure

In-depth, semi-structured interviews will be conducted on an individual basis. The interviews will be audio-taped and transcribed verbatim. It is anticipated that a list of interview questions will be used to help guide the interview. These will be developed in line with the research literature pertaining to QOL and HSCT and consistent with the aims of the study. To enhance the validity of the data, the questions will be checked by staff experienced in the care of HSCT recipients in order to ensure the questions adequately represent the research topic. The questions will be open-ended to allow for participants' individual interpretation and exploration of the issues. Probe questions will be used to obtain further information about particular issues. The semi-structured format is considered appropriate to explore individuals' perceptions of quality of life and the factors influencing it (Holmes et al., 1997).

Analytical procedure will be iterative, whereby the researcher will collect data through interviews, reflect upon the data and note emerging themes. A reflective diary will be kept throughout in order to facilitate the development of the researcher's subjective, reflexive views (Grbich, 1999).

Justification of sample size

Power calculations are not appropriate in qualitative research as sample size is not predetermined. The goal of qualitative studies is to capture the breadth of possible patient attitudes or experiences. In contrast to quantitative studies in which generalisability is critical, the goal of qualitative studies is not to obtain a statistically representative sample, but rather to achieve "symbolic representation". That is, "a unit is chosen to both represent and symbolise features of relevance to the investigation" (Ritchie & Lewis, 2003, p. 83). In fact, purposive or targeted sampling can be performed in order to ensure the spectrum of possible patient experiences is represented (Lee, 2004). Non-probability sampling will be used in order to select information-rich cases (Grbich, 1999). Data gathering will cease when it is evident that new data "no longer spark new insights" (Charmaz, 2003). This sampling technique means that the number of cases is unpredictable, however, it is anticipated that a sample size of approximately 8 will allow for sufficient detailed analysis of the data (Turpin et al.,1997) and is feasible within the context of a D.Clin.Psy research project.

Settings and Equipment

The Beatson West of Scotland Cancer Centre. Digital recording equipment. Qualitative analysis software. Telephone recording device for telephone interviews. For these interviews, the researcher would use a telephone in a private office at the Academic Unit of Mental Health and Wellbeing at the Academic Centre at Gartnavel Royal Hospital.

Data Analysis

A thematic approach will be taken to data analysis (Braun & Clarke, 2006). Data will be transcribed verbatim into written form, allowing the researcher to begin the process of becoming familiar with the data. The researcher will then repeatedly read the data in an active way, searching for meanings and patterns in order to become "immersed" in the data. Note taking will begin at this stage and initial ideas for coding will be documented. Initial codes will be produced from the data and, to some extent, will depend on whether the themes are "data-driven" or "theory-driven" (Braun & Clarke, 2006). Coding can be conducted either manually or through a software package. It is important to code for as many potential themes and patterns as possible at this stage and to include contradictory themes as these may add to our understanding of the experience. This initial coding frame will be shared with the academic supervisor to increase the reliability of the coding process. In order to minimise subjectivity and bias, the academic supervisor will blind code a proportion of the data to increase reliability. Themes will then be searched for, reviewed and defined. Thematic interpretative analysis of the data requires that any claims made as a result of analysis be "grounded in, but go beyond the surface of the data" (Braun & Clarke, 2006, p. 94).

Health and Safety Issues

Researcher Safety Issues

All interviews will take place at the Beatson West of Scotland Cancer Centre. The field supervisor and participants' medical consultants will be aware of the scheduled interviews and de-briefing sessions will be arranged between researcher and field supervisor. For participants who decide to take part in a telephone interview, the researcher will use a telephone in a private office at the Academic Unit of Mental Health and Wellbeing at the Academic Centre at Gartnavel Royal Hospital. All telephone interviews would take place within normal weekday working hours between 9am to 5pm.

Participant Safety Issues

By nature of the research, participants will all have undergone an aggressive medical treatment for their cancer and therefore their physical health status may well be compromised. The researcher will endeavour to provide a comfortable setting for participants during research interviews. It is estimated that interviews will last approximately 60-90 minutes. Refreshments will be provided. It is recognised that this study will involve participants discussing potentially distressing subjects and emotional support may be required. The researcher is trained to manage individuals' distress in a supportive manner and should participants wish to receive psychological support, they will be able to meet with the consultant clinical psychologist based within the BWoSCC. This provision will be made explicit to participants prior to their interview. For participants who decide to take part in a telephone interview, they will also be advised of the clinical psychologist's contact details should they wish further psychological support.

Ethical Issues (including where submissions will be made)

The transplant team at the BWoSCC reported their belief and experience that many patients are keen to discuss their experiences. Applications to the Local Research Ethics Committee and the Beatson Trials Executive Committee would be submitted. Potential participants will be informed of the study by their Medical Consultant. A patient information leaflet will be passed on to participants via the consultant, emphasising that participation is entirely voluntary. Refusal to take part in the study will in no way impact ongoing medical care. Participants will be able to complete and sign a tear-off slip and return to the researcher indicating their consent to be contacted by the researcher. Participants who do not wish to take part in the study do not need to return the consent form. Participants will be free to withdraw from the study at any point and this will in no way impact their medical care.

Financial Issues

Equipment costs, travel etc.

20 sheets of headed paper (photocopied) (5p per sheet)

20 A4 envelopes

Freepost for 20 participants (35p per letter)

Digital recorder and transcription software: Qualitative software QSR Nvivo Student 12 month. This should be provided via the Section's current facilities for qualitative research.

Sony ECM TL1 telephone recording device - £23.99. This will be ordered and paid for by the Section.

Timetable

April 2010 – Submit major research project proposal to course

August 2010 – Submit application to ethics committee

October 2010 – Begin data collection. Transcription and analysis of data will begin following the first interview to help inform future interviews

October 2010 to March 2011 – Ongoing data collection and analysis

April 2011 to June 2011 – Write up

July 2011 – Submit major research paper to course

Practical Applications

QOL data provide clinicians and patients with supplementary information to guide their treatment decisions and this helps keep the patient at the centre of care provision. This information is invaluable to patients who are faced with decisions which are clouded with uncertainty. In addition to aiding the decision making process, it is hoped that the findings from this study will help identify specific issues relevant to QOL among this group, which will in turn help clinicians in their ongoing evaluation of HSCT recipients' QOL. This knowledge could help ensure that particular issues are addressed during follow-up consultations which would allow recipients to then receive the appropriate support and intervention. The in-depth nature of the research would allow exploration of the subjective experience of a sub group of HSCT recipients which may well be different to other HSCT survivors, due to their increased age and particular treatment regimen. By establishing similarities and differences between sub-groups of HSCT recipients, it is possible to identify and target HSCT survivors at greatest risk for long term psychosocial difficulties, thus enabling clinical management efforts to be focused upon these individuals (Andrykowski & McQuellon, 2004). HSCT is a life changing event and it is therefore essential that individuals are prepared as much as possible for the ways in which their QOL may alter. It is currently not possible to fully inform RIC HSCT recipients of these changes, due to the lack of research. However, the proposed study would aim to add to current knowledge base and help inform recipients about QOL after RIC HSCT. It is hoped that research findings would contribute to the development of a handbook for individuals considering RIC HSCT.

Dissemination

The results of the study will be written up and submitted to the West of Scotland Doctorate in Clinical Psychology Programme for examination purposes. It is hoped that the final results and conclusions of the study will be published in a scientific journal.

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Appendix 2.9 Summary Table of Master and Super ordinate themes developed from Initial themes

Text	Initial Theme	Master Theme	Super ordinate Theme
James: for somebody that did you know a pretty responsible job and uh had a very busy life, it was a complete turnaround. (L191)	**loss of old self**	*Changed sense of self*	**Shifting sense of self and others**
David: I didn't find it easy cause I've been pretty independent all my life (L582)... Well, it makes you feel yourself to be less than you were. (L628)	**loss of independent self and self-esteem**		
Harold: But, what I find particularly frustrating is the loss of my vision...Because that's been the basis of my whole life really. (L206)	**loss of identity**		
Geoff: I went in to the transplant with a physical age maybe ten years younger than, eh, than my, sort of, normal age group. So, I, I think probably, probably one of the biggest shocks has been to age ten years in one. (L184)	**transformed physical identity**		
James: Well, you end up...just having almost well a completely different way of life really. (L157)	**separation, fragmentation, disconnection felt within family unit**	*Changed family life*	
David: It's distanced us a bit (L508)	**changed family relationships**		
Mary: brought us closer (L355)	**changed family relationships**		
Paul: I see them more now (L736)	**changed family contact**		
Paul: they'll no let me go on holiday...and [wife's name] loves the sun (L297)	**normal family activities disrupted**		
Geoff: I slip off for an afternoon's snooze but that does limit the sort of things that we can do together as a couple. (L327)	**interfering with joint family activities**		
Mary: I mean that's – it's not really a problem until I think, "Well, I should be going through and seeing my mum this weekend" (L541)	**impact on family roles and responsibilities**		

Helen: Em, although there’s no guarantees but within myself I felt [pause] more, em, how will we say, at peace with myself. (L218)	**improved emotional state**	*Changed emotional wellbeing*	**Shifting sense of self and others**
Mary: more positive about the future (L317)	**more optimistic**		
Geoff: y’know, you’re always looking over your shoulder and – is it coming back again? I think this is, this is a much better situation that I’m in. (L557)	**alleviation of worries**		
Isobel: The way I see it now y’know, I’m hoping to be here to see my grandchildren get married and y’know, graduate...when I was ill, I couldn’t see that...But now... I can see that happening. (L464)	**able to see a future life/more hopeful**		
Harold: I’m slightly more optimistic (L280)	**more optimistic now**		
Paul: I get awfully emotional...every time I take a cold now, I worry (L150; L577)	**increased anxiety and negative emotions**		
Harold: Well, I just find other things to do...there’s no point trying to be stuck – life is change (L365)	**using adaptive coping strategies and thinking style**	*Coping*	**Adaptation and managing the impact**
Geoff: Well, you’ve just got to get a balance really (L529)	**adapting and coping**		
James: I set small targets (L267)	**using goal setting**		
Isobel: I think if you go back to what you had and wishing that you could have that back – I think that would play on your mind...I think it would give you mixed feelings (L587)	**using adaptive thinking styles to cope**		
David: I’m not going to worry about it (L489)	**adaptive coping style**		
Paul: I just go quiet. I tend to keep myself to myself...dinnae do an awful lot (L582)	**maladaptive coping**		
Mary: I think when I feel like that I think, “well you’ve got to make the most of what you’ve got”.(L131)	**using adaptive coping style – positive thinking**		

Harold: I know people who haven’t had transplants who are just older, getting old, getting on – experience diminished capacity and it’s hard for them to cope with things the same as it is hard for me. (L334)	**being older normalises the losses associated with HSCT**	*Age and stage of life*	**Adaptation and managing the impact**
Isobel: . Em, if I was a younger person, I would maybe hope to have more go... if I was maybe in my twenties and thirties y’know, like, being more physical with, y’know sports and that – I would feel y’know, that would affect me. But, now I’m older – no (L535)	**being older makes it easier to cope with reduced physical capacity and activities**		
Mary: we’re getting to that age when we’re all falling to bits, I think [both laugh]. (L564)	**age and stage of life normalises experience of health problems and facilitates positive social comparisons to age similar peers**		
James: I was beginning to think of retiring in a year or so’s time anyway, so it probably wasn’t as big a decision as it really would have been a couple of years ago (L244)	**age and stage of life buffers potential biographical disruption**		
Helen: [Husband’s name] retired at the end of August...So, I mean, it was just a blessing as well that you know, in a way, that he didn’t have a full time job, because, that would have been a real strain on him and myself. (L626)	**being at older stage of life helps reduce burden on self and family**		
James: I had a very good network of friends that kept coming and seeing me...it lifts you up (L194)	**social support helps mood**	*Social support*	
Mary: she was a church visitor... I think it made a difference because she wasn’t involved in looking after me. She didn’t know what I had or – she was just someone who came in and had a chat and went off again. (L764)	**social support helps reduce illness identity and role**		

Paul: having [names of family members] there...it keeps me going (L740)	**social support helps with motivation**	*Social support*	**Adaptation and managing the impact**
Helen: another factor that did make a big, big difference to me was the support I got from my husband. (L615)	**social support helps**		
Geoff: the two of them have, have been very supportive of me and providing meals and one thing or another. (L344)	**social support helps with practical needs**		
Isobel: my husband had come with me and my sister was there and they kind of pushed me after my transplant...to get out of bed...It was an effort but y'know, they pushed me. So, I think the more support you have the better it is for you. Myself, anyway, if I didn't have the support I don't think I would have been able to, y'know – cope. (L364)	**social support helps you cope and motivates you**		
Harold: being married and having – my wife was with me the whole time and sitting in the room really, day and night and so that made a big difference (L286)	**social support helps**		
Paul: I used to get really angry at things...But now, I'd try to talk something through rather than lose the head (L405)	**improved interpersonal style**	*Personal growth and benefit*	**A new perspective on life and living**
Mary: I think you're much more accepting. I think you're less judgemental...you just appreciate em, what some people – you know I hate coming in here – em, what some people have to put up with and go through. (L496)	**more appreciative and tolerant**		
Helen: I'd never given any thought to the spiritual or religious part of life really...one thing I'm sure of is...There are miracles out there, I believe that. (L668)	**enhanced spiritual wellbeing**		
James: it's pushed me into a decision to uh, maybe think a bit more about myself rather than my work which all consumed me for the last 20 years. (L392)	**more aware of own needs**		

Geoff: I think I'm much more sympathetic to other people and just the realisation that, well, for a while, I kind of feel like the whole world revolves around you and your illness – you suddenly become aware that everybody's got these problems. (L466)	**more appreciative and understanding of others**	*Personal growth and benefit*	**A new perspective on life and living**
Mary: I used to think that I would travel quite a lot – I don't now...I'm quite happy to be at home. I think it's because you spend so much time away from home. (L292)	**redefining future priorities**	*Changed priorities*	
James: I put far too much over the years personally into work really...I've decided to take early retirement and get some quality of life back (L239)	**change in work priorities and definition of QOL**		
Geoff: I do feel that I shouldn't be wasting what time I've been given...I need to be doing something positive with it. (L447)	**new priorities – to use time more meaningfully**		
Harold: it's really time to retire now and take up another interest in life and find other ways of em, living. (L100)	**establishing new life priorities**		
Geoff: the immune system is ineffective but at least the haemoglobin levels have recovered, so that's brilliant (L196)	**physical losses are worth the gains**	*Reappraising and accepting- the losses are worth it*	
Mary: So, regardless of missing – you know there were quite a few things this winter that I had to cancel – em, which was disappointing, but you know, at the end of the day, you know, there's still tomorrow. (L283)	**although social life disrupted, it's worth it for the sake of having a future**		
Paul: I wouldnae say anything's changed for the better...physically – I'm worse. Eh, mentally, probably...I don't really do anything (L772)	**unable to see any gains – losses outweigh the gains**		

David: I don't know whether I will get fully back obviously but y'know – as long as I can get a long way back, y'know, it's good. (L684) , the other option is dead y'know, which isn't the one I want. I mean the transplant worked like a dream. (L692)	**accepting of losses – preferable to the alternative**	*Reappraising and accepting- the losses are worth it*	**A new perspective on life and living**
Isobel: the transplant wasn't easy. I'm not going to say I brushed it just under the carpet, because it wasn't. It was hard going. But em, [slight pause] I feel – well the doctors had said to me, y'know, I was so ill before it and look how I've come on now. Y'know? And just look at it like that. (L721)	**worth the hard journey for sake of improved health**		
Harold: Well, I mean, it's frustrating and sad but um, I can still do enough things and enjoy being with people and talking to people and having friends, that em, I'd rather be here than not [laughs]. So, it's like that. (L199)	**losses reappraised as being worth it for sake of being alive**		
Mary: but I think after a wee while, you're relationship kind of goes back – with all of them I think goes back to what it was like before...it's same old mum again. (L376)	**family relationships and sense of self returning to normal over time**		**Changing over time**
Isobel: after my transplant and that, when I was feeling really ill and down and that – you know, I said to my husband, look – I need to write letters and that...because I felt, em, I just felt that [slight pause] I didn't say enough, y'know, before. So, y'know, I'd done all that on paper and that but [tails off]. But now, it's just – it seems a pinch of salt now [laughs]. (L266)	**physical and emotional wellbeing improving over time**		
David: I've been able to get back to doing some things already so y'know, it's eh, I'm really quite positive about it. (L466)	**physical health improving over time**		
Geoff: I think we're picking up the pieces – we're doing things together again (L385)	**family life resuming over time**		