Quality of life assessment after Haematopoietic Stem Cell Transplant (HSCT)

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Abstract:

Introduction

Quality of life (QOL) is growing in importance as an outcome measure following HSCT. Treatment specific QOL tools exist and have been validated in patients receiving haematopoietic stem cell transplant (HSCT). FACT-BMT: [http://www.ebmt.org/6NursesGroup/Journal/FACT-BMT.pdf](http://www.ebmt.org/6NursesGroup/Journal/FACT-BMT.pdf), a validated self-report questionnaire uses a 5 point Likert scale and covers 4 specific domains that include physical, social and family, emotional and functional well-being. Scoring produces a range from 0-148, the higher the score, the better the QOL. FACT-BMT - allows a holistic assessment that identifies patient’s needs which may not be revealed by a standard clinical consultation.

Objective

The objective of the study was to 1) introduce QOL assessment in post HSCT patients, 2) use QOL assessment to identify unmet needs, 3) use responses to guide service provision.

Methods

Questionnaires were distributed when patients reached set timepoints at 6, 12, 18, 24 months and then annually. Questionnaires were distributed in clinics or posted to patients’ home address. A covering letter accompanied all questionnaires. Returned questionnaires are scored and appropriate action including referral and/ or multi-professional discussion initiated.

Results

There were 73 returns (all allografts, 38 male). Diagnoses: AML (27), MDS (21), CML (11), NHL (10), SAA (2), ALL (1), CLL (1). Mean age at HSCT: 47 years (17-68), mean time from transplant: 2.8 years (0.5 – 8.3). 60 recipients underwent reduced intensity conditioned (RIC) HSCT; 28 had sibling donors. Mean FACT-BMT score was 08 (range 22-48). 90% scored >75 and 50% were in the upper quartile. One patient regretted their transplant, one self referred for counselling after completing the form. Other items prompting specialist referrals were sexual dissatisfaction (25%) and lack of interest in sex (26%). Erectile dysfunction was identified in one patient at 7 years post HSCT.

Conclusions

FACT-BMT can be used in the outpatient setting to assess QOL. A wide range of scores and individual item responses were obtained in the study. It allows comprehensive and uniform assessment in this otherwise heterogenous group which is free from bias or the preconceptions of the health professionals. The assessment process reveals opportunities for patient reflection, identifies necessary referrals to services such as counselling, assisted conception, sexual dysfunction, social work and uncovers previously
Article:

Introduction

King’s College Hospital is the largest Bone Marrow Transplant (BMT) centre in the UK and performs in excess of 140 transplants a year, almost two thirds of which are allografts.

Since 2008, we have been formally assessing the quality of life (QOL) in our allograft recipients using the FACT BMT assessment tool.

FACT BMT is a combination of two tools. FACT-G (functional assessment of cancer therapy general) assesses the effects of cancer therapy in the four major areas of physical, social/family, emotional and functional well-being. Its development has been described previously and validated in a number of publications (Cella 1993, Webster 1999, Winstead-Fry 1997, Overcash 2001). BMTS (bone marrow transplant sub-scale) assesses specific BMT related concerns and was developed in collaboration with patients and experts in the field with the primary aim of capturing information on a variety of problems related specifically to HSCT (Haematopoietic Stem Cell Transplant). This tool has also been validated (McQuellon 1997).

FACT-BMT is a self-complete questionnaire using a 5 point Likert scale and takes less than 20 minutes to complete. Returns are scored from a range of 0-148 and the higher the score, the better the QOL. Although patients are required to respond to at least 50% of the items to produce a valid score, even incomplete assessments contain important information which is used to identify specific problems.

FACT-BMT applies consistency to patient assessment. This self-assessment is not compromised by pressure of time and by its very nature is not influenced by the preconceived ideas of the reviewing clinician, who may regard certain topics as unimportant or feel uncomfortable addressing them. FACT-BMT is comprehensive and holistic and the information can be used to identify referrals to other services eg counselling, sexual dysfunction, and assisted conception.

Although FACT-BMT is a generic transplant assessment tool, there are a variety of transplant methods, some well established such as standard transplantation and T-cell depletion as well as newer protocols including reduced intensity conditioning and umbilical cord transplantation. Very few studies have addressed the relative impact of these procedures upon quality of life.

Objectives

* Introduce QOL assessment in our post allograft recipients
* Use QOL assessment to identify unmet needs
* Use the responses to guide service provision for this patient group

Materials and methods

As this is a clinical assessment rather than research tool, consent is not required. Patients receive the forms at six monthly intervals for two years and then annually thereafter so that we can measure change in QOL over time. A covering letter accompanies the questionnaires and explains the purpose of the assessment, how the information will be used, and the potential benefits. It is emphasised that completion of the form is voluntary and choosing not to complete the form will not compromise the clinical management in any way. Completed forms are returned and are scored upon receipt. Any issues arising from individual item responses can be acted upon by contacting the patient, making appropriate referrals, or discussing the case further.
Results

There were 73 returns from 73 patients with a good response rate. 38 of the patients were male and the mean age at transplant was 47 years (range 17-68). The most common indication for transplant was AML (37%), followed by MDS (28%), CML (15%) and NHL (14%).

Transplant characteristics are shown in table 1.

Table 2 summarises the FACT-BMT scores and shows the mean total score as well as the ranges for the various domains. One patient reached maximum scores in all domains. 90% of patients had a FACT-BMT score greater than 75 and exactly 50% of the patient group were in the uppermost quartile.

We also examined mean FACT-BMT score by diagnosis, conditioning type, time from transplant and the results are presented in table 3.

Table 4 displays responses to individual questions relating to satisfaction with sex life, interest in sex and concerns regarding children. These particular items were selected to highlight the versatility of the assessment in covering difficult issues.

Table 1 Transplant characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from transplant / years (range)</td>
<td>2.8 (0.5 – 8.3)</td>
</tr>
<tr>
<td>Type of transplant (%)</td>
<td>Reduced intensity conditioning (82) Standard conditioning (18)</td>
</tr>
<tr>
<td>Conditioning therapy (%)</td>
<td>T-cell depleted (95) Non T-cell depleted (5)</td>
</tr>
<tr>
<td>Donor type (%)</td>
<td>Sibling (39) Volunteer Unrelated Donor (55) Cord (5) Haplo-identical (1)</td>
</tr>
<tr>
<td>Donor gender (male/female)</td>
<td>46/27</td>
</tr>
</tbody>
</table>

Table 2 FACT-BMT score.
* denotes maximum score

<table>
<thead>
<tr>
<th>Domain</th>
<th>Score (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>108 (22-148)</td>
</tr>
<tr>
<td>Physical</td>
<td>2-28 (28*)</td>
</tr>
<tr>
<td>Social/ family</td>
<td>6-28 (28*)</td>
</tr>
<tr>
<td>Emotional</td>
<td>0-24 (24*)</td>
</tr>
<tr>
<td>Functional</td>
<td>2-28 (*28)</td>
</tr>
<tr>
<td>BMTS</td>
<td>9-40 (*28)</td>
</tr>
</tbody>
</table>
Table 3 Mean FACT-BMT score by diagnosis/ conditioning type/ time from transplant

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>MDS</th>
<th>AML</th>
<th>CML</th>
<th>NHL</th>
<th>ALL</th>
<th>CLL</th>
<th>SAA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>105</td>
<td>112</td>
<td>101</td>
<td>106</td>
<td>89</td>
<td>119</td>
<td>105</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conditioning therapy</th>
<th>RIC</th>
<th>Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>107</td>
<td>115</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time from transplant</th>
<th>≤2 years</th>
<th>&gt;2 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>103</td>
<td>113</td>
</tr>
</tbody>
</table>

Table 4 Individual items
* denotes number of responders

**Satisfied with sex life %**

- Non-response: 23 (*17)
- Not at all satisfied: 25 (*18)
- Very satisfied: 15 (*11)

**Interest in sex %**

- Non-response: 10 (*7)
- Not at all interested: 26 (*19)
- Very interested: 19 (*14)

**Concerns about children %**

- Non-response: 7 (*5)
- Not at all concerned: 79 (*58)
- Very concerned: 10 (*7)

**Discussion**

The patient group assessed had a broad age range, which interestingly did not appear to affect return rate or indeed response to individual items. AML and MDS are the predominant diagnoses reflecting the transplant caseload at King’s where myeloid malignancy is the main indication for allografting.

The mean time from transplant was almost 3 years with RIC’s in the majority, reflecting current trends. Donor gender was predominantly male, reflecting current donor selection practices.

Patients who underwent a RIC have lower scores than standard conditioning (107 vs 115). This may be
a reflection on the patient characteristics such as age, performance status and co-morbidity of those selected for the respective procedures. We found that in patients who were reviewed at 3 years or more post-HSCT, the FACT-BMT score was higher than those within 2 years of the transplant, reflecting the recognised rise in QOL over time post HSCT (Molassiotis 1996).

Although there is a broad range of scores for the individual domains, the majority of responses are in the uppermost quartile. The excellent scores infer that a relatively good QOL is being experienced by this proportion of the population almost 3 years post transplant. This is relevant to create awareness during the pre-transplant decision-making process as it provides a realistic presentation of what is achievable in the long-term. However, some patients are experiencing very distressing and disabling symptoms. The patient scoring zero in the emotional wellbeing domain would have felt sad and unsatisfied with coping with illness. They were losing hope, feeling nervous, worrying about dying and worrying about a worsening condition. One patient regretted having their transplant.

The questionnaire can generate information on different aspects in a single area. The data in table 4 demonstrates that an interest in sex will not necessarily lead to satisfaction if for instance there is erectile dysfunction.

It is interesting to note the difference in non-response rates for these two items implying that more patients felt able to report their level of interest in sex than their level of satisfaction.

The mean age of our population probably explains the overall lack of concern regarding fertility. It is noteworthy though that for those of childbearing age, the inability to have children is well documented as being highly relevant to long term dissatisfaction with quality of life (Grundy 2001, Hayden 2004).

The mean age is also relevant to the sexual satisfaction and sexual interest items. One observation from these data is that despite the health professionals preconceived ideas regarding age and sex it is important to ask these questions.

Referrals to other services were generated by the assessment process. The responder with the lowest overall QOL score only realised the extent of her overall dissatisfaction with life when she completed the questionnaire. This had provided an opportunity for her to reflect upon her current position and consider how to move forward. The patient referred herself for counselling.

Conventional outpatient consultation had not identified issues requiring referral in this group of patients. However, examination of the completed questionnaires prompted the involvement of services such as counselling, assisted conception, sexual dysfunction and social work. Thus a comprehensive assessment such as this will raise issues that are otherwise not being identified.

Even when patients have a long term relationship with our service and have been experiencing continuity, longstanding issues can remain undetected or undisclosed. One example of this is a patient who was transplanted 7 years ago and who was only referred to an erectile dysfunction service after he completed the QOL assessment.

The increase in referrals generated needs to be factored into future plans for resource allocation and service provision, as the number of consultations requested from even this initial data set have been considerable.

To conclude, FACT-BMT is multi-functional allowing a comprehensive assessment of overall QOL and psychosocial well being. It also generates data that can be used to gauge the impact of new treatment regimes and responses to follow-up interventions.

It is cost effective to administer and is flexible enough to be used in the outpatient clinic setting and from this group of patients we have already seen that there is a wide range of scores generated. The majority of patients have a FACT-BMT score in the uppermost quartile at a mean of 2.8 years post transplant.
The questionnaire is sensitive enough to uncover longstanding issues and responses can form the basis for referral. Furthermore, the assessment generates a reflective opportunity for patients to gain insight into their own emotional state.

It is important to realise that utilising this tool not only increases our knowledge of this patient group, but may have a significant organisational impact on the range of services to which these patients are being referred as inevitably, referrals will rise as such issues are identified.

A long term prospective study of all our cases will be undertaken as part of our survivorship programme.

References


