Understanding HSCT Patients Psychosocial Concerns…

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ABSTRACT

Background:
Negative impact of HSCT (hematopoietic stem cell transplantation) correlated medical effects on physical and psychological wellbeing is well known. Nonmalignant late effects are heterogeneous and although, often not life threatening, they significantly impair quality of life (QOL). Studies on QOL show evidence that more than 60% of HSCT patients report good or excellent in 1 to 4 years after the transplantation. But cross-sectional data show impairment in QOL compared with healthy controls or population normative data, even beyond 3 years after HSCT. A qualitative approach seems to be necessary to explain the gap between minor deficits in self-reported QOL and objective impairments after HSCT.

Objectives:
The aim of this qualitative study is to improve our understanding of HSCT late concerns on quality of life, as a subjective perception of physical, emotional and social well-being. We explore alterations in QOL perception over time, adaptation to HSCT impairments, difficulties in returning to normal » as main aspects of HSCT patients’ experience.

Methods:
We interviewed thirty patients of different ages, one to five years post-HSCT. In-depth interviews were recorded, transcribed and analyzed to improve our understanding of HSCT experience and late QOL issues.

Results:
Time since transplantation seems to be an important variable in HSCT patients’ experiences. Over time, confrontation of expectations and experiences lead patients to adapt to their physical condition: QOL that was once considered as poor can at another stage, be considered as acceptable or good. Despite these efforts of adaptation, many patients do not consider themselves to “have returned to normal”. Fatigue, feelings of disability, sexual problems, difficult in relationships with close relatives, fear of relapses and barriers to social rehabilitation are frequent concerns. Fearing stigma of being a burden, patients have difficulties in reporting these psychosocial problems to staff.

Discussion:
Late HSCT psycho-social problems are not sufficiently addressed. Measuring QOL cannot replace health professionals in eliciting patients’ concerns. A psychological follow-up could be useful to help patients during the HSCT process.

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Article

Understanding HSCT patients’ late psychosocial concerns

QOL as a main issue for HSCT: Often not life threatening, nonmalignant late effects significantly impair quality of life (QOL) [1]. Furthermore, adverse impact of cGVHD on QOL has been well described [2; 3; 4; 5].

Even if significant deficits are observed on HSCT survivors (compared to population data) [4], the reported overall QOL is good/excellent 1 ≥ 4 years post HSCT. This discrepancy between self-reported QOL and objective impairments after HSCT is possibly due to inherent difficulties in measuring a subjective perception.

Actually, QOL varies between individuals with similar health status (gender and age influence the QOL perception) and seems to evolve over time for an individual person [6; 7]. We hypothesize that a bias of social desirability may affect QOL measures. Patients’ minimization of concerns regarding QOL may reflect medical staff discourse [8] that emphasizes vital issues rather than quality of life aspects.

We consider that a qualitative approach can provide a better understanding of HSCT late concerns on quality of life, as a subjective perception of physical, emotional and social wellbeing.

A qualitative approach

We interviewed thirty patients of different ages, one to ten years post-HSCT (see table I). In-depth interviews were recorded, transcribed and analyzed to get a better understanding of HSCT experience and late quality of life issues.

1. Hendriks et al. [9] have shown that physicians tend to overestimate their patients’ QOL.

We found that the time since transplantation modifies HSCT patients’ experiences due to improvements in physical condition or adaptation to physical impairments. Over time, confrontation of expectations and experiences lead patients to adapt to their physical condition: QOL that was once considered as poor can at another moment be considered as acceptable or good.

Despite this evolution in QOL perception, about 40% of interviewed patients do not consider themselves to “have returned to normal”.

Patients stress recurrent problems as fatigue, psychological distress, difficulties with relationships (including sexual) and psycho-social rehabilitation concerns. Described as a significant and persistent symptom after transplantation that possibly even increases over time [6; 10], fatigue awakens feeling of disability, increasing anxiety. In addition, it causes difficulties with relationships with close relatives after HSCT, period when patients are expected to be healthy again and to act as “normal”...

The discrepancy between their physical and psychological condition and the expectations of their close relatives is an important aspect of their psychological distress.

It has been shown that 5 to 40% of HSCT patients have symptoms of anxiety and/or depression symptoms even several years after the transplantation [1; 13; 14].

As a matter of fact, we know that psycho-social distress is under-reported by cancer patients. [15; 16; 17; 18]

Various reasons may explain this fact. Firstly, social discourse that, on the one hand, normalizes psychological distress of cancer patients and, on the other hand, recommend that “keeping one’s spirits up” is essential to heal.

Secondly, health providers’ behavior, like for instance premature reassurance, emphasizing vital issues, avoiding patients’ questions regarding their psychological problems. We’d like to stress that factors like...
time constraints and competing medical issues can also worsen doctors’ and patients’ attitudes toward these psychological problems.

Influenced by social discourse, patients may fear stigma (being weak, not able “to cope with” their disabilities), or the fear of being a burden for medical staff, or they may even think that psychological distress is cannot be addressed.

2. Hendriks et al. [9] have shown that physicians tend to overestimate their patients’ QOL.

Interviewed patients relate their feelings of “being different from the others”, their need (and difficulty) to “feel loveable”, their fear of disease recurrence, the gap between “being recovered » and « feeling recovered” [19] and the culpability that it provokes.

These feelings have an important impact on relationships with close relatives, notably with sexual partners.

Interviewed patients did not spontaneously refer to their sexuality. This subject emerges when they talked about the changed perception of their body image, disrupting perception of themselves as sexual beings.

Sexual dysfunctions after HSCT are linked to physical functioning, lack of desire and problems related to body image [20]. Its impact on global QOL has been recently described [21]. Nevertheless, these problems are not regularly discussed with their healthcare providers [20; 21]

In addition to fatigue, psychological distress and difficulties with relationships, interviewed patients report their concern about psychosocial rehabilitation.

Resume work is a main issue for them, meaning that they are “like other people”. But, returning to work means also being confronted with the changes that disease experience has operated, including in their own way of investing their professional lives.

Data show worse social well-being for younger patients [3]. The younger interviewed patients encountered more difficulties in social reintegration. For some of those who already had a job, the professional choice was questioned; for others, readjustment to work constraints was difficult. Those who were not in working life before their disease have encountered many obstacles in finding a job. Furthermore, these patients experienced a gap between themselves and their peers “who have a normal life”, referring to treatment sequel (notably sterility) and to the “rupture” that HSCT introduces in their life histories.

Conclusion:

Our study confirms the importance of assessing post-transplant QOL in follow-up care. We found that patients have difficulties to talk about late psycho-social issues to medical staff. Attempts to screen these problems by using questionnaires cannot replace health professionals in eliciting patients’ concerns. Enhancing patient-doctor communication assumes that the working conditions of the doctors allow them to take time to listen to patients’ needs. Furthermore, a multidisciplinary approach seems to be essential to accompany patients during the HSCT process. In this context, a psychological follow-up should be offered to patients after HSCT.

3. Data show that 84% of patients have a good social functioning recovery two years after HSCT [4].

4. Bieri et al. [7] has shown a better perception of health-related quality of life in patients that had returned to work.
References:


5. Pidala J, Kurland B, Chai X et al. Patient-reported quality of life is associated with severity of chronic graft-versus-host disease as measured by NIH criteria: report on baseline data from the Chronic GVHD Consortium. Blood 2011; 117 (17); 4651-57


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Author’s note:

We are some psychologists working in HSCT units and we would like to develop a network to exchange about our professional experiences in this field. If you are interested, and if you know other colleagues who would like to participate, please let us know.

Best regards,
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