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# The impact of allogeneic-hematopoietic stem cell transplantation on patients' and close relatives' quality of life and relationships<sup>☆</sup>

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## ABSTRACT

**Purpose:** Although evidence suggests considerable disruption to families, the impact of allo-Hematopoietic Stem Cell Transplantation (HSCT) on patients' partners and close relatives has not been sufficiently explored. The present mixed-methods study aimed to enlighten allo-HSCT effects on patients' and close relatives' quality of life (QOL) and their relationships.

**Methods:** Patients who received allo-HSCT between 2007 and 2010 (N = 58) and their close relatives (parents, partners and/or adult children) were asked to respond to an anonymous questionnaire including socio-demographic data, Likert-scale of the impact of HSCT on sexual, couple, family, professional and social life, as well as on perceived support. QOL of patients and close relatives was evaluated (by the FACT-BMT and by WHO-QOL-bref) as were the adjustments of the couples (patients/partners by the DAS). In-depth interviews were performed with patients and partners who consented to this proposition.

**Results:** Patients (N = 28) and close relatives (N = 48) reported fatigue, sleep and sexual problems, emotional distress and relationship difficulties. Patients were mainly concerned with « being a burden » to their close relatives. Close relatives' main concerns were changes in marital and family dynamics, disruptions in daily routine tasks and the responsibility for being the main provider of physical and emotional care. These difficulties increased after HSCT – notably when patients have to face the long-term consequences of the procedure.

**Conclusion:** HSCT has a negative impact on patients' partners and other close relatives' QOL. Data on this topic is still scarce and this study might pave the way for future research in this field and notably guide psychosocial interventions.

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## 1. Introduction

The impact of allogeneic-hematopoietic stem cell transplantation (allo-HSCT) on physical and psychological wellbeing has been well described. The procedure's late effects are heterogeneous, can cause mortality, morbidity and significantly impair quality of life (QOL) (Socié et al., 2003; Majhail and Rizzo, 2013), notably in the occurrence of chronic graft versus host disease

(cGVHD) (Fraser et al., 2006; Pidala et al., 2009, 2011; Wong et al., 2010).

QOL varies between individuals with similar health status (gender and age influence the QOL perception) and evolves over time (Bieri et al., 2008; Hjermsstad et al., 2004). Data show recipients' QOL impairment even beyond 3 years after HSCT but, paradoxically, more than 60% of patients report good or excellent overall QOL within this period (Pidala et al., 2009).

Research on QOL throughout HSCT course (from the transplantation to several years after the procedure) shows conflicting data regarding physical and social wellbeing and, surprisingly, indicates that – in spite of persisting problems in physical and social areas, emotional wellbeing increases over time (Bevans et al., 2006; Bush et al., 2000; Kisch et al., 2012; Lee et al., 2006; McQuellon et al., 1998; Pidala et al., 2009; Syrjala et al., 1993).

Considering that a qualitative approach could enlighten these

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data, we've performed a study exploring allo-HSCT patients' late concerns (Poloméni and Lapusan, 2012). Time since transplantation appears as an important variable in patients' experience. Actually, even if they can experience physical functioning limitations and ongoing bothersome symptoms, these problems are interpreted from a changed perspective on QOL all along the allo-HSCT trajectory. Over time, the confrontation of expectations and experiences lead patients to adapt to their physical condition. Despite these efforts of adaptation, many patients have not 'returned to normal' – as expected by their relatives: fatigue, feelings of disability, sexual problems, fears of relapse and barriers to social rehabilitation are frequent concerns. These issues affect patients as well as their family members.

Recent reviews on the effects of caring for a cancer patient demonstrate that family caregivers experience complex difficulties, health-related, emotional and social problems (Kim and Given, 2008; Northouse et al., 2012; Mellon et al., 2006; Stenberg et al., 2010).

Allo-HSCT is a particularly physically and psychologically exhausting treatment. Almost 25% of long-term survivors present chronic consequences of the transplant requiring care from family members (Socié et al., 2003). HSCT recipients' close relatives frequently develop physical and psychological symptoms described for other cancer patients' caregivers, such as fatigue, sleep disturbance, anxiety and depression (Wulff-Burchfield et al., 2013).

As reported for caregivers of patients suffering of other cancers (Kim and Given, 2008; Northouse et al., 2012; Stenberg et al., 2010), the incidence of emotional distress in HSCT caregivers is comparable to – if not higher than – patients'. (Çuhadar et al., 2014; Mellon et al., 2006). Actually, compared to HSCT patients, partners report equal emotional and greater social costs – even seven years after treatment. Nevertheless, depressed partners are less likely than depressed patients to receive mental health treatment (Bishop et al., 2007; Bishop, 2009). Caregivers also experience significant changes to their marriage and family dynamics: half of them declare decreased marital satisfaction after HSCT (Langer et al., 2010).

Although evidence suggests considerable disruption to families (Lesko, 1994), HSCT impact on partners and close relatives, as well as on their relationships, has not been sufficiently explored.

A critical review of the literature shows many limitations to current research, notably due to small and heterogeneous samples (Beattie and Lebel, 2011). A recent survey on supportive care needs of HSCT patients' informal caregivers found high unmet needs and psychological morbidity, but its' results are based on a sample of 75% autologous HSCT patients (Armoogum et al., 2013). In their interesting qualitative study on the HSCT spouses' experience, Sabo et al. (2013) did not distinguish between allogeneic and autologous transplant. As a matter of fact, comparisons of allogeneic and autologous HSCT show different trajectories of recovery, notably associated to acute and chronic GVHD. This specific allo-HSCT complication may be significantly physically and emotionally burdensome to patients and close relatives.

Another limitation of current research is due to transversal approach. Aiming to test interventions that address patient and caregiver during allo-HSCT, Bevans et al. (2010) performed a dyadic approach, but evaluations of symptom distress, family function and problem solving pertained to a short period (prior to HSCT and until 6 weeks after discharge). In the same way, the qualitative study of Wilson et al. (2009) on the spouses of HSCT patients focused on the acute phase of the transplant trajectory. And a very recent research investigated patients' and family caregivers' QOL, but only during the HSCT hospitalisation period (El-Jawahari et al., 2015).

Taking into account the importance of this issue to patients' care, our study aimed to enlighten the impact of allo-HSCT on

patients' and close relatives' QOL through a mixed methods approach. We also focused on patients and close relatives relationships as well as on couples' adjustment in this psychologically, socially and medically disabling setting of "life after allo-HSCT".

## 2. Methods

Patients who received allo-HSCT between September 2007 and March 2010 (N = 58) were asked to participate to this exploratory study. Only four patients were excluded: exclusion criteria were insufficient knowledge of French language and not living in France metropolitan area, to avoid communication difficulties. The study presentation sheet underlined the protection of their privacy and asked respondents a written informed consent. This sheet invited patients to ask their close relatives (parents, partners and/or adult children) to respond separately to an anonymous questionnaire including socio-demographic data and questions about the impact of HSCT on sexual, couple, family, professional and social life, as well as about perceived support. Self-rating scales were used to evaluate QOL of patients (Functional Assessment of Cancer Therapy Bone Marrow Transplant – FACT-BMT), close relatives (World Health Organisation Quality of Life – WHO-QOL-bref) and couples' adjustments (Dyadic Adjustment Scale – DAS).

The questionnaires and self-rating scales were sent by mail, with stamped envelopes to return.

Each patient received four sets of different colours to better identify specific patients', partners' and other close relatives' questionnaires and scales. Every tool was assigned a number in order to ensure patients' and their close relatives' anonymity, but allowing to perform coupled analysis and to correlate interviews statements with questionnaires' and QOL scales' data.

Given the downsized sample, quantitative analysis is only descriptive: results are expressed in numbers and percentages.

To explore quantitative data, we resorted to a qualitative approach: all participants were invited to note their phone number if they agreed to respond to an interview. We've performed telephone interviews of patients (n = 18) and partners (n = 10) and other close relatives (n = 8) who consented to this proposition. These semi-directive interviews, all performed by the same psychologist, explored the topics approached by the questionnaire. They were recorded and professionally transcribed.

To perform qualitative analysis, since our semi-structured interviews were based on questionnaire topics, we've referred to a framework approach (Ritchie et al., 2013). The interest of this method in healthcare research is discussed by Smith and Firth (2011). To avoid prematurely closing off recognition of another emerging themes (Sandelowski, 1995) and to better reflect the original accounts and observations of patients' and close relatives' experiences, transcripts were first independently coded by two investigators: different classifications were compared and disagreements resolved by consensus. A third investigator re-read transcripts, verified coding and participated to the thematic analysis. The interpretations suggested by the three investigators were validated by other co-authors (consensual validity).

### 2.1. Measures

#### 2.1.1. The questionnaire

The questionnaire was based on the results of our previous exploratory study (Poloméni and Lapusan, 2012). Its' first version was submitted to different professionals of HSCT staff (physicians, nurses, social workers, coordinator nurses) for suggestions. The final version was presented to ten patients (who received allo-HSCT after the study period) asked for their opinions about the

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