Quality of life in a heterogeneous sample of caregivers of cancer patients: an in-depth interview study

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To establish the best approach to develop a quality of life (QoL) questionnaire for cancer-patient caregivers, this study attempts to identify primary domains of QoL in terms of their impact on a purposive sample of caregivers. Seventy-seven informal adult caregivers of cancer patients (breast cancer, paediatric haematological malignancies or melanoma) with different relationships with the patients (parents, children, spouses, siblings, and friends) were recruited at three specialised French centres and extensively interviewed. Caregivers’ lives were altered in several domains: psychological well-being, leisure and everyday activities, relationships with institutional caregivers, occupation and finances, relationships with family and friends, physical well-being, and relationship with the patient. The relative importance of these domains varied mainly in association with the caregiver-patient relationship. Multiple correspondence analysis identified two isolated clusters: children, and, most significantly, friends and siblings. The latter groups emphasised the repercussions on their psychological well-being and their relationship with the patient, but were less willing to discuss the impact on their relationship with caregivers and on occupation, finances, leisure, and everyday activities. This study focuses on the caregiver’s perspective and advocates the development of a short QoL core questionnaire. Additional modules should be cancer-specific or dedicated to specifics of the caregiver-patient relationship.

Keywords: cancer, caregiver burden, informal carers, quality of life, psychometry, interviews.

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BACKGROUND

The impacts of a life-threatening illness such as cancer are not limited to the patient, but also affect family and caregivers (Lewis 1990, Nijboer et al. 1998). Negative caregiver experiences may affect their ability to care for the patient, resulting in restricted roles and activities and increased psychosomatic, anxious, or depressive symptoms (Nijboer et al. 1998; Schulz & Beach 1999; Cameron et al. 2002) and the impact of caregiving on caregiver quality of life (QoL) seems considerable (Wagner et al. 2006, Kim & Given 2008). The involvement of family caregivers is essential for the optimal treatment of cancer patients to guarantee treatment adherence, continuity of care, and social support. Therefore, preserving caregiver QoL is a noteworthy issue both for the caregivers themselves and, indirectly, for their patients’ health (Schulz & Beach 1999; Glajchen 2004).

Assessment of caregiver experiences can be performed using instruments that assess three broad areas: caregiver burden, needs and QoL (Deeken et al. 2003). Of the instruments used to measure the QoL of cancer-patient caregivers (Edwards & Ung 2002), two were developed specifically for caregiver populations: the Caregiver Quality of Life Index (CQLI) (McMillan & Mahon 1994) and the Caregiver Quality of Life Index-Cancer scale (CQOLC) (Weitzner et al. 1999). Neither of these instruments was specifically developed exclusively from caregivers’ point of view. The content validity of the CQLI was validated using a very small sample of five subjects, who were only asked to indicate the relevance of predefined items (McMillan & Mahon 1994). In the case of the CQOLC, 81 items were initially generated by a mixed approach, combining interviews of 22 matched cancer patient–caregiver dyads (Weitzner et al. 1997). Twenty of the 22 caregivers interviewed were spouses. Therefore, the heterogeneity of the cancer patient relationship was not fully represented, and the items generated may not capture all the domains of caregiver QoL that may be impacted by cancer. Specifically, the QoL of parents of ill children or of natural caregivers who do not reside at the patient’s home (such as close friends or siblings) may be particularly impacted.

Studies have shown an impairment of QoL in diverse samples of caregivers who have a specific relationship status with the cancer patient, such as spouses (Wagner et al. 2006), parents (Klassen et al. 2008), or children (Kim & Given 2008). However, to date, this fragmented approach has failed to elucidate whether caregiver QoL dimensions are homogeneous across different caregiver–patient relationships. If the impacted dimensions vary according to the type of patient–caregiver relationship, generic QoL measurement tools such as the CQLI or CQOLC might not be appropriate. Specific dimensions of concern might be assessed using additional modules, consistent with relationship status. At the extreme, if the QoL dimensions of concern are completely different, only questionnaires specific to each caregiver–patient relationship status would be reliable.

In order to establish the best approach to develop a caregiver QoL questionnaire (general questionnaire, core questionnaire with additional modules, or specific questionnaire), this study aims to identify the main domains of QoL, in terms of their impact on a purposive sample of natural cancer caregivers, independent of the cancer characteristics and of the relationship between patient and caregiver.

METHODS

Setting and population

The study was conducted at a French university teaching hospital, including both the inpatient and outpatient services of three specialised oncology wards (breast cancer, melanoma, and paediatric haematology), selected because they interact with heterogeneous caregivers according to their relationship status with their patients. Eligible subjects were 18 years or older, spoke French, and were a natural caregiver identified by a patient with a primary cancer. All participants provided informed consent. No protocol approval was required for this study.

Interviews and data collection

Qualitative interviews were used to identify the domains of impacted caregiver QoL (Britten 1995, Brod et al. 2009). First, an interview guide was developed (see Figure 1 for a description of the interview guide used) based on an analysis of the literature, to assess factors that described caregivers’ QoL (Nijboer et al. 1998; Edwards & Ung 2002; Deeken et al. 2003). Second, in-depth individual interviews, consistent with the interview guide were performed by a psychologist (AL) and a sociologist (AC) that did not had clinical activities in the oncology wards. Participants were asked to comment directly on the impact of their patient’s illness on their own QoL and areas of functioning. Both positive and negative aspects were considered. Sufficient latitude was provided to allow the interviewer an opportunity to explore other potentially emerging domains. The inter-
views took place in a private hospital office at a time of the caregiver’s choosing. The interviews were conducted individually to minimise any influence or other bias from other caregivers, and continued until no new ideas were forthcoming.

To determine the minimum required number of in-depth interviews, caregivers’ characteristics were obtained, including the relationship status with the patient and the localisation and severity of the patient’s cancer. The relationship status was defined as follows: spouse, child, parent, sibling, or friend. The primary cancer diagnoses of the patient included breast cancer, melanoma, or paediatric haematological malignancies. The sample covered a wide range of caregiver–patient relationships, including those of a partner or child with breast cancer or melanoma, and a parent with haematological malignancy. The severity of the illness was defined as follows: stage 2 or 3 for melanoma, presence of metastases for breast cancer, presence of renal failure, or severe infection for haematological malignancies. Twelve pre-defined groups were listed. We initially planned a minimum of three interviews per group (for a total of 36) but increased this number until the point of saturation, beyond which no new concepts were forthcoming from the interviewees. Features of the caregivers’ and patients’ socio-demographic and clinical characteristics were also recorded.

Thematic analysis

All face-to-face interviews were audiotape recorded and transcribed. Then, qualitative thematic analysis techniques were used, which are appropriate for exploratory textual investigations. These helped provide a systematic approach to organising and integrating relevant information [Silverman 2005]. The transcripts were interpreted by two of the authors experienced in categorising patient comments into major themes. The unit of analysis was an utterance, word, sentence, or part of a sentence, verbatim. Responses were divided into meaning units and coalesced into overarching, general themes according to the conceptual model of QoL developed by Ware [Ware 1984] and Cella [Cella & Bonomi 1995], in which QoL is considered as a multidimensional construct comprised of at least four major areas of well-being, namely physical functioning, emotional functioning, family functioning, and social functioning. Finally, the researchers read the data a second time to ensure that the themes were mutually exclusive and suitably grounded in the data and a third researcher independently reviewed the data and discussed themes.
Data analyses

For each caregiver, the number of meaning units categorised in each theme was divided by the total number of meaning units expressed by the caregiver in order to evaluate the relative importance of each theme in the interview. Thus, the theme importance for a caregiver was expressed as a percentage, and the average importance of a theme was compared among different groups of caregivers.

A complementary multiple correspondence analysis (MCA), was conducted using the SPAD 3.21 software package. Such an analysis provides a joint description of several variables by multivariate description of categorical data and allows the detection of clusters. Theme importance percentages were dichotomised using their median values to define two classes, namely high or low relative theme importance. MCA was then conducted projecting these dichotomised active variables onto a succession of two-dimensional planes. The relationships between variables can then be deduced from the relative positions of the modalities of the variables on the planes. Finally, caregiver and patient characteristics (illustrative variables) were also projected onto the previously identified planes in order to detect the heterogeneity of impacted QoL domains.

RESULTS

Interview characteristics

We included 77 caregivers of patients with haematological malignancy \(n = 33\), breast cancer \(n = 27\) and melanoma \(n = 17\). The interviewing of 37 parents \(25\) mothers of ill children\) was necessary to reach saturation. All caregiver and patient characteristics are detailed in Table 1. No caregivers refused the interview, generally viewing the interview session as an opportunity to explore their personal issues.

Domains impacted and relative importance in the interviews

Content analysis of the interviews identified 2518 meaning units related to caregiver QoL. Seven major themes described the impact of cancer on their lives (Fig. 2). Figure 3 shows illustrative extracts of the interviews. Table 2 describes the relative importance of each theme, according to patient and caregiver characteristics. The following is a description of these themes, illustrated with verbatim quotes and focusing on sources of variability, consistent with the caregiver–patient relationship.

Table 1. Characteristics of the natural caregivers and their patients

<table>
<thead>
<tr>
<th></th>
<th>All (n = 77)</th>
<th>Paediatric haematological malignancies (n = 33)</th>
<th>Breast cancer (n = 27)</th>
<th>Melanoma (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregivers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female gender</td>
<td>49 [64]</td>
<td>25 [76]</td>
<td>16 [59]</td>
<td>8 [47]</td>
</tr>
<tr>
<td>Age &lt;50 years</td>
<td>46 [60]</td>
<td>32 [97]</td>
<td>10 [37]</td>
<td>4 [24]</td>
</tr>
<tr>
<td></td>
<td>Spouse 24 [31]</td>
<td>–</td>
<td>12 [44]</td>
<td>12 [71]</td>
</tr>
<tr>
<td>Living with the patient</td>
<td>62 [81]</td>
<td>33 [100]</td>
<td>16 [59]</td>
<td>13 [77]</td>
</tr>
<tr>
<td>Living with a partner</td>
<td>68 [88]</td>
<td>29 [88]</td>
<td>24 [89]</td>
<td>15 [88]</td>
</tr>
<tr>
<td><strong>Patients</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female gender</td>
<td>56 [73]</td>
<td>17 [51]</td>
<td>26 [96]</td>
<td>13 [76]</td>
</tr>
<tr>
<td>At least 6 months since initial diagnosis or recurrence</td>
<td>47 [62]</td>
<td>27 [82]</td>
<td>9 [33]</td>
<td>11 [65]</td>
</tr>
<tr>
<td>Severe disease*</td>
<td>25 [32]</td>
<td>9 [27]</td>
<td>9 [33]</td>
<td>7 [41]</td>
</tr>
</tbody>
</table>

*Severe disease was defined as stage 2 or stage 3 for melanoma, presence of metastasis for breast cancer, presence of renal failure, or severe infection for haematological malignancies.
The most frequently described feelings were ‘worry’ and ‘doubt’, often focused on the future. The feeling of being powerless to change anything was frequently reported by the caregivers. Many other feelings were mentioned, such as anxiety, fear, stress, sadness, depression, insecurity and injustice/unfairness.

The psychological impact of cancer was described by all the caregivers independently of the caregiver–patient relationship, even for cancers with the most favourable prognoses. The parents of ill children were the most psychologically affected and sometimes reported feelings of guilt, related to the fact that they felt genetically responsible for the disease. Relative to the other domains of QoL impacted, psychological well-being was of particular importance for friends, siblings, women, and caregivers older than 50 years of age.

In terms of leisure and everyday activities, reorganisation of household life was frequent. The caregivers increased the amount of help they provided (for housekeeping, cooking, etc.) to better support the patient. Other sources of support (family, neighbours, etc.) were frequently mentioned. Some withdrew into themselves, delayed, or even cancelled various projects, such as travel, leisure activities, or pregnancy. Others made efforts to keep their lives and their family’s routine as normal as possible, or developed new projects to better enjoy life.

Modifications of leisure and everyday activities were of relatively weaker importance for women and for caregivers who did not live with the patient, such as friends and siblings. Caregivers of melanoma patients, in particular, reported a decrease in sun-related activities.
Relationship with institutional caregivers (Rel-CG)

Caregivers generally expressed gratitude for the opportunity to speak about their personal challenges. They reported rarely being involved in administering the medical care prescribed for their patients (e.g. bandages, injections).

Except for the closest relatives, such as parents of children or spouses, close contact with medical staff was uncommon. Parents played a greater role, as they had to supervise treatments and ensure communication between the various healthcare providers. Other caregivers often experienced a lack of direct information and minimal contact with physicians.

Occupation and finances (Oc-Fin)

Caregiving was generally well accepted in professional life, although schedules often needed to be adjusted. During treatment, expenses related to the disease were substantial (journeys to the hospital, including transportation and food, cosmetic aids, etc.) but these costs were sometimes offset by the concurrent reduction in social activities.

When occupational activities had to be completely abandoned, the financial impact became important, particularly for spouses or caregivers living alone with no one else to compensate for the lack of income. Occupation and financial metrics were also more problematic for men of...
under 50, who were more likely to be working at the time of cancer onset.

Relationship with family and friends (Rel-FF)

Cancer brought familial and social circles closer to the patients and their caregivers. Generally, a huge amount of emotional support was apparent. However, some people who were afraid of the disease were judged to be oppressive or tactless. Therefore, communication with such people was sometimes diminished, voluntarily or not.

In the case of couples for whom one of the spouses took care of someone else, this investment in supporting a patient was usually understood and well accepted by the caregiver’s spouse. Difficulty in communicating about the disease, particularly with children, was mentioned. Caregivers with children sometimes also experienced conflicts between caring for the patient or for their children.

Physical well-being (PhyWB)

With regard to physical health, sleep was the most affected, with insomnia or insufficient sleep regularly cited. Severe fatigue or lack of time to rest was often mentioned. Changes in weight were reported, with either loss of appetite or bulimic compensation. Related medical problems were reported rarely but included colitis, urinary infection, eczema and psoriasis. When health problems occurred, they often were minimised by caregivers.

All of the aforementioned issues occurred across all the different groups of caregivers that we interviewed.

Relationship with the patient (Rel-Pat)

The relationship with the patient was frequently not impacted. Caregivers reported frequently concealing their worry to convey a positive image to the patient, thinking they could better help her/him fight the disease. They sometimes reported that they were more attentive to and tolerant of the patients’ moods.

Globally, they often felt closer to their patients, and friends, especially when they had not been particularly close previously. Parents also reported tighter bonds with ill children.

Multiple correspondence analysis

The plane identified by the first two factorial axes, was found to explain 46% of the total inertia in the data (Fig. 4). The first factorial axis was mainly determined by the relationship with the patient (40%) and by occupation and finances (29%). The second factorial axis was mainly determined by psychological well-being (39%), relationships with institutional caregivers (22%), and by leisure and everyday activities (18%).

After projecting the characteristics of the patients and caregivers, the caregiver–patient relationship exhibited two isolated clusters. Although parents and spouses were in a central position, siblings and friends – and, to a lesser extent, children – were outliers. Compared with parents and spouses, other caregivers assigned more importance to the psychological impact of cancer and less to the relationship between caregivers and leisure or everyday activi-

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ties. Siblings and friends could also be distinguished from others, as they attached greater importance to the impact on their relationship with the patient and less to their occupation and finances.

Other characteristics (caregivers' age and sex and the localisation and severity of the cancer) were projected close to the centre of the plane. However, caregivers over 50 years of age who looked after breast cancer patients on the right of the plane seemed to be more concerned about their relationship with the patient and their physical well-being and less concerned about their occupation and finances, compared with younger parents of children with haematological malignancies.

**DISCUSSION**

This study concluded that not only the patients' clinical condition but also the caregiver–patient relationship may play an important role in determining the overall impact of cancer.

Our data yielded a rich and meaningful picture of the caregiving experience. The domains that were cited in the caregivers' interviews as being impacted covered a broad area of caregivers' lives, even though they had been described separately in previous studies. The 'saturation point' of the interviews was reached rapidly, except in the case of parents, who were over-represented in our sample. In accordance with other studies (Pitceathly & Maguire 2003; Vanderwerker et al. 2005), the major repercussion was psychological, even when the caregivers cared for patients with favourable prognoses, and serious physical effects were uncommon (Kurtz et al. 2004; Klassen et al. 2008). Contrary to some published results (Glajchen 2004), the natural caregivers surveyed were not normally in charge of nursing or medical procedures such as pain management, but they mainly took care of patients who had been diagnosed more than 6 months previously. Of note, caregivers of patients undergoing palliative care were not included in our study.

Figure 4. Multiple correspondence analysis, plane of the first two factorial axes (Factor 1 and Factor 2) representing relative importance of life domains impacted by cancer in caregivers interviews. Rounds = caregivers' characteristics; stars = patients' characteristics; squares = themes. PsyWB, psychological well-being; Lei-EA, leisure and everyday activities; Rel-CG, relationships with institutional caregivers; Oc-Fin, occupation and finances; Rel-FF, relationships with family and friends; PhyWB, physical well-being; Rel-Pat, relationship with the patient.
Contrary to results reported in caregivers of patients with end-stage renal disease (Wicks et al. 1997), the caregiver–patient relationship [in this study] influenced the domains of the caregivers’ lives that were impacted by cancer. In particular, friends and siblings emphasised the repercussions on their psychological well-being and on their relationship with the patient but were less willing to discuss the impact on their relationship with caregivers and on everyday life [leisure and everyday activities, occupation and finances]. Other caregiver characteristics were not associated with changes in the life domains that were impacted by cancer. However, caregiver characteristics might influence the level of QoL impairment, as suggested by studies showing individual variations among caregivers [Braithwaite 1996; Awadalla et al. 2007] depending on age [Mancini et al. 2006], employment status (Kim et al. 2006) or gender [Kim et al. 2007].

In the same way, only a small amount of variability in the importance of the QoL dimensions impacted was associated with patient characteristics, compared with the caregiver–patient relationship, as indicated by the MCA results. As previously reported [Wagner et al. 2006], disease characteristics such as cancer location, severity or disease duration might more strongly impact the level of QoL rather than affecting the importance of the domains impacted. The fact that caregivers of haematological patients mentioned difficulties in managing and communicating with their other non-ill children and felt responsible for the disease more frequently than other caregivers is probably linked more to their status as young parents [Eiser et al. 1995], rather than to the type of cancer.

On the one hand, some caregivers reported experiencing noticeable impacts in particular domains of their lives, and the ordering of the domains of importance was heterogeneous, underscoring the need for a multidimensional approach to measure QoL. On the other hand, commonalities in the descriptions of impacts across caregiver groups were significant, and all the groups reported impacts in terms of the seven major themes described. Therefore, the most appropriate approach would be the use of a core caregiver QoL questionnaire that captures only the dimensions shared by all the caregivers, complemented by additional modules [for children, spouses, etc. . .]. Among the instruments used with caregivers of cancer patients [Edwards & Ung 2002], the CQOLC [Weitzner et al. 1999] – which features the most extensively reported psychometric properties – was not developed with this in mind.

Several limitations of our preliminary study should be mentioned. Palliative cancer patients were not included [despite the fact that caregivers of such patients may experience important and specific impairments to their QoL]. Only three cancer localisations were considered, but our main objective was to identify the variations in the domains of caregivers’ QoL impacted by cancer that were dependent on the caregiver–patient relationship. These limits should be taken into account when a new QoL questionnaire is developed. As a substantial number of caregivers were interviewed to the point of saturation, we were able to conduct a quantitative analysis of the narratives. The statistical analyses were exploratory and no statistical tests were performed, owing to the small sample size. Our approach was based on relative counts rather than absolute counts that would have been dependent on interview length. It takes into account the relative importance in the narratives of the different domains of QoL impacted but is not designed to weight the extent of impairment of those domains.

**CONCLUSION**

Our analysis of caregiver interviews broadens our overall understanding of the impact of cancer on their lives. Focusing on the caregivers’ perspective, our work confirms the need for QoL assessment tools that are specifically designed for caregivers and that adequately record their own concerns and perceptions. Although our results need to be confirmed in larger studies that feature a broader range of caregivers and patients, our data reveal major commonalities in the importance to which caregivers’ life domains are impacted by cancer. We would advocate the development of a new short-core questionnaire. If modules are developed in addition to the core instrument, they should not only be cancer-specific but also specific to the caregiver–patient relationship.

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**COMPETING INTERESTS**

The authors declare that they have no competing interests.
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