Chapter 5

Help-seeking behavior of patients with hematological malignancies treated with autologous stem cell transplantation

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Abstract

Patients with hematological malignancies undergoing autologous stem cell transplantation face a life-threatening illness and stressful treatment. Whereas many patients report problems, relatively few patients report a need for additional professional care after treatment. We aimed to gain insight into the factors underlying this discrepancy by exploring patients’ needs and help-seeking behavior in relation to their experienced symptoms and problems. A qualitative research design following the grounded theory approach was used. Twenty patients, treated with autologous stem cell transplantation in the past two years, participated in an individual semi-structured interview. Factors contributing to patients’ help-seeking behavior were derived from our data and ordered in the following categories: (a) transition from symptoms to problems; (b) preference for dealing with problems themselves and with help from relatives; (c) problem categories and coping strategies; (d) motives for (not) bringing in professional help. We concluded that the mere presence of a symptom does not lead to help-seeking behavior: this relationship is modified by patients’ personal goals, future perspective, and phase of recovery. Patients seem to prefer to deal with problems without professional care. Patients’ actual appeal for professional care depends on their coping strategies, social network, and knowledge of available care.

Keywords: hematological neoplasms; quality of life; help-seeking; psychological; hematopoietic stem cell transplantation
Introduction

Autologous stem cell transplantation following high-dose chemotherapy (auto-SCT) is a common treatment for patients with various hematological malignancies. Approximately 11,000 and 17,715 auto-SCT's were provided in the U.S. in 2011 and Europe in 2012, respectively, to patients with lymphoma, leukemia, or multiple myeloma [1,2]. Disease and treatment are associated with major impairments in patients’ health-related quality of life [3,4], with a significant number of patients reporting physical, cognitive-emotional, and/or practical problems [5]. Remarkably, relatively few patients report unmet needs for additional professional care, especially when it comes to emotional problems [5,6]. Previous research on patients’ help-seeking behavior after stem cell transplantation showed that only 50% of patients with clinically significant distress had sought mental health services; a number comparable to that among other cancer populations [7].

Andersen and Newman proposed a framework for determinants of health care use [8,9]. They suggest that people's health care use is a function of: (a) their predisposition to use services, referring to background variables such as demographic factors; (b) factors that enable or impede use, such as social structure; and (c) their need for care. From previous research in cancer patients, a low perceived need for care seems a major reason for not seeking care. Motives for lung cancer patients not seeking care were patients’ current ability to manage, sufficient help from their own support networks, and viewing other patients as more needy than themselves [10]. Distressed cancer patients who had completed curative treatment also mentioned receiving adequate social support as a reason for their absent need for psychological services. Other motives were wishing to improve by themselves and considering help at a later point in time [11]. Impeding factors seem another relevant explanation for not seeking help. Earlier studies mentioned physical impairments [11], lack of knowledge, emotional barriers [7], not thinking that talking would help, not willing to talk about problems [11], and patients’ confidence that their doctor would have recommended treatment if available [10].

Although these are important insights, the evidence remains limited as it results from one qualitative study [10] and one quantitative study in which reasons for (not) seeking care were only a secondary finding [11]. Further, since the qualitative study was performed in lung cancer patients, it remains unclear whether these findings apply to patients with hematological malignancies. Therefore, the discrepancy between facing a life-threatening disease and stressful treatment on the one hand and on the other hand the low need for and seeking of additional care after auto-SCT needs further clarification. The aim of this qualitative study was to gain insight into the factors underlying this discrepancy, by exploring patients’ needs and help-seeking behavior in relation to their experienced symptoms and problems. Since emotional and physical functioning are closely related, we focused on emotional as well as physical symptoms and problems.

Materials and Methods

Design

A qualitative research design following the grounded theory approach was used. The study
was approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam, the Netherlands.

Sample and setting
Twenty patients were invited to participate in an individual, semi-structured interview. Eligibility criteria comprised treatment with auto-SCT for hematological malignancies in the past two years, and an adequate command of the Dutch language. We used two strategies for the recruitment of participants. First, eligible participants were selected from our department's research database, containing auto-SCT recipients at the VU University Medical Center, Amsterdam. Selected patients were telephoned to explain the study objectives, request their participation, and make an interview appointment. Second, participants were recruited by an advertisement on the website of the Dutch association for stem cell transplant survivors. Nurse practitioners from various hospitals in the Netherlands were asked to refer patients to this advertisement. Nine patients were recruited via the department's research database, two patients directly responded to the advertisement, and nine patients responded after referral to the advertisement by nurse practitioners. Informed consent was obtained from all participants.

Selection took place by both purposive sampling and theoretical sampling. Purposive sampling was used in the initial stages of the study, when we selected patients from our department's research database. This ensured sufficient variation in our sample with respect to age, gender, time since auto-SCT, and the presence of care needs. Finally, theoretical sampling, led by the interim results of our data analysis and progress in theoretical insights, guided further data collection. For example, the nurse practitioners were specifically asked to refer male patients, young patients, or patients who were known to have specific unmet care needs, to the advertisement. Saturation was a guiding principle for the sample size, referring to the point in data collection when no new or relevant information emerges with respect to the research questions.

Data collection
Data collection took place between December 2012 and February 2014. Data were collected by semi-structured interviews using a flexible interview guide. The interview guide, developed for the purposes of this study, consisted of a series of open-ended questions aimed at exploring patients’ needs and help-seeking behavior in relation to their experienced problems. It comprised three main questions: (a) how patients dealt with their specific problems after auto-SCT; (b) under which conditions patients’ problems did or did not transform into care needs; (c) under which conditions patients did or did not engage in help-seeking behavior for their unmet needs (Table 1).

The interviews were audio-taped with prior consent of each patient, and lasted between 40 and 84 minutes. Following patients’ preferences, interviews were conducted at the hospital, in the researcher's office, or at the patient’s house. During three interviews a third person was present; in two cases this concerned the patient's partner, in one case the patient’s mother.
Data analysis
All interviews were transcribed verbatim and stripped of identifying information. The data were collected and analyzed in an iterative process, led by the interim results of our data analysis and progress in theoretical insights (constant comparative method). The first author read all transcripts several times to familiarize herself with the data, and wrote down relevant code words in the transcripts. A preliminary code tree was created with the code words logically grouped into categories. The first author coded the interviews (open coding) according to the code tree, using the qualitative data analysis software ATLAS.ti. The code tree was adjusted if additional interviews led to new code words and categories. When data-analysis progressed, code words and categories were linked by axial coding to increase theoretical understanding [12]. During the entire phase of data analysis, content memos and methodological memos were made to gain further insight into the data and to make sound methodological decisions during the research process.

Table 1. Interview guide

<table>
<thead>
<tr>
<th>Start of the interview</th>
<th>You underwent treatment with high-dose chemotherapy and stem cell transplantation. I would like to discuss the time after the transplant with you. If you look back on that specific period of time, what was it like for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems</td>
<td>I would like to get more insight into the problems you have experienced in the months after the transplant. Could you tell me more about that? You just mentioned [problem]. Could you tell me more about that? What did/does the problem look like?</td>
</tr>
<tr>
<td>Prompt</td>
<td></td>
</tr>
<tr>
<td>Coping</td>
<td>I would like to know how you dealt with each problem. Could you tell me something about that? How did you cope with [specific problem]? How did it help you? Was the problem solved? To what extent?</td>
</tr>
<tr>
<td>Prompt</td>
<td></td>
</tr>
<tr>
<td>For unsolved or partly solved problems:</td>
<td></td>
</tr>
<tr>
<td>Care needs</td>
<td>You told you tried to deal with [specific problem] by [name coping strategy]. However, that did not / only partly solve your problem. Did you consider asking for help? Why (not)?</td>
</tr>
<tr>
<td>Care demands</td>
<td>Did you actually seek help? How?</td>
</tr>
<tr>
<td>Prompt</td>
<td>What kind of help? Could you tell me if and how this worked out for you?</td>
</tr>
</tbody>
</table>

Methodological quality
Several methods were used to ensure the validity and reliability of the research process. First, thick description improved generalizability of the results. Thick description refers to a rich and thorough description of the research setting and the participants. This enables determination of whether the findings are transferable to other contexts. Second, peer review was used to enhance credibility. The second author, experienced in qualitative research methods, two Clinical Nurse Specialists in the field of Hematology, and a hemato-
oncology nurse reviewed the content of the interviews and the results of the data analysis. The second author also read a selection of the interviews and reviewed the quality of the interviews and methodological aspects. The first and second author continuously discussed the individual steps in data collection and analysis. Finally, in a member check, a short summary of the interview and a description of the researchers’ interpretations were sent to the study participants, who were in turn asked to provide written feedback on the accuracy of the emerging interpretations and theoretical constructs [13].

Results

Twenty interviews were conducted. The sample comprised seven males and 13 females who were between five and 19 months after auto-SCT. Patients from six different hospitals participated. Sample characteristics are presented in Table 2.

Table 2. Sample characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male/female), n</td>
<td>7/13</td>
</tr>
<tr>
<td>Age in years at time of interview, mean (range)</td>
<td>52.3 (28-66)</td>
</tr>
<tr>
<td>Marital status, n</td>
<td></td>
</tr>
<tr>
<td>Living with partner</td>
<td>16</td>
</tr>
<tr>
<td>Living without partner</td>
<td>4</td>
</tr>
<tr>
<td>Diagnosis, n</td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>7</td>
</tr>
<tr>
<td>Multiple myeloma</td>
<td>13</td>
</tr>
<tr>
<td>Disease status, n</td>
<td></td>
</tr>
<tr>
<td>Remission</td>
<td>18</td>
</tr>
<tr>
<td>Progression (multiple myeloma)</td>
<td>2</td>
</tr>
<tr>
<td>Time after auto-SCT in months, mean (range)</td>
<td>12 (5-19)</td>
</tr>
<tr>
<td>Type of treating hospital, n</td>
<td></td>
</tr>
<tr>
<td>General hospital</td>
<td>7</td>
</tr>
<tr>
<td>Academic hospital</td>
<td>13</td>
</tr>
</tbody>
</table>

The following paragraphs firstly contain background information on patients’ physical symptoms and emotional concerns, necessary for interpreting the results. Subsequently, the factors contributing to patients’ help-seeking behavior will be discussed, ordered in
the following categories which were derived from our data: transition from symptoms to problems; preference to deal with problems themselves and with support from (close) relatives; problem categories and coping strategies; and motives for (not) bringing in professional help.

Physical symptoms and emotional concerns
All interviewed patients had had physical symptoms after auto-SCT, ranging from acute symptoms to longer-lasting symptoms such as neuropathy, impaired physical condition or fatigue. In addition, all patients acknowledged the emotional concerns related to having cancer and facing impairments after treatment. The severity of these concerns varied, as did the timing. For most patients, the time after diagnosis had been the most arduous, and the time after treatment completion was seen as a period for rebuilding and recovery. Others reported that the emotional processing had only just started after finishing active treatment.

Transition from symptoms to problems
A distinction between symptoms and problems became apparent from the interviews. If patients felt that a solution was desired for a specific symptom, that symptom was regarded as a problem. We identified three factors determining the transition from symptoms to problems. First, a symptom was only perceived as a problem if the symptom interfered with reaching a desirable goal. Patients’ goals varied from being able to take the dog for a walk to returning to work. If not hindered in reaching their goal, patients accepted remaining symptoms. P4 (female, 50 years, multiple myeloma) suffered from depressive symptoms, which interfered with her primary goal to return to work. She told about her decision to ask for anti-depressants: “After five weeks I was still stuck on negative thoughts, and felt out of control. I thought: I’m actually not doing well. I really didn’t want to stay home from work. I wanted the opposite: to build up [...] so eventually I went to my GP. I said [...] I just feel like I’m not going to make it.”

The transition of symptoms to problems was also determined by patients’ phase of recovery. During the acute phase after treatment, most patients were preoccupied with medical issues, by some literally described as ‘surviving’. Only when physical recovery had set in, they felt able to think about future goals. P19 (female, 34 years, Hodgkin lymphoma) had had many physical complications. She was, at 13 months post-transplant, still physically impaired, and said: “My main goal [now] is to generally feel better, that’s a goal. Yes, if I feel better, I will probably also be wanting those things [like work] again.” For some patients, emotionally dealing with what had happened only started after intensive treatment had ended. P13 (female, 49 years, multiple myeloma) told why the time after treatment completion was emotionally difficult for her: “During treatment [...] you are in the middle of it. You are just trying to survive and after the stem cell transplantation, you are back home. [...] You are quite isolated really and you have loads of time to think about that. [...] I got more interested in the disease [...] and then you actually are mourning, more or less, and you start to say goodbye to everything, because you won’t be there anymore. And yes, that’s quite depressing.” A third important factor for the transition of symptoms to problems was patients’ future perspective. All patients with multiple myeloma were aware that for them, treatment with auto-SCT had no curative intent: their disease would progress sooner or later. Most patients did not let this affect their way of life; they felt confident there would be other treatment options available. Two patients, however, faced a lack of future treatment options. They desired to spend their remaining time as effortless as possible and consequently set priorities, as P7 (female, 64
years, multiple myeloma) described: “The dentist [...] I have to go there. But then I’m thinking to myself: the other things [health] have to be good first. Because if there is anything wrong with that, I will think: leave it. I don’t want to suffer from pain [caused by dental treatment] those last years.”

Preference to deal with problems themselves and with support from (close) relatives
If patients experienced problems, they generally preferred to deal with these themselves rather than bring in professional help. They dealt with problems, for example their impaired physical condition, step by step, trying to extend their frontiers while adapting to their limitations. P17 (female, 58 years, non-Hodgkin lymphoma): “Despite you’re a mess, [...] all the time I had the willpower to remain busy. Just do my usual things, by myself, trying as much as I could. [...] And it could take me half an hour to clear the dishwasher, but then I would just rest for an hour.” In addition, most patients benefited from practical and emotional support from their network of (close) relatives. In some cases, patients preferred to process emotional problems alone, to spare their relatives and/or depending on their personal coping style. As P5 (male, 64 years, multiple myeloma) said: “I am an inhibited person and I process everything by myself. In general, no one can help me with that.” Patients who lived alone felt less able to discuss and normalize symptoms, and missed support during the acute phase after treatment. P3 (female, 57 years, multiple myeloma): “That you feel alone with your problems. [Interviewer: would it have made a difference if you could have shared this with someone at home?] P3: Yes, it would, because he/she would say: call the hospital. Or: you shouldn’t call. You constantly had to consider by yourself: should I call or not?”

Some patients looked for support from fellow patients via patient organizations or support centers, to gain or exchange information, to compare or normalize symptoms, and to exchange emotional support.

Problem categories and coping strategies
Patients applied different coping strategies for different problem categories. Problems which could not be solved, for example neuropathy, had to be accepted. Overall, the interviewed patients had been capable of doing that without professional help; they accepted that their remaining symptoms were part of the disease trajectory. As P20 (male, 50 years, multiple myeloma) said about the physical consequences of his disease and treatment: “I accept all of this as part of the disease. And I do not feel like it is a bad thing, [...] no, it’s a logical consequence of the fact that you have this disease.” And P14 (female, 42 years, multiple myeloma) about her neuropathy: “My feet, that numb feeling in my feet and toes, that’s such an odd feeling. [...] But if it doesn’t get worse than this, I say: fine.” For other problems, like fatigue, patients were told by their physicians that these would resolve in time. Some patients accepted this, others nevertheless tried to actively cope. Finally, some problems could be actively solved, like restoring one’s physical condition. Generally, patients aimed to deal actively with these solvable problems. P11 (male, 57 years, non-Hodgkin lymphoma): “They already said: it [physical recovery] will take about a year. [...] And I also felt: it got better, but I had to get back to work soon. And I just have an office job, but I had to get in better shape. And then I reached a point when I thought: I should go to the physiotherapist. Just to get stronger physically.”

Motives for (not) bringing in professional help
Patients did not hesitate to make an appeal to their physician for discussing physical problems or the need for medication. Further, several patients accepted the offer of participation in a group or individual rehabilitation program for improving their physical condition. Some
patients had not felt physically well enough to participate in any program or the offer was not made at the right point in time. About half of the interviewed patients preferred to recover by themselves; their major motive was their own capability to accomplish that.

Whereas patients perceived no barriers to discuss their physical problems and needs with their physician, emotional problems and needs were less often discussed. Emotional barriers like a stigma were not reported, however. Most patients had not experienced serious emotional problems or had been capable of dealing with these themselves or with help from their social network. For patients who had received professional mental health care, patients’ close relatives had played an important role in recognizing the problem, convincing patients to seek help, selecting a suitable psychologist or contacting the general practitioner. P13 (female, 49 years, multiple myeloma) described this as follows: “I don’t know. I kept thinking: I’ll work it out myself. No, someone else has to tell me. [Interviewer: Yes, so you already had thought about it before, that you could [ask for professional help], [...] if I understand correctly?] P13: Yes, but in those circumstances I always need people around me to get me going. That you [aimed at partner] find out for me where to find a psychologist.”

Knowledge about available care seemed to be an important condition for bringing in professional care. Most patients were well-informed regarding care options for physical problems. Available care options for emotional problems were less well-known. Although most patients had received information on available psychological services by their physicians or oncology nurses, some had not. Notably, all patients who proactively asked for professional care in dealing with emotional problems already had been in contact with professional counseling for emotional problems, either because of previous psychological problems or because of working in a mental health care environment. Finally, patients indicated that referral to a psychologist specialized in oncology would be preferable.

Discussion

The purpose of the present study was to explore patients’ needs and help-seeking behavior after treatment with auto-SCT, in relation to their problems. Patients’ personal goals, future perspective, and phase of recovery determined whether a symptom was experienced as a problem. Patients preferred to deal with problems themselves or with support from (close) relatives rather than bring in professional help. Finally, patients’ appeal for professional help depended on their coping strategies, social network, and knowledge of available care. A schematic representation of our main findings is presented in Figure 1.

Several factors seem to affect the transition from symptoms to problems. First, physical symptoms or emotional concerns were only perceived as problems if they interfered with a desirable goal. In their concept analysis of help-seeking behavior, Cornally and McCarthy [14] named, among other factors, the presence, cause, severity, and consequence of symptoms as contributing to problem recognition and definition. Our results highlight the importance of symptom consequences: symptoms transform into problems only if patients are impeded to reach goals important to them. Second, for both physical symptoms and emotional concerns, the successive phases of the recovery process appeared to be important. Patients were able to think about future goals only after the acute survival phase. This post-acute phase
led to new perspectives and goals (for example returning to work) and the corresponding need to deal with hindering symptoms (for example fatigue). Additionally, for some patients this time period was the first opportunity to deal with their emotional concerns. Both phenomena, the ability to think about future goals and dealing with emotional concerns, concur with the hypothesis of Bevans [15] that during and shortly after hematopoietic stem cell transplantation, the primary focus is on physical effects. When moving through the disease and recovery process and returning to daily activities, the impact on social and role function becomes clearer. Other studies also described the distinct trajectories of physical and psychological adjustment after cancer diagnosis and treatment completion, with 12-15% of patients reporting elevated distress after treatment completion [16-18]. Related is the third factor we identified as affecting the transition from symptom to problem: patients' future perspective. A limited future perspective led patients to set priorities, adjust their goals and thereby not perceiving certain symptoms as problems. This applied to both physical symptoms and emotional concerns.

![Diagram](image_url)

*Figure 1. Schematic representation of the main findings*

Patients in this study preferred to deal with physical problems and emotional problems themselves or with help from close relatives, concurrent with previous studies [10,11]. This points at cancer survivors' ability to resiliently cope with the consequences of their disease
and treatment [19] and concurrently highlights the importance of a well-organized support network, as shown previously [20,21].

Patients’ appeal for professional help was different for physical and emotional problems. Whereas patients did not hesitate to discuss physical problems and their need for medication with their physician, emotional problems were less often discussed. For both types of problems, however, our interview results pointed at the following factors determining the appeal for professional help: coping strategies, the availability of a social network, and knowledge of available care. Patients showed the ability to accept unsolvable problems, and tried to actively deal with solvable problems. Health care professionals had an important role in providing information about the nature of symptoms and whether or not patients could actively contribute to their recovery. The availability of a social network was helpful in recognizing the need for professional care, and in motivating and helping to actually obtain this care. Most patients had sufficient knowledge of physical care options. However, several patients reported a lack of knowledge regarding psychological care options, which could indicate a barrier for seeking professional care [7]. Notably, the interviewed patients did not perceive a stigma in discussing emotional concerns.

In line with Andersen and Newman’s framework [9] we found that need for care and enabling/impeding factors determine patients’ help-seeking behavior. However, time needs to be added to the framework: patients’ future perspective and recovery phase determine whether a symptom is experienced as a problem. Thus, the mere presence of a symptom does not lead to help-seeking behavior: interference with personal goals and issues related to time modify the relationship between symptoms and help-seeking behavior. The social network enabled patients to seek care, whereas a lack of knowledge of available care was an impeding factor.

From these findings, several suggestions can be derived on how to organize supportive care for patients with hematological malignancies undergoing treatment with auto-SCT. First, the abovementioned factors should be considered and supportive physical and psychological care should be organized accordingly. Instead of fixed format, we would argue that a highly flexible, personalized approach is indicated [22] in which support of patients’ self-reliance and need for professional care is well-balanced. Second, patients living alone and/or with a limited social network should be monitored closely and offered help in organizing support. Third, knowledge of available psychological help options could be enhanced [7,23].

Some limitations of this study have to be taken into account. To improve homogeneity of the study, we chose to only include patients treated with auto-SCT for hematological malignancies. Further, our sample may reflect a selection of patients without barriers to talk about their experiences, including emotional concerns. Also, our sample consisted of relatively few male patients. This may be of importance in interpreting the findings, since, for example, male patients have been shown to experience more emotional barriers for mental health service use [7]. We also should note that our results have to be interpreted in the context of the Dutch healthcare system: all Dutch citizens are obliged to have healthcare insurance. Finally, our study design enabled us to generate explanatory hypotheses, but testing these hypotheses in future research is an essential next step. An important strength of our study is that we included patients from six different hospitals across the Netherlands.
Taken together, specific factors determine patients’ help-seeking behavior after auto-SCT. The mere presence of a symptom does not lead to help-seeking behavior: this relationship is modified by interference of a symptom with personal goals and issues related to time. Patients prefer to deal with problems without professional care. Patients’ coping strategies, social network, and knowledge of available care determine whether they actually seek care. Our findings argue for a highly flexible approach to tailor professional care to patients’ needs. Support of patients’ self-reliance and need for professional care should be well-balanced. Patients with a limited social network should be monitored closely. Knowledge of psychological care options could be enhanced.

Conflict of interest

The authors have no conflict of interest to declare.
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