Leukemia Research 37 (2013) 496–502

Contents lists available at SciVerse ScienceDirect

Leukemia Research

journal homepage: www.elsevier.com/locate/leukres

Abducted by the illness: A qualitative study of traumatic stress in individuals with acute leukemia

Rinat Nissim[a,*], Camilla Zimmermann[a,b,c], Mark Minden[b,d,e], Anne Rydall[a], Dora Yuen[a], Ashley Mischitelle[a], Lucia Gagliese[a,b,f], Aaron Schimmer[b,d,e], Gary Rodin[a,b,g]

[a] Department of Psychosocial Oncology and Palliative Care, Princess Margaret Cancer Centre, University Health Network, Toronto, ON, Canada
[b] Ontario Cancer Institute, Princess Margaret Cancer Centre, University Health Network, Toronto, ON, Canada
[c] Department of Medicine, University of Toronto, Toronto, ON, Canada
[d] Division of Medical Oncology and Hematology, Princess Margaret Cancer Centre, University Health Network, Toronto, ON, Canada
[e] Department of Medical Biophysics, University of Toronto, Toronto, ON, Canada
[f] School of Kinesiology and Health Science, York University, Toronto, ON, Canada
[g] Department of Psychiatry, University of Toronto, Toronto, ON, Canada

ARTICLE INFO

Article history:
Received 16 September 2012
Received in revised form 1 December 2012
Accepted 11 December 2012
Available online 24 January 2013

Keywords:
Acute leukemia
Grounded theory study
Traumatic stress

ABSTRACT

Symptoms of traumatic stress are common in acute leukemia. The goal of the present qualitative study was to understand this traumatic stress, as perceived by patients. Participants were 43 patients with acute leukemia in Toronto, Canada. Participants were asked in serial interviews about their experience of diagnosis and treatment. A total of 65 interviews were analyzed utilizing the grounded theory method. Our findings provide insight into the traumatic experience of the diagnosis and treatment, as well as the initial psychological response to this trauma. Patients coped by surrendering control to the medical team, in whom they felt great trust. Patients also expressed a strong preference for limited information, with a preference to avoid discussions about overall prognosis. These results may inform interventions to relieve traumatic stress in this high risk population.

1. Introduction

Acute leukemia, a condition associated with considerable morbidity and mortality, is characterized by a sudden onset and a dramatic course, with a median survival of 6 weeks without treatment. Individuals affected require immediate hospitalization in order to initiate intensive induction chemotherapy. This initial treatment typically lasts at least 3 weeks and is usually associated with toxic effects including severe stomatitis, nausea, and bone marrow depression, with life-threatening pancytopenia-related symptoms such as bleeding, or sepsis.

Previous quantitative, questionnaire-based reports have highlighted the significant subjective distress associated with the diagnosis of acute leukemia and its initial treatment [1–3]. To further elucidate this experience, we are currently conducting a longitudinal mixed-method study to evaluate the pattern of physical and psychosocial distress in patients with acute hematologic malignancies throughout the treatment trajectory [4,5]. Analysis of the baseline quantitative data of 205 patients demonstrated that clinically significant symptoms of traumatic stress are common in acute leukemia, with 14% of 205 patients meeting DSM-IV-TR criteria for acute stress disorder, and an additional 18% meeting criteria for subsyndromal acute stress disorder [4].

Quantitative research on traumatic stress in this population allows questions to be answered regarding the frequency and correlates of this phenomenon. However, qualitative, interview-based studies may deepen our understanding of this experience by illuminating the meanings individuals attach to the experience of traumatic stress. In a previous qualitative study of 10 patients with leukemia or lymphoma, Xuereb and Dunlop documented the overwhelming sense of threat at the time of diagnosis [6]. Similarly, Koenigsmann [7] described in a sample of 12 patients with acute leukemia the shocking experience of diagnosis. Additional qualitative research is needed to more fully understand the patients' perspective and to inform interventions to prevent or alleviate distress [8].

In the present paper, we present a grounded theory analysis of qualitative data obtained from interviews with participants in a longitudinal study. This qualitative study was conducted to enhance our understanding of the traumatic experience of acute leukemia and its treatment, and of the factors that patients perceive

* Corresponding author at: Behavioural Sciences and Health Research Division, 9 Eaton North, Rm 235, Toronto General Hospital, University Health Network, 200 Elizabeth Street, Toronto, ON, Canada M5G 2C4. Tel.: +1 416 340 4800x3586; fax: +1 416 340 4739.
E-mail address: rinat.nissim@uhn.ca (R. Nissim).

0145-2126/$ – see front matter © 2012 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.leukres.2012.12.007

to diminish or enhance distress at different points of their illness trajectory. This information will inform therapeutic interventions to prevent and relieve distress in this high risk population.

2. Methods

2.1. Recruitment

This study was approved by the Research Ethics Board of the University Health Network; all participants provided informed, written consent. Participants were recruited from January 2008 to December 2011, from a larger pool of patients participating in a longitudinal, quantitative study of physical and psychological distress in patients with acute myeloid leukemia (AML) or acute lymphocytic leukemia (ALL) [4,5].

Potential participants for the quantitative study [4] were approached on an inpatient hematology ward or in a hematology outpatient clinic within one month of admission for treatment at the Princess Margaret cancer centre, University Health network. All participants were at least 18 years old, spoke and read English sufficiently to provide informed consent and complete questionnaires, and had no significant cognitive impairment, as demonstrated by a score of 20 or more on the Short Orientation-Memory-Concentration (SOMC) [9] test, administered by research staff at the time of recruitment. After providing informed consent, patients completed serial questionnaire packages for up to 18 months of follow-up. Medical and demographic data were obtained from the patients at the time of recruitment and extracted from their medical records.

Baseline data from the quantitative study were used to select a subset of participants for the present qualitative study. A quota sampling method [10] was used for this purpose to ensure that there were roughly equal numbers of older and younger men and women, and of interviewees with high and low scores on measures of psychological distress, including the Stanford Acute Stress Reaction Questionnaire [11], Beck Depression Inventory-II [12], and the CARES Medical Interaction subscale [13].

2.2. Interviews

Interviews were conducted by trained interviewers (members of the research team) at the convenience of the participants on the leukemia ward, in the clinic, or by telephone, if no other arrangement could be made. The interviews lasted up to 60 min, depending upon the participant's physical status and ability to engage in the interview. The interview protocol was semi-structured and discovery-oriented. The goal of the interviews, as explained to participants, was to understand the experience of living with acute leukemia and to complement the information gathered from the questionnaires of the larger study. Interviews began with an open-ended enquiry about the experience and understanding of the illness; probes then followed about illness-related stress, specific stressful experiences, the experience of treatment from diagnosis to current stage, support needs, sources of support, coping strategies and relationships with significant others. The interview also included probes on participants' experience of their relationships and interactions with their health care providers, and how they have changed throughout the illness and treatment trajectory. Follow-up interviews maintained a discovery-oriented protocol but also re-visited any themes that were discussed in previous interviews.

2.3. Analysis

Interviews were audio-recorded and professionally transcribed verbatim, and the data was managed with the qualitative software program Nvivo9. Meanings contained in transcripts were conceptualized into categories. The applicability of any given category to the text as a whole was checked through an inductive analysis of subsequent and preceding text in the same transcript, as well as in other transcripts [14,15]. This recursive process proceeded until theoretical saturation was reached, demonstrated by a category model that encompassed the variations of experiences [16].

3. Results

3.1. Sample

Eighty-one patients were invited to participate in a series of interviews. Of those, 45 agreed to participate, but data obtained from 2 patients was not included in this analysis due to faulty interview recording. The participants ranged in age from 21 to 71 years, with a median age of 47, and 18 (42%) were female (see Table 1 for additional characteristics of the sample). At the point of analysis, 24 participants were interviewed once, 16 twice, and 3 three times, leading to a total of 65 interviews.

Table 1
Characteristics of study participants ($N = 43$).

Sample characteristics	Description
Gender (male)	25/43 (58%)
Age (years) (mean [SD]; range)	47 (12.9); 21–71
Marital status	
Married or common-law relationship	31/43 (72%)
Separated/divorced/widowed	5/43 (12%)
Single	7/43 (16%)
Canadian born	29/43 (67%)
Education	
High School or Less	5/43 (12%)
College/University	38/43 (88%)
Disease type	
AML	35/43 (81%)
ALL	8/43 (19%)
Treatment status at time of 1st interview	
Induction/re-induction	6/43 (14%)
Consolidation/intensification	27/43 (63%)
Maintenance	4/43 (9%)
Bone marrow transplant	5/43 (12%)
Supportive care	1/43 (2%)

3.2. Findings

Our data collection included patients' narratives describing their experience throughout the treatment trajectory of acute leukemia from the time of diagnosis to the time of the interview. We focus in this paper on the analysis of the patients' narratives about the initial stage of diagnosis and hospitalization for induction chemotherapy (an analysis of narratives about later stages will be described in a subsequent paper). All participants underwent induction chemotherapy immediately following diagnosis, and all were asked in the study interviews to reflect about their current ($n = 6$) or previous ($n = 37$) experience of diagnosis and inpatient induction treatment. The mean time from the initiation of induction chemotherapy to the point of the first interview was 3 months (with a range of 17 days to 8 months). We did not identify any systematic differences in qualitative themes based on the timing of the interview in relation to diagnosis and induction therapy, or on other demographic or medical factors (e.g., gender, age, or disease type).

Our findings capture the experience of diagnosis, hospitalization and immediate treatment with two inter-related categories: the first describes the initial traumatic experience of diagnosis and hospitalization, and the second delineates the process of psychological response to the inpatient induction treatment.

3.3. The initial trauma: "Abducted" by the illness

Participants described the diagnosis of acute leukemia as dramatic and shocking, a "whirlwind" or "like getting hit by a truck that you didn't see coming." The diagnosis often occurred without any major prodromal symptoms, so patients had not suspected that they were ill. Thus, "out of the blue," they learned that their lifespan had been potentially reduced to as little as several weeks, and that immediate treatment was required to save their lives. As one participant remarked: "I went from seemingly healthy and feeling pretty good about everything in my life, into induction in twelve hours."

The diagnosis was often delivered in an emergency department setting to which participants were directed by their family doctor following an alarming blood test. It was typically delivered by a physician whom they had just met, and often in a manner that