



Research paper

The importance of meaningful activity in people living with acute myeloid leukemia

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ARTICLE INFO

Keywords:

Acute myeloid leukemia
Rehabilitation
Functional capacity
Qualitative research
Meaningful activity

ABSTRACT

Purpose: The symptom burden of acute myeloid leukemia (AML) and its treatment can accelerate physical deconditioning and impair mobility and quality of life. In the present study, we explore the subjective experience of functional capacity in people living with AML.

Methods: A secondary qualitative analysis was performed on a subset of interviews (n = 21) obtained from an observational cohort study of people with acute leukemia. Conventional content analysis was employed to identify key themes and concepts.

Results: Participants valued their physical function to the extent that it was required to pursue personally meaningful activities and interests. We identified Meaningful Activity as an overarching goal of participants. Three interrelated themes captured the obstacles participants reported facing when attempting to realize this goal: Compromised Body, Threatened Identity, and Shrinking World. Adaptation was common across themes, representing the strategies employed to overcome such challenges. Themes were consistent across participants, despite the variability in disease states at the time of the interview.

Conclusions: Dynamic interactions between physical, psychological, and environmental factors affect the pursuit and achievement of meaningful activity among people living with AML. It may be important to consider personal incentives when designing interventions for physical rehabilitation in this patient population.

1. Introduction

Acute myeloid leukemia (AML) is a life-threatening hematological malignancy with a rapid onset and an unpredictable clinical course [1]. This disease is curable in up to 40% of affected adults under the age of 60 years, but in as few as 5% of adults over the age of 60 [2,3]. Curative treatment for AML typically involves intensive induction chemotherapy, which requires hospitalization for four to six weeks. Complete remission post-induction is followed by conventional chemotherapy (i.e., consolidation therapy); in some cases, stem cell transplantation may be indicated [1,3].

The symptom burden of AML and the prolonged bedrest and hospitalization associated with its treatment can accelerate physical

deconditioning and adversely affect participation in activities of daily living and quality of life (QOL) [4–8]. The recent shift to deliver consolidation therapy in outpatient rather than inpatient settings may help to diminish the risks of deconditioning and functional limitations [9–11], and benefit QOL in people with AML [12]. However, little is known about these potential benefits from the patient perspective and the rehabilitative needs associated with outpatient management of AML.

The physical and functional wellbeing of people living with life-threatening disease such as AML is not well understood. Such knowledge may inform rehabilitative treatment approaches to support people with AML across the disease trajectory. The purpose of this study was to explore the subjective experience of functional capacity and activity

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participation in people living with AML. We aimed to explore responses to changes in functional independence, along with perceived incentives and barriers to rehabilitation in this population that may be of particular import during outpatient management of the disease. Such information could inform rehabilitative approaches to facilitate recovery among people with AML.

2. Methods

2.1. Participant selection

A secondary analysis was performed on data obtained from a 5-year, multi-method, observational prospective cohort study of physical and psychosocial functioning of people with acute leukemia [13, 14]. A subset of participants was invited to participate in a qualitative study to explore their experience of the disease and treatment [15, 16]. This study received ethical approval by the University Health Network Research Ethics Board (REB #06-0387-CE). All participants provided written informed consent to participate in the qualitative interviews. Transcripts of interviews with participants diagnosed with new-onset or recently relapsed AML were selected for inclusion in this secondary analysis.

2.2. Materials

2.2.1. Interview guide

Qualitative interviews were conducted by trained interviewers by telephone or face-to-face in ambulatory clinics or an inpatient unit. The semi-structured interview guide comprised discovery-oriented questions to elucidate the subjective experience of acute leukemia during intensive treatment and the transition to ambulatory care. Interview questions addressed stress and coping, personal relationships, and navigating the healthcare system. Interviews were audio-recorded and transcribed verbatim. Transcripts were managed and coded using NVivo 10 software (QSR International, Burlington, MA, USA).

2.2.2. Participant characteristics

Sociodemographic characteristics were collected using a self-report questionnaire completed by study participants. Medical and treatment characteristics were obtained from patient charts. Observer-rated performance status was assessed by a clinical research coordinator using the Karnofsky Performance Status Scale (KPS) [17]. The KPS is a widely used tool in oncology settings to assess capacity for self-care and participation in daily activities.

2.3. Qualitative analysis

The present findings were obtained from a secondary analysis of the qualitative interview transcripts. We first assessed the quality and appropriate fit of the primary data for this secondary analysis [18]. Although the original interview guide did not enquire explicitly about mobility and physical functioning, there was substantial discussion of these topics in the transcribed interviews. Participants spoke in detail about the experience and meaning of mobility and physical function during the course of their illness. We then employed conventional content analysis methodology [19] guided by interpretive description [20] to address our research questions.

An inductive approach was employed. The coding framework was developed in an iterative process by two study authors (AD and GG), and included codes related to immobility, mobility, self, identity, environmental factors, and coping processes. All data were coded by two independent coders (AD and GG). Rigour was enhanced using trustworthiness techniques recommended by Lincoln and Guba [21]; including the use of field notes, peer debriefing, and a comprehensive audit trail to document decision-making processes in coding and analysis. Coding discrepancies were resolved through discussion. We

Table 1
Participant characteristics (N = 21).

Participant Characteristic	Frequency (%)	Mean	SD	Range
Age (years)		49.27	12.78	21–71
Sex				
Male	17 (81.0%)			
Female	4 (19.0%)			
Married/common-law	14 (66.7%)			
Education				
High school or less	3 (14.3%)			
College/university education or above	18 (85.7%)			
Employment status				
Employed	14 (66.7%)			
Retired	4 (19.0%)			
Unemployed/on disability	3 (14.3%)			
Country of birth				
Canada	15 (71.4%)			
Other	6 (28.6%)			
Ethnicity				
Caucasian	17 (81.0%)			
Other	4 (19.0%)			
Disease state at time of interview				
Undergoing induction, consolidation, or allogeneic bone marrow transplantation for AML	6 (28.6%)			
Undergoing re-induction chemotherapy or consolidation for relapsed disease	2 (9.5%)			
Relapsed or refractory disease	9 (42.9%)			
In remission off-treatment	5 (23.8%)			
Karnofsky Performance Status (KPS)		77.6	11.4	60–100

adhered to the comprehensive COREQ guidelines for study reporting in qualitative research [22]. Major and minor themes emerged from the manifest and latent content and were assigned labels by the study authors. We present the themes and concepts with illustrative quotes and a conceptual model.

3. Results

3.1. Participant characteristics

Transcripts of the initial interviews with new-onset ($n = 17$) or recently relapsed ($n = 4$) people with AML who participated in the original study were included in this secondary analysis ($N = 21$). Interviews were conducted within a mean of 108 ± 34.5 days of admission to hospital for the induction/re-induction treatment phase (range = 27–179). We report demographic and disease characteristics of the study sample in Table 1. Briefly, participants were predominantly male (81%) with a mean age of 49.3 ± 12.8 years (range = 21–71). The majority of participants were born in Canada (71%), identified as Caucasian (81%), and reported English as their primary language (81%). Overall, participants were able to engage in self-care with minor impairment in daily activities and active work.

3.2. Findings

Our findings highlight perceptions of mobility and the experience of physical functioning in people living with AML. The inductive analysis of the manifest and latent content of the interviews identified an overarching theme and goal of Meaningful Activity. Three interrelated themes captured the challenges participants faced when attempting to realize this goal: Compromised Body, Threatened Identity, and Shrinking World. The theme of Adaptation was common across these interrelated concepts, representing participants' responses to the challenges posed by the altered Body, Identity, and World, and the strategies they utilized in order to achieve the goal of Meaningful Activity. These themes were consistent across participants, regardless of their

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