

Finding new bearings: a qualitative study on the transition from inpatient to ambulatory care of patients with acute myeloid leukemia

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Received: 3 January 2014 / Accepted: 21 March 2014 / Published online: 5 April 2014
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Abstract

Purpose Treatment of adult acute myeloid leukemia (AML) is intensive, with induction treatment initiated in an inpatient setting and subsequent consolidation therapy often conducted in an outpatient setting. The purpose of the present qualitative paper is to provide insight into the experience of patients in the transition from inpatient to ambulatory care.

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Methods Participants were 35 AML patients who were interviewed about their experience of the illness and treatment. Utilizing the grounded theory method, we describe the adjustment of participants to the transition to ambulatory care. **Results** As outpatients, participants described adjusting to the intensity of ambulatory treatment and to the need to assume greater responsibility for their care. They also expressed a growing desire to understand their long-term care plan, compared to their preference to focus on the present prior to discharge, and they were struggling to construct a new sense of identity.

Conclusions AML patients are now leaving acute care settings sicker and earlier. Considering their perceptions can inform interventions to facilitate adjustment during the transition to outpatient care.

Keywords Acute myeloid leukemia · Qualitative interviews · Care transitions · Adjustment · Health care delivery

Introduction

Treatment of acute myeloid leukemia (AML) typically begins within a few days of diagnosis, with the initiation of inpatient induction chemotherapy lasting 25–40 days, followed by intensive consolidation chemotherapy for a total of 3–4 months. Although consolidation chemotherapy is as intensive as induction therapy and has traditionally been given to inpatients, it is being increasingly administered on an outpatient basis. This shift is triggered by practical considerations regarding healthcare costs and limited inpatient resources. However, outpatient-based therapy requires frequent and long ambulatory visits for treatment, ongoing transfusion support, close monitoring for complications such as infections, and, for

patients living at a distance, coordination of care with local care providers [1].

The outpatient approach to consolidation treatment for AML has been reported to reduce costs [2] and to be safe and feasible in younger patients [3] and in those over the age of 60 [1]. This view is based on evidence from non-randomized studies that assessed rates of readmissions, infections, physical burden, intensive care (ICU) admissions, patient compliance, and mortality [4]. The shift of consolidation therapy to the outpatient setting is also predicated on assumptions regarding patients' preferences and satisfaction with treatment, quality of life, and ability to resume independent functioning and reintegrate into society [4]. However, there have been no previous studies that have examined patients' perspectives or satisfaction with treatment, and the psychosocial implications of the shift to outpatient-based therapy remain unknown [5]. A qualitative, interview-based, study would be a valuable starting point for exploring assumptions about the psychosocial consequences of early discharge, because it can provide insights into the personal experience and views of patients undergoing treatment [6, 7].

Previous qualitative studies that included AML patients provide some information on the experience of these patients at different time points, such as at diagnosis or at the end of treatment, and demonstrate the benefit of qualitative research in illuminating patients' psychosocial needs. A recent qualitative investigation [8] of the end-of-treatment experience of adult leukemia and lymphoma survivors revealed that at this phase, these patients tended to feel abandoned, unsupported and unprepared, and faced practical problems utilizing support resources and gathering information. Studies focusing on the stage of diagnosis and initial treatment [9–11] have elucidated the overwhelming sense of threat experienced by these patients. In our previous report [9], we described how the stage of diagnosis and initial inpatient induction therapy was perceived by 43 patients with AML or acute lymphoblastic leukemia (ALL). Our findings demonstrate the perceived trauma of the diagnosis and the immediate initiation of treatment, as well as the attempts made by patients to respond and cope with this trauma. For example, patients described a preference for minimal and gradual information-giving about their treatment and prognosis while hospitalized, in order to avoid feeling overwhelmed.

The present qualitative paper describes patients' accounts of the experience of completing their initial inpatient induction treatment; the experience of this transition through qualitative research gives voice to the needs and concerns of leukemia patients [7, 11] and can inform further research as well as the development of interventions to facilitate the adjustment of patients during transitions of care.

Methods

Recruitment

This study was approved by the Research Ethics Board of the University Health Network; all participants provided informed, written consent. Participants for the present qualitative study were recruited from a pool of 249 patients participating in a longitudinal, quantitative study of physical and psychological distress in patients with AML or ALL [12, 13]. Participants for the quantitative study were recruited on an inpatient hematology unit or in a hematology outpatient clinic within 1 month of admission for treatment at the Princess Margaret Cancer Centre, University Health Network, a large, comprehensive cancer center in Toronto, Canada. 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. Recruitment for the qualitative study utilized a quota sampling method [14] to ensure that there were roughly equal numbers of older and younger men and women and of interviewees with high and low scores on baseline measures of psychological distress [9].

Interviews

The interview protocol was semi-structured and discovery-oriented, designed to understand the experience of patients from diagnosis and throughout treatment. Interviews began with an open-ended enquiry about the experience of the illness; specific questions then followed, such as: "What is your experience of your treatment?"; "How is your relationship with the medical team?"; "What kinds of differences are there, if any, between the inpatient floors and the outpatient clinics?"; and "What was your understanding of the medical information that was given to you?" 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. In order to understand how their experience evolved over time, whenever possible, we attempted to conduct at least two interviews at different time points with each participant.

Analysis

Interviews were audio-recorded and professionally transcribed verbatim, and the data was managed with the qualitative software program Nvivo9. The study utilized the grounded theory method, as modified for psychological inquiry by Rennie [15, 16]. 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. This recursive process proceeded until theoretical saturation was reached, demonstrated by a category model that encompassed the variations of experiences.

Results

Sample

Interviews were completed with a total of 35 patients, of whom, 28 were diagnosed with AML and seven were diagnosed with acute promyelocytic leukemia (APL), a subtype of AML. The participants ranged in age from 26 to 71 years, with a median age of 47, and 13 (37 %) were female. At the time of their first interview, 29 participants were in remission, five were recently diagnosed or recently relapsed, and one participant was receiving supportive care. Although we attempted to interview all participants at least twice, most participants (21; 60 %) were only interviewed once, due to a number of barriers (e.g., participant willingness, treatment complications, loss to follow-up, death), and only 14 participants were interviewed more than once, leading to a total of 52 interviews. Most frequently, interviews were conducted with patients undergoing outpatient consolidation therapy, with some participants being interviewed after their consolidation treatment was completed, or when admitted for a stem-cell transplant (see Table I for additional characteristics of the sample population).

Findings

Our findings describe the transition to ambulatory care from the patient perspective. The findings are organized around the core category of Finding New Bearings. This category captures the experience of ambulatory care as “a new, uncharted territory” that one needed to get familiar with and navigate and that required new coping strategies. This effort to adjust to ambulatory care was doubly challenging, because it took place during intensive chemotherapy, which was physically and mentally draining, as one participant described:

“Nobody knows really what it’s like. Where you’re constantly climbing a hill, it’s constant work. You have these chemo drugs in you, and then drugs for the side-effects. So you’re so drugged up; it’s like carrying a knapsack full of bricks everywhere. You’re just constantly carrying that weight. So it’s fatiguing and it’s tiring mentally too.” [Participant #5014]

The core category, Findings New Bearings, subsumes four interrelated subcategories: (1) Readjusting Expectations—realizing the full impact and intensity of consolidation therapy,

Table I Sample characteristics ($n=35$)

Sample characteristics	Description
Gender (male)	22/35 (63 %)
Age (years) (M [SD]; range)	49 (12.3); 26–71
Marital status	
Married or common-law relationship	26/35 (74 %)
Separated/divorced/widowed	5/35 (14 %)
Single	4/35 (12 %)
Canadian born	24/35 (69 %)
Education	
High school or less	4/35 (11 %)
College/university	31/35 (89 %)
Time from first treatment to first interview [days] (M [SD]; range)	109 (38.6); 17–249
Time from first treatment to third (last) interview [days] (M [SD]; range)	335 (220.8); 90–706
Time between interviews [days] (M [SD]; range)	207 (163.3); 63–497
Treatment status at time of first interview ($n=35$)	
Induction/reinduction	5/35 (14 %)
Consolidation	22/35 (63 %)
Maintenance	4/35 (11 %)
Transplant	3/35 (9 %)
Supportive care	1/35 (3 %)
Treatment status at time of second interview ($n=14$)	
Reinduction	2/14 (14 %)
Consolidation	1/14 (7 %)
Maintenance	6/14 (43 %)
Transplant	5/14 (36 %)
Treatment status at time of third interview ($n=3$)	
Maintenance	2/3 (67 %)
Treatment completed	1/3 (33 %)

which participants tended to minimize prior to discharge; (2) A Sudden Shift of Responsibility—transitioning from a setting in which all aspects of care were taken care of for them to a setting in which participants were required to assume greater responsibility for their care; (3) Understanding the Long-Term Plan—during their inpatient stay, participants focused on getting through their induction therapy, while discharge brought new information needs and a growing desire to understand the long-term care plan; and (4) Reconstructing a Sense of Identity—going back home marked the beginning of a struggle to redefine one’s sense of self and ability to resume previous roles or adopt new ones.

Readjusting expectations

As inpatients, participants were focused on surviving their immediate inpatient treatment and getting to the point of discharge. They tended to automatically associate discharge with the notion of “recovery,” and their expectation was that

transitioning to ambulatory care meant that the worst was behind them. Therefore, despite being provided with information about their post-discharge therapy, participants felt surprised by the intensity of consolidation therapy and the impact it had on them:

“I wasn’t prepared. I thought, ‘well, this is outpatient, it’s going to be four days of chemo, one day of hydration, it will be a walk in the park.’ But with those infections lying there, waiting to come back, I said to my girlfriend, ‘jeez, this stuff, it must be more powerful, why would they give me this as an outpatient? I feel worse than I did when I was in the hospital.’” [Participant #5009]

When asked what could have helped them be better prepared, participants discussed a number of information barriers that could have been addressed. Some described feeling too overwhelmed to process the information about consolidation therapy that they were given pre-discharge:

“You read it but you don’t really take it in...like there were things that were said by the doctors that my wife heard and remembered and I didn’t get. I think you can only deal with so much at a time.” [Participant #5041]

Others felt that although their medical team did their best to provide information, it was difficult to comprehend the full meaning of the information they were given due to the complexity of the illness and its treatment. As one participant described, “this is not like breaking a knee, you cannot understand or relate to it.” Another said, “it was explained to me, but the fact was that I couldn’t relate to it. There was nothing that I could really understand.” Lastly, some commented that written materials were too general and that additional discussions about the details of the consolidation therapy, explained in lay terms immediately before or after discharge, would have been more helpful.

Subsequently, participants described readjusting their expectations of what consolidation therapy entailed through repeated discussions with their medical team while undergoing this treatment. In particular, they reported feeling reassured when they had an opportunity to discuss the side-effects of the therapy with the ambulatory care team. Such discussions enabled them to “put the pieces of a puzzle together” and helped them readjust their expectations of the impact of the consolidation treatment and reframe their experience of its side-effects as typical, rather than as indicative of a problem:

“Once they explained to me what scrambled eggs I had up in there for brains, then I understood why I was having frustration with myself with doing things. I don’t forget. I have a good memory and I was forgetting

conversations when people saw me...But once it was explained, then that was okay.” [Participant #5108]

A sudden shift of responsibility

As inpatients, participants were able to relinquish control of their care to the medical team. They had care providers meeting them in their inpatient room, monitor their symptoms daily, and book procedures or order prescriptions or services for them. The transition to ambulatory care required participants to assume greater responsibility for their care, to monitor symptoms, and to coordinate many aspects of their treatment on their own. As outpatients, they were required to adjust to frequent and long ambulatory visits during which they waited for, met with, and received care from a variety of care providers. They described learning to navigate these services and gradually gaining the skills and confidence to do so. The initial challenge of navigating their care on their own was multilayered, starting with the basic challenge of finding their way in a large center. As one participant described, “In terms of getting the information and appointments, that was really hard for me at this hospital, figuring out all the floors I’ve got to go to, where I’ve got to go.”

Participants slowly learned what each setting provides and how it runs and what services they needed to follow up with and when. It was, at times, overwhelming for them to deal with multiple settings and to meet and communicate separately with consecutive new sets of care providers. It was also anxiety-producing for them to recognize that “There’s too many people involved and there are too many places where things can completely mess up.”

The requirement to take over care responsibilities at discharge was especially challenging for participants who lived at a distance from the cancer center. These individuals found that they had to divide their care between clinics at the cancer center and those closer to their home. This organization of care required participants to learn how to relay complex information to their local care providers and to follow up on communications between settings, to ensure that they were accurate and complete. They also learned who and when to contact when complications occurred and to “take action myself to get things done.” At times, the need to coordinate their complex care across settings led to a delayed response to medical problems and admissions to a local hospital:

“You’re just more relaxed when you’re an inpatient because nobody’s going to wait for your haemoglobin to get so low that you’re feeling so terrible. I got a really bad headache from the low haemoglobin and I had to go into emergency actually to stay for three days. They got me my blood by the next day, thank God, because I just was like, ‘I can’t wait until my next transfusion.’” [Participant #5233]

When feeling lost in the maze of their complex care, participants were extremely grateful when members of the medical team at the cancer center responded immediately by telephone or e-mail to questions about symptoms that developed at home or to problems in navigating services:

“Honestly, when I consider how busy my doctor must be, I can’t say enough good [things]. I greatly appreciate what he does for our family. Even last week I realized that on my med cycle I needed a prescription for Sunday night and I forgot to call in and get some. I finally called here to the hospital, found out I didn’t have any refills, and I sent him off an e-mail. Within five minutes I had an e-mail back, ‘Give me your dosages, we’ll make sure that you have your prescriptions,’ and he had it all worked out.” [Participant #5161]

Lastly, in addition to assuming greater responsibility for their medical care, the transition to ambulatory care also meant a shift in the responsibility of locating and coordinating support services. As inpatients, participants had “a stream of people coming in” to their inpatient room to offer and coordinate different services, such as social work, spiritual care, or occupational therapy. As outpatients, participants were required to seek out support services within and outside the cancer center on their own, and they found this confusing and challenging:

“I know that they say there’s services out there that can help you with things, but when you’re so tired that you can’t do what you need to do around the house, to sit there and spend time on the phone narrowing down where you need to go to get help, I know it sounds like I’m whining, but it’s exhausting to think. I know I need to get some help, but I’ve got to get on the phone. Well, I’ve got to find out first of all where to call and then [call]. I know that there are handbooks there so I need to spend more time looking through the handbooks and figuring out where I can get help and support but when you’re tired, when you’ve got a disease that tires you so completely, it’s hard to go after those services.” [Participant #5235]

Understanding the long-term plan

The focus of participants during their inpatient stay was on surviving this phase, as one participant described, “You just think ‘I’m gonna beat this, I’m gonna be positive,’” and they avoided “taking in too much information” about their diagnosis and treatment. When the ambulatory phase of their treatment began, participants started to contemplate their long-term treatment plan and their overall prognosis, and wished to be

“prepped with what I’m going to be going through,” and understand “what’s coming down the road for me.”

“There’s this whole concept of knowing what’s coming next and having a little bit more visibility into what it means to me, in terms of the treatment plan and the side effects, and all these different things, and I’m not sure they can give it to me because I’m not sure they know. But if I could change one thing, it would be having a lot better understanding of, ‘here’s what’s gonna happen over the next twelve to eighteen months.’” [Participant #5041]

Participants were grateful when their medical team took the time and trouble to explain the treatment plan and answer their questions about “the big layout from start to finish.” Some identified barriers that hindered such discussions, the main one being the large patient volume and workload in the ambulatory clinic where, as one participant put it: “they are under-staffed and patients are over-sick,” thereby limiting the time participants had with their medical team:

“It’s hard to get questions answered, the doctors are in a rush. Trying to get questions answered, that’s the biggest problem I have...They do spend a very, very small amount of time with me...it comes down to just lack of doctors, because they are running from the exam room that I’m in to the next exam room where somebody else is waiting to see them for five minutes. So you can be asking questions and they’re trying to get out the door. It’s a bit frustrating for my part. Like, they know what’s going on because they deal with it every day, but this is my first time. And everybody says, ‘oh look it up on the internet.’ It’s not specific enough on the internet; I want to know what my situation is. That’s my biggest frustration...they’re doing a great job, don’t get me wrong on that, but - I’m here, I’m alive, hello! I have questions!” [Participant #5062]

In addition, some questions were left unasked because the desire of participants to know was balanced by their fear of finding out the answer. This barrier was typically mentioned in regard to the question of overall prognosis, as one participant described, “One day I think, possibly, five years from now, this could be over and I could be working...but I have a feeling that’s not realistic. And I’m afraid to ask the questions to the doctor about whether that is realistic...So when I think of the future, it’s a blank...I cannot picture the future.”

Reconstructing a sense of identity

Although the completion of inpatient induction therapy meant that participants were able to return to their familiar surroundings at home, nothing there seemed “normal.” Participants

were struggling at this time to find their bearings in terms of their sense of self, current roles, and relations to others. They were beginning to ask themselves questions such as: “what’s life gonna be like now?” or “will my life ever be normal?” One participant described: “[In the beginning] the biggest challenge was fighting it so I would reach remission. But now, the biggest challenge is adapting to the fact that I’ve had it.”

First and foremost, participants needed to adapt to their current “interim situation.” Many spoke about the literal difficulty of recognizing themselves in the mirror. One participant said, “When I look at myself in the mirror, I don’t see myself in the same way. I’m this sallow-cheeked, hairless, eyebrowless person. I sometimes look in the mirror and go like, ‘Who is that?’” Another said:

“When I look in the mirror I see a skeletal face because my eyes have sunken in and I’ve lost weight on my face. I look at myself and I say ‘Jesus,’ and I remember when I first went home my son didn’t want to look at me because I had no hair. I was thinking: ‘wow, this is only the beginning.’” [Participant #5065]

Participants also spoke about the difficulty of being at home while being so sick and dependent, “unable to do much for myself” and having “very little control over my life.” In a way, being back at home highlighted the contrast between life before and after the diagnosis, as one participant noted: “I’m not part of my previous world any more. I’ve been removed, sidelined.” Another remarked: “Once you’re home, there’s so much you can’t do. I can’t step right back into my life. I need help. I need help with basic day-to-day chores because I don’t have as much energy as I did.”

Adjusting to life post-discharge involved learning to rely on others, a state of dependency that sometimes undermined their identity as an independent and productive individual. As one participant described, “It’s frustrating to watch my wife do everything. I have two kids and I feel like my wife [has] become a single mom with a third kid now because of having to do everything.” Another commented:

“Now my husband will come home and he’ll switch a load of laundry over or whatever because I just haven’t got back downstairs to do it. I find it a bit frustrating that I’m home all day, doing nothing and I’m getting nothing done. I feel badly for my husband. He’s never said a word. He just plugs along and does what he needs to do, but my feeling in the world or in life is that, if I’m home all day, I should be able to keep the house clean and do the laundry and have dinner ready for the family when they get home.” [Participant #5209]

In addition, once back at home, participants began to struggle with emerging questions about their identity post-cancer. The construction of a future identity was influenced by

a new sense of uncertainty. As one participant described, “There’s all that uncertainty ahead of me. I know what’s behind me, and in front of me, I don’t know.” Another noted:

“I shed very few tears when I was first diagnosed, I said to my husband, ‘We can’t live on coulda, shoulda, woulda street. This is the diagnosis; this is what they tell me is going to happen. Crying is not going to solve anything. Now we have to fix it.’ But, the last few days at home, you think, ‘Okay, I never saw this coming, what else might be going on inside me that I might have to deal with? It’s like, am I going to get any other surprises?’ And, I think that has played on my mind the last couple [of] days, where it never did before. Now it’s like, okay, you let me down on this one. My body has let me down. And, that I haven’t thought about before.” [Participant #5033]

This new sense of uncertainty made participants question their ability to resume previous goals and roles. As one participant said, “I’m beginning to wonder if people who have leukemia ever have a totally normal life again... And I really want to go back to work. But there’s just so many unknowns, that it’s just overwhelming.” For younger participants, the sense of uncertainty led to questions about the ability to achieve important life milestones:

“What I worry about is how I’m going to, at my age, how am I going to meet someone and build a future with someone. I mean you can’t really promise the person that you may [be] there for a very long period of time. I don’t think it’s really fair to meet someone and be burdening them with your difficulties. So that’s the quandary I’m facing.” [Participant #5067]

Those who were already established in terms of relationships and careers also experienced a need to reconstruct their identity. This shift was informed by “a change of focus” and a new sense of “gratitude”, “humility,” and of life priorities. For many participants, the diagnosis served as “a wake-up call” and helped them rethink “what’s important and what’s not”:

“[Pre-cancer] I was pretty driven; I was on track to getting promoted. In terms of going back to my career now, I totally plan to do that, but I’m not so sure I want those same driven type goals anymore. I’m not sure that those are necessarily what I want to do. I look at life in terms of time, and I just sometimes think that those pursuits, those goals have cost me time with my family, my kids, friends, other things, and I start to question now is that what I really want to do? Do I want to be that career driven? And I’m not so sure I do anymore. I don’t think I care so much about that.” [Participant #5161]

Discussion

Although the shift to outpatient-based therapy for AML has been reported to be safe and feasible [1], its psychosocial implications are unknown. The present qualitative study identified and explored the transition from inpatient to outpatient care as a pivotal point of psychological adjustment for AML patients and enhances our understanding of the complex experience of transitions in care. We found that patients struggled to find their bearings during this transition and to reorient themselves to their new situation and future plans, while still being very sick and dealing with significant side-effects. Our findings indicate similarities between the impact of the transition to ambulatory care in the context of AML and that of other transitions involving a step-down in the level of care. For example, “transfer anxiety” or “relocation stress” has been identified in patients who were discharged from an ICU to a general ward [17], and the “crisis of discharge” was described in stroke survivors when they moved home from acute care [18].

The immediate task that participants described during the transition to outpatient care was to readjust their expectations regarding the ambulatory phase and their level of physical well-being during this phase. This is similar to the experience described by McKinney and Deeny [19] of patients discharged from an ICU. In their study, some patients reported feeling anxious and depressed because they were not as well as they perceived they should be. Our study illuminates some of the information barriers patients experienced. It is important to develop feasible learning tools that address these barriers and to assess patient understanding and recall of the expected intensity and side-effects of the ambulatory phase, in order to mitigate the anxiety that may arise from unrealistic expectations.

The transition to outpatient care also required patients to assume greater responsibility for their own care. In a previous report [9], we described the tendency of patients during their inpatient stay to relinquish control to the healthcare professionals. The present paper demonstrates the crisis that is associated with the need to “shift gears” at discharge and to learn how and when to access and coordinate care. This is consistent with the literature on the transition from an ICU to a general ward, which identifies a sense of “learned helplessness” post-discharge as a result of the high monitoring and total dependency patients experienced while in an ICU [19, 20]. The requirement to take over care responsibilities at discharge was especially challenging for participants who lived at a distance from the cancer center and had to divide their care between clinics at the cancer center and those closer to their home. These individuals may benefit from a “case-manager” approach so that problems are identified and addressed in a timely fashion.

Our study indicates that the transition to outpatient care was associated with an increased need of patients for

information on their long-term treatment plan and overall prognosis. This is consistent with the findings of Gansler et al. [21], who describe the evolving information needs of patients with hematologic cancers, shifting from a focus on immediate side-effects during hospitalization to a desire to know more about the long-term impact at discharge. Our study also illustrates that many questions were left unasked because of limited patient-physician interaction and because patients were afraid to find out some of the answers, particularly related to their prognosis. This is consistent with Yogaparan et al.’s [22] finding that over 80 % of older AML patients do not know or greatly overestimate their prognosis. As we previously described [9], participants had short-term goals during the inpatient phase and their informational needs matched that frame of mind. However, the capacity to take in information and the need for it expanded when patients transitioned to ambulatory care. In that respect, findings of the present study imply that the need for information and education about survivorship described at the end-of-treatment phase [8] actually begins earlier with the transition to outpatient treatment.

Finally, our study suggests that the movement from an immediate, survival-based mentality during the inpatient phase, to a more reflective state, creates the possibility to address existential concerns. Patients reported a new interest in the meaning and value of life and their direction in it and struggled to rebuild a new sense of identity. This is consistent with Little et al.’s [23] framework of understanding the experience of patients with cancer as one of a sustained liminal or transitional state. According to this framework, the diagnosis of cancer can be defined as a state of acute liminality, in which one is set apart from others and loses one’s previous identity and social position as a healthy individual. A state of sustained liminality follows, in which the former identity and social position are lost, but new ones are not yet established. As McGrath [24] suggests, the process of establishing a new identity is shaped not only by the sense of vulnerability and uncertainty associated with the illness, but also by a new sense of gratitude and appreciation of life.

Our findings are limited because they are derived from a small sample of English-speaking, well-educated patients from a single tertiary care cancer center, although this center serves patients from a large geographical area [25]. As well, since the perspective of this study is that of patients who still perceive some prospect of recovery, additional research is needed on the experience of patients with AML who receive only palliative care. Future studies should also address the potential impact of severe adverse events during the transition from inpatient to ambulatory care. Lastly, this study was limited to interviews with patients, although studies on transfers from ICU [17] have demonstrated the unique challenges of family members during this transition. We are currently seeking the perspectives of family caregivers of patients with acute leukemia, and these will be published separately.

The transition from inpatient to ambulatory care is one of the most vulnerable periods in an illness trajectory, especially as the acuity and complexity of the illness increases. AML patients are now leaving acute care settings sicker and earlier and are challenged to take on more responsibility for their own care while undergoing treatment. Considering their perceptions can yield valuable information that can be utilized to deliver evidence-based outpatient care that is sensitive to patients' preferences. Our study highlights the need to systematically assess the assumptions often expressed [4] about patients' benefits and preferences associated with the shift to outpatient-based therapy. The findings also suggest that it may be valuable to incorporate measurements of psychosocial distress when evaluating the benefit of providing consolidation therapy in an outpatient setting.

The difficulties experienced by patients during the transition to ambulatory-based therapy suggest that interventions at this transition would be useful. Such interventions can be informed by the various practice initiatives that have been developed to improve care during the transition from active treatment to the survivorship phase of individuals with solid tumors [26, 27] and by the ICU literature. For example, Brooke et al. [28] reported that an individualized educational intervention prior to ICU discharge was effective in reducing "transfer anxiety." The relative homogeneity of the AML population, compared to the range of conditions treated in the ICU, may also allow for the development of group interventions, such as peer support or peer mentorship programs. Such programs may alleviate the sense of isolation and address the increased informational and psychosocial needs during the transition to ambulatory care. Hospital-based programs may be ideal, given that patients at this stage are required to visit the hospital almost daily and may be too ill to locate and travel to programs in the community. Further studies are needed to develop and test interventions directed specifically at this important stage in the treatment of patients with AML.

Acknowledgments The authors would like to thank our study participants who kindly gave their time and effort, and our research and clinical staff who contributed to this project. We also would like to thank members of the Psychosocial Oncology and Palliative Care Scientists' Manuscript Review Seminar for reviewing earlier versions of this manuscript. This study was supported by a Canadian Institutes of Health Research Operating Grant (#MOP 84317, G.R. and C.Z., Co-Principal Investigators). This research was also funded in part by the Princess Margaret Cancer Centre Foundation Hertz Centre Fund, the Campbell Family Cancer Research Institute, the Ontario Cancer Institute at the Princess Margaret Cancer Centre, and by the Ontario Ministry of Health and Long Term Care (OMOHLTC). The views expressed do not necessarily reflect those of the OMOHLTC. G.R. is also supported by the University of Toronto/University Health Network Harold and Shirley Lederman Chair in Psychosocial Oncology and Palliative Care, and C.Z. by the Rose Chair in Supportive Care, Faculty of Medicine, University of Toronto.

Conflict of interest We have no conflicts of interest to declare. We have full control of all primary data and agree to allow the journal to review the data if requested.

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