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Clinicians' Understanding of Preferences and Values of People with Hematological Malignancies at the End of Life: Concurrent Surveys

Abstract

Background: People with hematological malignancies can deteriorate rapidly to a terminal event and have variable levels of engagement when transitioning to palliative and end-of-life care.

Objectives: To describe end-of-life care values and preferences of people with hematological malignancies and explore whether these align with hematology clinicians' perceptions.

Design: Two matched anonymous quantitative cross-sectional surveys explored: 1) patients' values and preferences around manner and timing of discussions regarding life expectancy and prognosis, involvement in decision making, and concurrent integration of palliative care with active treatment; and 2) clinicians' perceptions of their patients' values and preferences in relation to prognostic information.

Settings/participants: Concurrent online national surveys of people with hematological malignancies known to the Leukaemia foundation of Australia, and clinicians in Australia with membership to the Hematology Society of Australia and New Zealand.

Results: 509 (38% response rate) patients (median age 64 [min 20, max 89, interquartile range 56-70]) and 272 clinicians (21% response rate) responded to the survey. If their health was deteriorating, most patients wanted honest prognostic and life expectancy information (87%); welcomed involvement in decision-making (94%); felt they would be comfortable talking to the treating team about the possibility of death (86%); and would be comfortable seeing someone from a specialist palliative care team (74%). Clinicians generally underestimated most of these responses.

Conclusion: Although our findings indicate that most people believe they would be comfortable discussing prognosis, life-expectancy, and wishes at the end of life, clinicians were largely unaware of their preferences. This highlights the need to embed values clarification in routine care for each patient and family.

Introduction

Challenges providing end-of-life care for people with hematological malignancies largely relate to unpredictable and fluctuating illness trajectories, need for aggressive and high-technological treatments, and the potential for cure co-existing with advanced, refractory and relapsed disease.¹ This can lead to swift change in the goals of care, limiting patients' capacity to participate in shared-decision making, planning and preparing for death, and having autonomy near the end of life.¹ Timely integration of palliative care is recommended for people with hematological malignancies, concurrent to care of curative or life-prolonging intent.² However, it is difficult to know when and how to integrate palliative care, discuss planning for death, or transition to end-of-life care in such a clinical scenario.³ Hematologists are hesitant to discuss palliative and end-of-life care for fear it will diminish hope.⁴ Nurses struggle with helping their patients to 'fight the disease' while preparing them for the possibility of 'letting go'.⁵ It is possible that dissonance exists between perceptions of values and preferences for end-of-life care between patients and the clinicians caring for them.

Evidence regarding the desired level of prognostic information and involvement in decision-making in people with hematological malignancies is mixed. Research has reported that newly diagnosed patients chose to play a passive role in decision making and preferred their physician to play a paternalistic role.^{6,7} Alternatively, early qualitative work by McGrath highlighted that bereaved caregivers felt that lack of information impeded involvement in decision-making and challenges around communicating with medical staff impacted quality of end-of-life care.⁸ A commonly cited need of people with hematological malignancies at any stage of their illness is basic information on treatment options and side effects to enable shared decision-making.⁹ Honest sensitive communication around death and dying has been essential for a functional model of end-of-life care.¹⁰ However, a more recent literature review¹¹ reported that while some people with hematological malignancies wanted open, honest prognostic information, others did not want specific details of their prognosis. This discrepancy of opinion affects clinicians' confidence in the timing of end-of life discussions and patient preparation.

To date, studies have focused on a desire for prognostic information and involvement in decision-making when people are newly diagnosed, undergoing treatment (chemotherapy or hematopoietic stem cell transplantation), or at any stage of the illness trajectory.^{6,7,11-13} Limited research has focused on patient values and preferences around receiving prognostic and life expectancy information or involvement in shared decision-making specifically at the end of life.¹ Additionally, important questions remain around acceptance of integration of palliative care and transitioning to end-of-life care concurrent to 'active treatment'.

Aims

This study aimed to describe people with hematological malignancies' values and preferences regarding: 1) discussions around prognosis and life expectancy; 2) involvement in decision making; 3) integration of palliative care; and 4) time, organisational and clinical care at the end of life. An additional aim was to explore whether there was alignment between the perceptions of clinicians working in hematology regarding their patients' values and preferences. The overarching aim of this research was to inform practice and highlight the need for clarification of patients' individual preferences around such matters early in the illness trajectory.

Methods

Design

An anonymous quantitative cross-sectional online and paper-based survey explored patient values and preferences, and a concurrent survey explored clinicians' perceptions of their patients' perspectives.

Setting, participants and data collection

Inclusion criteria for the patient survey was: 1) over 18 years of age; and 2) diagnosed with hematological malignancies at any stage of the illness trajectory. People with hematological malignancies are potentially at risk of dying at any stage of their illness trajectory from the treatment or underlying disease, therefore the questionnaire was relevant to everyone. Inclusion criteria for the health care worker survey was: 1) over 18

years of age; 2) registered nurse or physician; and 3) currently providing direct care to people with hematological malignancies.

Both surveys were administered using the secure, web-based software platform REDCap (Research Electronic Data Capture).^{14, 15} An invitation email with direct link to survey was sent once to consenting people on the contact list of the Leukaemia Foundation of Australia who had been diagnosed within the past six months to three years. This time frame from diagnosis was chosen for email distribution to ensure no distress was caused to newly diagnosed people, and to capture people with current email addresses (people usually register with the Leukaemia Foundation when they are newly diagnosed). Responses were accepted from people at any stage of their illness trajectory if they somehow accessed and completed the survey. The Leukaemia Foundation is the lead not-for-profit organisation in Australia supporting people with all types of hematological malignancies across the lifespan in publicly and privately funded healthcare services in metropolitan, regional and remote areas. It is possible this population may be skewed towards people with higher social, emotional, physical or financial need. An invitation letter, paper copy survey (with QR code to the online survey), and return self-addressed stamped envelope was mailed to eligible patients (same criteria as above) receiving care at the local hospital, the Royal Brisbane and Women's Hospital; a tertiary hospital on the east coast of Australia with a large hematology and bone marrow transplant unit. Recently diagnosed patients (<6 months) were not contacted to avoid causing potential distress. An invitation email was distributed twice to Australian nursing and medical members of the Haematology Society of Australia and New Zealand (HSANZ), the peak professional body in the region. Delegates of the annual scientific meeting were invited to participate by members of the research team in person during break times between presentations. Clinicians working at the local hospital were approached in person and via email and invited to participate. As it was possible that there was overlap in the local and national sample, participants were clearly instructed not to complete the survey twice. No study sample was determined in advance for this exploratory study.

Questionnaires

Due to the specific research aims of the study, no appropriate validated tool existed. The questionnaires were developed by the research team based on the study aims which were targeted at addressing known gaps in knowledge. Where possible questions were based on questionnaires in similar research in other populations.¹⁶⁻¹⁸ Both surveys were piloted for content and face validity and acceptance with eight participants respectively, and refined accordingly. Questions on characteristics and preferences were answerable via multiple choice options informed by the literature and study aims. Questions on values were answerable on a Likert type scale of 1 (not important at all) to 5 (extremely important). The patient survey contained 12 characteristic questions and 23 questions on end-of-life care issues as shown in Tables 1 and 2. Patients were also asked if they found the survey distressing on a scale of 1 – not distressing at all to 5 – extremely distressing. The clinician survey asked 8 characteristic questions and 22 questions on end-of-life care as shown in Tables 1 and 2. Full questionnaires are available in Supplementary material.

Analysis

Descriptive statistics were used to summarise all responses. Questions on values that were answered via a Likert type scale of 1-5 were treated as continuous interval data, and one way analysis of variance (ANOVA) were used to test for differences in responses between patients and clinicians. Eta squared was calculated and measured for effect size for ANOVA. As the patient and clinician survey was conducted nationally and at a local hospital, comparisons were made between the two groups via t-tests and Chi-square to test for significant differences in the groups that may limit generalisability of findings. Chi-square tests were used to test for differences in patient preferences for communication, care and decision-making according to age, gender and level of education.

Ethical considerations

Approval was obtained from the Royal Brisbane and Women's Hospital Human Research Ethics Committee (HREC/2019/QRBW/56620).

Results

Response rate

The patient survey was distributed from November 2019 to March 2020; 519 people consented to participate (40%) and 509 participants went on to complete the survey (39% response rate). The clinician survey was distributed from October to November 2019 and received 272 (21% response rate). Breakdown of response rates for the national and local group of patient and clinician respondents is shown in Figure 1.

Participant characteristics

As shown in Table 1, the patient respondents had median age of 64 (IQR 56-70), were largely from the three most populous Australian States (Queensland [jurisdiction of the author], New South Wales and Victoria) with a predominance from the authors' jurisdiction. They were mostly living in households with others, more highly educated than the general population (36% had university qualifications vs. 18% overall in Australia's most recent census),¹⁹ over half (58%) gave importance to spiritual faith, and were largely (77%) in good-to-excellent self-reported health, despite experiencing a range of hematological malignancies diagnosed in the previous median time of three (IQR 2-7) years. The clinician sample was dominated by nurses (79%) who frequently dealt with patients at the end of life (72% >once/week and up to every day), generally experienced (two thirds had >5 years hematology experience), and over half of all occupational groups was from Queensland.

Preferences for communication, care and decision-making

Eighty-seven percent of patients wanted to know about prognosis and life expectancy if their health was deteriorating (60% even if they don't ask, and 27% only if they ask). Seventy-seven percent of people wanted to know as early as possible (likely 6-12 months) if they were likely to die; and 67% felt strongly about being involved in the decision making about their care near the end of life. If patients were deteriorating and told they might die soon, 28% said they would not lose hope for survival, but would remain positive, while 62% felt they would lose a little hope, but would want to be realistic (Table 3). Most patients reported they would be comfortable talking to the treating team about the potential for death so their values and preferences for care were known (86%) and would be comfortable seeing someone from a specialist palliative care team (74%).

Clinicians' perceptions of these matters suggest a different understanding of patients wishes and expectations. Nursing respondents believed that only 61% of patients wanted to know about prognosis and life expectancy, while physicians were more closely aligned with patients' responses, reporting that 81% wanted this information. However, both physician and nursing respondents underestimated how early patients wanted this information (39% and 41% as early as 6-12 months respectively). Physician and nursing respondents reported they felt only 9% and 16% of their patients respectively would feel strongly about having a choice and being involved in making decisions around their healthcare near the end of life. Physicians and nurses also underestimated the percentage of people who: 1) would remain positive if told they may be nearing the end of life (7% and 8% respectively); 2) would be comfortable discussing the potential for death (54% and 32% respectively); and 3) would be comfortable being seen by a specialist palliative care team (61% and 47% respectively) (see Table 3).

There were few statistically or clinically significant differences in patient preferences for communication, care and decision-making by gender, age and level of education (see Supplementary file 1). However, results may indicate that older people (80+) have a stronger preference to be told about their prognosis and life expectancy regardless of if they ask, while people with more education had a stronger preference to be told as early as possible. Slightly more females than males felt strongly about being involved in decision-making and people with higher education were less likely to lose hope if told they were likely nearing the end of life. Younger people were less likely to feel comfortable being referred to specialist palliative care services.

Values regarding time, organisational and clinical matters

The two primary time and organisational matters patients valued were 'saying goodbye to important people', and 'name a decision maker'. The lowest two ratings were 'plan place of death' and 'avoid being in hospital'.

For clinical care matters, patients valued 'using treatments to improve quality of life' and 'having a medical team who is comfortable talking about death and dying' the highest, and placed the lowest value to 'use all available treatments even if there is only a very small chance of cure' and 'not be connected to a breathing machine'.

There was a statistically significant difference between patient, physician and nursing responses for 12 of the 16 questions on values (Table 4). The differences between mean scores were largest for: 1) having treatment preferences in writing (patients reported higher scores than physician and nursing); 2) avoid being in hospital (patients reported lower scores than physician and nursing); and 3) name a decision maker (patients reported higher scores than physician and nursing). These values had a moderate effect size using Cohen's terms (0.01 small effect / 0.06 medium effect / 0.14 large effect). *Post hoc* comparisons using the Tukey HSD test indicated there were statistical differences in scores between patients and nurses for seven values; patients and physician for eight values; and nurses and physician for seven values.

Distress

Patients reported a median distress score of 1 – not distressed at all (min 1 / max 5, IQR 1-2) on completion of the survey.

Comparisons between national and local group

For the questions regarding preferences, there was a statistically significant variation between the national and local group for both patients (about diminished hope upon finding poor prognosis) and clinicians (about timeliness of life expectancy disclosure), however, this was with a small effect (ϕ 0.21-0.23) and was not in a meaningful direction (i.e., variation in the direction between responses in each question). For questions regarding values, there was a statistically significantly higher ratings for the national group regarding importance of being referred to supportive care organisations outside the hospital for extra support (mean 4.15, SD 1.07 versus mean 3.71, SD 1.5, t 2.08, $p=0.04$), and two questions in clinician responses: 1) resolve unfinished business (mean 4.43, SD 0.7 versus mean 4.2, SD 0.8, t 1.97, $p=0.04$); and 2) have financial affairs in order (mean 4.5, SD 0.7 versus mean 4.7, SD 0.76, t 2.52, $p=0.01$).

Discussion

Our results indicate that most patients want to be involved (67% very involved, 27% involved) in decision making if their health is deteriorating and they may die soon; more than nurses and physicians estimated. This differs from German research on recently diagnosed patients with hematological malignancies where most (64%) preferred a more passive role in the decision-making process.^{6,7} This difference could be explained by cultural and societal differences, changing preferences from a decade ago, or patients being earlier in their illness trajectory or having lower levels of health literacy. Another explanation for the differences is that people may seek more autonomy as they near the end of life. **Due to the self-reporting nature of our survey, it was not feasible to collect information on disease stage or illness trajectory of patients to assess differences in responses.** A recent Australian study of older members of the public indicated that people want to be more involved in decision-making if they are likely to die, than clinicians estimated¹⁶ so the culture of needing to protect patients from bad news may be changing.

Our findings also indicate that most patients want to know about their prognosis and life expectancy if they are likely nearing the end of life. This was underestimated by nurses but accurately assessed by physicians who are largely responsible for delivery of such information. Of note, half the participating clinicians perceived "end of life" in terms of clinical deterioration rather than timeframe (Table 2), potentially complicating timing of discussions. High levels of desire for prognostic information have also been reported in studies of people with newly diagnosed acute myeloid leukemia²⁰, high risk myelodysplastic syndromes²¹ and various hematological malignancies.²² In our study, both nurses and physicians under-estimated that patients want to know they may die as early as the final 6-12 months of life. A discrete choice experiment of newly diagnosed patients with hematological malignancies and solid tumours found that 69% of people wanted life-expectancy

discussions as soon as they were available rather than having to ask.²³ A recently published systematic review revealed most patients across all disease types are willing to discuss life expectancy.²⁴ Honest and timely prognostic and life-expectancy discussions are essential to enable participation in shared decision-making. Decision aids are known to reduce decisional conflict and increase patient knowledge, and risk interpretation, compared to standard care.²⁵

In this study, 50% of patients felt strongly about their family being involved in decision-making if they were unable to participate. However, 41% want to discuss this with family members in advance so they would know their wishes. This was under-estimated by physicians and nurses. Research on advance care planning prior to stem cell transplantation found that 63%²⁶ and 80%²⁷ of patients reported they had discussed their life support wishes with family and friends, but only 15-16% reported they had discussed life support wishes with medical team. Clinicians can be proactive at encouraging discussions with family members about their care preferences.

A unique finding in this research that was under-estimated by physicians and nurses is that very few patients (<5%) would lose all hope for survival if they were told there was a high chance they would die soon. This finding is reflective of the unpredictable illness trajectory experienced by many patients with hematological malignancies who live with uncertainty on a daily basis.¹ Our findings address the concern held by some hematologists that discussing palliative and end-of-life care may diminish their patients' hope.⁴ Most respondents reported that if their health was deteriorating but they were still receiving care of curative or life-prolonging intent, they would be comfortable discussing the potential for death so that their wishes could be known, and being referred to specialist and supportive palliative care services. This demonstrates that this patient population is open to early integration of palliative care concurrent to 'active treatment'.

Our findings also showed variation in patient perspectives (even when analysed via age, gender and level of education), as has been found in other research.²⁴ This highlights the need for value clarification for each patient and family. Previous research indicates this does not always occur in clinical practice. Qualitative interviews found that there was often a mismatch between preferences for information provision and communication provided between patients with myeloid leukemia and their physicians.¹² A US study of information giving and receiving in hematology consultations found that only 5% of patients were asked about their preference for desired level of information and 37% about role in decision-making by the physician.¹³ Our study was conducted on people with hematological malignancies at any stage of the illness trajectory. However, it is acknowledged that preferences can change as people deteriorate and approach the end of life. Therefore, it is vital that clinicians clarify the individual preferences of patients at relevant time points.

An important dichotomy was noted in that patients valued time and personal organisational matters such as 'saying goodbye to important people' most highly, and placed less importance on clinical care such as 'avoiding being in hospital'. This was in contrast to what clinicians felt was important to patients. This finding serves as a reminder that although people with hematological malignancies often experience highly complex technological care, their death is a not just a medical event, rather it is a natural life process that is experienced in a physical, psychosocial and spiritual context.²⁸ Of note, although most people with advanced cancer state home as their preferred place to die²⁹, for some patients with hematological malignancies, hospital is a 'safe haven' and they opt to remain in hospital for end-of-life care.³⁰

Limitations

We acknowledge the survey response rate was low for the clinician group, and it is possible that the patient sample was over-represented by people who were comfortable discussing the topic of end-of-life. Therefore, results may reflect a more positive attitude than what could be found in the general patient population. The difficulty recruiting clinicians for surveys even after offering incentives is well established.³¹ The distribution of respondents (79% nurses, 13% physician) wasn't too dissimilar from the Australian workforce distribution (57% nurses, 17% doctors)³², with slight over-representation of nurses. There were some differences between

respondents to the national and local survey however, there were no clear trends indicating no inherent differences between the group that would limit generalisability. Finally, our survey had low representation in people identifying as Aboriginal and/or Torres Strait Islander and those who mainly spoke a language other than English at home. Further research into the views of these vulnerable groups is warranted.

Conclusion

Findings indicate that most adults with hematological malignancies want to receive prognostic and life-expectancy information and engage in shared decision-making at the end of life, and are comfortable with integration of palliative care along-side 'active treatment'. Variation still exists in responses highlighting the need for values clarification. Our results can encourage clinicians working with people with hematological malignancies to initiate timely honest conversations and palliative care integration in a timely manner based on patient and family preferences. Findings can inform the clinical application of how and when clinicians can help patients with hematological malignancies to 'hope for the best, and prepare for the rest'.

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Authorship confirmation statement

All authors have contributed to the design and conduct of the study, and write up of the manuscript.

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