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

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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 Leukemia Foundation of Australia, and clinicians in Australia with membership to the Hematology Society of Australia and New Zealand.

Results: Five hundred nine (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.

Keywords: end of life; hematological malignancies; palliative care; patient preference; survey

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

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 e-mail with direct link to survey was sent once to consenting people on the contact list of the Leukemia Foundation of Australia who had been diagnosed within the past six months to three years. This time frame from diagnosis was chosen for e-mail distribution to ensure no distress was caused to newly diagnosed people, and to capture people with current e-mail addresses (people usually register with the Leukemia 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 Leukemia Foundation is the lead not-for-profit organization in Australia supporting people with all types of hematological malignancies across the lifespan in publicly and privately funded health care services in metropolitan, regional, and remote areas. It is possible this population may be skewed toward 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 e-mail was distributed twice to Australian nursing and medical members of the Hematology 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 through e-mail 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 through 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 Data S1 and S2.

Analysis

Descriptive statistics were used to summarize all responses. Questions on values that were answered through a Likert-type scale of 1–5 were treated as continuous interval data, and one-way analysis of variance (ANOVA) was 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 through *t*-tests and chi-square to test for significant differences in the groups that may limit generalizability 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.

TABLE 1. PARTICIPANT CHARACTERISTICS: PATIENTS

<i>Patients</i>	N	%
Total sample	509	100
National	455	89
Local hospital (Queensland)	45	11
Gender		
Female	263	52
Jurisdiction (two missing)		
Queensland ^a	182	36
New South Wales	125	25
Victoria	69	14
Western Australia	54	11
South Australia	41	8
Tasmania	20	4
Australian Capital Territory	14	3
Northern Territory	2	0
Age (years)		
Median 64 (min 20/max 89), IQR 56–70		
Time since diagnosis of malignancy (years)		
Median 3 (min 0.1/max 41), IQR 2–7		
Disease type (one missing)		
Myeloma	129	25
Lymphoma	128	25
Chronic leukemia	98	19
Acute leukemia	84	17
Myelodysplastic/myeloproliferative	59	12
Other/unsure	10	2
History of stem cell transplant (two missing)		
No	300	58
Yes, autologous	117	23
Yes, allogeneic	89	18
Language mainly spoken at home (two missing)		
English	492	97
Aboriginal and/or Torres Strait Islander (three missing)		
Yes	5	1
Household structure (two missing)		
Living with others (family/friend/carer)	393	77
Living alone	103	20
Other	11	2
Level of education (one missing)		
Less than high school	10	2
High school	129	25
Trade or diploma	185	36
Bachelor degree	102	20
Postgraduate qualification	82	16
Importance of spiritual faith (two missing)		
Very important	117	23
Somewhat important	177	35
Not important at all	213	42
Self-rating of general health (one missing)		
Excellent	52	10
Very good	160	32
Good	179	35
Fair	94	19
Poor	23	5

^aQueensland—jurisdiction of the author.
IQR, interquartile range.

Participant characteristics

As shown in Table 1, the patient respondents had median age of 64 (interquartile range [IQR] 56–70), were largely from the three most populous Australian States (Queensland

TABLE 2. PARTICIPANT CHARACTERISTICS: CLINICIANS

<i>Clinicians</i>	N	%
Total sample	272	100
National	147	54
Local hospital (Queensland)	125	46
Gender		
Female	218	80
State or territory		
Queensland	157	58
Victoria	43	16
Western Australia	31	11
New South Wales	30	11
South Australia	5	2
Tasmania	4	2
Australian Capital Territory	1	0
Northern Territory	1	0
Age (years)		
18–25	34	13
>25–45	164	60
>45	74	27
Occupation		
Registered nurse	206	76
Hematologist	38	14
Registrar/resident	21	8
Nurse practitioner	7	3
Experience working in Hematology (years)		
<1	14	5
1–5	76	28
>5–10	63	23
>10	119	44
Type of patients provide care for		
Hematology only	115	42
Hematology and other	157	58
Frequency of caring for patients at the end of life (three to six months)		
Every day	93	34
At least once a week	103	38
About once a month	63	23
Rarely	13	5
Never	0	0
Understanding of the term “end of life”		
The last year of life	13	5
The last few months of life	70	26
The last weeks of life	37	14
The last days or hours of life	19	7
Not a time concept, clinical trajectory of deterioration	133	49

[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 of 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 do not 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, whereas 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, whereas 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 health care 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 Table S1). Results indicated that older people (80+) had 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 if they were likely nearing the end of life. 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. There were no clear trends for preferences in the data according to age, gender, and level of education.

Values regarding time, organizational, and clinical matters

The two primary time and organizational matters patients valued were “saying goodbye to important people,” and

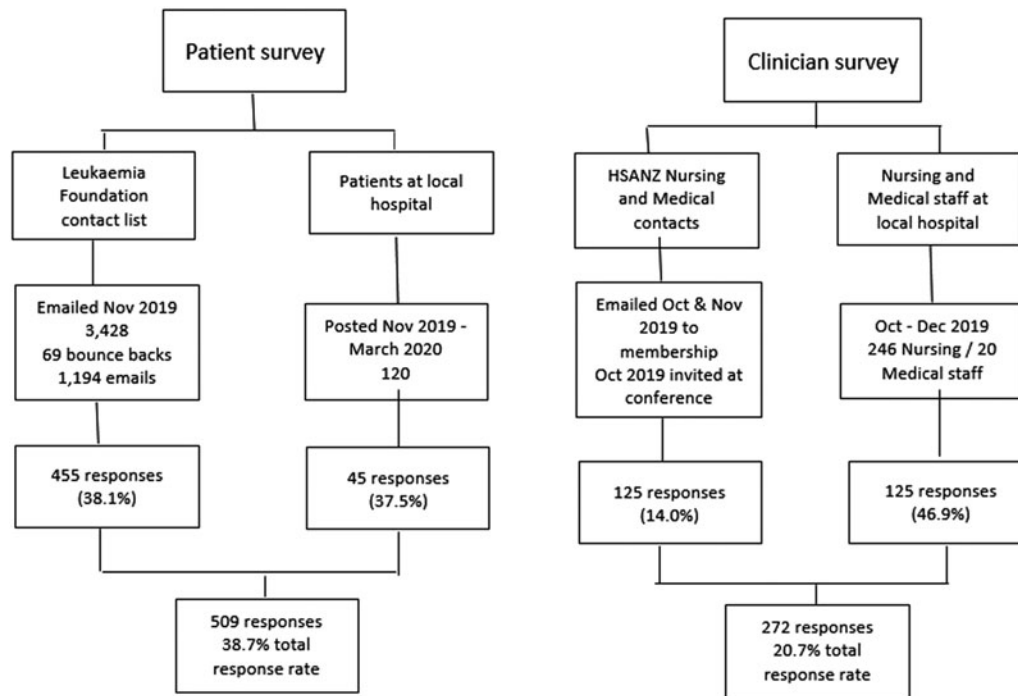


FIG. 1. Response rate for patient and clinician survey.

“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 among 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). *Posthoc* comparisons using the Tukey’s Honestly Significant Difference (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 groups

For the questions regarding preferences, there was a statistically significant variation between the national and local

groups 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 organizations outside the hospital for extra support (mean 4.15, standard deviation [SD] 1.07 vs. 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 vs. 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 vs. 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 the 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

TABLE 3. PREFERENCES FOR COMMUNICATION, CARE, AND DECISION-MAKING: N=213 NURSES, 59 PHYSICIAN

		Responses					
Questions about prognosis and life expectancy	Patient	Yes, it is the doctor's duty to tell me even if I don't ask	Yes, but only if I ask	No, I'd prefer not to know details but my family can hear them from the doctor if they want to	No, I'd prefer the doctor not tell me or my family	I'm not sure, but I would like for them to ask me if I want to know	I'm not sure
	Clinician	All	The majority	About half and half	A minority	None	I can't say, there is too much variation
What proportion of your patients with a terminal illness and deteriorating health choose to know details about their prognosis and life expectancy? (9 missing)	Nursing	11 (5%)	116 (56%)	38 (18%)	11 (5%)	0 (0%)	31 (15%)
	Physician	2 (4%)	43 (77%)	7 (13%)	2 (4%)	0 (0%)	2 (4%)
If your health was deteriorating, at what time point would you prefer to know you may not live? (23 missing)	Patient	If you were likely in your final 6-12 months of life	If you were likely in your final 3-6 months of life	If you were likely in your final weeks of life	If you were likely in your final days of life	I don't want to know at all	I'm not sure
	Clinician	In the final 6-12 months of life	In the final 3-6 months of life	In the final weeks of life	In the final days of life	Most don't want to know at all	I can't say, there is too much variation
If a patient's health is deteriorating, at what time point do you think most patients would prefer to be made aware of their potential life expectancy? (9 missing)	Nursing	85 (41%)	54 (26%)	10 (5%)	3 (1%)	3 (1%)	52 (25%)
	Physician	22 (39%)	17 (30%)	4 (7%)	0 (0%)	0 (0%)	13 (23%)
Questions about involvement in decision making	Patient	Very involved, I feel strongly about having a choice and being involved in making those decisions	Involved, but I would like more information and my family to be part of the decision	A little involved, but I'm not sure if I could decide what is good or not even after they give me the information	Not involved at all, I'll leave it to my doctors to decide	I'm not sure, but I would like for the doctor to ask me how much I want to be involved	I'm not sure
	Clinician	Very involved, they feel strongly about having a choice and being involved in making those decisions	Involved, but they often want more information and for their family to be part of the decision	A little involved, but they struggle to decide on a care/treatment path even after they are given the information	Not involved at all, they usually leave it to the doctors to decide	I can't say, but I think they would ask them how much they want to be involved	I can't say, there is too much variation
If a patient is aware they may die soon (3-6 months), how much do they usually want to be involved in decision making around their health care? (22 missing)	Nursing	33 (16%)	111 (54%)	25 (12%)	3 (1%)	21 (10%)	14 (7%)
	Physician	5 (9%)	37 (66%)	3 (5%)	0 (0%)	3 (5%)	8 (14%)

(continued)

TABLE 3. (CONTINUED)

Questions	Responses				
	Very involved, if I couldn't speak I feel strongly about my family having a choice and being involved in making those decisions	Involved, but I would like to discuss this with them in advance so they know what I would want	A little involved, but I'm not sure if my family could decide what is good or not even after they get the information	Not involved at all, I'd like them to leave it to my doctors to decide	I'm not sure, but I would like for the doctor to ask my family how much they want to be involved
Patient If you were very sick in hospital and were unable to participate in decisions about your care, how much would you want your family to be involved in decision making around your health care? (22 missing)	244 (50%)	198 (41%)	12 (3%)	10 (2%)	5 (1%)
Not applicable—I don't have family/next of kin (2, 0.4%)					
Questions about hope					
Patient If your health was deteriorating and you were told there was a high chance you could die in the next 3–6 months, but it was possible you could survive, would this diminish your hope for survival? (22 missing)	No, I would remain positive 138 (28%)	A little, but I would want to be realistic 305 (63%)	Yes, I would lose all hope 23 (5%)	I'm not sure 21 (4%)	—
Clinician If a patient who is deteriorating is told there was a high chance they could die in the next 3–6 months, does this usually diminish their hope for survival? (9 missing)	No, they often remain positive 17 (8%) 4 (7%)	A little, but they usually want to be realistic 133 (64%) 43 (77%)	Yes, they often lose all hope 24 (12%) 0 (0%)	I can't say, there is too much variation 33 (16%) 9 (16%)	—
Questions about discussing possibility of deterioration					
Patient If your health was deteriorating but you were still continuing with a treatment that might work (cure you or give you more time), would you feel comfortable with your treating team discussing the potential for death so they could understand your personal values and preferences for care? (22 missing)	Yes, I would like to tell them what is important to me 422 (87%)	A little, but it might be difficult for me to receive treatment and talk about end-of-life issues 48 (10%)	No, I don't think I would be comfortable with that 6 (1%)	I'm not sure 11 (2%)	—

(continued)

TABLE 3. (CONTINUED)

Questions	Responses			
Clinician If a patient's health was deteriorating but they were still continuing with treatment of curative or life-prolonging intent, do you think most patients feel comfortable discussing the potential for death so their personal values and preferences can be known? (11 missing)	Yes, I think they would like to tell the treating team what is important to them	A little, but it might be difficult for them to receive treatment and talk about end-of-life issues	No, I don't think they would be comfortable with that	I can't say, there is too much variation
Nursing	66 (32%)	102 (50%)	17 (8%)	20 (10%)
Physician	30 (54%)	17 (30%)	3 (5%)	6 (11%)
Questions about referral to specialist palliative care services				
Patient If your health was deteriorating but you were still continuing with a treatment that might work (cure you or give you more time), would you feel comfortable with seeing someone from a specialist palliative care team as an extra layer or support with physical, psychosocial, emotional, or spiritual issues you were facing? (22 missing)	Yes, I would like all supports available to me	A little, but I would be a little confused by continuing treatment and palliative care service	No, I don't think I would be comfortable with that	I'm not sure, but I would like to be asked if I would like the extra support
Clinician When a patient's health is deteriorating but they are still continuing with a treatment of curative or life-prolonging intent, do you think most patients feel comfortable seeing someone from a specialist palliative care team to address physical, psychosocial, emotional, or spiritual issues they were facing? (10 missing)	Yes, I think they would like all supports available to them	A little, but it would be a little confusing continuing treatment and talking to a palliative care service	No, I don't think they would be comfortable with that	I can't say, there is too much variation
Nursing	96 (47%)	79 (38%)	12 (6%)	19 (9%)
Physician	34 (61%)	14 (25%)	3 (5%)	5 (9%)
				7 (1%)

TABLE 4. VALUES REGARDING TIME, PERSONAL ORGANIZATIONAL, AND CLINICAL MATTERS

	<i>Patients</i>	<i>Nursing</i>	<i>Physician</i>	<i>ANOVA</i>	<i>p</i>	<i>Posthoc tests</i>	η^2
	<i>Mean (SD)</i>						
Time and personal organization							
Say goodbye to important people	4.60 (0.89)	4.82 (0.52)	4.55 (0.57)	$F(2, 716)=8.56$	<0.001	Patient to nurse** Nurse to physician*	0.02
Name a decision maker	4.59 (0.76)	4.23 (0.76)	3.76 (0.79)	$F(2, 703)=37.30$	<0.001	Patient to nurse** Patient to Physician** Nurse to physician**	0.10
Have financial affairs in order	4.58 (0.80)	4.50 (0.71)	4.02 (0.74)	$F(2, 712)=12.58$	<0.001	Patient to physician** Nurse to physician**	0.03
Feel family are prepared for patient's death	4.55 (0.87)	4.68 (0.63)	4.31 (0.77)	$F(2, 717)=5.80$	0.006	Patient to physician* Nurse to physician*	0.02
Have time to plan and prepare for death	4.38 (0.98)	4.29 (0.87)	4.09 (0.71)	$F(2, 716)=2.70$	0.021	—	—
Have treatment preferences down in writing	4.24 (1.07)	3.83 (0.94)	3.04 (0.94)	$F(2, 705)=37.79$	<0.001	Patient to nurse** Patient to physician** Nurse to physician**	0.10
Resolve unfinished business	4.21 (1.06)	4.34 (0.80)	4.36 (0.69)	$F(2, 710)=1.60$	0.142	—	—
Plan place of death	3.85 (1.30)	4.13 (0.94)	3.85 (0.73)	$F(2, 716)=3.89$	0.006	Patient to nurse*	0.01
Avoid being in hospital	3.51 (1.37)	4.18 (0.83)	4.11 (0.66)	$F(2, 724)=24.5$	<0.001	Patient to nurse** Patient to physician**	0.06
Time and personal organization matters combined	38.67 (5.57)	39.01 (4.31)	35.92 (3.98)	$F(2, 674)=7.62$	<0.001	Patient to physician** Nurse to physician**	0.02
Clinical care							
Use treatments that would improve quality of life	4.57 (0.82)	4.71 (0.54)	4.56 (0.60)	$F(2, 711)=2.77$	0.023	—	—
Have a medical team who are comfortable talking about death and dying	4.56 (0.75)	4.61 (0.62)	4.15 (0.69)	$F(2, 704)=0.96$	<0.001	Patient to physician** Nurse to physician**	0.02
Be referred to supportive care organizations outside the hospital for extra support	4.10 (1.13)	4.10 (0.95)	3.80 (0.79)	$F(2, 711)=2.02$	0.034	—	—
Be referred to supportive care services within the hospital for extra support	4.00 (1.19)	4.35 (0.70)	4.18 (0.64)	$F(2, 711)=8.39$	<0.001	Patient to nurse**	0.02
Use all available treatments that may give a little more time	3.62 (1.31)	4.07 (0.85)	3.35 (0.80)	$F(2, 705)=12.89$	<0.001	Patient to physician** Nurse to physician**	0.04
Not be connected to a breathing machine	3.62 (1.28)	3.98 (1.0)	3.75 (0.87)	$F(2, 679)=5.93$	0.001	Patient to nurse*	0.02
Use all available treatments even if there is only a very small chance of cure	3.43 (1.40)	3.75 (0.94)	2.81 (0.88)	$F(2, 698)=12.02$	<0.001	Patient to physician* Nurse to physician**	0.03
Clinical care matters combined	27.93 (4.77)	29.37 (3.05)	26.59 (2.85)	$F(2, 640)=10.46$	<0.001	Patient to nurse** Nurse to physician**	0.03

Questions were answered on a Likert-type scale of 1 (not important at all) to 5 (extremely important). * $p < 0.05$; ** $p < 0.001$. ANOVA, analysis of variance; SD, standard deviation.

making if they are likely to die, than clinicians estimated,¹⁶ 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 time frame (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 leukemia,²⁰ high-risk myelodysplastic syndromes,²¹ and various hematological malignancies.²² In our study, both nurses and physicians underestimated 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 tumors 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 with 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 underestimated by physicians and nurses. Research on advance care planning before 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 a medical team. Clinicians can be proactive at encouraging discussions with family members about their care preferences.

A unique finding in this research that was underestimated 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 analyzed through 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 organizational 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 die,²⁹ 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) was not 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 any inherent differences between the group that would limit generalizability. 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.”

Authors' Contributions

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

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Supplementary Material

Supplementary Data S1
Supplementary Data S2
Supplementary Table S1

References

- Moreno-Alonso D, Porta-Sales, Monforte-Royo M, et al.: Palliative care in patients with haematological neoplasms: An integrative systematic review. *Palliat Med* 2018;32:79–105.
- NICE: *Improving Outcomes in Haematological Cancers. The Manual*. London: National Institute for Clinical Excellence, 2003.
- Button E, Bolton M, Chan RJ, et al.: A palliative care model and conceptual approach suited to clinical malignant haematology. *Palliat Med* 2019;33:483–485.
- Auret K, Bulsara C, Joske D: Australasian haematologist referral patterns to palliative care: Lack of consensus on when and why. *Intern Med J* 2003;33:566–571.
- Leung D, Esplen MJ, Peter E, et al.: How haematological cancer nurses experience the threat of patients' mortality. *J Adv Nurs* 2012;68:2175–2184.
- Ernst J, Weissflog G, Brähler E, et al.: Participation of haemato-oncological patients in medical decision making and their confidence in decisions. *Eur J Cancer Care* 2011; 20:534–538.
- Ernst J, Kuhnt S, Schwarzer A, et al.: The desire for shared decision making among patients with solid and hematological cancer. *Psychooncology* 2011;20:186–193.
- McGrath P: Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nurs* 2001;24:413–421.
- Rood JA, Eeltink CM, van Zuuren FJ, et al.: Perceived need for information of patients with haematological malignancies: A literature review. *J Clin Nurs* 2015;24:353–369.
- McGrath P, Holewa H: An Australian model of end-of-life care for people with haematological malignancies. *Oncol Nurs Forum* 2007;34:79–85.
- Gray TF, Temel JS, El-Jawahri A: Illness and prognostic understanding in patients with hematologic malignancies. *Blood Rev* 2021;45:100692.
- LeBlanc TW, Fish LJ, Bloom CT, et al.: Patient experiences of acute myeloid leukemia: A qualitative study about diagnosis, illness understanding, and treatment decision-making. *Psychooncology* 2017;26:2063–2068.
- Alexander SC, Sullivan AM, Back AL, et al.: Information giving and receiving in hematological malignancy consultations. *Psychooncology* 2012;21:297–306.
- Harris PA, Taylor R, Thielke R, et al.: Research electronic data capture (REDCap) —A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42:377–381.
- Harris PA, Taylor R, Minor BL, et al.: The REDCap consortium: Building an international community of software partners. *J Biomed Inform* 2019;95:103208.
- Cardona M, Lewis E, Shanmugam S, et al.: Dissonance on perceptions of end-of-life needs between health-care providers and members of the public: Quantitative cross-sectional surveys. *Austral J Ageing* 2019;38:e75–e84.
- Steinhauser KE, Christakis NA, Clipp EC, et al.: Preparing for the end of life: Preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001;22:727–737.
- Steinhauser KE, Clipp EC, McNeilly M, et al.: In search of a good death: Observations of patients, families, and providers. *Ann Intern Med* 2000;132:825–832.
- ABS: *2071.0—Census of Population and Housing: Reflecting Australia—Stories from the Census, 2016*. Australia: Australian Bureau of Statistics, 2017. <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Educational%20Qualifications%20Data%20Summary%20~65> (Last accessed August 4, 2021).
- Yogaparan T, Panju A, Minden M, et al.: Information needs of adult patients 50 or older with newly diagnosed acute myeloid leukemia. *Leukemia Res* 2009;33:1288–1290.
- Efficace F, Gaidano G, Sprangers M, et al.: Preference for involvement in treatment decisions and request for prognostic information in newly diagnosed patients with higher-risk myelodysplastic syndromes. *Ann Oncol* 2014; 25:447–454.
- Rood JA, van Zuuren FJ, Stam F, et al.: Perceived need for information among patients with a haematological malignancy: Associations with information satisfaction and treatment decision-making preferences. *Hematol Oncol* 2015;33:85–98.
- Waller A, Wall L, Mackenzie L, et al.: Preferences for life expectancy discussions following diagnosis with a life-threatening illness: A discrete choice experiment. *Support Care Cancer* 2021;29:417–425.
- Björk E, Thompson W, Ryg J, et al.: Patient preferences for discussing life expectancy: A systematic review. *J Gen Intern Med* 2021;36:3136–3147.
- Stacey D, Légaré F, Lewis K, et al.: Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017. Issue 4. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub5.
- Joffe S, Mello MM, Cook EF, Lee SJ: Advance care planning in patients undergoing hematopoietic cell transplantation. *Biol Blood Marrow Transpl* 2007;13:65–73.
- Loggers E, Lee S, Chilson K, et al.: Advance care planning among hematopoietic cell transplant patients and bereaved caregivers. *Bone Marrow Transpl* 2014;49:1317–1322.
- Farber S: Living every minute. *J Pain Symptom Manage* 2015;49:796–800.

29. Higginson IJ, Sen-Gupta G: Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3:287–300.
30. Howell D, Wang H, Roman E, et al.: Preferred and actual place of death in haematological malignancy. *BMJ Support Palliat Care* 2017;7:150–157.
31. Asch S, Connor SE, Hamilton EG, Fox SA: Problems in recruiting community-based physicians for health services research. *J Gen Intern Med* 2000;15:591–599.
32. AIHW: 2020. Health Workforce: Australian Government. <https://www.aihw.gov.au/reports/australias-health/health-workforce> (Last accessed August 4, 2021).

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