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Patient values informing medical treatment: a pilot community and advance care planning survey

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ABSTRACT

Medicine regards the prevention of death as an important priority. Yet patients may have a range of priorities of equal or greater importance.

These other priorities are often not discussed or appreciated by treating doctors.

Objectives We sought to identify priorities of care for patients attending an advance care planning (ACP) clinic and among the general population, and to identify factors associated with priorities other than prolonging life.

Methods We used a locally developed survey tool 'What Matters Most' to identify values.

Choices presented were: maintaining dignity, avoiding pain and suffering, living as long as possible, and remaining independent.

Participants rated the importance of each and then selected a main priority for their doctor.

Participant groups were a purposive sample of 382 lay people from the general population and 100 attendees at an ACP clinic.

Results Living as long as possible was considered to be less important than other values for ACP patients and for the general population. Only 4% of ACP patients surveyed and 2.6% of our general population sample selected 'living as long as possible' as their top priority for medical treatment.

Conclusions 'Living as long as possible' was not the most important value for ACP patients, or for a younger general population. Prioritisation of other goals appeared to be independent of extreme age or illness. When end of life treatment is being discussed with patients, priorities other than merely prolonging life should be considered.

INTRODUCTION

A recent focus to identify 'what matters'¹ to patients when making goals of care decisions in health has led to consideration of what people value to live well.²⁻⁴ This is particularly important in people living

with a life-limiting illness to ensure that their care is consistent with their values and goals.⁴⁻⁷ To help doctors and other health professionals participate in patient-centred, values-based discussions, it is important to identify how community-based populations consider and prioritise certain values for living well.

Decisions regarding patient care should include consideration of patient's values to inform goals of care.⁸ This is the basis for shared decision-making.^{2 9} Unless patients communicate these values, doctors generally prioritise prolongation of life¹⁰ through care based on chance of cure or short-term benefit.^{4 11 12} In contrast, previous studies with patients suggest that important considerations in these decisions are maintaining dignity, relationships and independence.^{4 11} Many doctors believe that discussion of alternative goals only becomes appropriate for those who are very elderly or in the final stages of disease.¹³

A number of studies have described goals of care relating to disease and treatment decisions, in community and patient cohorts.^{11 13 14} Other studies have explored doctors' decision-making based on patient values such as independence and longevity.^{4 9 11 12} However, no studies have described the prioritisation of specific values to inform treatment decisions in a large community-based cohort.

The aims of this study were to identify how a community group and ACP client group rank and prioritise the four values of dignity, independence, freedom from pain and suffering, and longevity. We also sought to identify the effect of group, age and gender on the priorities expressed.

cohort. The baseline demographics are presented in [table 1](#). The response rate for the ACP group was 96%, with four of the patients handed the paper survey not returning it to the ACP consultant. These four attendees were not followed up and the sample size was considered final when 100 surveys were returned. We were unable to determine the response rate of the community cohort as that survey was online and only the results of those who 'submitted' were available. Also, it was not possible to include data from 18 participants in the community group due to incomplete data from the survey. The decision to remove these participants was to maximise representation of full data sets for matching priorities and ranking. The community cohort was significantly younger and had a larger proportion of female respondents.

The distribution of values by Likert scale scores for the community and ACP clinic patient cohorts are presented in [table 2](#).

Both cohorts rated highly dignity, avoidance of pain and suffering, and remaining independent (more than 90% regarding these values as somewhat important or vitally important) with longevity the lowest ranked value (30–35% regarded this as not important or not very important). These results were similar between groups with the exception of independence, which was rated significantly higher by the ACP group. When the cohorts were combined and compared by gender, a similar pattern was observed. Females rated dignity and independence significantly higher than males ([table 3](#)).

The distribution of value preferences was similar across all age ranges, with dignity, avoidance of pain and suffering, and remaining independent ranked highest, and longevity ranked lowest. The values of pain and suffering and independence varied significantly across age ranges, with the ranking of pain and suffering decreasing, and independence increasing in importance, with increasing age of respondents.

The values rated as most important are presented in [table 4](#). The relief of pain and suffering was ranked as the most important value by the highest proportion of participants in the community and ACP cohorts, followed by maintaining dignity and remaining independent. Living as long as possible was ranked as most important by the lowest proportion of participants. Analysis by referral source, age and gender revealed no differences in ranking.

DISCUSSION

Main findings

This study of two cohorts of adults, one community based and one referred to an advance care planning clinic, found that dignity, avoidance of pain and suffering, and remaining independent were the values considered most important by both groups, while longevity was least important. Older respondents placed less importance on avoidance of pain and suffering,

Table 1 Characteristics of community and ACP clinic cohorts 2

	Community	ACP	p Value
Number	382	100	–
Female	287 (75.1)	63 (63.0)	0.02
Age (years)			
18–24	6 (1.5)	0 (0)	
25–34	42 (11.0)	0 (0)	
35–44	74 (19.4)	0 (0)	–
45–54	104 (27.2)	1 (1.0)	–
55–64	99 (25.9)	2 (2.0)	–
65–74	41 (10.7)	20 (20.0)	–
>74	16 (4.2)	77 (77.0)	–
Mean	50.5 (±13.5)	77.1 (±5.9)	<0.0001

Data are shown as median (IQR), number (%) or mean (±SD). ACP, advance care plan.

Table 2 Distribution of values between community and ACP clinic cohorts

	Community	ACP	p Value
Dignity			
No importance	1 (0.3)	1 (1.0)	
Not very important	3 (0.8)	0 (0)	
Neutral	7 (1.8)	4 (4.0)	
Some importance	84 (22.0)	21 (21.0)	
Very important	286 (75.0)	74 (74.0)	
Median	5 [5–5]	5 [4–5]	0.75
Mean	4.71 (±0.6)	4.67 (±0.7)	
Longevity			
No importance	43 (11.3)	16 (16.0)	
Not very important	71 (18.6)	19 (19.0)	
Neutral	145 (38.1)	24 (24.0)	
Some importance	93 (24.4)	22 (22.0)	
Very important	29 (7.6)	19 (19.0)	
Median	3 [2,4]	3 [2,4]	0.43
Mean	2.98 (±1.1)	3.09 (±1.4)	
Pain and suffering			
No importance	0 (0)	0 (0)	
Not very important	4 (1.1)	2 (2.0)	
Neutral	12 (3.2)	3 (3.0)	
Some importance	85 (22.4)	28 (28.0)	
Very important	279 (73.2)	67 (67.0)	
Median	5 [4,5]	5 [4,5]	
Mean	4.68 (±0.6)	4.6 (±0.7)	0.21
Independence			
No importance	1 (0.26)	1 (1.0)	
Not very important	6 (1.6)	1 (1.0)	
Neutral	20 (5.2)	5 (5.0)	
Some importance	150 (39.3)	22 (22.0)	
Very important	204 (53.5)	71 (71.0)	
Median	5 [4,5]	5 [4,5]	
Mean	4.44 (±0.7)	4.61 (±0.7)	0.004

Data are shown as number (%), median [IQR] or mean (±SD). ACP, advance care plan.

Table 3 Distribution of value preferences by gender for all participants

Number	Male 132	Female 350	p Value
Age	58.6 (±17.4)	54.9 (±15.9)	0.03
Dignity	5 [4,5] 4.54 (±0.7)	5 [5,5] 4.76 (±0.5)	<0.0001
Pain and suffering	5 [4,5] 4.59 (±0.6)	5 [4,5] 4.69 (±0.6)	0.06
Longevity	3 [2,4] 3.01 (±1.2)	3 [2,4] 3.01(±1.1)	0.97
Independence	5 [4,5] 4.37 (±0.8)	5 [4,5] 4.52 (±0.68)	0.05

Data are shown as number, median [IQR] or mean (+SD).

and more importance on remaining independent. This age-related change in values could explain the difference between the ACP and community cohorts. Finally, the rating order of importance of values was the same for men and women, although there were significant differences in the rating of dignity and independence.

Relationship to existing literature

Patient-centred care requires identification of patient’s values and preferences or goals.¹⁸ Doctors’ inertia to discuss preferences and goals of care with patients with life-limiting illness is well documented.^{5 17 19 20}

The inability to identify patient goals and values could result in failure to respect patient autonomy, confusion among the treating team, failure to articulate clear points of treatment direction and limitation, and the continuation of unwanted, expensive and invasive medical care.²¹ This study adds to the current literature by identifying a list of values that the general community, including community-based people with a life-limiting illness, consider important when identifying goals of care. Previous studies have concentrated on patients listing values they consider important in the context of their current health status. This keeps the discussion around the disease/illness context rather than on what matters to them outside hospital. In this study, the identification of specific values and their importance for the general community and community-based patients with a life-limiting illness may help doctors overcome barriers to communication and planning.^{17 19 20}

Advance care planning focuses on identifying values for living well⁸ and associated goals of care and treatment limitation,²² in a patient population for whom hospitalisation and intensive medical treatment may not be beneficial. Often, these patients have a life-limiting illness and disease trajectory that changes with each hospital admission.²³ The ACP cohort in our study rated freedom from pain and suffering lower than did the general population. This is important as when considering how to communicate with patients, as the current literature defines preferences in terms of risk/benefit analysis of outcomes, including pain and suffering, longevity, and disability,^{11 17 24 25} there is evidence of a potential

Table 4 Distribution of top priority value comparing community and ACP cohorts

Top priority	Referral source		Age							Gender		p Value
	ACP	Community	18-24	25-34	35-44	45-54	55-64	65-74	>74	Male	Female	
	p Value	p Value										
No	100	382	6	42	74	105	101	61	93	132	350	-
Dignity	29 (29.0)	107 (28.0)	1 (16.7)	8 (19.0)	23 (31.1)	28 (26.7)	30 (29.7)	19 (31.1)	27 (29.0)	33 (25.0)	103 (29.4)	0.33
Pain and suffering	35 (35.0)	170 (44.5)	3 (50.0)	23 (54.8)	34 (45.9)	47 (44.8)	42 (41.6)	22 (36.1)	34 (36.6)	63 (47.7)	142 (40.7)	0.16
Longevity	4 (4.0)	10 (2.6)	1 (16.7)	1 (2.4)	0 (0)	4 (3.8)	3 (2.9)	1 (1.6)	4 (4.3)	4 (3.0)	10 (28.6)	0.92
Independence	32 (32.0)	95 (24.9)	1 (16.7)	10 (23.8)	17 (22.9)	26 (24.8)	26 (25.7)	19 (31.1)	28 (30.1)	32 (24.2)	94 (26.9)	0.55

Data are shown as number (%).
ACP, advance care plan.

mismatch between how doctors and patients prioritise treatment decisions,^{4 10–12} with doctors prioritising longevity. The finding that patients prioritise independence and dignity above both freedom from pain and suffering and longevity is an important addition to this area.

Strengths and limitations

The strength of this study is that it provides doctors and healthcare workers involved in communication with patients with a starting point to identify values that matter to patients to live well. Doctors find it difficult to keep conversations patient-centred and are more comfortable discussing disease context.^{3 19 20} This list may help doctors to direct the conversation towards living well rather than immediate medical treatment.

We developed a simple, paper-based tool called ‘What Matters Most’. We included values of dignity, independence, freedom from pain and suffering, and longevity (living as long as possible). While this tool cannot be used to comprehensively infer specific treatment preferences, it may help initiate shared decision-making, and facilitate discussions between healthcare professionals and patients about values, goals of care, treatment alternatives and priorities.

Values identified by patients in the literature include maintenance of relationships, communication, independence, feeling worthwhile with a sense of purpose, freedom from pain and suffering and living with a level of disability.^{4 12 13} To keep the survey simple for our wider population, we simplified some of these to dignity and independence. This should be tested qualitatively on a broad population to verify a community understanding of each of these in the health or illness context.

The advance care population surveyed was from a single geographic area in Australia, and results may be different in other social, cultural or religious groups. While our general population sample yielded similar values to the ACP group, this purposive sample was not selected randomly, and may not be representative of the wider community. We did not collect data on participant religion or ethnic background. Our sample had a large percentage of female respondents, which may influence results (though we are not aware of evidence of a gender difference regarding willingness to have a discussion about values in the shared decision-making, communication and end-of-life literature). The use of purposive sampling of social contacts may have led to participants with similar value considerations to the researchers. Future research should assess values in a larger, heterogeneous community sample.

Finally, doctors were excluded from this study in an attempt to obtain a representation of lay persons’ responses not influenced by professional health literacy. However, we did not exclude or identify other health professionals.

CONCLUSION

Discussions of priorities of care with patients should be structured around what is important to them for living well. While it is necessary to consider likely medical outcomes for treatment decisions, doctors should ask patients about what they value. From this study, it is apparent that people across a wide age range value remaining independent and living with dignity while minimising pain and suffering over longevity.

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Contributors SM was involved in planning, data collection and analysis, manuscript development and revision, guarantor of overall content, submitted study. CC was involved in planning, data collection, development of figure, manuscript development and revision. JS was involved in manuscript revision. NRO was involved in data analysis and development of tables. MB was involved in statistical analysis, manuscript development and revision. DW was involved in data analysis, table development, manuscript development and revision.

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