



A Reduced Deck of Conversation Cards of Wishes and Priorities of Patients in Palliative Care

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The individual wishes and priorities of patients with advanced disease are too often neglected, making a deck of cards with statements reflecting potential wishes and priorities a useful conversation tool. However, in the most ill patients, the card selection and sorting process may be too strenuous. The aims of this study were to explore the wishes and priorities of patients receiving palliative care and to reduce a deck of statement cards to be clinically useable even for the most ill patients. In interviews, participants selected their top 10 from a deck of 46 statement cards. Descriptive and analytical statistics were used. Thirty-nine patients from 5 specialized palliative care units in Sweden participated. Six participants died within 1 month of the interviews. "To be free from pain" was ranked as the highest priority by the majority, and "To have staff I feel comfortable with" was ranked highest by the 6 most ill participants. A deck of cards with the 20 statements most chosen by patients receiving palliative care was created. The cards cover physical, psychological,

social, existential, and practical aspects and are helpful for formulating goals of care for patients and informing the development of a core outcome set for palliative care.

KEY WORDS

cards, goals of care, palliative care, patient-reported outcome measures, wishes and priorities

The individual wishes and priorities of patients with advanced disease are too often neglected, despite ethical values and the legal demands of modern health care. These wishes and priorities can form the basis for the patients' goals of care. Discussing end-of-life (EoL) wishes and priorities may be challenging to health care professionals (HCPs) in terms of when to initiate the conversation or fear of causing discomfort to patients and/or families or jeopardizing their relationships.^{1,2} Research has shown that cards with statements reflecting potential wishes and priorities can facilitate conversations about the EoL in healthy adults³⁻⁵ and inform goals of care for patients in acute medical settings.³ Furthermore, the use of such cards was not found to increase anxiety in patients with advanced cancer.²

The Go Wish card game (GWG),⁴ a set of 36 cards, has been used in various contexts to discuss EoL care preferences and was shown to be feasible in conversations with community-dwelling older adults.⁶ Another set of cards, with statements derived and reformulated not only from international research but also from Swedish quality indicators, policy documents, and clinical and research assessment questionnaires, was developed to reflect the potential wishes and priorities of patients with palliative care needs.⁷ The cards (n = 46 plus 3 blank cards) (Table 1) were tested for feasibility and content validity and were found useful for patients with advanced disease receiving palliative care by helping them clarify thoughts and feelings, become aware of what is important to them, and share wishes and priorities.⁷ The study also showed that a high number of cards were challenging for patients with reduced energy. Thus, to enable the most ill patients to express their wishes and priorities using the cards, this number must be reduced. Therefore, the aims of this study were to explore the wishes and priorities of patients receiving palliative care and to reduce

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TABLE 1 Sum of Cards Selected by the 39 Participants and the Most Ill Participants (n = 6)

Statements ^a	All, n (%)	Most Ill, n (%)
1. To be free from pain	28 (71)	5 (83)
2. To have my family with me	20 (51)	4 (66)
3. To be able to move around	19 (48)	2 (33)
4. Not being short of breath	18 (46)	3 (50)
5. To be able to sleep well	17 (44)	3 (50)
6. To trust my doctor	17 (44)	3 (50)
7. To be able to eat and drink	16 (41)	2 (33)
8. To have staff I feel comfortable with	15 (39)	6 (100)
9. To have the energy to do what I want	14 (36)	1 (16)
10. To be mentally aware	13 (33)	0 (0)
11. To feel at peace	13 (33)	2 (33)
12. To be free from anxiety	12 (31)	2 (33)
13. To feel safe	12 (31)	1 (16)
14. Not being a burden to my family	11 (28)	2 (33)
15. To be treated the way I want	11 (28)	2 (33)
16. To feel well and comfortable	11 (28)	1 (16)
17. To maintain my dignity	10 (26)	2 (33)
18. To have smooth digestion	10 (26)	0 (0)
19. To not feel nausea	10 (26)	1 (16)
20. Not being connected to machines	10 (26)	1 (16)
21. Not dying alone	9 (23)	1 (16)
22. To be kept clean	8 (20)	1 (16)
23. To have someone who will listen to me	8 (20)	1 (16)
24. To not feel down	8 (20)	0 (0)
25. To have access to all the information I want	7 (18)	1 (16)
26. To have my financial affairs in order	7 (18)	1 (16)
27. To say goodbye to the important people in my life	6 (15)	2 (33)

(continues)

TABLE 1 Sum of Cards Selected by the 39 Participants and the Most Ill Participants (n = 6), Continued

Statements ^a	All, n (%)	Most Ill, n (%)
28. To have close friends nearby	6 (15)	1 (16)
29. To have an advocate who knows my values and priorities	6 (15)	0 (0)
30. To prevent arguments by making sure my family knows what I want	5 (15)	0 (0)
31. To be able to share how I feel with my family and friends	5 (15)	2 (33)
32. Not having pressure sores	5 (15)	1 (16)
33. To know how my body will change	5 (15)	1 (16)
34. To be able to choose the place of death	5 (15)	1 (16)
35. To have my family prepared for my death	4 (10)	1 (16)
36. To be able to help others	3 (8)	1 (16)
37. To receive help with practical issues	3 (8)	2 (33)
38. To receive human touch	3 (8)	0 (0)
39. To pray	3 (8)	0 (0)
40. To have my funeral arrangements made	3 (8)	0 (0)
41. To take care of unfinished business with family and friends	2 (5)	1 (16)
42. To remember personal accomplishments	2 (5)	1 (16)
43. To feel that my mouth is fresh and clean	2 (5)	1 (16)
44. To feel that my life is complete	1 (3)	0 (0)
45. To meet with clergy or a chaplain	1 (3)	0 (0)
46. To be able to talk about what death means	0 (0)	0 (0)
47. Blank cards ×3		

^aStatements derived and reformulated from international research, quality indicators, national policy documents, and clinical and research assessment questionnaires.⁷



the number of statement cards to make them clinically useable also for the most ill patients.

METHODS

Setting and Sampling

The design of the study has previously been described in an article exploring the feasibility of using the cards to facilitate wishes and priorities in EoL care patients.⁷ In brief, patients were recruited from 5 specialized palliative care units in the south of Sweden, including home care and inpatient wards, during 2016 to 2017. The inclusion criterion was to possess cognitive and verbal capabilities to participate in a 1-hour individual interview. A contact nurse from each unit provided potential participants with oral and written information, and if they expressed interest, a member of the research team contacted them within a week. If still interested, time and place were arranged according to the participants' preferences. Fifty-nine participants were asked to participate in the study; 41 agreed, and 39 participants were included, with 24 men and 15 women (Figure and Table 2). Six of the most ill participants died less than a month after data collection (range, 6–26 days; median, 20 days).

Data Collection

During individual interviews, participants were instructed to select the 10 most important cards to them at that moment using the Q-sort method.⁸ Between 9 and 14 cards were selected by the participants.

Data Analyses

Descriptive and analytical statistics were used. The probability of a card being chosen was calculated as the number of times a card was chosen divided by the number of

patients, and 95% confidence intervals were constructed from 10 000 bootstrapped samples (in each sample, the cards chosen by the participants were sampled with a replacement to achieve a set of 100 patients and their respective chosen cards). The probability of each card being chosen was then calculated. The 2.5th and 97.5th percentiles of the 10 000 probabilities were chosen as the lower and upper confidence limits for each card. To reduce the number of cards, we chose a probability of 0.25 as the cutoff point. All analyses were performed using R (version 3.4.2).⁹

Ethical Consideration

The study was approved by the Regional Ethical Review Board in Lund, Sweden (Dnr: 2015/809, 2016/408) and performed according to the ethical principles of research in a palliative care context.¹⁰ All participants gave informed consent. Interviewers with experience of caring for severely ill patients performed the interviews, and supported the participants' integrity and respected their fluctuating condition.

RESULTS

On the basis of the 46 statements, the cards most selected by the 39 participants were (1) "To be free from pain," (2) "To have my family with me," and (3) "To be able to move around." The cards most selected by the severely ill participants (ie, participants dying less than a month after data collection) were (1) "To have staff I feel comfortable with," (2) "To be free from pain," and (3) "To have my family with me" (Table 1).

On the basis of the probability of 0.25, 20 cards were analyzed as expressing the most common wishes and priorities (Table 3).

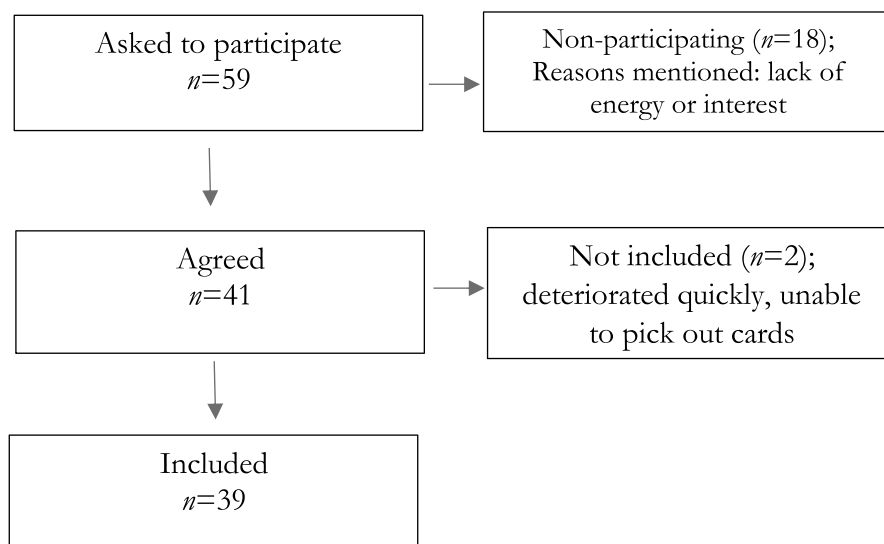


FIGURE. Flowchart of participants and dropouts.



TABLE 2 Participant Characteristics (N = 39)

Age, range (median)	38-87 (72)
Sex, men/women	24/15
Cohabitant/single occupants	37/2
Diagnosis, cancer/heart or kidney failure	35/4
Born in Sweden/another country	38/1
Interviewed at home/in another place	37/2

Six of the 39 participants used 1 to 3 blank cards and wrote wishes or priorities that were not included in the cards (Table 4).

DISCUSSION

“To be free from pain” was the most prioritized wish in this population, which was expected and confirms previous research.^{2,11} Other highly ranked statements were related to family and HCPs, but most of them referred to basic individual needs such as being able to move around, breathe easily, sleep, eat/drink, and feel safe. This emphasizes the need to focus the goal of care of these patients not only on symptom relief but also on function and basic needs in everyday life.

Among the 6 most ill participants, the wish “To have staff I feel comfortable with” was first, “To be free of pain” was second, and “To have my family with me” was third. These results indicate that patients' wishes and priorities may change along the illness trajectory and may reflect the fact that the well-being of the most ill participants is largely dependent on the care and approach of HCPs (cf. Klarare et al¹²). This needs to be confirmed in longitudinal studies exploring the wishes and priorities of patients with palliative care needs over time. The individual variation of why an issue was important or not during card sorting was recently explored by Eneslätt et al,⁶ using GWG, and showed that the participants tended to focus on either physical, social, or existential/spiritual dimensions when they were discussing various issues such as pain, mental awareness, or dignity. They argued the importance of exploring the reasoning and focus behind the chosen card. This means that it is also important that the various dimensions are represented in the deck of cards. This study shows that, among the most 20 prioritized cards, all aspects (ie, physical, psychological, social, existential, and practical) are included (Table 3).

Several of the most selected cards referred to basic individual needs with a focus on function rather than symptoms such as being able to move around, breathe easily, sleep, eat/drink, and feel safe. This emphasizes the need to also focus the care of these patients on basic needs in

TABLE 3 The Most Commonly Chosen Cards

Card	Probability of Being Chosen	95% Bootstrapped CI
1. To be free from pain	0.72	0.63–0.80
2. To have my family with me	0.51	0.41–0.61
3. To be able to move around	0.49	0.39–0.58
4. Not being short of breath	0.46	0.36–0.56
5. To be able to sleep well	0.44	0.34–0.53
6. To trust my doctor	0.44	0.34–0.53
7. To be able to eat and drink	0.41	0.32–0.51
8. To have staff I feel comfortable with	0.38	0.29–0.48
9. To have the energy to do what I want	0.36	0.27–0.45
10. To be mentally aware	0.33	0.24–0.43
11. To feel at peace	0.33	0.24–0.43
12. To be free from anxiety	0.31	0.22–0.40
13. To feel safe	0.31	0.22–0.40
14. Not being a burden to my family	0.28	0.20–0.37
15. To be treated the way I want	0.28	0.20–0.37
16. To feel well and comfortable	0.28	0.20–0.37
17. To maintain my dignity	0.26	0.18–0.34
18. To have smooth digestion	0.26	0.17–0.35
19. Not feeling nausea	0.26	0.17–0.34
20. Not being connected to machines	0.26	0.17–0.34

Abbreviation: CI, confidence interval.

everyday life. The card “To be able to move around,” not included in other card-sorting studies in palliative care, was picked by half of the total selection of patients in EoL and



TABLE 4 Participants' (n = 6) Statements Written on Blank Cards

• To be able to live my life as normally as possible
• To have fun and enjoy life
• To be treated with empathy
• To live in the present
• To avoid visiting the emergency department
• To not overmedicate so that other problem arises
• Humor and positivity
• Meaningful activities I can contribute to

also half of the most ill patients and may represent the wish to have the physical ability to independently perform basic needs as well as to have the freedom to do what is desired. Physical and functional disability of severely ill patients means losing everyday occupations and activities,¹³ and a recent study by Høgdal et al¹⁴ showed that more than 50% of patients in palliative care expressed unmet needs regarding physical activities, work, and daily activities.

On the basis of the probability of a card being chosen by participants, we reduced the number of statement cards to 20. Several statements resembled those on GWG^{4,6} but contained more statements related to basic needs. The findings differed from those obtained by Delgado-Guay et al,² in which patients assigned greater importance to spirituality than the participants in this study. This may reflect Swedish society, which has been described as secular.¹⁵ This may also reflect that the cards need to be culturally specific.

Several participants, including the most ill, chose statements from the 26 statements that were removed during the statistical analyses. These 26 statements cover well-known outcome measures within palliative care (Table 1). Some participants used the blank cards to convey their wishes and priorities (eg, to be able to live as normal as possible, to avoid visiting the emergency department) (Table 4), indicating the importance of including blank cards in the deck. Thus, the wide range of individual wishes and priorities relating to a unique life situation calls for a person-centered care approach, in which these cards may be a clinically useful conversation tool.

The present set of statements on the cards adds to the development of outcomes relevant to patients with palliative care needs. However, additional studies are required on different patient groups, care trajectories, and cultural settings to explore the variety of goals of care for patients in the last days and weeks of their lives. Further studies can examine the processes of conversations exploring

immediate needs and whether or how wishes and priorities change over time.

Limitations of the Study

The number of participants in this study limits the generalizability of the results. However, given the ethical considerations and practical difficulties of collecting data in the most ill participants in palliative care, this is the first study to explore the use of cards to discuss wishes and priorities in this context. All participants except 1 were born in Sweden, and the result must be interpreted in the light of a Swedish context and culture with western standards and high secularization.

CONCLUSIONS

On the basis of this study, a small deck of statement cards has been created that can be used by the most ill patients who are close to death. The statements contain wishes and priorities covering the physical, psychological, social, and existential dimensions and practical aspects of the last phase of life. The results show that a wide range of individual wishes and priorities may change with increasing dependency on care and whether one belongs to a secular or nonsecular society. This collection of statements is intended to be used as conversation cards to facilitate discussions between patients, HCPs, and/or family members and to help formulate goals of care for patients in EoL care. The prioritized statements can inform the development of a core outcome set for palliative care.

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