

Brief Report

Assessing Symptoms, Concerns, and Quality of Life in Noncancer Patients at End of Life: How Concordant Are Patients and Family Proxy Members?



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Abstract

Context. It has become commonplace to use family caregivers as proxy responders where patients are unable to provide information about their symptoms and concerns to health care providers.

Objectives. The objective of this study was to determine the degree of concordance between patients' and family members' reports of patient symptoms and concerns at end of life.

Methods. Sample dyads included a mix of patients residing at home, in a nursing home, in a long-term care facility, or in hospice. Diagnoses included patients with amyotrophic lateral sclerosis ($n = 75$), chronic obstructive pulmonary disease ($n = 52$), end-stage renal disease ($n = 42$), and institutionalized, cognitively intact frail elderly ($n = 49$). Dyads completed the Patient Dignity Inventory (PDI), the modified Structured Interview Assessment of Symptoms and Concerns in Palliative Care, and Graham and Longman's two-item Quality of Life Scale.

Results. Concordance was less than 70% for seven of the 25 PDI items, with the lowest concordance (65.1%) for the item "not being able to continue with my usual routines." For all but one PDI item, discordance was in the direction of family members reporting that the patient was worse off than the patient had indicated. Where discordance was observed on the Structured Interview Assessment of Symptoms and Concerns in Palliative Care and Quality of Life Scales, the trend toward family members overreporting patient distress and poor quality of life continued.

Conclusion. Understanding discordance between patients and family member reports of symptoms and concerns is a valuable step toward minimizing patient and family burden at end of life. *J Pain Symptom Management* 2018;56:760–766. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

End of life, proxy, quality of life, dignity, distress

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Accepted for publication: July 24, 2018.

Background

Quality of life is an important consideration for patients and their families at end of life. Health care providers strive to accurately assess the symptoms and concerns of these patients to offer appropriate treatment and management plans to maximize patient quality of life.^{1,2} Unfortunately, owing to symptom severity arising from the progression of disease, many patients are limited in their ability to be involved in formulating their care plans.² Where patients struggle to provide information about symptoms and quality of life concerns to health care providers, it has become commonplace for family caregivers to assist as proxy reporters for patients.¹

Patients with cancer have been the focus of most of the research studies regarding patient–family member concordance of symptoms and concerns. In these studies, patients' global quality of life,³ functional dependency,³ observable symptoms,⁴ level of physical functioning,² and physical symptom distress^{2,3} show stronger patient–family member concordance than affective components of quality of life² and psychosocial concerns,³ including anxiety and depression.⁴ In one study, higher concordance was found for more concrete, observable experiences about which patients and their family members were more likely to have conversations (e.g., breathing comfort).⁵ Subjective aspects of the patient experience, such as anxiety and depression, are less evident to caregivers⁵ and therefore less likely to be perceived as salient² and accurately estimated. Patient and family member perceptions of these subjective aspects are consequently less concordant than more observable aspects of the end-of-life experience.

Patient–family member concordance surrounding cancer patient preferences in dying has been found to be high for the following: keeping dignity and self-respect in dying, avoiding worry for loved ones, being unafraid, and being hugged or touched.⁵ In this study, family members overestimated the importance of clearing up bad feelings with others and discussing end-of-life wishes with physicians and underestimated the importance of patients' worries around being a strain or burden.⁵

When considering noncancer palliative populations, few concordance studies exist. In comparison to patients with advanced cancer, the context of end of life may be quite different for the institutionalized, frail elderly as well as patients with chronic obstructive pulmonary disease (COPD), amyotrophic lateral sclerosis (ALS), and end-stage renal disease (ESRD). In noncancer populations, the disease trajectory tends to be less certain, more prolonged, and noncancer patients are more likely to be unaware they are dying.^{6–10} These contextual issues may affect the

perceptions of both patients and their proxy family caregivers.

In one study where approximately 50% of the participants had noncancer diagnoses, the concordance between patient and family proxy reports ranged from 53% to 66%.¹¹ Family member caregivers overestimated patient pain and disability, underestimated caregiving needs, and perceived different future fears than did patients. Patients were more concerned with being perceived as a burden to family, while family members voiced more concern about the physical suffering of the patient. Both patients and caregivers were more likely to report as concerns those aspects of care that affected the other party more than themselves. The mutuality involved in being cared for and being the caregiver highlights the complexity involved in end-of-life care, and while this mutual care may be positive, it also may be problematic if needs go unmet.¹¹

In a concordance study of patients with chronic organ failure, proxy reporting was a less accurate reflection of the patient experience, with family members overestimating the number and severity of symptoms.⁶ Perhaps, as a result of the poor agreement surrounding symptom severity, there was poor-to-moderate agreement concerning symptom-related interventions, and family members were less satisfied with medical treatment than patients.

The present study sought to broaden our understanding of patient–family member concordance in palliative care by addressing noncancer patient populations at end-of-life, specifically those with a diagnosis of COPD, ALS, or ESRD, as well as the institutionalized, cognitively intact frail elderly population. The purpose was to determine the degree of concordance between patients' and family members' reports of patient symptoms and concerns at end of life. As these patients move toward dying, health care practitioners look to family members to aid in identifying patients' symptoms and concerns. Determining the extent of patient and family member concordance, and the direction of any discordance, may prove valuable as a first step in the minimization of patient burden.

Methods

A prospective design was used to examine symptoms, concerns, and quality of life of patients with advanced ALS, COPD, and ESRD, and the institutionalized, cognitively intact, frail elderly. This brief report presents the patient–family member concordance data for these populations. The cross-sectional patient data and a more fulsome description of the eligibility criteria and recruitment procedures were previously published.¹² Eligibility criteria within each of the

four study populations were designed to identify people whose current clinical status suggested imminently life-limiting circumstances, hence most likely to benefit from a palliative care approach. Study participants were recruited from Winnipeg, Canada (Health Sciences Centre, St. Boniface General Hospital, Winnipeg Regional Health Authority) and Edmonton, Canada (University of Alberta Hospital, Alberta Health Services, Covenant Health, and CapitalCare), after approval from the ethics boards at the University of Manitoba and the University of Alberta. Patients resided in a long-term care facility, hospice, and nursing home, or lived at home. A “nursing home” is distinct from a “long-term care facility,” with the latter referring to a residential facility that affords patients a more intensive level of nursing care than that provided in a nursing home, given a higher level of chronic illness and/or symptom severity, or having a life-limiting health condition that otherwise requires a relatively more time-intensive level of chronic nursing care.

All patients or residents meeting eligibility criteria were asked permission by the clinical staff to have their name released to the study nurse or research assistant, who then confirmed eligibility and obtained written consent. Basic demographic and personal health information was gathered. Patients and their family member proxies then completed three questionnaires assessing the following:

- i. Dignity-related concerns (Patient Dignity Inventory [PDI]¹³): The PDI is a 25-item instrument measuring an array of physical, psychological, and existential issues, with each item scored from 1 (not a problem) to 5 (an overwhelming problem) [a score of ≥ 3 denotes a problem]. To determine the applicability of the PDI to noncancer populations, the instrument was administered to 62 participants (13 with ALS; 21 with ESRD; 16 with COPD; and 12 frail elderly). On the basis of these pilot data, two items that made reference to sickness were revised to read health status, given that the frail elderly did not necessarily see themselves as sick.
- ii. Existential distress (modified Structured Interview of Symptoms and Concerns in Palliative Care [SISC]¹⁴): Five items from the SISC were used in this study: dignity, suffering, hopelessness, desire for death, and general life dissatisfaction. Scores range from 0 (not a problem) to 6 (extreme problem). Caseness was defined as a score of ≥ 3 (a moderate problem).
- iii. Quality of life (Graham and Longman Quality of Life Scale¹⁵): This two-item, 11-point instrument (0–10) assesses 1) current quality of

life—from “poor” to “excellent” and 2) satisfaction with current quality of life from “not satisfied at all” to “very satisfied.”

Analysis

All analyses were conducted using SAS version 9.3 (SAS Institute, Cary, NC). Descriptive statistics (mean, SD, and percentages, as appropriate) were calculated. The degree of concordance and discordance (overestimation and underestimation) was calculated for each measure. For the PDI, concordance was defined as the patient and family proxy member agreeing on whether the PDI item in question was a problem (≥ 3) or not a problem (< 3). For the SISC, concordance was defined as agreement between the patient and family proxy member regarding whether the SISC item in question was scored moderate/strong/severe rather than none/minimal/mild. For the Quality of Life Scale, concordance was defined as patient and family proxy member responses that were no more than 0–3 scale points apart, with discordance defined as responses 4–10 scale points apart. Formal statistical tests of concordance agreement were calculated, with the polychoric correlation used for the PDI and SISC, and the intraclass correlation coefficient used for the quality of life scale.

Results

Of 663 eligible patients approached to participate, 249 declined. Reasons for nonparticipation included not interested ($n = 222$), too busy ($n = 14$), did not respond to an invitation to take part ($n = 11$), or the family said “no” ($n = 2$). Of the remaining 414 patients who provided consent to participate, 10 patients either withdrew from the study ($n = 6$), or completed no questionnaires ($n = 3$), or were deemed too cognitively impaired to participate ($n = 1$). Family proxy responses were gathered from 218 of the remaining 404 patients. Of the 186 patients who did not have a participating family proxy, the main reason was unavailability, in that 100 (53.8%) of these patients were unable to identify a family member. There were 56 family members (30.1%) who were uninterested in being a proxy, 25 (13.4%) who were unreachable by the research nurse, four who consented but withdrew soon thereafter, and one who felt too unwell to participate. The 218 participating patients had the following ailments: 75 had ALS, 52 COPD, 42 ESRD, and 49 were frail elderly. Patient and family proxy sociodemographic details are presented in [Table 1](#). A large majority (89.3%) of study participants in the ALS, COPD, and ESRD cohorts were living at home,

Table 1

Patient and Family Proxy Sociodemographic Findings

Patients (<i>n</i> = 218)	
Population	
ALS	75 (34.4%)
COPD	52 (23.9%)
ESRD	42 (19.3%)
Frail elderly	49 (22.5%)
Location	
Edmonton	116 (53.2%)
Winnipeg	102 (46.8%)
Gender	
Female	101 (46.3%)
Male	117 (53.7%)
Partner status	
Married/common-law	117 (53.7%)
Other	101 (46.3%)
Current residence	
Home	151 (69.3%)
Nursing home	43 (19.7%)
Long-term care	16 (7.3%)
Hospice	3 (1.4%)
Other	4 (1.8%)
Missing	1 (0.5%)
Highest education attainment	
Postgraduate	15 (6.9%)
University/college	40 (18.4%)
Some university/college	36 (16.5%)
High school	33 (15.1%)
<High school	93 (42.7%)
Missing	1 (0.5%)
Family proxy (<i>n</i> = 218)	
Gender	
Male	55 (25.2%)
Female	163 (74.8%)
Partner status	
Married/common law	172 (79.9%)
Divorced/separated	22 (10.1%)
Widowed	4 (1.8%)
Never married	19 (8.7%)
Missing	1 (0.5%)
Highest education attainment	
Postgraduate	18 (8.3%)
University/college	57 (26.2%)
Some university/college	53 (24.3%)
High school	46 (21.1%)
<High school	42 (19.3%)
Missing	2 (0.9%)
Present employment status	
Retired	107 (49.1%)
Employed full time	67 (30.7%)
Employed part time	26 (11.9%)
Disability/sick leave	12 (5.5%)
Never employed	1 (0.5%)
Other	3 (1.4%)
Missing	2 (0.9%)
Relationship to patient	
Spouse/partner	109 (50.0%)
Adult child	72 (33.0%)
Friend	11 (5.1%)
Other relative	10 (4.6%)
Sibling	9 (4.1%)
Parent	2 (0.9%)
Other	4 (1.8%)
Missing	1 (0.5%)
Hours of care for patient per week	
0 hours	14 (6.4%)
1–4 hours	62 (28.4%)
4–8 hours	28 (12.8%)
8–12 hours	18 (8.3%)
>12 hours	93 (42.7%)

(Continued)

Table 1

Continued

Type of support provided to patient	
Coordination of care	159 (72.9%)
Communication	148 (67.9%)
Psychological	112 (51.4%)
Physical	110 (50.5%)
Spiritual	74 (33.9%)
Medication	71 (32.6%)
Nursing/medical	24 (11.0%)

ALS = amyotrophic lateral sclerosis; COPD = chronic obstructive pulmonary disease; ESRD = end-stage renal disease.

while all the frail elderly subjects were living in residential care. The mean age of the patients was 73.4 years, SD = 11.6.

The concordance findings are shown in Tables 2 (PDI and SISC) and 3 (QOL). Table 2 also presents the percentages of patients and family proxy members who indicated PDI problems and SISC concerns. All the PDI and SISC correlations were statistically significant at an alpha level of 0.001, with the exception of two items that were significant at an alpha level of 0.05 and one PDI item—"Concern that my spiritual life is not meaningful"—that was not significant. Nineteen of the 25 PDI items had a correlation in the moderate range, that is, between 0.400 and 0.600.

The average number of concordant PDI items per patient was 19.3 (SD = 4.2). Concordance was less than 80% for 15 of the 25 items. The highest concordance (92.7%) was for the item "Concern that my spiritual life is not meaningful," whereas the lowest concordance (65.1%) was for the item "Not being able to continue with my usual routines." For all but one of the PDI items—"Feeling that I have 'unfinished business'"—discordance was in the direction of family members reporting that the patient was worse off than the patient had indicated.

Concordance exceeded 80% for all five of the SISC items (range 80.7–91.7), with four of the five SISC items having a correlation in the moderate range (0.400–0.600). For four of the five items (dignity, hopelessness, suffering, and general dissatisfaction), discordance was in the direction of family members overreporting patient distress. Family underreporting of patient distress was significant for the "desire for death" SISC item.

Table 2 shows a trend toward higher concordance for items with lowest endorsement as a concern (PDI) or problem (SISC). The low rate of endorsement for the spirituality PDI item produced not only the highest concordance rate but also the lowest correlation value (0.144), considered to be weak.

For the quality of life measure (Table 3), concordance was 77.7% for the assessment of current quality of life, and 73.8% for satisfaction with current

Table 2
Patient–Family Proxy Member Indication of Problem/Concern and Concordance

	Problem/ Concern (%)		Concordance (%)	Discordance (%)		Polychoric Correlation	P-value
	Patient	Family Proxy		Overestimate	Underestimate		
Patient Dignity Inventory							
Concern that my spiritual life is not meaningful	1.9	4.3	92.7	3.2	0.92	0.144	0.386
Not feeling supported by my community	0.9	7.9	89.9	7.8	0.9	0.442	0.003
Feeling that I have not made a meaningful and/or lasting contribution in my life	3.7	7.9	87.6	7.3	3.2	0.355	0.004
Not feeling supported by my health care providers	2.8	9.9	87.2	8.7	1.8	0.504	<0.001
Not being treated with respect or understanding by others	4.6	11.5	87.2	9.6	2.8	0.430	<0.001
Not being able to accept the way things are	10.3	17.3	86.7	9.2	2.3	0.616	<0.001
Feeling like I am no longer able to mentally cope up with challenges to my health	7.9	12.1	85.3	8.7	4.6	0.390	<0.001
Not being able to think clearly	7.4	12.0	83.9	10.6	5.1	0.355	<0.001
Feeling that life no longer has meaning or purpose	15.8	17.2	83.5	10.6	4.6	0.559	<0.001
Feeling that I have “unfinished business”	17.5	15.2	82.6	7.3	9.6	0.500	<0.001
Not feeling worthwhile or valued	19.0	23.6	78.0	12.8	8.3	0.436	<0.001
Not being able to attend to my bodily functions independently	18.1	29.8	76.2	17.0	5.5	0.681	<0.001
Feeling depressed	16.7	29.6	76.2	17.9	5.1	0.585	<0.001
Feeling that I am a burden to others	26.0	28.8	73.9	13.8	11.0	0.440	<0.001
Feeling that how I look to others has changed significantly	12.1	24.7	73.4	18.8	6.4	0.498	<0.001
Feeling anxious	19.4	31.8	73.4	19.3	6.9	0.468	<0.001
Feeling that my health and care needs have reduced my privacy	17.1	24.5	72.5	17.0	9.6	0.469	<0.001
Not being able to carry out important roles	27.0	28.4	70.6	14.7	13.3	0.517	<0.001
Experiencing physically distressing symptoms	40.8	50.9	68.8	20.6	10.6	0.455	<0.001
Worrying about my future	24.4	37.3	68.4	22.0	9.2	0.506	<0.001
Feeling like I am no longer who I was	30.4	39.3	68.4	19.3	10.6	0.466	<0.001
Not being able to carry out tasks associated with daily living	36.2	43.6	67.9	19.7	12.4	0.573	<0.001
Feeling that I do not have control over my life	27.3	35.6	67.0	20.2	11.9	0.390	<0.001
Feeling uncertain about my health and health care	31.6	40.9	66.5	20.6	11.5	0.498	<0.001
Not being able to continue with my usual routines	39.4	48.8	65.1	21.1	13.8	0.452	<0.001
Structured Interview Assessment of Symptoms and Concerns							
Desire for death	4.2	3.3	91.7	2.3	3.2	0.551	<0.001
General dissatisfaction	3.3	7.1	91.3	4.6	0.9	0.495	<0.001
Hopelessness	7.6	8.1	84.4	6.4	6.0	0.463	<0.001
Loss of dignity	7.1	8.5	83.5	7.3	6.0	0.292	<0.001
Sense of suffering	11.8	19.0	80.7	11.5	4.6	0.452	<0.001

quality of life. Like the PDI and SISC findings, discordance was in the direction of family proxy members underestimating both current quality of life and satisfaction with quality of life. The correlations for both quality of life items were, however, weak, that is, below 0.300.

Discussion

The present study findings show that, in noncancer end-of-life patient populations, approximately 65%–90% of family members and patients are in concordance with regard to patient dignity, distress, and

Table 3
Patient–Family Proxy Member Percentage Concordance

Quality of Life Scale	Concordance (%)	Discordance (%)		Intraclass Correlation	P-value
		Overestimate	Underestimate		
Current quality of life	77.7	4.3	18.0	0.241	<0.001
Satisfaction with current quality of life	73.8	5.7	20.5	0.287	<0.001

quality of life. Conversely, approximately 10%–35% of family members and patients are discordant in their responses. Discordance was in the direction of family members overestimating patient distress and underestimating patient dignity, quality of life, and satisfaction thereof. These results are consonant with earlier empirical efforts in cancer-specific end-of-life patient populations.

Many dying patients lose their ability to speak for themselves or have compromised cognitive or verbal functioning that hampers efforts to communicate their physical and affective symptoms, needs, and preferences. Family caregivers often speak for the patient, representing the patient's voice in an effort to maximize patient care quality. Increasing numbers of patients are electing to die at home, with a relatively large percentage of the patient care burden being carried by family caregivers. The patient's health care team, including palliative home care staff, may rely on family proxies to represent the patient's voice. The present findings suggest that health professionals who are charged with managing patients' symptoms and quality of life concerns, and who often look to the opinions of significant others of patients when doing so, should keep in the mind the possibility of 1) discordant assessments by patients and significant other proxies and 2) the trend toward overreporting by significant others. It is the hope that taking these considerations into mind may improve the validity of patient assessments, thereby enhancing the quality of patient care that is informed by these assessments.

There are contrasting possibilities to explain the findings of discordance realized in the present study. First, and perhaps most seemingly obvious, some patients may accurately present their health concerns and related affective states, with family members regarding symptoms as abnormal and therefore perceiving greater patient distress and poorer overall patient well-being than patients. Second, dying patients might minimize their health concerns as a coping response, lowering their expectations of wellness as death approaches, with a potentially added perceived benefit of lowering family caregiver burden. This hypothesis is consistent with findings from McPherson and colleagues¹⁶ that to minimize burden on family caregivers, patients would try to conceal difficulties caused by their disease and develop an acceptance of their situation. Third, research demonstrates that dying patients engage in a repertoire of activities such as living in the moment and maintaining routines aimed at maintaining their sense of dignity.¹⁷ The bolstering impact such nominal activities have in supporting dignity may well go unrecognized by family members. Fourth, the hypothesis of "double awareness" suggests that many patients are able to adapt positively as death approaches by successfully

managing the psychological tension between living meaningfully in the present while preparing for inevitable death,¹⁸ and perhaps family members are less able to maintain or understand this tension, seeing the dying patient as hopelessly suffering and dying rather than positively adapting despite advancing illness. Family members interpret the patients' distress through the prism of their own experience, including their own affective state and concerns about the future. While patients may be able to live in the present moment and anticipate the "release" of death, family members may understand that the patient's death marks the beginning of bereavement and continuation of suffering. To the extent that discordance reflects the added burden of suffering experienced by the family member, discordance presents a clinical opportunity to acknowledge it, validate it as important, and explore it.

Future studies in this area should move beyond patient–family member concordance estimates, using qualitative methods to uncover and delineate the sources of, reasons for, and impacts of any discordance. Qualitative research methods might be particularly helpful in this regard, having patients and family members engage in a discussion about any discordance, with the goal of arriving at an understanding of what ails both parties, with an emergent care solution that maximizes the wellness of the dyad. Future research should also work toward the development of interventions to facilitate effective communication about symptom management and other end-of-life concerns between patients and family members. One such intervention, coined Dignity Talk, is a series of question prompts designed to facilitate important, sensitive end-of-life conversations between patients and family members. Early evaluation efforts show that Dignity Talk is well received by patients, family members, and health professionals.¹⁹

The present findings suggest that understanding discordance between patients and family member proxy reports of symptoms and concerns may be a valuable step toward minimizing patient and family burden at end of life. While it may be theorized that patient care is maximized when patient–family member health reports are concordant, an alternative consideration is that varying levels of discordance need not have any clinically significant bearing on patient care and associated health outcomes. Instead, by seeing the patient–family member dyad as the primary unit of care, rather than solely the patient alone, efforts to minimize discordance may be less clinically relevant than efforts to understand the underlying causes of any discordance so that the clinical focus can be on the symptoms, concerns, and wishes of the patient and family, expressed by either party, necessarily heeding the vocal expressions of the family

member when the clarity of the patient's voice has waned.

Disclosures and Acknowledgments

This work was supported by the Canadian Institutes of Health Research grant no. 93640. The funders had no role in study design, data collection and analysis, decision to publish, or article preparation.

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