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Original Article

Eliciting Personhood Within Clinical Practice: Effects on Patients, Families, and Health Care Providers

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Abstract

Context. Failure to acknowledged personhood is often the cause of patient and family dissatisfaction. We developed the Patient Dignity Question (PDQ) as a simple means of inquiring about personhood: "What do I need to know about you as a person to give you the best care possible?"

Objectives. This study aimed to evaluate the impact of the PDQ on patients and families, evaluate its influence on health care providers (HCPs), and determine if HCP characteristics mediate receptivity to PDQ-elicited information.

Methods. Palliative care patients or their family members were asked to respond to the PDQ. Responses were summarized, read to participants to ensure accuracy, and with permission, placed in their charts. Patient, family, and HCP responses to the PDQ were then elicited.

Results. A total of 126 participants (66 patients and 60 family members) responded to the PDQ; 99% indicated that the summaries were accurate, 97% permitted the summary to be placed in the chart, 93% felt that the information was important for HCPs to know, and 99% would recommend the PDQ for others. A total of 137 HCPs completed 293 evaluations of individual PDQs; 90% indicated that they learned something new from it, 64% that they were emotionally affected by it, 59% that it influenced their sense of empathy, and 44% that it influenced their care. HCP empathy, job satisfaction, having a meaningful life, and social support mediated responsiveness to PDQ-elicited information.

Conclusion. The PDQ offers an effective way of eliciting personhood, enhancing patient, family, and HCP experience alike. J Pain Symptom Manage 2015;■:■–■. *© 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Personhood, dignity, communication, empathy, job satisfaction

Introduction

Modern medicine is sometimes characterized as impersonal and routinized, with little attention being paid to issues of personhood.[1–4] This is often blamed on ever mounting time pressures and a focus on delivering technically appropriate evidence-based care. Perceived lack of caring can undermine trust, jeopardize the quality of patient/health care provider (HCP) relationships, and impede frank patient disclosures, leading to missed diagnoses and compromised patient safety.[4–9] When this happens, patients and families are more apt to feel that their real concerns have not been heard, acknowledged or addressed, increasing the likelihood of complaints or even litigation.[5,10–14] Although disengagement from the

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caring facets of medicine may seemingly protect clinicians from emotionally painful aspects of attending to seriously ill patients, it is often associated with HCP burnout and clinical ineffectiveness.[15,16]

Few would disagree that acknowledgment of personhood—seeing people in terms of who they are rather than exclusively in terms of whatever ailment they have—ought to be foundational within the culture of medicine.[9] Yet the anxiety in entering into these conversations regarding personhood is that it might take too long, detailing patient responses may be too onerous, or it could be emotionally evocative, for patients and HCPs.[17,18] However, failure to acknowledged personhood is often the root cause of patient and family dissatisfaction, and the reason why medicine is sometimes perceived as uncaring or emotionally abrasive.

The purpose of this study was to test a novel and brief way of eliciting information regarding personhood, by asking the question, "What do I need to know about you *as a person* to give you the best care possible?"—a question we coined the Patient Dignity Question (PDQ), given the association between sense of dignity and patients feeling known for who they are and what is important to them, rather than exclusively in terms of their diagnostic and medical specificities.[5,19,20] Because the PDQ elicits information regarding personhood, it may enhance dignity by way of changing HCP perspective regarding who patients are as persons. The following research questions were addressed: 1) What is the impact of the PDQ on patients and families?, 2) How does the PDQ affect HCPs' perceptions of patients? and 3) Do HCP characteristics mediate receptivity to PDQ-elicited information?

Methods

Patient and Family Participant Study Protocol

This study was coordinated by the Manitoba Palliative Care Research Unit, CancerCare Manitoba, and the University of Manitoba, Winnipeg, Canada. Between September 2011 and April 2013, consecutive patients receiving inpatient care at one of three palliative care facilities affiliated with the Winnipeg Regional Health Authority—St. Boniface General Hospital, Riverview Health Centre, and the Grace Hospice—or their family members meeting eligibility criteria, were invited to participate in this study. For patients, inclusion criteria included the following: 1) being 18 years of age or older, 2) receiving inpatient palliative care, 3) having a terminal condition with less than a six-month life expectancy, 4) being well enough to complete the study protocol, 5) not being delirious or otherwise cognitively impaired (based on clinical consensus), 6) willingness to respond to the PDQ, and 7) being able to read and speak English. In instances when patients were too unwell to take part, a family member was invited to do so on their behalf, if they were willing and knew the patient well enough to respond to the PDQ and they had the ability to read and speak English. The protocol was approved by the Health Research Ethics Board, University of Manitoba. All participants provided written informed consent.

The PDQ was designed to elicit a conversation of between 10 and 20 minutes. After collecting patient/family demographic data, the research nurse provided participants with a rationale for the study, consisting of a statement to the effect that "Although patients usually feel that their health care providers understand their illness, many worry they do not really know who they are *as a person*." This is followed by an opportunity for the participant to reflect, respond, or obtain clarification. The PDQ is then posed: "What should your health care providers know about you (your family member) as a person to give you (them) the best care possible?" Again, the participant is provided an opportunity to reflect, respond, or ask for clarification. The remainder of the conversation is constructed to guide the participant through a personalized response. Although this should feel spontaneous, flexible, and open ended, there are various prompts that can be used, only if required, to guide and inform this process: "What would you want any staff member walking in this room to know about you/them *as a person?*," "Are there special qualities you would want them to see?," "Are there key roles or relationships you would want them to know about?," and "Are there specific concerns, or important beliefs, you would want them to be aware of?"

Once the participant completes his or her response, the research nurse immediately prepares a brief written summary, one to three paragraphs at most, of what was said. The research nurse then returns to the participant with the PDQ summary, for the purpose of reading it aloud in its entirely, determining if there are any corrections that need to be made, and obtaining permission to have the PDQ written summary placed on the patient's medical chart. Participants are then asked to complete a six-item PDQ feedback questionnaire (Table 1).

HCP Study Protocol

All staff offering direct clinical care on participating palliative care units, that is, physicians, nurses, students (including nursing and medical students, residents, and interns), social workers, health care chaplains, and health care aides were eligible to participate; consent forms and written material with an explanation of the protocol were kept on the wards

Table 1
PDQ Participant Characteristics and Feedback Survey ($N = 126$)

Variable	N	%	Mean	SD
Who completed interview				
Patient	66	52.38		
Family	60	47.62		
Family was female	45	73.77		
Family age (yrs)			59.4	14.2
Palliative Performance Scale[a]	123		38.9	9.8
If family, relationship to patient	60			
Spouse/partner	25	41.7		
Sibling	5	8.1		
Adult child	27	43.6		
Other relative	2	3.2		
Other	1	1.6		
Years known to the patient			49.3	13.7

Feedback Survey: The PDQ ...	No. Responded Yes	%
Was accurate	124	98.4
Can be put in chart	121	96.0
Would like copy	95	75.4
Information is important for HCPs	107	84.9
Would affect the way HCPs give care	81	64.3
Recommended to others	117	92.9

PDQ = Patient Dignity Question; HCPs = health care providers.

[a] Ten-item functional assessment tool, with a range of 0 (death) to 100 (healthy); a Palliative Performance Scale of 40 corresponds to being mainly in bed, unable to do most activities, extensive disease, mainly assisted self-care.

throughout the course of the study. On providing written informed consent, basic demographic information, including gender, age, education, disciplinary affiliation, years in practice, and marital status, was obtained. HCP participants also were asked to fill out measures that might influence receptivity to PDQ-elicited information: 1) the Empathy Questionnaire;[21] 2) the Job Satisfaction Scale[22] assessing factors related to work life; 3) the Meaningful Life Measure[23] assessing personal well-being, a sense of purpose, excitement, principles, accomplishment, and values; and 4) the Multidimensional Scale of Perceived Social Support[24] measuring HCP social support. Thereafter, HCP participants were asked to assess their response to the PDQ, using an eight-item survey (with individual items ranging from 1 [strongly disagree] to 7 [strongly agree]) developed for this study (Table 2), each time a PDQ summary appeared in one of their patients' charts. To mitigate any social desirability bias, all HCP responses were anonymous; and they were asked to place completed forms in a locked metal box kept on the ward.

Data Analysis

The results of the patient/family participant PDQ feedback questionnaire and the HCP survey were tabulated. Summation of the latter items formed a composite PDQ Responsiveness Score (PRS), offering a global quantitative measure of the PDQ's effect on HCPs. Cronbach's alpha and correlations between individual PDQ items and the total PRS were used to assess internal consistency. HCPs were able to provide feedback on a variable number of occasions, thus creating an imbalanced repeated-measures design with multiple PRS per HCP. Therefore, linear generalized estimating equation models were used when investigating the association between HCP characteristics and the PRS, with individual HCPs treated as the clustering effect. Results from these models are presented as differences in means for categorical predictors and regression coefficients for continuous predictors. All presented models are univariate, as multivariable models were found to yield similar results. Descriptive statistics have been adjusted for repeated measures as appropriate. All analyses were performed with SAS, version 9.3 (SAS Institute, Inc., Cary, NC).

Results

Over the course of this study, 221 patients were approached to take part, 40 of whom were too ill, eight were too close to discharge, eight were cognitively impaired, 18 died before the study could be completed; and one did not speak English. Of the remaining 146 eligible patients, 80 declined (71 were not interested, eight were too busy, and in one

Table 2
Effect of PDQ on HCPs (Based on $N = 293$ Responses)

	Strongly Disagree or Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree or Strongly Agree
HCP Response to PDQ	N (%)	N (%)	N (%)	N (%)	N (%)
Learn something new from PDQ	18 (6.2)	6 (2.1)	4 (1.4)	26 (9.0)	236 (81.4)
Was emotionally affected by PDQ	31 (10.6)	9 (3.1)	66 (23.0)	62 (21.2)	125 (42.7)
PDQ influenced attitude	41 (14.1)	15 (5.2)	73 (25.2)	60 (20.7)	101 (34.8)
PDQ influenced care	67 (23.8)	8 (2.8)	82 (29.1)	53 (18.8)	72 (25.5)
PDQ influenced respect	45 (15.8)	7 (2.5)	96 (33.8)	37 (13.05)	99 (34.9)
PDQ influenced empathy	32 (12.0)	5 (1.8)	78 (27.9)	65 (23.2)	100 (35.7)
PDQ affected connectedness	23 (8.2)	6 (2.2)	74 (26.5)	55 (19.7)	121 (43.4)
PDQ affected satisfaction caring for patient	21 (9.4)	7 (3.1)	85 (38.1)	30 (13.5)	80 (35.9)

PDQ = Patient Dignity Question; HCPs = health care providers.

instance, the family did not forward the patient consent), leaving 66 patients to take part (a 45% response rate). Ninety-three family members—not associated with any of the patient referrals—were approached for enrollment; this was done in instances when patients were simply too sick to take part and, therefore, deemed ineligible. Twenty-five family members declined (20 not interested, three were too busy, one did not return the call, and one felt too stressed), and eight family members were ineligible (four patients deteriorated too quickly, three died, and one was discharged before the PDQ could be administered), resulting in 60 family participants responding to the PDQ on the patient's behalf (a 71% response rate). One hundred twenty-six PDQs were completed (66 by patients and 60 by family members) over the course of the study (Table 3). Just under half of these PDQs pertained to men (46%); the average age of patients was 73.5 years (SD 12.6); most of them (85%) had some form of end-stage cancer; and the remainder had various nonmalignant terminal conditions. Most of the 60 family participants were females (n = 45, 73.8%); had a mean age of 59.4 years (SD 14.2); included patients' spouses/partners (27, 43.6%), adult children (27, 43.6%), siblings (5, 8.1%), and other (3, 4.8%); and had generally known the patient for a very long time (49.3 years [SD 13.7]) (Table 1).

Of the 126 PDQ summaries, 98.4% of patient/family participants agreed or strongly agreed that they were accurate, 96% gave permission to have the summary placed in the chart, 75.4% wanted a copy, 84.9% felt the information was important for HCPs to know, 64.3% felt it could affect care, and 92.9% indicated they would recommend it for others.

With respect to HCPs, 190 consented to take part (Table 4). Their average age was 35.9 years (SD 12.6), with most being females (78%). They included nursing students (43%), registered nurses (24%), physician residents (14%), physicians (7%), health care aides (6%), medical students (3%), social workers (2%), and chaplains (2%). Although there was considerable variability, the average professional experience was 9.4 years (SD 10.2). One hundred thirty-seven

Table 3

Patient Demographics (N = 126)[a]

Variable	N	%	Mean	SD
Gender				
Male	58	46.0		
Female	68	54.0		
Age (yrs)			73.5	12.6
Education				
Less than Grade 12	22	17.5		
Grade 12	24	19.0		
Some university/college	14	11.1		
University college	57	45.2		
Postgraduate	9	7.1		
Diagnosis				
Cancer	109	86.5		
Lung	29	23.0		
Gastrointestinal	24	19.1		
Genitourinary	18	14.3		
Hematologic	10	7.9		
Breast	5	4.0		
Other cancer	23	18.3		
Noncancer	17	13.5		
End-stage cardiac disease	3	2.4		
Idiopathic pulmonary fibrosis	3	2.4		
End-stage pulmonary disease	3	2.4		
End-stage COPD	3	2.4		
Other noncancer	5	4.0		

COPD = chronic obstructive pulmonary disease.

[a] Sixty provided by patients and 66 by a family member.

Table 4

HCP Demographics (N = 190)

Variable	N	%	Mean	SD
Gender				
Male	42	22.1		
Female	148	77.9		
Age (yrs)			35.9	12.59
Profession[a]				
Physician	14	7.4		
Nurse	46	24.2		
Social worker	3	1.6		
Health care aide	11	5.8		
Chaplain/spiritual care	3	1.6		
Physician resident	26	13.7		
Nursing student	82	43.2		
Medical student	5	2.6		
Experience in profession (yrs)[b]			10.21	10.79
Employment				
Full-time	38	28.4		
Part-time	41	30.6		
Casual	7	5.2		
Student rotation	41	30.6		
Other	7	5.2		
Marital status				
Married/common-law marriage	99	52.1		
Never married	71	37.4		
Divorced/separated/widowed/other	15	7.9		
Education				
High school/some university	54	28.4		
University/college/postgraduate	136	71.6		
Had specialized palliative care training	58	31.0		
Toronto Empathy Questionnaire[c]			50.31	5.63
Job satisfaction[d]			14.32	3.98
Meaningful life measure[e]			130.03	19.19
Multidimensional Scale of Perceived Social Support[f]			71.50	10.43

HCP = health care provider.

[a] This represents 88% of eligible physicians, 92% of nurses, 100% of social workers and chaplains, 38% of health care aides, 12% of physician residents, 9% of medical students, and 18% of nursing students (trainees, i.e., physician residents, medical and nursing students spend two to four weeks on their palliative care rotation, thus their lower enrollment).

[b] This excludes physician residents as well as nursing and medical students.

[c] A 16-item scale, with a range of 0–64, with higher scores indicating more empathy.

[d] An eight-item scale, with a range of 8–40, with lower scores indicating higher job satisfaction.

[e] A 23-item scale, with a range of 23–161, with higher scores indicating a more meaningful life.

[f] A 12-item scale, with a range of 12–84, with higher scores indicating more support.

HCPs gave feedback one or more times (2.15 [SD 1.93]) regarding PDQ summaries in their patients' charts, yielding a total of 293 responses. Those who did not provide PDQ responses did not differ from responders by age, professional affiliation, or gender (all *P*-values >0.20).

Using an eight-item PDQ response questionnaire, HCPs indicated if the PDQ had had some influence on them. Specifically, 90% indicated that they had learned something new from the PDQ (Table 2); that they were emotionally affected by it (64%); that it enhanced their sense of connectedness to the patient (63%); that the PDQ influenced their empathy (59%), their attitude (56%), their personal satisfaction providing care for the patient (49%); their respect toward the patient (48%); and that it influenced their care (44%). Regarding the latter by way of example, HCPs said, "I will be more aware of his pain levels and watch for signs and symptoms of discomfort;" "[the PDQ] accelerates the building trust part of the therapeutic relationship." Ratings on each of these individual items were used to calculate a total PRS, ranging from a low of 8 (the PDQ had no influence) to a high of 56 (greatest possible influence) (Cronbach's alpha 0.868). HCPs responded equally favorably to patient- or family-elicited PDQs; PRS 37.85; 95% CI 36.26, 39.44, and 38.83; 95% CI 37.23, 40.43, respectively, *P*-value not significant.

There were some specific differences in PRS ratings across the sample (Table 5); for example, female HCPs were significantly more likely than males to be responsive to PDQ-elicited information ($P < 0.001$). Those reporting no professional experience and those reporting in excess of 15 years of professional experience demonstrated the highest responsiveness to PDQ-elicited data ($P = 0.004$). There was significant variation across disciplines, with physicians showing the lowest responsiveness; followed by physician residents, nurses, social workers, chaplains, and health care aides; nursing and medical students showed the highest responsiveness ($P = 0.006$). Baseline HCP characteristics, such as having more empathy ($P = 0.010$), lack of social support ($P = 0.040$), high job satisfaction ($P = 0.003$), and having a meaningful life ($P = 0.046$), were significantly associated with responsiveness to PDQ-elicited information (Table 5).

Discussion

Knowing who the patient is as a person has important implications for the practice of medicine.[1–3] Recognizing personhood increases the likelihood that patients feel cared about and, therefore, satisfied with the medical attention they receive. Taking an interest in who they are, what matters to them, and how they want to be seen enhances trust, increasing the likelihood that patients will disclose various personal factors that may influence their medical decision making, thus improving diagnostic accuracy and patient safety.[1,4–9,12–14,18]

Table 5

PDQ Responsiveness Score Relationships[a]

Variable	Mean	Standard Error	*P*-value
Gender			0.0004
Male	34.15	1.51	
Female	38.85	1.27	
Age			0.0973
<30	37.90	1.84	
30–40	35.33	1.63	
>40	38.32	1.16	
Marital status			0.0219
Divorced/separated	41.69	2.17	
Never married	37.41[a]	1.57	
Married/common-law	36.98[a]	1.19	
Other	27.57	4.94	
Professional affiliation			0.0058
Nurse or medical student	39.28[b]	2.42	
Social worker/chaplain/health care aide	38.85[b]	1.72	
Nurse	38.68[b]	1.34	
Physician resident	35.83[b,c]	2.67	
Physician	32.10[c]	1.95	
Years of health care experience			0.004
0	38.31[d,e]	2.04	
0–5	35.44[e]	1.61	
5–15	35.13[e]	1.57	
>15	40.00[d]	1.23	
Baseline characteristics	Estimates[f]		
Empathy	0.385	0.15	0.0104
MSPSS	−0.1651	0.08	0.0399
Job satisfaction	−0.4877	0.1626	0.0027
Meaningful life	0.1066	0.0533	0.0456

PDQ = Patient Dignity Question; MSPSS = Multidimensional Scale of Perceived Social Support.

[a] Not significantly different from each other; all other paired comparisons differ significantly $P < 0.05–0.006$.

[b] Not significantly different from each other; all other paired comparisons differ significantly $P < 0.001–0.003$.

[c] Not significantly different from each other; all other paired comparisons differ significantly $P < 0.001–0.003$.

[d] Not significantly different from each other; all other paired comparisons differ significantly $P < 0.003–0.005$.

[e] Not significantly different from each other; all other paired comparisons differ significantly $P < 0.003–0.005$.

[f] Change in average PRS Score per unit increase.

The PDQ offers a simple and effective means of placing personhood on the clinical radar. Its influence on patients, family members, and HCPs was substantial. Whether patients responded to the PDQ or family members did so on their behalf, the vast majority—in excess of 90%—reported that the information obtained was accurate, important for HCPs to know, and something they would recommend to others. The litmus test of PDQ endorsement, having the patient or family participant consent to having the PDQ summary placed in the medical chart, was realized in nearly every instance. In essence, if the PDQ conveys how people wish to be seen, or wish their ill family member to be seen, maximizing its visibility by placing it in the chart ensures that this perspective is as widely held as possible.

The influence of the PDQ on HCPs was significant, with no discernible difference as to whether the information came from patients or their families. That the vast majority of HCPs indicated they learned something new about the patient, in and of itself, makes this a worthwhile endeavor. Beyond that, however, the PDQ seemed to influence elements of care tenor,[25] that is, elements of caring related to emotional connectedness, respect, and empathy. The capacity for these feelings and attitudes toward patients is often described as immutable, perhaps innate, and not easily changed. The results of this study indicated that how HCPs feel toward patients can be shaped, in part, when they are able to access even brief information regarding what matters to patients and who they are as persons.[9,19]

Several HCP characteristics mediated responses to PDQ-elicited information. It is noteworthy that students with no professional experience and HCPs with the most experience were most responsive to the PDQ. For students, the humility that accompanies inexperience may promote openness to knowing as much about patients as possible. For senior practitioners, humility that accompanies clinical wisdom may foster a similar attentiveness to issues of personhood. Although the association between PDQ responsiveness and less HCP social support seems counterintuitive, perhaps a lack of support yields sensitivity to matters of personhood and an openness to hearing patients speak about those facets of themselves. As expected, HCPs reporting higher baseline empathy and "meaningfulness" in their lives were more amenable to PDQ-elicited information. Higher job satisfaction predicted a similar inclination, suggesting that those who are satisfied with their jobs are more likely to respond to matters regarding patient personhood; conversely, it is plausible that HCPs who inquire about patient personhood experience higher job satisfaction. Previous studies have connected meaningfulness with issues of work-life balance and staving off burnout,[15,16] whereas this study suggests that a personal life imbued with meaning may enable clinicians to attend to patient personhood while achieving higher job satisfaction.

Although the nature of information elicited by the PDQ ranged from practical issues to things of a more existential nature (Appendix: examples of PDQ summaries, available at jpsmjournal.com), great care was taken to ensure that PDQ responses did not heighten vulnerability by addressing things that might be deemed overly private or confidential. As such, posing the PDQ was framed in terms of what participants wanted *everyone looking after them* to know; not things they would want withheld or only selectively revealed. That nearly every participant elected to have the PDQ summary placed in the medical chart suggests that participants were able to select information they deemed appropriate for wide dissemination.

To mitigate selection bias, consecutive patients were approached to take part in the study; and those who refused or were not interested were, for the most part, too ill to take part. Most family members who were approached agreed to take part in the study, whereas those disinterested were largely too preoccupied with their family member's advanced and deteriorating illness. It is certainly possible that HCPs who elected to take part did so because of attitudes that embrace the importance of personhood within their clinical work. It is equally plausible that practitioners inclined toward patient-centered care chose not to take part in the study if they perceived the PDQ-elicited information redundant with what they normally inquired about during the course of providing care.

Although the generalizability of our findings beyond palliative care is speculative, it is unlikely that the issue of personhood is any less salient across the broadest spectrum of medicine. It also would seem likely, although remains to be confirmed, that health care professional characteristics associated with PDQ responsiveness would hold sway in other clinical settings. The association between meaningfulness, job satisfaction, empathy, and receptivity to PDQ-elicited information suggests that qualities of one's personal life shape how clinicians approach patient care, particularly their ability to appreciate who their patients are as people. For the purpose of this study, limited life expectancy in those receiving palliative care dictated that the PDQ be posed only once. It is likely that in other clinical settings, inquires about personhood might take place with greater frequency. Future research may consider examining the PDQ in various diverse clinical populations and settings, along with determining how often this type of inquiry should occur. Such research also might consider what impact the PDQ has on HCPs—in terms of treatment decisions and care tenor—over more protracted time intervals.

The PDQ is not meant to replace conversations with patients and families about their personal situation and what they deem important and wish to be known. However, it does appear to provide a convenient starting point for further inquiry into matters pertaining to personhood. It also offers a brief and effective way to help clinicians place personhood on their radar, thereby enhancing quality humane health care.

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Appendix

Examples of PDQ Summaries

Because of the highly personalized nature of responses to the PDQ, to protect the identity of individual participants, only excerpts from selected PDQ summaries are provided. In some instances, demographic information has been slightly altered to protect patient and family anonymity.

Patient B: 72-Year-Old Married Woman With End-stage Metastatic Breast Cancer

B. jokes that there are three important things in her life, in this order: hair, family, nails. This is B.'s way of saying that she is very particular (always has been) about her personal appearance. She is a very proper person who does not want to be seen in public without perfect hair, make-up, and being well-dressed. Lipstick and a little rouge continue to be a must for her. But the most important thing is her hair. She likes it to be done and that her hairdo remains intact.

Personal cleanliness is also extremely important to B. and part of her morning and evening routine. She would appreciate being able to maintain this routine while in hospital and, when she needs help, her preference would be to have a woman help her. B. can be very anxious. It is helpful if care providers explain what they are going to do before they do it. This would help her remain calm and not become short of breath. If she is experiencing pain, it is hard for her to be patient about waiting for medication.

Patient C: 74-Year-Old Divorced Woman With End-Stage Lung Cancer

C. feels her family has let her down. It has taken a long time but she realizes that sometimes you cannot change people. She doesn't want her family anywhere around her. They are not wanted. She stresses the importance of confidentiality. "I do not want them to know anything about me."

Patient D: 55-Year-Old Divorced Businesswoman With Uterine Cancer

D. describes herself as a mature, active, career-oriented corporate executive who gets the job done. An accomplished businesswoman, D. is accustomed to listening carefully to her clients and then creating and delivering solutions to their needs. She applies her own professionalism and business experience to the expectation she has of the health care system and her health care providers. She has taken an active learning role in the treatment of her illness and, therefore, expects a collaborative team approach from her caregivers, something she hears in words, but does not always see in practice. Rather than being seen as a sick person needing help, D. would rather be viewed as a businesswoman fighting cancer with a goal of conquering it, whether that be conquering it on a physical level or on an emotional and psychological level. She wants to be given "an ear" for airing her concerns. She appreciated being cared for with dignity and respect.

Patient E: 76-Year-Old Separated Woman With End-stage Stomach Cancer

On a practical note, E. says that her muscles and skin are very tender lately so she likes her caregivers to be very gentle when lifting or repositioning her. She also suggests patting rather than rubbing her skin when she is being bathed. O.'s appetite has been poor lately. She normally loves to eat. It bothers her when people coax her to eat. It's not that she doesn't want to each, she just cannot. E. cautions her caregivers not to be offended if she says something inappropriate or hurtful. That's not really her, but her condition. E. likes that staff explain to her what they're going to do that day, or that they are going to try this or that. E. treasures coming to this hospital. Her mother was cared for and died here many years ago. E. says, "I feel like she's looking after me."

Patient F: 64-Year-Old Married Woman With Pancreatic Cancer

F. acknowledges that her tough exterior hides a really soft interior. She says "I am covering up so they cannot really see me." She says the way she talks is not meant to be disrespectful to anyone. Sometimes she's trying to hide the fact that she doesn't remember things and doesn't want to appear stupid. She says she used to have a memory like an elephant but not now. She calls everybody sweetheart, pumpkin, or honeybunch because she has a hard time remembering people's names. F. says she is scared. She lets everyone believe that she can handle it, that she's a trooper. She pretends everything is fine but it's not. It brings her to tears when she thinks about dying. She doesn't want to die. F. says she wants people to know she has these feelings, that although she tries to hide it, there is a storm brewing inside. She feels that if people know that's how she really feels then she will not have to put up a front anymore. She also wants to be told the truth right away.

Patient J: 67-Year-Old Married Woman With Metastatic Lung Cancer

A very important part of J.'s life is her Christian faith. She was raised in the Anglican Church. Her faith helps her face her terminal illness with honesty and peace. She believes that all the work God wanted her to do here on earth will be finished and that she will go in comfort knowing that she has done everything she wanted to do. Hearing the truth from the doctors is very important to J. so that she can face the problem head on. She does not want to be patronized.

Patient L: 60-Year-Old Divorced Woman With Lymphoma

L. finds it hard to trust but usually still does until something happens to change that trust. She says she wants to be independent and do as much as possible by herself. To that end, she would prefer that the people caring for her ask, "What can you do?" or "How do you usually … ?" as opposed to "We're going to … ." L. describes herself as a well organized person—this keeps things from getting overwhelming. It's important not to move things without asking her. L. needs to pace herself or she runs out of breath or gets pain. To help her pace herself and keep organized, it's important that health care providers ask her before they do something to or for her or assume they know what she would like done and how.

Family O: O. Is a 48-Year-Old Daughter, Responding to PDQ for Her 87-Year-Old Father, P., Who has Myeloma

There are several characteristics that O. thinks are important for health care providers to know about her dad. He is a veteran of World War II and someone she describes as "truly a gentle giant." He's a person who puts the needs and wishes of others before his own. He can be easily persuaded and may go along with a person's suggestion although that may not be his preference. When someone asks him how he is, his tendency will be to respond with "I'm fine." If he is in pain, he may be reluctant to say so. He will not be forthcoming with problems unless you dig a little bit further. He just keeps it in and trudges along. O. observes that her dad also has some difficulty remembering. She is concerned that health care providers may be getting incorrect information. His answers may seem appropriate but after the health care provider leaves the room, he will acknowledge that he didn't really understand what was said.

Family U: U. Is the 40-Year-Old Daughter of V., a 79-Year-Old Widow With End-Stage Lung Cancer

V. is a very modest person and is acutely uncomfortable with males giving her any intimate care. She is sensitive and the discomfort she expressed regarding male caregivers was distressing and embarrassing for her as she felt misunderstood. Decreasing independence has been a real struggle for V. — she can sometimes become a little "snippy" because she wants to do as much for herself as she can. She appreciates eye contact—partly because she is hard of hearing and the direct eye contact gives her visual cues. In the past few weeks, she has had an increased sensitivity to noise and cannot tolerate more than a couple of visitors at a time. As well, she is no longer able to watch TV or listen to music—too much stimulation. She has always appreciated things in order and tidy but now more than ever. V. loves touch like back and feet rubs, her face being washed or hair being brushed—all these things calm her.

Family Y: Y. Is the 65-Year-Old Niece of a 100-Year-Old Woman, Z., With Myelodysplastic Syndrome

Y. describes her aunt Z. as a refined lady who is very particular—someone who likes things to be near, tidy and in order. Z., who will be 101 in December, lived in her own beautiful apartment until just last week. She was very healthy until about three years ago.

Z. was born in Canada and left for the United States in 1928. For many years Z. worked in Detroit City in a beautiful boutique where they sold exclusive fashion to people like the Fords and the Dodges. Z. is blind in her left eye. Her hearing is good. She has always had a lot of pain from osteoarthritis so appreciates slow and gentle turning and moving. Z. likes having her hair nicely combed, her face washed, her teeth brushed.