Original Article

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

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Abstract

Context. Failure to acknowledge 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;49:974–980. © 2015 American Academy of Hospice and Palliative Medicine. Published by *Elsevier Inc.* Open access under CC BY-NC-ND license.

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,

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© 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. Open access under CC BY-NC-ND license. 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 Download English Version:

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