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Research Paper

The TIME Questionnaire: A tool for eliciting personhood and enhancing dignity in nursing homes

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ABSTRACT

This study aimed at evaluating the effectiveness of the TIME (This Is ME) Questionnaire in eliciting personhood and enhancing dignity; specifically investigating the residents' and health care providers' perspectives in the nursing home setting. Residents (n=41) from six nursing homes in a Canadian urban center completed both the TIME Questionnaire and a feedback response questionnaire; health care providers (n=22) offered feedback both through a questionnaire or participation in a focus group. 100% of the residents indicated the summary was accurate. 94% stated that they wanted to receive a copy of the summary, 92% indicated they would recommend the questionnaire to others, 72% wanted a copy of the summary to be placed into their medical chart. Overall HCPs' agreed that they have learned something new from TIME, and that TIME influenced their attitude, care, respect, empathy/compassion, sense of connectedness, as well as personal satisfaction in providing care.

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Introduction

Personhood is defined by Kitwood (1997) as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8). In the nursing home setting, the quality of life and the quality of care of residents can be enhanced by acknowledgment of personhood. Health care providers (HCPs) knowing the resident as a person is essential to clinical judgment and resident advocacy. Residents are more likely to disclose their concerns through open communication in an environment of respect, empathy and trust, hence supporting their dignity. Hence supported, families worry that residents are not always being treated with respect or kindness. This may lead to feelings of embarrassment, shame, depression, hopelessness, a sense of burden and a loss of will to live. The standard standa

Chochinov and colleagues¹² developed a single item probe regarding personhood: "what do I need to know about you as a person to give you the best care possible?" It is termed the Patient Dignity Question (PDQ), as dignity is associated with people feeling understood for who they are and not just their medical diagnoses. The PDQ has been demonstrated as an effective method to support

personhood by identifying areas people feel HCPs should know about them. ^{12–14} In a recent study in the palliative care setting, ¹² 93% of patients felt the information elicited by the PDQ was important for HCPs; and 99% would recommend it to others. Ninety percent of 137 HCPs indicated they learned something new from the PDQ; and 59% indicated the PDQ influenced their empathy.

Based on identifying primary themes emerging within the qualitative responses to the PDQ, a set of questions was developed, coined the "THIS IS ME" Questionnaire (TIME) (see Fig. 1). The purpose of this study was to examine the perceived effectiveness of the TIME Questionnaire on various aspects of dignity and personhood in nursing homes. The specific research questions included: 1) How do residents perceive the impact of the TIME Questionnaire on HCPs and the care that they receive?; and 2) How does the TIME Questionnaire change HCPs' perception of residents?

Methods

Between June 2014 and May 2015, residents living in one of six nursing homes of the Winnipeg Regional Health Authority were invited to participate in the study. Both for-profit and not-for-profit organizations were involved in the study: Resident inclusion criteria included: 1) being age 65 or older; 2) being cognitively intact in order to complete the study protocol or have a family member participate by proxy; 3) willingness to respond to the TIME Questionnaire; 4) ability to read and speak English; and 5) ability to

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Questions:

What do we need to know about you as a person to give you the best care possible?

Are there particular relationships or personal connections you would like us to be aware of?

Are there specific accomplishments or roles you would like us to be aware of?

Are there important values you would like us to know about?

Are there particular qualities or characteristics that you would like us to know about?

Are there specific beliefs, religious or spiritual practices that we should know about?

Are there particular worries or concerns you would like us to be aware of?

Are there particular responsibilities or obligations you would like us to be aware of?

Are there things we should know about you, which might influence how to provide your care

(e.g. vision or hearing challenges; problems with thinking; mental health issues; other)?

Is there anything else about you as a person that you would like us to know, in order to give you the best care possible?

Fig. 1. This Is Me Questionnaire (TIME).

provide informed consent. The protocol was approved by the Health Research Ethics Board.

Residents meeting inclusion criteria were identified by the nursing home staff. Residents interested in taking part gave permission to have their names released to the researcher, who confirmed their eligibility and obtained informed consent. After explaining the study protocol, demographic information was collected from residents which included: age, gender, ethnicity, marital status, education, religious affiliations and the length of residence in the nursing home.

Residents were then introduced to TIME, a 10 item questionnaire designed to understand an individual as a person. While TIME was designed for self-administration, reading the questions and writing down responses verbatim and/or audio recording responses was more feasible in this population. A 15–20 min conversation was facilitated using TIME based on what residents felt comfortable sharing, from which a typed summary was then created. Contents included in the summary reflected what residents would want the HCPs to know about them, in order to enhance or inform their care, rather than disclosures of detailed personal material that might result in feelings of vulnerability.

Within 24 h, the research assistant went back to confirm the accuracy of the contents of the TIME summary. Any erroneous or missing details were corrected. By means of structured interviews to solicit feedback on their perceptions of TIME, residents or family members were asked: 1) to describe their perception of the TIME summary; 2) to give their permission to place the TIME summary in their medical chart and/or their room to share with HCPs; 3) to explain if they thought the contents of TIME was important for HCPs to have access to and why; 4) to share how the TIME summary might influence the way in which HCPs might care for them; and 5) to indicate whether or not they would recommend TIME to other residents and/or family members. Residents were asked to fill out a feedback questionnaire (rated from 1 [Strongly Disagree] to 7 [Strongly Agree]), eliciting their further impressions of TIME.

After the TIME summary had been created and placed on the resident's chart and/or in the resident's room, HCPs were approached in person at staff meetings, and/or on the unit. HCPs were informed of the existence of TIME summaries, and were approached to determine their interest in taking part in the study. Inclusion criteria included being a HCP (physicians, nurses, health care aides, and students in the respective fields) who cared for a resident who had completed a TIME Questionnaire. After obtaining written informed consent from the HCP, demographic information was collected. A total of two focus groups were held over the course of the study, where HCPs shared their impressions in addition to completing a feedback questionnaire. HCPs who were unable to

attend either of the focus groups had the option of solely completing the feedback questionnaire. The protocol was approved by the University of Manitoba Health Research Ethics Board.

Data analysis

Quantitative analysis was performed using the Statistical Package for Social Sciences (SPSS) software 14.0 for Windows (SPSS Inc, Chicago). Descriptive statistics such as means, standard deviations, and frequencies were used to describe the demographic characteristics of participants. Comparison of mean scores differences between residents and HCPs was analyzed by the Mann–Whitney U-test. Statistical significance was set at P < 0.05.

Results

One hundred and twenty eight residents were invited to participate in the study. Four did not meet eligibility criteria (3 were too ill, 1 was cognitively impaired, 2 had a language barrier). Of the remaining 122 eligible residents, 75 declined (majority due to lack of interest), leaving 47 participants (39% response rate). Six participants withdrew halfway and did not complete the procedures (2 were too ill, 4 were no longer interested). Forty-one TIME summaries were completed. Thirty-four percent of the participants were male; the average age was 83.3 years (SD = 9.8 years), with an average length of stay in the nursing home of 3 years (SD = 3 years) (Table 1). A broad approach to soliciting participation was used to invite HCPs. Of those who declined, majority were due to work priorities. The 22 HCPs who shared their perception of the TIME Questionnaire represented a convenience sample. Of the 22 participants, 90% female; their average age was 44.5 years (SD = 12.2), and average professional experience of 11 years (SD = 10 years)

Overall, residents highly endorsed TIME. According to the feedback questionnaire, 100% of the residents indicated the summary was accurate, 94% wanted to receive a copy of the summary, 92% would recommend the questionnaire to others, and 72% wanted a copy of the summary to be placed into their medical chart (Table 2). Residents indicated that TIME gave them a heightened sense of dignity (4.6, SD = 1.53). Residents believed the information in TIME is important for HCPs to have access to (5.5, SD = 1.25), and that the summary could affect the way HCPs look after them (4.6, SD = 1.70). Residents reported TIME could change the way HCPs see or appreciate them (4.2, SD = 1.65), could allow HCPs to know about what matters to them (5.1, SD = 1.75), allow HCP to know more about their personal concerns and worries (4.5, SD = 1.72),

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