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Project Title: The TIME Questionnaire: A Tool For Eliciting Personhood and Enhancing Dignity in Personal Care Homes

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SUMMARY: (no more than 250 words single spaced)

Context. Knowing each resident as a person is fundamental in strengthening the resident-health care provider relationship in the personal care home setting. The `This is Me' (TIME) Questionnaire is a tool designed to aid health care providers (HCPs) in understanding personal qualities of residents under their care.

Objectives. This study is aimed to evaluate the effectiveness of the TIME Questionnaire in eliciting personhood and enhancing dignity; specifically investigating the residents' and HCPs' perspectives.

Methods. Residents in six personal care homes of the Winnipeg Regional Health Authority were asked to complete the TIME Questionnaire. Subsequently, the qualitative responses were summarized, read to participants to ensure accuracy, and then with their permission, placed into their medical charts. Qualitative and quantitative feedback from residents and health care providers were then sought.

Results. A total of 41 residents completed the TIME Questionnaire: 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.

Conclusion. The TIME Questionnaire is a viable tool for HCPs to elicit personhood and enhance dignity centered care. While residents endorsed the value of TIME as a dignity enhancing intervention, their feedback suggested that these responses were less uniformly held than among HCPs.

Student Signature **Supervisor Signature**

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The TIME Questionnaire: A Tool For Eliciting Personhood and Enhancing Dignity in Personal Care Homes

Abstract

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Introduction & Background

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." (Pg. 8)[1] In the nursing home setting, the quality of life and the quality of care can be enhanced by acknowledgement of personhood. [2-4]Knowing the resident as a person by health care providers (HCPs) is essential to clinical judgment, and patient advocacy.[5] Residents are more likely to disclose their concerns through open communication in an environment of respect, empathy, and trust - hence supporting their dignity. [6-9] When dignity is not adequately supported, families worry residents are not always treated with respect or kindness. [10]This may lead to feelings of embarrassment, shame, depression, hopelessness, a sense of burden, and a loss of will to live. [11]

Chochinov *et al.* 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, what is significant to them, their concerns and struggles, and not just their medical diagnoses. The PDQ has been demonstrated as an effective method to support personhood by identifying areas people feel that HCPs should know about them.[12, 13, 14] In a recent study in the palliative care setting[12], 126 participants (66 patients; 60 family members) responded to the PDQ. 99% indicated the summaries were accurate; 97% placed the summary into their medical chart; 93% felt the information was important for HCPs; and 99% would recommend the PDQ to others. 293 evaluations were completed by 137 HCPs; 90% agreed or strongly agreed they learned something new from the PDQ; 59% indicated the PDQ influenced their empathy and 49% reported influence in satisfaction regarding providing patient care. Albeit an effective tool in the palliative and acute care setting, the application of the PDQ in the personal care home setting, however, has not been investigated.

Based on identifying primary themes emerging within the qualitative responses to the PDQ, a set of questions is developed - the “**T**HIS **I**S **M**E” questionnaire (**TIME**) (see Figure 1). The purpose of this study was to examine the perceived effectiveness of the TIME Questionnaire on various aspects of dignity and personhood in personal care homes. Specifically, research questions include: 1) How do residents perceive the impact of the TIME questionnaire on HCPs and the care that they receive? 2) How does the TIME Questionnaire change HCPs’ perception of residents?

Methods

Study Protocol for Residents and Family Member Participation by Proxy

Between June 2014 and May 2015, residents under care at one of six personal care 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: Saul and Claribel Simkin Center, Heritage Lodge, Charleswood Care Center, Kildonan Care Center, Concordia Place, and

Riverview Health Center. Resident inclusion criteria included: 1) being age 65 or older; 2) being well enough 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 provide informed consent. The protocol was approved by the University of Manitoba Health Research Ethics Board.

Residents meeting inclusion criteria were identified by the nursing home staff. Names of residents were released with the resident's permission, the student then explained the study, confirmed eligibility, and obtained informed consent. For residents who were not able to complete the study procedures due to cognitive challenges, family members were identified by the nursing home staff to participate by proxy. Inclusion criteria for family proxies included: 1) have a family member residing in a care home; 2) willingness to complete the study protocol; 3) adequate knowledge of the resident in order to respond to the TIME questionnaire in the best interest of the resident; 4) ability to read and speak English; and 5) ability to provide informed consent.

Demographic information collected from residents or family members included: age, gender, ethnicity, marital status, education, religious affiliations, and length of time the resident has been residing in the care home.

Residents or family members were then introduced to TIME, a 10 question document designed to understand an individual as a person. The questionnaire invited residents to share information that they would want HCPs to know about them in order to give them the best care possible. While TIME was designed for self administration, with the resident's permission, reading the questions and writing down responses verbatim and/or audio recording responses was more feasible due to the age group of the residents. A 15 to 20 minute conversation was facilitated based on what residents felt comfortable sharing. The student then produced a typed summary of what was said. Contents included in the summary reflected what residents would want the HCPs to know to in order to enhance or inform their care, rather than disclosures of detailed personal material that would result in feelings of vulnerability. Family members who participated by proxy had the choice of writing down their answers on the TIME questionnaire template, or to have the student record via writing and/or audio tape the facilitated conversation. A typed summary was then created based on the verbal responses.

Feedback from residents or family members was sought immediately following the return of the TIME summary when the student affirmed its accuracy. Any erroneous or missing details were corrected. By means of structured interviews, 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 think the contents of TIME is important for HCPs to have access to and why; 4) to share how 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.

Health-Care Provider Study Protocol

After the TIME summary has been created and placed on the patient's chart/Kardex and/or in the patient's room, HCPs were approached in person at staff meetings, and/or on the ward to determine their interest in taking part in the study. Email invitations were sent out by the nursing homes on behalf of the study. Inclusion criteria for health-care providers included physicians, nurses, health-care aides, and students in the respective fields. 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 verbal feedback in addition to providing written feedback via completing a questionnaire. HCPs who were unable to attend either of the focus groups had the option of completing the feedback questionnaire to share their perception of TIME. Responses were sent back via mail or picked up from the care home by the student.

Data Analysis

Qualitative data was transcribed and placed into an excel document. Consistent with Sandelowski's classic approach to qualitative data analysis,[15] first the content of the qualitative responses to the TIME questionnaire was read several times. Subsequently, it was coded independently by the student and an experienced qualitative researcher in the Manitoba Palliative Care Research Unit to identify common and recurring ideas expressed by the residents. Recurring ideas or codes were then clustered together into categories, and labeled to reflect the nature/type of the ideas. (See Figure 2) Coding schemas were then compared, with any differences in coding being resolved through discussion until consensus. This dual coder approach to data analysis is an important strategy that is used to ensure the rigor of the work as it is understood from a qualitative paradigm. [15] Qualitative responses to perceptions of the TIME summary by residents, family members, and HCPs was read several times and coded by the student. Comments provided to specific questions asked were first transcribed, then summarized, followed by the identification of key words. Common themes which arose were grouped into major themes and subthemes. All quantitative data were typed and coded into an excel document. Analysis was performed using the SPSS software, version 14.0, as well as Microsoft Excel, version 2003. Statistical comparison tests conducted include the T test and the Mann Whitney test, using 0.05 alpha level of significance.

Results

Quantitative Data

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 was no longer interested). Forty-one TIME summaries were completed. 34% of the participants male, 66% of the participants female, average age 83.3

(SD 9.8), average length at nursing homes 3 years (SD 3 years) (Table 1).

Of the 41 TIME Questionnaires completed: 100% of the participants indicated the summary was accurate. 94% wanted to receive a copy of the summary, 92% would recommend the questionnaire to others, 72% wanted a copy of the summary to be placed into their medical chart (Table 2).

Responses regarding perception of the TIME questionnaire were reported on a Likert scale 1 (Strongly Disagree) to 7 (Strongly Agree). Residents indicated that they believe the information in TIME is important for HCPs to have access to (average of 5.5 out of 7) and that the summary could affect the way HCPs look after them (4.6); could give them a heightened sense of dignity (4.6). Residents perceived that TIME could change the way HCPs see or appreciate them (4.2), could allow HCPs to know about what matters to them (5.1), to know more about their personal concerns and worries (4.5), their important values (4.9), and about areas in their life that they find are causing them distress (4.4). In addition, residents shared that TIME could tell HCPs something new they didn't already know (4.3). Residents believe that TIME could influence the attitude HCPs have towards them (4.2), the care they receive from the HCPs (4.2), the respect they receive from HCPs (4.2), the sense of empathy or compassion they receive from HCPs (4.3), and the sense of connectedness they receive from HCPs (4.2). Residents also indicated that they believe TIME will influence their personal satisfaction in their healthcare (4.8) (Table 2).

Six family members completed TIME by proxy over the course of this study. 100% of the participants male, average age 64.5 (SD 9.0), average length at nursing homes 3 years (SD 4 years) (Table 1). Of the 6 TIME Questionnaires completed by proxy: 100% of the participants indicated the summary was accurate. 80% wanted to receive a copy of the summary, 100% would recommend the questionnaire to others, 100% wanted a copy of the summary to be placed into their medical chart (Table 2).

Family responses regarding their perception of TIME were reported on a Likert scale 1(strongly disagree) to 7(strongly agree). Families indicated that they believed the information in TIME is important for HCPs to have access to (average of 6.8 out of 7) and that the summary would affect the way HCPs looked after the resident (5.7); that TIME would give their family member a heightened sense of dignity (6.5). Families perceived that TIME would change the way the staff see or appreciate their family member (6.0), would allow the staff to know about what matters to their family member (6.3), would help the staff to know more about the resident's personal concerns and worries (6.2), the resident's important values (6.2), areas in the resident's life that was causing resident's distress (6.3). In addition, TIME would tell HCPs something new they didn't already know about the resident. (5.0). Families believed that TIME would influence the attitude HCPs have towards residents (5.7), and influence the care residents receive from HCPs (5.3), the respect resident receive from HCPs (5.7), the sense of empathy or compassion residents receive from HCPs (6.0), and the sense of connectedness residents receive from HCPs (6.0). Families also indicated that they believed TIME would influence the resident's satisfaction with their healthcare (6.2) (Table 2).

From the total number of HCPs approached by the nursing home staff and the student, a total of 22 HCPs shared their perception of the TIME Questionnaire. Of the 22 participants, 10% were male, 90% female; their average age was 44.5 (SD 12.2), average professional experience 11 years (SD 10 years) (Table 1).

Responses were reported on a Likert scale 1(strongly disagree) to 7 (strongly agree). HCPs indicated they learned something new about the residents (average of 6.4 out of 7); that it influenced their attitude towards the resident (5.5),their care of the resident (5.3), the respect they felt towards the resident (5.9); their sense of empathy or compassion for the patient (5.8), their sense of connectedness (5.9), and their personal satisfaction in providing care for the resident (5.7) (Table 3).

There were significant differences in terms of the influence and utility of TIME, comparing residents with the HCPs (Table 3). HCPs rated the utility of TIME to be higher on average, whereas residents rated their perceived influence of TIME on HCPs to be lower on average. HCPs indicated they have learned something new from the TIME summary (6.4), whereas residents predicted HCPs will learn something new from the TIME summary at a lower rating (4.3) (P = 0.000). HCPs indicated TIME influenced their attitude (5.5), whereas residents predicted the influence to be lower (4.2) (P=0.0115). HCPS indicated TIME influenced the care toward the resident (5.3), whereas residents predicted the influence of care to be lower (4.2) (P=0.0312). HCPs rated the influence of TIME on respect for residents at 5.9, whereas residents rated the predicted the influence on respect they will receive at 4.2 (P=0.0012). HCPs rated the influenced of TIME on their empathy towards residents at 5.8, whereas residents predicted the influenced of TIME on the empathy they receive from HCPs at 4.3 (P=0.0015). HCPs indicated TIME influenced the sense of connectedness they feel towards residents (5.8), whereas residents predicted the connectedness HCPs will feel towards them at a lower rating (4.2) (P=0.0000). In addition, HCPs indicated TIME influenced their satisfaction in providing care for residents (5.7), while residents indicated that TIME will influence their personal satisfaction in receiving care at a lower rating (4.8) (P=0.0139). Overall, HCPs' ratings regarding the utility of TIME was higher on average compared to residents rating of the potential influence of TIME.

Qualitative Data.

The overarching theme emerging from the qualitative data within the TIME summaries was that of “Knowing Me”. Knowing Me consists of 6 major categories: *typical demeanor/personality, preferences, physical or psychological distress, accomplishments, important relationships, and qualities that residents value.* (See Figure2) Residents indicated it was important for HCPs to have an understanding of residents’ typical outward behavior or bearing, to know residents' *typical demeanor/personality*. In order to provide personalized care that was tailored to meet resident needs, it was important for HCPs to know resident *preferences* regarding diet, physical care, recreational, informational, religious/spiritual. The ability of HCPs to meet the physical and emotional needs of residents meant that they had to

be aware of any *physical or psychological distress* residents might be experiencing. Seeing the resident as a person with a life story beyond their present situation in the nursing home required that HCPs know about some of the things that residents had *accomplished* in the past and were proud of. For HCPs to relate to the resident meant knowing who is close to the residents and the *relationships that are important* to the resident. Building a trusting relationship meant it was important for HCPs to know the *qualities that residents value*.

Two major themes were identified regarding residents' perception of the influence of the TIME Questionnaire: *appreciation* and *concerns*. Two subthemes were found for *appreciation*: *helpfulness of knowledge* and *awareness of self*. Residents felt knowledge from the TIME summary could help HCPs provide individualized respectful care, and enhance resident likability. Some residents felt that TIME fostered their own self awareness, in that they reminiscence about parts of themselves they have not paid attention to. There were concerns raised by residents regarding how TIME might be interpreted and applied. For instance, some residents fear being judgement based on what was included in the summary, and whether the information would be processed to enhance care. Application concerns included whether the HCPs would access the summary once it was in the chart, and some residents thought HCPs would not have time to read the summaries. Family participants expressed similar themes: appreciation that knowledge could be helpful, and concerns regarding the practical application of TIME.

Similar themes were found for HCPs perception of TIME: *appreciation* and *concerns*. The subthemes for *appreciation* being *helpfulness of knowledge* and *awareness of self*. HCPs indicated that TIME was helpful in understanding the residents' behaviours and personalities, and also provided a template for dialogue with residents. TIME also allowed for self reflection, as it allowed HCPs to step back from focusing on the basic physical care needs of residents and stop to learn about the resident as a person. Regarding *concerns*, the subthemes varied from residents, where *interpretation concerns* was underrepresented, while the *practicality concerns* predominated. Practicality concerns include the feasibility of creating a TIME document for all residents as a regular part of care, when and how this would be accomplished, the best location to place the TIME summary to ensure that it would be read, and the presentation of the document as a word document or an alternative form for convenient application.

Discussion

Understanding the resident as a person can create an atmosphere of respect and care, in which the residents feel that their dignity is supported - leading to increased trust and disclosure, improving the accuracy of diagnosis, and increased satisfaction in health care.[5-8] The six categories of "Knowing Me" emerging from TIME provide an important framework from which to understand the resident as a person. (Figure 2) Understanding the residents' *typical demeanor/personality* provides insight regarding the patient's usual behaviors. Changes in or unusual behaviors can then be promptly identified, and the underlying reason from which the uncommon behavior is arising can then be efficiently assessed. This

behavioral approach is especially important for residents with dementia, whose cognitive challenges prevent the communication of symptoms. [16] With the increased co-morbidities of illness in the elderly, different residents may have different needs that fluctuate from day to day. Knowing the residents' *preferences* allows HCPs to provide individualized care tailored to flexibly manage resident needs. [17] To meet the physical and emotional needs of residents means HCPs first have to be aware of these *physical and emotional symptoms*. Symptoms such as pain are often poorly managed in the personal care home setting. [18] Similarly, depressive symptoms in the older adults are underreported despite its prevalence. [19] It may be easy to lose sight of who the person is, and to be unaware of the resident's life led prior to residing in the care home. Knowing the past *accomplishments* of the resident in the past and reminding residents of the things they are proud of can be helpful. This kind of recollection is a component of cognitive-reminiscence therapy, which can help with depressive symptoms. [20] Knowing who is close to the resident and their *important relationships* can help HCP relate to residents. Social support in the elderly has been linked to protection from depression[21], whereas the lack of it can increase the risk of mortality. [22] As such, it is critical that HCP be mindful of and responsive to the social needs of residents. In addition, knowing the qualities that residents value, such as kindness and respect, is important. These qualities can be emphasized by HCPs, in order to facilitate a trusting resident-health care provider relationship. [8-10] Although the information that populates the Knowing Me model may differ between residents, the framework itself can be applied to learn about each individual resident, and hopefully affirm personhood, enhance dignity and the quality of care received.

From the HCPs perspective, the TIME summary serves as an effective tool to elicit information regarding personhood and aid in delivering dignity conserving care. HCPs received the TIME summary favorably – including learning something new, and a heightened sense of empathy, connectedness, respect, and greater satisfaction in providing health care. This suggests that knowing more about the residents as a person can shape how HCPs feel regarding the resident. Understanding each individual experiences and attitudes, [28] what connects residents to others,[1] and the appreciation of residents as individuals may enhance the quality of care. The needs of the elderly in the health care setting are often not recognized. [23] Unmet social needs can lead to the loneliness of residents in nursing homes. [24] Elderspeak, which is a form of communication that sees HPCs using generic infantilizing language (eg. *honey, dear, sweety*), is perceived as a lack of respect and dis-acknowledgement of personhood, resulting in resistiveness in care and lower satisfaction for residents. [25 - 27.] By recognizing the needs of the elderly, whether its social support, or the preference in communication, and applying the information in the TIME summary, it is hoped that the acknowledgment of personhood can negate the negative effects from the lack thereof.

Compared to HCPs, residents tended to underestimate the influence that TIME would have on HCPs' perceptions. One explanation is the perceived limitations in the HCPs schedule. Many residents have acknowledged that while HCPs are proficient at their jobs, HCPs may not get a chance to read the TIME summary due to their busy schedules. If reading the TIME summaries would be lower on the priority list, then TIME is likely not to have much of an effect on HCPs. Another possible explanation is the vulnerability associated with being a resident,

and the issue of there being power differential in the relative roles of residents and HCPs. The literature speaks to the nature of dignity in the elderly and its association with 'not being a burden'. [29] In essence, having to depend on the care from health care providers can challenge a resident's sense of dignity. This loss of dignity may engender apathy and a less positive outlook [30-31] , perhaps lowering the expectations residents have regarding how TIME will influence their HCP. Although residents can hope that the TIME summary will influence HCPs positively, residents may feel more passive in that they cannot control the feelings, thoughts, or behaviors of HCPs. Residents may gain or lose by sharing their TIME summary, and are exposing themselves to the possibility that the tool may not be effective. On the other hand, TIME does not evoke any vulnerability for HCPs, who are at liberty to decide how to modify their feelings, thoughts and actions based on the information learned from TIME, which may explain the reason HCPs perceive TIME as having a great influence.

Despite underestimating the influence of TIME of HCPs, almost all of the residents regard the TIME summary as accurate and important, and would recommend the TIME to others. Over 72% consented to placing the TIME summary onto their medical chart. This suggests that residents believe in the importance of sharing, and the willingness to share this information. There were a small number of residents who were hesitant to place TIME into their medical charts. It is possible that these individuals prefer control over who has access to their information. By keeping the TIME summary with them, residents may feel comforted by the power of choice. For some residents, withholding of this information could be an expression of distrust of HCPs. The reluctance to share information was similarly found in a dignity therapy study with elderly residents. [32, 33]

There are several limitations in this study that are noteworthy. First is the issue of selection bias of the participants. It is certainly conceivable that HCPs and residents who chose to take part in this study may already have viewed personhood and dignity as important, and thereby were more likely to respond favorably to the TIME questionnaire. Alternatively, it could be argued that if there was a selection bias, these same participants would have deemed TIME as redundant, rendering the intervention ineffective; yet, that was not the case. Another foreseeable limitation is the practicability of implementing the questionnaire. Although it would be ideal to create a TIME summary for all residents, decisions need to be made regarding when and how this would be accomplished. Specificities include the appropriate location for the TIME summary to ensure it would be read and accessed, the time needed to read the summaries, and how the document should be ideally presented (e.g. as a Word document, a handwritten document, or alternative form). As noted by participants, due to the busy workload of HCPs, there is a risk that the TIME summary in the medical chart may be overlooked. Alternative locations for the TIME summary could include posting it on the wall of the resident’s room, or a location of the resident’s choosing. This would raise the visibility of the TIME summary, and residents could play more of an active role regarding if, when, and with whom to share TIME. An effective tool targeted to enhance person centered care in residents with dementia, lifestory books, which are documents designed to recognize the residents past, present and future, vary in form and media of presentation, and are displayed according to patient preference.[34 - 36] TIME could be adapted to be similarly individualized to fit

the preferences of the resident.

Future studies of TIME could explore utility of periodically updating or reapplying the TIME protocol. It would also be of interest to investigate the influence of the TIME summary on residents and HCPs over longer time intervals and/or at various time points in the resident's time in the nursing home. In addition, the family's perspective could be elicited. Literature has documented family dis-satisfaction with care of their loved ones in long term care, [37-39]it would be important to investigate whether TIME can have a positive influence on enhancing family satisfaction with care. Another area of investigation could be the focus on application of TIME for residents with dementia. The effects of TIME on families who complete TIME by proxy could be compared against the effects on residents and HCPs.

In the personal care home setting, HCPs regard the TIME questionnaire as an effective tool to promote a heightened sense of connectedness, empathy, and respect towards the residents they are caring for. From the perspective of HCPs, TIME was found to aid personhood centered and dignity conserving care[40]. While residents endorsed the value of TIME as a dignity enhancing intervention, their feedback suggested that these responses were less uniformly held than among HCPs. This study confirms that TIME provides a starting point for conversations, by providing a brief glimpse, beneath the mask of aging, about who the resident is as a person. With both TIME and time in the literal sense, one can have a profound appreciation of the vibrant and colourful personalities of the each unique resident. This appreciation could help transform the culture of care, with marked benefits for elderly residents and HPCs who care for them.

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References

1. Kitwood, T. (1997).Dementia reconsidered: the person comes first. Open University Press.

2. Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society*, *12*(03), 269-287.

3. Kitwood, T. (1991) 'Personhood, dementia and dementia care', in S. Hunter (ed) Dementia: Challenges and new directions, Research Highlights in Social Work 31, London: Jessica Kingsley Publishers.

4. Clarke, A., Jane Hanson, E., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, *12*(5), 697-706.

5. Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. R. (1993). The phenomenology of knowing the patient. *Image: The Journal of Nursing Scholarship*, *25*(4), 273-280.

6. Charon, R. (2001). Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA*, *286*(15), 1897-1902.

7. Teutsch, C. (2003). Patient–doctor communication. *Medical Clinics of North America*, *87*(5), 1115-1145.

8. Leape, L. L., Shore, M. F., Dienstag, J. L., Mayer, R. J., Edgman-Levitan, S., Meyer, G. S., & Healy, G. B. (2012). Perspective: a culture of respect, part 2: creating a culture of respect. *Academic Medicine*, *87*(7), 853-858.

9. Chochinov, H. M. (2007). Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ*, *335*(7612), 184-187.

10. Thompson, G., McClement, S., Chochinov, HM. (2011). How respect and kindness are experienced at the end-of-life by nursing home residents. CJNR, 43(3) pp96-118.

11. Chochinov HM. (2006). Dying, Dignity and new Horizons in Palliative End-of-Life care. CA: A Cancer Journal for Clinicians. 56(2):84-103.

12. Chochinov H. McClement S, Hack T, Thompson G, Dufault B, Harlos M. (2014). Eliciting Personhood Within Clinical Practice: Effects on Patients and Health Care Providers. Journal of Pain and Symptom Management. 2014 Dec. Doi: 10.1016/j.jpainsymman.2014.11.291.

13. Johnston, B., Pringle, J., Gaffney, M., Narayanasamy, M., McGuire, M., & Buchanan, D. (2015). The dignified approach to care: a pilot study using the patient dignity question as an intervention to enhance dignity and person-centred care for people with palliative care needs

in the acute hospital setting. *BMC Palliative Care*, *14*(1), 9.

14. Johnston, B., Gaffney, M., Pringle, J., & Buchanan, D. (2015). The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital. *International Journal of Palliative Nursing*, *21*(2), 71-77.

15. Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing, Science, 8, 27.

16. Nösman, B., Bucht, G., Eriksson, S., & Sandman, P. O. (1993). Behavioural symptoms in the institutionalized elderly—relationship to dementia. *International Journal of Geriatric Pychiatry*, *8*(10), 843-849.

17. Bayliss, E. A., Edwards, A. E., Steiner, J. F., & Main, D. S. (2008). Processes of care desired by elderly patients with multimorbidities. *Family Practice*, *25*(4), 287-293.

18. Martin, R., Williams, J., Hadjistavropoulos, T., Hadjistavropoulos, H. D., & MacLean, M. (2005). A qualitative investigation of seniors' and caregivers' views on pain assessment and management. *CJNR (Canadian Journal of Nursing Research)*, *37*(2), 142-165.

19. Lyness, J. M., Cox, C., Curry, J., Conwell, Y., King, D. A., & Caine, E. D. (1995). Older age and the underreporting of depressive symptoms. *Journal of the American Geriatrics Society*, *43*(3), 216-221.

20. Cappeliez, P. (2002). Cognitive-reminiscence therapy for depressed older adults in day hospital and long-term care. *Critical Advances in Reminiscence Work: From Theory to Application, 300-313.*

21. Holahan, C. K., & Holahan, C. J. (1987). Self-efficacy, social support, and depression in aging: A longitudinal analysis. *Journal of Gerontology*, *42*(1), 65-68.

22. Blazer, D. G. (1982). Social support and mortality in an elderly community population. *American Journal of Epidemiology*, *115*(5), 684-694.

23. Nolan M., Davies S., Brown J., Keady J. & Nolan J. (2002) Longitudinal Study of the Effectiveness of Educational Preparation to Meet the Needs of Older People and Carers. The AGEIN (Advancing Gerontological Education in Nursing) Project, Final Report. English National Board, London.

24. Williams, K. N., Herman, R., Gajewski, B., & Wilson, K. (2009). Elderspeak communication: Impact on dementia care. American Journal of Alzheimer's Disease and Other Dementias, 24(1), 11-20.

25. Ryan, E. B., Hamilton, J.M., & See, S.K. (1994). Patronizing the old: How do younger and older adults respond to baby talk in the nursing home?. *The International Journal of Aging &*

Human Development.

26. Ryan, E. B., Hummert, M. L., & Boich, L. H. (1995). Communication predicaments of aging patronizing behavior toward older adults. *Journal of Language and Social Psychology*, *14*(1-2), 144-166.

27. Settbo, A. (2008). Safe, but lonely: Living in a nursing home. Nordic Journal of Nursing Research, 28(1), 22-25.

28. Williams B. & Grant G. (1998) Defining 'People-Conditions': making the implicit explicit. *Health and Social Care in the Community* **6**(2),84–94.

29. Pleeserger, S. (2007). Dignity and the challenge of dying in nursing homes: the residents' view. *Age and Ageing*, *36*(2), 197-202.

30. Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age and Ageing*, *38*(4), 411-416.

31. Kane, R. A., Caplan, A. L., Urv‐Wong, E. K., Freeman, I. C., Aroskar, M. A., & Finch, M. (1997). Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. *Journal of the American Geriatrics Society*, *45*(9), 1086-1093.

32. Hall, S., Chochinov, H., Harding, R., Murray, S., Richardson, A., & Higginson, I. J. (2009). A Phase II randomised controlled trial assessing the feasibility, acceptability and potential effectiveness of dignity therapy for older people in care homes: study protocol. *BMC Geriatrics*, *9*(1), 9.

33. Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age and Ageing*, *38*(4), 411-416.

34. Thompson, R. (2011). Using life story work to enhance care: Rachel Thompson describes how staff can be supported to implement and sustain biographical approaches with clients. *Nursing Older People*, *23*(8), 16-21.

35. McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person‐centred care. *International Journal of Older People Nursing*, *5*(2), 148-158.

36. Thompson, R. (2011). Using life story work to enhance care: Rachel Thompson describes how staff can be supported to implement and sustain biographical approaches with clients. *Nursing Older People*, *23*(8), 16-21.

37. Vohra, J. U., Brazil, K., & Szala-Meneok, K. (2006). The last word: family members' descriptions of end-of-life care in long-term care facilities. Journal of Palliative Care, 22(1),

33-39.

38. Wetle, T., Shield, R., Teno, J., Miller, S. C., & Welch, L. (2005). Family 223 perspectives on end-of-life care experiences in nursing homes. The Gerontologist, 45(5), 642-650.

39. Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R. et al. (2004). Family perspectives on end-of-life care at the last place of care. Journal of the American Medical Association, 291(1), 88-93.

40. Chochinov, H. M. (2002). Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA*, *287*(17), 2253-2260.

Figures and Tables

Figure 1.
This Is ME Questionnaire (TIME)

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?

Figure 2.
Time Qualitative data: Knowing Me Categories

Overarching Theme: Knowing Me	
Categories	**Selected Data Exemplars**
1) Knowing my typical demenaor/personality	- "I'm a quiet person. I like peace, and don't like conflicts or arguments." - "When I get nervous, I usually joke around. This is how I keep my nerves down and how I deal with my stress"
2) Knowing my preferences	i) Dietary preferences "I like a variety food...salads...and not too much gravy, that gives me heartburn" ii) Physical care preferences "I would like a bath more than once a week" iii) Recreational activities preferences "I never played bingo before I got here, now I enjoy it." iv) Information preferences (like to know what is happening/going on) "I always want to know what's ahead, and if I don't know, I make a point to try as hard as I can to find out ways that I can find out about it."

	v) Religious/spiritual preferences "I'm a Roman Catholic...attend service every week here"
3) Knowing my physical and emotional symptoms	- "there is a lot of pain...it makes me dizzy" - " I feel very nervous...keeps me up at night"
4) Knowing about my accomplishments	- had my own business - “It's always been the things I made. I liked using my hands... soup... baking...my needlepoint pictures… I donated one of the bigger downstairs, they even put my name on it!" .- "I had a black belt in Juno, practiced for almost 40 years... had students...and competed in national and international championships."
5) Knowing about relationships that are/were important to me	- "my son has been my source of courage and strength to pursue multiple surgeries." - "I had one of the best marriages...almost 60 years, just 6 months short." - "I feel close with quite a few of the staff"
6) Knowing the qualities that I value	- “You can't be cruel, you have to be kind" - "Be honest. It was the way I was brought up, the way I brought up my children" - “I would like people to be treated with respect, not just myself, but others as well.”

Table 1
Demographics of residents, family, and HCPs

Categories	Sub -categories	Resident (N=41)			Family Member (N=6)			HCPs (N=22)		
		N	Average	SD	N	Average	SD	N	Average	SD
Age		41	83.3	9.8	6	64.5	9.0	22	44.5	12.2
Sex	Female	27	66%		6	100%		20	90%	
	Male	14	34%		0	0%		2	10%	
Race/Ethnicity	Caucasian	40	98%		6	100%		10	45%	
	Hispanic	1	2%		0	0%		0	0%	
	Asian	0	0%		0	0%		4	18%	
	Black	0	0%		0	0%		2	10%	
	Middle Eastern	0	0%		0	0%		1	5%	
	Aboriginal	0	0%		0	0%		1	5%	
Religion	Christian	34	83%		4	67%		19	86%	
	Jewish	3	7%		1	17%		0	0%	

	Atheist	2	5%		0	0%		0	0%	
	Hindu	0	0%		0	0%		1	5%	
	Other	1	2%		1	17%		1	17%	
	Prefer not to say	1	2%		0	0%		2	9%	
Martial Status	Widowed	23	56%		0	0%		2	9%	
	Divorced	7	17%		0	0%		4	33%	
	Never been married	5	12%		1	17%		4	33%	
	Married	4	10%		5	83%		12	55%	
	Prefer not to say	2	5%		2	5%		0	0%	
Education	Grade 1 – 6	3	7%		0	0%		0	0%	
	Grade 7 – 11	17	41%		0	0%		0	0%	
	Grade 12	6	15%		0	0%		1	5%	
	College 1 – 3	10	24%		1	17%		7	24%	
	College 4	2	5%		3	50%		8	5%	
	Graduate school	1	2%		0	0%		4	2%	
	Other	1	2%		2	33%		1	2%	
	Prefer not to say	0	0%		0	0%		1	2%	
Length of residence/work in PCH		41	3 years	3 years	6	3 years	4 years	22	11 years	10 years

Table 2

Effect of TIME on residents and family (Based on N = 41 Responses)

Effect of TIME	Residents' Average Rating (N=41)	SD	Families' Average Rating (N=6)	SD
TIME summary was accurate	100%		100%	
Permission to include summary in medical chart	75%		100%	
Would like copies of the TIME summary	94%		80%	
Would recommend TIME to others	92%		100%	
Post TIME Questionnaire*				
Information in TIME is important	5.5	1.25	6.8	0.41
TIME would affect HCPs	4.6	1.70	5.7	1.03
TIME would increase sense of dignity	4.6	1.53	6.5	0.55
See/appreciate?	4.2	1.65	6.0	0.00

TIME Matters?	5.1	1.75	6.3	0.52
TIME informs others of residents' concern/worries	4.5	1.72	6.2	0.41
TIME informs others of residents' values	4.9	1.65	6.2	0.41
TIME informs others of residents' distress	4.4	1.81	6.3	0.52
Will learn something new from TIME	4.3	1.79	5.0	2.00
TIME will influence HCPs' attitude	4.2	1.83	5.7	1.03
TIME will influence care	4.2	1.73	5.3	0.82
TIME will influence respect	4.2	1.81	5.7	0.82
TIME will influence empathy	4.3	1.62	6.0	0.63
TIME will affect connectedness	4.2	1.56	6.0	0.63
TIME will affect satisfaction in health care	4.8	1.73	6.2	0.41

* Responses were reported on a Likert scale 1 (Strongly Disagree) to 7 (Strongly Agree)

Table 3
Effect of TIME on residents versus HCPs

Effect of TIME	Residents' Average Rating* (N=41)	SD	**Effect of TIME**	HCPs' Average Rating* (N=22)	SD	T test P value	Mann Whitney P value
Will learn something new from TIME	4.3	1.79	Learned something new from TIME	6.4	0.67	0.0000	0.0000
TIME will influence HCPs' attitude	4.2	1.83	TIME influenced attitude	5.5	1.31	0.0115	0.0268
TIME will influence care	4.2	1.73	TIME influenced care	5.3	1.34	0.0312	0.0497
TIME will influence respect	4.2	1.81	TIME influenced respect	5.9	1.52	0.0012	0.0006
TIME will influence empathy	4.3	1.62	TIME influenced empathy	5.8	1.34	0.0015	0.0004
TIME will affect connectedness	4.2	1.56	TIME affected connectedness	5.9	0.79	0.0000	0.0000
TIME will affect satisfaction in health care	4.8	1.73	TIME affected satisfaction in health care	5.7	0.96	0.0139	0.0409
-	-	-	Was emotionally affected by TIME	5.7	1.17	-	-

* Responses were reported on a Likert scale 1 (Strongly Disagree) to 7 (Strongly Agree)