

**Title:****Complex contradictions in conceptualisations of 'dignity' in palliative care****Authors:**

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**Abstract****Aim:**

To highlight differences between family members' reports of dignity in the care provided to their relatives at the end-of-life as reported in the VOICES questionnaire and their narratives about the care their relatives received.

**Background:**

Increasing attention internationally is being paid to understanding patient experiences of healthcare. Within palliative care, the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire is commonly used for this purpose. Amongst its objectives is to ask family members if their relatives were treated with dignity at the end-of-life. This is regarded as useful for understanding the quality of healthcare received.

**Methods:**

Twenty-one cognitive interviews were conducted during a New Zealand pilot of the VOICES questionnaire.

**Results:**

Discrepancies between ratings of dignity, and the lived experience of care suggest that lay understandings of dignity may not be congruent to those used by healthcare providers.

**Conclusions:**

Bereaved family members' self-reports of dignity in end-of-life care captured using survey methods alone are inadequate to understand the complex ways in which individuals conceptualise and experience dignity within a health care context. We advocate consideration of multiple, complementary, approaches to gathering consumer experiences of end-of-life care, as well as

research which enables service users to interrogate what dignity in care means within an end-of-life context.

Keywords: Views of Informal Carers – Evaluation of Services (VOICES); Questionnaires; Dignity; Death and Dying; End-of-Life Care; Qualitative Research

## **Background**

Dignity is regarded as a fundamental tenet of palliative care and enshrined in its very definition. The World Health Organization (WHO) (2011, p.1) describes palliative care as focused on “improving the symptoms, dignity, and quality of life of people approaching the end of their lives.” However, whilst dignity “is embedded in many documents and papers” such as this one, “it is rarely defined” (Baillie 2008, p.25). Kennedy (2016, p.45) argues that although there is agreement dignity is a universal need and “fundamental to the well-being of every individual in all societies,” its practical meaning “remains complex and unclear because it is a multidimensional concept.”

Anderberg et al. (2007, p. 635) provide an overarching, and highly cited, definition:

Dignity may be defined as a concept that relates to basic humanity. Dignity consists of inherent and external dimensions, which are common for all humans and at the same time are unique for each person.

This emphasis on the uniqueness of individual conceptualisations of dignity points to a need to understand it as a socially constructed phenomenon, which Street and Kissane (2001) posit. In a similar vein, Trussardi and Gott (2015) frame dignity as a shared co-construction that is defined within the context of relationships and which takes on different meanings according to social and historical contexts. Indeed, it is a challenge to describe dignity as comprising any one set of characteristics.

However, despite these complexities of definition, dignity is still considered to be the foundation of good patient care (Kennedy 2016) and central to a patient-centered approach (Costantini et al. 2014; Pringle, Johnston and Buchanan 2016). Conversely, the loss of dignity is regarded as detrimental to patient outcomes (van Gennip et al. 2015; Solomon et al. 2016). In essence, patient dignity is framed as an overall outcome of good healthcare practice.

One context within which dignity has assumed particular importance is palliative and end-of-life care where the focus is on maximizing quality, not quantity, of life. It has been identified as a key indicator of good end-of-life practice (Quinn and Thomas 2017) and is mentioned as a goal of end-of-life care in palliative care policy internationally (Department of Health UK 2008).

One popular tool used to measure the quality of end-of-life care, which affords key importance to dignity, is the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire

(Addington-Hall and McCarthy 1995). VOICES was developed originally in the UK and is now used extensively for research and quality improvement purposes (Hughes et al. 2005; Addington-Hall and O'Callaghan 2009; Costantini et al. 2014; Andersson et al. 2017; Hughes, Seow, et al. 2017). VOICES is typically administered through the post to bereaved relatives. In the UK the questionnaire is addressed to the next-of-kin named on the death certificate. The purpose of VOICES is to collect information about the end-of-life care the recently deceased received in the last three months of life across various settings: hospice, hospital and/or residential care facilities. Specific questions also centre on the care received during the last two days of life. VOICES data has made an important contribution to the research literature, highlighting for example, not only the end-of-life experience of people dying with cancer but other conditions as well. (Addington-Hall and O'Callaghan 2009; Andersson et al. 2017).

Six items about dignity are included within the questionnaire; notably, these are always paired with, and positioned as equivalent to, 'respect.' Data regarding dignity collected from VOICES has supported interesting and important research findings. For example, Costantini et al. (2014, p.14) employed VOICES to evaluate an Italian trial of the Liverpool Care Pathway, noting that a "substantial improvement was . . . observed in the dimension exploring how much the patient was treated with respect, dignity, and kindness." In another example, VOICES was used to compare the quality of hospice in-patient care and hospital care for cancer patients. Respondents to the questionnaire reported their perceptions that the deceased were more than twice as likely always to have been treated with dignity in hospice rather than in a hospital, which the authors correlated to their overall satisfaction with the care they received (Addington-Hall and O'Callaghan 2009).

However, the definitional ambiguity pointed to in the introduction regarding professional understandings of dignity suggests the potential for a mismatch. Conclusions are drawn from quantitative survey data, and underlying understandings of dignity that families rely upon when assessing end-of-life care provision may not agree. Indeed, a discrepancy between the two provided the genesis for the analysis presented in this paper.

### **Aim**

The purpose of this paper is to explore through a thematic analysis and two case studies how dignity was conceptualised by recently bereaved family members who completed the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire.

### **Methods**

During the development of a New Zealand version of the VOICES questionnaire, the adapted

version was administered in face-to-face cognitive interviews (Frey et al., 2017). The adaptations were made following consultation with health professionals and included an alteration to the language of some questions to more adequately reflect New Zealand healthcare terminology. The overarching purpose of the VOICES pilot was to examine the acceptability of the adapted NZ VOICES questionnaire to target participants, namely bereaved family and whānau (a Māori term for family, including extended family).

#### *Recruitment and data collection*

Potential participants were identified from a hospital-based specialist palliative care service in one NZ city. Invitation letters were followed up a week later with a telephone call. The contact details of those who indicated an interest in the research were passed to the research team who scheduled interviews. A Māori interviewer, Stella Black (SB), completed interviews with Māori bereaved whānau and Gabriella Trussardi (GT) and Lisa Williams (LW) completed interviews with non-Māori bereaved family members. In total, 21 cognitive interviews were completed with 3 Māori and 18 non-Māori participants (see Table 1 for participant characteristics). Two of the Māori interviews also involved additional whānau. The non-Māori group included three participants who were of Māori descent but had not culturally identified themselves as Māori to the specialist palliative care team, hence the discrepancy in ethnicity totals in Table 1. Table 2 gives an overview of the characteristics of the deceased. The interviews took place in the participants' homes or a place they nominated. All participants were given an information sheet and provided informed written consent. The project received ethics approval from the University of Auckland Human Participants Ethics Committee (UAHPEC 010630) and the District Health Board's Research Office (A+ 5999).

#### *Cognitive Interview method*

Cognitive interviewing is an attempt to understand the thought processes of participants when they complete a quantitative survey tool, such as VOICES. The participants' answers are probed and queried in order to explore their interpretation of the questions asked; this information is then used to determine future iterations of the questionnaire. The main techniques in a cognitive interview involve "'think-aloud' interviews, probing questions, and paraphrasing follow-ups" (Singleton and Straits 2001, p. 63).

Regarding questions about dignity, VOICES asks specific ones according to the location in which care could have been delivered, as well as in general for the last two days of life. For care at home, the questions about dignity relate to care delivered by districts nurses and general practitioners

(GPs). The question regarding residential care facilities refers more generally to perceptions of staff. For the sections relating to hospice, hospital and the last two days of life, participants are asked to rate both doctors and nurses.

At the start of each interview, the researchers discussed the study information sheets with the participants and obtained their written consent. Participants received a \$30 petrol voucher as a gift of appreciation. The interviews were digitally recorded, and an independent transcriptionist transcribed the sessions verbatim, after signing a confidentiality agreement.

### *Data analysis*

GT and Merryn Gott (MG) carried out a thematic analysis in order to identify themes relating to participants' views on dignity in the context of their deceased friend or relative's experience with healthcare services at the end-of-life. Braun and Clarke (2006) describe thematic analysis as a useful method for researchers who are approaching their topic with a particular avenue of inquiry in mind as it allows them to narrow their focus by scrutinising particular aspects of the data. Additionally, two case studies were identified to highlight the discrepancies between participants' understanding of dignity, as compared to their reporting of the care and treatment their relative experienced. Case studies differ from thematic analysis and other qualitative research methods in that they allow for an intensive analysis of "a single unit or system bounded by space and time" (Hancock and Algozzine 2017, p.9). Their value lies in their ability to impart in-depth knowledge and understanding of a particular situation or event and the meaning entailed for those involved. (Hancock & Algozzine). Data were input into NVivo 10 to facilitate organisation and coding.

### **Results**

Responses to the questions about dignity were extremely positive across all settings. Ninety percent (n=18) of participants stated that nurses always treated their relative with dignity and none reported that nurses never treated their loved ones with dignity. Eighty percent (n=16) of participants stated that doctors always treated their relative with dignity, and only one participant reported that doctors never treated their relative with dignity.

Thematic analyses identified that the discussion generated within the interviews added context regarding participants' views about dignity and helped clarify the reasons informing their responses. In essence, they associated being treated dignity with three attributes: 1) staff displayed tolerance and patience; 2) staff paid attention to patients; and 3) staff carried out personal care tasks. Examples of each of these attributes are outlined below.

### *1/ Dignity was evident when staff were tolerant and patient*

Some participants regarded staff attitudes as a marker of dignity. For example, the participant quoted below said the care her mother received in hospital from the doctors and nurses was excellent. When questioned further about dignity and how this related to making her “happy with the care they’d given [her] mother,” she said:

*She’s a little bit, she nags sometimes, so then if they’re tolerant, yeah, that would be really. . . She little bit nagged if she wants something like I want to wear these socks, and then quickly she’ll change her mind . . . so if they’re tolerant, you know, that is what I always wished, yeah. [Interview 14020]*

Views on tolerance as a marker of dignity extended to care received during the last two days of life. For example, members of a Maori whānau regarded positively the doctors’ treatment of their older relative because they made allowances for the number of relatives who wished to visit: “*Yeah, they allowed a lot more, ‘coz they had moved us into a bigger room, they allowed the whānau to come in.*” [Interview 14024]

### *2/ Dignity was evident when staff attended to the patient*

In addition to tolerance and patience, participants equated paying attention to their ill relative with dignity. The participant quoted below refers to his wife’s last admission to hospital before her death. He said:

***[Interviewer] And when I say respect and dignity, what does that mean to you? What made it –***

*Checking, checking on her often. [Interview 14019]*

This attention could extend through the dying process. A man talking about his 91-year-old mother’s care during her last two days of life while in hospital equated dignity with how a nurse continued to communicate with her although she was in a coma. He said:

*It was quite amazing how a nurse would come and talk to her when there was no one to talk to, you know. She didn’t hear; she didn’t react. It was very obvious that she was basically on the way out. And they would talk to her, I would say with respect, with dignity. They would say, “[Name], sweetheart can you hear me, [name]? Well, I’ll only move you, it’ll be a little bit sore but don’t worry, we’ll help you, let me move your arm, let me move your leg.” I wanted to cry when I heard that. [Interview 14021]*

### *3/ Dignity was evident when staff carried out personal care tasks*

The completion of routine nursing tasks was seen as evidence for participants that their relative was being treated with dignity. For example, the following participant commented on the nursing staff's care for her husband during his last days in the hospital as follows:

***[Interviewer] How much of the time was he treated with respect and dignity in the last 2 days of his life?***

*Always. They were very, very good. I mean they turned him . . . They paid attention to his needs; they washed him. Couldn't shower him because he couldn't sit, stand. And they checked his pulse and medication . . . Yeah, they were very, very good, yeah, they turned him and washed him. [Interview 104018]*

## **Case Studies**

The case studies are useful for demonstrating how the narratives the participants shared were at odds with their answers to the questions posed about dignity in the VOICES questionnaire. Indeed, although as noted above most participants reported that their family members were treated with dignity, their stories about their relative's lived experience indicated that these responses belied unhappiness with both the healthcare system and staff attitudes. Ultimately, they reveal discrepancies between academic and professional understandings of dignity and those of family members when reporting on end-of-life care. They also clearly demonstrate that reports of "care provided with dignity and respect" do not necessarily translate into a family member's satisfaction with care received.

### ***Case study 1: Mr. B***

Mr. B, 75, was a keen sportsman who remained highly involved with the committee of his local sports club and had been widely acknowledged for his charity work. He was fit and healthy, although overweight, and lived in his own home. He saw his GP regularly and was on blood pressure medication. Mrs. B had recently died; he had spent the year caring for her, first at home, and then in hospice. Within a month of her death, Mr. B had a stroke and was taken by ambulance to the hospital.

During the interview, Mr. B's daughter was highly positive about the care her father had received. Indeed, she rated all items on VOICES relating to being treated with respect and dignity very positively, as exemplified in the following exchange:

**How much of the time was he treated with respect and dignity?**

*I'd say always.*

**Is that for both [nurses and doctors]?**

*Yeah for both. We just had a bit of an issue where they put a feeding tube in without any permission after we'd expressly asked to be consulted about that before they did it.*

However, when the interviewer asked Mr. B's daughter to elaborate, she recounted a story that indicated her father's care received contravened both his and the family's wishes. She explained:

*They weren't sure [Dad] was going to survive the first 24 hours, although they didn't tell us that. . . . His scans just showed the extent to the damage that had been done to his brain, and they said the likelihood of him making much of a recovery was very slim . . . He couldn't speak, he was paralysed down his right side. He did seem, obviously he did understand what was going on, but yeah he was pretty miserable.*

*We'd actually had a conversation on Christmas Eve, and he'd talked with his friends, and we knew that Dad didn't want to end up sitting in a rest home being able to do nothing for himself. That was his worst fear.*

*So we expressly said we want to be involved in any decisions that [the doctors] make. And we'd had conversations with the [doctor] about the possibility of a feeding tube because he couldn't swallow. And we wanted to be involved in that decision.*

With little likelihood of recovery, Mr. B made a decision to refuse treatment. His daughter said:

*He wasn't in a lot of pain I don't think. So they were giving him Panadol and stuff, but he sort of tried to reject quite a lot of it . . . Dad managed to convey to the doctors that he wasn't going to eat anymore. And they let him do that . . . They offered him food every day which was fine, and he would have a teaspoon of ice-cream and chuck everything away . . . choosing to stop eating was I think a pretty strong thing to do. Well, when he said he wasn't going to eat the doctors said, "Well, you understand the outcome is that you'll die." So, yeah.*

However, when Mr. B's children arrived at the hospital to visit him one day, he had been given a feeding tube. Mr. B's daughter recalled:

*They went ahead and did it without involving us in that . . . Listening to what the family has to say is, I think, really important. I think they're the ones that know people the best. And even, I mean like we said to the [specialist], "If this was you, what would you want?" And he said, "I wouldn't want a feeding tube, if it was me," so they understand. I guess there's that side that doctors have got to save people, but then I think they also really need to balance that with what life's going to be like. If they do save them, it's not necessarily always the best thing. You know, we say we wouldn't put our pets through what we put people through.*

*The doctor . . . took the blame for it, but we are fairly certain it was the nutritionist who sort of said she wanted it done. I don't know; I'm sort of surmising, you know, I'm guessing what went on. But we're fairly sure that she was adamant that he should have it. And I guess, I mean it's understandable I guess. I mean they're up there to save lives, that's what they do. But my brother and I, we knew what Dad would want. And yeah it was really tough, it was really tough. But he made the decision himself in the end, but yeah she kind of, I think she went over our heads, and almost over the doctors' heads and organised for it to happen. And then, as I say, the [doctor] took the blame himself, said that he'd given permission without thinking about it, you know, he'd sort of not taken into account what we had discussed. Yeah, and so she did it anyway.*

His daughter confronted the care team about the feeding tube: "We had a meeting about it, and they actually removed it."

Mr. B spent two weeks in the ward, before being transferred to the geriatric ward. He continued to refuse nutrition. He died twenty-two days after his stroke.

### ***Case study 2: Mrs. C***

Mrs. C, aged 70, lived with her second husband. They travelled extensively, and when based at home they enjoyed spending time with Mrs. C's children and grandchildren from her first marriage, who lived nearby.

After a private MRI scan showed abnormalities in the spine and head Mrs. C was urgently referred to the specialist at Hospital X. A bone biopsy was carried out, but the test was inconclusive. Mrs. C's

husband explained, "They had bloody learners doing stuff, this was over Christmas, and they had learners doing it, and they didn't get the right samples, and so they showed nothing."

A further bone biopsy was taken. Mrs. C's husband said:

*It was done on a Friday afternoon, and a senior doctor came in to supervise it. He took the sample away which was Friday afternoon and it appears from a report I saw later that nothing was done with it till the Monday. It sat there over the weekend . . . [on Monday] we were expecting this result, and the four of us sat around the ward all day from morning rounds through to the afternoon, and the doctors never came around. It was three o'clock when [the family] went to the nurse's desk and said. "Where are [the doctors]? They were going to have this result for us today." . . . A lady [said], "Oh, we're waiting for a report from the pathologist," because the pathologist had got the biopsy. She came back with that story, and I thought, "Yeah, this is bloody typical." So she's just a number . . . we're just waiting; nobody's pushing anything, nobody's interested in getting on with it. They're just going through the numbers.*

Mrs. C died before the results were available. The final report sent to her GP indicated the medical staff had diagnosed her with large B cell lymphoma several days prior to her death.

Mr. C also described how upsetting it was to have Mrs. C's monitor alarm silenced, with no explanation. He recalled:

*They put a monitor on her, on one of these clips, which monitors the pulse rate and oxygenation and it kept alarming all the time because her pulse rate was actually very high. No nurse came here to do anything about her, after a while we, somebody went to the nursing station and asked them, told them about it and her nurse was on tea break or something, and so another nurse came in and left it connected but switched off the alarm. [We thought] this is great, this is bloody great." I said, "What's the point of having it on there?" . . . So it wasn't impressive. We weren't happy with the way things went in there. Maybe it was the holiday staffing that had a lot to do with it.*

Overall, Mr. C was very unhappy with the treatment and care Mrs. C received. He explained:

*We weren't very happy, as a matter of fact, we almost sent in a formal complaint. We actually wrote one out and, but we sort of realised that she was probably too far advanced to be saved anyway . . . there was no urgency anywhere or no efficiency . . . I think she was*

*just a number that had to be accommodated. I don't think anybody was really keen to find out what the problem was, [they just] go through the routines.*

Mr. C felt that his wife had experienced a "poor nursing standard." He also felt there had been a lack of communication around Mrs. C's diagnosis. Mr. C said:

*They never bloody told her what they were looking for. They told her, you know, what tests they were going to do, what they proposed to do and then she was quite happy to undergo any sort of tests that they wanted to do, no problem there. But they didn't clearly indicate where they were heading . . . They were being so careful; they were not going to say anything which could be wrong. In the end [her death from lymphoma] took us totally by surprise.*

This lack of direct communication meant that Mr. and Mrs. C did not pick up the subtext in the doctors' communication. Mr. C said:

*One thing we found a bit strange at the time, after the MRI scan when we went back to this [doctor], he, although he didn't tell us what we were probably looking at, just more tests, he referred us to [the] hospice people. He had a strong idea what was going on but he didn't tell us, really and we thought, "Hospice? We don't need flipping hospice!" . . . we didn't feel that we needed any sort of help at that stage. Well, we didn't need any help.*

However, the most upsetting event for Mrs. C's husband was following his wife's unexpected – to him – death. The hospital phoned the participant, in the early hours of the morning, to tell him his wife had died.

*. . . When we got there she'd been moved; her bed had been moved into a flipping linen closet, linen room and that was the best that they could [do], that's where we had to sit with her for the rest of the morning . . . I thought surely they've got; they could come up with a better arrangement than that. It was a bit bloody strange.*

The doctor who eventually came to talk to the family was not one who had treated Mrs. C. Mr. C recalled:

*The nursing staff said one of the doctors will come around, probably around eight o'clock and explain it to you. They showed up about ten, and it wasn't the doctor who had anything to do with her case, nothing to do with it whatsoever. Never met him before.*

When asked if the staff dealt with him or the family in a sensitive manner, he replied, “No, in that case, they did not, no, that was poor, that was pretty poor.” However, when asked about the dignity shown to Mrs. C, the participant was positive:

***[Interviewer]*** And so in the last two days of her life would you feel that she was treated with respect and dignity by the nurses always, most of the time, some of the time, never or you don't know?

*Well probably most of the time, I suppose. I don't know, as far as respect and dignity is concerned, yes.*

***[Interviewer]*** Would you say that she was treated with respect and dignity by the hospital nurses?

*Generally, I think yes, just that this lapse about this bloody monitor was disappointing. But as far as her dignity and respect was concerned, yeah, I'd say they were.*

***[Interviewer]*** Would you say some of the time or most of the time?

*Most of the time actually.*

***[Interviewer]*** And what about the doctors?

*Yeah probably, in those terms, dignity, and respect, were probably all right, yes.*

## Discussion

This paper explores how dignity is conceptualised by family carers responding to a questionnaire about the experiences of health care at the end-of-life. Our findings indicate that participants framed dignity in two main ways; first, as a quality of emotional connection maintained in the interpersonal reaction between an individual health care provider and the healthcare recipient or their family. Such a framing equates to health care staff producing Hochschild's notion of emotional labour that involves workers, as an aspect of their job, displaying socially desired emotions (Hochschild 2012). In this understanding patients and their families may interpret "skilled performances" of a nurse's "smiliest happiest face" (Bolton 2001, p. 93) as care that upholds dignity.

Second, participants regarded dignity as the adequate performance of specific physical care tasks such as turning, washing, cleaning and checking on the patient. For participants, the idea that dignity is related to systemic aspects of medical care, such as the pressure to transfer patients from the overcrowded emergency department to full wards, long-standing underfunding and understaffing, the importance of hospital administrators meeting financial targets (Reid 2012; Cohen & Ezer 2013) was subsumed. Health care workers' overt affective displays and task performance took precedence as markers of dignity.

Culturally-specific meanings both of dignity and good end-of-life care were evident from our analyses. For example, for Māori whānau, dignified care involved the care environment being able to accommodate the number of whānau members who wanted to be present; an environment that allows whānau to practice their care customs is critical (Moeke-Maxwell T, Waimarie Nikora L and Awekotuku T 2014). This finding supports Street and Kissane's (2001) positioning of dignity as socially constructed and individually mediated. The need for methods which are flexible enough to capture these complexities in how people experience dignity within healthcare settings has also been identified by Frey et al., in their examination of cultural considerations related to the VOICES questionnaire (Frey et al. 2017).

What was clear in participants' accounts was that they did not necessarily associate being treated with dignity with being treated well. Such a finding suggests that a self-reported rating of being treated with dignity on the VOICES questionnaire may mask significant dissatisfaction with care. This care could include treatment that does not accord with professional definitions of dignity, such as its significance to quality end-of-life care or its status as a concept relating to basic humanity (Anderberg et al, 2007; World Health Organization, 2011). This not only raises concerns

regarding the interpretation of patients' and family members' self-reports of dignity in care, but also suggests that users of health care services may ascribe to a different meaning of dignity than health care professionals. Given the general acceptance that involving service users can support more patient-centred services, policy and research (Cook and Klein, 2005; Kemp, 2010), it is timely to recommend that similar processes are used to interrogate the key concept which underpins them.

Our findings have significant practical implications, particularly for methods of capturing service users' experience of end-of-life care. Most fundamentally, they indicate that reliance on quantitative closed-question survey tools to capture experiences of dignity is problematic. Our immediate response to this within the context of the NZ version of the VOICES questionnaire we have been developing was to add a free text box and invite participants to describe their reasons for describing care as dignified (or not). However, this obviously complicates analysis. New computer-based methods may help address the need to collect both quantitative and qualitative data regarding service user experience of dignity. Indeed, Gibbons et al. (2016, n.p.) have found that "machine learning algorithms can classify open-text feedback of doctor performance into multiple themes derived by human raters with high performance."

Although this study was conducted within the context of end-of-life care, it is likely that the findings have applicability in other areas. They support the conclusions of a recent primary care based study of GP/patient interactions that "positive responses on patient experience questionnaires can mask important negative experiences which patients describe in subsequent interviews" and, like them, we would also urge caution in the interpretation of any scoring of patient experience (Burt et al. 2017, p. 1).

#### *Strengths and limitations of the study*

Family members involved in the care of their relatives at the end-of-life are uniquely placed to offer insights about the experiences. However, the reliance on retrospective data from family carers means that the views of the deceased may not be expressed as they wished. These interviews were carried out in a large city in New Zealand, during the piloting of the UK VOICES survey tool. Similar results may not necessarily be found in other countries, although our findings are consistent with studies in other countries which have identified limitations in relying on surveys to capture the patient experience of health care (Salisbury et al, 2010; Baldie et al, 2018)

## **Conclusion**

A key focus of contemporary healthcare is patient-centered care that treats people with dignity. However, this study identifies an apparent disconnect between lay and professional understandings of dignity within a palliative care context. The limitations of capturing self-reports of dignity in care provided to patients and families using survey methods alone were also highlighted, and we advocate consideration of multiple, complementary, approaches to gathering consumer experiences of end-of-life care.

## **Key Points**

- Dignity is a fundamental tenet of palliative care and is considered a key indicator of good end-of-life practice
- Discrepancies exist between lay and professional understandings of dignity in a palliative care context  
Survey methods are limited in their ability to capture self-reports of dignity in care
- Multiple, complementary approaches to survey methods are required to better capture patient and family experiences of end-of-life care

## **CPD reflective questions**

- How do you define dignity in the end-of-life context for your patients?
- How do you think your definition might align with or vary from the experiences of patients and families in your care?
- Give some examples from your practice of end-of-life care that has upheld the dignity of patients and their families in a culturally-appropriate way.

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**Table 1: Participant characteristics**

Interview	Gender	Age Group	Ethnicity	Relationship to deceased
1	Male	60-69	Māori	Child
2	Male	70-79	European	Spouse
3	Female	50-59	Indian	Child
4	Male	30-39	European	Friend
5	Female	70-79	European	Spouse
6	Female	40-49	European	Child
7	Female	70-79	NZ European	Spouse
8	Male	80 +	European	Sibling
9	Male	80+	Māori	Spouse
10	Male	40-49	NZ European	Child
11	Female	70-79	NZ European	Spouse
12*	Male	30-39	Māori	Child
13	Male	50-59	Māori	Friend
14	Female	80+	European	Spouse
15	Female	60-69	European	Spouse
16	Male	60-69	European	Spouse
17	Female	50-59	Indian	Child
18	Male	60-69	European	Child
19	Male	70-79	European	Spouse
20*	Female	70-79	Māori	Spouse
21*	Female	40-49	Māori	Sibling

\*Interviews included Māori whānau (family, including extended family) other than the participant listed.

**Table 2: Characteristics of deceased**

	Total	%
<b>Gender</b>		
Male	10	50
Female	10	50
<b>Age</b>		
50-59	2	10
60-69	3	15
70-79	9	45
80+	6	30
<b>Ethnicity</b>		
New Zealand European/European	15	75
Māori /Māori & European	3	15
Indian	2	10
<b>Illness duration</b>		
Not Ill Died Suddenly	1	5
< 24 Hours	1	5
1 day or more, less than one month	4	20
1 month or more, less than 6 months	3	15
6 months or more, less than 1 year	1	10
Longer than one year	9	45
<b>Time spent at home during the last 3 months of life</b>		
Some time	16	80

No time	4	20
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