



**Conceptualisations of dignity at the end-of-life in Taiwan:
exploring theoretical and cultural congruence with Dignity
Therapy**

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Title:

Conceptualisations of dignity at the end-of-life in Taiwan: exploring theoretical and cultural congruence with Dignity Therapy

Abstract

Aim. To explore the conceptualisation of patients' dignity within the context of end-of-life care in Taiwan

Background. Dignity therapy (DT) - a novel psychotherapeutic intervention - has been demonstrated to have potential to alleviate terminally ill patients' psycho-existential distress in several western countries. In Taiwan, over half of terminally ill patients experience psychological-spiritual suffering and DT might prove helpful in improving this situation. Hence, a preliminary study to clarify Taiwanese conceptualisations of 'dignity' was conducted prior to planning a feasibility study in order to gauge the potential cultural fit of an intervention of this type.

Design. Qualitative exploration

Methods. Nine people with terminal cancer and ten health professionals were recruited from palliative care services in Taiwan in 2008. In-depth interviews were audiotaped and transcribed verbatim. A hermeneutic approach was employed to analyse and interpret data.

Findings. Being a valuable person is the core meaning of patients' dignity in the Taiwanese context and this comprised intrinsic characteristics and extrinsic factors. Intrinsic characteristics of dignity encompassed living a moral life, having peace of mind and a sense of existence involving the perception of resignation to God's will. Extrinsic factors that influenced patients' dignity included illness-related distress, care

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3 delivery and the perception of being loved. A dynamic relationship between these
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5 elements determined the state of patients' sense of dignity.
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7 **Conclusion.** The approaches of preserving dignity, living a moral life and resignation
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9 to God's will, in Taiwanese patients were distinguishable from western perspectives
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11 and the modification of DT in this context is warranted.
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21 **Key words:** Dignity therapy, palliative care, qualitative research, terminal illness
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Summary Statement

• Why is this research needed?

- ⊙ Dignity is of concern in healthcare as it relates to patients' physical, psychological and existential distress and also the support and care they receive.
- ⊙ The translation of DT into other cultures might improve end-of-life care in different populations and assessment of whether it is cultural-appropriate to apply the intervention in different contexts is essential.

• What are the key findings?

- ⊙ A sense of dignity was associated with whether a person is viewed by themselves or others as a valuable person.
- ⊙ The intrinsic characteristics of dignity were culturally influenced and involved a perception of living a moral life and resignation to God's will.
- ⊙ Extrinsic factors had both helpful and harmful influences on patients' sense of dignity, and approaches patients took to securing their dignity involved enhancing the intrinsic characteristics of dignity.

• How should the findings be used to influence policy/practice/research/education?

- ⊙ Modification of DT is warranted and culture-related perspectives of dignity should be addressed before implementation in the Taiwanese context.
- ⊙ Prior to applying a psychological intervention in another culture qualitative research methods can provide information as to what and how it might work.

Introduction

Dignity is a specific concern for those who are old or terminally ill due to the irreversible nature of aging and advanced and progressive diseases (Enes 2003, Matiti & Trorey 2004, Bayer *et al.* 2005). Loss of independence, cognitive deterioration and symptom distress threaten patients' self-image and identity and make people feel undignified (Enes 2003, Bayer *et al.* 2005, Franklin *et al.* 2006). Lacking a sense of dignity can furthermore induce feelings of worthlessness and the desire for a hastened death (Chochinov *et al.* 2002a, 2008). A psychological nurse-delivered intervention - Dignity Therapy (DT), was developed in response to concerns about patients' diminished sense of dignity at the end of life (Chochinov *et al.* 2005). Results from several exploratory investigations and trials in Canada, Australia, the UK and US have demonstrated it has the potential to alleviate patients' psychological-existential distress (Passik *et al.* 2004, Chochinov *et al.* 2011, 2012, Montross *et al.* 2011, Hall *et al.* 2012). In Taiwan, psychological-spiritual care offered to terminally ill patients does not yet reach the standard their families expect (Hu *et al.* 1999, Chang *et al.* 2002). One explanation for this situation could be that nurses lack skills and confidence in this area (Chao & Lo 2002). Hence, a study to evaluate the feasibility of transferring and applying this intervention in Taiwan was planned. Prior to this an exploration of the conceptualisation of patients' dignity in Taiwan was needed in order to assess the cultural appropriateness of DT.

Background

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3 The word “dignity” means the “quality of being worthy of honour or respect” (Oxford English
4 Dictionary 2010) and the idea of human dignity plays an imperative role in philosophy,
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The word “dignity” means the “quality of being worthy of honour or respect” (Oxford English Dictionary 2010) and the idea of human dignity plays an imperative role in philosophy, theology, law, political theory, and clinical health care practice (Jacobson 2007). The World Health Organization (2003) acknowledges dignity is fundamental to equitable, humane and patient-centred treatment. Strategies to achieve this vision in health care services have been widely investigated across different populations, involving medical patients, the elderly, people with disabilities and people with terminal illness (Enes 2003, Matiti & Trorey 2004, Bayer *et al.* 2005, Stabell & NÅden 2006). Key factors influencing patients’ sense of dignity across different populations include illness-related distress and the care services they received (Chochinov *et al.* 2002b, Matiti & Trorey 2004, Bayer *et al.* 2005, Stabell & NÅden 2006).

The relationship between patients and professionals inevitably influences the care patients receive and their sense of dignity (Pellegrino 2008). In particular, patients are placed in a vulnerable position in clinical settings due to their need for healing (Street & Kissane 2001). Nurses believe their attitudes and behaviours towards patients (such as communication, and facilitating personal hygiene and daily activities) contribute to maintaining or diminishing patients’ dignity (Royal College of Nursing 2008). Professionals furthermore report both organisational issues and professional characteristics that might hinder the provision of dignified care (Soderberg *et al.* 1997, Walsh & Kowanko 2002, Arino-Blasco *et al.* 2005, Stabell & NÅden 2006). For example, staff shortages adversely impact on patients’ needs (Walsh & Kowanko 2002, Arino-Blasco *et al.* 2005). Professionals’ awareness of, and sensitivity to, patients’ dignity affect the care they provide (Soderberg *et al.* 1997).

Patients’ own psychological and spiritual strengths have potential to help them preserve their own dignity in the face of progressive and irreversible physical deterioration

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3 (Chochinov *et al.* 2002b, Franklin *et al.* 2006). The dignity conserving model (DCM) at the
4
5 end of life developed by Chochinov *et al.* (2002b) revealed a “dignity conserving repertoire”
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7 that indicated the approaches patients can adopt to protect their sense of dignity from
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9 negative influences, namely continuity of self, role preservation, generativity/ legacy,
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11 maintenance of pride, hopefulness, autonomy, acceptance, resilience/ fighting spirit, living in
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13 the moment, maintain normalcy and seek spiritual comfort. Based on DCM, Dignity Therapy
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15 (DT) was developed and comprises interviews with patients and a creation of individual
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17 documents (Chochinov *et al.* 2005). The “dignity conserving repertoire” in DCM underpins
18
19 the core values of the therapeutic interview questions employed during the course of DT.
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21 Furthermore, the interview with patients is transcribed, edited with the patient’s advice and
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23 agreement leading to development of a document for the individuals, an approach based on
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25 the notion of leaving a legacy/ generativity outlined in the DCM (Chochinov *et al.* 2005).
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32 However, patients living in different cultures might use alternative approaches to protect
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34 their dignity (Billings 2008). For example, maintenance of pride, one of the dignity
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36 conserving approaches in DCM, has been recognised as inappropriate in Danish culture
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38 (Houmann *et al.* 2010). The approach of leaving a document to family members in DT was
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40 also found to be culturally unacceptable in Japan (Akechi *et al.* 2012). Furthermore, a sense
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42 of dignity in elderly people living in Hong Kong and Beijing was specifically found to be
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44 related to their relationship with their family, such as being cared for and appreciated by their
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46 children (Chan & Pang 2007, Zhai & Qiu 2007). In Taiwan, patients’ dignity has been
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48 explored in the hospital setting in relation to respect, caring, body image, a sense of control,
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50 autonomy, privacy and confidentiality (Lin & Tsai 2011; Lin *et al.* 2011), but no studies
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52 investigating patients’ dignity in the context of end-of-life care have been conducted.
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3 Identifying a relevant evidence base and theory is an important step to ensure that an
4 intervention can reasonably be expected to benefit the target population (Medical Research
5 Council 2008). Hence, this study was conducted to develop conceptual clarity about dignity
6 within the context of end-of-life care in Taiwan in order to evaluate whether it would be
7 appropriate to apply DT in Taiwan. Both patients' and professionals' perspectives were
8 sought in this study as professionals' interaction with patients and their awareness of patients'
9 dignity have an influence on patients' sense of dignity (Soderberg *et al.* 1997, Walsh &
10 Kowanko 2002).
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23 **The study**

24 **Aim**

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26 The purpose of this study was to explore the conceptualisation of patients' dignity within the
27 context of end-of-life care in Taiwan from both patients' and health care professionals'
28 perspectives.
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37 **Design**

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39 A qualitative approach was adopted and interviews with terminally ill patients and palliative
40 care professionals were conducted during 2008. Interview questions were developed from,
41 and underpinned by DCM, the fundamental framework of DT, including what impacts on
42 patients' dignity and how it can be maintained (Chochinov *et al.* 2002b). A hermeneutic
43 approach was embedded in the interpretive process of analysing the data.
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52 **Participants**

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54 Participants were recruited from the palliative care inpatient unit and home service of a hospital
55 in central Taiwan. Eligible patients were those with terminal cancer, receiving palliative care
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3 services and able to communicate verbally. Those suffering from multiple, complex, emotional
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5 issues or those who might die in the next few days were excluded. Eligible professionals were
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7 those who provided palliative care services to patients in this clinical setting. A minimum of 6
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9 participants in both the patient and professional groups were needed to explore the concept in
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11 sufficient depth (Schwartz-Barcott & Kim 1993). All patients and professionals who fulfilled
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13 the eligibility criteria were approached. Initially, clinical staff provided eligible patients with a
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15 brief verbal description of the study, and then they were introduced to the researcher (HL) if
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17 they were willing to participate. For professionals, the head nurse forwarded an invitation
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19 letter and a study information sheet to all palliative care team members. They were then
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21 contacted one to two weeks later to check whether they wished to participate.
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27 **Data collection**

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29 After formal written consent was obtained, semi-structured, in-depth interviews were
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31 conducted by HL, a nurse with palliative care experience. All except one were audio recorded.
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33 In this case the interview was typed up immediately afterwards to reduce memory bias. For
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35 patients the interview took place either in a private room, at the bedside or in their home,
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37 depending on their preference. Professionals were interviewed in a private room on the unit.
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43 It was anticipated that because dignity is an abstract and vague concept participants might
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45 have difficulty discussing it. Consequently the first few interview questions were designed to
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47 start the interview off on a comfortable footing before proceeding to questions regarding
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49 dignity e.g. “Can you describe your experience of care while in hospital?” Interview questions
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51 included: “What does ‘living with dignity’ mean to you?”, “Who or what things influenced
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53 your [patients'] sense of dignity?” and “Can you describe specific experiences in which your
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55 [patients'] sense of dignity was maintained or enhanced?” Active listening and empathy were
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3 employed and probing questions took the form of “what” rather than “why” questions (Koch
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5 1993). In Taiwan, most dying patients and their families do not like to directly discuss death
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7 or dying (Mak 2007). Therefore the word death or dying was avoided during the interview
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9 unless patients talked about it themselves. Recruitment ended when redundancy was revealed
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11 in data analysis (Marshall 1996).
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14 15 16 **Ethical considerations**

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18 Ethical approval was granted from Taichung Veterans General Hospital Ethics Committee
19
20 (C08043) and King's College London, College Research Ethics Committee
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22 (CREC/07/08-156).
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26 27 **Data analysis**

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29 The analytical strategies of hermeneutic circles and fusion of horizons from hermeneutics
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31 (Gadamer 1965, Koch 1993) were used to extract the meaning of dignity, factors impacting
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33 on dignity and ways patients conserve their dignity. Hermeneutics emphasises that the
34
35 meaning and understanding of data is tied firmly to context. Meanings emerge through the
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37 process of going back and forth between the whole text of interviews and its parts and also the
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39 researchers' own pre-understanding on dignity, end-of-life care, and participants' cultural
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41 background (Gadamer 1965, auOdman 1992). No specific protocol, however, exists to guide
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43 a hermeneutic approach to analysis (Gadamer 1965, Steeves & Kahn 1995). Three strategies
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45 commonly used to reveal meanings from in-depth descriptive data are: 1) discovery of
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47 paradigm cases 2) exemplars and 3) thematic analysis (Benner 1985, Leonard 1994). These
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49 strategies were combined in this study alongside thematic network analysis where themes are
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51 logically organised into a map-like visualisation (Attride-Stirling 2001). The interpretive
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53 process and steps taken are illustrated in Figure 1.
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5 Once the first interpretation had been undertaken in Mandarin, meaningful excerpts of
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7 data were translated by HL from Mandarin to English. The translations were then checked by
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9 a bilingual health professional prior to further data analysis with involvement from other
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11 members of the research team (AR, PS and JA). QSR NVivo 8 software was used to organise
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13 and classify data (Bazeley 2007). Both patients' and professionals' data were analysed
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15 separately.
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20 21 **Figure 1. The process and steps of data analysis**

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25 **Rigour**

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27 Patients' interview data were transcribed by the interviewer to limit potential difficulties in
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29 understanding the recorded discussions (Tilley 2003). The different steps of classifying data
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31 were saved in different files for audit purposes. A reflexive journal was kept to uncover the
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33 interviewer's pre-understanding of dignity. Regarding the fidelity of the interpretation,
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35 debriefing with experienced researchers was conducted to limit personal bias (Lincoln &
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37 Guba 1985). Preliminary findings from the professionals' data were confirmed by eight
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39 professional participants in a group meeting. A preliminary analysis of patients' data was
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41 undertaken after each interview and this informed and guided subsequent interviews
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43 (Sandelowski 1993).
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49 **Findings**

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53 Nine of the 13 patients approached agreed to participate and four of these were male. They had
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55 a range of different cancers and their age ranged from 29 to 77 years. Two of patients' family
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57 members were present during the interviews, but did not contribute to the discussion. Ten
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3 palliative care professionals, including nurses, doctors, social workers, art therapists and
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5 chaplains, were recruited. The healthcare professionals had worked in palliative care for a
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7 mean of 4.5 years and in clinical practice for 14 years. On average interviews with patients
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9 lasted 30 minutes and 56 minutes with professionals.
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14 After analysing the health professional and patient findings separately, it became clear
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16 the findings from both sets of accounts were consistent with each other, although a few
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18 subthemes only occurred in the professionals' accounts (not being afraid of death and being
19
20 reconciled with self/others). Three categories emerged from the analysis: the meaning of
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22 dignity; intrinsic characteristics of dignity; and extrinsic factors impacting on dignity. These
23
24 formed the basis of the conceptualisation of patient dignity at the end of life summarised in
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26 Figure 2. Presentation of these results and discussion in relation to each category is combined
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28 in the following sections and illustrated with excerpts from patients' and professionals'
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30 transcription.
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36 **Figure 2. Conceptualisation of patient dignity at the end of life in Taiwan**

37 38 39 40 **Dignity: Valuing oneself and being valued**

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45 The idea of valuing oneself and being valued by others emerged as the core meaning of dignity.
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47 In other words, a sense of dignity was associated with whether a person is viewed by
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49 themselves or others as a valuable person.
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52 “...it [dignity] is that we have to value ourselves then others will value us. We have to
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54 respect ourselves, encourage ourselves...” (Patient 06-p.10)
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3 “The key issue [of dignity] is that a person has to think he is important. He should think
4 he is still useful at this moment [dying process].”(Professional 08-p.25)
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10 11 12 **Intrinsic characteristics of dignity**

13 14 15 *Living a moral life*

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17 The idea that good and bad behaviour may preserve or damage a person’s dignity emerged
18 during the analysis and so the theme ‘living a moral life’ was generated. This theme is rarely
19 reported in previous studies (Chochinov *et al.* 2002b, Enes 2003, Bayer *et al.* 2005).
20 Furthermore, the judgement of ‘good’ or ‘right’ made by participants seemed to be rooted in
21 the cultural values of traditional Chinese morality.
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31 When asked “What makes you feel dignified?”, one patient replied “having obedient
32 children” (Patient 01). The interviewer, not sure what the patient meant by saying this, delved
33 further on this issue. The interviewer’s thoughts were:
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37 “I think I was preoccupied by the meaning of dignity derived from the literature and
38 only thought that she was a patient in a medical environment, but forgot she was a
39 person, someone’s grandmother. Her dignity was maintained by her social role in her
40 life, not only in the medical environment.” (Reflexive journal, 28/04/08)
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48 Having filial (obedient) children is an honour for parents in Chinese culture, since
49 teaching children to do the right thing is a key parental responsibility (Jennings 2004). The
50 tenet of ‘filial piety’ includes being obedient to parents, showing respect, not being perverse,
51 and ministering to parents whether sick or healthy (Cheng & Chan 2006).
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3 Behaving politely towards and caring for others were also mentioned by participants as
4 the right things to do and an emblematic feature of a person's dignity.
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7 "It [person's dignity] is shown in his interaction with others. If a person is friendly and
8 is easy to get along with, you would see it [dignity] from him." (Patient 04-p.5)
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10 "She [patient diagnosed with cervical cancer who had symptoms of vaginal bleeding]
11 was different from others... When I was looking after her, she expressed her concern
12 for me and asked me if my period was regular; if I had period pain. After she knew my
13 period was not regular, she kept asking me if I went to see a doctor... She came to
14 receive care, but she did not only think of herself, she also cared for me ... this relates
15 to a person's dignity." (Professional 02-p.2)
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27 *Having peace of mind and a sense of existence*

28 Achieving peace of mind and having a sense of existence were revealed as important
29 characteristics to demonstrate a person's dignity when confronting impending death.
30 Approaches reported included knowing one's own inner needs, not being afraid of death, being
31 reconciled with self/others, resignation to God's will, keeping an appropriate appearance and
32 living life to the full.
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43 Making an effort to understand a person is a sign of taking them seriously and respecting
44 them and so implies they are worth knowing (Dillon 1995). In line with this, knowing one's
45 own inner needs indicated patients treated themselves with dignity, and showed they were
46 important and deserved attention.
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51 "I am happy and always believe that I live with dignity all the time, because I have my
52 own ideas and know what I want to do." (Patient 09-p.10)
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3 “He [a person with dignity] should be a person who can express what he wants clearly.”
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5 (Professional 02-p.02)
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10 Dying patients may sometimes suffer from a fear of death, but some transcend this and
11 gain peace of mind (Kübler-Ross, 1975). In Chinese philosophy the goal of all human beings
12 is to transcend suffering in order to demonstrate their inner dignity (Gong 2005). In addition,
13 according to the Buddhist idea of karma (a person’s actions in this life will determine their
14 fate in the next life), reconciliation with oneself and others can help remove a persons’ bad
15 karma and earn more good karma so as to attain peace of mind (Hardo 2007). However, these
16 two ideas were only identified by professionals.
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27 “It’s like a knight or a samurai standing there with dignity. They calmly confront their
28 suffering. This kind of image makes me feel that they are dignified, because they are
29 able to face it [death].” (Professional 05-p.8)
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34 “It [dignity] is associated with whether a person can leave this world in peace...
35 achieving a successful conclusion to life is a very important thing... [which] refers to a
36 person’s relationship with others in this life and reconciliation with others... and
37 oneself.” (Professional 01-p.8)
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45 Resignation to God’s will is an approach terminally ill patients used to acknowledge the
46 terminal stage of their illnesses and be dignified. According to Confucianism, revering the
47 ordinances of Heaven is a fundamental principle of being “a superior man” (Jennings 2004).
48 “Heaven” refers to those who control humanity’s destiny, such as Gods, Buddha or other
49 high beings. Two Chinese proverbs derived from this idea are ‘to meet one's fate with
50 resignation’ and ‘to do one's best and leave the rest to God’.
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3 “What we need to do is to resign ourselves to our fate, just let it be.” (Patient 07-p.3)

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5 “It seems hard for a person who is unable to resign himself to his fate to preserve his
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7 sense of dignity.” (Professional 05-p.10)

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11 A well-cared-for appearance is related to a person’s dignity as it shows they value
12 themselves. Moreover, it shows that the person continues to live in the world, rather than be
13 confined by their illness, and reveals that they think living is worthwhile.

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18 “I want to live with dignity, I don’t want others to look down upon me. Therefore, I
19 would not allow myself to be a scruffy woman.”(Patient 06-p.9)

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22 “I would say a buccal cancer patient I have cared for was dignified...he lived his life
23 as normal. His life was not bothered by cancer. He still went out to see friends and chat
24 with them, although he had difficulty speaking. He kept doing everything he could.”
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29 (Professional 03-p.13)

30 31 32 33 34 **Extrinsic factors impacting on dignity**

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Illness-related distress, care delivery and being loved were mentioned by participants as extrinsic factors influencing a person’s sense of dignity at the end of life. These factors are similar to the categories of “illness related concerns” and the “social dignity inventory” in the DCM. The effect of being severely ill made patients feel they were different from before. Their concept of self was threatened, as they were less useful and suffering more than before, which induced feelings of shame or worthlessness.

“Since being ill has anything influenced your sense of dignity?”

“It’s no doubt. The physical suffering and pain” (Patient 04-p.4)

“It is shameful to rely on others all the time ...” (Patient 05-p.4)

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5 The way care is delivered was seen as a reflection of whether or not health care
6
7 professionals view their patient as a worthy person. Three subthemes were identified:
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9 appropriate treatment, professionals' attitude and psychological-existential support. Giving
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11 appropriate treatment is a way of respecting those who are ill. Patients exposed their
12
13 vulnerability to their carers constantly. Patients thus thought they were worthwhile if
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15 professionals behaved in a positive manner towards patients including being attentive,
16
17 friendly, kindly and caring.
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21 "Every day she comes and says hello to me... she is very attentive, caring and explains
22
23 everything clearly." (Patient 02-p.01)
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26 "The doctors and nurses are kind and friendly. The nurses seem like my daughters; they
27
28 always come to see me and call me "grandma, or granny"¹. The doctors are also nice.
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30 They always said "take your time, no worries." (Patient 08-p.2)
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34 Professionals reported a number of psychological-existential approaches they used to
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36 improve patients' sense of dignity, such as active listening, empathy, being a communication
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38 bridge, encouraging positive thinking, and affirming patients' meaning of life. One of the
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40 professional participants reported that he had cared for a patient who was a Japanese culinary
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42 chef who had confided in him one of his regrets. Namely, he no longer felt capable of preparing
43
44 the Japanese banquet he had planned to treat all the doctors who had ever looked after him as a
45
46 way of saying thank you. In order to help this patient to live his life to the full they held the
47
48 banquet in the palliative care inpatient unit with volunteers' help.
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52 "We bought all the food products he needed and set up a small space in the ward for
53
54 him to prepare the food... fried pork, fried tempura, sushi, preserved radish... when he
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57 ¹ In Taiwan when professionals wanted to greet elderly patients in a friendly way, they call them "granny X" or
58 "grandpa X", instead of "Mrs. X" or "Mr. X" in order to show their respect for the elderly person.
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3 was doing it, I was really impressed... he looked like a Japanese samurai, awesome and
4 dignified... At that time, his symptoms, vomiting and nausea disappeared.”
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7 (Professional 05-p.6)
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11 Love is a strong feeling of deep affection for someone, which involves a positive
12 evaluation of the person (Chazan 1998). Being loved by others had a crucial impact on a
13 person’s sense of dignity. Although patients were deteriorating and physically weak, their
14 families and friends loved them unconditionally which made them believe that they were still
15 worthwhile people.
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23 “What things enhance your feeling of dignity?”
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25 “From my point of view, it is being cared for by my daughters.”(Patient 07-p.1)
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30 **A paradigm case: Becoming attuned**

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34 Both the intrinsic characteristics of dignity and the extrinsic factors impacting on dignity
35 interact with each other within each person. A paradigm case emerged during study (See Table
36 1). In this patient’s scenario (Ms. F), although distress about her illness reduced her sense of
37 dignity, Ms. F altered her thoughts to overcome the challenge of illness. This is similar to the
38 idea of ‘attunement’ in Chinese philosophy, which means “to become attuned to the world is to
39 see its goodness and to know one’s place in the order of the world” (Wong 2009, p.3). In line
40 with this, a dignified person works to become attuned to the challenges of being terminally ill
41 and seek wisdom in order to face it.
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54 **Table 1. A paradigm case: Becoming attuned to illness and dying**

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Discussion

Study limitations

This study contributes a deep understanding of the conceptualisation of patients' dignity through in-depth description. However, some study limitations exist due to the end-of-life circumstances of the patient sample. Each patient was only interviewed once since repeated interviews were impractical because of physical deterioration. Changes to the meaning of dignity during the dying process were therefore not discovered and it is possible the single interview might not have given sufficient opportunity for patients and professionals to express their experiences and thoughts. Two patients' families were present during the interviews and six patients were interviewed in a shared room. These situations might have influenced the data, although patients reported that remaining in an environment they were familiar with made them feel more comfortable to talk rather than being alone with a researcher in a private room.

Integrated conceptualisation of dignity

This study provides an integrated conceptualisation of dignity in which two major philosophical perspectives on dignity are involved, namely "a quality of a person" and "the quality of a person" (Kolnai 1995). Dignity pertaining to "a quality of a person" refers to an inalienable and worthy quality that all human beings inherently possess and is commonly named as "human dignity" (Nordenfelt 2004, Jacobson 2007, Von der Pfordten 2009). Alternatively, dignity as "the quality of a person" refers to the quality of being a worthy

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3 person (Kolnai 1995), where a person's dignity is relative and based on a person's
4
5 achievement and is entitled "social dignity" (Jacobson 2007). The core meaning of dignity in
6
7 this study, valuing oneself and being valued by others, is rooted in both perspectives of
8
9 dignity. In addition, due to irreversible deterioration enhancing patients' human dignity
10
11 seems more achievable than social dignity in end-of-life care. As mentioned in the theme of
12
13 care delivery, professionals can assist patients to achieve some tasks with the purpose of
14
15 enhancing their social dignity. Nevertheless, when faced with dying, physical deterioration
16
17 and distress, a person's worth is gradually devalued as their capacity to fulfil their roles in
18
19 their families or society is reduced. Hence, patients may strive to value themselves through
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21 enhancing their intrinsic characteristics of dignity, living a moral life and having peace of
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23 mind and a sense of existence, so as to demonstrate their inherent human dignity as a person.
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30 The findings demonstrated that the conceptualisation of Taiwanese patients' dignity at
31
32 the end-of-life is not only comparable in certain respects with western perspectives, but is
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34 also influenced by their unique cultural and philosophical background. Extrinsic factors
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36 impacting on dignity identified in this study were similar to previous studies in western
37
38 countries, such as the care provided by professionals, and professionals' attitude (Royal
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40 College of Nursing 2008). However, 'living a moral life' and 'resignation to God's will' as
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42 intrinsic characteristics of dignity were distinguishable from western perspectives and heavily
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44 influenced by Chinese philosophy. According to Confucian ideology, morality is an innate
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46 motivation that helps people live well and maintain social order. It involves the ethical
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48 system of benevolence and righteousness, rules of propriety, and the five basic human
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50 relationships between sovereign and minister, father and son, husband and wife, old and
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52 young people, and friends (Tsai 2005). Furthermore, Confucianism also emphasises that if a
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54 person can live in harmony with the ordinances of God, they will be happy (Jennings 2004).
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3 Because of this, 'resignation to God's will' for gaining peace of mind and a sense of
4 existence is adopted by Taiwanese patients to maintain their dignity.
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10 The experience of dignity is embedded in human interaction. Preserving a sense of
11 dignity at the end of life is not only a patient's concern but also a professional's responsibility.
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13 In the aspect of extrinsic factors, care delivery has both positive and negative influence on
14 patients' sense of dignity. Therefore avoiding the harmful and enhancing the helpful
15 influences in the clinical setting could be argued to be valuable. Helping patients to find that
16 their lives are worth living and facilitating them to seek their own way of becoming attuned
17 to the challenge of dying might conserve a patient's sense of dignity.
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27 The subthemes, 'not being afraid of death' and 'being reconciled with self/others', were
28 only mentioned by professionals rather than patients. The reason for this might be that talking
29 about reconciliation with others might remind patients of past traumatic experiences.
30 Moreover, it might be too difficult for patients to express their feelings about death in the first
31 and only interview with a researcher, which is not helped by the fact that discussing death is
32 not an easy thing to do in Chinese culture (Mak 2007).
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43 **Is DT appropriate in Taiwan?**

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47 Compared to the DCM, living a moral life and resignation to God's will were particular to
48 Taiwanese culture. Furthermore, two of the key elements of the DCM underpinning DT,
49 'generativity/legacy' and 'maintenance of pride' were not reported in this study as
50 approaches to conserve patients' dignity. An analysis of the contrasting features of the
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3 findings from this study and Chochinov's conceptual framework of DT are outlined in Table
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10 **Table 2. Comparison of DT conceptual framework and the concept of dignity in Taiwan**

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14 As previously stated the extrinsic factors are rather similar to those of the DCM and
15 previous studies (Chochinov *et al.* 2002b, Enes 2003, Woolhead *et al.* 2006). In addition, the
16 DT approaches of "continuity of self" "hopefulness", "role preservation" and "living in the
17 moment" are related to the themes of 'having peace of mind and a sense of existence' in this
18 study. However, there are some important cultural distinctions. Whilst "maintenance of
19 pride" and "generativity/legacy" are important issues in DT, 'living a moral life' and
20 acquiescing to the ordinances of God so as to be attuned towards the challenge of dying and
21 obtaining peace of mind is emphasised in the Taiwanese conceptualisation of dignity. These
22 differences determined that modification of DT was essential to ensure cultural congruence
23 prior to a study being conducted to evaluate its effectiveness in Taiwan. Similarly, the results
24 from relevant DT studies in Denmark and Japan also support the need to modify the approach
25 in order to ensure the therapy fits with cultural norms (Houmann *et al.* 2010, Akechi *et al.*
26 2012).

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45 **Conclusion**

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49 This study is the first to offer an empirically derived description of concept of dignity from
50 multiple perspectives in the context of palliative care in Taiwan. The results suggest that
51 modification of DT is necessary prior to implementing it in Taiwan. The findings offer a
52 platform to develop personalised care that can engender patients' dignity in Taiwan and
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3 suggested that a person's sense of dignity is closely bound to a person's beliefs and cultural
4 background. This underlines the importance of assessing theoretical appropriateness before
5 translating a culturally- bound intervention into another cultural setting.
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Figure 1. The process and steps of data analysis

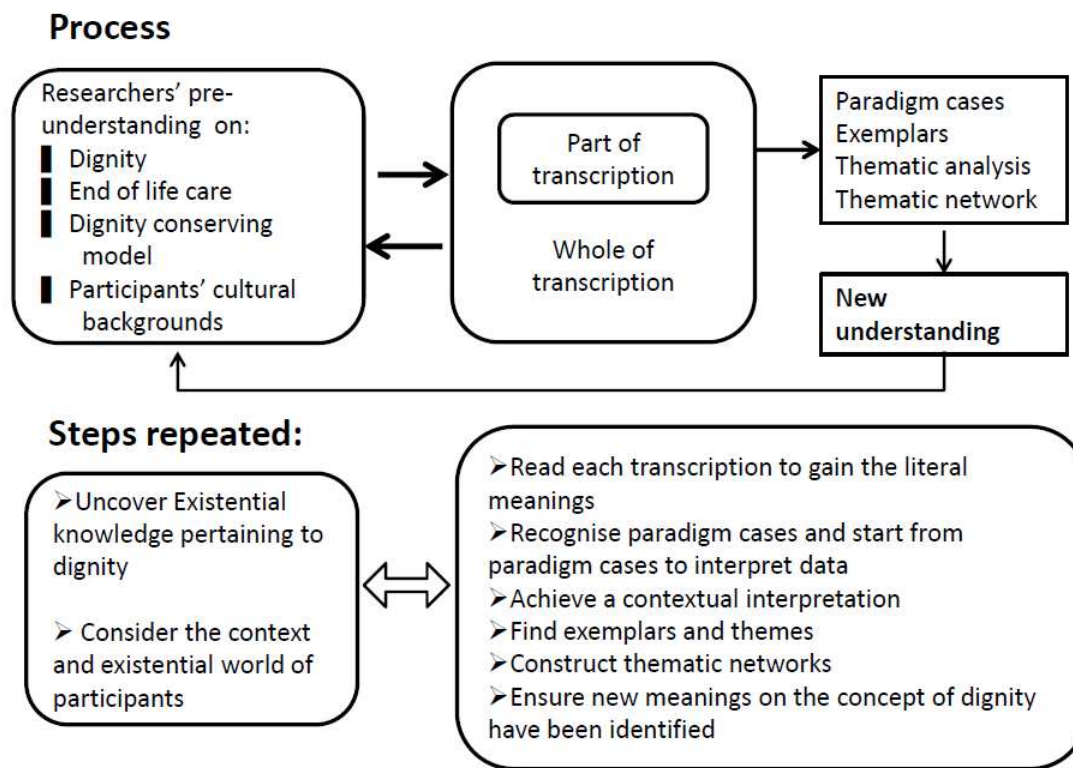
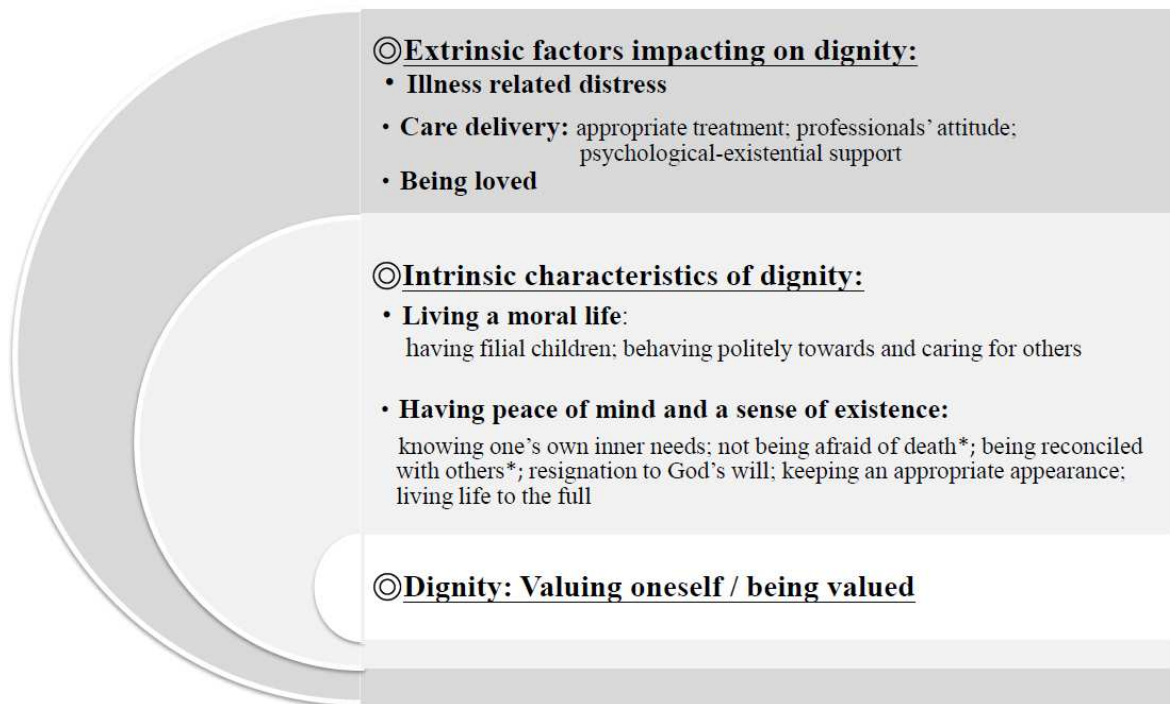


Figure 2. Conceptualisation of patient dignity at the end of life in Taiwan



“ * ”: Only professionals mention it

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Table 1. A paradigm case: Becoming attuned to illness and dying

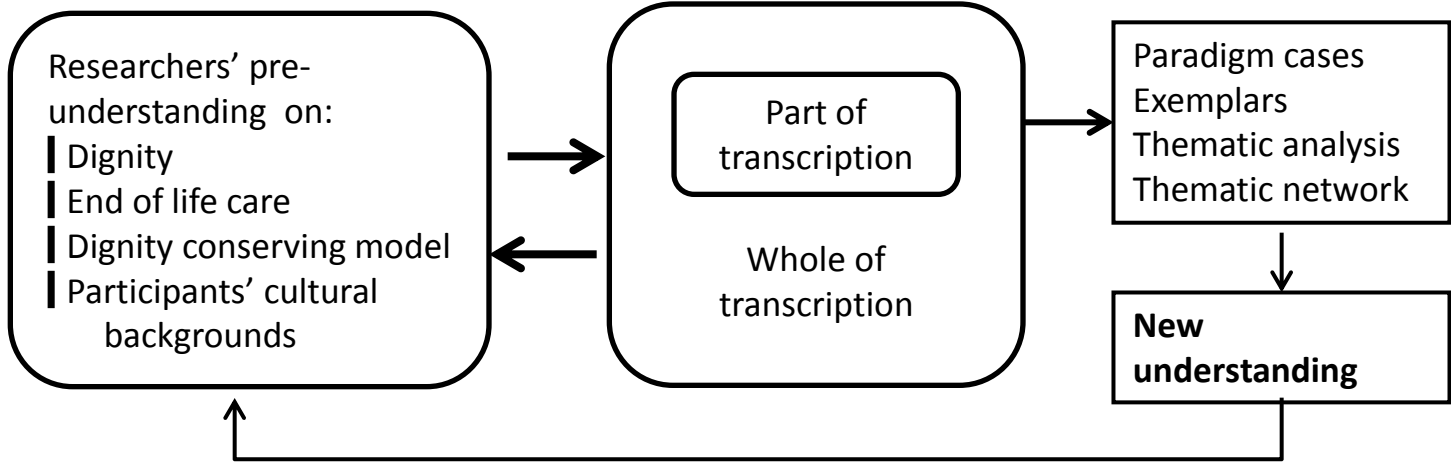
Themes	Patient scenario
Illness distress	Because of life threatening illness, the patient lost her eyesight, and needed help with daily living.
Not having peace of mind	<p>When she reviewed her early behaviour in the palliative care unit, she found she had been undignified, in that she was preoccupied with pessimistic thoughts and acted in an unacceptable manner, for instance, frequently getting angry.</p> <p>“How would you describe a person who is lacking dignity?”</p> <p>“Like the way I was when I stayed in the hospital before, as an ill-behaved patient. (Patient 06-p.13)...When I was in hospital I often flew into a rage, getting infuriated easily.” (p.11)</p>
Being loved	<p>She acknowledged she was really depressed when she was in the palliative care unit. However, after she went back home, she felt more settled and realised her family loved her very much:</p> <p>“I was always worried [in hospital] before, worried about whether they [my family] will give up looking after me (p.8)... [After I went back home], whenever I see my family around me... when I can see them every day, my mood becomes better.” (p.11)</p>
Care delivery/ psychological-existential support	After that, she started to persuade herself to change her attitude towards her illness. Finally, she found her own way to treat herself with dignity. This involved using her religious strength to calm her mood and distract her from her pessimistic thoughts.
Having peace of mind and a sense of existence	<p>She lowered her expectations of life and learned to live in the moment. As a result she grew to value herself again as a dignified person.</p> <p>“...stop thinking about why I cannot walk now? Just restart my life again from a zero point, and then my mind does not go into a tailspin.” (p.14)</p> <p>“...I recite Buddha’s name as taught by those volunteers. They told me it would make me feel more peaceful. When I have peace of mind, I am able to turn over a new leaf.” (p.10)</p>

Table 2. Comparison of DT conceptual framework and the concept of dignity in Taiwan

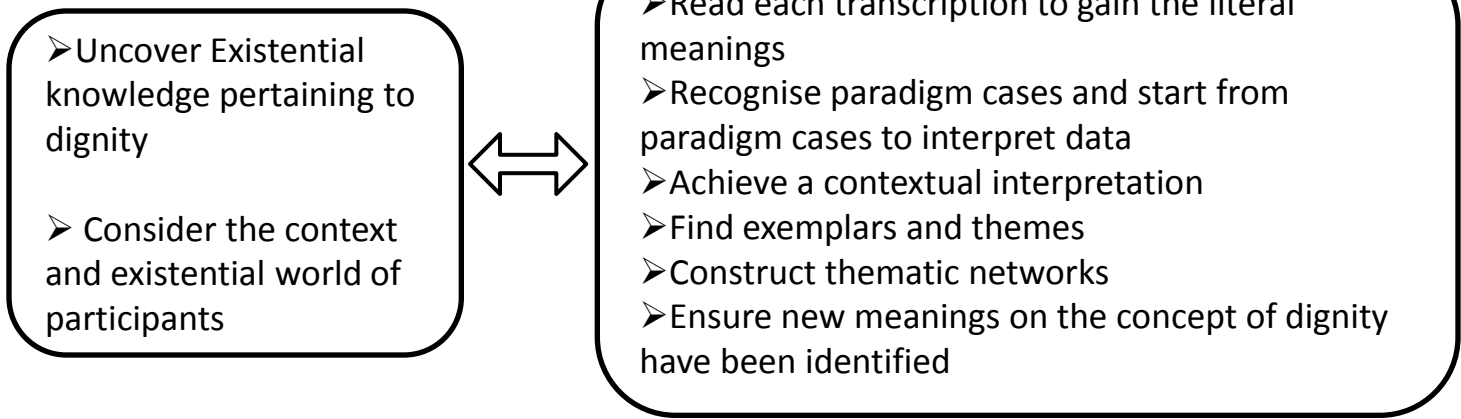
The Conceptual framework of Dignity Therapy (Chochinov <i>et al.</i> , 2002b, 2005)	The conceptualization of dignity in Taiwan
Similar Features	
<u>Illness related concerns</u> <u>Social dignity inventory:</u> Care tenor <u>Dignity Conserving Repertoire:</u> Continuity of self Hopefulness Role preservation Living in the moment	<u>Extrinsic factors impacting on dignity:</u> Illness-related concerns Social support Care delivery <u>Intrinsic characteristics of dignity:</u> Having peace of mind Having a sense of existence: Appropriate appearance Living life to the full
Divergent Features	
<u>Dignity Conserving Repertoire:</u> Maintenance of pride Generativity/ Legacy	<u>Intrinsic characteristics of dignity:</u> Living a moral life Having a sense of existence: Resignation to God's will

Figure 1. The process and steps of data analysis

Process



Steps repeated:



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Figure 2. Conceptualisation of patient dignity at the end of life in Taiwan

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◎ **Extrinsic factors impacting on dignity:**

• **Illness related distress**

• **Care delivery:** appropriate treatment; professionals' attitude; psychological-existential support

• **Being loved**

◎ **Intrinsic characteristics of dignity:**

• **Living a moral life:**

having filial children; behaving politely towards and caring for others

• **Having peace of mind and a sense of existence:**

knowing one's own inner needs; not being afraid of death*; being reconciled with others*; resignation to God's will; keeping an appropriate appearance; living life to the full

◎ **Dignity: Valuing oneself / being valued**

“ * ”: Only professionals mention it