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Reciprocal Dynamics of Dignity in End-of-Life Care:

A Multi-Perspective Systematic Review of Qualitative and Mixed Methods Research

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Abstract

Background: Preserving terminally ill patients' dignity and well-being through dignified and holistic care has become the overarching goal in palliative care services. However, dignity is a multifaceted concept with a wide range of interpretations under different cultural contexts. **Aim:** The aim of this review is to understand the variations in subjective interpretations and constitutions of dignity in palliative or end-of-life care via an integrative worldview. **Design:** This systematic review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline and used SPIDER tool to screen for appropriate and relevant articles for analysis. **Data Sources:** Four major databases were searched including CINAHL, ERIC, Medline, and PsycARTICLES between 2009 and 2018. Forty-eight qualitative studies that examined dignity from the perspectives of patients, family caregivers, and health-care professionals were selected for full text data analysis using thematic synthesis. **Results:** Analysis of the various concepts of dignity revealed 18 themes that were further categorized into 7 conceptual categories: (1) self-determination, (2) existential liberty, (3) relational connectedness, (4) caregiving revitalization, (5) mindful humanity, (6) patient–family care, and (7) sustainable culture. These 7 categories span across individual, familial, and institutional dimensions, forming a new Dynamic Reciprocity of Dignity model. **Conclusions:** The Dynamic Reciprocity of Dignity model highlights the importance of adopting a systemic lens to address dignity-related needs and concerns at the end of life, while providing insights on how compassionate care and self-compassion can serve as the foundation of dignified care, which in turn serve as a buffer against patients' existential suffering as well as caregivers' burnout and fatigue. Recommendations for clinical practice and future research directions are discussed.

*Keywords: dignity, end-of-life, palliative care, self-compassion, compassionate care,
Dynamic Reciprocity of Dignity*

PREPRINT

Reciprocal Dynamics of Dignity in End-of-Life Care:

A Multi-Perspective Systematic Review of Qualitative and Mixed Methods Research

Under the rubric of ageing population and increasing prevalence of chronic life-threatening illnesses, the demand for palliative care is rising in all advanced societies.¹ The World Health Organization has explicitly recognized palliative care as a basic human right,² and preserving patient's dignity and providing dignified care are identified as the overarching goals of palliative care services.³ However, the construct of dignity remained largely underdeveloped over the past few decades despite the frequent usage of the word in palliative care literature and guidelines. It was not until the emergence of Chochinov's Empirical Model of Dignity-Conserving Care has greater clarity been brought to the conceptual and practical knowledge of dignity in end of life contexts, as this body of work has served as the foundation to guide quality palliative care practices as well as subsequent dignity research across the globe.⁴

In spite of the important groundwork accomplished by Chochinov and this team in North America, dignity is a multifaceted and culturally-bound concept with a wide range of interpretations.⁵ Specifically, how patients experience dignity at the end-of-life can be vastly different from the perspectives of their family caregivers and their professional healthcare teams. These variations have a direct impact on the practice and delivery of dignified care.⁵ Additionally, patients' sense of dignity as they approach the final phases of life is more susceptible to enhancement or diminishment by the behaviours of others.⁶ As palliative care often involves family caregivers and healthcare providers, the interactions between these parties pose direct influence on patients' sense of dignity.⁷

Moving forward with the above understanding, it is important to examine the meaning of dignity from the joint perspectives of patients, family caregivers, and healthcare professionals.

The authors have conducted this systematic review to analyse the narratives included in qualitative and mixed methods research published in the past decade in order to gain a summative insight into the multifaceted nature of dignity.

Methods

Design and Research Strategy

This study comprises a qualitative systematic review that focuses on analysing the direct narratives in qualitative and mixed-method research studies, and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).⁸ A unique search string was developed to systematically search through four major databases including CINAHL, ERIC, Medline, and PsycARTICLES. Studies which addressed the lived experiences of patients, family caregivers, and healthcare professionals with regards to perceived dignity and relevant experience in palliative care or end-of-life care were included in the systematic review. For this study, a patient is defined as any adult who was diagnosed with terminal or terminally chronic illnesses; a family caregiver is defined as any family member who served as the primary caretaker and healthcare decision maker of a patient; and a healthcare professional is defined as any individual who served in palliative care or end-of-life care setting and had direct interaction with patients and family caregivers. The inclusion and exclusion criteria as well as keywords of the search string adopted in this review are presented in Table 1.

Table 1

Inclusion and exclusion criteria

	Include	Exclude
Population	(a) Patients who received hospice/palliative/end-of-life care, (b) caregivers who were caretaking family members in hospice/palliative/end-of-life care settings, and/or (c) healthcare personnel who served in hospice/palliative/end-of-life care settings	Any population that did not fit the inclusion criteria
Study Design	Structured/semi-structured interviews	Any study design that did not fit the inclusion criteria
Context	End-of-life care/Palliative care/Hospice care/Bereavement care	Any context that did not fit the inclusion criteria
Key Outcomes	Perspectives/Views on dignity or relevant experience pertaining to end-of-life/palliative care	Any outcome that did not fit the inclusion criteria
Research Design	Qualitative studies/Mixed method studies	Any design that did not fit the inclusion criteria
Period	1 Jan 2009-31 Dec 2018	Any study that was not published within the stated inclusion period
Language	English	Any study which was not in the English language
Type of Publication	Peer-reviewed journal articles	Any publication that did not fit the inclusion criteria

Keywords in used the search: dignity, dignity care, dignity-conserving care, end-of-life, palliative care.

Screening Process

During the initial screening process, first and second authors assessed the titles and abstracts of citations independently based on the prescribed inclusion and exclusion criteria. Studies deemed fit by either authors were then carefully evaluated for inclusion via full-text reading, guided by the SPIDER tool.⁹ A study was included only if both authors arrived at the same decision independently. In the event where there was a conflict between the first and second author regarding the appropriateness for inclusion, the third author conducted another round of full-text reading in discretion and made the final decision. The literature search identified 303 articles as potentially relevant, and of these, 120 articles were selected for full-text screening and 48 articles were included in the final analysis.^{7,10-56} The screening process is presented at Figure 1 and the overview of the 48 articles is presented in Table 2.

Figure 1. PRISMA flow diagram

Table 2

Overview of 48 articles included in the systematic review

Author (Year)/Country	Purpose of Study	Study Design	Data Analysis	Credibility Achieved via	Ethical Approval	Sample
Axelsson et al. (2011)/Sweden	To elucidate patients' lived experience of haemodialysis when nearing EOL.	Semi-structured interview	Phenomenological hermeneutical analysis	Prolong engagement, moderatum generalization	Yes	Patients (N=8)
Borhani et al. (2014)/Iran	To explore nurses' perspectives about EOL care in Islamic context.	Semi-structured interview	Inductive coding approach	Member checking, peer debriefing, audit trail	Yes	Nurses (N=12)
Brodtkorb et al. (2017)/Norway	To investigate ethical challenges in EOL care in nursing homes.	Focus group	Hermeneutical approach	Inter-researcher consensus, peer debriefing	Yes	Healthcare professionals (N=26)
Brown et al. (2011)/UK	To explore how nurses can support patients approaching death.	Focus group	Framework analysis	Inter-researcher consensus	Yes	Patients (N=8) Family caregivers (N=5) Healthcare professionals (N=17)

Chung et al. (2018)/Hong Kong	To explore the Chinese spousal experience with their dying loved ones suffering from terminal cancer.	Semi-structured interview	Thematic analysis	Inter-researcher consensus	Yes	Spouses ($N=15$)
da Silva et al. (2017)/Brazil	To investigate nurses' understanding of palliative care and the strategies to promote palliative care.	Questionnaire with written responses	Thematic content analysis	Inter-researcher consensus	Yes	Nurses ($N=13$)
Danielsen et al. (2018)/Norway	To examine factors facilitating home deaths.	Focus groups	thematic analysis	Inadequate information	Yes	Healthcare professionals ($N=19$)
Devik et al. (2013)/Norway	To explore the experience of patients receiving palliative treatment, while living alone in a rural area.	Semi-structured interview	Phenomenological hermeneutical approach	Inter-researcher consensus	Yes	Patients ($N=5$)
Diaz-Cortes et al. (2018)/Spain	To explore physicians' and nurses' experiences regarding conversation of dignity in EOL care in the emergency department.	Semi-structured interview and focus groups	Phenomenological hermeneutical approach	Inter-researcher consensus, member checking	Yes	Healthcare professionals ($N=26$)

Dwyer et al. (2009)/Sweden	To explore what dignity in EOL care means to nursing home residents.	Semi-structured interview	Content analysis	Inter-researcher consensus	Yes	Healthcare professionals (<i>N</i> =21)
El-Jawahri et al. (2017)/UK	To examine knowledge gaps on hospice care and perceived barriers for hospice utilization.	Semi-structured interview	Framework analysis	Inter-researcher consensus	Yes	Patients (<i>N</i> =10) Family caregivers (<i>N</i> =1)
Fernandez-Sola et al. (2017)/Spain	To define the attributes of dignity in EOL care in the emergency department.	Semi-structured interviews and focus groups	Hermeneutic phenomenological approach	Inter-researcher consensus, member checking	Yes	Healthcare professionals (<i>N</i> =26)

Gardner & Kramer (2010)/USA	To explore areas of congruence and incongruence between the subjective experiences of patients and family caregivers on EOL care.	Semi-structured interview	Template analysis	Prolong engagement, peer debriefing, negative case analysis, audit trail	Not reported	Patients ($N=10$) Family caregivers ($N=10$)
Grech et al. (2018)/Malta	To explore the lived experiences of nurses providing EOL care to patients with hematologic malignancies.	Semi-structured interview	Interpretative phenomenological analysis	Inter-researcher consensus and audit trail	Yes	Nurses ($N=5$)
Green et al. (2018)/Australia	To explore the perceptions of providing care to patients from culturally and linguistically diverse populations.	Focus group	Grounded theory analysis, constant comparative method	Inter-researcher consensus	Yes	Healthcare professionals ($N=28$)
Gysels et al. (2016)/UK	To explore what constitutes dignity for patients suffering from breathlessness with an advanced illness.	Semi-structured interview	Framework analysis	Inadequate information	Not reported	Patients ($N=20$)

Hall et al. (2009)/UK	To explore the generalisability of Chochinov's dignity model to patients in nursing homes.	Semi-structured interview	Content analysis	Inter-researcher consensus, negative case analysis	Not reported	Patients (<i>N</i> =18)
Hall et al. (2014)/UK	To compare the views and maintenance of dignity.	Semi-structured interview	Framework analysis	Inter-researcher consensus	Yes	Patients (<i>N</i> =16) Family caregivers (<i>N</i> =15) Healthcare professionals (<i>N</i> =90)
Hamoooleh et al. (2013)/Iran	To explore nurses' perception about ethics-based palliative care provided to cancer patients.	Semi-structured interview	Content analysis	Researcher consensus, peer debriefing, moderatum generalization	Yes	Nurses (<i>N</i> =14)
Hanratty et al. (2012)/UK	To explore patients' experience moving between care settings at their EOL.	Semi-structured interview	Framework analysis	Inter-researcher consensus, member checking with participants' caregivers	Yes	Patients (<i>N</i> =30)
Ho et al. (2013a)/Hong Kong	To examine the generalizability of Dignity Model to Chinese palliative care patients, and cultural influences on the conception of dignity.	Semi-structured interview	Framework analysis	Inter-researcher consensus, negative case analysis	Yes	Patients (<i>N</i> =16)
Ho et al. (2013b)/Hong Kong	To examine the processes by which Chinese terminal cancer patients achieve and maintain a sense of dignity.	Semi-structured interview, observation, field notes	Content analysis	Inter-researcher consensus, method triangulation	Yes	Patients (<i>N</i> =18)

Ho et al. (2016)/Hong Kong	To identify the interplaying dynamics, mechanisms, and systemic factors that underscore the implementation practice of End-of-life Integrate Care Pathway (EOL-ICP) in Hong Kong.	Focus group	Framework analysis	Inter-researcher consensus	Yes	Family caregivers (<i>N</i> =6) Healthcare professionals (<i>N</i> =24)
Holmberg et al. (2012)/Sweden	To describe patients' experiences of receiving nursing care in their private homes.	Semi-structured interview	Thematic analysis	Inter-researcher consensus, moderatum generalization	Yes	Patients (<i>N</i> =31)
Hopeck (2018)/USA	To examine healthcare professionals' experiences with family caregivers at the EOL.	Semi-structured interview	Grounded theory approach	Inadequate information	Not reported	Healthcare professionals (<i>N</i> =71)
Hov et al. (2012)/Norway	To describe conceptions of good nursing care, and its implementation at the EOL.	Semi-structured interview	Phenomenographic analysis	Inadequate information	Not reported	Nurses (<i>N</i> =14)
Isaacson & Minton (2018)/USA	To examine EOL communication practices between hospice/palliative nurses and patient/family.	Semi-structured interview	Hermeneutical analysis	Inter-researcher consensus	Yes	Hospice/palliative nurses (<i>N</i> =10)
Jack et al. (2014)/UK & Ireland	To explore family caregivers' perceptions of the Hospice at Home (HAH) service.	Semi-structured interview	Thematic analysis	Inter-researcher consensus	Yes	Family caregivers (<i>N</i> =20)
Kinley et al. (2018)/UK	To explore bereaved relatives' satisfaction with EOL care.	Mixed method with written text	Thematic analysis	Inter-researcher consensus	Yes	Family caregivers (<i>N</i> =110)

Kong et al. (2017)/Hong Kong	To examine and conceptualize practices that promote a sense of personhood among the dying elderly in residential care homes.	Semi-structured interviews	Comparative analysis	Inter-researcher consensus, reflexivity notes	Yes	Healthcare professionals (N=9)
Kortes-Miller et al. (2018)/Canada	To examine the unique needs of older LGBTQ+ adults nearing EOL.	Focus group	Inductive thematic analysis	Inter-researcher consensus	Yes	Patients (N=23)
Kuluski et al. (2013)/Canada	To identify important elements in patients' experience of care	Mixed method with semi-structured interview	Thematic analysis	Inter-researcher consensus	Yes	Patients (N=146)
LaValley (2018)/USA	To examine the support which EOL caregivers receive from existing social networks.	Semi-structured phone interview	Content analysis	Inter-researcher consensus	Yes	Family caregivers (N=61)
Lee et al. (2013)/Taiwan	To examine family caregivers' experiences and needs in relation to hospice home care.	Interview, observation	Content analysis	Prolong engagement, method triangulation, inter-researcher consensus, peer debriefing	Yes	Family caregivers (N=41)
Li et al. (2014)/Taiwan	To explore the conceptualization of dignity in the context of EOL care.	Semi-structured interview	Phenomenological hermeneutical analysis	Peer debriefing, self-reflexive journal, member checking	Yes	Patients (N=9) Healthcare professionals (N=10)

Livelo et al. (2018)/USA	To examine Filipino-American nurses' attitudes and experience toward EOL care.	Focus group	Colaizzi's analytical method of data analysis	Member checking	Yes	Nurses (<i>N</i> =15)
Luijckx & Schols (2011)/Netherlands	To explore the perceptions of terminally-ill patients and their family members regarding home and hospice.	Semi-structured interview	Non-specified analysis	Inter-researcher consensus	Not reported	Patients (<i>N</i> =13) Family caregivers (<i>N</i> =13)
Lundberg et al. (2013)/Sweden	To explore the supportive interactions that family members experience in palliative care.	Semi-structured interview	content analysis	Inter-researcher consensus	Yes	Family caregivers (<i>N</i> =25)
Moe et al. (2013)/Norway	To illuminate the meaning of receiving help from home nursing care for the chronically-ill elderly living in their homes.	Semi-structured interview	Phenomenological hermeneutical approach	Inter-researcher consensus	Yes	Patients (<i>N</i> =11)
Ong et al. (2018)/Singapore	To explore nurses' perceptions towards providing EOL care.	Semi-structured interview	Thematic analysis	Inter-researcher consensus, peer review, negative case analysis	Yes	Nurses (<i>N</i> =10)
Pattison et al. (2012)/UK	To explore the issues regarding EOL care, caregiving and death.	Semi-structured interview	Phenomenological hermeneutical approach	Audit trail, peer review, member checking, moderatum generalization, reflective journal	Yes	Patients (<i>N</i> =7) Family caregivers (<i>N</i> =12) Healthcare professionals (<i>N</i> =18)

Periyakoil et al. (2013)/USA	To explore factors instrumental to dignity at the EOL, including the influences of cultural and religious beliefs.	Mixed method with semi-structured interview	Grounded theory approach	Inter-researcher consensus	Yes	Nurses ($N=45$)
Råholm et al. (2014)/Norway, Sweden, & Denmark	To describe different perspectives of dignity in residential care.	Semi-structured interview	Phenomenological hermeneutical approach	Audit trail and inter-researcher consensus	Yes	Family caregivers ($N=28$)
Riggs et al. (2014)/USA	To analyse suggestions for improving EOL care in Veterans Affairs Medical Centres.	Semi-structured interview	Content analysis	Inter-researcher consensus	Not reported	Family caregivers ($N=54$)
Soroka et al. (2018)/USA	To explore family caregivers' experience with providing care to dying family members in the home setting.	Semi-structured interview	Narrative data analysis	Inadequate information	Yes	Family caregivers ($N=16$)
van Gennip et al. (2013)/Netherlands	To examine factors constituting dignity throughout illness trajectory.	Semi-structured interview	Thematic analysis	Reflexive journal, inter-researcher consensus	Yes	Patients ($N=34$)
van Gennip et al. (2015)/Netherlands	To explore the dynamics of patients' dignity throughout their illness trajectory.	Semi-structured interview	Thematic analysis	Prolonged engagement, inter-researcher consensus	Yes	Patients ($N=19$)
Wakunami et al. (2009)/Japan	To examine families' acceptance of near death.	Semi-structured interview, focus group	Constant comparative analysis	Peer debriefing, member checking, inter-researcher consensus	Not reported	Family caregivers ($N=10$)

Data Analysis

The narratives of participants in the 48 articles were treated as data points to eliminate the potential biased understanding based on primary authors' own interpretation of the data.⁵⁷

Thematic synthesis was adopted to analyse the narratives through three-stage process: (a) line-by-line coding of text, (b) developing descriptive themes, and (c) creating conceptual categories with new interpretations.⁵⁸

The QSR NVivo software package was used to manage the data. Coding and peer debriefing meetings were conducted regularly with all research team members to maximize credibility and authenticity of the analysis.⁵⁹ The coding framework, data interpretation, and confirmation of themes were agreed upon by all members, finalized by the fifth author, and compared to existing literature to ensure investigator triangulation and theory triangulation.⁵⁹ Reflexive memo was kept throughout the analysing process, recording awareness of assumptions and biases.

Results

The studies included in this review spanned across four regions, Europe ($N=28$), Asia ($N=11$), Americas ($N=11$), and Oceania ($N=2$), involving 412 patients, 459 family caregivers, and 523 healthcare professionals. Majority of the articles examined healthcare professionals' perspectives of dignity ($N=22$), followed by patients ($N=19$) and family caregivers ($N=19$). Thematic synthesis produced 18 themes, which were further organized into seven categories across the individual, familial, and institutional dimensions of dignity in end-of-life palliative care setting.

Individual Dimension

The individual dimension focuses on the psycho-socio-spiritual conceptual categories which constitute patients' dignity: 1) *self-determination* (i.e., patients' psychological need to be autonomous); 2) *existential liberty* (i.e., patients' spiritual need to explore their existential identities); and 3) *relational connectedness* (i.e., patients' social need to maintain and forge meaningful relationships).

Self-determination.

Planning for death (N of articles=26). Patients yearned to plan for a comfortable and dignified end-of-life care and death. Healthcare professionals observed that it was imperative for patients to verbalize their end-of-life care wishes, so that their death preferences could be adhered to without unnecessary conflict.

“Good death [is to] have the patient spell out what is important and honour those wishes. Bad death is prolonging the death of the person because of the wishes of overbearing family members.” (Healthcare professional)⁵⁰

However, family members were not necessarily comfortable engaging in such conversation.

“They don't seem to want to talk about it because it's an unpleasant thing and they don't always go for it, kind of push it back. But I want to talk a little more about this.” (Patient)²²

Informed medicine (N=22). Patients experienced greater self-determination and dignity when they were equipped with relevant knowledge and resources. While patients appreciated their family caregivers' intention not to distress them, they asserted that it was ultimately their right to be informed about their health and make necessary arrangements.

“They didn’t want me to be upset, I guess, but I have a right to know. I finally got the answer from a second doctor that I consulted, and honestly, I wasn’t upset to hear the news [...] After talking to my attending nurse, I signed off my advanced care directives so that my family members don’t have to make those difficult decisions for me.” (Patient)³¹

To facilitate this, healthcare professionals had to pace themselves when providing patients with medical information and available care plans.

“When a new patient comes in here, they do everything so fast that it’s hard to comprehend all the information that you’re getting.” (Patient)⁴⁰

Autonomous reliance (N=20). Autonomous reliance referred to the fine balance between patients’ needs for support and autonomy. Patients’ sense of autonomy and dignity were often challenged due to the gradual loss of function, and they consequently perceived themselves as a burden.

“I don’t think it’s human dignity really, not to be allowed to do as I wish at this point [...] I could die any time.” (Patient)¹⁰

While some patients acknowledged their need for assistance in receiving treatments and carrying out daily activities, they asserted that assistance should be offered to them in a respectful manner, and that they should be able to choose whom they could rely on for care and support.

“I couldn’t eat under my own strength and the nurses came by a few times offering to feed me. I have never been fed since childhood, but if life has come down to this, I would want my daughter to do it.” (Patient)³¹

Existential liberty.

Personhood maintenance (N=23). Personhood referred to one's perceived/established sense of identity. Some patients described feeling like an inconsequential object in need of medical treatment within the healthcare system, when they deserved to be regarded as the unique individuals that they were.

"That they can still see me as the person I once was. Not Mrs. So-and-So, not the patient, no, 'me'." (Patient)⁵⁴

Patients retained their sense of personhood by reaffirming their social roles and identities, particularly within the family systems. Similarly, family caregivers wished that patients can be treated as a person, instead of a body, after their death.

"I was dismayed that within one and a half hours of his death, my father had become 'the body' to be removed immediately... This lack of sensitivity nearly obviated my appreciation of the compassion which had been exhibited to my father and to me during the previous few days." (Family caregiver)³⁷

Transitional coping (N=17). Amidst the drastic transitions and emotional fluctuations associated with terminal illnesses, patients adopted unique coping strategies to preserve their sense of dignity.

"I see things somewhat differently now because I've realized that... apparently I can still mean something to someone else while sitting down." (Patient)⁵⁵

Some patients actively coped with their illnesses by sustaining a fighting spirit while others chose to embrace the changes by maintaining a sense of normalcy. Meaning making was especially helpful in empowering patients to cope with the transition, as they reconstructed the narratives of their lived experiences.

“Knowing that I am not alone and that my sufferings are small and insignificant in comparison, I begin to feel for them (other patients) ... I am beginning to understand the true meaning of humanity.” (Patient)³⁰

Personal sanctuary (N=7). Personal sanctuary referred to a space where patients could retain their privacy and secure their sense of individualism in the midst of receiving care.

“I can’t use the toilet. I have to use a commode in my room because I have to use the hoist. They’ll always draw the curtains and shut the door, you know, and that is what I want. Privacy is your dignity really, isn’t it?” (Patient)²⁷

Patients created their personal sanctuary by making specific requests or modifying the arrangement within their bed space. Apart from modifying their physical environment, patients ultimately needed a space where they felt safe and accepted.

“You need to make sure you have an environment where LGBTQ people will feel accepted, comfortable, acknowledged and not have to go back into the closet in order to be there.” (Patient)³⁹

Relational connectedness.

Empathic bonds (N=13). Patients yearned to cultivate empathic bonds within their social networks for empowerment and support.

“Just comradeship... [Having] people that are around that I will talk with, or will talk to me, and you would miss them if you don’t see them at least once a week, or more than that.” (Patient)²²

Some patients removed themselves from social circles due to undesirable attention that threatened their sense of relational connection. Patients who were able to establish an empathic social network found it to be imperative in safeguarding their dignity.

“I have got to know a number of nice people. We’re like a big family. With the time they have, we talk a little about anything other than illness. It’s also like therapy.” (Patient)³²

Familial connection (N=8). Connection with and social support from family members became essential throughout patients’ course of illness.

“My wife and children are most important to me now; they visit me almost every day and they are my main source of support. Without them, I don’t know where I’d be. I truly cannot thank them enough.” (Patient)³¹

Though falling ill had resulted in multiple losses, patients also observed that the illness drew them closer with their family. Being with family members enhanced patients’ sense of dignity, as it reminded patients of their roots and affirmed their roles within the family system.

“The relationship with people close to my family, has improved since my illness, has become more intense or something like that, and also my children are nearer to me than I ever noticed or felt before.” (Patient)⁵⁵

Familial Dimension

The familial dimension focuses on the *caregiving revitalization* (i.e., family caregivers’ need for psycho-socio-emotional support to facilitate their coping and strengthen their caregiving capabilities) conceptual category.

Caregiving revitalization.

Overcoming compassionate conflict (N=18). Compassionate conflicts referred to the collision between conflicting desires which had stemmed from love, compassion and a sense of responsibility the family caregivers had for patients. The accompanying emotional ambivalence and distress resulted in family caregivers struggling to manage caregiving and accept their loved ones’ impending death, in the midst of attending to other commitments and their own well-being.

“I wanted my husband to live longer, but, at the same time, because of his symptoms, I also wanted him to die early to get rid of his pain... this feeling of contradiction was torturing me.” (Wife)⁴²

Family caregivers reported coming to terms with patients’ impending death once they had recognized the continuing bond they could share with patients even after death. This was important to patients as their family’s acceptance of their end-of-life and the ability to plan for their death were considered dignifying for them. When family caregivers perceived caregiving as a compassionate behaviour instead of a responsibility forced upon them, they derived meaning out of their caregiving commitment. This in turn enhanced the patient’s need for empathic bonds and familial connection.

“The most important thing for me to learn is that you have to give yourself an opportunity to take care of your sick parents who have taken care of you since you were a child... I was really proud of being familiar with skills of care.” (Daughter)⁴²

Institutional support (N=15). Family caregivers often underwent a major transition where they struggled to cope with the accompanying emotional turmoil. Receiving adequate and comprehensible information related to patients’ condition was helpful in alleviating the unpleasant emotions. Family caregivers felt more reassured in supporting patient’s end-of-life care decisions after the healthcare professionals had provided rationale and discussed consequences of various care plan options available. This gave them the opportunity to further enhance the patient’s sense of dignity by adhering to his/her final wishes.

“[Patient] made the decision... not to put in the feeding tube. As it turns out... everything was shutting down [...] Because there were doctors here that were explaining that to us,

that took the guilt away... It really helped the family more in dealing with that.” (Family caregiver)⁵²

Apart from the psycho-socio-emotional and informational support, services like homecare support were particularly useful in providing pragmatic support to the family caregivers.

“It gave me a little bit more time to do things on my own, I could gather my own thoughts and rationalize things [...] it would give me a bit more time to think about, you know, what the children needed to do the next day after or their homework [...] so I think it’s benefited the family, you know, all of us.” (Husband)³⁶

Institutional Dimension

The institutional dimension focuses on conceptual categories which preserve patients’ dignity and support family caregivers’ caregiving through: 1) *mindful humanity* (i.e., healthcare professionals’ awareness of and the intention to reduce patients and families’ unique psycho-existential suffering via compassionate care), 2) *patient-family care* (i.e., healthcare professionals’ need to provide ongoing family-centered care and establish alliance with patients and families throughout care planning and delivery), and 3) *sustainable culture* (i.e., healthcare institutions’ need to uphold dignified care by expanding on care accessibility, providing ongoing support to and fostering interdisciplinary partnership among healthcare professionals, and creating a humane environment of care).

Mindful humanity.

Compassionate personalized care (N=30). The traditional curative medical model had resulted in healthcare professionals who instinctively attempted to alleviate a patient’s distress by immediately offering medicinal treatment.

“I once had a patient who told me she was had excoriating pain and she could not sleep. The first thing that I thought of was giving her a higher dose of morphine... But then she said, can you stay with me for a while? So I stayed by her bedside, and gradually, she was able to fell asleep. I realized then, all she ever wanted was some company.”
(Healthcare professional)⁷

However, compassionate personalized care was necessary and could be achieved by developing sensitivity to the unique needs of each patient-family unit. Through the practice of compassionate validation and attentiveness, healthcare professionals could alleviate the distress of patients and families.

“I remember sitting here... and people coming in and [seeing] that we had what we needed [...] I never felt alone. I felt there were people out there that I could call on [...] They cared for him (patient), and they cared about me.” *(Wife)⁵²*

Professional authenticity (N=24). Healthcare professionals who recognized and embraced their duties were better equipped to display compassion to patients and families as they derived meaning from their responsibilities.

We are not doing this because it is our job, but because we truly want our patients to find peace and comfort, we want them to find meaning at the end, and seeing that they do, we too can find meaning in our work.” *(Nursing home staff)⁷*

Essentially, patients and family caregivers wished to be cared for genuinely.

“We don’t want to leave them (patients) in the hands of somebody who doesn’t care about them... even though you guys aren’t family, you just... you treat them like you are.” *(Family caregiver)⁵³*

Patient-family care.

Therapeutic alliance (N=24). Instead of seeing patients and family caregivers as mere care recipients, healthcare professionals need to establish alliance and actively collaborate with them in care planning and delivery. In the event where patients and families were not ready to discuss the illness trajectory and care plans, establishing a therapeutic alliance created a safe space and provided buffering time for patients and family caregivers to share their concerns with healthcare professionals.

“The relaxed atmosphere between me and her (nursing staff) feels very safe. When she (patient) had been at home, the staff always sat down to listen to how she had experienced it.” (Family caregiver)⁵¹

Family caregivers were particularly appreciative of healthcare professionals, who having established a genuine alliance, accompanied them during patients’ health deterioration and death.

“[The nurse] left me alone with him for a few hours [...] She was obviously aware that, you know, it (patient’s death) was going to be very soon, so she came back in and sat with me... That was very good, she was tremendous.” (Family member)⁴⁹

Care continuity (N=21). Patients and family caregivers appreciated having the same designated interdisciplinary care team who could provide consistent quality of care throughout their journey of care, including continual support and follow-ups after patients’ death.

“I think the consistency of care a patient receives is very important. [...] It is wonderful that my wife can receive all the care that she needs with the same care team from the very beginning till her very last days.” (Husband)⁷

However, the continuity of compassionate care should not be restricted within palliative care units, but involve all relevant healthcare and allied health professionals.

“The nurses and doctors at the palliative care unit are the kindest souls [...] The everyday nurses and doctors just don’t care.” (Patient)³¹

Sustainable culture.

Care accessibility (N=18). Patients and caregivers saw limited human resource allocation in healthcare setting as a hindrance to their healthcare professionals’ delivery of quality care.

“They are understaffed here. I do know that. Like I understand understaffing and I think... I really think they are great nurses. I do. But because they have such high patient load, generally I wish some of my needs had been met a bit faster.” (Patient)⁴⁰

Families who did not have the financial means to support the significant cost of patients’ long-term care often faced challenges in securing quality care service, and subsequent emotional distress due to guilt.

“I honestly feel he would have been alive today were he under someone else’s care. But unfortunately, he didn’t have insurance and... I wasn’t able to pay for him... to go to a regular hospital... That’s part of what just haunts me.” (Daughter)⁵²

Therefore, healthcare institutions needed to examine the care accessibility in order to sustain patients’ dignity and their families’ caregiving.

Professional development & support (N=13). Healthcare professionals who were not adequately equipped to address the challenges of death and dying struggled to provide quality care to patients and families. Professional development was particularly helpful in preparing them to address challenges and death taboos, thus transforming them into advocates for good deaths.

“We used to be afraid to talk about death because it is a big taboo in our culture, but I think we have now become advocates for good deaths [...] We now feel much more competent in dealing with life and death situations.” (Healthcare professional)⁷

Although facing patients’ imminent death was one of the fundamental aspects of end-of-life palliative healthcare professions, they were often not given sufficient time and space to process their patients’ deaths.

“If he (patient) dies in another ward, it really always shocks me, and sometime I cry, yes, even now while I am telling you, I become emotional. [...] we are human, we are only human after all.” (Nurse)²³

This highlighted the crucial need to provide ongoing support to healthcare professionals to safeguard their wellbeing in the midst of providing care to patients and families.

Interdisciplinary equality and partnership (N=11). Physicians often held greater power in making decisions for patient’s care plans and delivery, without needing to consult the primary nurses. As such, nurses were usually expected to accept the decisions without question and were eventually conditioned to stop sharing their concerns or advocating for patients and families.

“[Doctors] would listen to you... but there’s no explanation if your concern is important or not, [and] you’ll feel discouraged. [...] What’s the point [of] telling them? They don’t listen.” (Nurse)⁴⁸

There was a need to acknowledge the contributions of all disciplines as multidisciplinary collaboration within the healthcare institutions is essential in delivering dignified care.

“We work like a team. Everyone has a duty [...] This participative approach is essential to work.” (Nurse)¹¹

Human-centered architecture (N=8). A conducive environment within healthcare institutions was essential in catering to both the physical and psychological comfort of patients and families. Patients appreciated the design of a healthcare setting that encouraged interaction as they were able to foster relational connectedness with others while waiting for their medical appointments.

“The waiting environment was just more comfortable, wasn’t just hard light and hard seats [...] the chairs were positioned you could really talk to people, you know.”

(Patient)²⁵

It was also important to allocate private spaces to patients nearing their end-of-life as it offered opportunities for families to bid farewell and for patients to die with dignity.

“I felt by moving him (patient) to a private room that he was allowed to die with some dignity and love and in a peaceful environment with people he loved around him, and we were allowed to express our feelings and emotions in a private way... I truly consider that a gift...” (Daughter)⁵²

Discussion

This is the first known study that comprehensively and systematically explores the multifaceted concept of dignity from the joint perspectives of patients, family caregivers, and healthcare professionals. The individual dimension addresses the psycho-socio-spiritual categories constituting patients’ dignity, specifically their need to be autonomous (self-determination), to affirm their existential identities (existential liberty), and to maintain meaningful relationships (relational connectedness). The familial dimension focuses on the family members’ need for ongoing psycho-socio-emotional support to sustain their caregiving in order to preserve patients’ sense of dignity (caregiving revitalization). Lastly, the institutional

dimension emphasizes on the pertinence of healthcare professionals' compassionate qualities (mindful humanity), ongoing family-centered care (patient-family care), as well as compassion-driven culture within the healthcare institution (sustainable culture) in safeguarding patients' dignity and supporting family members' caregiving.

Using the conceptual categories from the thematic synthesis, the authors then developed the Dynamic Reciprocity of Dignity model (see Figure 2). The model illustrates the dynamic nature of patients' sense of dignity (individual dimension) and its interlocking connection with family caregiving (familial dimension), and qualities exhibited by healthcare professionals and the healthcare system (institutional dimension). The dynamic nature of dignity and the call for compassionate care are not foreign to the field, though a systemic exploration is previously lacking.⁶⁰ The themes derived in this review are in line with Bronfenbrenner's ecological systems theory⁶¹, where patients' dignity is enhanced or diminished in response to their context and environment. Additionally, the themes also support the notion by Guo et al.⁶, where patient's dignity interacts with the behaviours of others in a reciprocal manner throughout their illness trajectory. The model presents a comprehensive systemic approach in delivering compassionate care to safeguard patients' dignity and sustain caregiving, of which is discussed in detailed in the subsequent sections.

Figure 2. Dynamic Reciprocity of Dignity Model

Self-Compassion as Potential Shield against Patients' Dignity Deterioration

Throughout the narratives, the authors noted several recurring elements:

1. Isolation, where (a) patients were exempted from updates on their prognosis and treatment planning, and received disempowering attention,^{39,54} and (b) family caregivers experienced overwhelming caregiving responsibilities and immense emotional turmoil without adequate support,^{42,52}

2. Self-judgment, where (a) patients criticized their value as a dignified person due to the gradual losses in their bodily functions,^{10,43} and (b) family caregivers experienced conflicted feelings over their roles in caregiving and making surrogate decisions;^{34,42} and
3. Over-identification, where healthcare professionals were trapped in their internal world of distress due to their overwhelming workload with tenuous resources and support.^{19,32}

The aforementioned elements pose deleterious effects on patients' perceived dignity and the physio-socio-emotional wellbeing of family caregivers and healthcare professionals. As such, the authors recommend the practice of self-compassion with its core elements of self-kindness over self-judgment, a sense of common humanity over isolation and mindfulness over over-identification as a potential shield against dignity deterioration. Self-compassion is defined as individuals' ability to respond to suffering with kindness, offer support to the self through mindful awareness, and view their experiences as part of the common human experience.⁶²

Through the practice of self-compassion, patients are able to cope with their negative health outcomes with enhanced subjective well-being.⁶³ Family caregivers and healthcare professionals are likely to derive greater sustainability in providing care when they adopt self-compassion as part of their self-care, since it is effective in reducing compassion fatigue significantly.⁶⁴

Self-Compassion & Compassionate Care within Systemic Framework

Self-compassion and compassionate care hold equal importance in palliative care,⁶⁰ and should be adopted as the basis of dignified care. Using the rubric of compassionate care (derived from the Dynamic Reciprocity of Dignity model) and self-compassion within the systemic framework of dignified care, the authors propose the following clinical implications.

Empowering patients' autonomous self. Family caregivers and healthcare professionals are encouraged to involve patients in the process of diagnosing their illnesses and subsequent care planning and execution. Healthcare professionals, in particular, are recommended to provide easily comprehensible information about patients' illnesses and treatment plans, and address any concerns they may have.

Family-centric compassionate care. Healthcare professionals are recommended to partner with patients and families in care planning, offer personalized care based on their respective cultural beliefs and pragmatic needs, and provide ongoing psycho-socio-emotional support throughout patients' illness trajectory, including post-bereavement period. In addition, training in basic counselling skills is recommended so that healthcare professionals can develop adequate competency to attend to the holistic needs of patients and family caregivers.

Advance care planning. Healthcare institutions are recommended to offer advance care planning services such that patients are able to communicate their preferred care plans, while family caregivers are relieved from the stress of being a surrogate decision-maker. Healthcare professionals can serve as a mediator in situations where patients and family caregivers have differing views, by discussing the rationale and consequences of various care plans with them. Healthcare professionals can attend professional development programs that address death and dying so that they can facilitate effective advance care planning conversations and become advocates for good deaths.

Strength-based meaning reconstruction. Meaning reconstruction interventions can help patients and family caregivers to revisit and reconstruct their experiences meaningfully.⁶⁵ Family-focused narrative approaches can facilitate dyadic conversations between patients and family caregivers to strengthen familial connections.

Teaching self-compassion. Healthcare institutions can provide self-compassion workshops to patients and family caregivers in a small group setting to promote self-kindness, while fostering empathic social connections and alleviating isolation. Allocating quiet rooms for personal mindfulness meditation can encourage the practice of self-compassion among patients, family caregivers and healthcare professionals.

Nurturing compassion within institutions as self-care. As an environment that supports ongoing self-care for staffs is critical in ensuring the delivery of dignified compassionate care,⁵⁰ healthcare institutions are recommended to offer compassion-based training to their staffs, in addition to providing regular supervisions and peer support groups.

Directions for Future Research

There is a need to further explore the dynamic relationship between dignity and self-compassion. This emerging line of inquiry can serve to progress dignified compassionate care towards a sustainable caregiving culture in the end-of-life palliative care setting. Most of the research questions in the included articles focus on factors constituting patients' dignity and the role of healthcare professionals' in promoting those factors. It is therefore essential to also explore the factors constituting the wellbeing of family caregivers and healthcare professionals and their respective needs for sustainable caregiving.

Strengths & Limitations

Although the use of thematic synthesis focused on respondents' lived experiences, the construction of the systemic model and themes were nevertheless susceptible to authors' own subjectivity, despite regular debriefing sessions and high level of inter-researcher consensus. Given the stringent inclusion and exclusion criteria, studies that contain pertinent information

relevant to the purpose of this review, but do not fit the scope, may have been excluded from the review at an earlier stage of screening.

Despite the aforementioned limitations, this review consolidates existing research to form a comprehensive understanding of the concept of dignity within a systemic framework. Furthermore, it lends support to the reciprocal interaction and dynamic nature of dignity between patients, family caregivers, and healthcare professionals in palliative care. Finally, this review offers practical recommendations for enhancing clinical practice and points out potential research directions to better support patients and families via dignified compassionate care.

Conclusion

The Dynamic Reciprocity of Dignity model highlights the interactive dynamics between patients' dignity, family caregiving, and healthcare professionals' compassionate qualities. The interlocking relationships between these three dimensions underscores the importance of adopting a systemic lens to address dignity-related concerns in the end-of-life palliative care setting. Multidisciplinary care teams can utilize the model as well as consider to adopt the proposed clinical implications, deemed fit in their respective culture and end-of-life palliative care settings, in the efforts of providing holistic support and dignified compassionate care to patients and families. Additionally, chief executives and commissioners need to consider the quality of interdisciplinary partnerships among healthcare professionals, as well as need for professional development and support to create a sustainable compassionate culture within the healthcare institutions.

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