

REVIEW ARTICLE

Concept analysis of dignity-centered care for people with chronic progressive disease

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Abstract

Aim: This concept analysis describes attributes, antecedents, and consequences of dignity-centered care for people with chronic progressive disease.

Methods: Rodgers' method of concept analysis was used to clarify the concept's defining attributes. Databases searched were PubMed, MEDLINE, EMBASE, CINAHL, and Ichushi-Web by NPO Japan Medical Abstracts Society, in English and Japanese, from 1976 to 2017. The combination of MESH and keywords used were (dignity), and (care), and (chronic disease) or (chronic illness).

Results: Three antecedents were identified: loss of physical function and reduced psychological capacity, independence and role; living with uncertainty of illness; and multi-faceted distress. There were four attributes identified: bolstering self-esteem, reducing multi-faceted distress, continued relationship, and protecting individual's rights. Four consequences were identified: improved self-esteem, relief from multi-faceted distress, deepening the purpose and meaning of life, and maintaining and/or improving the quality of life.

Conclusion: Dignity-centered care is defined as: care that results in improvement of self-esteem, deepens purpose and meaning of life, maintains and improves quality of life and provides relief from multi-faceted distress. This happens through protecting the individual's rights, bolstering self-esteem and reducing multi-faceted distress through continued relationships with family, friends, and providers. There is a need for continued involvement with those individuals who have lost physical function, psychological capacity, autonomy, and role. They live with uncertainty of illness and exhibit multi-faceted distress. This concept is a fulcrum for patient and nurse reciprocity enabling both to realize greater integrity and respect, and is useful for nursing practice and research.

KEYWORDS

chronic illness, chronic progressive disease, dignity, dignity-centered care, nursing

1 | INTRODUCTION

The word dignity originates from the Latin word meaning worthy or "of value" (Emery, 2011; Merriam-Webster, n.d.). The historical background of the concept of human dignity arises from both Eastern and Western philosophies and religions that

assert that the worth or value of a human life is divinely sourced (Dan-Cohen, 2011; Yadav, 2015). Hence, human dignity is the inseparable value ascribed to all people and is a cornerstone value in nursing. The International Council of Nurses' Code of Ethics for Nurses makes it clear that inherent in nursing is respect for human rights, including the right to life, to

dignity and to be treated with respect (International Council of Nurses, 2012). In addition, the first sentence of the Code of Ethics for Nurses of the Japanese Nursing Association (2003, p. 1) states, "Nurses respect human life, human dignity and rights." A clear understanding of the meaning of human dignity within the various contexts of nursing is necessary for adequate implementation. This issue becomes even more urgent because of the aging population (WHO, 2011), the increasing number of individuals with chronic, progressive diseases due to life-prolonging medical interventions and the increased use of palliative care (Etkind et al., 2017; Mori & Morita, 2016).

Dignity is considered a component of quality of life (Tranvåg, Petersen, & Nåden, 2013). Nursing aims to improve the quality of life for people within the context of palliative care, which has the same goals as nursing (WHO, 2002) and is strongly tied to the concept of dignity (Burnier, 2017). However, the concept of dignity itself remains unclear (Gallagher, Li, Wainwright, Jones, & Lee, 2008; Haddock, 1996; Walsh & Kowanko, 2002).

Chochinov (2006) developed the dignity model based on the findings of patients at the terminal stage of malignant disease, and although the model addressed dignity therapy, it did not provide a definition of dignity in care. However, its elements indicated that attitude, behavior, compassion, and dialog are key features of dignity-centered care. Dignity therapy has been reported to improve the quality of life of patients with chronic progressive disease such as dementia and terminal malignancies (Chochinov et al., 2012; Johnston et al., 2016). People with chronic progressive disease look to a future of declining health and are generally unable to alleviate their own symptoms; this restriction of agency is a threat to their ability to act with dignity and leads to further suffering (Oechsle, Wais, Vehling, Bokemeyer, & Mehnert, 2014). Therefore, nurses' emphasis on providing dignity-centered care is crucial for people with chronic progressive diseases.

In order to operationalize dignity-centered care within the context of chronic progressive diseases there is first a need to clarify the definition and concept of dignity-centered care. The purpose of this study was: (a) to clarify the concept of dignity-centered care for individuals with chronic progressive diseases when there is no expectation of recovery; (b) to explicate the characteristics of the concept; and (c) to identify its usefulness and application in nursing practice. Specifically I aimed to identify characteristics, antecedents, attributes, and consequences of dignity-centered care for people with chronic progressive disease.

2 | METHODS

2.1 | Definition of chronic progressive diseases

Chronic progressive diseases become worse over time; there is a decline in health and function and there are no periods

of remission. They include such diseases as Alzheimer's, chronic obstructive lung disease, and Parkinson's disease. Chronic progressive diseases include incurable and intractable diseases (Kanatani et al., 2017).

2.2 | Data sources

A comprehensive search of the following electronic databases, in English and Japanese, from 1976 to 2017 included PubMed, MEDLINE, EMBASE, CINAHL, and Ichushi-Web by NPO Japan Medical Abstracts Society database. The combination of MESH and keywords used were as follows: (dignity), and (care), and (chronic disease) or (chronic illness). The eligibility criteria included English and Japanese materials and publications, journal articles, abstracts and books. Excluded were documents containing the concepts of euthanasia, and dignified death, which were beyond the scope of the purpose of the search. The terms acute phase, and malignant tumor were also excluded. Moreover, the acute phase included acute exacerbations with the main target of care as control in the intensive care unit, which also placed those studies outside the scope of this study. The search date was March 5, 2018 and the search string was accessed on March 5, 2018.

2.3 | Analysis

This concept analysis was based on Rodgers' evolutionary method of concept analysis (Rodgers & Knafl, 2000), which is an established method for developing knowledge in nursing (Thompson, 2018). Rodgers' evolutionary method involves the following six steps: (a) identify the concept of interest and associated expressions (including surrogate terms); (b) identify and select an appropriate realm (setting and sample) for data collection; (c) collect data relevant to identify the attributes of the concept and the contextual basis of the concept (including interdisciplinary, sociocultural, and temporal antecedent and consequential occurrences variations); (d) analysis of data regarding the characteristics of the concept; (e) identify an exemplar of the concept, if appropriate and (f) identify hypotheses as well as implications for further development of the concept. The evolutionary approach emphasizes the dynamic nature of concepts, which change with time and context - these characteristics help to support the use of the approach in evolving nursing knowledge over time. Rodgers' model is grounded in the assumption that concept development is an ongoing process, and subject to change within contextual and temporal factors (Rodgers & Knafl, 2000). Since dignity is a phenomenon that changes based on the context of human history as well as specific contemporary conditions, Rodgers' evolutionary method was well suited for analysis of this concept. In order

to improve the validity of the analysis, a specialist in chronic disease nursing provided oversight of the analytic process. The antecedents, attributes, and consequences of dignity-centered care were identified using the Rodgers' evolutionary method of concept analysis, and constructed into a conceptual model based on the findings.

2.4 | Rigor

The purpose of concept analysis is to identify a consensus of the concept. Careful attention to the methodological steps for concept analysis using Rodgers' model (Rodgers & Knafl, 2000) helped to ensure trustworthiness.

2.5 | Ethical considerations

All study participants from reviewed studies provided informed consent. All research included in this concept analysis received ethical approval.

3 | RESULTS

The search identified 336 relevant articles. After carefully sorting through the relevant papers, 51 duplicates were removed. Applying the exclusion criteria to the remaining 249 articles nearly 50% ($n = 125$) related to dignity in death so were excluded as were articles pertaining to euthanasia ($n = 88$) and acute phase ($n = 36$); 36 articles were found appropriate and were included (Figure 1). For this concept, three antecedents, four attributes and four consequences were identified (Table 1). The results are presented in the conceptual model (Figure 2).

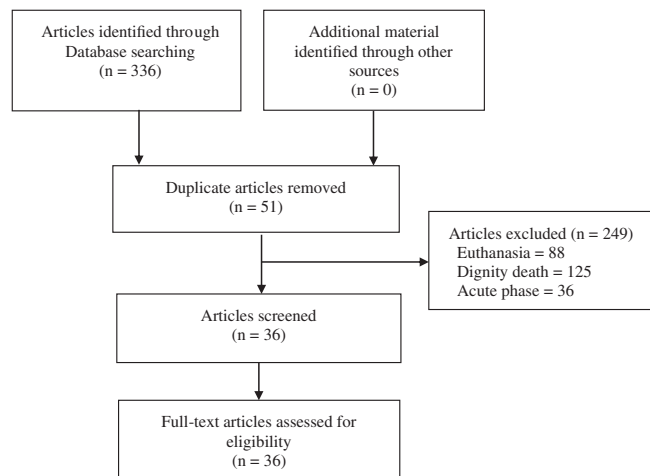


FIGURE 1 Flow diagram of articles selection

3.1 | Antecedents

3.1.1 | Loss of physical function and reduced psychological capacity, independence, and role

Declining physical function due to chronic illness resulted in poor health status (Albers et al., 2013; Oosterveld-Vlug et al., 2014; Reynolds & Kalish, 1974), altered body sensations (Monaro et al., 2014), increased symptom burden (Vehling & Mehnert, 2014), functional incapacity (van Gennip et al., 2015) and cognitive deterioration (Reynolds & Kalish, 1974). Individuals with chronic progressive disease have disabilities that interfere with daily life (Berg & Danielson, 2007; Wadensten & Ahlström, 2009) and they face progressive losses (van Gennip et al., 2015). The distressing symptoms and the inability to continue with usual routines results in a loss of autonomy, freedom, independence, and role (Albers et al., 2013; Tong et al., 2014), loss of spontaneity and personal freedom (Monaro et al., 2014), and a sense of vulnerability (Tong et al., 2014). Also described were feelings of shame and isolation (Hughes, 2007) and loss of social connectedness (Monaro et al., 2014).

3.1.2 | Living with uncertainty of illness

Chronic diseases targets all ages and remains with the person until death (Albers et al., 2013; Olsson et al., 2008; Oosterveld-Vlug et al., 2014; Reynolds & Kalish, 1974; Richardson, 1997; Söderberg et al., 1999). People with chronic progressive diseases live with their illness the rest of their life. Although death is inevitable for all people, loss of dignity is not limited to the end-of-life period (Sellars et al., 2018). They thought about how to live with uncertainty of illness. Advanced care planning by people with end-stage renal disease revealed they wanted to avoid undignified treatment (Solomon et al., 2016), even though the timing of death was uncertain.

3.1.3 | Multilayered distress

Multilayered distress exemplifies the complex presence of physical, psychological and existential distress (Albers et al., 2013; Chochinov et al., 2016; Solomon et al., 2016), stemming from loss of the sense of self (Monaro et al., 2014), bodily changes evident to others, and changes in one's appearance (Olsson et al., 2008; Solomon et al., 2016). These individuals also reported feeling ashamed, degraded, or embarrassed because of the stigma from their medical problems (Solomon et al., 2016).

3.2 | Attributes

3.2.1 | Bolstering self-esteem

Promotion of emotional resilience (Tong et al., 2014), early recognition of existential concerns and interventions

TABLE 1 Attributes, antecedents and consequences of dignity-centered care for people with chronic progressive disease

【Categories】	〔 Sub-categories 〕	<Codes>	Illness condition	Literature
Attributes				
Bolstering self-esteem	Affirming oneself	Helping to maintain one's personality by being valued	Chronic disease	Nawa, Yoshida, Furubuchi, Watanabe, & Yoshida, 2004
			Type 1 diabetes, colitis ulcerosa and patients with coronary occlusion in the rehabilitation phase	Delmar et al., 2006
		Having respect for oneself	Advanced HIV disease	Hughes, 2007
	Self-esteem related to self-management	Involved independence, self-control	Type 1 diabetes, colitis ulcerosa and patients with coronary occlusion	Delmar et al., 2006
			Inflammatory rheumatic diseases	Dager, Kjekken, Fjerstad, & Hauge, 2012
		A sense of control which influences self-confidence and motivation to engage in self-management		
	Revitalizing self-concept	Assuring their self-esteem	Spinal muscular atrophy	Helfand, 2003
		Maintaining their self-esteem	Disabilities	Wadensten & Ahlström, 2009
		Maintaining or restoring the person's sense of self	Terminal cancer	Aoun, Deas, & Skett, 2016
		Preserving self-identity	Chronic kidney disease	Tong et al., 2014
		To sustain their self-esteem and valuation as a person	Chronic, and life-threatening diseases	Delmar, Alenius-Karlsson, & Mikkelsen, 2011
Reducing multi-faceted distress	Support for existential distress	Promotion of emotional resilience	Chronic kidney disease	Tong et al., 2014
		Early recognition of existential concerns and interventions	Advanced cancer	Vehling & Mehnert, 2014
		Respecting and restoring the sense of personhood	Terminal cancer	Aoun et al., 2016
	Support of physical distress	Perception of dignity related to physical factors of symptoms, role and routines	Chronic disease	Albers, Pasman, Deliens, de Vet, & Onwuteaka-Philipsen, 2013
			Spinal muscular atrophy	Ho, Tseng, Hsin, Chou, & Lin, 2016
		Having the ability to remain ambulatory and active	Spinal muscular atrophy	Helfand, 2003
		Avoiding the sick role	Chronic pain	Skuladottir & Halldorsdottir, 2011
	Support of psychosocial, spiritual dimension and psychological distress	Support in both the psychosocial, and the spiritual dimensions	Either cancer, early-stage dementia, or a severe chronic illness	van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2013

(Continues)

TABLE 1 (Continued)

【Categories】	[Sub-categories]	<Codes>	Illness condition	Literature
Continued relationship	Continuation of reciprocal relations	Interventions that directly addressed end-of-life suffering	Terminal cancer	Aoun et al., 2016
		Focused on personal strengths and prevention of discouragement	Inflammatory rheumatic diseases	Dager et al., 2012
		Addressed psychological factors of depression	Chronic pain	Skuladottir & Halldorsdottir, 2011
		Negotiating mutual understanding	ESRD	Sellars et al., 2018
		Approaching patients as wholly worthwhile individuals	Cancer, early-stage dementia and severe chronic illnesses	van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2015
	Continuation of social support	Encouraging autonomy and its interplay	Chronic and life-threatening diseases	Delmar et al., 2011
		Providing respectful and attentive communication	Chronic kidney disease	Tong et al., 2014
		Managing behavior	ESRD	Richardson, 1997
		To participate in family and social activities to fight isolation and loneliness	Chronic pain	Skuladottir & Halldorsdottir, 2011
		Receiving good professional care and social support	Chronic disease	Oosterveld-Vlug, Pasman, van Gennip, de Vet, & Onwuteaka-Philipsen, 2014
	Continuation of individualized care	Having appropriate interdisciplinary care	COPD	Solomon et al., 2016
		Facilitating participation in support groups for patients and family	Chronic kidney disease	Monaro, Stewart, & Gullick, 2014
		To support adjustment to their new way of life	Chronic kidney disease	Monaro et al., 2014
		Being attentive, proactive and taking the individual seriously	Cancer, early-stage dementia and severe chronic illnesses	van Gennip et al., 2015
		Continuing to maximize function and independence	Alzheimer's and dementia	Reuben et al., 2013
		Making self-adjustments in their lifestyles	Spinal muscular atrophy	Ho et al., 2016
		Giving them opportunity to choose health care services	Chronic heart failure	Kogan, Wilber, & Mosqueda, 2016
			Older adults with chronic conditions and functional impairment	Karami-Tanha, Moradi-Lakeh, Fallah-Abadi, & Nojomi, 2014

(Continues)

TABLE 1 (Continued)

【Categories】	〔 Sub-categories 〕	<Codes>	Illness condition	Literature
Protecting individual's rights	Ensuring autonomy	Meeting individuals' needs	Terminal cancer	Aoun et al., 2016
		Taking self-responsibility	Type I diabetes, colitis ulcerosa and patients with coronary occlusion in the rehabilitation phase	Delmar et al., 2006
		Being involved in decision-making regarding their own care and treatment	Chronic heart failure	Karami-Tanha et al., 2014
			Chronic pain	Skuladottir & Halldorsdottir, 2011
		Giving attention to patient's rights	Chronic heart failure	Karami-Tanha et al., 2014
	Protection of privacy	Creating a pedagogical climate of mutual understanding	Chronic disease	Friberg, Andersson, & Bengtsson, 2007
		Meeting individuals with understanding while ensuring their integrity	People with disabilities	Wadensten & Ahlström, 2009
		Protecting their individual privacy	Chronic and terminally ill	Reynolds et al., 1974
		Advocacy against stigma	Vital role of health workers in reducing stigma	HIV
Coping with the stigmas	Either cancer, early-stage dementia, or a severe chronic illness		van Gennip et al., 2013	
Antecedents				
Loss of physical function and reduced psychological capacity, independence, and role	Declining physical function due to chronic illness resulted in poor health status	Not ambulatory	Chronic disease	Reynolds et al., 1974
		Poor health status	Chronic disease	Albers et al., 2013, Oosterveld-Vlug et al., 2014
		Changed body sensations	Chronic kidney disease	Monaro et al., 2014
		Increased physical problems	Advanced cancer	Vehling & Mehnert, 2014
		Functional incapacity	Cancer, early-stage dementia and severe chronic illnesses	van Gennip et al., 2015
	Disability that interferes with daily life	Cognitive deterioration	Chronic disease	Reynolds et al., 1974
		The actual caring relationship	Long-term illness	Berg & Danielson, 2007
		People with severe functional disabilities	People with disabilities	Wadensten & Ahlström, 2009
	Independence and loss of role	Distressing symptoms and the inability to continue with usual routines induces a loss of freedom, independence and role	Chronic disease	Albers et al., 2013
		Loss of spontaneity and personal freedom	Chronic kidney disease	Monaro et al., 2014

(Continues)

TABLE 1 (Continued)

【Categories】	[Sub-categories]	<Codes>	Illness condition	Literature
Living with uncertainty of illness	Impacts all ages and remains with the person until death	Vulnerability from a loss of autonomy	Chronic kidney disease	Tong et al., 2014
		Loss of freedom and independence	Chronic kidney disease	Tong et al., 2014
		Face progressive loss	Cancer, early-stage dementia and severe chronic illnesses	van Gennip et al., 2015
		Feelings of shame and isolation	Advanced HIV disease	Hughes, 2007
		Loss of social connectedness	Chronic kidney disease	Monaro et al., 2014
		Children with chronic disease	ESRD	Richardson, 1997
		Adults	Fibromyalgia, multiple sclerosis chronic autoimmune disease	Söderberg, Lundman, & Norberg, 1999, Olsson, Lexell, & Söderberg, 2008
		Older age	Chronic disease	Reynolds et al., 1974, Albers et al., 2013
			Rheumatoid arthritis and stroke	Oosterveld-Vlug et al., 2014
Multilayered distress	Avoid undignified treatment	Not limited to the end-of-life period	ESRD	Sellars et al., 2018
		To avoid undignified treatment	COPD	Solomon et al., 2016
	The complex presence of physical, psychological and existential distress	Perceiving the distressing symptoms, the ability to continue with usual routines and the ability to carry out one's roles	Chronic disease	Albers et al., 2013
		Anxious and depressive symptoms	COPD	Solomon et al., 2016
		Physical, psychological and existential distress	ALS, COPD, ESRD	Chochinov et al., 2016
	Distress over perceived loss of personality	Be associated with psychological suffering and loss of the will to live	Cancer, early-stage dementia and severe chronic illnesses	van Gennip et al., 2015
		Stemming from loss of the sense of self	Chronic kidney disease	Monaro et al., 2014
	Distress over changes in appearance	Bodily changes evident to others	Multiple sclerosis	Olsson et al., 2008
		Changes in one's appearance	COPD	Solomon et al., 2016
	Distress from stigmas	Threat to integrity	Fibromyalgia	Söderberg et al., 1999
Keeping the disease secret for enacted stigma		HIV	Russell et al., 2016	
Feeling ashamed, degraded, or embarrassed because of the stigma from their medical problems		COPD	Solomon et al., 2016	

(Continues)

TABLE 1 (Continued)

【Categories】	[Sub-categories]	<Codes>	Illness condition	Literature	
		Not treated as competent adults	People with disabilities	Wadensten & Ahlström, 2009	
		Discrimination and lack of comprehension	Hepatitis C status	Crofts, Louie, & Loff, 1997	
		Feeling rejected, ignored, and being belittled	Chronic pain	Werner & Malterud, 2003	
Consequences					
Improving self-esteem	Stability of self-concept	Preserving the personality	Chronic disease	Nawa et al., 2004	
		Reinforcing a positive identity and enhanced self-esteem	HIV	Russell et al., 2016	
		Shaping self-perception	Either cancer, early-stage dementia, or a severe chronic illness	van Gennip et al., 2013	
	Strengthening self-esteem	Increased self-respect	Chronic disease	Coventry, 2006	
			Advanced HIV disease	Hughes, 2007	
			Inflammatory rheumatic diseases	Dager et al., 2012	
		Sense of selfhood	Chronic disease	Reynolds et al., 1974	
		The maintenance of self-esteem	Chronic pain	Werner & Malterud, 2003	
Relief from multi-faceted distress	Relief of physical and psychological symptoms	Relief from the physical symptoms and whole-person care	Older adults with chronic conditions and functional impairment	Kogan et al., 2016	
		The perceptions of physical factors that reduced one's dignity	Chronic disease	Albers et al., 2013	
		Preventing discouragement and depression	Chronic pain	Skuladottir & Halldorsdottir, 2011	
		Relief of individual's psychosocial, and spiritual dimension	Alleviating the feelings of anxiety with regard to suffering	Either cancer, early-stage dementia, or a severe chronic illness	van Gennip et al., 2013
			Perceptions of being worthy of respect from themselves and from others	Chronic disease	Oosterveld-Vlug et al., 2014
Deepening the purpose and meaning of life	Relief of distresses while living	Attaining physical, mental, emotional and social well-being	Chronic pain	Skuladottir & Halldorsdottir, 2011	
		Promoting self-value	Chronic kidney disease	Tong et al., 2014	
		Relief of existential distress	Terminally ill	Oechsle et al., 2014	
		Finding meaning and purpose in life	Preventing demoralization resulting from existential suffering	Advanced cancer	Vehling & Mehnert, 2014
			Based on finding the value of living	ESRD	Sellars et al., 2018

(Continues)

TABLE 1 (Continued)

【Categories】	〔 Sub-categories 〕	<Codes>	Illness condition	Literature
		Perceiving meaning in one's life	Cancer, early-stage dementia and severe chronic illnesses	van Gennip et al., 2015
		Attaining a sense of well-being	Chronic kidney disease	Tong et al., 2014
Maintaining and improving the quality of life	Improving the quality of life	Strong correlation between personal dignity and quality of life	Chronic disease	Oosterveld-Vlug et al., 2014
		Maintaining or improving individual's quality of life	Rheumatic disease	Bergsten, 2015
	Maintaining the quality of life	Be reflected in the individual's quality of life	Spinal muscular atrophy	Helfand, 2003
		Attention to the quality of life	Chronic disease	Knau, Farmer, Bhadelia, Berman, & Horton, 2015

Abbreviations: ALS, amyotrophic lateral sclerosis; COPD, chronic obstructive pulmonary disease; ESRD, end-stage renal disease; HIV, human immunodeficiency virus.

(Vehling & Mehnert, 2014) and respecting and restoring the sense of personhood (Aoun et al., 2016) bolstered self-esteem. To maintain one's personality (Nawa et al., 2004) by being valued (Delmar et al., 2006) and having respect for oneself (Hughes, 2007) affirmed one's self-concept. Self-esteem related to self-management required independence, and self-control (Delmar et al., 2006). Sense of control influenced self-confidence and motivation to engage in self-

management (Dager et al., 2012). The vitalizing aspect of autonomy can be a driving force in patients' behaviors as they seek to sustain their self-esteem and valuation as a person (Delmar et al., 2011). Therefore, bolstering self-esteem is about maintaining or restoring the person's sense of self (Aoun et al., 2016), preserving self-identity (Tong et al., 2014), and assuring and maintaining their self-esteem (Helfand, 2003; Wadensten & Ahlström, 2009).

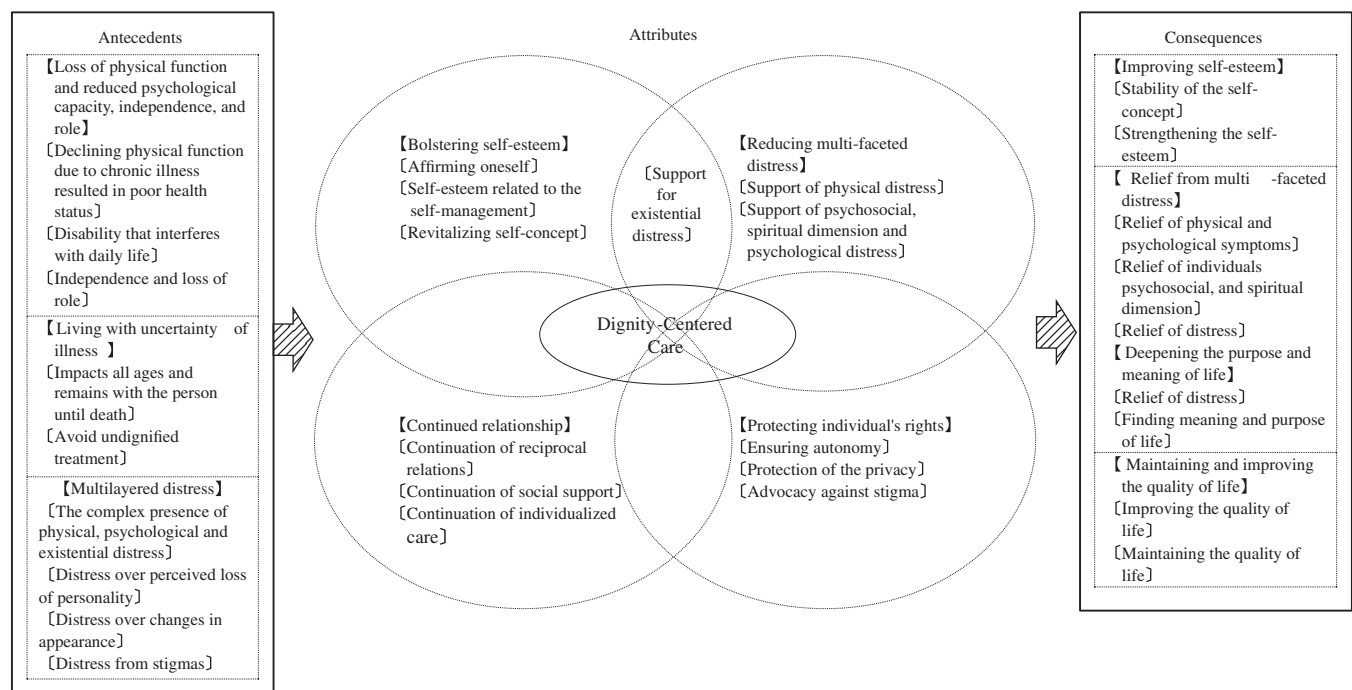


FIGURE 2 Concept analysis of dignity-centered care for people with chronic progressive disease

3.2.2 | Reducing multi-faceted distress

Positive coping with hardships from physical challenges brought relief from physical distress (Ho et al., 2016), as well as having the ability to remain ambulatory and active (Helfand, 2003). The perception of dignity related to physical factors of symptoms, role and routines (Albers et al., 2013) and avoiding the sick role (Skuladottir & Halldorsdottir, 2011) were understood as reducing multi-faceted distress. Reducing spiritual and psychological distress required support in both the psychosocial, and the spiritual dimensions (van Gennip et al., 2013). These interventions directly addressed end-of-life suffering (Aoun et al., 2016), focused on personal strengths and prevention of discouragement (Dager et al., 2012), and addressed psychological factors of depression (Skuladottir & Halldorsdottir, 2011).

3.2.3 | Continued relationship

Negotiating mutual understanding (Sellars et al., 2018), approaching patients as wholly worthwhile individuals (van Gennip et al., 2015), encouraging autonomy and its interplay (van Gennip et al., 2015) and providing respectful and attentive communication (Tong et al., 2014) brought about a continuation of reciprocal relations. Continuation of social support occurred by assisting individuals with chronic progressive diseases: (a) to encourage patients to participate in family and social activities to fight isolation and loneliness (Skuladottir & Halldorsdottir, 2011); (b) through facilitating participation in support groups for patients and families (Monaro et al., 2014); (c) to establish appropriate interdisciplinary care (Solomon et al., 2016) and (d) through providing good professional care and social support (Oosterveld-Vlug et al., 2014). Continuation of individualized care was fostered by: (a) being attentive, proactive and taking the individual seriously (van Gennip et al., 2015); (b) supporting adjustment to their new way of life (Monaro et al., 2014), and (c) continuing to maximize function and independence (Reuben et al., 2013). Assisting individuals to make adjustments in their lifestyles (Ho et al., 2016), meeting individuals' needs (Aoun et al., 2016) and providing them opportunities to choose health care services (Karami-Tanha et al., 2014; Kogan et al., 2016) also supported the continuity of the relationship.

3.2.4 | Protecting individual's rights

The autonomy of individuals with chronic progressive disease were supported by self-responsibility (Delmar et al., 2006), involvement in decision-making regarding their own care and treatment (Karami-Tanha et al., 2014; Skuladottir & Halldorsdottir, 2011), paying attention to patient's rights (Karami-Tanha et al., 2014), and creating a pedagogical climate of mutual understanding (Friberg et al., 2007). In

addition, staff must protect individuals' privacy (Reynolds et al., 1974), and meet individuals with understanding while ensuring their integrity (Wadensten & Ahlström, 2009). Moreover, the vital role of health workers in reducing perceptions of stigma (Russell et al., 2016) and assisting individuals to cope with stigma (van Gennip et al., 2013) brings them advocacy by shielding them from shame. Health workers need to provide people a sense of continuity of identity by reinforcing that their deeper sense of self is untainted by their disease; they always are the same person.

3.3 | Consequences

3.3.1 | Improving self-esteem

Preservation of personality (Nawa et al., 2004), reinforcing a positive identity and enhancing self-esteem (Russell et al., 2016) and shaping self-perception (van Gennip et al., 2013) supported the stability of self-concept. Sense of selfhood (Reynolds et al., 1974) increased self-respect (Coventry, 2006; Dager et al., 2012; Hughes, 2007) and the maintenance of self-esteem (Werner & Malterud, 2003) improved self-esteem. Stabilizing of self-concept and deepening self-esteem stabilized self-esteem and securely established self; these helped patients improve self-esteem.

3.3.2 | Relief from multi-faceted distress

Relief from distress that is multi-faceted includes relief from the physical symptoms through person-centered care (Kogan et al., 2016) and relief from the perceptions of physical factors that reduced one's dignity (Albers et al., 2013). Relief of psychological symptoms included preventing discouragement and depression (Skuladottir & Halldorsdottir, 2011), and alleviating the feelings of anxiety with regard to suffering (van Gennip et al., 2013). Support of individuals' psychosocial, and spiritual dimensions included perceptions of being worthy of respect from themselves and from others (Oosterveld-Vlug et al., 2014), and attaining physical, mental, emotional and social well-being (Skuladottir & Halldorsdottir, 2011). Relief of distress from their current life circumstance could explain both relief from multi-faceted distress and a deepening purpose and meaning of life.

3.3.3 | Deepening the purpose and meaning of life

For individuals with chronic progressive disease, dignity-centered care includes relief of distress by promoting self-value (Tong et al., 2014), relief of existential distress (Oechsle et al., 2014), and preventing demoralization resulting from existential suffering (Vehling & Mehnert, 2014). Deepening the purpose and meaning of life, was based on finding the value of living

(Sellars et al., 2018), perceiving meaning in one's life (van Gennip et al., 2015) and attaining a sense of well-being (Tong et al., 2014) that comes from having searched and found meaning and purpose in life.

3.3.4 | Maintaining and improving the quality of life

There is a strong correlation between personal dignity and quality of life (Oosterveld-Vlug et al., 2014) and also maintaining or improving individual's quality of life (Bergsten, 2015). Therefore, receiving dignity-centered care will be reflected in the individual's quality of life (Helfand, 2003). Hence, attention to the quality of life (Knaul et al., 2015) and maintaining and improving the quality of life are part of providing dignity-centered care.

3.4 | Surrogate and related terms

3.4.1 | Care with dignity

One term related to dignity-centered care for patients with chronic disease was “care with dignity” (Coventry, 2006). “Care with dignity” requires a caregiver-patient relationship that values autonomy, individual diversity, truth, justice, rights, and responsibilities.

3.4.2 | Respect

Another related term is that of “respect” (Delmar et al., 2006; Hughes, 2007). Being respected as an individual is closely connected to being enabled to manage on one's own and to be independent of others' help as much as possible.

4 | DISCUSSION

4.1 | Proposed definition

Individuals with chronic progressive diseases who have a loss of physical function, reduced psychological capacity, autonomy, and role, uncertain prognosis, and have multi-faceted distress need dignity-centered care. Dignity-centered care entails the improvement of patients' self-esteem, deepens their purpose and meaning in life, maintains and improves their quality of life and provides relief from multi-faceted distress. Dignity-centered care for people with chronic progressive disease is defined as care that bolsters self-esteem, and reduces multi-faceted distress through a continuous relationship while protecting patients' rights.

4.2 | Characteristics of the dignity-centered care for people with chronic progressive disease

This concept considers that people can then live as themselves and treasure receiving dignity-centered care. Promoting individuals' self-esteem is considered to protect people's dignity (Kennedy, 2016).

4.3 | Usefulness of dignity-centered care in nursing

Nursing care based on dignity-centered care is necessary for patients with chronic progressive disease whose dignity is threatened due to illness. Palliative care is strongly linked to the concept of dignity (Burnier, 2017). One of the consequences of dignity-centered care is the maintenance and improvement of an individual's quality of life. This is the same goal that is found in the WHO's definition of palliative care (2002). In order to improve the quality of life, relief from multi-faceted distress is also important. Through the nursing practice of dignity-centered care, it is necessary to show individuals that the value of their life is not threatened or diminished even if they are sick. In addition, support from a continued relationship can assist individuals with chronic progressive disease to feel they are worthy of being cherished by others. It is possible that stabilization of emotions could be achieved and deterioration of well-being caused by negative emotions could be alleviated.

Regarding “continued relationship,” Buber (1979) explained there is a different relationship between the attitude of the “I” toward an “It,” and “I” toward “You”. On the one hand the attitude of the “I” toward an “It” is seeing the patient as an object that is fundamentally separate from one's self and that one either uses or experiences. On the other hand the attitude of the “I” toward “You” is in a relationship that is not separated by objectifying the other and that encounter brings about an interactive human relationship. This also implies that in a context of dignity both patient and nurse benefit from the reciprocal nature of the relationship (Parandeh, Khaghanizade, Mohammadi, & Mokhtari-Nouri, 2016). Buber states that the “I”-“You” relationship brings about realization of meaning although it is difficult to express in words. D'Antonio, Beeber, Sills, and Naegle (2014) also remind the nursing profession of this very type of therapeutic relationship that was so carefully articulated by Hildegard Peplau in the 1950s and remains a core feature of nursing. It is thought that building a dignity-centered relationship with individuals with chronic progressive disease and with their families is targeting “I” toward “You” to reveal the meaning of one's life through relationships. Through such relationships comes the strengthening of the individual's self-concept, bolstering of self-esteem and support of the treatment.

Moreover, Frankl (1977) introduced lack of meaning in one's life as existential distress. Frankl found that if

individuals make an effort to find meaning in their lives, including their suffering, this enables them to overcome suffering experiences. Even in everyday situations, life has meaning and even suffering is meaningful. Frankl's idea of finding meaning in suffering may be useful for people suffering from chronic progressive diseases.

Using (Rodgers & Knafl, 2000) evolutionary concept development method we were able to elicit the structure of the concept of dignity-centered care for people with chronic progressive disease. Understanding and applying the concept could contribute to developing meaningful nursing care and improving quality of care. It should be noted that patient-centered care and dignity-centered care share some similarities. Patient-centered care should bring improvement in the quality of health and promoting patient involvement and individualization of patient care (Robinson, Callister, Berry, & Dearing, 2008). The consequences of dignity-centered care must include improvement of patients' self-esteem, a deepening of their purpose and meaning of life, maintaining and improving their quality of life and providing relief from multi-faceted distress through the interactive relationships of patients and nurses. This useful concept explicated attitudes and approaches for nurses to provide dignity-centered care for people with chronic progressive disease.

4.4 | Model case

A female patient aged 70 years has intractable idiopathic pulmonary fibrosis (IPF). She has been using home oxygen therapy for her respiratory failure. The doctor explains to her that acute exacerbations of IPF are life-threatening. This has led her to a state of chronic anxiety. She cannot freely move her body because it increases her cough and dyspnea. The way others look at her when they see her cannula for the home oxygen therapy, leaves her feeling stigmatized. Moreover, her IPF impedes her ability to talk with others so she has reduced communication with other people. Even her ability to do her housework is gradually becoming impossible, and she says, "I am incompetent for my family life and social life!" She has become depressed.

She had no opportunity to receive nursing support until recently. A certified specialist nurse (CNS) established regular interviews and discussions with her (Continued relationship). The CNS coordinates the home visiting nursing care that was considered to be the social resource necessary for her and to prepare her living environment (Protecting individual's rights). Moreover, the CNS educated her and her family about self-management methods and supportive daily activities. The CNS continued active listening with her, including family talks. Her symptoms and psychological stress were greatly relieved (Reducing multi-faceted distress). Because of the trusting relationship developed over time the CNS could

reinforce the idea that, "You need to use home oxygen therapy to live, even though the essential nature of yourself remains the same" (Bolstering self-esteem). Hence, her self-esteem has been restored. Although she cannot move freely, she is now accepting herself as she is and working on what she can do now.

4.5 | Limitations

The language restriction to English and Japanese was a limitation of this study. It was possible that despite efforts to locate all relevant extant articles, some were missed.

5 | CONCLUSION

For this concept, three antecedents, four attributes and four consequences were extracted. Dignity-centered care for people with chronic progressive disease is defined as: dignity-centered care bolstering self-esteem and reducing multi-faceted distress through the continued relationship and while protecting rights due to continued involvement with those individuals. Individuals who have loss of physical function, reduced psychological capacity, autonomy, and role, uncertain prognosis, and have multi-faceted distress require dignity-centered care. Therefore, dignity-centered care entails the improvement of patients' self-esteem, deepens their purpose and meaning of life, maintains and improves quality of life and provides relief from multi-faceted distress. Dignity-centered care is at the heart of patient and nurse reciprocity and enables both to realize greater integrity and respect. This concept can be applied to nursing practice and research for people with chronic progressive disease.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the author.

AUTHOR CONTRIBUTIONS

Y.I. contributed to the conception and design of this study, carried out the analysis, drafted the manuscript, and read and approved the final manuscript.

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