

Continuity of Care During End of Life: An Evolutionary Concept Analysis

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Search terms:

Concept analysis, continuity of patient care, end of life, palliative care

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PURPOSE: The purpose of this study was to clarify the concept of continuity of care during the end of life with a focus on the patient's perspective.

METHODS: Rodgers' method of evolutionary concept analysis was used. The analysis was based on literature published in English in the databases Cumulative Index for Nursing and Allied Health Literature, Medline, and PsycINFO.

FINDINGS: Analysis revealed that the continuity at life's end is a dynamic process that depends on the interaction among patients, families, and providers, and is strictly interwoven with the patient's time perception.

CONCLUSION: This analysis showed the complexities surrounding the patient's experience of continuity at life's end.

IMPLICATION FOR NURSING: Nurses can benefit from a deeper understanding of the patient's experience, both theoretically and in practice.

SCOPO: Lo scopo dello studio è stato quello di chiarire il concetto di continuità assistenziale durante il fine vita seguendo la prospettiva dei pazienti.

METODI: E' stato utilizzato il metodo dell'analisi del concetto della Rodgers. L'analisi ha interessato la letteratura pubblicata in Inglese nei database CINAHL, Medline, and PsychINFO.

RISULTATI: L'analisi ha mostrato come la continuità assistenziale sia un concetto dinamico che dipende dall'interazione dei pazienti, dei familiari e degli operatori sanitari, ed è strettamente intrecciata con la percezione del tempo.

CONCLUSIONIA: Questo studio mette in evidenza la complessità dell'esperienza di continuità assistenziale durante il fine vita.

IMPLICAZIONE PER GLI INFERMIERI: Gli infermieri possono trarre beneficio da una profonda conoscenza dell'esperienza dei pazienti, sia da un punto di vista teorico che pratico.

Because of the structure of the specialized healthcare system today, it is not unusual for patients to consult with many different specialists and/or settings. These consultations result in multiple sources of information and points of view, leading to contradictory recommendations concerning medications, duplication of care, delay of treatment, and lack of follow-up care. Fragmentation and discontinuity of care are difficult to avoid in such situations, and similarly connecting care in a coherent way can be challenging (Bomba, 2005).

The concept of continuity of care is becoming a "core value" in the organization of health services; it requires coordination and communication with assurance linkages across time, settings, providers, and consumers of health care (Brousseau, Meurer, Isenberg, Kuhn, & Gorelick, 2004; Ionescu-Iltu et al., 2007). Although its definition may vary, generally it is defined as a way in which a series of healthcare events are experienced as coherent and sequentially related with patients' needs and personal context (Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004).

Continuity of patient care is a fundamental tenet of nursing practice and is commonly viewed as an outcome of the nurse-patient relationship that is implemented by a series of interventions known as "case management" and "discharge planning" (Sparbel & Anderson, 2000a). Particularly in the nursing literature, the theme of continuity has focused on information transfer, coordination between various providers, and the linkage between hospital and community (Haggerty, Reid, McGrail, & McKendry, 2001). Although a highly important component of patient care, the meaning of continuity of care in the nursing literature is still elusively defined (Gulliford, Naithani, & Morgan, 2006; Haggerty et al., 2001; Sparbel & Anderson, 2000b).

An important multidisciplinary review attempted to develop a theoretical framework of continuity of care (Haggerty et al., 2003). The authors identified two "core elements," namely a focus on patients and the time frame that distinguishes continuity of care from other attributes of care. Additionally, three interrelated dimensions constitute continuity, namely informational continuity (the effective transfer and use of past and personal information), management continuity (a coherent, consistent, and timely coordination of care and services), and relational continuity (an ongoing therapeutic relationship between a patient and one or more providers).

Applying this concept to palliative care may create intrinsic problems since this patient population has unique care needs that distinguish it from other health disciplines. Using a concept developed in another context, therefore, may not be applicable to this specialized population (Widder & Glawischnig-Goschnik, 2002). For example, the experience of the proximity of dying has a major influence on how patients will make a decision between various treatment objectives and how they perceived the disease and life (Meier & Beresford, 2008). Further, as patients progress closer to death, they necessitate a sense of continuity into the present and redefined future. The lack of continuity is often interpreted as loss of interest, concern, and hope (Ryndes & Emanuel, 2003; Will, 1978). This confronts complex and unique challenges that threaten their physical, emotional, and spiritual integrity (Corrales-Nevaldo, Alonso-Babarro, & Rodríguez-Lozano, 2012; Department of Health, 2011; Field & Cassel, 2011; Ryndes & Emanuel, 2003).

With the consideration of the needs of this unique population, it can be noted in the palliative international literature that different attempts have been made to operationalize the continuity (e.g., GSF Gold Standards Framework, Project ENABLE, and Robert Wood Johnson Foundation) (Bakitas, Bishop, Caron, & Stephens, 2010; D'Angelo et al., 2012); however, attention has been given to the activities of care rather than the theoretical implications applied through the illness progression (Meier & Beresford, 2008). The focus of these previous continuity models was based on the building of networks with particular attention to the organizational integration, coordination, and consistency between different care settings and different members of staff, with little attention on patients' experiences of care

that underlies their satisfaction (Corrales-Nevaldo et al., 2012). Hence, the concept of continuity and its applications to patients with life-limiting illnesses remain underdeveloped (Meier & Beresford, 2008).

When the definition or the attribute of concepts is not clear, the capacity of the concept that supports the essential task is significantly impaired (Rodgers, 1989); therefore, there is a need to clarify and redefine continuity of care during end-of-life care (Gulliford et al., 2006; Michiels et al., 2007). The aim of this concept analysis is to define and clarify the concept of continuity of care during end of life to facilitate its consistent use.

Taking into account the vagueness of its meaning and the dynamic characteristics, we chose Rodgers' evolutionary concept analysis for this study. Rodgers' analysis is an inductive and circular approach that consists of six activities carried out simultaneously in an interactive manner. The following are the steps (Rodgers, 2000, p. 85):

1. Identify the concept of interest and associated expressions (including surrogate terms)
2. Identify and select an appropriate realm (setting and sample) for data collection
3. Collect data relevant to identify the attributes, the contextual basis of the concept including interdisciplinary, sociocultural, and temporal variations
4. Analyze data regarding the above characteristics of the concept
5. Identify an exemplar of the concept if appropriate
6. Identify implications, hypotheses, and implication for further development of the concept

This type of analysis allows us to consider the context and the different perspectives, use, and dimension that could link up to the concept of continuity of care. Based on the work by Haggerty et al. (2003), that describes the continuity of care referred to care experienced by an individual over time. Data were collected with a focus on patients' points and on the continuity of longitudinal characteristics centered around the patient.

Methods

Data Sources

Medline, Cumulative Index for Nursing and Allied Health Literature, and PsycINFO were searched with a focus on the continuity of care in palliative care. Literature published in English with a wide time frame (1960-2013) was chosen to capture the concept fundamentals. We searched Medline using the following search strategy, which was translated into the other database using the appropriate text words and controlled vocabulary.

1. Palliative care (Mesh)
2. Hospice (Mesh)
3. Terminal care (Mesh)

Table 1. Data Collection by Discipline

	Medicine		Nursing		Public health		Psychology	
	<i>N</i> _{tot} = 46	% = 61	<i>N</i> _{tot} = 21	% = 28	<i>N</i> _{tot} = 7	% = 9	<i>N</i> _{tot} = 1	% = 1
	<i>N</i> (%)		<i>N</i> (%)		<i>N</i> (%)		<i>N</i> (%)	
Type of article								
Conceptual paper	20 (43)		12 (57)		0		0	
Review	6 (13)		3 (14)		2 (29)		1 (100)	
Original article	20 (43)		6 (29)		5 (71)		0	
Sample of the studies								
Advanced cancer patients	13 (28)		8 (38)		3 (42)			
Seriously chronic ill patients	3 (6)		2 (9)					
Patients' needy PC	26 (35)		9 (42)		4 (67)		1 (100)	
Pediatric patients	4 (9)		2 (9)					
Non-explicit	0		0					
Type of continuity ^a								
Relational continuity	20 (43)		9 (43)		4 (57)		1 (100)	
Management continuity	16 (35)		9 (43)		1 (14)			
Informational continuity	15 (32)		7 (33)		2 (28)			
Non-explicit	5 (13)		3 (14)		1 (17)			

^aTotal exceeds sample size because some articles focused on more than a type of continuity. PC, palliative care.

4. End of life
5. Palliative care (Tiab) OR End of life (Tiab) OR Terminal care (Tiab) OR Hospice (tiab)
6. #1 OR 2# OR #3 OR #4 OR #5
7. Continuity of patient care (Mesh)
8. Continuity of care
9. Care continuity
10. Continuum of care
11. Care continuum
12. Continuity of patient care (Tiab) OR Continuity of care (Tiab) OR Care Continuity (Tiab) OR Continuum of care (Tiab) OR Care continuum (Tiab)
13. #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12
14. Case Management (Mesh)
15. Transitional care
16. Seamless service
17. Discharge planning
18. Transitional care (Tiab) OR Case Management (Tiab) OR Seamless service (Tiab) OR Discharge planning (Tiab) OR Discharge planning (Tiab)
19. #14 OR #15 OR #16 OR #17 OR #18
20. #1 OR 2# OR #3 OR #4 OR #5 AND #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #14 OR #15 OR #16 OR #17 OR #18

The literature search identified 335 articles. Two reviewers (DD and MGD) independently screened the titles, abstracts, and reference lists of the articles retrieved by literature search. Articles that did not specifically address the continuity of care during end of life with the focus on patients were excluded. The full-text articles retained were reviewed by the same two independent reviewers (DD and MGD) for relevance. Disagreements were resolved by con-

sensus by a third reviewer (CM). Through this process, a final 75 articles were determined to be relevant for analysis. For each article, we compiled an electronic database where the articles were categorized, according to their first author discipline, to one of the four categories (medicine, nursing, public health, and psychology). There were 44 medicine articles, 20 nursing articles, 6 public health articles, and 1 psychology article. Subsequently, each article was read by one team member, and the content was coded for the following: surrogate, related terms, attributes, antecedents, and consequences. Data collection also included information regarding reference data, typology of study (review, original article, conceptual article), typology of continuity conceived (informational, management, relational), and the sample of the study (Table 1).

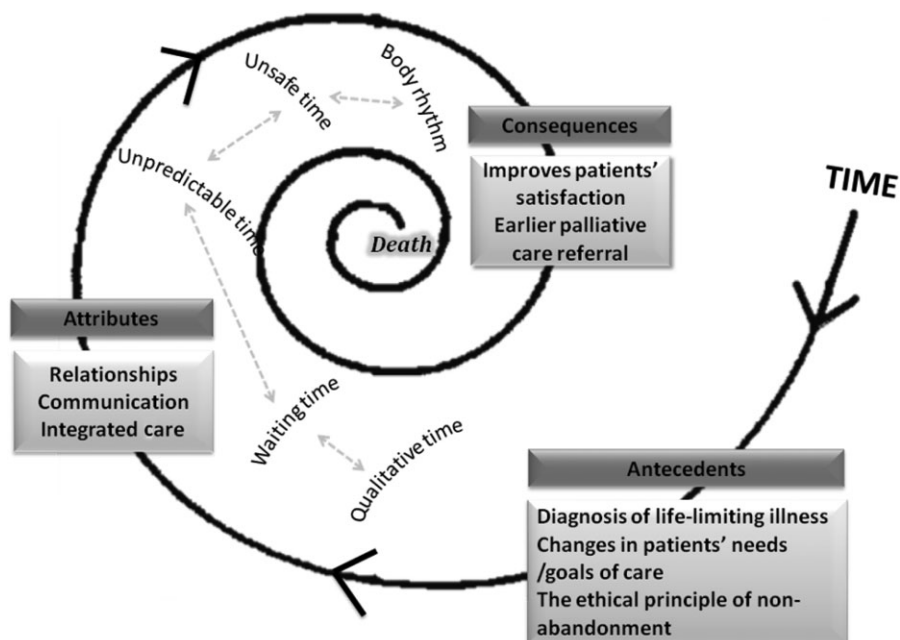
Findings

Surrogate and Related Terms

In the palliative care literature, an expression that is used interchangeably with continuity of care is *continuum of care* (Bakitas et al., 2010; Byock, 2000; Casas Fernandez de Tejerina, 2006; Choi & Billings, 2002; Meier & Beresford, 2007; Meyers & Linder, 2003). This term represents the integration of palliative care across the disease trajectory and not merely its application at the end of life (Sanft & Von Roenn, 2009). Related terms have some associations with the analyzed concept, but they do not have the same characteristics (Rodgers, 2000, p. 92). Continuity of care has some related terms, such as *seamless service* (Cringles, 2002; Reynolds & Croft, 2010), referred to as coordinated patient transitions between different healthcare settings;

Figure 1. The Relationship of the Antecedents, Attributes, Consequences, and Time Perception of Continuity of Care During the End of Life According to Patients' Perspectives

Notes. The figure illustrates a conceptual model that accommodates the findings discussed. The spiral represents the time during which the end of life experienced by patients is limited. This leads to a change in perception and meaning of time.



transitional care (Aspinal, Hughes, Dunckley, & Addington-Hall, 2006; Coleman & Berenson, 2004; Marsella, 2009), a series of linking interventions after hospital discharge; *case management* (Bomba, 2005; Coyle et al., 1985; Holland & Harris, 2007), a form of care to facilitate care integration and coordination; and *discharge planning* (Blackford & Street, 2001; Holland & Harris, 2007), the plan of intervention development able to arrange for patient care prior to leaving the hospital. Transitional care for patients with life-limiting illnesses represents the concept most used in the literature as a major emphasis is given to the transitions from curative to palliative care. During this phase, individuals change their focus from hope for a cure, to hope of not suffering and for a peaceful death (Marsella, 2009). Guarantying "smooth transitions" is one of the main aims of the "continuum of care" model.

Attributes

The concept of continuity of end-of-life care comprised three major attributes or central components, namely (a) relationship (Back et al., 2010; Borgsteede et al., 2006; Choi & Billings, 2002; Dumont, Dumont, & Turgeon, 2005; Finlay & Casarett, 2009; Heller & Solomon, 2005; Michiels et al., 2007; Peppercorn et al., 2011; Price & Lau, 2013; Sharma, Freeman, Zhang, & Goodwin, 2009); (b) communication (Barnet & Shaw, 2013; Blackford & Street, 2001; Borgsteede

et al., 2006; Burge, Lawson, & Johnston, 2003; Burt et al., 2004; Dumont et al., 2005; Fox, 2005; Hanson & Ersek, 2006; Hauser, 2009; Heller & Solomon, 2005; Joshua & Hauser, 2009; Lorenz et al., 2004; Michiels, 2007; Price, 2013; Reynolds & Croft, 2010; Ryndes & Emanuel, 2003; Schweitzer et al., 2009, 2011); and (c) comprehensive integrated care (Aubin et al., 2012; Byock, 2000; Casas Fernandez de Tejerina, 2006; Choi & Billings, 2002; Efsthathiou & Clifford, 2011; Lorenz et al., 2004, 2008; Maunder, 2004; Reynolds & Croft, 2010; Wiebe & Von Roenn, 2010).

Figure 1 illustrates the relationship of the attributes, antecedents, consequences, and the time perspective, and is described below.

Relationships. Because of the presence of the irreversibly lethal condition, patients' relationships change over time. During the illness progression, patients need stable and honest relationships that may be affected by a number of factors. The challenge of maintaining stable relationships, especially with the healthcare staff, grows directly as the number of professionals involved increases (Dumont et al., 2005; Michiels et al., 2007). Unfortunately, terminally ill patients often require treatment from multiple providers, which could lead to fragmented and uncoordinated care. Healthcare providers' difficulty in relaying bad news, their propensity to view patient deaths as personal failure, and

the paternalistic approach may affect the relationship they have with the patient (Finlay & Casarett, 2009). At the same time, during the end-of-life phase, the family caregiver is strictly involved in patient care, with family support often taking the form of a protective attitude toward patients, even though this facade may prevent a clear and honest relationship between family members and patients. Similarly, the patients "protect" the caregivers in the same way the caregivers believe they are "protecting" their loved ones (Parker et al., 2007). This "conspiracy of the silence" between healthcare staff and family caregiver does not allow patients to cope with stressful events, to make decision about their lives, to live as normal a life as possible, and to die "in a manner of one's own choosing" (Dawson, 2007; Schofield, Carey, Love, Nehill, & Wein, 2006).

Furthermore, when the patient's illness is incurable and life is coming to an end, the symptoms can be prevented, alleviated, or removed only temporarily, and the person's care dependence increases. As a consequence, patients experience anxiety over being a burden to others and feel guilty about being dependent, and fear that the helpers may abandon them. They try to adapt themselves as a "good patient" investing much time and energy to modify their behavior, leading to confusion of roles and expectations. They sometimes felt and masked their dependence so that it was difficult to discover.

Communication. Communication is indispensable to create a comfortable climate and represents an essential part of ongoing care planning process (Fox, 2005; Joshua & Hauser, 2009; Michiels et al., 2007). Communication comprised three levels of involvement, from simple passage of information to final negotiation. For example, during the transition from curative to palliative care, there is a need of an anticipatory preparation based on what to expect during this type of transition. The patients need information related to the structure (setting), the staff availability (physician, nurse, psychology, chaplain), the formal procedures (signatures and documents), information related to the disease progression, the treatment efficacy, the prognosis, and the symptom management. The dialogue offers the possibility to discuss these last difficult aspects through a better understanding of what illness means to patients, their hopes, beliefs, and needs (Choi & Billings, 2002; Hanson & Ersek, 2006; Peppercorn et al., 2011). The process is made possible, thanks to respectful listening, gentle exploration and honest explanation of the options, and encouraging the person to express his/her feelings (Aubin et al., 2012; Hanson & Ersek, 2006; National Consensus Project for Quality Palliative Care, 2009).

There are situations, however, with some patients who are competent but have not accepted their situation and end up dying in denial, which prevents them from having a peaceful sense of completion and comfortable transition. The process of understanding and acceptance takes time, so during the illness progression the process of dying is not linear, but rather a complex experience with alternations of

moods, hopes, and beliefs. Healthcare providers can help patients find a new balance by reorienting their hope and by negotiating goals appropriate for their stage of disease and level of function.

Comprehensive integrated care. Guaranteeing comprehensive integrated care allows patients to receive relief of physical (pain, shortness of breath, nausea, etc.) and psychological (fear, anxiety, concerns) symptoms, and to have their spiritual and social needs met (Barnato et al., 2005; Hall, Weaver, Gravelle, & Thibault, 2007). Hence, the integrated multidisciplinary team fosters adequate treatment of patients' complex needs (Brazil et al., 2007; Lorenz et al., 2008; Wiebe & Von Roenn, 2010). Additionally, regular and structured assessment allows for the recognition of patients' needs in a timely manner over a period of time (Efstathiou & Clifford, 2011; Porzio et al., 2005; Reynolds & Croft, 2010).

To facilitate a smooth transition during the end-of life phase, looking from patients' perspectives, the palliative care interventions should address three major components: the treatment of symptoms, the therapy responding to damages of self-image (bodily, symbolic, and social dimension), and the therapy dealing with the proximity of death (Widder & Glawischnig-Goschnik, 2002). A quality plan of care should anticipate, prevent, alleviate, or remove symptoms for as long as possible, keeping in mind that the ability to tolerate bothersome symptoms is less likely to be acceptable in a palliative versus a curative approach (Kuebler, Lynn, & Von Rohen, 2005). Sometimes, the treatment of symptoms itself brings about loss of bodily image. In such cases, the treatment value could be questioned. For symbolic and social dimensions, classical biomedical interventions will hardly be appropriate, but the integrated multidisciplinary team (physiotherapists, social workers, nurses, and others) may be able to guarantee the adequate treatment of patients' complex needs (Brazil et al., 2007; Lorenz et al., 2008; Wiebe & Von Roenn, 2010). The proximity of death and the finitude of the time span make the therapeutic approach extremely individualized, based on what patients perceive as their disease (Efstathiou & Clifford, 2011; Porzio et al., 2005; Reynolds & Croft, 2010).

Antecedents

Antecedents are events or phenomena that have previously been related to the concept (Rodgers, 1989).

A diagnosis of life-limiting illness with a poor life expectancy is the primary antecedent of continuity of care at life's end. Once the diagnosis is made, we may be faced with the dichotomous situation of the patient's awareness or unawareness of the prognosis. The "terminal awareness" perspective potentially renders the patients at risk to experience feelings of loss of control, abandonment, anxiety, fear, and concern. This may be an opportunity, however, to improve their ability to cope with challenging information. The "terminal unawareness" perspective may vary

depending on patients' desires and cultural beliefs, as well as their receptivity to prognostic information and to clinicians' paternalist approach (Finlay & Casarett, 2009). During the course of life-limiting illness, the necessity to guarantee the continuity of care is justified by the changes in patients' needs and goals of care (Lorenz et al., 2004; Marsella, 2009; Peppercorn et al., 2011). These changes occur when death and the finitude of life become clearer and encompass the physical, psychological, existential, and spiritual aspects of patients' experiences.

Another important antecedent of continuity of care during end of life is the ethical principle of non-abandonment, which represents a moral duty for professionals and those who are responsible for the plan and management of care services (Joshua & Hauser, 2009; Ryndes & Emanuel, 2003). This principle is strictly connected with the sense of responsibility in healthcare providers and organizations for "over time" care.

Consequences

Consequences are the events or phenomena that follow an occurrence of the concept (Rodgers, 1989). Little is known about the impact of continuity of care on patients with life-limiting illness. Efforts have been made to improve and operationalize the continuity of care interventions, such as the interdisciplinary approach, patient and family education, integration of care through each transition, etc. Unfortunately, to date, there is no specific evidence with respect to continuity and end-of-life care, and a solid comprehension of how and to what extent it makes a difference is still limited (Lorenz et al., 2007, 2008). However, during the analysis of the articles, two main benefits that seem to be linked with provider continuity emerged. These include patient satisfaction and earlier palliative care referral.

Patients satisfaction. Some studies have shown that "palliative patients" with greater provider continuity are more satisfied with their care (Burge, Lawson, Johnston, & Cummings, 2003; Choi & Billings, 2002) and have a better confidence in the quality of care received (Lorenz et al., 2004; Wiebe & Von Roenn, 2010). Satisfaction is enhanced whenever quality relationship is established between healthcare professionals and patients (Dumont et al., 2005). In palliative care, satisfaction of patients is an important indicator of quality of care also seen as an indicator of humanness of care provided, it is essential to assess patient experiences and to evaluate the effectiveness of interventions directed toward improving quality of life and symptoms.

Earlier palliative care referral. Providing care seamlessly throughout the illness progression would guarantee an early and ongoing utilization of palliative care services. One expectation of continuous palliative care programs would be the integration of palliative care interventions earlier in the trajectory of illness (Wiebe & Von Roenn,

2010). Often, the referral of patients to palliative care team occurs late in the trajectory of illness at an average of 30–60 days before death (Devi, 2010), even though patients with advanced cancer who received integrated palliative care early on during treatment had a better quality of life and survived for 2 months longer compared with patients who received standard care (chemotherapy). Indeed, early referral to palliative care not only facilitates timely diagnosis and treatment of symptoms, but also minimizes caregiver distress and aggressive measures at the end of life (Temel et al., 2010). Furthermore, an early referral to palliative service increased the patient's likelihood of dying at home (Back et al., 2010; Burge, Lawson, Johnston, & Cummings, 2003), reduced the numbers and severity of symptoms (Lorenz et al., 2008; Wiebe & Von Roenn, 2010), and reduced the use of hospital services (Burge, Lawson, Johnston, & Cummings, 2003; Meyers & Linder, 2003; Sharma et al., 2009).

Time Perspective

According to Haggerty et al. (2003), continuity of care is referred to how an individual's health care is connected over time. The time is a core element of the continuity that must be present for continuity to exist, and is defined as a sequence of longitudinal or chronological events (Haggerty et al., 2001). Therefore, to better understand how continuity matters, capturing the individual's experience of care is essential to best understand his/her time perspective. The time perception affects our actions, modifying the points of view and priorities. Ellingsen, Roxberg, Kristoffersen, Rosland, and Alvsvåg (2013), in a phenomenological study about the experience of time in terminally ill patients, stated that the focus shifted from "looking at the clock" to "listening to the rhythm of the body." The chronological feature of time is exactly the same for every person (60 s in a minute, 24 hr in a day), while the time necessary to make choices, to recreate hopes, and to define new goals depends on the personal characteristics. Healthcare providers should try to shape the care in harmony with the patient's rhythm, for example, for those needs related to elimination or feeding.

Living with terminal disease in which there is an ongoing weakening leads to a transition from safe to unsafe time, and a transition from predictable to an unpredictable time, where respectively you do not know what might happen tomorrow and how much time there is left to live.

Often, healthcare providers tend to "take time" to escape from an uncomfortable situation in which they cannot cope well. According to patients' perspectives, this "time" becomes a "waiting time" in which they experience a loss of control (Kuhl, 2011). In such situation, if a health worker offers care instead of the patient having to ask for help, the time appears as a time given, and the patient experiences a time in movement that is purposeful. Similarly, for patients, it is important that care goes beyond

their expectations and offers something extra (Ellingsen et al., 2013).

Discussion

The literature focusing on continuity of care during end of life is dominated by medical literature (61%), followed by nursing literature (28%), public health (9%), and psychological literature (1%). Relational continuity was most analyzed by the various disciplines of medicine (43%), nursing (43%), public health (57%), and psychology (100%). In nursing literature, a great deal of emphasis was also given to management continuity (43%) (Table 1). A possible interpretation could be found in the great interest that the nursing discipline has taken over the past several years in the development of models that enable them to follow patients' progress toward the end of life (e.g., the nurse case manager) (Reb, 2003). The organization of the

literature for findings, parallel to the collocation of most references by years of publication, has confirmed how the interest in continuity of end-of-life care has been growing since the last decade (Dumont et al., 2005; Reynolds & Croft, 2010) (Table 2).

It is known that the continuity of care is the result of a number of factors that include the interaction among patients, families, and providers, and that it can be perceived differently by them (Price & Lau, 2013). For this study, we have chosen patients' perspective to guarantee the continuity via a focus on their individual experiences (Haggerty et al., 2001), and thus bridging the care pathway with these discrete elements.

The main antecedent of continuity at life's end is the presence of a life-threatening illness that is clearly linked with the patient awareness/unawareness of diagnosis and prognosis. In both cases, the guarantee of the continuity of care is possible because the awareness process does not

Table 2. Literature Support for Findings

Surrogate
– Continuum of care
Byock (2000), Choi and Billings (2002), Casas Fernandez de Tejerina (2006), Meier and Beresford (2007), Finlay and Casarett (2009), Bakitas et al. (2010), Wiebe and Von Roenn (2010), Peppercorn et al. (2011)
Related terms
– Transitional care
Coleman and Berenson (2004), Maunder (2004), Dumont et al. (2005), Schofield et al. (2006), Aspinall et al. (2006), Marsella (2009), Lawson, Dicks, Macdonald, and Burge (2012)
– Seamless services
Cringles (2002), Joshua and Hauser (2009), Reynolds and Croft (2010), Wiebe and Von Roenn (2010)
– Case management
Coyle et al. (1985), Byock (2000), Bomba (2005), Lorenz et al. (2004), Brazil et al. (2007), Holland and Harris (2007), Bakitas et al. (2010), Aubin et al. (2009)
– Discharge planning
Byock (2000), Blackford and Street (2001), Holland and Harris (2007)
Attributes
– Relationships
Choi and Billings (2002), Dumont et al. (2005), Heller and Solomon (2005), Borgsteede et al. (2006), Michiels et al. (2007), Finlay and Casarett (2009), Sharma et al. (2009), Back et al. (2010), Peppercorn et al. (2011), Price and Lau (2013)
– Dialogue
Blackford and Street (2001), Burge, Lawson, and Johnston (2003), Heller and Solomon (2005), Ryndes and Emanuel (2003), Lorenz et al. (2004), Burt et al. (2004), Dumont et al. (2005), Fox (2005), Borgsteede et al. (2006), Hanson and Ersek (2006), Michiels et al. (2007), Schweitzer et al. (2009), Hauser (2009), Joshua and Hauser (2009), Reynolds and Croft (2010), Schweitzer et al. (2011), Price and Lau (2013), Barnet and Law (2013)
– Comprehensive integrated care
Byock (2000), Choi and Billings (2002), Lorenz et al. (2004), Maunder (2004), Casas Fernandez de Tejerina (2006), Lorenz et al. (2008), Aubin et al. (2009), Reynolds and Croft (2010), Wiebe and Von Roenn (2010), Efstathiou and Clifford (2011)
Antecedents
– Diagnosis of life-limiting illness
Lorenz et al. (2004), Finlay and Casarett (2009), Marsella (2009), Peppercorn et al. (2010)
– Changes in patients'/caregivers' needs and goals of care
Choi and Billings (2002), Ryndes and Emanuel (2003), Lorenz et al. (2004), Maunder (2004), Meier and Beresford (2007), Marsella (2009), Peppercorn et al. (2011)
Consequences
– Improves patients' and caregivers' satisfaction
Choi and Billings (2002), Burge, Lawson, Johnston, and Cummings (2003), Lorenz et al. (2004), Dumont et al. (2005), Wiebe and Von Roenn (2010)
– Earlier palliative care referral (the patients likelihood of die at home, reduction in the severity of symptoms, reduction in the use of hospital services)
Burge, Lawson, Johnston, and Cummings (2003), Lorenz et al. (2008), Back et al. (2010), Devi (2010), Reynolds and Croft (2010), Temel et al. (2010), Wiebe and Von Roenn (2010)

stop the illness progression and all its dramatic consequences. Healthcare providers should take into account that the process of understanding and elaboration takes time. Often, being unrealistic may help patients cope, and they should not expect patients who "are too realistic" (Johnson, 2007), so providers are required to accompany patients through the awareness process in light of their preferences. The main attributes of communication, relationships, and integrated care plans from our results coincide with the three types of continuity described by Haggerty and Reid: informational, relational, and managerial. Further, during the end-of-life phase, communication is the "glue" to support continuity, even though discussing life expectancy with the terminally ill is a difficult task both for healthcare providers and the family members. Studies suggest that patients prefer physicians who are realistic, sensitive, and empathetic in their delivery of a poor prognosis, and who allow time for questions (Finlay & Casarett, 2009). In general, most patients want information on their disease, treatment, and chance of cure, although fewer patients want direct estimates of survival as many patients seem to prefer a qualitative prognosis. Prognostic content can be provided with probabilities, averages, or temporal ranges rather than an absolute time frame (Finlay & Casarett, 2009; Parker et al., 2007). Improving relation continuity requires tailoring a healthcare system that is traditionally modeled for short-term care. Terminally ill patients require that more providers and support staff will be involved. Patients desire continuity of caretakers and find it difficult to form relationships when there is inconsistency of staff (Barnet & Shaw, 2013). During the disease progression, the patient's relationships with oneself and with others change over time as he/she strives to adapt oneself to the new situation (Eriksson & Andershed, 2008). Honest relationships during the end-of-life phase are hampered by a series of situations, such as the "conspiracy of the silence" between healthcare providers and caregivers, and the patient's feeling of being a burden to others. We should create honest relationships through careful patient/caregiver education to the extent they desire. A remedy to these issues is providers taking responsibility for commitment and integrated care (Kuebler et al., 2005; Price & Lau, 2013). Integrated care plans have the potential to improve continuity of care from diagnosis through end of life. To maximize this potential, particular attention should be placed in delivering treatment, with a focus on what the patients perceive as their disease rather than on purely relief of symptoms (Widder & Glawischnig-Goschnik, 2002). Hence, to address the complex care needs of terminally ill patients, we need a multidisciplinary approach, keeping in mind that palliative treatments are characterized by their relation to death, and deal with a condition that is terminal with or without treatment. To guarantee a coherent and coordinated patient care, the healthcare providers should direct their efforts toward achieving the highest possible quality of life as well as a comfortable transition to death.

In particular, time represents an intrinsic part of continuity (Haggerty et al., 2003). During the end-of-life phase, the life span appears as confined. Having a limited view of life allows for an opportunity for patients to make the most of each day, with particular attention to "being" rather than "having" or "doing," and to set short-term goals focusing on the present (Johnson, 2007). Hence, in such a situation, time loses its longitudinal and chronological characteristics to assume a qualitative meaning.

Limitations

A limitation of this paper is related to the choice of including the multiple terms of *end-of-life*, *palliative care*, and *terminal care*. This choice was justified by the fact that although these terms are distinctly different from one another (Reid, Gibbins, McCoubrie, & Forbes, 2011), generally they are used interchangeably (Kuebler et al., 2005). Considering that to clarify a concept, it is necessary to analyze how a chosen concept has been used within different disciplines; the exclusion of one or other terms would lead to the exclusion of a great volume of useful material. Another limitation was the inclusion of only web-based articles written in English; however, this analysis can serve as a starting point to extend future research toward other sources of documents.

Conclusions

This concept analysis portrays the continuity of care with the focus on terminally ill patients' perspectives. It demonstrates which factors may hamper the continuity achievement (deficient communication and relationships) and gives some advice to facilitate the care plan (attention to relief of symptoms, to self-image, and the closeness to death). Our results take into account how suffering from a life-threatening illness is connected with different time perspectives (bodily rhythm versus chronological one, waiting time, unpredictable time) and how healthcare providers can implement congruent clinical strategies, such as providing care in harmony with bodily rhythms, offering time rather than taking time.

References

- Aspinal, F., Hughes, R., Dunckley, M., & Addington-Hall, J. (2006). What is important to measure in the last months and weeks of life? A modified nominal group study. *International Journal of Nursing Studies*, 43(4), 393-403.
- Aubin, M., Giguere, A., Martin, M., Verreault, R., Fitch, M. I., Kazanjian, A., & Carmichael, P. H. (2012). Interventions to improve continuity of care in the follow-up of patients with cancer. *Cochrane Database of Systematic Reviews*, (7), CD007672.
- Back, A. L., Michaelsen, K., Alexander, S., Hopley, E., Edwards, K., & Arnold, R. M. (2010). How oncology fellows discuss transitions in goals of care: A snapshot of approaches used prior to training. *Journal of Palliative Medicine*, 13(4), 395-400.
- Bakitas, M., Bishop, M. F., Caron, P., & Stephens, L. (2010). Developing successful models of cancer palliative care services. *Seminars in Oncology Nursing*, 26, 266-284.

- Barnato, A. E., Labor, R. E., Freeborne, N. E., Jayes, R. L., Campbell, D. E., & Lynn, J. (2005). Qualitative analysis of Medicare claims in the last 3 years of life: A pilot study. *Journal of the American Geriatrics Society*, 53(1), 66-73.
- Barnet, M., & Shaw, T. (2013). What do consumers see as important in the continuity of their care? *Supportive Care in Cancer*, 21(9), 2637-2642.
- Blackford, J., & Street, A. (2001). The role of the palliative care nurse consultant in promoting continuity of end-of-life care. *International Journal of Palliative Nursing*, 7(6), 273-278.
- Bomba, P. A. (2005). Enabling the transition to hospice through effective palliative care. *The Case Manager*, 16(1), 48-52.
- Borgsteede, S. D., Graafland-Riedstra, C., Deliëns, L., Francke, A. L., Van Eijk, J. T., & Willems, D. L. (2006). Good end-of-life care according to patients and their GPs. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, 56(522), 20-26.
- Brazil, K., Howell, D., Marshall, D., Critchley, P., Van den Elzen, P., & Thomson, C. (2007). Building primary care capacity in palliative care: Proceedings of an interprofessional workshop. *Journal of Palliative Care*, 23(2), 113-116.
- Brousseau, D. C., Meurer, J. R., Isenberg, M. L., Kuhn, E. M., & Gorelick, M. H. (2004). Association between infant continuity of care and pediatric emergency department utilization. *Pediatrics*, 113(4), 738-741.
- Burge, F., Lawson, B., & Johnston, G. (2003). Family physician continuity of care and emergency department use in end-of-life cancer care. *Medical Care*, 41(8), 992-1001.
- Burge, F., Lawson, B., Johnston, G., & Cummings, I. (2003). Primary care continuity and location of death for those with cancer. *Journal of Palliative Medicine*, 6(6), 911-918.
- Burt, J., Barclay, S., Marshall, N., Shipman, C., Stimson, A., & Young, J. (2004). Continuity within primary palliative care: An audit of general practice out-of-hours co-operatives. *Journal of Public Health*, 26(3), 275-276.
- Byock, I. (2000). Completing the continuum of cancer care: Integrating life-prolongation and palliation. *CA: A Cancer Journal for Clinicians*, 50(2), 123-132.
- Casas Fernandez de Tejerina, A. M. (2006). Symptom management, supportive and palliative care: The continuum of care in the cancer patient. The SEOM's continuing care section. *Clinical & Translational Oncology*, 8(9), 629-634.
- Choi, Y. S., & Billings, J. A. (2002). Changing perspectives on palliative care. *Oncology*, 16(4), 515-522.
- Coleman, E. A., & Berenson, R. A. (2004). Lost in transition: Challenges and opportunities for improving the quality of transitional care. *Annals of Internal Medicine*, 141(7), 533-536.
- Corrales-Navado, D., Alonso-Babarro, A., & Rodríguez-Lozano, M. Á. (2012). Continuity of care, innovation and redefinition of professional roles in the healthcare of chronically and terminally ill patients. *Gaceta Sanitaria/S.E.S.P.A.S*, 26(Suppl. 1), 63-68.
- Coyle, N., Monzillo, E., Loscalzo, M., Farkas, C., Massie, M. J., & Foley, K. M. (1985). A model of continuity of care for cancer patients with pain and neuro-oncologic complications. *Cancer Nursing*, 8(2), 111-119.
- Cringles, M. C. (2002). Developing an integrated care pathway to manage cancer pain across primary, secondary and tertiary care. *International Journal of Palliative Nursing*, 8(5), 247-255.
- D'Angelo, D., Mastroianni, C., Vellone, E., Alvaro, R., Casale, G., Latina, R., & De Marinis, M. G. (2012). Palliative care quality indicators in Italy. What do we evaluate? *Supportive Care in Cancer*, 20(9), 1983-1989.
- Dawson, S. (2007). Interprofessional working: Communication, collaboration... perspiration! *International Journal of Palliative Nursing*, 13(10), 502-505.
- Department of Health. (2011). *End of life care strategy third annual report*. Retrieved October 15, 2012, from <http://www.dh.gov.uk/publications>
- Devi, P. S. (2010). A timely referral to palliative care team improves quality of life. *Indian Journal of Palliative Care*, 17(Suppl.), 14-16.
- Dumont, I., Dumont, S., & Turgeon, J. (2005). Continuity of care for advanced cancer patients. *Journal of Palliative Care*, 21(1), 49-56.
- Efstathiou, N., & Clifford, C. (2011). The critical care nurse's role in end-of-life care: Issues and challenges. *Nursing in Critical Care*, 16(3), 116-123.
- Ellingsen, S., Roxberg, Å., Kristoffersen, K., Rosland, J. H., & Alvsvåg, H. (2013). Entering a world with no future: A phenomenological study describing the embodied experience of time when living with severe incurable disease. *Scandinavian Journal of Caring Sciences*, 27(1), 165-174.
- Eriksson, M., & Andershed, B. (2008). Care dependence: A struggle toward moments of respite. *Clinical Nursing Research*, 17(3), 220-236.
- Field, M. J., & Cassel, C. K. (2011). Approaching death: Improving care at the end of life. *Health Progress*, 92(1), 25.
- Finlay, E., & Casarett, D. (2009). Making difficult discussions easier: Using prognosis to facilitate transitions to hospice. *CA: A Cancer Journal for Clinicians*, 59(4), 250-263.
- Fox, P. A. (2005). Developing primary palliative care: Continuity of care is paramount but needs to be tailored individually. *British Medical Journal*, 330(7492), 671.
- Gulliford, M., Naithani, S., & Morgan, M. (2006). What is "continuity of care"? *Journal of Health Services Research & Policy*, 11(4), 248-250.
- Haggerty, J. L., Reid, R., McGrail, K., & McKendry, R. (2001). *Here, there and all over the place: Defining and measuring continuity of health care*. Vancouver: Centre for Health Services and Policy Research, The University of British Columbia.
- Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: A multidisciplinary review. *British Medical Journal*, 327(7425), 1219-1221.
- Hall, P., Weaver, L., Gravelle, D., & Thibault, H. (2007). Developing collaborative person-centered practice: A pilot project on a palliative care unit. *Journal of Interprofessional Care*, 21(1), 69-81.
- Hanson, L. C., & Ersek, M. (2006). Meeting palliative care needs in post-acute care settings: "To help them live until they die." *Journal of the American Medical Association*, 295(6), 681-686.
- Hauser, J. M. (2009). Lost in transition: The ethics of the palliative care handoff. *Journal of Pain and Symptom Management*, 37(5), 930-933.
- Heller, K. S., & Solomon, M. Z. (2005). Continuity of care and caring: What matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing*, 20(5), 335-346.
- Holland, D. E., & Harris, M. R. (2007). Discharge planning, transitional care, coordination of care, and continuity of care: Clarifying concepts and terms from the hospital perspective. *Home Health Care Services Quarterly*, 26(4), 3-19.
- Ionescu-Iltu, R., McCusker, J., Ciampi, A., Vadeboncoeur, A. M., Roberge, D., Larouche, D., ... Pineault, R. (2007). Continuity of primary care and emergency department utilization among elderly people. *Canadian Medical Association Journal*, 177(11), 1362-1368.
- Johnson, S. (2007). Hope in terminal illness: An evolutionary concept analysis. *International Journal of Palliative Nursing*, 13(9), 451-459.
- Joshua, M., & Hauser, M. D. (2009). Lost in transition: The ethics of the palliative care handoff. *Journal of Pain and Symptom Management*, 37(5), 930-933.
- Kuebler, K. K., Lynn, J., & Von Rohen, J. (2005). Perspectives in palliative care. *Seminars in Oncology Nursing*, 21(1), 2-10.
- Kuhl, D. (2011). Exploring the lived experience of having a terminal illness. *Journal of Palliative Care*, 27(1), 43-52.
- Lorenz, K. A., Asch, S. M., Rosenfeld, K. E., Liu, H., & Ettner, S. L. (2004). Hospice admission practices: Where does hospice fit in the continuum of care? *Journal of the American Geriatrics Society*, 52(5), 725-730.
- Lorenz, K. A., Lynn, J., Dy, S. M., Shugarman, L. R., Wilkinson, A., Mularski, R. A., ... Shekelle, P. G. (2008). Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine*, 148(2), 147-159.
- Lorenz, K. A., Lynn, J., Morton, S. C., Dy, S., Mularski, R., Shugarman, L., ... Shekelle, P. G. (2007). A systematic review of measures of end-of-life care and its outcomes. *Health Services Research*, 42(5), 1848-1870.
- Marsella, A. (2009). Exploring the literature surrounding the transition into palliative care: A scoping review. *International Journal of Palliative Nursing*, 15(4), 186-189.
- Mauder, E. Z. (2004). The challenge of transitional care for young people with life-limiting illness. *British Journal of Nursing*, 13(10), 594-596.
- Meier, D. E., & Beresford, L. (2007). Hospitals and hospices partner to extend the continuum of palliative care. *Journal of Palliative Medicine*, 10(6), 1231-1235.
- Meier, D. E., & Beresford, L. (2008). Palliative care's challenge: Facilitating transitions of care. *Journal of Palliative Medicine*, 11(3), 416-421.
- Meyers, F. J., & Linder, J. (2003). Simultaneous care: Disease treatment and palliative care throughout illness. *Journal of Clinical Oncology*, 21(7), 1412-1415.
- Michiels, E., Deschepper, R., Van Der Kelen, G., Bernheim, J. L., Mortier, F., Vander Stichele, R., & Deliëns, L. (2007). The role of general practitioners in continuity of care at the end of life: A qualitative study of terminally ill patients and their next of kin. *Palliative Medicine*, 21(5), 409-415.
- National Consensus Project for Quality Palliative Care. (2009). *Clinical practice guidelines for quality palliative care, second edition*. Retrieved September 11, 2011, from <http://www.nationalconsensusproject.org>
- Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., ... Tattersall, M. H. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: Patient/caregiver preferences for the content, style, and timing of information. *Journal of Pain and Symptom Management*, 34(1), 81-93.
- Peppercorn, J. M., Smith, T. J., Helft, P. R., Debono, D. J., Berry, S. R., Wollins, D. S., ... Schnipper, L. E. (2011). American Society of Clinical Oncology

- statement: Toward individualized care for patients with advanced cancer. *Journal of Clinical Oncology*, 29(6), 755-760.
- Porzio, G., Ricevuto, E., Aielli, F., Verna, L., Cannita, K., Pollice, R., . . . Ficarella, C. (2005). The Supportive Care Task Force at the University of L'Aquila: 2-years experience. *Supportive Care in Cancer*, 13(6), 351-356.
- Price, M., & Lau, F. Y. (2013). Provider connectedness and communication patterns: Extending continuity of care in the context of the circle of care. *BMC Health Services Research*, 13(309), 1-10.
- Reb, A. M. (2003). Palliative and end-of-life care: Policy analysis. *Oncology Nursing Forum*, 30(1), 35-50.
- Reid, C. M., Gibbins, J., McCoubrie, R., & Forbes, K. (2011). Palliative care is not same as end of life care. *British Medical Journal*, 342, d2735.
- Reynolds, J., & Croft, S. (2010). How to implement the Gold Standards Framework to ensure continuity of care. *Nursing Times*, 106(32), 10-13.
- Rodgers, B. L. (1989). Concepts, analysis and the development of nursing knowledge: The evolutionary cycle. *Journal of Advanced Nursing*, 14(4), 330-335.
- Rodgers, B. L. (2000). Concept analysis: An evolutionary view. In *Concept development in nursing foundation, techniques, and application* (2nd ed., pp. 77-102). Philadelphia: Saunders Company.
- Ryndes, T., & Emanuel, L. (2003). Is discontinuity in palliative care a culpable act of omission? *The Hastings Center Report*, (Suppl.), S45-7.
- Sanft, T. B., & Von Roenn, J. H. (2009). Palliative care across the continuum of cancer care. *Journal of the National Comprehensive Cancer Network*, 7(4), 481-487.
- Schofield, P., Carey, M., Love, A., Nehill, C., & Wein, S. (2006). "Would you like to talk about your future treatment options"? Discussing the transition from curative cancer treatment to palliative care. *Palliative Medicine*, 20(4), 397-406.
- Schweitzer, B., Blankenstein, N., Deliens, L., & Van der Horst, H. (2011). Out-of-hours palliative care provided by GP co-operatives in the Netherlands: A focus group study. *European Journal of General Practice*, 17(3), 160-166.
- Schweitzer, B., Blankenstein, N., Willekens, M., Terpstra, E., Giesen, P., & Deliens, L. (2009). GPs' views on transfer of information about terminally ill patients to the out-of-hours co-operative. *BMC Palliative Care*, 8, 19.
- Sharma, G., Freeman, J., Zhang, D., & Goodwin, J. S. (2009). Continuity of care and intensive care unit use at the end of life. *Archives of Internal Medicine*, 169(1), 81-86.
- Sparbel, K. J., & Anderson, M. A. (2000a). Integrated literature review of continuity of care: Part 1, conceptual issues. *Journal of Nursing Scholarship*, 32(1), 17-24.
- Sparbel, K. J., & Anderson, M. A. (2000b). A continuity of care integrated literature review, Part 2: Methodological issues. *Journal of Nursing Scholarship*, 32(2), 131-135.
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small cell lung cancer. *New England Journal of Medicine*, 363, 733-742.
- Widder, J., & Glawischnig-Goschnik, M. (2002). The concept of disease in palliative medicine. *Medicine, Health Care, and Philosophy*, 5(2), 191-197.
- Wiebe, L. A., & Von Roenn, J. H. (2010). Working with a palliative care team. *Cancer Journal*, 16(5), 488-492.
- Will, L. A. (1978). Continuity of care for patients with malignant disease. *Postgraduate Medical Journal*, 54(632), 391-394.