This thesis reports several studies concerning continuity of care during the end-of- life, particularly regarding theoretical, organizational, and assessment issues.

As better explained below, it was the result of a process started with the need to explore the continuity of care at life’s end. End of life is a most difficult time for patients and their families. To ensure comfort and that all needs are met, attention to continuity of care is essential. The concept of “continuity of care at life’s end” has not been fully explored; therefore a conceptual model was created, beginning with a concept analysis. The process is continued with the model exploration to better understand what operational features we have to guaranty the continuity of care for those who suffer from a life-limiting illness (multidisciplinary team, regular assessment) and what elements could influence its achievement (care transitions).

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In the final phase of life “continuity of care” contributes to desirable outcomes and represents a part of the ethical principle of non-abandmanent. Its lack is therefore an avoidable moral shortfall for professionals and those who are responsible for the management of the care system. Currently, the continuity of care is considered to be an important characteristic of high quality health care, it is considered a basic public health and medical care tenet -a sine qua-non-to “good” care.

Continuity of care is a wide-ranging concept, which encompasses several different aspects of health care, whose significance may vary in different settings. In general, the emphasis is given to the organizational integration or to the building of networks in order to guarantee -the effective co-ordination of care between different team members and between agencies to provide a “seamless service” that meets the goals of efficiency, effectiveness and responsiveness to patients needs.

Continuity in the delivery of care encompasses aspects, such as management continuity or informational continuity, which are more relevant to the providers of care including health professionals and health-care organizations. Following these perspectives the continuity of care is described as a series of connected patient-care events both within a health care institution and among multiple settings. Its requires coordination and linkages across time, settings, and consumers of health care.

Step I
Develop the model

A comprehensive review of the literature focused on continuity at life's end matters led us to the perspective of viewing continuity as something *delivered* to service users, towards one in which the continuity is something *constructed* by professionals and service users over the delivery of care. According to this perspective, there is not a single way of achieving continuity. For those people who are vulnerable, with rapidly deteriorating conditions or whose condition fluctuates considerably, the continuity must be the result of the interaction of service users, carers, and providers and how this can be facilitated, rather than focusing on one perspective or another.

Following these approaches, the coordination, the communication, and the building of network are prerequisite for, but in itself, do not equate to continuity of care. The continuity is not considered a characteristic of providers or organizations but rather an experience of a coordinated and smooth progression of care from the patient's point of view. This experience needs to be constructed arising from the interaction between patients, careers, and providers.

The Hospice movement itself is described as a "living system" where the system are constantly changing its component and have the ability to self organize. The important feature of this "movement" is the interconnectedness of all its component, and the relationships between components are more important in understanding that the components themselves. Hospice is considered as a form of care rather than a physical location, which embraces the dynamic and flexible aspects of hospice services that should be built around the needs of those who use them to meet their needs.

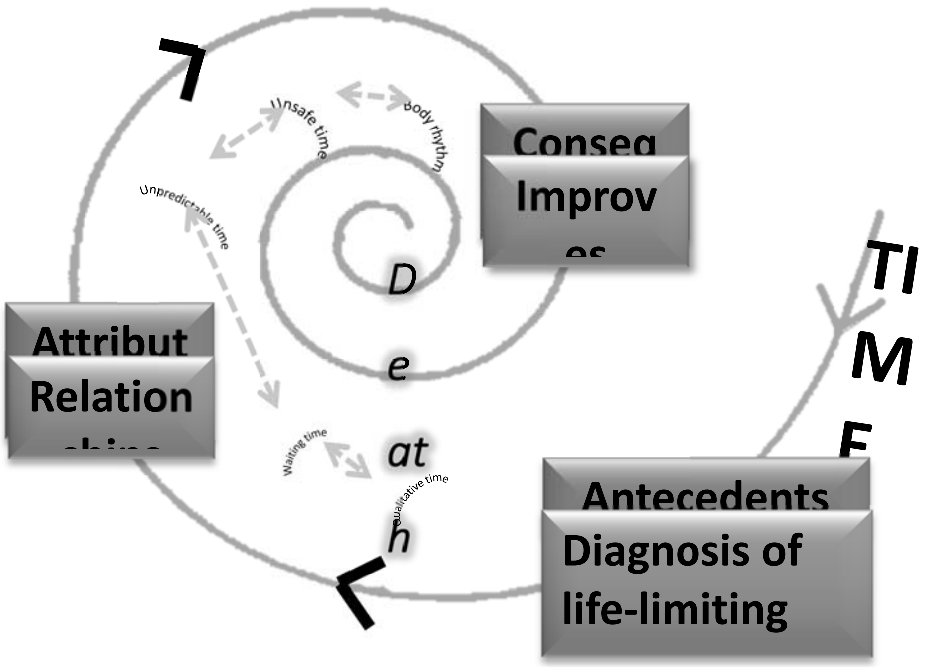
This new perspective led to drafting an editorial on which the focus was to restore the patients-centeredness of health service especially at life’s end, and in which we concluded that continuity of care is a concept best defined by how it is experienced by patients rather than how it is delivered by services.

After this, considering the Hospice uniqueness and the patient’s unique care needs that may create intrinsic problems to apply a concept developed in another context such as that by Haggerty et al. 2003, and also because when the definition or the attribute of concepts are not clear, the capacity of the concept which supports the essential task is significantly impaired. We have decided to draft a paper focused on the concept of continuity of care during the end of life,

Its findings give us an overview on continuity:

- “surrogate terms” which derived from the idea that different ways and expressions could exist to mean the same concept;
- “related terms” which have some relationships with the analyzed concept but they do not have the same characteristics;
- “attributes” which constitute the core of concept analysis because they provide a better definition of concept characteristics;
- “antecedents” which are events or phenomena that have previously been related to the concept;
- “consequences” which are the events or phenomena that follow an occurrence of the concept.

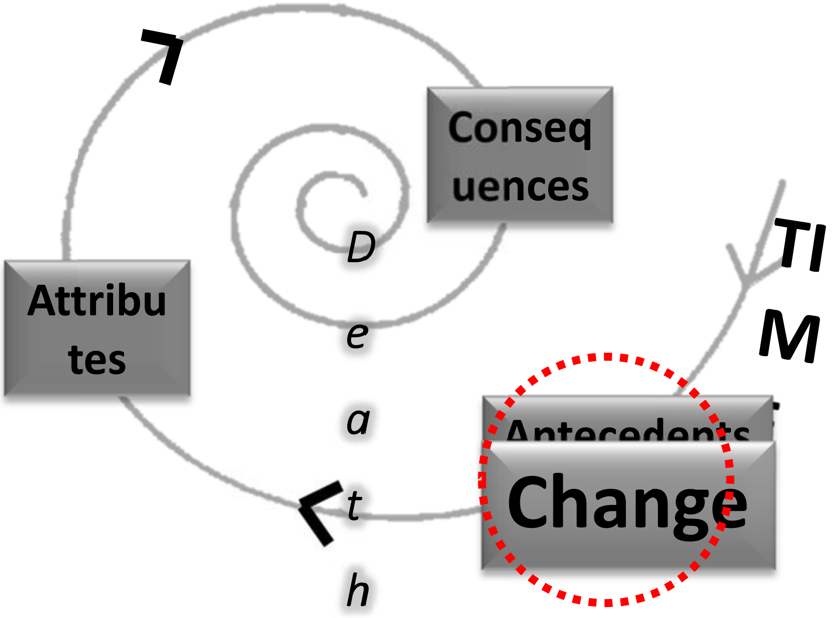
Furthermore, it demonstrates which factors may hamper the continuity achievement (deficient communication and relationships), which advices could facilitate the care plan (attention to relief of symptoms, to self-image, and the closeness to death), and how the view of time is embodied with the experience of continuity. These results have led to develop of a conceptual model that accommodates those elements characterizing the continuity at life's end as follows.



Despite we know that, the practice of a concept analysis can be seen problematic as it is operating in territory where the subject of analysis, "the concept", may be disputed and the method used to analyze are influenced by the skill, knowledge, culture and understanding of the analyst. Indeed, a primary reason that the usefulness of the concept may be questioned is the fact that results rarely are used in practical situations or, if they are being used, this use along with evaluation and refinement, is seldom documented. We hope that this theoretical effort can serve as a starting point to extend future research toward more pragmatic studies, also because the concept analysis is not an end point in concept development; instead, the major focus is to provide a clear and rationale starting point to future inquiry.

Step II
Apply the
model

Hence, for this dissertation, the continuity at life's end is discussed with a focus on some elements of the model to try to capture relevant situation and phenomena for its consistent development: the *antecedents* and the *attributes*.



Between all the antecedents we have analyzed the "changes in patients' need and goal of care" that are the necessary pre-requisites for the need to guarantee continuity. These "changes" occur within the continuum of life where there is a close and solid connection between the biological aspects of life (health, illness, organ impairment) and the biographical ones (hope, project, feelings). Supporting and maintaining the biological and biographical dimensions of life means supporting the whole person.

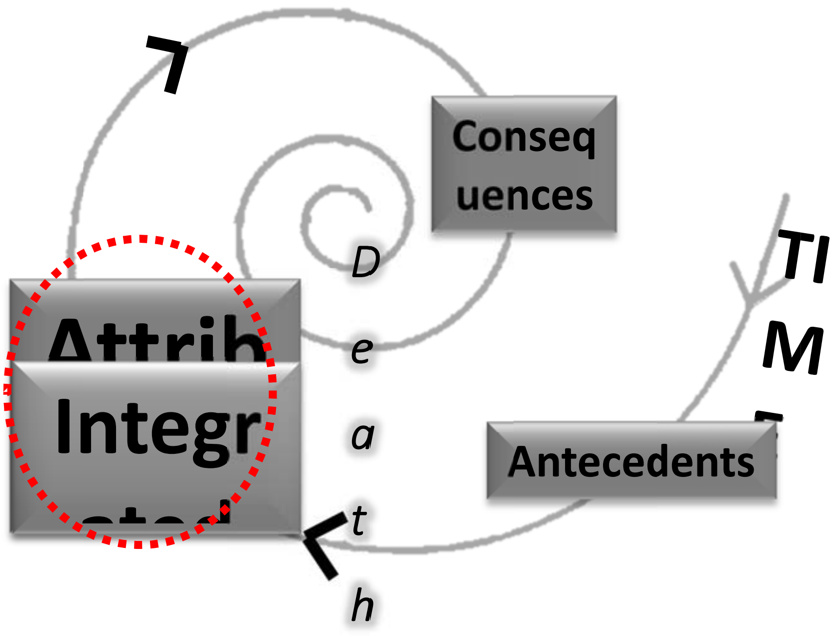
In palliative care, where people are characterized as having special status due to their vulnerability and complex care needs, interventions generally entail highly specific approaches involving several medical specializations. Persons whose conditions necessitate complex continuous management frequently require care from different health professionals in multiple settings. The supply of different types of assistance, in response to the altered needs and desires of patients and family, represents a typical characteristic of palliative care services which are not recognized as being single physical places (residential care, home care, consultation service) as much as an assistance network which is able to interface and integrate.

In this situation could exist a large number of shortcoming, such as communication problems, inefficient information transfer, and lack of coordination between health care providers. Most transitions across care settings are unplanned or unnecessary and the movement of terminally ill patients among settings may compromise the continuity of care.

In order to better explore issues that could affect the continuity at life's end, we have conducted a study about the transitions experienced by patients after their enrollment in a palliative care setting. Results from this study indicate that almost 30% of patients had at least one transition after their enrolment in palliative program. This population needs attention because these could have negative impacts such as discontinuity of care, poor coordination, and increase of psychological distress both for patients and their families. Consequently, there is a need of planning and promoting clinical interventions able to reduce unnecessary transitions.

According to concept analysis the 'attributes' constitute the core of concept analysis because provide a better definition of concept characteristics that make possible to identify situations that can be categorised under the concept.

Between all the attributes, we have analyzed the "integrated care" that allows patients to receive relief of physical (pain, shortness of breath, nausea, etc) and psychological (fear, anxiety, concerns) symptoms and to have spiritual and social needs met.



Considering that, a comprehensive integrated care is made possible by: a *multidisciplinary team* which fosters adequate treatment of patients' complex needs, and a *regular assessment* which allows for the recognition of the patients' needs in a timely manner over a period of time. Our efforts have been directed to analyze these two different angles.

Multidisciplinary team

During the disease trajectory many patients receiving active disease-modifying treatment will need palliative and supportive care as part of a comprehensive care plan. For patients with advanced and refractory cancer, when the risks outweigh the benefits of anticancer treatments, palliative care becomes the most important paradigm of good cancer care. Consequently, it is now widely acknowledged that a palliative and supportive care approach to care should utilized whenever needs are identified, irrespective of the stage of the disease, and not only at the end of life.

We have embraced the challenge of ensuring that patients with complex needs (physical, psychological, social, spiritual) would received satisfactory care. Our key tasks were to identify those who have specific needs, and the provision of supportive and palliative care interventions as part of routine cancer care trying -to guarantee the application of the “continuum of care” model.

Practically, this has implied a strict cooperation between the oncological health care providers (Campus Bio Medico) and the palliative care providers (Antea Network) to make sure that two specialized team with expertise in different field used the each other’s distinct but complementary skills to collaborate together.

This integration of efforts directed at maintaining the patient’s quality of life in all stages of cancer treatment is endorsed by the European Society for Medical Oncology (ESMO) which has formalized the criteria for accreditation the Center dedicated to cancer diagnosis, supportive and palliative care. As a “reward” of our efforts described above, the oncological ward at Campus Bio Medico in Rome has received the accreditation as a designated center of Integrated Oncology and Palliative Care in July 2011.

After this “first success” both clinical and institutional, we have made some consideration about what really the integrated health service means. We have concluded that for a good *process* of integrated care we need: common evaluation methods, the use of evidence-based practice across the continuum of care, the development of care plans and symptom management guidelines. While the *outcome* of the integrated care happens when there are mergers, contracts or strategic alliances between different providers/ specialties / institutions, when decisions on policies, financing, regulation or delivery are not inappropriately compartmentalized.

Finally, we have concluded that exist a different perception of integration between providers and users. For the user, integration means health care that is seamless, smooth and easy to navigate. Users want a coordinated service which minimizes both the number of stages in an appointment and the number of separate visits required to a health facility. They want health workers to be aware of their health as a whole (not just one clinical aspect). For providers, integration means that separate technical services (and their management support systems) are provided, managed, financed and evaluated either together, or in a closely co-ordinated way. Hence, a first provider challenge lies in abandonment the organization around the needs of the institution to embrace as ultimate validator of the quality of care the consumer perspective.

Assessment

After these two approaches useful to analyze the clinical reality both in an oncological unit and in a palliative care service, we have focused our attention on analyzing the measurement issues. The evaluation process, constitutes a fundamental tool for the continuing improvement of services, interventions, and outcomes. It also offers the possibility to compare subjective impressions to objective benchmarks and considering that, the measurement is expensive and difficult to undertake, it is fundamental that measures evaluate the right things.

Furthermore, indicators and measures are important both for researches, such as studying the influence of continuity of care on specific outcomes and the trade-offs that improving continuity brings, and for monitoring the performance and quality assurance.

In addition to guaranty the achievement of continuous quality improvement our efforts were to catalogue indicators and tools available for measuring the end of life issues, to recommend contexts where they may potentially be applied and to identify areas where further development or refinement of measure is needed.

Our findings highlighted that areas with more indicators/measures in Italy, included the physical and psychological aspects of care (pain, dyspnea, fatigue, anxiety, depression). While areas with less indicators/measures development included spiritual, existential, and cultural aspects of care. These facts are probably correlated with the necessity to have evidence or expert opinion on which building the assessment tools. For some domains, such as pain, there have been numerous indicator development efforts, but many questions remain, including how to meaningfully apply the indicators and improve outcomes. For other domains important to end of-life care, such as spirituality, a few guidelines have been developed, and consequently there has been little evidence to support their validity or translation into quality indicators.

Another question pointed out was the need to balance between measuring process and outcomes, such as balancing between documenting that a process has occurred and whether there was high-quality performance. For more advanced domains such as pain, demonstrating relationships between processes and outcomes and documenting outcomes are now needed. For less developed domains, measurement can start with documenting performance of clinical assessments or interventions, but should be refined in the future toward the quality of those processes and linkages to improved outcomes.