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## **Nurses as human beings in end-of-life care - a tentative theory model**

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## **Nurses' as human beings in end-of-life care - a tentative theoretical model**

### **Abstract**

This paper presents a tentative theoretical model of nurses' becoming as human beings in end-of-life care. As human beings nurses are vulnerable and caring for patients at the end-of-life can strengthen their own understanding of life and death. In the caring communion nurses gain contact with life and themselves as human beings. Nurses becoming as human beings in end-of-life care can be understood as a strength and a willingness to act in love and compassion as they strive to understand and be reconciled with their own life situations, happiness, and grief.

**Keywords:** becoming, care, caring community, end-of-life, hermeneutics, human beings, nurses, theoretical model

## **Introduction**

The existential situations faced by nurses seem to have received little attention in research on end-of-life care. One way to open for new perspectives and increase the understanding of nurses is to reflect on being both a nurse and a human being in end-of-life care. This paper presents a tentative theoretical model of nurses' becoming as human beings in end-of-life care.

Nurses are emotionally involved in end-of-life care as their own vulnerability as human beings awakens the inner will to care (Karlsson, 2016). Encountering the patients' suffering means both responding to it and remaining respectful to the sorrow of the journey through dying to death, a journey where human relationships are central (Wright, Brajtman & Bitzas (2009). Nurses providing palliative care are willing to help the patient with existential and spiritual care, but experience a lack of both time and the necessary skills (Keall, Clayton & Butow, 2014). Nurses struggle to do the best for the patient even at the expense of their own existential well-being, as their own suffering can arise in the relationship with patients. Caring for patients with existential distress can be emotionally demanding for nurses (Fay & OBoyle, 2019).

Tornøe, Danbolt, Kvigne & Sørli (2015) show that it is emotionally challenging to uncover and relieve spiritual and existential anguish in end-of life care, due to nurses' feelings of helplessness and failure as a professional. Sarafis et al. (2016) found that contact with death causes occupational stress for nurses and has a negative impact on their health-related quality of life. In an analysis of the concept of compassion fatigue, Cross (2019) contends that the immersion with dying patients and their caregivers in palliative care can be a stressor for nurses and if prolonged, results in compassion fatigue. As a consequence, the care can become effective and technical, but with the risk that the patient as a suffering and vulnerable human being will be forgotten. Recognition of the risks and development of compassion satisfaction are suggested as preventive actions. Self-care models have been proposed as a means to

maintain the ability for compassionate care in palliative settings, a field still in need of enhancement (Mills, Wand & Fraser 2018). In a cross-sectional study, a multidisciplinary group of Spanish palliative care professionals (N=387) tested a self-care awareness model aimed at increasing the understanding of factors associated with the professionals' inner life. They reported that self-care abilities seem to be a necessity for coping with frequent exposure to death (Sansó et al., 2015). The study further supported the relationship between coping ability, development of self-awareness and quality of life that is also likely to enhance the quality of caregiving. However, explicit factors regarding existential and spiritual questions seem to be missing from the variables in the model.

During the past decade research has focused on patients' existential questions and spiritual concerns, especially existential suffering as shown by Boston, Bruce and Schriber (2011). Based on an integrated review of 156 articles the authors contend that although there is agreement in the literature on the importance of the ability of healthcare professionals to respond to existential suffering in their patients, research on their own vulnerability and developing a model for palliative care nursing is limited. Kirkpatrick et al. (2017) briefly describe the palliative care nurses' self-awareness as an antecedent in the model. Self-awareness in their model involves the nurses' own values, attitudes and beliefs pertaining to life, death, and dying as well as their own spirituality. However, Kirkpatrick et al. (2017) do not further describe this dimension.

Awareness of death can give meaning and understanding of one's own life if nurses can manage their own life situations. To live is to be in a movement of change and to have a feeling of the existence (Nyström, 2014).

If nurses are able to manage their own life situations, the awareness of death can give meaning to and an understanding of life. Death belongs to human existence and awareness of the

finiteness of earthly life can touch a deeper dimension of human existence. To live is to be in a movement of change and to have a feeling of existence (Nyström, 2014). In order to relieve family caregivers' feeling of powerlessness in relation to death and dying when they are caring for a next of kin with dementia, nurses must act as advocates and support them by means of dialogue and interactions. When nurses support family caregivers in end-of-life care their own questions about dying and death arise, which could constitute an obstacle in the relationship with family caregivers (Høgsnes, Norberg & Melin-Johansson, 2019).)

Martens (2009) shows stress factors that affect nurses when providing end-of-life care for patients. The participants in Martens' study were asked how they experienced different stress factors on a scale from 1 (low stress) to 6 (high stress). The stress factors that nurses rated highest were "to make mistakes in treating a patient" with a mean value of 4.89, followed by "insufficient personnel to handle the workload" with a mean value of 4.70. The lowest stress factor was communicating with a patient and family about death, which had a mean value of 2.35 (Martens, 2009). The result of Martens' study illustrates how nurses take responsibility when they struggle to do the best for the patient when providing end-of-life care. However, the most surprising finding was that nurses did not find it stressful to communicate with families about death, which raises the question of whether they fail to address this subject when communicating with patients and families.

Being a nurse and a compassionate fellow human being can be described as being at the center and being able to share special situations with the patient can remind nurses of their own experiences of dying and death (Cameron, 2004). In a caring presence, feelings can arise that both increase and decrease the suffering of nurses and patients. The presence makes the nurse more available, open, able to see beyond, and genuine in her/his being (Covington, 2005).

Nurses may have a feeling of not having enough time as revealed by Holst, Sparrman and Berglund (2003); Sørli, Larsson Kihlgren and Kihlgren (2004). When nurses feel that there is insufficient time to care for patients, it can cause feelings of frustration and inadequacy (Holst et al., 2003). Due to the fact that care times are becoming ever shorter, a high number of patients are admitted to and discharged from a nursing ward on a daily basis. Nurses are unable to keep up to date with what is happening in the ward and have insufficient time to listen to patients and provide the care they feel the patients need (Sørli et al., 2004). Nurses can experience feelings of inadequacy, making it difficult for them to be both a human being and a nurse when caring for the patient (Hem & Heggen, 2003).

Studies indicate that end-of-life care can cause both work-related stress and affect nurses' health-related quality of life. Lack of time for the patient can lead to frustration and feelings of inadequacy for nurses. At times, being both a fellow human being and a professional nurse is challenging. Caring for a patient with existential distress can also be emotionally draining and nurses can experience helplessness and feelings of professional failure. As human beings nurses are vulnerable and caring for patients at the end-of-life can make them question their own understanding of life and death. Theories and models for conceptualizing and guiding nurses on the path to development as human beings and professionals seem to be lacking. A theoretical model that can help the nurses to understand their becoming as human beings in end-of-life care is needed.

### **The theoretical perspective**

The theoretical perspective in the study is the theory of caritative caring (Lindström, Lindholm, & Zetterlund, 2010). It is also a perspective on caring ethics described as the inner ethics of human beings in the caring communion (Eriksson, 2003). A care based on ethos means that care is performed with love and responsibility for the other (Eriksson, 2001). Ethos stands for

home, a home where the human being can find security, strength, protection, and rest. It is also ethos that makes the human being responsive to what the inner voice wants to say (Kemp, 1991).

The human beings' duty consists of being in communion in reciprocity, love, and service (Edlund, Lindwall, von Post & Lindström, 2013). It is the nurses' attitude, knowledge, and responsibility that create the caring relationship. The love of fellow human beings is fundamental in shaping the caring relationship. The nurses' sensitiveness and susceptibility to the patient and the responsibility they feel cannot be renounced. The suffering patient's story appeals to the nurses' compassion. The nurses are touched by the story and thus become involved (Kasén, 2002).

Although the relationship is asymmetrical because of the patient's suffering and the nurses' compassion, the relationship in a caring conversation is subject to reciprocity. Nurses give of their presence and the patient invites the nurses to their world to tell them about the suffering (Fredriksson, 2003). Nurses can develop in the understanding of life by experiencing their own struggle and suffering when meeting patients who are suffering (Rehnsfeldt, 1999).

## **Method**

The methodological approach guiding the design is Gadamer's (2013) hermeneutical philosophy. The tentative theoretical model presented is developed in a hermeneutical dialogue between four separate published studies (Karlsson, 2016). A detailed presentation of the material and the methods is found in each respective article. The four separate studies are synthesized in a theoretical model in a movement of the horizon of understanding, where they revealed new questions and guided us to seek new answers about nurses' becoming as human beings in end-of-life care (Karlsson, 2016). In this paper we present the substance of the

theoretical model that emerged from the hermeneutical dialogue between the four separate studies.

### **The hermeneutical interpretation**

Our horizon of understanding unfolded from a caring science perspective, based on Eriksson's (Lindström et al., 2010) theory of caritative caring (Figure 1.).

Please insert Figure 1. here

Figure 1. The hermeneutical movement of the interpretation.

In order to develop a theoretical model of nurses' becoming as human beings in end-of-life care, our hermeneutical dialogue began with nurses' descriptions of experiences of ethical dilemmas and ethical problems related to end-of-life care (Karlsson et al., 2010; Karlsson et al., 2013). To broaden the understanding, a meta-synthesis of 20 qualitative scientific articles on nurses' experiences of ethical dilemmas and ethical problems in end-of-life care was conducted (Karlsson et al., 2015). The new understanding of the nurses' deep commitment to care revealed by the meta-synthesis raised questions about the nurses' existential situation in the caring communion at the end of life. Therefore, the fourth study (Karlsson et al., 2017) focuses on understanding nurses' existential issues in caring by means of three focus group interviews.

When nurses experience difficult situations, ethical dilemmas, and ethical problems in the caring communion when providing end-of-life care it can touch their inner feelings and raise existential questions about human health and suffering, life, dying and death. When nurses feel hindered by external conditions in care they encounter resistance, which can



be related to their responsibilities. When nurses struggle to do what is good for the patient they are touched as human beings. Becoming reconciled in one's own life situation can be understood as being at home in oneself in love and compassion. Feeling at home as a human being can provide strength and happiness in caring for the patient (Karlsson, 2016).

The overall hermeneutical dialogue in the study can be described as a spiral movement from the new understanding contributed by each of the four studies, which together form a new horizon of understanding. We then moved back from the whole to the parts in order to interpret them against the new whole. This movement shed new light on nurses' becoming as a human being and a nurse in a caring communion at the end of life. Three types of logical reasoning: induction, deduction and abduction, can be identified as contributing to the process of forming the theoretical model.

The induction in the study has moved from an understanding of the four studies about the nurses' experiences of ethical dilemmas and ethical problems in end-of-life care towards a more complex understanding of what it means to become as a human being and a nurse in a caring communion at the end of life.

Through deduction, the assumptions that emerged through induction were loaded with a theoretical reasoning based on selected texts by Kierkegaard (2011) to gain an ontological understanding of what it means to be a human being and a nurse in a caring communion. We included Kirkegaard's (2011) text about deeds of love in our hermeneutical dialogue in order to gain a new understanding of the nurse's love and commitment to the patient.

Finally, through abduction, the theoretically loaded empirical assumptions were mirrored in the caring science perspective and a tentative theoretical model was formed. Abduction differs

from induction and deduction by taking a leap beyond the pure facts based on already existing theory-laden empiricism and is dedicated to the interpretation of patterns (Alvesson & Sköldberg, 2017). Abduction begins with already interpreted material that is synthesized as an abstraction, a so-called abductive leap (Eriksson & Lindström, 1997). From this leap new patterns of caring can be formed because “deeper levels of knowledge (the maybes), which go ‘beyond the lines’, are perceived through a result of developing both the theory and the empiricism” (Eriksson & Lindström 1997, 198). In this study the abductive leap revealed patterns in the theory loaded assumptions, which were further developed when mirrored in the theory of caritative caring, thus providing a possible understanding of what it means to be a human being and a nurse in the caring community.

Through the combination of induction, deduction and abduction the richness of meaning of a phenomenon in the caring reality can be revealed. The combination makes it possible to understand on a deeper level and go beyond that which is apparent (Eriksson & Lindström, 1997).

### **Ethical considerations**

The study was conducted in accordance with the The Finnish Advisory Board on Research Integrity (TENK) (2012), Ethical guidelines for nursing research in the Nordic countries (2003), and the Helsinki Declaration (2013).

### **The tentative theoretical model - becoming as a human being and a nurse in a caring communion in end-of-life care**

The theoretical model that emerged from the hermeneutical dialogue between the four separate, published studies and Kierkegaard’s (2011) texts shows the need for nurses to come into contact with their mental and spiritual dimension in order to become a human being in a caring communion. This movement involves striving to become whole on a deeper level (Karlsson, 2016).

**Please insert Figure 2. Here**

Figure 2. A tentative theoretical model of becoming as a human being and a nurse in a caring communion in end-of-life care. (Modified from Karlsson, 2016 s. 67)

The theoretical model is developed in a hermeneutical movement on three levels, where the upper level illustrates the nurses' becoming to reconcile with their lives and themselves as human beings (Figure 2). 'Becoming' as the essence of the model is in motion and not a static condition. The movement in the model is ongoing and highlights the nurses' positions in their becoming as human beings and as nurses in the caring communion in end-of-life care. The movement in components of the theoretical model of becoming as human beings and nurses in the caring communion in end-of-life care is italicized in the text below.

The nurses' *becoming to be themselves as human beings* means that nurses *in the caring communion gain contact with life and themselves as human beings*. Being touched in the caring communion with the patient at the end of life means that the nurses are present and encounter the patient with openness and as a human being. When the nurses see and understand the patient as a suffering human being in the caring communion it appeals to them, thus enabling them to gain contact with life and themselves as human beings. In this caring situation the patient's suffering appeals to the nurses both as professionals and as human beings. The nurses are touched, which causes an inner awakening, an inner movement to the consciousness to be tested in their love for the other and ability to love unselfishly. To be touched as nurses can be understood as an inner movement of love indicating that the patient needs the nurses (Karlsson, 2016).

Furthermore, the guilt to love means that the nurses as professionals become aware that the patient needs them in the caring communion and feel responsible for helping the patient. This can make the nurses feel guilty for not providing sufficient care. Responsibility can evoke feelings of guilt. Feelings of guilt in the becoming as human beings and as nurses in end-of-life care should be understood in relation to love (Karlsson, 2016).

In addition, when the nurses *in the caring communion gain contact with life and themselves as human beings* and have a *feeling of guilt* and responsibility in relation to the patient, the nurses as human beings strive to be *reconciled in their own life situation with all its happiness and grief*. Being reconciled with their own life situation as human beings means understanding and accepting their own life and themselves as human beings, including all their difficulties, grief, and happiness, in order to find their inner ethos (Karlsson, 2016).

Moreover, *based on an ethos in which the human being is at home in love and compassion* the nurses' becoming as human beings has a foundation in their inner ethos and feels at home in love and compassion. It can provide a sense of security and presence when caring for the patient at the end-of-life. When the nurses *have an understanding of life and themselves as human beings* they comprehend that life contains both life and death, as well as happiness, suffering, and grief and that the human beings is suffering and vulnerable but has an absolute dignity. In the *guilt to love that gives an inner strength and happiness* the nurses' feeling of guilt is understood in relation to love, the guilt to love that gives the nurses strength and willingness to act in love and compassion and to become of their own understanding of life (Karlsson, 2016).

Furthermore, when the nurses are *reconciled and at home in ethos, love, and compassion* they are reconciled to themselves as human beings and with their own lives and feel at home in their ethos in love and compassion. When the nurses have an *inner strength and happiness that*

*opens for the eternal and holy*, they have the strength and the willingness to act in love and compassion when providing end-of-life care and to become of their understanding of life. Becoming of one's own understanding of life can make human beings receptive to the inner voice of the heart, an inner strength and happiness that opens to the eternal and holy. To serve the human being with unselfish love is a care that combines the requirements of love with the need to express itself in the practical care of what is true, beautiful, and good for the patient at the end of life (Karlsson, 2016).

## **Discussion**

Nurses who encounter patients and relatives in extremely vulnerable situations such as end-of-life care must be aware of their own vulnerabilities as human beings. In the caring communion the nurses' inner is touched, which can affect the nurses' becoming and health as human beings. The substance of the presented theoretical model about becoming as a human being in end-of-life care can be useful regardless of the caring context. Within nurses as human beings there is a striving for a deeper understanding of one's own life and oneself as a human being (Karlsson, 2016).

Using their own understanding of life in caring can increase the nurses' courage to witness patients' suffering in end-of-life care (Arman, 2007). In the meeting with the patient, it is an art to create a good relationship in which the patient feels that she/he is on the same wavelength in caring (Nåden & Eriksson, 2002).

The presented theoretical model provides ontological evidence about what it means to become a human being and a nurse in the communion of care. The evidence in caring science needs to be highlighted in order to strengthen the nursing profession. Nurses as vulnerable human beings in end-of-life care can be forgotten due to the fact that they strive to do the best they can for the

patient with unselfish love in the caring communion. The model shows how nurses strive to become themselves as human beings and to experience themselves as a whole with reverence for their own life and for themselves. According to Eriksson (1990), being a whole and complete human being in guilt to love can be understood as the ontology of love.

When nurses meet patients at the end of life it can lead to them changing their own view of life (Holst et al., 2003). Nurses can become emotionally involved in patients (Eriksen Ådnøy, Arman, Davidsson, Sundför & Karlsson, 2013) and find it easier to identify themselves with younger human beings who are at the end of life (Holst et al., 2003). Nurses who care for patients in their own homes can be affected by the patients' situation, which makes them more present both as professional nurses and fellow human beings (Andrée et al., 2004).

A prerequisite for a caring communion is the nurses' willingness to take responsibility in caring. Responsibility is associated with the conscience, while guilt is the strength in caring and generated from freedom, love, the true, beauty, and goodness (Wallinwirta, 2011). For example, situations that may make it difficult for nurses to enter into the communion with patients are when nurses do not have access to verbal language with the patient, which means that they may have to use other ways to interact (Sundin & Jansson, 2003). Nurses can experience a balancing act between verbal and non-verbal dialogue and between closeness and distance (Hansebo & Kihlgren, 2002). Nåden and Eriksson (2004) show that becoming as a caregiver means taking responsibility, showing respect, and being honest. The driving force is the nurse's inner calling to show compassion and love to another human being (Nåden & Eriksson, 2004). According to Kirkegaard (2011), the tree is recognized by its fruits and human beings' love is recognized by their actions and words. It is how actions are performed, how the words are said and how they are meant that determine whether love is recognized in the fruits (Kirkegaard, 2011). Although love does not show itself, it is constantly in motion and can only

be recognized by its fruits. It is impossible to say how nurses can show love, as it is as it only becomes apparent in the actions and words in the caring communion (Karlsson, 2016).

The human being's innermost essence consists of the will to live, love, and the responsibility or conscience that manifests itself by the human being turning to the other (Eriksson, 1990). If nurses listen to their ethos, the inner ethical guidance in the caring, they can experience a freedom to make ethical choices and be more open to the unknown. Listening to one's inner self and following the demands of love in caring and not holding back what feels true, comfortable, and good for the patient can be a way to overcome external obstacles in order to do what feels right for the patient in unselfish love. In unselfish love, nurses can look away from themselves with a focus on the patient and selflessly help the patient to grieve and be reconciled at the end of life (Karlsson, 2016).

The presented theoretical model shows the nurses' 'deeper levels' where human beings' inner resources exist. Nurses' becoming to be themselves as human beings in the caring communion involves striving to become whole on a deeper level in the soul and spiritual dimension. The ideal is that nurses becoming as human beings should find the inner strength, happiness, and be reconciled with their own life situation (Karlsson, 2016). Suffering and grief are connected and in a reconciled whole, suffering and grief are the unit in what is life (Gustafsson, 2008). Reconciling with one's own life situation also involves taking responsibility for one's own life and understanding the difference between one's own life and the life of others in end-of-life care, as otherwise it is easy to lose focus if identifying with the patient (Karlsson, 2016). As a suffering human being, patient is in her/his own suffering and needs to meet nurses who can see and respond to it (Eriksson, 2001).

According to Holopainen, Kasén and Nyström (2014), feeling allied to the patient in caring is to be in a special place where nurses can contribute themselves as a human being in dialogue with the patient. This togetherness can provide a glimpse of the mystery of life that cannot be explained or understood, but can give life meaning (Holopainen et al., 2014). Several studies (Eriksen Ådnøy et al., 2013; Holst et al., 2003; Sørli, Larsson Kihlgren & Kihlgren 2004) show that by being open and seeing opportunities in care nurses contribute to development and that work becomes more meaningful for them (Sørli et al., 2004).

The presented theoretical model shows that the human being's inner awakening takes place in the communion with the patient, which can enable contact with life and oneself as a human being (Karlsson, 2016). Frilund (2013) found caring communion, dignity, security, and integrity as ideal for the caring ethos. In the caring communion there is warmth and caring, and dignity includes the nurses' will and ability to see and respect the other's needs and wishes. The protection of the patient's integrity is promoted through nurses' respect for human beings, responsibility, and self-determination as well as equality (Frilund, 2013). Hilli (2007) symbolizes the home as human beings' innermost space, their ethos. It is in communion with others that this home is created. Karlsson (2013) found 'to be in place' is to be at home in one's mind as a human being in body, soul, and spirit and be able to become oneself as a human being. To be touched as a human being is to care for one's fellow human being (Karlsson, 2013). In the inner room of health there is good, and the struggle to find their value as human beings and their own health resources takes place in the movement of health. A human being receives strength and energy in the inner room of health, which is then reflected in the caring (Wärnå, 2005). To gain an understanding of life and be at home in the ethos can be understood as an inner strength that can open to the eternal and holy for the human being (Karlsson, 2016).



When nurses are in deep communion with patients and relatives, they become more prominent as fellow human beings (Sundin & Jansson, 2003). Nurses' own vulnerability can help them become more visible in their encounter with patients, as has been shown in a psychiatric context (Hem & Heggen, 2003). When nurses have an understanding of the patient's situation, the patient is allowed to be a patient or in other words to be a suffering human being (Nordman, 2006). However, if nurses have an understanding of the becoming as human beings it can help them to focus on the patient and better understand her/his situation (Karlsson, 2016).

## **Conclusion**

Nurses are vulnerable human beings and become touched by the patient's suffering. In the caring communion at the end of life nurses' inner dimension as human beings will be touched and existential questions can arise about health and suffering, dying and death. In the becoming, when nurses gain contact with life and themselves as human beings, they struggle to be reconciled with their own life situation and be at home in themselves in love and compassion. They have an understanding of life and a feeling of inner strength and happiness as human beings and as nurses in end-of-life care. Love is in every human being and is revealed in the actions performed in communion with others. It is not possible to say that nurses show love if they act in a certain way, because love must come from human beings themselves (Karlsson, 2016).

Regardless of the context of care, the presented theoretical model is considered to contribute to a deeper understanding of the human being in the caring communion. In their inner dimension the nurses as human beings struggle to reach a deeper understanding of their soul and spiritual dimension, life and becoming oneself as a human being. The model can guide nurses in the present complex care reality, which demands both efficiency and high quality care. Nurses need to find and preserve their inner strength and happiness as human beings, be capable of resisting

external demands and obstacles, and be able to see, be present, witness, and take responsibility for the patient in the caring communion.

### **Clinical implication**

In order for care to be sustainable it is important to understand how nurses' existential situations in end-of-life care can affect them as human beings. The theoretical model can provide a basis for clinical supervision and can also help nurses to achieve a deeper understanding of what it means to become as human beings and as nurses in the caring relationship and to reconcile in their own life situations.

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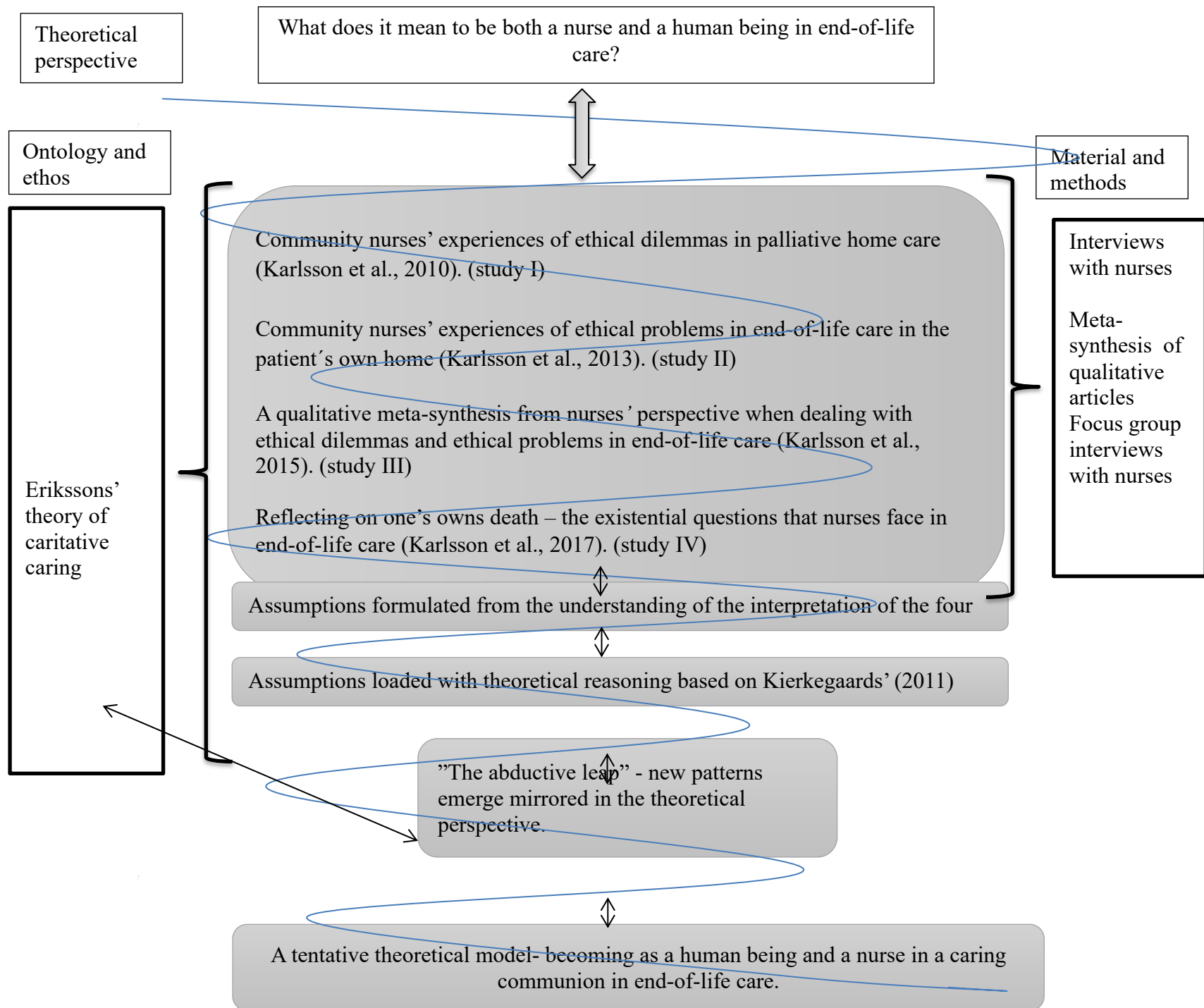
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Theoretical perspective

What does it mean to be both a nurse and a human being in end-of-life care?

Ontology and ethos

Material and methods

Erikssons' theory of caritative caring

Community nurses' experiences of ethical dilemmas in palliative home care (Karlsson et al., 2010). (study I)

Community nurses' experiences of ethical problems in end-of-life care in the patient's own home (Karlsson et al., 2013). (study II)

A qualitative meta-synthesis from nurses' perspective when dealing with ethical dilemmas and ethical problems in end-of-life care (Karlsson et al., 2015). (study III)

Reflecting on one's own death - the existential questions that nurses face in end-of-life care (Karlsson et al., 2017). (study IV)

Interviews with nurses

Meta-synthesis of qualitative articles

Focus group interviews with nurses

Assumptions formulated from the understanding of the interpretation of the four

Assumptions loaded with theoretical reasoning based on Kierkegaards' (2011)

"The abductive leap" - new patterns emerge mirrored in the theoretical perspective.

A tentative theoretical model- becoming as a human being and a nurse in a caring communion in end-of-life care.

Figure 1

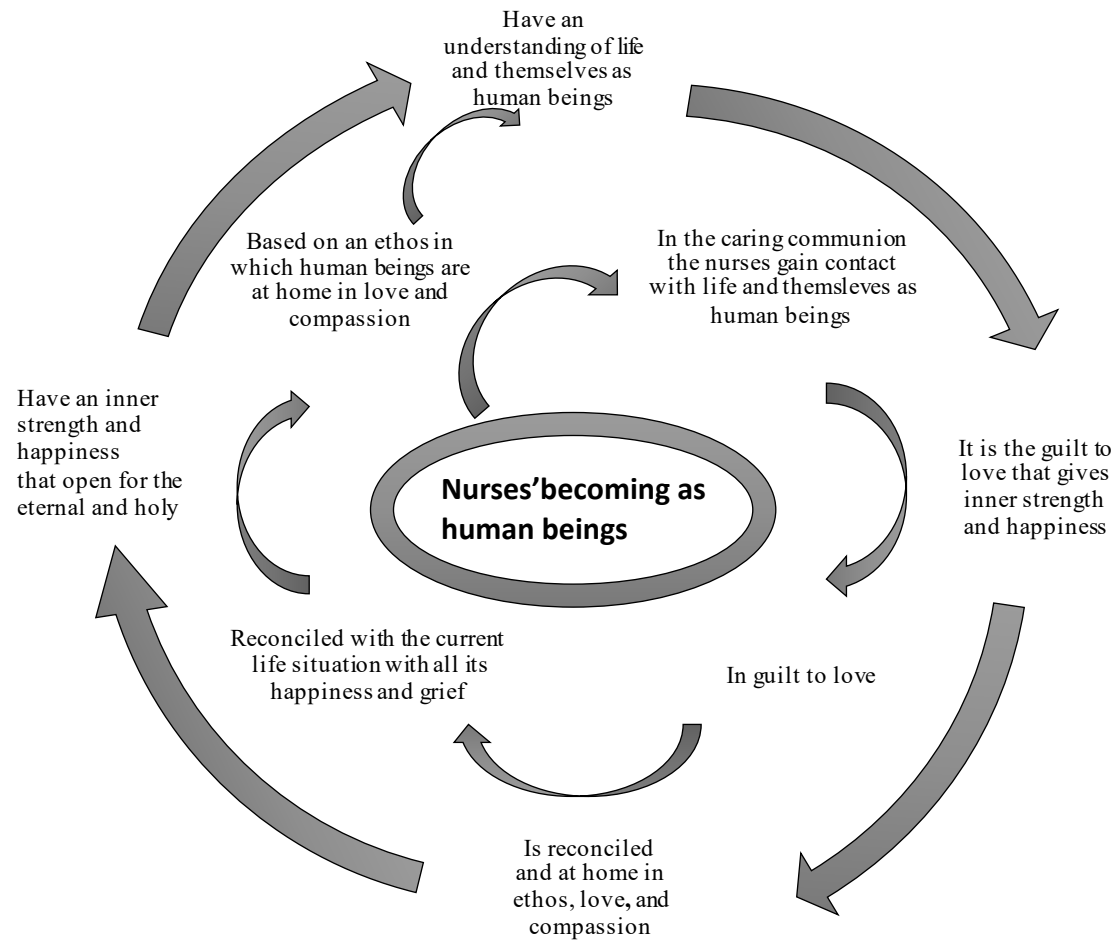


Figure 2