The feeling of being a burden by the elderly in a long-term care:

How can the nurse help to alleviate this self-perceived burden?

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# Table of Content

Abstract .......................................................................................................................... 5

1. Introduction .................................................................................................................. 6
   1.1 Rationale .................................................................................................................. 6
   1.2 Presentation of problem, scope and limitation ......................................................... 7
      1.2.1 Patient group ..................................................................................................... 7
      1.2.2 Other considerations ......................................................................................... 7
   1.3 Definition of terms .................................................................................................. 8

2. Methodology .................................................................................................................. 9
   2.1 Systematic search of articles ................................................................................... 9
   2.2 Source critique ........................................................................................................ 10
      2.2.1 Critique of Research articles ........................................................................... 10
      2.2.2 Critique of related literature ............................................................................ 11

3. Theories ........................................................................................................................ 13
   3.1 The Elderly patient .................................................................................................. 13
      3.1.1 Elderly in the society ......................................................................................... 13
      3.1.2 Elderly patient and chronic illness ................................................................... 14
   3.2 Self-perceived burden (SPB) .................................................................................. 14
      3.2.1 Prevalence of SPB ............................................................................................ 15
      3.2.2 Describing the patient’s experience of feeling like a burden ......................... 16
   3.3 SPB and Suffering .................................................................................................... 16
      3.3.1 Alleviation of suffering ..................................................................................... 17
   3.4 Role of the Nurse ..................................................................................................... 17
   3.5 Joyce Travelbee’s Nursing theory .......................................................................... 17
      3.5.1 Human-to-human Relationship ......................................................................... 18
      3.5.2 Communication ................................................................................................. 18
      3.5.3 Non-verbal Communication ............................................................................. 19
      3.5.4 Hope .................................................................................................................. 19
      3.5.5 Critique of Travelbee’s nursing theory ............................................................. 20
   3.6 Kari Martinsen’s Philosophy of Caring ................................................................... 20
      3.6.1 “Seeing with the Heart’s eye” .......................................................................... 21
   3.7 Dorothea Orem’s Self-Care Theory ....................................................................... 21
3.7.1 Critique of Orem’s Self-care theory .......................................................... 21

4. Findings .................................................................................................................. 22
4.1 Struggling to be/show oneself valuable and worthy to get care. One aspect of the meaning of being dependent on care- A study of one patient, his wife and two of his professional nurses................................................................. 22
4.2 Elderly people’s perceptions of how they want to be cared for......................... 22
4.3 Self-perceived burden in terminally ill cancer patients: A categorization of care strategies based on bereaved family member’s perspectives........................................ 23
4.4 Feeling like a burden: Exploring the perspectives of patients at the end of life overview ............................................................................................................... 23
4.5 Meaning of Dependency on Care as narrated by 10 Patients ............................. 23
4.6 Feeling like a burden to others: a systematic review focusing on the end of life ...... 24

5. Discussion .............................................................................................................. 25
5.1 The nurse’s role in alleviating the patient’s sense of burden.............................. 25
  5.1.1 Knowing the person and being available....................................................... 25
  5.1.2 Affirming the patients dignity and worth as a person................................. 28
  5.1.3 Supporting patient’s efforts to be active in their care................................... 31

6. Conclusion and Summary ..................................................................................... 34

References: ............................................................................................................. 36

Attachment: ......................................................................................................... 39
“But a Samaritan, as he travelled, came where the man was; and when he saw him, he took pity on him (The Holy Bible, Luke 10:33).”
Abstract

**Title:** The feeling of being a burden by elderly patients in a long-term care.

**Purpose:** To find out how the nurse can help the patient alleviate this perceived burden.

**Method:** Integrative literature review

**Result:** Suggestions like knowing the patient, supporting patient’s autonomy and independence and affirming the patient’s dignity, and worth as a person were found in the literature. The importance of giving good quality care for the chronically ill elderly is also found to be essential in helping to alleviate the patient’s sense of being a burden.

**Key words:** “self-perceived burden”, “burden”, “care recipient”, “elderly”, “nursing homes”, “nurse-patient relationship”, “caregiving”, “dependency”, and “chronic illness”
1. Introduction

As one ages, the person’s view of himself also changes. In a culture where independency and freedom are highly valued, a deteriorating health and the onset of illness and eventually being dependent on others for help is enough to make a person feel “small and useless”. Many elderly assume that as their health deteriorates, they also begin to be a burden to their family members, the staff and the society. They now assume a different role, from a productive, and functional body, to a dependent, resource-weak group. This kind of thinking lead the elderly to feel a certain frustration, shamefulness and finally despondency on being so dependent and un-useful. This results in feelings of distress, loss of control and a negative self-concept. In one study by McPherson et al (2007), this is referred to as Self-perceived burden (McPherson et al, 2007).

This research study aims to give better understanding on the phenomenon SPB and finally to find out how the nurse together with the patient, lessen this feeling of being a burden.

1.1 Rationale

My choice of topic is inspired by my interest and curiosity in understanding the behavior of elderly in response to their situation considering their illness. This choice of topic is influenced by various exposures to nursing homes and long-term care facility, which has given me the opportunity to interact and at the same time observe older people.

As a nursing student, I came to realize that caring for the elderly is both a privilege and a responsibility. I also came to understand that to be able to give quality care for the elderly patient requires understanding, skills, patience and genuine compassion. This has gradually fueled my interest to focus on the importance of the nurse and patient relationship in the caregiving situation.

Furthermore, a nursing student is being “trained” to give care, so that the idea that one has done the other good seems to be logical to assume. On the other hand the same experiences led me to the realization that it is not the case with all patients. During my internship period, I have seen different reactions on how the elderly would receive the care given to them.
Most of the time it is met with positive response and gratitude. However there are also occasions where patients are indifferent and passive, avoiding being a burden to the nurses. These reactions have left me baffled for a time, but eventually it helped me to see the importance of taking into consideration the well being of the one who receives the care in the caregiving situation.

I believe that good quality care is a big factor that can influence the patient’s quality of life and well being and to some patients, it can also help to alleviate their feeling of being a burden.

1.2 Presentation of problem, scope and limitation

“The feeling of being a burden by the elderly in a long-term care: How can the nurse help to alleviate this self-perceived burden?”

Listed below, are the short description of the thesis’ scope and limitations:

1.2.1 Patient group

Self-perceived burden is commonly observed in terminally ill patients. But some studies show that it can be present in elderly patients who have a chronic diagnosis (Dyeson 2000). In this paper, the focus will be on chronically ill elderly patients, with the age group from 70 years and above. This group of elderly must be receiving continuous care or assistance in one form or another in a long-term care facility. This study only includes elderly patients who have intact cognitive capabilities.

1.2.2 Other considerations

This research would like to focus on the sense of burden experienced by patients in response to being dependent on the nurses/staff regarding their care needs.
1.3 Definition of terms

In this part, definitions of terms related to research problem will be defined.

**Alleviate**- to make a problem or suffering less severe (Oxford Online Dictionary)

**Burden**- something that is emotionally difficult to bear; source of great worry or stress; a duty or misfortune that causes worry, hardship or distress (Free Dictionary, Oxford Online Dictionary)

**Long-term care facility**- a facility that provides rehabilitative, restorative, and/or ongoing skilled nursing care to patients or residents in need of assistance with activities of daily living. This includes nursing homes, rehabilitative facilities, and a long-term chronic care hospitals (MedicineNet)
2. **Methodology**

In this part, there will be a short introduction of methodology used in this research. This will be followed by a description on the systematic search of the literature. Lastly, an evaluation and critique of the sources will also be presented.

According to Aubert, *Method* is a procedure; it is a means to solve problems and arrive at a new knowledge. Methodology tells us how we should work to obtain or to verify information. It is important to choose a right method for research, one that gives good data and answers the research question in an academic and at the same time in an interesting manner (Dalland 2000: 70-71).

This study is an integrative literature review. In addition to the use of the primary literature, consisting of original research articles, secondary literature such as textbooks and other related materials were also employed.

### 2.1 Systematic search of articles

Database such as CINAHL, Nursing Allied and PubMed were used when searching for related articles. There was a use of combined and singularly searched key words such as: “self-perceived burden”, “burden”, “care recipient”, “elderly”, and “nursing homes”, “nurse-patient relationship”, “caregiving”, “dependency”, and “chronic illness”.

Different search words were also used to capture related articles.

The search yielded 932 results. The results mostly consisted of articles focusing on the burden experienced by the caregiver. These articles were excluded since the focus in this research is on the burden experienced by the care recipient. To narrow it down, the literature search was restricted from articles ranging from the year 2000 up to present. The second search yielded 132 articles. Relevant articles were then sorted out through reading abstracts and titles. Due to the limited resources retrieved concerning the topic, it was later decided to include article/s which are a bit older, but nevertheless significant for the research.

I came across the article about a systematic review of SPB by McPherson et al (2007), “Feeling like a burden to others: a systematic review focusing on the end of life. It shows
that evidence as to the prevalence of SPB is limited, but the available studies indicated that it is a common concern for people with advanced disease. Using this article, I made use of the “snowballing” method, searching the article’s references and index for related articles and books. The articles should be able to give enlightenment to the research problem: How can the nurses help alleviate the sense of perceived burden experienced by the patient. Because of insufficient studies made on this subject and the difficulties met in searching for the topic SPB, some of the articles chosen, do not directly focus on interventions to alleviate it. Reason for choice of articles will be explained on the next part.

### 2.2 Source critique

To critique the source means to evaluate and describe all the literature and sources used in the research study. Its aim is to orient the readers on the reflections one has made on the relevance and validity of the literature when it comes to answering the research problem (Dalland 2000).

#### 2.2.1 Critique of Research articles

The following will give a short justification for including each scientific article:

Article by Strandberg et al (2002), “Struggling to be/show oneself valuable and worthy to get care”, gave insights and understanding on how the patients experience receiving care, their personal struggle to preserve their identity and dignity as a person. Since SPB emerges from being dependent on care, the result in this study is in my opinion relevant for this research.

One article of McPherson et al (2007), “Feeling like a burden: Exploring perspectives of patients at the end of life”, identified coping strategies that patients used to minimize the sense of being a burden. Because of the relatively low number of participants (N=15) and the fact that it focused on the end of life, uncertainty as to its relevance arises. However, results showed important evidence, which in my opinion is applicable to patients who have chronic diagnosis, and is therefore significant for my research.
“Elderly people’s perception of how they wanted to be cared for: an interview study with healthy elderly couples in Northern Sweden” article by Harrefors et al (2008), was also chosen, it is a study of how elderly people wanted to be cared for. This article, although not having directly answered how to alleviate SPB, gave rich insight on what good care is based on the perspective of the elderly people.

Another article, “Meaning of Dependency on care as narrated by 10 patients”, by Strandberg et al (2003), was also chosen as this gave rich insight on the meaning of dependency on care from the patients perspective and its implication in the nursing practice.

The article by Akazawa et al (2010), “Self-perceived burden in terminally ill cancer patients: A Categorization of Care Strategies based on bereaved family members’ perspective”, was also reviewed in this research. Although this study focuses on the terminally ill patients, results showed that some of the interventions identified by the bereaved family members are also applicable to patients who are chronically ill.

2.2.2 Critique of related literature

The sources used in this research project are both primary and secondary literature. Nursing books, most of which are textbooks used throughout the whole course period is an important source for this research. Other books significant to the topic are found through BIBSYS.

Textbooks such as “Geriatrisk sykepleie” (2008) by Kirkevold, Brotkorb and Ranhoff, gave deep insight and understanding on aging and the elderly patient and the role of nursing in this phase of life. I found this book helpful since the focus of this study is on elderly patients.

“Grunnleggende Sykepleie” (2005) by Kristoffersen, Nortvedt and Skaug proves to be helpful and informative since it is a book focusing on the fundamental of the nursing practice focusing on the needs of patients in different aspect of life. This serves as a guidebook that keeps me focused on the domain of nursing.

Eide and Eide’s book, “Kommunikasjon i relasjoner” (2010), is also one of the textbooks used. This book offered enlightenment to the different aspects in communication and how it is important in the nurse-patient relationship. The book offered comprehension on how to make communication as a tool to achieve a better nursing practice.
The book entitled “Interpersonal Aspects of Nursing” (1997) by Joyce Travelbee was also utilized in this research. Albeit a bit older, it provides rich insights and reflections in the interaction between nurse and patient that is still applicable and relevant to the nursing practice in the present time.

Other books like “The Suffering Human Being” (2010) of Katie Eriksson, gave a comprehensive description of the suffering human being, its alleviation and most especially the chapter which discusses the suffering related to healthcare had been useful in this research.


“Coping with Chronic Illness” (1992) an old book by Miller, was also utilized which illuminated important pointers that showed how the nurse could support chronically ill patients.

Another book on gerontology and nursing, “Eldre, aldring og sykepleie” (1997) by Karoliussen and Smeby was also used as it give a comprehensive understanding on aging and the elderly both on the individual and societal level.
3. Theories

In this part, theories on the elderly patient and their role in the society will be presented. This will be followed by a brief explanation on SPB and its consequences. A short explanation on the suffering of care and its alleviation is also included in this part together with the ICN’s Code of Ethics for nurses, Travelbees nursing theory, Martinsen’s caring philosophy and Orem’s self-care theory.

3.1 The Elderly patient

The term elderly patient comprises a huge heterogeneous group, each of whom possesses a certain uniqueness that is why generalization gives a wrong picture. Age range in this group is from 60 to 100 years. The elderly patient is an old person who has acquired one or more health related problems, which made him seek the assistance of the health care system. These people have lived a long life, different life experiences, intellectual capacity, emotions, social conditions, health etc. It is therefore important to take into consideration these individual differences among the elderly (Ranhoff 2008: 75).

3.1.1 Elderly in the society

In this part of the world, society plays a big role in determining the importance of the different age groups. Productivity, activity, youth and beauty among others are given high priority nowadays. Accordingly, a person’s worth (human dignity) is automatically related on these social ideologies. It seems therefore logical that people who live up to these expectations are considered worthy and deserves social recognition (Smeby et al 1997).

Elderly group are however among those who have less possibilities to live up to these social values and expectations. Thus, they considered as being a problematic age group since they do not anymore seem to have a function in the society. These social values and the society’s view of the aging people have its implications on the elderly. Many elderly would try to live up to these norms and ideologies to try to retain their self-respect. They try to deny and delay
the changes brought about by aging by using more cosmetic products and those who are working toils harder than their frail body can tolerate (ibid).

To have control over one’s life, to be independent and self-sufficient in all circumstances is highly esteemed traits in the western culture. Thus, illness, a circumstance which leads to dependency and state where one would require help from another individual often leads to feelings of suffering. Illness and the treatment that follows often leads to changes in the person’s physical appearance and functionality. This is a deviation from important norms and social ideals. For the individual, it can be a big challenge to experience the feeling of being a worthy person during this time (Kristoffersen et al 2005:167).

3.1.2 Elderly patient and chronic illness

Chronic illness is defined as the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function and prevention of further disability (Miller 1992: 4).

Chronic illness can exacerbate the feeling of powerlessness and lack of control among the elderly since it requires them to be dependent on others for help on the activities of daily living. The elderly is then subjected to take the role of being chronically ill and dependent help seeker, thereby limiting their sense of control and independence (ibid: 137).

3.2 Self-perceived burden (SPB)

Self-perceived burden is defined as:

Emphatic concern engendered from the impact on others of one’s illness and care needs, resulting in guilt, distress, feeling of responsibility and diminished sense of self (McPherson et al 2007: 425).

People who are terminally or chronically ill and is dependent for help over a period of time often feels that they have become a burden to their caregivers. There is evidence that dependency and need for physical assistance are factors contributing to the patient’s sense of
burden (McPherson et al 2007). SPB can be understood from the social psychological perspectives of Equity theory. Equity theory states that individuals strive to maintain balance between benefits (receiving help and support) and contributions (giving help and support) within their relationships. Inequity arises when individuals give more than they receive or vice versa. When inequity transpires, it causes a certain distress, which motivates the individual to restore equity through altering the contributions given and received, or by altering their perception of the situation to restore psychological equity. Unfortunately, serious illness reduces the opportunity of the care recipient to reciprocate and restore equity, a consequence that they may perceive themselves as being a burden (McPherson et al 2007).

### 3.2.1 Prevalence of SPB

The following statistics is retrieved from McPherson’s systematic review of literature focusing on SPB at the end of life (McPherson et al 2007: 118).

In a study by Wilson et al (2005), of the 70 patients with advanced cancer, 77% were distressed about burdening others to some degree, 38% reported that they were moderate to extremely distress about burdening others. In a larger Canadian study of 379 patients, the figures were lower, 26% reported a moderate to extreme level of distress related to SPB. In another study, de Faye et al (2006), found that 65% of the 52 patients receiving palliative care for cancer experienced SPB in a minimal level, and 19% moderate to extreme level. There are also studies that examined patients concern as reported by family members or during assessment of nurses, which showed that being a burden was a prevailing concern. The finding that health professionals may underestimate SPB has been supported in a quantitative survey of patients, their families and other care providers. One example is a study to examine factors at the end of life, 89% of the 340 seriously ill patients reported being a burden to family as a very important concern, and 81% rated burden to society as similarly important (ibid).

Although the literature found focused primarily on the terminally ill patients, there is reason to believe that feeling of being a burden is also experienced by patients who are suffering from chronic illness.
3.2.2 Describing the patient’s experience of feeling like a burden

Studies on self-perceived burden has shown to have a negative effect on the patients quality of life, psychological health and existential factors such as hopelessness, loss of control, and a negative self concept arise. Listed below are the descriptions of the patients’ feeling of being a burden.

In the different studies, feeling of being a burden is expressed in different ways. This is described by patients guilt feelings and regret at the hardship endured by other. Patients are also found to have difficulty asking for help even when the need for it arise. Some patients ended up in isolation. Feeling of being a burden evoked strong emotions among patients such as anger and frustration at being dependent on others for help; this is also accompanied by self-blame even if the cause of one’s illness is beyond one’s control. To some patients, feelings of being useless and a negative self-concept and self-esteem is also correlated to the feeling of being a burden. Another study shows that patient’s feel that they have loss control over one’s life. This is associated with powerlessness, hopelessness and inferiority in the sense that patients feel that they are subjected to the nurse’s benevolence. Some patients feel that they should always be pleasing to the nurses to avoid being burdensome. One study also revealed that patients who felt that they are burdening others are more prone to depression (McPherson et al 2007, Strandberg et al 2003, McPherson et al 2007, Dyeson 2000).

3.3 SPB and Suffering

Feeling of being a burden can be categorized in what Eriksson described as suffering of life. The suffering of life affects the total life of a person. This can be brought about by illness, poor health and the situation of being a patient. The suffering of life can include from a threat to one’s total existence to a loss of ones possibility to pursue social task (Eriksson 2006: 85).

Because being dependent on caregivers for help brings about SPB, the caregiver’s attitude and manner of giving care can either worsen or lessen the patients feeling of being a burden. One study focusing on SPB revealed that medical practitioners positively added to patients feeling of being a burden (Akazawa et al 2010).
Suffering related to health care and caring is referred to as the Suffering of care. This can be summarized in four major categories: violation of the patient’s dignity, condemnation and punishment, assertion of power, and omitted care or non-caring. Eriksson further says that all professional caregivers, to some extent, unconsciously cause this suffering in caring. This is the result of an absence of reflection and lack of knowledge in the human suffering. She adds that health professional’s view of reality in caring is still shaped by a reductionist and illness-centered perspective and overconfidence in technology. To be able to avoid this unnecessary suffering in caring one should be able to be vigilant to the ethics of caring and consciously strive for good care, the one which as its foundation in love and responsibility for the other (Eriksson 2006: 89).

3.3.1 Alleviation of suffering

Eriksson gave a summary on how the human suffering can be alleviated. The first one focuses on the development of the culture of caring where the patients feels welcome and invited and that he has a place. The second, stresses the importance of making him feel loved, confirmed and understood. The patient is met with dignity and experiences the right to be a patient, at the same time having a shared responsibility as a person. The third one points out that suffering can be lessened through getting care and treatment that the illness and the person as a unique individual needs (2006: 89).

3.4 Role of the Nurse

Nurses have four fundamental responsibilities: to promote health, to prevent illness, to restore health and to alleviate suffering. The need for nursing is universal (ICN Code of Ethics for Nurses 2006:1).

3.5 Joyce Travelbee’s Nursing theory

One essential part of Travelbee’s nursing theory is its focus on the alleviation of suffering among ill persons. In her definition of nursing, it states that it is an interpersonal process
whereby the professional nurse practitioner assists an individual, family or community to prevent or cope with the experience of illness and suffering and if necessary, to find meaning in these experiences. Hope is also a central theme on lessening the patient’s burden. To instill hope to patients who are suffering means to help them conquer their sufferings (Travelbee 1997, Kristoffersen 2005: 27).

### 3.5.1 Human-to-human Relationship

Travelbee’s major assumption is that the purpose of nursing achieved through establishing human-to-human relationship. This approach challenges one to look away from the stigma of being a patient and see the individual as a human as a holistic human being. This means that the patient is not just a set of symptoms and a case to be dealt with but more than anything he is a person subjected to feel the physical symptoms of his illness and suffer the consequences of being ill. The nurse understands that he also has the need to be accepted and regarded with dignity and respect. Understanding the patient as a human being leads one to the understanding that his illness has a psychological and spiritual dimension too. All of these factors affect the patient. Having a holistic view of the human person, the nurse understands that these factors needed to be addressed in order to help the patient (Travelbee 1997:18-35).

In meeting the patients needs, a nurse must possess and use disciplined intellectual approach to problems combined with therapeutic use of ones self. A disciplined intellectual approach describes the nurse ability to help the patient solve problems related to nursing by using her previous knowledge and insights (ibid: 17-18). Therapeutic use of self is the ability to use one’s personality consciously in an attempt to establish relatedness with the patient. The goal is to promote change within the patient, this change is considered therapeutic when it contributes to reduce or relieve the patients discomfort and distress (Kristoffersen 2005: 32).

### 3.5.2 Communication

One way to become aware of the self perceived burden and its implication is by communicating directly with and listening to the one who is experiencing the burden.
Through communication the nurse has the opportunity to get to know the patient as a unique individual thereby guiding her to respond accordingly. She is able to know his needs, and understands his concerns and in the process establishing a strong relationship with the patient. Communication enables the nurse to help the patient by influencing his manner of thinking, thereby helping him to see his situation in a different light. Through communication the nurse gradually bring change within the patient by showing him understanding and offering support throughout the process (Travelbee 1997: 95-98).

By understanding her patients manner of coping with stress and illness and his behavior when experiencing distress she will be equipped with an insight that will enable her to assist him in a meaningful way. Seeing the nurse’s genuine interest to be of help, patients will be more likely at ease in asking for help or assistance (ibid).

### 3.5.3 Non-verbal Communication

Non-verbal communication is the transmission of messages without using words; communications takes place by gestures, facial expressions, and body movement. Non-verbal communication accompanies verbal communication and this gives another dimension of meaning to what has been said (Travelbee 1997: 96).

Eide og Eide (2010), described non-verbal communication as a spontaneous reaction, a reaction that an individual is not always aware of. As a helper, we should be vigilant to the non-verbal communication and be able to know how to interpret it. A helper’s non-verbal communication is also as important in dealing with the patient. It is through non-verbal communication that one signalizes one’s willingness to help and to listen, something that makes the patient feel accepted and secure. It is important that the verbal and non-verbal communication corresponds to each other and is not in conflict (Eide og Eide 2010: 199).

### 3.5.4 Hope

According to Travelbee, *Hope* is a mental state characterized by the desire to gain an end or accomplish a goal combined with some degree of expectation that what is desired or sought is attainable. Furthermore, she describes that hope is strongly related to dependence on others and that it is closely related to trust and perseverance (Travelbee 1997).
3.5.5 Critique of Travelbee’s nursing theory

Travelbee’s theory revealed an essential and often overlooked aspect of the individual’s illness and suffering, namely, that these are personal experiences, which the individual relates his own meaning to. She has also shown which consequences it has for nursing practice (Kirkevold 2001).

However, there are some weak points in Travelbee’s theory. First, her description of reality is very individual-oriented. Although this is an important aspect in nursing, her theory does not sufficiently take into account the social and cultural aspect of the individual’s life. These aspects are important factor that also affects the individual (ibid).

Kirkevold further states that Travelbee’s description of the nurse’s interaction with the ill person is at all times conscious and planned, something that deviates from the author’s experience. Moreover, her specification underestimates the condition the nurse and patient is in and that the human interaction happens in a spontaneous, intuitive and creative manner without having been planned beforehand (ibid).

3.6 Kari Martinsen’s Philosophy of Caring

Martinsen’s philosophy is based on the belief that relationship is a fundamental element in a person’s life. The fact that persons are interconnected to each other makes one dependent of the other. Furthermore, Martinsen says that trust and compassion are among the two important virtues inherent in a human relationship. In her definition of caring there are three things that must be simultaneously present: caring must be relational, practical and moral. Relational in the sense that caring requires at least two people, wherein the one has concern and anxiety for the other, so that when one suffers, the other suffer with him and provide for the alleviation of pain. Caring is about concrete and practical action trained and learned through its practice. Lastly, caring is moral in the sense that the person giving the care must relate to the other from an attitude, which acknowledges the other in light of his situation. Martinsen stresses that one must neither overestimate nor underestimate the person’s ability to help himself (Tomey and Alligood 2006).
3.6.1 “Seeing with the Heart’s eye”

“But a Samaritan, as he travelled, came where the man was; and when he saw him, he took pity on him (The Holy Bible 1985, Luke 10:33).” This excerpt is taken from the story of the Good Samaritan. Martinsen (2006) explained what it means to see with the heart’s eye and its importance in the nursing practice. From the story of the Good Samaritan, this described the picture of a man being moved by compassion towards his neighbor who is beaten half to death. The man acted out of compassion and seeing with the heart’s eye he recognizes that his fellow human being is in a very vulnerable state and needs help. The Good Samaritan did not think twice, nor did he consider his culture or tradition to interfere with what his conscience dictates him to do in that situation. (Martinsen 2006: 82-87)

3.7 Dorothea Orem’s Self-Care Theory

Orem defined Self-care as the practice of activities that maturing and mature persons initiate and perform, within the time frames, on their own behalf, in the interest of maintaining life, healthful functioning, continuing personal development, and well-being through meeting known requisites for functional developmental regulations (Tomey and Alligood 2006:269). The nurses’ major role is a complementary one related to the individual’s needs and ability to undertake Self-care. Orem claims that a person, whether in health or ill-health, there is a balance between the ability to carry out self-care and demands made on this. Nursing intervention is needed when there arises an imbalance between universal self care needs and self-care abilities (Aggleton, P. and Chalmers H. 1986: 65).

3.7.1 Critique of Orem’s Self-care theory

Orem’s theory emphasizes the importance of specific descriptions of actions needed to ensure the patient’s physical integrity and function. However, minimum focus was given to the mental, psychological and social adjustment that is required when a person is faced with serious illness, injury or disability. The theory did not provide guidelines on how nurse should respond to the person’s experience of suffering, sorrow, pain, etc. (Kirkevold 2001).
4. Findings

In this section, the relevant findings from research articles will be presented. The tables showing the abstract of each article is referred to in the attachment.

4.1 Struggling to be/show oneself valuable and worthy to get care. One aspect of the meaning of being dependent on care- A study of one patient, his wife and two of his professional nurses

This study gives an in depth understanding on the meaning of dependency on care when it appears negative. Result shows that the patient is reluctant in showing dependency on care although it is expected to be expressed and/or respected as it is shown. The patient strives to decrease the feeling of being a burden by refraining from talking about his needs to the nurse. Dependency on care is somehow concealed. The meaning of being dependent on care is understood as a two-dimensional struggle for existence. One dimension is to be or to show oneself worthy to get care, because dependency on care holds a fear of being abandoned. The other dimension is to be or to show oneself valuable a human being, because identity is built upon being able to manage oneself and be strong (Strandberg et al: 2002).

4.2 Elderly people’s perceptions of how they want to be cared for

This study gives an overview of how elderly people wanted to be cared for. Maintaining self and being cared for with dignity to the end is found to be an important element on what the elderly define as good care. The results also showed that there was a pervading concern among the elderly about the risk of not being seen as an individual person and becoming a nobody with no meaningful relations (Harrefors et al: 2009).
4.3 Self-perceived burden in terminally ill cancer patients: A categorization of care strategies based on bereaved family member’s perspectives

This study gives an overview of what the bereaved family members considered to be effective care strategies in lessening the perceived burden in terminally ill cancer patients. Terminally ill cancer patients often experience a self-perceived burden that affects their quality of life however there hasn’t been standard care strategies established for coping with this kind of suffering. One of the aims of the study is to assess the usefulness of expert-recommended care strategies and to categorize care strategies. The family members came up with recommendations on effective care strategies, one of which is to support patient’s efforts to care for themselves (45%) (Akazawa et al: 2010).

4.4 Feeling like a burden: Exploring the perspectives of patients at the end of life overview

This study provides insight on the patient’s perspective regarding SPB. Results show that SPB were reflected in two major interrelated categories. ”Concern for others” included the physical, social, and emotional hardships participants believed they were creating for others, as well as concerns about the future and likely the effect of their death on those around them. ”Implications for self” reflected feelings of responsibility for causing hardship to others, resulting in distress and a diminished sense of self. ”Minimizing burden” is a category also identified, these described coping strategies used by participants to alleviate the burden on others and to reduce the negative impact on themselves. In this section participants identified “being active in care” as an important factor (McPherson et al: 2007).

4.5 Meaning of Dependency on Care as narrated by 10 Patients

Results shows that being dependent on care involves a struggle to get care at the same time taking care to keep a good relationship with the nurses for fear of being abandoned. Patients lose much of their freedom of choice in daily life and grieve their loss of ability and value. Results also described how patients feel overpowered by nurses when it comes to care received and decision-making regarding one’s health (Strandberg et al: 2003).
4.6 Feeling like a burden to others: a systematic review focusing on the end of life

The study provides a systematic review of the literature addressing the phenomenon self-perceived burden. Review revealed that SPB is a significant problem by 19-65% of terminally ill cancer patients and is correlated with loss of dignity, suffering, and “bad death”. It has been found to be a relevant factor in death hastening acts and clinical decisions such as acceptance of treatment (McPherson et al 2007).
5. Discussion

The discussion will revolve around the results found from articles, from personal views and the theories presented at the beginning of this paper. It will attempt to give enlightenment on how the nurses can help to alleviate the patient’s sense of burden.

5.1 The nurse’s role in alleviating the patient’s sense of burden

Travelbee states that it is the role of the nurse to be able to identify and be able to bring about change in a purposeful, enlightened, thoughtful manner (Travelbee 1997). In the case of the elderly person who feels that he has become a burden, it is the nurse’s role to help him change his pattern of thinking. By using herself therapeutically and using the intellectual approach it is the goal of the nurse to promote positive change in the patient. In the review of the articles, three main common areas of concern are identified which the nurse can focus on to help the patients lessen their feeling of being a burden.

5.1.1 Knowing the person and being available

It is impossible to nurse anymore of a person than that person allows us to see. If we permit him to utilize our freely offered closeness, he will not only let us see more of him, but he will allow himself to see “more of him”, so that he may, with excellent professional nursing, emerge as a “whole person (Johns 2000: 73).

Results from several studies showed that patients have some doubts about the ability of the nurses to guess what kind of care they needed. Further the same study also showed that nurses expected patients to take the initiative to ask for the help that they needed and that care is based on what the patient demands. The patients, having observed that the nurse is busy, would want to lessen the sense of burden by refraining from asking help and expressing what he needs (Strandberg et al 2002, Strandberg et al 2003). The findings in this study revealed an important area in caregiving that should be addressed because of its negative implication to the patients. Patients who feel that they are a burden may run the risk of suffering from the symptoms of their illness that can lead to further degeneration of their condition. Not seeing and knowing the patient can worsen the feeling of being a burden in
the same way as leaving the person alone in her aloneness can lead to suffering. Katie Eriksson referred to this as one form of suffering in healthcare categorized as omitted caring or non-caring (Eriksson 2006: 84). Furthermore, she adds that this kind of suffering is due to a lack of ability of the healthcare professionals to see and determine what the patients needs. This is also a result of the nurses’ lack of ability to empathize with the patients (Kristoffersen 2005: 170).

As stated in the ICN Code of Ethics, it is one of the nurse’s responsibilities to help alleviate the suffering of her patients. But to be able to help the patient, one must know how to be available and to develop the ability to empathize and sympathize with him. Travelbee once said that the ability to sympathize means having the desire to alleviate the suffering of the other but it is through empathy that we allow ourselves to be “touched” by the suffering one is experiencing. Empathy calls to our moral duty to respond and do something about it (ICN Code of Ethics for nurses, Travelbee 1997: 143, Kristoffersen et al 2005: 171).

**Knowing the person and seeing her needs**

To help alleviate the patient’s burden, the nurse must take the time to know the person, and understand the perspective and the meaning the patient gives to his illness. It helps the nurse to see and accept the person’s uniqueness and respond to their needs as a fellow human being. When providing holistic care, the nurse needs to identify and manage personal issues that may hinder her from seeing and responding to the concerns of the patient. Healthcare professionals who experienced difficulty in meeting people who are suffering and not doing anything about their own emotion and reactions tend to make it easier for themselves by avoiding to acknowledge the patients suffering, but this can be a hindrance in giving a good care (Johns, 2000: 79-84; Kristoffersen et al, 2005: 171).

**Good communication**

The nurse’s honesty and openness in communicating with the patient signalizes the nurses’ sincere concern for her well-being and also her willingness to become involved with them (Appleton 1993). Communication plays an important part in alleviating the patient’s sense of burden. Through communication, the nurse has the opportunity to be near the patient. “Near” in the sense that one is available for the other. It gives the other the chance for opening up
one’s self and sharing one’s fears, dreams, hope and perspective in life to the other person. To be near gives a good opportunity to be able to pay attention to the non-verbal signals that patients try to communicate and to observe patterns in the patient’s behavior that can lead the nurse to discover deeper issues (John 2000). The person who is suffering from the feeling of being a burden can show external signs such as body language, facial expression, unusual behaviors such as the patient’s withdrawal, apathy, resignation, or anxiety (Miller 1992:149).

Good communication entails listening actively. Meaning, the nurse gives her full attention and presence to the patient, in this stage of conversation it is important that the nurse also expresses understanding and thoughtfulness to the patient at the same time help him see another perspective in his suffering. Listening actively gives the patient the assurance that someone understands and shares his suffering, thereby motivating him to be more open about her concerns to the nurse and in the process gaining each other’s trust. This can pave the way to a better nurse and patient relationship (Travelbee 1997, Kristoffersen et al 2006: 188).

**Building a good relationship**

According to Martinsen, relationship between two people is the most essential part of caring. This is supported by Travelbee’s interpersonal aspect theory in nursing where she introduced her human-to-human relationship approach. This approach shows the importance of seeing the patient beyond his physical symptoms, and past his role as a patient and its negative connotations by actually seeing the person as a fellow human being. As human being we are able to see the others humanness in the sense that we can identify his vulnerability to our own. Seeing the other person in the face of suffering, allow us to see our own need for acceptance and caring, the need for safety and security, for recognition, self-respect and the need to be loved. Our experiences with suffering and our own expectations can guide us on how to help alleviate the suffering of the patient. It is also through this, that we develop empathy (Travelbee 1997, Kristoffersen et al 2005).

The results from the study showed that nurses in some way or another excuses themselves for not having the time give the patients the “nearness” they needed in caring. Interestingly, the nurses are also aware of the patients suffering but blamed their shortcomings on the uncontrollable work situation, so that the patient is then left the task to ask what he needs.
The patient’s message to the nurses in this study is that they need to learn more about the silent patient’s needs (Strandberg et al: 2002).

According to Eriksson, the person who suffer needs help from someone in her surroundings who sees her needs and desires and intervenes without having to ask for help. To the patients who are feeling like a burden and who are trying to conceal their care needs this could exacerbate their feeling of being a burden. To be forced to ask for help with their basic needs and to experience that no one sees or understands what one needs leads to further misery (Eriksson 2006: 34). Once again, the finding in the study illuminated shortcomings in the present healthcare system that needed to be addressed.

Not having this “nearness” in a caregiving relationship could be a hindrance from fully knowing the person. This does not only hinder one from observing patterns and signs that can give the nurse insight into what the person is truly feeling but also lessen the opportunity to establish rapport with the patient. Although Eriksson stresses the need of the suffering patient to have space and be by himself, it does not necessarily imply that the patient must be totally left alone to suffer. Giving the patient time to be reconciled with his suffering at the same time assuring him that someone nearby can see and understand his condition can help alleviate the feeling of being a burden. It is therefore the role of the nurse to balance nearness and distance in caregiving (Kristoffersen 2005: 187).

5.1.2 Affirming the patients dignity and worth as a person

Threat to losing self and one’s dignity is portrayed in several forms from the different studies. It is described by feeling useless and unable to fulfill important roles, not being seen as a unique person, not getting help even when they asked for it. Moreover, description such as being submissive to the nurse’s manner of helping them, and being overpowered in decision-making regarding ones health problems are also mentioned (Akazawa et al, 2009, Strandberg et al, 2003).

In a study conducted with 12 healthy elderly couple, with the aim to find out how they wanted to be cared for when dependency on care becomes inevitable, one of the relevant findings is the elderly’s desire to be cared for with dignity to the end. This is further described by being treated as a unique person and to be able to maintain the self, in spite of
illness and state of mental health or situation. To be treated without dignity meant not being seen as a unique person and not being able to relate to persons they knew (Harrefors et al 2009).

The results from these the different studies showed how important it is for the elderly to be seen and respected as a unique person when one becomes dependent on care. Failure to recognize and acknowledge the patients dignity in caregiving can lead to further suffering (Eriksson 2006).

According to Martinsen, caring has a moral responsibility, so that in a caregiving situation the nurse has the duty to give the patient the possibility to experience his full worth and prevent all forms of violations. In the book, the Suffering Human being, Eriksson mentioned the importance of experiencing one’s personal worth even as a patient as this has a fundamental significance to one’s health (Martinsen 2006, Eriksson 2006).

**Respecting the patient**

Respecting the patient means helping the patient to maintain his personal integrity and having the understanding that he is a unique individual with distinctive needs and a different perspective (Kirkevold 2008). One way to show respect to the patient is by keeping the trust he has given by remembering appointments or promises made with him. Another way is acknowledging the subjective experiences brought about by his illness. Remembering to protect his need for privacy by closing doors during intimate hygiene and while discussing personal issues is also another way of showing respect (Kristoffersen 2005, Eriksson 2006). Giving the patient the individual care that he needs, involving him in decision making regarding his health concerns and providing enough information are ways of illustrating that he is a worthy human being. This way he can maintain the feeling of being in control and a sense of competence despite of his illness and condition (Eriksson 2006: 87-89; Miller 1992: 29).

**Retaining the patient’s sense of self**

In a busy everyday within the institution, it is easy to overlook small details that are so important to the patient. These small details oftentimes define the persona of the patient. And
to them remembering small details, may it be in his preferences for food, his morning routines, or asking a follow up on the stories that he had shared a few day ago can make a difference on how he perceives himself. Calling him by his first name, or giving a hug or caress would mean that one remembers him not only by his illness and symptoms but also by the things that mean most to him. Allowing the patients to maintain their personal routines is also one way of affirming their worth as persons (Eriksson 2006, Smeby 1997: 207).

Offering a different perspective
One way to affirm the patient’s dignity and worth is by helping the patient see a different perspective and find meaning amidst his illness and suffering. To remind the patient of who he is and who he had been, and to confirm his worth by reminding that he is still the same person who once had an important role to contribute to the society, can give a positive self-concept (Kristoffersen et al 2005: 191, Smeby 1997: 216). In one study this is referred to as entitlement, one coping strategy used by patients to lessen the sense of burden. Entitlement can be described in a caregiving situation wherein the patient felt that they earned whatever help they are receiving knowing that they have done their part in the past. This kind of thinking can be explained by the Equity theory wherein individuals try to restore balance in a relationship when inequity arises. By not being able to reciprocate the benefits received, patients have adapted different coping strategies; one form is by changing their perception of the situation. Helping the patient see his personal strengths and realize his remaining intact roles enhances self-esteem (McPherson et al 2007: 426, Miller 1992: 29).

Instilling hope and finding meaning
According to Travelbee, maintaining hope and helping patients to find meaning amidst their illness are two of the most important role of the nurse. Hope is closely related to dependency on others. Patients who are chronically ill are dependent on the nurses and hope for their assistance even though he may not always express it. They learn to trust the nurses to give them assistance when it is required. To be able to help maintain the hope in chronically ill patients, the nurse must be able to keep the trust that is given to her. This can be shown by being honest and reliable (Travelbee 1997, Smeby 1997).
By using herself therapeutically, the nurse can help the patient to maintain hope and avoid hopelessness. One way of instilling hope to the chronically ill elderly patient is by helping him realize that there is still someone or something to live for despite of the circumstance he is in at the present (Miller 1992: 33). One example of this is by talking to the patient about something that he values most, for instance talking about his family, about the rich experiences of his past, the contributions he made to the society and the positive things that one still possess. This can be a reminder that all is not lost. Another thing to instill hope is to support the patient’s effort to practice her faith (Smeby 1997: 808).

In a study to find out the meaning of dependency on care, one of the positive side is that some patients express joy in reevaluating their potentials in life. Patients find joy and gratitude in the fact that they are still able to wash their face and still have the privilege of having an intact cognitive function (Strandberg et al 2003). In this regard, one measure that can affirm patient’s value and dignity is by supporting her efforts to do things for herself and maximizing the potentials that she still possess.

5.1.3 Supporting patient’s efforts to be active in their care

In one study in Japan, bereaved families of patients who passed away ranked “minimize patients disability” category as one of the three most important care strategy that the nurses can use to help lessen patient’s perceived burden. “Minimizing patients disability” refer to care strategies for increasing patient’s independence (Akazawa et al, 2010). This is also supported by the findings of McPherson et al, wherein patients consider being active in their care, as significant (McPherson et al, 2006).

It is important that the nurse realize the need for elderly patients to be independent. One important role of the nurse is to support the chronically ill elderly’s effort to care for himself or develop his self-care abilities based on what he considers as important (Kirkevold 2008: 105-107).

Dorothea Orem’s theory is built on the assumption that individuals, whether in health or in ill health have the ability to maintain balance between the ability to perform self-care and the demands made on this. However, in the event that patient’s self-care demands exceed his self-care abilities, it is then that the need for nursing intervention arises (Aggleton et al,
1986:65-67). Orem’s theory appears to have an important role in promoting self-control among patients in the sense that the nurses’ intervention focuses on providing the patients opportunity to be involved in their care. Nursing interventions such as guiding, providing physical and psychological support, teaching the patient and modifying an environment that supports development can help the chronically ill elderly to cope with their illness at the same time giving them the sense that they are still in control (Kirkevold, 2008: 104; Aggleton et al, 1986: 65).

**Assisting patients in setting realistic goals**

Chronically ill patients should be given the opportunity to participate in their total plan of care. To achieve this, the nurse assist the patient identifies realistic goals, validating the elderly´s self-care skills and confirming their unique strengths. Patient’s cooperation in the decision-making regarding one’s health increases perceived control, this also lessens the feeling of powerlessness (Miller 1992: 307).

**Increasing patient’s knowledge about his situation**

The importance of giving information about ones illness and its management to the chronically ill elderly is important as it enables him to make decisions and take action regarding his condition. This gives the elderly the feeling of having control thereby lessening his feeling of being powerless (Miller 1992: 308).

Results from one study showed that some nurses take over patient’s autonomy and independence by taking over the things that the patient could have done for himself. This can be explained by the fact that nurses find it more effective to do things for the patient than allowing the patient to do things for himself (Davies et al 2000, Kirkevold 2008). Similarly, another study showed that patients felt being overpowered by nurses in the sense that they are excluded from decision-making regarding their health concerns. The patients in this study showed compliance and resignation to the routinized care the nurses are giving. Because of the fear of being abandoned to care for themselves, patients try to be pleasing to the nurses by not trying to be bothersome and not criticizing the nurses (Strandberg et al 2003).
The results illustrated an example of the suffering that Eriksson classified as *assertion of power and punishment and condemnation* (Eriksson 2006: 83). The patient’s experiences are sufferings in relation to being dependent on care. Here can we see, how the nurse, indirectly uses her power over the patient by taking away the opportunity to do things which he is still capable of doing and to make decisions regarding his health, this renders powerlessness. Once again, there is moral aspect that needs to be addressed, as carelessness and lack of reflection in the nurse’s manner of giving help to patients can lead to worsen the feeling of being a burden. Promoting patients autonomy and independence goes beyond supporting patient in their functional ability, it also means that nurses must help patients maintain the right to make decision for himself and to be in control of their lives (Johannessen 2007).

Interestingly, doubts on the self-care model in nursing were found in some literature. The self-care model main focus on the patients’ functional activity can lead practitioners to fail to see the person in their distress at a crisis point and it fails to address the psychological, mental aspect of the patient’s life. Furthermore, it contends that failure to see and respond to patients in terms of the meaning and impact of illness on their whole lives is uncaring and contributes to suffering. (Kirkevold 2001, Johns 2000: 77) This is supported by Martinsen whose doubts on the self-care model is apparent as she stands by the philosophy that caring is a goal in itself and that self-care, independency and functionality is not a realistic goal for the larger patient group in need of caring. Moreover she adds that self-care, as a goal in itself will shift the focus to other things than caring (Kristoffersen et al, 2005: 63).

In spite of the different opinions met by the self-care model, results of the studies mentioned above showed how independency, wherein patients become active participants in their care needs, have a positive result on patient’s well being (McPherson et al 2007, Akazawa et al 2010).
6. Conclusion and Summary

SPB is a phenomenon that is experienced by chronically ill elderly patients. This is one area of concern that needed to be addressed because of its negative effect on the elderly’s quality of life. One important finding from the articles is that nurses can have a positive effect on the patient’s feeling of being a burden (Akazawa et al 2010). The result revealed shortcomings on the caregiving situation that calls to our attention in order to improve the quality of nursing given to the elderly. In the course of writing this paper, I found out an important element in the nursing practice that seems to be slowly heading its way to extinction. This is the virtue of compassion, where genuine concern for the other originates. Through compassion, the person responds with a loving care to the other. It is the kind of care that one would have wanted to receive had she been on the same situation. According to Eriksson this kind of genuine caring can alleviate the patient’s suffering (Eriksson 2006). In addition to this, it entails the nurses’ ability to sympathize, to be available, and to be able to respect the uniqueness of every patient. In giving good care, she faces the challenge of being more open and in some level accept as one’s own the suffering of the other. However, some people shows reluctance in opening one’s self in the face of suffering as this leads them to face their own vulnerability as a human being. This can be an overwhelming experience (Smeby 1997: 209, Kristoffersen et al 2005: 168-171).

In the literature, many factors had been mentioned that lead to the deterioration of giving a good and holistic care. External factors like the restricted resources in the healthcare sector and as a consequence, care given to the patient is only limited to practical, routinized tasks, thus less focus is given on the other aspect (Strandberg et al 2002, Kristoffersen et al 2005). Another factor is the nurse’s attitude towards meeting the elderly patients. Society’s view on the elderly can be a factor that can influence the nurse’s attitude towards the elderly thereby compromising the quality of care given to them. In this regard, the nurse is challenged to examine one’s value and to be able to regard the person’s absolute worth regardless of age, race and functional capabilities as this might cause the patient and her family unnecessary suffering (Kristoffersen et al 2005).

In the discussion part, I have included different nursing assumptions and theories having learned that individual situations sometimes do not fit to a particular nursing model and is
best explained by using these different assumptions. In my opinion, these different nursing models should work in a way that complements the other.

This research highlighted some aspects in nursing that needs to be improved to be able to give the patients a good quality care. The topic SPB and elderly’s feeling of being a burden is one area in nursing that is under researched. It is therefore quite a challenge to find literature that point directly to the topic. Because of its negative consequences to the patient’s quality of life, I believe that it is an important arena in nursing that should be given attention. I therefore suggest that further studies be made to better understand SPB as it is a complex theme and also the meaning of being dependent on care. Further research is also needed to find out nursing strategies and interventions that could lessen the feeling of being a burden of the elderly patient. Given a chance in the future, this is one important area of interest that I would consider studying further.
References:


Travelbee, Joyce (1997), *Interpersonal aspects of Nursing*, Oslo: Pensumtjeneste
http://www.diakonhjemmet.no/stream_file.asp?iEntityId=5760 (read: 15.03.2012)

(read: 12.03.2012)

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The ICN Code of Ethics for Nurses. 
**Attachment:**

The tables presented below shows the findings of the research articles reviewed in this study.

<table>
<thead>
<tr>
<th>Author, Year, Country</th>
<th>Methods</th>
<th>Purpose of the study</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strandberg, Gunilla Åstrom, Gunilla Norberg, Astrid (2002) Sweden</td>
<td>Phenomenological-Hermeneutic Interviews with an old man with a chronic disease, his wife and two of his professional nurses.</td>
<td>The aim was to describe the meaning of being dependent on care when it appears ”negative”.</td>
<td>-reluctance in showing dependency on care A two dimensional struggle for existence. -to show oneself worthy to get care (being easy to deal with etc.), as dependency on care holds a fear of being abandoned. -to be/show oneself valuable as a human being, as identity is built upon being able to manage oneself and being strong. (e.g participant strive to decrease the feeling of being a burden by concealing care needs)</td>
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<tr>
<td>Author(s)</td>
<td>Study Design</td>
<td>Participants</td>
<td>Aim(s)</td>
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<tr>
<td>Harrefors, Christina Savenstedt, Stefan Axelsson, Karin</td>
<td>Qualitative inquiry</td>
<td>12 elderly couples</td>
<td>-to describe the elderly peoples perceptions of how they wanted to be cared for</td>
</tr>
<tr>
<td>Akazawa et al (2010), Japan</td>
<td>-Good death Inventory was used to evaluate patients SPB and a 27-item questionnaire to assess usefulness of care -429 bereaved family members of patients who had died</td>
<td>-to investigate prevalence of SPB -to assess the usefulness of expert-recommended care strategies -to categorise care strategies</td>
<td>Key words: -25% experienced mild SPB -25% experienced moderate to severe SPB -recommendations of care strategies from the family: -eliminate pain and other symptoms that restrict</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Participants</td>
<td>Findings</td>
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<tr>
<td>McPherson et al (2007), Canada</td>
<td>Interpretative Phenomenological study</td>
<td>15 patients</td>
<td>Support patient’s effort to care for themselves, medical professionals can have a positive influence on SPB experience by adapting routine practice</td>
</tr>
<tr>
<td>Strandberg, G. et al (2003), Sweden</td>
<td>Phenomenological-hermeneutic method</td>
<td>10 elderly patients</td>
<td>SPB is shown in three categories: Concern for others, implication to self and minimizing burden by being active in their care</td>
</tr>
</tbody>
</table>

Patients expressed doubts on the
| **McPherson et al (2007), Canada** | **Standard search strategy** | **ability of the nurses to detect what kind of care they needed)**  
-grieve loss of ability and value  
-found to be a significant problem by 19-65% of terminally ill patients  
-correlated with loss of dignity, suffering etc.  
-relevant factor in clinical decisions | **-to identify prevalence of SPB  
-identify the correlates of SPB  
-to investigate significance of SPB in decision making** |