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The impact of HOPE in nursing home patients

A study on cognitively intact nursing home patients and the importance of hope.

Thesis for the Degree of Master of Health Science

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Thesis overview

This master thesis consists of a scientific document summarizing the study and two articles, and is an independent part allocated to G. Haugan's PhD project which, was published in 2013 (Haugan, 2013).
The thesis consists of a scientific document summarizing the master project and two scientific articles.

Paper 1 "*The value of hope for cognitively intact nursing home patients*" provides a theoretical overview of the concept of hope and symptoms, as well as quality of life in nursing home patients. Paper one holds the requirements of ***European Geriatric Medicine*** *(https://www.elsevier.com/journals/european-geriatric-medicine/1878-7649?generatepdf=true*)

Paper 2 ***"Hope related to symptoms and quality of life in cognitively intact nursing home patients"*** is based on a survey using a cross-sectional design exploring hope related to physical and emotional symptoms and quality of life. Paper two is following the instructions of ***Geriatric Nursing*** (http://www.gnjournal.com)

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Contents

Abstract

Introduction: Over the next decades the generation of older adults is expected to increase significantly worldwide. As elderly are often suffering from multimorbid an increasing number will be in need of nursing home care. Hope is found to be needed by all persons throughout the life cycle including the end of life, and is viewed as a resource to provide strength when experiencing illness and losses. In this thesis hope is defined as a multidimensional dynamic life force characterized by a confident, yet uncertain expectation of achieving a future that, to the hoping person, is realistically possible and personally significant.
Therefore, the overall aim of this study is to explore and elaborate the concept of hope for cognitively intact nursing home patients in Norway in relationship to symptom burden and quality of life.

Method: In Paper 1 a qualitative method was used performed by a systematic literature search. With a phenomenological approach data was categorized and thereafter analyzed.
In paper 2 a quantitative approach was applied. Here data was collected by a descriptive cross-sectional design, and analyzed by descriptive, correlation and regression statistics.

Results: Hope is found to be an essential coping resource among older adults, and to provide strength in times with suffering (Paper 1). Nursing home patients are found to be hopeful, at the same level as other patient' groups. Findings indicate that physical and emotional symptoms have a significant relationship to hope, as well as to quality of life. Multiple regression analysis showed a positive relationship between hope and quality of life, and insomnia was found to have a slightly negative impact on hope (Paper 2).

Conclusion: Based on the findings hope is a multidimensional dynamic life force with an expectation of achieving good, and a vital resource for nursing home patients experiencing multimorbid and losses. Emotional symptoms seem to have a positive relationship to hope, and physical symptoms such as fatigue, nausea/vomiting, dyspnea and insomnia are shown to have a negative relationship to hope. Furthermore, increased insomnia is also found to have a direct negative impact on hope in nursing home patients, while quality of life has a positive effect on hope.

1 Introduction

1.1 Background and objective

The last 100 years, life expectancy has increased worldwide, and more and more elderly will experience limitations by the end of their lives. Therefore, governments are now focusing on capacity and quality of health services. In addition, the concept of family and family care has been changing. In Norway today family members are not obligated any more to take care of their close relatives. This concern is expressed in the white paper 25 (St.Meld.26, 2005) focusing on the elderlies` need for nursing home services, with a special attention to dementia and physical restrictions (St.meld. nr 25 (2005-2006)). Elderly have both physical, mental and spiritual needs (Eriksen & Bussing, 2013). Their physical and mental needs are provided for in nursing homes, while their need for spiritual support, such as hope, tends to be ignored (Haugan Hovdenes, 2002).

1.1.1 *The concept of aging*

In 1968 psychoanalyst E. Erikson defined the concept of aging (Erikson, 1968). In his work "Generativity and ego integrity", Erikson shows that the development theory has had a major impact on how we view aging as part of the lifecycle. The development theory comprises of eight development stages, where each stage is characterized by an important psychological challenge that can be resolved with a positive or a negative outcome. The transitions between the eight stages are depending on the personal development and personal maturity.
Ageing people have different ability to adjust to, and master, critical situations, (Richmond, Law, Kay- Lambin, 2011; Bondevik, 2012) based on how they have handled critical changes earlier in life (Bondevik, 2012). Erikson's last developmental stage focuses on aging with physical and psychological challenges. In this phase, a meaningful whole out of one's entire life and the life story becomes important (Erikson, 1968). According to Erikson, hope is recognized as a fundamental function throughout life (Erikson, 1976).

1.1.2 *Nursing home population in Norway in the years to come*

Demographic forecasts indicate a strong growth in the number of people over 80 years worldwide (World Health Organization, 2017). This demographic change is also seen in Norway. Today, the Norwegian nursing home population is approximately 32.000 elderly mainly over 67 years old (Statistics Norway, 2016). With ageing, the risk of diseases

increases, and diagnosis such as dementia, diabetes, arthrosis, and cancer are more prominent in patients with an increased lifespan (Campisi, Chappelli et al, 2009). Today, those diagnoses are not terminal, but fall under the category chronic diseases.

Elderly are often suffering from more than one chronic illness at a time. This condition is called multimorbidity, and affects the nursing home patients` functional capacity, quality of life, and/or mental health (Norwegian Institute of Public Health, 2016). In Norway, the probability of multimorbidity is higher among elderly over the age of 80 (Norwegian Medical Association, 2001). Many nursing home patients are in need of permanent daily care, as their life-situations are marked with poor health with a high rate of disease and significant disability (Gibson & Gorman, 2012). In nursing homes caregivers' qualifications and motivation are to provide good care (The Norwegian Medical Association, 2001). Research has shown that the focus of nursing home care has been on physical health and cognitive functions (Caprio, Hanson, Munn et al., 2008; Creighton, Davison & Kissane, 2017; Duggleby, Holfslander, Steeves, Duggleby-Wenzel & Cunningham, 2010).

1.1.3 *Hope in relation to age and health*

Ageing is the process of growing old or maturing. This multi-dimensional process affects almost every aspect of human life. Literature suggests that ageing involves an accumulation of losses (physical, mental and social), multiple health problems, decreased self-sufficiency, and limited coping strategies (Miller, 2007). But ageing is also associated with life transitions such as retirement, relocation, and the death of friends and partners.

Hope is needed by all persons throughout the life cycle and through the health illness continuum, including at the end of life (Miller, 2007). After relocation into a nursing home the perception of hope can be reduced (Farran, Herth & Popovich, 1995). Hopelessness might be experienced when confronted with difficult life challenges (Farran et al., 1995:26).

Hope can be seen as an essential resource when dealing with such challenges (Miller, 2007). In long term care such as nursing homes, the sensation of hope is not seen as an invariable state; hope can change over time in response to one`s situations and circumstances. Therefore, finding ways to foster hope is essential (Moore, Hall & Jackson, 2014). It is evident that hope has a spiritual quality acknowledging a trust in something larger, more encompassing (Moore

et al., 2014). With that, health care professionals have a great impact on symptoms and quality of life by fostering hope in elderly in their last phase of life (Moore et al., 2014).

1.1.4 *The purpose of the study*

The concept of hope is seen to be essential for cognitively intact nursing home patients. Here the interactions between nursing staff and patient is essential (Haugan, 2014a). In Norway only few studies have investigated the impact of hope at the final stage of life. Therefore, the focus of this thesis is to illuminate the relationship of hope to both symptoms and to quality of life among cognitively intact nursing home patients in Norway.

1.1.5 *The structure of the thesis*

This thesis is defined by two parts, a qualitative and a quantitative part.
The qualitative part is elaborated in detail in Paper 1 (Appendix 9.1), while the quantitative part is presented in Paper 2 (Appendix 9.2). The thesis is therefore only summarizing the project as a whole without going into details.

2 Theoretical framework

2.1 Definition and concept of hope

The concept of hope has been highlighted in philosophical, theological, psychological and sociological literature. Nursing literature contains multiple references to the phenomenon of hope (Miller, 2007). In this study, the theoretical background is primarily based on the theories of Joyce Travelbee, Karin Dufault and Benita Martocchio. The concept of hope used in this study is defined as a multidimensional dynamic life force characterized by a confident, yet uncertain expectation of achieving a future that, to the hoping person, is realistically possible and personally significant (Dufault & Martocchio, 1985: 380). Hope is also seen as a holistic phenomenon, involving a complexity of thoughts, feelings and actions. Furthermore, Dufault and Martocchio describe hope as consisting of six dimensions; affective, cognitive, temporal, contextual, affiliative and behavioral dimensions, surrounded by two spheres; the generalized and the particularized hope (Dufault & Martocchio, 1985). In Paper 1enclosed as Appendix 9.1, the multidimensional model of hope is described in detail. The generalized dimension of hope is found to be comforting to the hoping person, while particularized hope

is linked to something concrete or tangible (Dufault & Martocchio, 1985). Travelbee defines hope as a mental stage characterized by the desire to achieve a goal, combined with some degree of expectation that it is achievable (Travelbee, 1971).

In Norway, researchers, Vibeke Lohne and Tone Rustøen, have made a significant contribution to the field of hope through their research and theory development. Within the nursing profession, there has been a growing interest in the phenomenon of hope. This may be due to the increasing proportion of chronically ill people. Loss of functions and roles, and often an unpredictable future could lead to the experience of hopelessness (Rustøen, 2001). Hope can make it easier to cope with such situations. Hope has been measured in the general Norwegian population demonstrating that participants who were satisfied with their own health reported higher levels of hope than those who were less satisfied with their health (Rustøen, Wahl, Hanestad, Lerdal, Miaskowski & Moum, 2003).

2.2 **Hope as a resource**

In this thesis hope is also seen as a psychosocial resource (Westburg, 2003). As stated in Paper 1 (Appendix 9.1.), literature suggests that hope has a strong impact on people dealing with the burden of disease, more than any other factors (Travlebee, 1971). Hope is seen as a crucial factor for not giving up, and at the same time providing the strength to cope with losses, tragedies, boredom, loneliness and suffering (Travlebee, 1971). Rustøen suggests that hope, gives an inner strength and energy, and helps the individual to proceed in life (Rustøen, 2001). The experience of hope is therefore seen to be connected with an experience of meaning in life (Haugan, 2014b).

2.3 **Hope as a light for the future**

The "future" is experienced as a prospect vision, independent to whether the life expectancy is short or long (Rustøen, 2001). Rustøen highlights that a person with hope is able to see that there is a future even if you have to live with disease and suffering. One would expect elderly to have a decreased hope because of their serious health condition. Nevertheless, studies on the sensation of hope among people with heart failure and cancer have shown that patients with cancer and heart failure had higher score of hope than the general population (Rustøen, 2005, Utne et al., 2008). Hence, this might indicate that older people will adapt to their situation, and are thankful for every extra day. In addition, old nursing home patients might

appreciate other things than they did before (Rustøen, 2008). Another explanation may be that having a serious disease makes hope more applicable.

Much of the existing nursing research regarding hope is related to patients with serious somatic illnesses or injuries and palliative patients, and hope is often related to the patient's experience of hope (Rustøen, 2001, 2008; Rustøen, Howie, Eidsmo & Moum, 2005, Lohne 2006, 2008). Few studies explore hope among nursing home patients (Haugan, 2014b). Paper 2 (Appendix 9.2) elaborates on the literature describing hope in patients with multimorbidity, palliative patients as well as nursing home patients (Haugan, Utvær & Moksnes, 2013).

2.4 Symptoms and quality of life

Hope in relationship to health and quality of life are two concepts with many common features (Rustøen et al., 2003). Quality of life as seen by Mæland, is a larger and more comprehensive concept than health (Mæland, 2009). The following concepts might be found in the definition of quality of life; health status, physical functioning, symptoms, psychological adjustment, well-being, and life satisfaction (Rustøen, Cooper & Miaskowski, 2010). Health can be understood as one's physical condition, while quality of life refers to mental and emotional dimensions of human life and the more subjective part of the health concept, which only the person experiencing it can define (Rustøen, 2001).
The theory of health by Mæland (2005) is based on the World Health Organization`s definition, and shows that health is a state of complete physical, mental and social well-being. In this state of well-being, hope, desire, and resilience contributes to the sense of comfort which is a part of well-being (Eriksson, 1976). The importance of health in relation to quality of life varies in the life cycle, and is of increasing importance when growing older (Anderson & Burckhardt, 1999). To what degree people experience that their illness influences their health will vary (Espnes & Smedslund, 2012). Social functioning is perhaps the most important health aspect (Mæland, 2009). Here a study shows that self- assessed health was the most prominent variable to predict hope (Rustøen et al., 2003). Symptom severity and quality of life can be seen as independent variables (Appendix 9.1 and 9.2), and in this study the following definitions were used:

Symptoms are a derivation from normal function or feeling, noticed differently among people. The definition applied in this study is as following "*Any subjective or objective*

evidence of disease apparent to the patient, healthcare worker and others. Anxiety, low back pain, and fatigue are all symptoms; only the patient can perceive them" (based on Medicine.net, 2017)

Quality of life

The World Health Organization defined quality of life with reference to the importance of having a perspective beyond disease and morbidity (Rustøen, 2001). Therefore, the definition applied in this study is as follows: "*Quality of life is individuals` perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns*" (World Health Organization, 2017). The starting point is the idea that quality of life is both subjective and multidimensional, involving factors such as physical and physiological challenges, social relationships, environment and spirituality (Rustøen, 2001).

3 Research question

3.1 Overall aim and overall research question

The overall aim of this study is to explore and elaborate on the concept of hope for cognitively intact nursing home patients in Norway in relationship to symptom burden and quality of life. The research question is therefore: Does hope have an impact on nursing home patients` experience of quality of life and symptom burden?

3.2 Aim and research question paper 1

The aim of paper 1 is to present the theoretical framework and previous research that sheds light on hope in relation to physical and emotional symptoms, and quality of life amongst older adults in nursing homes. In a qualitative approach the research question in paper 1 is: Does hope have an impact on the experience of quality of life and symptom burden in nursing home patients?

3.3 Aim and research question paper 2

The aim of paper 2 is to investigate the impact of hope associated to physical and emotional symptoms, and quality of life in cognitively intact nursing home patients.

The research question in paper 2 is: Is there a correlation between hope and symptoms, and hope and quality of life?

The hypothesis are as follow:

H1: There is an association between hope and different symptoms.

H2: There is an association between hope and quality of life.

4 Methods

In this study both a qualitative and quantitative approach is used to shed light on the overall research questions.

The study population in this thesis is cognitively intact patients/older adults living in nursing home settings.

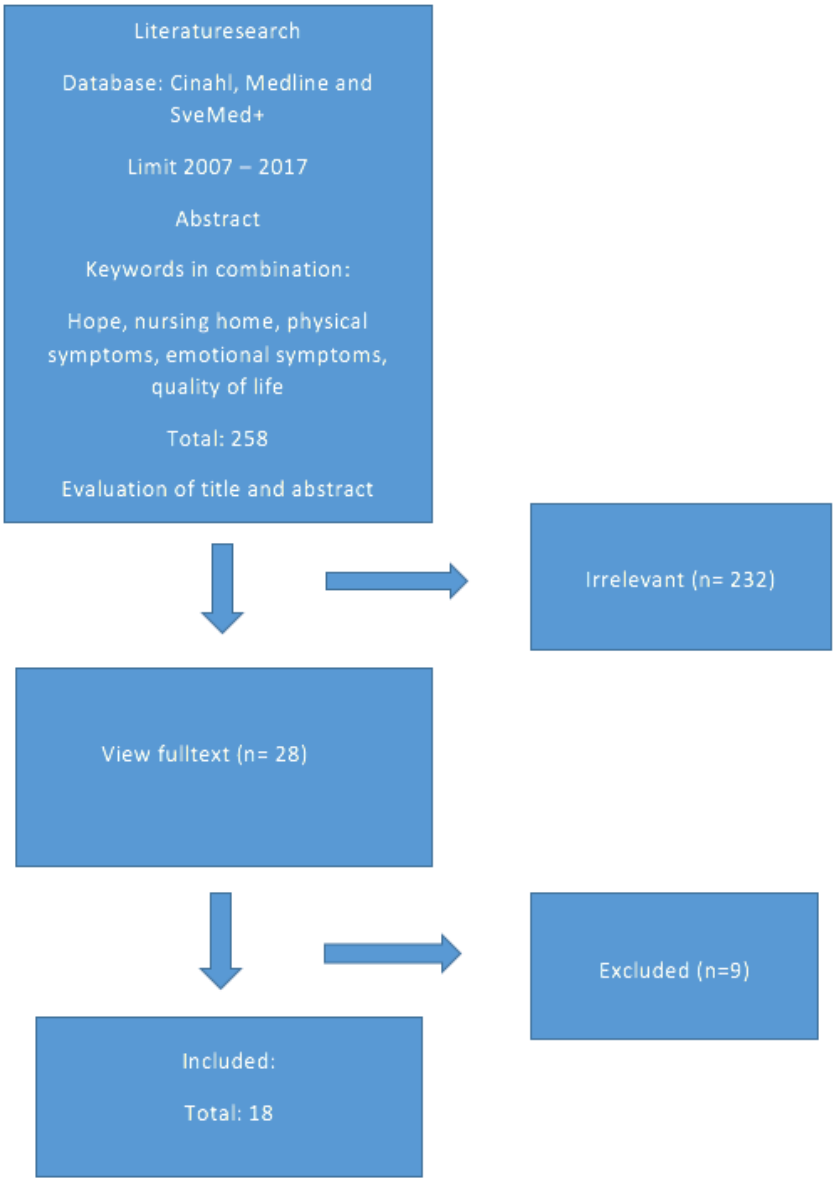
Here the qualitative methods seek to understand the topic in a broader context and present relevant research. This method will ensure structured search for literature that will form the knowledge base (Aveyard, 2014). Based on a systematic literature search a phenomenological approach is used, and data has been analyzed and organized in categories and into two clusters. Interpretation of literature that relates to a particular topic search in order to get a broad understanding and overview of the topic (Aveyard, 2014).

Quantitative method was conducted to investigate hope in relation to symptoms and quality of life. Cross- sectional design is applied, and data has been analysed by descriptive, correlation and regression statistics (Singh, 2007).

4.1 **Paper 1 (Appendix 9.1)**

The purpose of the literature searches focusing patients` experiences of hope, was to investigate and suggest an understanding of hope in relation to common symptoms and quality of life. Data for this study is based on a structured literature search using the following databases; OVID, Cinahl, Medline and SweMed+. The search was limited to the period between 2007-2017, and only English and Scandinavian languages were selected. Both theoretical and empirical research articles were included. Combinations of the following keywords were used: nursing home, hope, physical symptoms, emotional symptoms, and quality of life. The process of the literature search is illustrated in Figure 1.

Figure 1: Flow diagram of search



4.2 Paper 2 (Appendix 9.2)

Data was collected in 20 municipalities in Norway as a part of a larger survey among cognitively intact nursing home patients (Haugan, 2013). Professor Gørill Haugan has published the majority of the dataset, except the dataset included in this current study.
A sample of 250 nursing home patients, residents of 44 nursing homes met the inclusion criteria; 1) long-term residents in nursing home care granted by local authority`s, 2) residential time of minimum six months, 3) a responsible doctor and nurse approved consent competence, and 4) patients were capable of being interviewed (Haugan, 2013). Long-term

nursing home care was defined as 24-hour care (Haugan, 2013). Patients suffering from dementia, short-term care patients and rehabilitation patients were excluded. 202 patients were included after giving informed consent.

Three trained researchers through one-on-one interviews using a structured questionnaire (Haugan, 2013:39) collected data during the years 2008 and 2009. Each researcher read the questionnaire, including 130 items, for the participants, and completed the form according to the responses (Haugan, 2013). Hope was measured by the Herth Hope Index (HHI), a shorter version of Herth Hope Scale (HHS) based on the definition of hope developed by Dufault and Martocchio (1985). HHI includes three subscales defined as; 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness (Herth, 1991). HHI was found to be a reliable and valid instrument for assessing hope in nursing home patients (Haugan et al, 2013).

Common symptoms were assessed by the palliative care questionnaire QLQ-C15-PAL. This is a15 items version of the EORTC QLQ-C30, including two multi-item functional scales, two multi-item symptom scales, five single-item symptom scales, and one question referring to overall quality of life (Haugan, 2014a:1032). Item 7 and 11 are labeled *fatigue*, while item 13 and 14 are labeled *emotional functioning* (Groenvold & Petersen, 2006) (Appendix 9.5).

Cross-sectional data included in paper 2 were analyzed by descriptive, correlational and multiple regression statistics using PASW version 18 (PASW Statistics, 2015). To investigate the connection between hope, common symptoms and overall quality of life, Pearson`s correlational was used. Regression analysis was used to estimate the value of hope based on the value of physical or emotional symptoms or quality of life. Univariate linear regression analysis were performed to examine the impact of the independent variables where hope was set to be a dependent variable. Independent variables such as predominant symptoms or the experienced quality of life with significance (p-value < 0,05) were included in multiple regression analysis (Singh, 2007: 182). Multiple regression analysis was used to examine the relationship between hope and the relevant common symptoms and perceived quality of life. Beta values were computed to give an estimate of the relative impact each independent variable has on the dependent variable, which is hope. Another benefit of the regression analysis is that it predicts the level of hope related to physical and emotional symptoms and quality of life.

4.3 **Limitation of the study**

The study has several limitations. Literature shows that the use of self-reported data often leads to a recall bias (Patton, 2002). Response bias on the other hand is one of the most common phenomena. Leading questions or social desirability might be experienced (Singh, 2007). Additionally, a total of three researchers assisted the participants completing the questionnaires. This might have caused bias into the respondents` reporting, although statistical tests showed no significant differences (Haugan, 2013).

Two scales were used in this study, QLQ-C15-PAL and the Herth´s Hope Index. Both were part of a questionnaire comprising of 130 items. This large amount of questions, given to elderlies with a restricted ability to concentrate, can cause a possible bias (Haugan, 2013). Therefore, the researchers were reading the questionnaire for the participants. By that, the participants might have replied in a socially expected manner (Patton, 2002).

Detailed information about limitation of part 1 and 2 of the study is found in paper 1 and paper 2 (Appendix 9.1. and Appendix 9.2).

4.4 **Reliability and validity**

Test reliability shows the extent to which an instrument measures the same results on repeated trials. It says something about the study`s accuracy. According to Singh (2007), reliability measures are related to the stability, internal consistency and equivalence of the items in the scale. The most common method used for measuring internal consistency is Cronbach α. In this study Cronbach α was 0,76 indicating an acceptable level of inter-item measurement consistency.

Internal validity assesses sample bias, information bias, and statistical validity (Singh, 2007). The sample is taken directly from the target group. Information bias may occur if patients report incorrect answers. In this study that might be due to researchers reading the questionnaire. Statistics validity is dependent on the use of proper statistical tests in the study. The Herth Hope Index applied in this study is found to be valid in nursing home patients in Norway (Haugan et al., 2013).

External validity signifies the extent to which a research study can be generalized to other situations (Singh, 2007). This requires that internal validity is present.

4.5 Ethical issues

This study was submitted for ethical approval from The Regional Committee for Medical and Health Research Ethics in Central Norway (Ref.no.4.2007.645) (Appendix 9.3) and was accepted by the Norwegian Social Science Data Services (Ref.no 16443) (Appendix 9.3), as well as the 44 nursing home management units. All the participants were required to provide informed consent (Haugan, 2013:39). The informants were given the option to voluntarily withdraw their informed consent, and their personal data has been kept strictly confidential throughout the study.

5 Main results

The results of this study are described in detail in Paper 1 (Appendix 9.1) and Paper 2 (Appendix 9.2). Therefore, in this chapter only the main results will be presented.

5.1 Hope: general findings

The general findings indicate that hope is seen as an essential coping resource among older adults with chronic illnesses, and among palliative patients. Hope, as a multidimensional concept, is found to be future oriented, providing strength, and has the ability to change (Dufault & Martocchio, 1985). Studies suggest that hope has a positive impact on how patients cope with suffering and illnesses, and that they tend to experience greater hope than their dependents. The literature search showed that hope is essential, and that it has a strong impact in times of despair (Paper 1). Palliative patients were found to be hopeful, and that hope was not lost, but rather relevant and improving (Paper 1). Findings of hope described in long-term care residents indicate that hope is not lost but rather relevant and possible to achieve.

5.2 Hope in relationship to physical and emotional symptoms

Physical and emotional symptoms burden among nursing home patients are found to be high (Haugan, 2014b). In Paper 1 hope was found to strengthen and be an important resource through suffering and illnesses, while physical and emotional symptoms were found to have a connection to hope among nursing home patients. Hope shows a significant association to the following symptoms; nausea/vomiting, emotional functioning, insomnia. These findings are presented in Paper 2. The results show a moderate correlation between hope and emotional

symptoms (Paper 2). While the aim of the study was to explore whether there is a relationship between hope and symptom burden, this research also revealed that insomnia shows a negative relation to the level of hope (Paper 2).

5.3 Hope in relationship to quality of life

Hope is in various studies suggested to have an influence on quality of life (Paper 1). Hope is among patients described to be a coping mechanism improving quality of life, and a positive resource to hold on to (Duggleby & Wright, 2004). In this current study a relatively strong correlation was found between hope and quality of life in nursing home patients.
While the aim of the study was to explore whether there is a relationship between hope and quality of life, this research also revealed that quality of life displays a positive impact on the level of perceived hope (Paper 2).

6 Discussion overview and practical implications

This section includes the main discussion representing a brief summary based on the discussion section in Paper 1 and Paper 2 (see enclosed in the Appendix 9.1. and 9.2).

6.1 Hope in cognitively intact nursing home patients

The current study found hope to be an important factor in nursing home patients in relation to symptoms burden and quality of life (Paper 1). The hope mean score in this population is within the range of hope measured among palliative patients and patients living with chronic illnesses (Haugan et al, 2013; Rustøen et al., 2003; Benzein & Berg, 2003; Rustøen, et al., 2004). This indicates that nursing home patients are not experiencing less hope than other groups of patients. While the focus of hope might change from getting better and living longer, to avoid suffering and experiencing a peaceful death by the end-of life, the level of hope seems to stay within the same range. Based on the retrieved data hope can be found to be crucial for not giving up in difficult life situations (Paper 1).

6.2 The relationship between symptoms and hope

Based on the data analyzes in Paper 2 one can see a relation between hope and symptom burden (Paper 2), where the most significant symptoms proved to be nausea/vomiting, insomnia and emotional functioning. The results suggest that nursing home patients are

suffering from insomnia, which has a negative impact on their level of perceived hope (Paper 1). Therefore, sustaining and restoring hope might be important for healthy living for patients living in nursing homes. Greater hope is associated with better adjustment to chronic illnesses (Madan & Pakenham, 2014), and might also have a positive effect on the subjective experience of plagues.

6.3 The relationship between quality of lift and hope

In this study quality of life was found to have a significant positive relation to hope in cognitively intact nursing home patients (Appendix 1). This indicates that nursing home patients might experience some degree of quality of life even if they suffer from several chronic illnesses and losses. Studies suggest that patients suffering from illnesses are generally hopeful, (Paper 1 and Paper 2), as with the general Norwegian population (Rustøen et al., 2003). Paper 1 and Paper 2 indicate that the environment might influence the level of hope. The nurse-patient interaction is found to relate directly to the nursing home patients' experience of hope (Haugan, 2014a), and therefore a focus on nurses` knowledge and understanding of how to nurture hope in nursing home patients is needed.

6.4 Implications for the findings of the study

The practical implication of this study is the increased knowledge and awareness of hope as significantly associated with nursing home patients` experienced quality of life and symptom burden. Further research should focus on different ways nurses might support patients to maintain and increase their experience of hope. This research is a follow up on a large study by professor Gørill Haugan`s research on self-transcendence (Haugan, 2013). Therefore, the study carries both an exploratory and interpretive nature, as well as it raises a number of opportunities for future research, such as to investigate interventions nurses can perform in facilitating hope in nursing home patients. Research is also needed to measure the effect of these actions.

7 Conclusion

The overall conclusion is that the concept of hope in relationship to physical and emotional symptoms and quality of life in cognitively intact nursing home patients can be defined as a concept consisting of multiple dimensions. Hope is found to be an essential resource through all phases of illness, including the end of life, and an important resource for coping with chronic and terminal illnesses. Hope is furthermore found to have a significant association in nursing home patients, and is related to quality of life and symptom burden. Furthermore, as Paper 1 shows, nursing home patients are marked with a high level of physical and emotional symptom burden.

Paper 1 presents the theoretical framework and sheds light on hope in the relationship to physical and emotional symptoms and quality of life. The study concludes that hope is related to the experience of quality of life and symptoms in nursing home patients. Here the analysis indicated that hope is an essential coping resource among nursing home patients characterized by multimorbidity and palliative old patients. Hope has further been found to be a multidimensional concept that is future oriented, providing strength with the ability to change (Dufault & Martocchio, 1985). More detailed findings can be found in Paper 1.

Paper 2 shows the impact of hope in relationship to quality of life and physical and emotional symptoms. As paper 2 (Appendix 9.2.) shows there is a significant correlation between hope and symptom burden, and hope and quality of life. The analysis showed a significant correlation in both independent variables. The symptoms revealing significant correlations were; nausea/vomiting, emotional functioning and insomnia. Here the multivariate analysis displayed that insomnia negatively correlate with hope, while the self-reported quality of life exposed a positive association to hope.

More research is needed to investigate nursing staff intervention to foster hope in cognitively intact nursing home

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9 Appendix

9.1 Paper 1

The value of hope for cognitively intact nursing home patients

(following the guidelines of *European Geriatric Medicine)*

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Abstract

Introduction: Hope is regarded as a dynamic multidimensional concept, which changes over time and across important life events. Frailty and numerous diagnoses and diseases often characterize nursing home patients. Hope, and the process of hope, are viewed as important for healthful living and quality of life. Efforts to assist nursing home patients to achieve or maintain hope may help ease the symptom burden and foster quality of life.

Aim: To explore hope in relation to symptoms and quality of life in nursing home patients

Method: In this study a literature search was conducted using the electronic databases OVID, Cinahl, Medline and SweMed+. Keywords used in combinations when searching the databases were; *hope, nursing home, physical symptoms, emotional symptoms and quality of life.*

Results: The literature indicates that hope is an essential coping resource among older adults with chronic illnesses and among palliative patients. Hope, as a multidimensional concept, is found to be future-oriented, providing strength, and has the ability to change. Hope is associated with improved quality of life, and is found to be possible to achieve.

Conclusions: Hope is an important resource for patients experiencing multiple diseases, and facing the end of life. For nursing home patients, who often are characterized by a heavy physical and emotional symptom burden, the focus might not be on getting better, but to find comfort, peace and to maintain relationships. According to the studies examined, hope is positively associated with health and quality of life.

Introduction

The number of older adults is increasing significantly worldwide, and will continue to grow. Between 2015 and 2050, the proportion of the world's population over 60 years of age will nearly double, from 12% to 22%, with the segment representing those over 80 years of age increasing at the fastest rate (1). In high-income countries, rates of severe disability among the elderly have declined over the past 30 years, but no significant change in mild to moderate disability over the same period has been found. If the elderly experience these extra years of life in good health, and live in a supportive environment, the ability to take part in activities they value will be little different from that of a younger person. The implications for older people and for society are more negative if these added years are dominated by declines in physical and mental capacity (1).

The Nordic countries have built welfare states founded on shared values that will ensure citizens equal access to various welfare commodities. The demographic changes have caused an increased focus on health and care for the elderly, with a major task identified; to help maintain good health. These demographic changes will undoubtedly have an impact on how health care services will need to be organized and developed (2). In Norway, the number of people aged over 70 constitutes more than 11 percent of the population. This percentage will rise relatively quick, and it is assumed that in year 2060 approximately 19 percent of the population will be 70 years or older. The fastest growing age groups, will, as in the rest of Europe and the World, be those aged 80-89 years. This group is expected to increase from 4 percent in 2016 to about 10 percent, and the population over 90 years old, will increase from 0.8 percent to 3 percent in 2060 (3). This prognosis predicts a future situation that raises a number of challenges that need to be addressed today.

Issues such as physical illness and frailty at the end of life may reduce functioning among older people, leading to increased need for nursing home care (4). In Norway, there are approximately 33.000 nursing home residents (5). Nursing home patients need daily care, and their life-situations are marked with a high rate of disease and significant disability. The caregivers' qualifications and motivation is crucial for the elderly to be well cared for (6). Therefore, an investment in both availability and quality in nursing home care is

needed. Common to many of the studies that have been carried through on older people is that the studies focus on physical health and cognitive functions, while the ageing population's need for spiritual support, such as hope, tends to be ignored (7).

Hope can be a crucial factor for not giving up, and it can provide the strength to cope with losses, tragedies, boredom, loneliness and suffering (8). This points to hope as a necessary factor to perceive life as good to live (9). It gives inner strength and energy, which can help people to move forward in life. Hope can also give strength to solve problems (9), and can serve as a strong coping resource that empowers people to deal with, and resolve, threatening situations. Loss of functions and roles, and often an unpredictable future, could lead to the experience of hopelessness (9). Nursing home patients suffer from several diseases and experience multiple losses; thus hope might be a resource and strength to make life easier to live.

The theoretical framework

The concept of hope has been defined a number of times from different perspectives throughout the years (10). From a psychological perspective, hope is a fundamental function throughout life (11). Fromm argues that hope is a basic condition of life, and one of the key elements in order to change direction in life, so that it becomes more livable (12). Hope is viewed as a spiritual dimension that is understood to have an effect on health (13).

The nursing theorist Joyce Travelbee has defined hope as a mental stage, where the desire to reach a goal is combined with a certain level of expectation that it is achievable (8). Whoever lacks hope sees no solutions to the problems or views to changes or improvements in life. Hope can give strength to cope with losses, tragedies, loneliness, and suffering, and thus be a vital factor for not giving up (8).

Dufault & Martocchio view hope as multidimensional (14). They propose a theoretical conceived model from a longitudinal study of 35 elderly cancer- and 47 terminally ill patients. The themes that emerge from these two studies generate a Multidimensional Model of Hope (MMH). The process of hope is viewed as a complexity of many thoughts, feelings and actions that change over time (14). Their definition of hope has often been quoted in nursing research (15 - 18), and will be the guiding definition in this thesis.

Dufault & Martocchio`s definition of hope is:

> "A multidimensional dynamic life force characterized by a confident, yet uncertain, expectation of achieving a good future which, to the hoping person, is realistically possible and personally significant" (14 p. 308).

This definition highlights the multiple dimensions of hope, and how hope becomes a "life force".

Fig. 1 Multidimensional Model of Hope (MMH)

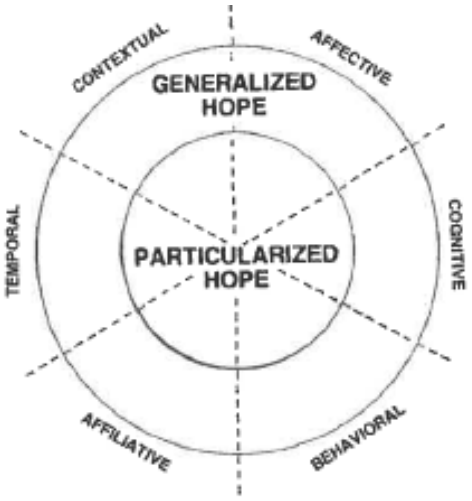

Figure 1. Spheres and dimensions of hope.

(Ref.: Dufault &Martocchio, 1985)

Dufault & Martocchio argue that hope is a process consisting of two spheres and six dimensions (14). One sphere is a generalized hope; a general feeling which, by providing a positive glow of life, protects the person hoping. The second sphere is the particular hope, attached to an object that can be abstract or concrete. They claim that hope is both generalized and particularized at the same time. The six dimensions are 1) an affective dimension, 2) a cognitive dimension, 3) a contextual dimension, 4) a temporal dimension, 5) an affiliative dimension, and 6) a behavioral dimension (14).

The affective dimension focuses on many different emotions that are part of the hope process. It can be both optimism and uncertainty about hope in the future. A feature of this dimension is the waiting aspect (14). How to assess reality in terms of hope is central to the cognitive

dimension (14). If hope no longer is founded on reality, one will still continue to seek reasons to hope. The hope will then either slowly change, or one will seek other sources of hope (9). It is important that the starting point is the reality of the hoping person, and not that of relatives or health professionals (14). Hope will be temporal in the sense that it implies an expectation to achieve something in the future (14). Hope is inherently forward looking in the sense that one can see that there is a future even if it is lived with disease and suffering (9). The contextual dimension of hope is about the person` life situation, and how this affects hope. Hope is not seen as a stable trait, but rather as a state that depends on the context. The environment influences us, and therefore plays a part in human hope. Optimistic surroundings can strengthen hope, but optimism alone will not provide hope (9). The importance of being involved with other people in order to maintain hope is primarily related to the affiliative dimension. Dufault & Martocchio here focus on social interaction, interdependence and closeness to others (14). They underline the connection of good interpersonal relations to hope, either to other people or a religious affiliation. Faith is closely linked to hope. The behavioral dimension of hope is related to which actions the hoping person chooses. The actions can take place at the psychological, physical, social or religious level (14). Actions at the psychological level may be mental activities, like planning, making decisions or setting goals (14, 8). The physical plane addresses specific actions, such as activity, rest, or eating a proper diet (9). Actions on the social and religious level might be about having relationships with other people, God, animals or nature (14)**.**

Symptoms and quality of life

Symptoms are described as a derivation from normal function or feeling, noticed differently among people (19). Common physical symptoms among nursing home patients are pain, dyspnoea, incontinence and fatigue, and common emotional symptoms are anxiety and loneliness (20).

Quality of life is defined as "an individual perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals" (1). Factors that enhance or promote quality of life can be both subjective and objective. Perceived good health is a determining factor in quality of life (21).

Aim

As the aging population will have an increasing significance on society, factors that influence their life experience must be considered. Therefore, the aim of this study is to present theoretical framework and previous research that sheds light on hope in relation to physical and emotional symptoms and quality of life among nursing home patients. The research question is: Does hope have an impact on the experience of quality of life and symptom burden in nursing home patients?

Method

A structured literature search was used to give an overview of literature relevant for the research question, using the following databases; OVID, Cinahl, Medline and SweMed+. The search was limited to 2007 – 2017. Only publications in English and Scandinavian languages were included. Both theoretical and empirical research articles were included. Combinations of the following keywords were used: *nursing home, hope, physical symptoms, emotional symptoms, and quality of life.*

The literature search gave 258 results, of which 18 were found relevant to the research question. Articles that exclusively view older adults with cognitive impairment were not included. In addition, other articles were included because they elaborate on the topic. These were found through further search from some of the studies that were included. Using a phenomenological approach, data was organized into two clusters identified through invariant themes based on the research question (22). The articles were organized into two tables; hope and symptoms, and hope and quality of life (Table 1 a Table 2)

Results

The 18 studies included represent research conducted on hope, symptoms and quality of life among older adults and palliative and chronic ill patients in different countries. The populations are experiencing a variety of medical diagnoses such as; cancer, multiple sclerosis, muscle endurance, pain, dyspnea and anxiety. Hope is viewed as a multidimensional complex construct, with an anticipation of a future that is good (23), and is found to be one psychological resource important for older adults in coping with life`s adversities (24).

Hope related to physical and emotional symptoms

The level of emotional and physical symptoms is found to be high among cognitively intact nursing home patients (4, 25). A study among 296 people with chronic illness found that greater hope was associated with better adjustment to their disease (26). The resources for hope were found to be both internal and external processes (27). Hope was found to mediate the relationship between health status and psychological distress in a meaningful way, indicating that hope is an important resource with a significant impact on quality of life (16), and the focus of hope was found to be on comfort, peace and maintaining relationships (28). Physical symptoms, such as pain and dyspnea, were not associated with reduced quality of dying indicating the focus might be on nonphysical sources at the end- of- life (29). Anxiety is associated with lower perceived quality of life, yet hope in relation to anxiety among nursing home patients is a less studied variable (30). Among nursing home patients meaning in life is associated with functional and emotional well- being (20) (Table 1).

Hope related to quality of life

A study among long term care residents with cancer indicated that they were generally hopeful, and that hope was relevant and possible to achieve (31). Palliative patients are found to require hope to cope with their stress and improve their quality of life (32), and holding on to the positive reaching for the future (33). Environmental conditions were found to have an indirect effect on quality of life via health satisfaction (34), and nurse- patient interaction was found to directly relate to the nursing home patients` experience of hope (20) (Table 2).

Table 1 Article overview - Hope related to physical and emotional symptoms

Author	Title	Aim	Method	Results
Bautmans, I., Njemini, R., Predom, H., Lemper, J. C. & Mets, T. (2008)	Muscle endurance in elderly nursing home residents is related to fatigue perception, mobility and circulating tumor necrosis factor-Alpha, interleukin-6 and heat shock protein 70	To explore the relationships between muscle endurance, self-perceived fatigue and mobility in elderly nursing home patients without severe cognitive dysfunction	Qualitative study – an exploratory design. A sample of 77 residents	The sensation of fatigue in frail elderly nursing home patients is related to lower muscle endurance, which is related to reduced mobility.
Caprio, A.J., Hanson, L. C., Munn, J. C., Williams, C. S., Dobbs, D., Sloane, P. D. & Zimmerman, S. (2008)	Pain, dyspnea, and the quality of dying in long-term care	To evaluate the relationship between pain, dyspnea and family perceptions of the quality of dying in long-term care	Qualitative study – interviews from facility staff and family caregivers for 325 deceased residents	Pain and dyspnea were not associated with a poorer quality of dying. To improve the quality of dying should focus on the alleviation of nonphysical sources, not only on physical symptoms.
Creighton, A. S., Davison, T. E. & Kissane, D. W. (2017)	The correlates of anxiety among older adults in nursing homes and other residential aged facilities: a systematic review	To synthesize and summarize the studies examining the correlates and predictors' of anxiety in older adults living in residential aged care	Qualitative study- a systematic review. 34 studies were included. A sample of 1 543 554 participants	Lower perceived quality of life is associated with anxiety. Hope is a less studied variable in association with anxiety among older adults in nursing homes and other residential aged care facilities.
Duggleby, W., Holtslander, L., Steeves, M., Duggleby-Wenzel, S. & Cunningham, S. (2010)	Discursive meaning of hope for older persons with advanced cancer and their caregivers.	To explore how hope is socially constructed by print media, and to explore the hope of older palliative patients, their significant other and primary nurse.	Qualitative study – analyze and explore 43 newspaper articles, open-ended interviews with three triads (patient, sign.other, nurse)	Newspaper articles was conveying that hope for a cure was the only legitimate hope existing for persons with cancer. Their own focus of hope were on comfort, peace and maintaining relationships at the end of life.
Duggleby, W.,Hicks, D., Nekolaichuk,C.,Holtslander, L., Williams, A., Chambers, T. & Eby, J. (2012)	Hope, older adults, and chronic illness: a metasynthesis of qualitative research.	To report a review of qualitative research studies exploring the hope experience of older persons with chronic illness.	Qualitative study – a metasynthesis review. 20 studies were included. A sample of 305 older adults	Hope may change base on its interactions with suffering with two interrelated processes of transcendence and cognitive appraisal. Resources for hope are both internal and external.The concept of hope may differ for older adults than for younger adults.
Hanson, L. C., Eckert, J. K., Dobbs, D., Williams, C. S., Caprio, A. J., Sloane, P. D. & Zimmerman, S. (2008)	Symptom experience of dying long-term care residents	To describe the end-of-life symptoms of nursing home and residential care/assisted living residents, compare staff and family symptom ratings	Qualitative study – interviews. A sample of 674 staff and 446 caregivers for deceased residents	A study among staff and caregivers for dying residents points out that nursing home patients have high rates of physical symptoms and need for more- effective palliation of symptoms.
Haugan, G. (2014b)	Meaning-in-life in nursing-home patients: a correlate with physical and emotional symptoms.	To investigate the associations between meaning-in-life and physical, emotional, functional and social well-being in a cognitively intact nursing-home population	Quantitative study – a cross-sectional design. A sample of 202 nursing home patients	The level of physical and emotional symptoms among cognitively intact nursing home patients are high and detriment to their quality of life. The study suggest that meaning- in- life is an important resource to reduce symptoms and nurture quality of life.
Haugan, G. (2014c)	Meaning-in-life in nursing- home patients: a valuable approach for enhancing psychological and physical well-being?	To investigate the associations between meaning-in-life and physical, emotional, functional and social well-being in a cognitively intact nursing-home population	Quantitative study – a cross-sectional design. A sample of 202 nursing home patients	The study suggest that meaning in life relate directly to functional and emotional well- being, and an indirect influence on social well- being.
Madan, S. & Pakenham, K. (2014)	The stress-buffering effects of hope on adjustment to multiple sclerosis	To examine the direct and stress-moderating effects of dispositional hope and its components (agency and pathways) on adjustment to MS	Quantitative study – a sample of 296 people with multiple scleroses	The study indicated that greater hope was associated with better adjustment to multiple scleroses, indicating that hopeful thinking can serve as a buffer against stressors and foster adjustments.

Table 2 Article overview- Hope related to quality of life

Author	Title	Aim	Method	Results
Alidina, K. & Tettero, I. (2010)	Exploring the therapeutic value of hope in palliative nursing.	To explore and analyze the meaning and perception of hope in palliative patients.	Qualitative study- a comprehensive literature review	The MMH has contributed to the understanding of hope in palliative settings. Most terminally-ill patients require hope to cope with their stressors and improve their quality of life..
Ellefsen, B. (2012)	Living as dying	To acquire knowledge about how older patients with terminal illness experience and handle their situation.	Qualitative study - a descriptive design. In-depth interviews. A sample of ten terminally ill patients	The terminal ill patients expressed their experiences and four theme were identified. The story of illness (about hope and despair), enduring life, holding on to the positive and securing the future.
Gibson, G. & Gorman, E. (2012)	Long-term care residents with cancer and their health care providers reflect on hope.	To examined hope in long- term care residents with cancer from the perspectives of both residents and health care providers.	Qualitative study – an exploratory, descriptive design. Interviews. A sample of 8 health care providers, 10 residents	The study found that Herth Hope Index scores were high, indicating that the residents were generally hopeful. Hope for the residents diagnosed with cancer were not lost but rather relevant and possible to achieve.
Halvorsrud, L., Kirkevold, M., Diseth, A. & Kalfoss, M. (2010)	Quality of life model: predictors of quality of life among sick older adults	To explore how depressive symptoms, physical function, health satisfaction, age and environmental conditions predict quality of life.	Quantitative study – a cross-sectional study. A sample of 89 older adults receiving community health care in Norway	The quality of life was manifested by significant direct effects of environmental conditions and health satisfaction. Environmental conditions had indirect effect on quality of life, most via depressive symptoms and health satisfaction. No evidence was found for age predicting quality of life.
Haugan, G., Utvær, B. K. S. & Moksnes, U. K**.** (2013)	The Herth Hope Index**— a** psychometric study among cognitively intact nursing home patients	To investigate the psychometric properties of the Norwegian version of the Herth Hope Index among cognitively intact nursing home patients	Quantitative study – a cross-sectional design. A sample of 250 nursing home patients	The results found Herth Hope Index (HHI) to be a reliable and valid instrument for assessing hope in nursing home patients. The HHI might be used to assess hope and changes in the hope process.
Haugan, G. (2014a)	Nurse-patient interaction is a resource for hope, meaning in life and self-transcendence in nursing home patients.	To investigate the associations between hope, meaning in life, self-transcendence and nurse-patient interaction in a nursing home population.	Quantitative study – a cross-sectional design. A sample of 202 nursing home patients	The results indicate that the nurse- patient interaction directly relate to the nursing home patients experience of hope, self- transcendence and meaning in life, and might be an important resource in relation to patients` health and well- being.
Haugan, G.**,** Moksnes, U. K., & Løhre, A. (2016)	**Intrapersonal self-transcendence**, meaning-in-life and nurse-patient interaction: powerful assets for quality of life in cognitively intact nursing-home patients	To investigate the associations of hope, self-transcendence, meaning and perceived nurse-patient interaction with quality of life	Quantitative study – a cross-sectional design. A sample of 202 nursing home patients	Intrapersonal self- transcendence, meaning and nurs-patient interaction were found to be key assets for improving quality of life in cognitively intact nursing home patients
Miller, J. F. (2007)	Hope: A construct central to nursing.	To enhance understanding of the concept of hope from a synthesis of varied perspectives	Qualitative study – a comprehensive literature review	Hope is a multidimensional complex construct with definitions from a variety of disciplines and perspectives. Hope is an anticipation of a future that is good.
Rustøen et al. (2010)	The importance of hope as a mediator of psychological distress and life satisfaction in a community sample of cancer patients	To evaluate the relationships between demographic and clinical characteristics, health status, hope, psychological distress, and life satisfaction and evaluate whether hope mediated the relationship between psychological distress and life satisfaction.	Quantitative study - a longitudinal study A sample of 194 participants	The study found that hope mediates the relationship between health status and psychological distress in a meaningful way. Findings indicate hope as an important resource for cancer patients because it has an impact on their quality of life.

Discussion

Nursing home patients are experiencing a high level of physical and emotional symptoms that are detriment to their quality of life (20). Rustøen (16) suggests that hope gives strength to deal with challenging situations ahead, and is of importance to quality of life. Therefore, maintaining and restoring hope can enrich lives. For nursing home patients hope might be a resource for dealing with their everyday situation, where the focus could be to accept the reality of living with several illnesses, and needing help in daily activities. Hope is found not to be lost when experiencing illnesses, but rather increasing and possible to achieve (31).

This study indicates that nursing home patients might experience increased quality of life even if they suffer from several chronic illnesses, and additionally feel generally hopeful (31). Travelbee (8) suggests that hope is reaching for the future, and is characterized by being forward-looking and realistic. This temporal dimension is directed towards positive expectations to the near future (23), and based on the patients` own perception (14).

The future view among nursing home patients is changing, and the focus might not be on getting better (20), but rather on comfort, peace and maintaining relationships (24, 28). Therefore hope, described in palliative patients and patients suffering from chronic illnesses might be applicable for nursing home patients (18). Dufault & Martocchio (14) describe the cognitive dimension, where the reality of life is changing, and therefore also the focus is on hope. It is of importance to make the hoping person's reality the starting point, even if it deviates from that of the health personnel. To change the direction of hope is a process where emotions and thoughts are being processed, and seek reconciliation with the things that in reality cannot any longer be changed. For nursing home patients, being in the last phase of life, the character of hope might change. Travelbee suggests that hope has to involve a certain degree of realism connected to the outcome of the expectation (8). Meaning-in-life might be an important resource in relation to nursing home patients` physical and emotional health and quality of life (20). Finding meaning and positive reappraisal are important strategies to help older adults with chronic illnesses maintain their hope (27). Facilitating meaning can be an essential component in fostering health and well- being in nursing home patients (20). A study among cognitively intact nursing home patients found meaning, nurse- patient interaction,

and intrapersonal self- transcendence to be key resources for improving quality of life (35). Therefore, studies of hope, show that participants who were satisfied with their own health reported higher levels of hope than those who were less satisfied with their health (15). Dufault & Martoccchio found in their study a positive correlation between hope and health (14). Madan & Pakenham found in their study that greater hope was associated with better adjustment to multiple scleroses (26). As hope is found to be a resource for coping with chronic illness, it might also be an important resource for nursing home patients. For persons with a chronic illness hope has been described as a psychological resource essential to life (27). In line with this nursing home patients might experience hope as a crucial factor for not giving up.

A study among a Norwegian population of older adults receiving community health care shows that quality of life is manifested by the direct impact by environmental conditions and health satisfaction (34). In the contextual dimension, the focus is on how different life situations are a part of hope. Some have resources and circumstances around them that make it easier to stay firm in the hope (9). The focus of hope for older terminally ill cancer patients was on comfort, peace and maintaining relationships at the end of life (28). The actions the hoping person chooses, defined as the behavioral dimension, may be within the psychological, physical, social or religious level (14). To improve the quality of dying in long-term care, the focus should not only be on physical symptoms, but also on the alleviation of nonphysical sources of suffering at the end of life (29). A study among ten older people with terminal diseases describes how they experienced and handled their situation. The result of this is summarized in four themes; the history of illness, enduring life, holding on to the positive, and securing the future (33). The study showed that all the patients strived to hold on to the positive (33).

The character of hope is changing through different phases of life, and is found to be important when experiencing suffering and illnesses, and in the last phase of life. For older adults at the end of life, living with hope is essential, and they expressed a desire to live each day to the fullest until they died (36).

Conclusion

This study has explored the concept of hope, both by presenting a theoretical framework and by an extensive literature search (Table 1 and 2), in relation to symptoms and quality of life. Hope has been defined in multiple dimensions, and as an essential resource through all phases of illness, including at the end of life. Hope is seen as an important resource for coping with chronic and terminal illnesses. Studies found in the literature search indicate that nursing home patients are characterized by a high number of physical and emotional symptoms. A high measure of hope is associated with better adjustment to chronic illness and improvement of quality of life. The changing character of hope suggests that focus might change from getting well to comfort, peace and maintaining relationships. Thus, hope might is an important factor for nursing home patients to increase their quality of life.

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9.2 **Paper 2**

Hope related to symptoms and quality of life in cognitively intact nursing home patients

(Article 2 is following the guidelines of *Geriatric Nursing* (http://www.gnjournal.com))

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Abstract

Hope has as a concept been defined as multidimensional consisting of thoughts, feelings, actions, interactions, time and context. Hope can therefore be expressed through a variety of processes within a person, and is associated with experienced health and quality of life. The aim of this study is to explore hope in relationship to physical and emotional symptoms and quality of life in cognitively intact nursing home patients.

By using a cross sectional design, 202 nursing home patients from 44 nursing homes in Norway were included in the survey, and results analyzed by regression analysis. Findings from this study suggest that hope has a positive association to emotional symptoms and quality of life in cognitively intact nursing home patients, and a negative association to physical symptoms. This study suggests that hope is an important resource for cognitively intact nursing home patients.

Introduction

Demographic projections indicate strong growth in the number of people over 80 years of age worldwide (1). In Norway, it is estimated that 25% of older adults will need nursing homes. Therefore, there is a need for increased investment, both in terms of availability and in quality. Nursing homes, also referred to as long-term care facilities, provide skilled 24-hour medical assistance to people who are unable to handle their basic living needs due to poor health (2). Average lifetime in nursing homes is one to three years, and approximately 48% of all deaths in Norway each year happen in nursing homes (3). This proportion will probably increase, because the average age in nursing homes is increasing.
Nursing home patients suffer from chronic illnesses and losses, and have entered the last phase of life. They are not getting healthier. The literature describing hope in palliative patients might also describe hope in nursing home patients (4).
In this study, hope is defined in accordance with the model of hope described by Dufault & Martocchio (5). Hope is here defined as a multidimensional dynamic life force that is characterized by a confident, yet uncertain expectation of achieving good, which is realistically possible and personally significant (5).

The nursing home population is generally marked with high age, high level of physical symptoms, and multimorbidity (6). Therefore, nursing home patients will be in need of support in personal care, while support in spiritual needs, such as hope, tends to be ignored (7). Here the nurse- patient interaction in nursing homes significantly influences hope in cognitively intact nursing home patients (8).

Nursing literature highlights the importance of hope, and focuses on maintaining, sustaining, and restoring hope in patients (5). Travelbee describes hope as future-oriented, related to choice, desire, trust, and courage strongly linked to dependency on others (9). Hope is understood to be important for healthy living and is described as a substance, something one actually hopes for, and a process, which takes place over time. Hope as a phenomenon is described as future oriented, and as having a positive essence (10). Dufault and Matocchio`s understanding of hope is described as two spheres; generalized hope and particular hope (5). In addition, there are six dimensions. The generalized hope, which is broad in scope, is found to be most dominant and contextual, while the particular hope is linked to a concrete object, being more concerned with the substance of hope (5). The six dimensions of hope are cognitive, behavioral, affective, affiliative, temporal and contextual. Changes within and

among these dimensions describe the processes of hoping (5). The different dimensions might be active in the same person at the same time, and it can be difficult to separate them (10).

Hope is found to be important for healthy living (5), and nurses should therefore assist persons to achieve or maintain hope (10). Elderly patients with advanced illness defined hope as an inner resource and a coping mechanism essential for their quality of life (11). Hope is a general phenomenon important to all humans throughout life (12). Many definitions of hope have been presented in the scientific nursing literature, indicating poor agreement about the concept.

Aim

The aim is to investigate the impact of hope associated to physical and emotional symptoms, and quality of life in cognitively intact nursing home patients. The research question is: Is there a correlation between hope and symptoms, and hope and quality of life? Two hypotheses are therefore tested:

H1: There is an association between hope and different symptoms

H2: There is an association between hope and quality of life.

Material and methods

Study design and participants

A cross-sectional design was applied in this study (13). Data were collected during the years 2008 and 2009 in 20 municipalities in Norway as a part of a larger survey among cognitively intact nursing home patients. A total of 44 nursing homes were included to participate in the study. A sample of 250 nursing home patients met the inclusion criteria (14). The data included in the current study has not been published before.

Inclusion criteria: 1) long-term residents in nursing home care granted by local authorities, 2) residential time of minimum six months, 3) a responsible doctor and nurse approved of their consent competence, and 4) patients were capable of being interviewed (14). Here longterm nursing home care was defined as 24-hour care (14).

Exclusion criteria: 1) Patients suffering from dementia, 2) short-term care patients, 3) rehabilitation patients were excluded.

Data were collected by three trained researchers through one- on- one interviews using a questionnaire (14:39). Each researcher read the questionnaire for the participants, held a

large- print copy of the questions and the alternative answers in front of them, ticked in the form according to their responses (14).

Measurements

The pretested questionnaire that was used included 130 items (14), and 22 items relevant for the research question were included in this study. Two scales, one measuring hope and one measuring common symptoms and quality of life, were used.

Hope was measured by the Norwegian version of the Herth Hope Index (HHI) (15), a shorter version of Herth Hope Scale (HHS) based on the definition of hope developed by Dufault and Martocchio (5). HHI includes three subscales defined as; 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness (16), and contains 12 items using a 4- point Likert response format (from stronger disagree to stronger agree). The score range is from 12- 48, with high scores indicating greater hopefulness. HHI was found to be a reliable and valid instrument for assessing hope in nursing home patients (8).

Common symptoms were assessed by a palliative care questionnaire QLQ-C15-PAL. This 15-item version of the EORTC QLQ-C30 included two multi-item functional scales, two multi-item symptom scales, five single- item symptom scales and one question referring to overall quality of life (6:1032). Relevant for this study were 10 of the 15 items. The responses are rated on a numeric scale from 1 (*not at all*) to 4 (*very much*), except for the global quality of life, which is rated from 1 (*very poor*) to 7 (*excellent*) (6).

Statistical analysis

Data were analyzed using PASW version 18 (17) by descriptive, correlational and multiple regression statistics. Correlation analysis, using Pearson`s correlational coefficient, was applied to look at the association between hope and common symptoms and overall quality of life. Univariate linear regression analysis was performed to examine the impact of the independent variables, where hope was set to be a dependent variable. Multiple regression analysis was used to examine the relationship between hope and the relevant common symptoms and quality of life. Regression analysis explains the impact the independent variables, symptoms and quality of life, have on the dependent variable, hope (18). P values of 0.05 or less were interpreted as statistically significant for all analysis.

Ethics

The study was submitted for ethical approval to The Regional Committee for Medical and Health Research Ethics in Central Norway and accepted (Ref.no. 4.2007.645) (see appendix 9.3). The study was also given approval from Norwegian Social Science Data Services (Ref.no 16443) (see appendix 9.3) as well as the 44 nursing home Management Units. All the participants were required to provide informed consent, and were given the option to withdraw from the study at any time. Their personal data was kept strictly confidential throughout the study.

Results

Sample characteristics of participants

The total sample comprised of 202 (81%) of the 250 nursing home patients. The participants` ages ranged from 65 to 104 years, with a mean of 86 years (SD 7.65). The population comprised 146 (72.3%) females and 56 (27.7%) males. The mean residential time was 2.5 years.

Mean, SD and Cronbach`s α

The Hope score in this study ranged from 12- 48 with mean score 35.14 (SD 4.18). The highest single-item mean-score was found to be "I have short and/or long-range goals", "I can see a light at the end of tunnel", and "I have a sense of direction".

In this study, Cronbach`s α was 0.77, indicating an acceptable level of inter - item consistency in the measurements.

The means and standard deviations (SD) for the QLQ- C15- PAL subscales are listed in Table 1. The most common physical symptoms were found to be fatigue, pain, constipation, and dyspnea. The emotional function showed a high mean score (83.37), and the means for overall quality of life was 65.51 (SD = 23.66) (Appendix 1).

The relationship between hope, physical and emotional symptoms, and quality of life.

The Pearson`s correlational coefficient (r) measures the association between two or more variables, and also whether it is positive or negative (varies from -1 to +1), and the strength of the relationship (13). In this study, hope shows significant negative correlation related to the following symptoms; fatigue, nausea/vomiting, dyspnea and insomnia, and a moderate positive correlation between hope and emotional symptoms (r=0.254). The majority of the physical symptoms did not display significant value in correlation to hope. A relatively strong

positive correlation was found to be between hope and overall quality of life (r=0.346) (Appendix 1).

Regression analysis

In order to analyze whether symptoms and quality of life showed an effect on hope, univariate linear regression analysis was conducted. A significant association between hope and six out of nine independent variables with $p<0.05$ were found. The independent variables indicating to have an influence on hope, were; fatigue (p=0.042), nausea/vomiting (p=0.002), emotional functioning (p=0.000), dyspnea (p=0.031), insomnia (p=0.001) and overall quality of life (p=0.038) (Table 2). These were therefore included in the multiple regression analysis. Two independent variables were shown to have a significant impact on hope. A highly significant positive association ($p<0.01$) between quality of life and hope was found, (b=0.046). Insomnia was found to have a slightly negative impact on hope (b= -0.021).

Discussion

Hope in nursing home patients

This study indicates that cognitively intact nursing home patients experience a moderate level of hope, with mean score 35.1. This coincides with studies among older long-term patients, where hope mean score was between 35.8 and 38.0 (16, 19), and studies among the general Norwegian population, palliative patients, and patients with chronic illnesses (20 - 22).

"I can see a light at the end of tunnel" (mean 32.55), one of three statements with highest hope score in this study among nursing home patients, indicates a positive view of the future. Bondevik found that the majority of elderly people expressed a joy of living (23). The focus of hope might change by the end- of life (5), but the level of hope seems to stay the same. According to Dufault & Martocchio hope is temporal in the sense that it implies an expectation to accomplish something in the future (5).

As already mentioned a study among long- term care residents with cancer found that hope was not lost, but rather appeared to be relevant and possible to achieve (24). This is supported in our study by statement items in statement items in a questionnaire like "*I have short and/or long-range goals"* (mean 32.78), and *"I have a sense of direction* (mean 32.53) having the highest scores among the participants. Hope is found to help older adults cope with chronic and terminal illnesses (11, 16), and if redefined towards the end of life, it could make a significant difference with respect to keeping on or giving up. In similar studies, older patients with terminal illnesses described their hope in terms of not suffering, experiencing a peaceful

death (and life after death), and hope for their families (11). This also applies to nursing home patients, as hope is found to be present even when close to dying (25).
Hope has been proven to give a sense of meaning to seriously ill people, even those with a strong negative prognosis (26, 27). Meaning- in- life is found to be an important resource for nursing home patients with respect to reducing physical and emotional symptoms as well as nurturing quality of life (6).

Hope and physical and emotional symptoms
Hypothesis 1 postulated an association between hope and different symptoms. Here the literature shows that nursing home patients often are subject to chronic illnesses, and found to experience a high level of physical and emotional symptoms (6). Also in this current study, a significant correlation between hope and symptoms could be demonstrated (Table 1). As seen in table 1, where the most significant physical symptoms proved to be nausea/vomiting and insomnia. As seen in table 2 nursing home patients suffering from insomnia were found to experience decreased level of hope. Therefore, appropriate sleep patterns is needed for nursing home patients. Greater hope is associated with better adjustment to chronic illnesses (28), and therefore might also have a positive effect on symptoms. Moderate hope score in our study was followed by lower physical symptom severity and better emotional function. A moderate positive correlation (r=0.254) between hope and emotional functioning indicates, as expected, that hope is a resource for emotional well- being. The level of well- being reported by older adults is found to be high, and no different from that of younger adults (29).
The focus on hope as a process is central in the cognitive dimension of hope (5). A study among older palliative patients found that their focus was on comfort, peace and maintaining relationships at the end of life, and not hope for a cure, as has been claimed by newspaper articles (30). This may be of importance in nurse-patient interaction. Resources for hope were found to be both internal and external (31), suggesting that the environment might influence the level of hope. The nurse-patient interaction is found to relate directly to the nursing home patients' experience of hope (32), and the nurses' presence might influence the patients` experience of hope (27). Optimistic surroundings might strengthen the experience of hope (26). Hope is found not to be static, and it can change over time in response to one`s situation and circumstances (33).

Hope and quality of life

Hypothesis 2 postulated an association between hope and quality of life. Literature shows that factors enhancing, or promoting quality of life, can be both subjective and objective. Perceived good health is a determining factor in quality of life (34). Accordingly, hope seems to be a vital resource for quality of life among cognitively intact nursing home patients, including both physical and emotional health. Most researchers include one or more of the following concepts in their definition of quality of life: health status, physical functioning, symptoms, psychological adjustment, well-being, and life satisfaction (35).

In this current study, quality of life was found to have a significant impact on hope in nursing home patients, and the correlation between hope and emotional function and overall quality of life was found to be stronger than the correlation to physical functions. These findings refer to hope as a phenomenon involving a complexity of thoughts and feelings (5). Symptoms and quality of life was in this current study found to explain 14.8 % (R^2= 0.148) of the concept of hope. This indicates that hope is a comprehensive phenomenon, influenced by different factors. Dufault & Martocchio`s (5) definition of hope as a multidimensional concept attempts to capture this complexity (5).

Based on the hope score nursing home patients reported in this current study, that they experienced an "inner strength", "that life has value", and "each day has potential". This is consistent with previous research, where hope was experienced as a strength and inspiration to carry on (10). Interviews conducted with palliative patients have suggested that hope is defined as an inner resource (36), and a coping mechanism essential for their quality of life (37). This is supported in our study indicating that hope has a stronger association to emotional wellbeing than to physical wellbeing. When the experience of becoming ill is accompanied by hope, the individual is found to focus his/her energy on reestablishing health and wellbeing (38). Hope is an essential dimension for successfully dealing with illness, and for preparing for death (39). This study has revealed that hope might be a vital resource for quality of life among cognitively intact nursing home patients. Nursing staff contributing to quality of life in nursing home patients might strengthen their hope, which will in turn have a positive impact on their lives. Further research on fostering hope in nursing home patients is needed.

Limitations

Quantitative research methods were applied in this study, using a structured questionnaire with closed questions leading to limited outcomes. The respondents had limited options for responses, based on the selection of the questionnaire.

One limitation of this study might be that researchers assisted the participants in completing the questionnaires, and therefore were at risk of introducing some response bias, although no significant differences in the responses were found in the statistical tests.

The nursing home patients were exposed to a battery of nine questionnaires including 130 items, and were at risk of being exhausted by the completion of the one- on- one interviews. However, short prescheduled breaks were part of the standard procedure conducted by the researchers to reduce this risk. Only three interviews had to be completed the next day due to the participant`s fatigue.

Conclusion

Nursing home patients are found to experience moderate level of hope. Findings in this study show a positive correlation between hope and emotional functioning in cognitively intact nursing home patients, and a negative relation between hope and physical symptom such as fatigue, nausea/vomiting, dyspnea and insomnia.

Insomnia and quality of life were found to have significant impact on hope. Findings suggest insomnia to have a negative impact on hope, while an increased experience of quality of life seems to have a positive impact on hope.

Nurses may use this knowledge as a basis for clinical judgment when hope is threatened in nursing home patients. An enhanced understanding of hope in this population might contribute to increased quality of nursing home care.

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Appendix 1

Table 1
Common symptoms; means and standard deviations (SD), Pearson`s correlational coefficient (*r*), in nursing home patients (N=202)

QLO-C15-PAL Subscales	Mean	SD	Pearson`s correlational coefficient (*r*): Hope
Fatigue	32,56	30,50	-0,144*
Nausea/Vomiting	4,95	13,52	-0,223**
Emotional Functioning	83,37	22,52	0,254**
Pain	23,65	30,02	-0,121
Dyspnoea	25,58	34,56	-0,152*
Insomnia	21,23	30,96	-0,239**
Appetite Loss	14,36	27,57	-0,075
Constipation	26,83	34,84	0,003
Quality of Life	65,51	23,66	0,346**

** Correlation is significant at the 0,01 level
*Correlation is significant at the 0,05 level

Appendix 2

Table 2
Model Summary – Linear Regression. Hope related to physical and emotional symptoms and quality of life in nursing home patients

	Univariate analyses			Multivariate analyses		
	B	CI 95%	p-value	*B*	CI 95%	p-value
Fatigue	-0,020	-0,039 – -0,001	0,042*	0,018	-0,004 - 0,040	0,102
Nausea /Vomiting	-0,071	-0,114– -0,027	0,002*	-0,039	-0,084 – 0,006	0,087
Emotional Functioning	0,047	0,022 – 0,072	0,000*	0,016	-0,011 – 0,044	0,231
Pain	-0,017	-0,036 – 0,002	0,087			
Dyspnoea	-0,018	-0,035– -0,002	0,031*	-0,008	-0,025 – 0,009	0,348
Insomnia	-0,032	-0,051– -0,014	0,001*	-0,021	-0,040 - - 0,002	0,032*
Appetite loss	-0,011	-0,033 – 0,010	0,293			
Constipation	0,000	-0,016 – 0,017	0,971			
Quality of life	0,061	0,038 – 0,084	0,000*	0,046	0,019 – 0,073	0,001*

Dependent variable: Hope HHI
R^2= 0,148, the incremental proportion of total variation in the dependent variable
Levels of significance: *= p <0,05
B= Unstandardized Coefficients
CI=Confidence interval for B

9.3 **Ethical clearance**

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

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Harald Hårfagres gate 29
N-5007 Bergen
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Org.nr. 985 321 884

Gøzll Haugan
Institutt for sosialt arbeid og helsevitenskap
NTNU
Dragvoll
7491 TRONDHEIM

Vår dato:	Vår ref:	Deres dato:	Deres ref:
29.01.2007	16443/SM		

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 23.02.2007. Meldingen gjelder prosjektet:

16443	*Livskvalitet hos langtidspasienter i sykehjem*
Behandlingsansvarlig	*NTNU, ved institusjonens øverste leder*
Daglig ansvarlig	*Gøzll Haugan*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/endringsskjema. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/database/

Personvernombudet vil ved prosjektets avslutning, 01.12.2010 rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Siv Midthassel

Kontaktperson: Siv Midthassel tlf: 55 58 83 34

Vedegg: Prosjektvurdering

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OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
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NTNU
Norges teknisk-naturvitenskapelige universitet

Det medisinske fakultet
Regional komite for medisinsk forskningsetikk
Helseregion Midt-Norge

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Vår dato:	Vår ref.:	Deres dato:	Deres ref.:
10.04.2007	4.2007.645		

Livskvalitet hos langtidspasienter i sykehjem.

Komiteen vurderte prosjektet i møte 23. mars 2007 med følgende merknader og tilråding:

Målsetningen er å beskrive langtids sykehjemspasienters livskvalitet. Hvordan har pasientene det? Hvilke behov er ivaretatt - hvilke behov er ikke ivaretatt? Man ønsker å utforske eventuelle sammenhenger mellom sykehjemspasientens fysiske og åndelige funksjon; for eks. hvordan samvarierer pasientens fysiske plager som smerte, kvalme, fatigue etc. med åndelige kvaliteter som håp, mening, selv-transcendens? Det skal kartlegges hvordan sykehjemspasienten vurderer sentrale kvaliteter i pasient-pleier-relasjonen. Man skal bidra til en utvidelse av den bio-psyko-sosiale modellen for helse til en biopsykososial-åndelig modell for helsearbeid. Til slutt ønsker man å veilede sykehjemspersonell og sykepleiestudenter for å videreutvikle den kliniske sykehjemsomsorgens kvalitet. Undersøkelsen er en tverrsnittsundersøkelse. Data samles inn ved at deltakerne sammen med forsker fyller ut validerte spørreskjema.
Følgende spørreskjema er aktuell for studien:

1. EORTC QLQ-C15-PAL, FACT-G:27, FACIT-Sp-12, HERTHS HÅPS-INDEKS, SELF-TRANSCENDEENCE SCALE (STS), Purpose In Life-test-20 items, HADS: Hospital Anxiety og Depression Scale, Family and Friendship Contact Scale-8, VAS-skala PASIENT-PLEIER-RELASJONEN.

Det er planlagt å gjennomføre en pilot-test for å vurdere hvordan spørsmålene fungerer samt hvor lang tid utfyllingen tar. Ut fra disse erfaringene gjøres en utvelgelse av spørreskjema blant de 9 ovenfor nevnte. Studien har to utvalg: et bestående av 200 kognitivt intakte langtidspasienter i sykehjem, og et utvalg av sykepleiere i sykehjem.

- Komiteen viser til prosjektprotokollen og et sentralt spørsmål er hvordan samtykkekompetansen til potensielle deltakere skal vurderes. Komiteens forslag er at samtykkekompetansen vurderes av tilsynslegen i samarbeide med den sykepleier som kjenner pasienten best.
- Komiteen stiller spørsmål ved om responsbyrden er for stor for denne pasientgruppen da det legges opp til at de skal besvare et stort antall relativt kompliserte spørreskjemaer.

- Komiteen vurderer dette som en pilot-studie og en eventuell hovedstudie må fremlegges komiteen på nytt.

- Komiteen viser til informasjonsskrivet som må gjøres mindre førende. Jeg-formen fjernes og appellerende utsagn bør utelates.
- Det må stå at studien er meldt til Norsk Samfunnsvitenskapelig Datatjeneste (NSD) og Regional komité for Medisinsk Forskningsetikk, Midt-Norge.
- Nytt skriv må sendes inn og godkjennes på fullmakt før studien settes i gang.

Tilråding:
"Komiteen godkjenner at prosjektet gjennomføres med de merknader som er gitt."

Med hilsen

Arne Sandvik
Professor
Leder i komiteen

Jacob C Hølen
Seniorkonsulent

9.4 **Questionnaire**

Herth's Håps-Indeks

Nedenfor er det listet opp en rekke utsagn. Les hvert utsagn og sett ett kryss i den boksen som best beskriver hvor enig du er i utsagnet *akkurat nå.*

	Veldig uenig	Uenig	Enig	Veldig enig
1. Jeg ser positivt på livet				
2. Jeg har kort- og /eller langsiktige mål				
3. Jeg føler meg helt alene				
4. Jeg ser en lysning i tunnelen				
5. Jeg har en tro som gir meg trøst				
6. Jeg er redd for hva framtiden vil bringe				
7. Jeg kan huske lykkelige/gode stunder				
8. Jeg har en indre styrke				
9. Jeg er i stand til å gi og motta omsorg/ kjærlighet				
10. Jeg har en følelse av retning i livet mitt				
11. Jeg tror at hver dag har sine muligheter				
12. Jeg føler at mitt liv har verdi				

EORTC QLQ-C15-PAL (versjon 1)

Vi er interessert i forhold vedrørende deg og din helse. Vær så vennlig å besvare hvert spørsmål ved å sette en ring rundt det tallet som best beskriver din tilstand. Det er ingen «riktige» eller «gale» svar. Alle opplysningene vil bli behandlet konfidensielt.

Pasientnummer: **Fødselsdato:**

Pasientens initialer: **Dagens dato:**

	Ikke i det hele tatt	Litt	En del	Svært mye
1. Har du vanskeligheter med å gå en kort tur utendørs?	**1**	**2**	**3**	**4**
2. Er du nødt til å ligge til sengs eller sitte i en stol i løpet av dagen?	**1**	**2**	**3**	**4**
3. Trenger du hjelp til å spise, kle på deg, vaske deg eller gå på toalettet?	**1**	**2**	**3**	**4**

I løpet av den siste uka:

4. Har du vært tung i pusten?	**1**	**2**	**3**	**4**
5. Har du hatt smerter?	**1**	**2**	**3**	**4**
6. Har du hatt søvnproblemer?	**1**	**2**	**3**	**4**
7. Har du følt deg slapp?	**1**	**2**	**3**	**4**
8. Har du hatt dårlig matlyst?	**1**	**2**	**3**	**4**
9. Har du vært kvalm?	**1**	**2**	**3**	**4**
10. Har du hatt treg mage?	**1**	**2**	**3**	**4**
11. Har du følt deg trett?	**1**	**2**	**3**	**4**
12. Har smerter påvirket dine daglige aktiviteter?	**1**	**2**	**3**	**4**
13. Har du følt deg anspent?	**1**	**2**	**3**	**4**
14. Har du følt deg deprimert?	**1**	**2**	**3**	**4**

Som svar på de neste spørsmålene, sett en ring rundt det tallet fra 1 til 7 som best beskriver din tilstand.

I løpet av den siste uka:

15. Hvordan har livskvaliteten din vært i løpet av den siste uka?

1	2	3	4	5	6	7
Svært dårlig						**Helt utmerket**