The official title of the study:

# Implementation of Knowledge-Based Palliative Care for Frail Older Persons in Nursing Homes

NCT number: NCT02708498
Date of the document: April 8, 2015, updated October 6, 2020

The original study protocol is approved by the Regional Ethics Review Board in Lund, according to Swedish ethical review act (SFS 2003:460). The number of the decision is 2015/4. The Regional Ethics Review Board was a state authority under the Swedish government 2004-2018, reorganised January 1, 2019 into the Ethics Review Authority under the Ministry of Education and replaced the Regional ethics review boards: https://etikprovningsmyndigheten.se/for-forskare/vad-sager-lagen/

## Implementation of Knowledge-Based Palliative Care for Frail Older Persons in Nursing Homes

### PURPOSE AND AIMS

Earlier studies have shown that older people do not have the same access to palliative care as younger people. One reason for this could be that it is difficult to identify the breakpoint for palliative care. Older people often have several progressive diseases at the same time with complex needs, making it difficult to recognize when the last days before death begins. The purpose of this project is to implement and evaluate how a knowledge-based model for palliative care in nursing homes affects the quality of life and the participation in the care process for older persons in nursing homes and their next of kin. A second aim is to explore the staff's experiences of the implementation process of palliative care and the role of the leadership. The final aim is to investigate which factors (barriers and facilitators) that affect the implementation process of this model.

### SURVEY OF THE FIELD

The research on ageing during the last couple of decades has increasingly focused on questions regarding the quality of life and life satisfaction of the older people. The concept of good ageing (active and healthy) has permeated the welfare of older persons despite the fact that an advanced age comes with the increased risks of poor health and disabilities. Older people generally suffer from an increased frailty due to decreased physiological reserves (Bilotta *et al.* 2010). Yet the research indicates that when it comes to the final stage of life, the end includes unnecessary suffering and decreased quality of life (Davies & Higgingson 2004). Common morbidity among the older people is high blood pressure, diabetes, stroke or other cardiovascular diseases, dementia and arthritis. In a research overview (Marengoni *et al.* 2011), it clearly shows that multiple morbidity can be found among 55-98 % of the population over the age of 80. Older people who suffer from morbidity with disabilities describes a reduced social network, increased levels of depression and lower life satisfaction than those with an intact health (Enkvist et al.2013).

Palliative care has traditionally been predominately provided successfully to persons dying from incurable cancer while older people dying of multiple morbidities or “old age” has received far less of this type of care. This in spite of the fact that sixty percent of all people who died in Sweden in 2010 were at least 80 years old and that the dying among older people often is a prolonged period of suffering. One reason might be that it is more difficult to identify when the final stages of life begins for older persons and this knowledge is missing outside specialist care units for palliative care. Today, demographic changes are increasing the number of people who are 65 years or older, thus also increasing the need to develop palliative care for older persons (Hall et al. 2011).

Nursing homes strive to provide good care for older persons in their final stages of life. However, the principles of palliative care which has been developed within specialized palliative care and hospices are too often neglected (Davies & Higgingson 2004). There is scant research on how the principles palliative care can be implemented in nursing homes with the intention of providing the best possible palliative care and at the same time involve the older persons and their next of kin in the care process (Beck 2013, Orrung Wallin 2013). Involving the older persons in the care process is something which must be done in advance as it is often not feasible to do this when they are in the last days of life (Davies & Higgingson 2004). Health care professionals need to provide palliative care based on equal rights to this care based on needs (SFS 1982:763) and must also consider the fact that the frail older person is often single or has next of kin of the same age who may have health-related problems of their own (Socialstyrelsen 2012, 2013).

The National Board of Health and Welfare has formulate the goal that everyone should have access to knowledge-based palliative care when the need arises, regardless of diagnosis, care form, age or where in the country a person lives (Socialstyrelsen 2013). Two documents have been produced in order to provide support for developing, implementing and following up knowledge-based palliative care for persons in their final stages of life: A national care program by the Regional Co-operative Cancer Centers (Regionala cancercentrum i samverkan 2012) and a national knowledge support document by the National Board of Health and Welfare (Socialstyrelsen 2013). However, it is well established that it takes an unpredictable amount of time before research results, recommendations and guidelines find their way to health care professionals and become routine practice.

This project contributes new and unique knowledge about implementation of knowledge-based palliative care based on core values developed within hospice and palliative cancer care. The project takes the national care program and the national knowledge support document as its starting point when investigating the implementation of a knowledge-based palliative care in nursing homes. The project uses an educational intervention targeting nursing home staff to facilitate the implementation. The outcomes are then analysed with focus on the quality of life as well as the participation in the care process of the older person and their next of kin. If effective, this educational intervention, which is directed at nursing home staff, can be disseminated to other regions of the country and can be implemented as part of a knowledge-based approach to provide palliative care within the care of frail older people in the end of life.

## Palliative care

The participation of older people in the care process is nowadays a right given by law. It has been noted that when the old person has shown a weak interest in communication, that person has not perceived that there are alternatives to consider. It has happened at times when the old person has been questioned about choices in surgery, medicines, and diagnostic procedures and in routine testing of preventive care. In order for the very oldest to become active in decision making processes, physicians and health care professions need to provide enough time for consideration, goals and preferences with different alternatives (Bynum *et al.* 2013).

A knowledge-based palliative care is based on available scientific evidence, best practice and the preferences from the patient, next of kin and health care professionals. The palliative care should meet the needs of the patient and be seen as a process. The meaning of ”a good death” is a restored self-image and integrity, to maintain self-determination and social relationships, having the opportunity to experience meaning and see the context as well as a good symptom relief. It is important that the care is planned and conducted in cooperation with the older person and the next of kin in a systematic way which includes continuous improvements in accordance with an knowledge-based palliative care (Prop 2009/10:116, Socialstyrelsen 2012, Regionala cancercentrum i samverkan 2012).

It has been shown that the availability of palliative care is unequal across the country (Socialstyrelsen, 2006). A study based on data from the Swedish Register of Palliative Care (SRPC) shows that people that died from other diagnosis than cancer did not have the same access to palliative care as persons with cancer diagnosis (Brannstrom, Hagglund, Furst, & Boman, 2012). The National Board of Health (Socialstyrelsen, 2013) has, because of the unequal availability of palliative care in Sweden, been commissioned to draw up a national knowledgebase that focuses on proper palliative care. The knowledgebase proposes eight quality indicators for good palliative care. Because older people and people with chronic diseases has proved to be particularly disadvantaged in terms of palliative care (Socialstyrelsen, 2004) and that up to 40 % of all deaths occur in nursing homes (The Swedish Register of Palliative Care, 2013) it is of great importance to examine the quality of palliative care offered there.

A good cooperation between the next of kin and the health care professionals is necessary to provide a good palliative care. It is made easier when health care professionals, the patient and the next of kin have a shared view of the process (Socialstyrelsen 2013). The role and participation of next of kin in the care process and their degree of stress, is directly dependant on the quality and degree of care the older person is being provided by the society (Moen & Chermack 2005). A noticeable increase of the stress on the next of kin can be seen during periods of rapid decrease of the health status in the frail older person (Summer Meranius 2010). It is therefore important to support next of kin of older persons with long-term morbidity, especially when the next of kin themselves are older. WHO recommends that unlike in cancer care where palliative care is provided at the last week, palliative care for older persons with multiple morbidity should be provided offered alongside other treatments over a longer period of time (Davies & Higgingson 2004). If the participation of next of kin is non-existent or decreasing due to the fact that they themselves do not have the strength to do so, the quality of life of the older person is affected negatively. Studies on the degree of participation of next of kin in the care process are central in order to be able to explain the burden which they carry (Andershed 2006, Aoun *et al.* 2012, and Kouikia & Madianos 2005).

Research has shown that leadership that promotes comfort and trust within the health care organization influences the way the organization fulfils its goals in a meaningful way (Cummings et al. 2010, Dutfield et al. 2011). However, knowledge about the importance of leadership within palliative care is very limited. Research has predominantly focused on the contents of the delivered care and the specialist competences needed to provide care as well as educational issues and team cooperation. During the last few years, organizational leadership, culture and resources of the organisation have gained an increasing importance with regards to providing knowledge-based palliative care (Klarare et al. 2013).

## PROJECT DESCRIPTION

## THEORETICAL FRAMEWORK

The project is based on a theoretical implementation framework that provides a structure for analysis of mechanisms (i.e. “the black box”) of the implementation of knowledge-based palliative care. Studies which apply implementation research theories are increasingly requested and this application fosters improved knowledge accumulation of the interplay between which determinants that affect health care professionals’ use of knowledge-based practices (Eccles *et al*., 2005; Michie *et al*., 2011; Nilsen *et al*., 2012).

**Table 1: Implementation determinants in this project**

| Determinant | The five key-factors and application in this project |
|---|---|
| Characteristics of the **implementation object** (Described in the method sections in future publications) | Features of the intervention itself (i.e. the “**implementation object**”). The “object” that is implemented is typically a specific knowledge-based practice, program, service, etc. that has been found to be effective in research.<br>**In this project**, the implementation object of palliative care is a binder constructed specific for this project based on national knowledge-based documents produced by the National Board of Health and Welfare and the Regional Co-operative Cancer Centers. The educational strategy for implementation is based on these documents. |
| Characteristics of the **target population** | Features of the receivers of the implementation intervention, i.e. **target population**. The target population consists of the individuals on which an implementation endeavour is ultimately intended to have an impact.<br>**Studies 1-4** investigate the characteristics of the target populations who are the frail older persons in nursing homes, and their next of kin. |
| Characteristics of the **implementers** | Features of the professionals who use and deliver the intervention (i.e. “the **implementers**”). The implementers are those responsible for delivering the implementation object.<br>**Studies 5-7 and 8** investigate the characteristics of the implementers, who are all the nursing home staff as well as the managers working at the included nursing homes. |
| Effectiveness of **implementation strategies** used | **Strategies** and activities chosen to implement the intervention object. Implementation strategies (also referred to as implementation interventions) are conscious efforts to influence the implementation process in order to achieve desired changes in clinical practice.<br>**Studies 1-3, 5-8** investigate the effectiveness of an educational intervention and coaching during six months in Kronoberg County in 2015 and Skåne County in 2016. |
| Characteristics of the **context** in | The **context** is the social environment in which implementation takes place. It is customary to distinguish between the inner and outer context |

| | |
|---|---|
| which the implementation occurs | of the implementation; the former represents features of the workplace or organization and the latter is related to the wider environment within which health care organizations reside, i.e. the wider society. The context represents influences on the implementation process and impact that is, at least partially, beyond the control of the implementers and target population. |
| | **Study 1, 5-7, and 8** investigates the characteristics of the context in nursing homes, in which implementation of knowledge-based palliative care takes place. |

This project applies a theoretical framework that specifies a number of determinants (barriers and facilitators) for implementation outcomes. The framework is a synthesis of several similar frameworks in the implementation literature, including those described by Damschroder *et al.* (2009), Greenhalgh *et al.* (2004), Grol *et al.* (2007), Nilsen *et al.* (2010) and Nutley *et al.* (2007). The framework is well-tried as it has been used in many implementation studies on health and caring. The five key factors (which all affect each other) and how the different parts of this project relate to the implementation research terminology are shown in table 1.

Research has shown that a successful implementation depends on interplay between the effectiveness of the implementation strategies chosen to support the implementation and characteristics of the implementation object, the implementers, the target population and the context of the implementation (Table 1).

**Updated design of the implementation research**
The project was planned to be conducted using a cross-over design in two counties in south of Sweden based on a feasibility/pilot study that was conducted during fall 2014 *co-created palliative care educational intervention through seminars for professionals in nursing homes*. Due to a more significant amount of drop-outs compared with expected (and for not receiving the total amount of applied foundation), the plan needed to be revised. The knowledge-based palliative care intervention was conducted as a non-randomized control trial, implemented over a six-month period in 30 nursing homes in two different counties in the south of Sweden (County A and County B). The data collection was made in two sequential periods in each county. First, the intervention was implemented in ten nursing homes in County A (Kronoberg County from April 2015), while ten nursing homes in County B served as a control group. Then, County B implemented the intervention (Skåne county from August 2016), and ten new nursing homes in County A, which had not received the intervention, were chosen as a control group. After the two sequential time periods were data from one intervention and one control group analysed. The selection through voluntary participation resulted in a mixture of both larger and smaller nursing homes within the two counties (cluster samples), as well as both from urban and rural areas.

**Implementation object**
According to the National Board of Health and Welfare, palliative care should be based on four cornerstones: symptoms relief, multi-professional cooperation, communication and relation as well as support to the next of kin (Socialstyrelsen 2012). The aim of palliative care is to reduce suffering and promote the quality of life for patients with progressive, incurable illnesses or injuries. The care should address physical, psychosocial and spiritual needs as well as provide support to the next of kin. The definition by the National Board of Health and Welfare closely

adheres to the definition of palliative care by the World Health Organization (WHO), (Socialstyrelsen 2013).

### Implementation intervention/strategies

The educational strategies will be based on *co-created palliative care educational intervention*, which consists of a series of seminars and coaching. The education has been planned together with staff, informal caregivers and patients. The educational material for use in the seminaries has been developed as well as empirical tested in the feasibility study during the fall 2014. The strategies was tested in this feasibility study at four nursing home in Kronoberg County during the autumn 2014, in order to understand how the implementation object can be translated into practice at nursing homes. Seven educational meetings were reduced to five as a result of the study.

Every seminar group meetings once a month includes different professions (unit manager, district nurse, assistant nurse, and other staff i.e. occupational therapist and physiotherapist). There will be 5 meetings with 8-10 participants in each group from each nursing home. The total intervention period is 6 months in each nursing home.

The educational strategies are based on the two national knowledge documents concerning palliative care in the end of life and the Swedish Register of Palliative Care (SRPC). The educational binder was developed based on the content in the two national knowledge documents and is used in this intervention. Each participant is provided a binder at the beginning of the intervention. The educational material consist of six themes; values in palliative care, symptom relief, dignity and a dignified death, collaborative co-creating care, support to next of kin and dialogue with older persons and next of kin about death and dying. The content of the different themes will have a common core for each nursing home but will be adjusted based on the expressed needs of each nursing home. In addition, there will be a list of references available for further self-studying by the participants.

The seminar groups will be led by two experienced clinical nurses and researchers from the field of palliative care and geriatric care. The participants in the seminar groups will reflect together over the content of the developed binder of educational material and will relate it to their own work in order to identify areas suitable for changes and/or development. These areas will also be identified based on the Swedish Register of Palliative Care (SRPC). The knowledgebase for discussions in the seminar groups is seven selected quality indicators out of the total of 27 questions concerning essential aspects of palliative care. The seven quality indicators are: Prevalence of pressure ulcers, documented individual prescription when needed of opioid and anti-anxiety drugs, oral health assessment, talks about the substance and direction, pain analysis and regular estimation of pain intensity and regular use of instrument for symptom assessments.

### The evaluation of the implementation

Data collection is made before and after the implementation, same time for intervention- and control groups. The implementation of the educational intervention will be evaluated by using qualitative and quantitative methods (see Table 2).

**Table 2. Sub studies and data collection i Kronoberg County and Skåne County 2015 and 2016 for the implementation of knowledge based palliative care.**

| Subjects | Method | Selection in the implementation nursing homes | Selection in the control nursing homes* |
|---|---|---|---|
| **Sub study 1:** Older persons | Structured interview (based on WHOQOL-BREF (26 items), WHOQOL-OLD (24 items), P-CAT (13 items) and The Person-Centered Climate Questionnaire (17 items) | 20 older persons were interviewed before and after three months after finished implementation | The same as for the implementation nursing homes |
| **Sub study 2**: Next of kin | Qualitative interviews participation and structured interview WHOQOL-BREF (26 items), WHOQOL-OLD (24 items) | 20 next of kin before and three months after finished implementation | 20 next of kin before and three months after finished implementation |
| **Sub study 3**: Next of kin | The participation of next of kin in palliative care at nursing homes (36 items) WHOQOL-BREF (26 items), WHOQOL-OLD (24 items) | 100 next of kin before and after nine months | 100 next of kin before and after nine months |
| **Sub-study 4:** | Psychometric study; test-retest, explorative factor analysis | See above | See above |
| **Sub study 5**: Staff | Focus group interviews (preparedness for implementation) | 20 staff divided into 3 groups before and after the implementation is finished | |
| **Sub study 6**: Staff | Questionnaires at two occasions: Experiences of palliative care (46 items), P-CAT (13 items) and the Person-Centered Climate Questionnaire (14 items) | 100 staff before and after the implementation is finished | 100 staff with 6 months in between |
| **Sub study 7**: Managers | Two individual interviews with managers (organic preparedness for implementation) | 20 managers at different levels-, during the intervention and after six months | |
| **Sub study 8:** Implementation context | An ethnographic study: Observations and qualitative interviews | Observations on 28 occasions at 7 nursing homes with a strategic selection of qualitative interviews during the implementation | |

## THE OVERALL AND SPECIFIC AIMS

The overall aim of this research project is to evaluate the outcomes and effectiveness of the implementation method of a knowledge-based model for palliative care in nursing homes. The overall aim can be broken down into four specific research questions and nine different studies:

1. What is the outcome of the implementation intervention in terms of quality of life, participation and quality of care in older persons and next of kin at nursing homes before and after? (Study I, II-IV)
2. Investigates the staff's implementation process of palliative care and the role of the leadership and (Study V-IX).
3. Investigate which factors (barriers and facilitators) that affect the implementation process of this model (Study V, VII-IX).

The evaluation consist of 8 studies and involves four implementation outcomes in accordance with the framework proposed by Proctor *et al.* (2011): **Acceptability** - The perception among implementers (nursing home staff and managers) that a given knowledge-based practice (palliative care in nursing homes) is agreeable, towards benefit or satisfactory; **Appropriateness** - The perceived fit, relevance or compatibility of an knowledge-based practice (palliative care), for a given practice setting, provider, or consumer (older persons and their next of kin); **Feasibility** - The extent to which an knowledge-based practice (palliative care) can be successfully used or carried out within a given agency or setting (nursing homes); and **Fidelity** - The degree to which an knowledge-based practice (palliative care in nursing homes) was implemented as it was prescribed in the original protocol (the knowledge documents concerning palliative care).

### Participants in studies

The persons asked for participation in this study, i.e. older persons, next of kin, staff and leaders are recruited from the included nursing homes in both Skåne and Kronoberg counties. The persons are selected consecutively until the stipulated figures are reached (Table 2).

### Methods and instruments

The following methods and instruments will be used in this project:

*Questionnaires*

Quality of life: The WHOQOL-BREF questionnaire (WHO, Manual 1996) and the WHOQOL-OLD questionnaire (WHO, Manual 2006) assessed quality of life. The older persons and next of kin will answer to the questions in a structured interview. The WHOQOL-BREF is often used together with the WHOQOL-OLD module and both are psychometric tested by the WHOQOL Group (Power et al., 1999). The WHOQOL-OLD module have been validated for old people in several countries, for example Sweden (Power *et al.* 2005) and can be used in a wide variety of studies including cross cultural investigations, population epidemiology, health monitoring, service development, and clinical intervention trials in which issues about quality of life are crucial (WHO, Manual 2006). The project has acquired permissions from WHO to use these questionnaires and in order to make it easier to answer the questionnaires, the answer alternatives will be enlarged on a separate paper and used during the interview.

The Person-centered Care Assessment Tool (P-CAT) measures the extent to which an aged care setting is person-centered. The tool is primarily intended for use by staff but expanded with a version for the older person's self-reporting. The Swedish version of the P-CAT has been found to be valid, reliable, and applicable for further use (Edvardsson et al. 2010, Sjögren et al. 2012). Person-centered care is increasingly regarded as being synonymous with best quality care. In this project, both the staff version and the version for the older will be used.

The Person-Centered Climate Questionnaire: The Person-centered Climate Questionnaire exists both in a patient and a staff version. The instruments have been shown as being a valid and reliable contribution for assessing to what extent the climate of care environments is person-centered. The factors are safety, everydayness and hospitality. The instrument enables descriptions and comparisons of environments, exploration of correlates between person-centeredness and patient outcomes and/or measure results of various interventions (Bergland *et al.* 2015, Edvardsson et al. 2013).

The newly developed self-reported questionnaire was named Next of Kin Participation in Care (NoK-PiC): Before the start of this project, there was a complete lack of instruments designed to measure the participation of next of kin in palliative care in nursing homes. To deal with this, a questionnaire for next of kin's participation was developed before the beginning of the project. Literature reviews of previous research about the next of kin´s participation was performed including all types of care in general as well as focus on palliative care and the care at nursing homes. The systematic literature review resulted in a questionnaire with 36 items about next of kin´s participation in palliative care. The new questionnaire was psychometrical tested on 400 next of kin (Westergren et al. 2020).

Experiences of palliative care: The staff will also answer a questionnaire with 47 items, newly constructed to capture changes in health professionals' attitudes, knowledge and assessment of the quality of palliative care; before (one month's), and after finishing the implementation intervention. Validation of the questionnaire is ongoing (Östlund et al. 2014).

*Focus group interviews and individual interviews*

Focus groups interviews: focus group interviews with the staff at nursing homes were chosen as the method to emphasise the interaction between respondents with a common frame of reference (McLafferty 2004). This method gives an opportunity to elicit data on how a group of staff describes their experiences of the implementation process of palliative care in elderly care. An interview guide was applied, consisting of open questions about the preparedness of the organisation to implement palliative care. The focus groups include 3-12 persons as well as a moderator who leads the discussion and an observer. Immediately after each interview, the observer made field notes, including a summary of the areas discussed, the order of speakers and the group dynamics, to ensure the quality of each group session (Kreuger 1994). The content analysis of the data was performed.

Individual interviews: To obtain comprehensive data, the interviewer create a dialogue that was designed to capture the participant's experience of the phenomena of interest (Kvale & Brinkmann, 2009). The interviews with the leaders as well as with the next of kin adopted a semi-structured interview guide and began with an open-ended question. The interview questions to the next of kin were about the quality of life and participation. The interview with the leaders focused on the preparedness of their organisation to implement palliative care. The number and formulation of follow-up questions depended on the richness of the participant's answer to the open-ended question.

*Participants observations*

Ethnographic methods such as participant observations or *go along* and interviews applies in order to get a deeper understanding of how palliative care is framed and described and how it unfolds over time in everyday practice at home will be used. Participant observations make it possible to explore the trivial details of everyday life which are essential for understanding how people create meaning. Following the staff at nursing home forms the potential to make available the experience of the individual. This kind of observation is called *go along* (Kusenbach 2003), and this concept emphasises the perceptions of place and space and is applied to explore the individual's lived experience. Likewise, the informal conversations that occur between the staff and the researcher during the observation are of equal importance and significance (Pink 2009). Participant observations also involve studying the materiality to be handled as medications and assistive devices, but also everyday objects in the nursing home.

The social relations between staff and the older person are expressed, negotiated and transformed and how meaning is created. The information from the participant observations will be collected as field notes and analysed from the ethnographic approach.

## SIGNIFICANCE

This project contributes scientific knowledge about the outcomes, barriers and facilitators, for the implementation of a knowledge-based palliative care in nursing home. Research on frail older people in nursing homes in terms of participation and quality of life has been relatively neglected in the past. But the growing need for palliative care in nursing homes means that the need for research can no longer be neglected. The intervention involves leaders which in recent research has shown to be necessary in order to maintain sustainable changes when staff implements palliative care in nursing homes (Beck 2013).

There is currently no research study that examines the quality of the palliative care at nursing homes, influencing factors or whether there are differences in quality of palliative care in urban and rural districts. A comprehensive national register study of the quality of palliative care in nursing homes could make it possible to analyze and interpret the results from an implementation perspective and put the results in a broader picture. It is of great importance to examine the quality of the palliative care offered because older people and people with chronic diseases has proved to be particularly disadvantaged in terms of palliative care (Socialstyrelsen, 2004) and up to 40 % of all deaths occur in nursing homes (Swedish Register of Palliative Care, 2013).

The importance of the context has increasingly been emphasized in implementation research, with organisational culture and leadership being identified as two key aspects of this context (Nilsen *et al*. 2013). This project explores the importance of nursing home leadership and culture for the implementation of palliative care. Organisational culture is defined as common values (goals, ideals, and priorities), norms (behaviours which are expected, accepted and supported), basic assumptions and views of reality which have been developed within a group or organization (Schein 2004). Culture is closely connected with leadership; leaders impact the culture since they have the power to influence their co-workers with their values, norms and views of reality. At the same time, an established culture influences who become leaders (Schein 2004). Leadership can be defined in many different ways, but most definitions reflect the assumption that leadership involves a process whereby intentional influence is exerted by one person over other people to guide, structure and facilitate activities and relationships in a group or organization (Gill 2011, Yukl 2006).

## ETHICAL CONSIDERATIONS

The research project is guided by the research ethical principles for medical research (the Declaration of Helsinki). The researchers will work carefully to generate valuable knowledge while minimizing harmful consequences. To maintain the principle of non- maleficence, the participants are guaranteed confidentiality, this is taken into account when reporting the findings through abstracted findings presented at the group level. The PI and the project administrator at Lund University are the only two persons to possess the names and addresses of the participants, and the personal information will be kept secure. Confidentiality will be increased by using codes in the correspondence between a researcher and a participant and when the transcriptions and analyses of the qualitative data are performed.

In accordance with respecting the participants' autonomy, all the participants will be informed that they have the right to withdraw from the study at any time without suffering any consequences for their future care. The participants will give their written informed consent before the study begins. In the interviews, the author will be aware of power issues, in that an interview is not a conversation between two equal individuals. The researcher has control over the situation. This power issue will be treated with respect, and during the course of the interview, the participant will be asked if the author's interpretation is correct. In accordance with the participants' autonomy, the healthcare professionals will be asked individually for their permission to use the observations note and recordings of the interviews.

Respectful encounters will be applied and all efforts will be done with the utmost sensitivity to the participants' signs of tiredness, which are a common part of frailty and high symptom burden. In the interviews, we will attempt to obtain beneficial knowledge while minimizing harmful consequences (Kvale & Brinkmann, 2009). The interviewer will be aware of the consequences when the situation may involve private concerns. If an older person or a family member in the study is found to undergo emotional difficulties or stress, the researcher will offer to help with contacting healthcare professionals. The interview time will also be taken into careful consideration. The researcher will give the participants opportunity to reflect on what they have said in the interviews, and time will also be available for the participants to ask questions.

Not all participants in the project will receive the implementation of palliative care as that will only be implemented for those in the intervention group. The control group will receive ordinary care and social service. In accordance with the principle of justice, it is important to send the findings from this project to the two nursing homes involved only as control groups. However, after the study period, these nursing homes will be given the teaching about palliative care in according with their own preferences. The *co-created palliative care educational intervention* is based on equal partnership and mutual learning in the process of knowledge creation.

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