Evaluating the Swedish Dignity Care Intervention within municipality healthcare

This thesis is dedicated to
my beloved father Lennart Eriksson (1944 - 2006)
and
my childhood friend, Erika Wase (1980 - 2020)

Never give up.
The world needs people who have walked through the hardest and darkest times.
The person who has carried what was heavy. The person who has fallen and risen again.
The one that has got strong arms to reach out to those who walk through the night.

Freely translated from Sofia Sivertsdotter (2020)

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Evaluating the Swedish Dignity Care Intervention within municipality healthcare -

for older persons with palliative care needs

Title: Evaluating the Swedish Dignity Care Intervention within municipality healthcare - for older persons with palliative care needs
Publisher: Örebro University 2021
www.oru.se/publikationer

Print: Örebro University, Repro August/2021

ISSN 1652-4063
ISBN 978-91-7529-380-6

Abstract

Annika Söderman (2021): Evaluating the Swedish Dignity Care Intervention within municipality healthcare - for older persons with palliative care needs. Örebro Studies in Medicine 242

Background: Palliative care in Sweden is not equal in terms of age, disease, and place of care. An essential value within palliative care is dignity, therefore healthcare emphasizing this value must be prioritized. However, older persons are concerned their dignity would not be considered and dignity interventions are rare. **The overall aim** of the thesis was to evaluate the Swedish Dignity Care Intervention (DCI-SWE) and its implementation within municipal palliative healthcare in order to conserve older persons' dignity and quality of life. **Methods:** Qualitative and mixed methods were used. Data were collected with an integrative review (study I), focus group and individual interviews with community nurses (CNs) (studies II, IV), healthcare professionals and managers (study IV), individual interviews with older persons and relatives (study III), reflective diaries and field notes (studies II, IV), and questionnaires measuring older persons' dignity-related distress and quality of life (study III). Data were analysed using thematic synthesis (study I), inductive content analysis (study II), inductive thematic analysis and comparative statistical analysis (study III), directed content analysis and descriptive statistical analysis (study IV). **Results:** Within dignity-conserving care, broad outcomes like dignity-related distress and quality of life have been used. However, communication outcomes should also be considered (study I). The DCI-SWE has clear benefits if it is used with background of who the older person is and with respect of personal needs (studies II - IV). The feasibility of the DCI-SWE depends on the healthcare organization's engagement and capacity (studies II, IV). The DCI-SWE can support CNs in communicating with older persons (studies II, IV). However, more communication training is needed, and managers leadership is an important component (studies II, IV). The implementation intervention needs further development, and the use of a behavior change model may be beneficial.

Keywords: Community-based healthcare, Dignity, Evaluation, Implementation, Intervention, Older persons, Palliative care

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List of studies

This thesis is based on the following studies, which are referred to in the text by their Roman numerals.

I. Söderman, A., Östlund, U., Werkander Harstäde, C., & Blomberg, K. (2020). Dignity-conserving care for persons with palliative care needs — identifying outcomes studied in research: an integrative review. *Palliative and Supportive Care*, 18(6), 722-740. doi:10.1017/S1478951520000139

II. Söderman, A., Werkander Harstäde, C., Östlund, U., & Blomberg, K. (2021). Community nurses' experiences of the Swedish Dignity Care Intervention for older persons with palliative care needs – a qualitative feasibility study in municipal home healthcare. *International Journal of Older People Nursing*. 00:e12372. https://doi.org/10.1111/opn.12372

III. Söderman, A., Werkander Harstäde, C., Hälleberg Nyman, M., & Blomberg, K. To value the individual – older persons' and their relatives' experiences when using the Swedish Dignity Care Intervention in municipal palliative healthcare: a mixed method study. Submitted.

IV. Söderman, A., Hälleberg Nyman, M., Werkander Harstäde, C., & Blomberg, K. A process evaluation of the Swedish Dignity Care Intervention within municipal palliative healthcare – maintaining older persons' dignity. Manuscript.

List of Abbreviations

BCW	Behaivour Change Wheel
CN	Community nurse
COREQ	Consolidated Criteria for Reporting Qualitative Research
DCC	Dignity-conserving care
DCI	Dignity Care Intervention
DCI-SWE	Swedish Dignity Care Intervention
EPOC	Effective Practice and Organization of Care Group
EPR	Electronic patient record
FGI	Focus group interview
HCP	Healthcare professional
HSL	Swedish Health Care Act
KTA	Knowledge to Action
IAHPC	International Association for Hospice and Palliative Care
MAS	Medically responsible nurse
MQOL-E	McGill Quality of Life questionnaire – Expanded
MRC	Medical Research Council
PDI	Patient Dignity Inventory
RCC	Regional Cancer Centre
QoL	Quality of life
SCB	Statistics Sweden
SKR	Swedish Municipalities and Regions
SOU	State's Public Investigations
SSF	Swedish Nurses' Association
SÄBO	Special Accommodation (for older persons)
TREND	Transparent Reporting of Evaluations of Non-randomized designs
WHO	World Health Organization

Introduction

My interest in palliative care started in nursing school when practising at a nursing home. I was amazed at how much you as a nurse can do with seemingly small – but extremely important - means for those you care for and their relatives.

After a few years as a nurse, I applied to work at a hospice, and as a nurse I felt at home. Some years later, I myself became a relative in palliative care, when my father unfortunately got cancer, and died 3 months later. This tough experience led me to continue my training, and so I started my district nurse education. After working as a district nurse at a healthcare clinic, I started working as a lecturer in nursing at Örebro University in 2012. In 2016 I enrolled as a PhD-student at the Research School of Successful Ageing at Örebro University. This opportunity allowed me to immerse myself in the topics of palliative care and care of older persons. The concept of successful ageing incorporates "*dignity, autonomy, social engagement and absence of suffering, but not absence of sickness and dependence, which constitutes an inevitable part of aging" (1)* [p. 162]. Therefore, dignity is a central part of successful ageing (2) and is a concept within the healthcare sciences (3). My PhD journey has focused on dignity-conserving care [DCC] for older persons with palliative care needs, and on implementing and evaluating the Swedish Dignity Care Intervention [DCI-SWE] in a municipal healthcare context. The overall motive for this thesis has been to support healthcare by means of an intervention for enhancing older persons' dignity and improving their quality of life [QoL]. Researchers and healthcare professionals [HCPs] must never give up on this goal.

Background

Older persons

Ageing and health

At the beginning of this PhD project, chronological age, which defines persons aged 65-79 years as "young old", and those aged ≥80years as "the oldest old" (4) [p. 13] was central to my research. However, gradually through the PhD journey another perspective has become more relevant for this thesis. This is, the life-course perspective, which recognizes that a person's subjective age is equally important and that every person gradually goes through life phases until the end of life (4). In 2019, there were 2,011 native-born older persons in Sweden aged ≥100 years. Furthermore, the Statistics Sweden [SCB] prognosis for children born in 2017 is that 12% of girls, and 7.3% of boys are expected to reach the age of 100 years (5).

Some of the biggest concerns for older persons are their need for care and loss of independence, as well as concerns about mobility and health (6). Chronic diseases and/or disabilities entail an increased risk for older persons' health (4) and the number of older persons with severe illnesses is increasing (7). Therefore, older persons are often considered as frail, which has been defined as "*an increased risk of chronic disease, loss of independence, mortality and increased healthcare use" (8)* [p.140] and which the WHO describes as an ongoing age-related decline that creates extreme vulnerability to stressors (9). It has further been reported that up to 70 years of age, healthcare needs are not significantly different from those of a younger population (10).

Healthcare services for older persons

After the age of 80, older persons' need for municipal healthcare services increases. Municipal healthcare services are provided to older persons in a nursing home or in the older person's own home through home healthcare (10). However, the number of places for older persons in special accommodations (in Sweden called "SÄBO") has decreased and older persons undergo a needs assessment before they can get accommodation at SÄBO (11, 12). In 2019, 6.5% of Swedish women and 3.9% of Swedish men aged ≥65 years lived at SÄBO homes. The corresponding figures for home healthcare were 14% for women and 9.4% for men (13).

Healthcare professionals caring for older persons

Older persons receiving municipal healthcare services meet different professionals in their daily life, such as nurses, nurse assistants, occupational therapists, and physicians. All HCPs work in Swedish municipality healthcare is governed by the Health Care Act [HSL, SFS 2017:30] (14) and the Social Services Act [SFS 2001: 453] (12). In the text, the term "HCPs" is used, to include community nurses [CNs]. However, in some cases the term "CNs" is used alone to highlight the specific actions of CNs in this project. They have the responsibility for all nursing care and in this thesis their role is central. The Swedish Nurses' Association [SSF] (15) have stated that specialist nurses working with older persons in municipal healthcare should promote health, prevent and alleviate older persons' symptoms. Specialist nurses in municipal healthcare have a broad role, of being nursing experts, leaders, developers, and educators. Their work includes informing and educating older persons and their relatives to create security and involving them in care decisions (15). Today there is a lack of specialist trained nurses and therefore it is not unusual that registered nurses are responsible for the older persons' healthcare.

Both the HSL (14) and the Social Services Act (12) highlight the importance of working to conserve older persons' dignity.

Dignity

Dignity is essential when providing care to older persons; however, the concept is considered ambiguous and complex (16). As dignity is a primary focus in this thesis, a clear definition of the term was searched for in the literature. The philosopher Barclay's definition was chosen, as it clarifies the importance of person-centered care: *"a person has dignity within healthcare when he or she is able to live in accordance with his or her principles and values" (17)* [p. 136]. Although several dimensions of dignity have been described in the literature, it is particularly important to elucidate the meaning of "*dignity of identity*" (18) in the municipal palliative care context. Notably, "*the human dignity*" dimension is described as something that cannot be taken away from a human (18); hence, it is "already there" and may be harder to influence. Therefore, in this thesis the dignity of identity is discussed.

Dignity of identity

Older persons particularly strive to maintain their dignity when it comes to their self-image and identity (19). This dimension of dignity is described as the "*dignity of identity*", which may be compromised by disrespectful behaviour (18). In this dimension of dignity, inner, personal aspects are characterized by older persons feeling their worth, and having self-esteem, and an inner calm, which means that they do not perceive themselves as a burden to others (20, 21).

Personal external aspects such as personal appearance, the ability to retain previous roles, the continuity of self, and getting to present oneself decently are important for older persons' dignity (20, 21). However, older persons sometimes feel that these aspects can be difficult to maintain because of loss of body control (20). Therefore, good symptom control is important for maintaining their dignity within this dimension (17). Older persons have listed vulnerability, futility and loneliness as aspects influencing their dignity (20, 21). By considering individual preferences in healthcare, the dignity of identity can be supported (22) in older persons and help them maintain control over care and the remaining time of life (18, 20).

Loss of dignity

When an older person experiences loss of dignity this can generate a feeling of total despair and of not being human (18). A severe consequence can then be that the older person feels like a burden to others and loses the will to live (23, 24). Hence, a strong association has been reported between the sense of being a burden to others, the loss of will to live, and a fractured sense of dignity (25). Therefore, older persons' well-being and hope are central to maintaining dignity (21).

Theoretical foundation

"Person-centred care" is the paradigm (26) that together with Chochinov's "*dignity model*" (27) was chosen as a theoretical foundation for the DCI-SWE project as it served as a framework when developing both the original version of the Dignity Care Intervention [DCI], and the DCI-SWE. Also, Chochinov's framework of "*The A, B, C, and D of dignity-conserving care*" (28) served as a theoretical foundation, as this framework was used when introducing the DCI-SWE in the municipality healthcare context.

Person-centred care

There has been a paradigm shift in the care provided to older persons from a medical technical view to a more person-centred view for the last 20-25 years. Person-centred care is underpinned by several traditional care theories where the practical care is grounded on theoretical perspectives (26). The quite new paradigm (and its components self-determination and control over decisions) has been seen as a human's right (29). Furthermore, person-centred care has been described as useful when implementing strategies for older persons, and this type of care is among other values guided by dignity (26). Person-centred care focuses on the older person when making decisions about the care and consideration what is most important for the individual (29). The medical view that has dominated the care of older persons contributes to an individual's loss of power, motivating the provision of person-centred care. It is central to focus on outcomes of care instead of only how the care has been provided (26). While providing person-centred care, all HCPs on daily basis work with older persons' beliefs and values, as well as their need to be involved. Shaping a partnership with the older person where decision-making can be shared is important (29).

The dignity model

Chochinov's dignity model (27) was developed from interviews with patients with terminal illnesses in a palliative care setting in Canada. A person's dignity, as well as indignity springs from many sources as can be seen in Figure 1. It spans physical, psychological, existential and social aspects. The dignity model constitutes a therapeutic map that is useful as a guide in clinical work when aiming to conserve a person's dignity. The dignity model includes the main categories: Illness-related concerns; the Dignity-conserving repertoire; and the Social dignity inventory.

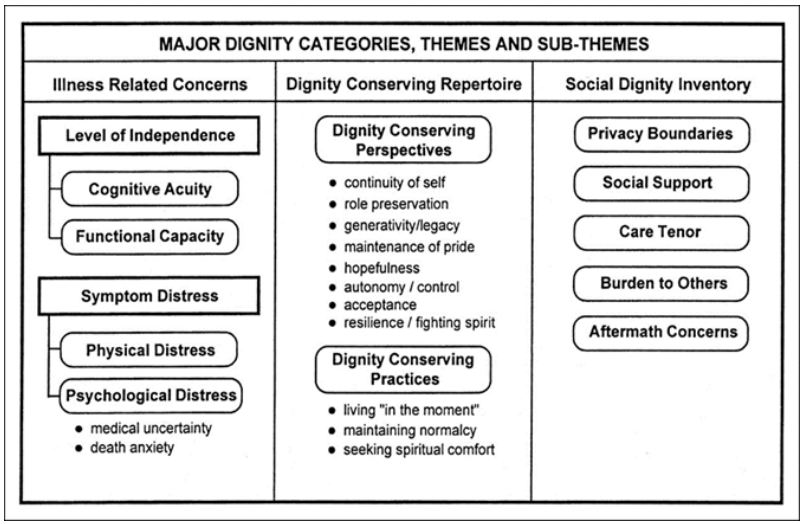

Figure 1. Chochinov's dignity model (27) (used with permission from the author)

Dignity-conserving care

Chochinov's framework "*The A, B, C, and D of dignity-conserving care*" (28) aims to remind HCPs of the fundamental aspects of caring for and about a person. According to this framework, DCC is underpinned by attitude, behavior, compassion, and dialogue which can guide HCPs while providing care. "*Attitudes*" can influence how HCPs deal with their patients, as attitudes makes someone behave or react in a predisposed way. Healthcare professionals' attitudes can influence how patients see themselves and what worth they give themselves. Moreover, HCPs "*behaviour*" can be underpinned by respect and kindness and in this way give the care a personal touch. An HCP with "*compassion*" has an awareness of a person's suffering and a wish to relieve it. This includes empathy and is often given naturally through both spoken and unspoken communication. By using "*dialogue*", HCPs can build trust and openness, and they can get information about what their patients need. This enables them to provide the patients with the best possible care.

Palliative care as an arena for dignity-conserving care for older persons

Palliative care for older persons

Today, older persons with frailty are embraced by the palliative care philosophy (30). This encompasses support for the person to live with dignity and well-being, and care for physical, psychological, social and existential concerns (19, 31). As older persons have not always been included in the palliative care philosophy, an inclusive definition of "*palliative care*" is important (30). An inclusive new, consensus-based definition of "*palliative care*" has been developed by the International Association for Hospice and Palliative Care [IAHPC]:

> *Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life (32)* [p. 755]

This definition focuses on suffering instead of having the focus on life-threatening illness (33).

Historically, palliative care in Sweden started at the end of the 1970s when advanced home care was provided in Motala. In 1982, a palliative home care unit started at Ersta in Stockholm (34).

Of those persons who are currently dying in Sweden, 60% are ≥80years old. The most common causes of death among both women and men are tumour diseases and diseases of the cardiovascular system (35). Since the Elderly Reform Act in 1992, more than 50% of persons aged ≥65 years have died outside of hospitals (31). This means that most older persons are cared for and die in home healthcare or nursing homes (36). In 2017, 36% of those who died in Sweden, died in nursing homes/at SÄBO, and 19% died in a private residence (37). Hence, about 50% of persons with palliative care needs are cared for in the municipalities by HCPs with basic palliative care knowledge, while the remainder receive basic palliative care at hospitals or specialized palliative care at palliative care units or by palliative care teams (19, 37). An evaluation of the Swedish palliative care (National Board of Health and Welfare, 2016) showed deficiencies when it came to continuing education and supervision for HCPs.

To have palliative care needs includes needing specialist palliative care, having considerable physical symptoms, and/or having complex psychosocial needs (38, 39). Therefore, holistic care is essential, no matter how old the person is (30). Still, the access to specialized palliative care in Swedish county councils is relatively scarce and palliative care is unequal when it comes to where people live, and their age and disease. It has been reported that older persons get less qualified palliative care (40) and do not have the same access to specialized palliative care compared with persons with cancer, for example (19, 41). As palliative care of older persons is complex (16) it is important that HCPs have relevant knowledge (42, 43).

At a person's transition to palliative care, a breakpoint conversation with the older person should be held by a physician, usually when there is a restriction on treatment (44, 45). Often the transition is clearer for those persons diagnosed with cancer, than in those with chronic obstructive pulmonary disease, heart failure, or dementia (44, 45). The palliative care provided should be underpinned by the four cornerstones: symptom relief, multi-professional teamwork, communication, and relations with a support for the person's relatives (31). A person can be in an early palliative phase for many years and treatment will be provided with the aim of prolonging life and enhancement of QoL (45). Central aspects of QoL in palliative care are cognitive, emotional, physical, preparatory, social, and spiritual dimensions, besides personal autonomy and healthcare provision (46). The late palliative phase is when the person enters the last weeks or days of life (in this thesis, this phase is referred to as "*end of life*"), and symptom relief becomes central (44, 45). However, palliative care ought to be introduced in an early stage (47). With early detection, and effective prevention and treatment, older persons' palliative concerns can be reduced (48).

The WHO state that a central part of palliative care ought to be to maintain the older person's dignity (9). Therefore, knowledge about dignity is essential, and to provide high-quality palliative care the value of dignity must be considered by those providing care to older persons (9, 32). The HSL (14) and the Social Services Act (12) likewise underline the value of dignity as something that needs to be conserved in older persons, as well as the Swedish National values within municipal healthcare emphasize the importance of older persons getting to live a dignified life (49). In UK, an alarming 71% of older persons have reported that they are not confident they would be treated with dignity in a nursing home (50) and 50% of older

people in nursing homes feel that their dignity is undermined (51). Hence, moving to a nursing home can be a challenge (20, 21). On the other hand, moving to a nursing home, where they can participate in a social context and their dignity can be supported, can also provide older persons with a sense of security (20, 21). Then again, asking for help and being dependent can pose a threat to dignity.

To prevent suffering in older persons it is necessary that HCPs take older persons' needs into account and observe and handle concerns related to their dignity (41, 52). By focusing on dignity, HCPs can be reminded that there is a lower limit to how humans may be treated by others (24). Furthermore, if not putting too much emphasis on the help the older person needs, it is possible to protect their dignity (22). Healthcare professionals can facilitate for older persons to have privacy when they need it. Also, HCPs can strive to treat the older person as an equal and give the support they need to remain as independent as possible (53). However, dignity care interventions helping HCPs provide this type of care are quite rare (16).

Interventions in palliative care

Previous research has focused on psychological/psychosocial interventions (54-57), existential interventions (58), interventions with biographical approaches (59), personal narrative interventions (60), and death anxiety interventions (61). Some interventions that have been used are Dignity therapy (62-65), the TIME questionnaire (66) and the DCI (67-69).

The DCI was developed in the UK and was chosen for this PhD project as it is broad and includes both communication support and suggestions on care actions related to dignity.

The Dignity Care Intervention

The DCI is an intervention aiming at conserving dignity for persons with palliative care needs, developed by Johnston and colleagues in Scotland in 2010 (67-71). The DCI comprises: (1) the Patient Dignity Inventory [PDI], a 25-item questionnaire assessing dignity related distress; (2) reflective questions that are useful for deepening conversations with patients and enhancing knowledge of the older person's concerns; and (3) evidence-based care actions related to dignity. The PDI has been validated in English (72, 73). The original DCI was evaluated in both Scotland and Ireland. The CNs found the intervention acceptable but it required communication skills.

Some CNs found it challenging to initiate deeper conversations about dignity and felt they needed more support and training to address such an issue (71, 74). However, from the patients' perspective the support they received through the DCI was adequate. The DCI enabled them to discuss important issues more openly with CNs, issues they might otherwise not have raised (70). The DCI including the PDI has been translated and adapted into Swedish (the Swedish version being DCI-SWE) comprising a multi-step process of forward translations, negotiated consensus, expert group discussion and cognitive interviews (75). The Swedish version of the PDI includes 26 items. Care actions were culturally adapted by carrying out a review of Swedish studies (76) and by performing focus group interviews [FGIs] or individual interviews with persons with palliative care needs, their relatives, and HCPs (77). See Appendix 1 for the DCI-SWE.

The procedure of using the Swedish Dignity Care Intervention

The use of the DCI-SWE can be seen as a process (Figure 2) requiring CNs to set up at least two meetings with the older person (70). The first step in the process is for the CN in consultation with the older person to take a clinical decision to use the intervention. Then the person's dignity related distress is assessed using the Swedish PDI (see Appendix 2) to make concerns visible (75). The PDI can be completed in different ways: either by the older persons themselves, or together with their relatives or the CN. The older persons can also tick the questions they want to discuss. Concerns rated as a problem or worse (≥3) are considered as something that should be further explored. Then CNs can use the reflective questions and care actions from the DCI-SWE, for example to acknowledge the older person. Each reflective question and care action is related to a specific item in the PDI. Reflective questions can support CNs in having meaningful conversations with older persons. Furthermore, if a CN discuss and proposes relevant care actions from the DCI-SWE with the older person it can facilitate DCC. The DCI-SWE is then followed by using the PDI yet again, some weeks after care actions have been incorporated in the older persons care or if the person's health deteriorates. In this way HCPs including CNs can see if the older person's concerns have been relieved or if new concerns have emerged. Thus, the DCI - process continues.

A framework for implementing the DCI-SWE in practice was used together with implementation strategies. These aspects are further described in the Methods section.

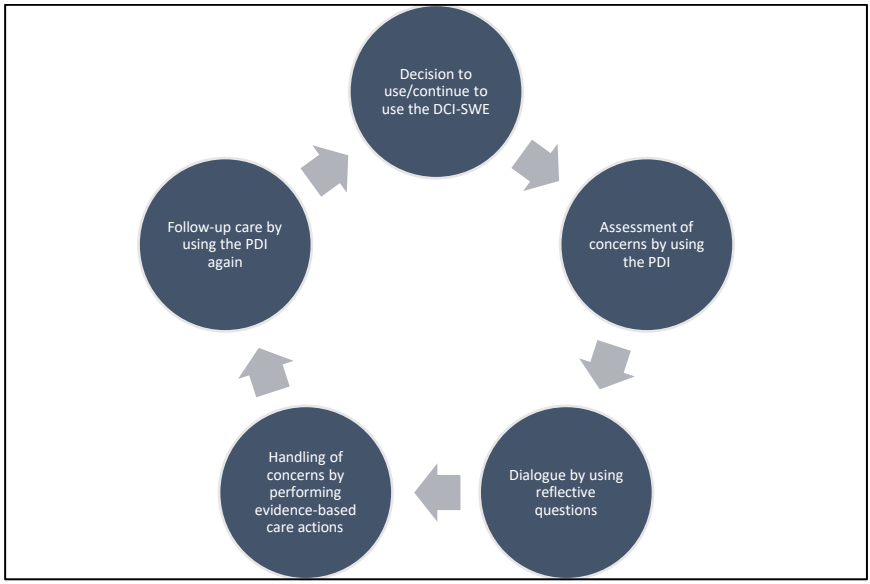

Figure 2. Process of using the Swedish Dignity Care Intervention [DCI-SWE]. PDI=Patient Dignity Inventory

Rationale

Although dignity is a central goal in palliative care and governments are recommended to ensure access to adequate palliative care for vulnerable groups (30, 32), developed and well-proven interventions for DCC largely do not exist (41). Furthermore, as older persons have scant access to specialized palliative care the general palliative care within municipalities must be a priority for development. Older persons' dignity needs to be protected and respected and solutions need to be created to help older persons live a dignified life until they die. Therefore, awareness of the importance of maintaining dignity must be raised and research initiatives need to continue until dignity for the majority of older persons' can be maintained within healthcare. For this purpose, interventions for DCC would be valuable. Since evaluation of the original DCI showed acceptance and usefulness (71), this intervention may be useful in a wide range of cultures and contexts. Hence, there are reasons to assume that the DCI-SWE can become a significant new way of working towards conserving the dignity and QoL of older persons with complex and palliative care needs in Swedish municipal healthcare.

Aim

The overall aim of this thesis was to evaluate the Swedish Dignity Care Intervention and its implementation in municipal palliative healthcare in order to conserve older persons' dignity and quality of life.

Specific aims

The included studies aimed to:

I. Identify outcomes studied in dignity-conserving care and how these have been operationalized through instruments.

II. Describe experiences of the DCI-SWE from community nurses' perspective.

III. Describe older persons' and their relatives' experiences of dignity and dignity-conserving care when using the DCI-SWE in municipal healthcare.

IV. Perform a process evaluation of the implementation of the DCI-SWE in a municipal healthcare context with focus on implementation, mechanisms of impact and context.

Methods

The framework for the whole DCI-SWE project was the British Medical Research Council [MRC] Guidelines for developing and evaluating complex interventions (78). An overview of the included PhD studies can be seen in Table 1.

Table 1. Overview of the PhD project studies.

Study	Design	Participants/Articles	Data collection	Data analysis
I	Integrative review study.	Articles (n=26)	Searches in CINAHL, MEDLINE, Psyc INFO and Web of Science, and manual searches of reference lists.	Thematic synthesis.
II	Feasibility study with a qualitative descriptive design.	CNs (n=11)	FGIs, one individual interview, reflective diaries.	Inductive content analysis.
III	Mixed method study, convergent parallel design.	Older persons (n=18), relatives (n=8)	Outcome measures: the MQOL-E and the PDI, individual interviews.	Comparative statistical analyses. Inductive thematic analysis.
IV	A process evaluation study with a mixed method design and a sequential qualitative dominant approach.	CNs (n=11), HCPs (n=5) (assistant nurses and occupational therapists), managers (n=5)	FGIs and individual interviews with CNs, HCPs, and managers, one CN's reflective diary.	Directed content analysis. Descriptive statistics.

CN = community nurse; FGI = focus group interview; HCP = healthcare professional; MQOL-E = McGill Quality of Life questionnaire - Expanded; MRC = Medical Research Council; PDI = Patient Dignity Inventory.

Design

The designs that were used to achieve the overall aim where: an integrative review study (I) (79), a feasibility study with a qualitative descriptive design (II) (80), a mixed method study with a convergent parallel design (III) (81), and a process evaluation study (78) with a mixed method design using a sequential qualitative dominant approach (IV) (82). The implementation of the DCI-SWE (studies III-IV) was realized with a Hybrid 1 design (83) focusing on testing a clinical intervention while gathering information on its delivery, and on its capacity for implementation in a real-world situation.

The Medical Research Council's framework

The MRC describes the process of developing complex interventions as a dynamic process where input from stakeholders is central (78). The MRC framework of actions for intervention development as it relates to the DCI project is presented in Table 2.

Table 2. The Medical Research Council's guidance on intervention development in relation to the Dignity Care Intervention project.

Actions for intervention development	**The DCI project**
Plan the development process	Started in 2012
Involve stakeholders, including those who will deliver, use, and benefit from, the intervention	Started when adapting the PDI into a Swedish version. Renewed contact with municipal healthcare in 2016 for the PhD project.
Bring together a team and establish decision-making processes	In 2012 - 2013, the DCI-SWE project group was established.
Review published research evidence	Earlier DCI studies underpinned the process of putting together the DCI-SWE (during 2017). The integrative review (study I) was also conducted to study outcomes.
Draw on existing theories	Chochinov's dignity model (see Figure 1), Chochinov's "A, B, C, and D of dignity-conserving care"
Articulate the programme theory	The KTA framework and EPOC - taxonomy
Undertake primary data collection	Studies II-IV
Understand the context	Studies II-IV
Pay attention to future implementation of the intervention in the real world	Study IV
Design and refine the intervention	After the feasibility study (study II) and again in the next phase (after the PhD project)

DCI-SWE = Swedish Dignity Care Intervention; EPOC = Effective Practice and Organization of Care Group; KTA = Knowledge to Action; PDI = Patient Dignity Inventory.

Samples and settings

Integrative review, study I

The context for the included articles in the review can be seen in Table 3.

Table 3. Inclusion and exclusion criteria for articles.

Inclusion criteria	Exclusion criteria
Match the aim of the review.	Qualitative studies, reviews or case studies.
Focusing on palliative care (or synonyms for this term, e.g., "end-of-life").	Quantitative studies only including surveys, feedback questionnaires and single-item scales.
Evaluating interventions for dignified care/DCC.	Focusing on instruments that measure dignity but do not include an intervention.
Describing quantitative outcomes of the care provided or of the planned care.	Focusing on a dignified death in relation to euthanasia.
Including adults ≥18 years old in home care or nursing homes, alternatively in palliative care units and palliative care teams (in or out of hospital).	Not allowing extraction of results from adults. Exclusively including persons with dementia or severe cognitive disorders.
Being based on the perspective of adults, or the perspectives of the persons' relatives or HCPs.	

DCC = dignity-conserving care; HCP = healthcare professional.

Feasibility study, study II

The context of study II was urban and rural home healthcare in a medium-sized municipality in Sweden. Two home healthcare units (one consisting of smaller units), where CNs worked with older persons were included. The CNs were recruited with help from first-line managers (the nearest manager) through a purposive sample where mixed genders and an age range were aimed for (80). Eighteen CNs were provided with information about the DCI-SWE during face-to-face unit meetings, and twelve consented to take part in the study. One CN dropped out because of a change of workplace. The CNs asked older persons for permission to use the DCI-SWE in their care. For inclusion- and exclusion criteria for CNs, and criteria for CNs' use of the DCI-SWE on older persons, see Table 4. For sociodemographic data on participating CNs, see Table 5.

Table 4. Inclusion- and exclusion criteria for community nurses, and criteria for CNs' use of the Swedish Dignity Care Intervention on older persons.

Inclusion criteria	Exclusion criteria
Community nurses	
Working in general palliative care Having worked in municipal home healthcare for the past 2 years Having experience of caring for persons with palliative care needs Having participated in the DCI-SWE workshop and/or used the DCI-SWE in their care work	Having a close relative with palliative care needs, currently cared for in the municipality included in the study
Criteria for using the DCI-SWE in older persons	
Receiving municipal home healthcare Being ≥65 years old Being perceived by the CN as having palliative care needs Being perceived by the CN as being frail Having diverse diagnoses (e.g. heart disease, chronic obstructive pulmonary disease, kidney failure, cancer or multi-morbidity)	Having dementia Having cognitive problems, being unable to make the older person reflect on and remember what has been said in conversations with the CN

CN = community nurse; DCI-SWE = the Swedish Dignity Care Intervention

Table 5. Sociodemographic data on participating community nurses.

Variables	**(n=11)**
Age, yrs, mean (SD)	51.5 (10.03)
Median	51
Min; max	37; 70
Female, n (%)	9 (81.8)
Education, n (%)	
Nurse education	11 (100)
Nurse specialization	5 (45.5)
District nurse	3 (27.3)
Medicine and Surgery	1 (9.0)
Surgery	1 (9.0)
Course in Palliative Care, 20 or 30 credits	2 (18.2)
Working area, n (%)	
Rural	5 (45.5)
Urban	6 (54.5)
Worked at the unit, yrs, mean (SD)	3.8 (4.41)
Median	2
Min; max	0.5; 15

SD = standard deviation

Studies III-IV

The context of these two studies was home healthcare (in different units than included in study II) and nursing homes in one municipality in Sweden (same as in study II), where general palliative care was provided. Two urban nursing homes and one home care unit serving both rural and urban areas were included and selected on recommendation from head managers (care organization managers). The healthcare units were of different sizes (for more information, see Table 6).

Table 6. Description of healthcare units (studies III-IV), along with an overview of data collection for study III.

Type of unit	Description of unit	Healthcare available	Number of older persons invited to participate	Number of older persons included	Number of baselines	Number of follow-ups	Number of interviews with older persons	Number of interviews with relatives
Nursing home A	Urban environment. 71 apartments distributed over eight units. Four units are care residences, one is a group residence for persons with dementia, one is a care residence for older persons with dementia, and two are departments for older persons with mental disabilities. Seven nurses worked at the nursing home; two nurses used the DCI-SWE.	One nurse is available during daytime and evenings. At night, a nurse patrol service is available. The older persons have a nurse in charge of their care, and a physician can visit their apartments if needed. An occupational therapist and physiotherapist can be contacted if needed.	16	2	2	2	1	1
Home health care	Urban and rural environment. The care organization provides services to about 500 older persons receiving home healthcare. At the time of the study 19 district nurses/nurses were employed in the service; three district nurses/nurses used the DCI-SWE.	The care is carried out by nurse assistants, nurses, and occupational therapists. A nurse is available 24 hours a day; the physiotherapist is available during daytime. Occupational therapists are available upon appointment. The physicians and emergency healthcare are employed by the county council.	16	10	7	7	4	3

Nursing home B	Urban environment. The home consists of 81 apartments distributed over ten units. Three units are for persons with dementia; seven units include a somatic focus. At the time of the study five district nurses/nurses were permanently employed; six district nurses/nurses used the DCI-SWE.	Nursing assistants around the clock. Community nurses are available during daytime and in the evenings, and an occupational therapist is available during daytime on weekdays. At night, a nurse patrol service is available. The unit works in collaboration with a health care centre and through this has access to physicians and physiotherapists.	13	11	9	8	5	4
Total			45	23 (45%)	18 (40%)	17 (38%)	10 (22%)	8

DCI-SWE = Swedish Dignity Care Intervention.

Mixed method study

The mixed method study (study III) (81) included older persons and their relatives. Older persons and their relatives were continuously selected during the study, identified and recommended to be recruited by the responsible CN after permission was obtained from the respective head manager in home healthcare or nursing home care. The CNs asked the older persons' for permission for the researcher to contact them. If the older person accepted, the author of this thesis gave further information about the study (orally and in writing). If CNs struggled to identify older persons for the study the surprise question "Would I be surprised if this person dies within a year?" was used. If the answer was "no" this indicated that the person had palliative care needs and could be included (84).

Out of the older persons invited to participate (n=45) a consecutive sample of 23 older persons agreed to participate in the study. The sample decreased (n=18) because two older persons were unable to attend owing to Covid-19; one had severe memory problems, one died, and one dropped out because of lack of interest. In addition, one older person died during the study (n=17). The researcher or the CN asked the included older persons for permission to contact their relatives, and if they approved a researcher contacted the relatives via the telephone to give study information. All relatives invited to participate accepted, which constituted a consecutive sample. For older persons' and relatives' inclusion- and exclusion criteria see Table 7, and for their sociodemographic aspects, see Table 8.

Table 7. Inclusion and exclusion criteria for older persons and their relatives.

Inclusion criteria	Exclusion criteria
Older persons	
Receiving municipal home healthcare or care in a nursing home Being ≥65 years old Being perceived by CNs as having palliative care needs Being perceived by CNs as being frail Having diverse diagnoses (e.g. heart disease, chronic obstructive pulmonary disease, kidney failure, cancer, or multi-morbidity)	Having dementia Having cognitive problems, being unable to make the older person reflect on and remember what has been said in conversations with the CN
Relatives	
Being related to an older person who has received the DCI-SWE Speaking and understanding Swedish	Having dementia Having cognitive problems being unable to reflect on and remember what has been said in conversations with the CN or researchers

CN = community nurse; DCI-SWE = Swedish Dignity Care Intervention.

Table 8. Sociodemographic data on the sample of older persons and their relatives.

Older persons	**(n=18)**
Age, yrs, mean (SD)	88 (6.8)
Min; max	74; 98
Median	88
Female, n (%)	13 (72)
Marital/social status, n (%)	
Married/living with partner	2 (11.1)
Widowed/living alone	16 (88.9)
Type of health care, n (%)	
Home care	7 (38.9)
Nursing home	11 (61.1)
Relatives	**(n=8)**
Age, yrs, mean (SD)	68 (10.8)
Min; max	47; 83
Median	69
Female, n (%)	6 (75)
Relationship to the older person, n (%)	
Wife/husband	1 (12.5)
Sibling	2 (25.0)
Daughter	2 (25.0)
Son	2 (25.0)
Friend	1 (12.5)

DCI-SWE = Swedish Dignity Care Intervention;
SD = standard deviation.

Process evaluation study

The process evaluation study (study IV) included purposive samples of CNs, HCPs and healthcare managers. The HCPs and CNs were identified with help from first-line managers at the included healthcare units. Eleven CNs were included and participated in one or two DCI workshops, and then used the DCI-SWE with older persons. The HCPs got involved based on the care provided to older persons. They were identified with help from CNs or first-line managers. Three nurse assistants and two occupational therapists participated. Head managers (n=2) and first-line managers (n=3), both from home care and nursing homes, were included in the study. For inclusion- and exclusion criteria, see Table 9; sociodemographic data, see Table 10.

Table 9. Inclusion and exclusion criteria for community nurses, other healthcare professionals, and managers.

Inclusion criteria	Exclusion criteria
Community nurses	
Working in general palliative care Working in municipal home healthcare or a nursing home Having experience of caring for persons with palliative care needs Having participated in the DCI-SWE work shop and/or used the DCI-SWE in their care work	Having a close relative with palliative care needs, currently cared for in the municipality included in the study
Healthcare professionals	
Working in a context where DCI-SWE is used by CNs Having experience of caring for older persons with palliative care needs	Having a close relative with palliative care needs currently cared for in the municipality included in the study
Managers	
Working in a context where DCI-SWE is used by CNs	Being a manager for HCPs not including CNs

CN = community nurse; DCI-SWE = Swedish Dignity Care Intervention; HCP = healthcare professional.

Table 10. Demographics of community nurses, healthcare professionals and managers.

Variables	
Community nurses	**(n=11)**
Age, yrs., mean (SD)	46 (12.7)
Min; max	27; 65
Median	44
Female, n (%)	8 (73)
Profession, n (%)	
Registered nurse	7 (64)
District nurse	4 (36)
	19 (13.0)
Number of years as a nurse, mean (SD)	
Min; max	2; 40
Median	18
Healthcare professionals	**(n=5)**
Age, yrs., mean (SD)	46 (8.2)
Min; max	36; 57
Median	47
Female, n (%)	5 (100)
Profession, n (%)	
Nurse assistant	3 (60)
Occupational therapist	2 (40)
Number of years in their profession, mean (SD)	17 (12.2)
Min; max	3; 30
Median	14
Managers	**(n=5)**
Age, yrs., mean (SD)	47 (6.0)
Min; max	37; 53
Median	47
Female, n (%)	4 (80)
Profession, n (%)	
Registered nurse	3 (60)
District nurse	1 (20)
Oncology nurse	1 (20)
Type of manager, n (%)	
Head manager	2 (40)
First-line manager	3 (60)
Number of years as a manager, mean (SD)	9 (5.7)
Min; max	2; 17
Median	9

SD = standard deviation.

Procedure, studies II-IV

Implementation

The DCI-SWE was implemented for older persons in the municipal healthcare context. Key concepts in implementation science are context, adaptation, strategies, outcomes, fidelity, and sustainability (85).

The "*context*" refers to the setting where the intervention is implemented (86). By "*adapting*" the intervention to the local context, it can increase the fit between the intervention and the context (87). Interventions are not always implemented as intended and therefore "*strategies*" can be set up to facilitate implementation (88). By measuring "*outcomes*" eventual effects of the intervention can be identified (89). To evaluate the implementation, "*fidelity*" can be considered (90) along with acceptance and "*sustainable*" use of the intervention (91). In the next section the framework for implementing the DCI-SWE is described.

The Knowledge to Action framework

"*The KTA model*" (Figure 3) was used as a framework for the DCI-SWE's implementation. It has undergone extensive evaluation and takes culture factors into account (92). The KTA focus on "*knowledge creation*" and "*actions*" (93). At first, the original DCI (67-71) was selected to conserve older persons' dignity. Then the DCI was translated and adapted to the Swedish context (75-77) in a knowledge creation phase (92). The new research knowledge was put together by the researchers to the Swedish DCI. Knowledge regarding outcomes were studied (study I) to give guidance on how to evaluate the DCI-SWE. Further, CNs used the DCI-SWE in a feasibility-study (study II), and barriers to its use were studied. After that study, the implementation intervention was tailored to fit the local context (municipal palliative healthcare). Implementation strategies for the DCI-SWE were chosen (see next section and Table 11) (studies III-IV). The strategies intended to support a sustained use of the DCI-SWE (92). In studies III-IV, the use of the DCI-SWE was monitored, while the implementation intervention was monitored in study IV. However, quantitative outcomes of the DCI-SWE were evaluated in study III (92).

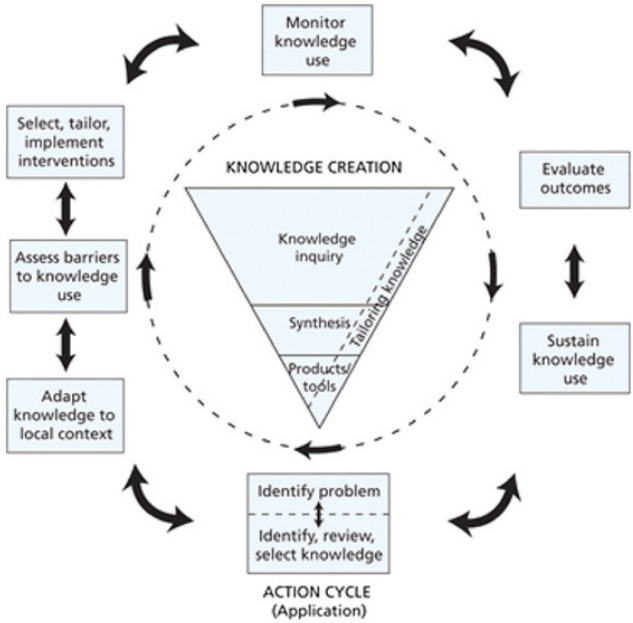

Figure 3. The Knowledge to Action [KTA] Framework (92) (used with permission from the creator).

Implementation strategies, studies III-IV

The implementation strategies (the implementation intervention - see Table 11) were chosen from "the Cochrane *Effective Practice and Organization of Care* Group [EPOC] taxonomy" (94). The EPOC taxonomy is thoroughly processed and includes several domains of implementation interventions. In the DCI-SWE project the domain of implementation strategies was used, including interventions designed to create changes in healthcare organizations, HCPs' behaviour or healthcare recipients' use of healthcare services.

If CNs struggled to identify older persons for the study the surprise question "*Would I be surprised if this person dies within a year?*" was used. If the answer was "*no*" this indicated that the person had palliative care needs and could be included (84). Furthermore, a method support for

documentation in a "*DCI-SWE care plan*" was developed with help from one CN, who had documentation responsibility within the municipality.
The availability of a facilitator at every healthcare unit, who could support CNs in questions related to the DCI-SWE, was added. The facilitators functioned as local opinion leaders (94) and contact persons for the DCI project. They were employed in the project for 6 months, 5% of their working time. Furthermore, the CNs received contact details for specialized conversational support where needed. During FGIs with CNs, time was set apart for reflection about the use of the DCI-SWE together with the researchers.

Table 11. Supporting structures for implementing the Swedish Dignity Care Intervention (studies III-IV).

Part of intervention	Specific aim	Participants	Evidence applied	Time frame
Information about the DCI-SWE project	To spread knowledge about the project to the municipal actors on the municipality's intranet.	Everyone who accessed the municipality's intranet.	The KTA cycle, strategy from the EPOC taxonomy: use of information and communication technologies.	Spring – autumn 2019
Meetings with the municipal organization	To give information about the DCI project and establish engagement.	Head managers, first-line managers, CNs, palliative care coordinators, other HCPs, and researchers.	KTA cycle; organizational strategies from the EPOC taxonomy: marketing, distribution of pedagogical materials.	Started 1 year before implementation and continued during the study on several occasions, 1 - 1.5 hours per session. Before workshop 1, at least three meetings with head- and first-line managers, and one meeting with CNs at each unit were held. Ten meetings with different managers were held during the study.
Workshop 1 December 2018, February 2019 (nursing home A and home healthcare), October 2019 (nursing home B)	To give information about the DCI-SWE orally and in writing (e.g. the DCI manual), teach CNs the DCI-process (Figure 2), give practical training on using DCI-SWE. To give information about the knowledge translation (flowchart of CNs' practical step-by-step procedures, documentation support, and overview of study participation).	CNs. First-line managers were invited but not all attended. Two researchers on each occasion.	KTA; action strategies from the EPOC taxonomy; pedagogical meetings, distribution of pedagogical materials, procedures for assuring professional competence.	2 hours in each unit. One follow-up session in February 2019 for two of the units.

Workshop 2 September 2019 (nursing home A and home healthcare)	For CN - participants to meet each other as well as researchers and collaborators, to discuss their participation and questions related to the DCI-SWE and the project. Included information about the DCI-SWE and practical training on using the DCI-SWE. The CNs were given contact information to conversational support if needed.	CNs, internal facilitator/local opinion leader, head managers and first-line managers. Three researchers.	KTA; action strategies from the EPOC taxonomy; pedagogical meetings, distribution of pedagogical materials; local opinion leaders; procedures for assuring professional competence.	3-hour workshop at the university
Employing CNs as facilitators	To engage CNs and facilitate implementation.	One CN at each unit acting as a facilitator.	KTA, monitoring of knowledge use; action strategy from the EPOC taxonomy; local opinion leaders.	Three CNs were employed in the DCI project, using 5% of their employment time on the intervention for 6 months during the study.
Informal meetings	To provide support from researchers; giving verbal recommendations and encouragements, helping CNs to prioritize communication with older persons, and creating interest in the DCI-SWE.	CNs. One or two researchers on each occasion.	KTA, monitoring of knowledge use; action strategies from the EPOC taxonomy; educational outreach visits/academic detailing (providing information with the aim of changing practice); audit and feedback; local opinion leaders; and marketing.	Approximately 1 hour at each unit on several occasions (n=26).

FGI I About 1 month after study start	To evaluate the DCI-SWE. To engage in interprofessional learning where a tutorial was provided by researchers.	CNs. Two researchers, one moderator and one co-moderator.	KTA; evaluation of the DCI-SWE and its implementation. Action strategies from the EPOC taxonomy; inter-professional (interactive) education; audit and feedback.	CNs (n=8): three occasions in autumn 2019
Workshop with facilitators Early spring 2020	To provide support from researchers; giving verbal recommendations and encouragements, helping CNs to prioritize communication with older persons, and creating interest in the DCI-SWE.	CNs acting as facilitators. Two out of three CNs were able to attend. Two researchers.	KTA, monitoring of knowledge use; action strategies from the EPOC taxonomy; educational outreach visits/academic detailing (providing information with the aim of changing practice); audit and feedback; local opinion leaders; and marketing.	2 hours
FGI II After care actions were introduced in older persons' healthcare	To evaluate the DCI-SWE. To support interprofessional learning where a tutorial was provided by the researchers.	CNs. Two researchers at FGI:s, one researcher at individual interviews.	KTA; evaluation of the DCI-SWE and its implementation. Action strategies from the EPOC taxonomy; inter-professional (interactive) education; audit and feedback.	CNs (n=8): four occasions in spring to early autumn 2020, of which one was an individual interview.

FGI III At study end	To evaluate the DCI-SWE. To support interprofessional learning where a tutorial was provided by the researchers.	CNs; HCPs (nurse assistants, occupational therapists); head and first- line managers. Two researchers at FGI:s, one researcher at individual interviews.	KTA; evaluation of the DCI-SWE and its implementation. Action strategies from the EPOC taxonomy; inter-professional (interactive) education; audit and feedback.	CNs (n=4): two occasions at the turn of year 2020 – 2021 of which one was an individual interview. HCPs (n=5): four occasions of which three were individual interviews. Managers (n=5): three occasions of which two were individual interviews.

CN = community nurse; DCI-SWE = Swedish Dignity Care Intervention; EPOC = Effective Practice and Organization of Care Group; FGI = focus group interview; HCP = healthcare professional; KTA = Knowledge to Action.

Data collection

Database searches, study I

Database searches were undertaken in the following databases: CINAHL, MEDLINE, PsycINFO and Web of Science, and limited to the time period 1997–2018. A broad and inclusive approach was used in preliminary searches to scope out the field. Indexing terms were established by searching for available MeSH terms, and key words for free-text searching. Free-text key words were only used as a complement to indexing terms. In Web of Science, only free-text key words are available.

The searches were started in CINAHL, where terms related to dignity (synonyms such as "*personhood*") and terms related to palliative care (synonyms such as "*end of life care*") were combined with Boolean operators "OR" and "AND". More-over, the searches were limited to English language, peer-reviewed, and "*all-adult*" (aged ≥18 years) studies. Where needed, the combination of search terms in CINAHL was modified for MEDLINE, PsycINFO, and Web of Science. The search strategy was discussed with and validated by a librarian.

The database searches identified 1,619 articles. In addition, a manual search was conducted by networking within the research group and searching through reference lists of the already included articles, generating a further 59 articles (giving a total of 1,678 articles). In the selection of articles, the inclusion criterion "*match the aim of the review*" was applied to all titles, which meant that 758 articles were excluded.

All inclusion and exclusion criteria were used on the titles and abstracts of the remaining articles by the author of this thesis and the main supervisor separately before they compared their independent selections and discussed them to reach agreement. To validate the selection process, two co-supervisors reviewed a selection of preliminarily included and excluded articles. This process led to discussions among all researchers about the selection criteria until consensus was reached. This process excluded a further 784 articles. Full-text papers were then retrieved, read in full, and reviewed by the author of this thesis and the main supervisor, leading to exclusion of 61 articles (75 articles remaining). After further discussions among all the researchers to validate the result, 40 articles remained. There

were 16 duplicates, so the final selection included 24 articles. An updated search was done in February 2019, which added two more articles to the number (n = 26).

Focus group- and individual interviews, studies II-IV

Interviews with community nurses, healthcare professionals, and managers

To stimulate discussions among CNs, HCPs and managers and to capture a range of opinions, FGIs were conducted (95) (studies II, IV).

In study II, FGIs were conducted with CNs after they had used the DCI-SWE. In study IV the FGIs with CNs were conducted on three occasions during the study period (after about 1 month, after care actions were introduced in the older persons' care, and at the end of the project). The group size that was sought for all FGIs was between four and eight participants, because larger groups can limit participants' expressions (95). However, sometimes it was difficult even to get a group of four people together because of participants' difficulty in leaving their work.

All FGIs were held at the healthcare units, in an undisturbed location if possible. However, once the Covid-19 pandemic had started (studies III-IV), FGIs and individual interviews were conducted online via digital platforms Teams/Zoom, as well as conducting individual interviews over the telephone. A semi-structured interview guide (Appendix 3) with questions on participants' experiences of the DCI-SWE was used (studies II, IV). In study IV, questions regarding implementation were added. For example, asking, "*Can you describe your experience of the focus group meetings*?" At the FGIs the author of this thesis acted as a moderator asking the research questions, and the main supervisor or one of the co-supervisors worked as a co-moderator. As a complement to all FGIs, individual interviews were used.

In study II, three FGIs and one individual interview were conducted with CNs. The FGIs on average lasted 65 minutes, and the individual interview lasted 34 minutes. In study IV, seven FGIs and two individual interviews were conducted with CNs. Furthermore, one FGI was conducted with HCPs at the end of the study together with three individual interviews. One FGI was conducted with managers/first-line managers together with two

individual interviews, also at the end of the study. The FGIs lasted on average: CNs, 53 (range 36 – 67) minutes; HCPs, 41 minutes; and managers, 72 minutes. The individual interviews lasted on average: CNs, 31 (range 31 – 31) minutes; HCPs, 37 (range 21 – 51) minutes; and managers, 53 (range 42 – 63) minutes. All interviews were audio-recorded with the participants' permission and were transcribed verbatim by a professional transcriber.

Interviews with older persons and their relatives

In study III, individual interviews were conducted by the author of this thesis with older persons (n = 10) and their relatives (n = 8). The interviews were conducted in parallel to administering questionnaires. This method of collecting data was a way to provide a deeper understanding of the DCI-SWE and allowed for both convergent and complementary quantitative results (96).

A semi-structured interview guide with questions on the participants' experiences of dignity and DCC when using the DCI-SWE was used (Appendix 3). Interviews with older persons were conducted face to face (n = 5) in the older persons' nursing home apartment or home, or by telephone (n = 5) (M = 36 minutes [range 22 – 55]) because of the Covid-19 pandemic. In some cases, interviews were interrupted to continue another day, in consideration of the older persons' health.

Altogether, eight relatives participated in interviews, either in their older relative's home (n = 3), or at their workplace (n = 1), or by telephone (n = 4) (M = 37 minutes [range 23 – 60]). All interviews were recorded, and later transcribed by a professional transcriber, except in one case, where a relative was uncomfortable with being audio-recorded, and the researcher therefore took notes instead.

Reflective diaries and field-notes, studies II and IV

Additional to the interviews, the CNs were instructed to write a reflective diary (97) about their use of the DCI-SWE. The CNs were informed not to write any personal information in these that could identify a particular person. They were reminded by e-mail to bring the diaries to the FGIs in case they wanted to discuss anything they had written with researchers or colleagues. In study II, the diaries yielded 0.5 – 1.5 pages on average.

However, in study IV, only one CN submitted a reflective dairy after the study (9 pages).

In addition, the author of this thesis wrote field-notes (97) following meetings with managers, CNs and HCPs after visiting the healthcare units (studies II, IV). Notes from when the author of this thesis accompanied the CNs were documented with guidance from concepts in the Alberta Context Tool (98, 99), and resulted in a 27-pages document file (study IV).

Questionnaires, study III

Two questionnaires were used to measure outcomes of DCC: the PDI (75) (see Appendix 2) and the McGill QoL questionnaire - Expanded [MQOL-E] (100). The findings from study I guided us in choosing outcomes for study III. The questionnaires were collected from older persons over time, at baseline [T^0] (n = 18) and once during the intervention, after care actions had been introduced in the older persons' care (follow-up = T^1) (n = 17). Thus, the timing of the follow-up was individual. Both questionnaires took 30-60 minutes to complete. Where an older person was unable to fill in a questionnaire a CN or researcher asked the older person the questions. In one case a relative together with the older person answered the questions.
If the older person was in hospital or had recently died, the questionnaires were filled in by the CN and were marked "*by proxy*". The questionnaires were collected in parallel with interviews with the older persons and their relatives (study III).

The Patient Dignity Inventory

Older persons' dignity-related distress was measured with the Swedish PDI (75), a 5-point Likert scale ranging from 1 (not a problem) to 5 (an overwhelming problem). The scoring was based on the sum of the scores for all items. In item 1, if the older person had a different score for different symptoms the worst symptom/score was used.

The PDI was considered to be relevant for older persons as it has not been developed for any specific diagnosis (101, 102). Previously, in a review by Johnston, Flemming, Narayanasamy, Coole and Hardy (103), it was recommended for use and an integrative review (study I) showed that it has been frequently used when evaluating DCC.

The PDI has been psychometrically validated in several countries, with good results (72, 104-110). The international version has demonstrated good internal consistency ($\alpha = 0.93$) (73). The PDI has previously been translated and adapted into Swedish (75) but has only been tested in a Swedish context in a feasibility study (study II). Hence, the Swedish version has not yet been psychometrically validated. However, no other translated dignity instrument was available when starting study III.

McGill Quality of Life questionnaire - Expanded

Older persons' QoL was measured using the multidimensional Swedish MQOL-E, with 22 items measured on a 10-point scale (100, 111). The MQOL-E includes eight domains: physical, psychological, existential, social, healthcare quality, burden, environment and cognition. The scoring consists of three parts: a single-item scale measuring overall QoL, nine subscales (physical, psychological, existential, social, burden, environment, cognition, healthcare quality, finance), and a total score which is the mean of the nine subscales scores. Some scores were transposed before they were calculated. The MQOL-E was chosen for the study as it is often used in palliative care and is an instrument with many dimensions.

In Sweden, there is evidence for the MQOL-E's content validity, linguistic equivalence and cultural appropriateness as shown by Axelsson et al. (100). However, since the Swedish version has not yet been psychometrically tested (as a large enough sample is needed) the measurement relies on the validated English version (111) where a factor analysis showed that the MQOL-E has good construct validity. Internal consistency reliability has been shown in five out of eight of the MQOL-E domains (psychological, existential, social, healthcare, cognition) (111). The Swedish version (100) is based on the same context as the English version.

Data analysis

Thematic synthesis, study I

The text of the identified articles was analysed using a thematic synthesis approach intended for mixed or qualitative method research (112). An abductive approach (113) was used, to discover patterns and generate a deeper understanding about outcomes. Hence, themes related to the outcomes were created inductively, while cluster themes were created deductively.

To identify themes, the author of this thesis - together with one supervisor read and then reread the articles focusing on manifest data related to the aim of the study. First, five articles were analysed separately. Then the articles were discussed together to establish and validate what should be extracted from the articles. All researchers were involved in the analysis of the articles. Data were collated using an inductive method based on questions derived from the study aim: "*What outcomes were studied?"* and "*How were outcomes operationalized?"* This process resulted in seven themes.

Moreover, the three main categories in Chochinov's dignity model (27), *"Illness-related concerns, the Dignity-conserving repertoire, and the Social dignity inventory"* (see Figure 1), were used as a grid to deductively gather results into cluster themes. Some themes could not be clustered to the three main categories, and consequently a fourth cluster theme, "*Themes regarding overarching Dignity issues"*, was generated. For trustworthiness, themes and cluster themes were validated through discussions within the research group. In the last step, an agreed synthesis was produced, reporting main results.

Qualitative content analysis, study II

Data were analysed using inductive content analysis (114). In the preparation phase, data transcripts were read for familiarization. Units of analysis (extracts from interviews; field notes; reflective diaries) that corresponded to the study's aim were selected and organized by the author of this thesis. The analysis focused on both manifest and latent content and was conducted in NVivo 12 (QSR International, Doncaster, Australia).
Open coding nodes were noted, and the content of the units of analysis was described. The coding nodes were then gathered on a coding sheet for an overview of data content and variances. Nodes were then grouped by the research group, based on similarities and differences in the data, to generate subcategories. Subcategories were named based on their content, further compared and, in line with the researchers' interpretations, grouped into two main categories. Finally, categories were further discussed for clarity to reach consensus in the research group, and quotations to illustrate the findings were identified, all to increase trustworthiness.

Thematic analysis, study III

A thematic inductive analysis was conducted (115).
The author of this thesis read all interviews (data corpus) for familiarization and noted initial ideas about patterns. Interview data were entered into the N-Vivo 12 program (QSR International, Doncaster, Australia), which was used throughout the analysis. Then features (data extracts) from interviews were systematically coded in relation to the study aim and put into different codes, creating meaningful groups. These were further discussed within the whole research group. Thereafter, the relation between codes and how they could be combined into initial semantic subthemes was considered by the author of this thesis and one co-supervisor. Then, initial subthemes were reviewed by all researchers to see if they worked in relation to coded extracts and also to the whole data set to check if they needed refinement. During analysis of the subthemes, initial overarching latent themes were formulated. Thereafter, the themes were clarified, defined, and named based on their true essence (all researchers).

Further, a thematic map was developed to get a clear overview. Then a narrative of the themes was written, and quotes were identified to increase credibility. The analysis of the themes was conducted in parallel with, but separately from, the quantitative data analysis in study III, using mixed method design (81).

Directed content analysis, study IV

A directed content analysis according to Hsieh and Shannon (116) was used to interpret the meaning of data, from FGIs, individual interviews, diaries and field-notes. To validate the description of the evaluation process and do a deductive category application, aspects from the MRC's process evaluation framework were chosen as a matrix for analysis. Thus, initial coding categories were "*Implementation, Context and Mechanism of impact*" (head categories) (78).

All analysis work was done using the NVivo 12 program (QSR International, Doncaster, Australia). At first, all interviews were read through, and all text that appeared to be related to the coding categories was highlighted to increase trustworthiness. For each coding category, an operational definition from the MRC (78) facilitated the coding of data. All highlighted text was then coded using the predetermined coding categories. Furthermore, because of the breadth of the head categories, categories and

subcategories were identified in subsequent analyses. To achieve consensus and trustworthiness, all categories were discussed within the whole research group. In conclusion, to establish credibility, the findings were again considered in relation to the MRC process evaluation framework (78) and quotes were used to illustrate the findings.

Statistical analysis, studies III-IV

The analysis of the PDI (75) and the MQOL-E (100) was performed using nonparametric tests (study III). The Wilcoxon signed-rank test was used to study differences over time (117). All analyses were performed using IBM SPSS Statistics version 26 (IBM Corp., Armonk, NY, USA). P-values (two-tailed) < 0.05 were considered statistically significant. The analysis of the outcomes was performed in parallel but separately to the qualitative data analysis (study III) using a mixed method design (81).

Furthermore, descriptive statistics (study IV) were used to describe data from field notes regarding fidelity, dose, reach and adaptation (78) where it could be applied.

Ethical considerations

To ensure that resources for the DCI project were available in the municipality, written permission (a resource certificate) was obtained from the head of the municipal healthcare (studies II-IV), since the responsibility for the safety of older persons with palliative care needs and the HCPs within the DCI project lies with the general palliative care at Örebro municipality. Ethical approval was obtained from the Ethical Review Board in Uppsala, Sweden, Reg. No. 2014/312 (study II), and Reg. No. Ö 10-2019 (studies III-IV).

The DCI project was guided by the principles stated in "*the Helsinki Declaration*" (118). Informed consent was collected from all study participants, both orally and in writing, before collecting data (studies II-IV). Where an older person was unable to read the consent information by themselves (for example, because of visual impairment), the researcher read it out aloud to them. An exception was study II where older persons were not required to consent to participation in the study as the DCI-SWE was evaluated from the perspectives of CNs. All participants in the DCI project were informed that their participation was voluntary and that they could withdraw their participation at any time.

As sensitive data were collected "*the General Data Protection Regulation*" [GDPR] was followed (119). The participants were informed that all data would be handled with confidentiality. The data on participants were encoded so that individuals would not be traceable and stored in a locked cabinet which only the researchers had access to. The CNs, first-line managers and head managers were informed that data collected by them during home healthcare or at nursing homes ought to be stored in a locked cabinet at the healthcare units. No unauthorized persons had access to these cabinets, where data were stored until the researchers retrieved the data to be stored at the university. The CNs were given paper boxes for this purpose, marked with the researchers' names to avoid unauthorized persons' attention.

Older persons were not in a dependent relationship with the researchers who collected the data, since it was the CNs, not the researchers, who provided them with care. The researchers conducted all the interviews and strove to take the participants' integrity into account to minimize any

possible suffering related to the study. All data were displayed on a group level to protect all participants identities. Older persons' "*integrity*" always needs to be safeguarded, which means protecting the personal sphere around the individual (24). For this reason and because of the way the DCI-SWE works (it requires active participation from the older person, and it also requires the older person to participate in reflective conversations), persons with dementia were excluded from the DCI project.

During the interviews conducted, the researchers sought to be responsive to the participants' needs. Especially the older persons and their relatives, could be considered as being in a sensitive position in relation to the researchers and regarding the palliative care context. To start from who the older person considers themselves to be was central for the researchers. The researchers strove to request all the participants' views and opinions during interviews.

The researchers and the CNs required respect for the older persons' "*autonomy*" and "*self-determination*" throughout the project. A prerequisite for autonomy is that the older person is involved in decisions (24). Therefore, the researchers and CNs, strove to have a responsiveness to if older persons wanted to participate or not, or if their will to do so had changed. For example, researchers had an awareness of that the condition of the older persons' health rapidly could change regarding the palliative care context. The researchers regularly discussed with the CNs, if some of the older persons were considered too frail to continue their participation. It was also considered that older persons often have a will to participate in research (120).

Concerning that the DCI-SWE could include existential conversations, the CNs had access to conversation support if needed, throughout the DCI project. Furthermore, the research group had experience of palliative care and competence in communication; hence, they could refer older persons and their relatives to other HCPs if needed. Because palliative care involves the making of tough decisions about how someone want to live at the end of their lives (121) indicating it could be a challenging time.

Results

The findings will be presented in the following order:
"*Experiences of dignity and dignity-conserving care*"; "*Experiences of the Swedish Dignity Care Intervention*"; "*Outcomes in dignity-conserving care*"; "*Implementation of the Swedish Dignity Care Intervention*", and "*Synthesis of the findings*".

Experiences of dignity and dignity-conserving care

The findings presented here reflect CNs' (studies II, IV), older persons' and their relatives' (study III) as well as managers' and HCPs' perspectives (study IV).

The CNs emphasized (study II) that older persons' thoughts about dignity should be focused while working with the DCI-SWE. According to them, dignified care could be about knowing when it is appropriate to talk about existential questions. However, the CNs raised that in the Swedish culture people do not talk about death. At the same time, they also mentioned that CNs must be able to talk about it. Existential aspects were something that the CNs thought was easily overshadowed by other duties. Furthermore, the CNs stated that if older persons were not appropriately informed about their situation, they might get lonely having to face their problems on their own, which could negatively affect their dignity. Knowing about their own condition enabled older persons to decide what they wanted to do while they were still able to. At some healthcare units (study IV), CNs described they strived to provide DCC all the time, which was confirmed by the HCPs. The CNs defined DCC as care that does not only see the older person as a patient, but also strives to find what makes the individual person happy. As a part of conserving dignity, they had to treat the older person with respect and consider their preferences while providing healthcare.

The older persons and their relatives (study III) described dignity through life and how they related to dignity. While the concept of dignity was unfamiliar to and diffuse for some participants, others had a clear view of it. Even if some older persons and relatives were uncertain about the concept many could describe what was important for older persons' dignity. The interviewed older persons linked dignity to being understood and respected, and being friendly to each other, while their relatives linked dignity to showing love and consideration. From both perspectives it was described

that maintaining health, abilities and social roles was important for older persons' dignity. When an older person's condition changed, this often led to limitations to do things. In this situation, if the older persons had the ability to speak for themselves and continue in their social roles this helped maintain their dignity. Additionally, accepting one's situation and being accepted by others was important for older persons' dignity. Both the older persons and their relatives described how older persons' mental strength influenced their dignity: when older persons had self-esteem, their dignity was not so badly affected by others' treatment.

Moreover, as a part of DCC, being seen and heard by the HCPs was important for older persons (study III). Creating a relationship with the older person was therefore essential for the HCP. The older persons expressed that if an HCP showed they wanted to help, was sensitive to their needs and knew them by name, this contributed to DCC. The importance of building relationships with older persons was confirmed by the HCPs, and some CNs described that they got closer to the older person by using the DCI-SWE (study IV). Some older persons had been unworthily treated (study III), and it was clear that such treatment could demolish older persons' QoL and impact their dignity. However, most older persons had no experiences of undignified care. Furthermore, relatives highlighted the importance of person-centred care, and a pleasant care atmosphere and meaningful activities were described by both older persons and relatives to be important for DCC. With compassionate staff, older persons could experience dignity.

The older persons talked about activities they were no longer able to do (study III). Some relatives thought that living in a nursing home could negatively affect older persons. For instance, they mentioned outdoor activity as something that should be a regular part of DCC. Additionally, the older persons and their relatives expressed that care competence and continuity were essential for DCC. The relatives described that knowledge about dignity in care was sometimes lacking; they highlighted that HCPs must be able to communicate with older persons. Older persons were often concerned when HCPs were inexperienced and did not know about the older person's preferences. Both the older persons and their relatives expressed that older persons' QoL increased when they received the right kind of help. The older persons emphasized that not meeting so many different HCPs was central for their dignity.

Further, adequate resources were highlighted (study III) by both older persons and their relatives as important for achieving DCC. Whether HCPs listened to older persons or not often had to do with staff availability, and limited time was seen as a barrier to solving concerns. The relatives expressed that they wanted CNs to participate more in care to enhance the quality of care.

The managers (study IV); described that being aware of older persons' dignity makes HCPs approach the conversations that need to be held to provide person-centred care. Further, they believed that talking about dignity was a way to deepen the contact with the older person. They expressed that DCC is about optimizing a situation where no one wants to be. They also felt that there is no support for handling dignity and DCC in the municipalities' data systems.

In addition, to the above views, the HCPs (study IV) highlighted that older persons' dignity had to do with their own health and how their health changed from day to day. They also expressed that DCC means giving good care and striving to preserve the abilities that the older person wants to keep.

Experiences of the Swedish Dignity Care Intervention

Findings presented in this section (studies II-IV) focused on the DCI-SWE as an intervention.

Some older persons did not know what could be done for their dignity but expressed that they were hoping that the DCI-SWE would become useful (study III). For the CNs, the DCI-SWE was helpful in practising the palliative approach while responding to palliative care needs (study II). It gave structure and it gave the CNs an overview of what could be done for the older person. Discussing older persons' needs through the DCI-SWE gave CNs an opportunity to plan the care according to the older persons' wishes (study II). According to the older persons' relatives, the DCI-SWE allowed CNs to follow an older person over time (study III) and include older persons' opinions in the planning of the care.

The DCI-SWE was also described by CNs (study II) as supporting them, as it was useful in measuring the older persons' symptoms and enabled CNs to concentrate on their most important concerns. Likewise, the older persons

expressed that the DCI-SWE presented an opportunity to ventilate their thoughts and resolve their concerns (study III). The CNs felt that through the DCI-SWE's reflective questions they got suggestions on how concerns could be resolved (study II). Managers, HCPs and CNs thought that the DCI-SWE was a way to personalize the older person's healthcare because of the way the intervention is structured (study IV).

Using the DCI-SWE helped some CNs to develop their communication skills (studies II, IV). However, some CNs felt uncomfortable in using the DCI-SWE as it meant having deeper conversations, for example about existential aspects (studies II, IV). In FGIs, the CNs described that CNs could be hindered by their own fear of death. Some CNs suggested that other professions should take care of the deeper issues, for example a curator or the occupational therapist (study II, IV). Others felt a need for more communication training (study IV). However, managers (study IV) highlighted, that with time, use of the DCI-SWE can contribute to professional pride and that it is crucial that deeper conversations become a natural part of nursing.

Most older persons had confidence in their CN and felt safe to have DCI conversations (study III). Through the conversation, some older persons became closer to their CN. They described that they had been listened to and had been given the time they needed. The findings showed that the DCI-SWE gave older persons opportunities to be confirmed as a person (studies II, IV), which older persons and relatives felt was essential in DCC (study III). According to the CNs, the DCI-SWE helped older persons to express their thoughts, and it was a way for them to gain insight into their situation (study II). The older persons and their relatives (study III) thought it was important to put dignity and communication on the agenda, while CNs, HCPs and managers viewed the DCI-SWE as a way to put conversations on the agenda (study IV). From every perspective the DCI-SWE was seen to be useful in maintaining older persons' QoL (studies III, IV). The QoL could be affected by the older person feeling safe and having a social context, and by them being heard and receiving the right kind of help through the DCI-SWE.

The CNs believed that the DCI-SWE enabled older persons to discuss difficult topics with others (study II) and some older persons felt that they got closer to their CN by using the DCI-SWE which was confirmed by CNs

(studies III, IV). Managers, CNs and HCPs felt that the intervention was a way to deal with older persons' loneliness and acceptance of their life situation (study IV). The DCI-SWE enabled older persons' existential questions, for example about death, to be raised and was a way for CNs to respond to existential and sensitive needs (study II). However, the CNs described that it could be challenging for some older persons to participate in the DCI-SWE (studies II, IV), both because of the included topics and because of limited strength. Likewise, the older persons and their relatives described that it required concentration to complete the PDI and expressed that some questions were difficult (study III). Still, one older person had expressed to the CN the need for talking more about spirituality (study II), and older persons and relatives felt that completing the PDI was useful and served as a reminder of important things (study III). Also, even though some older persons declined participation, others wanted to participate although they thought it was challenging (study III).

Furthermore, some relatives (study III) reported that they lacked a context for discussing end-of-life issues. They suggested that meetings with the CN should be held more often, in every third month. The CNs expressed the need for clear documentation of the DCI-SWE to be able to follow up the care of the older persons and decide what care actions to use (studies II, IV). Some CNs described that the effects of the DCI-SWE could be seen immediately, while others thought it would take weeks or months for the intervention to have a visible effect (study II).

Outcomes in dignity-conserving care

The findings on outcomes of DCC (studies I, III) are presented in this section.

Study I showed, in DCC, outcomes have been evaluated after using the Family dignity intervention, the Patient dignity question tool, the Revie ⊕ life review intervention, the Dignity-Conserving End-of-Life Care Programme, and an intervention targeting fundamental values. Further, Dignity therapy was frequently evaluated with different outcomes.

Seven themes of studied outcomes in DCC were found, together with four cluster themes (study I): Themes referred to Illness-related concerns; the Dignity-conserving repertoire; the Social dignity inventory; and Themes of outcomes with an overall approach. For instruments and references related

to an outcome, see Appendix 4: "*Overview of outcomes studied in DCC*". The findings showed (study I) that DCC is often evaluated in terms of outcomes that could be linked to "*Themes referred to Illness- related concerns*". These outcomes had a focus on performance, symptoms and emotional concerns, but also on end-of-life and existential aspects. While evaluating DCC, outcomes that were linked to the "*Themes referred to the Dignity-conserving repertoire*" were used on a slightly smaller scale. These outcomes were about essential life values, such as hope, meaning and spirituality. This theme also included outcomes related to personal strength and coping. For example, it included outcomes such as self-efficacy, resilience and empowerment. The least studied outcomes were related to "*Themes referred to Social dignity inventory*". This theme included outcomes of the care tenor, for example person-centred care, and social support. Lastly, in DCC it was common to use overall outcomes. These outcomes were classifiable under more than one of the three main categories in Chochinov's dignity model (27) (see Figure 1). Therefore, they were considered to be broader and were gathered under the "*Theme regarding overarching dignity issues*". This theme included aspects of dignity, gratitude and appreciation of life. Additionally, aspects of QoL were included. However, the findings lacked concrete communication outcomes.

In study III, older persons' dignity-related distress and QoL were measured (n = 18 at T^0, n = 17 at T^1). For results, see Tables 12 and 13. The findings from the PDI showed that older persons' dignity-related distress did not significantly change over time (it slightly increased but as the change was not statistically significant, p=0.44, no clear conclusions can be drawn). Therefore, it is reasonable to assume that the dignity-related stress remained relatively stable over time. The item that had the highest mean, both at baseline and at follow-up, was "*Experiencing physically distressing symptoms*". The highest rated PDI-items (rated ≥3), in %, were "*Experiencing physically distressing symptoms*" (67% at T^0 and 63% at T^1) and "*No longer being the person I was*" (56% at baseline and 53% at follow-up).

Further, the older persons' overall QoL did not significantly change over time (it decreased slightly, but as the change was not statistically significant, p=0.64, no clear conclusions can be drawn). Therefore, it is reasonable to assume that the overall QoL remained relatively stable over time. Only in

the psychological dimension was the decrease statistically significant (p=0.01), which can therefore be considered as a reliable change.

It was also the psychological dimension that had the highest decrease from baseline to follow-up (mean difference = -1.7).

Table 12. Older persons' outcomes regarding dignity-related distress measured with the PDI

PDI questionnaire, items	N	Mean (SD), baseline (T^0)	Range	N	Mean (SD), follow-up (T1) (after care actions were introduced)	Range	Difference (T^1)–(T^0) mean score	*P*-value[a]	Items rated ≥3 at T^0 (%)	Items rated ≥3 at T^1 (%)
1. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea)	18	**3.0† (0.97)**	1–4	16	**3.0† (1.21)**	1–5	–	0.59	**67%**	**63%**
2. Feeling depressed	18	1.9 (0.90)	1–4	17	1.9 (1.05)	1–4	–	1.00	22%	24%
3. Feeling anxious	18	1.7 (0.83)	1–4	17	2.2 (0.95)	1–4	**0.5**	0.09	11%	29%
4. Feeling uncertain about my illness and treatment	18	1.9 (1.06)	1–4	17	2.1 (0.86)	1–3	0.2	0.33	39%	41%
5. Worrying about my future	18	1.8 (1.04)	1–4	17	1.9 (1.00)	1–4	0.1	0.59	22%	29%
6. Not being able to carry out tasks associated with daily living (e.g. washing myself, getting dressed)	18	2.1 (1.28)	1–5	17	2.1 (1.03)	1–4	–	0.59	33%	29%
7. Not being able to independently attend to my bodily functions (e.g. needing assistance with toileting-related activities)	18	2.2 (1.15)	1–5	17	2.1 (1.17)	1–4	0.1	0.56	39%	24%
8. Not being able to think clearly	18	1.7 (0.91)	1–4	17	1.5 (0.62)	1–3	-0.2	0.38	17%	6%
9. Feeling that how I look to others has changed significantly	17	1.8 (1.09)	1–4	17	1.8 (1.03)	1–4	–	0.74	24%	18%
10. Feeling like I am no longer who I was	18	2.4 (1.10)	1–4	17	2.7 (1.11)	1–4	0.3	0.13	**56%**	**53%**

11. Not feeling worthwhile or valued	18	1.5 (0.86)	1–4	17	1.5 (0.94)	1–4	–	1.00	11%	18%
12. Not being able to carry out important roles (in relation to family, friends or society)	18	1.8 (0.92)	1–4	17	1.8 (0.97)	1–4	–	0.53	22%	24%
13. Feeling that life no longer has meaning or purpose	18	1.4 (0.71)	1–3	16	1.7 (1.01)	1–4	0.3	0.10	11%	25%
14. Feeling like I have not made a meaningful and lasting contribution during my lifetime	18	**1.2†† (0.43)**	1–2	17	1.2 (0.39)	1–2	–	0.56	**0%**	**0%**
15. Feeling that I have "unfinished business" (e.g. things left unsaid or incomplete)	18	1.4 (0.61)	1–3	17	1.3 (0.59)	1–3	-0.1	0.16	6%	6%
16. Feeling that I don't have control over my life	18	1.8 (0.94)	1–3	17	2.0 (1.06)	1–4	0.2	0.10	33%	29%
17. Not being able to accept the way things are	18	1.8 (0.86)	1–3	17	1.7 (0.85)	1–3	-0.1	0.79	28%	24%
18. Feeling that I am no longer able to mentally "fight" the challenges of my illness	18	1.8 (0.94)	1–4	17	2.1 (1.14)	1–4	0.3	0.16	22%	29%
19. Not being able to continue with my usual routines	18	2.1 (1.00)	1–4	17	1.8 (0.95)	1–4	**-0.3**	0.38	39%	24%
20. Feeling concern that my spiritual life is not meaningful	17	1.3 (0.59)	1–3	17	1.2 (0.56)	1–3	-0.1	0.32	6%	6%
21. Feeling that my illness and care needs have reduced my privacy	18	1.4 (0.78)	1–4	17	1.7 (1.05)	1–5	0.3	0.40	6%	12%

22. Not feeling supported by my community of friends and family	18	**1.2†† (0.55)**	1–3	17	**1.0†† (0.00)**	1–1	-0.2	0.10	6%	**0%**
23. Not feeling supported by my health care providers	17	1.3 (0.77)	1–4	17	1.2 (0.56)	1–3	-0.1	0.56	6%	6%
24. Not being treated with respect or understanding by others	18	1.4 (0.61)	1–3	17	1.4 (0.61)	1–3	–	1.00	6%	6%
25. Feeling that I am a burden to others	18	1.9 (1.00)	1–4	17	1.9 (0.93)	1–4	–	0.74	22%	24%
26. Feeling concerned about how my death will affect my family and friends	18	1.6 (0.85)	1–3	17	1.6 (1.06)	1–4	–	0.74	22%	18%
Sum of all ranks	16	45.1 (13.26)	29–76	15	47.1 (12.33)	28–65	2.00	0.44		

Scoring: 1 = not a problem; 2 = a slight problem; 3 = a problem; 4 = a major problem; 5 = an overwhelming problem (higher scores indicate greater dignity-related distress). [a]*Wilcoxon signed- rank test; †the highest and ††the lowest means scores in rated PDI items at baseline [T^0] and follow-up [T^1]; the largest and smallest difference between T^0 and T^1 are marked in bold.*

Table 13. Older persons' outcomes regarding quality of life measured using the McGill Quality of Life questionnaire – Expanded [MQOL-E].

MQOL-E questionnaire, dimensions	**N (T^0)**	**Mean (SD), baseline (T^0)**	**N (T^1)**	**Mean (SD), follow-up (T^1)**	**Difference T^0–T^1, mean score**	***P*-value**
Overall QoL	18	6.0 (1.82)	17	5.8 (3.07)	-0.2	0.64
Physical dimension	18	**5.9**†† (**1.73**)	17	**4.5**†† (**2.33**)	-1.4	0.08
Psychological dimension	18	7.7 (2.14)	17	6.0 (3.25)	**-1.7**	**0.01**
Existential dimension	18	7.3 (1.84)	17	6.9 (2.67)	-0.4	0.38
Social dimension	18	8.4 (1.75)	17	7.9 (1.78)	-0.5	0.46
Burden	18	8.3 (2.89)	17	6.9 (3.67)	-1.4	0.12
Environment	18	7.6 (2.87)	17	8.1 (2.36)	**0.5**	0.98
Cognition	18	7.7 (2.24)	17	7.9 (2.35)	0.2	0.26
Health care	18	8.6 (1.59)	17	8.3 (1.34)	-0.3	0.19
Finance	18	**8.8**† (**2.48**)	17	**9.1**† (**2.19**)	0.3	0.89
Total	18	7.8 (1.11)	17	7.3 (1.62)	-0.5	0.16

MQOL-E items ranked from 0 to 10 (the higher the estimate, the better the QoL). †The highest and ††the lowest means, rated in MQOL-E items at baseline [T^0] and follow-up [T^1]. The largest difference and the smallest difference since T^0 are marked in bold.

[a] *Wilcoxon signed- rank test. SD = standard deviation.*

Implementation of the Swedish Dignity Care Intervention

Findings presented here relate to qualitative responses about the implementation of the DCI-SWE and the process evaluation (studies II and IV). By studying researchers' field notes, findings about fidelity, reach, dose, and adaptations were able to be described (study IV).

Barriers and facilitators

The CNs, HCPs and managers described facilitators and barriers to the use of the DCI-SWE (studies II, IV). Not all in the healthcare units were ready for the change that the DCI-SWE entailed (study IV). Some HCPs expressed that they already tried to work in a person-centred way and to preserve dignity in older persons, while others highlighted the tradition of focusing on illness-related concerns (study IV).

The CNs described the workshops as facilitative and expressed that it had inspired them and clarified important issues (studies II, IV). For some CNs it was challenging to grasp the DCI-SWE approach (study IV). The use of DCI-SWE was perceived to be facilitative by CNs who were comfortable - not seeing the DCI-SWE as threatening or as something that took them out of their comfort zone (studies II, IV). Although it is hard to know, the lack of engagement to use the DCI-SWE on the part of some CNs, may have been due to CN's own fear of holding deeper conversations (studies II, IV). Managers described, that if someone wanted to avoid having deeper conversations it would be easy (study IV).

Support that was appreciated by the CNs included support from their colleagues, the CNs facilitators, the reflections at the FGIs, and from the DCI-SWE itself (studies II, IV). Despite this support, some CNs felt they needed more communication training. Managers also highlighted this and expressed if CNs lacked conversation skills it would be difficult for them to use the DCI-SWE (study IV).

The CNs raised the importance of managers' leadership and engagement (study II, IV). In some cases, the lack of this became a barrier at the workplace. The CNs expressed that, given more engagement from managers, they might become more confident in using the DCI-SWE.

Lacking resources was described as an obstacle for the use of DCI-SWE (studies II, IV). The CNs mentioned the reorganization in home healthcare

(study II), time constraints and a shortage of CNs (studies II, IV). Some CNs had to put the DCI-SWE on hold even if they wanted to use it. If the CNs had to carry their work phones with them, it hindered them from having uninterrupted meetings with the older persons (studies II, IV).

Suggestions for the establishment of the Swedish Dignity Care Intervention

The CNs, HCPs and managers made proposals for establishing the DCI-SWE within the municipal healthcare context, and for refinement of the DCI-SWE approach (studies II, IV). The CNs advocated the creation of a routine to facilitate the use of the DCI-SWE (study II) and asked for the DCI-SWE to be put on their working scheme (study IV). The CNs suggested that smaller groups at the workshops would be beneficial (study II) while managers suggested that the DCI-SWE could be introduced in small steps over time (study IV). Managers emphasized that enhanced communication training could be a part of the nursing education to clarify for CNs that deeper conversations are a part of their professional work. They expressed, the DCI-SWE could lead to pride in the nursing profession (study IV).

The CNs suggested that more focus should be put on older persons with frailty when identifying persons for the DCI-SWE, and described it was challenging to identify older persons suitable for the DCI-SWE (study II, IV). The DCI-SWE was considered best suited for older persons with palliative care needs, those who are not so open and talkative, and those that need to accept their life situation. However, others expressed that it could also be used in those without severe concerns or palliative care needs (studies II, IV). Older persons in the late end- of- life stage were considered unsuitable for the DCI-SWE (study II).

To ask the DCI questions at the right time was considered important (study IV). Further, to let the older person choose which part of the DCI-SWE (the Illness-related concerns, the Dignity-conserving repertoire, or the Social dignity inventory) they would like to start with, would personalize the DCI-SWE approach. The HCPs suggested to emphasize the DCI-SWE more as a "*guide*" to care, to not make it mandatory. Furthermore, the amount of text in the DCI-SWE could be shortened, and the PDI could have fewer questions and answering options (studies II, IV). Yet most participants considered the DCI-SWE format as good, although some suggested a smartphone application instead (study II). What was said during a DCI conversation could be documented in a care plan, and, to save time, the PDI (loose pages)

could be incorporated into older persons' EPRs (study II). The methodological support, which was developed to help CNs with their documentation of the DCI-SWE, was described by them as clarifying the DCI-SWE approach (study IV).

The CNs described time for reflection was needed in connection with using the DCI-SWE (study II). However, the working environment was often too stressful for this to be possible (studies II, IV). Still most CNs felt that by cooperating among themselves, they could make the DCI-SWE work within the organization (studies II, IV). The DCI-SWE could be used in conjunction with other meetings. For example, at drug reviews or when an older person enrolls in a nursing home (studies II, IV). The HCPs suggested that older persons' contact persons (which were nurse assistants) could use the DCI-SWE because they often already had established a relationship with the older person (study IV).

Fidelity, dose and reach

In terms of "*fidelity*", it was analysed whether the DCI-SWE was being implemented as intended (study IV). The plan was to include at least 20 CNs to participate in the project and use the DCI-SWE. Twenty-eight CNs participated in the DCI workshops, but only eleven used the DCI-SWE during the study period. All managers were invited to the workshops, but not all attended. Researchers took up contact with two municipalities before the project started, but only one started the project. The other suddenly did not have a permanent manager and several of its CNs changed their workplace at this time. It was planned to involve more healthcare units during the study, but the Covid-19 pandemic stopped this plan and only three could be included. The reflective diaries were not used by CNs to the intended extent, as only one CN submitted a diary of data (9 pages) after the study.

Regarding the "*dose*", the quantity of the DCI-SWE implemented was analysed (i.e. frequency of use, and number of persons involved) (study IV). Most CNs in the nursing homes attended the workshops. It was more challenging for CNs in the home healthcare to be able to attend, therefore a follow up workshop was held to reach out to more CNs. It was arranged that the CNs would attend three FGIs each during the study; however, most of them only attended on one to two occasions because of difficulties in leaving their other duties. A few times the first-line manager booked them

for other jobs, despite knowing that the researchers would be coming to the unit that day. Researchers experienced a good collaboration with the CN facilitators, although two of them were exchanged during the study period (one was on sick leave for a long time and the other retired) and two new facilitators were engaged.

In terms of "*reach*", whether the older persons came into contact with the intervention, and how was analysed (study IV). Researchers through the workshops reached out to about 90% of the regular CNs working in the healthcare units. The CNs were instructed to use the DCI-SWE with at least 3 older persons each during the study period (= 60 older persons). This was not achieved as not all educated CNs used the DCI-SWE, and they who used it, did so with between one or three older persons each. The reason was that the DCI-SWE took more time to carry out with each person than expected, but also CNs' ability to get time for research and the Covid-19 pandemic played a part, which meant that CNs needed to prioritize differently.

The number of older persons invited to participate in the DCI-SWE was 45. Out of these, 23 (51%) agreed to participate. Reasons for declining included health deterioration and lack of energy. Furthermore, the sample decreased as one older person dropped out because of lack of engagement, two persons because of the Covid-19 pandemic, one person died, and one had severe memory problems. Baseline measures were carried out with 18 (40%) older persons. Follow- ups were completed with 17 older persons (38%) as one older person died during the study. Individual interviews were conducted with ten out of 17 older persons. All relatives invited to participate in an interview accepted (n = 8).

Adaptations

The 6-month study period (studies III-IV) first was extended by 6 months to include more older persons and CNs. Then it was extended a second time by a further 6 months on account of the Covid-19 pandemic. Therefore, in all, the study period was 18 months (September 2019—February 2021). From March 2020 the researchers were unable to visit the healthcare units because of restrictions of the pandemic. This forced researchers to communicate with the CN facilitators/CNs by telephone or email. Starting up the DCI-SWE with more older persons was a struggle during Covid-19 because CNs had to change their priorities. The project now mostly focused on completing the DCI conversations that had already begun with older

persons before the pandemic. During this period the FGIs and individual interviews were held by telephone or online via Microsoft Teams, or Zoom. Overall, it worked well but, in some cases, it was difficult with older persons having problems with hearing.

Something that was discussed with CNs during the study was how they would tell older persons about the research project, as older persons may find it a bit scary to participate in research. The CNs were instructed in the first place to focus more on the DCI-SWE and what it would do for the older persons in terms of dignity, and at their next visit to ask whether the researcher could pay them a visit to give information and ask for consent.

Synthesis of the findings

Dignity is a relevant value for older persons' quality of life. Dignity was sometimes hard to describe for older persons' and their relatives, but they all could relate to things that were important for maintaining their dignity. Maintenance of older persons' health, abilities and social roles, together with acceptance of one's life situation and having a mental strength contributes to keeping the dignity intact.

When it comes to DCC, the older person needs to be seen and heard in the caring meeting. Loneliness was described as prevalent among older persons, and the DCI-SWE can be an opening for the older persons to talk with someone who is listening. It needs to be used with older persons in an early phase, to help them accept their life situation. Further, the care atmosphere needs to be pleasant and include meaningful activities for the older persons to feel treated with dignity.

Sometimes there where shortcomings regarding care competence, continuity and adequate resources to be able to achieve DCC. Concerning "*care competence*", HCPs need to be able to create relationships with older persons and have deeper conversations with them. Then HCPs can be informed about the older person's preferences, which creates opportunities for person-centred care. Further, "*continuity*" of visits with a small number of HCPs caring for the older person can provide security for older persons and help to maintain their dignity. "*Adequate resources*" with enough staff having time to sit down with the older person are crucial for the provision of DCC.

Most commonly, DCC has been evaluated through outcomes related to "*Illness-related concerns*", and to a lesser extent through outcomes that can be related to a "*Dignity-conserving repertoire*" or "*Social dignity inventory*". Evaluating outcomes related to communication were missing in DCC. However, broad outcomes associated with dignity issues where commonly used, for example QoL and dignity-related stress.

The DCI-SWE contributed to put CNs conversations with older persons on the agenda. While some of the healthcare units embraced the new way of working with the DCI-SWE, others seemed not ready for the change that the intervention entailed. More communication training and enhanced manager engagement were requested by CNs. This can help them to become

more comfortable in using the DCI-SWE. If the DCI-SWE is promoted more as a guide than an intervention, it would not be so mandatory.

The whole professional healthcare team in the municipality shall provide DCC together to be able to reach further in the help that is provided to older persons. The dignity concept can become more visible in the documentation system in older persons EPRs. The DCI-SWE can support HCPs in what important work they do in every meeting with the older persons. It was considered contributing to pride in the nursing profession.

Discussion

The findings will be discussed in the order following order: "*Building relationships to conserve older persons' dignity*"; "*Requirements for achieving dignity-conserving care*"; "*Selection of outcomes in dignity-conserving care*"; and "*Challenging the role of community nurses*".

Building relationships to conserve older persons' dignity

The CNs described the DCI-SWE as a way to confirm older persons (study II). The older persons had a need to feel valued by the HCPs to uphold their dignity (study III). In many cases older persons were heard and seen by HCPs but this was not always the case. It has previously been stated that when dignity is missing persons feel uncomfortable, out of control and devalued (122).

The participating relatives made the observation that CNs, by using the DCI-SWE, were able to follow older persons over time and include their opinions when planning the care (study III). However, they commented that the CN was not always accessible to an older person and their relatives. Therefore, CNs might need to be more visible and get closer to the older persons they care for. Building relationships needs to become central for CNs and HCPs (study III) to ensure the dignity of older persons. Then, the DCI-SWE can be a useful tool, as it helps build relationships between the HCP and the older person, which is crucial (123). By this way it deals with older persons' loneliness too (study IV). Loneliness contributes to human suffering, especially in older persons (124). Furthermore, older persons' dignity depends on relationships, and may help them deal with negative feelings such as grief and fear (125). Therefore, it is important for the HCPs to have a relationship with the older person, and to be able to implement the DCI-SWE well (study III). Although the process of building personal relationships between CNs and older persons is complex (126) it is important if older persons are to feel valuable and DCC is to be achieved (125). More research may be needed to further investigate the importance of building relationships in DCC.

The relatives expressed a need for HCPs to provide person-centred care as a part of DCC (study III). Perhaps merging DCC with person-centered care would be optimal for older persons. By finding out the older person's beliefs and wishes the providers of DCC may be able to include a person-centred

approach in care. This goes hand in hand with the definition of "*dignity*" that was chosen for the DCI project, which states that in healthcare a person has dignity when able to live according to their principles and values (17). This definition points to the importance of person-centred care in achieving dignity. Person-centred care has also been described as guided by the principles of dignity (26) showing that these aspects are related. It has been argued elsewhere that healthcare organizations need to shift from a task-oriented system to a person-centred approach, where dignity and respect are of the greatest value (127). The DCI-SWE provides a concrete tool to provide person-centred care that promotes dignity.

Requirements for achieving dignity-conserving care

Most older persons who started the DCI-SWE completed their participation in the project (studies II, IV). However, it can be questioned whether some of the healthcare units were ready for the change brought by the DCI-SWE (study IV). The healthcare units were very different in terms of CNs' and managers' engagement and having time for the project (studies II, IV). Organizational readiness for change refers to "*organizational members psychological and behavioural preparedness to implement change" (128)* [p. 217]. By being ready for change the members of the healthcare units transform their commitment: then there can be an increase in "change efficacy" (128).

The findings in study IV showed that some components of the implementation intervention (e.g. discussions with local opinion leaders/facilitators) worked better than others (e.g. procedures for assuring professional competence). The implementation intervention (92, 94) needs to be further developed to incorporate more communication training during the DCI workshops. Furthermore, to deal with possible gatekeepers in the field, that prevent the start-up of the DCI-SWE in older persons, a more comprehensive behavior theory may be useful. It can help researchers to work with attitudes and engagement to increase the opportunity for a more sustainable implementation. The CNs who used the DCI-SWE (study IV) showed an interest in continuing with it after the study, so it is very much about how to reach those CNs who are dealing with their own fear of conversations or lack of engagement. How to support behaviour change is not always obvious, it requires careful science leading to a deep understanding of what motivates people, and of the social and economic pressures that act upon them (129).

In this context, "*the Behaviour Change Wheel*" [BCW] (130) can be tried out. This theory includes three overall phases (131): (1) to describe barriers to evidence-based care, the behaviour in question and the individuals or groups of those who carry out this behaviour are identified; (2) an understanding of the target behaviour (being able to hold conversations through the DCI-SWE) and its effects is created; (3) the target behaviour is specified in as much detail as possible (e.g. who needs to perform the behaviour and in what context). The BCW might facilitate a more tailored implementation of the DCI-SWE.

It is suggested that managers inform all HCPs when a new way of working, as the DCI-SWE, is about to be implemented. This was not always the case in study II and IV but this must be essential for implementation. Some of the managers proved to be helpful by stressing the need for the DCI-SWE, while other managers were less engaged (studies II, IV) which CNs sensed. Thus, some managers were more unclear in their role towards CNs and HCPs, although they had a need for managers' leadership. Hence, leadership shall not be confused with management that is more about a position (131). A leader uses their influence, with a view to achieve certain purposes (131), as for example to maintain older persons' dignity. Leaders should aspire to provide transformative leadership in which goals are set and psychological rewards are used. This type of leadership creates the conditions for all HCPs' development so that they can exceed over their expectations (131).

Although it can be a challenge for managers and nursing leaders to incorporate dignity components, promoting dignity requires effective communication at all levels by all involved (122). This implies that all professionals have a responsibility for DCC to be achieved. Furthermore, to adapt the delivery and evaluation of interventions in palliative care requires a staged approach, where knowledge building and implementation take place continuously on a thread. Funding investment is needed to help researchers develop expertise in creating evaluative research methods and research to improve the outcomes for older persons with palliative care needs (132).

Selection of outcomes in dignity-conserving care

The findings on outcomes (study I) may be useful for researchers, underpinning future research where DCC is implemented and evaluated, and contribute to providing evidence-based palliative care for older persons.

Outcome evaluation should be tailored to the specific intervention and use the most rigorous study design feasible (133). But implementation of evidence into practice is an extensive process incorporating several steps (134) of which choosing outcomes and instruments is only one part. The DCI-SWE was evaluated with outcomes in study III, where Dignity-related distress and QoL were chosen as outcomes. However, there are more important outcomes that the researchers can consider measuring in future studies.

While evaluating DCC (study I), a greater focus on outcomes relating to the "*Dignity-conserving repertoire*" and the "*Social dignity inventory*" in Chochinov's dignity model (27) (see Figure 1) is needed. Otherwise, these components of older persons' dignity will remain unknown and therefore could be an unidentified source of loss of dignity. Both dignity and social aspects are important for older persons, as confirmed by previous research (125, 135).

As the results lacked concrete communication outcomes (study I), a greater focus on communication outcomes is needed in DCC. This is so because communication is a large part of providing palliative care (31) and the dialogue is an important component of DCC (28). Older persons themselves consider how HCPs talk to them as an aspect that impacts their dignity (136). Outcomes regarding person-centred care (study I) can also be relevant to consider, as the DCI-SWE was shown to underpin this type of care (study IV). Further, it may be useful to add "*life closure*" as an outcome as acceptance issues were shown to be relevant when using the DCI-SWE in older persons (study IV). Accepting one's life situation is important for older persons (137).

Challenging the role of community nurses

The DCI-SWE was a way for the CNs to respond to existential and sensitive needs and it enabled older persons to discuss difficult aspects of their lives (studies II-IV). However, the findings indicated that CNs were sometimes prevented by their own fears from discussing deeper aspects, for example about death (studies II and IV). Some CNs were not comfortable in using the DCI-SWE and some wanted to refer existential issues to other professions. This can be referred to that human culture normally keeps the fear of death at bay, to allow the person functioning from moment to moment without becoming overwhelmed by the fact that everyone shall die (138). However, this can be a barrier in the municipal healthcare context to enabling DCC with the DCI-SWE in older persons.

It could be argued, as essential that CNs include psychosocial dimensions in their work and look at the psychosocial dimensions of older persons' life situations to be able to help conserve their dignity. The CNs must see their own role as one of working with communication. The findings suggest that CNs need more support in communicating with older persons to be able to meet older persons' psychosocial needs (studies III, IV). As CNs most important responsibilities are to promote older persons' dignity, ensuring their safety and enhancing their QoL (139), CNs' communication skills must be essential to be able to identify older persons most urgent needs in this regard. The CNs require knowledge, competencies, and experience to provide high-quality care for older persons (139). Therefore, core elements of nursing professionalism are education, lifelong learning and evidence-based practice (140).

It can be argued that it may not primarily be a question of whether CNs are in need for a tool for conversation. Rather, that the older persons and relatives are requesting the CNs' presence and conversations. Multi-professional care needs to include meetings between CNs and those whom they are caring for – precisely to create trust and knowledge exchange and provide new insights (141). Therefore, as managers suggested (study IV), enhanced communication training could be incorporated in the nursing education. Discussing dignity must begin early in nursing education and continue as nurses move into the workforce, as novice nurses have been found to place less value on dignity than more experienced nurses (142). Consequently, this might lead to enhanced pride in the nursing profession and ultimately provide a better quality of care.

The findings showed that many older persons do not feel like the person they used to be (study III), and without the DCI-SWE this issue might never have been identified. In fact, the DCI-SWE was found to be a way to deal with acceptance issues (study IV). If older persons processes of accepting their situation are understood and confirmed by nurses, family and friends, it supports their experience of living a meaningful life, which further can ease eventual existential loneliness (137).

Further, in study III, older persons' psychological QoL was the only dimension that significantly decreased over time (p=0.01) when using the DCI-SWE, which suggests a need for psychosocial interventions. The requirement of ensuring that older persons' psychosocial needs are met, regardless of how challenging this is, has previously been highlighted in DCC research (68). However, CNs' psychosocial relationships with older persons have also been described as rewarding (140). Therefore, the DCI-SWE can help healthcare organizations to work with communication and dignity issues. This is especially important as stakeholders have identified dignity and staff competence as two of the highest priorities for quality in community-based healthcare (143).

Methodological considerations

To underpin methodological considerations different checklists were used: the Consolidated Criteria for Reporting Qualitative Research [COREQ] checklist (study II) (144); the Transparent Reporting of Evaluations of Non-randomized designs [TREND] checklist (study III) (145); and The MORECare statement (study IV) (120).

Trustworthiness

Trustworthiness in relation to the studies is discussed below in terms of credibility, transferability, dependability and confirmability (146).

Study I

The credibility (146) was enhanced by using inclusion and exclusion criteria to identify relevant studies, as well as by discussions among all researchers about the criteria. For example, it was decided, after discussions, to include studies of adults ≥18 years old as palliative care for adults was not considered to be very different from palliative care for older persons. In this way, more studies became included to contribute with outcomes within DCC. Four databases and a manual search were performed, which provided

an extensive base of articles to explore and enhanced the credibility (146). The search yielded many duplicates, indicating saturation. Some articles did not use the term "*dignity-conserving care*" but instead referred to "*an intervention to enhance dignity*". These articles were also included as there still are not many DCC interventions, and it was thought that they might provide valuable information.

To underpin the transferability (146) of what outcomes can be applied in DCC, researchers sought for a clear and rich description about outcomes, and an overview was completed to facilitate for other researchers within the dignity research field (see Appendix 4).

As the aim was not focused on designs or on finding effects, a critical appraisal of articles was not conducted. This may have influenced the dependability (146), but there is no agreed standard as to when to perform a critical appraisal of the quality of articles. According to Whittemore and Knafl (79) a quality appraisal should be done if fulfilling a meaningful purpose.

It was found challenging to assign some of the outcomes to a theme because outcomes often overlapped. This may be due to the complexity of the palliative care context; according to Alvesson (113), themes in an analysis cannot always be completely isolated. By using Chochinovs' dignity model (27) as a grid in an abductive analysis, the confirmability was enhanced (146).

Studies II-IV

The researchers had expertise in both qualitative and quantitative research, which enhanced the trustworthiness (146) of the findings.

The credibility (146) was enhanced by using many different perspectives (the perspectives of the older persons, relatives, CNs, HCPs and managers) and different methods in the studies (studies II-IV). Further, quotations were used to illustrate the findings, and a caution was taken not to reveal the participants' identities through these.

To enhance the transferability (146), the researchers strived to describe the methods in detail so that an understanding of strengths and weaknesses

could be accomplished (studies II-IV). A detailed and informative description of the study context was also given.

In terms of dependability (146) the analyses were discussed among the researchers and checked afterwards to ensure the relevance of the categories or themes in the studies (studies II-IV). To improve confirmability (146), the link between the data and the results was shown through illustration of the abstraction process in the Tables.

Below, the respective studies are discussed in a little more detail.
In study II, the low number of older persons on whom the CNs tested the DCI-SWE (n = 7) was a limitation. An explanation could be the CNs' emphasis on including persons clearly receiving palliative care instead of also including those regarded as frail. However, the difficulties of recruiting participants to palliative care studies are well known (147). For this reason, small-scale projects are recommended (148). A major reorganization had recently taken place at the home healthcare setting and was still affecting the organization, for example with time constraints and lacking resources. These are aspects that can affect implementation of interventions (149).

In study III, it was beneficial to use mixed methods. In this way the knowledge comprehensiveness was enhanced and the confidence in findings was increased. However, because of the small sample size the results must be interpreted with caution and should draw on supporting evidence. The sample size may be explained by the finding that only a small percentage of those in nursing homes are suitable for the DCI-SWE, as the proportion of older persons moving to nursing homes and dying shortly after has increased (150). Many older persons in nursing homes can be too cognitive impaired and too frail to participate in DCI-SWE as with advancing age their participation in research normally declines (151). A larger focus on home care may help recruit more participants for future studies.

In study IV, to help CNs set aside time for the DCI-SWE, some managers' engagement in research need to increase. In some cases, there were no clear directives from managers that research should be prioritized. Some CNs were not given the time to participate while others had this support. In terms of fidelity (78), one weakness may have been that researcher's information meetings were not conducted individually with the respective managerial level (separately with first-line managers and head managers) in the

beginning of the study, which may have affected managers engagement. It can also be considered that the readiness for change may be more accessible in smaller organizations than in large, complex organizations (148). This can be considered in future studies, but interventions need to be developed regardless of context. Nevertheless, to implement a new way of working during a Covid-19 pandemic, was by the participants considered as challenging.

A strength was the collecting of data from CNs at multiple time points during FGIs (study IV), which enhanced the credibility. However, a weakness was, the CNs did not make as much use of the reflective diaries as planned. Researchers therefore need to be clearer about why CNs must use the reflective diary (it yields important data). Perhaps a system is needed for filling in the diary that might facilitate CNs' understanding. Researchers can plan into the design to set aside time for CNs to write in the diary during meetings with the researcher. It can still be argued that the study had enough "informational power", as the different participant perspectives held rich information, that were relevant for the study. Then a lower number of participants is needed (152).

Validity and reliability

Validity and reliability (153) are described below in relation to studies I and III.

Study I

A limitation of this study may be that it did not check whether the instruments measuring outcomes had been validated or provided reliability. This is left for researchers themselves to judge, which can be difficult if knowledge about what gives instrument quality is lacking. Therefore, the need to select instruments that have been psychometrically tested and validated can be stressed (154). However, researchers must use those instruments that are available to be able to continue developing them.

Further, it is most likely that many of the included studies suffered from type 2 errors (where real effects cannot be found even though they exist) (153). This proves that more studies with a more robust study design, and including more participants, are needed if effects are to be identified.

Study III

A crucial aspect of evaluating an intervention is the choice of outcome measures (85). A limitation in this study was that the the PDI and the MQOL-E had not been psychometrically tested in the Swedish context. Therefore, the validity and reliability of the Swedish versions of the instruments can be questioned. However, study I showed that these instruments have been used previously in evaluating DCC, and both the instruments are internationally validated (73, 111).

Since the study used the PDI, which is also included in the DCI-SWE, there was a clear risk of bias (154). The researchers were aware of this but prioritized testing the Swedish PDI in a Swedish context. In future studies, another dignity instrument may be beneficially used for this purpose. Here, the researchers used instruments that were available at the time of the study.

The results from measuring older persons' dignity-related distress and QoL should be discussed in terms of confounders (153). It is valid to think that there were several confounders that influenced the outcomes. This is reasonable to assume as the older persons were in a palliative care context, where confounders such as illness and symptoms usually are present (48). It should be mentioned that the researchers' expectations of the results were not that these outcomes would improve, but rather, that they would remain stable over time. Researchers must continue the work in creating conditions for conducting a randomized controlled trial.

Clinical implications

When introducing the DCI-SWE to a new healthcare unit, it is suggested that managers attend a start-up workshop to learn about the intervention. It is important that they should be educated in the DCI process before the CNs are, so that they can support their employees if needed. Researchers' support of CNs is simply not enough as the researchers are not at the healthcare units every day.

As CNs and HCPs had concerns about the volume of the DCI-SWE (including the PDI), this might need further consideration. Another approach to its use was suggested by CNs. They suggested that the older person can choose which section of the DCI-SWE to start with. Thus, either the older person chooses to start with Illness-related concerns, or with the Dignity-conserving repertoire or the Social dignity inventory depending on what aspect is most urgent for the older person. In this way, the DCI-SWE can be used in a more person-centred way and may not feel so extensive.

A further suggestion was, that physicians, CNs and HCPs should collaborate more about DCC and the use of the DCI-SWE, in order to make current meetings with/about the older person more complete. Developing a relationship with the older person before using the DCI-SWE was considered beneficial. The older person's contact person was identified as someone who could help CNs in their use of the DCI-SWE. However, the person holding the DCI conversations needs to feel comfortable with it.

Future research

Future research could emphasize evaluating aspects that could fit Chochinov's dignity model and its main categories "*Dignity-conserving repertoire*" and "*Social dignity inventory*". It would be relevant to increase the use of communication outcomes in DCC to conserve older persons' dignity. To avoid bias when evaluating the DCI-SWE in the future, translating and adapting another dignity instrument (an instrument other than the PDI to measure dignity) would be necessary. Further, to increase the usability of the DCI-SWE, future studies may use the DCI-SWE together with the relatives of the older persons. Then also older persons with dementia could be included, which might be beneficial for them if their dignity was threatened. A financial evaluation can be included in future research to establish that all managers realize the value of the DCI-SWE. A suggestion for accomplishing a randomized control study is that research teams within palliative care should merge and together evaluate DCC.

Conclusions

In DCC, outcomes related to dignity, QoL and communication should be considered. The DCI-SWE has clear benefits for older persons if the background and needs of the older persons are taken into account in its use. The QoL could be affected by the older person feeling safe and having a social context, and by them being heard and receiving the right kind of help through the DCI-SWE. The feasibility of the DCI-SWE depends on the healthcare organization's engagement and capacity to prioritize healthcare development. In the present research, the DCI-SWE was acceptable to those CNs accepting deeper conversations with older persons as part of their profession. However, if the DCI-SWE is to be used successfully by all CNs, fear of deeper communication needs to be addressed. The CNs need to be supported with relevant communication training and with the managers taking on a leader's role. Thus, the implementation intervention needs to be developed to incorporate education in enhanced communication and the use of a behaviour change model. This might facilitate future implementation of the DCI-SWE and in the longer term it might conserve older persons' dignity as well as lead to pride within the nursing profession.

Svensk sammanfattning (Summary in Swedish)

Bakgrund

Den palliativa vården i Sverige är inte likvärdig avseende ålder, sjukdom och vårdplats. Äldre personer har sämre tillgång till specialiserad palliativ vård, trots att de i hög grad har behov av palliativ vård. Äldre personer oroas också över att deras värdighet inte ska tas i beaktande samtidigt som värdighetsrelaterad stress är en verklighet för många äldre personer. Socialstyrelsens utvärdering 2016 visade att sjuksköterskor inom kommunal vård inte har tillräckligt med stöd och fortbildning när det gäller palliativ vård. Vidare är evidensbaserade värdighetsinterventioner sällsynta inom svensk hälso-och sjukvård även om bevarande av värdighet är grundläggande inom palliativ vård. Därmed behöver vårdkvaliteten inom kommunal hälso- och sjukvård förbättras och hälso- och sjukvården behöver prioritera vård som betonar värdighet. Den svenska värdighetsbevarande interventionen DCI-SWE syftar till att bevara äldre personers värdighet. Den inkluderar instrumentet Patient Dignity Inventory, reflekterande frågor och evidensbaserade vårdhandlingar relaterade till värdighet.

Den svenska DCI-SWE och dess implementering har utvärderats inom ramen för denna avhandling.

Övergripande syfte

Det övergripande syftet för avhandlingen var att utvärdera den svenska värdighetsbevarande interventionen DCI-SWE, och dess implementering inom den kommunala palliativa hälso-och sjukvården, i syfte att bevara äldre personers värdighet och livskvalité.

Metod

Delstudierna i avhandlingen omfattar både kvalitativa, kvantitativa och mixade metoder och utgick ifrån det brittisk medicinska forskningscentrets riktlinjer för utveckling och utvärdering av komplexa interventioner.

Kontexten för DCI projektet var kommunal palliativ hälso-och sjukvård inklusive vårdboenden och mindre hemsjukvårdsenheter. Äldre personer (≥65år) med palliativa vårdbehov som kommunsjuksköterskor bedömde som sköra inkluderades.

Delstudie I. En integrerad sammanställning om vilka utfallsmått som använts inom värdighetsbevarande vård hur dessa har operationaliserats genom instrument. Datainsamlingen omfattade: sökningar av artiklar i databaser (CINAHL, MEDLINE, PsycINFO, och Web of Science). Kvalitativa data (n = 26 artiklar) analyserades genom tematisk syntes.

Delstudie II. En beskrivande genomförbarhetsstudie för att studera kommunsjuksköterskors erfarenheter av DCI-SWE. DCI-SWE användes av kommunsjuksköterskor under en tre månaders studieperiod. Hur länge DCI-SWE användes tillsammans med varje person var individuellt utifrån samtal och vårdhandlingar. Datainsamlingen omfattade fokusgruppsintervjuer och individuella intervjuer med kommunsjuksköterskor (n = 11), deras reflekterande dagböcker och forskares fältanteckningar. Data analyserades genom induktiv innehållsanalys.

Delstudie III. En mixad metodstudie för att studera äldre personer och närståendes erfarenheter av värdighet och värdighetsbevarande vård när DCI-SWE används i kommunal hälso-och sjukvård. DCI-SWE användes av kommunsjuksköterskor under 1,5 år och hur länge DCI-SWE användes tillsammans med varje person var individuellt utifrån samtal och vårdhandlingar. Datainsamlingen omfattade individuella intervjuer med äldre personer (n = 10) och närstående (n = 8), samt frågeformulär (livskvalitet och värdighetsrelaterad stress) med äldre personer (n = 17) som utvärderades vid baseline och vid en uppföljning. Kvalitativa data analyserades med tematisk analys, och kvantitativa data med jämförande statistik.

Delstudie IV. En processutvärderingsstudie av DCI-SWE's implementering i en kommunal hälso- och sjukvårdskontext med fokus på genomförande, effektmekanismer och kontext. Datainsamlingen omfattade fokusgruppsintervjuer och individuella intervjuer med chefer (n = 5), kommunsjuksköterskor (n = 11) samt vårdpersonal (n = 5). Vidare via kommunsjuksköterskors reflekterande dagböcker och forskares fältanteckningar. Kvalitativa data analyserades med dirigerad innehållsanalys, och kvantitativa data med beskrivande statistik.

Implementeringen av DCI-SWE under delstudierna III och IV guidades av Knowledge to Action (KTA) modellen och underbyggdes med implementerings strategier från Cochranes Effective Practice and Organization of Care (EPOC) taxonomi.

Resultat

Delstudie I. Inom internationell forskning har värdighetsbevarande vård tidigare utvärderats med fokus på sjukdomsrelaterade besvär och med mindre fokus på värdighetsrelaterade eller sociala utfallsmått. Breda utfallsmått såsom livskvalitet och värdighetsrelaterad stress har vanligtvis använts, medan utfallsmått inom kommunikation inte använts.

Delstudie II. Utbildningen som kommunsjuksköterskorna fick inför användandet av DCI-SWE beskrevs som inspirerande och klargörande. DCI-SWE gav struktur till det palliativa arbetet och var ett sätt att besvara äldre personers existentiella och sensitiva behov. Genom DCI-SWE gavs möjlighet till att bekräfta de äldre personerna. Det underlättade för kommunsjuksköterskorna om de var informerade om sin situation innan DCI samtalen påbörjades.

Hinder för att använda DCI-SWE som beskrevs var bristen på resurser i form av tid och vårdpersonal (studie II). Några kommunsjuksköterskor var inte bekväma med att hålla i djupare samtal och behövde mer stöd. Den närmaste chefens ledarskap och engagemang ansågs vara centralt, men även fortsatt träning i att använda DCI-SWE, samt möjligheten att få tid till reflektion.

Delstudie III. Äldre personer och närstående ansåg att det var bra att lyfta värdighet och kommunikation inom hälso-och sjukvården. DCI samtalen värdesattes av de äldre personerna även om de ibland kunde upplevas som svåra. Vidare var begreppet värdighets innebörd inte alltid självklart för äldre personer och deras närstående. De ansåg dock att bevarande av hälsa, förmågor och sociala roller har betydelse för äldre personers värdighet. Det var viktigt att den äldre personen accepterade sin situation och hade en mental styrka. Att de äldre personerna blev sedda och hörda av vårdpersonalen var centralt, liksom en trevlig vårdatmosfär och meningsfulla aktiviteter. Adekvata resurser, kontinuitet och vårdkompetens ansågs behövas för att underbygga en värdighetsbevarande vård.

De äldre personernas livskvalitet och värdighetsrelaterade stress förändrades inte signifikant över tid (studie III). Endast äldre personers psykologiska livskvalitet visade på en signifikant minskning över tid. Det var vanligt att äldre personer inte längre kände sig så som de hade varit, men många kände ett stöd från familj och vänner.

Delstudie IV. Det var svårt att identifiera äldre personer för DCI-SWE då många ansågs alltför sköra. DCI-SWE beskrevs av chefer, kommunsjuksköterskor och vårdpersonal vara ett sätt att hantera ensamhet och acceptans hos den äldre personen. DCI-SWE innebar att samtal med de äldre personerna blev en tydligare arbetsuppgift för kommunsjuksköterskorna samt gav dem möjlighet att personifiera vården. Några kommunsjuksköterskor upplevde att det var svårt att greppa arbetssättet DCI-SWE. En stegvis introducering föreslogs samt mer utbildning gällande samtal.

Cheferna beskrev (studie IV), att DCI-SWE bekräftar det viktiga arbete som genomförs i varje möte med de äldre personerna och att DCI-SWE kan leda till stolthet hos kommunens sjuksköterskor och annan vårdpersonal. Vårdpersonal önskade få inkluderas mer i arbetet med DCI-SWE och lyfte att de äldre personernas kontaktpersoner (vanligtvis undersköterskor) kan genomföra samtal då de ofta redan har en etablerad vårdrelation. Några kommunsjuksköterskor saknade chefernas engagemang vid införandet av DCI-SWE. Det stöd som fanns upplevdes dock positivt, till exempel reflektionstillfällen med kollegor och forskare under fokusgruppsträffar. Kontexten utmanades under studien av Covid-19 pandemin som hindrade arbetet med DCI-SWE.

Konklusion

DCI-SWE har fördelar för äldre personer om interventionen används med bakgrund av vem den äldre personen är och dennes önskemål. Framför allt kan DCI-SWE bidra till att de äldre personerna känner sig sedda och att eventuell ensamhet hanteras. DCI-SWE:s genomförbarhet är avhängig vårdorganisationens engagemang och möjlighet att prioritera samtal med äldre personer. Om DCI-SWE ska kunna användas framgångsrikt av alla kommunens sjuksköterskor måste rädslan för djupare samtal hanteras och en utökad utbildning i kommunikation tillhandahållas. Implementerings strategierna behöver således utvecklas och en beteendeförändringsmodell kan inkluderas. Detta kan underlätta ett framtida genomförande av DCI-SWE och på längre sikt bevara äldre personers värdighet.

Acknowledgements

This thesis would not have been accomplished without the engagement and support of many persons, to you I will forever be grateful!

I would like to thank all older persons, relatives, community nurses, healthcare professionals, and managers that I have met in this PhD-project and that have made this thesis possible. Together we have strived to develop the healthcare to older persons in order to conserve their dignity!

A special thanks to all my supervisors,

Karin Blomberg (main supervisor), thank you for choosing me to be a part of the Swedish Dignity Care Intervention project. It has meant a great deal to me, professionally but also personally. You have shared your expertise and helped me develop along the way. I would not have done this without you!

Ulrika Östlund, thank you for sharing your knowledge in research and supporting me while I needed it. Your kindness made me believe I could contribute to research. Thank you for providing me the chance to follow up the research on the Dignity Care Intervention-UK.

Carina Werkander Harstäde, thank you for providing your support and believing in me! We have had a lot of fun doing research, especially at your home in Gotland. Thank you for having patience with my English and giving me helpful questions!

Maria Hälleberg Nyman, thank you for coming into my PhD-project (2019) with all the knowledge that you have, especially regarding implementation and SPSS. Your friendly face has kept me going for the last few years, and I am thankful for that!

Professor Eva Benzein (Linné University), for sharing your knowledge and giving me the support in the beginning of my PhD-journey (2016).

A special thanks to Professor Bridget Johnston (Glasgow University, Scotland) for valuable research discussions on DCI-SWE and for being a co-author of study IV.

Further, I would like to thank:

The Research School of Successful ageing at Örebro University for giving me the opportunity to do this research. Thanks to Eleonor Kristoffersson and to all my PhD colleagues in the research school. A special thank you to PhD-student Magnus Schoultz who read my Kappa and gave me valuable input.

The Department of Health Sciences at Örebro University.
Thanks to Elisabeth Ericsson, Karin Falk-Brynhildsen and Christina Hedenskog, you have all encouraged me along the way!
Thanks to all my colleagues that have followed my journey, first as a junior lecturer and then as a PhD-student.

A special thanks to Karin Jackson who got me started to write a scientific article and later to start working at the Örebro University. You showed me the possibility of choosing the academy as a workplace! You have since then given me valuable support during the years and becoming a dear friend of mine!

A special thanks to Inga-Lill Källström Karlsson, for all you taught me as a new junior lecturer in 2012. We shared the interest for palliative care and you encouraged me while developing my skills as a teacher.

A special thanks to Samal Algilani for being a good colleague, and beyond that also being a friend.

Thanks to Marie Holmefur and Agneta Anderzén Carlsson who read my Kappa and gave me appreciated input.

My dear PhD colleagues,
Lisa Spang and Elin Lundin, you have enlightened my days as a PhD-student! Thank you for all the precious support during this long journey. I can only thank my lucky star that you showed up to share the office with me. We have shared our PhD-journeys and developed together. Still, most important is our friendship.

My best friends,
Katie och Martina, thank you for being there, sharing joyful moments and less good days! Thank you for just letting me be me!

Finally, thanks to my family!
To my mother Birgitta who always have believed in me and filled me with courage, my father Lennart who gave me the working spirit and whose loss gave me the reason to fight through this journey; my twin sister Pernilla who never left my side in my early years, you know me inside and out. You also have taught me what resilience is, and you have a special place in my heart. My two other sisters, Åsa and Karolina thank you for just being you, even if I do not always tell you, you are valuable to me!

Henrik,
how is it possible, five years of PhD-studies already have passed! I am thankful for you putting up with my sometimes-working late hours. Above all I am grateful for the love you have given me through the years. I love you!
Agnes and Elias,
how boring my world would be without you – I love you forever and ever. Thank you for giving me energy, love, and appreciation!
Arne and Eva,
my in-laws, you are so dear to me, and I cannot thank you enough for encouraging me and walking by me and my children's side through this journey. You are family to me!

Erika, my childhood friend,
even if you were not my family by blood, I appreciated you as such a member when I was growing up. The loss of you in the year 2020 gave me a reminder of what is important in life. I will never forget the moments and laughter that we have shared together.

APPENDIX 1. The Swedish Dignity Care Intervention (DCI-SWE)

SJUKDOMSRELATERADE BESVÄR		
Skattade besvär	**Förslag på frågor för reflektion**	**Förslag på vårdhandlingar**
1. Att ha fysiskt besvärande symtom (som smärta, andnöd, illamående)	⮝ Vilka kroppsliga symtom upplever du som besvärande? ⮝ Berätta vad som ger dig mest besvär? Vad kommer sen? ⮝ Vad tror du kan hjälpa dig att hantera dessa besvär?	⮝⮝ Bekräfta att du ser hur personen mår och inge hopp om att det finns lindring. ⮝⮝ Använd omvårdnadsteamets kompetens när symtom ska undersökas och hanteras. ⮝⮝⮝ Erbjud individuell symtomhantering. ⮝⮝ Arbeta förebyggande. ⮝⮝ Utbilda personen och dennes närstående om vanliga symtom och hur de kan hanteras. ⮝⮝ Ta hjälp av närstående om personen har svårt att kommunicera sina symtom. ⮝⮝ Se till att åtgärder görs utan dröjsmål, och att behovsordinationer finns tydligt angivna. ⮝ Använd både medicinska och icke-medicinska interventioner t.ex. meditation, avslappning och massage. Prova en åtgärd i taget. ⮝⮝ Använd basal omvårdnad t.ex. hjälp vid hygien och lägesändringar. ⮝⮝ Använd skattningsskalor vid utvärdering.
2. Känner mig nedstämd	⮝ Du verkar nedstämd, känner du dig deprimerad? ⮝⮝ Hur ofta känner du dig nedstämd? ⮝⮝ Hur kan jag stötta dig att hantera de här känslorna?	⮝⮝ Berätta för personen att man kan känna sig nedstämd. ⮝⮝⮝ Använd skattningsskalor för att bedöma psykologiska symtom. ⮝⮝⮝ Uteslut medicinska orsaker till ångest. ⮝⮝⮝ Diskutera och planera vården tillsammans med vårdteamet. ⮝⮝⮝ Stötta personen att prioritera problem och sätta realistiska mål. ⮝⮝ Använd både medicinska och icke-medicinska interventioner t.ex. avslappning och distraktion. ⮝ Var tillgänglig för samtal, ta tid att sitta ner och lyssna. Var lyhörd inför det som sägs och det som inte sägs. ⮝ Undersök vilket socialt närverk som finns tillgängligt och underlätta samtal inom familjen.
3. Känner oro/ångest	⮝ Du verkar orolig och spänd, kan du beskriva hur du känner? ⮝⮝ Vad är det som oroar dig? ⮝⮝ Vad skulle kunna göra det bättre?	

4. Ovisshet kring sjukdom och behandling	➢ Vad har du förstått utifrån det du fått veta om din sjukdom? ➢ Vad mer skulle du vilja veta om din sjukdom?	➢ Etablera tidig kontakt och eftersträva kontinuitet. ➢ Ge information om hur kontakt kan tas med vården, och hur vårdpersonal kan nås. ➢ Informera steg för steg om sjukdomstillstånd, behandlingar och undersökningar. ➢ Förklara att det finns lindring för smärta, oro och ångest samt tillgång till praktiskt och emotionellt stöd. ➢ Utbilda personen och närstående om medicinering och specifik utrustning, t.ex. dränage och kateter. ➢ Diskutera realistiska mål i vardagen. Uppmuntra personen att genomföra saker medan orken finns. ➢ Respektera att personen ibland inte vill ha information eller prata om döden. ➢ Hjälp personen att kontakta andra vårdgivare vid behov. ➢ Informera om och bekräfta att vården kommer fortgå/finnas tillgänglig tills personen dör.
5. Oroar mig för framtiden	➢ Vad oroar dig när du tänker på framtiden? ➢ Vad skulle kunna hjälpa digatt hantera din oro?	➢ Utgå ifrån att det kan finnas outtalad oro eller behov av samtal. ➢ Skapa en miljö som underlättar för samtal. Inkludera både personen och närstående, var öppen för om de inte vill samtala tillsammans. ➢ Tala om döden och eventuell rädsla att dö, lyssna och bekräfta personens uppfattningar. ➢ Gör personen delaktig i beslut för att skapa en känsla av kontroll. ➢ Hjälp personen med ouppklarade saker innan personen försämras. ➢ Identifiera känslor av ensamhet och berätta att dessa är normala. ➢ Lämna inte personen ensam om denne inte vill.

6. Att inte kunna genomföra dagliga aktiviteter (t.ex. tvätta mig, klä på mig) 7. Att inte kunna sköta mina kroppsliga funktioner utan hjälp (t.ex. behöver hjälp med toalettbesök)	➢ På vilket sätt har din sjukdom gjort dig beroende av andra? ➢ Vad kan du göra själv? ➢ Hur vill du helst få hjälp/stöd? ➢ Från vem/vilka vill du helst ha hjälp?	➢ Informera om vad som är normalt för personens tillstånd och främja egenvård. ➢ Se till att personen är symtom lindrad. ➢ Skapa god framförhållning och hjälp personen planera för aktiviteter och vila samt dagliga rutiner. ➢ Respektera personens självbestämmande över när och vilken vård som ska ges. ➢ Stötta personen att se det friska och den egna förmågan. ➢ Stötta personen att fortsätta göra aktiviteter denne klarar av, bistå när behov finns. ➢ Föreslå och tillhandahåll hjälpmedel som kan underlätta oberoende. Involvera personen och närstående i beslut kring hjälpmedel. ➢ Tolka personens icke verbala språk/tecken när förmågan att uttrycka sig är begränsad. ➢ Värna alltid om den personliga integriteten.
8. Att inte kunna tänka klart	➢ Har du svårigheter med att tänka? ➢ Om ja, på vilket sätt?	➢ Kartlägg kognitiva brister med skattningsskalor, ta hänsyn till när personen är som mest alert. ➢ Granska om medicinering kan påverka personens mentala kapacitet. ➢ Lär känna personen exempelvis genom dennes livsberättelse och via närstående, använd kunskapen i vården. ➢ Informera att den kognitiva nedsättningen kan ha sin förklaring i sjukdomen. ➢ Använd ett enkelt, tydligt vardagsspråk. ➢ Se till att vårdpersonal finns tillgänglig, kan vägleda och påminna vid behov. ➢ Uppmuntra personen till att hålla sitt sinne aktivt t.ex. genom att se på TV och läsa. Föreslå personen att skriva upp saker som stöd för minnet. ➢ Uppmuntra till social kontakt. ➢ Hjälp personen planera framåt, t.ex. diskutera fullmakt i ett tidigt stadium.

VÄRDIGHETSBEVARANDE REPERTOAR		
Skattade besvär	**Förslag på frågor för reflektion**	**Förslag på vårdhandlingar**
9. En känsla av att det sätt andra ser på mig har förändrats mycket på grund av min sjukdom 10. Känner mig inte längre som den jag varit	➢ Vill du prata med mig om det här, eller vill du ha kontakt med någon annan? ➢ Vilken är den största skillnaden i hur andra ser dig/ hur du ser på dig själv, jämfört med tidigare? ➢ Hur tänker du att de här förändringarna kan hanteras?	➢ Bemöt personen som en jämbördig samt bekräfta dennes situation. ➢ Var noga med konfidentialitet. ➢ Stötta personen att vara öppen om sin sjukdom och situation, om denne önskar. ➢ Respektera om personen inte vill skylta med sin sjukdom t.ex. inte använda hjälpmedel inför andra. ➢ Hjälp personen att upprätthålla sitt yttre som denne vill ha det, t.ex. kläder, make-up och rakning. ➢ Vidrör den förändrade kroppen, om det är ok för personen. ➢ Uppmärksamma personens intressen och lär känna personen bakom ”sjukdomen” genom levnadsberättelser. ➢ Möjliggör för personen att vårdas hemma om denne önskar och acceptera hur personen vill ha sin hemmiljö. ➢ Erbjud personen sluten vård om denne önskar. Bistå med att personifiera miljön. ➢ Underlätta aktiviteter och rutiner.
11. Upplever mig inte som uppskattad eller värdefull	➢ Hur kan vi stötta dig så du känner dig värdefull och uppskattad? ➢ Vad är du mest stolt över i relation till dig själv och ditt liv?	➢ Behandla personen som en jämlike. ➢ Bekräfta personen genom att vara närvarande, visa intresse samt skapa relation genom t.ex. fysisk beröring. ➢ Möjliggör för personen att genomföra dagliga aktiviteter, t.ex. toalettbesök, tvätta sig och klä på sig, så självständigt som möjligt. ➢ Stötta personen att upprätthålla sitt yttre enligt dennes preferenser. ➢ Uppmuntra personen att genomföra sådant som kan glädja och ha betydelse för andra.

12. Att inte kunna fungera i viktiga roller (i relation till familj, vänner eller samhälle)	➢ Vilka roller har varit mest betydelsefulla för dig innan du blev sjuk? ➢ På vilka sätt är dessa roller fortfarande viktiga för dig och hur kan de bäst uppfyllas? ➢ Hur påverkas du och andra när dina roller förändras?	➢ Uppmärksamma de roller som personen anser vara viktiga och stötta i att upprätthålla, anpassa eller avsluta dessa. ➢ Stötta personen i att bevara familjerelationer och annat socialt umgänge. ➢ Underlätta för personen att vara fortsatt aktiv i vardagen på olika sätt t.ex. genom medicinering, hjälpmedel och involvering av närstående. ➢ Uppmuntra personen att tänka positivt kring sådant denne fortfarande kan göra. ➢ Underlätta för personen att bo kvar hemma samt vara delaktig i samhället. Samtala om att hjälpinsatser kan behövas. ➢ Uppmuntra personen att prata öppet om sin situation med andra. ➢ Ge stöd till närstående att acceptera ev. rollförändringar i familjen.
13. Upplever att livet inte längre har mål eller mening.	➢ Hur länge har du känt så här? ➢ Vad har hänt dig som fått dig att känna så här? ➢ Vad är fortfarande möjligt?	➢ Visa personen att denne kommer bli omhändertagen och få en god vård. ➢ Stötta personen och närstående att förstå hur situationen är och samtidigt behålla saker att se fram emot. ➢ Ha en icke-dömande och öppen hållning även om du inte håller med personen. ➢ Visa att det är tillåtet att vara ledsen och att inte acceptera sin förestående död. ➢ Hjälp personen att sätta upp kortsiktiga mål som kan göras ”här och nu”, men låt personen fantisera om framtiden. ➢ Ge stöd och praktisk hjälp att genomföra saker. ➢ Främja fysisk aktivitet för att få en känsla av att vara fysisk stark och oberoende. ➢ Uppmuntra personen att samtala om sådant denne gjort och som varit betydelsefullt i dennes liv. ➢ Förebygg fysiska och psykiska besvär som kan påverka upplevelsen av hopp. ➢ Visa närstående vad man kan göra tillsammans t.ex. lyssna på radio/musik/bok, eller se på film. ➢ Uppmuntra personen att umgås med närstående och att ha kontakt med andra i liknande situationer. ➢ Uppmuntra personen att prata om ouppklarade delar av dennes liv. ➢ Var förberedd på att samtala om personens eventuella tankar på dödshjälp eller självmord.

14. Känner att jag inte har gjort något meningsfullt och bestående under mitt liv	➢ Vill du prata med mig om det här, eller vill du ha kontakt med någon annan? ➢ Berätta om sådant du gjort i livet och som du är stolt över. ➢ Hur vill du bli ihågkommen?	➢ Lyssna till berättelser om personens liv, lyft sådant som denne åstadkommit. ➢ Balansera i samtalet svåra och positiva saker som skett i personens liv. ➢ Uppmuntra personen att omge sig med foton och minnen. ➢ Föreslå personen att skriva dagbok och lämna något konkret till närstående som minne. ➢ Prata med närstående om viktiga händelser i personens liv och sådant som skapar samhörighet i familjen. Använd detta i samtal med personen. ➢ Möjliggör för personen att ha kontakt och umgås med närstående.
15. Upplever att jag har något som är ouppklarat (sådant som inte blivit sagt eller gjort)	➢ Vill du prata med mig om det här, eller vill du ha kontakt med någon annan? ➢ Vad skulle vara viktigast för dig att klara upp? ➢ Hur kan vi hjälpa dig att uppfylla det?	➢ Underlätta för personen att göra upp planer för sådant denne vill ordna upp, på vilket sätt, med vilka och i vilken ordning. ➢ Underlätta för personen att reda ut familjekonflikter och att få ta avsked. ➢ Möjliggör för närstående att ordna upp saker med personen. ➢ Hänvisa till andra professioner vid behov, t.ex. gällande ekonomi, rättsliga och andliga frågor.
16. Upplever att jag inte har kontroll över mitt liv	➢ Hur har din upplevelse av att ha kontroll förändrats? ➢ På vilka sätt skulle andra kunna stötta dig att öka din kontroll? ➢ Hur mycket vill du vara inblandad i beslut som rör din hälsa och vård? ➢ Hur känner du för att involvera dina närstående i sådana diskussioner?	➢ Ge relevant information kontinuerligt. ➢ Involvera personen i beslut kring den egna vårdplaneringen där också närstående kan bjudas in. ➢ Samtala med personen om vad som är viktigt för att uppleva kontroll, ge tid att uttrycka känslor samt bekräfta det som sagts. ➢ Stötta personen att göra sådant denne fortfarande kan göra och i att bo kvar hemma om så önskas. Närstående kan t.ex. involveras för att hjälpa personen att kunna klara av vardagshandlingar. ➢ Bidra till balans mellan vad som är realistiskt och hopp om att saker kan göras som förut t.ex. genom hjälp att prioritera, acceptera hjälpmedel och ta hjälp från andra. ➢ Bidra till att uppfylla personens önskemål, t.ex. vara dennes förespråkare gentemot andra. ➢ Arbeta för att närstående ska orka finnas där för personen.

17. Kan inte acceptera att saker och ting är som de är	➢ Hur känner du för det som händer dig? ➢ Hur känner du för att använda hjälpmedel eller involvera andra personer till hjälp? ➢ Finns det någon annan som du skulle vilja samtala med om din situation?	➢ Ha en öppen och ärlig dialog kring personens situation, samtala om att använda hjälpmedel och ta emot hjälp för att kunna göra det mesta av saker denne tycker om. ➢ Bjud in personen att reflektera över livet och lyfta fram värdefulla livserfarenheter men också att få vara ledsen. ➢ Samtala med personen om tankar och känslor kring dagliga aktiviteter som inte längre är möjliga eller behöver göras på annat sätt. ➢ Uppmuntra personen att försöka vara som vanligt även om saker görs på andra sätt och livet blivit annorlunda. ➢ Möjliggör andrum från negativa känslor t.ex. genom att skratta tillsammans med andra. ➢ Underlätta för personen att umgås med närstående samt stötta i att ta avsked.
18. Känner att jag inte längre orkar kämpa emot svårigheter som sjukdomen innebär	➢ Skulle det vara till hjälp att prata om det här med mig? ➢ Vad kan göras för att du ska kunna tänka på annat än sjukdom och känna dig bättre? ➢ Vad i dig är starkast just nu?	➢ Stötta personens vilja att leva och vara positiv genom att t.ex. skapa god vårdrelation, lindra smärtsamma symtom, samtala om behandlingsalternativ och second opinion. ➢ Försök stärka personens acceptans genom att ge information på ett ärligt sätt anpassat till denne och låt det ta tid. ➢ Stärk det mentala välbefinnandet genom att använda humor då det är lämpligt. ➢ Underlätta kontakt med närstående genom att stötta personen i att samtala med sina närstående och låta dem vara delaktiga vid information om personen så önskar. ➢ Uppmuntra personen att fortsätta göra vardagliga saker genom att anpassa aktiviteter till dennes funktionstillstånd.

19. Att inte kunna fortsätta med mina vardagsrutiner	➢ Även om dina rutiner har förändrats hur skulle du kunna bli hjälpt i att känna att livet fortsätter som vanligt? ➢ Vad skulle få dig att känna att du lever mer i nuet? ➢ Vad tycker du om att göra på dagarna?	➢ Uppmuntra personen att genomföra aktiviteter och behålla ansvaret för sådant denne gjort tidigare. ➢ Ge förslag på hur aktiviteter kan underlättas och att ta tillvara de stunder när personen känner sig stark och inte har ont. ➢ Underlätta för personen, t.ex. att sitta eller ligga i sängen och se ut genom en dörr eller ett fönster om denne har svårt att komma ut. ➢ Uppmuntra och underlätta för personen att följa vad som händer i samhället genom t.ex. tidningar, radio och TV. ➢ Lindra personens oro för framtiden t.ex. genom att samtala om det förflutna eller något denne kan se fram emot (behöver inte vara realistiskt). ➢ Var lyhörd för om personen inte vill tala om döden utan önskar försöka fortsätta som vanligt. ➢ Skapa tillfälle till ”egentid”, en fristad för personen.
20. Bekymrad över att mitt andliga liv inte ger mig mening	➢ Med vem skulle du vilja prata om andliga frågor? ➢ I vilken utsträckning känner du frid? ➢ På vilket sätt skulle du vilja bli stöttad när det gäller detta?	➢ Samtala kring samt och bekräfta andliga och existentiella tankar och behov. ➢ Samtala om mening i det som varit och det som är. ➢ Stötta personen att behålla befintliga andliga kontakter och sammanhang. ➢ Informera om och erbjud tillgängligt andligt stöd, t.ex. kontakt med andlig ledare och hjälp med kost, i enlighet med personens livssyn. ➢ Föreslå besök i naturen, kanske en speciell plats och kulturella upplevelser, t.ex. konst och musik.

SOCIALT VÄRDIGHETSREGISTER		
Skattade besvär	**Förslag på frågor för reflektion**	**Förslag på vårdhandlingar**
21. Upplever att min sjukdom och mitt vårdbehov har begränsat mina möjligheter till avskildhet och privatliv	➢ Hur upplever du att ditt privatliv samt avskildhet kan värnas när du behöver vård? ➢ Hur viktig är den privata sfären i hemmet i relation till utrustning och personal från hälso- och sjukvården?	➢ Visa hänsyn som ”gäst” i personens hem/vårdrum t.ex. knacka och stäng dörren efter dig. ➢ Möjliggör avskildhet och/eller enskilt rum, om personen så önskar. ➢ Skapa en privat, hemlik och fridfull miljö t.ex. genom tystnad, musik, ljus och besök av husdjur. ➢ Involvera personen i planering av vård och visa flexibilitet för nya lösningar. Respektera och tillåt personen få vara som denne vill vara. ➢ Visa respekt för personens vardagliga rutiner och anpassa vården, speciellt vid hjälp med personlig hygien. ➢ Visa empati, lyhördhet och ödmjukhet i alla praktiska moment t.ex. hur huden torkas efter ett bad, hur dörrar stängs. ➢ Var lyhörd för vilken personal som fungerar bäst med personen t.ex. om det finns önskemål om kön på vårdpersonal vid intimvård.
22. Känner mig inte stöttad av mina närstående 23. Känner mig inte stöttad av personalen i vården	➢ Vilka personer är viktigast för dig? ➢ Vem känner du står dig närmast? ➢ Hur vill du helst bli stöttad av dina närstående? ➢ Hur skulle du vilja bli stöttad utav vårdpersonalen?	➢ Uppmuntra till gemenskap med närstående och/eller vårdpersonal. ➢ Ge möjlighet att ha kontakt via internet eller telefon. ➢ Agera som ”spindel i nätet”, skapa trygghet och vägled i kontakt med vården t.ex. informera, lämna tips och förklara svårförståelig information. ➢ Involvera närstående i vården samt informera om möjligheten för närstående att få avlastning. ➢ Uppmuntra att personen och närstående delar med sig av känslor kring den förestående döden. ➢ Agera ställföreträdare för personen vid behov. ➢ Lämna inte personen ensam, om denne inte önskar och var lyhörd för behov av fysisk kontakt. ➢ Främja en positiv attityd och använd humor om det bedöms lämpligt. ➢ Ta hjälp av de generella vårdhandlingarna på sidan 3 (se DCI-SWE:s manualhäfte).

24. Att inte bli behandlad med respekt eller förståelse av andra	➢ Vad i det sätt som andra bemöter dig kränker din känsla av värdighet? ➢ Hur skulle du vilja bli bemött?	➢ Bygg upp en förtroendefull relation där du visar tillgänglighet och kompetens. ➢ Sprid en positiv öppen atmosfär. Bjud in till samtal där det är tillåtet att prata om det som bekymrar. ➢ Arbeta för att göra den fysiska miljön inbjudande med en känsla av att vara omhändertagen och betydelsefull. ➢ Behandla personen som en unik person. ➢ Vid vårdplanering, utgå från personens önskningar och behov och låt inte rutiner styra. ➢ Vårda med omtanke utan att visa stress. ➢ Använd humor om det är lämpligt. ➢ Lös eventuella konflikter i samverkan och låta alla inblandade få sägasitt.
25. Känner att jag är en börda för andra	➢ Du verkar bekymrad över att vara en börda för andra, för vem/ vilka särskilt? ➢ På vilket sätt känner du dig som en börda? ➢ Vilken är den största skillnaden i relationen till (personen man känner sig som en börda inför) jämfört med innan du blev sjuk?	➢ Bjud in till samtal om hur personen uppfattar sin situation och involvera närstående, om denne vill det. Var även uppmärksam på det som förs fram vagt. ➢ Åtgärda fysiska och psykiska symtom samt stötta acceptansen att ta emot vård och ev. vårdutrustning genom saklig information. ➢ Diskutera ekonomiska och sociala frågor och förmedla den hjälp som behövs. ➢ Uppmuntra kommunikation mellan personen och närstående om deras behov och känslor. ➢ Berätta för personen att närstående ofta mår bra av att hjälpa men att de kanske inte alltid har möjlighet eller orkar engagera sig i vården. ➢ Stötta närstående i deras vårdande roll. ➢ Ta över ansvaret för den mer omfattande omvårdnaden. Erbjud avlastningsvård om det bedöms nödvändigt.

26. Bekymrad över hur min död kommer att påverkamin familj och vänner	➢ Vem oroar du dig mest för? ➢ Vad bekymrar dig mest över de personer du kommer att lämna efter dig? ➢ Hur kan du bäst få stöd i att prata med de som står dig närmast?	➢ Ha framförhållning gällande problem som kan uppstå och upprätta en plan så de fortare kan lösas. ➢ Stötta personen att ordna för de som lever kvar såväl ekonomiskt som praktiskt men också genom att skapa minnen de kan ha kvar. ➢ Bjud in till möten med personen och dennes närstående om både deras relation samt det praktiska, var lyhörd för det som sägs men även för det osagda. ➢ Hjälp personen att reda ut relationsproblem, om så önskas. ➢ Förmedla kontakter med andra instanser som kan stötta personen och närstående t.ex. stöd till yngre barn där specialistkunskap kan behövas. ➢ Berätta kontinuerligt för personen vad som ordnats och gjorts.

APPENDIX 2. The Swedish version of Patient Dignity Inventory

Frågeformulär för Personlig Värdighet (anpassad till DCI)

För varje påstående ange hur stort problem du tycker att detta varit för dig under de senaste dagarna.

1. Att ha fysiskt besvärande symtom (som smärta, andnöd, illamående)

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

2. Känner mig nedstämd

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

3. Känner oro/ångest

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

4. Ovisshet kring sjukdom och behandling

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

5. Oroar mig för framtiden

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

6. Att inte kunna genomföra dagliga aktiviteter (t.ex. tvätta mig, klä på mig)

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

7. Att inte kunna sköta mina kroppsliga funktioner utan hjälp (t.ex. behövt hjälp med toalettbesök)

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

8. Att inte kunna tänka klart

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

9. En känsla av att det sätt andra ser på mig har förändrats mycket på grund av min sjukdom

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

10. Känner mig inte längre som den jag varit

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

11. Upplever mig inte som uppskattad värdefull

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

12. Att inte kunna fungera i viktiga roller (i relation till familj, vänner eller samhälle)

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

13. Upplever att livet inte längre har varken mål eller mening

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

14. Känner att jag inte har gjort något meningsfullt och bestående under mitt liv

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

15. Upplever att jag har något som är ouppklarat (sånt som inte blivit sagt eller gjort)

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

16. Upplever att jag inte har kontroll över mitt liv

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

17. Kan inte acceptera att saker och ting är som de är

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

18. Känner att jag inte längre orkar kämpa emot svårigheter som sjukdomen innebär

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

19. Att inte kunna fortsätta med mina vardagsrutiner

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

20. Bekymrad över att mitt andliga liv inte ger mig mening

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

21. Upplever att min sjukdom och mitt vårdbehov har begränsat mina möjligheter till avskildhet och privatliv

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

22. Känner mig inte stöttad av mina vänner och min familj

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

23. Känner mig inte stöttad av personalen i vården

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

24. Att inte bli behandlad med respekt eller förståelse av andra

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

25. Känner att jag är en börda för andra

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

26. Bekymrad över hur min död kommer att påverka min familj och vänner

1	2	3	4	5
Inget problem	Ett litet problem	Ett problem	Ett stort problem	Ett överväldigande problem

Chochinov et al. 2008. Adapted for the Dignity Care Intervention 2010, and into Swedish 2013 by the DCI-SWE research group. Do not spread.

APPENDIX 3. Semi-structured interview guide (studies II-IV)

Frågeområden med fördjupade/bredare frågor

Till personer med palliativa vårdbehov (studie III)

Kan du med egna ord beskriva vad värdighet innebär för dig?
- Hur skulle du beskriva din värdighet just nu?

Har din upplevelse av värdighet förändrats över tid, om du jämför hur det var när du var yngre, och i så fall vill/kan du berätta hur?
- Kan du ge ett konkret exempel på hur din upplevelse av värdighet har förändrats?
- Kan du berätta om din vård har förändrat din upplevelse av värdighet? (Upplever du den annorlunda och i så fall hur?)
- Den vård du har fått, kan du berätta hur den utgår från dig som person och dina behov.

Du har fått vård av sjuksköterskor/en sjuksköterska som har använt ett nytt arbetssätt för värdighetsbevarande vård och nu har jag några frågor om hur du har upplevt det.
Din sjuksköterska och vårdteamet har använt ett arbetssätt i vården av dig i syfte att bevara din värdighet och din livskvalitet. Vad är din samlade upplevelse av att ha fått vård av personal som arbetar utifrån att vården ska vara värdighetsbevarande?
- Hur har det uppfyllt dina förväntningar?
- Hur har det skiljt sig från den vård du fått tidigare (ev. på annan vårdenhet)?
- Kan du beskriva/ge exempel på sådant som varit bra?
- Kan du beskriva/ge exempel på sådant som varit dåligt?
- Är det här ett arbetssätt som du tror kan hjälpa andra personer med palliativa (lindrande) vårdbehov?

Har arbetssättet för värdighetbevarande vård påverkat din livskvalitet på något sätt, i så fall hur?
Har arbetssättet för värdighetbevarande vård påverkat din kommunikation med vårdpersonalen på något sätt, i så fall hur?

Hur var det att fylla i frågeformuläret som handlar om sådant som kan påverka en persons upplevelse av värdighet?
- Fyllde du i frågorna själv? Eller fick du hjälp av någon, i så fall av vem?
- Hur tyckte du det var att svara på frågorna?
- Var det frågor som var svåra att förstå, vilka och hur?
- Var det frågor som handlade om sådant som är jobbigt att tänka på, vilka och på vilket sätt?
- Var det frågor som berörde något väldigt viktigt för dig att få prata om? Vilka och på vilket sätt?
- Kändes frågorna relevanta för dig och din upplevelse av värdighet?
- Var det någon fråga som du tyckte saknades och som borde ha tagits upp?

Efter att du svarat på frågorna var det en sjuksköterska som hade ett samtal med dig utifrån hur du svarat. Hur upplevde du det/de samtalet/n?

- Hur ser du på samtalet som följde upp dina svar från frågeformuläret?
- Kan du berätta lite vad ni pratade om?
- Fick du möjlighet att berätta om sådant som bekymrar/oroar dig?
- Kunde du berätta vad du tror kan hjälpa dig att lösa/hantera dina problem/besvär?
- Fick du förslag av sjuksköterskan på sådant hen kan hjälpa dig med för att lösa/ hantera dina problem/besvär?
- Kunde ni tillsammans bestämma hur ni ska gå vidare (med vårdhandlingar)?

Du fick förslag av sjuksköterskan på hur hen kan stötta dig att hantera det som bekymrar/oroar dig, det vi kallar vårdhandlingar. Är det något som har använts i din vård?

- Vilka förslag/vårdhandlingar pratade ni om? Vilka för slag/vårdhandlingar användes? Kan du berätta?
- Vad tyckte du om förslagen/vårdhandlingarna?
- Har dessa förslag/vårdhandlingar påverkat din känsla av värdighet? I så fall på vilket sätt?
- Har förslagen/vårdhandlingarna hjälpt dig på något annat sätt? Kan du beskriva?

Situationen med covid-19 har inneburit att många äldre personer hotas av sjukdom och inte får ta emot besök.

- Vilken betydelse kan arbetssättet DCI-SWE ha för äldre personer i en sådan här situation? Kan du/ni beskriva/ge något exempel?
- Vilken betydelse kan arbetssättet DCI-SWE ha för närstående i en sådan här situation? Kan du/ni beskriva/ge något exempel.
- Vilken betydelse kan arbetssättet DCI-SWE ha för sjuksköterskor/vårdpersonal i en sådan här situation? Kan du/ni beskriva/ge något exempel.

<u>Närstående till personer med palliativa vårdbehov (studie III)</u>

Kan du med egna ord beskriva vad värdighet betyder för dig? (täck in det nedan)

- Hur skulle du beskriva din närståendes upplevelse av värdighet just nu?

Har din närståendes upplevelse av värdighet förändrats sedan hen blev sjuk och vill du i så fall berätta hur?

- Kan du ge ett konkret exempel på hur hens upplevelse av värdighet har förändrats?
- Kan du berätta om hur den vård din närstående fått har påverkat hens upplevelse av värdighet? (Upplever du den annorlunda och i så fall hur?)
- Den vård din närstående har fått, kan du berätta hur den utgår från hen som person och hens behov.

Din närstående har fått vård av sjuksköterskor/en sjuksköterska som har använt ett nytt arbetssätt för värdighetsbevarande vård och nu har jag några frågor om hur du och din närstående har upplevt det.

Din närståendes sjuksköterska och vårdteamet har använt ett arbetssätt i vården i syfte att bevara hens värdighet och livskvalitet. Vad är din samlade upplevelse av att din närstående har fått vård av personal som arbetar utifrån att vården ska vara värdighetsbevarande?

- Hur har det uppfyllt dina/hens förväntningar?
- Hur har det skiljt sig från den vård din närstående fått tidigare (ev. på annan vårdenhet)?
- Kan du beskriva/ge exempel på sådant som varit bra?
- Kan du beskriva/ge exempel på sådant som varit dåligt?
- Är det här ett arbetssätt som du tror kan hjälpa andra personer med palliativa (lindrande) vårdbehov?

Har arbetssättet för värdighetbevarande vård påverkat din närståendes livskvalitet på något sätt, i så fall hur?
Har arbetssättet för värdighetbevarande vård påverkat din närståendes kommunikation med vårdpersonalen på något sätt, i så fall hur?

Hur tyckte din närstående det var att fylla i frågeformuläret som handlar om sådant som kan påverka en persons upplevelse av värdighet?

- Fyllde hen i frågorna själv? Eller hjälpte du eller någon annan till, i så fall vem?
- Hur tyckte hen det var att svara på frågorna?
- Var det frågor som var svåra att förstå, vilka och hur?
- Var det frågor som handlade om sådant som är jobbigt att tänka på, vilka och på vilket sätt?
- Var det frågor som berörde något väldigt viktigt för hen att få prata om? Vilka och på vilket sätt?
- Kändes frågorna relevanta för hens upplevelse av värdighet?

Efter att din närstående svarat på frågorna var det en sjuksköterska som hade ett samtal med hen utifrån hur hen svarat. Deltog du vid något sådant samtal? Hur upplevde du/hen det/de samtalet/n?

- Hur ser du på samtalet som följde upp det hen svarat på frågeformuläret?
- Om du deltog vid samtalet, vill du berätta lite vad ni pratade om?
- Fick hen/du möjlighet att berätta om sådant som bekymrar/oroar hen/dig?
- Kunde hen eller du berätta vad hen/du tror kan lösa/hantera hens problem/besvär?
- Fick hen förslag av sjuksköterskan på sådant som kan hjälpa hen lösa/hantera hens problem/besvär?
- Kunde ni tillsammans bestämma hur ni ska gå vidare (med vårdhandlingar)?

Din närstående fick förslag av sjuksköterskan hur hen kan bli stöttad att hantera det som bekymrar/oroar, det vi kallar vårdhandlingar. Är det något som har använts i din närståendes vård?

- Känner du till vilka vårdhandlingar som har diskuterats och använts? Kan du berätta?
- Kan du berätta mer om vad du/hen tyckte om vårdhandlingarna?
- Har dessa vårdhandlingar inverkat på din närståendes känsla av värdighet? I så fall på vilket sätt?
- Har vårdhandlingarna hjälpt din närstående på något annat sätt? Kan du beskriva?

Situationen med covid-19 har inneburit att många äldre personer hotas av sjukdom och inte får ta emot besök.
- Vilken betydelse kan arbetssättet DCI-SWE ha för äldre personer i en sådan här situation? Kan du/ni beskriva/ge något exempel?
- Vilken betydelse kan arbetssättet DCI-SWE ha för närstående i en sådan här situation? Kan du/ni beskriva/ge något exempel.
- Vilken betydelse kan arbetssättet DCI-SWE ha för sjuksköterskor/vårdpersonal i en sådan här situation? Kan du/ni beskriva/ge något exempel.

Sjuksköterskor/distriktsköterskor (studie II; studie IV*)

Inledande fråga: Vad innebär värdighetsbevarande vård för sköra äldre personer med palliativa vårdbehov, för er? Kan du/ni beskriva?

Hur upplevde du/ni utbildningen du fick för att använda DCI-SWE?
- Var utbildningen relevant för vad du upplever behövs för att använda DCI-SWE? På vilket sätt?
- Gjorde utbildningen så att du/ni kunde använda DCI-SWE på ett adekvat sätt? På vilket sätt?
- Vad skulle kunna förbättra den utbildning du/ni fick för att använda DCI-SWE?

Berätta hur du/ni gick tillväga för att identifiera personer som du/ni bedömde skulle ha nytta av en vård där DCI-SWE används?
- Var det någon person som du/ni använde DCI-SWE med som tackade nej till att delta?
- Om så, angavs någon orsak till varför?

Berätta om era erfarenheter kring de besvär som finns med i DCI-SWE och som kan påverka personers värdighet?
- Hur relevanta är besvären?
- Finns det andra besvär du/ni tycker borde inkluderas, i så fall vilka?
- Tror du/ni dina/era patienter upplever andra besvär än de som frågades om? Om så vilka?

Berätta om dina/era erfarenheter kring frågeformuläret (PDI) som är en del i interventionen?
- Hur upplever du/ni frågorna?
- Hur upplever du/ni svarsalternativen och poängsättningen?

- Skulle du/ni vilja ändra något i frågorna eller svarsalternativen? Om så, vad och varför?

Berätta om dina/era erfarenheter av att använda de reflekterande frågorna som är en del i DCI-SWE.
- Var frågorna till hjälp för att hitta lösningar på patientens problem? Om ja, hur då? Om nej, varför inte?
- Fanns det svårigheter med att använda dessa frågor? Om ja, vilka och varför?

Berätta om era erfarenheter kring de evidensbaserade vårdhandlingar som är föreslagna för att stötta personer i att hantera olika besvär.
- Ger DCI-SWE er möjlighet att identifiera fler vårdhandlingar? Kan ni ge något exempel.
- Påverkar DCI-SWE möjligheten för er att ge en personcentrerad vård? I så fall på vilket sätt? Ge exempel.

Har du/ni förslag på förändringar och förbättringar som borde göras i DCI-SWE?
- Om så, i vilka delar och varför?
- Hur skulle dessa förändringar kunna se ut?
- Vilka delar av DCI-SWE önskar ni behålla som de är?
- I vilken utformning/ format skulle ni vilja ha DCI-SWE?

Berätta hur användandet av DCI-SWE varit till hjälp för personer med palliativa vårdbehov?
- Vilken inverkan bedömer du/ni att DCI-SWE kan ha på den äldre personen? På närstående?
- På vilket sätt var det till hjälp för personerna att identifiera sina besvär och förmedla dem till dig?
- Hur hjälpte det personerna att samtala med dig om svåra saker som de annars inte skulle ha pratat om?
- Har arbetssättet för värdighetbevarande vård påverkat den äldre personens livskvalitet på något sätt, i så fall hur?
- Har arbetssättet för värdighetbevarande vård påverkat den äldre personens kommunikation med er inom vårdpersonalen på något sätt, i så fall hur? *studie IV

Situationen med covid-19 har inneburit att många äldre personer hotas av sjukdom och inte får ta emot besök. *studie IV
- Vilken betydelse kan arbetssättet DCI-SWE ha för äldre personer i en sådan här situation? Kan du/ni beskriva/ge något exempel?
- Vilken betydelse kan arbetssättet DCI-SWE ha för närstående i en sådan här situation? Kan du/ni beskriva/ge något exempel.
- Vilken betydelse kan arbetssättet DCI-SWE ha för dig/er som sjuksköterska/sjuksköterskor i en sådan här situation? Kan du/ni beskriva/ge något exempel.

Berätta om dina/era upplevelser av att bedöma hur ofta DCI-SWE bör användas i vården av enskilda personer.

- Hur ofta har du/ni använt DCI-SWE för varje patient?
- Vilka faktorer har påverkat hur ofta DCI-SWE har använts?
- Har det varit svårt att bestämma hur ofta DCI-SWE bör användas? Om så, vad kunde ha varit en hjälp för de besluten?

Vilka hindrande och underlättande faktorer har du/ni upplevt i användandet av DCI-SWE?

- Har du/ni upplevt några hinder för att framgångsrikt kunna använda DCI-SWE? Om så, berätta.
- Vilka var hindren och hur skulle dessa kunna hanteras?
- Vilka möjligheter kan du/ni identifiera vid användandet av DCI-SWE? Kan du/ni berätta?
- Finns det några faktorer som har eller skulle kunna underlätta användningen av DCI-SWE? Vilka? Kan du/ni berätta?

Vi har utifrån den tidigare pilotstudien identifierat några hinder och underlättare för värdighetsbevarande vård: *studie IV

- Bristen på resurser i verksamheten; har ni några förslag på hur detta hinder kan hanteras så att en värdighetsbevarande vård kan ges?
- Sjuksköterskor som är obekväma att genomföra djupare samtal med hjälp av arbetssättet DCI-SWE, har ni några förslag på hur detta hinder kan hanteras?
- En underlättare och ett sätt att göra sjuksköterskor mer bekväma i att genomföra samtal var chefens engagemang, har ni några förslag på hur vi kan involvera chefer mer i ett initiativ som DCI-SWE?

Hur har situationen med covid-19 påverkat din/er möjlighet att genomföra arbetet med DCI-SWE? *studie IV

- Vilka hinder har du/ni stött på? Kan du/ni beskriva.
- Vilka möjligheter kan du/ni se med att använda ett arbetssätt såsom DCI-SWE i samband med en pandemi som corona/covid-19?

Kan du/ni berätta hur du/ni organiserade arbetet för att kunna använda DCI-SWE?

- Hur fungerade det upplägget?
- Kan du/ni se att något annat sätt att organisera arbetssättet med DCI-SWE hade varit mer fördelaktigt?

Vilken betydelse har användandet av DCI-SWE haft för dig/er?

- Under användningen av DCI-SWE har vi haft återkommande fokusgruppsträffar där ni har fått möjlighet att utbyta era erfarenheter av DCI-SWE med oss forskare samt med era kollegor, kan du/ni beskriva er erfarenhet av det? *studie IV
- Under användningen av DCI-SWE har vi haft en kontaktsjuksköterska på varje enhet, kan du/ni beskriva er erfarenhet av det? *studie IV

Hur tänker du/ni att DCI-SWE bäst kan användas i befintlig verksamhet?

- På vilket sätt kan DCI-SWE ha en plats i klinisk verksamhet?

- Vilka förändringar behöver göras för att DCI-SWE framgångsrikt ska kunna implementeras i klinisk verksamhet?
- Hur anser du/ni att DCI-SWE bäst kan dokumenteras?
- Hur skulle DCI-SWE kunna användas inom flera verksamheter i landet?

Avslutningsvis, vilken är din/er samlade upplevelse av att ha använt DCI-SWE?

<u>Övrig vårdpersonal och chefer (studie IV)</u>

Inledande fråga: Vad innebär värdighetsbevarande vård för sköra äldre personer med palliativa vårdbehov, för er? Kan du/ni beskriva.
På vilket sätt kom du i kontakt med DCI-SWE?

Har du/ni varit med att identifiera personer som du/ni bedömde skulle ha nytta av en vård där DCI-SWE används? Kan du/ni i så fall berätta hur du/ni gick tillväga?
- Var det någon person som du/ni identifierade för DCI-SWE men som tackade nej till att delta?
- Om så, angavs någon orsak till varför?

Berätta om dina/era erfarenheter kring de besvär som finns med i DCI-SWE och som kan påverka personers värdighet?

- Hur relevanta är besvären?
- Finns det andra besvär du/ni tycker borde inkluderas, i så fall vilka?
- Tror du/ni att dina/era patienter upplever andra besvär än de som frågades om? Om så vilka?

Berätta om dina/era erfarenheter kring frågeformuläret (PDI) som är en del i interventionen?
- Hur upplever du/ni frågorna?
- Hur upplever du/ni svarsalternativen och poängsättningen?
- Skulle du/ni vilja ändra något i frågorna eller svarsalternativen? Om så, vad och varför?

Berätta om dina/era erferenheter kring att använda reflekterande frågor som är en del i DCI-SWE.
- Kan frågorna vara till hjälp för att hitta lösningar på patientens problem? Om ja, hur då? Om nej, varför inte?
- Känner du/ni till hur den äldre personen har upplevt frågorna? Kan du/ni berätta.
- Känner du/ni till hur sjuksköterskan har upplevt det att använda sig av frågorna? Kan du/ni berätta?
- Kan det finnas svårigheter med att använda dessa frågor? Om ja, vilka och varför?

Berätta om dina/era erfarenheter kring de evidensbaserade vårdhandlingar som är föreslagna för att stötta personer i att hantera olika besvär?

- Ger DCI-SWE sjuksköterskan/er möjlighet att identifiera fler vårdhandlingar? Kan ni ge något
  exempel.
- Kan DCI-SWE inverka på möjligheten för er att ge en personcentrerad vård? I så fall på vilket sätt?

Har du/ni förslag på förändringar och förbättringar som borde göras i DCI-SWE?
- Om så, i vilka delar och varför?
- Hur skulle dessa förändringar kunna se ut?
- Vilka delar av DCI-SWE önskar ni behålla som de är?
- I vilken utformning/ format skulle ni vilja ha DCI-SWE?

Berätta hur användandet av DCI-SWE varit till hjälp för personer med palliativa vårdbehov?
- Vilken inverkan bedömer du/ni att DCI-SWE kan ha på den äldre personen? På närstående?
- På vilket sätt var det till hjälp för personerna att identifiera sina besvär och förmedla dem till dig eller sjuksköterskan?
- Hur hjälpte det personerna att samtala med dig/sjuksköterskan om svåra saker som de annars inte skulle ha pratat om?
- Har arbetssättet för värdighetbevarande vård påverkat den äldre personens livskvalitet på något sätt, i så fall hur?
- Har arbetssättet för värdighetbevarande vård påverkat den äldre personens kommunikation med er inom vårdpersonalen på något sätt, i så fall hur?

Situationen med covid-19 har inneburit att många äldre personer hotas av sjukdom och inte får ta emot besök.
- Vilken betydelse kan arbetssättet DCI-SWE ha för äldre personer i en sådan här situation? Kan du/ni beskriva/ge något exempel?
- Vilken betydelse kan arbetssättet DCI-SWE ha för närstående i en sådan här situation? Kan du/ni beskriva/ge något exempel.
- Vilken betydelse kan arbetssättet DCI-SWE ha för dig/er som vårdpersonal i en sådan här situation? Kan du/ni beskriva/ge något exempel.

Berätta om dina/era upplevelser av hur ofta du/ni bedömer att DCI-SWE bör användas i vården av enskilda personer.
- Hur ofta har sjuksköterskan använt DCI-SWE för varje patient?
- Vilka faktorer har påverkat hur ofta DCI-SWE har använts?
- Har det varit svårt att bestämma hur ofta DCI-SWE bör användas? Om så, vad kunde ha varit en hjälp för de besluten?

Vilka hindrande och underlättande faktorer kan du/ni se i användandet av DCI-SWE?
- Har du/ni upplevt några hinder för att framgångsrikt kunna använda DCI-SWE? Om så, berätta.
- Vilka var hindren och hur skulle dessa kunna hanteras?
- Vilka möjligheter kan du/ni identifiera vid användandet av DCI-SWE? Kan du/ni berätta?

- Finns det några faktorer som har eller skulle kunna underlätta användningen av DCI-SWE? Vilka? Kan du berätta?

Vi har utifrån den tidigare pilotstudien identifierat några hinder och underlättare för värdighetsbevarande vård:
- Bristen på resurser i verksamheten; har ni några förslag på hur detta hinder kan hanteras så att en värdighetsbevarande vård kan ges?
- Sjuksköterskor som är obekväma att genomföra djupare samtal med hjälp av arbetssättet DCI-SWE, har ni några förslag på hur detta hinder kan hanteras?
- En underlättare och ett sätt att göra sjuksköterskor mer bekväma i att genomföra samtal var chefens engagemang, har ni några förslag på hur vi kan involvera chefer mer i ett initiativ som DCI-SWE?

Har du/ni kännedom om/kan du/ni berätta hur situationen med covid-19 har påverkat sjuksköterskans/vårdpersonalens möjlighet att genomföra arbetet med DCI-SWE?
- Vilka hinder har du/ni sett? Kan du/ni beskriva.
- Vilka möjligheter kan du/ni se med att använda ett arbetssätt såsom DCI-SWE i samband med en pandemi som Corona/Covid-19?

Har du/ni kännedom om/kan du/ni berätta hur sjuksköterskan organiserade arbetet för att kunna använda DCI-SWE?
- Hur fungerade sjuksköterskans upplägg?
- Kan du/ni se att något annat sätt att organisera arbetssättet med DCI-SWE hade varit mer fördelaktigt?

Vilken betydelse har användandet av DCI-SWE haft för dig/er, sjuksköterskan?
- Under användningen av DCI-SWE har vi haft en kontaktsjuksköterska på varje enhet, har du/ni någon erfarenhet av det? Kan du/ni beskriva.

Hur tänker du/ni att DCI-SWE bäst kan användas i befintlig verksamhet?
- På vilket sätt kan DCI-SWE ha en plats i klinisk verksamhet?
- Vilka förändringar behöver göras för att DCI-SWE framgångsrikt ska kunna implementeras i klinisk verksamhet?
- Hur anser du/ni att DCI-SWE bäst kan dokumenteras?
- Hur skulle DCI-SWE kunna användas inom flera verksamheter i landet?

Avslutningsvis, vilken är din/er samlade upplevelse av DCI-SWE?

APPENDIX 4. Dignity-conserving care – outcomes studied in research

Cluster theme	Themes related to Illness-Related Concerns	
Theme of studied outcomes	Performance, symptoms and emotional concerns	
	Operationalization of outcomes	References
	<u>Performance status</u> The Palliative Performance Scale The Palliative Performance Scale–version 2 (PPSv2)	 Chochinov et al., 2011 (155) Houmann et al., 2014 (156)
	<u>Symptoms</u> The Edmonton Symptom Assessment System (ESAS)	 Chochinov et al., 2011 (155); Vergo et al., 2014 (157)
	<u>Symptoms and concerns</u> The Structured Interview for Symptoms and Concerns (SISC)	 Chochinov et al., 2011 (155); Houmann et al., 2014 (156)
	<u>Psychophysiological wellbeing</u> Heart rate variability (HRV)	 Ho et al., 2017 (158)
	<u>Distress</u> The Distress Thermometer	 Vergo et al., 2014 (157)
	<u>Affective states</u> The Positive and Negative Affect Schedule (PANAS)	 Montross-Thomas et al., 2015 (159)
	<u>Psychological wellbeing</u> The Life Closure Scale (LCS) consisting of 20 items	 Montross-Thomas et al., 2015 (159)
	<u>Psychological distress</u> The Geriatric Depression Scale The Distress Thermometer	 Hall, Chochinov et al., 2009 (160) Hall, Edmonds et al., 2009 (161)
	The Hospital Anxiety and Depression Scale (HADS)	Hall, Goddard, Opio, Speck, Martin et al., 2011 (162)
	Patient Health Questionnaire-9 The Structured Interview for Symptoms and Concerns (SISC)	Ho et al., 2017 (158) Chochinov et al., 2011 (155)
	The MQOL questionnaire	Ho et al., 2016 (163)
	<u>Depression</u> The Hospital Anxiety and Depression Scale (HADS)	 Chochinov et al., 2011 (155); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162); Houmann et al., 2014 (156); Julião et al., 2013 (164); Julião et al., 2014 (165); Montross-Thomas et al., 2015 (159); Rudilla et al., 2016 (166)
	The 15-item Geriatric Depression Scale The second edition of the 21-item Beck	Hall, Goddard, Opio, Speck & Higginson, 2011 (167)
	Depression Inventory	Johns, 2013 (168)

	The Zung Self-Rating Depression Scale	Passik et al., 2004 (169)
	Anxiety The Hospital Anxiety and Depression Scale (HADS)	Chochinov et al., 2011 (155); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162); Houmann et al., 2014 (156); Julião et al., 2013 (164) Julião et al., 2014 (165), Montross-Thomas et al., 2015 (159); Rudilla et al., 2016 (166)
Theme of studied outcomes	**End of life and existential aspects**	
	Operationalization of outcomes	**References**
	End of life psychological experiences Through the Demoralization Syndrome (DS) criteria, Desire for Death scale and Sense of Dignity (PDI)	Julião et al., 2017 (170)
	Palliative care needs The Palliative Care Outcome Scale (POS)	Hall, Edmonds et al., 2009 (161); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162)
	Goals of care and treatment preferences at end of life The Hypothetical Advanced Care Planning Scenario (H-CAP-S)	Vergo et al., 2014 (157)
	Sense of life closure The Life Closure Scale (LCS) The Herth Hope Index (HHI)	Montross-Thomas et al., 2015 (159) Hall, Goddard, Opio, Speck, Martin et al., 2011 (162)
	Existential wellbeing The Functional Assessment of Chronic Illness Therapy-8-item Spiritual Well-Being Scale (FACIT-Sp.)	Bernat et al., 2015 (171)
	Existential distress The Structured Interview for Symptoms and Concerns (SISC)	Chochinov et al., 2011 (155)
	On five items (anxiety, sense of suffering, desire for death, lack of wellbeing, perceived loss of dignity) - lower scores indicating less existential distress	Johns, 2013 (168)
	Purposelessness The Purposelessness, Understimulation and Boredom (PUB) scale	Passik et al., 2004 (169)
	Will to live A will-to-live visual analogue scale included in the Edmonton Symptom Assessment System (ESAS)	Chochinov et al., 2005 (172); Chochinov et al., 2011 (155)
	Desire for death The Desire for Death Rating Scale (DDRS)	Julião et al., 2017 (170)

Cluster theme	Themes related to the Dignity-Conserving Repertoire	
Themes of studied outcomes	Essential life values	
	Operationalization of outcomes	References
	<u>Hope</u> The Herth Hope Index (HHI)	Bentley et al., 2014 (173); Montross-Thomas et al., 2015 (159)
	<u>Hopefulness</u> The Herth Hope Index (HHI)	Aoun et al., 2015 (174); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162); Hall, Chochinov et al., 2009 (160); Hall, Edmonds et al., 2009 (161); Hall, Goddard, Opio, Speck & Higginson, 2011 (167); Ho et al., 2017 (158)
	<u>Meaning in life</u> The Life Evaluation Questionnaire (the 5-item Appreciation of Life subscale, the 8-item Contentment subscale and the 8-item Social Integration subscale)	Montross-Thomas et al., 2015 (159)
	A modified Cancer Coherence scale	Ho et al., 2017 (158)
	<u>Spirituality</u> The Grupo de Espiritualidad (GES) questionnaire	Rudilla et al., 2016 (166)
	The Dignity Impact Scale (DIS)	Scarton et al., 2018 (175)
	<u>Spiritual wellbeing</u> The Functional Assessment of Chronic Illness Therapy-12-item Spiritual Well-Being Scale (FACIT-sp.)	Aoun et al., 2015 (174); Bentley et al., 2014 (173); Chochinov et al., 2011 (155); Ho et al., 2017 (158)
Theme of studied outcomes	Aspects of personal strength and coping	
	Operationalization of outcomes	References
	<u>Self-efficacy</u> The General Self-Efficacy Scale (GSE)	Montross-Thomas et al., 2015 (159)
	<u>Resilience</u> The Connor-Davidson Resilience Scale (CD-RISC)	Montross-Thomas et al., 2015 (159)
	The Brief Resilient Coping Scale (BRCS)	Rudilla et al., 2016 (166)
	<u>Empowerment</u> The Empowerment Scale	Roos et al., 2016 (176)
	<u>Post-traumatic growth</u> The Posttraumatic Growth Inventory (PTGI)	Da Rocha Rodrigues et al., 2016 (177)
	<u>Psychological adaptation</u> The Life Closure Scale (LCS)	Montross-Thomas et al., 2015 (159)
	<u>Death acceptance</u> The Terminal Illness Acknowledgement (TIA) questionnaire	Vergo et al., 2014 (157)

Cluster theme	Themes related to the Social Dignity Inventory	
Theme of studied outcomes	Aspects of care tenor and social support	
	Operationalization of outcomes	References
	<u>Person-centred care climate</u> The Person-centered Climate Questionnaire-patient (PCQ-P) measuring three subscales: a climate of safety, a climate of everydayness and a climate of hospitality	Johnston, Gaffney et al., 2015 (178); Johnston, Pringle et al., 2015 (179) Roos et al., 2016 (176)
	<u>Empathy</u> The Consultation and Relational Empathy (CARE) measure	Johnston, Pringle et al., 2015 (179)
	The Empathy questionnaire (for healthcare professionals)	Chochinov et al., 2015 (180)
	<u>Social support</u> The Duke-UNC-11 Functional Social Support Questionnaire	Rudilla et al., 2016 (166)
	A modified version of the Inventory of Social Support	Ho et al., 2017 (158)
Cluster theme	Themes regarding Overarching Dignity Issues	
Theme of studied outcomes	Aspects of dignity and gratitude	
	Operationalization of outcomes	References
	<u>Sense of dignity</u> The PDI	Julião et al., 2017 (170); Ho et al., 2017 (158)
	<u>Dignity-related distress</u> The PDI	Aoun et al., 2015 (174); Bentley et al., 2014 (173); Bernat et al., 2015 (171); Chochinov et al., 2011 (155); Hall, Chochinov et al., 2009 (160); Hall, Edmonds et al., 2009 (161); Hall, Goddard, Opio, Speck & Higginson, 2011 (167); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162); Houmann et al., 2014; Rudilla et al., 2016 (166); Da Rocha Rodrigues et al., 2016 (177)
	<u>Gratitude</u> The Gratitude Questionnaire Six-Item Form (GQ-6) measuring experience of gratitude, forgiveness and spiritual transcendence	Montross-Thomas et al., 2015 (159)
	<u>Appreciation of life</u> The 5-item Appreciation of Life subscale as one subscale in the Life Evaluation Questionnaire	Montross-Thomas et al., 2015 (159)

Theme of studied outcomes	Aspects of Quality of Life	
	Operationalization of outcomes	**References**
	Quality of Life	
	The Amyotrophic Lateral Sclerosis Assessment Questionnaire-5 (ALS-FRS)	Aoun et al., 2015 (174)
	A two-item QoL Scale with ratings of QoL and satisfaction with QoL	Chochinov et al., 2005 (172); Chochinov et al., 2011 (155); Hall, Chochinov et al., 2009 (160); Hall, Edmonds et al., 2009 (161); Hall, Goddard, Opio, Speck & Higginson, 2011 (167); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162); Vergo et al., 2014 (157)
	The Euro QoL Five Dimensions (EQ-5D)	Hall, Chochinov et al., 2009 (160); Hall, Edmonds et al., 2009 (161); Hall, Goddard, Opio, Speck & Higginson, 2011 (167); Hall, Goddard, Opio, Speck, Martin et al., 2011 (162)
	Items from the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life C30 Questionnaire (EORTC–QLQ–C30)	Rudilla et al., 2016 (166)
	The MQOL	Ho et al., 2016 (163)
	The World Health Organization (WHO) QoL Scale-8	Ho et al., 2017 (158)
	Satisfaction with life	
	The Satisfaction with Life Scale (SWLS) The Life Satisfaction Questionnaire (LSQ)	Da Rocha Rodrigues et al., 2016 (177) Roos et al., 2016 (176)
	Health-related Quality of Life	
	The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life C15 Questionnaire Palliative care (QLQ-C15-PAL)	Houmann et al., 2014 (156)
	Functional Assessment of Chronic Illness Therapy-Palliative Care version 4 (FACIT-PAL)	Johns, 2013 (168)
	Nursing home Quality of Life	
	The Nursing Facilities QoL scale	Ho et al., 2016 (163)

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