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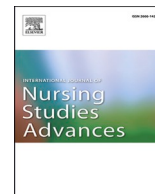
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Enhancing ethical self-efficacy among dementia caregiver staff: A mixed-methods feasibility study of the care programme

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ABSTRACT

Background: The global population living with dementia is rapidly increasing, with projections estimated at 78 million by 2030 and 132 million by 2050 due to ageing demographics. Despite the increasing prevalence of dementia, effective treatments remain limited. High-quality care is critical, but it presents complex ethical challenges, including balancing autonomy with best interests, addressing the needs of individuals with dementia and their caregivers, and equitably allocating resources. To address these challenges, we introduced the CARE programme, a systematic approach to ethics work, in nursing homes to enhance the ethical self-efficacy of nursing home staff.

Objective: This study assessed the feasibility of the CARE programme in a community-based Danish nursing home setting. Using the framework of Bowen et al. and a mixed-methods research design, we conducted six face-to-face focus group interviews with nursing home staff, two telephone interviews with nursing home managers, and a survey among 90 participants. Data were collected in the spring and fall of 2022.

Method: Quantitative data were analysed using STATA for descriptive statistics, while qualitative data were processed using a six-step template analysis framework.

Results: The results indicate high feasibility and acceptance of the CARE programme among the nursing home staff. To a high/some degree, 97 % expressed satisfaction, 95 % found the programme relevant to their work, 90 % believed it would improve dementia care, and 82 % felt better equipped to handle ethical dilemmas. Both the management and staff acknowledged the programme's effectiveness in filling the critical gap in ethics training in nursing homes. Appreciation for external facilitation, participation from multiple nursing homes, and cross-institutional group work emphasised the value of the programme.

Conclusion: The quantitative results indicate high levels of satisfaction and relevance, with the majority of participants believing that the program improves care and enhances their ability to manage ethical issues. Qualitative insights further emphasize the program's success in meeting the need for ethics training, facilitated by external researchers and cross-institutional collaboration. Full implementation of the CARE programme requires a cultural shift in nursing homes that advocates for universal staff involvement in ethics training and promotes open dialogue about ethical issues. Moreover, policy changes may be necessary to secure funding and establish minimum training standards for nursing home staff.

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What is already known

- Dementia care is intertwined with ethical issues.
- Nursing home staff express a need for ethics training.
- Only a few countries have implemented systematic ethics programs in nursing homes.

What this paper adds

- The CARE programme improved the staff's confidence in making ethical decisions.
- Group work, literary texts, and external facilitation were effective.
- The staff felt that participation in the programme would improve care.
- The programme requires a cultural shift and additional funding for staff education.

Alzheimer's, the dark doctor, seems to have claimed all memories of our life together before his time.

—John Bayley, *A Memoir of Irish Murdoch*

1. Introduction

According to the European Union and World Health Organization, dementia is a major global health challenge (Commission E, 2021; Organization WH, 2017). In 2019, 55 million people had been living with dementia, and the number is expected to increase to 78 million by 2030 and 132 million by 2050 owing to population ageing. Among those aged 70 years and older, dementia is the second leading cause of disability and the seventh leading cause of death (Organization WH, 2017).

Despite its widespread impact, no effective treatments have been established for dementia or Alzheimer's disease, which accounts for up to half of all dementia cases. Although four drugs are available for Alzheimer's, they do not provide lasting effects. New treatments such as agonistic TREM2 or anti-amyloid antibodies offer a potential for cure by targeting the root causes of the disease. However, these treatments face challenges, including high costs, potential side effects, and the need for careful prioritisation (Belluck, 2020).

Hence, the primary intervention for people living with dementia remains high-quality care. However, dementia care is intertwined with challenging ethical issues that often stem from the complex task of balancing autonomy and best interests while addressing the needs of both the individuals with dementia and their caregivers, and ensuring fair resource allocation amid scarcity (Bolmsjö et al., 2006). Issues arise when fundamental ethical principles such as autonomy, beneficence, non-maleficence, and justice are in conflict (Strech et al., 2013). A study in 2015 showed that 97 % of nursing home staff described ethical problems as a burden, and 81 % asked for more training in how to deal with them (Bollig et al., 2015). While countries such as Norway and the Netherlands have implemented systematic ethics work in nursing homes, it remains uncommon across Europe, where a standardised approach is lacking (van der Dam et al., 2012; Lillemoen and Pedersen, 2013). In particular, there seems to be a lack of involvement of caregivers and people living with dementia in such work (Bollig et al., 2017; van der Dam et al., 2014). The limited attention given to involving individuals with dementia and their caregivers in developing tools for managing ethical issues in dementia care is a notable gap in the current research.

To address this shortcoming, we developed the CARE programme as a model for systematic ethics work in nursing homes, with the active participation of individuals living with dementia and professional and family caregivers (Lauridsen et al., 2023; Skov et al.). Systematic ethics work has been defined as a systematic use of, among other things, ethics education and ethical deliberation in nursing homes to enhance ethics discussions among staff (Bollig et al., 2015). To be relevant to the work experiences of nursing home staff, the CARE programme uses a newly designed didactic approach based on case studies, a shared reading of excerpts from carefully selected literary texts about living with dementia in various ways, and group work inspired by the principles of moral case deliberation and narrative medicine. Narrative medicine emphasises that exploring various types of literature may help care providers better recognise patient narratives, which leads to more empathetic care. By contrast, moral case deliberation suggests that instead of delegating moral deliberation to experts or committees, care providers should engage in discussions with peers about their moral dilemmas to improve their ability to address ethical issues (van der Dam et al., 2012; Charon, 2017).

The primary objective of the CARE programme is to enhance the ethical self-efficacy of nursing home staff, emphasising their confidence in effectively managing the ethical challenges encountered while living with dementia. While the concept of self-efficacy has been used as an outcome measure in studies within the other domains of dementia care (Tonga et al., 2020; Fortinsky et al., 2002), it has not been specifically applied to ethical decision-making in dementia care. The programme's underlying assertion is that improved ethical self-efficacy empowers nursing home staff, fostering greater confidence in navigating and mastering the ethical complexities that may arise throughout the progression of dementia. Greater confidence in managing ethical issues may lead to more effective handling of these challenges (Schou-Juul et al., 2024a; 2024b). Research suggests a general correlation between self-efficacy and positive outcomes (Bandura A: Self-efficacy 2010), but there is currently no direct evidence to support this relationship specifically in the context of ethical self-efficacy.

The aim of this study was to assess the feasibility of the CARE programme and, more specifically, the demand for the programme and its acceptability among nursing home staff and its implementation, practicality, and integration into existing organisational structures in a Danish community-based nursing home setting.

2. Materials and methods

To evaluate the feasibility of the CARE programme, we conducted a convergent QUAN+QUAL mixed-method study where data were simultaneously collected and analysed, giving equal weight to both types of data (Creswell, 2017). The quantitative part of the study consisted of a survey focused on nursing home staff's acceptance of the programme in terms of, among other things, satisfaction, intention to use, and implications for the care of residents. By contrast, the qualitative part consisted of interviews to provide an in-depth understanding of the participants' demand for and acceptance of the programme and its implementation, practicality, and integration (see Table 2).

The study was conducted in collaboration with the Danish Alzheimer Association by an interdisciplinary research group, with the following participants from the National Institute of Public Health at the University of Southern Denmark and Rudersdal municipality: a research manager with a background in bioethics and public health who had extensive experience in working with ethical issues in dementia care [male]; a PhD student with a background in public health science [female] and a PhD student with a background in bioethics [male]; a research assistant with a background in sociology [female]; a student assistant with a background in sociology [female]; and an experienced municipal coordinator with a background in public health science [female].

In the following, we describe the content, structure, and inclusion criteria of the intervention programme, the evaluation framework we used to investigate its implementation, and finally, the methods and strategies we used for collecting and analysing data.

2.1. Content and structure of the CARE programme

The CARE programme aimed to create an inclusive environment in which nursing home staff could engage in guided discussions surrounding ethical issues in dementia care. The programme consisted of two teaching modules, each lasting four to five hours. The modules were structured to include the following components, which are presented in Table 1.

The CARE programme's ethical principles and issues were identified through a three-step process involving bioethical, ethnographic, and literary studies. First, the ethical principles of self-determination, best interest, privacy, manipulation, and dignity were identified from relevant bioethical literature, including those from the ethical framework of principlism by Beauchamp and Childress (Holm, 2001). Next, these principles were organised into a template to guide an ethnographic study that examined ethical issues in dementia care settings across three nursing homes in Rudersdal municipality. The ethnographic study identified several ethical issues, including how to balance care responsibilities between relatives and staff, how to respect the privacy of nursing home residents, and

Table 1

Content of modules 1 and 2 in the CARE programme.

Module 1		
1	Introduction	Introduction to the purpose, background, and organisation of the CARE programme
2	Why do we act as we do?	Introduction to cultural, pragmatic, legal, and moral reasons for acting in specific manners
3	Exercise 1	Group work on how the different kinds of reasons have been used in the participants' daily work
4	Ethics and dementia	Brief introduction to ethics, informed consent in care, and ethical challenges posed by dementia
5	Exercise 2	Group work focused on situations where the participants experienced difficulties with obtaining consent from residents on care decisions
6	Exercise 3	Shared reading and discussion of a literary text about a man with dementia who does not understand why he must take his pills ¹
7	The CARE Analysis Model	A model of how ethical issues arise when the principles of dignity, justice, self-determination, and best interests come into conflict with one another
8	Exercise 4	Shared reading and discussion of a literary text about a man with dementia who wishes to die and refuses to take in drink and food ²
9	Assignment	The participants were asked to use the CARE analysis model to identify situations where they had to make an ethical decision, which would be discussed during the following module
Module 2		
1	Summary	Revisit of what the participants had worked on in the previous module
2	Exercise 1	Presentation and discussion of the participants' own cases
3	Dignity	Introduction to different theories of dignity and dementia care
4	Exercise 2	Discussion of the participants' concepts of dignity
5	Exercise 3	Shared reading and discussion of a literary text exploring a relative's contemplation on the concept of dignity concerning his father during his severe illness with Alzheimer's disease ³
6	Manipulation	Introduction to different concepts of manipulation
7	Exercise 4	Group work focused on the participants' experience with manipulation in their daily work
8	Privacy	Introduction to the meaning of privacy in a nursing home context
9	Exercise 5	Shared reading and discussion of a literary text exploring how a nursing home resident experienced privacy being violated ⁴
10	Summary	Review and evaluation of the two modules of the programme

Literary excerpts from ^{1,3}Frederik Lindhardt, *Pieces of Dad* (2017)

² Kirsten Thorup, *No Man's Land* (2004), and ⁴Delphine de Vigan, *Gratitude* (2019) (our translation of the titles from Danish into English).

how to balance the needs of individuals with dementia with the needs of other residents in the nursing home. Finally, the identified ethical issues were articulated as literary cases derived from a literary analysis of predominantly Danish autobiographical prose, chosen both with attention to literary quality and the author's authentic experience with living with dementia (Lauridsen et al., 2023). These ethical principles and issues identified throughout the initiary studies forms the framework for the CARE programme in Table 1, including the structure and subjects in the teaching programme and the chosen literary texts presented.

Once developed, the CARE programme was tested in the context of the community-based nursing home of Rudersdal municipality in Denmark, a welfare state with free and equal access to health care, including nursing homes.

The two teaching modules of the programme were held at 7-day intervals. They were first pilot-tested and refined in November 2021 and subsequently tested six times in the spring and fall of 2022, with staff participating from four nursing homes in Rudersdal municipality. In total, 14 modules were tested, including the pilot test. Data from these 14 modules are included in this paper. The programme was aimed at equipping caregivers with the necessary concepts to identify, analyse, and address ethical dilemmas in dementia care. The hypothesis was that introducing caregivers to ethical issues through real-life cases followed by group discussions, as artistically articulated through literary excerpts, would enhance their moral sensitivity (van der Dam et al., 2012; Charon, 2017). This approach would improve their understanding of ethical complexities and increase their confidence in navigating such issues (ethical self-efficacy).

The facilitators of the programme were FSJ, PhD-student with a background in bioethics and SL, research manager with a background in bioethics and public health, with the support of the municipal coordinator and a student assistant.

2.1.1. Feasibility framework

To assess the feasibility of the CARE programme, we used components from an analytical framework designed by Bowen et al. (Bowen et al., 2009). This allowed us to assess the participating nursing home staff's demand for systematic ethics work, how acceptable they found the programme, its implementation, and how it could be practically executed within and integrated into the organisational context of the participating nursing homes (see Table 2). Hence, the feasibility framework evaluates five dimensions: Demand, Acceptability, Implementation, Practicality, and Integration, with guiding questions and outcomes for each. The data collection methods were equipped to answer different questions posed by the feasibility framework. While surveys measure acceptability, focus groups and manager interviews provided qualitative insights across all dimensions. This mixed-method approach intends to ensure a comprehensive and reliable evaluation of the intervention.

2.1.2. Participants and setting

The participants and the programme's test setting were coordinated by a local municipal coordinator in collaboration with managers from the four nursing homes in the municipality from which participants worked at. Nursing home managers recruited participants based on the eligibility criteria, which included working day or night shifts at a local nursing home, motivation to engage in the programme, and proficiency in Danish to comprehend ethical issues presented in literary texts. The number of participants in each module and the study size was decided upon based on ensuring sufficient representation across the participating nursing homes while maintaining manageability for the study facilitators and the organizational supporting team. No relationship to participants existed before the study was initiated.

2.2. Data collection

Qualitative and quantitative data were collected during the spring and fall of 2022.

2.3. Qualitative data collection

2.3.1. Interviews

The qualitative data collection was comprised of two types of interviews:

Table 2
Feasibility framework and data collection.

Area of focus	The feasibility study asks...	Outcomes of interest	Data collection method
Demand	to what extent the target group requested the intervention	Perceived demand	Focus group, Interview
Acceptability	to what extent the intervention was judged as suitable and attractive to the recipients	Satisfaction Intent to continue use	Focus group, Interview, Survey
Implementation	to what extent the intervention was successfully delivered to the participants	Degree of execution Factors affecting implementation ease or difficulty	Focus group, Interview
Practicality	to what extent the invention could be carried out within the existing organisational context	The ability of the participants to carry out intervention activities	Focus group, Interview
Integration	to what extent the intervention can be integrated within the existing organisational nursing home structure	Perceived fit with infrastructure Perceived sustainability	Focus group, Interview

- Focused group interviews (six) with staff working in a nursing home in Rudersdal municipality. Four to six staff members participated in each interview lasting approximately one hour. Four nursing homes participated in the study. The focus group interviews were conducted face-to-face at relevant nursing homes in the municipality. Data saturation was achieved.
- Individual telephonic interviews (two) were conducted with the managers of the nursing homes included in the study.

The interviews were conducted, for the most part, within 14 days after the programme's completion but a little longer in some cases. There were no non-participants present in the interviews. In the Results section, focus group interviews are denoted as FG:1, FG:2, and so on, and manager interviews are denoted as M:1, M:2 throughout the paper. To protect confidentiality, any staff names mentioned were pseudonymised. Interviews were conducted by MEB and FSJ.

The interviews followed a semi-structured interview guide, and a separate guide was developed for each of the two types of informants. The interview guides expressed the themes in the feasibility framework, as outlined in Table 2. Both interview guides consisted of questions in the domains of structure (form), content, self-efficacy, the use of literature, implementation and usefulness of the program. However, the interview guides differed in their focus of the specific questions, as the interviews of the managers focused on the managers general and professional insights on behalf of the staff and workplace, whereas the interviews of staff focused on more subjective discussions, experiences and opinions.

The municipality of Rudersdal recruited informants using convenience sampling. In total, 26 participants (one man and 25 women) and two managers (women) were interviewed. Informants were informed about the goal of the study before beginning the interviews.

2.3.1.1. Survey among participants. In addition to the qualitative interviews, we conducted a two-wave survey of the staff participants which received the programme, which constitutes the data the quantitative analysis is based on. The facilitator handed out a paper questionnaire form before the first module was started (pre-intervention) and immediately after the last module was completed (post-intervention). This paper presents the survey data on the participants' sociodemographic characteristics from the pre-intervention study, including age, gender, work-experience in the field and education and 9 items on statements about satisfaction with the programme from the post-intervention study, rating agreement with items from 1 (not at all) to 4 (to a high degree). The pre- and post-intervention surveys also included several items measuring baseline self-efficacy and self-efficacy after the intervention, which will not be reported on in this paper. The complete questionnaire comprised 19 items, including six supplementary questions that assess how frequently participants encounter doubts when addressing ethical issues in their work practices and how they manage these situations. These additional items constitute the validated DemESE scale. The Content Validity Index of the scale for relevance of appropriate items was 1.00 and for item clarity: 0.75. Reliability and validity testing showed a Cronbach's alpha value of $\alpha = 0.89$. For more information on the items on self-efficacy, see previously published papers reporting on the CARE programme (Schou-Juul et al., 2024a; 2024b).

The items in the questionnaire were developed specifically for this investigation. To assess the relevance of the items for professional caregivers, a workshop involving 14 participants was conducted in December 2021. The workshop facilitated discussions on the complexity, relevance, and practical applicability of the items in everyday caregiving scenarios. Participant feedback was instrumental in refining the wording of the items, improving clarity, and ensuring their meaningfulness. The feedback provided enhanced validity of the survey, by ensuring that items were relevant and contextually appropriate. In addition, cognitive interviews, following the method of Willis et al. (2013), were conducted with 10 professional caregivers representing diverse educational backgrounds who were employed at nursing homes in Rudersdal municipality (Willis and Artino, 2013). These interviews provided further insights into the comprehensibility and appropriateness of the items and allowed for the revision and refinement of several items, ensuring that questions were interpreted as intended, improving reliability. The post-intervention survey also included questions about the programme's impact on the respondents' ethical self-efficacy (data will be reported in a forthcoming article).

A total of 113 staff members agreed to participate in the evaluation and completed the pre-intervention survey. Among the pre-intervention respondents, 83.33 % ($n = 98$) participated in the post-intervention survey. Of the respondents who participated in both surveys, 91.84 % ($n = 90$) completed the select items relevant to the feasibility study. Therefore, the quantitative data are based on $n = 90$ respondents. The high response rate in both waves suggests good reliability in terms of consistent participation.

2.4. Data analysis

Quantitative data were analysed using descriptive statistics in STATA. The qualitative data analysis adhered to the six-step framework outlined in template analysis by Brooks et al. (Brooks et al., 2015), which involved (1) familiarising ourselves with the data, (2) conducting preliminary coding, (3) organising emerging themes, (4) establishing an initial coding template, (5) applying the template to additional data and refining it as needed, and (6) finalising the template. The first author conducted an initial reading of the transcripts to gain an overall understanding of the material. Preliminary patterns and themes were identified within two-thirds of the transcripts, with a simultaneous exploration of our pre-conceived themes such as utilising dementia-related literature and the relevance of ethical topics. We pre-identified themes that would likely aid in our analysis and align with our research question. The initial coding template, including the defined theme clusters and their hierarchical relationships, was presented and discussed among the co-authors. The first author then applied the coding template to the remaining third of the transcripts, making minor adjustments as necessary. Subsequently, the final coding template was completed and deliberated upon by the co-authors. Data was coded ad verbatim by SL in the NVivo 12 software which was utilised to facilitate the analytical process and theme management. Transcripts were not returned to informants for commenting.

3. Ethics approval and consent to participate

The study received approval from the research ethics committee of the University of Southern Denmark (Case No. 20/61405). It was compliant with the Danish Data Protection Regulation (RIO Legal Services; No. 11.154), the General Data Protection Regulation (EU) 2016/679, and the principles outlined in the Declaration of Helsinki. Before participation, staff members in Rudersdal municipality were provided written information that their involvement was voluntary and that all data would be treated with confidentiality.

Nursing home managers and staff members provided informed consent before participating in the study.

4. Results

In this section, we report on each theme in our feasibility framework and related sub-themes, presenting QUAN+QUAL data in conjunction with each other (Guetterman et al., 2015). We begin by reporting on nursing home management and staff's demand for ethics education. We then report the results on the acceptability of the CARE programme and its implementation and practicality (see Table 3 for an overview of the themes and the analysis results).

4.1. Characteristics of the participants

The quantitative data are based on $n = 90$ respondents. Most participating staff members were women (93 %), and the mean age was 50 years. More than half of the participants had >8 years of work experience in dementia care (52 %). The participants' most prevalent educational backgrounds were social work and health care (40 %), followed by social work and healthcare assistants (27 %). See Table 4 for an overview of all participants' characteristics.

4.2. Perceived demand for an ethics education program

To assess the feasibility of implementing and institutionalising the CARE programme as a model for systematic ethics work and a means to enhance ethical self-efficacy in dementia care, we first examined the perceived demand for the programme among management and staff in Rudersdal municipality.

4.2.1. Merits of the CARE programme

This investigation of the perceived demand for systematic ethics work revealed that the decision to participate in the CARE programme was made exclusively at the senior management level in the municipality. Consequently, local nursing home management and staff were largely uninformed about the programme's specifics until its commencement. As a result, the staff at these nursing homes were largely unaware of the programme's details before attending its first module, with some having no knowledge of it whatsoever. This lack of awareness echoes findings from previous studies where it has been identified as a significant barrier to the implementation of systematic ethics work (Weston et al., 2005). Consequently, for some staff members, realising their need to engage in discussions and learn about ethical issues in dementia care was unexpected during the programme. For example, one participant expressed mild astonishment upon recognising the multitude of ethical challenges they faced daily, a revelation that had eluded them previously.

Despite the centralised decision-making process, nursing home managers displayed considerable enthusiasm for the institutions and staff participating in the programme. Their enthusiasm stemmed from two primary factors. First, they recognised that the programme addressed an unrecognised and unmet need among their staff, as exemplified in the above-mentioned instance. Second, they perceived the programme as an opportunity to provide valuable on-the-job training in a critical and complex subject matter, which would not only benefit current staff but also serve as an attractive offering for future employees. In this way, the programme could potentially contribute to staff retention and recruitment efforts, thus addressing labour shortages within the sector. One nursing home manager articulated this perspective as follows:

Table 3
Themes, sub-themes, and results of the analysis.

Themes	Subthemes	Qualitative results	Survey results
Demand	Merits of the CARE programme	Valued for subject, staff recruitment, and cross-sectional sharing	N/A
Acceptability	Connecting ethics to practice	Teaching adequacy, work impact, and facilitator appreciation	High satisfaction, intention to implement, and improved patient care and satisfaction with the use of literary texts
	Contextualised dilemmas	Satisfaction with materials, with some too philosophical, valuing group work and facilitator open-mindedness	
Implementation and practicality	Potential for programme integration	Management sees a potential for integrating ethics into the current structure	N/A
	Staff scepticism	Staff sceptical regarding integrating ethics into the current structure, citing a need for cultural change	

Table 4
Participants' characteristics.

(N = 90)			
	n	Mean (SD)	%
Age		50 (11.04)	
Gender			
Male	6		6.7
Female	84		93.3
Years of work experience in dementia care			
0–2 years	21		23.3
3–5 years	13		14.4
6–8 years	9		10.0
>8 years	47		52.2
Educational background			
Social and health-care assistant	24		26.7
Physio- or ergo-therapist	1		1.1
Social and healthcare worker	36		40.0
Medical assistant	2		2.2
Nurse	6		6.7
BA in Social Education	10		11.1
No relevant education	11		12.2

'But there have just been so many valuable insights to bring forward to the entire leadership team and say, "We need to do something," because if we are also going to recruit to a difficult sector, then we need to have some incentives for all of us and especially for the new employees, and I think maybe this program could be it.' (M:2)

This sentiment resonated with more staff members but for slightly different reasons. They also recognised the programme's dual benefits. First, they valued the opportunity to acquire new knowledge and competencies in ethics within dementia care. Second, they appreciated the programme's role as a hub for knowledge dissemination and fostering a sense of community across different work shifts and care facilities within the municipality. One participant encapsulated this in the following statement:

'So, we have talked a lot about how important it is to get some education because we lack so much education in this field here. But we have been really hindered by corona and everything else, right? So this could really give a boost so that we could do something across the board. You just taught us at a workshop, and did it really, really well, right? And it's clear people would like more of this education here.' (FG:3)

4.3. Acceptability of the CARE program

Regarding acceptability of the program, the evaluation showed a predominantly positive attitude towards the CARE intervention. Throughout the post-intervention survey, only a few respondents expressed negative attitudes towards the questions asked. The responses to the survey will be described in the following section, and the specific distributions can be found in Table 5.

Table 5
Perceptions of learning and relevance and impact on ethical decision-making in dementia care.

Question asked	To a high degree	To some degree	To a lesser degree	To no degree
Theme: perceptions of learning and relevance				
I'm satisfied with what I've learned throughout the course.	60 (66.7)	28 (31.1)	2 (2.2)	0 (0.0)
I believe the course's focus on ethical dilemmas in caring for people with dementia is relevant to my work.	64 (71.1)	21 (23.3)	5 (5.6)	0 (0.0)
I believe that the form of the course was suitable for learning how to handle ethical dilemmas when caring for people with dementia.	56 (62.2)	27 (30.0)	7 (7.8)	0 (0.0)
Theme: Impact on ethical decision-making in dementia care				
I believe that the course will generally contribute to better care for our residents with dementia.	40 (44.4)	41 (45.6)	9 (10.0)	0 (0.0)
I believe that the course has given me more knowledge on how to solve ethical dilemmas in my daily work with people with dementia.	30 (33.3)	47 (52.2)	13 (14.4)	0 (0.0)
I have become better at assessing whether a challenging situation in dementia care is an ethical dilemma.	33 (36.7)	44 (48.9)	12 (13.3)	1 (1.1)
I have become better at assessing which ethical considerations are relevant to include when faced with ethical dilemmas in dementia care.	32 (35.6)	51 (56.7)	7 (7.8)	0 (0.0)
I have become better at making good, informed decisions in ethical dilemmas in dementia care.	28 (31.1)	46 (51.1)	16 (17.8)	0 (0.0)

The table is based on N = 90 respondents, and all answers are shown as n (%).

As shown in Table 5, >97 % of the participating staff members stated that they were satisfied, to a high/some degree, with what they learned throughout the programme, and 94 % believed that the focus on ethical dilemmas in dementia care during the programme was relevant to their work to a high/some degree. Furthermore, 92 % thought the programme's structure and characteristics were useful, to a high/some degree, for learning how to handle ethical dilemmas in dementia care.

Moreover, in the questions on ethical decision making in dementia-care, a positive evaluation is prevalent, as illustrated in the second theme in Table 5. Most participants (90 %) believed, to a high/some degree, that the course could contribute to better care for citizens living with dementia. Likewise, most participants stated that the course provided them with better knowledge on how to solve ethical dilemmas (85 %) and that it had made them better at recognising ethical dilemmas (85 %). Furthermore, many respondents reported that they have become better, to a high/some degree, at assessing which ethical considerations are relevant to which ethical dilemmas (92 %) and, overall, have become better at making good, informed decisions regarding ethical dilemmas in dementia care (82 %). These items measuring the programme impact on ethical decision making were based on the respondents self-measured feeling of self-efficacy in their work in dementia care, and representative for respondents' subjective opinions of impact.

4.3.1. Connecting ethics to practice

Numerous staff members highlighted in the interviews that despite the diverse educational backgrounds of the team, ranging from trained nurses to those without relevant formal education, the competency level was satisfactory. According to one participant, the programme effectively bridges the gap between ethical theory and practical application: 'It's precisely that connection that I believe was well articulated. It made one feel that it could be practically useful, guiding us to where we need to focus our efforts.'

This sentiment resonated with several nursing home managers. One manager noted the impact of the programme in the days after each module, observing as follows:

'We hold overlapping meetings every day, and that's where I can hear that suddenly some things are being brought up that maybe haven't been talked about before.' (M:1)

However, another nursing home manager expressed concern that the programme's level might have been 'a bit too advanced for the target audience', suggesting that more practical tools for everyday dilemmas would have been appreciated.

Both the management and staff agreed on the benefit of having external facilitators lead the modules. As one nursing home manager stated, 'I believe that outsiders bring a more objective perspective to these matters. They may not harbour as many pre-conceptions.' Nonetheless, the experience of engaging with university researchers was novel for most participants, eliciting some playful remarks. One manager recounted how an employee jokingly referred to the facilitators as 'university gimmicks', while a staff member noted that one facilitator seemed unfamiliar with the practicalities of their work, joking, 'He's not used to wiping people's behinds.' Despite this, they recognised his ability to structure discussions professionally and effectively, saying, 'He created a fantastic framework for us and guided the conversation in a respectful and grounded manner.'

In a broader sense, the staff emphasised the importance of the facilitators' attitude. They valued the facilitators' curiosity and respect for their work, acknowledging the complexity of ethical dilemmas without seeking easy answers while also steering discussions towards meaningful insights, as exemplified in the following statement:

'I think you've done really well in the first module. You come here, talk to us, try to be curious, and then start the dialogue with us. I think that's really good, so we're not just sitting and talking; I mean, we need to take action. You were curious; it was really good that you came and listened to what we're talking about.' (FG:1)

However, the playful description of the facilitators as 'university gimmicks' subtly revealed some initial hesitancy among the staff. This playful term hinted at a divergence in work culture and what Bourdieu calls 'habitus', the ingrained social structures influencing individuals' behaviours and perceptions (Bourdieu, 2018).

Nonetheless, this divergence in work culture and habitus also had a positive impact on teaching dynamics. Some staff members appreciated that the programme was part of a research project, interpreting it as a validation of the significance of their work in dementia care and a sign of respect. For instance, one participant viewed the presence of researchers as particularly encouraging, believing it reflected a genuine commitment to taking the field of ethics and dementia seriously:

'And then I think it's super cool that you come as a research team. I mean, that's what you do. Because it just shows that attention is being drawn to this area and that work is being done on it. So, I really like that, and that we are then invited to hear about how far you've come and what we need to focus on a little. I think it's great; I like that.' (FG:2)

4.3.2. Contextualised dilemmas

The content of the modules, including the written materials, texts, and facilitation, adhered to the recognised principles for effective continuing education and was tailored to align with the participants' daily practices (Guetterman et al., 2015). The overarching goal was to equip participants with ethical concepts and frameworks that enabled them to analyse, comprehend, and confidently navigate the complex ethical dilemmas inherent in dementia care (self-efficacy).

When asked to respond to the survey question, 'I will use what I've learned in the course in my daily work with dementia moving forward,' 68.9 % of the participants answered that they would do that to a high degree, 28.9 % would do it to some degree, and only 2.2 % would do it to a lesser degree.

The interviews revealed a prevailing sentiment among the participants that the module content directly resonated with their caregiving responsibilities. One participant succinctly articulated this sentiment: 'I find they're all relevant, whether we're talking

about respect or dignity. They're all pertinent in our context, aren't they?' However, despite the overall satisfaction with the breadth of ethical issues covered in the programme, some participants, upon further probing, expressed a desire for more explicit exploration of ethical considerations related to residents' sexuality:

'We have definitely experienced the issue with residents who suddenly found each other, and then sweet music arose, and how we then handled it in the group because we only had one room. And everything that could happen on the bench and how much it pushes our boundaries, and there was really a lot going on, and the family that comes from outside, they say "Stop it," right?' (FG:3)

To contextualise ethical dilemmas within the practical realities of the participants' professional experiences, we opted to use excerpts from literary texts that were mostly authored by individuals closely associated with those affected by dementia. This method, inspired by the field of narrative medicine, allowed us to portray ethical considerations not as theoretical constructs but as nuanced challenges intertwined with the everyday realities of caregiving (Charon, 2017; Felski, 2008). In the survey, 72.2 % answered that to a high degree, 'I believe that it was good to use the short stories to talk about ethical dilemmas.' Of the respondents, 23.3 % responded to some degree, and only 4.4 % responded to a lesser degree. Feedback from the staff equally indicated a general appreciation for this didactic approach. As exemplified by one seasoned staff member:

'There was a text about a person who was "full of days". It was depicted from the resident's perspective, and I found it very relevant to see things from that viewpoint. The text conveyed what we, as health professionals, do when we encounter people who are tired and nearing the end of their lives. It also sparked some important reflections; it related to our job and how we conduct ourselves in it.' (FG:1)

Nevertheless, there was some ambivalence regarding some text excerpts, and some were deemed too abstract or distant from the participants' daily work. In the words of one staff member, some of the texts 'were super relevant and very interesting', while others 'didn't quite fit the level'.

The practicality of the course and its widespread use of group work were mentioned as conducive to relevance, learning, and understanding of ethical issues. Some staff members had previous experience in attending more classic abstract ethics classes, which they contemplated would not have benefitted them in their current work. It was also mentioned that group work facilitated learning and the exchange of experiences across institutions, as participants would often group with people working at institutions other than their own. This paved the way for sharing knowledge among staff from different nursing homes on how to deal with ethical issues and complex patient cases.

'[Participant 1] Well, how the course was structured could benefit everyone here on site. But it's because it was so practical, something that concerns everyone involved in caregiving.

[Participant 2] Yes, there are dementia patients everywhere, even in the somatic units and departments, right?

[Participant 1] I think it's been terrific, and I completely agree that it's so great that it was so practical. That it wasn't just a review of duty ethics and utilitarian ethics. That's a bit of what I remember from my education. I didn't get much out of it, did I? So, it was very practical, and it was easy to understand what one meant when talking about ethical dilemmas and how to argue in them.' (FG:3)

4.4. Implementation and practicality of the CARE program

The idea of the CARE programme has been to design an intervention that is implementable within the current structure of Danish municipalities, that is, both in the short and long terms, to improve nursing home staff's ethical self-efficacy while simultaneously institutionalising a framework for systematic ethics work in terms of an organisational structuring of an ongoing conversation on ethical issues among participating care facilities.

4.4.1. Potential for program integration

The management of the participating nursing homes envisioned that it would be possible to keep the conversation on ethical issues in dementia care going at their facilities by integrating a focus on ethics into their regular team meetings. At these meetings, held every third week of the month, management and staff reported going through incidences that have occurred among residents during the past period. This is a common organisational structure in most, if not all, of the Danish nursing home sector. The idea was that staff could also discuss the ethical dilemmas they encountered in that period. One manager proposed that in this way, they can 'keep the pot boiling' regarding ethical dilemmas in dementia care. Another manager stated as follows:

'I think that it will always be realistic if planned because one can say that we are fortunate to have staff meetings together every third week, so when planning things, one can make changes to things. So instead of having a staff meeting, we have this here. Everything is about planning because a staff meeting is good, but it is just as good to have learning during the staff meeting and create shared learning.' (M:1)

4.4.2. Staff scepticism

The staff members agreed that the team meetings every third week of the month would be the natural arena for continuously focusing on ethical issues in their work. Still, they were also sceptical as to how realistic this was. Some staff members were positive,

and one suggested that the responsibility for selecting an ethical case to discuss at the staff meetings could go around among the staff members, which is a methodology (ethical case deliberation) they learned during the programme. Others were less positive and found the idea of integrating a discussion of ethical issues into team meetings unrealistic. First, their scepticism was based on practical reasons. Team meetings tend to be packed. There are always many items on the meeting agenda; therefore, it would be challenging to prioritise discussing ethical issues. Second, as the participants began discussing among themselves during the focus group interview, a more profound social issue related to the work culture at the care facilities became evident. It turned out that many staff members feared that colleagues who had not participated in the CARE programme would find it strange to engage in discussing ethical issues. They observed an 'invisible expectation' in their institutions that ethical problems do not exist, which led them to believe that colleagues might not feel comfortable opening up and discussing challenging ethical issues, as one staff member put it:

'But I think it has to do with this invisible expectation that there aren't any problems, I mean, dilemmas. And maybe there aren't any overarching ones, but individually, we might still have some dilemmas, but they just aren't—they just aren't brought up in a staff meeting.' (FG:4)

The staff members who were somewhat sceptical regarding integrating ongoing discussions of ethical issues into the existing structure of team meetings thus contended that this would require a change in the workplace culture that is promoted and supported by management, thereby creating a safe space that allows staff to openly talk about, share, and display vulnerabilities and uncertainty regarding how to address complex ethical issues.

'[...] it's also about creating a sense of security in being okay to ask questions to each other and say, "I was in this situation, and I'm finding it difficult, you know. Should I have done this or that? Now I did it this way, and I saw this reaction, but if I had done it like this, could it have been different?" Having an openness to discuss ethical dilemmas requires a lot [...]. It requires psychological safety in a staff group to be able to discuss these things openly.' (FG:1)

In continuation, several staff members mentioned that for mainly two reasons, it would be beneficial if the nursing homes in Rudersdal municipality could participate in a new round of a possibly further developed ethics programme. First, it would be beneficial because it would refresh staff members' ethical competencies and integrate new staff into a culture where ethics matter. Staff turnover in the nursing home sector in Denmark is high. Therefore, as participants in the programme may be quickly replaced by new staff, it is crucial to integrate newcomers into the ethics programme. Only in this way will a continuous discourse on ethics and dementia (i.e. systematic ethics work) be ensured in the municipality.

A more important observation is that staff members also emphasised the importance of involving most, if not all, staff at participating institutions in the programme. The background for this consideration was that during the test of the CARE programme, only selected staff at the participating institutions were invited to participate. However, to establish a 'shared understanding' of how to deal with ethical issues in dementia care and create safe spaces for sensitive ethical discussion, they believed that all staff, including students, should participate in the programme.

'I also think that, as Maja mentioned, maybe some of our other colleagues should join in, so they know what we've been through in this course, and we can talk together. Instead of, as you say, "It's not right here" where we have such a problem. I think the others should join in; that would be good.' (FG:2)

As more staff members explained, it is difficult to promote new perspectives on and concepts for understanding ethical care dilemmas to people who have not been methodically trained in this, especially staff with varying educational backgrounds, including many with no relevant health professional or other relevant education. In such cases, the staff members believed that they would risk meeting a lot of organisational resistance from their colleagues if they tried to introduce conversations on ethical issues. Therefore, they suggested that it would be much better if all participated in the programme because they would have a 'common foundation' and point of reference from which to speak. From their perspective, it was therefore 'really unfortunate that the whole department' had not been involved in the programme.

5. Discussion

Some key quantitative findings from this feasibility study indicate that an overwhelming majority of participants in the CARE programme expressed satisfaction, to a high/some degree, with their learning experience (97 %) and found the programme relevant to their work (94 %). Moreover, a large proportion of participants (90 %) believed, to a high/some degree, that the programme would contribute to improved care for individuals living with dementia, and 85 % felt that their ability to make informed decisions regarding ethical dilemmas in dementia care had been enhanced by participating in the programme.

In the qualitative aspect of the study, both management and staff expressed that the programme addressed a previously unmet need for ethics training. They valued the external facilitation by researchers and appreciated the participation of staff from different nursing homes. They also appreciated the use of cross-institutional group work, which facilitated learning and knowledge sharing across institutions. Staff members welcomed the programme's focus on aligning with their work practices, including, in most cases, the use of literary excerpts to stimulate discussions on ethical issues.

Several studies have highlighted the need for ethical support within nursing homes (Bollig et al., 2015; Preshaw et al., 2016). The approach we utilise, moral case deliberation, has been proposed as a potential framework for implementing systematic ethics practices in nursing homes (van der Dam et al., 2012; van der Dam et al., 2013), offering an alternative to methods such as ethics committees (Libow et al., 1992). Nonetheless, few countries actively incorporate systematic ethics work within their nursing home systems (Bollig

et al., 2017).

Bollig et al. (2015) identified two key models for introducing systematic ethics work in nursing homes relevant to this study. The first model emphasises the education of staff in ethics, which is deemed essential for enabling staff to identify and address ethical issues. As Bollig et al. stated, 'You don't perceive what you don't perceive,' which is why education is a fundamental requirement for working systematically with ethics at nursing homes. The second model relevant to this feasibility study involves establishing facilitated ethics meetings concerning ethical issues at the nursing home (Bollig et al., 2015).

The CARE programme contains elements related to both models of Bollig et al., focusing on educating nursing home staff on ethics and advancing sustained ethics conversations facilitated by management within the existing organisational structure. However, the feasibility study of the CARE programme revealed several barriers to both ethics education and the establishment of ongoing facilitated ethics discussions.

First, regarding the ethics education model, the project's limited budget meant that only a select group of nursing home staff could participate in the CARE programme. This limited participation posed a challenge for conducting broad ethical discussions after the completion of the programme, as most staff members lacked the necessary training and tools. This finding aligns with those of other studies that indicated that limited budgets for education in nursing homes hinder organisational changes, including the implementation of systematic ethics work. As a result, the responsibility for driving change falls on the few trained individuals, which is challenging in resistant work cultures (Doyle, 2009) and because, more generally, 'employees and organisations simply do not like change' (Cheraghi et al., 2023).

Second, concerning facilitated ethics meetings, while nursing home management recognised the programme's potential to integrate ethics discussions into existing organisational meetings, some staff members expressed concerns. They worried about prioritising ethical discussions during already packed team meetings and highlighted the difficulty of discussing ethical issues in a culture where acknowledging problems and dilemmas is implicitly discouraged. This challenge has been identified in other studies that emphasise the importance of culture change and of educating the 'whole nursing home staff' in ethics (Bollig et al., 2016).

Third, several staff members emphasised the crucial role of external facilitation in the success of the CARE programme. While internal resources could potentially be used for ethics education, the specialised nature of the field makes external facilitation necessary, at least initially, to drive the organisational change required for systematic ethics work. This need for external support is particularly challenging in a sector with severely limited budgets. A study on organisational change in nursing homes highlighted how 'restricted financial resources' make it difficult 'to carry out continuous professional education to achieve quality care for older people' (Nilsen et al., 2018).

Thus, the feasibility study of the CARE programme suggests several practical implications. First, the CARE programme constitutes a viable solution to an identified need for systematic ethics work at nursing homes. Secondly, implementing systematic ethics work in nursing homes requires a cultural shift to create an environment where uncertainties and vulnerabilities related to ethical care can be openly discussed. Thirdly, (regular) ethics sessions for all employees are necessary to establish a common framework for deliberating ethical issues in dementia care. Fourthly, at a policy level, the financial constraints on ethics education for nursing home staff necessitate additional resources for staff education, organisational development, and potentially minimum training standards for nursing home staff to ensure the effective implementation of systematic ethics work.

There are now two primary tasks for future research. First, it is imperative to assess the effectiveness of the CARE programme, as an example of systematic ethics work, expanded to address additional aspects such as sexuality, using methodologies such as a randomised controlled trial or realistic evaluation. Second, there is a need to explore strategies for organisational change in nursing homes to prioritise ethical issues in caring for individuals with dementia. This effort should entail examining how central decision-makers, particularly those at the municipal level in Denmark, can collaborate with nursing home managers to champion such changes. In addition, it should encompass the development of comprehensive implementation strategies that actively engage nursing home staff and administration in the process.

5.1. Strengths and limitations

The use of a mixed-method research design in combination with a proven feasibility framework constitutes a strength of this study, allowing for the elucidation and systematic investigation of the essential features of the implementation of the CARE programme. The support of the implementation of the CARE programme by senior management in Rudersdal municipality is another strength that enabled the recruitment of a considerable number of participants to both the programme and data collection. A potential limitation of the study is that nursing home managers and staff were not included in the initial planning of the CARE programme. Moreover, it is a limitation that the senior management of the municipality was not interviewed as part of the study, as this would have elucidated their view on integrating the learnings from the CARE programme into the institutional structure of the municipality's nursing homes. Finally, it is a limitation that the study did not involve a more longitudinal element in terms of inquiring into the programme's implementation after, for example, 6 months.

6. Conclusion

The CARE programme presents a feasible model for implementing systematic ethics work tailored to diverse nursing home staff, leveraging literature discussions, cross-institutional collaboration, and ethical theory informed by narrative medicine and moral case deliberation methodologies. The findings of this study underscore the programme's value in enhancing ethical self-efficacy among nursing home staff. The quantitative results show high satisfaction and relevance, with most participants believing that the programme

improves care and enhances their ability to handle ethical issues. Qualitative insights further highlight the programme's accomplishment in addressing the need for ethics training facilitated by external researchers and cross-institutional collaboration.

However, the full implementation of the CARE programme requires a cultural shift within participating nursing homes, advocating for universal staff involvement rather than selective participation. To achieve this, policy changes may be necessary to allocate more funds for nursing home education and to establish minimum training standards for dementia patients' professional caregivers. This approach ensures that all staff members are equipped with the necessary ethical training, advancing an environment in which ethical discussions and deliberations are integral to the care process. Such comprehensive implementation will help sustain the positive outcomes observed in this feasibility study, which will ultimately lead to improved dementia care and ethical practices across nursing homes.

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Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors used OpenAI to improve the language and readability of the manuscript. After using this tool/service, the authors reviewed and edited the content of the paper as needed. The authors take full responsibility for the content of the published article.

CRediT authorship contribution statement

Sigurd Lauridsen: Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Sofie Smedegaard Skov:** Writing – review & editing, Methodology, Formal analysis. **Lucca-Mathilde Thorup Ferm:** Writing – review & editing, Methodology, Funding acquisition. **Marie-Eva Berg:** Writing – review & editing, Formal analysis. **Anna Paldam Folker:** Writing – review & editing, Validation, Investigation. **Peter Simonsen:** Writing – review & editing, Validation, Investigation. **Frederik Schou-Juul:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

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