

STUDY PROTOCOL

Reminiscing together – Study design of a community based participatory dementia care intervention in two Inuit communities in Greenland

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ABSTRACT

Introduction: This article outlines the study design for the research and development project “Reminiscing together – care development for people with dementia in Greenland”. Longevity is increasing in the world, including Greenland, and the increase in the number of older people brings with it an increase in the number of people living with dementia. Only few materials and care methods are adjusted to or developed in the Greenlandic Inuit context and knowledge about the disease is scarce. In this study we will investigate images of ageing among care workers and how these images affect the day-to-day care work in two nursing homes in Qeqqata municipality.

Methods: We will co-design designated spaces for reminiscence activities for residents in nursing homes and co-create smaller reminiscence actions to be integrated into daily care work. Theoretically we draw on the concepts of Identity and identification from sociology, Reminiscence as practiced cultural history from ethnology and The older person as ‘the other’ inspired by postcolonial feminist theory. Methodologically we will apply ethnographic fieldwork methods including participant observation, in-depth interviews and sharing circles, design thinking and co-design workshops as well as implementation and monitoring tools from promising practices.

Dissemination: The results of this multidisciplinary community based participatory project will be disseminated widely in research and practice through articles, guidelines and instructional videos.

Keywords: Inuit, dementia care, co-design, community-based, participatory, ageing, Greenland.

Abstract in Español at the end of the article

INTRODUCTION

As longevity in Greenland is increasing, so is the amount of people with dementia, but general knowledge about the disease and methods for and culturally adapted tools in dementia care are scarce. In 2011, 254 people in Greenland were diagnosed with dementia [1]. The numbers are inaccurate because few people are assessed and diagnosed in the healthcare system [2, 3] since access to diagnostic expertise varies a great deal depending on where people live [4]. Only recently have the assessment tools RUDAS-test and MiniCog been adapted

to the Greenlandic Inuit context and language [4], but they are yet to be implemented across the country [3]. Despite underdiagnosis, around 25 % of nursing home residents have been referred based on dementia [5] and the number is expected to increase [6]. Many care workers are uneducated [7, 8] and even among educated care workers, specialisation in dementia care is insufficient [7, 9]. Simultaneously, there is a lack of services and activities targeting home dwelling people with dementia and their relatives [3, 10]. Despite political awareness on dementia seen in, for example, the national dementia

conference in Ilulissat in 2021 organised in collaboration between the research and development project Ageing in the Arctic, the Department of Health and the Department for Social Affairs and Justice [10] and the latest national strategy *A good life in old age – Room for manoeuvre, welfare and strengthening the future. Naalakkersuisut's strategy for elders* [11], there is a lack of systematically generated knowledge and practice development of dementia care in Greenland [10, 12, 13]. Dementia is a disease heavily affecting the people with dementia as well as their relatives [13] and deeper understanding, knowledge and locally developed culturally suited tools and solutions are key to improving this area.

Dementia leads to amnesia and behaviour changes challenging social interaction and belonging for people living with dementia [14, 15, 16]. Research on dementia care has focused on how care affects the quality of life for people with dementia [17]. However, studies show that even small opportunities for active mastery among frail elderly people increase feelings of well-being [18, 19]. One approach focuses on the importance of consciously working with different methods and using various stimuli and approaches in working with people with dementia. This can include reminiscence work focusing on involvement of objects, surroundings, sounds, and smells evoking memories [20, 21, 22]. Other methods use artistic means [23] such as music [24, 25, 26]. A growing arena for reminiscence work is special programs and professional training in open-air museums developed and tested in museums in Europe [27] bringing experts of cultural heritage into development of dementia care. People living with dementia that have participated in such programs experience deeper and more detailed memories than people living with dementia in control groups [28]. The Danish Museum Den Gamle By (The Old Town) has a department called The House of Memories offering these kinds of programs for nursing home residents with dementia, home dwelling people living with dementia and their partners, care workers and priests. The program activities take place in an apartment decorated as in the 1950' and 1960s when most of the people living with dementia were young adults. The staff in the House of Memories are specialised in using objects and communicating verbally with people living with dementia in ways that evoke individual memories and leave room for these memories to be shared. Hence, the persons with dementia and partners get to connect with who they are and were before dementia set in and care workers get to know sides of the people living with dementia that can support the care for and identity work with them in the nursing home [28].

Most dementia care research including culture is about Western contexts and how Western culture influences caregivers' perceptions of people with dementia, or how staff or organisational culture can affect dementia care practices [29]. There is little on dementia care in Indigenous communities. In Greenland, the only known widespread reminiscence tools developed in the Green-

landic Inuit context are photo books [30, 31, 32]. One book [30] is structured around themes such as childhood, youth, the home, shopping, holidays etc. Based on the book, thematic posters have been produced and sent to all nursing homes in Greenland. The other two books [31, 32] focus on the life of either men or women.

The project described in this paper contributes to the development of dementia care and to dementia research with a focus on Indigenous culture in relation to care practices drawing on the fields of social gerontology and community based participatory research in the Greenlandic Indigenous communities of Sisimiut and Maniitsoq. In the project named *Reminiscing together - care development for people with dementia in Greenland* we aim to explore how images of ageing are reflected in dementia care in Greenland and how development of culturally specific reminiscence tools and methods can increase the quality of life of people living with dementia and their relatives and help understand the concepts of space and temporality related to postcolonial structures reflected in public care for older people.

Project aim

By combining ethnographic research on images of ageing among care workers with methodological development of culturally suited reminiscence spaces and tools through co-creation in a Greenlandic Inuit context, we want to accelerate Greenlandic dementia research and contribute to the practice of dementia care in Inuit communities for the benefit of people with dementia, their relatives and care workers in Greenland.

The role of older people in Greenland has changed since the first half of the 20th century. While collective narratives and policies often emphasise older people's wisdom and knowledge [33], in practice, older people do not have the same status [34] as for instance Elders in North American Indigenous communities [35, 36]. A study of Inuit Elders in Canada showed that people did not feel old until they could no longer contribute to their community [37]. This witnesses a relational perception of health and ageing where the connection between individual and community is in the centre. While older Inuit in Greenland might not enjoy the same status as Canadian and Alaskan Inuit, they still want to contribute to their community [38]. Dementia challenges the ways older people can take part in community life and contribute in the same ways as they used to before they developed dementia. The rapid modernisation of Greenlandic society has led to people growing old in a world that is significantly different than the world they grew up in. This can make it difficult, especially for younger care workers, to understand and help triggering early life memories of people living with dementia. Furthermore, the increasing age of the Greenlandic population means that dementia is a relatively new phenomenon in Greenland and that knowledge about it is scarce.

The project creates a link between cultural analytical understandings of ageing and dementia as a phe-

nomenon negotiated between medicine, everyday life, past and present to local solutions based on existing local knowledge and healthcare systems. New methods for dementia care developed with care workers and residents in nursing homes within the frame of the project have the potential for dissemination and implementation in all of Greenland and similar communities.

The aim of this article is to present the study protocol of the project including our theoretical framework and our methodology.

Greenland and Qeqqata municipality

Greenland is an autonomous territory within the Kingdom of Denmark. It has a population of approximately 56,000 people. The vast majority—about 89%—identify as Inuit or mixed Danish-Inuit, primarily Kalaallit, the indigenous people of Greenland. The remaining 11% are mostly ethnic Danes and other Europeans, often residing in larger towns like Nuuk. The population is relatively young, but aging trends are emerging. As of 2024, about 10.4% of Greenlanders are aged 65 or older, while roughly 20.8% are under 15 years old. The median age is around 34.5 years. Life expectancy is approximately 74 years, with women typically living longer than men [39].

This project is conducted in collaboration with Qeqqata municipality, located in central-western Greenland. The municipality includes the towns of Sisimiut and Maniitsoq and six villages or settlements. Sisimiut has a population of about 5,500 while Maniitsoq has around 2,500 residents [39]. Like in the general Greenlandic population, the citizens of Qeqqata municipality are mainly Inuit/Kalaallit and the most used language in most spheres of daily life is Kalaallisut while official documents and announcements from the administration is in both Kalaallisut and Danish.

There are two nursing homes in Qeqqata municipality – one in each of the towns. Practical help in the home offered by the municipality for older citizens is available in both towns and in some of the villages. The two towns also have three very active associations for older people. Many people in the two towns are related through kinship and long-term family friendships over generations. Hence, many of the staff in nursing homes also know many of the residents from the community as neighbors, family and family friends.

The authors of this article have worked closely with civil society and the municipality on research and development projects regarding old age and care for older people since 2017 [7,8,38,40,41]. Through long-term and ongoing collaboration and trusting relationship between researchers and community members representing the municipality as well as older people, the topics of research in the field of ageing have been carefully chosen according to needs and interests pointed out by community members throughout the years.

Analytical framework

There are three underlying theoretical perspectives informing the way we approach the project: identity and identification, reminiscence as practiced cultural history, and the older person as ‘the other’. The combination of perspectives allows us to dig deeper into positions and understandings of older people and care workers as well as the interplay between them in the specific cultural and professional context of the two nursing homes based in Inuit communities in Greenland. With its focus on identity, practiced culture and cultural history in reminiscence work, the project is inscribed in the general field of cultural gerontology.

Identity and identification

Perceptions of older people influence practices and planning of care work [42, 43], which is seen in care work itself when care workers’ values and personal images of older people affect the actions of care [3, 7, 44], but can also be seen in public representations of care [445, 46]. An underlying premise for the project is an understanding of identity as described by Jenkins [46] who emphasise that identity is something people do rather than something we are. Jenkins emphasise that much of the time many of us can take identity for granted in the way we understand ourselves and the people in our lives. Other people seem to relate to us in the same way. However, there are a lot of situations where people’s identity is questioned by others related to historical events and political decisions where systems and groups question the identity and legitimacy of other individuals or groups and there are situations where individuals’ identity is stolen with the purpose of scam and fraud. All these affect human experience [47]. Identity work is an ongoing human activity related to the individual as well as to the collective and is about self-identification as well as the identification of others. In this sense identity work or identification can be understood as a mapping exercise helping humans to establish who’s who and what’s what. We categorise ourselves and others to navigate social worlds – a categorisation and navigation taking place on both individual, interpersonal and institutional levels [47]. As such this analytical lens can also contribute to processes of decolonisation since it helps create awareness of different processes leading to specific categorisations of people. This awareness is important in ongoing identity work and decolonisation of care workers, older people, relatives and policy makers in the field of care for older people. As mentioned above, dementia leads to amnesia making an analytical framework of identity work and understanding relevant in this project because memory loss highly impacts one’s ability to engage in identity work on all levels. The framework is also important for the understanding of care workers’ identification of people living with dementia and support for their identity work. All people need to be confirmed in their identity by others including nursing home residents living with dementia. In nursing homes

residents live without their relatives who knew them before they had dementia. This means that the nursing home staff are the ones to confirm the identity of people living with dementia daily based on knowledge of the individual resident's history. They can do that by facilitating that the person can bring out their own memories and identity in meaningful ways and in this way confirm their feeling and understanding of self [48]. Analysis of identification processes among care workers and nursing home residents will guide the project before the intervention, during the co-design of reminiscence areas and care practices as well as during the evaluation of the reminiscence interventions.

Reminiscence as practiced cultural history

Another underlying assumption is our understanding of cultural history as something that is practiced between individual and collective memories, bodily and material experiences, and new and old narratives of identity [49, 50]. The conveyor of cultural history facilitates form and structure of history and in this practice, history as well as conveyance are of understandings of the past and goals for the future [51]. In opposition to positivistic understandings of history, the field of memory and history use emphasise that everyone can be part of the establishment of history since there is no such thing as 'a true or objective history' [52]. Cultural history is related to societal events and power relations but focuses on the history of everyday life and established narratives hereof. Hence, cultural histories are constantly established, destabilised and practiced in new ways [51]. Thus, the practice of cultural history also influences perceptions of older people. Reminiscence activities based on cultural history can support the memory work with people living with dementia and bridge a generational gap when older people share individual memories. The shared memories might tell a different story than the collective history of a hunter society which is often emphasised today. Reminiscence activities and items have the potential to bring out nuances adding to collective history and in this way enrich care workers' understanding of not only the older nursing homes residents' individual stories but also their own knowledge of the near and distant local history. As such cultural historically based reminiscence work works as a way of caring for people living with dementia supporting their challenged identity work related to the dementia diagnosis and simultaneously working together across generations of nursing home residents and care workers on collective identity work that knit past and present together in a shared practice.

The older person as 'the other'

Inspired by Ahmed's theory on 'the other' and feminist post-colonial theory [53], one can understand older Greenlanders as 'the other'. While Ahmed emphasises race and gender as important factors for individuals regarding their ability to follow social and cultural directions [54], we understand age as another such factor.

Ahmed uses concepts such as lines and orientation as analytical tools and explains how people who do not align with dominant expectations become disoriented and can feel out of line [54]. The Greenlandic society has changed dramatically in a few decades to become the universal welfare society it is today. Thus, older people grew up in a society very different from what younger generations have ever known possibly leading to a gap of understanding or lack of identification between older and younger generations. To younger people, elders might represent 'the other' or someone representing a 'strange culture' [55] of the past in a post-colonial colonial encounter. Older people might not follow dominant expectations and will then be disoriented and experience difficulties following the straight lines. We will be guided by Ahmed's understanding of ethics as something involving response to 'the other' in a present that carries traces of the past and is simultaneously an opening to the future [55]. This will help understanding the temporality and spatiality at play in reminiscence work practiced by care workers and people living with dementia in the present. Simultaneously, older people as 'others' might act as connection points in de-colonising processes when sharing their memories, experiences and knowledge from a near past when everyday life in Sisimiut and Maniitsoq was very different from today.

Co-creation across professional and cultural arenas

The project team consists of researchers from Center for Public Health in Greenland at the University of Southern Denmark, staff and residents from the nursing homes Qupanuk in Sisimiut and Neriuaq in Maniitsoq, both part of Qeqqata municipality and, finally, a consultant from The House of Memories at the open-air museum Den Gamle By. The combination of team members with experience and expertise in care-work, nursing homes, Greenlandic Inuit culture, ageing research, reminiscence work and training, ethnography and co-design will secure the relevance of the results for practice as well as for research in social and cultural gerontology and dementia. Majority of the nursing home residents, management and care workers are Inuit, and the researchers are Danish with long-term experience of working community based and participatory in Greenlandic Inuit communities and specifically in Qeqqata municipality. The consultant from the House of Memories is Danish with some experience in working with reminiscence development in a Greenlandic context.

METHODOLOGY

The project is guided by principles of community based participatory research [56, 57] ensuring that the project is continuously relevant, appropriate and useful to the communities it takes place in. It is just as important that topics, methods and results of the research and the development in the project are adjusted to the local contexts in collaboration between the partners and the research participants as it is to disseminate learn-

ings and results to the broader Greenlandic society for others to learn from it as well. Through the long-term collaboration between the researchers and community members representing administration, policy makers, care workers and older citizens, development of methods and knowledge about care for people living with dementia has been expressed as a community need for a long time. The collaboration on different projects conducted over the last decade has given the opportunity to try and adjust various ways of working together and testing different formats of collective data generation with different groups of people for the mutual benefits of all facilitators and participants in activities led by both researchers and community members. Based on these experiences and collaborative relationships in the communities, the methodological points of departure of this project are ethnographic fieldwork [58] and co-creation [59] that are both flexible and sensitive approaches. During ethnographic fieldwork, our main methods will be participant observation and in-depth interviews [60, 61] giving participants the opportunity to be involved in shared worldmaking by engaging in analysis and theorisation of the phenomena studied [62]. We are prepared for research participants to change the ways questions are asked and answered and how the co-design of reminiscence spaces and tools are developed, implemented, and evaluated [63].

Images of ageing

Care workers' perceptions of old age and older people will be examined through ethnographic fieldwork in the two nursing homes over the course of three months including in-depth interviews with > 5 care workers and 4 residents in each nursing home allowing adequate data to give a rich and multifaceted understanding [64]. To explore different perceptions of older people in different generations, it is important that the interview participants among the care workers are of different ages (20-60 years). Participant observation in the two nursing homes at different hours of the day and in different situations and care routines as well as including informal conversations will add to the interview data by showing how perceptions of old age and older people are reflected in the day-to-day care of the nursing home residents. It will be possible to explore values on institutional and individual levels and observe how these come into play in care practices. The combination of observational data (fieldnotes and photos), informal conversations (fieldnotes) and interview data (transcripts) will create a rich data set allowing thick empirical descriptions and analysis of the link between images of ageing and care practices in the specific Greenlandic context. The data will be analysed using reflexive thematic analysis [65].

Co-designing reminiscence spaces

In both nursing homes we will develop and test designated spaces such as a room or a defined area to suit reminiscence work with the nursing home residents. The spaces will be co-designed with care workers, nursing

home residents, researchers and a reminiscence expert from Den Gamle By. We will use design thinking [66] based on participatory research traditions [67] and work with the phases exploring, ideation and testing through various design exercises [67, 68, 69]. Through a series of workshops in each nursing home, we will explore what is already included in daily care for the residents, what is available – materially and non-materially – in the nursing home and in the surrounding community. We will develop ideas of how the space should look and what it should contain as well as how it should be used when it is ready. The workshop activities will be informed by the ethnographic fieldwork and what we learn from that phase about images of ageing as well as about the individual nursing homes' facilities, routines, rhythms, values and images of ageing. Specific exercises and facilitation will be developed in close collaboration with key people from each nursing home that will be recruited during the ethnographic fieldwork. We expect >20 people to take part in the co-design process at each nursing home. The people joining the workshops will be researchers, care workers and residents with and without dementia. The specificity of participants for each workshop will most likely vary depending on the specific staff working and residents' well-being and fitness on the particular day. Our experience with similar processes [40,70] is that different participants have different wishes regarding when, how and how much they wish to participate. Hence the process should be as open and flexible as possible to make participation available and desirable for as many stakeholders/participants as possible. During the workshop, we will produce different materials via the design exercises. Between each workshop, the researchers will analyse the materials and adjust the exercises for the next workshop. Each workshop will begin with a summary of the results from the previous workshop and end with a short introduction to the following workshop to make the whole process as transparent as possible and for collective decisions to be made on an informed foundation.

When we have worked through the design phases, the spaces will be furnished for reminiscence activities adjusted to the Greenlandic Inuit context of the nursing homes. Then the spaces will be tested over a period of approximately 12 months allowing to integrate seasonal activities and various care workers to have time getting accustomed to the spaces and learn how to use them together with the nursing home residents and potentially also with visiting relatives. There will be a follow-up workshop during the 12-month implementation period with the purpose of sharing experiences and adjusting the spaces and use of them.

Reminiscence thinking

The last part of the project is the integration of reminiscence thinking in the daily care work. During co-design workshops we will also discuss possible actions and ways of talking that include reminiscence think-

ing. In this part of the project, we will continue the development of ideas and routines for ways to incorporate knowledge and newly acquired reminiscence tools in the day-to-day care starting from existing resources, structures, and staff. We will use implementation and monitoring tools from promising practices [71] and focus on testing, documenting, and evaluating small reminiscence-oriented actions in day-to-day care. Inspired by process evaluation [72], continuous testing ensures integration of new initiatives in the work along with the process and the effect being evaluated and results and insights being disseminated. This approach allows for many different ideas to be tested and evaluated early on leading to quick decisions on whether to further develop or discard an idea and try a new idea. These small everyday tests will be done by the staff in nursing homes who can share their experiences with colleagues who can join the ongoing tests and developments. Reminiscence actions integrated in the care and documentation and evaluation of them will be developed by care workers in a researcher facilitated process. The facilitation of the process [73] will integrate methodological elements developed in and for the Greenlandic contexts such as, for example, sharing circles [74]. There is a strong tradition of storytelling in Inuit culture [75, 76] and words of wisdom as well as various teachings and pedagogical methods are often passed on and practiced in subtle ways leaving the ‘receiver’ to make their conclusions and interpretations on their own [77]. This means that a straightforward question is not always answered with a straightforward response. It can be answered with a story that the listener does not necessarily understand in connection with the question in the moment. When the listener is ready, has specific experiences or finds themselves in a particular situation, they might remember the story and realise what the message or the teachings in the story were actually about [73]. Building on the oral tradition of storytelling, the sharing circle allows all participants to share whatever they find relevant in the context and for others to interpret what is shared in a way that makes sense for the individual in the situation. In a sharing circle, the right to speak is passed on from one participant to another in a circular movement. The stories or points shared are not discussed, but participants can choose to relate what they share to what others have shared before them (Figure 1).

Ethical considerations

The project will be conducted in accordance with the Declaration of Helsinki and the Danish Code of Conduct for Research Integrity and is registered and approved by The Scientific Ethics Committee in Greenland as well as Research and Innovation Organization, University of Southern Denmark in accordance with the GDPR (EU) 2016/679.

All participants will sign a consent form before participating in the project. The content of the consent will also be explained orally to participants. People living

with dementia experience cognitive impairments and might not remember if they have consented or fully understand what they have consented to. This might make it impossible for them to participate in interviews. However, it is important that vulnerable groups are also given a voice in research regarding their lives and living conditions. Thus, the project will continuously consider perspectives of people living with dementia but will mainly rely on researchers’ observations and on accounts of care workers regarding residents’ experiences with the reminiscence tools and spaces developed in the project. We will get consent from guardians of people living with dementia participating in the study if they are not themselves able to consent. Participants will be anonymised and if necessary, we might create ‘personas’ representing specific themes and matters from the findings to make sure that they are not recognisable in scientific articles and other media used for dissemination. Interviews will be conducted in participants’ preferred language and interpreters will be used during interviews and workshops.

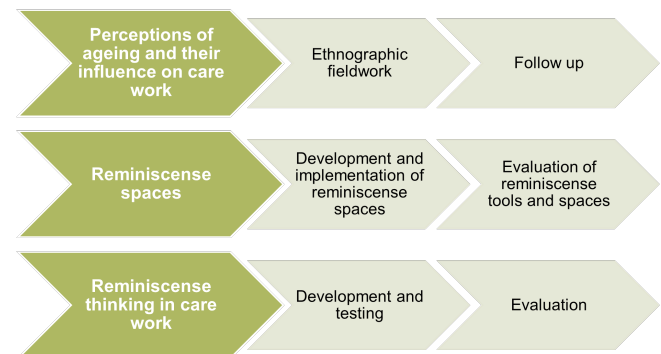


Figure 1. Phase model

Data storage and ownership

Data from the project will be stored at Ilismatusarfik, University of Greenland. Besides, all materials produced during co-design workshops as well as evaluation development and results will be available for all stakeholders. Discussions and development are collective activities belonging to everybody participating. Each nursing home will store materials from their own process and researchers will keep electronic copies of the materials. The nursing homes and the municipality can continue the work and the use of materials as they wish.

Dissemination of results

The results of this project will be of importance to Qupanuk and Nerijsaaq nursing homes and the daily care work taking place with residents. However, we want the results to be usable and inspire other nursing homes and home care units as well as relatives of people living with dementia which is why we will produce different materials guiding others in how to integrate reminiscence thinking in socialisation with people living with dementia and how to develop designated spaces

for reminiscence work. We will produce a guide to integration of reminiscence thinking in daily care practices, 3 short videos on the use of reminiscence spaces and methodological guidelines for developing locally and culturally specific reminiscence spaces and materials. These materials will be produced in collaboration with the nursing homes and will be shared specifically with institutions, municipalities and Department of Social Affairs, Labour Market and Domestic Affairs and will also be available in Greenlandic and Danish online. Key partners participating in the project will be invited to contribute to scientific papers with co-authorships and all participants will be acknowledged in acknowledgement sections of scientific papers.

Conclusion

Knowledge on images of old age and of dementia care in Greenland is sparse. This project will significantly contribute to Greenlandic and international research on ageing and the impact of images of old age on public care work in local healthcare systems as well as development of culturally specific reminiscence tools and methods.

The project will strengthen Danish research in the field of Arctic social science and public health research. The findings are key to improve Greenlandic local healthcare for the elderly in general and dementia care in particular and thereby help improve the quality of life of people living with dementia as well as of their relatives. Further, the findings can inform education, practice, service delivery, and policy as well as research. Practically, the project has the potential to develop new methods for Greenlandic dementia care, and for people in similar communities and disseminate this knowledge nationally to care workers, which has not been done before.

DECLARATIONS

Competing interests

The authors report no competing interest.

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Author contributions

KN has developed the protocol and drafted the paper. SC has contributed to the co-design methods and description of them.

Data availability

Not applicable.

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Henning Lindberg has shared his knowledge and methodological enthusiasm regarding reminiscence work in a museum context. Tenna Jensen has taken part in discussions about the project idea. Participants and presenters from National Demenskonference in Ilulissat in November 2021 have shown us how important it is to make this research and development project happen so we can all learn and share the results across Greenland. Older people and care workers from most towns of Greenland and particularly from Qeqqata municipality have engaged in research and development projects on ageing and municipal care for older people. Our ongoing dialogue with various stakeholders in the field has suggested and supported various ideas, needs and wishes for research in the field for almost a decade.

Indigenous peoples or populations engaged in the study and/or preparation of this paper

As mentioned earlier, the vast majority of the population in Greenland is Inuit/Kalaallit and the same is the case for the citizens of Qeqqata municipality where this project will be conducted. The project is a collaboration between Danish researchers and Inuit community partners representing the administration, care management, care workers in nursing homes and older citizens of Qeqqata municipality. The study design ensures that all partners are equal participants with rights and opportunities to shape the directions of the project along the way. The co-design part of the project is a process where all participants contribute to the process on equal terms.

The project was proposed based on experiences from the research and development project Ageing in the Arctic (2017-2022) which was a collaboration between community members from four Greenlandic municipalities, four research institutions including Ilisimatusarfik, University of Greenland, two Greenlandic ministries, Greenland's National Museum and Archives and many public institutions and civil society organisations as well as other collaborations that followed Ageing in the Arctic. The researchers in this project have worked continuously with Inuit stakeholders of Qeqqata municipality. Hence this project builds on years of trust, collaboration and mutual learning in ways developed with and for the local community. The protocol itself has been developed by the authors who are not Inuit. Future publications about the project will be written in collaboration with partners and participants as the project progresses.

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ABSTRACT IN SPANISH

Recordando juntos – Diseño del estudio de una intervención participativa comunitaria para el cuidado de la demencia en dos comunidades Inuit de Groenlandia

Introducción: Este artículo presenta el diseño del estudio para el proyecto de investigación y desarrollo “Recordando juntos: desarrollo de cuidados para personas con demencia en Groenlandia”. La longevidad está aumentando en todo el mundo, incluida Groenlandia, y con el incremento del número de personas mayores también crece el número de personas que viven con demencia. Existen muy pocos materiales y métodos de atención adaptados o desarrollados en el contexto Inuit groenlandés, y el conocimiento sobre la enfermedad es limitado. En este estudio investigaremos las imágenes del envejecimiento que tienen los trabajadores del cuidado y cómo estas imágenes influyen en el trabajo cotidiano en dos residencias de ancianos en el municipio de Qeqqata.

Métodos: Codisñaremos espacios específicos para actividades de reminiscencia dirigidas a los residentes de las residencias y co-crearemos pequeñas acciones de reminiscencia para integrarlas en el cuidado diario. Teóricamente, nos basamos en los conceptos de identidad e identificación desde la sociología, la reminiscencia como historia cultural practicada desde la etnología, y la figura de la persona mayor como “el otro”, inspirada en la teoría feminista poscolonial. Metodológicamente, aplicaremos métodos etnográficos de trabajo de campo, como la observación participante, entrevistas en profundidad y círculos de diálogo, además de pensamiento de diseño, talleres de codiseño y herramientas de implementación y monitoreo provenientes de prácticas prometedoras.

Difusión: Los resultados de este proyecto multidisciplinario, basado en la comunidad y de enfoque participativo, se difundirán ampliamente tanto en la investigación como en la práctica mediante artículos, guías y videos instructivos.

Palabras clave: Inuit, cuidado de la demencia, codiseño, basado en la comunidad, participativo, envejecimiento, Groenlandia.

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