SDU
University of Southern Denmark

Co-Actors and Inequities in Digital Health from a Nursing Home Perspective

Nielsen, Amalie Søgaard; Grønning, Anette

Published in:
European Journal of Health Communication

DOI:
10.47368/ejhc.2025.201

Publication date:
2025

Document version:
Final published version

Document license:
CC BY

Citation for pulished version (APA):
Nielsen, A. S., & Grønning, A. (2025). Co-Actors and Inequities in Digital Health from a Nursing Home Perspective. *European Journal of Health Communication*, *6*(2), 1-16. https://doi.org/10.47368/ejhc.2025.201

Go to publication entry in University of Southern Denmark's Research Portal

Terms of use
This work is brought to you by the University of Southern Denmark.
Unless otherwise specified it has been shared according to the terms for self-archiving.
If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim.
Please direct all enquiries to puresupport@bib.sdu.dk

Download date: 14. Nov. 2026

EJHC | European Journal of Health Communication

ISSN 2673-5903
ejhc.org

Article *Special Issue on (In)Equalities and (In)Equities*

Co-Actors and Inequities in Digital Health from a Nursing Home Perspective

DOI: 10.47368/ejhc.2025.201
2025, Vol. 6(2) 1-16
CC BY 4.0

Amalie Søgaard Nielsen, Anette Grønning
Department of Design, Media and Educational Science, University of Southern Denmark, Denmark

Abstract
How are digital media used among older people at nursing homes? This qualitative study investigates the use of digital media in healthcare among individuals aged 75 and over who reside in nursing homes in Denmark. Focusing on the essential role of relatives and care takers, the research analyses the challenges faced by older individuals, particularly those without immediate relatives, in accessing and utilising digital health solutions and health communication. Through in-depth interviews and observations, we explore how digital health technologies often fall short of meeting the need for joint use among the older individual, relatives and nursing home staff, which leads to a digital divide that intensifies existing inequities in healthcare access. Our findings underscore the critical need for personalised assistance and support mechanisms to bridge the gap between older individuals and digital health technologies. By highlighting the importance of warm experts, co-actors in health and proxy users, this study offers insight into effective strategies for improving the digital health experiences for residents in nursing homes with the ultimate aim of contributing to more inclusive and equitable healthcare solutions.

Keywords
Digital health, ageing, digital media.

Residents in nursing homes reside there to receive assistance in various aspects of their lives, including support with daily routines, their health management and, as part of that, the use of digital media and communication. At a time defined by fast technological advancement, digital media and communication have become a growing part of healthcare. For older adults over the age of 75, who often have complex health needs, this digital transformation has introduced a new dimension into their healthcare (Van Houwelingen et al., 2018; Vergouw et al., 2020). The

Corresponding author:
Amalie Søgaard Nielsen: amani@sdu.dk

increasing accessibility of digital platforms has not only expanded the scope of healthcare services but has also redefined the dynamics of care provision. At the heart of this transformation is the role of older adults themselves who often become active participants in their healthcare through digital media (Terp et al., 2021). However, several studies show the importance of relatives, neighbours, healthcare staff and other relations in the role of co-actors in (older) adults' use of digital media in healthcare (Andersen et al., 2024; Swane, 2017). This can be as a *proxy user*, which is when someone uses a digital device or service on another person's behalf (Dolničar et al., 2018; Nansen et al., 2015), or as *warm experts*, which is when an (older) adult's relatives help introduce and use a digital device or service (Hänninen et al., 2021; Olsson & Viscovi, 2018).

When someone moves into a nursing home, they are often dependent on others due to cognitive and physical limitations. Sherwin and Winsby (2011) proposed that a resident's ability to act autonomously depends on the affordances available in their environment, social relations, the political and cultural situation, skills and other prerequisites, including media access and use, and on how those affordances relate to the citizen's goals and preferences. In a nursing home, the resident is often highly dependent on another person as a co-actor who is thus included in the resident's communication (Swane, 2017). As such, moving into a nursing home creates a new relational situation for the resident: it limits many choices in the resident's everyday life but also offers new affordances through both caregivers and relatives (Sherwin & Winsby, 2011).

Consequently, studying the use of digital media in healthcare among older adults and its consequences for equity in health calls for broadening the object of study to include more actors than the older adult per se. The aim of this study is to examine the role of the older adults and their co-actors regarding media practices and the resulting challenges regarding equity of care. Hence, we pose the following research questions: How do media practices affect the autonomy of the citizen and health professionals' daily work? And how does this affect equity in health? In this article, we present and discuss findings from our nursing home study with a focus on media practices regarding digital communication in the interaction between healthcare services, nursing homes, citizens and their relatives.

Nursing Homes in Denmark

In Denmark, the societal model has been developing toward a welfare state since the end of the 18th century and the expansion of the welfare state took off in the 1960s (Pedersen, 2024). Hence, in the contemporary Danish welfare state, caring for older citizens is formally not considered a family job but the responsibility of the state, and nursing homes constitute a central part of the care system for older citizens. For many years, a political vision of "longest possible stay in own home" with extended homecare services has been predominant (Platz, 1987), and this has resulted in a 11% decrease in the number of nursing home residents, from 58,000 residents in 2010 to 51,800 in 2022 (Danmarks Statistik, 2022). Moreover, in the public debate, the costs of nursing homes versus the costs of living in one's own home are continuously discussed (see Nørmark & Siggaard, 2016). However, nursing homes still play a significant role in the Danish care system, with 9% of citizens aged 75 years and over and 31% of citizens aged 90 years and over living in nursing homes (Danmarks Statistik, 2022).

The Digital Health Communication Context

Nursing homes are typically public institutions run by local government or self-owned care centres that follow the same rules and regulations as public nursing homes (Hjelmar & Kjældgaard Jensen, 2020). Nursing homes provide a setting in which residents have their own small apartment or room with a bathroom and a kitchenette and have constant access to care from trained healthcare staff. Meals are provided by the nursing home, either in the residents' own apartments or in a common area. Most residents rely on staff members to help them get out of bed and get dressed and for personal hygiene. In addition, some staff members are trained nurses who provide medication to the residents as specified in prescriptions from general practitioners or hospitals (Hjelmar & Kjældgaard Jensen, 2020). The nursing home typically has a dedicated nursing home doctor, who is a local general practitioner that visits the nursing home regularly (Rytter et al., 2015). Most residents use the nursing home doctor, but they may also keep their family doctor or find another general practitioner of their own choice. All Danish residents must be registered with a specific general practitioner, who acts as their primary care physician.

Only citizens with a high level of need for daily help are allocated a place at a nursing home. This means that residents are usually very ill: between 65 and 80% of residents are living with dementia, and more than half of nursing home residents receive treatment for sleeplessness or anxiety (Nationalt Videnscenter for Demens, 2021). In addition, nursing home residents have often experienced many losses, most often of spouses and other close relations, of neighbours and friends and of the routines of a long life (Swane, 2017), and most can be said to live alone (without spouse, friends and family members), even though they are surrounded by others. Residents find themselves in a new setting in which care regarding the body (e.g., healthcare and hygiene) and some of the practical care routines (e.g., cleaning and food preparation) are handled by healthcare staff, while other routines of daily life (e.g., practical matters regarding communication and finances, and togetherness) are left to the residents themselves or are taken care of by their relatives, who live elsewhere.

The Danish healthcare system is largely run by public institutions, all of which use the public digital email system Digital Post as the primary communication platform for citizens. However, by the end of 2021, 27% of citizens aged 75–84 were exempted from use of this digital service, and 59% of citizens aged 85 and older were exempted from use (Epinion, 2023). These citizens receive physical letters rather than electronic messages from healthcare services, including information about new appointments. In addition to Digital Post, the Danish healthcare sector provides several digital services that allow citizens online access to making appointments with their doctor, viewing their medical record or renewing prescriptions by using a national digital ID (MitID). Citizens exempted from use of Digital Post are not necessarily also exempted from use of MitID, but this is often the case.

In addition, all public healthcare institutions and private practitioners have access to the Danish Health Data Net (SDN) which enables secure communication between institutions and is used for, among other things, sending information letters from nursing homes to hospitals when a resident in a nursing home is admitted to hospital or sending letters between general practitioners and nursing homes regarding changes in medication. The provider of SDN also specifies electronic standards for communication which allow different media platforms throughout the healthcare system to interact and enable messages to be sent from one system

to another (MedCom, 2023). SDN is a central part of the political vision of seamless transactions among healthcare sectors.

Modern day nursing homes in Denmark are highly dependent on digital communication regarding the residents, and residents are living in a predominantly digital world in which digital communication is facilitated and encouraged. For instance, 66% of citizens aged 75–84 use the Internet every day or almost every day (Danmarks Statistik, 2023). Moreover, letters from public authorities often refer to additional information that is only available online.

Warm Experts, Proxy Users and Co-Actors

Studies indicate that the cohort of older adults, aged 75 and over, differs significantly from younger cohorts in their technology usage patterns (Olsson et al., 2019). Nonetheless, many older adults have gained confidence in using information and communications technology (ICT) and report improved digital skills over time (Hänninen et al., 2021). However, when we focus on older adult residents at nursing homes, specific challenges become apparent: while the exterior of digital devices has become sleek and user-friendly, their internal complexity has increased. Modern smartphones, for instance, are equipped with numerous functionalities that require navigating intricate menu structures and diverse navigation elements. This complexity poses challenges, particularly for people with limited prior experience with ICT and with cognitive difficulties, and this emphasises the need for assistance (Hänninen et al., 2021; Nguyen et al., 2020).

Bakardjieva (2005) introduced the concept of *warm expert* which denotes individuals who help so-called 'digital immigrants' adapt to technology later in life, persuading them to use common ICTs such as mobile phones, the Internet and social media. Since the introduction of this concept (2005), the landscape of technology and society has transformed significantly. At first glance, it may seem as if technological advancements and the passage of time have reduced the demand for such warm experts (Hänninen at al., 2021) who provide older adults, as well as everyone else, with user-friendly and informative systems tailored to all users. However, as time has passed, a new reality has emerged: the divide has not disappeared but has evolved. Some older adults, especially those who live at nursing homes, with higher risk of age-related cognitive and motor limitations, continue to face challenges in adopting and effectively utilising digital technology. These challenges necessitate a discussion about the risks of digital inequality at various levels, particularly with a focus on the risk of digital inequities in health. Residents in nursing homes come from diverse backgrounds and have varying histories of chronic conditions and illnesses, technological abilities and other factors that contribute to different levels of digital health literacy (Eriksson-Backa & Ek, 2022; Norgaard et al., 2015). They also have different relational situations that significantly impact their use of digital health technologies, and this is the focus of the paper. Bakardjieva's concept of warm experts has been used by Olsson and Viscovi (2018) and Riita Hänninen et al. (2021) to understand the role of (often younger) relatives with a close relation to the older person in the domestication (Silverstone, 2002) process of ICT. The concept refers to relatives of the users of ICT who are considered helpers in the appropriation process and in all the other steps of the domestication process while the older adult is always the central user.

In contrast, the concept of proxy user leaves room for the older adults to actually not touch the computer themselves. This could be due to a lack of skills, lack of willingness or other reasons for the older person to resign from use (Bagger et al., 2023). Nansen et al. (2015)

explore the concept of proxy user within the context of human-computer interaction and Internet studies. They address the increasing complexity of digital media engagement which surpasses traditional distinctions between users and non-users, online and offline, and self and other. In their understanding, the concept of proxy users refers to individuals or entities that mediate or perform actions on behalf of others in the context of digital technologies and the internet. The different forms of proxy use are classified into three categories: enabling, asserting, and inhabiting. Nansen et al. (2015) highlight the diversity of agents, roles, contexts and motivations involved in proxy user interactions. Their research emphasises the ever-evolving nature of digital engagement and the need to move beyond binary classifications of users and non-users to be able to understand how people, including older adults at nursing homes, use digital media in healthcare.

In the context of older adults' use of self-services and communication services in the healthcare sector, it is important to recognise the multifaceted role of their relatives. These relatives play an essential role, acting both as warm experts, as proxy users, and also as co-actors within the digital healthcare setting.

Co-actors in health can be seen as relatives of older adults, who not only assist with technology but also become co-actors in the broader healthcare context. This collaborative role thus extends beyond the digital services and involves active participation in the healthcare journey, including taking on the task of advocating for older family members and ensuring that their healthcare needs are met. Co-actors facilitate communication between the older adult and the healthcare professionals, including translating medical information, asking questions and providing updates (Gerber et al., 2020; Hoffmann et al., 2023). In some cases, relatives physically accompany older adults to medical appointments, consultations or diagnostic tests. Their presence offers emotional reassurance, especially in situations involving diagnoses, treatment decisions or hospitalisations. Their presence can alleviate stress and enhance the overall well-being of older family members.

In addition, co-actors' presence helps bridge potential gaps in understanding or communication (Gerber et al., 2020; Mitchell et al., 2020). Co-actors may also take on responsibilities on a more daily basis in relation to medication management, ensuring that prescriptions are filled, dosages are administered correctly and that any potential side effects are monitored. They may even have an impact on health promoting interventions, such as encouraging the older adult to do exercise or to go to the doctor at certain times (Ho et al., 2022).

In summary, the involvement of relatives in the healthcare journey of older adults, including the digital health communication context, goes beyond being mere caregivers: the relatives play integral roles as warm experts on digital use and as co-actors and proxy users in the healthcare setting and of health in general. Recognising and harnessing the supportive contributions of these family members is crucial for enhancing the digital healthcare experience for older adults and for ensuring their overall well-being in an increasingly technology-driven healthcare landscape (Bonde Nielsen, 2005).

Methods

In the research project 'healthy ageing in a digital world,' we investigate the use of health-related media among the oldest old. Because of the significant number of older citizens living in nursing homes, we included residents in nursing homes in our data.

This sub-study is based on observations at three nursing homes in Denmark (two public and one self-owned) and interviews with five staff members and seven residents (aged 84 – 91). In addition, we interviewed five relatives who helped their family members with health and IT issues. The residents were interviewed once or twice in interviews that lasted from 40 to 90 minutes. This resulted in nine interviews with an average duration of 60 minutes. Participating residents were suggested by staff members. Only residents living with a mild degree of dementia or no dementia were interviewed. Staff members were also interviewed once or twice in interviews that lasted from 17 to 60 minutes. This resulted in six interviews with an average duration of 35 minutes.

The interview guide was based on prior research in media studies and in cultural gerontology and had four overall themes: (1) Establishing where the participant is on the user/non-user spectrum, (2) Specifics of digital media use, (3) Digital media and health, (4) Participation, feelings and experiences in health. The first draft of the interview guide was presented to members of the target group during a group discussion facilitated by the first author. The group consisted of seniors (age 68–88) living alone in social housing facilities in an urban area in Northern Denmark.

All interviews were transcribed verbatim by a research assistant, coded for thematic analysis (Braun & Clarke, 2006) following an interative, open coding process. The process of generating initial codes, creating themes, reviewing themes and defining and naming themes was supported by the software NVivo 14 and conducted by the first author of this paper. Theme names and definitions were discussed by all six research project members of the overall project. In all the interviews, it was evident that the theme of involvement of relatives was significant. This theme was therefore explored further using the concepts of proxy users, warm experts and co-actors described above as analytic lenses. Last step of the thematic analysis, producing the report, was therefore conducted on this theme alone. Written informed consent was obtained from all participants. All names used in this paper are pseudonyms to ensure anonymity.

Relational Autonomy in Nursing Homes

As mentioned in the introduction, residents' ability to act autonomously depends on the affordances available in their environment. Residents' view of their relatives' (often children) use of net-banking on their behalf constitutes one example of a new affordance, as illustrated with this quote from a 91-year-old male resident:

> I do not use a lot of money. Of course. I use money. But it is my daughter who does it. Completely. She withdraws money for me when I have to use some. The bank is informed. (Carl, 91, public Nursing Home 3)

Even though Carl does have digital access to his internet banking, he is never the direct user of the service. Carl's daughter is both a co-actor in finance and a proxy user of Carl's digital banking system, and she takes care of all his financial matters while she visits him, or even when she is at home away from Carl. Carl's autonomy regarding his financial situation relies on his relationship with his daughter and their common practices related to his financial

transactions. Even though Carl lives at a nursing home, the daughter still functions as the proxy user.

A second example is the case of Annelise, a 90-year-old woman who lives in nursing home 3 which is situated on a small island in Denmark. Annelise used to work as a nurse and has lived her entire life on the small island with her husband who passed away four years ago. She has three daughters, six grandchildren and three great-grandchildren. One of her daughters, Hanna, lives nearby and helps her a lot by driving her around to doctor's appointments and so on. Hanna is also Annelise's primary co-actor in the digital healthcare system. Annelise has poor eyesight and rarely touches a computer. She watches TV, which in her case means that she turns it on and listens to the sound of mainly sports matches. She also listens to plenty of audio books, and she has a dedicated audio book reader for that purpose. She handles the audio book reader herself, but she gets Hanna or Hanna's husband to order new audio books for her at the library. Hanna's husband takes care of all Annelise's financial business, and he also receives all Annelise's digital mail from public authorities. Annelise told us about her digital health communication:

> Annelise: They use the computer for all sorts of things. They schedule everything that way.
>
> Interviewer: Do they do anything else for you?
>
> Annelise: Yes.
>
> Interviewer: Do you know what, for example?
>
> Annelise: Well, for example, if I need to see an ear specialist. I just went, and Hanna had scheduled it for me. Also... I have a condition that requires me to occasionally connect with geriatric psychiatry, and I had an appointment with the doctor about that last week. Hanna also spoke to Peter, the doctor, about an appointment. She does that for me.
>
> […]
>
> Annelise: Yes. He [the doctor] is a great guy. He's just so nice and so good. So, I'm really happy with him. I have a conversation with him occasionally. But I'm going to have another conversation with them on December 13th. But it will be over video. And it's with Hanna. We agreed on that last time.
>
> Interviewer: How will you do it?
>
> Annelise: Well, it's from Hanna's computer.
>
> Interviewer: So, she'll bring it here?
>
> Annelise: Then we can see them. And they can see us. And then we talk to each other and ask each other. Talk about what's...
>
> Interviewer: Have you tried it before?
>
> […]

> Annelise: Yes, yes. I've tried that many times. I have. Also with Hanna and the others... […]. We've also tried it with [name of municipality] before. We've tried it maybe three or four times.
>
> Interviewer: And then Hanna just sits beside you? And she makes it all work...
>
> Annelise: (interrupts) Exactly. She makes it all work. It's fantastic that it can be done. I think so. (Annelise, 90, public Nursing Home 3)

Both Hanna and her husband are co-actors in Annelise's digital health communication context and proxy users of the digital services. Hanna takes part in the consultations and all information is therefore shared with her. They also schedule all appointments. Annelise herself is a more passive actor.

A similar situation applies to letters from public authorities, including healthcare services, as illustrated by this quote from an 88-year-old female resident:

> Interviewer: And what about e-boks and letters from the hospital?
>
> Eliza: From the government? I've been able to... But I don't think I'm good at accessing it anymore. And it's nonsense, really...
>
> Interviewer: So, do others do it for you?
>
> Eliza: Yes, one of the kids does it. One of the sons, it turns out. Camilla [the daughter] could also do it, to be honest. But those two are the ones who do it. They check inside the e-boks to see what's there. (Eliza, 86, Public Nursing Home 2)

Eliza also experiences use-by-proxy, that is she uses digital services for interaction with healthcare services and others, but with her relatives as proxy users. This constitutes a difference between digital solutions and analogue solutions: nursing home staff is not allowed to help people access their digital or analogue mail. However, we encounter a difference here:

> When Jane (Nurse, 40 years) arrives, she tells me that an employee distributes the physical mail from the mailbox by the door to the individual mailboxes every day. If there is a letter from the hospital, it is taken and given to the leading nurse. She then takes the letter to the resident and makes sure to open the letter together with the resident. In this way, the staff ensures that the letter is opened and read and does not have to sit in the mailbox and wait for, for example, visits from relatives. (Fieldnotes from self-owned Nursing Home 1)

Physical letters provide a situation that nursing home staff can control to a greater extent compared to digital communication – and control better than most relatives can. One daughter to an 83-year-old man who lives on his own says:

> […] So, it's just because he didn't keep an eye on his physical mailbox. It's not being emptied […] There were also some issues regarding the fact that he had initially opted out of digital mail, and then he had to be re-registered because he hadn't checked either one or the other. (Anja, 53, relative)

The nursing home staff's special role in this matter is underlined by another quote from a staff member at another nursing home, stressing the need to intervene:

> So, the physical mail is delivered to some mailboxes outside the units. Then we distribute it. We have an agreement that if we can see that it is from the hospital, we open it. Because it can be time-sensitive, and if a relative comes once a month, they might not see it. (Mette, 45, certificated healthcare worker (SSA) at public Nursing Home 2)

The staff members feel obliged to ensure communication between healthcare sectors to confirm that residents will attend their medical appointments and are well informed about their healthcare. However, communication about residents' medical appointments can be difficult to handle due to the transition between sectors (hospital, GP, nursing homes, municipalities etc.) and the fact that the information intended for residents is often unavailable to nursing home staff.

Relatives' access to digital information is not without problems, as one interview with a 75-year-old wife to a 10 years older husband who recently passed away reveals:

> She repeatedly experienced her husband receiving public digital mail from parties who should have known perfectly well that he was terminally ill and therefore unable to read the mail. She still read them herself with a bit of guilt, acknowledging that she was actually doing something illegal, according to her own perception and associated advice. (Field notes from interview with Maya, 75, female relative)

Health-related media usage becomes a shared responsibility among staff, residents and relatives, which constitutes a complex situation. Furthermore, when appointment letters are sent through Digital Post, they are not as visible to staff members as physical letters are. This creates additional difficulties as illustrated by this conversation with a certificated healthcare worker at self-owned Nursing Home 1:

> Yes. Yes, yes, but it's also because it's often at inconvenient times. If we're not aware of it, then suddenly a relative shows up. I recently experienced that. I was asked why we didn't wake him up, he needs to go because the relative was driving him. He needs to go to the hospital now, and I've said it twice, and I've been trying to call all morning, but no one's answering the phone. And that's just regrettable, and I can understand her frustration. And it's just so annoying to be in because we seem totally unprofessional. I mean... It's just so frustrating for the citizen, for the relatives, for the hospital... It's a waste of time for everyone. But she had passed on the message, but that was it, it wasn't written down anywhere and then it slipped away. We don't have a... a simple calendar. You have to go in and set up a visit, and that takes a bit of time. It would be much easier to be able to write it by hand. Room 13 is going to the hospital on that day and should be ready at that time. Then I could see it from the morning. Right? And it would have taken a minute to write at most. Yes. So, some of the old ways of communicating. They worked better. (Hanne, 48, healthcare worker at self-owned Nursing Home 1)

Usually, residents are satisfied with their co-actors and proxy users. However, not everyone readily accepts use-by-proxy as a positive solution as illustrated by this extract from a conversation with the 88-year-old woman Claire who recently moved into the self-owned Nursing Home 1:

> Interviewer: Did you previously work with computers?
>
> Claire: Yes, I did. But they [her children] took it away from me.

> Interviewer: When you came here [at the nursing home]?
>
> Claire: Yes
>
> Interviewer: How?
>
> Claire: They did not expect me to be able to use it. But that is wrong. I could have had much joy in using it.
>
> […]
>
> Claire: I used it for sending emails and things like that. And to manage my finances and things like that. But that is over now.
>
> Interviewer: How do you manage your finances now?
>
> Claire: My daughter takes care of it. I am completely incapacitated, let me put it that way. (Claire, 88, self-owned Nursing Home 1)

As illustrated in this conversation, Claire feels sorry about the loss of her computer, and even 'incapacitated'. She feels that she has lost her sense of autonomy and that her relatives use the technology on her behalf without her involvement instead of as co-actors.

These collective case studies illustrate the multifaceted nature of digital health technology users, encompassing older individuals with children, relatives and caregivers, entangled in intricate network of direct and indirect usage and collaborative interaction, surrounding a variety of technologies.

Discussion

Based on the research questions, we see at least two important points of discussion. Firstly, some residents may not have any family or relations to other people whom they can rely on as co-actors in media-related matters, and this implies a potential risk of increased health inequities. Secondly, we must consider the possibility that some relatives may be restrictive towards their older family members and may thus limit their family member's sense of autonomy in their media-related choices and actions.

As to the first point of discussion, staff members may need to involve residents' relatives as proxy users to complete different tasks, e.g., financial transactions (Dreyer et al., 2009), since nursing home staff can only account for a part of the proxy-use, such as reading the physical letter from the hospital, but not the digital aspects. One major risk in such situations is that some residents do not have relations to other people who they can rely on to co-act with them or to act as a proxy. A recently published American study shows that more than 8% of older adults diagnosed with dementia were kinless at dementia onset (Taylor et al., 2023). In terms of relational autonomy, kinless older citizens are not more autonomous than those who have close relations; their web of relations is simply different, and their dependence on healthcare staff may increase instead. When we see many nursing home residents depending on relatives as proxy users of digital media, we may even see that kinless older citizens are limited in their level of autonomy, as that option is not available for them. This contributes to greater inequity in health, as people with a limited social network often face other health problems as well

(Taylor et al., 2023) and it calls for a more structured inclusion of other forms of assistance that build on relations (Andersen et al., 2024).

As to the second point of discussion, relying on and being dependent on relatives is a highly vulnerable situation, even for some of the residents who have a close relationship with their relatives. Sometimes conflicting interests emerge, and the acting relative may make decisions regarding important circumstances (e.g., housing, financial matters or treatment plans) in contradiction with the resident's wishes, thereby compromising their autonomy. The full story of Claire contains several examples of this. Compromised autonomy is a challenge particularly in the light of the Nordic welfare state which endorses the individualistic and autonomous life of older citizens, in contrast to more family- or community-based societies.

Sharing of sensitive health information among older adults and their co-actors becomes an essential aspect of the older adults' digital health communication context. The exchange of personal health data often takes place within the online health portals, mobile applications and virtual consultations where the older individual uses digital technology for their well-being (Wolff et al., 2022). The implications for the older adult are diverse. On the one hand, sharing sensitive health information may lead to enhanced coordination of care, better-informed decision-making and increased support from their co-actors. Increased support can facilitate proactive interventions, early detection of health issues and a sense of empowerment in managing their healthcare journey. On the other hand, however, the act of sharing also exposes the older adults to potential vulnerabilities, including sharing information they consider private, potential misuse of their data, privacy breaches or inadvertent disclosure to unintended recipients.

Conversely, for co-actors, the experience of engaging with their older family members through digital healthcare channels presents its own set of considerations. These relatives are entrusted with the responsibility of safeguarding the older person's health information, often acting as intermediaries between the digital healthcare system and their family member. This role places them in a position of dual responsibility: to support the older adult in managing their health while also ensuring the security and confidentiality of their data. In many cases the digital services are not built for involvement of third parties in a formal and legal way, which leaves the relatives on their own as the supportive part in the system.

Understanding the divergent implications for the older adult and their co-actors is essential for acknowledging the complexities of this evolving digital health communication context. These complexities underscore the need for tailored interventions, educational resources and policy measures that address the specific concerns and vulnerabilities of older adults. Training, inclusive design and increased health literacy may help some individuals use digital media in healthcare themselves (Llorente-Barroso et al., 2023), but this was not the case for the informants in our study. Therefore, the complexities that we have described call for a careful examination of the ethical dimensions of information sharing within the context of digital health communication in which the delicate balance between autonomy, trust, and data security must be preserved (Geber et al., 2021).

Several Danish healthcare technologies are not designed for co-action in healthcare, and the proxy users can therefore not attend the healthcare in legal and ethically sound ways. One way to handle some of this is to use shared access which allows patients to authorise care partners to access their portal accounts with their own login credentials. Shared access can have several implications and has been studied in various contexts. One example is the study by Wolff et al. (2022) of a German healthcare portal during the Covid-19 pandemic. In their paper, Wolff et

al. describe how patient portals played a crucial role during the pandemic by facilitating telehealth, Covid-19 test result communication and vaccination coordination. The focus of the paper is older adults. According to the study, efforts to promote patient portal use have primarily focused on patient engagement but often overlook the involvement of family, friends, caregivers and other care partners who play a significant role in patient care (Wolff et al., 2022). However, care partners' ability to access patient health information is crucial for effective care coordination. The study highlights the importance of systematically involving care partners through shared access to patient portals and discusses policy and practice considerations in expanding shared access.

Shared access offers benefits such as patient autonomy, care partner legitimacy, transparent communication and integrity of patient-generated information. Nonetheless, the adoption of shared access has been limited, often due to concerns about data privacy, complex portal design and low incentives for implementation, according to the study by Wolff et al. (2022). Simplifying registration processes, enhancing awareness and differentiating patient and care partner identities can improve adoption of digital healthcare technologies. In addition, efforts should target vulnerable populations, recognising that care partners are an integral part of the care ecosystem. User-friendly portal design and role-based privacy controls can further enhance usability. Importantly, shared portal access can benefit both patients and care partners and contribute to improving convenience, continuity of care and understanding. As healthcare increasingly relies on digital health solutions and electronic information exchange, involving care partners systematically will become more important. Even though some digital services do have a proxy access, it is up to individual providers to decide and design such a solution. Common guidelines are needed.

Conclusion

The aim of this study was to examine the roles of older adults and their co-actors, including proxy users and warm experts. As described, their roles are highly complex within the context of digital health. We argue that this complexity challenges not only the older adults themselves but also their relatives and the health professionals who take on roles as co-actors, proxy users and warm experts. Furthermore, we argue that the consequences of this complexity, and the lack of helpful affordances when it comes to the systems for the digital healthcare journey, may lead to increased inequity, especially for those who do not overcome their digital struggles. Studying the use of digital technologies in healthcare among older adults and its consequences for equity in health calls for broadening the object of study to more actors than the older adult per se. Hence, we argue that a redistribution of inequality in digital health must be considered, as the roles and circumstances, in terms of digital competencies and responsibilities, may change across the lifespan, both for the older adults themselves, for their relatives, family, friends and for the health professionals.

Moreover, several ethical questions are raised with regard to the grey zone of the relations between the older adults and their co-actors. As mentioned, the involvement of relatives in the healthcare journey of older adults, including the digital health communication context, goes beyond being mere caregivers: the relatives play integral roles as warm experts in digital use and as co-actors and proxy-users in the healthcare setting and in health in general. As shown in our study, this has to do with both structural, organisational and policy levels that are closely

interlinked within the framework of the Nordic welfare model. Therefore, on the issue of responsibility, we need to conduct studies such as ours to bring out more nuances to understand health inequities at a micro level in everyday life.

Ethical Approval

The study was approved by the institutional review board of the University of Southern Denmark, the Research and Innovation Organization (RIO; Journal no. 11638) and conducted in accordance with the GDPR and AoIR's report Ethical Decision-Making and Internet Research.

Funding

The research project has been funded by the Kamprad Family Foundation (grant no 20212004) via SLS in Finland and the Future Challenges in the Nordics Research Programme.

Conflict of Interest

The authors have no conflicts of interest to declare.

References

Andersen, S. B., Skovbæk, S., Lassen, A. J., & Jespersen, A. P. (2024). Støtte i den offentlige digitalisering - *En kvalitativ undersøgelse af digital støtte og digitale støttepersoner i Danmark*.

Bakardjieva, M. (2005). *Internet Society: The Internet in Everyday Life*. Sage Publications

Bagger, C., Einarsson, A. M., Andelsman Alvarez, V., Klausen, M., & Lomborg, S. (2023). Digital resignation and the datafied welfare state. *Big Data & Society*, *10*(2).

Bonde Nielsen, E. (2005). *Samarbejde mellem plejehjemsbeboere, pårørende og personale: En treklang med mislyde?* (Bd. 2). Videnscenter på Ældreområdet.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Danmarks Statistik. (2022). Pleje- og ældreboliger 2022. *Nyt fra Danmarks Statistik*, *2022*, 3.

Dolničar, V., Grošelj, D., Filipovič Hrast, M., Vehovar, V., & Petrovčič, A. (2018). The role of social support networks in proxy Internet use from the intergenerational solidarity perspective. *Telematics and Informatics*, *35*(2), 305–317. https://doi.org/10.1016/j.tele.2017.12.005

Dreyer, A., Forde, R., & Nortvedt, P. (2009). Autonomy at the end of life: Life-prolonging treatment in nursing homes—relatives' role in the decision-making process. *Journal of Medical Ethics*, *35*(11), 672–677. https://doi.org/10.1136/jme.2009.030668

Eriksson-Backa, K., & Ek, S. (2022). The Essential Role of Health Information Literacy in Seniors' Healthcare Communication. I *Information Practices and Knowledge in Health* (s. 71–95). John Wiley & Sons, Ltd. https://doi.org/10.1002/9781119902058.ch4

Epinion. (2023). *Befolkningens oplevelser og udfordringer i et digitalt samfund—Med fokus på ældre*. https://www.aeldresagen.dk/presse/viden-om-aeldre/analyser-og-undersoegelser/2023-oplevelser-udfordringer-digitalt-samfund

Geber, S., Frey, T., & Friemel, T. N. (2021). Social aspects of health communication—Towards a research agenda. *European Journal of Health Communication*, *2*(2), I-IV. https://doi.org/10.47368/ejhc.2021.200

Gerber, K., Lemmon, C., Williams, S., Watt, J., Panayiotou, A., Batchelor, F., Hayes, B., & Brijnath, B. (2020). 'There for me': A qualitative study of family communication and decision-making in end-of-life care for older people. *Progress in Palliative Care*, *28*(6), 354–361. https://doi.org/10.1080/09699260.2020.1767437

Hjelmar, U., & Kjældgaard Jensen, J. (2020). *Normeringer på danske plejecentre: Et overblik baseret på en survey blandt plejecentre – 2019*. VIVE. https://www.vive.dk/da/udgivelser/normeringer-paa-danske-plejecentre-dx3y79vb/

Ho, Y.-C. L., Mahirah, D., Ho, C. Z.-H., & Thumboo, J. (2022). The role of the family in health promotion: A scoping review of models and mechanisms. *Health Promotion International*, *37*(6), daac119. https://doi.org/10.1093/heapro/daac119

Hoffmann, E., Andersen, P. T., Mogensen, C. B., Prinds, C., & Primdahl, J. (2023). Relatives' negotiations with healthcare professionals during older people's admission in an emergency department: An ethnographic study. *Nursing Open*, *10*(9), 6381–6389. https://doi.org/10.1002/nop2.1886

Hänninen, R., Taipale & Luostari, R. (2021). Exploring heterogeneous ICT use among older adults: The warm experts' perspective. *New Media and Society*, *23*(6), 1584-1160. https://doi.org/10.1177/1461444820917353

Llorente-Barroso, C., Abad-Alcalá, L., & Colombo, F. (2023). Communication for seniors' inclusion in today's society: The effects of digitisation on active ageing. *Media and Communication*, *11*(3), 1–5. https://doi.org/10.17645/mac.v11i3.7039

MedCom. (2023). Sundhedsdatanettet (SDN). *MedCom*. https://medcom.dk/systemforvaltning/sundhedsdatanettet-sdn/

Mitchell, J., Hawkins, J., Williams, E.-D. G., Eggly, S., & Albrecht, T. L. (2020). Decoding the role of companions in supporting the health communication of older African-American Men With Cancer. *Journal of Patient Experience*, *7*(3), 324–330. https://doi.org/10.1177/2374373519844098

Nansen, B., Arnold, M., Carter, M., Wilken, R., Kennedy, J., & Gibbs, M. (2015). Proxy users, use by proxy: Mapping forms of intermediary interaction. In B. Ploderer, M. Carter, M. Gibbs, W. Smith, & F. Vetere (Eds.), *Proceedings of the annual meeting of the australian special interest group for computer human interaction* (pp. 294–298). Association for Computing Machinery. https://doi.org/10.1145/2838739.2838789

Nationalt Videnscenter for Demens. (2021). *Stort forbrug af medicin mod angst og søvnløshed på plejehjem*. https://videnscenterfordemens.dk/da/nyhed/stort-forbrug-af-medicin-mod-angst-og-soevnloeshed-paa-plejehjem

Nguyen, M. H., Bol, N., & King, A. J. (2020). Customisation versus personalisation of digital health information: Effects of mode tailoring on information processing outcomes. *European Journal of Health Communication*, *1*(1), 30-54. https://doi.org/10.47368/ejhc.2020.003

Norgaard, O., Furstrand, D., Klokker, L., Karnoe, A., Batterham, R., Kayser, L., & Osborne, R. H. (2015). The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowledge Management & E-learning*, *7*(4), 522–540. https://doi.org/10.34105/j.kmel.2015.07.035

Nørmark, M., & Siggaard, P.F. (16/11-2016). 'Længst muligt i eget hjem' koster kassen. *DR*. https://www.dr.dk/nyheder/regionale/trekanten/laengst-muligt-i-eget-hjem-koster-kassen

Olsson, T., Samuelsson, U., & Viscovi, D. (2019). At risk of exclusion? Degrees of ICT access and literacy among senior citizens. *Information, Communication & Society*, *22*(1), 55–72. https://doi.org/10.1080/1369118X.2017.1355007

Olsson, T., & Viscovi, D. (2018). Warm experts for elderly users: Who are they and what do they do? *Human Technology*, *14*(3), 324–342. https://doi.org/10.17011/ht/urn.201811224836

Pedersen, J.S. (2024). Den digitale velfærdsstat. Syddansk Universitetsforlag.

Platz, M. (1987). *Længst muligt i eget hjem: En undersøgelse blandt ældre i Odense*. Socialforskningsinstituttet.

Rytter, L., Hellebek, T., Mink, A., & Sørensen, P. T. (2015). Lægebetjening af plejecentre ved praktiserende læger. *Ugeskrift for Læger*. https://ugeskriftet.dk/videnskab/laegebetjening-af-plejecentre-ved-praktiserende-laeger

Sherwin, S., & Winsby, M. (2011). A relational perspective on autonomy for older adults residing in nursing homes. *Health Expectations*, *14*(2), 182–190. https://doi.org/10.1111/j.1369-7625.2010.00638.x

Silverstone, R. (2002). Complicity and collusion in the mediation of everyday life. *New Literary History*, *33*(4), 761–780. https://dx.doi.org/10.1353/nlh.2002.0045

Swane, C. E. (2017). Gamle menneskers mediehverdag på plejehjem. In C. L. Christensen & A. Jerslev (Eds.), *Ældre mennesker i et mediesamfund* (pp. 96–129). Frydenlund.

Taylor, J. S., Figueroa Gray, M. S., Mar, C. M., Crane, P. K., Kariya, H., Freitag, C., Taneja, P., Ramaprasan, A., Shell Duncan, B., O'Hare, A. M., Berridge, C., Vig, E. K., Wheeler, S. G. B., Thakral, M., Hawkes, R. J., & Larson, E. B. (2023). Kinless older adults with dementia: Qualitative analysis of data from the adult changes in thought (ACT) study. *The Journals of Gerontology: Series B*, *78*(6), 1060–1072. https://doi.org/10.1093/geronb/gbad030

Terp, R., Kayser, L., & Lindhardt, T. (2021). Older patients' competence, preferences, and attitudes toward digital technology use: Explorative study. *JMIR Human Factors*, *8*(2), Article e27005. https://doi.org/10.2196/27005

Van Houwelingen, C. T., Ettema, R. G., Antonietti, M. G., & Kort, H. S. (2018). Understanding older people's readiness for receiving telehealth: Mixed-method study. *Journal of Medical Internet Research*, *20*(4), Article e123. https://doi.org/10.2196/jmir.8407

Vergouw, J. W., Smits-Pelser, H., Kars, M. C., Van Houwelingen, T., Van Os-Medendorp, H., Kort, H., & Bleijenberg, N. (2020). Needs, barriers and facilitators of older adults towards eHealth in general practice: A qualitative study. *Primary Health Care Research & Development*, *21*, Article e54. https://doi.org/10.1017/S1463423620000547

Wolff, J. L., Dukhanin, V., Burgdorf, J. G., & DesRoches, C. M. (2022). Shared access to patient portals for older adults: Implications for privacy and digital health equity. *JMIR Aging*, *5*(2), Article e34628. https://doi.org/10.2196/34628

Author Contributions

Conceptualisation (main idea, theory): Amalie Søgaard Nielsen & Anette Grønning
Funding acquisition: Anette Grønning
Project administration: Anette Grønning
Methodology (design, operationalisation): Amalie Søgaard Nielsen & Anette Grønning
Data collection: Amalie Søgaard Nielsen
Data analysis: Amalie Søgaard Nielsen & Anette Grønning
Writing – original draft: Amalie Søgaard Nielsen & Anette Grønning
Writing – review & editing: Amalie Søgaard Nielsen & Anette Grønning

Author Biographies

Amalie Søgaard Nielsen is postdoc at the Department of Design, Media and Educational Science, University of Southern Denmark. She holds a PhD in public health and has been working with different aspects of difficulties in use of digital media in health.

Anette Grønning is associate professor at the Department of Design, Media and Educational Science, University of Southern Denmark. Her research interests include analytical aspects of digital communication such as participation, affordances, and social presence.