Digital Inertia: A Qualitative Study with a Caregiver Association Network About Informal Caregivers' Non-Use of IT Applications

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Abstract. Informal caregivers, crucial contributors to healthcare, face myriad challenges in supporting individuals with health needs. While IT applications offer promising solutions, some caregivers hesitate to adopt them, favoring traditional communication approaches with healthcare and support providers. This study, conducted in Sweden, presents why caregivers are reluctant to use IT applications. Through a qualitative approach involving group interviews with caregiver association members, four key themes emerged, namely, need for in-person support with grief and stress, need for private support spaces, cognitive impairment, and financial constraints. Understanding these barriers is crucial for developing inclusive caregiving strategies that balance IT-based solutions with in-person assistance, promoting a sustainable caregiving support ecosystem.

Keywords. Informal caregiving, non-use, IT applications, caregiver associations

1. Introduction

Informal caregivers are individuals who provide care to their relative suffering from a disability or an illness for a duration of time that goes beyond the usual care in the relationship [1]. Informal caregivers, hereby referred to as caregivers, play a crucial role in assisting with health needs supporting the well-being of patients at home. These caregivers can be spouses, children or parents of care recipients and may provide care for conditions like Parkinson's, dementia, cancer, stroke or other illnesses. They must be acknowledged for their critical role in healthcare [2] as they are essential for maintaining outpatient care for their relatives [3]. Supporting caregivers helps prevent burnout and significant health impacts they may experience, ensuring their well-being [4].

In recent years, integrating Information Technology (IT) applications has emerged as a promising avenue for supporting caregivers in their caregiving roles. These IT applications encompass a wide range of tools and platforms, including mobile apps, web-

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based platforms, and wearable devices, designed to assist caregivers in managing various aspects of caregiving [5]. From medication management to accessing educational resources, IT applications offer convenient and accessible support to caregivers.

Despite the potential benefits of IT applications, a phenomenon known as digital inertia – the reluctance or delay in adopting and using digital solutions despite their availability and potential benefits – remains prevalent among caregivers, a key aspect this study seeks to explore further. Inertia refers to the resistance or hesitation towards the adoption and effective use of new digital technologies due to many reasons [5]. Recent studies have suggested that caregivers may find it difficult to integrate new technologies into their established caregiving practices [6]. Studies also emphasize that there is a need for solutions to be tailored to the diverse preferences of caregivers, including considerations for gender, and diversity [6]. Moreover, caregivers need to understand how the technology works and how it can benefit them in their caregiving role [7]. Technologies perceived as adding to the caregiving burden are less likely to be adopted [7]. Caregivers have diverse preferences when it comes to technology and factors such as accessibility and familiarity of use are important to influence their decision to adopt technology [7]. These factors may collectively affect the seamless integration of these technologies into daily practices. Hence, this study addresses why caregivers may not use IT applications, as reported by caregiver support organizations in Sweden. To devise a sustainable solution for caregiving, we must gain insights into the reasons behind caregivers' inertia to use IT applications. By comprehending these factors, we can effectively balance IT-based solutions and in-person support for caregivers. This approach ensures that caregiving strategies are inclusive and adaptable to caregivers' diverse needs and preferences. Integrating technological and interpersonal approaches can create a sustainable and effective caregiving support ecosystem.

2. Methods

This study employed a qualitative research approach using a group interview with members of caregiver associations in Sweden. This study received approval from the Swedish Ethical Review Board (Dnr: 2021-03656). Four members from caregiver associations participated in a semi-structured group interview. Specifically, two participants were affiliated with Anhörigas Riksförbund (National Association for Relatives), while the other two were associated with the local rehabilitation department in Sweden. These associations provide information and support to caregivers across Sweden. All participants have 10+ years of experience in supporting caregivers. They were asked about the needs and challenges of caregivers, including any pandemic-related issues, support services they provide to caregivers with(out) using IT applications. The semi-structured group interview was conducted via a video-conferencing platform and was audio and video recorded. The interview was facilitated by an intern and the primary researcher in Swedish and English. Finally, the intern transcribed the recording verbatim and translated them into English. Inductive thematic analysis was employed to analyze the data [8]. The lead researcher thoroughly reviewed the data multiple times to become familiar with it, noting any emerging ideas. An initial set of codes was systematically created relevant to the research aim. These codes were then analyzed to identify broader themes. The broader themes were further reviewed and refined to ensure their relevance to the research question, with quotes linked. The most significant themes were selected

and defined. Finally, these themes are described in the results section, including the researchers' interpretations and illustrative quotes.

3.   Results

Four themes emerged as reasons caregivers did not prefer IT applications.

3.1.   *Need for In-Person Support with Grief and Stress*

Participants conveyed that some caregivers preferred in-person interactions with healthcare professionals to address their grief and manage stressful situations encountered during their caregiving journey rather than relying on technology-mediated approaches. They emphasized the significance of human connection in navigating emotional challenges, underscoring the belief that the personal touch offered through in-person interactions is invaluable. When many support services transitioned to online platforms during COVID-19 pandemic, many caregivers were hesitant towards virtual engagement. This reluctance stemmed from a deep-seated preference for the comfort and reassurance derived from direct, interpersonal contact with healthcare professionals, especially when grappling with complex emotions associated with caregiving and grief. Despite the convenience and accessibility of digital alternatives, caregivers strongly desired the warmth, empathy, and understanding that can only be conveyed through face-to-face interactions.

"We started up Walk and Talk groups, so that you are outside. And then we mixed people regardless of caregiving problems, and the results are actually very good! Because you connected with each other with this- so this with the guilt, this with the anxiety that you put it at that level. It was a good dynamic in the group. And they seemed to like it better than being online." [Member of Rehabilitation department]

3.2.   *Need for Private Support Spaces*

Participants in the study emphasized the need for caregivers to have open conversations about their caregiving experiences, including discussing frustrations related to caregiving tasks, care recipients, and relationship dynamics. Caregivers wanted to speak freely without worrying about being overheard by other family members or their care recipients. This need for privacy underscores the importance of creating confidential spaces where caregivers can seek support and guidance without fear of judgment or intrusion. Moreover, caregivers providing care to children with Attention Deficit, Hyperactivity Disorder (ADHD) often needed to step aside to care for their children or ensure they didn't get into harm's way, making it difficult to find a suitable environment for therapy sessions online. The constant need to monitor and attend to their children posed a significant obstacle to accessing online counseling services, as caregivers struggled to find the privacy and focus necessary for therapeutic interventions. This challenge was further exacerbated when caregivers lacked additional support from family members, leaving them solely responsible for the care and supervision of their children.

"For some parents it was online instead, but many parents who have home-based children as care recipients so to speak, they can't sit in psychological sessions and talk when the children are around, so therefore it became an obstacle when it came to a

video. But I think for example children with autism who can be quite hyperactive or so then they simply often can't sit alone. So, it has been based on the fact that they have been able to get away and come to us so that they can have privacy and the opportunity to talk." [Member of Rehabilitation department]

3.3. Cognitive Impairment

The study's participants also emphasized that some caregivers may have cognitive impairments, which can be a barrier to using IT applications. This issue is pertinent among older adults, who may experience challenges navigating technology due to age-related cognitive decline. The concept of digital exclusion becomes evident in these circumstances, where individuals encounter difficulties in engaging with digital platforms and applications due to cognitive limitations. This exclusion impedes their access to essential resources and support and exacerbates feelings of isolation and dependence.

"There will be a digital exclusion. People suffer from cognitive impairment without suffering from a dementia impairment that makes you may not be able to use the digital." [Member of Anhörigas Riksförbund]

3.4. Financial Constraints

Participants also disclosed that some caregivers may encounter financial constraints, which could hinder their access to IT applications. This revelation sheds light on an essential aspect of caregiving dynamics: Financial limitations hinder the adoption of digital tools. The inability to afford necessary technological resources, such as a laptop or the inability to pay for an app may prevent caregivers from fully leveraging the benefits of IT applications in their caregiving responsibilities. This disparity in access underscores broader socioeconomic disparities that impact caregivers' ability to utilize technology for support and assistance.

"It will always and always be, well, it will be the case that not everyone is digital. Both that you don't have the capacity to use the digital, but also that it requires resources, financial resources to be part of the digital." [Member of Anhörigas Riksförbund]

4. Discussion and Conclusions

Our study illustrates digital inertia among informal caregivers, highlighting the barriers to IT application adoption. One limitation of this study is the small sample size, with four participants. This limited number of participants may not adequately capture the diversity of experiences and perspectives. Consequently, the findings should be interpreted with caution. These barriers reflect broader themes identified within the healthcare technology adoption literature. The preference for in-person interactions over digital solutions, when requiring emotional support, underscores the value of human connection. Recent literature highlights preference for personal over digital communication in sharing personal health data with caregivers and others [9]. The need for private support space in terms of being able to share their experiences and concerns without being overheard by their family members or care recipients is also emphasized. Recent literature has also highlighted the importance of confidentiality of information, ensuring caregivers can communicate and seek support without fear of judgment or intrusion [9]. This indicates

that not all caregivers may prefer to use technology-based support during their caregiving journey. Cognitive barriers to technology adoption, especially among older caregivers, were emphasized in recent literature, too. They highlight a reluctance among older caregivers to use digital health services due to physical and cognitive decline [10]. This suggests a critical need for accessible and user-friendly technology solutions that accommodate caregivers' cognitive and technological proficiency spectrum. Financial constraints underscored by participants point to broader socioeconomic factors influencing technology adoption. Video consultations, financial and educational barriers significantly impact the willingness and ability to engage with digital solutions [11].

In conclusion, our findings call for exploration into the synergy required between in-person and technology-based support for caregivers. Future research should investigate the potential of hybrid support ecosystem that integrates the strengths of digital and in-person support, potentially mitigating factors contributing to digital inertia. Further efforts are required to develop inclusive caregiving strategies balancing IT-based solutions with in-person assistance, promoting a sustainable caregiving support ecosystem.

Acknowledgment

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