Collaborative Futures: A Technology Design Approach to Support Living Well with Dementia

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ABSTRACT

This paper presents insights into Younger Onset Dementia (YOD) offering clear differentiation in the circumstances, needs and challenges of people with YOD from those with late onset dementia. We point to opportunities for the potential role of digital technology to improve the experiences of people living with YOD. This is important because while HCI has long engaged with dementia, these efforts have been predominantly focused on designing technologies for elderly people experiencing dementia. In particular, this paper highlights concerns raised by people with YOD which have significant impact for HCI researchers when engaging people with YOD in research and in technology design. As such, this paper argues for a broadening of HCI research to include YOD and to rethink current research and design methods in 'dementia and technology' settings.

CCS CONCEPTS

• **Human-centered computing → HCI theory**; General and reference~General conference proceedings

KEYWORDS

Younger onset dementia; YOD; design; digital technology; collaboration; human rights; co-researcher.

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1 DEMENTIA AND YOUNGER ONSET DEMENTIA (YOD)

Dementia is not one specific disease. It is an overall term that describes a wide range of symptoms affecting the brain [22, 41]. These symptoms vary from person to person and involve a slow deterioration in memory, sensory challenges, changes in thinking, judgement and behavior that impacts the ability to perform everyday activities [41]. In Australia, dementia is the second leading cause of death overall [11, 12] and has surpassed heart disease as the leading cause of death in women [2].

In the past, impaired memory was thought to be a natural and expected part ageing [17], with Alzheimer's disease (the most common cause of dementia symptoms) being a so-called 'old timer's disease' [16]. However, the direct association between dementia and the ageing process is no longer true [41]. Dementia also affects younger populations in their 30s, 40s and 50s. Younger Onset Dementia is an emerging trend both locally and globally [11, 36] and is classified as having symptoms of dementia under the age of 65 years and 50 years for Aboriginal peoples [37]. This paper presents information about YOD, highlighting the significant differences of YOD from the more well-known late onset dementia. In addition to this, we argue that HCI could extend existing research and design methodologies to develop better understandings of the people living with YOD. The deliberate focus on YOD in this paper is not to negate those living with late onset dementia, rather it is to draw attention to the unique situations, needs, challenges and opportunities of the younger onset group. This paper describes some of these similarities and differences, and offers a fresh perspective for the HCI researchers and designers to consider when supporting living well with dementia.

2 TECHNOLOGY DESIGN AND DEMENTIA

Most research efforts to understand dementia focus on addressing the medical and socio-economic impacts of the condition [11, 44] and mainly on those living with late onset dementia. While medical research is keen to develop pharmacological interventions and improve diagnostic methods [26], governments and organisations have conducted widespread research to grasp the socio-economic impacts of dementia. From a local perspective, it is estimated that dementia will cost Australia $14.67 billion in 2017 [1]. Again, most economic reports are concerned with the negative impacts of dementia in the late onset dementia group [31, 42]. There are very few population-based studies on the

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epidemiology of YOD [34] and the complexity and impact of YOD is still coming to light. One literature review [35] looked at the development of support services and found significant gaps in understanding the impact of YOD. This report [35] called for more accurate and up-to-date estimates to assist in the service planning required to address this gap. Further review of literature showed the contributions from the non-HCI communities such as; Psychiatry, Nursing, Social Science and Disability sectors have mainly addressed the safety and independence challenges in dementia [6, 8, 9]. In terms of technology, these non-HCI sectors are offering valuable technical solutions for cognitive, physical, emotional support and social engagement [30, 33].

Human–Computer Interaction (HCI) researchers have also been highly engaged in the dementia setting for some time designing digital technologies to support people with dementia and their caregivers [13, 24, 25]. However, like the non-HCI research areas most of this work has focused on people with late onset dementia; designing technologies to support safety outcomes through monitoring and surveillance which enable people with dementia to maintain independence longer. The emphasis on safety and monitoring was also seen on systematic review of literature where researchers looked at the trends and gaps to guide future research efforts in dementia care [18]. In this work, the authors found that the most common theme was safety devices, with many of the assistive technologies being used to specifically address ‘ease of living’ and not focusing on the social aspects of quality of life.

Some examples of technology use with dementia are GPS tracking [8, 25], used widely to track activity of those with the more advanced stages of dementia and wearable technologies [10] such as a smartwatch which provides insights into the daily activities of a person with dementia. This has allowed caregivers the ability to monitor and improve the health and safety of an elderly person with dementia. This technology goes a long way in supporting those in the more advanced stages of dementia, however there are more immediate issues and challenges to address for those living with younger onset dementia - before surveillance measures will be required. These challenges will be broken down and discussed in *Section 3: People Living with YOD.*

Whilst providing critical safety support, the monitoring devices highlighted above, could also be seen as intruding on privacy and freedom. This raises ethical and human-rights issues that need to be addressed, particularly in the area of YOD. One difference is that people living with YOD are generally in earlier stages of life and the physical and cognitive abilities and disabilities vary greatly to that of a person in the later stages of life. Instead of surveillance and monitoring technologies, Arntzen, et al. [6] recommends that technologies for the YOD group should (i) address practical, emotional, and relational challenges; (ii) fit well into, or be a better solution for, habitual practice and established strategies; (iii) generate positive emotions, and become a reliable and trustworthy tool; (iv) be user-friendly, adaptable, and manageable; and (v) interest and engage the family carers [6]. With this in mind, digital technologies have been developed by HCI to engage people with dementia and their carers through music and reminiscence [19, 32, 43]. For example, to facilitate engagement, touchscreen devices such as iPads [20] were configured to support interactions; being tactile, versatile and very simple to use, the apps make it easier to play accessible games/puzzles and help improve memory and interactions. They are found to be suitable for use for those with more the advanced symptoms of dementia [4]. In addition to designing digital technologies for use in the dementia setting, HCI researchers are working directly with people living with dementia and their caregivers to develop research design guidelines [29, 32]. For example, one study describes how caregivers and family members could assemble a life story of the person living with dementia using a digital multimedia system [13]. While these HCI research efforts with digital technologies and dementia are highly encouraging and making valuable contributions, they are still primarily focused on addressing the needs of an older person living with dementia [9] and often the carer is acting as a proxy for the person with dementia. This approach needs to be adapted for those living with YOD.

3 PEOPLE LIVING WITH YOD

There are both differences and similarities in how dementia is experienced between YOD and late onset dementia. One major difference is the life-stage of the person with YOD. Being diagnosed with dementia at 30, 40 or 50 years of age creates a different paradigm in dementia care from that of late onset dementia. Key examples are that all people with YOD are of employable age (by definition under 65 years), many might be the main income earner and some will be a parent of young children [34]. People diagnosed with YOD are generally fit and in good physical health. This, together with their marked age differences, makes their integration into mainstream dementia services extremely difficult [6, 44]. Consequently, people with YOD often fall outside the age limits of aged care services and are deemed as not meeting the criteria for care. The lack of age-appropriate support and services, greatly increases stress on the caregivers, family members and on the healthcare system. There are diagnostic delays associated with YOD and misdiagnosis as it is hard to imagine a younger person might have dementia [5]. Many people with early symptoms of YOD have been initially diagnosed with stress or depression [37]. This, coupled with a lack of support services are impactful events on the lives of a person with younger onset dementia; more so than that of the late onset dementia [17, 37, 44]. As such, the carer of a person with YOD will face higher levels of anxiety, depression and marital problems than carers of older people with dementia [6].

3.1 The YOD Experience and Technology

Receiving a diagnosis of YOD is often unexpected and can be a shock as the person with dementia who is suddenly having to make sense of their world, not as they have known it, but how they are yet to experience it [27, 30, 33]. The traditional view of people with dementia was one of a loss of self, an erosion of the mind. A view that the person has somehow disappeared. In more recent years, this has been challenged, particularly the notion of the complete loss of self [23]. Researchers looking at this more closely suggest people living with dementia are still people with a unique life; with feelings and personalities all of which interact with the neurological impairment of dementia [15].

Research by the social and health care sectors has significantly contributed to understanding the YOD experience, mostly from a quality of life perspective, yet still not to the same extent as late onset dementia. A literature review by Greenwood and Smith [22] on the experience of YOD, found that accounts of the YOD experience are rare when compared to those in late onset dementia. The authors concluded the experience of YOD goes beyond those of older people living with dementia resulting in an even greater negative impact on their lives. Their recommendations included providing interventions to facilitate peer support to allow people with YOD to engage in meaningful activity. This is valuable information, however, more empirical research needs to be conducted to strengthen these insights and better understand the lived experiences of YOD and the carer [6].

In terms of YOD and technology, most of what we are learning about the use of technology in their everyday lives is coming from popular media; such as online blogs, social media outlets and documentaries. This hints at opportunities for HCI to understand the nuances of YOD by fostering direct and strong research collaborations with people living with YOD.

However, we are aware of a need to first explore 'how' we can ethically engage people with YOD in research. This is especially so, given that our current understandings are drawn from review of limited literature and social channels mentioned above. We know this is a complex area of research and having to answer a lot of questions regarding the ethical considerations in our *University Ethics Application for research with people living with YOD,* further reminded us to tread carefully before launching into research. So, the first author chose to attend the 2017 Alzheimer's Disease International (ADI) Conference in Kyoto, Japan. The goal was to learn more about YOD, talk to both researchers in the field and those living with YOD and hopefully make contacts to pave the way for the research.

3.2 Alzheimer's Disease International (ADI) Conference, 2017

ADI is the world's largest and most important conference on dementia and Alzheimer's disease with scientific and non-scientific content about the latest advances in dementia care. The ADI conference focuses on medical research, however, there were several sessions that dealt with technology, e.g., "Disrupting Alzheimer's: Global Opportunities for Technology". This session presented ideas and solicited discussions on opportunities for technology to create solutions for people with Alzheimer's and related dementias and their care partners.

In 2017, there was a strong representation at ADI of people with YOD from around the world. One keynote speaker being Kate Swaffer. Diagnosed with YOD at 49, Kate is Chair, CEO and Co-founder of Dementia Alliance International (DAI), Member, World Dementia Council, Board member and SE Asia Regional ambassador. Kate spoke about the "systematic and gross underestimation of the capacity of people with dementia" [41].

3.2.1 Impact of stigma and language. There were several key messages from the YOD representatives. Issues were raised surrounding the stigma they experience with a YOD diagnosis and how the inappropriate use of language in communication can reinforce this stigma. People with YOD do not want to be known as 'sufferers' or seen as a 'burden'. They fiercely reject the word 'demented' given the negative connotations this symbolizes. They are seeking opportunities to "live well with dementia, not just die from dementia" [21]. Alzheimer's Australia has written Dementia Language Guidelines to promote consistent use of appropriate language. The words chosen to talk and write about dementia can have a significant impact on how people with dementia are viewed in the broader community.

3.2.2 Human Rights. The key global YOD advocacy body at ADI was **Dementia Alliance International** (DAI). DAI is a NFP organisation, with membership exclusively for people with dementia from around the world. This organisation is widely accepted as 'the global voice of dementia'[14]. DAI achieved a landmark moment in 2016 with the adoption of rights-based approach to dementia care by ADI; this included access to the United Nations Convention on the Rights of Person with Disabilities. What this means is, that people living with dementia are legally entitled to be included in any policy or process that affects them - not just consulted or represented by others in matters that concern them directly [14]. People living with YOD have expressed that they want to be included in all work that concerns their future. DAI has adopted the philosophy of "Nothing about us, without us" [14]. While there has been valuable work in the area of supporting personhood in dementia [39] this could extended to include the variation in needs, abilities and circumstances of those with YOD as described earlier. To understand these perspectives better, I (first author) made appointments to follow-up with speakers from ADI to talk to them further and better understand their concerns and goals. These conversations reinforced the goals and aspirations shared at the ADI conference for 'inclusion and independence'. It was said by keynote speakers from DAI that dementia has a "beginning, middle and end". People living with YOD are asking to be seen as more than just the condition of dementia. They have asked to be seen as "whole people", as they were before a diagnosis often enjoying careers in areas such as; Teaching, Research, IT, Healthcare and Law. HCI have an opportunity here to support these collaboration goals, particulary as interest in the area of dementia and role of digital technology grows [3].

4 RETHINKING HCI RESEARCH AND YOD

The explorations presented above show the lack of empirical research to develop deeper and richer understandings of how people with YOD experience their everyday lives and where technology is being used to support their day-to-day experiences. From our investigations, we understand that information on the YOD experience is mostly generated through popular media channels. We know that researchers need to support a human rights approach when researching in the area of dementia, and better understand the experience of YOD. What we learned is that they are very different from elderly people living with later onset dementia in their health status, stage of life, career aspirations; they have younger families to consider and so on. While there might be cognitive decline, many people with YOD are high functioning, independent and actively engaged with life. Their trajectories and aspirations are vastly different from their older counterparts. We also expect that people with YOD are likely to be more digitally literate than those older adults with a limited technology repertoire, this is not to say that being digitally literate is exclusive to younger adults. We base this assumption on age-related uptake of technology in the general population [28]. As suggested in conversation with the YOD community, technologies designed and employed at the YOD stage may well continue through and have greater benefits than 'adopting' new technologies at later stages of dementia. However, in HCI we have yet to develop a nuanced understanding of the ways people with YOD are currently using digital technologies. It is fairly safe to point to out that technologies designed for people with dementia, including those in care institutions, will not be appropriate for the relatively independent people with YOD. From what people living with YOD are saying, and their concerns with human rights raised at the ADI conference, technologies for surveillance and monitoring (e.g., [7, 22]) are unlikely to be accepted.

What we argue instead is for HCI researchers to develop deep understandings of the lived and felt experiences of people with YOD. We need to first understand how people with YOD are adapting, utilising and using digital technologies to support and mediate their lives, practices and interactions with friends, colleagues, family members, carers and how this in turn shapes their daily experiences. Establishing such understandings on the YOD experience and the role of technology will provide HCI researchers insights into designing digital technologies that are more useful in supporting positive experiences. In other words, how can digital technologies be designed to provide people with YOD the opportunities "to live well with dementia" as asserted by the DAI organisation?

4.1 From Participant to Collaborator

Besides deeply rich and sensitive qualitative and phenomenological studies of the lifeworld of people with YOD, our current exploration has revealed the need for HCI to explore and to formulate appropriate research methods and approaches when researching people with YOD. Currently, we do not believe that there is a suitable approach within HCI. Designing with an elderly person living with advanced dementia may involve methods that can act as a proxy for a person with dementia, allowing designers to gain experiences and insight as to what it is like to provide care for and live with this person. But this is not necessarily the case with YOD.

Given their unwillingness to be seen as 'sufferers', the HCI design approach should steer away from reinforcing the stigma around YOD (directly or indirectly). This can be achieved by taking a more positive approach that recognises the heterogeneity of people living with YOD and their unique experiences. Future research efforts should include developing a richer understanding of the YOD experiences and supporting their values, goals and aspirations to live well with dementia. In other words, as Shirl Garnet states, people with YOD demand to be recognised as *"living with dementia not dying from it"* [21]. Although we agree with the efforts proposed by Vines, et al. [38] to include 'vulnerable' people in research, perhaps people with YOD, who are still independent, may not see themselves or wish to be seen as being vulnerable? We would like the HCI community to explore this notion further. Similarly, while there is a strong ethical component in what Waycott, et al. [40] proposes, after our explorations, we do not believe people with YOD would want to be seen as soley as being part of research in sensitive settings, being couched as vulnerable and marginalised. Approaches that portray a person with YOD as a 'sufferer', 'patient' or as 'vulnerable' [38, 39] would not be appropriate. In addition to this, we would propose supporting the inclusion of more positive language in ethics applications where dementia is classified as being one homogeneous group. This has broader implications with regard to informed consent and when working with a person with YOD that need to be explored.

Designing with/for people with YOD calls for more tailored research methods by HCI that take a human-rights approach. An approach that recognises the heterogeneity of dementia and the uniqueness in the expression of dementia symptoms for each person; understanding that dementia affects not only memory, it can affect language, behaviour, mood and sensory perception. As such, we need to evolve current HCI research methods to better address these aspects of dementia. Future researchers should also be mindful of the language used in all forms of communication As the Alzheimer's Australia language guidelines highlights [7], when interacting with a person with dementia, we are encouraged to use positive and empowering language. Approaches that portray a person with YOD as a 'sufferer', 'patient' or as 'vulnerable' [38, 39] would not be appropriate.

5 CONCLUSION

We strongly believe that HCI can develop tailored research methodologies that would be more inclusive of people living with YOD. However, we need to first address the challenges raised in this paper and deal with the vulnerability for both the person with YOD and the researcher. We need to better understand the associated stigma specific to YOD, their call to maintain self-hood and to take a human rights approach at all stages of the research and design process. This will certainly require new ways of thinking. We need to better understand how technology is currently being used in YOD which will require adapting the current research methods and probably creating new ones. Whatever it is, we believe that this can only happen through close collaboration with those living with YOD. Through this, we hope that HCI can better design digital technologies with, and for, those living with dementia to support them to live well and experience life more positively.

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