

Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers

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ABSTRACT

The design of assistive technology is dictated by the narratives surrounding a particular impairment and its impact on one's life. This in turn affects the perceptions of the users – both the role of technology as well as their own sense of identity. In the case of those with a mild cognitive impairment, a precursor to dementia, home-based technologies that are disability and change focused shape the identity of the very people they are to help – reifying their dependency and their loss of self. With this study, we set out to better understand the narratives of people living with a mild cognitive impairment as well as their partners that live with them and provide care. Within this investigation, we uncovered the predominance of a disease-focused narrative – one that laments loss of identity and the struggles of daily care. However, we also uncovered a different narrative centered on the role of technology to provide support within the dyads' life. These technology narratives were evidence of a need to support the biopsychosocial aspects of autonomy for both parties and improved relationships. We use our findings to further discuss the driving force behind design goals for home-based technologies for those with a mild cognitive impairment.

CCS Concepts

• Human-centered computing→Empirical studies in HCI • Human-centered computing→Accessibility • Social and professional topics→Seniors

Keywords

Cognitive impairment; Dementia; Home-based technology.

1. INTRODUCTION

For those with a cognitive impairment, technology has typically aimed to improve a care recipient's memory and cognition [3] prevent their falls [7], or generally protect the vulnerable care recipient [7, 44] through close monitoring via sensors [8], [11] and assistive technologies [20, 22, 24]. Likewise, caregiver-based technology solutions have focused on the burdens of caring for someone with cognitive impairment [1, 21, 43, 48], including characterizing the caregiver as the second invisible patient and attempting to improve their quality of life through mobile applications that aid in connecting to peer support [4, 33, 45, 48]. In this regard, the problematization and solution for technology interventions has been focused on the medical, declinist, and disease mod-

el driven view of cognitive impairment [46]. In other words, the care receiver is often seen as deficient and in need of help while the caregiver is shouldering a burden and needing relief.

This framing in the development of new technologies ultimately is apparent to the users of that technology [19, 35, 50]. A declinist perspective is not lost on both the care receivers and caregivers and so this technological framing, in turn, affects how the person with cognitive impairment and the caregiver sees themselves, their role, and their relationship to one another. In essence, technology based on the medical model reifies an illness narrative held by the impaired and their caregivers and even may elevate it to a prominent place in their daily lives [35]. Over the long term, such a framing can have consequences on one's quality of life through a loss of one's autonomy, which does not promote a very person-centered perspective [46]. Technology that is framed by the medical model is a pervasive concern in the ASSETS community and has spurred the exploration of other models for technology design. For instance, a social model focuses its efforts on obtaining access, reducing oppression, and supporting activism [35]. These alternative frames can in turn produce technology that shapes the personal and social narratives one may have of the impact of their impairment and their place in society and relationships.

Our study was motivated to identify the potential of a model for framing the design of home-based technology for those with a progressive cognitive impairment and their spouses that serve as a caregiver. This is ultimately in hopes of creating technology that elevates one's personhood and provides a realm where technology improves the narratives of care in the home leading to a better quality of life. We set out to do this by first investigating the narratives that the population holds – both in their daily lives, but also in technology's place in those narratives.

In the following paper, we present evidence from our interviews with older adults with mild cognitive impairment (MCI) and their caregivers. These interviews revealed how the disease narrative view was prevalent in how caregivers and care recipients defined their experiences, expectations, and relationships. However, when the pair discussed the benefit of technology in the home to be used by both actors, the discussion moved to one of opportunity for *autonomy* and *safety* for both actors. This change in perspective reframes the role of the caregiver and care recipient from one of managing burden to that of recognizing opportunity – from an Illness Narrative [39] to a Biopsychosocial Narrative [23]. From these findings, we discuss how this can manifest in different forms of technology support in the home. One that can complement the current illness narrative-led design motivation – thus, not eschewing it completely – but, rather one that can inspire new technology directions for the home to offset the predominance of the illness narrative.

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2. RELATED WORK

2.1 Models for Design

Within the ASSETS community, there has been a shift in how to think about and design for disability or impairment. Mankoff et. al [35] began this discussion with literature from Disability Studies as a lens to critically reflect on the work in assistive technology. In particular, they argued that the model that a researcher or designer holds had a determining effect on the technology that was designed as well as the way it was evaluated. Consequently, they highlighted the technology may have negative consequences on a user's life experiences. For instance, the *medical model* of disability can be oppressive and lead to ostracization and segregation. And, importantly, any technology resulting from this mindset, no matter how much the designers think they are coming from a helpful place, is ultimately complicit in feeding these negative outcomes.

The medical model of aging is a fairly prominent viewpoint in the HCI and ASSETS literature, specifically. There is a tendency to view aging and any age-related disease as experiencing some form of deficit and that the role of technology is to alleviate the effects of that deficit. Carroll et. al [10] highlighted this problem in the assumption that older people are living in isolation and technologies are needed to connect them to family and friends. However, Carroll points out that this is often not the case and older adults currently play key roles in communities.

But this medical model dominates much of the studies of older adults and, in turn also dominates the body of knowledge that HCI researchers draw upon in their framing of technology support. Vines et al's [50] discourse analysis of 644 SIGCHI-venue papers also highlighted the framing of technology as solving the "problem" of aging. It is difficult to blame technology designers as there is much to be desired by this framing. Focusing on one's physical and functional limitations provide actionable challenges and a mechanism to show measurable results [35]. However, Vines et al [50] highlighted how a turn away from a medical model allows for the individual to define for themselves what successful aging is and how that may provide the needed sense of worth in the face of any illness or challenges.

As an antidote of sorts to the medical model, Mankoff et al. [35] highlighted the benefits of a *social model* that may allow for a designer to turn their attention away from "fixing" the individual and instead address the problems of access, oppression, and activism. This in turn highlights the need to care for the individual as a person and putting the power of leading that care in the hands of the individual with the impairment. Mankoff et al.'s social model was further termed the *social creationist* model by Frauenberger [19] to better distinguish it from the post-modern *social constructivist* model. The latter model's focus is instead on how language is used to define what is a disability and how that does or does not open up a space for one's disability to be viewed as a form of "normal".

Frauenberger [19] expertly pointed out, though, that all of these models are reductionist in nature. They see disability as being defined and best addressed by one factor and, so, the technological solutions guided by these models are too one-sided. Frauenberger [19] attempted to put forth a philosophical position to address the dichotomy between the medical model and social models of disability. The *critical realist* model that he puts forth argues that it is not fruitful to be fixated on conceptualizing disability as either determined in the biological condition or as a purely social construct. This dichotomy simply leads to technologies that

either focus on individual support or attempt to change the environment. He instead argues for a multi-layered and interactional conceptualization of disability, which addresses multiple aspects of the disabled experience: the biological, the psychological, the psychosocial and emotional, the cultural, and so on, all at the same time. This creates a need for a problem-solving approach that has aspects of both the medical and social models, particularly because the experience of those with a disability and those who care for them is multidimensional and diverse [19].

Finally, Lazar et. al [31] recently built on this epistemological turn and argued for the *critical dementia* perspective in design for those specifically with dementia-related impairments. This framework recognized people with cognitive impairment as making meaning in a contextualized and social manner, engaging in similar physical and embodied interactions that display meaning, responding to and participating in the world through sensory experiences, and continuing to engage in emotion and affective experience. Thus, very much a perspective that engages in technology design for both intrinsic and extrinsic values as Frauenberger argued for.

All of these models can inform how HCI researchers engage with the experience of those with cognitive impairment and ultimately how technology design can be focused in its fulfillment of user needs [31]. What is not clear is how these models relate to the lived experiences of those with dementia. To better understand this lived experience, we turned our attention to the literature on Life Narratives that are both a product of experiences as well as a shaping force on one's lived experience.

2.2 Life Narratives

Although the Models for Design outlined above are useful for conceptualizing and designing for the disability experience, how one views themselves and how others view and treat them is encompassed in one's Life Narrative. Multiple components of identity including, personal, social, illness, and their story lines make up an individual's experience. In the gerontology literature, these components are referred to as "narratives" – the way one frames one's experiences as well as how their world is being framed by others [9]. As individuals, we all have narratives in which we conceptualize our lives and our relationships, however with the introduction of an illness or in this case a cognitive impairment diagnosis, one's narrative can significantly change. There is a dominant issue of identity, and how that may change and transforms for those with the impairment as well as those around them or who care for them – for example labeling from "normally functioning" to "cognitively impaired" and from "spouse" to "caregiver". A new diagnosis alters the relationship between the person, how they view themselves, and how they view their surrounding world. This leads to the attempt of "reconstructing" one's life story [52]. In order to make sense of what is happening, to give meaning to this disruption, the newly diagnosed individual is forced to direct their attention and efforts to rebuilding their identity after diagnosis, in the framework of this new life [26] – this is facilitated and evidenced by the narratives they hold and share. The person has to work to reconstruct their narrative in order to understand their illness in terms of past social experience and to reaffirm the impression that their life still has meaning and purpose [52]. This narrative view is less about the factual account and more about understanding how an individual makes meaning that they live by after a diagnosis. Similar to the models in disability discourse and assistive technology, there are two narratives that are prominent in the gerontology literature that can be applied

to those with a physical or cognitive impairment: the illness narrative and the biopsychosocial narrative.

The *illness narrative* is a story a person tells and significant others retell to give coherence to the disruptive events that have had an effect on the family system and all actors in it. This typically results in a narrative of loss and change that can be overwhelming for all people involved. The individuals with cognitive impairment see themselves as well as are seen through the lens of their illness, which identifies them based on condition, disease and diagnosis [47]. Such views position those with cognitive impairment as “objects” of their illness rather than “participants” in it [13]. If this narrative persists, it becomes difficult for the person to maintain their sense of identity and self-esteem, which should continue to be maintained for as long as possible. Fostering ‘personhood’ and psychosocial factors of dementia is essential to care [15].

The *biopsychosocial (BPS) narrative* can provide a more accurate and complete picture of the experience of the individual with cognitive impairment. The BPS narrative is a holistic approach to care that brings empathy and compassion into medical practice [5]. Its main pillars include self-awareness when caring for someone with an illness, active cultivation of trust, empathy, forming a therapeutic relationship and communicating in order to foster dialogue not just medical application of protocol. This model fosters a more productive emotional climate between patient and clinician [5]. We extend this narrative framework to our work with caregivers and care recipients, specifically couples. By shifting the illness narrative to one that is more positive, supportive and constructive, a biopsychosocial narrative can provide opportunity for the dyadic interactions to not only be viewed as influenced by the stressors of change, but also as an opportunity for a positive outcome. Seeing dementia as a social process full of opportunity helps one understand the role of experience of memory loss rather than giving prominence to the disease [23]. If technologies used early on in the disease cycle – i.e. while the care recipient is still able to remain in their home – can be designed to shift the narrative from that of illness to that of biopsychosocial success, then we can support and enhance the lives of all actors in the family system going through this disruptive process.

3. METHODS

As it is often the goal in HCI studies to generalize, a typical user study does not consider the “universe of one” of those dealing with a progressive cognitive impairment [36]. The deficits experienced by those with cognitive impairment are often highly variable and prohibit attaining generalizability, and so those of us who are interested in working with this population should consider the best methods to approach such studies. Because of this, building relationships with the dyads was critically important for our study and we employed empathy as a defining characteristic of our research [53]. “Knowing the user” and understanding the shared experience of the dyads starts with a conversation, particularly building “empathy through dialogue” [53]. Methodologically, HCI has adopted several qualitative approaches for eliciting experiences in order to understand the user in the design process, including interviews, narratives, scenarios, simulations, and role playing [3].

Mulvenna et.al [40], discuss that it is imperative that voice is given to both the caregiver and care-recipient with dementia in order to gather the most appropriate, user centric data from technology studies. This approach to technology studies and dementia have

led to a more person-centered or “emotion oriented” method that focuses on the individuals suffering from the disease and uncovering their experiences *as well as* those caring for them. Thus, an integral part of these interviews was to consider the caregiver-care recipient as a unit as opposed to separate entities. The sense of identity of the person with cognitive impairment is a product of the dyadic caregiver- care recipient relationship, which is both dynamic and multidimensional [51].

3.1 Participants

For this study, we focused on individuals with mild cognitive impairment (MCI). MCI is defined by a noticeable decrement in cognitive functioning that goes beyond normal changes seen in aging [42], but is not clinically defined as dementia as of yet. Studies from the Mayo Clinic have demonstrated that close to 15% of individuals over the age of 70 have cognitive impairment [41] and there is a significant rate at which individuals progress from MCI to dementia – 10% per year [41]. We began with this population due to their interest in staying in their home for as long as possible and the increased likelihood of sustaining an extended length interview.

The first phase of our study included participants from the Integre Institute, which serves the local community and helps families and patients deal with a dementia diagnosis. The participants were part of the Institute’s outpatient clinic and do not live on the premises as residents, but rather at home with a family member. Participants were recruited with the help of the Institute’s Director of Research. The inclusion criteria was a diagnosis of mild cognitive impairment by an on-staff neurologist at the clinic. In total, five couples were interviewed. The sample size was constrained due to (1) the narrow inclusion criteria of a diagnosis of MCI and limited availability of clinical sites and (2) saturation was quickly reached by five dyads. Applicable demographics are presented in Table 1.

Table 1. Care Receiver and Caregiver Demographics

Participant Dyad ID	Care Receiver	Caregiver Relationship
D1	P1 Male	C1 Wife (did not attend)
D2	P2 Female	C2 Husband
D3	P3 Female	C3 Husband
D4	P4 Male	C4 Wife
D5	P5 Female	C5 Husband

3.2 Procedure

Patients were recruited from the Institute with the help of the Director of Research. A flier was distributed to all of the applicable clinic patients indicating for them to call the Dementia Research and Education Associate at the Integre Institute if they were interested in participating in the study. Those who indicated an interest in being involved would then schedule a visit with the first author of this paper through telephone or email. The interviews with the first author occurred on the Institute’s premises (D1, D2) in a private conference room or in the participant’s homes (D3, D4, D5) if they preferred. Participants had to have the ability to provide informed written or verbal consent to being involved in the research.

A strong ethical framework was essential in guiding our research [34], particularly because we were working with a vulnerable population. This framework focuses on several aspects: respect of

the individual with impairment and their caregiver (not looking at our participants through the medical model lens, or as disabled or sick); making sure the opportunities for research participation are available in the least intrusive and restrictive way [34] and assuring that all confidentiality protocols have been followed closely, including gathering and storing our data. We have firmly complied with our IRB's requirements to "do no harm" to those who are considered vulnerable, particularly cognitively impaired older adults [34]. There is a general consensus that a diagnosis of a dementing illness does not presume incompetence [37]. In order to participate in this study, we asked that the person's caregiver or "surrogate" [25] provide consent for them; in our case surrogate consent was provided by the partner. We also asked the individual with cognitive impairment to provide written and if unable, verbal consent. Upon completion of the IRB requirements we proceeded with our interview.

Semi-structured interviews were employed including questions focusing on home technology use adapted from Davis [14]. The interviews began by getting to know the family unit with a background on events prior and following the diagnosis of cognitive impairment. We asked them to share any family history they felt comfortable with, and on more than one occasion we would hear about love stories, children, and be shown Bat Mitzvah home videos. All of the participants in this study were kind enough to share details about their daily life, daily care and how they were coping with everyday life. Specifically, we asked them how using technology in their home enhanced their experience as a caregiver in providing daily care and how using technology in their home enhanced their experience as a care-recipient in their daily care.

3.3 Data Collection

Interviews were video and audio recorded and later transcribed for detailed content analysis. Since we were asking participants about technologies they enjoy using, they sometimes showed us their smart phone or other device so video recording was essential to capture these demonstrations. The video recordings allowed us to revisit important elements of the conversations and pick up on cues, particularly from the person with MCI. The recordings also serve as evidence on which interpretations can be made by others in order to establish validity [17]. By using a semi-structured interview method, we were able to elicit deep and meaningful narratives about the family's lives. The primary advantage of conducting interviews in a health related problem space is to allow the researcher to focus on the participants' perceptions and ultimately inform about their experiences and those of their caregivers [17]. Marital relationships and coping with dementia have been discussed as an important aspect of analysis [2, 12, 16, 32]. This perspective is also important in how we chose to conduct our interviews – involving both partners in the caregiver/care-recipient marital relationship.

3.4 Analysis

Thematic analysis was chosen to systematically analyze the data while also allowing us to tap into latent themes that manifested in the data collected [6]. This provided us with the ability to move beyond surface level similarities to more tacit themes [38]. Subsequent integration of these latent themes with our interpretation of the literature on technology design for the home helped us form the basis for the introduction of technology that should support alternative narratives [18]. The analysis focused on how the dyads spoke of their life experiences as well as their perspective on the place for technology in the home. Coding was organized first around the broad theme of 'narratives'. The evidence that narratives were different depending on if they were speaking of current

experiences or future technology needs led to further classifying the data into the type of narratives that were prominent in each of these reflection points. The two main themes that emerged were the predominance of an illness narrative when discussing the couple's everyday lives and the predominance of a biopsychosocial narrative when discussing their current use of technology or needs for technology in the future. All quotes are evidence of the existence of those two main themes. There is no interrater reliability as the researchers brought varied but valid perspectives to identify themes in the data.

4. RESULTS

4.1 The Prominent Illness Narrative in Everyday Life

A large portion of every interview allowed the participants to speak of their lives and reflect on their experience living with MCI and caring for someone with MCI. The dynamics of the relationship change after the diagnosis [2] as can be seen by the narratives that will follow – there was sometimes tension, anger and uncertainty about what life would be like. Each dyad had their own set of coping mechanisms and ways to continue to preserve their way of life, but the illness narrative dominated when discussing their daily lives. It became apparent that each of the participants had established their roles in the family as either caregiver or care-recipient, which was evident in their narratives. The pressures and responsibilities that the caregivers felt were often overwhelming at the initial stages of the diagnosis. This was also the case for the individual receiving the diagnosis. When asked to share some of their initial experiences with the diagnosis, our participants centered their discussion around coping, managing and understanding the illness. The illness narrative was evident particularly in how the disease was managed by the medical staff which often lacked compassion.

P5: "Yea, and he said [the physician] you have dementia and walked out!"

C5: "Not as quickly as that but basically that's- he has a certain amount of time he spends with patients and regardless of what's going on it's like when that time is up, he goes out of the room and I remember one time we were sitting and I actually stopped him. I said, "Hold on, doctor" and he froze and I said "I have some questions". I got him to come back in but he looked at [P5], got some background and he gave her some tests and he just said- just said nonchalantly "You have dementia"."

On several occasions the partners shared their disappointment with how their treatment was handled by medical staff and how little information was given to them about the diagnosis and how to find resources. The lack of psychosocial support for both caregiver and care recipient was evident with our couples.

C5: And then when I asked what to do, they gave me a list of internet sites and books and I'm thinking where do I start? And then one of the things they said was that they usually have the book "The 36 Hour Day" and they didn't have any copies of that in the library but I found it online. I had to read it 'cause I needed to get the information- it scared the day-lights out of me. And it still is a frightening book to read. Because it's worse case scenario. It just simply gives you all the facts but there's no good ending to it. And I said no no...this is not going to be [P5]. I said no way in my mind- I either blocked it or I said we're gonna find something but this is not the case...

P5: *We got to do everything we can do.*

Once the family navigated through this new phase in their life, they shared that it was often difficult to go back to the way things were. For example, some partners took their new role as caregiver very seriously – they felt they had to helicopter over their loved one, making sure they are safe, secure and all the details of their care is anticipated. For example, C3 discussed an incident with his wife where he was out of town for a day and she had forgotten to feed herself, felt faint, and had to be taken to the hospital by neighbors.



Figure 1. Dyad 3, P3 on right. Interview occurred in their home.

C3: *"If I go somewhere she goes with me, it's just that's what we do... if only occasionally, last year I had a strike which put me on an emergency assignment which left her in a really rough spot there about 53 days as I drove to Eastern Shore and back every day. I would've been staying there but I couldn't because I had to be home at least at night and my son works. She was here 3 days so we had coverage, even her daughter would get on the phone and walk with her every day... so I had a period of time where I had to be away during summer but that was the last time I think and she only ended up in the emergency room once during that time."*

P3: *"What was that for?"*

C3: *[to his wife] "Because you didn't eat!"*

C3: *[to the interviewer] "So she didn't eat and got shaky so she described that to her daughter in Florida who can't see her, so she didn't know but I knew it was cause of low sugar cause my grandfather used to get it. She doesn't have diabetes or anything like that..."*

P3: *"Peanut butter jelly works for me."*

C3: *"So they [the neighbors] took her to the hospital. I would have taken her to the urgent care if I was there."*

This event evidently caused him great distress, which really shifted the nature of their partnership to managing the illness. This has manifested in several activities he has now taken control over, including handling her medications:

C3: *"I sort the medications now...she used to always do them by herself and put them in the pill boxes herself, but I noticed she was getting confused so I took that over. I have a tendency, if something really makes her miserable...and to me crying is miserable and if she's crying because she's confused over something I will help her or take over, she doesn't have*

to do it... that may not be the perfect solution but I don't want her suffering more than necessary..."

This caregiver was very much focused on supporting his wife's needs and wanted to make sure she is safe and taken care of. He approached her care from a positive standpoint, however it seemed that he may have hindered some of her autonomy in order for her to be safe, or rather for him to feel that she is safe.

Dyad 4 had a similar relationship where the caregiver felt that having everything very organized and regimented would benefit her partner and his well-being. She mentioned that her background as a teacher has helped her with this:

C4: *"I like organization, everything has its place and it does! And has something been done with dementia and that? With organization... because I'm just, I mean both of us have backgrounds in Special-Ed... you know he has been very very very good! The glasses, the wallet, and the keys, he has done very well. Another reason why I say that is that medication is a very important aspect and believe me we are going through all that. I found out unless you have a routine I mean he has two pillboxes and so I do the 7 days..."*

As we can see from this quote, C4's narrative was dominated by handling her partner's daily tasks and ensuring that he was prepared to take on the daily schedule. She shared that it made life easier for both if she was very well organized. Her partner would then expect for her to plan his day and follow the schedule, which did not allow much room for him to make autonomous decisions. It was also interesting to note her decision to take her husband off his medication, so he would enjoy himself on their vacation:

C4: *"You know in Florida we took an 11-day cruise and we had a grand time, there were some mix ups but we had a grand time and I took him off his medication and I had a reason for that because we were having wine and eating so I didn't want them to interact and so we enjoyed it..."*

Interviewer: *So it was the right thing for you?*

C4: *"For him too, I would like to go back and I think photographs are important and have many of those... and I think the most important thing is the acceptance and realistic. If things get overwhelming then for two people to be down then that can't be. I even looked into programs like that but we are not there yet..."*

The autonomy of the care-recipient would often be compromised due to the need for safety that was expected by the caregiver. Like most caregiver-care recipient relationships, this was not associated with any negative intentions. The caregiver felt this was the best decision for their care partner at that time and coping with the illness narrative was often difficult:

C4: *"So as a caregiver you have to get over your anger because he was the one doing everything and he was mad and I was mad also because I had to change my schedule...and then I realized it's a process and you kind of feel alone. And you have to think about the whole process and see what you can do. I think I have gotten over it..."*

The illness narrative becoming the predominant daily narrative was most striking in our experience with Dyad 1. The caregiver for P1 chose not to participate in this study after a phone conversation with the first author of this paper. From that conversation and comments from the staff at the clinic, it was observed that C1

was not interested in being that involved in P1's care at the Institute or to be involved in any studies with him.

Clinic Director via email: "[C1] is really not as informed as [P1], they are very different than the [D2]. She hasn't been as involved in his care. I'm happy to reach out, but I can imagine you won't be able to get as much from her..."

From our conversation with P1, it became clear that his wife was burdened by his diagnosis and felt overwhelmed with all that she was now having to take on where at one time he took care of everything.

P1: "Sure I can do online banking, I can set up most of these things. Once in a while the password doesn't work. But more than not it's my wife...she was never interested in doing this and she still has difficulty but she's taken on a lot of that from me too... Yeah the responsibility to check it."

[A little while later, he continued on this thread]

"I am not saying that I have Alzheimer's because they don't know exactly, but I am on that track, I lose things all the time, you know, when am I going to find them, but I still have good driving skills. My wife prides me on the fact but I am very cognizant that I need to kind of schedule myself and without the help of my wife to help me do that schedule, that would be very difficult for me."

Although P1 did not directly comment on why his wife did not wish to participate in this study, it became evident that as the primary breadwinner he had been responsible for a lot of the household and financial responsibilities and those obligations had to be taken on by his wife following his diagnosis and progressive cognitive decline.



Figure 2. P1 during his interview. His wife did not join him.

The illness narrative, specifically the loss of self and search for identity of the person with MCI was particularly evident when the discussion reached a point of tension. This was evident when the care recipient would say something "odd" or not in the same grain as the conversation. C4, for example, felt extremely uncomfortable when her husband took over the discussion and reflected on a negative memory from his childhood:

P4: "The book is about two things it starts off first part about where I lived and born and was brought up and I was like...because I was left handed my mother did not want me my mother would call me "my black baby" so... and it was because I was left handed they thought I was retarded but I knew everything other kids knew too..."

C4 immediately refocused the conversation indicating that this was not something she felt comfortable sharing and really determined to show the research team that her husband was successful and accomplished prior to his diagnosis. The caregiver would then sometimes act as a gatekeeper who may be well meaning but perpetuates the idea that their partner is no longer themselves and must be supervised.

C4: "He was writing his book, and I think my husband has been a very successful person I mean he was very successful in high school he got full scholarship going to college, he was on the dean's list, but his interest has always been in sports and when he graduated from college I didn't know but found out he was a terrific basketball player, he was third round draft for the Detroit Pistons... you know when he graduated from college he was fantastic but something happened, someone ran into him and that was his end of career..."

Despite the predominance of an illness narrative in all of our discussions, some couples still attempted to balance autonomy and safety. This is a struggle within an illness narrative that required a lot of concerted effort and work. It can manifest in attempts to do more activities together, such as planning travel, participating in research projects, and even retiring at the same time in order to adjust to the changes as a couple. For example, C2 noted that having a better understanding of the genetic components of his wife's condition was now his role as a caregiver.

C2: "See it's up to me to read up about my wife, I know what's going on with the latest research now that she's in these studies, then I'll participate in that because it's meaningful to me. I'm doing a lot of what I'm doing with my wife is because she has a possible gene that could affect the brain, as the years go on I want to make sure I understand and can be there for her as best as I can."

Likewise, D5's relationship demonstrated that it was led by the illness narrative and coping with the loss. Thus, C5 felt protective of his wife's needs and safety; however, over time he realized he also needed to encourage her to continue to remain as independent as possible.

C5: At the beginning, I realized I was finishing P5's sentences she would hesitate and then I stopped and I said lemme see where she's going with this. She's able to..."

P5: Talk.

C5: And whatever you're thinking of. And sometimes we have a signal, she will hit a word and I think you just did it before, she'll be looking for it and so I'll fill it in. Like yesterday we were talking to this group they asked her the address and I know sometimes P5 has problems with numbers but I said alright because the last time someone asked for an address and you turned to me. But this time you ended up answering it and I just sat back."

P5: "I answered it the whole way. I did it."

C5: "You knew the address, you knew the phone number and so I don't jump in. I know I can be, my first thought was that-I have to be protective. I have to be able to let her do what she can do."

As the diagnosis became a permanent part of the couples' daily life, the majority of our participants felt the most important aspect in coping with this life event was to simply control the effects of the illness to the best of their ability. This often overrode other aspects of a healthy relationship such as simply supporting one

another, continuing to do the things they enjoyed, and finding a balance. This is not the life experience that we want to support. It is one that, with the introduction of technology with a medical model bent, would persist. However, in the following section, when the couples began discussing the place for technology in their lives, we see a noticeable shift. One that does not play into the illness narrative that was so prevalent in the prior discussion, but rather how technology was actively supporting a biopsychosocial perspective.

4.2 Technology Shaping a Place for the Biopsychosocial Narrative

When our interviews shifted to technologies each partner enjoyed using or was familiar with, the narratives used to frame their experiences seldom centered on the illness. The focus was often on being able to connect with family and friends, personal entertainment, or managing finances or schedules online – in other words, continuing to live their life to the fullest. All of the care recipients had an example of some technology that was continuing to engage them in their lives: P3's children lived in Florida and she used Facebook to look at their photos and videos, P4 was adamant about pulling his iPhone from his pocket to show us his calendar and tell us about the book he's writing about his life, P2 and P3 discussed their favorite games, and P5 talked about doing puzzles on the Kindle and watching shows with his wife on their Roku. This in turn led to the caregivers to also discuss the place of new technologies in their lives that were not focused on an illness narrative.

C5: "My kids got me a Roku for my birthday a couple of years ago I had no idea what it was. I figured it out and discovered all the channels- because I had Amazon we had some movies there. We had Netflix so I switched it over to streaming. But [P5] would be sitting here watching television and say there's nothing on. Like Saturday night there's nothing on television. I said well there's Roku, it's set up I can show it to you. It's got all the shows you like, and you can go to it and select a show you like."

In fact, all of our dyads felt technology was valuable when used to benefit them and their partner's well-being. C2, 3, 4 and 5 utilized technology in their "down time" to relax and consume media that was enjoyable for them. P2 was interested in playing games and engaging her cognitive abilities.

P2: "I play a word game on there [iPad] a lot. I have Jackpot Party which ... I don't know what you call it... I can't think of the word for it! ...Slot machine! Slot machine!" And I just got two new things that are for elderly people it's supposed to be helping with their memory. One's called Brain IQ and one's called Lumosity"



Figure 3. Dyad 2. C2 (right) discussing the computer games P2 (left) likes to play.

C3 was particularly interested in his partner being more engaged with technology in their home that could support their family unit.

C3: Well her favorite thing, I will tell you more about me but her favorite thing right now is solitaire so she plays it right over there, she still beats it, she can figure it out and so for me well I don't know... I keep trying to figure out how I could use the technology to make it better for her or to make it better for me or both of us, because I think the technology for her would be different than for me so if you look at it at a caregiver perspective its different."

Technology also provided a sense of independence for both actors in the family system which was important in order to achieve some balance in the caregiving relationship. C3 talked about being on his phone late at night after his wife had gone to sleep, as "me time", when he could watch a show or browse the net and do activities he enjoyed.

Likewise, P1 and P2 were proud of the fact that they were the ones who booked the family trips online, even though the final supervisory step (i.e. checking that all information was correct before pressing the final button) was done by their caregiver, it gave them a sense of autonomy and their care partner a sense of safety.

P1: "So after I get her [caregiver wife] more involved in this technology [booking vacations, paying bills online] over time... and given she's done fairly well in doing that. And so I'm relying on the fact that if my problems were to increase that she would be there to do that for me."

Providing the space for the care recipient to be independent and engage in things they enjoy doing or even new activities was realized and encouraged by the caregivers. Our caregivers used technology as a form of engagement and relationship building that we didn't see when they were discussing their everyday lives. For instance, C5 was always looking for new games that P5 might enjoy and both of them were very proud of her ability to complete them.

C5: "We discovered Jigsaw puzzle on the kindle and..."

P5: I love it!

C5: At the beginning, she couldn't finish them I would see where she would have one piece at the wrong place and she would show it to me and I started to pull those out and I would say ok try it again and then she would finish it...she hasn't asked me to do it in weeks..."

P5: “Yea I can do that”

P5: “Of course I did read something that said you need to vary the kind of things you're doing if all you did were jigsaw puzzles then it just means you'd be very good at jigsaw puzzles...”



Figure 4. Dyad 5 showing the technology both C5 (right) and P5 (left) use in their home.

It is evident from these discussions that everyday technology that was not built from the frame of a medical model, was better at engaging the participants and enriching their relationships and daily life. This in turn led to a biopsychosocial narrative surrounding the use and need for technology in their daily lives. Most technology that was used in the home was able to support the individual and collective needs of the partners without much fear of safety or loss of autonomy for both actors. This ultimately indicates that the narratives of daily life of older adults with cognitive impairment is critical in inspiring new directions for designing technologies to support the family system. This perspective on design could potentially elevate the lived experience and shift the narrative to one of biopsychosocial opportunity over that of illness.

5. DISCUSSION

In this study, we have uncovered the predominance of an illness narrative of daily life of caregivers and care recipients with MCI. This narrative was one that gave prominence to the impact of how their lives have changed since the diagnosis. It gave prominence to a concern over the continued safety and management of the person with the cognitive impairment. However, when the discussions shifted to that of current commercially available technology the couples were using, a biopsychosocial narrative was much more prevalent. In our conversations around technology, we were told stories that aligned with the psychosocial aspects of the couples' lives. The illness was still present, yet the idea that the dyad could continue to be successful and supported through technology was evident. It is clear that a focus on the illness and disease can hinder the lived experience, self-esteem, and identity of the individual with cognitive impairment and restrict the potential for a BPS narrative to have a positive shaping effect on the relationship between the care partners. However, technology designed and used in the context of cognitive impairment care does not need to reify this illness narrative; instead it can be a central figure in a BPS narrative.

Our findings also challenge the perspective that the caregiver or care recipient need support separately. We argue that the family system is deeply affected by the onset of the illness and must cope with it together in order to reach a more opportunistic narrative. Technology that supports the family system has the potential to

further foster the BPS narrative and provide a space for the rebuilding of each partner's identity in the relationship.

Finally, we show that being immersed in the narratives of daily life of those with MCI and their caregivers provides researchers with an opportunity to “successfully engage” [29]. It is important for those of us working with disabled or impaired individuals to apply the critical realist model in order to better understand the multidimensional aspects of the lived experience of those with dementia and related disorders. This could also provide us with the ability to better understand this unique population's experience – specifically how the family system is affected by the onset of the illness and examine the dynamic of the relationship. Because of our findings and experiences learning from our participants, we have formulated both a framework to understand how there is a relationship between the concepts of autonomy, safety, and narratives as well as a goal for the design of technologies to support the biopsychosocial lives of those with cognitive impairment and their caregivers.

5.1 The Relationship between Autonomy and Safety in Narratives

Two distinct aspects emerged from the analysis of the narratives—the sense of autonomy and feelings of safety for *both* partners in the family system. Autonomy, in the context of the dyadic relationship, is defined by how a person's sense of autonomy is affected by those around them. This means that both actors depend on the other for support in gaining more autonomy [27]. Safety concerns for both partners includes managing and preventing physical injuries, including falls, wandering, and misuse of medications [28].

When discussing their daily lives, our findings demonstrate that *both* of the carepartners' autonomy was caught up in the illness narrative, which in our participants' cases focused on coping with the burdens of the diagnosis and care of cognitive impairment. The caregiver had to cope with, determine the boundaries of, and understand their new role after the diagnosis (D4, D5) and the illness narrative made it clear that their autonomy was impeded by this new set of responsibilities. This meant that in the balance of the relationship, some of their autonomy was forfeited, which, in turn, affected their new life narrative. Similarly, the care recipient's sense of autonomy was disrupted after the diagnosis, which led to the realization that they are now dependent on their partner in some capacity, which in turn shifted the focus of their narrative to one of illness. The shift in autonomy was manifested when the caregiver would have to make the best decision possible in a difficult or challenging situation (D4), for example to withhold medication for their partner, or give up some of their independence in order to support the needs of their partner (D3, D4), for instance lack of focus on their own emotional and physical well-being. We observed the caregiver choosing to “rescue” their spouse from what was perceived as an uncomfortable situation (P4 discussing racial issues), thus taking away some of their partner's choice to share aspects of their experience [51]. Thus, a loss of autonomy for both partners was evident in the illness narratives told by all of our participants.

Similarly, when safety concerns for the care recipient arose during discussions, the caregiver would often tell a story of taking a well-meaning, yet paternalistic approach to supporting the care recipient's needs. The caregivers were tempted to substitute their own judgement, particularly when they felt they had better insight into what constituted a safe environment for their partner. This in turn would be agreed upon by the care recipient and thus intensify the illness narrative. For instance, following an incident where P5

forgot to turn off the stove, C5's reaction was to take over the cooking responsibilities and P5 quickly relented. Thus, there was a hyper concern for safety that was evident in the illness narrative that led to potentially more drastic than necessary measures to be put into place in order to secure the safety of the care recipient. These measures were decided upon by the caregiver, but were readily agreed to be the care recipient – again indicative of the shaping effect of the illness narrative on both actors perception of their roles and needs.

Thus, there is clearly a relationship between autonomy and safety that manifest in an imbalance for both actors leading to as well as exacerbated by the illness narrative in their daily lives. The illness narrative they began with soon after diagnosis led to a predominant concern for safety. This led to the caregiver instilling and monitoring the safety of the care recipient, which in turn diminished the autonomy of both carepartners. Thus, continuing to reify the illness narrative in their lives.

However, we saw a slightly different dynamic between autonomy and safety when discussing the use of technology in their lives. In the BPS-centered narratives of technology use, there was a focus on how to engage technology in a way that balanced both of their needs for autonomy and safety. For instance, P1's initiative to continue to book vacations for the family with C1 signing off prior to completing the final step. Thus, both maintained a semblance of their own autonomy and yet, safety for the care recipient was still achieved. This balance in autonomy in turn continued to reify a BPS narrative. This shows us that couples could cope with new challenges surrounding the diagnosis and find a solution that balanced the relationship between autonomy and safety. This balance is what the design of technology for those with a cognitive impairment should strive for.

5.2 Designing Technology for a Biopsychosocial Narrative

The narratives that shape the experiences of our care receivers and caregivers is a different concept than the disability frameworks spoken of in prior work. What we attempt to clarify through the accounts here is that the models we focus on as designers and researchers shape how we approach designing technologies to support those with cognitive impairment and their caregivers at home. In turn, those technologies have a shaping effect on the narratives that are predominant in one's use of the technology. Prior work has focused on moving away from designing through the lens of the medical model and taking a more holistic, person-centered approach to designing for impairment and disability [30, 49]. In particular, the work by Frauenberger [19] highlighted how the complex relationship between the many factors those individuals with disabilities experience, including biological, cultural and psychosocial, are important to consider in order to support diverse experiences. We particularly agree with this model for design as the illness narrative led to a constraining of options for our participants while a biopsychosocial narrative was cognizant of how the impairment could be addressed in a multidimensional manner that allowed for relational opportunities to be realized.

A deeper analysis of the dominant narratives in the family system can provide for a better understanding of how the context of dementia can influence design. Our findings open up the potential for technology in the lives of older people with cognitive impairment and their caregivers. Specifically, we show how there is an opportunity for greater relationship support in the dyad. One way to achieve this is to support the autonomy of both individuals while maintaining the safety of the impaired person. For instance, technology can afford those affected with MCI with the self-

reliance they thought they loss, afford the caregiver with a feeling of safety for the person they care for, and afford both actors with a sense of maintaining their own autonomy as the disease progresses.

A mutually supportive technology – a technology that could potentially maintain both actor's biopsychosocial needs – will allow for an adequate negotiation of autonomy and safety between the care recipient with MCI and their familial caregivers. This, in turn, may shift the actors' predominant narrative from the impact of the decline on both actors to the state of the biopsychosocial well-being of both actors. Specifically, in order to design technology that is supportive of the family system, we must consider several aspects. First, technologies that support the autonomy of both actors. For the care recipient, this means avoiding a catch all paternalistic approach and focusing on one that respects the individual's wishes and choices. For the caregiver, honoring their new role while supporting their ability to live a fulfilling life. Second, understanding that designing for safety and risk, whilst important, must not sacrifice the care recipient's sense of autonomy or take away from their BPS narrative.

6. CONCLUSION

The consideration of the life narratives of those living with cognitive impairment can provide a clearer lens in designing technologies for the home to support the family system. Building on prior work on models for assistive technology design, [19, 29, 30, 35] we have presented an approach to better understand the life narratives of older adults living with cognitive impairment and their caregivers in the home. Our work provided an insight into the daily life of couples where a partner has been diagnosed with a life-changing illness and how narratives play a role in shaping autonomy and the sense of safety of both the older adult with cognitive impairment and their caregiver. Our approach revealed that although an illness narrative was dominant in the discussions around their daily lives, the role of technology could shift that narrative to a more opportunistic model – one of biopsychosocial success. Further, this perspective can be the driving force behind design goals for home-based care technologies for those with progressive cognitive impairment.

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