

Approach Matters: Linking Practitioner Approaches to Technology Design for People with Dementia

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ABSTRACT

Technology design for dementia is an active and growing area. Though work to date has largely addressed functional needs, there is a growing recognition of the importance of supporting meaningful activities. However, technology for active, rather than passive, engagement is relatively novel beyond specific applications (e.g., music or reminiscence therapy). To better understand how to support active engagement of people with dementia in activities, we interviewed nineteen practitioners. Our findings reveal differing approaches to making sense of the actions of people with dementia, as well as to engaging them in activities. We discuss the importance of tracing epistemological understandings of dementia to different configurations of technology for people living with dementia and provide a practical guide to support designers to do so. Finally, we discuss considerations for the design of dementia technologies around facilitating self-actualization and managing emotional exposure for care-providers.

Author Keywords

Dementia; design; meaningful activities; practitioners

CSS CONCEPTS

• **Human-centered computing—HCI theory, concepts and models**

INTRODUCTION

HCI research on technology for dementia is an active and growing area. Goals of this research include diverse purposes, from reminiscence [37,38] to monitoring sleep and motor activity [54]. Systems used with people with dementia are similarly diverse, including shared tabletops [2], virtual reality [66], robotic pets [8,9], and multi-sensory experiences [25]. Interest in this domain is mirrored in national initiatives that urge researchers, industry, and service organizations to consider technology as a way to support the growing population of people with dementia.

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At the same time as promising new technologies are investigated to support people with dementia, surveys of the literature note that technologies often involve only passive engagement by the person with the condition, such as monitoring location via GPS [67]. Further, these systems often focus on functional needs [67] – which are important, but not the only areas in which people with dementia can benefit from technology. In particular, engagement in meaningful activities is one of the greatest unmet needs for people with dementia [9,30,60]. Regular engagement in activities increases positive affect [64] and mental well-being [42] and delays the progression of cognitive decline [14,46].

Though there is some understanding of the types of activities people with dementia see as meaningful [30] and purposeful [63], substantial barriers exist to the actual provision of activities for people with dementia. The ability to engage in hobbies and leisure activities becomes more challenging as dementia progresses, to the extent that one's ability to do so is incorporated into a scale that assesses severity of dementia [58]. As dementia progresses, caregivers must provide an increasing amount of support to people with dementia to engage in activities: but caregivers often have health conditions or jobs that prohibit focusing on supporting activities for those with dementia they care for [9,60]. Paid care providers in settings such as memory care units and nursing homes are also not always able to focus their attention on individualized activities for their clients with dementia, as their primary focus is on physical and safety needs [30]. Technology is being pursued as a way to assist practitioners in providing personalized meaningful activities to each of their client, while optimizing their time by working with more than one client at once [33,45].

HCI research is increasingly attending to the ways that the values of researchers and stakeholders make their way into the design of technology [27,48]. One key player that is involved in the design and delivery of technologies for people with dementia is the practitioner that engages people with dementia in meaningful activities and activities of everyday living [18,35,44,53]. These include activities directors, speech language pathologists, and occupational therapists. In this paper, we extend past work that considers practitioners that espouse critical views of dementia [43] to present a fuller understanding of practitioners' perspectives, and tensions that arise in practice between the different views

that exist in the landscape of dementia care. Based on interviews with nineteen practitioners, we outline differing approaches to making sense of the actions of people with dementia, as well as to engaging them in activities. By understanding these different, sometimes strongly opposing approaches, we can begin to understand how our technologies either advance or challenge these views, and how the systems that we design may end up being used by practitioners and others involved in the care of people with dementia. From these findings we discuss the importance of understanding what is at stake in these debated approaches, trace the ways that different epistemological understandings of dementia may configure different technological futures, and describe new directions for technology design in HCI.

RELATED WORK

Below, we review the related work on technologies to support activities in dementia, the importance of understanding societal perspectives towards disability in HCI, and a summary of different Western models of dementia care.

Technology to Support Activities in Dementia

Technology designed for people with dementia primarily address safety and security [67]. Most technologies for people with dementia (e.g., wearable GPS tracking [12,57] and monitoring [55,74,75]) are designed for active involvement by caregivers, with people with dementia as passive recipients of care via being tracked or monitored [67]. Researchers in HCI are increasingly looking to technology to support engagement in activity, often with the goal of supporting quality of life. Examples of technologies to engage people with dementia in meaningful activities include applications for reminiscence therapy [40,41] and music therapy [52,62], which draw on the ability of people with dementia to recall events and stimuli from the past. Sensory involvement is a growing approach to engage people with dementia in meaningful activities, such as interaction with virtual reality [31,66] or robotic pets [8,9]. Some of this work finds that key benefits of these technologies are the social interactions that take place because of the shared focus on a stimuli (e.g., a robotic pet [15]). These kinds of social interactions are pursued directly in other research (e.g., [51,76]). Playful interactions with games have been explored through games on tablets and desktops, such as Piece by Piece, which uses nostalgic content on tangram-style puzzles [77]. Additionally, technology has been designed to facilitate agency [26,32], personhood [73], and a sense of self [71,72].

As articulated by Baecker et al. [3], much of the above research can be seen as meeting the different levels of Maslow's Hierarchy of human needs, from basic physiological needs through some aspects of self-actualization, such as reminiscence of past life experiences for personal reflection and development [49]. However, in this paper, we articulate a gap in terms of work to meet other important dimensions associated with self-actualization –

specifically, the need for a sense of vocation, a calling, or a cause [3,49].

The Importance of Societal Perspectives

Past research has examined how societal perceptions shape the ways technology is designed for [27,48] and received by [47,65] people with disabilities. Mankoff, Hayes, and Kasnitz draw on disability studies to critically reflect on assistive technology, arguing the world views of technology designers may have negative consequences for users with disabilities [48]. Specifically, technologies created through the lens of the medical model of disability, even if the designers are coming from a helpful place, can lead to exclusion and other negative outcomes [48]. Some researchers in HCI are adopting a neurodiverse stance, where cognitive disabilities are seen as different processing styles, and design shifts away from the goal of having users with diverse abilities conform to social norms [8,17,27]. In regards to dementia, Madjaroff and Mentis add to this discussion by highlighting the need for technologies to be designed with the perspective of autonomy for people with dementia and their caregivers [47]. They argue the models designers and researchers focus on shape the ways that technologies are designed, and are then perpetuated in developed technologies through the shaping of how users with and without dementia view themselves and the world around them [47]. Past work has also examined practitioner perspectives on dementia [43], though focusing primarily on practices that challenge traditional views of dementia. We are missing an understanding of the spectrum of contemporary practices of engaging people with dementia – a necessary area to understand both for critically reflecting on the values that technologies perpetuate, as well as to ensure that the technologies that we design will fit into the ecosystem in which they end up being used.

Past work urges the HCI community to collaborate with practitioners while conducting technology research with older adults with disabilities [35]. Although this work highlights the potential of this approach in informing our understanding of older adults' needs [35], we have yet to understand how practitioner views may affect this collaboration. It is particularly important to understand this topic as practitioners often train family members, propagating their approaches to engage individuals with dementia in activity [18]. In this paper, we look to understand current perspectives in some areas of dementia care, how these perspectives affect the activities practitioners engage their clients in, and may in turn affect technologies designed for people with dementia.

A Brief History of Western Models of Care in Dementia

In order to understand how to design technologies in this space, we must understand the approaches and models which inform our understanding of dementia to date. Below we provide a brief history of Western dementia care and some of the major shifts that have occurred in terms of what are considered to be best practices.

Dementia was originally described in terms of a biomedical model, with pathological explanations. Symptoms of dementia were attributed purely to the obstruction of neural pathways [68]. However, few clinicians today truly follow this model. Best practice has shifted to a biopsychosocial model, where behaviors are understood to be the result of the interaction between people with dementia and social or environmental factors [21,22]. Yet the biopsychosocial model has been critiqued for its view of the person with dementia as a “passive victim,” where “actions and expressions are attributed to the labeled condition” [20]. This view highlights the need to manage Behavioral and Psychological Symptoms of Dementia (BPSD) [5], which include behaviors such as wandering, agitation, hypersensitivity to noises, aggravation, anger, sadness, hallucinations, apathy and aggressive outbursts [34].

This model has been referred to as the disease model and accused of “diagnostic overshadowing” as a result of viewing dementia solely as a brain disease [20]. This contrasting view led to the development of the person-centered care model, where practitioners move away from focusing on deficits instead focusing on the remaining capabilities of their clients [21]. In this model, the changes associated with dementia are seen in social context [37]. The focus is not on inner qualities of the person with dementia, such as their brain’s capacity to problem solve or remember, but instead on the interactions of someone with dementia in the context of the world around them [34]. Therefore, for practitioners to understand the actions of someone with dementia they must attune to their relationships with their clients with dementia, requiring practitioners to have “inter-subject insight” [38].

In this paper, we trace how different Western models and views of dementia can lead to different technological futures for people with dementia. It is important to note that all of the practitioners in this study work in North American healthcare systems, and consequently their views do not reflect a universal approach to dementia care.

METHOD

Below, we describe data collection, the participants who took part in this study, and our approach to analysis.

Data Collection

We recruited participants by posting study information on Facebook group pages for specific practitioner’s societies (e.g., American Occupational Therapy Association), word of mouth and snowball sampling. We obtained consent from participants before each interview. Each interview session was approximately one hour and was conducted either in person or remotely, based on the interviewee’s proximity to our university. Interviews included questions concerning the practitioner’s general professional strategies, the meaningful activities they engage their clients in, and the types of technologies, if any, they use to aid this engagement. We did not provide practitioners with a definition of meaningful activities. Instead, we asked questions like, “Can you tell me

about some of the meaningful activities you support people with dementia in?” and “Would you take me through a recent time you worked with someone with dementia to support a meaningful activity and what this looked like?” This allowed the practitioners to define what meaningful activities were according to their own experience interacting with people with dementia. Participants received a \$20 Amazon gift card for their participation in this study. All procedures were approved by the University Institutional Review Board.

Participants

In order to qualify to participate in the study, participants had to have at least three years of experience working primarily with people with dementia. Nineteen semi-structured interviews with seven different types of practitioners were conducted by the first author. All practitioners were interviewed separately with the exception of two who were interviewed together to accommodate their time constraints. Participants had 15 years of experience on average working with people with dementia (ranging from 3 to 46 years). Their average age was 48 years (ranging from 26 to 70 years old). All participants identified as female. Seventeen identified as Caucasian, one as Asian, and one as Multiethnic. Seventeen participants practice in the United States and two practice in Canada (P14, P15). Table 1 provides additional details about each practitioner and the care environment in which they practiced.

Analysis

In total, 18 hours of interviews were audio-recorded and transcribed. We analyzed this data using a constructivist grounded theory approach [10]. The first four interviews were each open coded by the first author to pull out major themes in the data. Some of the initial codes included “safety versus autonomy”, which related to the higher level theme of “understanding the actions of practitioners towards people with dementia”. More focused coding was then conducted on the following interviews, looking for major themes seen in the first four interviews and for discontinuities in the data. Axial coding was then conducted to bridge themes and get a broader sense of the structure of the data. Analysis took place over an iterative process of engagement with the data and the participants, memoing, and discussions amongst our research team. This iterative process informed the types of questions asked in later interviews, allowing us to probe deeply into interesting and contrasting codes of practitioners. All codes and major themes were agreed upon by the first and second author. In the last three interviews, P17-P19, questions were modified to highlight major tensions in practitioners’ approaches that emerged during analysis. Additionally, future technology ideas which align with these tensions were pitched to the practitioners for their feedback. Further focused coding was conducted on these final three interviews to clarify ambiguities in the theory presented.

PID	Age	Type of Practitioner	Environment of Care	Primarily Working With	Years of Experience
P1	70	Occupational Therapist	In home consulting ^a	Moderate-Severe Dementia	4
P2	31	Occupational Therapist	Skilled Nursing ^b /In home consulting	Mild-Moderate Dementia	5
P3	31	Occupational Therapist	In home consulting	Mild-Moderate Dementia	8
P4	32	Occupational Therapist	Retirement Community ^c	MCI-Severe Dementia	8
P5	54	Speech Language Pathologist	Skilled Nursing/In home consulting	Mild-Severe Dementia	30
P6	30	Activities Service Supervisor	Long-term care ^d	Moderate-Severe Dementia	7
P7	56	Activities Director	Long-term care/Assisted Living ^c	MCI -Severe Dementia	12
P8	61	Life Style Director	Long-term care/Assisted Living	MCI -Severe Dementia	15
P9	56	Life Enrichment Associate	Skilled Nursing/ Long-term care	Moderate-Severe Dementia	15
P10	58	Activities Service Provider	Assisted Living	Severe Dementia	4
P11	26	Memory Care Activities Coordinator	Long-term Care	Moderate-Severe Dementia	4
P12	54	Gerontologist Consultant	Assisted Living	MCI -Severe Dementia	30
P13	53	Occupational Therapist	In home consulting/Hospice ^f	Moderate-Severe Dementia	20
P14	55	Executive Community Director	Long-term care, Assisted Living and Day Programs ^g	MCI -Severe Dementia	30
P15	40	Manager of Community Development and Engagement	Long-term care/Assisted Living and Day Programs	MCI -Severe Dementia	12
P16	39	Director of Adult Day Care and Respite	Day Programs	Mild-Moderate Dementia	20
P17	52	Dementia Consultant/Advocate	Assisted Living/ In home consulting	Mild-Severe Dementia	20
P18	62	Director of Quality Assurance and Education	Long-term care/Assisted Living and Day Programs	MCI-Severe Dementia	46
P19	42	Dementia Care Educator	Long-term care/Assisted Living	Mild-Severe Dementia	3

Table 1. Participant Demographic Information. Practitioners worked at a range of settings, which encompasses many of the settings in which people with dementia receive care. a. *In-home consulting*: Practitioners provide care in clients' homes [56]. b. *Skilled nursing*: Communities with nursing care available 24 hours a day. Residents can have short rehabilitating stays or long-term care [56]. c. *Retirement communities*: Residential communities for older people [1]. d. In *long-term care*, a sub-branch within skilled nursing, patients require hands on care and supervision 24 hours a day but may not require skilled nursing care [56]. e. *Assisted living*: Home-like environments with varying levels of supervision and medical care [56]. f. *Hospice*: Care for dying individuals and their loved ones through pain medication, therapy and counseling [56] g. *Day programs*: Also known as adult day care. Refers to part or full-day care in group settings, often providing social activities, health related assistance, and meals [56].

The constructivist grounded theory approach requires that we reflect on our own position as researchers and the perspectives that we bring to the research. We have been strongly influenced by postmodern views of dementia as socially constructed [29], taken up in critical dementia and calls for an epistemological shift in HCI away from the biomedical or disease model [43,47]. We support the use of technology to facilitate interdependence [7], self-determination [47] and self-management; enabling people to

take an active stance in their own health and well-being through supportive decision making and recovery-focused approaches [4,11].

FINDINGS

Below we first contextualize our findings by describing how practitioner's define meaningful activities with their clients. Second, we describe two approaches practitioner's take to make sense of the actions and expressions of people with

dementia: 1) interpreting their actions as symptoms of the disease or 2) attributing significance to their actions. Third, we describe two different approaches of practitioners when engaging people in activities: 1) being pragmatic and doing what works and 2) prioritizing dignity and respect at all times. Finally, we discuss how practitioners' shift between interpreting the actions and expression of people with dementia to seeing them as symptoms of the disease depending on the stage of dementia of their client, their own disciplinary thought, time pressure, and to create emotional distance from their clients.

Practitioners describe meaningful activities for people with dementia not only as enjoyable activities [P13] (e.g. shopping, going to the senior center, playing games) but also as “everyday basics” [P2] – activities like personal grooming, grocery shopping, and cooking. Meaningful activities are unique for people with dementia [P6] and often focus on “whatever it is that they're [the person with dementia] not doing that they want to be able to do again or do better.” [P13]. The unique desires for meaningful activities are accommodated for by practitioners when they ask their clients, “You have dementia, where do you want to go from here? What are your goals? What legacy do you want to leave behind?” [P17] and then listening to their responses and engaging them in the activities to realize these goals. This strategy of asking individuals with dementia what they would like to do is especially applicable when clients are in the early stages of dementia and still able to verbally communicate. However, this becomes more challenging with the complex communication needs associated with dementia: as P4 states, “sometimes it's hard to figure out [what the person with dementia wants] because we do have individuals again that aren't very verbal and cannot answer your questions.” Even with the challenges, practitioners strive to facilitate activities which “can meet different people's needs at the different places that they are.” [P16]. Particularly when people with dementia are no longer able to communicate verbally to express their needs or desires, practitioners use different strategies to continue to engage people with dementia in meaningful activities. These strategies are informed by their differing views on dementia.

Interpretation of Actions and Expressions

In this section, we discuss two different approaches, as seen in medical literature, to making sense of the actions of people with dementia. At times, expressions and actions are seen as Behavioral and Psychological Symptoms of Dementia (referred to as BPSD in the medical literature) [5]. At other times, practitioners attribute significance to expressions as reflecting deeper meaning and an intent to communicate [21]. Based on the approach that is adopted, practitioners use different strategies when engaging with people with dementia in activities.

“That's not the person, It's just the disease”

At times, practitioners see the actions and expressions of people with dementia as behaviors stemming from a disease

rather than actions expressing underlying meaning [39]. As P9, who works mainly with people with more severe dementia explains, “Sometimes you're going to get that physical pinch and kick and spit, but that's not the normal person, that's just the disease.” This “normal person” would never act aggressively towards other people. P18 explains a discourse she has often encountered is to tell care partners to “Remember, it's the disease and not the person.” Practitioners explain that this strategy is often used to comfort care partners, allowing them to continue to see a beloved, familiar individual even with the changes they see in their loved one with dementia.

Behaviors are either labeled as negative, and prevented, or positive, and supported [20]. Practitioners, typically in-home consultants, are sometimes brought into the picture by caregivers who are asking them “to prevent or diminish some sort of behavior.” [P3]. Caregivers and practitioners see behaviors as negative when they are a potential safety hazard for the person with dementia or to the caregiver (e.g. aggressive outbursts). P2's entire organization focuses on safety and reducing injuries and hospitalizations for people with dementia. From this approach, practitioners emphasize stopping or diminishing activities by adapting the environment – for example, P3 places a “curtain over the passageway into the kitchen” to disguise it as a part of the wall in order to prevent someone from going in.

With this perspective, the use of **validation and redirection** is a key principle to engaging people with dementia in activities [80]. P8, working in a long-term care and assisted living facility, gives the example of someone walking around the assisted living community asking for their mother. In this situation, P8 acknowledges the reality of the situation “Of course you know their mother is gone.” However, she does not point out or try to explain this reality to her client, instead she validates the emotions being felt by the individual “you just say, “Oh okay, I understand. Let's just see if we can go find your mom.”” Finally, she redirects the client, distracting them from their current situation, “just sit them down and then get them into doing something else. Give them something to look at like a magazine and before you know it they've forgot.” With the strategy of redirection there is a right way and a wrong way to do an activity, where the practitioners' mold their clients to fit the way they believe the activity should be done: “I do try to redirect the person because like if they're doing an exercise, I want them to do it correctly... I use words or approaches that would lead the person to my consideration of the correct performance rather than just letting them practice getting it wrong over and over again.” [P5]. In this example, P5's clients were not reflecting the actions she perceived as correct for the speech exercise. Therefore, she redirects their actions to reflect her standard of correct participation, reflecting the view of certain actions as negative and to be diminished [20].

Additionally, with this perspective, **any kind of response** to the actions of the practitioner can be taken as a **positive sign**

of engagement. P9 stated: “If you're going to do regular stretching exercises... I may have three other people with their eyes closed but if I hit a balloon at them, they're going to open those eyes.” The display of boredom or sleepiness is seen as a negative behavior, perhaps indicating apathy, which should be changed by whatever means necessary. Practitioners who are not attributing significance to the actions of someone with dementia as attempts to communicate or express deeper meaning, see any response, like opening eyes, as a sign of positive engagement, as they look to engage someone with dementia in any way they can. This same tactic, though, was deemed by P12 (who primarily takes the interpreting significance view) to be a “use of startled response to get people awake”, which she sees as unkind and disregarding how being startled makes someone feel.

Like Being a Detective: Interpreting to find the “Why”

All practitioners in this study at one point described attributing significance to actions of people with dementia – seeing actions as showing desires, interests, and discomforts. P18 explains that, “[an action is] not a symptom, it's telling you something, that there's an unmet need.” From this approach, practitioners focus on the ways people interact with their environment, caregivers, and objects, building “a mosaic of a person in order to engage them.” [P12]. P3 builds this mosaic by “spending time with that person where I'm kind of a fly on the wall. I want to see how they interact with their environment, because then I want to emulate that.” Practitioners interpret these actions to understand the needs and desires of people with dementia who can't communicate verbally in two major ways.

First, practitioners look to their **actions as a form of communication.** Practitioners work to understand what each person is trying to communicate through their actions so that they can devise activities that respond to the needs they are attempting to express. As past work has noted [43], attending to affect is essential: P16, director of an adult day care center, explained that people with dementia “might get up, or they might have an outburst, or they might get angry, or they might just visibly be uncomfortable.” Rather than attributing these observations to the presence of dementia, she interprets these actions as “a visible sign that they're not enjoying [the activity].” Paying attention to emotions can lead to an understanding of whether someone is interested in or trying to avoid a particular activity. To understand why individuals react in this way, and how to adjust activities to better fit people's needs, practitioners describe their role as “like being a detective.” [P8].

P5 shared an example of someone in a skilled nursing home crying out after lunch to go home. She explained that an ineffective response would be to say “You know this place is your home now,” as “That may not change the behavior, because what's the underlying reason for crying out in the afternoon to go home?” For an individual from a multi-generational home where the entire family lingered over

lunch, a new living environment where people went back to their rooms alone after lunch might feel alien and isolating. P5 responded in this example by ensuring her client had socialization after lunch, which ended the habitual crying out to go home. When actions are not seen as communication and the context of situations is not taken into consideration, this can lead to practitioners labeling someone's actions as symptoms of dementia, which can have a negative impact on their access to activities and socialization with others. P19, who works in long-term care and assisted living, explains how viewing actions as symptoms of dementia can make things worse – when she catches herself labeling actions as “cycling” (emotionally repeating oneself about a certain topic), she realizes this is linked to her having slipped into seeing their actions as behaviors – the person with dementia cannot get out of that cycle “because I did not listen to them enough for them to settle in and feel vulnerable.” This strategy is a contrasting approach to validation and redirection, where a practitioner would just try to affirm their emotions and distract them from their current circumstances instead of working to understand what their client is trying to communicate.

Second, practitioners look to past **formative experiences to explain actions** and understand how to engage people in a way that is individually meaningful to them. Practitioners often draw on people's former occupations to incorporate familiar ways of interacting with the world. P17 was working with one client in assisted living who kept saying she was bored. After further talking to the client, P17 learned she had worked as an emergency room nurse. Her career was “high adrenaline and always something. So, you know for her to be in a community, yeah it's pretty and everyone there is dressed well but she is bored to tears.” [P17]. Once it was understood that she needed more intense stimulation in activities than other clients, P17 was able to give her a checklist of things to do to keep her busy. P17 explains, “What I have found is that when she stays busy and feels more in control of her environment she excels.” It could be any profession or habitual activity as P8 explains, “If they were bowlers then you bring them to bowling. If they were a mailman, you would have them engage in some kind of activity where they could bring people their mail.” The emphasis here is to get to know the person, as P12, a gerontologist consultant, explains, “the biggest secret, the secret sauce so to speak is that no one takes the time to know that person. Know their likes their dislikes, their family history. Were they a mom, a banker? Did they run the PTA?”

Practitioners note that these strategies are quite “time intensive.” [P18]. P12 devised an approach to scale these tactics to larger groups by finding the “generalities going on” when getting to know each individual. Practitioners can then “take the generalities and build a theme and then you build programs around themes... because you can't have one on one for everybody.” [P12].

Pragmatism versus Respect

Our findings show practitioners take two different approaches to engage people with dementia in meaningful activities. With the pragmatic approach, the most important element of working with people with dementia is doing what works well, on a practical level, for practitioners and their clients. Practitioners are less concerned with infantilization, respect, and self-actualization, and more focused on ensuring the basic wellbeing of their clients. In contrast, the respect approach values self-actualization and dignity-centered interactions with their clients.

Doing What Works: A Pragmatic Approach

With the pragmatic mentality, the goal is to support wellbeing to the maximum extent possible, while acknowledging the real changes that occur with the condition. To understand this perspective, we offer an example that came up in many interviews: “higher order” needs, as described in Maslow’s hierarchy (i.e. for self-actualization, as opposed to basic safety or food and shelter) [49]. Specifically, the need to contribute to society. As P7, an activities director who works in long-term care explains, “I find that folks that are in the facilities for long-term... They don't want to keep sucking it out of everybody for stuff. They want to get together and give back somehow to the community or each other and that's really important.” With the pragmatic mentality, the goal of an activity to meet this self-actualization need would be to make someone feel that they were contributing. P1, an in home consultant, gives the example of a client who, “really wanted to be helpful to her daughter”, who she lived with, so P1 designed a “folding activity” for her client. In this activity the laundry that was folded was never used, as P1 advised “just get a laundry basket. Get some old towels or some towels you don't need and just keep those in the basket. Those are for her activity.” P1 elaborates that the focus of the activity is more on enjoyment than on supporting someone in actually contributing back to others: “it's not for a particular outcome or product.”

When practitioners focus on facilitating feelings of helpfulness without facilitating a client actually being helpful, it can be seen as denying someone their self-determination, or the ability to control their own life. This is a common practice in parent-children relationships, and can therefore lead practitioners to make analogies to children: like P8 who stated, “They act like children, they go back in age.” Consequently, these practitioners might draw on childlike activities to engage people with dementia because these activities seem familiar and failure-free [P9]. Childlike activities practitioners describe include coloring activities strictly using crayons, playing children’s computer games, blocks, stuffed animals, puzzles, and balloon volleyball. Terms used in this approach might be associated with children, such as “Adult Day Care” [P16], “sweetie, darling, baby,” [P17] or “honey” [P18]. Infantilization and other aspects of the pragmatic mentality are ultimately practiced by well-meaning individuals [P14], who believe that the best

way to care for someone with dementia involves keeping them comfortable and feeling positive.

Prioritizing Self-actualization: A Respect Approach

Practitioners who take an approach of respect facilitate self-actualization and self-determination whenever possible, focusing on safeguarding “dignity and independence.” [P16]. Unlike the pragmatic approach, the respect approach sees people with disabilities such as dementia as able to contribute to society [7]. The example of folding laundry was considered “busy work,” [P17] and letting the person with dementia think they are helping when they are not. This disregards a person with dementia’s ability to self-actualize, or “become, be, what it is and who it is that you [the person with dementia] want to be.” [P14]. As P12 explains, “We do art projects for reasons. We make cards for people in the hospital. We take refurbished stuffed animals for children in the hospital. We do activities for purpose.” Even those in the furthest stages of dementia are considered able to give back, though it looks different than traditional modes of volunteering. P19, who works in long-term care and assisted living explains, “every time they [a client] interact with me they have volunteered their time and their precious energy, which is finite.” As the dementia progresses, these interactions get “harder, it's a real effort.” [P19]. Therefore, “even if someone is hours from death, if they've chosen to engage with me, if I have been present with them and they've decided to be present with me,” they are giving back [P19].

Because the respect approach focuses on someone’s capabilities and self-determination, practitioners reject any form of infantilization, even in the most severe stages of dementia. Instead, they are “treating people like adults because they are adults.” [P16]. P16 explains, “These people have lived full lives, they have served in the military, they have raised children, they have contributed to the community and the workforce and the social betterment of all of us.” When people don’t treat people with dementia as adults, even though it is not intentional, “you're excluding somebody, demeaning somebody, and diminishing somebody.” [P14].

Practitioners carefully avoid anything that would be construed as childlike. P17 lets her clients decide what they would like her to address them as. She always starts her interactions with clients by addressing them with a formal title, “Would you like Mr. Smith?” These practitioners are mindful of non-verbal forms of infantilization, recognizing that, “we accidentally treat people like children when we're not even aware of it, just the pitch of our voice and the facial expression we're affording,” or by “lean[ing] over someone to talk to them.” [P19]. And, activities that practitioners engage people in must remain adult. Childlike activities are abhorred: “I hope and pray that we won't have ball toss or balloon volleyball. I don't allow it in any of the communities I work in... We never use crayons, ever! Or anything that infantilizes an elder.” [P12].

Shifting Between Approaches

In this study, practitioners at times shift between understanding the actions of someone with dementia to be a result of the disease and attributing significance to actions, though they were stable in terms of having either a pragmatic or respect approach. The shifts in approach are linked to stage of dementia, evolving disciplinary thought, time pressure and to create emotional distance.

Stage of Dementia

When practitioners shifted from attributing significance from the actions and expressions of people with dementia to viewing these actions as symptoms of the disease, it occurred primarily when they were discussing people at the end stages of dementia. At this stage, practitioners can no longer use the approaches described above to interpret significance of actions. P8, who works with people at all stages, explains that once someone is in a later stage of dementia, “they could say, one thing, you know, “I miss my mother” but they may be missing their husband or their sister.” In these instances, practitioners first try to interpret the significance of their actions and the context of the situation as well as try to understand what their client is trying to communicate even though they may no longer have the ability to verbally communicate. If the practitioner is unable to interpret the person with dementia’s actions, that’s when “you just have to go along with where they are and just try and comfort them and validate them and redirect them” [P8]—a strategy that aligns with an interpretation of the action as symptoms of dementia.

Evolving Disciplinary Thought

Several participants described their evolution from a disease model of dementia care (e.g., as described in [34]) to a social constructivist or personhood-oriented approach [37]. P18, the most experienced practitioner with 46 years working in the field, describes how when beginning her training, “it was an unspoken thing that I learned early on that it was the disease why the person was like this.” [P18]. This traditional approach was accepted for many decades and still followed today: P16 explains how even though she has since distanced herself from the disease model, it was a part of her training: “It comes from the people that taught me in my career. I learned through them.” However, Kitwood’s formative works on person-centered care [37] and the influence of activists living with dementia (e.g., Kate Swaffer’s #BanBPSD campaign [69]) together form a new perspective: “today, it’s like BPSD with a red line through it like, ‘STOP!’” [P18].

Time Pressure

P18 explains that “it’s easy to just blame it on the dementia... It’s easy to become not thoughtful and not intentional.” [P18]. And what is easy can be the only option, at times — caregiving is an underpaid, under supported activity [30]. Practitioners do not always have time to act as detectives and interpret significance — leading to a “knee jerk ‘aww it’s Alzheimer’s’ or that knee jerk, ‘oh that’s their dementia’.”

[P17]. P19, who would never speak to clients in terms of their behaviors symptoms of dementia, explains that the term BPSD is used “when we’re charting stuff” because “we’ve got to be efficient and effective.”

Creating Distance and Emotionally Coping

P19 uses the simile of a medical doctor using a stethoscope to check a patient’s heart rate to compare why a practitioner might label an action as a symptoms of dementia. The invention of the stethoscope allowed a doctor to check a patient’s heart rate from a distance rather than “put[ing] their head up against our chest.” [P19]. P19 believes that, like the stethoscope, using the term BPSD creates a (emotional rather than physical) distance. P19 explains this is appealing because caregiving “is a painful, painful thing for professionals.” The shift to using the term BPSD is an attempt to “sanitize” [P19] dementia when it becomes too difficult. A common discourse in dementia care involves practitioners explaining to families and care partners that certain actions are “the disease and not the person” [P18], propagating the approach of the practitioner [18] to “sanitize” the actions of someone with dementia by labeling them as symptoms of the disease in order to emotionally distance themselves and others from the pain of caregiving.

Limitations

It is important to note that though we present a close examination of practitioner perspectives, this study did not include direct input from people with dementia. There is a need for other work to unpack the experiences of those living with dementia when encountering these different approaches. Some of our findings and discussion points touch on technologies such as monitoring systems. It is imperative for future work to consider the ethics of such systems from the perspective of people with dementia. Additionally, our results do not include the perspectives of home health aides or certified nursing assistants, or of informal, unpaid caregivers — each of these groups are likely to bring different perspectives to their interactions with people with dementia. In particular, the intermittent interactions some of our practitioners had with clients, rather than sustained, daily interaction, may have affected their ability to interpret the actions of their clients.

Finally, our findings come from participants practicing dementia care in North America. Therefore, our findings are certainly influenced by the geographic and cultural settings within which our participants practice. For example, previous research describes Western society’s hyper-cognitivism, or valuation of cognition over other attributes or qualities [6,34,61]. Other work has noted the predominance of the disease, or biomedical model of dementia care in Western societies [21], but absent or limited to health professionals in other settings (e.g., Faure-Delage et al.’s work in the Republic of Congo [24]). Future research is needed to understand how different national and cultural contexts affect dementia care.

DISCUSSION

This paper details the approaches practitioners have when working with people with dementia. These views are based on personal experiences but are also informed by training and contact with evolving forms of thought. Training and these thoughts, in turn, are shaped by fierce divisions between dementia advocates (individuals in this study mentioned Dr. Al Powers, Teepa Snow, Dr. Sylwia Górska, and Dr. Loken, among others) and advocacy organizations. These perspectives—particularly coming from active organizations such as the Alzheimer’s Association – surely trickle into our own views, though we may not have the awareness of our own stances that practitioners do. Unpacking epistemologies of dementia is also important for researchers working with dementia practitioners (advocated in past work [35] and taken up in work with people with disabilities, e.g. [13,50,70]) and people with dementia. The perspectives or even terms that we may assume are benign can carry substantial meaning for those we work with. For example, though the term BPSD is common in the medical literature and has been adopted by many, for practitioners such as P18, BPSD has “a red line through it like, ‘STOP!’” [P18]. Framing a project as preventing BPSD is unlikely to garner support from practitioners like P18. Below, we trace the ways that different epistemological understandings of dementia lead to different configurations of technology for people living with dementia. We then describe new directions for technology development.

Tracing Epistemologies to Technologies

Previous research shows how technologies shape the narratives of people living with dementia and their informal caregivers and urges technology designers to be aware of the models of care their technologies may fall into [47]. Other work begins to trace values to a particular technology [57]. Our findings extend this past work by unpacking how different epistemologies affect technology design for people with dementia. We present two cases below.

First, we consider a case of a sensor system emerging in the literature (e.g., [19]) and US patents. These kinds of systems monitor the nonverbal input such as affect, expression, or gaze of people with dementia to assess states such as level of pain or cognition [23]. Depending on one’s understanding of dementia, this same system might be configured for widely varying purposes. With the perspective that actions of someone with dementia are just symptoms of a disease, sensor information might be used to adjust a pharmacological intervention or initiate an activity to distract someone from negative behavior. In contrast, if actions are seen as expressing underlying meaning, the system might be designed to correlate expressions with preceding events, or find patterns that indicate underlying intent (e.g., crying always taking place at meal times).

As another case, we consider extended reality systems to aid people with dementia in activities of daily living, such as multi-step cooking activities (a concept emerging in the

literature [78,79]). From the pragmatic approach, a virtual reality (VR) system might be designed, as it could simulate passive engagement in a cooking activity, allowing the person with dementia to focus on the enjoyment of the cooking activity without risking failure. In this way, the VR system facilitates the person with dementia to feel as though they are completing an activity independently, even if only in the virtual world. From the respect approach, an augmented reality system would be better to aid people with dementia in a cooking activity because it would facilitate active engagement by the person with dementia in the activity through assistance and prompting [79]. This distinction bears on Hodge et al.’s call for the development of interactive personalized extended reality environments to engage people with dementia in meaningful activities [31].

The two cases above are examples of how epistemological understandings can lead to different technologies. In Table 2, we present a way for researchers to critically reflect on which epistemologies they are advancing through their work, by linking the technologies that they are creating or studying back to approaches to dementia care.

Approach	The technology...
Attributing to disease (BPSD)	Takes any form of attention (e.g., open eyes) as engagement
	Utilizes redirection when symptoms of dementia are present
	Has a single “right” way for users to engage
Attributing Significance	Searches for underlying meaning of actions
	Interprets context of situations
Pragmatic	Uses child-like strategies, words, visual appearance, or other feedback
	Focuses on cultivating a feeling of independence or self-actualization
Respect	Uses strategies, words, visual appearance, and other feedback that communicate dignity
	Facilitates self-actualization (e.g., through volunteering, giving back)
	Focuses on completing an activity independently

Table 2: Assisting Self-reflection of Approach

Though the above table presents the approaches as though they are all equally viable, it is important to clarify that we do not believe that all of the perspectives revealed in this paper are equally acceptable. We advocate an approach that interprets significance and is respect-based, which aligns with a direction of dementia and disability research in HCI that stresses the need to respect the self-determination of

people with dementia [47] and challenges a view of people with disabilities as solely receivers of help [7]. At the same time, our findings reveal the ways that being undercompensated and under supported can cause individuals to shift into seeing behaviors as symptoms of a disease or take on the pragmatic approach (e.g., when there is time pressure). Therefore, even as researchers investigate their own attitudes, it is important to work towards alleviating the conditions that shift practitioners into a disease attribution approach. This could include research to alleviate the emotional impact of caregiving, which we discuss below, or to develop efficient charting systems that suggest alternatives to BPSD language.

Considerations for Design of Dementia Technology

Our analysis suggests new directions for research: to support higher level needs, and to manage emotional impact on care providers.

Facilitating Higher Meaning and Purpose

Practitioners who take pragmatic as well as respect approaches support activities such as volunteering that accommodate higher level needs such as esteem and self-actualization. Other researchers have drawn on the tiers of Maslow's hierarchy to link to technologies that can fulfil these needs [49]. Current research that focuses on the higher level needs of people with dementia, however, focus on aspects related to renewing a sense of self and personhood [72,73]. For example, reminiscence is used as a way to critically reflect on past experiences and facilitate personal growth [3,49]. However, these aspects only represent one dimension of higher level needs – our work highlights the potential in focusing on another dimension established as part of higher level needs – specifically, fulfilling the sense of a vocation, calling or cause [49]. Future research should investigate how best to design technologies to draw on the abilities of people with dementia to contribute as active members of society. Additional research is needed to understand how contributions will change through the progression of dementia. A first step might look into supporting volunteering, which past work has found to have a positive impact on quality of life for people with mild to moderate dementia [28].

Manage Emotional Exposure of Care Providers

Our findings reveal ways that some practitioners emotionally distance themselves from their clients by labeling their actions as symptoms of a disease. Though much work seeks to alleviate the burden of caregiving in terms of alleviating safety issues [67], we have less of an understanding of how the sociotechnical systems that we design and study impact the emotional experiences of both professional and family caregivers of people with dementia. Research may take for granted that monitoring systems help family members who live far away keep someone with dementia safe, but what emotional impact does viewing this record and seeing changes have? Future research is needed to understand the emotional impacts on caregivers, and how to support preferred emotional distance.

In introducing this design direction, it is important to note the tension that emerges between the need to care for those affected by the system, such as caregivers, without ignoring that these approaches may at times reinforce ableism and shift focus away from the urgent need to change current care practices to better respect people with dementia. Much further work is needed to address this tension.

CONCLUSION

This paper investigates how practitioners support meaningful engagement in activities for people with dementia. We describe two deeply differing approaches practitioner's take to make sense of the actions and expressions of people with dementia as well as two different approaches in engaging people in activities. Our findings show practitioners shift between interpreting the actions and expression of people with dementia to seeing them as symptoms of dementia depending on the stage of dementia their client is in, their own disciplinary thought, time pressure, and to create emotional distance from their clients. These different epistemological views of dementia have implications for the design of technologies for this population. We encourage technology designers to identify their own perspectives towards people with dementia concerning concepts such as infantilization, BPSD, respect and self-actualization, as these perspectives will shape the way technologies are designed and perceived by people with dementia. In doing so, we advocate for perspectives that prioritize dignity and respect, while recognizing and caring for the needs of the practitioners trying to operate within the existing system.

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