

Why Technology for Caregivers Fail: A Qualitative Study of GPS-Based Technology
Supporting Alzheimer's Caregivers

by

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Abstract

The purpose of this research is to understand the usability challenges of wearable Global Positioning System (GPS)-based technologies for at home caregivers managing wandering effects for loved ones with Dementia, specifically those with Alzheimer's disease. A total of four devices and 14 U.S. participants were studied using semi-structured, in-person qualitative usability methodology and an open coding system in the style of Grounded Theory. Though the study evaluated issues solely related to usability, the results expanded to a much larger design paradigm to be considered for improved and more directed solutions for future advancements that is symbiotic between a company and its end user. The proposed "life-proofing ecosystem", which contains eight pillars within its framework (user experience, customer experience, accessibility, governance, marketing, business, technology, cultural sensitivity) aims for more balanced product evolutions and progressive innovation. Future studies may provide scalar measurements for assessments beyond the proposed framework and ecosystem. Ultimately, the goal is to provide practical guidelines for designing life-proof solutions in today's highly connected society.

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Chapter 1: Introduction

The Purpose

The purpose of this research is to understand the usability challenges of wearable Global Positioning System (GPS)-based technologies for at home caregivers managing wandering effects for loved ones with Dementia, specifically those with Alzheimer's disease. At this stage, wearable GPS-based technology will be defined as technologies required to manage the activity levels of Alzheimer's patients who exhibit high tendencies of negative wandering behavior. A vast majority of products within this specific category that are available today lack user friendly designs that make it feasible, adoptable, and affordable to integrate into all homes. With the largest aging population retiring (baby-boomer generation), it is imperative to ensure that these technologies reach their full potential.

Many caregivers have a deep love and care for loved ones afflicted by Alzheimer's disease. One can only try to empathize with caregivers and the stress they endure in an effort to turn back the clock to a time when their loved ones were as they remembered. The notion that a caregiver's relationship with their loved ones will never be the same may be a painful reminder that life may never get easier. Certain caregiving priorities therefore, become co-mingled with day to day experiences in a way in which new memories may be somewhat tainted. While the caregiver may not regret their life today, daily challenges create sobering reminders of a need for new solutions to help their daily struggles. For instance, family members may wish to reduce their daily worries that a primary caregiver is well supported. Family members and caregivers alike may all wish to reduce the daily uncertainty associated with unpredictable behaviors stemming from a loved ones' fight with Alzheimer's disease. Ultimately, family members may want more confidence in knowing how their role in supporting a caregiver may lead to a more settled home.

By doing a literature review of past studies, product reviews, and informal interviews with known Alzheimer's interest groups, and with the combination of the types of products, suggestions, and solutions that are frequently given to Alzheimer caregivers, I am able to distinguish what the most used technologies are. From this list, the top four products (Pal (Protect and Locate) by Project Lifesaver, TRiLOC GPS Monitoring by SafeTracks, GPS SmartSole by GTX Corp, and Keruve by Vision Localization Systems) were chosen to be reviewed in greater detail through qualitative usability inquiries. Possible solutions are created as a result.

The Scope

A study involving a review of current technology solutions aimed at assisting home caregivers for Alzheimer's patients. GPS-based technology, with the consideration of other products that are available outside of Alzheimer and Dementia patients, are evaluated to understand what is prohibiting the flourishing of these products in homes. By researching at-home caregivers for practical needs that will better support them in caring for their loved ones, the results of the study may provide insights into usability design efficacies for GPS-based medical devices aimed at Alzheimer's patients exhibiting wandering effects.

Chapter 2: Literature Review

Home Caregivers Trends and Incidence

Assistive technology (AT) supporting home caregivers and people with dementia has been far overlooked. A vast majority of research have been from the perspective of healthcare providers versus caregivers and mainly focuses on medical outcomes (Adler & Mehta, 2014). In a review based on eight scientific databases between the years 1992 and 2007, of a total of 66 original studies found, only 15 focused on family caregivers and 10 on formal caregivers in relation to AT (Topo, 2009). These findings show that the role of dementia care and technology is still in its infancy, and the use of AT remains rare. With dementia being one of the largest challenges in a person's quality of life and healthcare technology constantly being seen as a secondary solution, it is no wonder that caregivers are having a difficult time adopting new technology. In recent years, advancements in monitoring technology have been growing and continue to do so as there is increasing awareness (Hall et al., 2014). A deeper understanding of the caregiver's psychological and environmental factors will help the AT community develop higher empathy and thus better positioned to pursue design projects that will support caregiver and patient needs (Hagen et al., 2004).

Caregiving is extremely common and is on the rise. According to the National Alliance of Caregiving (2015), there are more than 43.5 million unpaid caregivers over the age of 18 in the United States, and of this group, approximately 30% are caring for those who are suffering from Alzheimer's disease or similar conditions. For those who are not currently caring for someone, 47% of adults say that it is likely that they will be responsible for an aging family member at some point in their life (Fox, Duggan, & Purcell, 2013). The estimated total hours spent on caregiving adds up to 37 billion hours and an economic value of \$470 billion in 2013 of their unpaid contributions. By 2050, this number will rise to \$1.1 trillion dollars (2016 Alzheimer's Disease Facts and Figures, 2016). To put this in perspective, the current estimated amount spent is much larger than

the total amount Medicaid spent in both federal and state contributions (Reinhard, Feinberg, Choula, & Houser, 2015).

In general, home caregivers can be a friend, a family member, or a neighbor who is not paid to provide assistance needed due to illness, injury, or natural aging. Responsibilities can range from simple routine household tasks, emotional support, activities of daily living, instrumental activities, or even to highly complex medical procedures. Caregivers can be any age, but for the vast majority of caregivers, the average age falls between 45 to 64 and is typically more prevalent among women versus men distributed across all types of educational levels, income levels, race and ethnicity (Adler & Mehta, 2014). Nearly 70% are working while the rest of the population are not employed while caring for someone. Eight in ten (82%) are taking care of one versus multiple persons; 85% provide care for a relative or parent, and one in ten provides care for a spouse (National Alliance of Caregiving, 2015).

According to the National Alliance of Caregiving (2015), home caregivers are separated into two major categories, lower-hour caregivers and high-hour caregivers. Lower-hour caregivers provide 20 or fewer hours per week and represent the vast majority. High-hour caregivers provide at minimum 21 hours (averages 44.6 hours) per week and are more likely to take on more strenuous daily living activities such as transportation, housework, bathing, dressing, preparing meals, managing finances, distributing medication, and nursing tasks. Unfortunately, as caregivers spend more hours caring for loved ones, experts have shown a dramatic decrease in their own personal health due to pure stress and self-neglect. In a study conducted by Masanet and La Parra (2011), they found a large correlation between poorer mental health and the number of hours devoted to caregiving tasks in informal care. Both women and men in various ages and social classes experienced poorer mental health as the number of hours increased. Similarly, in another study conducted across eight European countries, psychological well-being and overall health in association to caregiving intensity was also measured.

They found that with every additional hour given per day, health decreased by 0.16 and 0.42 index points (Bremer et al., 2015).

Current Landscape

Today the issue of providing homecare is not speculative, but rather a reality. This is especially true in long-term care. The U.S. Senate Special Committee on Aging highlighted in a report that “the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning... Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition” (Special Committee on Aging, 2000). In 2012, the total cost spent in the U.S. related to long-term care was \$219.9 billion, which accounted for 9.3% of all personal health care spending (National Health Policy Forum, 2014). In the case of Alzheimer's disease or other dementia, 14.9 million caregivers were identified in the U.S. in 2011 (Family Caregiver Alliance, 2015). Understanding what direct and indirect costs are related to the demand in products and services related to Alzheimer caregiving may provide insights into the needs for directing additional solutions in addressing the related healthcare needs (Deb et al., 2017).

Any obstacles that exist when providing quality long-term care to loved ones represents a larger paradigm; identifying key themes relating to possible solutions may assist in providing better healthcare products. To further investigate, this may require acknowledging some macro factors that may influence the development of helpful aids to caregivers. Several forces affecting innovation in healthcare include industry actors, sources of funding, public policies, technology, customers, and accountability (Herzlinger, 2006). However, the U.S. Food & Drug Administration (FDA) has regulations monitoring the safety and quality of new medical device products. Code of Regulations (CFR) Title 21 addresses the quality standards required for products to claim health-related benefits. In particular, part 890 addresses standards for physical medicine

devices; these standards primarily relate to direct costs of illnesses. In other words, managing Alzheimer's diagnosis are included, yet managing symptoms relating to long-term care are not. Indirect costs associated to the illness, symptoms such as negative wandering effects, are seemingly passed onto the caregiver with little oversight from the FDA. While there is overtone to include more inclusive design applied to at home care with medical devices (Bitterman, 2011), the business and governance of devices related to managing indirect costs related to informal care require more investigation.

Additional studies have shown that resources dedicated for home caregiving may be in shortage. For example, literature referred by the Alzheimer's Association cited, "there is a shortage of good nursing homes beds in many states" (Mace & Rabins, 2006). This underlines the fact that more focus on homecare is slowly being conducted. For example, "a number of authors looked at skills training for ADRD [Alzheimer's disease and related dementias] caregivers. One study, for example, determined that three personality components were needed for caregiver skills training: openness, connectedness, and involvement" (Chee, Dennis, & Gitlin, 2005).

In other studies, similar recommendations for research were being made. As further example, "The Environmental Skills Building Program utilized a three-pronged approach: caregiver education, home adaption, and caregiver skills training" and "placed visual cues and installation of alarms to keep track of movement were used" (Corcoran et al., 2002). Other examples include using occupational therapy to train home caregivers. One study explored the competence-environment press theory by "explaining why a caregiver has not adjusted to the increased responsibilities brought on by the diagnosis. That is, a poor fit exists between the abilities of the caregiver and the demands of the new environment created as a result of ADRD diagnosis... Often the caregiver denies wandering and the potential severity of the behavior" (Corcoran et al, 2002).

As stated previously, the impact of managing homecare can take a toll on the caregiver. Examples of declining health for the caregiver are not rare. This is highlighted

by potential “high rates of clinically significant anxiety...but a focus on depression has meant that little is known about risk factors for caregiver anxiety” (Cooper, Katona, Orrell, & Livingston, 2008). However, the same researchers proposed a possible remedy which includes important emotion-focused and problem-focused intervention strategies when working with the caregiver. These strategies are:

“Emotion Focused Strategies: accepting the reality of ADRD and learning to live with it, emotional support and comfort from others, humor, positive reframing, and religion;

Problem Focused Strategies: active coping; Instrumental Support: getting help and advice from others about what to do;

Planning: coming up with a strategy about what to do.”

Ultimately however, “family caregivers favored quality of life and independence over potential risks” (Robinson et al., 2007).

Taking Care of Loved Ones with Alzheimer's Disease

Caregivers who are taking care of loved ones with Alzheimer's disease face even more extreme difficulties versus any other condition (Wilks & Croom, 2008). Attempting to predict and cope with erratic behaviors long-term can be one of the most trying aspects of this disease. With every year, Alzheimer's disease is growing as the population ages and as a result, caregivers are needed more than ever. Alzheimer's disease, as we know, is the most common form of dementia that occurs later in life and is not part of the natural aging process. It is the sixth-leading cause of death in the United States, fifth for adults 65 years and older, and of the top 10 causes of death is the only one so far that cannot be medically prevented, cured, or slowed down (Xu, Murphy, Kochanek, & Bastian, 2016). Today, one in three seniors cause of death is from Alzheimer's, or another form of dementia, and almost two thirds are women (2016 Alzheimer's Disease Facts and Figures, 2016).

Alzheimer's disease is a progressive neurodegenerative disease marked by the gradual decline in cognition and behavior. Speculation regarding possible pathogenesis revolve around a combination of genetics, lifestyle, and environmental factors and personal choices. Bartolotti and Lazarov (2016) discussed the consideration of age, physique, mental health, occupational, and nutritional activities that exacerbates onset, along with exposure to certain pollutants and metals within an individual's environment. Other possible risk factors might include hormonal fluctuations, inflammation, and obesity (Christensen & Pike, 2015). Although environmental and lifestyle factors are not fully understood within the medical community, we have a better grasp of its genetic dispositions and its effect on the brain. In other words, Alzheimer's disease kills brain cells and because of that, causes a less healthy brain. According to Wostyne, Audenaert, and De Deyn (2007), major abnormalities are caused by plaques called beta-amyloid and tangles that are associated to multiple regions of the brain. These proteins are found to also be related to other types of dementia and brain traumas due to injuries from shear stress on the cell's physiology. By using diagnostic genetic markers, experts can hopefully track the evolution of the disease to possibly gain better recognition to key symptoms (Laforce, 2011).

Though there is a growing amount of research in the underpinnings of Alzheimer's disease, it is truly difficult to detect what exact causes are in fact the true cause of onset per individual (Melrose et al., 2011). Not only that, but early diagnosis is difficult since it is often mistaken for normal aging or other diseases due to either atypical symptoms, a lack of an improved diagnostic criteria, or the patient purposely hiding early symptoms hoping no one would take notice (Latest Research: Early-Onset Alzheimer's Often Misdiagnoses, 2012; McKhann et al., 2011; Larsen, 2016). Misdiagnosis, either failing to diagnose when disease is present or even diagnosing when disease is not present, occurs all too frequently and has been estimated to range from 10 to 30% of cases in past studies (Alzheimer's Association, 2016; Beber & Chavez, 2013).

Misdiagnosis can be extremely devastating emotionally and damaging to the quality of life for both patient and caregivers. In addition, misdiagnosis can contaminate a person's memory and cause a series of wrong decisions, including treatment (Merckelbach, Jelicic, & Jonker, 2012; Mendel et al., 2011). Early detection, diagnosis, symptomatic medical treatment, and the usage of AT are the only methods to improve quality of life for those who have Alzheimer's disease as of today. However, like any disease, each individual case comes with its own unique set of challenges relating to and around specific scenarios.

Personal Pain Points

Cognitive Dissonance

Before evaluating the issues with AT devices, a further exploration of pain points may provide better insight into the problems at hand. One of the common issues in addressing Alzheimer's caregivers is their denial that their relative has the disease or that their loved one has changed, and they are often also dealing with the patient's own denial. For example, studies have highlighted, "Alzheimer's disease and other dementias may give rise to severe burden in caregivers who provide continuous day-to-day supervision and care, are involved in activities of daily living, and cope with inappropriate or violent behaviors of their demented relative" (Ankri et al., 2005). Other research supports these findings by highlighting, "when faced with a major life loss, one tends to cycle through a series of coping mechanisms. First stage is described as denial; *'not me, it can't be true'*...There are four other stages of grief identified: anger, bargaining, depression, and acceptance" (Kubler-Ross, 1969).

The problem may be in how the caregiver evaluates their own role in caring for a loved one. A caregivers' burden may be tied to their own perception of their situation. As an example, the Zarit Burden Inventory identifies three kinds of emotional burdens: "social consequences, psychological burden, and feelings of guilt...spouses scored higher

in area of social consequences, children scored higher in feelings of guilt, which increased as the disease progressed” (Ankri et al., 2005).

Types of issues range in severity. One issue is,

“dysfunctional coping strategies... behavioral disengagement (giving up trying to deal with it/the attempt to cope), denial (saying to myself ‘*this isn't real/refusing to believe that it has happened*’), self-distraction (turning to work or other activities to take my mind off things/doing something to think about it less), self-blame (criticizing myself/blaming myself for things that happened), substance use (using alcohol or other drugs to make myself feel better/ to help me get through it), venting (saying things to let my unpleasant feelings escape/expressing my negative feelings)” (Cooper, Katona, Orrell, & Livingston, 2008).

Another issue involves the caregiver believing “grief is often disenfranchised because of the shame, secrecy and stigma associated with Alzheimer's disease” (Silverberg, 2006). Furthermore, “denial appears to be more evident among family caregivers... with a tendency to value independence of ADRD patient over potential risk involved” (Robinson et al., 2007).

However, experts believe that having a personal strategy can help caregivers overcome such weighty burdens. As an example, it is recommended that “you must fully accept that these behaviors are not just stubbornness or nastiness but a response that the person with dementia cannot help. The person is not just denying reality or trying to manipulate you” (Mace & Rabins, 2006). This cannot be a “blame game” as it can sever relationships within families and friends, as the caregiver is typically too close to their loved ones and cannot see clearly to manage.

Cognitive Overload

When caring for loved ones with Alzheimer's disease, there is a multitude of responsibilities that forces caregivers to juggle life since their loved one is highly

dependent on them. Caregivers personal lives are put on hold and taking care of one's health becomes less of a priority. In a study by Steinhardt (2012), he mentions "the 'sandwich generation' ... a term that is applied to females who attempt to provide care for the elderly parents while also taking care of children and work... a generation of people, typically in their thirties or forties, responsible for bringing up their own children and for the care of their aging parents."

Capturing this scenario with other scholarly work may be juxtaposed to the entity relationship model. The entity relationship model, also called an entity-relationship (ER) diagram, compares "exposure to demands at home and/or at work [that] may result in negative outcomes, in the case where it is difficult to recover sufficiently from the effort investment" (Boumans & Dorant, 2014). Moreover, "the demands these double-duty caregivers have to meet require too much effort that cannot be compensated by sufficient recovery possibilities" (Boumans & Dorant, 2014). An example of the pressures is the mental functioning associated with caregiver support, so that tasks such as a "bath or getting supper prepared, eaten, and cleaned up can become daily ordeals" (Mace & Rabins, 2006).

The consequences of such pressures may not be easily identified. Take for example, double-duty caregivers. Double-duty caregivers are professional caregivers as well as at-home caregivers to their own family members. These individuals are at extreme risk of overload. They require "a higher need for recovery at home, emotional exhaustion and presenteeism... are at risk for developing mental and physical symptoms of overload" (Boumans & Dorant, 2014). However, like all caregivers, finding aid to reduce overload is a common concern. Also, "caregivers lack the time to learn about technology that may be useful to them" (Adler & Mehta, 2014).

Mental and Physical Stress

Among all the additional pain points, emotional and physical stress are some of the top contributors to caregiving distress and could cause large health declines, including severe depression and frustration. Emotional stress is a common occurrence among caregivers. As an example, several statistics from Family Caregiver Alliance (2006) regarding emotional stress include:

- a substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives.
- estimates show that between 40 to 70% of caregivers have clinically significant symptoms of depression, with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression.
- depressed caregivers are more likely to have coexisting anxiety disorders, substance abuse or dependence, and chronic disease. Depression is also one of the most common conditions associated with suicide attempts.
- 16% of caregivers feel emotionally strained and 26% say taking care of the care recipient is hard on them emotionally. An additional 13% of caregivers feel frustrated with the lack of progress made with the care recipient.

Furthermore, in studies relating to measuring mental health of caregivers, many highly burdened individuals reported depressive-like symptoms. One study reported, “nearly half of the 161 caregivers were highly burdened and almost one fourth were depressed” (Mougias et al., 2015). The burden to caregivers is heightened by a prolonged

state of emotional stress brought on by caregiving. For example, “patients with longer duration of dementia, greater severity of dementia, and lower education levels significantly differ in anxiety and depression mean scores. Conclusion: the presence of caregiver burden in AD patients is strongly associated with the duration and severity of dementia and the educational level of patients” (Garcia-Alberca, Lara, & Luis Berthier, 2011).

In another study, Lou et al. (2015) conducted one of the largest studies on caregiver burdens to measure the correlation between anxiety, depression, and apathy. The study found that caregivers who had “higher levels of depression were independently associated with higher numbers of additional caregivers, lower educational background and being a spouse of the patient. Higher levels of burden were associated with longer duration of being a caregiver and being the spouse of the patient” (Lou et al., 2015). In addition, a study on caregiver mental health in relation to the use of additional in-home assistance found that even with additional assistance, “the strongest predictors of caregiver depression is worsening of the caregiver’s subjective physical health status and burden, and short-term use of in-home respite assistance. These findings suggest that caregivers who experience deterioration in levels of physical health and burden and who use in-home respite on short-term or sporadic basis may be especially vulnerable to the chronic stress of providing long-term in-home care” (Whitlatch, Feinberg, & Sebesta, 1997).

As Alzheimer’s disease worsens, daily independent activities such as driving are no longer possible due to potentially dangerous circumstances, causing heightened caregiver anxiety and stress. A study found that,

“changes in eyesight and reaction time, such as driving, even mild ADRD have been found to be associated with worse performance on such driving measures as collision avoidance, and impaired visual reaction times...[These changes may be]

particularly difficult because it means a loss of independence and autonomy for seniors...[who] often lack the judgment to understand the need to stop driving” (Frittelli et al., 2009).

As a result, the Family Caregiving Alliance (2006) have found that it is common for caregivers feel “a loss of self-identity, lower levels of self-esteem, constant worry, or feelings of uncertainty.” Even worse, studies have found that “behavior change such as giving up driving as one of the most difficult aspects of providing care...describes the powerful feelings of discrimination, devaluation and social exclusion in response to the loss of driving privileges” (Aminzadeh, Byszewski, Molnar, & Eisner, 2007).

Compounding this trend is the fact that women caregivers seemingly are at higher risk. Again, the Family Caregiving Alliance (2006), showed that “female caregivers (who comprise about two-thirds of all unpaid caregivers) fare worse than their male counterparts, reporting higher levels of depressive and anxiety symptoms and lower levels of subjective well-being, life satisfaction, and physical health than male caregivers.”

With all of these emotional stressors impacting caregivers, it would seem natural for a call for additional policy review regarding public health and safety. Research shows that “the imperatives of public health may override individual rights and preferences when the threat is certain and the burden of lost rights reasonable. Nearly 30% of cognitively impaired adults continue to drive...in fact, in about 60% of cases...caregivers stated that they were unable to discuss their concern about driving issues prior to the cognitively impaired driver having an accident... asking the older adult to retire from driving can be a substantial blow to the person’s pride and sense of control” (Kennedy, 2009).

In addition to mental and emotional stress, physical stress contributes to extreme levels of health breakdown due to round-the clock demands. According to Family Caregiving Alliance (2006), “more than one-fifth (22%) of caregivers are exhausted when they go to bed at night, and many feel they cannot handle all their caregiving responsibilities.” In a 2012 survey, family caregivers who provided complex chronic care, like medical and nursing tasks, reported “being frightened or upset about their ability to carry them out properly” (Adler & Mehta, 2014).

When analyzing the emotional and social responses of caregivers, Croog, Burleson, Sudilovsky, and Baume (2006) found “that 41% of the spouse caregivers had scores on feeling ‘anger-resentment’ toward the patient.” This study suggested that the “responses to the burdens may involve both direct as well as unexpressed hostility toward the patient, resentment of the burdens and stresses”, which “could lead to harmful caregiving behaviors and further loss of morale.” In addition, “anger has been associated with depression, anxiety and caregiver stress, often from caregiver’s problem behaviors.” Additional damaging behavior is often closely associated. For example, when loved ones refuse to bathe because they can’t remember, “the term catastrophic reaction [is used] to describe this behavior.... Often a catastrophic reaction does not look like behavior caused by a brain illness. The behavior may look as if the person is merely being obstinate, critical, or overemotional. It may seem inappropriate to get so upset over such a little thing. Catastrophic reactions are upsetting and exhausting for [the caregiver] and for the confused person” (Mace & Rabins, 2006).

These stressors demonstrated how overwhelming both the emotional and physical nature of caring for a loved one with Alzheimer’s can be. Regardless of a caregiver’s competence, these difficulties are bound to test a person’s limits. Subsequently, “a priority concern in care management plan should be providing strong positive support to caregivers, especially those who are experiencing anger as well as psychoeducational

skill-based interventions focusing on anger management” (Gallagher-Thompson & Coon, 2007).

These pain points help underscore the various incarnations of challenges facing any of a variety of situations that may encumber the patient and by extension, the caregiver. Each situation may pose challenges in day-to-day activities as well intangible characteristics, such as culture, that may influence approaches to home care. This kind of cultural sensitivity may help underscore the need to account for variations in solutions for patients and caregivers alike (Resnicow et al., 1999). Invariably, accounting for cultural sensitivity may act as an overarching theme by which a framework for understanding how to manage development of informal care solutions might be examined.

Relationships

The family structure of the caregiver may also be impacted by the difficulties in care of a loved one. A family structure may include a variety of related members of the family, but the “stress and emotional impact of caregiving on the caregiver can affect the rest of the family” (Hall et al., 2014). This may mean that “families are often disenfranchised due to distance and time constraints” (Wilks & Croom, 2008). In fact, “most caregivers toil in isolation that not only deprives them of emotional support that others could provide, but also means that people do not learn from each other’s experiences and knowledge” (Adler & Mehta, 2014).

The experiences of a caregiver are unique and can be lonely. The stress of being a primary caregiver is understandably difficult. Moreover, the limited freedom a caregiver has to take care of one’s relationships may have unforeseen consequences. For instance, “one study has shown that low participation in social activities in late life may increase the risk of dementia” (Saczynski et al., 2006). The same research cites, “feelings of loneliness may be the key aspect of low socialization responsible for cognitive decline” (Saczynski et al., 2006).

In some cases, the association of being a caregiver may prove just as challenging. A study finds that caregivers “may feel the stigma that is often associated with mental illness. To avoid shame and embarrassment, caregivers may become withdrawn from friends and family, and may subsequently feel alienated and lose self-esteem” (McCann, Lubman, & Clark, 2011). Furthermore, “in this study, openness did not always result in support from family members and friends, a finding that has also been affirmed in a study of caregivers from different cultures” (McCann, Lubman, & Clark, 2011). Other research has found “relatives would collude with wrong beliefs... carers expressed guilt and felt they were wrong to lie, but wanted to avoid a confrontation, or the truth of the situation was having no impact” (Dodds, 1994).

However, there are other studies that advocate for social support as not only a mechanism for survival, but for caregivers themselves to thrive. For instance, one study showed “social support contributed to higher levels of resiliency in caregivers when moderate levels of stress were present” and “family support had even greater impact than friendships” (Wilks & Croom, 2008). Adding to the social dynamics, “people often live within interwoven networks of mutual caregiving” and “understand that patients are not merely individuals but are part of families” (Adler & Mehta, 2014). Seeking to accommodate these social networks that caregivers live through, emerging solutions for caregiving are available. In fact, “monitoring from a distance would allow care-recipients to retain a higher level of autonomy in that a caregiver could give the recipient more personal space and alone time” (Hall et al., 2014).

Impact of Wandering Behaviors on Caregivers

There are three major stages caregivers have to understand about Alzheimer's disease in order to plan out proper personal coping mechanisms due to their loved one's cognitive limitations and physical decline: mild, moderate, and severe stages. With mild Alzheimer's disease, initial memory loss causes forgetfulness to short-term memory and incremental changes to a patient's personality (National Institute on Aging, 2009).

Reduced ability to plan and organize are typically key symptoms. During the moderate stage, misjudgment, confusion, and physical disorientation become highly obvious and typically cause the most prolonged grief among caregivers. Memory impairment, ability to reason and use good judgment, difficulty with motor activity and controlling bowels, language, and other disturbances profoundly impair daily life. The last stage, also known as late-stage, typically means all daily needs and activities are assisted by caregivers (National Institute on Aging, 2009).

A hallmark behavioral change that can occur at any stage in Alzheimer's disease and highly impacts caregivers are negative wandering behaviors; effecting three out of five people with Alzheimer's disease, translating to 60% of its population. Though there are many other behavioral changes that occur, wandering is the most significant issue regarding safety and overall well-being. According to the Alzheimer's Association (2016), those who wander, "if not found within 24 hours, up to half of those who get lost risk serious injury or death." Depending on diverse situations and stages, mortality rates can vary between 0.7% to 46% with the vast majority averaging 40% (Koester & Stooksbury, 1992; Rowe & Glover, 2001). Though there have been fluctuation regarding the precise rates, the acknowledgement that wandering is a highly notable issue is undeniable.

Wandering can occur at any time and when least expected. The unpredictability of a cognitively impaired person is high and can even occur when the home caregiver is physically present, but distracted or asleep. Increased vulnerability also occurs in unfamiliar situations or when living with others, such as children (Rowe & Glover, 2001). Though the word wandering lacks specific meaning, Hope and Fairburn (1990) studied the typology of wandering in order to help define it. After interviewing 29 patients and caregivers, nine typologies emerged:

1. *Checking/trailing*. Repeatedly seeks the whereabouts of the caregiver or follows the caregiver around excessively.

2. *Pottering*. Walks around the house and ineffectively carries out tasks of their own accord.
3. *Aimless walking*. Walking around about without any evidence of a purpose.
4. *Walking directed towards inappropriate purpose*. Walking appears to be directed towards an inappropriate purpose (e.g. searching for a deceased relative).
5. *Walking directed towards an appropriate purpose, inappropriately frequently*. Walks for a purpose but this activity is repeated with inappropriate frequency.
6. *Excessive activity*. Walks an abnormally large amount of time while awake and does not sit for more than a few minutes at a time.
7. *Night-time walking*. Walks around inappropriately at night.
8. *Needs to be brought back home*. Unable to get home without help and has been brought back to his or her home at least once.
9. *Attempts to leave home*. Attempts to leave the residence but is prevented by caregivers.

In addition to Hope and Fairburn's typologies, the frequency of night time wandering can increase when a behavioral complication called sundowning is present (Sharer, 2008). Sundowning is typically associated with memory-impairing illnesses and appears to increase restlessness, anxiety, confusion, and paranoia in the evening hours. Wandering is the resulting behavior, caused by the person's attempt to reduce anxiety and increase stimulation (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007). Though there are not a lot of studies that consider the direct relation of sundowning to wandering behaviors, there is no doubt that there is an existing correlation with Alzheimer's disease. With this, it is clear that wandering encompasses a large range of behaviors and is difficult to be summed into a single definition.

Since wandering adds to a loved one's laundry list of disruptive behaviors and amplifies the complexity of their care, a caregiver's perceived level of their own stress and burden is significantly increased (Sales, 2003; Corcoran et al., 2002). With

Alzheimer's disease lasting much longer than any other diseases related to aging, the impact against a caregiver's physical, social and emotional well-being is high. In turn, women caregivers tend to report more behavioral issues, like depression, and higher reactionary behaviors versus their male counterparts (Roth et al., 2003).

Unfortunately, one common strain stems from a possible shift in family roles. Montgomery, Rowe, and Kosloski (2007), found that when there is a shift in the loved one's level of dependency that is inconsistent with their views of themselves as defined by their previous role, frustration and tension occurs for both parties. Caregivers who previously had a weaker role, especially when trying to control wandering behaviors, are typically more fearful and will sometimes tend to act like all was normal (Silverberg, 2006).

It is also common that caregivers show higher levels of anger-resentment towards their loved ones (Croog, Bursleson, Sudilovsky, & Baume, 2006). In a qualitative study, Dodds (1994) found that all caregivers that were interviewed admitted to being angry or irritated. Another caregiver admitted to being physically aggressive due to their own resentment and the repetitive behaviors exhibited by their patient. Due to lack of sleep from night time wandering, caregivers even admitted to shouting at their patient to go away because they were on edge (Dodds, 1994). With the lack of tools and knowledge of how to appropriately intervene during incidents, like wandering, it is dangerous for the Alzheimer's patient due to high levels of caregiver stress and frustration. Dysfunctionality and lack of proper coping strategies is correlated to a caregiver's anxiety (Cooper, Katona, Orrell, & Livingston, 2006).

In general, all caregivers are genuinely concerned about the safety of their loved one. The main differentiation is their reaction and the precautions that they take to secure their concerns about wandering effects within their homes. In a study, Dickson (2014) found three distinct groups of caregivers: (1) those who reacted to problem behaviors and minimally intervened, (2) those who were proactive and actively made modifications, and

(3) those who had mixed responses and did the best they could. The first group, caregivers who intervene minimally and are more reactionary, could be a result from grieving. A diagnosis of Alzheimer's disease is extremely devastating for both parties, often so much that the caregiver does not make the appropriate lifestyle modifications that are necessary to keep a loved one safe (Ablitt, Jones, & Muers, 2009). Within the grieving process, denial and shock has been identified as the first stage. Many times, caregivers deny the diagnosis and therefore deny their new role (Silverberg, 2006). It is only when six to eight wandering incidents or a serious injury occurs, that a caregiver may finally realize that this is a large issue and escalate to becoming more proactive instead of reactive (Robinson et al., 2007).

In the second group, caregivers who were much more proactive included modifications to their environment and routines before an event is triggered. Those caregivers who are within this category usually indicate that they have higher levels of emotional support and lower caregiver stress due to their confidence in their appropriate interventions or prevention techniques (Drentea, Clay, Roth, & Mittelman, 2006).

Lastly, with those caregivers who give mixed responses, they do the best of what they can with what they currently have in their possession. While these caregivers make some adjustments to their homes, there is often still a hesitation to take proactive preventive measures (Silverberg, 2006; Adams, 2006). Unfortunately, many caregivers delay changes until a crisis occurs (Adams, 2006). The impact of wandering effects on caregivers is a central issue when caring for loved ones with Alzheimer's disease.

Assistive Technology

The Assistive Technology Industry Association defines AT by considering the usefulness and its specialization of its technology employed to aid a person. More precisely, "assistive technology is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of

a person with disabilities” (Assistive Technology Industry Association). A distinction in technology for Alzheimer's caregivers can be made by evaluating the “5 categories of devices: things that lock up the home, things that keep the home safe, things that alert the caregiver, things that allow communication, things to help if a wandering event occurs” (Mace & Rabins, 2006). These 5 categories provide focus in how good design may provide targeted solutions for caregivers, especially related to wandering events.

With the growing usage of AT within the caregiving population, “caregivers increasingly rely on technology to help with medication management and reconciliation, to get information on treatment or diagnosis, to find support, and to search for services” (Adler & Mehta, 2014). In fact, “technology has been identified as one tool that can be used to improve independent living, improve the safety and autonomy of people with dementia, and support the quality of life of such people and their family carers” (Topo, 2009).

According to Pew Research Center, the vast majority (86 percent) of family caregivers have access to the internet (Reinhard, Feinberg, Choula, & Houser, 2015); many which use this technology to help navigate healthcare. In one study, when comparing non-caregivers to caregivers, caregivers have been found to use technology at higher levels, especially in pursuit for information, support, care, activities, and advice by going on the internet (Fox, Duggan, & Purcell, 2013). Nine in ten caregivers own a cell phone and one-third have used it to gather information.

Though technology advancements are on the rise, “development and use of this technology in family caregiving contexts is in its infancy” (Hall et al., 2014). Hall et al. (2014) found three major issues that exist with regards to AT: quality and quantity of interaction, boundary issues, and possible implications for anxiety. In addition, with the emergence of more holistic approaches to healthcare, customer experience has been emphasized as a cornerstone need in future development (Zaccai, 2009). In fact, as at-home care increases, the need for reliable technology infrastructure like 5G mobile

networks (Ravikumar & Prasad, 2016) may be instrumental in providing the right technology base to address a complex customer experience in areas like AT, which may have yet to have matured.

Application of AT to the Problem of “Wandering”

The pain points of caring for loved ones with Alzheimer's disease extend far beyond managing symptoms of the illness and is typically present in many cases related to the notion of wandering effects. Issues surrounding the efficacy of long-term care can be compounded by individual circumstances. Poor applications of AT may cause additional stress wherein “caregivers [can] find themselves in often chaotic and confusing [states], which makes it difficult for them to think systematically... [and] able to clearly define and understand a problem to be addressed” (Adler & Mehta, 2014). The lack of systematic design for applications addressing symptoms such as wandering effects may be an issue for consideration.

Taking a broader view of the problem, especially AT solutions directed at wandering effects, may provide insight and clues into how personas for solutions may be developed. For example, addressing segmented generational users can be problematic. In one study, “elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63% higher mortality rate than non-caregivers of the same age” (Schulz & Beach, 1999). The strain and stress of caregiving may have detrimental consequences for caregivers that may influence the way AT manufacturers approach designing products.

Again, wandering effects impact caregivers and loved ones differently and AT solutions that address the complexities related to wandering effects may prove to be market worthy; these complexities could include age demographics and economic demographics as considerations. With resources, an expectation might be more well-to-do families may provide better care for their loved ones. However, “one study found that nearly 9 in 10 middle-income people in midlife said family caregiving was harder than

they anticipated, necessitating more emotional strength, patience, and time than expected” (Reinhard, Feinberg, Choula, & Houser, 2015). Furthermore, “the burdens of caregiving have a tremendous impact on the physical and mental health and financial and social situations of caregivers, as well as on their economic productivity” (Adler & Mehta, 2014). While addressing various AT applications may seem orthogonal in nature, the fact that the caregiver does not consider the issues separate, means that the design must be integrative.

Furthermore, the application of technology could play a larger role in reducing anxiety for caregivers. For instance, “care delivery systems is a nightmare to navigate, makes it difficult for those with chronic conditions to gain access to services and coordinate them across the different types of care needed” (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007). What this means is, “people who are developing technologies to support caregiving often fail to recognize that much of the challenge of caregiving is emotional and not functional...functional burden makes caregivers emotionally more vulnerable and less resilient” (Adler & Mehta, 2014). Therefore, the challenge for good design is imperative.

Beyond the technology used to create a device, caregivers are also considered with the broader network of technologies and devices used in parallel. Overlaying multiple constituents impacted by wandering effects of patients may mean the AT solutions consider other complexities. For example, “technology [is seen] as being potentially difficult for older people, who they assume may lack knowledge or have preconceived ideas about technology” (Newton et al., 2016). As an example, a study that explored the use of tracking AT found that participants “were not familiar with using new technologies such as mobile phones (some of which have been recently been developed to incorporate tracking devices) and said they would find the use of such technology confusing, difficult to learn and distracting” (Robinson et al., 2007). Furthermore, “family carers identified the following problems with the use of tracking and tagging

devices: cost, extensive training and technical support required, technical problems, size of the device, difficulties fitting and remembering to test batteries, increased demand on family carers in terms of using the equipment, monitoring, and searching for their relative, especially if the carer was also elderly” (Robinson et al., 2007). Most disturbing may have been the potential of tracking AT to have a “steep learning curve” and the potential to “produce more anxiety if it creates ‘false alarms’ or encourage a caregiver to become an alarmist due to misinterpretation of medical data...concerns about the reliability and functionality of smart wear could thus produce more anxiety” (Hall et al., 2014). Of course, this may be speculative due to the lack of research published addressing user experience for devices in healthcare.

AT Design

Typically, products are designed for patients, but not caregivers — technology has yet to address caregiver needs. Therefore, products for caregivers may merely be addressing perceived needs versus actual needs. For instance, one study “cautioned against overly complex or poorly designed solutions that actually create more burdens for caregivers” (Adler & Mehta, 2014). Another issue is that “people with dementia expressed concern that tracking devices could be embarrassing if they emitted a noise when they were out in public, and that mobile phones used as tracking devices could be stolen from them. Familiarity of the use was of paramount importance...[caregivers] felt it should be the choice of the person with dementia whether or not they use such devices” (Robinson et al., 2007). In other words, the caregiver faces challenges from their loved ones as well as their own needs leading to researchers acknowledging that solutions must be tailored to caregiver needs and abilities (Adler & Mehta, 2014). However, according to one industry expert, Patrick Bertagna, GTX CEO, “one barrier to adoption is that people with dementia tend to be suspicious of new products—especially something as personal as a pair of shoes...the problems with people who have dementia is that paranoia

sets in...Introducing new products can be challenging. They reject them” (Schiller, 2014).

Some existing AT available have expanded to wearable technology. Wearable technology refers to “devices that can be integrated into clothing worn by care-recipients that potentially monitors location and certain health indicators while transmitting information remotely to a computerized receiver” (Hall et al., 2014). Advanced wearable technology also considers “Proactive Computing (systems that learn our needs and change their behaviors accordingly), Pervasive Connectivity (devices that have continuous access to computational and data storage capabilities in the cloud), High-resolution Sensing (cheaper, smaller and more sensitive sensors arranged in body area networks) and Orchestrated Devices (devices that automatically interconnect and work cooperatively)” (Adler & Mehta, 2014). An example of this was demonstrated by a program called Safe Return (SR), who was administered by the Alzheimer's Association. Registered individuals wear identification jewelry to indicate that they have a memory problem and can be discovered by 24-hour SR operators when a patient is left unattended or becomes lost. Since the program has been facilitated, over 5,000 persons have been found and over 60,000 are currently registered (Medic Alert Foundation, 2016).

Alternative to the usage of high technology, unconventional mythologies have come to light for new coping techniques since AT is not well prevalent. One study assessed the usage of old, familiar songs since “music seemed to be embedded in part of [the patient's] mind“ (Mace & Rabins, 2006). Patients were able to respond positively to the music, despite their dementia, and therefore founded that emotions were intact. In contrast, another study evaluated the effects of using coloring activities versus music and found that “simple leisure activities, such as picture coloring, might help patients with Alzheimer's disease reduce wandering...The coloring condition promoting high levels of constructive engagement” (Lancioni, Perilli, Singh, O'Reilly, & Cassano, 2011).

A common view outside of using technology is that caregivers become creative in using what is already in their household. Ensuring the overall household safety is seen to be of utmost importance versus using technology for its own sake. "Caregivers are often advised by medical professionals such as physical therapists and occupational therapists to adapt the home environment with an eye for potential safety risks" (Doraiswamy & Gwyther, 2008). There are a variety of "non-pharmacological intervention strategies directed at reducing wandering and similar restlessness disorders" (Algase, Moore, Vandeweerdt, & Gavin-Dreschnack, 2007). Furthermore, "when the disease itself cannot be stopped, much can be done to improve the quality of life of the impaired person and of the family" (Mace & Rabins, 2006). However, "a person with a dementia may not be able to take responsibility for his own safety. He is no longer able to evaluate consequences the way the rest of us do, and, because he forgets so quickly, accidents can easily happen" (Mace & Rabins, 2006). Again, these concerns in technology underlies the issue of misappropriation of technology to application. Technology must mirror the needs of proper at-home care.

Affordability and Financing

At-home care has several benefits over nursing homes. A perspective on proper care for loved ones with serious conditions helps underscore the bond of family and friends. Specifically, "gerontologists remind us that older adults should be permitted to 'age wherever they want to live', that is, they should not be forced to relocate" (Alkema, Wilber, & Enguidanos, 2007). Arguments supporting at-home care are not difficult to find. Even in the public eye, "nursing home scandals hit the papers in San Diego with tales of neglect and woefully inadequate care...there are no federal ADC standards or oversight" (Alkema, Wilber, & Enguidanos, 2007). However, "studies have found that when caregivers are educated about the diagnosis and feel that they have appropriate support, they are more likely to care for the patient in the home and community for a longer period of time" (Mittelman, Roth, Haley, & Zarit, 2004).

While it seems like common sense to have at-home care, the challenges in financially providing for loved ones are exasperated by a lack of subsidies and a restriction of employment opportunities. One statistic states, “unfortunately, 46% of families who have reported to have lower incomes, typically indicated not having made plans for their future care” (National Alliance of Caregiving, 2015). Furthermore, “it is well known that about 15% of the population lacks basic health insurance coverage, but most people are not aware that traditional health insurance generally does not cover chronic care services such as custodial care in a facility, HCBS, and respite for caregivers. Traditional health care is financed through employer-based funding mechanisms, yet most working individuals do not need or demand long-term care insurance coverage. About 90% of Americans lack long-term care insurance coverage to pay for chronic care services. Although most people believe that they are unlikely to need these services, the data suggests otherwise” (Alkema, Wilber, & Enguidanos, 2007). Currently, “the efforts of family caregivers get little attention. For example, the affordable care act (ACA), the biggest government effort in healthcare in decades, barely has anything for family caregivers (the only provision in the ACA designed to help caregivers, the CLASS Act, was rescinded even before it went into effect” (Adler & Mehta, 2014). Ironically, “a study estimated that Alzheimer disease alone cost the United States \$100 billion in 1998”, yet investments in caregivers may not have the visibility to have substantive impact in addressing at-home care solutions (Mace & Rabins, 2006). This demonstrates a need for increased regulations and federal funding structures.

Caregivers may face further hardships as it relates to possible disruptions in income flow. Nearly, “two-thirds of employed AD caregivers report missed work time due to caregiving obligations, while 25% report financial hardship” (Wilks & Croom, 2008). Unfortunately, “informal caregiving is associated with a lower probability of employment, reduced working hours, wage penalties and a higher risk of future poverty” (Bremer et al., 2015). Supporting this notion, one study found “unemployed family

caregivers said family care affected their ability to look for or accept a job... estimates of income-related losses sustained by family caregivers age 50 and older who leave the workforce to care for a parent are \$303,880, on average, in lost income and benefits over a caregiver's lifetime...it has been estimated that U.S. businesses lose more than \$25 billion annually in lost productivity due to absenteeism among full-time working caregivers. The estimate grows above \$28 billion when part-time working caregivers are included...nearly 4 in 10 (38 percent) family caregivers of adults' report experiencing moderate (20%) to high degree (18 percent) of financial strain as a result of providing care" (Reinhard, Feinberg, Choula, & Houser, 2015).

The challenges facing families are already strenuous without a change in public attitudes towards Alzheimer's caregiving. The current climate states that "Western healthcare systems are increasingly relying on the contribution of informal caregivers...It is anticipated that in the coming years, greater demands will be made on informal care as a result of the increased ageing of the population and the higher thresholds for the allocation of professional care. Healthcare employers and policymakers should become aware that double-duty caregivers are at risk of developing mental and physical symptoms of overload" (Boumans & Dorant, 2014). Therefore, "greater attention should be paid to the difficulties for caregivers dealing with the health care system in their role of mediators and advocates for the patient" (Sales, 2003). These factors in application, design, and financing underscore the need for further research when developing a solution for AT. Invariably, the advancement of AT requires further development as a practical tool and a coordinate effort to mature the market for mass adoption.

Chapter 3: Methodology

In order to understand how well existing AT aimed at the problem of wandering succeeds at meeting the needs of loved ones and caregivers, research was conducted to gain a deeper insight and understanding of any apparent issues.

GPS Devices

The devices that were used in this study had to adhere to the following criteria: (1) contained GPS technology that allows caregivers to seek out their love one's current location anywhere, anytime, (2) are consistently recommended as top devices to families through different online sources, stores, and associations worldwide at the time, (3) contained two components — a receiver and a tracker, (4) did not matter the physical form of design, but had a user interface (with a map) and a tangible device, and (5) is readily available as a loaner for testing without cost or associated benefit to the brand.

While there is a multitude of general GPS tracking devices available to the general public, the devices obtained were specifically made for Alzheimer's patients and caregivers who use the devices primarily for real-time tracking for safety due to wandering effects.

The four devices that were obtained that met the above criteria and were tested are: Pal (Protect and Locate) by Project Lifesaver, TRiLOC GPS Monitoring by SafeTracks, GPS SmartSole by GTX Corp, and Keruve by Vision Localization Systems. Pal (Protect and Locate) was obtained through the Alzheimer's Association's resources and directly from Project Lifesaver. TRiLOC GPS Monitoring and GPS SmartSole were on loan through Health Trends, a company who evaluates AT for home safety. Keruve was obtained directly from Vision Localization Systems. All devices, along with instructional pamphlets, demo login credentials and free credits for usage were obtained. Since this particular Keruve device was delivered from Spain, it was delivered and implemented half-way through this study.

Table 1. Features of the Devices

Major Features	Pal	TRiLOC GPS Monitoring	GPS SmartSole	Keruve
Receiver (Device)	x	-	-	x
Receiver (Website)	x	x	x	-
Receiver (App)	-	x	x	-
Tracker (Device)	x	x	x	x
Tracker (Device) Safety Lock	x	x	-	x
Tracker (Device) Panic Button	x	x	-	-
Tracker (Device) Fall Detection	-	x	-	-
Tracker (Device) Two-way voice	-	x	-	-
Locate	x	x	x	x
Map	x	x	x	x
Turn by Turn	-	-	-	x
History	x	x	x	-
Custom Geofence	x	-	x	x
Bad weather mode	-	-	-	x
Indoor mode	-	-	-	x
Flight Safety mode	x	x	-	-
Alert - Text Message	x	x	x	-
Alert - E-mail	x	x	x	-
Alert - Sound	x	x	x	x

Participants

All participants were recruited at random through well-known associations, newsletters, facilitation groups, care nursing homes, University of Baltimore students and faculty, friends, and family across the United States with a focus on Maryland, Washington D.C., New Jersey, San Francisco, and Los Angeles. E-mails and flyers were created as recruitment materials and snowball sampling was used. Chosen locations had nothing to do with demographic or cultural considerations, but were constrained by personal travel restrictions.

All respondents were given an online survey (14 questions) to fill out in order to weed out those who are already familiar with GPS tracking devices and who are not or have not been a home caregiver. General demographic and contact information were obtained. All participants were chosen to represent a range of sex, age ranges (above the age of 18 years old), location, technology comfort levels, ethnicity, education levels, and length of time as a caregiver.

Of a total of 14 chosen participants, nine (64%) were women and five (36%) were men, with seven from the east coast (50%) and seven from the west coast (50%). The ethnicity of these participants were as follows: three participants were White (21%), six were Asian (44%), one Hispanic/Latino (7%), one Black/African American (7%) and three were considered other (21%). The importance of choosing a range of sex, location, and ethnicity were to keep any cultural or locational biases at bay.

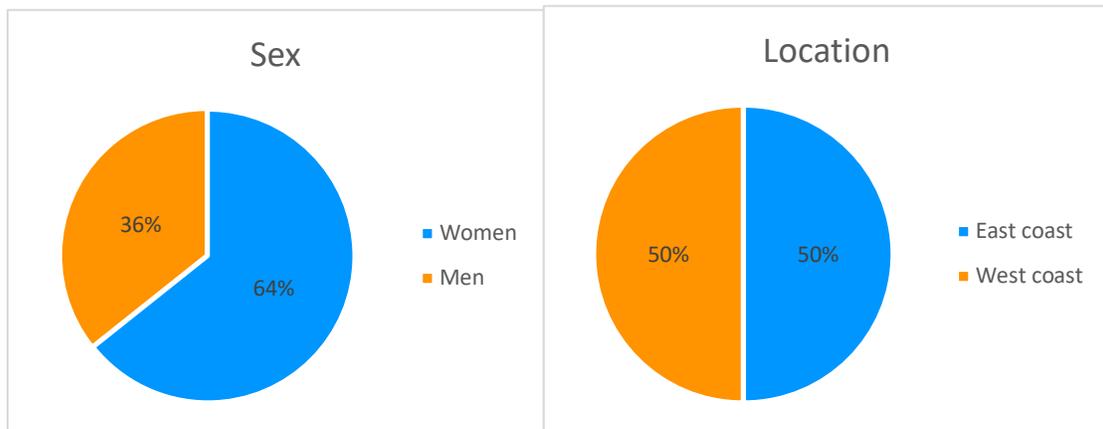


Figure 1. Participant women versus men

Figure 2. Participant locations

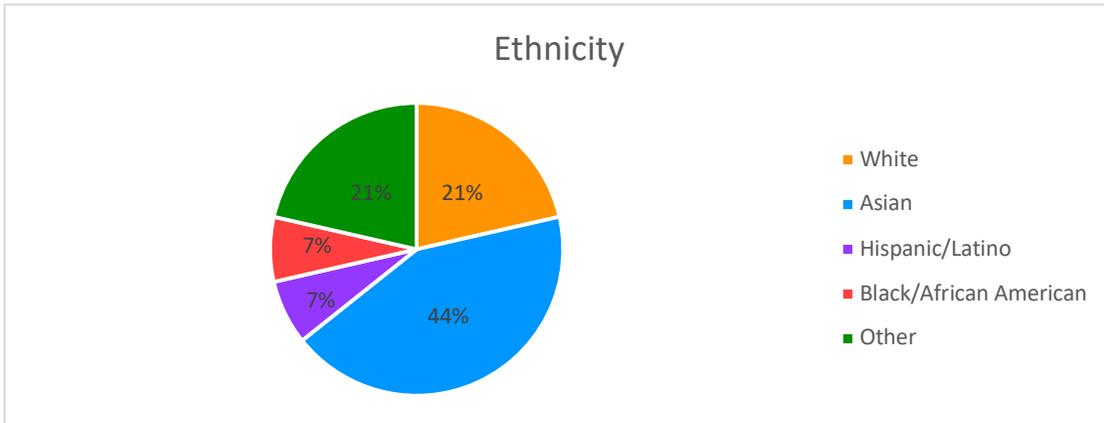


Figure 3. Participant ethnicity groups

In order to determine the range of technology comfort in relationship to age and education, two participants were between the ages of 25-34 (15%), one between 35-44 (7%), one between 45-54 (7%), eight between 55-64 (57%), one between 65-74 (7%), and one 75 or older (7%) were chosen. Of these participants, one had a High School Degree (7%), four had some College (29%), six had a College Degree (43%), and three had a Graduate Degrees or higher (21%), all ranging from one being not comfortable with technology at all (7%), six being somewhat comfortable (43%), and seven being comfortable (50%). None of the respondents to the online survey stated they were ever very comfortable with technology.

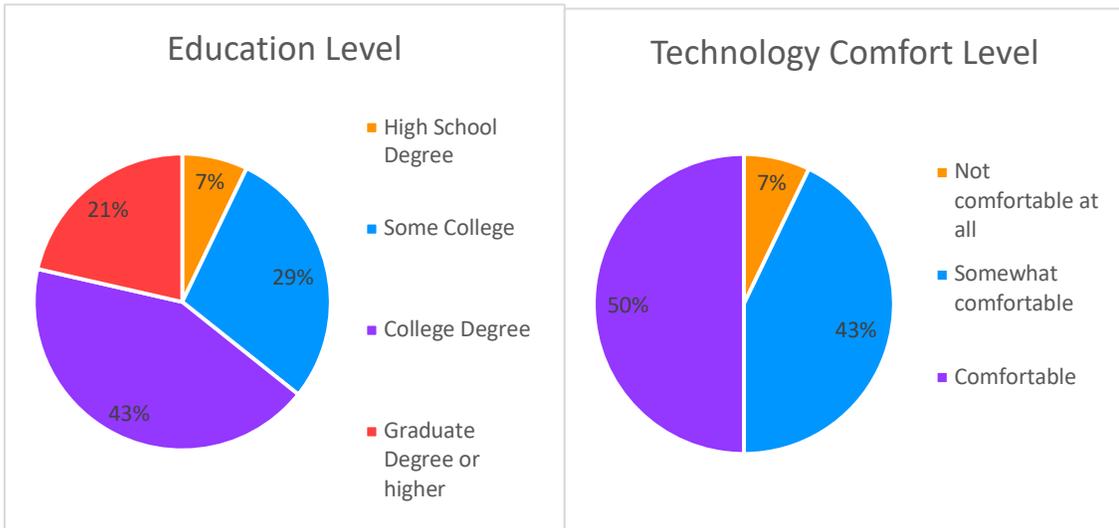


Figure 4. Participant education levels

Figure 5. Participant technology comfort levels

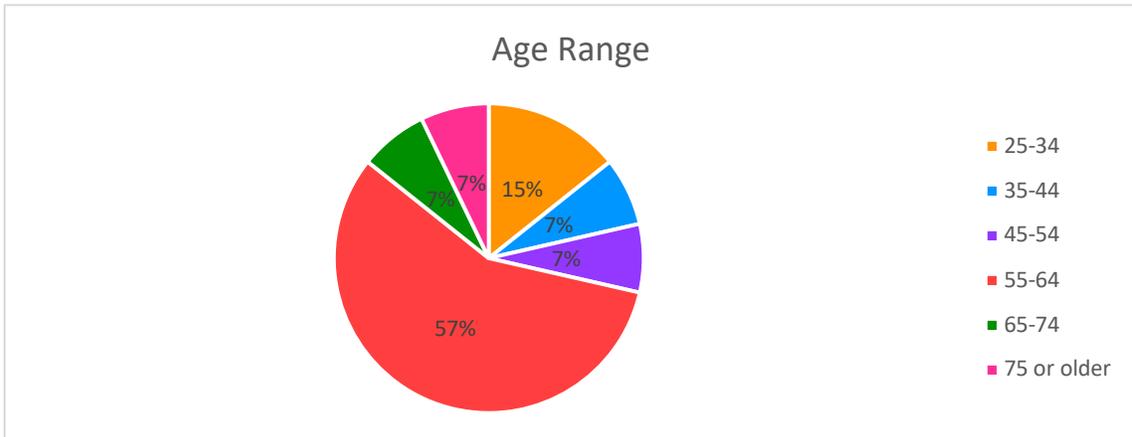


Figure 6. Participant age ranges

Of the types of caregivers, all participants were full- or part-time home caregivers (100%), five of them being both home and hired caregivers for others outside of their family and friends (36%). In terms of how long they have been caring for their loved ones, they ranged from 1 year to 25 years.

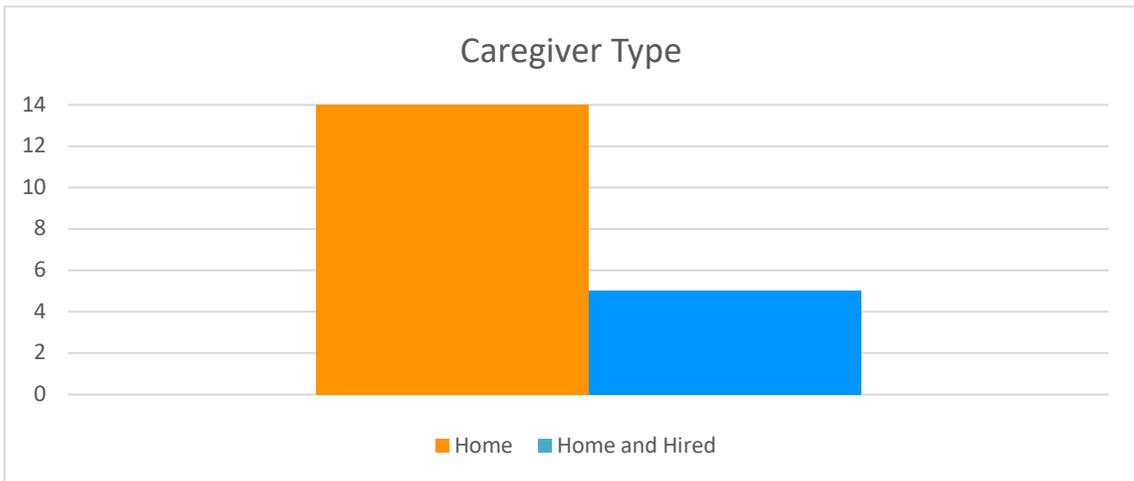


Figure 7. Participant caregiver type. Home versus both home and hired

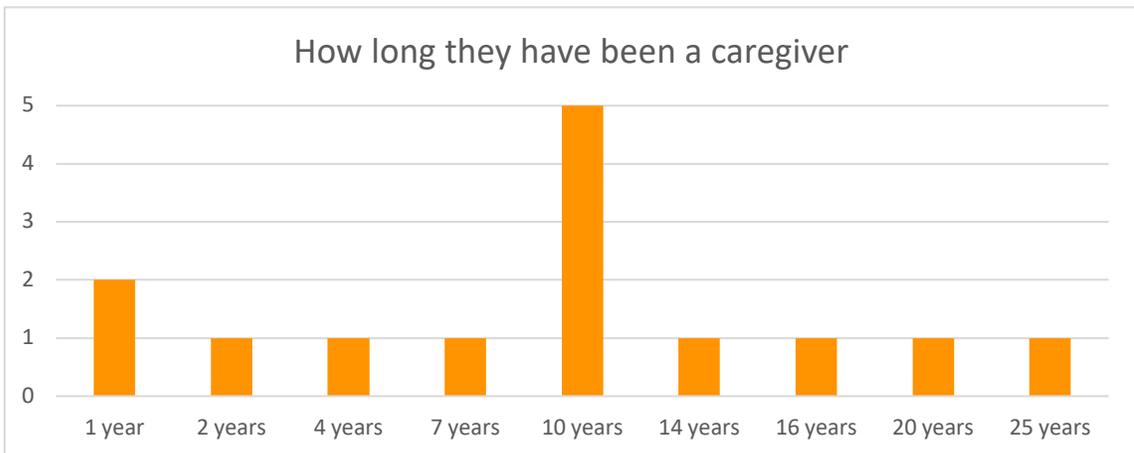


Figure 8. Participants current length of time being a caregiver

Usability Testing

The methodology used was a semi-structured, in-person qualitative usability method, which included attitudinal and behavioral dimension observations, timed task-based oriented questions, and open-ended questions. All questions asked were geared to answering the following: (1) what is the social dimension of a caregiver and their relationship with technology, (2) what is the initial perception of technology related to their knowledge from caregiving, (3) what commonalities do caregivers have when using

technology in caregiving, (4) have there been any changes in their perception of technology since the session began, and (5) what lessons can be taken away from the current usage of technology in caregiving.

During each session, each participant was asked to sign a consent form, with an emphasis that there is no affiliation to the device’s company. Talk-out loud was heavily encouraged. Across all products, one timed task-based question and feature was consistent: finding the participant’s current location. The other two task-based questions that were used, adjusting a geofence and setting up an alert, were not available on every product. Tasks were timed once the tasked question was given and stopped when the task was either completed or the participant gave up.

Table 2. Research and Interview Questions

Progression	Research Questions	Interview Questions
Start	What is the social dimension of a caregiver and their relationship with technology?	Tell me about yourself and your experience with caring for a loved one? What are your thoughts about technology? Have you used GPS technology before? Have you heard of it before?
Per Device	What is the initial perception of technology related to their knowledge from caregiving? What commonalities do caregivers have when using technology in caregiving?	What are your first impressions? Familiar with geofence/geolocation? (Timed task) Can you set up a geofence? (Timed task) Can you set up alerts? (Timed task) If someone is wearing the watch/sole, can you figure out where they are? What did you like about it? What did you not like about it?

		Additional follow-up questions
Wrap up	<p>Have there been any changes in their perception of technology since the session began?</p> <p>What lessons can be taken away from the current usage of technology in caregiving?</p>	<p>How do you feel about GPS technology now?</p> <p>What did you like the most overall?</p> <p>What did you not like the most overall?</p> <p>Other comments and/or questions?</p>

Each participant tested with at least two different GPS devices, alternating the presentation order to reduce recency and primacy effects the previous device(s) they were exposed to. Pal was tested on 11 participants, TRiLOC was tested on 9 participants, GPS SmartSole was tested on 10 participants, and Keruve was tested on five participants since the device arrived mid-way during testing.

Each session was approximately an hour long and at the end of each session a compensation gift card of \$20 was provided as a reward for their voluntary time.

Data Preparation and Analysis

All responses were recorded and transcribed. From there, responses were analyzed using an open coding system in the style of Grounded Theory (Creswell, 2013).

Chapter 4: Findings

In relation to the five research questions, five themes arose: social dimensions, technology and social relationships, device design and feature evaluation, device task-based sequencing, and reconciling cognitive dissonance of devices.

Social Dimensions

When caring for a loved one with Alzheimer's disease, the social dimensions of what that could look like varies. Nine participants were grown children caring for their parent(s), four were children caring for extended family member(s) or friends, three were considered hired help, and two cared for their spouse. The combination of parent, extended family members to friends, hired help, and spouse caregiving varied; many participants duplicated their caregiving efforts to multiple members throughout their life with different involvement levels. However, the most prominent combination for part- or full- time caregiving was the relationship between child to parent(s) (50%).

With home caregiving, it is not defined that caregivers had to live under the same roof with the ones they are caring for. 57% of the participants practiced, or still practices, remote living situations as long as they could hold off. Eventually in most situations, loved ones would either move in with them or were already living with them to start (64%), or explored different options for housing. For instance, participant 3 bought an apartment right next door to hers so she could keep an eye on her mother, along with hired help during the day.

“She's experienced forgetfulness, and I notice if we take her someplace, we come back, she doesn't remember where she was... When she was living in Chinatown, she would go out, and she would get lost, and so we would have to go find her, and bring her back to our apartment. I guess her forgetfulness, and the timing to eat, and to go to bed, and all of that has been distressing, so that's why we feel that she needs to have somebody with her all the time now” (P5).

Whether caring primarily remotely or under the same roof, nearly all of the participants (71%) had additional help from family members or friends, majority having siblings to offset tasks and financial responsibilities while juggling scheduling conflicts; while four participants (29%) received absolutely no help from family or friends. Of all the participants, 21% sought for hired help to assist in daily tasks.

“Next door neighbor, they know us...she keeps an eye on them... She came with her daughter, she pops by and stayed with her for a while until we got home” (P8).

Juggling career, life, and other priorities was more than distressing. All the participants were in the work-force and felt pressure.

“You gotta be patient. I mean, sometimes it's to the point where you just scream your head off” (P8).

Though 64% of the participants took time-off from work due to caregiving responsibilities, 36% of participants were luckily able to keep working full-time without any interruption. Of the 64%, many experienced extreme difficulties pursuing their careers while juggling life's expectations and social pressures from family, no matter the age.

“It was horrible. I worked... And so their social upbringing was very old fashioned, ‘Japanese.’ And so there're certain expectations of the kids... I used my bilingualness to get into the company; I was really fighting and moving up the corporate ladder there. And then, with my father having dementia and needing care and refusing actually to go back home, that created a big problem. There was a lot of stress... And it was very, very stressful, ‘cause I traveled a lot across the United States. As time went on and we got closer to the 10-year mark, which was around 2000, you could see his forgetfulness. I was working in downtown L.A... I used to actually go out during my lunch break, go see him, come back and do work, and then go out after. That would basically take place five days a week

while I was working, and then I'd go see him on the weekends. It was very, very taxing. I think the most stressful period, to be honest, was that. There was one period where it was really bad, where I probably lost 10 pounds in one month. Because you know, even though I set those things in place, you kind of worry...How's that gonna be paid? What do I have to do? And I actually left my company in the year 2000 and I was not working for four years" (P14).

With the majority of the participants taking time-off work or even taking leave from their jobs, receiving financial help was problematic, especially when seeking hired help or considering assisted living.

"You pretty much kinda have to have money to really go there, because they didn't have it really strong with Medicare at that time. So people's families paid out of pocket" (P7).

"The other thing is, is that, you know, people work. There's so many more working couples than there used to be. The problem is, is that with assisted living, it's almost all private pay and that's a real challenge because it's not cheap ...It's hard, and it's a hard decision for families. A lot of time, that's kind of the only option. In order to qualify for Medicaid, a family, you can keep the house, you can keep the car, but pretty much have to spend down everything else, and that's a ... For some people, they're already there, and for other people, you know that's where they go. ... It's funny, but the most challenging for both the family and everybody else are the people who are perfectly healthy except for the dementia, in part, because they live forever, and that's a terrible thing to say, but they can live 20 years with this disease if they're doing well otherwise" (T. Bennett, Alzheimer's Association, personal communication, April 10, 2015).

Not only was it difficult on their pockets, but also physically and mentally. 100% of the participants used negatively associated terms like “difficult”, “horrible”, and “challenging” when describing their experiences.

“You have no guidance and quite frankly in the ‘90s, the Alzheimer’s national was quite frankly of no help. That was about the period when having seminars and speakers and that whole shebang caught the interest of everybody. Also, you go to all those things. It’s not that you become cynical but you become ... It’s reality. You sit there long enough and you figured they’re not telling you anything... You learn early on, there are no magic capsules, lozenges, whatever. You learn and educate as you go on and actually you learn how to survive” (P12).

All of the participants caring for loved ones with Alzheimer’s disease also cared for a whole host of other ailments as well. The underpinnings of the disease itself required a lot of daily adjustments.

“...she tends to forget very easily. We have to constantly repeat things. What day it is, things like that. Where everything is. However late it was then ... now. One minute, two minutes, so it’s constant... She follows you everywhere. She never wants to be left alone. She’s very insecure that way... She’s very picky” (P6).

Of the four participants whose loved ones were deceased, one participant had very strong feelings about moving on with his life and not looking back.

“I’ll be very honest with you, since my wife died, and I don’t know if it’s anything psychological or whatever... It’s almost like, ‘Damn, that’s something to put aside.’ You don’t dwell on it. It’s not that I don’t have sympathy for caregivers, and Alzheimer’s impacted families but I’m not ... I didn’t turn into gung-ho, ‘Damn, I’m going to devote the rest of my life trying to support and assist caregivers.’ It’s maybe not a very Christianized attitude but basically, that’s the truth” (P12).

Technology and Social Relationships

It is apparent that technology is prevalent in all of the participant's lives no matter the degree of self-reported technology comfort level. All participants have interacted with today's current technology including computers and/or laptops. Of the 14 participants, 7% is using a flip phone, 79% are using smart phones, and the last 14% did not specify.

When asking about their overall thoughts and attitudes about technology in general, 71% of the participants reported having a positive outlook. Of these participants, they used words like "good" (50%) and "helpful" (30%), along with other associations like "effective" and "assist". No participants reported negative feelings, while the rest (29%) reported neutral feelings towards technology.

Though the overall consensus is positive, 11 participants (79%) verbally mentioned that using technology has limitations. Whether there is a perception that it may not be reliable 100% of the time due to past experiences.

"I tend to think ... You know technology is ... To me it has its ups and it has its downs. It does help us out...because the mind sometimes tends to get overloaded. That's when technology steps in, and it is a helping hand. You know. I mean it does have some glitches in technology, but I think that technology is good" (P2).

That the application of technology is dependent on how it is being used by an individual and their additional use cases.

"Well, I think it depends on the person. If they are mobile, then yes...But as far as a GPS or something like that, she can't get that far. But, for the norm, yeah, sure" (P3).

It was clear that for most situations, the technology is not the full solution and can never replace the need for people.

“When it was turned on, and that was on the charge of the CNA's. Making sure that these devices were working properly on the wheelchairs or sometimes it would be on the person” (P7).

Participants also explained that technology, in general, can still be intimidating to learn.

“I mean I still have problems with a smartphone but that's typical of older...and... Although I would like to be current with everything, all the apps and blah, blah, blah. I'm not moved to the point where I would study nor spend time to catch up with everybody” (P12).

It is clear that technology and people live together, highly intertwined.

“Sometimes I'm technology challenged. Gosh everybody has a smartphone and you see little kids, I have a granddaughter who is two and half and she can do things on the iPad and it's just amazing. Definitely it's part of everybody's life right now...I think definitely it's the future” (P13).

Besides simple medical alerts, 100% of the participants have never used GPS technology specifically for caregiving, but are all familiar with the general application of GPS like maps on smart phones when driving or walking (for example, Google Maps and Apple Maps). Though all participants are familiar with GPS maps, only one of the 14 participants (7%) have ever heard of geofencing or geolocation.

Since the participants have never used GPS technology for caregiving, six participants (43%) continued and spoke towards their own personal solutions either when caring and the associated benefits they have either already experienced, or their needs and wants of what they would like to experience.

Four of the six participants (80%) mentioned that having cell phones have been helpful in being assistive due to various reasons. One participant noted that being able to get rapid access to the resources they needed or tracking daily activities increased their productivity.

“I think it would help a lot. Just being young and aware of all the technology available... I would look up a lot of stuff for my mom. I know if it was just her or if my dad, who was older, was there taking care of her, he wouldn't have been able to look up a lot of resources that I was able to. Just like researching what are the resources available, where her doctors are. I did a lot of stuff, because there were so many appointments and stuff, I needed to keep track of everything. Being in touch with her doctors, I had apps downloaded on my phone where I was constantly messaging her doctors and looking up stuff. It really does supplement, assist you in doing what you're doing” (P1).

Having cell phones also allowed family members to contact each other; therefore, can help be an indicator for trending behavior or inactivity, allowed for check-ins, and if something was wrong, be able to call and locate their loved ones.

“She fell, and she was on the floor, and so I called because it was around the time that she was supposed to have eaten lunch, because see, she would get Meals on Wheels, and usually they'd come a certain time, but then I would call and say, ‘Oh, did you eat? Did you remember to eat?’ It was around lunchtime, and the first time I called, she didn't answer. The second time, she answered but she was on the floor, and so I knew to come. She was in total pain, but she said she couldn't get up” (P5).

Lastly, two participants mentioned that cell phones enhanced and allowed for more coherent communication, while saving time among different members of the family.

“I like technology... Well, there's good and bad things because I've gone through a lot of transitions to see without technology, but I think the good part of it is that if you use it effectively it can make you be more efficient, I think. Also, we started to just use just simple things like group text with my parents and that was really, really helpful where I still see my husband's family doesn't do that and so

they're calling each other, telling each other different things and where we're all sort of on the same page, so if one person did something we let everybody know..." (P11).

When addressing needs and wants based on previous experience, one participant wished to be more generally connected between all parties; therefore, making communication more efficient and less challenging. This could be applied when there are multiple caregivers, or when loved ones are living independently.

"That's part of the issue because we're not there and we're not there to go with them to see the doctors. We're just relying on what they tell us, which sometimes after... It's kind of what they wanted to hear and not really what the doctors said. And so it makes, kind of care can be a little bit more challenging but if we were able to kind of talk them and see them, we'd probably get a little bit more... All together, it just seems a little bit more disjointed and because they all live in different places" (P11).

Three participants verbalized the want for using cameras in order to visually see the overall well-being on their loved ones, possibly giving some emotional relief.

"We were thinking maybe putting in cameras, so we could see in her apartment, see if she was all right or not. I think it would be ... Technology is of course a positive in helping be aware of where she is, and how she's doing" (P5).

There was also a want for a mid-level solution to assist with caregiving before an issue gets escalated to the most extreme cases and allows for more self-sustainability.

"I've heard of the little bands and the necklace that you can press and it alerts 911, but I feel like that's extreme. You might not need that, you might just need to get in touch with your family member first before it escalates to something bigger. I like that it can keep track of where they are, have that reassurance" (P1).

Device Design and Feature Evaluation

When evaluating the four GPS devices, participants were first asked to give their initial impressions. Overall, 59% of the participants had positive first impression, 41% had a neutral impression, and none of the participants had any negative first impressions.

When given the devices, obvious design and feature opportunity themes emerged. With first impressions, eight participants (57%) verbalized the need for more compact, friendlier designs, all based on their existing caregiving experience. One participant noted that when a tracker is visibly attached to their loved one, there is a probability of their loved one becoming frustrated with the product.

“...[Y]ou know with the watches you can't take it off. They might get a little bit maybe frustrated. Maybe with this, they won't ... out of sight, out of mind, kind of thing. They might not think about it” (P6).

When the tracker was designed to be hidden, three participants mentioned it would most likely be better received. Being compact, portable, and the perception of looking very easy to use were all important and were specifically mentioned by five participants.

“I like this because it looks very compact and looks like more touchscreen, so just on that basis I like it as well. And it has a menu and all the stuff. I think just on the basis, I like it a lot and it looks very, like this is very easy because it's pretty compact. You can just probably carry it with you. It's about the size of my smartphone so it's a good size, too. And then this looks pretty easy to recharge and stuff so that's good, too” (P11).

Since many of the devices had an average of two to three major pieces, nine participants (64%) verbalized the need for consolidated devices as much as possible, as their upmost concern.

“It's great that you can just put it on your phone, so you don't have to worry of what another piece, or...things like that” (P6).

Having the product's website or app accessible on their existing devices like their phones was a high preference for six participants, across varying ages.

"Is it a mobile website?...Are there other apps for these websites?...Because you know that's what they all need, right?...The other part of this is, if there's no phone app for it then it's useless for my generation. For our generation. We do everything on our phones" (P9).

In addition, ten participants (71%) of the 14 participants would heavily rely on having an easy step-by-step instruction manual for assistance when the device's interface either is or seems too complicated to interact with.

"This isn't very intuitive. I don't like it...Because I don't know where it is right now. I don't know how to get the history. I have reports but ... I can select a date range. I don't know what are my active dates that I'm allowed to select from...I need some instructions" (P9).

"I would read the book. I would read the whole book to try to figure it out" (P6).

Industrial Design

While evaluating the devices, all participants gave their opinions regarding the physical design of the products that were glaring to them. Of the 14 participants, 100% of all participants voiced a concern in regards to comfort levels for both trackers (attached to their loved ones) and towards the devices the caregivers themselves would use (receivers). For the trackers, the vast majority of these participants used words like "big", "bulky", and "uncomfortable" most often than none. These concerns were associated to their loved one's anticipated low level of acceptance, especially if they believed they did not have Alzheimer's.

"It's big. Very large. If the person has a very small wrist, and I'm assuming probably if they're older, could be female, that this rubber part also may bother them...like if it were my father, he would get fixated on this and probably pull

this out, is one...I'm pretty sure if you had someone who is not dementia, and you tried to put it on, they will probably object, is what I can see...when they still have that cognition, they may still refuse to wear it, because they may think, I don't have Alzheimer's" (P14).

"So I think there has to be some sensitivity to that for the individual. You know as a caregiver, you say, 'you've got to wear it because you wander,' but the person who's wearing it, it can be embarrassing for them. You don't want that to happen" (P14).

Though some trackers distributed the bulkiness and made certain areas thinner to accommodate for this attribution, comfort was still a large issue. For the more hidden trackers that was located at the feet, four participants were concerned if the material chosen was comfortable and was unsure if it would be bothersome when walking due to additional existing conditions.

"Thickness? Because, it does affect the size of the shoe. You know? You have to make sure it's comfortable. With older generation, we look for ... also for problem with their feet and walking. So, anything foreign, that I call, that you insert, because it has to accommodate it" (P8).

For the receivers, two participants mentioned that weight would be an issue.

"Having to keep this with you, well, it's heavy. It's like you can stick it in your pocket and my purse is already so heavy. It's a little, it's kind of heavy" (P13).

Of all the participants, eight participants (57%) mentioned they could see charging for all devices being a large concern for multiple reasons. Primarily, there would be an issue of forgetting to either charge or losing the charger itself.

"So I guess it would be a little challenging if you had someone away from that wasn't necessarily near you on a regular basis, so you can keep track of this being charged and ... Because I have a friend whose parent has dementia and one of the

biggest things is getting her to charge her cell phone...Because she keeps losing the charger, and so it was just making me think of someone having to remember to charge these" (P7).

Or in anticipated situations where the battery could be drained and there was down time when their loved one was no longer protected.

"Maybe depending on their lifestyle pattern, again, if they wander more at night then you have to just remember when you're charging it and to put it back on them. The downtime could be a concern...to find that two-hour window to charge it, it's hard" (P13).

Or also if the battery was drained, they wondered how could they rely on this product.

"So basically this probably, maybe it won't locate it because the battery went out, do you think?" (P2).

Two mentioned the need for a better solution in relation with technology.

"You have to take the sole out of the shoe?...Can't you just put the shoe on top of it?...That's dumb. It's a pain in the ass. If you're going to have that, you need to have the charger strong enough so that I'm not going to have to take it out, put it in, take it out. You need a stronger charger so it goes through the soles of shoes" (P9).

"Probably advances in technology, where they can just have it out and it would automatically charge, might be something to think about...like in my case it was just by myself, and if I go on a business trip or get busy with something, you may forget to charge. Because sometimes when I went on a business trip, be gone for a week or several days" (P14).

For other overarching features, three participants pointed out that the waterproof and water-resistant features were positive additions.

When specifically looking at watch-based trackers, three participants liked that it showed the time since they are constantly being asked what time it was. Three other participants of the five (60%) that tested a customizable watch, liked the idea of customization and allowing their loved ones to choose type of face for personalization.

“Well, first of all, I like the design of the watch and that you could customize it a little bit. I think that's really a nice feature. It doesn't look as bulky as the other one. It just looks more like a watch. I like that” (P11).

The locking mechanism was mostly positively received by five other participants, though one participant voiced a concern if their loved one was ever in a dangerous situation where they had to remove it.

“Even though it's locked in, if they went someplace, let's say meet a bad person or something...” (P14).

Having the functionality of a panic and SOS button was positively received. However, one of the larger concerns across eight participants out of 11 participants (73%) was that the buttons themselves were extremely small, cumbersome, and were not feasible for those with Alzheimer's.

“Again, I feel for Alzheimer's it should be on top... and visible, and not a button like this because they can't even dial a phone: ... because this is too small” (P3).

Six participants noted that with memory loss, loved ones would not remember where to push the button – or even be aware that they are in an emergency situation.

“But my thing is how would the panic button work if they didn't know to push it? Or being as though you can tell them over and over again, but from time to time they may forget. I'm just saying how would they know to push it if they don't know if they are actually in a situation?” (P2).

“The best thing so far is the panic button...Then again, she has dementia, so you'd have to remind her. She might not remember that she has a panic button...my mom's short-term memory is gone. I bought her a water bottle. This is that model. Mom, this is how you drink out of it. Still can't figure it out. Still can't remember. She just opens the fucking bottle and drinks from it. This is all nice and fancy, but she's not going to remember the basic of if you fall press this button. You don't know if she is going to remember the function” (P9).

The button color blended into the tracker's design and did not stand out. Three participants suggested that the button should be red to elicit danger. In addition, typically those with Alzheimer's were of an older age and have other ailments like arthritis.

“...especially if they have arthritis in their hands, in their fingers, how easy is it for them to press this... Maybe on the face of it or something, but-I wouldn't use this for her...Just because of the size. It's on the side” (P3).

When specifically looking at the shoe-based tracker, nine out of 10 participants (90%) had concerns. Even though the participants were aware that there were different sizes available and they could adjust them by using scissors, three participants still wondered if sizing was an issue. Then looking at various situations, eight of these participants raised questions regarding situations of interchangeability and even situations when loved ones don't wear shoes, therefore leaving them unprotected.

“What if they have on a different pair of shoes. They could have on their slippers. They could go out there bare footed ...I don't think that it would be always beneficial to every person. You don't know the severities of their mind, you know?... you never know a loved one might get up and just tend to walk outside without shoes on. No one is gonna sleep with their shoes on” (P2).

Components and Elements

When looking at the components and elements that make up an interface, eight participants pointed out that the ability to enlarge the text size would be extremely helpful and would make it easier to read. Of the four devices tested, one of the devices that had a feature to allow for the adjustment of text sizes, was positively received.

“That’s good, too because some people probably have a hard time seeing and so doubling the size of the letters of the font is better” (P11).

Of the vast majority, participants were unfortunately confused due to the interface’s design: “It’s not the greatest. I don’t know how much I can do” (P8). For example, all fourteen participants (100%) all had various comments regarding the map’s design. In regards to the icon that displays the current location, six participants (43%) either: one, did not see the icon indicator at all,

“They should make it a different color, though...Blends in. You’ve got brown on top of green and brown. It should be like red or yellow” (P9);

two, other icons within the map used higher contrasting colors causing those areas to stand out more,

“It’s not bright enough. I guess it kind of blends in. Because this is more brighter. You see these marks here? That would grab my attention, rather than that one there...Yeah, I saw those things. Even this one is brighter too. It must be a bus stop or something. There’s like a fuel station here. Because it’s really hard to see this” (P14);

or three, participants were not able to decipher which colors represented what when multiple colors were visible.

“I don't know if the purple stands for them being still. I don't see a color code. Let me look at labels. The labels are not coming up. I think the last place ... that was it at 12:24” (P7).

In addition, in one device when receiving the tracker's current location and the map was out of sight, four of the five participants (80%) noted that the representation of the information was not ideal and needed translation, especially in cases of emergency.

“P11: ...I don't know how that works together with the coordinates. Has coordinates.

Me: Is that helpful for you?

P11: No. [laughs] no. Longitude and latitude, no. It's not going to help me.

Me: What would be more helpful for you?

P11: Probably the streets or something. The cross streets or something like that would be better. Intersection. Because also, too if you were trying to tell somebody where you we're, you probably wouldn't give them longitude and latitude. I mean, even when you call 9-1-1 they ask you for the address or the cross streets, intersection” (P11).

Six participants also either wished for zooming on the maps, or the zooming to be larger.

“Yeah, actually. You know what, this is kind of small, I mean but the first one was easy to look at but I think it's pretty, it's not, but I wonder can you just- I guess that, you can't open it like that” (P11).

Lastly, within the map there were two areas that were positively received by participants. One participant pointed out that they liked the live tracking arrow option, and three other participants noted that seeing landmarks and additional points of interest were helpful in understanding what possible harms were around their loved ones.

"I got a local breakfast, bed and breakfast, Taco Bell, see look at that, I like that...I like to be able to see streets... I think knowing exactly where they are and what's around them, what could do them harm, things like that...See the neighborhood. Yeah" (P7).

In general, specific images and icons were found to be confusing. Eight participants clicked on un-clickable images and labels thinking they were buttons, and continued to click multiple times out of frustration. When hero images did not match the represented targeted audience, two participants pointed out it was a bit perplexing.

"Is this something that hikers use? ...Picture of a hiker and mountains. It looks like something a hiker would use if they get lost in the wilderness" (P9).

"Seems like more of a workout app" (P1).

Icons needed to be distinguishable and clear in association to specifically what it is in reference to; otherwise, users took their best guess.

"When I think of clocks, I think of the time, so I don't think of...I just didn't, I don't equate the time symbol with history, I guess" (P7).

When conducting tasks and looking for certain features, seven participants missed important call-to-action areas because they were visibly small and hidden.

"Oh where we were at first. Oh okay. I wish it was a little more obvious" (P1).

"It's hidden. Oh, my Heavens" (P3).

Of these participants, the lack of visual grouping caused them to be confused as to what areas were correlated with each other and how they affect one another.

"I still don't know what the hell this calendar is for. It's really bugging me that nothing happens when I change the dates" (P9).

In addition, inconsistent visual behavior was found to be confusing.

“This isn't very intuitive. I don't like it... I can select a date range. I don't know what are my active dates that I'm allowed to select from...At one point the dates were bolded now they're not. I don't know why they were bolded and why they're not anymore” (P9).

When clicking on elements within an interface, four participants verbalized frustration and confusion when instant visual feedback to indicate something is happening was not occurring.

“Website's broken...I don't know how to set the fence...I don't know! It doesn't show me anything! Yes. I give up. I tap out” (P9).

“Okay ... I guess it's locating where we are. It's not doing anything. That's everything, so I don't know what ... what it's supposed to do” (P6).

“Okay, so this part, I don't really understand what it's doing at all. It's scanning something and I'm not sure...Okay. I don't know. This part is much more difficult because it's not as intuitive obviously” (P11).

When instant feedback was not continuously available, three participants rationalized it to either being related to the device's technology and/or poor connection to the internet, causing a negative perception.

“I'm trying to click yes, but it won't click yes. Is that your computer or the website?... I don't know what the fuck this thing's doing. Is it a bad connection?...because the TVs are on? Can I hit refresh?” (P9).

“That doesn't look like anything. It's taking too long. And I don't know if that depends on your internet, like how well the connection or- It's actually taking a really long time” (P11).

Nomenclature, Taxonomy, and Instructions

Nomenclature, taxonomy, and instructions, or lack of, have been found to be a large issue while evaluating these devices. All participants (100%) struggled through various levels, whether it was meaning behind individual words, non-intuitive organizational structures, or unclear or incomplete instructional text. For instance, nine participants verbalized their struggle to complete tasks due to lack of instructions within the interface.

“P7: I just didn't know, sorry. Because I saw that multiple times but I was like oh maybe that's not what it is.

Me: What made you think that it wasn't that one?

P7: Because it didn't ... the email mobile number didn't really have any directions or instructions. Says click, reset, center, and then it starts to give you instructions about this, but it doesn't really say that this email or mobile number is going to send you alerts. So I was looking for something that said that this was for alerts. And I didn't find it. And when I thought of alerts, I thought of something that would be under preferences, so that you can, you know, but the only preference that I was offered was change your password” (P7).

Though some instructions were helpful, four participants found the instructions to also be incomplete.

“So there's a cost difference, depending on how far the radius is?” (P14).

“...what if you run out of credit? What happens? Do you just loose that person?” (P10).

When looking at the individual devices, seven of 11 participants (64%) were unclear what the words high, medium, low were in reference to when attempting to set the range.

“I got to that part where it says set range, I just don't know how I can set it. That's where I am ... I am lost. It has the high, low and medium range, but is that what it needs to be in? Or does it need to be like a mile perimeter... That's it? High, medium and low? So who determines what that means, you know?” (P1).

When attempting to setup an alert, since the word 'alert' was used in different areas within multiple related devices, this caused confusion for two participants.

“P11: I don't know how to do it on this. This one has an alert here so you can choose your contact that you want to do... That was pretty... that but there might be other alerts, but I just don't know how to do that.

Me: What makes you think there are other alerts?

P11: Just because on this it says range alert so maybe there's other things just set on it” (P11).

When acronyms were used within the interface, six participants (55%) were confused as to what the words meant.

“I guess maybe I just don't understand all these like I didn't understand what arc mode meant and stuff so I think it makes a lot of assumptions that you already know how to use the system before you use it” (P11).

Five participants were unclear what 'latitude', 'longitude', and 'kilometers' meant and how it was translated to become meaningful data that can be used by them.

“P13: Latitude and longitude to me it's meaningless, I don't know... I don't view any location by latitude and longitude. Basically, for me it would be radius... I don't like it, it's too complicated. I would want to say ... Okay, if this was my house, if I lived here... I would just want to be able to say, 'Type in your current location, type it in, my address and then what is your radius, your desired radius?’

I would probably say, 'About two blocks'...Radius, I would say again something that's meaningful because meters mean nothing to me.

Me: What would be better for you?

P13: Miles or blocks or basically" (P13).

Three participants verbalized the words 'geozone' or 'reverse geocode', which were found to be unfamiliar to them.

"Geo-zone. So this is the geo-zone?" (P9).

"What's a reverse geocode? Where you can't go?" (P1).

Other additional words that caused clear confusion in relation to their meanings in various participants were: find, lock/unlock, clasp open, mezostatus, sat count, v-indoor, coordinates, bad weather mode, overspeed, getting time, and flight safe.

Navigation

Ideally, when navigating through interfaces, there is an inherent need to move through it quickly and easily in order to be perceived as a friendly and intuitive device. Of all the devices evaluated, one device had physical buttons that were correlated to an interface, and would light up while conducting certain actions. These physical buttons, though at first perceived to be seemingly easy, were difficult to navigate for nine of the 11 participants (82%) and were confusing as to the meaning behind the lights.

"Because it's more like pressing this reminds me of like an old phone. The older phones where you had to go down and click to put in names and stuff. It's not quite as easy as what you would use to use like on a smartphone or something where you could swipe it or find it or just push on it. And it's not clear to me how you actually- What all the functions are. I don't know how to switch back to the menus... Okay, so I don't really get it. I guess it's not intuitive for me. How you use it or how you would reset it back. And like that one after the range thing, the

only one light went on so the other two lights were off and then I press it and now it's at this stage and so I don't know what happened. It's on mute...When it said mute, only this light was on. And then when I pressed it, it went to this screen and I have no idea that means but then it- Now no lights are up so I don't know how if you were to try to go back to let's say the main menu, how you would do that. I don't know how that's done" (P11).

Of the participants who had difficulty moving through the physical buttons, two participants tapped on the digital screen, thinking it could have been a touchscreen.

When looking at digital interfaces, nine of the total 14 participants (64%) verbalized confusion when the navigation did not respond the way they expected it to. It was clear that participants had a specific path that made the most sense to them when trying to reach their end goal.

"It knows where you are and then it would define the perimeter based on where you are. That so, I don't know how it works but it doesn't seem like it's picking up" (P11).

"I gotta find the address. I start it up with saying I need to find the address, then continue it from the address. All right? Isn't that the basic? So, like through there, to there...I'm not sure I know where I'm gonna go. Okay, so...Okay, where are you getting the address from, or where you're going to? I can't see where I want to go" (P8).

However, the path that was laid out for them did not meet their expectations.

"I was trying to, because I think I had to reset, I had to go back to reset from the address, which I didn't do. I had somebody else's address in there, right? I think I did, because I had to turn on the flight safe on, and the sound on, but I guess I hadn't really changed the address first, but I didn't do that" (P5).

“I feel like that is a very misguided place to set up your parameter. I would never think the history would be, I would think it should be under setup or something” (P7).

It was not intuitive enough, nor did the interface behave how they anticipated it to, and many participants got lost while looking for certain elements.

“Okay. You would have to ... I don't know, do you have to like, drag it? Hm. Like, this is the area that was already set up. I mean I clicked on it. It didn't say anything” (P6).

While exploring, there were apparent findability issues within the interfaces for actions that participants wanted to conduct. Because of these seemingly limitations, participants got frustrated. For instance, when attempting to complete tasks, three participants wanted to enter their contact information but could not figure out how to.

“How do I get my name. I get my name on here...How do you enter a name? No, no, no. No. Give me any other options...I can't seem to send myself. I can't seem to find out, where do I put my phone number or my email” (P5).

Or when two participants were able to add their contact information, but were not able to figure out how to delete their information right after.

“Why can't I delete someone? I got to tell you, I'm not impressed...No, that's useless. Why can't I delete the contact I just made? [sighs] How do I do that in my details? How do I delete someone from the alerts list? Seriously. Tell me there's nothing there now. Like this sweet little button, delete. Remove. Right here. We have the list of the users. That's where it should be...It sucks” (P9).

When not being able to do what they intuitively want to take actions on, seven participants (50%) consistently looked for an exit route in order to start over due to growing impatience, even causing some to accidentally log out multiple times.

“And then I'm not sure, like now, how you get back to where you were. To exist door. Reset. Oh, no” (P11).

“I hit the back button. I was trying to go back to ...Somehow the map thing, I was trying to click on the...I'm sorry. I think I'm just impatient” (P7).

Functionality

Quick speed and high responsiveness are expected from devices. Ten of the 14 participants (71%) verbalized that the loading time took extremely long, therefore causing the perception that nothing was happening, diminishing their patience, and eventually they exited out.

“I don't know. Oh wait, loading. It takes a while to load...It takes a while to load after you first click on it, and then I end up clicking on it multiple times” (P7).

“I thought that's what it was, but it took too long, I didn't know what I was doing so I got impatient and did something else” (P9).

While the devices, both receiver and tracker were right next to each other, participants expected it to react quicker since the distance was minimal versus when it might be blocks away.

“Yeah, through 'find.' And it's locating ... it's really slow. What is it locating? It says it's locating and I think it has us pinged on here?” (P1).

“So this is supposed to locate the launch, right?...Why isn't it locating. [sigh] It's right fucking next to you dumb ass” (P9).

This quick negative lack of speed and responsiveness caused participants not to want to go through the experience again. One participant stated, “Yeah, I'm afraid to push find me again because it's been so long finding me” (P7).

For those participants who received their current location, accuracy was the utmost importance when attempting to find their loved ones. One participant stated:

“P5: We’re actually over here, so that’s not exactly where we are. We’re over here. That’s our house, so it’s not exact. I’ve experienced that with, there’s this other app that I use where it’s called 360. What is it called, where you could locate where you are with your phone, but that’s not exact either. So you know that person is if they allow you to. Yeah, 360 some ... It’s a 360 something, but they didn’t have an exact location either, so we’re a little off. I guess if we’re off, then we really can’t put a perimeter around exactly where we are?”

Me: Say if your mom was wearing this, can you track where she is right now using this product?

P5: No, because it would ... This is saying that she’s over there. She’s not here” (P5).

Of all the additional features included in the four devices, four participants stated they liked the fall detection to automatically track if something was wrong.

“If there was product, a technology product, that could sense when she fell, that would be helpful, then I’d automatically, you know. Your body weight dropped a certain level at this time and this angle. could measure it, okay, that means that a fall must have happened. You have a device or something where a service could call you and say we measured that we think you fell. Kind of like credit card fraud call. Did you fall? If you fell then we’ll send over help, if you did not fall that’s fine.” (P9).

“Does it detect fall? They could be dead and still have their shoes on” (P3).

Four participants like that some devices showed the address of there they currently were located at and six participants liked being able to receive alerts through text messaging. While nine participants felt there was value in having two-way calling, however, even with this, there were limitations in which a person with Alzheimer’s might not understand what is happening in their surroundings.

“That’s what they want to hear right away. Your voice. Even when you go, like when I go into the bathroom, she calls me. As long as I say, ‘I’m here, I’m here.’ Even though she knows that the door is closed because I’m in the bathroom, ‘Where are you? Where are you?’ As long as I have the voice, I think they feel more secure. This is good with the voice” (P6).

“...even when they’re hearing someone’s voice, they just may look at this, like where’s it coming from? Look around. And they may not be able to respond to that” (P14).

Device Task-Based Sequencing

When completing all timed-tasks, step-by-step paths were tracked; therefore, gauging frequency, typical sequential trends, and ease-of-use. To gauge perceived difficulty, these tasks were timed and bucketed into three categories: fail, success not confident, and success confident. Fail was defined as a lack of being able to complete the task either by verbally giving up or the participant became extremely side-tracked and proceeding to forget the task at hand. Success not confident was defined as being able to complete the task but either verbally or physically shown hesitation that they were not at the correct location, or did not realize they completed the task and kept moving along. Success confident was defined as there was verbal or physical confirmation that they are done and were confident that the task-at-hand was completed.

In cases where there were multiple types of devices that had individual settings per device, a website was chosen 61% of the time versus a physical device that was chosen 39% of the time at first reaction (see Table 3). After the initial selection, the participants switched between the devices a total of nine times in order to figure out which contained the actions the participants felt they needed. In cases where there was only one device to choose from, no issues in selection was found.

For Pal, three tasks were asked. When adjusting the geofence, the most frequent combined path found between participants were: menu (50%), set range (30%), and then subsequent paths ended. This was consistent to the correct path when using the device. The second highest path was found lived within the website and not the device. This path was either immediately switching out of the website to the device (37.5%) or choosing my details (25%), then live track (37.5%), and then subsequent paths ended. Of the 11 participants, a total of seven participants failed the task with an average of 3 minutes and 26 seconds. Only one participant felt success confident with a timed average of 21 seconds, and two others achieved success not confident with an average time of 3 minutes and 59 seconds (see Table 3). Though generally the group majority chose the correct sequencing in their path, this is not a reflection of an individual's path.

When setting an alert, the most frequent path found between participants when looking at the website were: first between alerts (40%) and modes (40%), then between home (20%), alerts (20%), or ending (20%), and then subsequent paths ended. The correct path is to first go to alerts, and then end. The second most frequent path but found on the device was: first going to either find (50%) or menu (50%), then either to set pref (50%) or end (50%), and all subsequent paths ended. The vast majority, seven participants, felt success confident when completing this task at an average of 1 minute and 72 seconds. Only one participant felt success not confident and three other participants failed the task with an average of 4 minutes and 79 seconds.

When finding their current location, the most frequent path found between participants on the device were: find (70%) and then ending from there. This is aligned with the correct path. The second most frequent path was going on the website and choosing: live track (83%) and then ending all subsequent paths. Of all tasks, all 11 participants felt the most comfortable with task versus all three tasks. Eight participants confirmed success confident with an average of 1 minute and 29 seconds, while three participants failed with an average of 7 minutes and 12 seconds.

For TRiLOC GPS Monitoring, even though the geofence could not be altered, the nine participants typically tried to find it under setup (44.4%), then either mode setting (22.2%) or locate (22.2%), then more (33.3%), and ending with setup (33.3%). When setting an alert, the most frequent path found between participants were: first setup (55.5%), then contact (55.5%), and proceeding to end from there. This is consistent to the correct path. However, only three participants were successfully confident, four were success not confident, while two participants failed the task at hand.

When asked to find their current location, most of the participants went to find me first (55.5%) and then ended from there. This is also consistent to the correct path. Eight participants completed the task on an average 64 seconds with success confident, while only one participant failed to complete the task, making this task the easiest of the three.

For the GPS SmartSole, ten participants were asked the same three questions. When setting the geofence, the large majority of participants proceeded to click around the map first (90.0%), and either went to edit geozone (40%) or preferences (30%), then proceeded to either end from there (50%) or continue looking around the site. This behavior was inconsistent to the correct path. The majority of the participants (five) were defined as success not confident, while three participants were success confident, averaging 52 seconds. The remaining two participants failed the task.

When setting up an alert, again 70% of the participants went to click around the map first, either went to edit geozone (30%), main menu (20%), or map (20%), thirdly went to either email or mobile phone (30%) or edit geozone (20%), and then lastly either ending (60%) or continuing to look around the site. This behavior again was relatively inconsistent to the correct path. Not surprisingly, six of the ten participants failed this task, while three were success not confident, and one being success confident. However, when participants were asked to look for their current location, all participants looked at the map first, and some (10%) proceeded to look around the website. Eight participants,

with an average of 46 seconds were success confident and the remaining two participants were success not confident, averaging 1 minute and 15 seconds.

Of the five participants who looked at Keruve, one participant preferred a walk-through, question-answer version instead of solely going over the device themselves; therefore, accounting for the 20% within Table 3. All the participants who went through the devices themselves, got all the tasks in the right order with no little to no difficulty. When completing the geofence task, four participants averaged 36 seconds, and for current location, they averaged 14 seconds; all landing success confident.

When evaluating the behaviors across all tasks, finding the current location was the easiest and most confident task available. Interestingly enough, while going through the geofence and alert tasks, the majority of the participants felt the need to find the current location first, in order to find the geofence, and then proceed to set an alert.

Table 3. Task-based pathways with frequency percentages. This is not reflective of individual paths, but combined paths.

De-vice	Task	Type	# Initial Start	# of switch	Path 1 (Name)	Path 1 (%)	Path 2 (Name)	Path 2 (%)	Path 3 (Name)	Path 3 (%)	Path 4 (Name)	Path 4 (%)
Pal	Geofence (correct path)	Device			Menu		Set Range					
		Device	4	2	Menu	50.0	Set Range	30.0	X	40.0	X	70.0
					Find	30.0	Set Pref	20.0	Last Address	20.0	Menu	10.0
					X	20.0	Menu	20.0	Set Pref	20.0	Find	10.0
							X	20.0	Get Time	10.0	Set Range	10.0
							Get Time	10.0	Menu	10.0		
		Website	7	4	X	37.5	Live Track	37.5	X	50.0	X	75.0
					My Details	25.0	X	25.0	Edit	12.5	Map	25.0
					History	12.5	Alerts	12.5	Select All	12.5		
					Modes	12.5	Select All	12.5	Live Track	12.5		

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					Alerts	12.5	Preferred Language	12.5	Logout	12.5		
	Alert (correct path)	Website			Alerts							
	Alert	Website	9	1	Alerts	40.0	Home	20.0	X	60.0	X	80.0
					Modes	40.0	Alerts	20.0	Alerts	20.0	(read manual)	20.0
					My Details	20.0	X	20.0	History	10.0		
							Edit	10.0	Mode	10.0		
							My Details	10.0				
							Modes	10.0				
							History	10.0				
		Device	2	1	Find	50.0	Set Pref	50.0	X	100.0	X	100.0
					Menu	50.0	X	50.0				
	Location (correct path)	Device			Find							
	Location	Device	7	1	Find	70.0	X	70.0	X	70.0	X	100.0
					Menu	30.0	Last Address	20.0	Find	20.0		
							Set Pref	10.0	Last Address	10.0		
		Website	4	0	Live Track	83.0	X	49.0	X	60.0	X	83.0
					Map	17.0	History	17.0	Mode	17.0	(read manual)	17.0
							Alerts	17.0	Home	17.0		
							Logout	17.0				
Tri-LOC GPS Monitoring	Geofence (correct path)	App			NA							
	Geofence	App	9	0	Setup	44.4	Mode Setting	22.2	More	33.3	Setup	33.3
					Map	22.2	Locate	22.2	Alerts	22.2	Alert	11.1
					X	11.2	Find Me	11.1	Setup	22.2	History	11.1

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					Find Me	11.1	More	11.1	History	11.1	More	11.1
					Show All	11.1	Setup	11.1	X	11.1	Locate	11.1
							Alerts	11.1			(read manual)	11.1
							X	11.1			X	11.1
	Alert (correct path)	App			Setup		Contact					
	Alert	App	9	0	Setup	55.5	Contact	55.5	X	55.5	X	77.7
					Alerts	22.2	Setup	22.2	Contact	11.1	Contacts	11.1
					Find Me	11.1	Locate	11.1	Setup	11.1	Acknowledge All	11.1
					Locate	11.1	Find Me	11.1	Alerts	11.1		
									(read manual)	11.1		
	Location (correct path)	App			Find Me							
	Location	App	9	0	Find Me	55.5	X	66.6	X	88.8	X	88.8
					Map	33.3	Find Me	22.2	Map	11.1	Find Me	11.1
					X	11.1	Logout	11.1				
GPS Smart Sole	Geofence (correct path)	Website			Edit Geozone							
	Geofence	Website	10	0	Map	90.0	Edit Geozone	40.0	X	50.0	X	50.0
					Main Menu	10.0	Preferences	30.0	Map	20.0	Edit Geozone	20.0
							Show Location Details	10.0	Main Menu	10.0	Mapping	10.0
							Whats New	10.0	Get Report	10.0	Map	10.0
							Tracking My Family Location On A Map	10.0	Timezone	10.0	Main Menu	10.0

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	Alert (correct path)				Edit Geozone		Email or Mobile Phone					
	Alert	Website	10	0	Map	70.0	Edit Geozone	30.0	Email or Mobile Phone	30.0	X	60.0
					Preference	30.0	Main Menu	20.0	Edit Geozone	20.0	Reports	10.0
							Map	20.0	Reports	10.0	Email or Mobile Phone	10.0
							Select Date Range	10.0	Replay	10.0	Main Menu	10.0
							Reports	10.0	Preferences	10.0	Map	10.0
							X	10.0	Detailed Reports	10.0		
									X	10.0		
	Location (correct path)	Website			Map							
	Location	Website	10	0	Map	100.0	X	90.0	X	90.0	X	90.0
							Date Range	10.0	Logout	10.0	Map	10.0
Ker- uve	Geofence (correct path)	Device			Menu		Security Area Radius					
	Geofence	Device	5	0	Menu	80.0	Security Area Radius	80.0	X	100.0	X	100.0
					X	20.0	X	20.0				
	Location (correct path)	Device			Locate							
	Location	Device	5	0	Locate	80.0	X	100.0	X	100.0	X	100.0

Table 4. Task-based completion rates and times

Device	Task	Fail #	Fail Avg Time (min)	Success Not Confident #	Success Not Confident Avg Time (min)	Success Confident #	Success Confident Avg Time (min)
Pal	Geofence	7	3:26	3	3:59	1	0:21
	Alert	3	4:79	1	0:55	7	1:72
	Location	3	7:12	0	0	8	1:29
TRiLOC GPS Monitoring	Geofence	NA	NA	NA	NA	NA	NA
	Alert	2	1:83	4	1:14	3	1:99
	Location	1	NA	0	0	8	0:64
GPS SmartSole	Geofence	2	6:26	5	2:53	3	0:52
	Alert	6	2:33	3	2:44	1	2:31
	Location	0	0	2	1:15	8	0:46
Keruve	Geofence	1	NA	0	0	4	0:36
	Alert	NA	NA	NA	NA	NA	NA
	Location	1	NA	0	0	4	0:14

Reconciling Cognitive Dissonance of the Devices

Near the end of each session, participants were asked about their feelings towards using technology and their overall experience in order to gauge if there had been any change in attitude due to their exposure to the devices they evaluated. Of the total 14 participants, 11 participants (79%) felt they saw the possible overall positive benefits from having GPS technology while caregiving and the assistance they could receive. Some were, even relieved to know that this technology is available and that there are companies that are looking to improve caregiving lifestyles.

“Like I said, the experience, I’ve had knowing the problems that caregivers confront daily, I mean, damn, anything that’s of help to me is great” (P12).

Given that this technology intervenes with the controversial topic of invasion of privacy and possible deception, two participants mentioned that the benefits outweighed that cost.

“...people complain about-...Invasion of privacy and everything, but yeah safety is important especially with dementia residents” (P13).

Though these 11 participants felt generally positive towards the end of each session, they did not all start off positive. Before being exposed to the devices, six participants verbally stated they were intimidated and felt hesitation in regards to the devices.

“I'm not the most technology proficient person, I find it a little intimidating” (P13).

While interacting with the devices, immediately after any kind of difficulty (either not being able to either easily navigate through the interface, comprehend what was going on, or being able to complete a task), an additional eight participants immediately blamed themselves or felt embarrassed.

“Oh shoot. I just keep logging in until I figure it out. I'm probably worse than a woman with no technology skills” (P7).

“I don't know, maybe I'm not smart enough” (P8).

Some participants even resorted to blaming their comfort level on their age, while thinking those who are younger than them could have an easier time understanding how to use the devices.

“Have somebody in their 20's and 30's they'd know right away. I think it's a generational thing... Kids younger are going to know exactly what to do. I think I am technology inexperienced and uneducated... I would need somebody to do it for me. Yeah, definitely, I would need somebody to do it for me” (P3).

“Let’s talk about the sons like my kids, late ‘50s. Now, they’re totally immersed in this electronic ... Nothing fazes them but with me and mine, you start out at ground zero because you don’t even understand the language, let alone the function of all these apps. You’re a greater fog that you were to begin with...It’s like when you ask a question, since I’m e-dumb, I don’t have an answer because I don’t know what we’re talking about” (P12).

No matter the experience level, all the participants (100%) verbalized the need for vast improvements across the devices.

“I mean I still, like I think I stated to you, it has its perks and it has its disadvantages. But if it’s something that’s gonna make our loved ones safer...” (P2).

When using any device, there are preconceived expectations of the level quality and experience based on previous familiarities.

“I don’t think it wasn’t great compared to other things I think I’ve done” (P11).

Six of the participants referred to the devices as a “concept” and three participants referred to it as an “idea” – stating there are a lot of areas, specifically regarding usability, that need to be further developed in order to truly be considered for their use.

“I think the concept and the idea of it is good, but there are some things in terms of usability of the...if there is a mobile component or the actual web that needs tweaking before could say that I could are really, because at the same time you want it to be simple for the person who wears the device, but you always want it to be user friendly or easy for the person who has to set up the device or setup and making sure it’s pretty detailed and easy to navigate even if you don’t have the directions right on hand, you know? It would be easier to kind of play around with it to figure it out. I think there were some components of each that it wasn’t so simple to figure it out” (P7).

Of these participants, six participants felt the GPS technology for caregiving has not perfected itself and needs improvements; even though four participants expressed that technology, in general, is the way of the future and is becoming, or already is, part of our daily lives.

“Useless. They don't really have it perfected yet. There's too many holes in the products” (P9).

“It's a good starting point. They're pretty far out there, but it's good they're trying to make it better” (P1).

“Because I know we have friends who have used the GPS when they're traveling. And the math is not always correct” (P14).

This perception applies even to brands and the technology behind brands.

“This isn't Google Maps. This is Bing. I don't like Bing” (P9).

When these expectations were not met, the devices seem outdated.

“This was very hard to use I think. It's not, what I said, for myself it wasn't very intuitive. It just didn't seem, it seemed a little bit not as technology advanced as I would have maybe thought just because I think we're all used to using smartphones and stuff and so I was expecting to be a little bit more like that where pretty easy. You can just navigate really easy and figure out. With a lot of things I use my smart phone I can use it the first or second time and I know how to use it just by pressing on, pushing or whatever” (P11).

In continuation, one of the major comments that all participants (100%) corresponded upon was that the devices and their associated interfaces needed to be simplified and generally, need to be easier to use.

“A clean interface...so the more simplistic probably the better” (P7).

“That’s your main issue ... is make it easier to operate for us all to work it, you know. So when we grab it off the shelf, want to buy it, better make sure that we know what we’re doing” (P8).

The interfaces did not match their current expectation, or level of knowledge, therefore making it difficult for participants to comprehend easily what was happening.

“I think it makes a lot of assumptions that you already know how to use the system before you use it” (P11).

“The features are cool. It’s just not, it’s not very user friendly. It’s not intuitive. I’m being able to figure some stuff out by playing with it, but I know a lot about Google Maps and GPS and everything like that. So I’m trying to translate what I know about Google Maps into this format. Someone, I don’t think my dad would have done too well with this because he doesn’t know a lot about technology and Google Maps, so if you have someone that’s new to GPS stuff trying to use this, it’s going to be difficult for them to use. It’s difficult for me to use and I use Google Maps all the time” (P9).

The interface also seemed too complex when trying to figure out how to move around, giving a negative experience.

“I’m not too crazy about the [website], there’s not like back button. It’s hard to really do anything with it, I mean I see it, and the find me, it takes too long to find me, I know where I am” (P7).

“I couldn’t figure out how to set the range, so that was a little ... that’s what I don’t like” (P1).

This complexity caused the majority of the participants to feel they would have to take the time to sit down and learn how to use the devices instead of intuitively figuring out how to move around the interfaces by themselves.

“The website's not user friendly. I don't know what I'm doing. I could figure it out, I suppose, but it's not, I'd have to play with it for a very long time. If there's no instruction booklet, I'd have to waste a lot of time trying to learn how to use it or Googling it, or something” (P9).

After moving through the devices, seven participants verbally stated that they would need a manual, or some type of training, to figure out how they worked.

“If you have someone who's by themselves, you can't afford home care, I'm assuming this would be a good alternative. But, I can't figure it out how to work, I've got to read the manual. And no one likes reading the manual” (P9).

“No, I don't have confidence, because I need the training” (P8).

While two other participants mentioned they would just have someone younger than them figure it out and then re-teach it back to them.

“I'd have somebody do it for me. I'd get a teenager downstairs to do it for me. I had a teenager do that for me. Because I just couldn't do it. He just picked it up and boom, boom, boom, boom. It was done” (P3).

Compounded with the need for simpler interfaces, nine participants (64%) mentioned that the navigation, labels, and instructions in general was too difficult and unclear.

“It's too much information they're hitting you with. You should be able to operate them easily. You know, that's what I mean by too much. You need to do too much to achieve” (P8).

“A little bit challenging for me, to be honest with you. I'm not the best at it to be honest with you. I'm not...I guess figuring out which of the buttons are most appropriate to push, and deciding which one's what, and what they mean. What each one means, because I guess I'm just doing it off the top of my head, just looking at this” (P4).

All participants (100%) agreed and mentioned the need for more streamlined instructions – whether that meant there was a lack of instructions, unclear instructions, or generally needed more simple and understandable instructions on the devices.

“Didn’t really have much information on how to put in ... It didn’t give me ... I wasn’t able to put a perimeter around the area” (P5).

“Seriously, because again I use my daughter as an example. Her husband sent me all of these instructions on how to use all of their DVD players, get to their YouTube and Netflix because my granddaughter likes to watch certain programs. I just looked at it, I emailed him back and said, you know what, you lost me at turn power on” (P13).

This also included the manuals that were with the devices.

“I guess, just looking through the booklet, I know that I say I read a lot of things, but after a while, there’s something that sometimes it’s very verbose, so if they can just, I like things that are short and bullet point. Any explanations, you want to do this, then do one, two, three, four, five. Always, read it, one, two, three, four, five. It’s much easier when someone is looking at something... And I’m pretty sure also, when something happens, when it goes off, and you have to refer to this later, you’re in a panic mode too probably” (P14).

Four participants suggested that in order to make it easier, YouTube might be a possible solution to streamline instructions versus an instructional booklet.

“If there’s a little YouTube tutorial or something, just to walk us through it... because I know a lot of people ... I don’t know, I don’t like reading these things, it can be confusing” (P1).

After moving through all the devices, a total of 10 participants (71%) also made comments specifically regarding the speed and how quick the devices were reacting. This

was frustrating to all the participants who made note of this, particularly those who expect quick speeds based on previous experiences.

“See, I’m kind of impatient. I like things to move pretty fast and when you get stuck it just seems like it’s taking forever because there are some apps that go really, really fast. You start getting used to those ones that you think okay, these are better because they’re highly responsive to what you doing” (P11).

The vast majority made inferences that if there was an actual emergency, and these devices were trying to locate their loved ones, something terrible could have already occurred due to the long wait time; therefore, not accomplishing one of their many needs.

“The longer it takes, the more frustrating it is... because you’re just concerned about finding your ... I’d be out on the street. I wouldn’t be doing this. I’d be out on the street looking... Yeah, probably just the time because every second counts and your loved one is wandering and... yeah, I’d rather put a leash on her” (P3).

“I feel as though that it could be a quicker jump... They could be in harms way, they could be hurt, hypothetically walking out in the street and don’t know to look both ways. And before you know it, that’s how you get to the person. They could be caught dead. They could be hit or lying down having a heart attack. You never know what the case maybe” (P2).

Once the location is found, it needs to be accurate.

“I think the technology is pretty good...If it works, I think...Idea of GPS is positive, but has to WORK. there is a perception of quick, location, accuracy” (P11).

When looking outside of the digital interfaces and specifically at the features being offered, one suggestion voiced by nine participants (64%) was to merge multiple devices into the least number of devices for better portability and therefore, also preventing the chance for items getting lost in the daily shuffle.

“If you have your own phone, and you have to carry this one also, then the issue is you have to carry two. If you're searching for someone, I mean, you're carrying this, and you're calling someone on the other phone going like this, that could be an issue. And if you have to travel or be going someplace, you always have to have two. Two of them” (P14).

“...stand alone devices will be lost” (P10).

Eight participants (57%) preferred that the devices had an application-based property because they could simply add it to their existing smartphones, or even their smartwatches, for convenience.

“I think it's just more convenient. It's something that I'm used to, as opposed to figuring out on that separate docking station” (P1).

“It would probably be easier if it's incorporated with a smart watch...Because, the smart watches already have a lot of apps...that makes things more convenient for the customers” (P8).

One participant's main concern was – what happens if the device was stolen and it was not application-based. There would be no backup device, especially in cases of emergency.

“What happens when you become stolen? And someone could steal this, thinking that it is a phone. Then what happens? What's your fall back on that? Whereas I think if you had a phone, and it was tied into a phone, I might have a phone and someone else in the family might have a phone, too, then you could use their phone. But if this is the only thing that you're able to use, and it's gone” (P14).

The second feature suggestion for improvement voiced by three participants was giving strategies on how to properly introduce wearing these devices to loved ones with Alzheimer's disease in order to increase the acceptance rate.

“So I guess when they are marketing, for the caregiver, for the person with Alzheimer's, is it suggested, how do you explain to the person who has to wear this, because you're forgetful you have to wear this? Or is it, we just got you a new watch? Here it is” (P14).

“They're very uncomfortable wearing anything. If someone is adamant, you cannot convince them to do something they don't want to do. It would be imperative that something like this is introduced in a right way. You can't do it surreptitiously because whatever transpires in somebody's head there's just certain things you just cannot ... There's barriers you cannot cross or reach ... It's nothing to do with what a caregiver thinks. It's the patient herself. Will she accept something like this? Just because it's camouflaged like a watch, I mean, I can see a from Madison Avenue point of view, Oh my god. That's perfect. It's disguised as a watch.' Somebody that's got Alzheimer's, they don't give a damn. A Tiffany, if they don't feel comfortable, they're not going to wear it” (P12).

For the third feature suggestion, three participants proposed adding a layer for analyzing predictive behavior. They wanted to be able to track their love one's daily patterns and when behaviors become variable, they could be notified.

“If the person stops, it would be nice maybe they could put a red balloon there instead. That you would know if this is a pattern, do they always stop at the same 711 or not or there is no pattern, it's just aimless wandering. I would want to know that. If the reports tell me that they always start and end at the same destination, I would [not] worry as much but definitely if there is a variance and there's a lot of starts and stops and changing directions like they don't know where they're going. Then that would be helpful” (P13).

In addition, six participants (43%) stressed the need to support a network of individuals. This was said to be especially helpful when they were frequently away from home, possibly due to work or travel.

“If someone goes on a business trip, like myself, you might have someone else who's sort of covering for you while they're here in Los Angeles. I, maybe somewhere in the East Coast or someone maybe on the East Coast, it's an alert system also where she goes there and you get secondary notice that there's been a breach, for the individual has wandered around, something like that” (P14).

“You have multiple people because obviously caregivers have family members so you'd want multiple people to know at the same time. Because then maybe sometimes, maybe the person that is in charge of the thing may not be the person closest by always. If somebody close by is also to get that message, they could then just double check to make sure the person's okay. What happened? Is it working? That would be the only thing” (P11).

This also could apply in cases of emergency where multiple, extended, caregivers from a family would be simultaneously contacted in order to expedite the speed of searching and enhance communication between parties.

“If you only have this, only one person can go. I mean, you're kind of going to make sure that you find the individual. That I can see that if you could get into the phone where everyone is seeing the same thing, you go this way, you go this way... You know, various phones and your family and they would broadcast when someone does wander. Because you may need to call in your resources and go search for this individual. Because time is of the essence when it happens” (P14).

Lastly, while family members and friends were being notified during a time of crisis, the option to automatically forward information and alert police officers that a person went missing was mentioned by five participants (36%). Being able to have

complete access to what the caregiver was seeing on their devices, these participants said it would expedite the process and would bypass the need to get out their phones, causing extra time wasted.

“Oh yeah I would image the police department would enjoy something like that” (P12).

In instances if the wandering individual ran into a stranger, and neither caregiver or law enforcement were available, the help of an identification tag might come in handy and would possibly decrease the chance of endangerment.

“Maybe a possibility is that the screen, if it's digital, you can put an alarm on it where all of a sudden it says, ‘I have Alzheimer's. I'm lost. Please call the police.’ That way, you have the option of searching yourself” (P14).

While looking at the devices and its technology holistically, there were three major apprehensions that were stated by nine participants (64%). First, all nine participants identified that though they felt positive there is a place for these devices, they recognized its limitation and questioned if these devices would be helpful enough to alleviate their chief anxiety when trying to protect their loved ones from endangerment.

“...I think it's a good backup. It does give me peace of mind, if I don't know where to look for her I could always go back and look for her before I freak out or something, but I would still try to accompany her wherever she is just to be on the safe side. So I think it's a good security blanket...but you know...I think that would be a benefit, but I think we're just too afraid to let any... just not have a companion with her. Just let her out in wherever with just a device, I don't think we would be comfortable with just that...I don't know, it might take a little getting used to” (P1).

“If you're more of an individual and you're trying to use this, I can see, drawing on personal experience, where this, you may assume that this is okay, but you may really be endangering the individual's life, too” (P14).

Especially in situations where there is a single main caregiver and the learning curve for the device is high, one participant's concern was if there was any additional support available.

“And if this [manual] were to get lost, like is there a number that the families to acquire this, can they call 24/7, like a hotline for something that they, you know... If we had this, and we can't find this book, what do we do? Or if we have a question on this, to help me set this up where I have an issue with this, I'm trying this but I can't seem to get this to work properly” (P14).

Secondly, seven participants (50%) stated that given their experience with these devices were short, they could already weigh the cost benefit. One, being that in general this technology is expensive, especially when there was a need to purchase multiple devices in order to be sustainable.

“I guess you'd probably have to have one pair of soles for every shoe you have I guess. That could get expensive I guess, because you've got to buy these things” (P4).

“I guess the question would be how much would it actually cost ... that would be how much is it going to actually cost you to keep it on and to make sure that your person or your loved one is secured and stuff. But if it's going to cost you a whole lot, then it may not be worth it” (P11).

Two, due to the lack of usability of the interfaces and in product design, participants were not impressed; therefore, giving the perception the investment was not worth their wild.

“Website's broken...I don't know how to set the fence. Is that supposed to be the red mode? How much are these things? They seem overpriced...Why can't I

delete someone? I got to tell you, I'm not impressed. These websites, I mean, come on, for all the stuff that websites can do they did not invest much money in these websites' usability. Functionality. Are there other apps for these websites?...Because you know that's what they all need, right?...The other part of this is, if there's no phone app for it then it's useless for my generation. For our generation. We do everything on our phones" (P9).

"They've got great stuff on there but it's all of it way more expensive than it needs to be...I find myself, you got a pill dispenser and it costs \$189? To what end? Yeah, it's got a little motor in it, but it just, it makes no sense" (T. Bennett, Alzheimer's Association, personal communication, April 10, 2015).

Three, caregiver financial cash flow overall is a large problem. Therefore, causing caregivers to find alternative methods that provide more cost savings.

"Similar, if you come to the top parts technician, that ... if this one costs you 65 bucks a pair, the 2nd one costs you \$500 a pair, and they both do the same job" (P8).

Again, when looking at the more generalized viewpoint, participants recognized there are much larger factors that come to play when looking at these devices as a long-term investment and how they apply to them and their families. Four participants stated that it really depended on current level of Alzheimer's disease their loved ones had and over time, while that level of dementia increases, this technology would be questionable as a sustainable asset. The technology would become insufficient.

"Oh, I think it definitely has its place. Like I said, depending on the level of dementia" (P3).

"I think it's to what degree the individual who's suffering from, or has Alzheimer's or dementia, has to how useful that technology would be. You know, if you put a GPS on them if they wander a lot, is that sufficient? Because if they

start wandering, you really have to, I would think that you really would have to think, you know. Is it just one time, or is it the beginning stages? It may be okay, but over time as it gets worse, the GPS I don't think is going to be enough. I mean, maybe to locate them, but still. I think that there's danger that's there" (P14).

In addition, participants mentioned that environmental factors and accessibility factors would be a concern.

"My concern would be, depending upon the degree of the cognition loss, whether, when you're trying to locate them or you're trying to talk to them... They may become confused and not know, or they may not even hear. You have the outside noise, where there's cars, you hear the wind blowing through the trees or what have you. They may not register that in their hearing because they. Especially if they're older also, there may be some hearing loss there too" (P14).

At the end of the sessions, two participants stated that what it really boiled down for them was highly dependent on how comfortable they, and their loved ones, would feel when using the devices in relation to how it meets their needs and wants.

"That's what it's all about is how you feel that your loved one is gonna be more safer" (P2).

"I think there has to be some sensitivity to that for the individual" (P14).

Chapter 5: Discussion

The research conducted in this study demonstrates GPS-based technology made specifically for caregivers who may lack the ability to modularly maneuver through real-life application. It was ambiguous as to what specific features were needed versus what was wanted across the devices, from both the device manufactures and from the caregivers themselves — other than being able to geo-locate, all devices seemed not to have coherent use-cases they were trying to address. When providers are consumer-centered, or have a consumer-directed care, where the recipient directs the decisions rather than being dictated to about their approach and about what concerns or questions were considered, this consumer focus would extend product feasibility (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007). This study highlights the need to “life-proof” products, especially when involved in healthcare and when one of the primary goals is to assist in alleviating caregiver stress.

By examining the social dimensions and existing lifestyle and behaviors of the users who are using the devices, use-cases can be applied to improving product design. Establishing benchmark definitions for the application of attributes to address parameters may facilitate the acceleration of new devices that adequately address real needs of the user. It is also important to note that in the findings, judgements if the devices would fit appropriately to their lifestyle were based on past personal experiences and exposure to their loved ones associated behaviors.

Challenges

Caregivers who are taking care of loved ones with Alzheimer's disease face a magnitude of challenges that were seemingly unforeseen. The application of these devices runs parallel with the severity, or stage, of Alzheimer's their loved ones are at and their current care needs. Of the vast majority of the participants, many start off in remote situations. Considerations for different cohabitation arrangements was among the

issues most commonly mentioned. The devices were not adaptable for different housing and relationship combinations, especially for remote caring and support from multiple caregivers caring at once. A caregiver's support structure was mostly made of up family members, but sometimes hired help due to limited access to family and friends. No matter the case, typically there was always more than one individual.

The impact to a caregiver's personal life causes traumatic psychological and physical stress, for which many caregivers were unprepared. Due to varying behaviors of their loved ones, a lot of daily adjustments were needed, with a need for a high learning curve and anticipation. Moreover, the findings of this study highlight several themes which when examined as a holistic model may provide a more comprehensive approach to addressing the usability of caregiver-centric devices.

The findings underscored a general commonality between participants in that devices need to be more accommodating and forgiving to large moments of disruption and caregivers who are on-the-go in order to stay connected. With the constant shift in attention, caregivers are easily overwhelmed and need devices that accommodate for any missteps, especially when it comes to recharging devices or associated down-times. Also, adding more devices to the ever-growing amount of technologies already being carried around adds to the number of items caregivers have to track on a daily-basis.

Caregivers who work are highly impacted due to their internal conflict for career and financial growth. Many who took time off from work, or discontinued their careers, had large impacts of their quality of life as well as significantly reduced financial resources. Those who kept working struggled to sustain the double burden. Financial and legal problems add to the psychological stress to caregivers and their persons with dementia (Shrestha et al., 2011). This finding suggests financial assistance from both companies and government is an overlooked policy gap. If and when investing in devices, these devices need to be financially sensible and display a level of sizable, personal value.

Though the devices were aimed for caregivers, part of devices were also made for the patient with Alzheimer's disease to wear. When examining the products, caregivers considered their loved ones' current state and typical, or atypical, behaviors and were in constant worry. This familiarity is usually gained from personal experience rather than knowledge transfer from health, or social care professionals (Newton et al., 2016). The level of understanding for their loved ones cognitive and physical limitations elicited the need for certain features and design considerations that were clearly not met. This also included even the need for proper introduction techniques for improved on-boarding and retention processes.

A general sense of frustration by the participants raised a concern to whether the products' design lacked clear definition of feature usage or if the products themselves were at all relevant. All participants acknowledged that technology devices may be helpful in better assisting the caregiver in his or her daily responsibilities. Furthermore, several participants stated that the products potentially offer real value to the needs of caregivers. Therefore, frustration from attempting to use these devices can be considered a result of poor usability rather than a lack of appreciation for the tool. Following general standard usability criteria, each of the devices failed to address common best practices in device development and technology utilization.

When running through the individual tasks, or even while perusing around the interfaces of the devices, participants easily got lost and therefore, lost motivation quickly. Given from past personal experiences, devices were expected to be simple, react quickly and be intuitive. According to the Expectancy theory (Vroom, 1964), caregivers are looking to make their effort efficient for the expected result. When they fail to reach the expected result within their desired outcome, caregivers were easily prone to quitting the tasks and blaming themselves harshly, rendering them feeling inept.

In regards to navigation, there is a lack of appropriate application of information architecture and gestalt psychology, which helps render higher findability. Understanding

the common sequential trends from the task-based sequencing and improving visual hierarchy would assist in providing an enhanced experience consistent to current expectations, and reduce user frustration while giving more sense of control.

Other areas that fail to meet general usability criteria also include implications from accessibility and cultural sensitivity. Not only was there a perception that malfunctions were due to lack of visual feedback, the device's interfaces also missed opportunities to support zooming, alternative text sizing, the need for higher contrasting color features, and the usage of universally understandable icons across all caregivers.

Within the selected pool of participants, technology adoption is predominantly valued. Whether the current climate embraces technology or that these participants were considered well-adjusted is unknown. However, all caregivers, no matter the age, were still intimidated to learn new technologies available and are likely to approach new technology in a cautious manner due to known limitations within the growing field. It is apparent though, that matching the right technology for the given use-cases is of utmost importance. Choosing a single location for settings and a single omni-connected platform which multiple caregivers use, a platform that consolidates and administers coherent communication for all parties, will reduce the number of possible challenges no matter the co-habitation situation. Given the current temperature of caregiver expectations, slow reaction times for speed and reduced responsiveness within the devices did not meet expectations, especially in anticipated emergency situations. These shortcomings left participants with the perception that the technology was not advanced enough or reliable. Carers require reliable, accurate, and up to date information about their loved one's location in order to feel confident when using AT (Newton et al., 2016). Each of the tested products failed the criteria mentioned here.

Another theme that emerged was a lack of standardized nomenclature with regards to usability in each product. With unclear or incomplete instructions, both within the manuals and the devices, and the usage of acronyms or technical words, caregivers

were confused as to what actions to take. The terminology used, though possibly not technical in nature, might also not be appropriate due to the lack of contextual meaning or to inconsistencies within the industry domain. Utilizing plain language techniques would be beneficial.

Thus far, these manufactured GPS devices left consumers with the perception that the devices are still in the conceptual phase and are not mature enough to fully be implemented into real life situations due to the lack of adherence to current device standards in design and lack of expected personal feedback and features. The participants were unable to reconcile their expectation of the product versus what real value they would receive. Efforts to educate, rather than train smart wear users could encourage more positive outcomes (Hall et al., 2014). However, it is generally more successful to redesign technology than to attempt to change user behavior. Until these GPS devices are built to support a consistent set of user stories, they are unlikely to meet the needs of actual caregivers.

Call for Industry Standards

The lack of standards presented as part of these devices suggest that room for improvement may come from established industry practices. Common user experience (UX) practices can be imported to provide greater efficacy in device usage with more specific UX techniques and relevant governmental regulations used to address the particularities associated with domain specific devices, such as Alzheimer caregivers.

Life-Proofing Ecosystem

Based on the themes and characteristics uncovered in this study, a conclusion can be made that outlines the notion of “life-proofing”. By taking into consideration general usability practices and intertwining them with the needs identified by caregivers, a framework for examining life-proof usability may be best articulated as an ecosystem. Good design must be mutually beneficial for both the business and the person using the

tool. This should be viewed in the most holistic way possible with a balance of eight major areas.

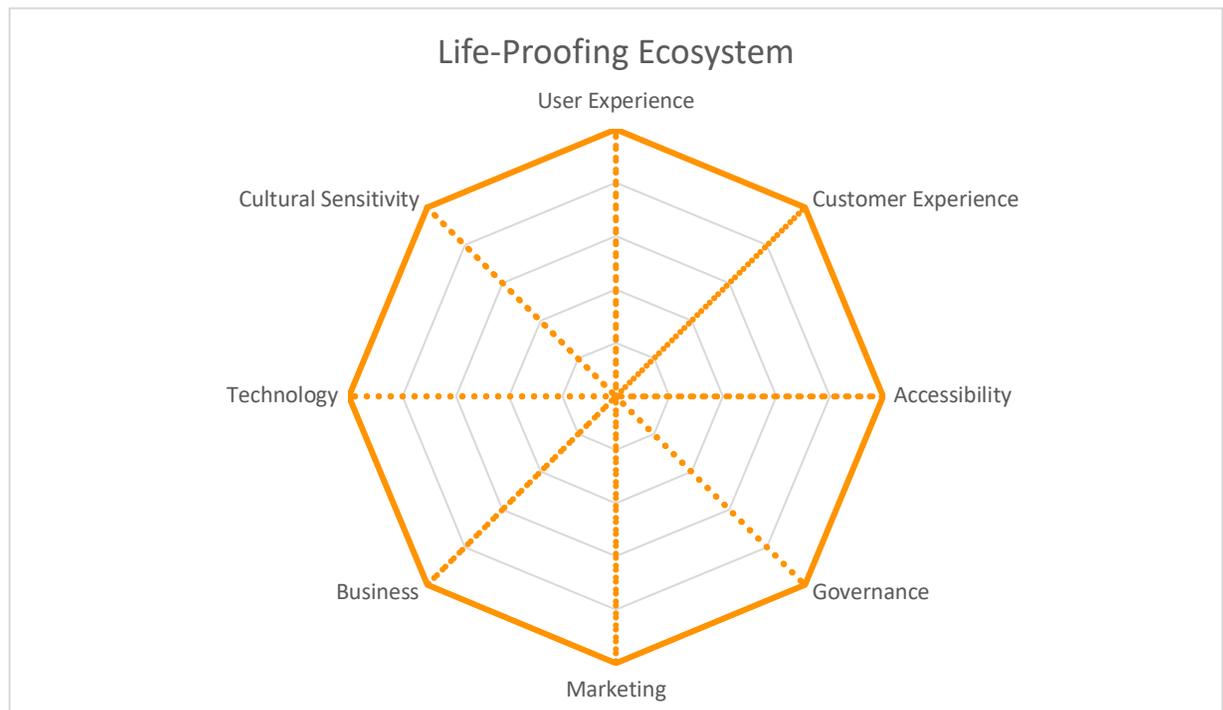


Figure 9. Life Proofing map

1. User Experience

The most evident issues pertaining to these devices in this study extend from the lack of basic UX criteria applied. “It’s a pain in the you know what ... unless I have to really get suggest what to do. I can’t just grab it and go. I need to be instructed...To show me what to use. You need to make it simple enough where you don’t have to worry about it, you know” (P8). Also, “when I can’t do something, it makes me feel inadequate” (P10). UX understands, examines, and creates solutions for full user journeys across products involving an all-inclusive spectrum of behavioral, psychological, and physical understandings. UX and Human Factors have become key components to many business models and

produce sustainability and viability of products (Frasier & Plewes, 2015). This includes, ideally:

- (1) user research
- (2) experience design
- (3) content strategy
- (4) visual design
- (5) industrial design
- (6) development and engineering

2. Customer Experience

Participants bemoaned the lack of support for these devices. For instance, P14 asked if there was an available hotline that they could contact if an issue while using the devices arise, like losing their manual, or even if their loved ones wander, would there be available support. These issues raised concerns with participants' confidence in the products. A lack of designated support at various touch points cast doubt of the long-term viability of such devices as solutions in their lives.

3. Accessibility

Outside of the traditional sense of accessibility and extended to situational and temporary disabilities, accessibility with usability and plain language techniques allows for extended market segmentation and improved experiences. Regardless the age of the participants, the often-confusing nature of the products drove many complaints from the participants. "I think easier to read, especially for people at that age because you can't see. I mean, I have to put my glasses on..." (P6). In fact, these products created an artificial barrier of entry to competently using these

devices. To minimize technology on-boarding difficulties, the use of accessibility techniques may mitigate frustrations by users.

4. Cultural Sensitivity

Due to the lack of race and ethnicity homogeneity within the participants, cultural sensitivity issues could not be directly addressed as a function of the products tested. P14 stated that when growing up Japanese, there were undeniable expectations and given behaviors across multi-generations within their family. Including socio-cultural anthropological research could add a layer in understanding behaviors, localization, and internationalism and how it relates to product design.

5. Governance

It was unclear to the extent that the manufacturers considered local and global regulatory standards. Participants assumed that these devices were compliant with U.S. government guidelines for medical devices and data security. However, the lack of transparency on this topic may be a liability for device manufacturers in the future and may create distrust in products. "As caregiver, you're doing this so you can keep track of the individual, but...I mean it could be construed as deceptive, their cognition level. And some people may accept that. Other people may fight that" (P15).

6. Business

Participants of this study often questioned to whom these products were really made for. While it has been evident that the devices lack clear usability, the issue of the specific market segmentation is also unclear. Affordability was a general concern discovered through the interviews and value of a long-term commitment to the product was questioned. "And financial is a real-...It is a huge issue" (P3). It would seem the misalignment between product strategy and market response

may impact future growth of these products. However, from a product development perspective, there are several approaches that can account for better user alignment to market expectations and sentiment. Balancing and prioritizing known product requirements and use cases, along with understanding top challenges of user personas could benefit in the sustainability for a product. Many designers have supported using the Kano Model when deciding what features would meet customer satisfaction and needs, while others are evolving towards additional methodologies (Borgianni & Rotini, 2015).

7. Marketing

None of the participants had heard of these products prior to the study. With the exception of major Alzheimer non-profit organizations providing links to certain technology assisted devices, caregivers are left to roam the internet for possible solutions. According to Newton et al (2016), most caregivers wish they could consult with an expert with the most up to date knowledge regarding AT, but most were unclear who these experts would be. The need for more comprehensive, reviewed, and detailed information about products and services offered is lacking. In fact, even the lack of published consumer reports prevents effective evaluation of these solutions. Couple these market factors with inconsistent product marketing and messaging associated with the devices, and product adoption becomes much less likely.

8. Technology

Many of the participants were surprised by the technology embedded in each of the devices. The response most commonly received was how surprising it was that the technology did not meet their expectations. "Does it usually take you that long to give you the location?... You know, you never know if the person could be

really in trouble. I mean I'm just making a statement, you know" (P2). Having a device that would respond to their needs was a common concern. Matching technology to meet consumer expectations may be a central decision for future producers as they decided whether the product may actually have an impact on a targeted addressable market.

Chapter 6: Conclusion

This study set out to investigate top GPS-based technology made specifically for Alzheimer's caregivers on how they could be improved upon and if or why they are not highly adopted within this population. Based on my personal caregiving experiences and frustrations, I was curious to learn what others experience as well.

Within this study, clear themes emerged as a result of the products failing to meet caregiver wants, needs, and basic expectations. All of these conclusions coincided with not just usability, but with an ecosystem of issues that should be addressed. The proposed "life-proofing ecosystem", which contains eight pillars within its framework (user experience, customer experience, accessibility, governance, marketing, business, technology, cultural sensitivity) aims for more balanced product evolutions and progressive innovation. This outlined framework could better assist companies, not just for AT, to improve on their approach when designing and delivering enhanced products viable for life, and that will be beneficial for both the company and the person using the products. Moreover, successful product differentiation as an outcome of product innovation may require greater intentional design in deciding between incremental and radical innovation (Norman & Verganti, 2014). Thus, device producers may accept the requirement of more precise needs profiling as part of the usability architecture and subsequently invest in developing the talent pools within their organizations and across industries.

In general, today's technology has changed the way people interact with each other, and even the way we conduct ourselves on a daily basis. Technology is one of the cornerstones in today's society that cannot be avoided. When developing products, creating just to create is sometimes tolerated. But for products to be successful in the marketplace, consumers have developed higher expectations, and the new baseline is that we expect products to fit into our lives perfectly. This includes the incorporation of good design strategies like understanding behaviors related to low literacy and accessibility,

which in fact, increases usability for all users without reducing any user satisfaction (Summers & Summers, 2005). While products and technology evolve, we too should care how well we deliver and support these experiences. Unlike technology determinists who insist on shoe horning any and all technology to churn out products based on fanciful notions of hopeful aspirations, the need for device producers in the future to focus on task-technology as a marriage between technology and usability will be critical for product adoption (Haythornthwaite & Andrews, 2011). Rogers' law of innovation diffusion states the need for a great amount of effort to be invested upfront so that the majority may benefit (Rogers, 2003). More studies are needed by researchers into methods on how social and technical conditions may minimize disparate R&D methods for devices aimed at addressing serious health issues, like how caregivers manage wandering effects associated to Alzheimer's disease. Even extending design practices like co-design (Walsh, 2010) may be required to help fully realize the sort of end state in discussion.

Increasing the amount of formalized studies that aim towards the application and need for usability would help solidify the need for integrating a more holistic approach to improving product design within companies. This framework may not be revolutionary — however, this would help provide foundation for the need for product design standardization approaches. Established disciplines like UX are still evolving and could benefit from normalization. Future research may be applied in overlaying this proposed ecosystem with other studies in an attempt to provide further quantification of how to rate and evaluate readiness and/or performance. Advancing the design paradigm as a more closely interrelated discipline of product development by connecting research to specific areas of application in products may further support the notion and the need for life-proof products.

Limitations of Study

Limitations of this study were related to social constructs, metrology methods, and technology. In addition, there was a lack of available formalized studies in relation to the design of GPS-based AT and its application to caregivers dealing with Alzheimer's wandering effects. This dearth of prior research made it difficult to find supporting baseline information.

When looking towards social constructs, the recruited participants reflected a more generalized caregiver population. Financial well-being and cultural dynamics were not considered. The results from this study may not translate smoothly for those living within the extremities of low- or high-income brackets, or across all cultural dynamics. In addition, participant biases like the Hawthorn effect and social desirability could plausibly have caused participants to be more vigilant and careful in their responses. This study did not seek to gauge this as there is no sure way to completely rid of such biases, but only to reduce it.

In regards to metrology methods, timed task-based sequencing paths were measured based on completion rates fitting to the device's given path. Due to the nature of qualitative studies, interruptions and distractions both from external factors and additional appealing features within the devices were outside of control. Methodical approaches for measuring time based sequenced activities were lacking due to a deficiency of industry standardization.

Lastly, the devices tested had some technologically limiting circumstances. A few of the interfaces needed an internet connection at all times — being dependent on its location's internet could possibly have some weight on the device's effectiveness. Though all the devices were on loan, one device was not able to track the current participant's location, but instead tracked someone else's, causing additional confusion. Also, some devices frequently ran out of batteries even though initially charged at full

capacity — which made it necessary to plug them in during testing, even while some had full charging stations. All of these circumstances were outside of my control.

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