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# Go&Grow: An Evaluation of a Pervasive Social Exergame for Caregivers of Loved Ones with Dementia

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## Abstract

Caregivers of persons with dementia (PWD) experience higher rates of stress, social isolation, and poor mental and physical health compared to non-caregiving populations. There is a vital need for engaging, sustainable, and scalable resources to support social, physical, and emotional wellbeing amongst caregivers of PWD. To explore this open design space, we designed and conducted a 6-week mixed-method evaluation of Go&Grow, a pervasive social exergame in which flowers grow as users increase physical activity and interact with other caregivers of PWD. Our findings showed that using Go&Grow helped participants relieve stress, increase physical activity, and develop empathy for and patience towards the loved one with dementia that they cared for. At the same time, tension arose as some caregivers desired to learn about the life challenges that Go&Grow users faced, while others hesitated to share such content. We discuss our findings and

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recommendations for future technology that promotes caregivers' time for themselves, understanding of PWD, and connections with other caregivers.

## Additional Key Words and Phrases

Exergame; People with Dementia; Caregiver; Physical activity; Social connectedness; Intervention

## 1 INTRODUCTION

Informal caregivers are those who provide unpaid care for their loved ones (e.g., family members or friends). The Alzheimer's Association indicates that over 16 million family members and friends provided 18.6 billion hours of unpaid care to persons with dementia (PWD) in 2019 [1]. Moreover, 86% of unpaid caregivers provided care for at least a year, and approximately 75% were concerned about maintaining their own health [1]. Indeed, caregivers of PWD experience significantly higher rates of stress as well as poor mental and physical health compared to non-caregivers [4, 40, 48, 93]. Dementia care also differs from non-dementia care in important ways. For example, caregivers of PWD are more likely to have a sedentary lifestyle than other kinds of caregivers due to the intensity and amount of care they provide for their loved ones [9]. Besides engaging in more hours of care than non-dementia caregivers, caregivers of PWD also report greater physical health problems, and less leisure activity time [49]. As such, there is a vital need for targeted technological interventions that can support social connectedness, as well as emotional and physical wellbeing, in the population of people caring for PWD [12, 20].

In our work, we are exploring the potential for *exergames* to provide such caregiver support for informal caregivers who are providing unpaid care for their loved ones (e.g., family members or friends) with dementia. Exergames are digital games in which the play involves real-world physical activity. Prior work in human-computer interaction (HCI), computer-supported cooperative work (CSCW), and the health sciences has demonstrated the effectiveness of exergames for improving physical health and wellbeing [7, 10, 26, 89]. These systems can help make physical activity more fun, so people of all ages can enjoy and engage in physical activity, which in turn increases wellbeing [13, 37, 75, 76]. Prior work has also begun to explore exergames as a genre of intervention that shows promise for wellbeing and social promotion amongst caregivers of PWD [90]. However, while researchers have investigated exergames that leverage stationary gaming consoles (e.g., Nintendo Wii), less work has investigated the potential of *pervasive social exergames* for caregivers of PWD. In such games, play is not restricted to one setting and does not require access to a game console, which means that the user can play the game and have social interactions with others on the game anywhere and at anytime. Such games may be particularly valuable for caregivers, given their time and location constraints associated with caregiving [8]. Additionally, CSCW and HCI researchers have conducted formative work to identify design recommendations for pervasive social exergames for caregivers [38, 85, 88]. This work has documented the importance of incorporating such tools into caregivers' daily routines, facilitating social interactions with other caregivers, and designing for minimized and low-burden interactions with the system [38, 85, 88]. However, there has been little

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research evaluating the efficacy of and engagement with such pervasive social exergames amongst caregivers of PWD. As such, our work contributes currently unavailable empirical evidence through our field evaluation of a functional pervasive social system.

This paper contributes to CSCW and HCI research on pervasive social exergames and caregiving by answering the following research question: *How can pervasive social exergames help caregivers of PWD increase their physical activity and social connectedness, and what factors contribute to the adoption of such tools?* We report on a 6-week evaluation of a pervasive social smartphone exergame we created for caregivers of PWD, Go&Grow. In Go&Grow, caregivers complete fitness challenges and communicate with other caregivers via a story sharing feature. We found that Go&Grow helped caregivers to have more time for themselves. They could focus on their own wellbeing, which increased their physical activity and relieved caregiving stress. Caregivers also increased empathy for and patience towards their loved ones. Our findings also highlight important factors that contributed to and hindered a sense of connection to other caregivers and the stories shared in Go&Grow. Our contributions to CSCW research on caregiving include: 1) new empirical evidence regarding the efficacy of and engagement with a social pervasive exergame designed for caregivers of PWD, and 2) a set of novel recommendations for the future design of such systems.

## 2 BACKGROUND

### 2.1 Physical Activity Promotion in Caregivers of PWD

Caregivers of PWD are at risk for more poor health outcomes because they are less engaged with preventive health behaviors compared to caregivers who are not caring for PWD [72]. In addition, many informal caregivers of PWD are older adults who are already facing physical and cognitive decline as a result of existing health issues [96]. Physical activity interventions seeking to improve physical health are important for caregivers of PWD [45]. According to the U.S. Department of Health and Human Services, adults should do moderate-intensity aerobic exercise for at least 150 minutes per week and muscle-strengthening activities for at least 2 days per week; or a combination of vigorous and moderate activities per week [60]. However, caregivers of PWD are less physically active compared to other kinds of caregivers [8]. Furthermore, caregiver reductions in physical activity are associated with more depressive symptoms, self-reported caregiving burden, and poorer psychological health [45].

Despite the importance of physical activity interventions for caregivers of PWD, few studies of interventions for this population exist. When community-dwelling caregivers of PWD in Japan were randomly assigned to come to intervention groups for moderate exercise, there was a significant reduction in the feeling of burden [35]. A landline telephone-based exercise intervention designed for women caring for spouses with dementia showed a reduction in caregivers' perceived stress and an increase in exercise self-efficacy [16]. Home-based interventions can be convenient for caregivers who are constrained to the home [44, 95]. However, the studies reported here were limited in their scalability, sustainability, and accessibility because they either were confined to the home, required people to come to a specific location at a specific time, or required dedicated staff to deliver the intervention.

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Researchers have begun to explore the design of exergames for caregiving populations. One study evaluated an exergame that provided movement, balance, and cognitive activities for PWD and their caregivers [88]. Caregivers in that study were able to increase their social interactions in the group setting with those they were caring for and other caregivers. However, the exergame required the use of a game console, which constrained the gameplay. In addition, the game was played in a group setting that involved others watching the players perform, which made some people uncomfortable [88]. Furthermore, because many caregivers of PWD face time constraints and have busy schedules [6, 83], restricting gameplay to one setting could make this type of game inaccessible to many caregivers.

## 2.2 Social Interventions for Caregivers of PWD

Because of the nature of the care they provide, caregivers of PWD are also known to experience a significantly higher rate of perceived burden, stress, social isolation, and loneliness compared to caregivers who are not caring for PWD [3, 42, 63]. As a result, a growing number of health interventions have sought to improve the psychological and emotional wellbeing of caregivers of PWD [15, 17, 22, 32]. Social connectedness with others has a protective effect for caregivers during times of stress [35]. However, past studies have often focused on the general wellbeing of caregivers of PWD as an outcome, when social connectedness is also critical for this population [16].

Social intervention studies utilizing online communities have been helpful in increasing care- givers' social connectedness with others and improving their relationships with their loved ones [5, 21, 50, 55, 62]. Online communities for caregivers of PWD have provided various features, such as public forums, chatrooms, social networking groups, online group messaging systems, and private chats [44, 50]. Participation in these virtual communities is not restricted by location or time, allowing caregivers to access support in their limited time without leaving their homes [55, 62]. Online communities enable caregivers to receive peer support through informational and emotional support, and through the expansion of their social network [21]. One study also found that participation in an online support forum for caregivers improved the quality of their relationship with the PWD [50]. While the researchers did not directly study the mechanism behind such relationship improvement, they hypothesize that it may have been due in part to gaining more information about how to care for their loved ones [50]. These studies suggest that online group interactions hold promise for connecting caregivers with other caregivers that have shared experiences, and that accessible and flexible online information sharing with other caregivers helped them better care of their loved ones.

However, it is important to note that while social interactions in online communities can be positive, they may also have unintended consequences if they lead caregivers to continually focus on their problems without connecting them to resources that can support effective management of their caregiving challenges [80]. Indeed, prior work has investigated the extent to which caregivers convey negative experiences within online forums. For example, one study used content analyses of a caregiver forum on ALZConnected.org to reveal that many forum posts involved negative emotions, with caregivers feeling fatigued from the constant caregiving burden [70]. In addition, caregivers also experienced frustration and

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disappointment when their peers did not actively participate or when caregivers' emotional needs were not reciprocated [21]. These prior works, which demonstrate both the benefits and limitations of online caregiver communities, highlight an important opportunity for technological innovation to be multicomponent in nature. Specifically, there is a need for work that examines the potential benefit of combining online forums that enable social support with additional intervention components that catalyze health-promoting behaviors. Such tools should be designed to mitigate against challenges such as feelings of caregiver burden, as well as a lack of support reciprocity among peers.

CSCW and HCI research has recommended that future interventions enhance the social connectedness of informal caregivers of PWD by 1) encouraging them to develop relationships with caregivers who share similar experiences and situations [81], while also 2) helping caregivers continue their own leisure activities (e.g., leaving the house and enjoying outdoor activities) [82]. The creation of technologies that help meet these joint needs may be an important way of supporting more holistic wellness promotion and social engagement amongst caregivers. Our work addresses this open area of research through the creation and evaluation of such technology.

## 2.3 Pervasive Social Exergames

Our work examines how mobile apps can deliver more accessible interventions that jointly encourage physical activity and social connectedness for caregivers of PWD, as a means of fulfilling their social needs and helping to relieve stress from caregiving. We are specifically examining the potential of *Pervasive social exergames* in this population. *Pervasive social exergames* are digital games in which play involves real-world physical activity while also allowing for social activities with others during the gameplay. Much of the prior social exergaming research has focused on digital coaching systems in a stationary video game context [11, 24, 41, 59, 98]. These studies have demonstrated improvements in players' physical strength, socialization, and mood [10]. Prior work has also demonstrated players' experience of enjoyment during exergames [47, 52]. Such enjoyment can come from the sense of competence players feel in accomplishing their goals as well as a sense of relatedness or a feeling of connection with other players in real life and in the virtual world [31, 47, 52]. The enjoyment, motivation, and social experiences exergames can bring to users can also promote and facilitate physical and social wellbeing for caregivers of PWD.

Some studies have focused on evaluating social exergames for PWD and their caregivers. *MobiAssist* is an exergame that uses stationary equipment (e.g., a sensor-augmented TV) to improve the wellbeing of PWD and their caregivers at home and in the day-care center setting [88]. MobiAssist includes a variety of training and game modules targeting areas such as strength training and balance. The evaluation of MobiAssist demonstrated improvements in the physical and cognitive capabilities of PWD and social interactions for the participants [88]. Incorporating the game into the daily routines of PWD and their caregivers also helped provide caregiving relief for both informal and professional caregivers [88]. A participatory design case study involving the redesigned social exergame system also showed the importance of enabling social interactions in exergames, as the informal caregivers in the study had pleasurable interactions with their family members with

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dementia [87]. The same social exergame system was evaluated and re-designed over two years and another study was carried out for a different set of PWD and their caregivers [86]. Results of the study were consistent with the previous studies, showing the system's effectiveness in facilitating physical movement and in encouraging social interactions between PWD and their caregivers, along with the relief of daily caregiving pressures among the caregivers [86]. The results of these social exergame studies show the value of designing systems that promote and motivate physical activity and social interaction for both caregivers and their loved ones. This work also highlights the importance of creating tools that can tightly integrate into caregivers' daily routines to better support their physical and social wellbeing in their daily life.

While past social exergame studies have shown benefits for both PWDs and their caregivers, these studies were evaluated qualitatively exclusively, while utilizing a mixed-method approach of both qualitative and quantitative data can provide additional insights. In addition, prior studies focused primarily on the physical and cognitive levels of PWD, and the social interactions between PWD and their caregivers. Additional limitations of past social exergame studies include the requirements of stationary equipment (e.g., TVs and game consoles) and the restriction of gameplay to one setting (home or day-care centers) [86, 88, 90]. There is thus an opportunity for increased examination of how pervasive social exergames can better support caregivers of PWD directly and in community with other caregivers, at any location and time.

*Pervasive social exergames* help address this inaccessibility barrier, as play and social interactions are not restricted to one setting and do not require access to a game console [30]. Such games show promise for caregivers of PWD because given the nature of caring duties, caregivers often face constraints such as having very limited time to engage in physical activity, and reduced psychological capacity to engage with a mentally taxing intervention [77]. Furthermore, given that caregivers experience reduced social support [66], pervasive social exergames present an opportunity to promote social connectedness in the caregiver population, while also allowing caregivers to engage in leisure activities for themselves at any time and place. Pervasive social exergames have been shown to increase physical activity level, mental and social wellbeing in adolescents and young adults [53, 63], older adults [34, 46, 69], and various vulnerable populations [27, 36, 41, 67]. Yet, to our knowledge, no studies have evaluated the efficacy of a functional pervasive social exergame system designed primarily for caregivers of PWD. Our work seeks to fill this significant research gap with empirical evidence describing the experiences of caregivers of PWD using a pervasive social exergame.

### 2.4 Summary of Research Gap

In summary, caregivers of PWD are more likely to have a sedentary lifestyle, more stress, and less support than caregivers to individuals with other conditions [4, 40, 48, 93]. There is a need for interventions for caregivers of PWD to address both physical activity and social connectedness. Past physical activity and social interventions for this population tend to stand on their own, addressing *either* physical activity *or* social connectedness [22, 35, 45, 67, 81, 91]. However, pervasive social exergames can serve as an intervention that

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intertwines these two components together to maximize the health benefits for caregivers of PWD [77]. While formative pervasive social exergame research has been conducted, focused on identifying design requirements for informal caregivers (family members and friends who take care of those in need of care) and PWD [44, 69, 73, 76], there has been little work evaluating a functional pervasive social exergame system designed for caregivers of PWD. Additionally, past work evaluating functional social exergame systems has often focused on PWD, rather than systems promoting physical activity, social connectedness, and wellbeing of their caregivers [86, 90]. Those exergame interventions that were designed for caregivers of PWD, while important, have been limited in their scalability, sustainability, and accessibility, for example, due to the use of stationary equipment, the time commitment required, or being in an inaccessible location [18, 23, 90].

We address these gaps in research by exploring opportunities for pervasive social exergames in the context of caregivers of PWD. Such games can also provide caregivers of PWD with an opportunity to connect with other caregivers virtually while also having space for themselves to have more leisure and outdoor activities anywhere and anytime (which was not viable in prior social interventions for caregivers of PWD) [86, 88–90]. Importantly, our work is one of the first to evaluate the efficacy of a wearable activity tracking-driven, pervasive social exergame designed for caregivers of PWD. Given the growing prevalence of wearable fitness platforms and applications, it is crucial to investigate their viability within the caregiver context, to avoid creating intervention- introduced inequalities that can arise when interventions are more accessible and effective for socially advantaged groups [78].

## 3 THE GO&GROW SYSTEM

Our system design was informed by findings from a formative study we conducted to investigate caregivers of PWD's perspectives on pervasive social exergames [77]. Using semi-structured interviews and participatory design methods, we identified caregivers' preferences for a garden- themed game, caregiver-tailored goal setting, minimized and flexible system interaction, and low-burden social interactions and connectedness [77]. First, the study revealed that in terms of virtual rewards, caregivers were more interested in the concept of walking to grow a virtual flower rather than creating virtual artwork [77]. Second, given their limited time and unexpected day-to-day schedules, they wanted caregiver-tailored goal setting that is achievable and realistic [77]. Third, they desired brief and flexible interactions with the system that could fit into their schedules easily, given the unpredictability of their days and the guilt they felt engaging in self-care [77]. Finally, given their daily caregiving roles and unexpected progression of their loved ones' conditions, they desired low-burden social interactions and connectedness with other caregivers of PWD, to share advice and informational support [77].

Using our prior work as a guide, we designed *Go&Grow*, a garden-themed, pervasive social exergame for Internet-enabled Android smartphones. The game aims to encourage (1) *physical activity* and (2) *social support* among caregivers of PWD. To encourage physical activity, we designed a *fitness challenges* feature with a metaphorical plant growth visualization. To encourage social support, we created a *social story* feature. To track caregivers' physical activity, we used Fitbit Alta HR activity-tracking wristbands.

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### 3.1 Feature Overview

The app was divided into the Nursery, My Garden, and Community Garden tabs. In the *Nursery* tab, caregivers could grow flowers, track their daily steps and workouts, and view social stories. In the *My Garden* screen, caregivers could view their garden and access their profile pages. The profile page consisted of the caregiver's username, icon choice, location, the stage of illness of the person they were caring for and their relationship with this person, and a fun fact about themselves (Figure 1.F). In the *Community Garden* tab, caregivers could look at other caregivers' gardens and profile pages (Figure 1.E).

A caregiver would start a fitness challenge by choosing a 7-day daily step goal. Then they would plant the flower seedling in the Nursery screen (Figure 1.A). Throughout the week, Go&Grow would download their step data as tracked by their Fitbit. As caregivers meet their daily goals, the seedling would gradually grow into a flower. At the end of the 7-day period, the challenge would be complete, and the caregiver could plant the flower in the My Garden screen (Figure 1.D). The goals that caregivers could choose were based on the average steps the caregiver took the week before. These goals were categorized into easy, medium, and hard levels, which were 90%, 100%, and 110% of the average of the last seven days' daily steps, respectively. Each level grew different types of flowers, with more intricate flowers for the more challenging levels.

Caregivers could multiply the flowers they were growing and unlock new flower packs. To mul- tiply flowers, caregivers needed to log at least 14 workouts during the 7-day challenge. Caregivers could log an exercise by 1) going to the Nursery screen, 2) pressing the Workout button, 3) choosing a workout tutorial (on endurance, strength, balance, and flexibility), and 4) finally logging the workout once they have done it (E.g., users could do and log sets of strength exercises). Users could then monitor their weekly exercise progress (Figure 1.C). To unlock new flower packs (e.g., flowers from the four seasons), caregivers needed to share anything on their mind as a *social story* (Figure 1.B). Caregivers could share a story by 1) going to the Nursery screen, 2) pressing the Stories button, and 3) tapping the Post Story button. In the Post Story screen, users could choose *story prompts* that provided optional topic guidance. A caregiver could also choose to write any prompt they wanted with the *"What's on your mind?"* option. Additionally, caregivers could read, like, and reply to other caregivers' stories.

### 3.2 Design Rationale

To facilitate aerobic activity, caregivers could choose a *fitness challenge* to grow flowers as they achieved daily step count goals and plant these flowers into their garden. The flower growth metaphor and imagery aimed at showing physical activity progress visually, which was often preferred by fitness tracking users [65]. We created this fitness challenge feature because in prior work, supporting action planning and reinforcing effort towards behavior was highly associated with self-efficacy and physical activity [94]. A meta-analysis found that interventions using feedback and goal setting increased self-efficacy and physical activity for participants [3]. Informed by prior work that revealed that caregivers of PWD had unpredictable weekly schedules and events [77]. Go&Grow did not set the users' step goals, but instead allowed caregivers to choose their goals based on the steps they took in the

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previous week [17]. We designed this feature to support goal-setting that avoids putting too much pressure on caregivers.

To encourage *physical activity* in terms of *muscle conditioning*, caregivers could log muscle-conditioning workouts to multiply their flowers. We included tutorials from the U.S. National Institute on Aging to support caregivers' self-efficacy in muscle-strengthening workouts [61]. These workouts were suitable for adults of all ages, and users could log the number of times they did each workout.

To facilitate *social connectedness*, users could share stories, visit other caregivers' gardens, and like and reply to stories shared by other caregivers. These features aimed to help caregivers to interact with one another and exchange information, guidance, and encouragement, for example, around caregiving experiences and physical activity pursuits [92]. Such online support could help caregivers interact with users from numerous places, and thus collect a variety of perspectives from people facing similar situations [92].

We provided story prompts to help bootstrap story creation before caregivers post stories. The story prompts primarily focused on reflections on the positive dimensions and challenges of caregiving. Guided by prior work [14, 29, 74], we created example prompts such as: *"What is a positive caregiving experience you had this week?"* [7], *"What are some of the challenges you faced this week?"* [74]. Furthermore, we developed additional prompts to encourage caregivers to share their physical activity experiences, for example: *"How did you increase your physical activity this week?"*. We also included a broad *"What's on your mind?"* prompt to support more varied story sharing.

To further support social connectedness, caregivers could indicate their relationship with their loved ones in a publicly viewable User Profile page. This option was motivated by our formative study demonstrating the importance of enabling caregivers to find others who were similar to them (e.g., based on relationships to the person they are caring for) [77].

## 4 METHOD

We conducted a 6-week mixed-methods study to evaluate caregivers' experiences with Go&Grow and its impact on their wellbeing. The authors' training and domains of expertise include psychology, HCI, CSCW, gerontology, and empirically qualitative and quantitative methods. Across our team, we have studied the needs of caregivers of PWD in the context of technology design for 4 years. Prior to recruitment, this study was approved by Northeastern University's Institutional Review Board.

### 4.1 Participant Overview

We recruited eighteen caregivers through community centers, Craigslist, and snowball sampling. Our inclusion criteria were as follows. First, participants needed to be a caregiver who spends a significant amount of time with a family member, partner, or friend with Alzheimer's Disease or related dementia. They were also required to be 18 years or older, be able to walk for at least 20 minutes at a time, have regular access to an Android smartphone with Internet access, be comfortable wearing a fitness tracker for the duration of the study,

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have not had a cardiovascular event or a fall in the past 6 months, and be located within the Massachusetts, New Hampshire, Rhode Island, Connecticut, and New York City regions. In addition, participants needed to be cognitively healthy, as identified by passing the Pfeiffer screener with less than two errors [64]. As compensation, participants kept the Fitbit Alta HR we provided them with after the study.

Eighteen caregivers participated in the study from April to August 2019 (Table 1). Most partici- pants were female (N=16), and they ranged in age from 22 to 70 years old (m=49, sd=15). 44.4% of caregivers were White, 27.8% were Black/African American, 16.7% were Asian, and 11.1% were Hispanic or Latin American. 11.1% of the caregivers had some high school, 22.2% of the caregivers completed high school, 5.6% had some college education, 41% completed a college degree, and 16.7% completed graduate school. Just over half of caregivers (55.6%) had never used a mobile physical activity app before. Participants were caring for their parents (N=10), other family members (N=6, grandmother, cousin, sister-in-law, partner's aunt, godfather), or a friend (N=2). The age of the person they were caring for ranged from 68 to 94 (m=80, sd=7.7). Participants had been a caregiver ranging from 6s months to 10 years and spent from 2 to 7 days a week with the person they were caring for. 78% of participants were caring for individuals diagnosed with Alzheimer's Disease, and the rest were caring for loved ones diagnosed with dementia.

## 4.2 Procedure & Data Collection

**4.2.1 Session 1.—**In the first meeting, participants completed the consent form, demographic survey, and a pretest survey that measured their management of distress [43], which is the amount of time caregivers spent on themselves doing leisure activities when they were under stress from caregiving. Participants then received the Fitbit Alta HR, a Fitbit training, and a paper guide on how to use the Fitbit. Participants were asked to wear the Fitbit for the following week to assess their baseline physical activity level.

**4.2.2 Session 2 & Deployment Period.—**After one week of using the Fitbit, participants were trained on how to use Go&Grow (The Go&Grow Guide is included in supplementary materials). Caregivers were then asked to wear the Fitbit and use Go&Grow at least once every other day for 6 weeks. Automated system logs collected data regarding participants' use of Go&Grow, such as when users logged into Go&Grow, when a story was posted, viewed, liked, or replied. Each week, participants also responded to a survey that asked whether the gameplay interfered with their caregiving responsibility on a scale from 1 (strongly agree) to 7 (strongly disagree) [43] (The weekly survey items have been added to the supplementary materials). Participants were compensated with a $5 Amazon gift card for completing the weekly survey each week.

**4.2.3 Session 3.—**After six weeks of using Go&Grow, we conducted semi-structured interviews using the Data-Driven Retrospective Interviewing method [73]. Before the Session 3 interview, we reviewed each caregiver's log data (e.g., number of days logging onto Go&Grow, and number of stories posted) to begin assessing their Go&Grow engagement; we probed identified data patterns in the interview to examine how and why participants used Go&Grow, game enjoyment, physical activity, motivation, and social

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connectedness. (The interview guide is included in supplementary materials). Note that while this study aimed to focus on informal caregivers, 4 caregivers revealed that besides being an informal caregiver (See Table 1), they are also professional caregivers. However, in the beginning and throughout our interviews, we explicitly asked them to talk about their experiences with their loved ones.

Finally, participants completed a software assessment survey that evaluated user satisfaction and technology acceptance [97], and a posttest survey that was the same as the pretest given at baseline (Surveys are included in the supplementary materials). We would like to note that because of participant family emergencies, we were unable to conduct the Session 3 interview for two participants (P07 & P18), and P07 did not get to complete the posttest and the system usability test.

### 4.3 Analysis

A paired T-test was conducted to analyze caregivers' pre & post management of distress scores. This measure assesses the frequency of doing various leisure activities while under stress from caregiving (see supplementary materials for items). Scores were measured by summing all activities from 1 (never) - 4 (very often).

Multilevel modeling using R tested the relationship between the number of times a participant logged into Go&Grow during a week and steps taken during a week (as measured by participants' Fitbits) on a within-person (WP) level. Each caregiver's weekly variation in the number of times they logged onto Go&Grow (WPlogging) was compared with their own overall average across all weeks (avg log) during the 6-week period. WPlogging was the fluctuation of number of times logging in each week for the same individual, from week to week in the study. Positive WPlogging scores represented weeks with an above-average log-ins, whereas negative WPlogging scores represented a below-average log-ins. A significant positive ß for WPlogging would indicate on weeks when a participant logged in more than their own average weekly log-ins across 6 weeks, there was a significant increase in the individual's weekly steps. We used the following model:

$$\text{Level 1: Weekly steps}_{ij} = \beta_{0j} + \beta 1 \text{ WPlogging}_{ij} + e_{ij}$$

$$\text{Level 2: } \beta_{oj} = \beta_{00} + u_{0j}$$

Weekly steps at level 1 were expressed as a wp intercept, wp logging & wp error term. For level 2, wp intercept was expressed as a function of fixed intercept (Avg Log).

Qualitative analyses were conducted using Atlas. TI, using an inductive thematic analysis ap- proach informed by Grounded Theory [19]. The first author qualitatively analyzed interview transcripts using open coding to inductively characterize concepts reflected in the data. These low-level codes were then clustered to characterize higher-level themes through writing memos, constant comparisons, and interrogating the data through asking questions of the data to identify themes, their dimensions, properties, and relationships to other themes. In our Findings sections, we provide a sense of the prevalence of each theme across our sample by denoting the number of participants who expressed the various perspectives

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and experiences reflected in the themes. The first author met with other authors regularly to discuss the codes and emergent themes.

## 5 FINDINGS

When designing systems for caregivers of individuals living with dementia, it is important to create user interactions that compliment rather than detract from caring duties. Based on our weekly survey rating results (1 (strongly agree) to 7 (strongly disagree), we found that across the study period, caregivers in our study felt that playing Go&Grow did not interfere with their caregiving responsibilities (m=5.02, sd=1.5, n=17, one of the participants did not complete any weekly surveys (P15), therefore we did not have this weekly survey data to report on for this participant). This sentiment likely resulted from the game's simplicity, flexibility, accessibility, and low time commitment. With regard to its simplicity and flexibility, P04 felt that Go&Grow *"was simple enough that it wasn't like using up time that I needed to do it elsewhere"*. This finding is consistent with the results of the system usability survey (1=strongly disagree to 7=strongly agree), in which, overall, participants agreed that the system was easy to use (m=5.06, sd=1.18) and flexible to fit into caregivers' schedules (m=5.02, sd=1.33). Some participants disagreed that the system was easy to use and flexible, primarily due to unexpected system downtimes and bugs that arose during the study. In terms of accessibility, P03 said, *"It wasn't labor-intensive to go on the app. Like if it was on the computer and I didn't have access, that would be."* This quote highlights how being on a smartphone facilitated Go&Grow's accessibility, which enabled caregivers to go on the game in any setting and at any time. In addition, all caregivers indicated that Go&Grow was not time-consuming. They felt that it only took about two to three minutes to sync the steps, log exercise, and check on others' gardens and stories. P10 mentioned that it wasn't a *"major production"*, that *"the time used to play the game did not interfere with any of my other daily activities"*, and it was easy to fit into his daily schedule.

In the remainder of this section, we unpack the benefits that Go&Grow afforded our participants, as well as challenges that arose. Our findings shed insights into how a pervasive social exergame can impact the wellbeing of caregivers of PWD, their relationships with the person they provide care to, and their relationships with other caregivers.

### 5.1 Benefits of Game Play for Caregiver Wellbeing

**5.1.1 Stress Relief.—**Consistent with prior work [95, 99], participants in our study felt that caregiving responsibilities impacted their personal lives, making it very difficult to have time solely dedicated for themselves (n=12), which can be stressful. Playing Go&Grow helped caregivers relieve caregiving stress. Quantitative analyses using paired T-test showed that, compared to baseline, caregivers had a significant increase in management of distress (df=16, t=2.93, p=.01), which measured the amount of time caregivers spent on themselves doing leisure activities when they were under stress from caregiving. Interview results also revealed that caregivers (n= 8) viewed Go&Grow as a mental break. After spending much of their time with caregiving duties, the game allowed them to spend time taking care of their own health:

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**P10:** "[Go&Grow] will give me stimulus to make sure I do my activity. To spend some time on myself. Not forget that, I have needs as well as who I'm taking care of".

Go&Grow served as a reminder for P10 to take care of himself. It also allowed caregivers to manage the emotional impact of caring for their loved one:

**P13:** "If you're literally down [emotionally] after you deal with a [loved one] and you have time to play with Go&Grow, all the [feelings of being] down is gone from you. It's not like I have to carry over the [challenges I experienced with a loved one] over there [to Go&Grow]."

Caregivers viewed the mental break as a chance to relax because of the garden-themed nature of this app. For example, P12 said, *"I relax because you know I like my plants"*. Caregivers felt that the garden elements of the game were *"calm"* and *"pleasant"*:

**P04:** "[the garden] was pleasant. It was kind of a nice, calming area to kind of do the whole thing with the flowers and stuff. I mean, who doesn't like gardens and flowers?"

Similarly, P13 felt that going on Go&Grow and watching plants grow was relaxing after a busy day:

**P13:** "I like to [go on Go&Grow] anytime I have time, like before I go to bed I like to open [the game]. Because I'm usually busy all the time, and it's like, "This is relaxing me." I saw plants. My God, the plant is growing."

Caregivers (n=3) also indicated in the interviews that Go&Grow helped them relieve stress because of their increased physical activity level. For example, P02 noted that this stress relief made her became a better caregiver, since she would be able to better deal with any future potential caregiving stress:

**P02:** "Playing the game [Go&Grow] helps me in a sense that when you're physically active, you relieve stress. You feel good. When you feel good about yourself, of course you're gonna be better caregiver. You're gonna handle next time stress, the difficulty will get better."

The usage of Go&Grow benefited the caregivers' mental health by providing them a space to have a mental break and relax, which helped with relieving their caregiving stress.

**5.1.2 Increased Physical Activity.—**In addition to benefiting their mental health, using Go&Grow enabled caregivers to increase their physical activity. In fact, we found a direct relationship between opening the app and activity levels. Our quantitative data analysis using multilevel modeling showed that on weeks when caregivers spent more days logging on to Go&Grow, there was a significant increase in their weekly steps as measured by their Fitbit, df=81.24. t=1.99, p=.05. N=15 (83%) logged into Go&Grow at least 3 days per week during the study period, with N=9 (50%) logging on for at least 90% of all study days. Also, N=9 (50%) continued using Go&Grow (2 weeks - 4 months) after the study ended. Our finding of a significant correlation between use and steps is promising, and the continued Go&Grow use may suggest engagement beyond a novelty effect. Interviews with

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our caregivers further illustrated that Go&Grow served as an exercise motivation while not impacting their caregiving schedule. Go&Grow served as a reminder to be active (n=9) instead of being sedentary:

**P06:** “[Instead of] sitting, eating, watching TV and knowing that I’m never going outside, [Go&Grow] mentally comes, “Oh, why don’t you do some exercise.”

Go&Grow broadened participants’ perspectives on opportunities (e.g., physical activity tracking, exercise tutorials, and exercise-related stories) available to them beyond caregiving (n=8). For example, P03 said:

**P03:** “[Go&Grow] made me more cognizant that there were other ways of mitigating some of the [caregiving] responsibility. For example, I could go and track my exercise, or see what other people had to say about it, even though I felt like [what other caregivers posted in stories] was limited. It was still an opportunity to find those things outside of my own sphere. [Go&Grow] gave me an opportunity to look outside my circle and focus on some other aspects of what I was doing besides just caregiving. Like tracking exercise, and seeing what other people had to say.”

Caregivers’ motivation to increase their physical activity was not only derived from trying to get virtual flowers as rewards (n=9), but also knowing that because of their improved physical wellbeing, they would be able to become a better caregiver to their loved one with dementia (n=7):

**P12:** “I never thought I would be walking so much. The first thing when I wake up in the morning is to go out and walk to make my points [for steps]. But I am very, very, very, very, very, I’m very happy. I got to take care of my father, even better because if I’m better myself, it’s for him. I really enjoy this because like I said, it’s a game for me. It’s to get to be healthy and to be mind clear.”

Using Go&Grow enabled caregivers to better take care of themselves by relieving their stress and increasing their physical activity. Caregivers were aware that by taking care of themselves, they would become even better caregivers for their loved ones.

## 5.2 Caregiver’s Interactions with Loved ones Living with Dementia

Our findings show multiple ways in which playing Go&Grow impacted participants’ relationships with their loved ones living with dementia. For example, some caregivers (n=5) mentioned that because of Go&Grow, they were physically active with the person they were providing care to. Instead of spending time with them sedentarily, they went for a walk together:

**P12:** “[Before, I was] very lazy. Sitting all day. Watching TV with my father. Now I’m walking with him, he does something and I can run behind him. He’s old but he can walk, so much energy. So then I can run behind him to catch him. I feel very good.”

Besides taking walks together, caregivers acknowledged the benefits of physical activity and tried to motivate their loved one to do more physical activity:

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**P08:** "Oh! You wouldn't believe it! I take my mom to walk everyday. Morning and evening. That's the good part. And I take so many pictures from the exercise session and I put it on her wall. So I don't want to tell her, "Mom do what I do." I just leave [the exercising pictures] there."

As this quote demonstrates, while caregivers increased their own physical activity level, they also tried to promote the physical health of their loved one who was living with dementia.

**5.2.1 Developing Empathy & Patience.—**We found that beyond motivating more physical activity, Go&Grow helped caregivers and their family members to empathize, that is, understand and share the feelings of the person they are caring for by imagining themselves in their loved one's position (n=5). P06 described how before using Go&Grow, she did not understand dementia and how it affected her mother. However, the caregiver community on Go&Grow urged her to learn more about the sickness and what her mother was experiencing.

Additionally, P08 mentioned that the interactions with other caregivers on Go&Grow is positive because the caregiver community on Go&Grow urged her to not just try to please her parent, but to understand:

**P08:** "When you are dealing with a parent who has Alzheimer's or dementia, I have to be in their shoes. Even though I have my own boundary, not always pleasing them. But I have to try to understand them".

Similarly, P12 shared stories to help other caregivers better understand the illness and the pro- gression of dementia symptoms. A better understand the nature of the condition could help other caregivers empathize and *"put themselves in the shoes of their loved one living with dementia"*.

Beyond developing a sense of understanding, several caregivers also expressed that Go&Grow increased their patience with their loved ones living with dementia (n=7). P13 said that when her sister did not want to do activities, she would show her sister the flower she was trying to grow in Go&Grow and explained the game to her sister with patience. As her sister watched the flower growth in Go&Grow each day, P13 felt very happy:

**P13:** "[I learned that I] have to be patient. I, myself, have to be patient… For example, [my sister] didn't want to do anything, and I just tell her "Let's do something, like growing plant, and this is from the little seed that we will be growing." And she is watching every day. I feel happy and proud of myself."

Similarly, P09 felt that because the nature of Go&Grow was to grow a type of flower slowly, she gained patience through playing. Developing patience made her a better caregiver for her mother:

**P09:** "I learned that I had to be more patient. Because sometimes I want to do things fast. And with the game you have to do it a little slower. Like the plant will grow, and be patient.

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And then as a caregiver, I had to be patient with my mother, so I feel like I did probably gain a little more patience.”

Using Go&Grow not only allowed caregivers to be active with their loved ones with dementia, but it also helped them be a better caregiver by increasing their empathy and patience towards their loved ones.

## 5.3 Connecting with Caregivers and Shared Content

Confirming prior online communities research [3, 19, 41], our participants valued having a caregiver- specific community (e.g., P02: *“there are tons of Fitbit like this… This [app] is specific to caregivers and all the members are caregivers.”*). This sense of belonging enabled caregivers to connect with other caregivers (n=6) and relate to others about what they were dealing with (n=5) while learning from others (n=7), which were all of the factors that motivated caregivers to share more stories. Beyond this basic sense of identification with other caregivers, our findings highlight additional types of interaction that participants sought with caregivers to help them create stronger connections to the stories shared and to one another.

**5.3.1 Tensions Surrounding the Sharing of Caregiver Challenges.—**For example, a tension arose from participants’ differing perspectives on sharing positive versus negative experiences. Several caregivers wanted to see positive stories in Go&Grow as a way to cheer up (n=7). P03 said that *“I think you need the positive stories, or else everybody’s going to be down in the dumps.”* Similarly, P16 said that positive stories would *“let us feel better. Bring our spirit up.”*

In contrast to caregivers who wanted to see positive stories, some participants felt that there was a positivity overload in the stories (n=6), with not enough discussion of the challenges that caregivers face on a day to day basis:

**P01:** “[I want to have] a community that’s willing to open up about their experiences, not always positive, with caregiving and how they’re feeling and what they’re struggling with. That would have helped me to really feel like I was getting support.”

Like P01, other caregivers (n=5) also conveyed that stories of struggle would help with handling difficult situations:

**P14:** “[I want the caregivers on Go&Grow to talk] about situations they’re struggling with, more of like a friendly aspect if that makes sense. Maybe allowing to talk to someone on the app and be like, “Hey, I’m dealing with the same situation you may be dealing with. And how do you handle it?”

Despite several participants expressing a desire to hear stories about caregiving struggles, others felt that Go&Grow users might not want to hear such stories (n=6), which hindered them from sharing such content. Even though story prompts included sharing challenges, none of the caregivers used these story prompts to write their stories. P16 conveyed her concern that she might be unfavorably assessed by others if she shared negative experiences:

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**P16:** "I think they won't like [me sharing my challenges] or they'll judge me [negatively], so that's why I don't really put nothing out there."

Similarly, P01 was concerned that others would judge her because she would differ from the group norm of *"everyone else is being so happy"* and she would be the only *"negative person"*. In addition, she wasn't sure how others would respond to stories about challenges, which kept her from sharing the challenges she was experiencing:

**P01:** "I would feel like I'm being this total negative person who's talking about stuff. Everyone else is being so happy for the most part, so positive. I just feel like God, what are they going to think of me? I'm like this doom and gloom person talking about my bad feelings or hard time. I'm just too afraid to because I don't know if people want to go there. I just don't get the impression that the others want to really talk because no one is sharing [any negative experiences]. I don't want to be the only one sharing and putting my heart on my sleeve and have no one react to it."

In summary, a tension arose because most caregivers shared positive stories, which hindered other participants from sharing their challenges out of a concern that they would be judged and viewed negatively by others.

**5.3.2 Developing a Sense of Connection.—**Caregivers' concerns around being viewed negatively could derive from their unfamiliarity with the other caregivers in the Go&Grow community and the fact that they did not know the other caregivers in real life. Even though caregivers on Go&Grow could begin to establish connections through their identity as a caregiver to a loved one with dementia, several caregivers (n=6) noted that they still did not really "know" the others (e.g., P14 said *"I've never met them, They're just people on an app to me"*). This unfamiliarity with others made P06 feel *"uncomfortable"* talking about herself around others. Similarly, because she did not know the users in real life, she was also concerned about others questioning her intentions when replying to stories shared in the app: *"And I don't want this person to think; Why is she asking me this?"* Moreover, even though a total of 6 caregivers knew at least one other person using Go&Grow as part of the study, some of these individuals still discussed challenges developing a connection with Go&Grow users whom they do not know. For example, some said that they have a hard time sharing stories with others (n=3) because they might be *"judged"* by people who do not know them (n=2). Others said that they could not relate to Go&Grow users because there were no deep stories shared (n=3). These findings show that even caregivers who knew users outside of the game had concerns around being viewed negatively by others whom they did not know.

Because of the unfamiliarity and lack of visual information about other caregivers (e.g., pictures, videos), caregivers (n=6) questioned the *"realness"* of the other caregivers in the community. To protect participant anonymity, we made the design choice to allow caregivers to choose a profile image from a set of images that our research team created. Without being able to post one's own photo, P02 felt that the lack of visual information made it harder to feel that others were a *"real person"*. P13 also felt that it would be hard to really *"know"* someone in the app:

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**P13:** "They don't know me because there's no picture over there. You know, like Facebook? You have your picture over there. But [Go&Grow] don't have pictures. It's just your name."

In addition to knowing the *"realness"* of other caregivers, some participants also wanted more "realness" in terms of caregivers' relationship with the person they were caring for (n=5). Participants described how visual information could help better bring these relationships to life. For example, P15 noted that, in future versions of Go&Grow, having other caregivers posting more pictures with the person they were providing care to would make their stories more *"believable"*:

**P15:** "I think that people can post some pictures sometimes. About activity, or what kind of activity they can do with their children or family members, friends. Things like that. When you can see something, you can believe more."

In addition to making stories more believable, P02 indicated that she and others would *emotionally connect* more with the other caregivers if they shared more visual information about their loved ones with dementia:

**P02:** "Maybe they can share some pictures of their daily life or take pictures of the person they're caregiving for. It can be like more visual, you see what they're doing. Having visuals, you get more information about the people. You see the real person behind who's writing all the stories."

P09 reported that more visual information with caregivers and their loved ones with dementia would also facilitate *clearer communication*, by better illustrating the experience being shared:

**P09:** "I like posting a picture. Say my mother spilled coffee. [I could] take a picture, so everybody can see it. Because some people are visual. Some like to see what's going on. even if you say, "Oh my mother spilled it." They might just think she spilled it on the floor. But if you see it, it's actually on the table. So they see it, and they can know what I'm talking about."

In summary, participants questioned the "realness" of other caregivers whom they do not know. They desired a greater sense of familiarity and authenticity through visual information about other caregivers and their loved ones with dementia. Visual content was seen as beneficial because it could help make the stories shared more believable, emotionally resonant, and clearly communicated.

**5.3.3 The Benefits of Offline Friends Online.—**In addition to visual content being important for facilitating a sense of connection to other caregivers, we found that those participants who had real-life friends on Go&Grow felt an increased *sense of community* (n=6). For example, P14 said that she liked to see what her real-life friends *"are up to. It adds a sense of community to the app."* P09 also felt that she could get to know her real-life friends at another level on Go&Grow and continue the connection from her offline life to the online world. This connection also motivated her to do more exercise:

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**P09:** “It was nice that I have some other friends I know on there. So I guess it’s a benefit to that. I can know them outside of this world, and go virtual. I think [Go&Grow] captured a lot [of interest for me]. The motivation [to exercise]. I like to be with people I knew, on there. You’re always more comfortable with people you know. It’s like, “Oh, yeah. We can do [exercise] together [virtually]. ”

Because of their desire to build connections with others on Go&Grow, some participants mentioned that they would like there to be more local Go&Grow users so there would be a chance to meet offline (n=5). P01 mentioned that there could be a greater affinity with someone local:

**P01:** “If you ever struck up a relationship with somebody maybe you could meet them offline if you felt like you had a lot in common or help each other or call them on the phone. Who knows? I don’t know. I feel like I would, and just, I feel like I could maybe relate more to someone that’s local”.

To summarize, caregivers expressed a desire to connect with other Go&Grow users. This sense of connection was facilitated by their shared identity as caregivers and when participants knew other users from their offline lives. However, challenges to the building of community and deriving of value from this community arose from differing opinions around sharing positive and negative experiences, and when caregivers were not able to determine the “realness” of others (e.g., due to not knowing them in real life and a lack of visual content). There were several properties of this concept of realness within the Go&Grow community, including whether or not participants knew the user in real life, the perceived authenticity of stories shared, the ability to connect with and clearly communicate these stories emotionally.

## 6 DISCUSSION

As rates of dementia diagnoses continue to rise [1], family members and friends are providing vital care to these loved ones. Almost half of the older adults caregivers in the U.S. provide care to an individual living with dementia [1]. Prior work has repeatedly documented significant caregiver health inequities. As compared to caregivers of individuals without dementia, caregivers to PWD have increased social, emotional, and physical challenges. Caregivers to PWD report higher levels of loneliness, social isolation, stress, anxiety, and depression than caregivers of individuals with other conditions [1, 4, 68]. These elevated stress levels further increase caregivers’ vulnerability to poor physical health [25]. In addition, caregivers to PWD are more likely to have reduced levels of physical activity [8]. While various non-technological caregiver interventions have been developed, there is a need for more work investigating how interventions can be made more widely accessible to caregivers of PWD [1].

The broader CSCW and HCI health research agendas (e.g., [10, 11, 26, 28, 41]) have demonstrated that novel technologies (and pervasive social exergames in particular) offer an exciting opportunity to provide scalable supports for health promotion in the general population, due in part to the growing ubiquity of mobile and networked devices [39].

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However, despite the pressing public health need to improve the wellbeing of caregivers to PWD, little research has evaluated the efficacy of wellbeing promotion systems (in terms of promoting physical activity and social connectedness) designed for this population. While various formative studies have been conducted to identify design directions (e.g., [6, 42, 51, 77]), without evaluations of functional systems, innovation cannot move forward. There is a need for empirical evidence demonstrating how caregivers engage with these systems, their impact on social, emotional, and physical wellbeing, and how such tools can be made more engaging and effective in the future.

Our work directly addresses this striking gap in research. Through our 6-week evaluation of Go&Grow, we contribute to CSCW research on caregiving and health promotion technologies by providing an understanding of how a pervasive social exergame can support the wellbeing of informal caregivers of PWD in terms of their physical activity and social connectedness with others. In particular, our findings reveal that Go&Grow had a positive impact on the caregivers' wellbeing in personal and interpersonal ways. At the personal level, using Go&Grow benefited caregivers' physical and mental wellbeing by increasing their physical activity and relieving caregiving stress. These are significant findings given that a lack of physical activity and high rates of stress are widespread in caregivers of PWD [45, 48, 68], at even higher rates than caregivers for individuals with other conditions [49]. Demonstrating that a pervasive social exergame can generate improvements in these areas of wellbeing suggests the viability of this type of health technology for caregivers of PWD.

At the interpersonal level, using Go&Grow impacted caregivers' relationships with the loved ones they provided care for, as well as other caregivers. More specifically, caregivers improved their sense of empathy for and patience with the loved ones to whom they provided care. Alzheimer's Disease and related dementias can be challenging conditions to care for, in part, because of the emotional impact of seeing one's loved one go through significant cognitive, personality, behavioral, and physical changes. As such, this finding from our work is important because it shows the value of a social exergame for helping caregivers cope with such changes in their loved one through increased feelings of empathy and patience.

Lastly, caregivers appreciated the opportunities to connect with other caregivers through Go&Grow; however, our work also highlights several challenges that arose as caregivers sought to build connections with other system users. These challenges represent important issues that future researchers should consider when designing social health promotion tools for caregivers of PWD. Social connectedness can help promote caregiver wellbeing during times of stress [58]. Our work provides direction for vitally needed future work examining how technology can facilitate connectedness amongst caregivers of PWD.

In the remainder of this section, we provide design implications for future technologies that support caregivers of PWD by encouraging them to take time for themselves, helping to nurture empathy towards their loved ones living with dementia, and helping caregivers develop connections with one another.

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### 6.1 Helping Caregivers to Have Time for Themselves

Caregivers reported that logging onto Go&Grow was a time of relaxation and a mental break from caregiving duties, which assisted in relieving stress connected to these duties. Instead of taking sedentary breaks from caregiving (e.g., watching TV), Go&Grow reminded and encouraged caregivers to be active by offering digital rewards (e.g., flower growth) for engaging in physical activity. Our data suggest that Go&Grow helped caregivers to focus more attention on their wellbeing, which in turn assisted them in providing more attentive care.

Underscoring the importance of caregivers' attention to their own wellbeing and self-care, we suggest the need for design elements that *increase attention to self*. There is a need for systems that empower caregivers to reprioritize their wellbeing and celebrate such self-care. That is, we recommend design elements that support caregivers in honoring moments when they can take care of their own wellbeing, which can enable them to provide higher quality care for their loved ones. Creating such tools requires sensitivity to the emotional impact and logistical barriers to self-care that may arise for caregivers. For example, designing virtual affirmations that are commonly used in gamified interfaces (e.g., badges) may not be sufficient nor appropriate for acknowledging caregivers' self-care efforts. Formative research is needed to examine to what extent various approaches to digital affirmation are seen as appropriately appreciating the emotional struggle of taking time for oneself amidst the significant challenges faced by a loved one with dementia. It may be that more nuanced, subtle, or implicit affirmations of and encouragement towards self-care are needed in this context.

One example of a design element that could encourage caregivers to focus on their wellbeing is an exergame that unlocks self-care digital content (e.g., guided meditation and yoga) when caregivers reach a physical activity goal. Prior work has shown that yoga and meditation helped caregivers of PWD cope with stress [33] and reduce depression and anxiety [91]. Such an approach would subtlety affirm the time caregivers spent attending to their physical health by offering digital resources that can help them continue such self-care.

Another direction would be to design features that help caregivers focus on positive *bodily experiences* (e.g., increased calmness and energy) as they progress through exergame levels [67]. The goal would be to increase caregivers' intrinsic motivation to gradually increase their fitness levels through the triangulation of their visualized exercise data with their felt, in-body sensations—the visceral benefits of exercise. In short, the goal of creating designs that *increase attention to self* is to help caregivers not only focus on caregiving duties but also themselves as caregivers, that is, engaging in self-care.

### 6.2 Helping Caregivers Better Understand Loved Ones Living with Dementia

Caregivers in our study indicated that Go&Grow impacted their relationships with the loved ones they cared for in two ways. First, while Go&Grow was designed specifically for caregivers, it nevertheless yielded benefits for their loved ones with dementia (e.g., by encouraging some caregivers to be physically active with their loved one). Second, some caregivers developed an increased sense of empathy and patience towards the person living

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with dementia. Our work builds upon prior research demonstrating the value of exergames for both caregivers and PWD. For example, prior work evaluating a videogame that supported movement, balance, and cognitive activities for PWD and their caregivers found that using the game increased both the feelings of collaboration and social fulfillment for both caregivers and PWD [28]. Thus, our work and this prior research demonstrate various ways in which having engagement from PWD in a system can foster a positive relationship between caregivers and PWD. Furthermore, caregivers being physically active with PWD can potentially improve the health and wellbeing of PWD. However, depending on the stage of dementia and their physical limitations, PWD will have varied ability to perform tasks within an exergame system.

We suggest the need for exergame mechanics that support *asymmetric collaboration* between caregivers and PWD [32]. Asymmetric collaboration refers to exergame mechanics that deliberately allow the caregiver and the PWD to play together towards a shared goal but with different challenges and opportunities to contribute [32]. Such challenges and opportunities may be tailored to the cognitive capacities and physical capabilities of both the caregiver and the PWD. Given that prior work by Harris et al. showed that asymmetric collaboration in games could make players feel more connected with their partner, this suggested design approach could improve the caregiver and the PWD’s feelings of connectedness [32]. Future work should examine an exergame that invites the caregiver to exercise and allows PWD to complete a task that is matched to their physical capability. Tasks for PWD with fewer limitations may be a moderate walking or balancing game. For individuals with more limitations, the task might be an art challenge.

There is a great opportunity for future research to explore how asymmetric gameplay can be designed to not only support collaborative play, but also help nurture feelings of patience and empathy amongst caregivers. As mentioned previously, one participant articulated that the benefit of our garden-themed exergame was growing a flower slowly. This game mechanic reminded her of the importance of being patient with her mother who lives with dementia and helped her practice this patience. Integrating live role playing with a virtual reality (VR) simulation of an experience of living with dementia can also foster empathy for caregivers [5]. In a study using VR, participants experienced a first-person view of living with dementia [5]. This experience increased participant awareness of how PWD would feel as a result of a caregiver’s engagement with them (e.g., if caregivers left them alone in a room) [5]. Participants in the study reported greater understanding and empathy for those living with dementia and their caregivers [5]. Building on this research, we encourage future research that investigates the creation of other patience and empathy-building mechanics (e.g., simulated live experiences) in exergames that foster asymmetric gameplay for caregivers of PWD.

### 6.3 Helping Caregivers to Connect with Other Caregivers

Most participants in our study saw using Go&Grow as an opportunity to connect with other caregivers. Although this finding showed Go&Grow’s positive impact, some caregivers indicated there was a positivity overload in the Go&Grow community. Because the stories shared were overwhelmingly about positive experiences, connecting with other caregivers

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felt challenging for some participants. This issue was further complicated by caregivers' feelings of uncertainty regarding 1) what kind of reactions they might receive from other caregivers, and 2) the "realness" of other caregivers (e.g., due to questions about the authenticity of stories shared, not knowing caregivers in real life, and limitations in their ability to emotionally connect with and clearly communicate stories).

Collectively, these tensions hindered some caregivers' engagement with the Go&Grow commu- nity. This emergent finding can be explained using the group dynamic theory. Group dynamic theory describes how individuals within a social group behave and interact with each other [84]. Within this theory, group development goes through the following four stages: group forming, storming, norming, and performing [84]. First, groups are *formed* and established because everyone shared the same social role (e.g., caregivers of PWD). Second, in the *storming* stage, in-group conflicts may rise in terms of differing opinions (e.g., preferences for sharing positive and negative experiences). Third, in the *norming stage*, the group establishes informal rules that group members seek to maintain. Finally, in the *performing stage*, group members adapt to the function of the group towards a common end goal [84].

In our study, we found that many caregivers tended to share positive caregiving stories. We do not, however, believe this was due to the prompts we provided, as many caregivers did not choose to use the story prompts. Since many stories were emotionally positive, it appeared that the caregivers *normed* their group to share positive stories. Furthermore, caregivers expressed their concerns around sharing negative experiences, which suggests that the caregivers attempted to maintain this informal rule. Despite 6 caregivers knowing at least one other person on the game, most still were concerned about being viewed negatively by others whom they did not know. Our findings suggest that caregivers did not want to deviate from the group norm (i.e., not sharing challenging experiences), because doing so would hinder them from reaching the final stage, *performing* [84]. In summary, at the interpersonal-peer level, our data highlight *the importance of facilitating a sense of familiarity, authenticity, and emotional connection* when designing health systems for caregivers of PWD. In particular, our caregivers expressed the value of and need for local relationships, stemming from the five issues that we discussed in this paper: 1) caregivers' desire for positive stories as well as stories of caregiving struggle from the community, 2) their hesitance to share their challenges, 3) the uncertainty of the "realness" of other caregivers and their experiences with PWD, 4) the benefits of having real-life friends in the Go&Grow community, and 5) caregivers' desire to meet other caregivers offline. In response to these concerns, we propose two design directions.

To address caregivers' desires to share both stories of struggle and positivity (issue #1 above), we suggest future work examine how to help virtual caregiver groups consider their norms. For example, in virtual groups such as Go&Grow, we suggest the addition of a separate channel focused on discussing the logistics of using the app. This dual-channel approach would allow the content and the logistics of content shared to be delineated so that caregivers can continue to have a space to share stories based on the current norms as well as a space to share ideas on how to make their group more inclusive to other perspectives.

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To further help caregivers feel more comfortable in sharing ideas while minimizing concerns over peers' judgment, caregivers could have an option *to write and share completely anonymous messages*. This feature can allow caregivers to talk about anything they want without being afraid of breaking the group norm or being "judged" by others. Even though many virtual spaces offer some level of anonymity in online communities, the extent of anonymity can impact users' participation in terms of the content they are willing to share. Studies have shown that completely anonymous online social platforms for caregivers provide an opportunity for caregivers to vent and express more sensitive topics freely [15?], which resonated with our findings: Because caregivers identified themselves with their real first name or nicknames in the game, they might feel that it was not completely anonymous. This might have affected the content that they choose to share, regardless of whether they knew other caregivers in real life or not. At the same time, other research has found that full anonymity in virtual environments has been an important catalyst for both the disclosure of sensitive and stigmatized experiences as well as the receipt of social support in this context [56, 57].

Given this mixed prior work on the implications of anonymity online, there is a need for future work exploring the implications of anonymity in online caregiver communities. For example, future caregiver-focused social apps could allow caregivers to anonymize their usernames and share their struggles without hindrance, which could help address communication tensions among caregivers. At the same time, research would need to investigate the implications of such anonymous sharing on the sense of community and system users' motivations to contribute and reply to shared content. Research would also need to examine how various approaches to facilitating anonymity impacted caregivers' assessments of the "realness" of other system users (e.g., through emotional connection and assessments of the authenticity of their stories).

Indeed, this was an important concern amongst several participants in our study, who wanted to establish the "realness" of other caregivers in Go&Grow, and develop emotional connections with them (issues 3 and 4 above). To this end, we suggest that future work investigate features that invite caregivers to *share more personal visual information with other caregivers in the context of the game, such as superimposing virtual rewards onto personal photos*. For example, a system like Go&Grow could allow caregivers to put virtual rewards from the game on top of photos that are meaningful to them. In the Go&Grow context, caregivers could put the flowers they grew on top of pictures of nearby parks they visit with their loved one with dementia, or even photos of themselves. The superimposed image and caption written by the caregivers can help caregivers to carefully disclose their experiences in the context of the game. For example, caregivers could put the flower grown in Go&Grow on top of the photo of their kitchen to explain how they can find peace in the morning by being alone in the kitchen. To further develop peer connections, sharing virtual rewards on top of personal pictures can be designed as a weekly challenge with specific themes. Example themes might include places for self-care, rooms in the house for spending time with PWD, or favorite places to exercise. Sharing virtual rewards that are superimposed on personal photos could enable caregivers to reflect on their weekly progress while building a personable virtual community with other caregivers.

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Lastly, given that participants valued having friends from their offline lives in Go&Grow and desired to meet Go&Grow users offline (issues 4 and 5 above), one clear direction for future work is to connect exergame systems with real-world meet-up opportunities. This could be done, for example, in conjunction with the various offline caregiver support groups that exist [2]. Systems such as Go&Grow could help to bridge the gap in-between meetings, especially given that prior work has found utilization of these support groups to be low [79]. Such offline engagement may not be consistently feasible for caregivers of PWD due to the significant time and geographic constraints of caregiving [54, 71, 77]. Still, having even sporadic in-person contact may be enough to help nurture more substantive emotional connections to other caregivers within a virtual, pervasive social exergaming context. Future work should investigate such multi-component interventions (e.g., those that provide both offline support group opportunities and a pervasive social exergame), to understand how varying levels of combined participation with each online and offline component impacts important health outcomes such as feelings of social connectedness, physical activity levels, and management of distress.

## 7 CONCLUSION

Few wellness technologies promoting physical activity and social connectedness have been designed to meet the needs of caregivers of PWD. This paper presented several findings around these caregivers' experiences with a functional pervasive social exergame app. We found that Go&Grow not only benefited caregivers by increasing their physical activity and relieving their caregiving stress, but also helped them improve their caregiving through increased empathy for and patience towards the people they care for. Our results also highlighted caregivers' desires to better connect with caregivers. Future work should examine how systems can better help caregivers take time for themselves, gain empathy and patience for their loved ones living with dementia, and build deeper connections with caregivers.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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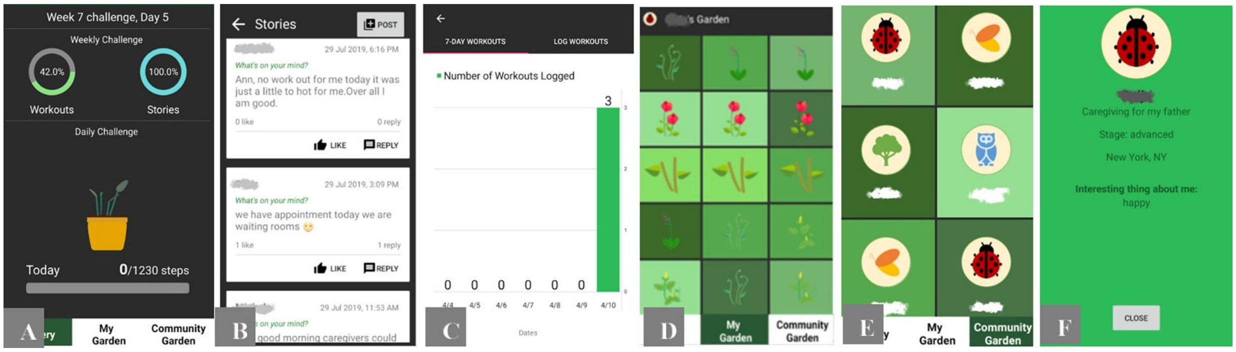
**CCS Concepts:**

- **Human-centered computing → Human computer interaction (HCI)**; *Empirical studies in HCI* ; *Empirical studies in collaborative and social computing.*



[redacted] 29 Jul 2019, 6:16 PM
What's on your mind?
Ann, no work out for me today it was just a little to hot for me.Over all I am good.
0 like 0 reply

[redacted] 29 Jul 2019, 3:09 PM
What's on your mind?
we have appointment today we are waiting rooms 🙂
1 like 1 reply

[redacted] 29 Jul 2019, 11:53 AM
on your mind?
good morning caregivers could

[redacted]
Caregiving for my father
Stage: advanced
New York, NY
Interesting thing about me:
happy

**Fig. 1.**

Users can see their daily steps & weekly progress for workouts and stories in nursery (A). Users can see what others posted or post their own stories (B). Users can track their weekly workouts or log workouts (C). Users can look at their own garden (D) check out other caregiver's gardens (E) or other's profile page to learn more about other caregivers (F).

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## Table 1.

Demographic information for each individual participant. Caregiving time indicates the number of days in a week caregivers spent taking care of their loved ones. * indicates that besides taking care of their family members, they are also a professional caregiver.

| ID | Age | Sex | Race | Education | Care Recipient (Age) | Caregiving Length (Time) |
|---|---|---|---|---|---|---|
| P01 | 46 | F | White | College | Parent (78) | 3 years (7) |
| P02 | 22 | F | White | College | Grandparent (93) | 8 months (7) |
| P03 | 60 | F | White | Graduate School | Parent (85) | 3 years (5) |
| P04 | 26 | F | White | College | Grandparent (89) | 7 years (3) |
| P05 | 60 | F | Black | College | Godparent (79) | 2 years (4) |
| P06 | 57 | F | Black | High School | Parent (72) | 7 months (3) |
| P07 | 50 | F | Black | Some College | Parent (79) | 10 years (7) |
| P08 | 48 | F | Asian | Graduate School | Parent* (94) | 5 years (2) |
| P09 | 50 | F | White | College | Parent (70) | 3 years (7) |
| P10 | 70 | M | White | Graduate School | Friend (80) | 3 years (2) |
| P11 | 47 | M | White | College | Parent (75) | 2 years (7) |
| P12 | 55 | F | Hispanic | Associate | Parent (72) | 5 years (5) |
| P13 | 67 | F | Asian | High School | Sister-in-law* (80) | 7 years (3) |
| P14 | 24 | F | White | College | Partner’s Aunt* (70) | 1 year (3) |
| P15 | 29 | F | Hispanic | High School | Parent* (85) | 1 year (3) |
| P16 | 64 | F | Black | High School | Cousin (82) | 4 years (4) |
| P17 | 58 | F | Black | Some High School | Friend (68) | 6 months (4) |
| P18 | 54 | F | Asian | Some High School | Parent (80) | 7 years (7) |