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Self-tracking technology for senior health: existing practices and unmet needs for wellness, self-management, and recovery

DISSERTATION

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for the degree of

DOCTOR OF PHILOSOPHY

in Informatics

by

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Dedication

To my family, for their abiding support from near and far.

Table of Contents

Page

List of Figures **vi**

List of Tables **vii**

Acknowledgments **viii**

Vita **ix**

Abstract of the Dissertation **xvi**

Chapter 1 Introduction **1**

Chapter 2 Background **6**
- 2.1 Self-tracking for health . . . 6
  - 2.1.1 Wellness tracking . . . 8
  - 2.1.2 Self-management tracking . . . 10
  - 2.1.3 Recovery tracking . . . 12
- 2.2 Health technology for seniors . . . 14
  - 2.2.1 Self-tracking for Older adults . . . 15
- 2.3 Impact of self-tracking . . . 19
  - 2.3.1 Reflection and self-knowledge . . . 19
  - 2.3.2 Behavior change . . . 21
  - 2.3.3 Negative experiences with self-tracking . . . 22
- 2.4 Conclusion . . . 24

Chapter 3 Research overview **26**

Chapter 4 Impact of age and health factors on self-tracking habits **31**
- 4.1 Introduction . . . 32
- 4.2 Background . . . 32
- 4.3 Methods . . . 34
  - 4.3.1 Survey questions . . . 34
  - 4.3.2 Analysis . . . 36
- 4.4 Findings . . . 37

4.4.1 Scatter plots . . . 37
4.4.2 Chi-squared tests . . . 38
4.4.3 Regression analysis . . . 42
4.4.4 Summary of findings . . . 43
4.5 Discussion . . . 45
4.6 Conclusion . . . 48

Chapter 5 Self-tracking practices and barriers among seniors 49
5.1 Motivation . . . 49
5.2 Research questions . . . 50
5.3 Methods . . . 50
5.3.1 Data collection and analysis . . . 52
5.4 Findings . . . 53
5.4.1 Self-care . . . 53
5.4.2 Retirement community care practices . . . 59
5.4.3 How different forms of care are connected . . . 64
5.5 Discussion . . . 66
5.5.1 The fear of being dependent affects monitoring systems . . . 68
5.5.2 Unmet needs of older adults in self-tracking systems . . . 69
5.6 Conclusion . . . 70

Chapter 6 The role of self-tracking in medical recovery among stroke survivors 72
6.1 Motivation . . . 73
6.2 Telerehab system . . . 75
6.3 Research questions . . . 78
6.4 Methods . . . 78
6.4.1 Study design . . . 78
6.4.2 Participants . . . 81
6.4.3 Data collection . . . 82
6.4.4 Data analysis . . . 83
6.5 Findings . . . 83
6.5.1 Providers' telerehab practices . . . 84
6.5.2 Information providers wanted from the telerehab system . . . 87
6.5.3 Patients' telerehab practices . . . 91
6.5.4 Data visualization artifacts . . . 96
6.5.5 Information Patients Want from the Telerehab System . . . 101
6.6 Discussion . . . 106
6.6.1 Aligning telerehab design with patients' practical goals . . . 106
6.6.2 Temporal aspects of telerehab . . . 108
6.6.3 Promoting hope and encouragement . . . 110
6.6.4 Decision making with personal data . . . 111
6.7 Conclusion . . . 113

Chapter 7 Discussion 115
7.1 Self-tracking practices among seniors . . . 116

7.1.1 Wellness . . . 116
7.1.2 Self-management . . . 117
7.1.3 Recovery . . . 118
7.2 Perceived “normal” data and behavior . . . 120
7.3 Meaningful information . . . 122
7.4 Dealing with (anticipated) loss . . . 124
7.5 Engaging and encouraging seniors . . . 125

Chapter 8 Conclusion **129**

Bibliography **134**

List of Figures

Page

4.1 Scatter plot of tracking activity by age, showing an increase for both kinds of tracking among older adults. 38
4.2 Chronic illness prevalence by age among survey respondents. 39

5.1 P9's blood pressure log (left), P10's pain log (right). 58
5.2 Morning check button. 63

6.1 The stroke telerehab system used in Study 3 76
6.2 Score screen, shown at the end of a game. 77
6.3 Data visualization examples 80

List of Tables

Page

3.1 Overview of the three studies. 27

4.1 Survey questions used in the analysis 35
4.2 Chi-squared test results among the three age groups for different conditions. Each column shows the results of one test. 40
4.3 Chi-squared test results among the three age groups for individual illnesses. Each column shows the results of one test. 40
4.4 Chi-squared test results among the age groups for different health statuses. Each column shows the results of one test. 41
4.5 Results of four logistic regressions: wellness or self-management tracking by individual or multiple chronic conditions. 43

5.1 Characteristics of senior participants. 51

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Abstract of the Dissertation

Self-tracking technology for senior health: existing practices and unmet needs for wellness, self-management, and recovery

by

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As societies across the globe grow progressively older, it is important to find ways to leverage technology to benefit seniors by assisting them to care for their health. Self-tracking is a strategy that can be used for health management and augmented by using technology such as smartphones and wearable devices. Although most seniors use self-tracking for health, they most commonly rely on either paper or their own memories when tracking health data. Because their adoption of self-tracking technology is very low, seniors miss any benefits that might be gained from using self-tracking technology, such as self-knowledge, encouragement, or reduced burden. Overcoming this issue requires designing tools that appeal to seniors and meet their specific needs. Although past research has found multiple barriers for seniors' use of self-tracking technology, such as lower accuracy when counting steps due to gait or walking speed, there is still much we do not understand about how to create self-tracking technology that better meets their needs. My research investigates self-tracking for health among older adults, with the goal of understanding their existing tracking practices, their perspectives towards self-tracking technology, and their needs as potential users. In this dissertation I discuss three kinds of health-related self-tracking among seniors: wellness, self-management of chronic conditions, and recovery from a major health event. Through a quantitative survey data reanalysis, I investigate the relationships of age and health status with tracking habits to understand the influence of each of these factors on self-tracking practices. Based on empirical evidence, I also describe seniors' existing use of and perspectives towards self-tracking for health and the barriers for adoption of self-tracking technology among seniors. Lastly, I investigate the role of self-tracked medical recovery data among stroke survivors and healthcare providers by describing their existing use of the data, the barriers limiting further use, and participants' perspectives on potentially useful insights. Building upon these projects' findings, I discuss barriers for senior use of self-tracking technologies, what unmet needs they exhibit, and promising directions for the design of effective self-tracking technology for seniors' wellness, self-management, and recovery.

Chapter 1

Introduction

Older adults are a growing population worldwide. People who are 65 or older are projected to grow from 11% of the world's population in 2019 to 16% in 2050. By 2050, the proportion of older adults will double in Asia, Latin America, and North Africa, and reach 25% in North America and Europe [311]. This substantial demographic shift is likely to impact seniors' well-being and public policy, due to expected higher demand and potential lower accessibility to health care services [94, 110].

As populations age around the world, it is increasingly important to seek strategies to support health management among older adults and promote their well-being. In older age, there is an increase in chronic illness incidence. Gradual and sudden functional decline also affect this population's quality of life [75]. Health technology has the potential to increase accessibility and efficiency for both healthcare services and self-management resources [87]. To reach this potential, we need to better understand how to design technology for older adults that facilitate their health management work, while also meeting their needs and aligning with their perspectives and goals.

Self-tracking is a prominent area of research in health technology, and it has the potential of supporting the older population to manage their health. Self-tracking refers to repeatedly measuring and recording information about oneself. In the case of self-tracking for health, such information may include activities such as meals, medication intake, physical activity, and health indicators such as blood pressure, and occurrence of symptoms.

Tracking involves collecting personal data, reflecting and potentially acting based on it [182], and it can be used for purposes such as gaining awareness of habits, changing behavior, and self-experimenting to answer a question (e.g., testing triggers for a symptom or allergy). Tracking can also be used to monitor changes over time, such as periodically measuring blood pressure or a child's height. People who self-track can use the data to see momentary measurements, observe changes over time, learn about relationships among different data (e.g., measuring stress levels by days of the week), or even just gain perspective and encouragement from reflecting on their data or sharing the data with others.

While older adults already use self-tracking for health, they seldom use self-tracking technology, and their existing self-tracking practices are not well understood. According to a 2012 survey, seniors are more likely to use tracking for health than any other age group in the U.S., yet they rarely use self-tracking technology [103]. Their usage patterns of tracking for health differ substantially from other populations. Unlike younger adults, who engage primarily in wellness tracking, seniors are more likely to track health data such as blood pressure and blood glucose [103].

The majority of the self-tracking technology industry and related research focuses on the needs of the younger population. However, seniors have particular needs when it comes to self-tracking. In comparison to younger age groups, they have a higher prevalence of chronic illness and disability [323], track different health indicators, and use different tools to track [103]. Each of these factors can influence their needs and goals in self-tracking.

Health management among older adults is a broad topic, as it can vary due the individual's contexts and objectives. In my dissertation, I investigate three health contexts to unpack the role that tracking may play in their health management: 1) wellness-related activities such as walking (e.g., distance walked), 2) self-management, including prevention and management of chronic conditions (e.g., blood pressure readings), and 3) medical recovery from incidents such as accident or surgery (e.g., physical therapy).

Data related to wellness is the most common form of health data to self-track. 60% of U.S. adults and 71% of older adults track data about their exercise, weight, or diet [103]. While these data can be used for managing chronic conditions as well, they are primarily associated with prevention, fitness, and self-improvement. Several research projects have investigated tracking physical exercise (e.g. [64, 114]) and eating habits (e.g. [69, 333]). Popular devices and mobile apps including Fitbit and MyFitnessPal [295] have tens of millions of active users in the U.S., and many other similar tools are commercially available. Despite being more likely to track this kind of data, seniors have low adoption of wellness self-tracking technology such as activity trackers [103].

Self-managing health refers to actions taken to prevent, cure, or control chronic illness. It can include managing symptoms, following treatments, periodically visiting physicians, having medical tests, maintaining daily habits, and managing the psychological impact of illness [61]. One third of U.S. adults and the majority of U.S. seniors self-track data related to chronic condition management. Those who have chronic conditions also are more likely to use self-tracking for health management [103]. Self-management involves handling symptoms, treatment, coping with a chronic condition [23, 67]. Tracking can be used to help or facilitate many self-management tasks. For example, self-knowledge can help patients to better understand a condition and make informed decisions. Tracking can also help with habit formation or provide motivation to common daily activities such as taking medications [174]. Many studies have investigated self-tracking to support the self-management of specific diseases. Examples include heart conditions [115, 188, 321], asthma [9, 134, 173], Parkinson's disease [204, 212, 282], and diabetes [50, 83, 90, 252, 165].

Medical recovery is a third possible application of self-tracking for health. For example, when recovering from an injury or surgery, individuals may benefit from self-tracking their related tasks (e.g., physical therapy exercises), and also direct and indirect measures of their improvement (e.g., pain level, range of motion, walking speed). Self-tracking in the context of recovery has the potential to promote reflection [249], motivation [44, 131], and to encourage and inform about their progress [5, 250].

While past work has found barriers for the use of tracking technologies among older adults, such as lower responsiveness to theory-based interventions [106], there is still much we do not know about their practices and perspectives. Most of the studies in this theme have either used quantitative methods or focused on design and usability, such as participatory design (e.g., [74]) or user studies with prototypes or existing tools (e.g., [1, 43]). There remains a knowledge gap about their existing practices and perspectives towards self-tracking and tracking technology.

This research is motivated by the need to better understand existing barriers for adoption and use of self-tracking technology among seniors, and to explore how we can better meet their needs, perspectives, and goals when designing self-tracking for health. To that end, this research seeks to understand seniors' existing practices for tracking, as well as a yet under-explored application of tracking in the context of medical recovery.

This dissertation is comprised of three studies investigating tracking among seniors from different angles to understand their experiences with and perspectives towards tracking. Two studies investigate existing tracking practices with older adults, while a third study focuses on a particular application of tracking in the context of recovery from stroke.

The first study focuses on tracking practices among different populations, revealing how age and health status both influence tracking habits. This study contributes to our understanding about what leads individuals to self-track and about barriers.

The second study investigates seniors' current practices and perceptions of self-tracking and tracking technology, along with barriers for adoption. Through this study I was able to learn why those barriers exist and discuss potential directions for future research to understand how to design better fitting tools for seniors.

Lastly, the third study focuses on a specific context of medical rehabilitation after stroke, by discussing participants perspectives towards tracking and their own self-tracked data. This study contributes to our understanding of tracking for recovery, a context that was highlighted as important in the first study and that we know little about.

Together, these studies help us to understand current tracking practices among seniors, their motivations and perspectives. But also they point towards directions to better serve this population with systems that meet their needs, contexts, and goals in health management. These studies provide novel insights about three different goals for tracking among seniors: self-management, wellness, and medical recovery.

The findings emphasize how important it is for us to design to empower users, particularly in the case of populations that have complex health needs such as seniors and stroke survivors. Wellness tracking should seek to validate and encourage, including when users have complex health needs. Tracking for managing or preventing chronic conditions should add more value or reduce burden for seniors. There is an opportunity to design with the intention of providing users hope for the future when they are going through medical recovery.

This research contributes to the HCI literature by providing novel insights about the needs, perspectives, and use of self-tracking for health among seniors in the context of wellness, self-management, and medical recovery. This work informs future technology design of self-tracking systems for older adults, discussing challenges, opportunities, and directions for future research.

Chapter 2

Background

This chapter presents a review of the literature on self-tracking and health technology for older adults. The first section discusses self-tracking in the context of health, and the different types of health tracking: wellness, self-management, and recovery. Section 2 covers the literature on health technology for seniors, including self-tracking, followed by impacts of self-tracking. The last section summarizes the literature discussed on this chapter and highlights the gaps and opportunities that my research aims to address.

2.1 Self-tracking for health

The practice of registering information about oneself has existed as long as written language [263]. Self-tracking consists of repeatedly measuring and recording information about oneself. It can take place in several ways, such as keeping records of sleep schedule on a notebook, using a wearable device to automatically measure heart rate at fixed intervals, or rating mood in a likert scale daily. It can also be used for diverse purposes, including financial transactions and time spent commuting. In the last couple of decades, the popularization of mobile devices such as smartphones and smartwatches created opportunities for digital self-tracking by using sensors, mobile apps, and connectivity.

There are five main reasons to self-track [58, 46, 137, 146, 183, 72]:

Self-knowledge: Learning about oneself. Such as habits (e.g., how many meals per week are had in restaurants), or learning about how an illness manifests (e.g., what kinds of symptoms are present, and when).

Behavior change: Changing a habit, either by acquiring a new habit or breaking one (e.g., quitting smoking).

Self-experimentation: Purposefully testing the effects of a behavior or circumstance by tracking data both when it is present and when it is not and comparing the results.

Assessment: Temporarily evaluating what is being tracked through several measurements. For instance, measuring blood pressure daily for a week to estimate its average or observe how it fluctuates.

Monitoring: Continuously observing the tracked variable to observe changes, and take action if needed based on the data. For example, measuring blood glucose daily and using medication or meal planning to address low or high blood sugar.

In health applications, tracking can be used for various purposes such as bringing awareness about health related behaviors, supporting new habits, or learning about one's own condition and needs. Intille has classified health technology in three categories: systems that detect a crisis, systems that detect declines in health, and systems that motivate healthy behavior [137]. Self-tracking can be used for each of these purposes. Health related variables that can be tracked include emotional indicators (e.g., mood, stress), process data (e.g., step counts, digital traces such as location history), and physiological data (e.g., heart rate) [266].

Variables that can be measured or estimated independently by people, with or without specific tools, can be self-tracked. While it is possible to self-track using simple tools such as pen and paper, many digital tools have been created for this purpose. They allow users to store a large amount of data, measure variables more accurately, or require less effort than measuring manually. Data tracked electronically can also be used to deliver adaptive interventions, send notifications, and informative visualizations.

Smartphones have been leveraged for self-tracking, as applications can be designed to use the phone's sensors to infer users' activities or to record self-report data [161, 64]. Self-report applications have been used to track variables such as food and physical activity [172, 228, 309], glucose and insulin injections [236], and medications [175]. Sensors used for tracking can measure breathing and heart rate [2], physical activities and caloric expenditure [64, 77, 198]. Cameras have been leveraged for tracking food and exercise [107, 289], or general daily activities [130].

I classify health tracking into three different kinds based on what data is collected: wellness, self-management, and recovery. Data regarding wellness and prevention activities can include diet, exercise, and sleep patterns. Tracking blood pressure and symptoms such as pain would be classified as self-management tracking. And medical recovery includes tracking physical therapy, or the healing progress of an injury. These categories may overlap, since for example, diet can be tracked both for wellness and for self-management purposes.

2.1.1 Wellness tracking

Senior wellness benefits from stress management, maintaining life purpose and independence, socializing with family members and friends, learning, sleeping, reading, balanced eating, and exercise [256]. Exercise delays functional decline, improves cognition [84, 105], and supports emotional, social, cognitive, and perceived physical function [302]. Walking is among the most beneficial and popular activities for seniors [84, 163]. Barriers to exercise include fatigue, lack of energy, low motivation, low experience, self-consciousness, lack of time, fear of falling, and lack of enjoyment [154, 41, 257]. Chronic conditions such as arthritis, chronic pain, injury, physical disability, heart problems, asthma, and incontinence have been cited as barriers to physical activity [153].

Consumer health technology can help people to manage their own health and well-being by providing information about preventative behavior, and by helping users to adopt those behaviors in their daily lives [76]. Self-tracking systems can be designed to support habit formation, and at the same provide relevant, personalized information to users.

For instance, self-tracking food and exercise is common. An estimated 60% of U.S. adults track their weight, diet, or exercise. Among those who track, 46% say that it affected their approach to health management [103]. While evidence about effectiveness in impacting health outcomes is still limited [241], pedometer use has been found to be associated with more physical activity, lower body mass index and lower blood pressure [39]. Studies have investigated self-tracking several daily behaviors such as food intake and exercise [70, 39, 185, 217], hydration [55], sleep habits [56], mood [85], and posture [284].

A few studies have investigated the perspectives of particular populations using self-tracking tools, and found that they may have particular needs. For example, Knaving et al. found that amateur runners can benefit from features supporting their existing motivations, instead of attempting to increase motivation [164]. For teenage girls, appearance of devices and limited resources about the practice of self-tracking are barriers [177]. Meyer et al. have proposed four guidelines to make self-tracking tools more widely accepted amongst different populations: invisible or fashionable design, interventions that evolve with time, robustness and perceived robustness, and choosing reliability over precision [216]. Based on an examination of appropriation of self-tracking tools, Storni argued for the need to overcome technology determinism, by considering different responses from different users, and evaluate the interests of different stakeholders (e.g. users, tool manufacturers, public health officials, clinicians), and reexamining system evaluation studies to make sure they take into consideration users' perspectives as well as clinicians' [298]. Tracking has many potential applications for promoting well-being and addressing acute diseases, but past research most often focused on chronic conditions [96].

2.1.2 Self-management tracking

Chronic conditions may require burdensome lifelong management activities. Self-management refers to the actions taken to prevent or manage a chronic illness, such as managing symptoms, treatments, changes in lifestyle, and coping with the psychological impact of illness [67, 234]. Self-management of chronic illness is generally focused on mitigating symptoms and preventing or delaying illness progression [76]. It requires self-knowledge, self-efficacy, knowledge about the illness, and problem solving skills to make informed choices [36, 61, 62]. Perceived control over illness is associated with better self-management. On the other hand, interpreting illness as natural aging can discourage effective self-management [75].

Effective self-management is crucial for older adults because it can significantly affect their health outcomes [75]. Their needs often differ from other age groups, as the likelihood of co-morbidity increases with age. The management of different conditions might create conflicts. For instance, a medication that is normally prescribed for a particular condition might aggravate another pre-existing illness.

Generally, technology aiming to support chronic self-management must focus on developing skills [156] and facilitating the learning process [201]. People with different conditions can utilize self-tracking to monitor their symptoms, gain motivation for self-care activities, and gain self-knowledge about how different strategies affect them [195, 227]. Many illnesses share similar self-management needs, such as coping with the disease and maintaining an active lifestyle [23]. Thus, interventions might address populations with diverse conditions. For instance, the Chronic Disease Self-Management Program (CDSMP) has been designed to teach self-management skills to people with different conditions, and it led to reduced medical visits, improved self-efficacy, and improved symptoms. Self-tracking was among the strategies the CDSMP utilized [191, 190]. Self-tracking can help people to better understand their conditions and make decisions, for example it can help to identify potential triggers for specific symptoms (e.g., allergic reaction), determine the required dosage of a medication (e.g., insulin), and augment communication with physicians.

Many studies have investigated self-tracking to support the self-management of specific diseases. Examples include heart conditions [115, 188, 321], asthma [9, 134, 173], Parkinson's disease [204, 212, 282], diabetes [50, 83, 90, 252, 165, 168, 200, 104, 123], cancer [152, 170, 206, 160], psorasis [281], kidney failure [292], chronic pain [93], bipolar disorder [108], and multiple sclerosis [208]. But even people with the same illness can have very different self-management needs. For instance, those who have experienced the illness for several years will likely be more knowledgeable about it, and for them it is more appropriate to focus on new experiences rather then tracking activities they have mastered [35].

For many diseases, there are specific health indicators that can be tracked. For instance, self-tracking for those with hypertension most often focuses on blood pressure [115, 188, 321], but more sophisticated devices like ECG monitors have also been proposed [271, 315, 316]. For asthma, users can self-track peak respiratory flow [9, 134]. Those with Parkinson's disease can self-track gait and speech volume [204, 212]. Glucose and diet are highly relevant for people with diabetes [83, 90]. It is also possible to track symptoms and treatment side effects for several conditions [108, 152, 281].

In comparison with the general population, people with chronic illnesses often have particular preferences that are not directly connected to their illness. For instance, they might be less receptive to playful data visualization (e.g. fish tank or flowers) [20]. Most technology for promoting exercise is also unlikely to be successful for people with chronic pain, as emotional responses caused by the disease affect exercise independently of pain level and capability, and the fear of causing harm causes exercise avoidance. Promoting self-efficacy, reduced anxiety, and preventing overexertion is likely to lead to better results [287]. In general, encouraging curiosity, self-discovery, and exploration can encourage adoption and adherence [196]. For some conditions, such as cardiac rehabilitation, it is best to use personalized goals, rather than general population guidelines, to set appropriate expectations and provide adequate feedback to users [197]. Data interpretation for those with chronic conditions might also differ from the general population, even if the variable tracked and the tool are the same. For instance, an activity monitor might interpret a high heart rate reading as a positive sign of physical activity, but for a user with a heart condition, it might indicate overexertion.

Technology designed for supporting self-management must fit within patients' everyday lives, and consider the role of caregivers and clinicians within their self-management [234]. Tracking as part of chronic illness management is often part of a social context including informal caregivers and clinicians who may share the work of tracking or interpreting the data [318]. Activities that are part of self-managing chronic conditions are deeply intertwined with people's everyday lives, and might not align with designs based on common medicalized perspectives that isolate or prioritize medical needs from mundane needs and tasks [233].

2.1.3 Recovery tracking

Recovery or rehabilitation is a process that aims to restore, maintain, or improve skills or abilities that have been lost or impaired because of an illness, injury, or disability. Individuals often go through rehabilitation to recover from a stroke, surgery, or to manage progressive illnesses such as Parkinson's and Multiple Sclerosis [238]. Recovery can include physical therapy, occupational therapy, and speech therapy. Rehabilitation technology could allow patients to achieve significant improvements when they do not have access to in-person therapy services (e.g., due to costs, insurance limitations, or transportation [335]).

There are several examples of research investigating technology for physical or occupational therapy [267, 247]. For example, SenseCap is a wearable system that collects data about physical therapy neck exercises [135]. Another system called Physio@Home used visual guidance and feedback to guide users through exercises [301]. Past work has studied rehabilitation technology in the context of transition from hospital care [250], knee [14, 121, 122] and wrist [307, 306] rehabilitation, Parkinson's disease [29], cardiovascular disease [222], and stroke [214].

Medical recovery is a promising application of tracking. Researchers have argued that tracking can help patients reflect [249], understand their progress, support self-efficacy [5, 250], and promote awareness, motivation [32, 131], and habit formation [44]. Self-tracking can be used to support recovery self-care activities (e.g., daily physical therapy exercises) and to measure and monitor progress through time. For example, ArmBeta [187] was a wrist worn prototype system designed to monitor progress by detecting activities involving arm movements (e.g., opening a door). In the long term, an increase in arm movements could indicate recovery progress.

Physical therapy patients benefit from two kinds of feedback: knowledge of performance and knowledge of results [329]. Knowledge of performance refers to feedback about exercise form (e.g., moving in the correct direction and speed), while knowledge of results refers to feedback about the outcome (e.g., hitting the target). Past research has investigated systems that provide both kinds of feedback. For example, using data visualization in real time to guide movements [14, 29].

Data obtained from digital rehabilitation systems can be used both by patients and by healthcare providers. Data collected from these systems also has been used to measure and track progress in rehabilitation [29, 121, 122, 214]. Information about progress is useful for both patients and clinicians, and it can support collaboration and decision-making [171, 66]. However, there are challenges involving aligning the goals of patients and providers, data quality, data interpretation, and taking action based on those insights [326].

Rehabilitation technology often involves games, or video game systems such as the Nintendo Wii or Microsoft Kinect [79, 253]. Off the shelf game systems can be useful due to their accessibility and relative low cost [171]. Additionally, researchers believe that games can improve motivation and adherence among rehabilitation patients [167, 171]. Games have been leveraged for rehabilitation in different contexts, including stroke [276, 322], cerebral palsy [141], and upper limb recovery [78].

2.2 Health technology for seniors

Seniors are generally slower to adopt new technologies in comparison with younger age groups [8]. The adoption of health technology presents a similar pattern. While previous research has found that older adults are often interested in mobile health technology (mHealth), very few use it [320]. Low use is affected by general technology adoption barriers. For instance, in 2013 only an estimated 18% of US older adults owned smartphones, and 27% owned tablets or e-readers [288]. But there are also specific issues affecting the adoption and use of mHealth by the senior population.

Attitude towards systems has a large impact on adoption. Interest in health technology largely comes from the perception that it can meet an existing need [242]. However, a lack of awareness of existing systems and their benefits limits interest. Thus, health IT should be simple, have its benefits demonstrated, and provide training and support to these users [126]. More evidence on health outcomes could support increased awareness and interest from potential senior users [294, 320]. Other important aspects for adoption include social factors, digital literacy, usability, physical ability [231], actual or expected cost, and privacy concerns [320]. Some of these issues are likely cohort effects, expected to be mitigated with time as technology improves, its use to assist seniors becomes more common, and individuals who are familiar with technology age into late life [334].

Stigma associated with old age, illness, and disability can cause resistance to the adoption of technology for health and assistance. Due to stigma, many seniors prefer mainstream tools to those designed for specifically for them [184]. Making mainstream technology more friendly to seniors could help to reduce the barriers caused by stigma, and make for more cost effective tools [81, 129]. However, it is still important to work on overcoming stigma so that tools that are needed by seniors, such as Aging in Place or monitoring technology [317, 109], can become more accepted.

2.2.1 Self-tracking for Older adults

While older U.S. adults are more likely to self-track, their practices and goals differ from other age groups. Seniors are more likely to track data related to self-management, such as blood pressure and blood glucose. In comparison with younger adults, they are also much less likely to use technology such as mobile phones and computers to track, and more likely to use paper [103]. They often use memory to track, due to effort required in registering data, disruption of routine, difficult tools, avoiding thinking about illness, and fear of losing the data [218]. Seniors have expressed interest in tracking several health related data including rest, social interactions, blood and urine tests results, diet, exercise, symptoms, and weight [74]. Most self-tracking technology that is commercially available is designed and marketed for young adults. These technologies often do not meet seniors' motivations and goals, or their needs regarding usability and accuracy.

Seniors' needs and attitudes towards tracking differs from other age groups. They benefit from intrinsic motivation strategies, as their goals for exercising are related to preventing or reversing impairments, gaining or maintaining functionality. They can exhibit a self-conscious perspective towards exercise, and benefit from positive feedback and reassurance. In comparison, younger people were interested in extrinsic motivation strategies (e.g., virtual medals) [6, 145, 144]. In a project that investigated an intervention to promote physical activity, only participants who wanted to be active but needed more motivation found it beneficial. Active participants did not find it useful, and unmotivated seniors were more interested in playful approaches. Playful designs included abstract art-like visualizations of Fitbit data [89].

Designers and researchers of self-tracking systems often use theories such as the Transtheoretical Model of Behavior Change and Goal Setting Theory with the intention of leveraging evidence-based strategies to help users achieve their goals. However, many of these strategies are significantly less effective among older adults [106]. There are no specific theories that can guide the design of behavior change systems for seniors.

Several studies have focused on technology for self-management of chronic illness among seniors. Examples include diabetes [12, 186, 328], heart health [221, 148, 189], pain management [21, 22, 205, 310], medication tracking [273], and fall detection [112].

Research has also investigated the role of self-tracking in promoting physical activity in seniors. Step counting has found mostly positive results, such as 23%-83% increase in step count after 6 months, as well as improvements in fear of falling, locomotive function, leg strength, walking speed, and blood pressure [13, 291, 331]. However, multiple studies found no significant increases in activity levels when incorporating a Fitbit into an existing intervention [210, 304]. Strategies used to promote or facilitate physical activity have included personalized goal setting, problem solving, social comparisons and support [157], haptic feedback [255], wearable camera, activity tracker [124], and video [17].

Previous research has also evaluated commercial activity trackers with older adults. The results indicate these devices have great potential, but also reveal many existing challenges.

In an activity tracker study with participants over 50 years old, 45% reported increased motivation for healthier habits, and 46% reported increased activity, improved sleep or eating habits. Participants enjoyed learning about their exercise and sleep habits, confirming activity levels, and some reported ease of use [1, 43]. Several other studies have also found positive results and experiences [215, 262, 209, 278, 244]. A few studies also found satisfactory accuracy in comparison with self-report [293], and visually counted steps [243].

A few user experience issues have been identified for activity trackers. These include perceived inaccuracy, unclear instructions, discomfort or difficulty putting on and taking off, frustrations with syncing process [1, 43], device falling off, underestimating steps [158], failing to detect steps in a treadmill [92], difficulties setting up device and interpreting data [215], and insufficient error prevention [251]. Attitudes towards these devices can become more negative over time, with most participants abandoning after two weeks [92]. Older seniors tend to use them less consistently, abandon earlier [1, 43], and to perceive the device as a 'gimmick' [278]. The findings of another study suggested that the senior population tends to be more concerned about accuracy [261], and more interested in tracking steps and heart rate, while younger users are more interested in sleep and distance [261, 278].

Validation studies have found that activity trackers underestimated steps of free walking participants by up to 27%, and those who used a cane or walker had worse accuracy [99]. For them and for slow walking seniors, ankle worn devices tend to be more accurate [99, 162, 286]. Activity trackers have also been shown to not increase physical activity of seniors with cognitive impairments [314]. Aiming towards the goal of 10,000 daily steps can also cause overexertion in older adults [278].

Tracking devices have been used for monitoring seniors. For instance, Casilari et al. used smart watches and smartphones for fall detection [49]. USEFIL (Unobtrusive Smart Environments for Independent Living) monitors seniors' activities and heart rate, and notifies remote caregivers [3]. Wearables have been used to monitor indoor location and activities [176, 260, 300], and to measure steps of patients who had knee surgery [268]. Studies have also investigated a food diary for the smart home [37], privacy controls [45], and medication tracking [174]. Such studies have found that seniors are more interested in seeing exceptions or mistakes (e.g., days when they forgot to take a pill) than regular 'correct' behavior in the tracked data [174].

Supporting doctor-patient communication between older adults and caregivers is a promising application of self-tracking, because senior care can involve both self-care and receiving care from others, including professional caregivers as well as family and friends. Nonetheless, while 58% of older adults who self-track share data with a health provider [103], communication may be hindered by incompatible expectations between patients and health providers regarding patient-generated data [53, 60]. Participants of a study on home technology for self-management found it useful for making decisions. However, a few participants preferred interacting with a clinician than a system, and distrust system measurements. Participants who were not able to afford medication disliked having a reminder of their health issues, when they were not able to address those issues due to financial constraints [148].

To overcome these challenges, it is necessary to specifically research and design for seniors to better meet their goals and needs. Detailed and easy instructions, transparency about data collection, robustness, comfort, and targeting specific conditions are also important [1, 43]. Increased awareness of the benefits of activity trackers for this population is also essential to promote adoption [92]. Specific appropriate guidelines (e.g., ideal step count) could also help with interpreting data and setting goals [278]. Future research should investigate attitudes towards exercise, behavior change, and adoption of technology to inform design of devices and interventions [10]. Further, it is important for more projects to propose and test solutions to these issues through user-centered and participatory design with seniors [220].

2.3 Impact of self-tracking

2.3.1 Reflection and self-knowledge

After collection, users must interpret their data to achieve their goals for self-tracking. Interpretation can take different forms depending on the kind of data collected, tool used, and the users' goals. For instance, those who self-track to monitor a health indicator can simply examine whether their data is within a range of values they consider desirable. But, for purposes such as self-knowledge and behavior change, the process of engaging with the data can be more complex.

Systems designed to support reflection and self-knowledge are an emerging theme in third wave HCI [27], and particularly in self-tracking [15, 25]. Baumer defines reflection as "reviewing a series of previous experiences, events, stories, etc., and putting them together in such a way to come to a better understanding or to gain some sort of insight" [27]. Reflection is one of five major stages of self-tracking, and it allows trackers to gain self-knowledge [182]. The Quantified Self movement, subtitled "self-knowledge through numbers" is based on the interest of increasing self-knowledge through self-tracking and reflection [330].

Research has shown that there are two phases of reflection in self-tracking. An exploratory "discovery phase" where self-tracking is used to answer questions about history, goals, and context. And a "maintenance phase," when users ask questions about status (e.g., whether they are meeting a specific goal), discrepancies, and influencing factors. The maintenance phase is better supported by current tools than the discovery phase [183].

Contextual information can offer more opportunities for reflection and self-knowledge, such as: social (comparison with others), spatial (relationship between space and behavior), historical (comparison with past data), metadata (e.g. nutrition facts of a meal), and context from other data sets (e.g. weather, calendar). When trying to identify triggers, possible triggers should be included in the tracked data [58, 266].

Self-tracking systems designed to foster reflection have shown positive results. A mood tracking system increased understanding of mood patterns and stress management exercises. As a result, participants significantly lowered their levels of anger, anxiety, and sadness [224]. The Mobile Health Mashup, a system that presented correlations from several health-related sensors helped users gain insights they otherwise would not have obtained from the separate data alone [305]. Manual methods of self-tracking can induce higher awareness and reflection [181]. Some users purposefully choose manual self-tracking methods because of the opportunity for reflection [229].

Supporting reflection involves providing tools to record and visualize data, allowing and encouraging users to ask questions from the data, providing the ability to format data, record different kinds of data, visualize data in different granularities, and analyse different kinds of data together [98]. Different data visualization styles, granularity, and temporal displacement can better promote reflection than others. These differences appear to be personal preferences, not related with particular goals [86]. While lack of information may limit reflection, too much information may confuse users. Because the optimum amount of information varies between users and changes with time, it may be necessary to adjust utilizing contextual cues [246].

Reflecting on tracked data can serve different purposes in chronic condition management, such anticipating what might happen in the future [258], coping with the condition [249], increasing self-knowledge, supporting everyday tasks, and making decisions [149]. Reflection can take place differently depending on the person's goals. In the case of managing diabetes, for example, there are three modes involving data interpretation: habitual, sense-making, and contextual reasoning. In habitual mode, patients use heuristics to monitor their health (e.g., checking that blood glucose is within desired range). Sense-making mode requires more intentional effort to answer questions or find cause and effect (e.g., how a certain meal impacts blood glucose). Contextual reasoning involves quickly using data to improvise and problem solve. Contextual reasoning is based on known information, but it requires more cognitive effort than habitual tasks [149].

Barriers to reflection and self-knowledge include lack of time, visualization limitations (e.g. not displaying the right granularity), self-criticism (e.g. negative meaning or emotion attached to the data), difficulty interpreting the data, difficulty finding the desired data, lack of contextual information, not enough data due to irregular data collection, lack of trust in data, data not being useful or being counter-intuitive, and tracking variables that are difficult to manipulate (e.g., stress) [146, 182, 258].

2.3.2 Behavior change

Technology designed to support behavior change aims to help users overcome undesired habits (e.g. addictions) or adopt new ones (e.g. daily exercise). Self-tracking can facilitate changes in behavior through increased reflection and self-awareness [140, 132]. Just tracking a desired behavior such as studying, with no additional intervention, has been shown to increase its frequency [40]. Because behavior change interventions can result in the opposite of the desired outcome [48], designing effective systems requires understanding the mechanisms of behavior change.

Reactivity, i.e. the degree of behavior modification [166], decreases when tracking multiple unrelated data [125], when tracking involves obstructive devices [230] and when tracking undesirable behavior [207, 270]. Promoting behavior change is more effective when goals are set [151, 194], the target behavior is concrete, important, observable, and the intervention is motivated by moderate distress [143]. Being monitored by others and receiving feedback may also increase reactivity [151]. While training people to self-track has been shown to increase data accuracy, but not reactivity [230], inaccurate data may be poorly perceived by users, and hinder reactivity [239].

Fogg argued that behavior change requires motivation, the ability to perform the target behavior, and a reminder simultaneously [102, 100]. Reminders should be short and easy to understand, and avoid bothering users [137]. Further, the mechanisms of tracking must be realistic. For instance, tracking cigarettes smoked can be difficult, as this often happens in social settings [239].

Most studies of persuasive technology for health have presented positive outcomes. However, mixed, negative, and no results have also been reported. These studies targeted behavior, attitude, motivation, awareness, or self-efficacy. Studies based on a theory were more likely to have positive results [237]. Context aware and event-based reminders have also shown significant results. However, most currently available apps do not leverage context [296, 142].

Most systems designed for promoting behavior change focus on health, mental health, or education [101]. Physical activity and diet are the most common targeted behaviors [237]. Self-tracking has also been used as a behavior change strategy for smoking cessation [4, 239], sunscreen use [11], nail-biting [211], recycling [303], and household chores [97].

2.3.3 Negative experiences with self-tracking

Self-tracking can lead to negative experiences in situations where the data is interpreted negatively, particularly among vulnerable populations. Preventing adverse experiences requires careful consideration when designing self-tracking systems.

Providing negative feedback, such as displaying data that could be interpreted as undesirable, could create guilt, disappointment, and embarrassment among people with mental illness [275, 155]. For women with eating disorders, using diet tracking apps can exacerbate disordered behaviors [82]. Tracking technologies could also negatively impact the physical and emotional wellbeing of older adults by damaging their self-concept [213]. Interpreting the data as a failure can lead to self-blame when the cause is attributed to internal factors (i.e., the person's efforts or qualities) rather than external factors (i.e., circumstances or other individuals) [274].

In situations with power imbalance, self-tracked data can create concerns and lead to negative experiences. When managers or bosses have access to their self-tracked data, workers can feel pressured to manage their reputation (e.g., by being less active in case of office work) [117]. In the context of factory work, tracking can create pressure and stress for workers when the data is visible to managers [127].

Discrepancies between tracking devices and users' expectations can lead to incorrect data interpretation and frustrations [332]. Users are reportedly particularly frustrated when their efforts are underestimated [64]. When people experience difficulties with achieving their goals through self-tracking, they can also have negative experiences with health data, feeling burdened, obsessive, trapped, or abandoning tracking [71].

To prevent these negative experiences, researchers have argued for designing to to increase the sense of control among users [24], highlight and celebrate success and positive data [274, 127], and be careful to avoid framing data negatively [275]. Increasing transparency about what the device is capable of measuring and uncertainties could also help to mitigate issues [283].

2.4 Conclusion

The shift in care enabled by patient-centered health technology will require new responsibilities for both patients and clinicians. The design of these systems must be informed by the needs of patients and clinicians. Still, many gaps remain on our knowledge about these needs, and about how to design technology that makes a positive impact by empowering seniors.

While several studies have described barriers for seniors' use of self-tracking systems, we need to better understand their relationships with tracking technology and their needs as potential users. In-depth qualitative research is required to understand the reasons behind the limited adoption of tracking technology among seniors, and how seniors currently use self-tracking for health.

It is also important to investigate how seniors differ from other populations in their use of self-tracking for health. We cannot assume that psychology models and other insights based on research with younger people apply to seniors [106]. Understanding where these differences lie could help guide future research and also lead to useful implications for design of health technology for older adults.

Several rehabilitation technologies have been designed and studied, but there is little work in HCI aiming to understand patients and clinicians' interactions with the data collected by these systems. These data could be used by patients and clinicians. But similarly to other kinds of self-tracking discussed in this chapter, details such as what kind of data to collect and how to display these data are very important to effectively support reflection and understanding for all stakeholders, to support their specific goals, and to prevent negative experiences.

The research in this dissertation was planned and conducted to address these gaps. Chapter

3 provides an overview of the three studies.

Chapter 3

Research overview

This dissertation research investigates self-tracking among older adults through three different studies. Each study has used different methods to try to understand existing barriers and opportunities in this space. I refer to them as study 1, 2, and 3. Studies 1 and 2 investigate seniors' current use of and perspectives towards self-tracking, while study 3 focuses on a potential application of tracking in the context of medical recovery from stroke. As discussed in Chapter 2, there are important gaps in our knowledge about how to design health technology to support seniors in their self-care work. This research aims to contribute to the literature by providing novel insights about seniors' needs for healthcare technology.

Table 3.1 provides an overview of the three studies. The first study uses quantitative analysis of survey data to investigate how different factors, such as age, chronic conditions, and other health factors influence self-tracking practices. This study allows us to further understand the findings from studies 2 and 3, whose participants had complex health contexts. By examining the impact of age and health on tracking, we can better understand if the challenges found are linked to age, health status, or both.

An exploratory qualitative study with older adults, study 2 investigated how seniors think of

	Study 1	Study 2	Study 3
Investigates	Tracking practices by different populations	Seniors' tracking practices and barriers	The role of tracked data for stroke recovery
Motivation	To learn how age and health impact tracking	Little was known about seniors' use and non-use of self-tracking	Following Study 2, to understand self-tracking in a recovery context
Methods	Pew survey reanalysis	Interviews	Interviews and focus group using data visualization artifacts
Participants	3,000 US adults	18 seniors, 5 staff members of a retirement home	10 stroke survivors, 4 healthcare providers
Health data type	Wellness health indicators	Wellness, health indicators, recovery	Recovery

Table 3.1: Overview of the three studies.

self-tracking, self-tracking technology, what role this practice plays in their self-management, and what barriers exist for adoption of self-tracking technology among this population.

Lastly, the third study investigates a particular context of self-tracking by focusing on recovery from chronic stroke. This qualitative study aimed to understand self-tracking in a game-based tele-rehabilitation system. Specifically, this study investigated the perspectives of health care providers and stroke survivors towards the data tracked by the system through interviews and a focus group. Each of the interview and focus group sessions used visualization of tracked data to prompt discussion among participants.

These three studies used different methods to understand seniors' unique perspectives towards tracking, including their practical needs in terms of specific goals pursued, and the more psychological aspects of self-tracking and interacting with tracked data. Below, I describe each study in more detail.

Study 1

The first study investigated how different variables such as age and health status influence tracking practices. This study consisted of a reanalysis of survey data from the Pew research center project titled "Tracking for Health" [103]. The survey dataset includes data from over 3,000 participants in the U.S., and over 30 different questions. The reanalysis took into consideration two different kinds of tracking: wellness (i.e., exercise, diet, weight) and health indicator tracking (other health data such as blood pressure). Chi-squared tests and logistic regressions were used to investigate tracking practices among different populations. These tests controlled for other demographic variables, including education and income.

The Pew survey on tracking for health found that tracking is more prevalent among seniors and among those who had one or more chronic condition [103]. Further examining these data allows us to better discern tracking use among different demographics. For example, because Study 2 participants were seniors who had multiple chronic conditions, it was not clear whether the barriers found are due to their age, health status, or both. Although there is an increase in the prevalence of chronic conditions with age, separating these factors is useful to understand tracking practices in different contexts.

Study 2

This exploratory project was intended to address a gap in the literature, as prior work had found that seniors use self-tracking for health, but do not use self-tracking technology [103]. However, we did not know what barriers existed, or how to address them. This study sought to understand existing self-tracking practices among seniors, their perspectives towards self-tracking and self-tracking technologies, and existing barriers by answering these research questions:

In this study, we interviewed 18 seniors and 5 employees of a retirement community. Their ages ranged from 74 to 100, with a median of 84. We also interviewed two social workers, a fitness trainer, a nurse manager, and a computer technician who worked in the same retirement community.

Study 3

Study 3 investigates how stroke survivors and healthcare providers respond to self-tracked data in the context of physical and occupational therapy. Stroke is a medical event that affects seniors more than other age groups. This study focuses on tracking in the context of medical recovery. In comparison with the previous studies, this project aimed to understand a potential application of self-tracking rather than existing practices and barriers.

This was a qualitative study involving a 2-hour focus group with 4 physical and occupational therapists and interviews with 10 stroke survivors. Both the interviews and the focus group used visualizations in the form of line graphs, diagrams, and calendars. The objective of the artifacts was not to evaluate their design, but to prompt discussion and understand the perspectives of the participants about the data. All visualizations were created using real patient data collected by the telerehab system and by Fitbit devices.

This work combines three studies investigating tracking among seniors from different angles, aiming to contribute to our understanding of their experiences with and perspectives towards tracking.

The second study focuses on tracking practices among different populations, revealing how age and health status both influence tracking habits. This study contributes to our understanding about what leads individuals to self-track and about existing barriers. Through the second study, I was able to investigate existing barriers to seniors' use of self-tracking technology, and discuss potential directions for future research to understand how to design better fitting tools for seniors. Lastly, the third study contributes to our understanding of tracking for recovery, a context that was highlighted as important in the first study and that we know little about.

Together, these studies emphasize the importance of designing technology to empower users, particularly in the case of populations that have complex health needs such as seniors and stroke survivors. Wellness tracking should seek to validate and encourage, including when users have complex health. Tracking for managing or preventing chronic conditions must provide value or reduce burden for seniors. There is an opportunity to design with the intention of providing hope to users when they are going through medical recovery.

The next three chapters thoroughly describe studies 1, 2, and 3, including their motivations, findings, and implications. Subsequently, chapter 7 provides an overall discussion of the three studies.

Chapter 4

Impact of age and health factors on self-tracking habits

Self-tracking is commonly used for health purposes, such as preventing or managing illnesses. Tracking is particularly prevalent among those who are older or have chronic conditions. However, little is known about how different aspects of health individually affect tracking behaviors. Better understanding the population of self-trackers is essential to the design of self-tracking technology. This chapter investigates the relationships between tracking and age, illness, and self-reported health status based on data from a Pew Research Center survey. The results show that there is a significant relationship between age and tracking habits even when controlling for disease and health status. Chronic conditions and health status also influence both wellness and self-management tracking. This study provides novel insights into the differences in tracking habits among different populations, and common motivations for tracking.

4.1 Introduction

In the U.S. and Canada, more than 60% of people utilize self-tracking for health management. However, a substantial proportion of the population does not leverage any technology to assist in their self-tracking practices [103, 240]. Most HCI research on technology-assisted self-tracking has focused on early adopters or enthusiasts – a population that is younger, more educated, and have higher socioeconomic status (SES) than the general population [240]. While this body of research has provided valuable insights, self-tracking is most common among older adults (65 and older), whose adoption of self-tracking technology is below 2% [103]. To design effective self-tracking tools, it is necessary to understand potential users, their needs, and motivations. There remains a knowledge gap about how self-tracking is currently used, such as what people want to track and who will likely track. This study aims to address this gap.

In this study, I aim to investigate different factors that may influence tracking habits. To explore how tracking habits are impacted by age, chronic illness, and perceived health status, I analyzed data from the Pew survey on Tracking for Health [103]. With the use of statistical analyses, I have found that wellness tracking is most common among healthier individuals. Those who have chronic illnesses are more likely to track other health information, such as blood pressure. This study has led to novel insights about the population of trackers, and the health-related motivations behind tracking. This work contributes to the literature focusing on self-tracking and technology for health management.

4.2 Background

Self-tracking can be used for both prevention and management of complex chronic conditions. It can help people to monitor and detect a decline in their health [46], to learn more about themselves, including their habits and health status [182], to change behavior, such as exercising more [200], and to self-experiment, for example, to find symptom triggers [147]. There are many different kinds of health information that can be tracked. Wellness-related information such as exercise, diet, and weight are among the most common [193]. This kind of self-tracking can be used by people who want to make changes to their lifestyle, become more physically fit, have a more balanced diet, or manage their weight. Many popular mobile applications and activity trackers focus on tracking this kind of information (e.g., Fitbit, Nike Sportsband, and pedometers [119, 193]).

Self-management tracking includes other other kinds of health information that are particularly relevant for people with certain chronic conditions. For example, people with diabetes often self-track their blood glucose, and tracking blood pressure is particularly relevant for people with cardiovascular diseases [31]. This kind of information can be tracked to manage an illness, to try to detect it early, or to assist in behavior change by supporting activities recommended for managing the condition [159].

In the U.S., 60% of adults track wellness information, and 33% track other health indicators or symptoms. Self-tracking is most common among seniors: 71% of them track wellness information, and 52% track other health indicators. Tracking is most common among people with chronic conditions, particularly those with multiple illnesses. People with chronic conditions take tracking more seriously: they are more likely to register their data on paper or using technology, track regularly, and share their data with clinicians. They are more likely to report that tracking has influenced their approach to managing health and making healthcare-related decisions [103].

While older adults self-track more in comparison with younger age groups, both technology and research to date have focused mostly on younger users. Previous studies have shown that older adults have different needs when it comes to self-tracking, and experience barriers when trying to use tracking technology due to differences in their contexts in comparison with younger populations, including a mismatch between their needs and the technology, issues with low accuracy, and ease of use [47, 92, 158]. To better serve this population, we need to pursue a better understanding of the needs, motivations, and challenges that they experience.

While the Pew survey [103] has provided extensive information about trackers, we cannot draw conclusions about the predictors of health tracking behavior based on the reported results. A more in-depth analysis of their dataset can provide more information about the influence of different factors associated with self-tracking, such as age and incidence of chronic illnesses. Examining these factors in detail will provide us with more information about what leads people to track, and which populations are more likely to self-track.

4.3 Methods

To better understand how different health-related factors influence tracking, I have conducted a series of statistical analyses on a public dataset from a survey on tracking for health [103]. The Pew Research Center conducted this phone survey in 2012 with a total of 3,014 respondents. All participants were adults (18 or older) who lived in the United States. The calls were conducted in English and Spanish.

4.3.1 Survey questions

The survey asked over 30 questions about different topics, including demographic information, health status, tracking habits, caregiving, and use of technology. Table 4.1 includes the main questions used in this study.

The first two questions are about self-tracking habits. Question 24 asks about what I call

#	**Question**	**N**
24	Now thinking about your health overall... Do you currently keep track of your own weight, diet, or exercise routine, or is this not something you currently do?	1,929
25	How about any other health indicators or symptoms? Do you happen to track your own blood pressure, blood sugar, sleep patterns, headaches, or any other indicator?	1,117
2	In general, how would you rate your own health?	
	Excellent	858
	Good	1561
	Only fair	486
	Poor	136
3	Are you now living with any of the following health problems or conditions?	1,498
	Diabetes or sugar diabetes	374
	High blood pressure	895
	Asthma, bronchitis, emphysema, or other lung conditions	376
	Heart disease, heart failure or heart attack	260
	Cancer	116
	Any other chronic health problem or condition I haven't already mentioned	544

Table 4.1: Survey questions used in the analysis

wellness tracking (i.e., tracking activities related to weight, diet, or exercise). Question 25 refers to self-management tracking (i.e., all other health-related information such as symptoms or vital signs).

The other two questions included in the analysis are health status (question 2) and chronic conditions (question 3). Health status is a self-reported assessment of the person's health in one of four categories: excellent, good, only fair, or poor. These ratings provide a measure of the respondent's overall health, including how challenging and severe any ailments are. Self-reported health status is a reliable indicator of health, as it can accurately predict outcomes [136]. Question 3 asked whether participants had chronic illnesses. The interviewer asked about five types of diseases in random order, and then asked about any additional conditions they might have. The last column of the table (N) shows how many participants answered ‘yes’ to each question.

4.3.2 Analysis

The analysis focused on the 2,136 participants who reported using tracking for health, i.e., those who answered “yes” to question 24 or question 25. First, I utilized scatter plots to observe how self-tracking prevalence changes with age. In this plot, I grouped people who were 90 or older due to a relatively small sample of respondents above 90.

Then, I conducted a series of chi-squared tests within different sub-groups of participants. These tests aimed to understand the influence of age on tracking habits for people with different chronic conditions, and different health statuses. All of these tests were based on 2x3 tables: 3 age groups and having answered yes to tracking (questions 24 and 25), and all had two degrees of freedom. I report these results in Tables 4.2-4.4. For each test, I report the chi-squared statistic and p-value. Only the percentage of people who responded ‘yes’ to each question is reported, as these questions had binary answers.

Lastly, I used logistic regressions to analyze the contribution of each aspect of health – age, illness, and health status – to the likelihood of tracking. I conducted four different logistic regressions. First, I tested how different illnesses contributed to tracking individually by including each illness in the model. Then, I analyzed the effect of multiple chronic conditions on tracking. For each of these tests, one regression evaluated tracking of wellness information and the other evaluated self-management tracking. I used different models to investigate the influence of having multiple chronic conditions, as this variable was not independent of the chronic illness variables. The logistic regressions controlled for demographic information (education, income, and ethnicity).

The two types of tracking behaviors included in the dataset, tracking wellness information and tracking health-related indicators, are tested separately in all of the analyses. I chose to analyze these questions separately because they are used in different kinds of health management, and they show different patterns in the dataset. With these methods, I was able to evaluate how individual factors influence tracking habits. I report the results of the statistical tests in the next section.

4.4 Findings

The findings show that both age and health are independent predictors of tracking behaviors. While having a better health status or cardiovascular diseases increases the odds of tracking wellness information, having other chronic conditions, such as diabetes or cancer, do not.

4.4.1 Scatter plots

The first plot (Figure 4.1), shows the different rates of tracking wellness and health indicators among different ages. Each point in the plot shows the percentage of people of that age who self-track. Wellness tracking is common among all ages (>40%). It decreases slightly between the early 20s and mid-40s, increasing between 40 and 70, and it peaks around 70 (>60%). In comparison, tracking other health indicators is much less common among people in their 20s and 30s (<40%). Similar to wellness tracking, there is an increase from the mid-40s until 70s, and this kind of tracking peaks around 70.

These data reveal a few trends in tracking for different age groups. The practice of self-tracking is relatively stable between ages 18-45, it increases between ages 45-70, and decreases after age 70. Between ages 18-45, most people track wellness-related information. After 45, there is a growing diversity in tracking practices, with a larger percentage of self-management tracking.

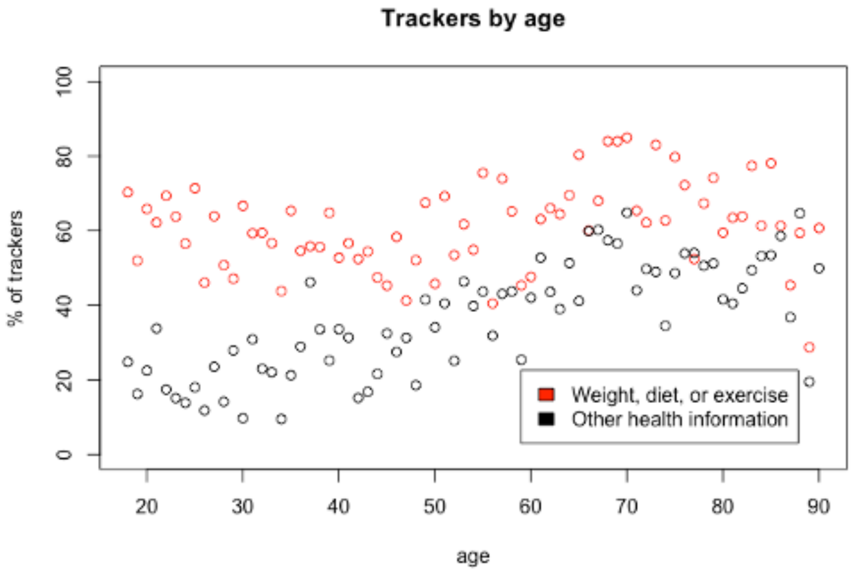


Figure 4.1: Scatter plot of tracking activity by age, showing an increase for both kinds of tracking among older adults.

These patterns illustrate differences among different age groups regarding their motivations, practices, and experiences with tracking. These differences might be influenced by changes in health, as chronic illness prevalence increases with age.

The next plot (Figure 4.2) shows the prevalence of chronic illness among the respondents. Similar to the the previous plot, there is a low prevalence before age 45, and an increased prevalence rate between the mid-40s and 70s. Based on these data, it is possible that the differences in tracking patterns for different age groups are driven mainly by chronic illness prevalence. The statistical tests below were used to evaluate the influence of age and health, in order to understand how each of these two factors impact tracking practices.

4.4.2 Chi-squared tests

To further examine the relationship between age, chronic illness, and self-tracking, I provide the results of several chi-squared tests. These tests were conducted for the entire sample,

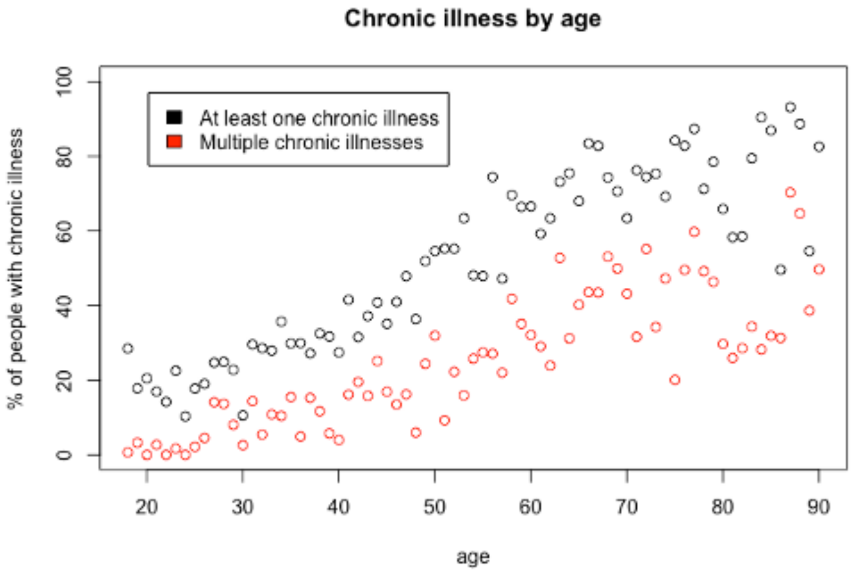


Figure 4.2: Chronic illness prevalence by age among survey respondents.

for people with or without chronic conditions, for people with multiple chronic conditions (Table 4.2), and individually for five types of chronic illnesses (Table 4.3).

As the plots suggested, there is a significant relationship between age and tracking. Overall, older people are more likely to track both wellness information and health-related indicators (Table 4.2). This relationship is also present in the entire sample (all respondents), and among those with at least one chronic condition. However, age has no significant influence on tracking among people with multiple chronic conditions. Among those without any chronic condition, age does not influence wellness tracking, but it does influence self-management tracking. In other words, people with two or more chronic conditions are likely to self-track regardless of age. Other groups track significantly more when they are older. Those without chronic conditions are more likely to track health indicators when they are older, but for them, age does not influence wellness-tracking.

When analyzing illnesses individually (Table 4.3), I found almost no significant relationship between tracking and age. People with diabetes, high blood pressure, respiratory illnesses,

	All respondents		No conditions		1+ conditions		2+ conditions	
Tracks	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI
18-45	58%	23%	58%	16%	59%	42%	59%	61%
46-70	62%	41%	62%	25%	62%	52%	65%	61%
71+	68%	48%	60%	22%	71%	56%	68%	64%
χ^2	11.87	132.75	2.86	15.10	8.70	15.06	2.48	0.34
p-value	**0.003**	**<0.001**	0.240	**0.001**	**0.013**	**0.001**	0.290	0.845

Table 4.2: Chi-squared test results among the three age groups for different conditions. Each column shows the results of one test.

	Diabetes		High BP		Respiratory		Heart		Cancer		Other	
Tracks	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI
18-45	62%	72%	59%	57%	57%	44%	72%	56%	75%	25%	62%	43%
46-70	67%	74%	65%	59%	66%	48%	63%	64%	60%	37%	62%	54%
71+	61%	65%	70%	61%	68%	59%	75%	66%	70%	58%	71%	49%
χ^2	1.32	1.95	4.26	0.12	3.34	2.99	3.09	1.22	2.03	7.18	2.45	5.35
p-value	0.52	0.38	0.83	0.66	0.19	0.22	0.21	0.54	0.36	**0.03**	0.29	0.07

Table 4.3: Chi-squared test results among the three age groups for individual illnesses. Each column shows the results of one test.

cardiovascular illnesses, and other illnesses were similarly likely to track both wellness and other health information regardless of their age group. However, among people with cancer, older respondents were significantly more likely to track health indicators. When analyzing other specific disease populations, age did not seem to have a significant effect on tracking habits. Most conditions showed high levels of tracking both wellness and health indicators.

The disparity in results between Tables 4.2 and 4.3 is intriguing. Since there is a relationship between age and tracking overall and among people with one chronic condition, I would expect to find a similar relationship among a few chronic conditions. The relationship ob-

	Excellent		**Good**		**Fair**		**Poor**	
Tracks	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI	Wellness	Other HI
18-45	63%	20%	58%	23%	44%	28%	61%	63%
46-70	70%	31%	62%	40%	60%	51%	42%	56%
71+	76%	41%	65%	46%	72%	53%	59%	57%
χ^2	6.49	21.37	3.32	0.19	18.93	25.39	3.54	0.35
p-value	**0.039**	**<0.001**	0.190	**<0.001**	**<0.001**	**<0.001**	0.170	0.838

Table 4.4: Chi-squared test results among the age groups for different health statuses. Each column shows the results of one test.

served among people with cancer does not explain these results, as they represented a small subgroup of the dataset. Other factors may explain the difference between these results, such as the influence of other aspects of health.

To better understand the relationships between tracking, age, and health state, I also analyzed data about the respondents' self-reported health statuses. Table 4.4 reports the results of chi-squared tests among those with excellent, good, fair, or poor health. These tests included all respondents, both those with and without chronic conditions.

These results show significant relationships between age and tracking among people with excellent, good, or fair health. Those with poor self-reported health were similarly likely to self-track regardless of their age. Among those with good health, the relationship between tracking and age was only significant in the case of self-management tracking.

Those with fair health exhibit the most drastic increase in tracking with age among all different health statuses. They have the lowest proportion of tracking wellness information in the 18-45 age range. Although the proportion of older trackers with fair health is similar to the excellent health group, the difference in wellness tracking among young people with excellent or fair health suggests that the tracking practices or the motivations for tracking differ between people with these two different kinds of health rating.

Overall, these results indicate that people with worse health, such as those with poor health and those with multiple chronic illnesses, have enough incentive to self-track, regardless of their age. In contrast, people who have good to average health are less motivated to track. For them, being older represents an additional reason to self-track.

4.4.3 Regression analysis

Table 4.5 shows the results of four logistic regressions used to test how age and different health factors predict wellness and self-management self-tracking. The first two models include specific illnesses, while the last two include multiple chronic conditions. Table 4.5 includes the odds ratio (OR), confidence interval (CI), and p-value for each variable in the model. Because health status ranges from 1 (excellent) to 4 (poor), an OR < 1 for health status can be interpreted as worse health leads to less tracking.

The first model tested wellness tracking and specific chronic illnesses. Only health status, age, and cardiovascular diseases are significant predictors of wellness tracking. The results show that people who are older, have cardiovascular disease, or have better health are more likely to track wellness related information. However, no condition other than cardiovascular disease was a predictor of wellness tracking.

The second model tested self-management tracking and specific chronic illnesses. Most illnesses predicted health indicator tracking, along with age. However, health status did not predict tracking in this case. Older adults, as well as those with diabetes, high blood pressure, respiratory and cardiovascular diseases, are more likely to track health indicators.

The third model tested wellness tracking and multiple chronic illnesses. Health status, age, and having multiple conditions all predict wellness tracking. People who are older, have

	Wellness tracking				**Self-management tracking**			
Individual conditions	OR	CI [	]	p-value	OR	CI [	]	p-value
Health status	0.81	0.71	0.93	**0.002**	1.06	0.92	1.22	0.415
Age	1.01	1.00	1.01	**0.007**	1.01	1.00	1.01	**0.005**
Diabetes	1.11	0.83	1.50	0.475	3.71	2.72	5.12	**<0.001**
High blood pressure	1.09	0.87	1.36	0.472	2.83	2.28	3.52	**<0.001**
Respiratory Illnesses	1.29	0.99	1.70	0.065	1.54	1.17	2.03	**0.002**
Cardiovascular illnesses	1.45	1.02	2.10	**0.044**	1.72	1.19	2.49	**0.004**
Cancer	1.11	0.70	1.79	0.675	0.73	0.45	1.17	0.191
Other chronic conditions	1.15	0.90	1.48	0.261	1.21	0.94	1.56	0.133
Multiple conditions	OR	CI [	]	p-value	OR	CI [	]	p-value
Health status	0.82	0.73	0.94	**0.003**	1.12	0.98	1.27	0.096
Age	1.01	1.00	1.01	**0.002**	1.02	1.01	1.02	**<0.001**
Has 2+ chronic conditions	1.43	1.12	1.83	**0.004**	3.44	2.72	4.36	**<0.001**

Table 4.5: Results of four logistic regressions: wellness or self-management tracking by individual or multiple chronic conditions.

better health, and who have multiple chronic conditions are more likely to track wellness information.

Lastly, the fourth model tested health indicator tracking and multiple chronic illnesses. Age and having multiple chronic conditions predict tracking of health indicators. Health status is not a significant predictor when the model includes age and having multiple illnesses. People who are older or have multiple chronic conditions are more likely to track health indicators, regardless of their health status.

4.4.4 Summary of findings

Age is one of the main predictors of self-tracking even when accounting for other aspects of health. Still, health conditions and health status influenced self-tracking practices.

Wellness tracking

While wellness tracking is prevalent across all age groups, it is most common among people with better health. Better health status predicts wellness tracking, suggesting that wellness tracking is used primarily for prevention purposes. Its popularity also increases with age, as shown in Figure 4.1.

Most conditions included in the survey, including diabetes and high blood pressure, were not predictors of this kind of self-tracking. However, there is an increase in wellness tracking in the case of having cardiovascular disease or multiple chronic conditions.

Self-management tracking

Tracking health indicators is associated with chronic illness management. Few younger people engage with this kind of tracking, and its use is predicted by having chronic diseases such as diabetes, high blood pressure, respiratory and cardiovascular illnesses.

While tracking health indicators is most common among people with chronic conditions, illness severity does not influence this practice. Health status is not a significant predictor of tracking health indicators, according to the regression results, when chronic illness is included in the model.

Differently from other illnesses, we found no evidence that self-tracking is used to manage cancer. Cancer is not a significant predictor of self-tracking, and it was also the only chronic illness with a low prevalence of tracking among the youngest age group (25.2%).

Tracking health indicators is also used for prevention. Many people, particularly those who are older than 45, track health indicators even when they have no chronic conditions. Thus, health indicators are also tracked for chronic condition prevention in specific contexts.

Age and self-tracking

Age is positively associated with self-tracking activities, regardless of other health factors. Older respondents seem to have more incentives to track. For that reason, their health status is less influential to their tracking habits.

The influence of age on tracking was weaker among people that already have a high prevalence of tracking habits in the youngest age group (18-45). In the case of wellness tracking, that was observed among people with good health and no chronic illness. In the case of health indicator tracking, people with worse health or multiple chronic conditions had this pattern.

The increase of tracking with age is less pronounced among people with worse health (e.g., multiple diseases or poor health status). Among the populations whose tracking behavior does not vary significantly by age, all age groups have a high proportion of trackers - typically above 50%. Younger people with worse health likely have a stronger incentive to track. The incentive is enough that there is no statistical difference between tracking for different age groups among those with worse health.

4.5 Discussion

This study has led to novel findings about self-tracking behavior and how it is influenced by age, chronic illness, and health status. In this section, I discuss the findings, implications, and directions for future work.

Finding that healthier people are more likely to track wellness information is surprising because wellness-related activities are often recommended to manage chronic illnesses [36]. The only illness associated with wellness tracking, among the five examined in the survey, is cardiovascular disease. Others such as diabetes, high blood pressure, also are influenced by diet and exercise, but they do not predict wellness tracking. It is possible that tracking wellness helps people to maintain their health, or that people who track wellness information also have more motivation and are better at caring for their health. Perhaps for people with worse health, wellness tracking is not as much of a priority as other tasks involved in health management. It is not possible to know the reason based on this study. However, future research should aim to understand what is causing this difference in order to address the problem.

Tracking health indicators was most common among people with worse health, or older age. People are more likely to self-track health indicators if they are older or have a chronic illness. It is likely that the practice of self-tracking differs between people of different ages, and also between people with and without chronic illnesses. We also do not know what leads older people to track health indicators more than younger people when they are healthy. Thus, it is important to investigate the tracking practices of seniors. Examining the tracking practices of the second age group (46-70) could also provide insights into the reasons behind the increase of self-tracking in that age range.

Having a cardiovascular disease or multiple chronic illnesses impacted self-tracking differently in comparison with other conditions. Cardiovascular disease was the only illness that was associated with a higher likelihood of tracking wellness information. Moreover, having multiple chronic conditions was significantly associated with tracking wellness and health indicators. People with multiple conditions represent a substantial portion of the population (26%) [323], and their self-tracking might warrant particular attention. Since they are caring for multiple illnesses, they might be more likely to run into issues caused by different tools that are not compatible or face high burden from not having a centralized platform for tracking [58].

Age is a significant factor influencing tracking, even when controlling for other health aspects. Still, most self-tracking technology focuses on a younger population. Previous work has found challenges older adults face with self-tracking technology, including a mismatch between their needs and the technology [92]. This study expands on this literature by further investigating how age influences tracking. The findings reveal that older adults can benefit from tracking health indicators even when they do not have chronic diseases. This is one direction to pursue in the future regarding tracking among seniors.

The populations using tracking and the purposes behind it are diverse. This diversity indicates that designers should avoid making assumptions about users' health and goals. Trackers can be of all ages, health statuses, and have different illnesses with different severity. They can also use tracking for prevention or management of chronic conditions. Self-tracking technology needs to support these different backgrounds and goals. There are several aspects of tracking that future research should investigate. Examining why healthier people are more likely to use wellness tracking is essential to understand how to better support those who are not as healthy. Also, what does it look like to track health indicators for prevention, and track wellness information for managing an illness? These practices have not been investigated much, but they are relatively common, particularly among older people. These are different goals, and it is likely there are differences in tracking for different health purposes. Lastly, there is an opportunity to investigate why self-tracking is not used for managing cancer. Past studies have discussed the use of tracking by cancer patients (e.g., [152]), it could be useful to understand why this population does not currently use this practice.

The Pew survey on tracking for health [103] revealed several interesting trends regarding self-tracking and demographics. For example, it showed that tracking is most common among people who have chronic conditions, and people who are older. However, since there is a correlation between age and chronic condition prevalence, it was not possible to discern which factors influenced tracking based on the survey report. In this study, we conducted further analysis of the survey data. We provide a more detailed examination of tracking habits, expanding our understanding of the characteristics of trackers and their motivations.

We found that both age and chronic illness influence self-tracking habits differently.

Because the data used in this paper was collected in 2012, and the adoption and use of new technologies can evolve substantially after a few years [178], it is likely that self-tracking habits have changed, and use of technology has become more common. A recent survey among Canadian residents found a similar proportion of people who self-track (66.2%, in comparison with 66.8% in the Pew survey), but a significantly higher proportion of people who use technology for tracking (40.6%, in comparison with 21%) [240]. Given cultural and economic similarities between Canada and the United States, it is likely that the use of self-tracking technology has also increased similarly in the U.S. The increase in use of self-tracking technology highlights the need for research in this area. However, since advances in health are slower than technology advances, the motivations behind tracking are less likely to have changed substantially in this period.

4.6 Conclusion

This work contributed to an understanding of the population who uses self-tracking for health management. We have examined how age and health factors influence self-tracking. The findings indicate that wellness tracking is most common among people with good health of all ages. Tracking of other health information is also more prevalent among people who have one or more chronic conditions, and older adults. Self-tracking technology for health is rapidly growing in popularity and adoption. This work provides insights for the design of self-tracking technology and for future research aiming to better understand self-tracking behaviors, motivations, and how to best support this practice.

Chapter 5

Self-tracking practices and barriers among seniors

5.1 Motivation

While previous work has investigated older adult care and self-care and proposed technologies for aging in place, understanding their use of self-tracking can reveal existing issues and opportunities to advance this field. In this project we investigated the use of self-tracking in the context of seniors' self-care and external monitoring, and examine its effectiveness and impact on independent seniors.

Grönvall and Verdezoto [115] have suggested that, while self-tracking is empowering and educational, older adults may not be able to remain tracking due to requiring more assistance. Better supporting this population's self-tracking practices requires understanding how they currently engage in self-tracking, and examining the reasons that limit technology adoption.

This project was conducted in collaboration with several researchers, and published at the

CSCW conference [47]. While I led the project, including its conception, data collection and analysis, and writing, my collaborators have made major contributions to this work. Thus, in this chapter I use plural pronouns (e.g., we) to refer to actions taken during the project.

5.2 Research questions

This study sought to understand existing self-tracking practices among seniors, their perspectives towards self-tracking and self-tracking technologies, and existing barriers by answering the following research questions:

RQ1 How do seniors use self-tracking for health?

RQ2 How do seniors perceive self-tracking and self-tracking technologies?

RQ3 What barriers exist for use of self-tracking technology among seniors?

RQ4 How do seniors experience having their health monitored by others through tracked data?

5.3 Methods

To answer these research questions, we conducted a qualitative study in the independent living unit of a retirement community in the United States.

The study consisted of interviews with 23 participants: 18 independent residents and 5 staff members of the retirement community. Among the residents interviewed, 11 were female and 7 were male. Their ages ranged from 74 to 100, with a median of 84. Each of them had at least one chronic illness, including hypertension, arthritis, cancer (in remission),

	Age	Gender	Tracks	Physical disability	Tech use
P1	95	male	glucose	moderate	low
P2	87	male	steps	none	high
P3	82	female	glucose	none	moderate
P4	77	male	glucose	none	low
P5	74	female	blood pressure	moderate	high
P6	75	female	blood pressure	none	low
P7	89	female	blood pressure	moderate	low
P8	83	female	blood pressure	mild	low
P9	79	female	glucose	mild	moderate
P10	94	female	pain	moderate	moderate
P11	85	female	blood pressure	mild	moderate
P12	84	male	wife's blood pressure	mild	high
P13	91	female	-	moderate	moderate
P14	84	female	steps	none	high
P15	84	male	blood pressure	mild	high
P16	100	male	-	none	moderate
P17	87	male	glucose	mild	high
P18	80	female	glucose	mild	high

Table 5.1: Characteristics of senior participants.

diabetes, hearing loss, and gastrointestinal conditions. However, these chronic conditions are controlled without daily assistance from caregivers. These participants are described in more detail in Table 5.1.

Residents lived independently in their own apartments or houses in the community property. They did not have significant cognitive impairments, but they had a wide range of physical disabilities, from being very active and regularly playing sports to using assistive mobility devices such as a cane, walker, wheelchair, or electric scooter (see Table 5.1). Moderate disability in Table 5.1 refers to not being able to walk unassisted for at least 15 minutes, and mild disability refers to not being able to walk unassisted for at least 2 hours. Participants who exhibited high technology use browsed the internet for 1 hour or longer at least 4 times per week, while those who had moderate use browsed the internet at least 2 times per week. Residents' movements and daily activities were not controlled or closely monitored. Many had cars and maintained active social lives. As these labels were created in this study to describe the different characteristics of the participants, they are defined relative to this group. For example, those considered to have high technology use are among the most tech literate among all senior participants.

Among the retirement community staff, we interviewed: two social workers (S1 and S2), a computer technician (S3), a fitness trainer (S4), and a nurse manager (S5). The social workers' primary responsibilities were to ensure that residents were receiving appropriate care, and communicate with residents' family members. The computer technician assisted residents who had questions regarding computers and mobile devices, as well as technical problems. The fitness trainer led group exercise classes for the residents and provided personal training sessions. The nurse manager oversaw the nursing staff in the independent living section of the retirement community.

5.3.1 Data collection and analysis

We conducted semi-structured interviews with each of the participants. We asked residents about their technology use, their current health issues, and their health management practices. We also inquired about self-tracking and the care practices of the retirement community. We asked staff members about their roles in the residents' health care, and about the different care practices of the institution. We first interviewed eight residents and one staff member, discussed the preliminary data among all four researchers, and revised the interview protocols for the remaining interviews. The interviews were audio recorded and lasted 40 minutes on average. Each participant received 25 dollars for participating in the interview.

In addition to the interviews, we also observed the general practices of the retirement community and attended open events related to health or technology. These events were: three separate talks about hypertension, fall prevention, and nutrition; a residents meeting; a discussion circle about interacting with health providers; and a computer group meeting. Each event lasted between 40 minutes and one hour. The observations occurred before and during our interview phase over a period of 8 months. Observational data were collected in handwritten notes. This chapter is based on interview data, but observations were essential for formulating interview questions and conducting interviews. This study was approved by UC Irvine's ethics review board, and informed consent was obtained from all participants.

To analyze the data, we utilized a Grounded Theory-oriented approach [42, 299]. We transcribed each interview, and two authors separately coded a subset of the data following an open coding technique. Both sets of codes were discussed and combined, and one author proceeded to code the remaining interview and observation data. We used axial coding as our final analysis step.

5.4 Findings

Our data show that the seniors' health management involves several interdependent forms of care, including both self-care and collaborative care, wherein spouses, neighbors, health providers, and retirement community staff play roles in the residents' care.

5.4.1 Self-care

This study's findings reveal several barriers for adoption of self-tracking technology among older adults, their goals and needs when it comes to self-tracking, and opportunities to better support seniors in their self-care by focusing on monitoring and medical recovery. Senior self-care involves managing their health care and health information as well as self-tracking health indicators including blood pressure and glucose. These activities are largely preventive, as they are used to prepare for emergencies or to identify worrisome changes in health indicators, such as spikes in blood pressure.

Wellness tracking

Tracking for wellness is uncommon among participants. Tracking exercise, for example, was not perceived as useful for behavior change, even among those who used it. Activity trackers were seen as potentially useful for validating existing habits. However, for those who were not very active, these devices could instead highlight physical limitations or impairments.

Only three participants, who already were very physically active, used step counters to validate or check their existing activity levels. They did not see or use tracking as a tool to motivate them. Rather, these tools were used to validate what they already did.

P2 and P14 used pedometer apps on their smartphones, but they did not change their routine or increase the amount of exercise based on their step count. P14 said, *"I think it's psychological more than anything else. [...] I like to know I'm moving, and you know, not just sedentary."* P2 stated, *"If I feel that my day is kind of sedentary I'll get up and walk on the park. But, do I have a budget that I'm meeting everyday? No. I don't."* Both expressed that they 'like to see' their data, but the data does not encourage them to become more active. P2 further explained that he does not gauge how active his day has been based on the numbers, but rather on his own observation of his activities.

Most participants had goals aligned with the purpose of activity trackers, such as exercising more or more consistently, but they did not perceive exercise tracking as useful for providing motivation. Participants who were interested in exercising more expressed how the kind of feedback provided by tracking steps was not as motivating as the benefits they received from exercising, such as improved symptoms or improved balance or gait; or even social accountability from scheduling a time with a trainer or friend. Further, many of them reported that they had experienced adverse effects from particular kinds of exercise or due to exercising too much. After these instances, they changed their habits or goals regarding physical activity. Among seniors who were not able to reach a high level of physical activity, tracking could serve instead as a negative reminder of their disability or condition.

Participants also expressed disinterest in tracking routine activities such as diet because their habits were very repetitive and predictable. Keeping track of those existing habits would not be informative either.

Overall, we found that seniors associate activity trackers with fitness goals of young people. The seniors who use these devices are physically able and active, and use them only to reaffirm their own activity levels rather than to change their behavior. This barrier was both functional and conceptual, as these devices are not designed for the particular needs of older adults and are most often perceived as not useful by seniors who have special needs.

Tracking for physical recovery

Most participants reported having experienced a period of recovery from major health events (e.g., fall or surgery). Self-care in these situations required learning, burdensome work, and activities such as physical therapy or particular kinds of exercise. Although recovery is among the potential applications of tracking technology, tracking was still not seen as useful for recovery purposes by participants. In this situation, similar to the case of behavior change, it is likely that improvements upon existing tools could help them to better align with seniors' needs.

Participants who exercise to manage pain or to improve their balance did not track their specific exercises. Instead, they use time to mentally measure their activities (e.g., walking for 20 minutes). Balance training is one of the most common exercise sought by the seniors to maintain their autonomy, as S4 said, *"Most just want to remain independent. So it definitely comes into functional fitness, which is just to continue doing daily activities with ease. [...]*

Balance is a key issue."

According to the fitness director, activity trackers and other self-tracking tools are not beneficial for this kind of functional training for two reasons: first, they do not measure relevant data; second, they provide less motivation than the direct results of the physical activity. As she explains,

> *"a lot of what we do is getting people from a walker to a cane, and from a cane to walking independently. [...] That includes weight shifting, that includes balance, that includes strengthening the legs and keeping them flexible. So in that mode, a pedometer or heart rate monitor is not going to affect their outcome."*

The benefit provided by exercising, namely reduced pain or increased mobility, is tangible, and more powerful than motivation provided by self-tracking could be. S4 explained, *"If they're feeling better they are going to know it, they are going to feel it and it's going to be obvious, and they won't need to sign in a sheet [to self-track]."* For example, P10 walks in the mornings to manage her pain: *"It helps to take the pain away. And by noon or one o'clock the pain is gone, and I have no more pain the rest of the day or at night."* P1 participates in balance training classes, and he notices how that helps him. He said, *"I occasionally lose my balance temporarily or reach too far or something, and I find that I do get responses, correction responses with [balance training classes]. So I guess I will continue with those."*

These tangible benefits provide motivation to keep exercising. However, they are not registered anywhere. P5 said,

> *"I don't usually go back and look at the past because I know mentally that I'm way down from where I was when I started. [...] I know, I judge where I am and how I feel. And I know that I am better today than I was in February."*

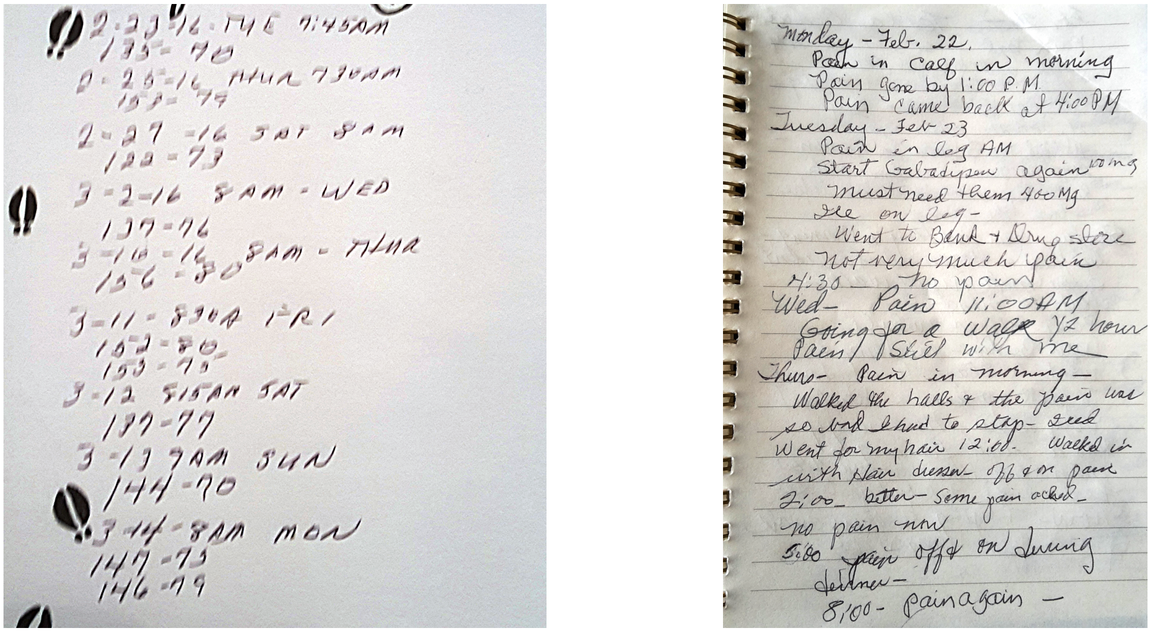
Activity trackers are not seen as potentially helpful in a recovery process. For instance, P18 was recovering from a hip surgery at the time of the interview, and while she was walking unassisted, she had not fully recovered. She owns an activity tracker and planned to use it when she was able to be more active, but she did not think that it could help in her recovery. She explained, *"I do have the Fitbit, but I haven't gone online to activate it yet because I didn't think it was much use doing it when I am not back to my normal self, but soon I'll do it."* P18 walked without assistance at the time, but in her perception the activity tracker would not be useful until she could walk 10,000 daily steps again.

Tracking for health management

To monitor their health and detect any undesired changes, many of our participants self-track health indicators such as blood pressure and glucose, and about one third of them share these data with health providers. This kind of tracking was used both by participants who had a related diagnosis (e.g., hypertension) and by those who did not - either for purposes of diagnosis or prevention.

Their self-tracking process is short, and consists mainly of checking whether the health indicator is in a predetermined range, as P11 explained, *"I know I have to keep [my blood pressure] in a certain range, that's all you worry about, really. And that works."* They expressed that self-tracking helps them to feel in control of their own health. P8 said, *"I think if I had a sudden spike in blood pressure, I would be very concerned. And maybe it's just a preventative thing."* P8 tracks her blood pressure daily, this habit allows her to be more confident about her well-being.

Interestingly, we found that participants who do not share their data with health providers are less likely to measure their health indicators regularly, or to register their data in writing. As P1 stated, *"I don't write [my glucose] down. It's not with a great regularity either."*



2-23-16 TUE 7:45AM
135-70
2-25-16 THUR 7:30AM
153-77
2-27-16 SAT 8AM
122-73
3-2-16 8AM - WED
137-76
3-10-16 8AM - THUR
156-80
3-11 - 830A FRI
152-80
153-75
3-12 515AM SAT
137-77
3-13 7AM SUN
144-70
3-14 - 8AM MON
147-75
146-79

Monday - Feb. 22.
Pain in calf in morning
Pain gone by 1:00 P.M.
Pain came back at 4:00 PM
Tuesday - Feb 23
Pain in leg AM
Start Gabadipen again 100 mg
Must need them 400 Mg
Ice on leg -
Went to Bank + Drug store
Not very much pain
4:30 — no pain
Wed - Pain 11:00 AM
Going for a walk 1/2 hour
Pain / Still with me
Thurs - Pain in morning -
Walked the halls + the pain was
so bad I had to stop - Iced
Went for my hair 12:00. Walked in
with hair dresser - off + on pain
2:00 - better - Some pain ached -
no pain now
5:00 pain off + on during
dinner -
8:00 - pain again -

Figure 5.1: P9's blood pressure log (left), P10's pain log (right).

They are more likely to self-track more often when experiencing symptoms. P6 explained, *"Sometimes if I feel very low, I'll take [my blood pressure]."* Similarly, P7 said, *"I check [my blood pressure] maybe once every couple of days. Unless I'm symptomatic, then I'll check it every couple of hours."*

In contrast to what was indicated in prior literature, we have found that our participants primarily track their current health status in order to detect changes in condition. Similar to having periodic blood tests to assess their current state, their measurements aimed to identify any abnormalities that might be occurring at the time.

All participants highlighted that they use self-tracking to monitor their health, and would take action if they noticed a worrisome change. For example, P5 monitors and writes down her blood pressure daily, and calls her doctor if she is discontent with it:

> *"I just write it down and sometimes I take it to the clinic and they fax it for me. So if we're going over I'll hand it to [my doctor] and he scans it in our chart,*

> *my chart. I'll call him if I have a concern about my blood pressure. [...] If I'm not happy with it, then I will call him and say 'hey, this is getting a little high' or 'hey, it's not gotten too low yet'."*

Older adults use self-tracking to monitor their health for changes that might signal a decline in health and require an intervention. P7 reported that her tracking was not regular, and changed according to her perceived need. When asked about tracking her blood pressure, she said, *"I check it maybe once every couple of days. Unless I'm symptomatic, [then] I'll check it every couple of hours".* When P7 judges the 'unusual' to be more likely, she increases the frequency of measurements in order to be able to detect it sooner.

As described in this section, seniors have particular needs for self-tracking. Their main motivation is to monitor changes in condition that might be alarming and warrant an intervention.

5.4.2 Retirement community care practices

The retirement community has care practices that aim to ensure the safety and well-being of seniors in independent living. These practices allow the community staff to understand the needs of each resident, and to help the older adult remain in independent living as long as possible. These practices are also designed to detect and prepare for emergencies, such as falls. While independent living residents are not closely monitored, the retirement community does provide quick access to medical care in case of emergencies, as S5 explained: *"We do a lot with the paramedics across the street, [...] they're here at least once a day. Because we have such a big population."* Accounting for approximately 400 residents in four levels of care, these emergencies occur most days.

While the residents are not closely supervised, retirement community staff maintain an awareness of residents' general status through their day-to-day interactions. If they see something that they find different or worthy of a note, they will document it and discuss in a staff meeting, as S2 explained:

> *"we talk about how the resident is behaving with other residents. We talk about whether the resident is doing isolating behavior and just staying to themselves. We talk about the resident's temperament, ability to walk, ability to self-care, ability to do their own shopping, cleaning."*

These behaviors are mostly observed informally, rather than assessed in a formal setting. Nurses and social workers have informal conversations with residents when they meet in the common areas of the property. After these encounters, these employees will sometimes add notes to the resident's files if they notice a change in mood or behavior. This informal monitoring helps to determine seniors' overall health and wellness status, and to inform decisions regarding their care.

To assess whether they are still able to live independently, each resident has their cognition, mental health, fitness level, and overall health formally evaluated once a year. According to the nurse manager, this assessment is particularly helpful to monitor the most independent seniors who do not use the health center frequently: *"it gives us a chance to touch base, especially with the ones that are extremely independent, who don't like to go to the nurses for any reason."* Residents understand the purpose of the test, and find it important for their own well-being. Health monitoring by retirement community also allows some residents to track their health conditions over years. As P14 said,

> *"you have a chance to see where are you now in comparison to what you did or said last year. [...] I'm not as quick as I used to be. There's a whole lot of difference between 69 and 84. And so you expect to have some measure of slowing*

> *down or not being able to do as many things as you did previously or as rapidly."*

On the other hand, the cognitive test generates anxiety in older residents. The test carries high stakes because a poor performance means that they are experiencing decline, and that might cause them to move to the next level of care. According to S2, *"there is a great number of residents who are older, maybe in their 90s, who tend to get anxious about it."* This anxiety is still present in seniors who perform well on the assessment, as P5 stated,

> *"I've been very fortunate, I've been above where I'm supposed to be all along. So it makes it even harder, because you want to keep achieving that goal, and the day comes when you're not going to be able to."*

The test includes tasks such as subtracting a number from 100, or recalling a list of 5 words after a few minutes. Seniors strive to maintain their independence, and in order to maximize their results they prepare for these tasks by teaching themselves techniques to perform well. P13 trained for the subtracting task, as she explained, *"I can subtract 7 [from 100] to 0 today. Last year I only did it 3 times, I think."*

The health center staff members also monitor residents' ongoing health issues and communicate with seniors' health providers. The community staff has both an electronic medical records (EMR) system and a paper-based medical records system that they use to keep track of the residents' health. They keep copies of services that the seniors receive both in the health center and from other health providers, including doctor's appointments and examinations. For instance, if an older adult goes to the health center to get their blood pressure checked, that data will be registered in the retirement community's records, as S5 reported: *"we keep a copy of that because it's good information to have. And we make sure with them it's okay to keep."* According to S5, the health center communicates directly with seniors' doctors: *"we have their name and phone number. And it's plastered all over our EMR and* *our blue chart. So if we needed to get a hold of them, we could."* Doctors are informed when seniors experience an emergency and are sent to the hospital, when they want to change medications, and when they have other relevant updates. The health center also keeps a face sheet for each resident with their basic demographic and health information, and that document accompanies seniors who are sent to the hospital. Maintaining this information allows the health center to be aware of the health status of each older adult, to understand what their needs are and to make sure that they are being cared for.

The retirement community has two electronic monitoring systems in place for independent older adults. The daily check-in system can identify seniors who may have had an accident or health issue in their residence. Residents have a 'check' button in their bathroom (Figure 5.2) that they are required to press every morning, between 5:30 and 10:00AM, to signify that they are doing well. This system allows the staff to monitor the well-being of seniors through minimally invasive means. Every morning an employee of the community calls those that have not pressed the check-in button. If there is no answer, a nurse goes to the apartment to check on them. Our participants understand the purpose of this process and value it, as P14 said, *"it's a benefit to know that people know I'm okay."* There are many instances of people who forget to check-in, but according to S5 the community staff always contacts them: *"and there's always some people that don't, they forget. [...] Very rarely, when we go up we find that somebody has fallen or gotten sick. You never know. But it's something that we do every single day without fail."* Oldest seniors associate forgetting to press the button to a memory decline. To them, the check-in is not only a safety system, but it also reminds them of aging-related issues. P13, who is 91, said, *"I am embarrassed when I don't do it in the morning. [...] I noticed in the last year and a half they have to call me. And I hate to slow down mentally, but there I am."*

For emergencies and other urgent needs, each senior has a pendant with an emergency button that they can wear on their neck or wrist. Anywhere on the community property, the button

Figure 5.2: Morning check button.

will alert the staff of an emergency, and send the approximate location of the user along with the alert. Although seen as extremely important, there is significant resistance to wearing the device, as the nurse manager reported: *"It is a wonderful thing when they wear them, but it's really hard to get them to wear them. They don't like it, they feel it's a tie to us and they want to be independent. [...] They know that they're declining, [...] they struggle for every ounce of independence."* For our participants, the button is an unwelcome reminder of aging, and the problems that could occur. They also do not like its size and appearance, as P18 explained, *"I do not wear the pendant, and I know I should. [...] I couldn't sleep with it because I thought it was choking me and I was scared that I was going to roll over and press it."* According to S5, the button was pressed unintentionally *"nine times out of ten"*. During the fall prevention event, another senior said that she stopped wearing the pendant after it was triggered in her sleep.

Combined, these different factors lead to high levels of non-use of the emergency pendant amongst older adults. Although they did not want to wear the device constantly, two of our participants placed the pendants in strategic places instead, such as P12: *"I don't wear mine nor does my wife, but I have them down low in the bedroom and down low in the living* *room."* Since the check-in device in the bathroom already has an emergency cord, P12 used his and his wife's pendants to add this resource to two other important rooms in the house. P12's solution reduces burden, reduces accidental activations, and removes discomfort caused by wearing the device. Most other participants also did not wear the pendant for similar reasons. Seniors who are more afraid of falling, such as P1 and P10, expressed being likely to wear the pendant regularly, as it provides a sense of security to them. Interestingly, privacy did not seem to be a significant issue for our informants, as none of them mentioned privacy concerns with the retirement community's monitoring. We also found no relationship between attitude towards the pendant and attitude towards technology in general.

The care practices of the retirement community are highly collaborative, as they require active participation from the seniors. Collaborative care allows the retirement community to provide care in a minimally invasive fashion that significantly preserves their agency. The challenges involved in these practices arise from older adults striving to maintain their independence. The consequential nature of monitoring gradual functional decline and stigmatizing care, such as the emergency pendant, cause tensions between older adults and retirement community staff.

5.4.3 How different forms of care are connected

These different aspects of care are highly interconnected due to their collaborative nature. For instance, self-tracking a health indicator and sharing the data with a clinician to support treatment decisions is at the same time self-care, and collaborative care with the clinician.

Self-care is connected to each of the other aspects of care. For instance, many participants reported going to the retirement community health center to have their blood pressure or glucose measured when their own device failed or ran out of batteries. Others who do not have a measuring device do the same (e.g., those who are only tracking temporarily by a doctor's request). Several participants who self-track regularly also share their records with the health center. Thus, the retirement community plays a supplementary role in senior self-care. Clinicians also often instruct seniors to self-track, and married participants who track sometimes talk informally about their measurements, or receive help with tracking devices from their spouses. Additionally, a few participants 'self-track' the results of medical exams. Through collaboration, other forms of care can facilitate older adult self-care.

In contrast with self-care, the retirement community care practices are less empowering for the seniors. Self-tracking activities are either initiated by the individual person, or recommended by a doctor who deems it appropriate for a particular person. Care from the retirement community is more general, as it is intended for all independent older adults. When not recommended by healthcare providers, self-tracking is seen as "opt-in," each person having the autonomy to decide whether it is needed. Not wearing the pendant, however, is seem by the community staff as non compliance. More active and independent seniors are more likely to want to participate actively in their health management, and not to wear the emergency pendant. A tension lies in the negotiation of the care practices between residents and staff. From the seniors' perspective, self-care activities such as self-tracking provide more agency and less stigma in comparison with external monitoring systems. From the perspective of the community, monitoring systems provide older adults with additional protection.

Overall, in this study we found that although seniors live independently, senior care is highly collaborative in nature and it involves self-care as well as care from the retirement community they lived in, from doctors, relatives, neighbors, and part-time caregivers. These different forms of care are interconnected and complementary. Nevertheless, collaborative care practices led to tensions due to seniors' desire to remain independent.

5.5 Discussion

The health management of our participants involves both self-tracking and monitoring by others. While frequently seen as separate, we recognize that these activities are often interconnected, collaborative, and provide complementary benefits to seniors. For example, collaborations involving self-tracking [60] and health record management [54, 245] between health providers and patients have been studied in the context of chronic illness management. In the case of seniors, this process can involve other stakeholders, including family members, the staff of a retirement community, or peers who care for one another. These care practices are inherently sociotechnical, and the balance between individual control and safety is nuanced and heavily dependent on context [65]. While previous work has investigated older adult care among seniors living with caregivers [232, 280] or living on their own [225], as well as health management practices specific to a particular illness [298, 116, 232], they have not addressed the complicated and nuanced needs of independent seniors with diverse conditions in a retirement community. Thus, our findings could inform the design of sociotechnical systems for aging in place by characterizing the challenges and successes of collaborative care systems in a retirement community setting.

Collaborative care practices have been discussed in the literature in different contexts, including spouses managing a chronic condition [68], careworkers and family members [59, 118, 280, 232], patients and clinicians [88], and independent elderly neighbors [264]. We observed care practices similar to each of these, as married participants care for their spouses, seniors collaborate with their part-time caregivers, with the retirement community staff, with clinicians, and with neighbors they had befriended. In this context, the retirement community is responsible for part of the coordination work usually conducted by patients with their clinicians, and seniors also use self-tracking to facilitate this work [312, 265]. While Nunes et al. [232] have shown the collaboration between older adults with Parkinson's and their caregivers, we found similar dynamics between independent older adults and the retirement community.

Both external care and self-care are collaborative. Older adults as well as those responsible for their monitoring play important and active roles in both self-tracking and monitoring. Monitoring relies on active participation from older adults. The morning check, a monitoring system geared towards identifying seniors who need immediate help, requires each senior to push a button everyday at a particular window of time. Self-tracking health indicators such as blood pressure is often part of being monitored by health providers. These collaborative dynamics have two main complimentary advantages. First, they enable older adults to have agency over their health management. Second, they allow others to ensure their well-being through minimally invasive means.

Furthermore, collaboration can improve the effectiveness of care activities in multiple ways. For instance, we observed that seniors who share their data with health providers self-track more consistently, which might improve their self-care. Training for the annual assessment may also characterize self-care, as previous work suggests that cognitive training can delay the progression of cognitive impairments in seniors [28]. Having access to patient-generated data can also be informative for health providers. Our findings suggest that the accountability that arises from collaborative care can benefit all stakeholders. However, since our interviews focused primarily on older adults, future work should further investigate other perspectives in collaborative care, such as those of health providers, caregivers, or retirement community staff.

In addition to the benefits we found in collaborative care, combining monitoring and self-tracking in a collaborative process could facilitate the adaptability required to support the gradual aging process of older adults. The independent living section of the retirement community is an “in-between” setting [38], a transitional space between the home and assisted living. It houses people in different health conditions, and there is a nuanced interplay of agency and safety between independent and assisted living. While evolving needs for assistance can gradually reduce the capacity of the user to self-track or actively participate in their own monitoring, it is important to preserve agency for more independent seniors. Combining monitoring and self-tracking could allow a gradual shift that accompanies the aging process of the older adult.

5.5.1 The fear of being dependent affects monitoring systems

Although the monitoring practices for independent seniors were designed to be minimally intrusive, they are associated with an undesirable impression of dependency, and thus face resistance from older adults. While our informants perceive monitoring to be important for their safety, they still resist being monitored by refusing to wear or use monitoring devices. In our study, this issue was most evident in the case of the emergency pendants. For the retirement community staff, the devices allowed seniors to maintain their independence without compromising safety by providing them the ability to summon help only when necessary. Residents, however, resist wearing the pendant, due to the device being unattractive, inconvenient, error-prone, and, more importantly, being a reminder of aging. Similarly, the annual cognitive assessment also causes anxiety among some older adults, and leads them to practice to increase their performance. Seniors also associate forgetting the morning check-in with a cognitive impairment. Technologies meant to support independence and aging-in-place face the inherent friction that, in addressing the functional challenges of aging, they also often serve as unwelcome reminders of the users' senior status. These findings indicate that monitoring technology should aim to avoid triggering these negative perceptions.

Older adults have an emotional response to their interaction with these systems. Their data has meaning, it reflects their abilities, which may be in decline, and impacts the decision of whether or not to move to a more advanced level of care. The meaning attached to the data affects the perception of and interaction with the system [7, 113, 308]. Furthermore, emergency systems such as the pendant can be stigmatizing [34, 285], and their non-use is prevalent [128]. Non-use of devices due to stigma has been discussed in literature focused on vulnerable populations, such as people with disabilities [91], eating disorders [82], and those struggling with fertility [71]. A proposed way to overcome such issues is to use mainstream devices that provide the same functionality [285]. In the case of the emergency pendant, it has a simple functionality that could be integrated into popular mobile devices such as smartwatches and smartphones.

Another way to mitigate these negative associations might be to monitor actions or instances that have positive connotations. For instance, a study found that self-tracking days when one resisted an urge to smoke produced significantly better results than self-tracking days when one smoked [207]. The check-in system in the retirement community did have a positive connotation, as it monitored the seniors' well-being. For this system, the negative association was not related to the monitoring itself. Instead, it was about how it is designed - the fact that it requires older adults to push the button every morning, when memory issues are associated with old age. Designers of technologies for aging in place must acknowledge these emotional responses, and investigate how to mitigate them. Because older adults want to retain a sense of independence, technologies designed for their care should provide it.

5.5.2 Unmet needs of older adults in self-tracking systems

Self-tracking is an important aspect of self-care among seniors, and their practices are influenced by the purpose that led them to track. Those who track their blood pressure or glucose want to find if these indicators are at a good level (i.e. inside their target range). The older adults who use the data to communicate with health providers are more likely to self-track regularly, and register their data in writing. Older adults generally do not use technology for self-tracking beyond the medical devices that are required to measure health indicators such as blood pressure [103]. Instead, most register their data on paper. However, there are design opportunities to assist the communication between them and their health providers, and help them to see patterns in a longer term. If the data was made available for medical research, it could also be used to find earlier signs to illnesses than what is currently known [33].

Furthermore, seniors seldom use self-tracking to promote physical activity, and they perceive electronic activity trackers to not be useful for other purposes. Many older adults' primary reasons for exercising are symptom management and functional training. However, activity trackers are designed with the assumption that the users' primary goals are to become more physically active. This issue is also connected to seniors' perception of activity trackers, as these devices are largely marketed for younger users. This perception is a cultural barrier to the adoption of these systems. Real improvement is more important than registering data about their activity, and our participants repeatedly expressed that they do not think that activity trackers can bring them real improvements in their particular goals. However, these devices have been used for broader purposes, such as tracking progress of post-surgery recovery [66]. Improving seniors' adoptions and perceptions of these devices requires investigating how they can be used by older adults with mobility impairments. Because our findings suggest that balance training is important for seniors to conduct everyday tasks and maintain their independence, studying how to use wearable devices to support this particular kind of activity could be a promising focus of aging in place research.

5.6 Conclusion

This study investigates the health management practices of independent residents of a retirement community, and how the combination of monitoring and self-care allows them remain independent for longer. The findings reveal several barriers for adoption of self-tracking technology among older adults, their goals and needs when it comes to self-tracking, and opportunities to better support seniors in their self-care by focusing on monitoring and medical recovery.

We discuss how these practices can inform technology that aims to assist a broader population of older adults who live on their own, and allow them to extend their independence. We argue that the intersection between monitoring and self-tracking is a promising space to investigate minimally invasive monitoring of independent older adults. Furthermore, the meanings associated with monitoring systems focused on aging need to be acknowledged and addressed in the design of more effective systems for this population.

Study 2 follows this study to further investigate wellness and self-management tracking among seniors, and the relationship of tracking practices with age and health status. Study 3 builds on findings about recovery tracking by studying self-tracked data in the context of stroke rehabilitation.

Chapter 6

The role of self-tracking in medical recovery among stroke survivors

Study 3 investigates the experience of stroke survivors and healthcare providers with game-based telerehabilitation and self-tracked data in the context of physical and occupational therapy.

Stroke affects seniors more than other age groups. Stroke rehabilitation shares several similarities with recovery in other contexts, such as a long recovery process involving speech therapy, physical therapy, and occupational therapy [238, 169]. Patients can be affected in diverse ways and may recover at different rates.

Home-based systems designed to support patients in the process of rehabilitation have the potential to empower, inform, and motivate them, and can also play a role in communication with providers. Because there is no in-person guidance, the patient has more responsibility in this situation.

Rehabilitation systems can support self-tracking practices by collecting and displaying patients' data to themselves and other stakeholders. Study 2 found barriers to recovery tracking because of seniors' skepticism about its potential benefits. This study investigates recovery tracking in greater depth by studying seniors' perspectives on tracked personal health data in a stroke recovery context.

6.1 Motivation

Stroke is a leading and growing cause of serious long-term disability. Approximately 800,000 people suffer a stroke each year, and its prevalence is projected to increase by over 20% between 2012 and 2030 [30]. Stroke can cause both mental impairments (e.g., cognition, speech, temperament) and physical impairments (e.g., limited mobility, balance, or dexterity). Recovery is a long and complicated process that requires different specialists, such as physical and occupational therapists [169].

Using technology to promote recovery from stroke is among the most promising research areas to improve outcomes for stroke survivors. Home-based systems for telerehabilitation (telerehab) have the potential to lower costs and increase access to rehabilitation by substituting or augmenting in-person occupational or physical therapy [51, 73]. Increasing access and lowering costs is important because many patients face barriers to receive treatment because of financial or health insurance constraints or difficulty traveling to physical therapy clinics [73]. One of the challenges in designing such systems is how the lack of close professional supervision affects patients and their caregivers as responsibility is transferred to them to monitor progress, maintain accountability, and make adjustments to the treatment. For this reason, these systems must be carefully designed to present information in a way that helps patients to manage the rehabilitation process by providing feedback and maintaining accountability.

Researchers have argued that providing feedback to stroke patients is important and can affect their health outcomes, particularly when it provides information or leads to insights that were previously unknown to patients [313]. However, we do not yet have an in-depth understanding of how to design feedback mechanisms for technology-mediated stroke rehabilitation. Particularly in the case of telerehabilitation technology, since much of the research on feedback has focused on the clinical context. For example, studies have found that when physical therapists provide feedback to patients during a session, patients might perform better and improve their motor learning [329, 313]. However, game-based telerehab systems measure progress through game points, which is different from the kind of feedback that in-person therapists provide. Still, while this kind of information could have a positive impact on users, we have a limited understanding of how to display it to users.

How information is displayed can influence users' experiences and outcomes. Different kinds of visualization can impact how users interpret the information, the decisions they make as a result, and important internal processes such as self-efficacy [57, 86]. Prior work has investigated information visualization for personal data in other contexts (e.g., exercise trackers [86]), finding that individuals can benefit from diverse kinds of perspectives into their data, even those that do not directly align with their reported goals. These different kinds of visualizations might lead to meaningful or actionable insights for users about their current status, changes over time, their goals, a discrepancy between status and goals, or factors affecting their habits or performance [183].

Collecting and reflecting on their health data could be useful for recovery purposes, as it could motivate patients and help them to understand their progress. However, self-tracking systems are rarely designed to support rehabilitation. It is also unclear how findings from self-tracking studies with other populations translate to populations such as stroke survivors.

This study focuses on tracking in the context of medical recovery. It aims to understand patients' and providers' expectations of and relationships with tracked data in a telerehab system. Medical recovery is an important challenge for seniors, as indicated in study 2. In comparison with the other two, this project aimed to understand a novel potential application of self-tracking rather than existing practices and barriers.

6.2 Telerehab system

In this project, I studied patients and healthcare providers who used the Stroke Tele-Rehabilitation (TR) system. This system was designed by physicians, physical therapists, and medical researchers from The Neural Repair Lab at UCI to facilitate access to stroke rehabilitation [73]. The TR system provides physical and occupational therapy exercises for stroke patients through games and videos. Figure 6.1 displays the system.

The TR system consists of a table with a monitor and several controllers including buttons, joystick, pressure sensors, Nintendo Wii, Playstation Move, mouse trackpad, driving wheel, foot pedals, and a foot camera for augmented reality games. There are more than 20 games that can be played, Figure 6.1(b) shows four examples. Each controller was chosen, and each game was designed, to replicate physical and occupational therapy exercises. Besides games, the system also has video guided exercises for users. The games are part of the system to make the exercises more engaging and to provide motivation to users.

The system was created for stroke survivors to use daily in their homes. Providers prescribed routines consisting of a list of games or exercises the patient follows six days per week. The users also received guidance from therapists remotely through video calls once every two weeks.

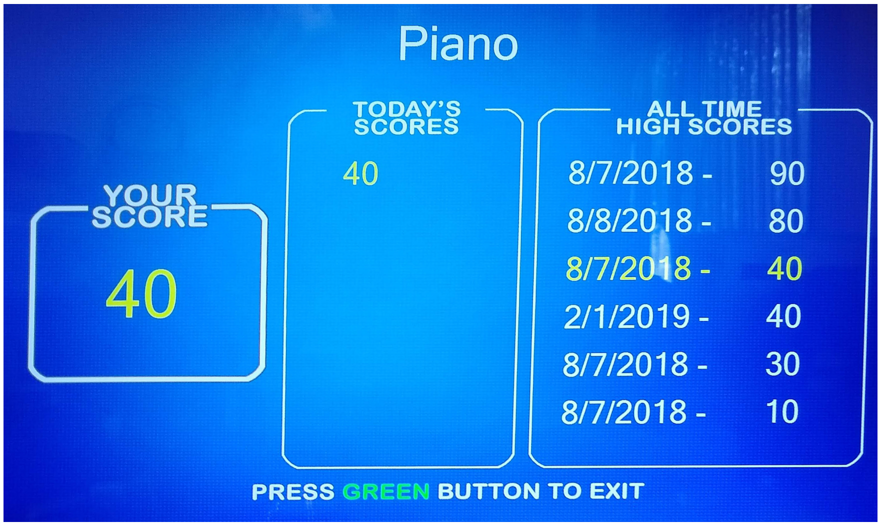
This system generates data that could be useful for both patients and therapists, such as activity logs showing when different games were played, and game scores that could serve as indirect measures of progress or ability. The data could help providers to monitor patients,

(a) System in use

(b) Four game examples

Figure 6.1: The stroke telerehab system used in Study 3

and also could be used by patients as a form of self-tracking. For example, patients could benefit from tracking rehabilitation data for motivation or to observe their rehabilitation progress.



Piano

YOUR SCORE

40

TODAY'S SCORES

40

ALL TIME HIGH SCORES

8/7/2018 -	90
8/8/2018 -	80
8/7/2018 -	40
2/1/2019 -	40
8/7/2018 -	30
8/7/2018 -	10

PRESS GREEN BUTTON TO EXIT

Figure 6.2: Score screen, shown at the end of a game.

While both patients and providers have some access to telerehab data, their access was limited. Patients are shown their score at the end of a game session, along with a list of their high scores for that particular game (Figure 6.2). For them, that was the only feedback available through the system. Physical and occupational therapists had access to extensive detailed data in the form of bar graphs but did not have the ability to manipulate the data or the visualizations to find useful insights.

A randomized trial found that this telerehab system is as effective as traditional as in-clinic rehabilitation [73]. However, it is not clear how the data collected by the system could be used to support the work of patients and clinicians. We set out to study their relationship with these data, and understand how we can leverage telerehab data to support both patients and clinicians.

6.3 Research questions

To investigate the current practices and needs of patients and clinicians, study 3 sought to answer the following research questions:

RQ3a What kind of insights do patients and healthcare providers seek from telerehab data?

RQ3b How does the telerehab system support patients' rehabilitation goals and practices?

RQ3c How do healthcare providers monitor patients' activities and progress through a telerehab system?

RQ3d What challenges exist for patients and healthcare providers to use telerehab data?

RQ3e How should a data-driven telerehab system be designed to support the needs of both stakeholders?

6.4 Methods

To understand the experiences and perspectives of patients and clinicians, we collected data through a focus group, interviews, and talk-aloud exercises using data visualization artifacts. Both patients and clinicians were recruited for the study.

6.4.1 Study design

We conducted a 2-hour focus group with 4 physical and occupational therapists and 45-minute interviews with 10 stroke survivors. All sessions were audio-recorded.

All participants were involved in a pilot study of the TR system, either as patients or healthcare providers. Patients used the system to follow a prescribed daily routine of games and exercises for 12 weeks. They also wore a Fitbit during this time. The therapists prescribed activity routines to patients with games and exercises and had video calls with patients every two weeks (Figure 6.1).

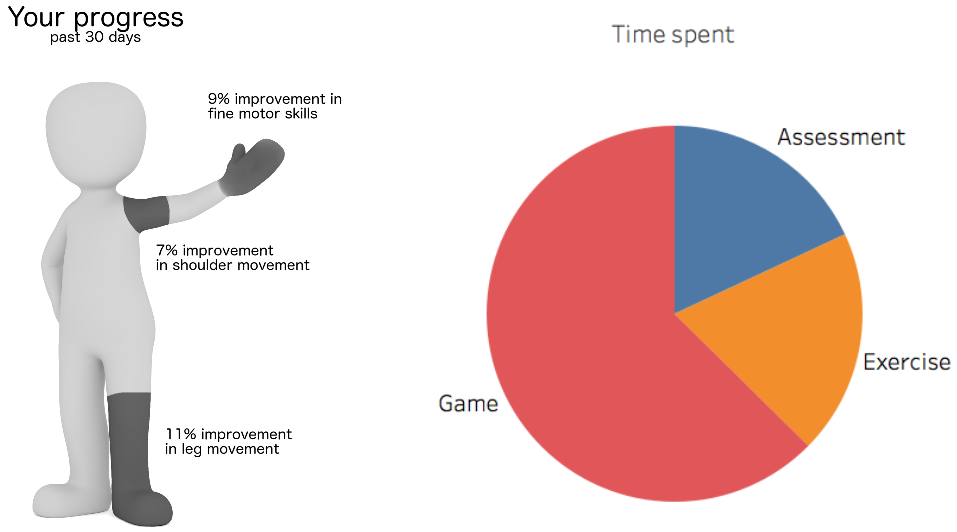
While the TR system had many important features for rehabilitation, such as a diverse set of configurable games and exercises to fit patients' needs, conversation with the research team revealed that there was an opportunity to investigate how to utilize the data collected. For patients, the data has the potential to provide feedback and motivate. For healthcare providers, the data has the potential to support their work and decision-making. To understand the needs of these two populations, we created different data visualizations that were used in the study sessions.

Data visualizations

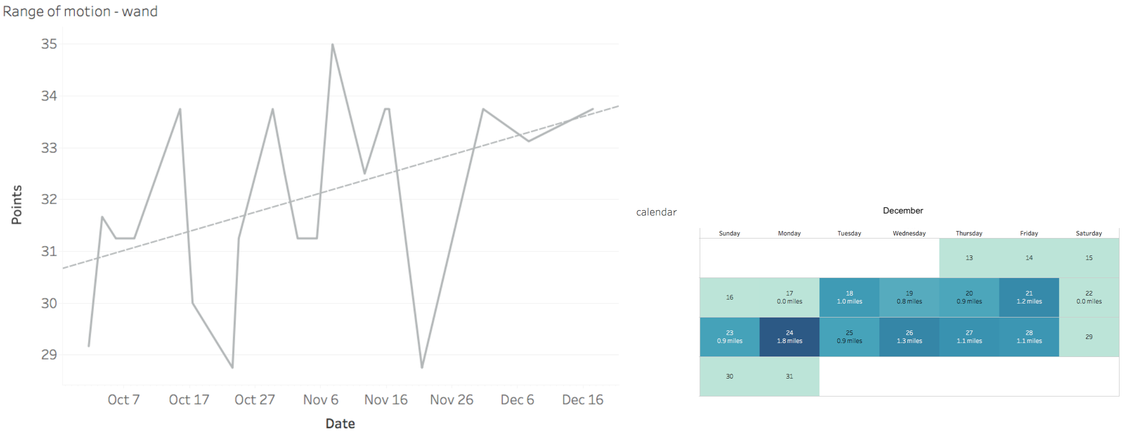
Both the interviews and the focus group used visualizations in the form of line graphs, diagrams, and calendars as tools to prompt discussion about the data and the telerehab system. Figure 6.3 shows four examples of these visualizations. The objective of using the artifacts in the study was not to evaluate their design but to prompt discussion and help us to understand the perspectives of the participants about the data. Because patients had limited access to their data, these visualizations allowed us to provide a few different examples they could react to and discuss.

The visualizations were prepared using Tableau using real patient data collected by the telerehab system and by Fitbit devices. Visualizations were created individually for each participant and printed on paper to be used in the study sessions. Patients were shown visualizations with their own data.

Participants were shown four different kinds of visualization for telerehab data: improvement rates on a body diagram (Figure 6.3 (a)), a pie chart of time spent per activity in the telerehab



(a) Progress by body part (b) Time spent in different TR activities



(c) Game scores over time (d) Distance walked in calendar

Figure 6.3: Data visualization examples

system (Figure 6.3 (b)), game points over time for individual games or a particular limb or movement (6.3 (c)), and Fitbit data on a calendar or bar chart (6.3 (d)). We also had variations, such as data from all games involving shoulder exercises in the same line chart, and a slope line indicating an improvement metric (6.3 (c)).

These different variations on the data visualization were created to help understand what kinds of data, insights, and visualizations participants were interested in seeing. We aimed to create diverse visualizations with the data, which consisted of a log of games and exercises listing points, difficulty level, and metadata (e.g., duration in seconds and a timestamp). Different variations allowed us to prompt discussion among participants and understand what kind of insights were of interest to them.

These artifacts were created through and iterative process with the goal of offering a diverse set of designs, types of insights, and levels of details for the participants. Because they were created using the participants' data, the designs were limited to what was possible to calculate and display based on the original database.

Patients did not have access to these data before the study session, except for a list of their highest scores (Figure 6.2). Beforehand, they were not able to see the history of their game scores and did not have access to their Fitbit data, as it was only collected for research purposes.

6.4.2 Participants

Providers

Two of the healthcare providers were occupational therapists, and two were physical therapists. All four of them were involved in multiple iterations of clinical studies with the telerehab system. Patients used the system for 6 or 12 weeks. The providers saw patients in person to collect demographic data and collect baseline and updates on physical disability measurements using the Fugl-Meyer protocol [111]. They also created treatment plan routines using the system and had video calls with the patients through the telerehab system periodically throughout the trial.

Patients

Most patients were in their 50's and 60's (median = 61.5). Six patients were male, and four were female. They had diverse experiences with stroke. Their time since stroke ranged from one to four years. Several participants were close to considering themselves fully recovered, but all had physical disabilities. All but one were able to walk unassisted, and only one participant reported requiring help at home for daily tasks (e.g., cooking). Eight participants were working or looking for work, one was retired, and one was receiving disability benefits.

6.4.3 Data collection

Focus group with healthcare providers

We held a 2-hour focus group in two parts with four physical and occupational therapists. The focus group consisted of one hour of questions about their past use of the system and patient data, and the second hour involved discussing visualizations, how they could use it for telerehab, and its limitations.

They were asked about their work and decision-making process. How they used the patient data they had, how they decided on what games and activities to prescribe, what kinds of questions they needed to be answered, and how they found answers to those questions. During half of the focus group, they discussed the systems they used to see patient data and make decisions. They also discussed what kind of data visualization or information would be useful to support their work. The focus group took place before the patient interviews, and it informed the creation of the data visualization artifacts.

Patient interviews

The sessions with 10 stroke survivors consisted of an interview followed by a talk aloud exercise. In the interview, they were asked about their experiences with the telerehab system and in-person stroke rehabilitation. They were asked about their background, their medical history relating to stroke, their overall health management experiences, and use of technology for health. Overall, sessions with patients lasted between 40 minutes and one hour.

Each person was presented with 8-10 visualizations of their own data and asked questions to prompt reflection about their experiences, and about what they were interested in learning from the data. Each person chose what kind of data visualization they found more useful or interesting, and discussed why.

6.4.4 Data analysis

All study sessions were audio-recorded and transcribed. The data were analyzed using an iterative inductive process. First, one researcher read through the transcripts. Then the data were coded using an open coding method. An iterative process was used to conduct axial coding, write memos about the data, and discuss emerging themes among three researchers. After coding the data and discussing themes, the researchers collaborated to synthesize the themes found to answer each of the research questions.

6.5 Findings

Both patients and healthcare providers had very practical, goal-oriented perspectives towards the telerehab data. However, their outlooks differed: while patients focused on their desired rehabilitation outcomes such as improved independence, therapists wanted information to make treatment decisions.

6.5.1 Providers' telerehab practices

When prescribing a routine for a patient, providers needed to choose which games or exercises would fit their abilities and needs. They needed to choose a difficulty level, duration, and number of repetitions in the case of exercises. They also monitored adherence and wanted to make sure that patients were moving correctly while using the system. Although they had access to telerehab data, including game points and activity history, providers rarely used it to inform their treatment decisions due to challenges with accessing and interpreting the data, or due to data limitations.

Difficulty level

Providers needed to find what the right amount of challenge was for a specific person, and when to increase the difficulty as they made improvements. The right difficulty was important for the game to provide therapeutic benefits without being boring or beyond the patient's ability. A participant explained how they estimated the right level of difficulty:

> T: "It is important that they're challenged but not overly challenged to the point of frustration. And usually, you want them to be like 70% successful at least in order to know they're having to work at it, but they can get some level of success."

Providers used video calls to observe patients' performance and to ask them whether they found the game too easy or too difficult.

Although it had the potential to provide these insights, telerehab data was not used by the providers to make decisions. The data was difficult to interpret, and it was also difficult to access in the system they used to see patient data and prescribe game routines. It was not easy for them to know or determine what a good score was, or what the maximum score was for each game, as the following quote illustrates:

> T: "I think [the points] need to be based on percentage versus a number. We don't know what the number means. You could say, okay, they could do they did this right 25% of the time. And you could look at that meaningful data over time. [...] So both meaningful and historical. It has to be meaningful first."

The process of creating exercise routines was cognitively difficult for therapists. They discussed how it would be useful for them to have precise data about performance and compliance, but that was not the case yet. The data they had access to was difficult to interpret because it lacked a clear frame of reference (e.g., percentage), because there was a lot of it, and it was difficult to examine it all. The process of making sense of the system data differed greatly from existing clinical practices, and they used resources such as video calls to obtain information instead.

Adherence and preferences

Patient adherence to the treatment was important for the providers. They monitored low adherence by noting when patients had not interacted with the system for multiple days.

One provider described how she monitored patients closely to detect issues with adherence early:

> T: "I usually go on there every day and then check who has done it or who has not done it. [...] We get a notification if they haven't complied for three days."

When detecting low adherence, they would contact the patient to understand if there was an issue and work with them to solve the problem.

Sometimes patients preferred only to do exercises and not play any games. The opposite also happened where patients preferred only to play games. There was also the possibility that patients had an issue with a specific game or exercise, such as pain. In these cases, providers sought to understand the issue by talking with them and revised their prescribed activities to address the issue.

In the following quotes, providers explain how they watch for any problems and ask about patients' preferences. This information is then used when they are creating exercise routines:

> T: "You always want to find out if they're having any discomfort or pain or difficulty. Make sure that we're not making anything worse."
>
> T: "You always want to discuss if they're having pain, any problems." [...]
>
> T: "Part of it is patient preference. If they hate a game, we don't assign it. We need a lot of variability. We need a lot of repetition. you want something that's environmentally contextually relevant for people."

Instances in which patients were facing problems were found through conversation with them through video calls. Providers adapted the prescribed routine to those patient preferences. They listened to patients' experiences and wanted to update the prescriptions to align with what patients wanted while still providing physical therapy benefits that suited patients' needs and rehabilitation goals.

Exercise form

To gain the intended benefits from using the system, patients must perform the movements correctly. Because they use the system on their own and at a distance, providers had limited ability to monitor movement form and make corrections when needed.

To assess movement form, providers used the scheduled video calls with patients. They observed while patients played the games to verify correct movements and provided guidance in case they felt that a change was needed. The video calls were essential to make sure patients were moving correctly, as a participant explained:

> T: “We wanted to watch them play the game as it was on so we could sort of see how they’re moving and whether they’re doing it correctly. [...] If we observe them during videoconferencing and it turns out they’ve been doing it all wrong, we don’t have any way of knowing that until a videoconference.”

The providers relied heavily on video calls to obtain information about how patients were doing. They watched patients while they played and asked questions throughout the session to determine if they needed to make changes to the prescribed routine. System data was only used to signal low adherence, and in that case, the providers also contacted patients to find if there is an issue they should address.

6.5.2 Information providers wanted from the telerehab system

Physical and occupational therapists expressed interest in information about how each patient is progressing, and about any issues that need solving. This information would be useful to determine what games and exercises to prescribe. Physical and occupational therapists had an objective perspective towards patient data. In constrast, as described in the next section, patients had very personal perspectives towards their recovery data.

Informing treatment decisions

Providers needed to be aware of problems that the patients might be facing, such as pain or frustration, low adherence, incorrect exercise form, or inadequate difficulty level. These problems are essential to determine what exercise routine they should prescribe.

Although the system had a built-in notification for low adherence, providers still wanted more detailed information. A therapist explained how it was difficult to know how engaged patients were when using the system:

> T: "We know what we assign, but we don't ever really know what they do. So we could be increasing him, but we don't know if they are keeping up with that. [...] The only way we view compliance is if the computer is on."

Besides turning on the system, other data such as performance could indicate whether patients are engaging with the games or exercises. For example, a null or very low score could indicate that the patient is not playing the game, or that the difficulty level should be adjusted.

Data collected in the system in the form of game scores were also not useful to judge whether patients' movements were correct. A provider explained:

> T: "People can score high on the games by either cheating or compensating. And so what we don't want to do is foster abnormal movements."

In this case, the controllers of the telerehab system were not able to detect whether the movement form was correct. Patients might find ways to play a game by overcompensating with a different hand to muscle, achieving high scores despite not doing the rehab exercises correctly.

The excerpt below illustrates how providers obtain information about how patients are doing in the present, and use it to inform the treatment:

> T: “You assess them. You see what their level is, and then you design your treatment plan relative to that.”
>
> T: “So you might ask, show me this. Or ask them what they’re doing that’s new. Or try to get out of them how they’re progressing. And that might be different for every patient, what you’re targeting.”
>
> T: “Sometimes you ask, is there anything new that you can do now that you couldn’t do before? Like, are they transferring what they’re gaining from the system to their daily life.”

While patients inherently already had information about their current state based on their own lived experiences, providers did not. The providers who participated in the study highlighted how the remote nature of telerehab limited their abilities to observe progress on their own. As a result, they relied primarily on patients’ accounts. Overall, healthcare providers relied on video calls to get answers to these questions by observing patients and talking to them. Although there was potential in the system to support their work in other ways, the design of the scores and the data visualization led them to use other sources of information. However, this strategy limits the scalability of the telerehab system.

Although game performance could be an indicator of adherence and engagement, providers did not rely on that data because it was difficult to visualize and interpret. While they had access to extensive data from each patient, the data were very labor-intensive to manipulate and interpret. They needed very high usability to access and interpret the data for efficient use in decision-making.

Professional perspective towards patient data

Healthcare providers had a goal-oriented and straightforward frame of mind towards the telerehab system and its data. Providers have a very pragmatic perspective on understanding patient data. They interpret it to make treatment decisions regarding what games or exercises to prescribe, such as what is the right difficulty for a patient.

Among providers, the lack of personal relationship with tracked data was clear from how they talked about it and contrasted with how patients discussed their own data, as is described in the next section. This impersonal attitude led their decision-making making process to be very matter of fact, with little hesitation.

Differently from patients, providers did not show concern about variations in-game score data, such as having lower scores at times instead of a steady increasing trend. While patients could see this kind of data as negative, physical therapists viewed that as desirable. While discussing a graph that showed a zig-zag pattern of performance over time (i.e., alternating high and low scores), a provided said:

> T: “That’s actually optimal for motor learning too. You want variability, variation. [...] You want a trend, but you want this. They are trying. They are trying.”

This professional and straightforward perspective towards the data was expected because they are healthcare professionals. Their relationship with the data was important for decision-making among providers, and their attitude stood out in contrast with the patients’ deeply personal connection with the data, as described in the next section.

6.5.3 Patients' telerehab practices

Telerehab patients were very focused on making improvements. While they primarily discussed their recovery in terms of activities of daily living (ADL) that they could accomplish independently, they still used telerehab data. Game points were often interpreted as granular indications of gradual improvement, and as a positive reward for effort. Still, several participants did not trust the data or had difficulty interpreting it.

Making progress in recovery

Stroke survivors talked about their progress through stories, using ADL (e.g., cooking on their own) or mobility aids (e.g., wheelchair or cane) to describe how their abilities have changed in the past. They use these factors to compare their current state with the past and with what they want for the future. When talking about their rehabilitation, they often mentioned their past, current, and desired goals for the future. All participants discussed having made progress and still wanting to make more improvements.

P8 described how it was difficult to regain the ability to walk unassisted while still highlighting that he was not done:

> "For me, it's still a work in progress, and I'm not satisfied. [...] It was an effort to get back on my feet at all. Walking is still an effort. Hopefully, that is part of why I'm working so hard here, is I'm hoping to reduce that, this feeling, this effort that's a big thought to walk." - P8

P4 described his own progress by talking about the different mobility aids needed in the past, while still mentioning that there are things he wants to improve upon:

> "I can drive and everything. I just drag my foot. It's hard to pick my arm up

> but I can do it. [...] I couldn't even move my arm. Now I can at least move it and everything. The acupuncture, I did acupuncture. That helped me out a lot. Went from a wheelchair to a walker to a cane. Then I had AFOs, a knee brace. Now I don't wear any of that." - P4

Many of these accounts took the form of comparisons between their current abilities and how things were before the stroke, after the stroke, and their goals for the future.

Making progress in their recovery process was a priority for participants. They consistently talked about physical therapy games and exercises in a way that highlighted their practical purpose, i.e., how they would benefit from it. The game being fun or not fun was less important and rarely mentioned. For example, P8 explained how he valued the games because they could help to increase his speed and range of motion:

> "I was interested in some of the games because I was interested in increasing my speed and agility, because that was more of my focus, but I think of the other stuff and I saw the benefit of it. I also use my range of motions pretty good." - P8

Participants consistently discussed the impact or benefit in their abilities when asked about their experience with the system. There was more emphasis on liking a game when they noticed that it did make a practical difference for them.

Maintaining progress

At the same time that they wished for more progress, a few participants also expressed concern about maintaining their abilities. I only observed this concern among people who had a stroke at least three years before the study and had experienced loss in regained abilities in the past. Although losing their progress was a possibility for all participants, only those who had gone through it valued maintenance.

For instance, P9 described how important it is to maintain a level of ability and independence, and how that takes effort and is part of the rehabilitation:

> "Sometimes it's very simple for me to fall off the wagon and not do it for a couple of days. After the ablation, I didn't do anything for two weeks. The consequences were so severe. [...] If I take two weeks off, it takes a month to regain anything I lost. Double down to recover the one I lost." - P9

P9 knew from experience that physical and occupational therapy were important to prevent a decline. P4 also had experienced a regression in his abilities. He explained that he constantly worked to maintain the progress he had made:

> "If I sit at home all day and don't do nothing I get weak. I start dragging and this and that. I have to exercise. If I can't exercise, I can't walk. [...] I'll get worse. I'll go back. I don't want to do that" - P4

Those who had experienced a regression in their rehabilitation knew the value of maintaining their current abilities, but they still wanted to see improvements.

Use of Telerehab Data

Participants used the system feedback in the form of scores to get an indication of improvement. Framing their progress in terms of ADL or mobility aids was useful for remembering the progress they have made, but it did not help observe gradual improvements or anticipate future progress. It was difficult for them to know whether they will recover further.

Patients compared their last score with the high scores to check if they were getting better. For example, P2 described how she interpreted the game points as indications of increased ability and progress in recovery:

> "Some days, if I do the balloon game, it may say the score may be 31. Then I see a score like 50, so I notice the improvement right there. By the end of the week, the score will be a lot higher if I look at them all together. [...] I saw the scores getting bigger, some start off real small, but I improved as it went on and went on. They score you, so I look at the scores, whatever that meant." - P2

Game points were not the only means through which they observed progress. Patients noticed their improvement by seeing that they were doing better during gameplay, or through medical tests, or noticing changes in their ability to carry out certain tasks. P6 explained that he knew he was improving because he was able to observe a better performance in the game when he was able to shoot all the ducks very quickly.

> "The duck hunt, my goal always was to get a perfect score, of course. I get them all before the duck leaves the screen. [...] That means I did very well. I'm getting the ducks going back and forth. It got to the point where the ducks were terrible. They wouldn't even get out of the grass, and I'd shoot them." - P6

Observing performance during gameplay, as described by P6, was at times more trusted than the game scores as indicators of improvement. Patients noticed that they were better able to play the game (e.g., hitting the target often) in comparison with past experiences.

Game Points as Encouragement for Engagement and Effort

Most participants reported making an effort to beat their highest scores by trying to do very well in the game. Their intent was not only to get the satisfaction of doing better, but there was also an explicit underlying belief that working hard at the exercises and games would help them to improve more.

P4 was among the participants who tried to do better than their previous high score. He described that this was a constant effort, and it was rewarding to see an improvement:

> "It was good for my left arm, moving things. I tried to challenge myself, shoot the gun thing. I used my left arm. [...] I tried to get better every day. I go, yeah, that's my high score. I felt good doing that." - P4

Similarly, P2 also aimed to get higher scores every time she played by working hard:

> "You gets the same score some days, so I say, 'I'm just going to have to work a little bit harder.' That's what I was thinking to myself. It was not easy, but the next day, I may score five points higher than the day before that. That's some progress to me." - P2

Because they interpreted higher scores as indicators for improvement, participants made an effort during gameplay to improve their chances of getting a higher score. This effort was considered positive not only as a way to confirm that they were making progress but also as a strategy to benefit more from the game.

However, since patients did not always know how to interpret their scores, sometimes they were not sure if making an effort would matter. This issue occurred when they lacked a frame of reference for the scores or if they felt that the game had become too easy.

Barriers to the Use of Telerehab Data

A few participants did not understand or did not trust the data. As a result, they did not pay attention to it. They discussed that this lack of trust came from not always understanding what the system was measuring, or what the benefits of a certain game were.

For example, P10 did not know how to interpret his telerehab data:

> "Just, how am I doing? There was nobody to tell me how I was doing other than some numbers on a score that didn't make sense to me. [...] Did I lift my arm to a certain level? Does it look at me? I don't know." - P10

Participants such as P10, who did not receive useful feedback from the system, emphasized how they still wished for information about their progress. However, they were uncertain about how to interpret the data they could see or how much they could trust it. To interpret the scores, participants needed not only an absolute value but also relative performance in relation to the maximum. However, their relative performance was not clear to them based on the scores, only based on game performance (e.g., hitting all the targets).

6.5.4 Data visualization artifacts

Patients found game data valuable, as visualizing past improvement was often interpreted as a sign that of making progress in the present and future. However, they wished to have access to body-centered data instead, and hesitated to engage with data that indicated a plateau or loss in their recovery.

Trends as indication of future improvement

When shown data visualizations of historical performance and improvement rates, participants responded by focusing on that information as an indication that they would continue to improve in the future. Past performance was not of interest in itself, because it measured past ability, something they already knew well. However, upwards trends of performance were of interest for them because it could signal that they would continue to get better.

For example, P4 said in response to seeing a calculated improvement rate of 15%:

> "Can you imagine if I got 15 percent better per month, if I can walk better? That would be great, wouldn't it?" - P4

P4 expressed a similar need to what the clinicians requested, a frame of reference to more easily interpret the game scores.

While observing a historical graph for his game scores on the telerehab system, P6 explained that he was looking for improvements or indications that he would improve:

> "I'm always driving for success, hopefully, in life. An improvement would be where I'm striving to get to, yes. With my foot, I'm striving to get my flat foot."
> - P6

The progress feedback data was not used to understand what they did or how they were doing in the present. These abilities were known to the patients based on their own daily tasks and perceptions. Instead, the information was seen as helpful as an indication of progress in the future.

Patients were interested in seeing performance over time (i.e., game points), but not interested in activity history. There was little interest in seeing activity logs, such as what exercises and games were done each day, or which were used more often. These data were not useful for them to provide insights on progress. They also did not find this kind of data actionable.

Patients were interested in the system feedback regarding their progress and most paid attention to it. However, they also recognized that there were limitations to the points, and sometimes did not trust it as a reliable indicator of ability or performance. While all patients wanted information about improvements, they also wanted the information to be more accurate and easy to interpret. The degree to where they trusted the data from the telerehab system varied. Participants showed less interest in the data visualizations when they were less trusting of the game point data.

Body-centered data

Participants preferred body-centered rather than game-centered data. For example, seeing data indicating the progress of a body part was more interesting to them than seeing data about performance in individual games.

All participants showed interest in a simple overview of their ability in the form of a body diagram (Figure 6.3 (a)). P6 explained this preference by describing that it was easier to interpret:

> “This is a lot better than any lines and numbers. This is better. This is visual. You can visualize it. ‘There we go, nine percent for my hand, my shoulder.’ Then you see it in relation to the body. I like this. You could always visualize a picture compared to writing with sentences and graphs.” - P6

The body-centered data visualization aligned more with the patients’ perspectives. They were interested in understanding how their abilities and movements were evolving, such as strength, flexibility, dexterity, and precision. It can be difficult to translate system data (e.g., game points) into tangible insights related to their goals (e.g., walk better or cook independently). The lack of interest in game-centered data was also often explained as a personal lack of interest in digital games.

Game-centered data, such as scores over time, generated mixed responses. Only a few patients were interested in these data. Those that preferred granular game scores either mentioned that they are inherently curious and enjoy detailed data, or they wanted that information to inform their efforts while playing the games.

For example, P8 and P9 said that they would like to have access to both detailed game data and body-centered data:

> “I liked the graphs. [...] I just think it’s more analytical.” - P8

> “Because I’m a numbers brain, I’m analytical, this helps tremendously. [...] I love data. I love to review historical data. [...] ”How am I doing?” versus did I kill more ducks than I did last time.” - P9

The granular data were still used for the same purposes, understanding progress and estimating improvements. However, it required more effort to translate it from game points to movements and body parts, and that was what they were really interested in knowing. Game data was also seen as less trustworthy and confusing by the participants.

Fear of Negative Data

Patients wanted to see improvements continuously, and they feared that the data would instead indicate plateau or regression. They preferred not to see such “negative” data.

Similar to the study in the previous chapter, stigmatization associated with the health data influenced participants' relationships with the data and with the technology itself.

A few participants explicitly said they would prefer not to see negative data. P9 told us he would only want to see feedback from the system if it showed improvements:

> "If you're having failures, it'd probably not be good information for you to share with someone, but improvements are good to have. " - P9

Other participants showed their concerns about negative data through their tone or by focusing on instances where they had a dip or some kind of trouble with the scores.

For example, P2 explained how she could get upset after seeing a low score in the system:

> "If I see the history compared from today, see the margin, if it's as good, it's good. If it's low, it's like, 'Ah! What happened?' " - P2

Lack of improvement in the form of a plateau in the scores could also be interpreted as negative by patients. In the example below, P9 discussed a graph showing a plateau for a game in the telerehab system:

> P9: "See, I had a great day in November and I'm going down here in December. I thought I had the hang of it here in December, but I disappointed myself because I did not have the hang of it, apparently. That's what it's telling me. I didn't know I did so much better in November. That's disappointing, because I really thought I had the hang of it in December."
>
> Interviewer: "It's possible that you're just hitting the maximum score right here."
>
> P9: "I'd like it if that were the case."

Because they wanted to see improvements consistently, for P9, a plateau was interpreted as bad news, and as disappointing.

6.5.5 Information Patients Want from the Telerehab System

Stroke survivors wanted to be informed about their treatment and progress while focusing on their practical long-term goals. They also wanted actionable information about what they should be doing to improve outcomes.

Confirmation that They are Improving

Patients expressed interest in knowing if they are making progress if the effort that they are making is leading to real improvement. The data collected by the telerehab system could be useful to provide this information by displaying gradual increases in performance.

For P3, having confirmation of improvements from the system, either through game points or a different kind of feedback, was important:

> “Family could tell me that I was doing better, but I needed to either see it physically or hear from a professional. Not that I didn’t trust family and friends, but it means something a little bit different when it’s coming from a professional or when you can see it.” - P3

Despite having different ways to notice progress, participants believed that the telerehab system could provide valuable feedback. The system data could be interpreted as an objective measure that was useful for participants.

To be accessible and useful to patients, the feedback should be clear and aligned with their concrete goals. Participants had practical goals for their recovery in terms of ADL or personal or professional goals. A lack of clarity of how to translate game points into insights about their goals represents a barrier to effective use of telerehab feedback.

Encouragement

Patients had very personal perspectives towards the data, as they linked it to their progress and to their ability to reach recovery goals. Their deep investment in the rehabilitation process affected their relationships with the system data.

When reviewing their scores and progress during the study, patients wanted not only to know how they were doing for informational purposes. They wanted confirmation that they were progressing because that was important to give them hope and encouragement and to validate their effort.

P8 explained that encouragement through feedback from the system was important to keep patients engaged, and to provide support when they feel discouraged or overwhelmed:

> “If you had a way to track that progress and to go back and see what the progress is, it could be a great encouragement. At some point, that’s extremely important because this is a very, very tough fight. A lot of people, in my opinion, stop at a certain point. Then next, where are they going to be? They’re going to stay there.” - P8

Patients consistently wanted to see improvements from the data. Many of them framed it as a form of encouragement. P3 also explained the importance of receiving positive news from the system about how they are progressing:

> “More encouragement. The best thing for me, and I could probably say this for

> most stroke recovery patients, you always want to know the cause, so you know what you're doing, that what you're doing is getting you somewhere. When I was in the hospital, part of it was mental. I was going crazy because I didn't feel like I was doing any better. So just the cause, so you know the progress that you're making, even if it's a little bit. To see tangible evidence that you are improving, that's huge. [...] If you're learning how to walk again, like I had to or if you're coming back from having different impairments, it's such a huge, huge thing to physically see your progress" - P3

As these quotes show, patients' interest in feedback about their improvements was not only informational. It was important for them as a form of encouragement and psychological support because of the difficult and personal nature of recovering from a stroke.

Actionable Information

Patients wanted to know what more they could do to improve beyond what they were already doing. Participants wanted to feel challenged and feel like they were doing as much as they could to keep making improvements and progressing in their recovery. To that end, they wanted information that was actionable and more direct recommendations.

For patients, the game data in the form of points was not very actionable. They did not know what they should do based on game points besides trying to increase their scores.

For P6, having a game be too easy was frustrating because it meant that it was not challenging and beneficial enough for her recovery. She described how that happened with the duck hunting game, where ducks move on the screen to be shot with a gun controller:

> "It got to the point where the ducks were terrible. They wouldn't even get out of the grass and I'd shoot them. They got to speed that up." - P6

A few patients expressed a need for clear recommendations from providers or from the system itself on what they should do. While looking at his historic data, P10 talked about how it would have been useful for the feedback to also include advice informed by his performance:

> "It would have been nice to have something like this along the way and maybe something that says, 'You need to spend more time on the abduction with dowel.' [...] This would've helped then. [...] A recommendation, you should get more steps in." - P10

For both Fitbit and telerehab data, actionable data and recommendations also needed to be timely. Participants expressed how they wanted information in real-time to guide their exercise activity, but looking back on past data was not useful because it was not current and less actionable.

Transparent Process

Patients valued games and exercises in the telerehab system to the extent that they believed each activity was beneficial for their recovery. They wanted to understand their recovery process, instead of just following their prescribed routines. Consistently across participants, they wanted to understand how each game or exercise will help them to achieve their goals. This perspective was sometimes motivating, when they understood the purpose of a game or frustrating when they did not.

P2 noticed that one of the games, Simon Says, had a positive impact on her left hand. Noticing this benefit made her value and like the game:

> "There's certain games I like, like the Simon Says because it make you just reach out a little bit more. It made me just use [my left hand] more than I realize I

> was using it.” - P2

The system did not explain to participants what was the benefit or purpose for any of the games, but participants were able to figure it out most of the time based on the game design, the movements, or the difference they noticed. However, in a few instances, patients did not understand the purpose of a game. Not knowing why a game or activity was prescribed caused frustration. Participants wanted to know the purpose behind it, how it would benefit them.

For example, P3 talked about not understanding the purpose or benefits behind some of the games:

> “Some of the games are self explanatory. There was one, the shooting ducks helps with your range of motion. I just like to know, why am I doing this? [...] Why is this going to help me? It’s great that the exercises were explained. It just would be cool to know this works like this sort of muscle, this is the result, so this is the ideal result from it.” - P3

When the benefit was not clear, it often led to participants not valuing the game or activity. For example, P10 preferred exercises rather than games in the system, because he only understood the value of exercises, as he described:

> “The exercises, that’s benefiting me more than playing a game like this. That’s probably what I liked more about it.” - P10

This perception led P10 not to want to play the games and focus instead only on the exercises.

Patients understood the purpose and benefits of a game to the extent that they interpreted its design and movements. But when the benefits were difficult to discern, they disliked it and were not sure the game was even helpful at all.

Patients wanted information that spoke to their goals and at the same time was clear and actionable. They wanted to know that they were making progress, to understand the purpose of each game and exercise, and to know what more they could do to improve. The telerehab system helped patients to find these answers but to a limited extent.

6.6 Discussion

Stroke survivors can benefit from rehabilitation technology that provides actionable information about their progress while at the same time promoting hope and encouragement. Such information can be based on users' tracked data measuring their use of the system and performance over time.

It is essential for them that technology supports both their illness work and their biographical work (i.e., psychologically coping with illness) [67]. After a stroke, patients go through difficult biographical work to reconstruct interpretations of their self-identity, understandings of boundaries of responsibility among patients, caregivers, and healthcare providers, and reconcile with their new normal [150]. This work is part of their rehabilitation process.

Designing tools for this context requires focusing on their ADL-centered goals, and encouraging them. It is necessary to provide positive and supportive feedback based on self-tracked data, framing such data into information that supports their needs.

6.6.1 Aligning telerehab design with patients' practical goals

As our findings show, although game points can provide feedback and encouragement to patients, they can face challenges translating self-tracked data into concrete or actionable information that aligns with their particular goals and perspectives. It is important for patients to understand the benefits of games and exercises in telerehab. They also need information about the progress they are making towards their goals. Systems must be designed to align with patients' primary focus of recovering their abilities to provide understandable and useful information for users.

Stroke survivors approach recovery with the aim to overcome personal or professional challenges associated with their impairments (i.e., restrictions to their participation in social and professional activities) rather than their specific disability (i.e., restrictions in motor or cognitive function) [63, 120]. These challenges affect most stroke survivors, having a significant impact on self-identity and quality of life even when accounting for disability [203], including for those who have minor disability or have made a full recovery of physical function [80]. Focusing on disability differs from patients' perspectives, limiting engagement with treatment, and it does not adequately address the needs of this population [63, 80, 120].

Stroke telerehab systems would better align with patient's needs if they communicate to patients how each game or exercise will help them to regain the ability to do a specific task. For example, ADLs such as cooking can be broken down into smaller tasks (e.g., turning on the stove, opening a can) and each movement could be linked to a game or exercise. Making these links visible could help to clarify for patients the benefits of each game. Showing how each game can help patients to achieve their goals is important, particularly when that is not easy to guess.

Displaying progress based primarily on body movements and ADL goals, rather than based on game points, would lead to more meaningful data for patients and providers. For example, telerehab systems could provide feedback showing that patients are 40% to the goal of being able to drive. This kind of design would speak more directly to their goals and perspectives. It could also help to encourage patients to try an ADL task when they get close to 90 or 100%. This kind of system could help guide them about when to try new tasks, while at the same time showing incremental progress.

For the tracked data to be useful and trusted by both stakeholders, it is important to design collection tools that are validated, and also to make the data easily interpretable. In order for performance data (e.g., game points) to be meaningful in a recovery context, it should measure ability in a reliable manner. To that end, it is necessary to translate movements and game performance into measurements of physical ability. These measurements could be calculated based on performance on one game or multiple games. For example, agility could be estimated based on performance on target shooting games and on rhythm games. How the data is measured must be chosen carefully, including what hardware is used and how the movements are quantified.

To make the tracked data intuitive to interpret, it is important to use a standard scale such as percentage points. This kind of standard would help users to easily understand what the score means. It is also important to provide data in different levels of meaning, such as by game, movement, body part, or ADL. Information about specific movements and body parts could be calculated based on performance in games that use them. ADL ability could be quantified based on each movement and limb that it requires (e.g., handwriting could be calculated based on data about hand, wrist, grip strength, and fine motor control). This translation of data would help patients and providers to more easily interpret system measurements according to what insights they are looking for.

6.6.2 Temporal aspects of telerehab

The experience of using the telerehab system involved temporal aspects for both patients and providers. Patients tended to have a long-term perspective and focus primarily on the future (i.e., their future progress). On the other hand, providers had a more short-term perspective and focused on the present (i.e., how patients are doing currently).

Patients wanted to understand what to expect in the future, and at the same time they wanted to see that their abilities were improving. Patients kept a long-term perspective about their rehabilitation. They knew very well their past and current abilities, but they were uncertain about future improvements.

Stroke survivors were invested in what would happen to them in the future, and how their rehabilitation would progress. However, the future was very uncertain for them. They interpreted self-tracked data as an indication of future improvement when it showed a positive trend.

Healthcare providers had a more short term perspective towards the patients' abilities and progress. They continuously sought to understand how each patient was doing in the present to make any needed corrections or updates in the prescribed routines.

Providers needed to understand patients' current abilities, limitations, needs, and preferences to decide what should be prescribed. Incremental changes were important for them to inform their decision making. For example, to determine whether they need to increase the repetitions for an exercise, or increase the difficulty for a game.

Because of their different perspectives, patients and providers seek different insights from the same tracked data. Thus, they need substantially different interfaces for interacting with telerehab data. While patients would benefit from a design that highlights long-term positive trends, providers require more granular information from the recent past highlighting potential issues that should be addressed. However, in systems where patients have the primary responsibility to make treatment decisions, such as direct-to-consumer apps and devices, it might be necessary to combine these two needs.

6.6.3 Promoting hope and encouragement

Our findings show that patients wanted the feedback that fostered hope and encouragement. They looked primarily for an upwards trend in their tracked data, to see that they were making progress and could expect to see more improvements in the future. This interest in positive tracked data was not only informational, it shows a need for validation, and for feedback that is reassuring. Patients also did not wish to see data that they considered negative, such as indications of a regression or plateau in their rehabilitation.

Rooksby et al. [269] describes how tracking is most often prospective rather than retrospective. People use information to “navigate” their lives to pursue a high level goal. We found that was the case for stroke survivors in this study. They sought from the data some indication that they were still making progress and actionable information.

To meet those needs, technology must provide high granularity data to display gradual progress, and highlight accomplishments. Granular information that highlights gradual progress can provide awareness to users of small changes that might not be a discernible in their daily lives. Designs that inform users about how quickly they are progressing towards their practical goals (e.g., using percentages as mentioned in the previous section) could help users to see and value the progress they are making, while being informed and anticipating their future improvements. Not taking past progress for granted is needed to support maintenance, encouraging users to maintain their efforts for rehabilitation even if they are not progressing as quickly as they wish.

At the same time, designers must be careful to avoid creating expectations for progress that might not occur in reality. Seniors in particular might experience declines in health and abilities that can be caused by factors other than the condition they are recovering from. Balancing fostering hope with preventing disappointment is a challenging problem to solve because even when based on reliable data, predictions involve uncertainty.

6.6.4 Decision making with personal data

The personal relationship that seniors going through a process of recovery have with their data is very different from the straightforward perspective of healthcare providers. This contrast represents an important and difficult challenge for the design of technologies aiming to help empower patients. Different perspectives indicate different needs for kind of feedback and data framing, meaning that patients and providers should have specific interfaces and data interactions to meet their needs. However, many self-tracking systems for health involve little or no guidance from physicians and rely on the user to take a medical perspective towards their own health. This issue is not specific to the context of medical recovery, as it was also present in the study discussed in the previous chapter. However, patients going through medical recovery face specific challenges such as estimating their progress over time and making decisions based on it.

Consumer health technology aiming to support self-knowledge and making informed decisions for self-management must display tracked data to users in a way that is informative and actionable, while still providing hope and motivation. Combining the pragmatic outlook of providers (i.e., data that supports decision-making) with the more subjective and personal interpretations of patients (i.e., data that is encouraging) can be challenging because the two goals are contradictory. There are conflicts between objectively interpreting data for making health-related decisions, and having a personal relationship with the data.

This tension has been described in previous work. Mishra et al found that at the same time that Parkinson's patients showed avoidance and denial about symptom progression, they still wanted to be able to predict decline [219]. Another study focusing on game-based rehabilitation found that stroke survivors can become demotivated when they lose or get a low score [322].

Because of patients' close relationship with their data and hesitation to see negative information, receiving more information and responsibility could be more burdensome than empowering for them. Researchers have argued for consumer technology that supports patients' work without prioritizing medicalized perspectives [233, 139]. Patients in stroke recovery could benefit from information that is actionable and encouraging. However, they will still need guidance from healthcare providers who are able to have a more objective relationship with the data and make treatment decisions for rehabilitation.

Patients need information about their treatment process, their progress, and actionable insights. For them, providing a clear trajectory or roadmap linking data, treatment, and goals would be useful. A linear historic view that displays progress in terms of specific ADLs would help them to see gradual improvements and estimate what to expect in the future. For example, a progress bar could inform patients that, in the last three months, they progressed from 65% to 80% towards the goal of being able to drive a car. Based on this information, patients would be reassured that they are getting closer to that goal and roughly estimate when they can expect to achieve the goal. Showing past progress and highlighting achievements is important to encourage patients, particularly when they are progressing slower than they want to. Past progress can be taken for granted if it is not acknowledged, and it is an alternative to recent progress for encouraging them.

If a user wants to know more details, they should be able to access more granular information, for example to see which movements or limbs need more improvement to reach the goal, and which games or exercises are recommended. This ability to understand their progress in detail would provide transparency to patients and help them to find actionable information so they can, for example, prioritize pursuing certain ADL.

Providers could use telerehab data to monitor patients in a way that is more efficient, effective, and scaleable if they have access to an interface designed to support their work. Similarly to patients, they also would benefit from having different levels of information (e.g., game scores, quantified limb or movement function) with a high-level overview that allows them to navigate to more detailed information when needed. This kind of design would allow them to quickly answer high-level questions (e.g., is the patient progressing towards their goal?) while also being able to see more specific data when necessary. Functionalities that detect and flags issues such as low engagement, low adherence, or a need to update difficulty levels (e.g., if patients' scores are too high or too low) would help providers to make data-driven decisions without the need for a burdensome process. For example, the system could flag a potential issue if a patient has performing lower than expected on multiple days. Even if adherent, this information could indicate lower engagement or motivation, discomfort, or even faulty equipment.

6.7 Conclusion

In this study, I investigated the experience of senior stroke survivors and of physical and occupational therapists using a game-based tele-rehabilitation system. Using qualitative methods, I sought to understand how the system supported the work of these different stakeholders, what challenges they experienced, and their relationship and interaction with patient-generated data. Visualizations of game scores and other rehabilitation data were used to investigate self-tracking in the context of medical recovery among seniors.

The findings show that both patients and healthcare providers have complex needs for telerehab systems. Patients wished for transparency in their treatment and in understanding their progress, as they wanted to feel hopeful for the future while still knowing what they can expect. Healthcare providers needed information to support their treatment decisions, including adherence and knowing how the patient is progressing.

The results of this study revealed opportunities to integrating tracking strategies into rehabilitation systems to support both patients and healthcare providers. It is important to design for their specific needs, rooted in stroke rehabilitation. For physical and occupational therapists, telerehab data could help them to evaluate and monitor the patient and make treatment decisions. For patients, telerehab data could help them to understand their progress and achievements, encourage them, and inform them about what to expect in the future.

Chapter 7

Discussion

The results of the three studies described in chapters 4, 5, and 6 provide different perspectives on seniors' use and perceptions of self-tracking for health. These studies revealed challenges in the use and design of tracking technologies for older adults, but they also revealed opportunities on how to support them in their health management activities.

Not only are seniors more likely to self-track, but they have different needs, approaches, and opinions about tracking. Previous research has found that seniors have particular needs when it comes to self-tracking, such as a strong preference for intrinsic rather than extrinsic motivation, aiming to maintain their health rather than pursuing improvements [6, 106, 144, 145], and low responsiveness to theory-based self-tracking strategies [106]. In agreement with prior work, we find that seniors have specific needs and perspectives towards tracking, including their goals, preferences, motivations, and kind of insights that were of interest to them. For example, seniors were interested in self-tracking exercise for validation when they were already active, but not for supporting behavior change even when they wanted to exercise more or more consistently. Researchers and technology designers need to consider this population specifically in their work, as due to these differences, many findings from other populations might not translate to the context of older adults.

7.1 Self-tracking practices among seniors

7.1.1 Wellness

Although health factors influence tracking, age is also a factor that affects seniors' tracking behaviors, as older individuals are more likely to self-track wellness data, regardless of their health status. Despite their use of wellness tracking, as study 2 revealed, technology adoption is limited because seniors reject technology that is aligned with younger people's perspectives (e.g., more exercise is always better) or reminds them of goals that might be unrealistic for them (e.g., 10,000 daily steps), leading to demotivation. Wellness tracking technology is used among seniors primarily to validate their existing behavior, as they do not believe exercise tracking would be beneficial for behavior change or recovery, as shown in study 2. This lack of confidence limits the population that benefits from tracking, representing a barrier for adoption even among seniors who would like to pursue a goal such as walking more. In order to adopt and use wellness self-tracking technology, seniors need tools that better meet their unique goals, contexts, abilities, and needs for health management and wellness.

It is essential to design tools that can support seniors in their wellness habits as they might find that most available tools are not suited for their needs. For example, exercise trackers could better support seniors by focusing on self-tracking data that, unlike counting steps, does not lead to them feeling pressured or believing the underlying goals of the technology are not for them. Seniors could benefit from targeted programs that reflect specific goals they might have, such as maintaining or improving their balance and walking speed, maintain their independence and avoid falls. Still, to prevent reinforcing aging-related stigma and negative associations, these designs should not assume that senior users have disabilities or are frail.

7.1.2 Self-management

Other than wellness information, seniors often track self-management information to detect health issues early, even when they do not have a chronic condition that requires it, as found in studies 1 and 2. For example, older adults might self-track blood pressure without a diagnosis of hypertension.

Seniors care about detecting any health issues that might occur, even if those issues are not yet diagnosed conditions. Monitoring their health through self-tracking is valuable both as a reassurance that they are doing well and as a resource that can help them to detect abnormalities early. For example, tracking blood pressure might show out-of-range values, differing from previous days, and suggesting a need for action or intervention. In study 2, we found preventive self-management tracking among seniors who did not have that specific condition (e.g., hypertension in the case of blood pressure tracking) because they knew it ran in the family, or because they knew someone who had the condition. Due to being concerned about the potential risks of developing a new condition, they may start tracking even without having symptoms. Knowing that health decline happens among seniors, they paid attention to signs that they might face a new or worsening health issue. In comparison, younger healthy individuals might focus primarily on pursuing improvements, such as increasing their fitness level [145].

Seniors who self-track for prevention purposes might need different information, settings, or different feedback in comparison with those who track the same data to manage a condition. Technology that allows for preventative self-management tracking could support seniors' practices. For example, specific systems for self-tracking health indicators could be designed for prevention, or self-management systems designed for people with specific chronic conditions could be designed to also allow for users who do not yet have the disease.

A significant barrier for self-management tracking technology adoption among seniors is not perceiving any benefits from it that justified its use. Because their reflection process was brief, consisting only of checking that the value was within range, they did not see a need for electronic systems providing different data visualizations or long-term data storage. For that reason, technology was not seen as needed, or even as an improvement in comparison to the paper tools they already used. A system designed to support their work involving self-management tracking should offer features that provide more value than paper. For example, helping seniors to detect health declines based on their data, or providing targeted information about potential risks and recommendations for prevention can be valuable features for seniors.

7.1.3 Recovery

As found in studies 2 and 3, seniors undergoing recovery have little interest in information about their current states, as they already know how they are doing by observing their daily tasks. However, they are very interested in information that indicates future progress and helps to reassure them that they will continue to improve. Still, they are reluctant to receive any feedback that would tell them the opposite.

Study 3 indicated several needs and barriers for recovery tracking among seniors regarding their interpretation and use of their data. Recovery patients show interest in information about their progress and what to expect in the future. Because they have a very personal connection with the data, they not only wished to gain information from it but also support and encouragement. Data displaying continuous progress can provide validation and foster hope for more progress, while data that could be perceived as negative (e.g., plateau or decrease in performance) was feared as it could be demotivating instead.

Rehabilitation has much in common with illness management, as it requires different self-care tasks, medications, and guidance of clinicians. Similar to illness management systems and apps, rehabilitation systems also can integrate the practice of self-tracking to support the work of patients and clinicians. Older adults do not seek tracking for recovery as they do not believe that past information will be useful. However, they did notice the data when it was integrated into a telerehabilitation system. Tracked data can be useful for seniors when they interpret it as an indication of future progress, for example, a consistent upward trend in their performance in a game or exercise.

This interest in predicting future improvements could translate to other contexts as well, such as chronic conditions that do no involve rehabilitation. Managing chronic conditions may involve the goal of mitigating or reversing symptoms, even if slowly, and patients might be interested in knowing what to expect in the future. However, this perspective is particularly of interest to people undergoing rehabilitation, as the process focuses primarily on regaining physical ability. In comparison, self-management tracking focuses primarily on maintenance and detecting and preventing health issues through continuous monitoring.

Rehabilitation systems can increase the responsibility required from patients, particularly when they have little to no guidance from providers. That is the case with many mobile health apps. For patients, the tension involved in interacting with personal data means that it can be much more complicated to make decisions about their treatment. Transferring decision-making responsibilities to recovery patients would require them to see data indicating a plateau or loss, which could have demotivating impacts.

As part of a bigger system supporting rehabilitation, recovery self-tracking might play a supporting role rather than being the main focus of a system. In this case, the feedback provided to patients based on the tracked data can be more limited, since more information is not always beneficial for them. Instead, it is important to determine what and how much information is needed and helpful for the user at each point in time. These users can benefit from feedback focused on progress that is intuitive and easily interpretable on the level of their goals, feedback framed to be encouraging, and provide actionable information such as tailored recommendations based on their data.

7.2 Perceived “normal” data and behavior

Interpreting self-tracked data requires users to understand what is “normal,” i.e., what is an acceptable or desirable range of values, to contextualize and make sense of their own data [95]. Seniors might find this process challenging because what is considered normal often assumes healthy and able young individuals. For example, there is a common notion that 10,000 steps as an ideal daily activity goal, but that might not be true for many older adults, particularly those who have certain illnesses or disabilities. Realistic goals must match a person’s context, abilities, and needs.

This perspective of aiming to achieve perfect health is founded in healthism [192], a belief that associates health and healthy behavior to personal responsibility, ethics, and values the pursuit of health as a kind of empowerment. This kind of belief is utopic, unrealistic for anyone. However, they are particularly detrimental for seniors, who by definition already deviate from the supposedly ideal young healthy body, and whose limited control towards their health or fitness may be implicitly framed as a personal failure.

In recovery, there is an inherent goal to improve continuously, although in reality, fluctuations in progress might be normal. Seniors undergoing rehabilitation might compare themselves with what is normal for a person without disabilities, or with their past selves before an event such as a stroke or a fall. These comparisons might not be beneficial or adequate, as full recovery to their prior state might not feasible.

For self-management tracking, what is considered normal might be defined as a predefined range (e.g., normal blood pressure). Monitoring is used to detect “abnormal” states (i.e., out of range). Encountering abnormal measurements (e.g., planning a meal based on a low blood sugar reading) might lead users to take action, such as taking a medication or seeking help from a healthcare provider.

When using self-tracking systems, people can create an understanding of what is normal or healthy by observing data from other users [26, 95, 254]. This construction of norms can lead to behavior change [248], and it can be leveraged to promote reflection [95]. However, users’ understandings of what is normal might not align with what experts would consider healthy [26]. Comparison with others can highlight struggles and lead to adverse consequences such as rumination [226].

Holding themselves to a perceived normal or ideal standard of health or behavior could be detrimental for seniors. Technology designers must be mindful of users’ tendencies of self-comparison with ideal or self-constructed standards. Comparison with others could lead to demotivation for seniors, particularly those with disabilities [199]. Using specific metrics that are more comparable across populations, or carry a little stigma, could help to prevent issues caused by these comparisons. For example, minutes of moderate physical activity is more comparable than steps or running speed among people of different ages and fitness levels, since what constitutes moderate activity is specific to the individual.

Because seniors are very diverse, even people of similar ages might not be comparable. Instead of comparing with others, it might be more useful to orient social features towards helping users to support and encourage one another [52]. For example, by sharing limited data showing to other users only that the person has measured their blood glucose or completed a workout that day, and offering supporting features such as likes or kudos.

7.3 Meaningful information

Seniors show interest in self-tracked data only when the data leads to new and relevant insights for their goals or concerns. For example, participants in studies 2 and 3 did not find that reflecting on past self-tracked exercise data as useful because it did not provide any new knowledge. From their perspectives, they knew how they were doing and remembered enough about what exercises or telerehab games they had done in the past. For example, a person who had a habit of walking 30 minutes daily did not see value in collecting exercise data, as it was already a known habit. In order to provide meaningful information to users, feedback based on self-tracked data should aim to be informative, relevant to users' lives, easily interpretable, personalized to the user, and transparent.

Seniors benefit from insights that are informative due to being perceived as relevant and previously unknown. In other words, they value information that is new for them and that they perceive as useful in a practical sense. That was the case of their future progress in the context of recovery tracking, and medical information (e.g., blood pressure) in the context of self-management tracking, as such measurements or estimates are difficult for them to obtain or observe on their own. However, they often described tracking certain data as not useful if they could observe it easily, such as dietary habits, symptoms, or even past improvements in recovery.

Meaningful feedback must be closely aligned to individuals' daily lives, their goals, and mindsets, rather than medical perspectives. Health technology should not be designed to help patients change their lifestyles to address a disease, but to reconcile self-management needs with their personal, social, and professional lives [139, 223]. People use tracking as a tool to support long-term concrete goals, navigating their decisions to get to where they want to be [269]. To be effective, the information shown to users should align with their goals and decisions. For example, in the case of stroke recovery, providing information about progress towards ADL goals (e.g., driving) would be meaningful to seniors because it speaks directly to their goals.

Meaningful or relevant information should be easily interpretable by seniors. They must be able to understand what that information means for them. For example, heart rate measurements will not be meaningful if they are not sure what it means, or what to do about it. If tracking systems perform information translation and guidance, explicitly translating measurements into meaningful insights, this information can become clear and actionable for them. The need for more meaningful information is not exclusive to older adults, as it could provide benefits to all users. Here, I highlight this need as an existing barrier to this particular population, whose self-tracking technology adoption is very low.

Because they have different perspectives and priorities, meaningful information might be different for patients and healthcare providers [259]. For example, providers might be interested in objective statistical data, while patients might prefer subjective information (e.g., sharing experiences with others) [199]. It is crucial that the high-level goals of each stakeholder be taken into consideration during the design process so that the system can provide meaningful information in a format that aligns with their perspectives.

Lastly, transparency is important to foster user trust in the information provided. Transparency requires informing users about how the data are measured or obtained and how much accuracy should be assumed when interpreting the data. Further, users should also be informed about how the systems calculate information by processing data (e.g., calculating physical therapy progress based on measured performance) [133, 332].

7.4 Dealing with (anticipated) loss

Providing feedback to users who anticipate or might experience health deterioration is perhaps the most challenging aspect of designing self-tracking for seniors. Certain data can be demotivating rather than empowering, such as when the data remind them of stigma, disability, or indicate a negative outlook towards their future (e.g., they did not improve in rehabilitation in multiple months). Seniors might be facing conditions that progress to become worse or even develop new conditions over time.

Data perceived as negative could serve as a reminder of stigmatized aspects of aging, promote fear of losing independence or reinforce pessimistic prospects on recovery or future developments. This issue is present in each of the three kinds of health tracking. For example, study 2 found that seniors avoid wellness tracking technology such as pedometers because they could serve as a reminder of their aging and physical limitations. From the same study, preventative monitoring systems such as the emergency button pendant caused resistance due to serving as a negative reminder of potential medical emergencies they might face due to frailty or a chronic condition. From study 3, participants preferred not to see any data that could indicate a plateau or loss in function. If positive feedback is contingent on improvements, then a lack of improvements may signify negative feedback and distress.

Negative perceptions or stereotypes of aging have a measurable impact on longevity and health. Research has found that seniors who have more positive perspectives on aging live longer [327, 180] and are less prone to developing Alzheimer's disease [179]. Seniors who live in countries where older adults are viewed more positively also test higher in cognition [290].

It may be difficult to promote positive feedback when users realistically fear or anticipate health issues that might impact their independence or quality of life, such as functional loss, a condition worsening, or plateau in recovery. At the same time that tracking can give people reassurance, agency, and a sense of control, it can also lead to negative feelings, and reminders of their illness [16] and reinforce such fears. While it is important to motivate and encourage them, seniors might be dealing with a condition that naturally worsens over time. They might also reach a maximum point of recovery before they reach their goals.

Supporting seniors requires designing to promote a positive outlook in their data. For example, we can compare two senior monitoring devices used by participants in study 2; an alarm pendant used to ask for help in an emergency and a button used for daily check-ins. Although both were used to detect emergencies, the latter was much more appreciated and valued by seniors, as it highlighted positive rather than negative data.

Designers must have caution and be aware that tracking can lead to negative experiences among seniors. It is essential to meet the person's needs in their current state of mind while promoting positive relationships with health data and to design and test systems using data of potentially undesired states to make sure feedback mechanisms are in place to support users [71]. It is also important to exercise caution about how or when to provide feedback that could be interpreted as negative by users. Seniors can be vulnerable to negative self-affirmation based on negative feedback from tracking systems, similarly to other populations such as individuals with mental illness [155, 213, 275]. Highlighting positive accomplishments could help users not to take their progress for granted when reaching a plateau in recovery tracking.

7.5 Engaging and encouraging seniors

Consumer health technology, including those involving self-tracking, often are discussed as a tool for patient engagement or empowerment. These tools tend to focus on supporting knowledge (e.g., access to health information) and action (e.g., behavior change) [319, 277]. Knowledge and action are two psychological aspects of empowerment. However, having a feeling of control and self-efficacy is also important [279]. For seniors, similar to other populations who are vulnerable to negative impacts from tracking, self-efficacy is crucial for adoption, use, and benefiting from health tracking. It is necessary that designers not only acknowledge and avoid potential negative impacts from self-tracking but actively design to promote positive psychological outcomes. Below, I discuss two possible directions for supporting seniors by aiming to enhance self-efficacy and promoting encouraging causal attributions.

Self-efficacy

Information that is perceived as discouraging for seniors, such as a lower performance in a physical therapy exercise, might reduce their self-efficacy. Self-efficacy refers to a person's confidence about their ability to accomplish a task [18], and it impacts people's mental well-being, their actions, and their health outcomes [18, 75]. Self-efficacy is particularly important for populations that are older or have a chronic condition [52, 287].

Designers can foster higher self-efficacy by intentionally creating feedback and framing data visualization to be encouraging to users. Self-efficacy is influenced by how the person interprets information. Facilitating certain outlooks towards the data can help to achieve more encouraging interpretations. The most effective way to increase self-efficacy is through performance accomplishments, i.e., succeeding at the task in question. To promote this experience, it is essential to guide users to goals and exercises at the right difficulty level (i.e., not too easy or too hard) and foster celebration of success, so users feel and reflect on this success, internalizing it and absorbing it as encouragement [18, 138]. Other strategies that improve self-efficacy can also be implemented in self-tracking systems, such as vicarious experience (i.e., observing others succeed at the task) through social data sharing, and verbal persuasion [18] through encouraging messages personalized based on the users' data or goals.

Causal attribution

Participants in studies 2 and 3 avoided negative data, which sometimes led to them avoiding tracking itself. However, even for data that tends to be interpreted as negative or demotivating by seniors, it might be possible to encourage users by framing the system feedback towards encouraging causal attribution. The causes of an event such as achieving or not achieving a daily exercise goal, as interpreted by the user, influence how they act as a result, and also on how the event affects them psychologically. Success can lead to confidence, pride, or apprehension depending on its perceived causes, while failure can lead to shame, anger, or even hope [325].

According to Causal Attribution Theory, people who attribute failure to internal (i.e., characteristics or behaviors of the individual), stable (i.e., unlikely to change), and uncontrollable causes have lower self-efficacy, higher performance anxiety, higher stress reacting to failure, and feel less in control in comparison with people who attribute failure to external, unstable, and controllable factors [202, 297, 324]. Informed by this work, technology design can foster more positive outlooks on “negative” data by framing potentially negative data as not being the users’ fault (i.e., caused by external factors), and as something the user can change by trying again (i.e., the outcome is unstable and controllable). In the case of positive data, systems should provide feedback encouraging users to interpret it as their own accomplishments (i.e., caused by internal factors) and as something they can achieve again (i.e., the outcome is stable and controllable).

Promoting a sense of control for users is important, regardless of whether the data is perceived as negative or positive. It is important to design feedback that highlights controllable factors so that users attribute success to themselves, but not failure [274]. A sense of control is particularly relevant for seniors, it can create more intrinsic motivation for that activity [272], as promoting intrinsic motivation is important for supporting seniors’ needs [145, 144]. As found in study 3, users also can feel more in control when they understand their data, what to expect in the future, and have access to meaningful and actionable information.

Chapter 8

Conclusion

In this dissertation I investigate seniors' existing self-tracking practices, what barriers are limiting their adoption of self-tracking technology, and what specific needs they have for self-tracking technology.

This work was motivated by the yet unfulfilled potential for self-tracking technology to assist seniors in their health management work, either as a way to facilitate it by reducing burden or improve it by providing more insight, encouragement, or promoting behavior change. Seniors' existing adoption of self-tracking for health, but not of self-tracking technology indicates that there are issues in existing tools that limit the adoption and use by seniors. This work provides novel insights into several existing barriers in three different kinds of tracking (wellness, self-management, recovery). The outcomes of this research describe concrete steps for future research and technology design to better understand seniors and provide more effective and beneficial tools for them. Specifically, Seniors need tools that focus on empowerment by fostering self-efficacy, without highlighting aspects of their health or behavior that carry stigma.

The first of the three studies was a quantitative study investigating the influence of age and health factors on self-tracking behavior. Understanding these impacts is necessary due to the relationships between health and age - as certain health conditions might be more common in old age. The findings of this study reveal that both age and health influence self-tracking, meaning that findings from studies 2 and 3, as well as findings other studies on self-tracking for health, might not translate for individuals of other ages or another health status. Further, this study revealed a tendency of older adults to engage in self-management tracking (i.e., tracking data associated with a chronic condition) even when they have not been diagnosed with that condition - revealing a need for tracking technology that supports self-tracking for prevention purposes.

The second study, an interview with older adults residing in a retirement community, aimed to investigate seniors' perspectives towards tracking and their existing self-tracking practices with or without technology. This study encompassed the three kinds of self-tracking and revealed several novel insights. In terms of wellness tracking, only seniors who were very active already used technology such as pedometers. This issue is attributed mainly to an association of physical activity tracking with goals that are not realistic for many seniors. This study also described how seniors use self-management tracking for monitoring their health and detecting issues early. Lastly, self-tracking was not seen as useful by seniors for supporting medical recovery nor behavior change.

The third study was a qualitative project investigating a potential application of self-tracking technology in the context of recovery from stroke. Recovery is a promising application of self-tracking technology for health, and this project yielded several insights about patients' and healthcare providers' needs and perspectives towards self-tracked recovery data. While reflecting the findings from study 2, where participants did not perceive recovery data as particularly interesting or useful, this study also revealed that participants showed interest in actionable information and insights about their future recovery prospects.

Overall, the results of this research describe several challenges and opportunities for designing self-tracking technology for seniors. Understanding their need for meaningful and encouraging information provides directions for future research, as neither objective is trivial to accomplish. Leveraging users' tendency to conceptualize normalcy to interpret their health data in beneficial ways, while avoiding its pitfalls, is also a challenge that requires further research. While chapter 7 discusses a few possibilities to pursue these goals, more work is needed to develop strategic strategies to translate existing research into designs and to validate them with users.

Self-tracking involves an underlying narrative of pursuing improvement, behavior change for the better, take control of your health for example. This narrative contradicts the fears and often the experiences of seniors, who face declines in health in their own lives and see it happening to those around them. A perspective of pursuing a bright future and cultivating the optimal health for a bright future contradicts seniors' reality. Instead, bringing awareness to their habits or situations, which do not fit the assumed ideals embedded in healthist culture, highlights these stigmatized aspects of their lives. Then, it is not surprising that the majority of seniors rejects self-tracking and monitoring technology for health. When these systems are thought of as tools of accountability to the pursuit of health and youth, they are inherently at odds with the abilities and goals of older adults.

Across different age brackets, a person's short- and long-term goals may differ significantly. While younger populations may pursue tools such as self-tracking as a way to improve their fitness in the short term and prevent chronic conditions in the long term, seniors have much more concrete goals. For example, managing pain, managing already existing chronic conditions, prevent or reduce disabilities. The impact of health in their lives is more tangible and urgent, making these concrete outcomes a priority. [how this affects their practices, needs]

Instead, these population needs tools that empower them and ease the burden involved in the care they already pursue without highlighting stigmatized aspects or behaviors. For this reason, research must investigate how to design technologies that effectively empower individuals and communities, not focusing primarily on whether the intervention works (e.g., leads to behavior change) but prioritizing a positive impact on self-efficacy and locus of control.

Discussions about user and patient empowerment are often embedded within self-tracking communities. The concept of power has different facets, such as agency itself (i.e., ability to take action) and the self-perception of having power (i.e., perceived control) [279]. While tools designed to collect and present self-tracked data may provide enough information to increase patient agency, this benefit must not come at the expense of reduced self-efficacy. Perhaps a consequence of primarily investigating individuals who already are already interested in self-tracking technology - either by studying existing trackers or by offering tracking devices as compensation for participation in the study. Cannot take it for granted. Data is feedback, and whenever provided to users we must consider whether this feedback is beneficial and motivating for them. Whether its interpretation, accurate or not, is demoralizing rather than empowering.

To better provide empowerment to seniors through self-tracking technology, we must highlight positive data through design, rewarding positive behavior. We must actively avoid designing around targets or standards, implicit or explicit, that could be perceived as stigmatizing. We must anticipate this issues during the design process, and specifically focus on detecting them during the user testing phase. Beyond the data, the experience itself of using the technology should be psychologically empowering. Users may gain further awareness and reflect on their context and actions in the process of using or wearing a self-tracking device. That experience itself also must be designed to foster self-efficacy for users.

This research contributes to our knowledge about how to create effective technology for older adult health. The findings and implications discussed in this dissertation reveal several issues that should be taken into account for future research and future technology design addressing older adults. In the long-term, health technology for seniors has the potential to facilitate their work and that of caregivers and healthcare providers, reducing burden, improving their well-being, and also impact health outcomes.

The need for a greater focus on empowerment and psychological well-being is not exclusive to seniors, rather it is an important factor to consider for many communities that experience stigma, such as those struggling with opioid addition [235], infertility [71], or weight loss [19]. These individuals need access to tools that support them without causing perceptions of failure. Ultimately, these tools would also benefit the population of self-trackers at large. But for these particular contexts, overcoming stigmatizing design is necessary in order for them to adopt these tools more widely, receive benefits, and have them make an impact on their lives.

Bibliography

[1] AARP. *Building a Better Tracker: Older Consumers Weigh in On Activity and Sleep Monitoring Devices.* 2015.

[2] F. Adib, H. Mao, Z. Kabelac, D. Katabi, and R. C. Miller. Smart homes that monitor breathing and heart rate. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 837–846. ACM, 2015.

[3] V. Ahanathapillai, J. Amor, and C. James. Assistive technology to monitor activity, health and wellbeing in old age: The wrist wearable unit in the usefil project. *Technology and Disability*, 27(1, 2):17–29, 2015.

[4] S. Ahmed and M. Sharmin. Why do mobile phone-based smoking cessation interventions struggle and how can we make them more effective? *iConference 2015 Proceedings*, 2015.

[5] G. Alankus, R. Proffitt, C. Kelleher, and J. Engsberg. Stroke therapy through motion-based games: a case study. *ACM Transactions on Accessible Computing (TACCESS)*, 4(1):3, 2011.

[6] M. Altmeyer, P. Lessel, S. Hosseini, and A. Krueger. Silvercycling: Evaluating persuasive strategies to promote physical activity among older adults. In *Proceedings of the 2018 ACM Conference Companion Publication on Designing Interactive Systems*, pages 45–50. ACM, 2018.

[7] J. S. Ancker, H. O. Witteman, B. Hafeez, T. Provencher, M. Van de Graaf, and E. Wei. “you get reminded you’re a sick person”: Personal data tracking and patients with multiple chronic conditions. *Journal of medical Internet research*, 17(8), 2015.

[8] M. Anderson and A. Perrin. Technology use among seniors. *Washington, DC: Pew Research Center for Internet & Technology*, 2017.

[9] J. Anhøj and C. Møldrup. Feasibility of collecting diary data from asthma patients through mobile phones and sms (short message service): response rate analysis and focus group evaluation from a pilot study. *Journal of Medical Internet Research*, 6(4):e42, 2004.

[10] J. Araullo and L. E. Potter. Promoting physical activity in seniors: Future opportunities with emerging technologies. In *Proceedings of the 2016 ACM SIGMIS Conference on Computers and People Research*, pages 57–64. ACM, 2016.

[11] A. W. Armstrong, A. J. Watson, M. Makredes, J. E. Frangos, A. B. Kimball, and J. C. Kvedar. Text-message reminders to improve sunscreen use: a randomized, controlled trial using electronic monitoring. *Archives of dermatology*, 145(11):1230–1236, 2009.

[12] M. Arnhold, M. Quade, and W. Kirch. Mobile applications for diabetics: a systematic review and expert-based usability evaluation considering the special requirements of diabetes patients age 50 years or older. *Journal of medical Internet research*, 16(4):e104, 2014.

[13] M. C. Ashe, M. Winters, C. A. Hoppmann, M. G. Dawes, P. A. Gardiner, L. M. Giangregorio, K. M. Madden, M. M. McAllister, G. Wong, J. H. Puyat, et al. "not just another walking program": Everyday activity supports you (easy) model—a randomized pilot study for a parallel randomized controlled trial. *Pilot and feasibility studies*, 1(1):1, 2015.

[14] M. Ayoade and L. Baillie. A novel knee rehabilitation system for the home. In *Proceedings of the SIGCHI conference on human factors in computing systems*, pages 2521–2530. ACM, 2014.

[15] A. Ayobi, P. Marshall, and A. L. Cox. Reflections on 5 years of personal informatics: Rising concerns and emerging directions. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems*, pages 2774–2781. ACM, 2016.

[16] A. Ayobi, P. Marshall, A. L. Cox, and Y. Chen. Quantifying the body and caring for the mind: self-tracking in multiple sclerosis. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 6889–6901. ACM, 2017.

[17] N. Bagalkot and T. Sokoler. Magicmirror: towards enhancing collaborative rehabilitation practices. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work*, pages 593–596. ACM, 2011.

[18] A. Bandura. Self-efficacy: toward a unifying theory of behavioral change. *Psychological review*, 84(2):191, 1977.

[19] A. M. Barbarin, L. R. Saslow, M. S. Ackerman, and T. C. Veinot. Toward health information technology that supports overweight/obese women in addressing emotion-and stress-related eating. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 321. ACM, 2018.

[20] J. E. Bardram, M. Frost, K. Szántó, M. Faurholt-Jepsen, M. Vinberg, and L. V. Kessing. Designing mobile health technology for bipolar disorder: a field trial of the monarca system. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 2627–2636. ACM, 2013.

[21] L. H. Barg-Walkow, S. E. McBride, M. J. Morgan, T. L. Mitzner, E. E. Clarke, D. T. Bauer, C. C. Knott, and W. A. Rogers. Efficacy of a system for tracking and managing osteoarthritis pain for both healthcare providers and older adults. In *Proceedings of the International Symposium on Human Factors and Ergonomics in Health Care*, volume 3, pages 108–111. SAGE Publications, 2014.

[22] L. H. Barg-Walkow, S. E. McBride, M. J. Morgan, T. L. Mitzner, C. C. Knott, and W. A. Rogers. How do older adults manage osteoarthritis pain? the need for a person-centered disease model. In *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, volume 57, pages 743–747. SAGE Publications, 2013.

[23] J. Barlow, C. Wright, J. Sheasby, A. Turner, and J. Hainsworth. Self-management approaches for people with chronic conditions: a review. *Patient education and counseling*, 48(2):177–187, 2002.

[24] R. Bates. A critical analysis of evaluation practice: the kirkpatrick model and the principle of beneficence. *Evaluation and program planning*, 27(3):341–347, 2004.

[25] E. P. Baumer. Reflective informatics: conceptual dimensions for designing technologies of reflection. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 585–594. ACM, 2015.

[26] E. P. Baumer, S. J. Katz, J. E. Freeman, P. Adams, A. L. Gonzales, J. Pollak, D. Retelny, J. Niederdeppe, C. M. Olson, and G. K. Gay. Prescriptive persuasion and open-ended social awareness: expanding the design space of mobile health. In *Proceedings of the ACM 2012 conference on Computer Supported Cooperative Work*, pages 475–484. ACM, 2012.

[27] E. P. Baumer, V. Khovanskaya, M. Matthews, L. Reynolds, V. Schwanda Sosik, and G. Gay. Reviewing reflection: on the use of reflection in interactive system design. In *Proceedings of the 2014 conference on Designing interactive systems*, pages 93–102. ACM, 2014.

[28] S. Belleville. Cognitive training for persons with mild cognitive impairment. *International Psychogeriatrics*, 20(01):57–66, 2008.

[29] A. Belmonte-Hernández, T. Theodoridis, M. B. González, G. Hernández-Peñaloza, V. Solachidis, J. J. Ramos, F. Álvarez, N. Vretos, L. Carrasco, and P. Daras. A novel framework for physical therapy rehabilitation monitoring and assessment in parkinson disease patients using depth information. In *Proceedings of the 12th ACM International Conference on PErvasive Technologies Related to Assistive Environments*, pages 535–539. ACM, 2019.

[30] E. J. Benjamin, S. S. Virani, C. W. Callaway, A. M. Chamberlain, A. R. Chang, S. Cheng, S. E. Chiuve, M. Cushman, F. N. Delling, R. Deo, et al. Heart disease and stroke statistics-2018 update: a report from the american heart association. *Circulation*, 137(12):e67, 2018.

[31] M. S. Bernardes. *O monitoramento domiciliar das condições crônicas e a tomada de decisão por idosos diabéticos e hipertensos.* PhD thesis, Universidade de São Paulo, 2016.

[32] L. Beursgens, F. Boesten, A. Timmermans, H. Seelen, and P. Markopoulos. Us'em: motivating stroke survivors to use their impaired arm and hand in daily life. In *CHI'11 Extended Abstracts on Human Factors in Computing Systems*, pages 1279–1284. ACM, 2011.

[33] M. J. Bietz, C. S. Bloss, S. Calvert, J. G. Godino, J. Gregory, M. P. Claffey, J. Sheehan, and K. Patrick. Opportunities and challenges in the use of personal health data for health research. *Journal of the American Medical Informatics Association*, page ocv118, 2015.

[34] R. Bispo and R. Branco. Designing out stigma: the role of objects in the construction of disabled people's identity. In *Dare to Desire: 6th International Design and Emotion Conference*, 2008.

[35] K. S. Blondon and P. Klasnja. Designing supportive mobile technology for stable diabetes. In *International Conference of Design, User Experience, and Usability*, pages 361–370. Springer, 2013.

[36] T. Bodenheimer, K. Lorig, H. Holman, and K. Grumbach. Patient self-management of chronic disease in primary care. *Jama*, 288(19):2469–2475, 2002.

[37] M. Bojic, O. A. B. Henkemans, M. A. Neerincx, C. A. Van der Mast, and J. Lindenberg. Effects of multimodal feedback on the usability of mobile diet diary for older adults. In *International Conference on Universal Access in Human-Computer Interaction*, pages 293–302. Springer, 2009.

[38] C. Bossen and E. Grönvall. Collaboration in-between: The care hotel and designing for flexible use. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*, pages 1289–1301. ACM, 2015.

[39] D. M. Bravata, C. Smith-Spangler, V. Sundaram, A. L. Gienger, N. Lin, R. Lewis, C. D. Stave, I. Olkin, and J. R. Sirard. Using pedometers to increase physical activity and improve health: a systematic review. *Jama*, 298(19):2296–2304, 2007.

[40] M. Broden, R. V. Hall, and B. Mitts. The effect of self-recording on the classroom behavior of two eighth-grade students. *Journal of Applied Behavior Analysis*, 4(3):191–199, 1971.

[41] D. G. Bruce, A. Devine, and R. L. Prince. Recreational physical activity levels in healthy older women: the importance of fear of falling. *Journal of the American Geriatrics Society*, 50(1):84–89, 2002.

[42] P. Burnard. A method of analysing interview transcripts in qualitative research. *Nurse education today*, 11(6):461–466, 1991.

[43] K. E. Burton. *Evaluating Activity and Sleep Tracking Technologies for Older Adults.* PhD thesis, 2016.

[44] A. G. Büyüktür, M. S. Ackerman, M. W. Newman, and P.-Y. Hung. Design considerations for semi-automated tracking: self-care plans in spinal cord injury. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pages 183–192. ACM, 2017.

[45] K. E. Caine, C. Y. Zimmerman, Z. Schall-Zimmerman, W. R. Hazlewood, L. J. Camp, K. H. Connelly, L. L. Huber, and K. Shankar. Digiswitch: A device to allow older adults to monitor and direct the collection and transmission of health information collected at home. *Journal of medical systems*, 35(5):1181–1195, 2011.

[46] C. Caldeira, M. Bietz, and Y. Chen. Looking for the unusual: How older adults utilize self-tracking techniques for health management. In *Pervasive Health*. Springer, 2016.

[47] C. Caldeira, M. Bietz, M. Vidauri, and Y. Chen. Senior care for aging in place. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing - CSCW 17*. ACM Press, 2017. DOI: `https://doi.org/10.1145/2998181.2998206`.

[48] R. A. Calvo and D. Peters. The irony and re-interpretation of our quantified self. In *Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration*, pages 367–370. ACM, 2013.

[49] E. Casilari and M. A. Oviedo-Jiménez. Automatic fall detection system based on the combined use of a smartphone and a smartwatch. *PloS one*, 10(11):e0140929, 2015.

[50] Y. Chen. Take it personally: accounting for individual difference in designing diabetes management systems. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems*, pages 252–261. ACM, 2010.

[51] Y. Chen, K. T. Abel, J. T. Janecek, Y. Chen, K. Zheng, and S. C. Cramer. Home-based technologies for stroke rehabilitation: A systematic review. *International journal of medical informatics*, 2018.

[52] Y. Chen, Y. Chen, M. M. Randriambelonoro, A. Geissbuhler, and P. Pu. Design considerations for social fitness applications: Comparing chronically ill patients and healthy adults. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, pages 1753–1762. ACM, 2017.

[53] Y. Chen, K. Cheng, C. Tang, K. A. Siek, and J. E. Bardram. The invisible work of health providers. *interactions*, 21(5):74–77, 2014.

[54] Y. Chen and K. Pine. When medical expertise meets record expertise: The practices of patient accessible medical records in china. In *COOP 2014-Proceedings of the 11th International Conference on the Design of Cooperative Systems, 27-30 May 2014, Nice (France)*, pages 409–426. Springer, 2014.

[55] M.-C. Chiu, S.-P. Chang, Y.-C. Chang, H.-H. Chu, C. C.-H. Chen, F.-H. Hsiao, and J.-C. Ko. Playful bottle: a mobile social persuasion system to motivate healthy water intake. In *Proceedings of the 11th international conference on Ubiquitous computing*, pages 185–194. ACM, 2009.

[56] E. K. Choe, S. Consolvo, N. F. Watson, and J. A. Kientz. Opportunities for computing technologies to support healthy sleep behaviors. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 3053–3062. ACM, 2011.

[57] E. K. Choe, B. Lee, S. Munson, W. Pratt, and J. A. Kientz. Persuasive performance feedback: The effect of framing on self-efficacy. In *AMIA Annual Symposium Proceedings*, volume 2013, page 825. American Medical Informatics Association, 2013.

[58] E. K. Choe, N. B. Lee, B. Lee, W. Pratt, and J. A. Kientz. Understanding quantified-selfers' practices in collecting and exploring personal data. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*, pages 1143–1152. ACM, 2014.

[59] L. R. Christensen and E. Grönvall. Challenges and opportunities for collaborative technologies for home care work. In *ECSCW 2011: Proceedings of the 12th European Conference on Computer Supported Cooperative Work, 24-28 September 2011, Aarhus Denmark*, pages 61–80. Springer, 2011.

[60] C.-F. Chung, K. Dew, A. Cole, J. Zia, J. Fogarty, J. A. Kientz, and S. A. Munson. Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. 2016.

[61] N. M. Clark, M. H. Becker, N. K. Janz, K. Lorig, W. Rakowski, and L. Anderson. Self-management of chronic disease by older adults a review and questions for research. *Journal of Aging and Health*, 3(1):3–27, 1991.

[62] N. M. Clark, W. Rakowski, J. R. Wheeler, L. D. Ostrander, S. Oden, and S. Keteyian. Development of self-management education for elderly heart patients. *The Gerontologist*, 28(4):491–494, 1988.

[63] P. J. Clarke, S. E. BLACK, E. M. BADLEY, J. M. LAWRENCE, and J. IVAN WILLIAMS. Handicap in stroke survivors. *Disability and rehabilitation*, 21(3):116–123, 1999.

[64] S. Consolvo, D. W. McDonald, T. Toscos, M. Y. Chen, J. Froehlich, B. Harrison, P. Klasnja, A. LaMarca, L. LeGrand, R. Libby, et al. Activity sensing in the wild: a field trial of ubifit garden. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 1797–1806. ACM, 2008.

[65] S. Consolvo, P. Roessler, B. E. Shelton, A. LaMarca, B. Schilit, and S. Bly. Technology for care networks of elders. *Pervasive Computing, IEEE*, 3(2):22–29, 2004.

[66] D. J. Cook, J. E. Thompson, S. K. Prinsen, J. A. Dearani, and C. Deschamps. Functional recovery in the elderly after major surgery: assessment of mobility recovery using wireless technology. *The Annals of thoracic surgery*, 96(3):1057–1061, 2013.

[67] J. Corbin and A. Strauss. Managing chronic illness at home: three lines of work. *Qualitative sociology*, 8(3):224–247, 1985.

[68] J. M. Corbin and A. L. Strauss. Collaboration: Couples working together to manage chronic illness. *Image: The Journal of Nursing Scholarship*, 16(4):109–115, 1984.

[69] F. Cordeiro, E. Bales, E. Cherry, and J. Fogarty. Rethinking the mobile food journal: Exploring opportunities for lightweight photo-based capture. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 3207–3216. ACM, 2015.

[70] F. Cordeiro, D. A. Epstein, E. Thomaz, E. Bales, A. K. Jagannathan, G. D. Abowd, and J. Fogarty. Barriers and negative nudges: Exploring challenges in food journaling. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 1159–1162. ACM, 2015.

[71] M. Costa Figueiredo, C. Caldeira, E. V. Eikey, M. Mazmanian, and Y. Chen. Engaging with health data: The interplay between self-tracking activities and emotions in fertility struggles. *Proceedings of the ACM on Human-Computer Interaction*, 2(CSCW):40, 2018.

[72] M. Costa Figueiredo, C. Caldeira, T. L. Reynolds, S. Victory, K. Zheng, and Y. Chen. Self-tracking for fertility care: collaborative support for a highly personalized problem. *Proceedings of the ACM on Human-Computer Interaction*, 1(CSCW):36, 2017.

[73] S. C. Cramer, L. Dodakian, V. Le, J. See, R. Augsburger, A. McKenzie, R. J. Zhou, N. L. Chiu, J. Heckhausen, J. M. Cassidy, et al. Efficacy of home-based telerehabilitation vs in-clinic therapy for adults after stroke: A randomized clinical trial. *JAMA neurology*, 2019.

[74] J. L. Davidson and C. Jensen. What health topics older adults want to track: A participatory design study. In *Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility*, page 26. ACM, 2013.

[75] K. Dean, T. Hickey, and B. E. Holstein. *Self-care and health in old age: Health behaviour implications for policy and practice*. Routledge, 1986.

[76] G. Demiris, L. B. Afrin, S. Speedie, K. L. Courtney, M. Sondhi, V. Vimarlund, C. Lovis, W. Goossen, and C. Lynch. Patient-centered applications: use of information technology to promote disease management and wellness. a white paper by the amia knowledge in motion working group. *Journal of the American Medical Informatics Association*, 15(1):8–13, 2008.

[77] T. Denning, A. Andrew, R. Chaudhri, C. Hartung, J. Lester, G. Borriello, and G. Duncan. Balance: towards a usable pervasive wellness application with accurate activity inference. In *Proceedings of the 10th workshop on Mobile Computing Systems and Applications*, page 5. ACM, 2009.

[78] J. E. Deutsch, M. Borbely, J. Filler, K. Huhn, and P. Guarrera-Bowlby. Use of a low-cost, commercially available gaming console (wii) for rehabilitation of an adolescent with cerebral palsy. *Physical therapy*, 88(10):1196–1207, 2008.

[79] J. E. Deutsch, A. Brettler, C. Smith, J. Welsh, R. John, P. Guarrera-Bowlby, and M. Kafri. Nintendo wii sports and wii fit game analysis, validation, and application to stroke rehabilitation. *Topics in stroke rehabilitation*, 18(6):701–719, 2011.

[80] G. Dowswell, J. Lawler, T. Dowswell, J. Young, A. Forster, and J. Hearn. Investigating recovery from stroke: a qualitative study. *Journal of clinical nursing*, 9(4):507–515, 2000.

[81] J. Durick, T. Robertson, M. Brereton, F. Vetere, and B. Nansen. Dispelling ageing myths in technology design. In *Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration*, pages 467–476. ACM, 2013.

[82] E. V. Eikey and M. C. Reddy. It's definitely been a journey: A qualitative study on how women with eating disorders use weight loss apps. In *Proceedings of the 2017 CHI conference on human factors in computing systems*, pages 642–654. ACM, 2017.

[83] O. El-Gayar, P. Timsina, N. Nawar, and W. Eid. A systematic review of it for diabetes self-management: are we there yet? *International journal of medical informatics*, 82(8):637–652, 2013.

[84] K. Elward and E. B. Larson. Benefits of exercise for older adults. a review of existing evidence and current recommendations for the general population. *Clinics in geriatric medicine*, 8(1):35–50, 1992.

[85] R. A. Emmons and M. E. McCullough. Counting blessings versus burdens: an experimental investigation of gratitude and subjective well-being in daily life. *Journal of personality and social psychology*, 84(2):377, 2003.

[86] D. Epstein, F. Cordeiro, E. Bales, J. Fogarty, and S. Munson. Taming data complexity in lifelogs: exploring visual cuts of personal informatics data. In *Proceedings of the 2014 conference on Designing interactive systems*, pages 667–676. ACM, 2014.

[87] G. Eysenbach. What is e-health? *Journal of medical Internet research*, 3(2):e20, 2001.

[88] S. Y. Fagerhaugh and A. L. Strauss. *Social organization of medical work*. Transaction Publishers, 1997.

[89] C. Fan, J. Forlizzi, and A. Dey. Considerations for technology that support physical activity by older adults. In *Proceedings of the 14th international ACM SIGACCESS conference on Computers and accessibility*, pages 33–40. ACM, 2012.

[90] A. Farmer, O. Gibson, P. Hayton, K. Bryden, C. Dudley, A. Neil, and L. Tarassenko. A real-time, mobile phone-based telemedicine system to support young adults with type 1 diabetes. *Journal of Innovation in Health Informatics*, 13(3):171–177, 2005.

[91] H. A. Faucett, K. E. Ringland, A. L. Cullen, and G. R. Hayes. (in) visibility in disability and assistive technology. *ACM Transactions on Accessible Computing (TACCESS)*, 10(4):1–17, 2017.

[92] C. B. Fausset, T. L. Mitzner, C. E. Price, B. D. Jones, B. W. Fain, and W. A. Rogers. Older adults' use of and attitudes toward activity monitoring technologies. In *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, volume 57, pages 1683–1687. SAGE Publications, 2013.

[93] S. Felipe, A. Singh, C. Bradley, A. C. Williams, and N. Bianchi-Berthouze. Roles for personal informatics in chronic pain. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare*, pages 161–168. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), 2015.

[94] Z. Feng, C. Liu, X. Guan, and V. Mor. China's rapidly aging population creates policy challenges in shaping a viable long-term care system. *Health Affairs*, 31(12):2764–2773, 2012.

[95] C. Feustel, S. Aggarwal, B. Lee, and L. Wilcox. People like me: Designing for reflection on aggregate cohort data in personal informatics systems. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, 2(3):107, 2018.

[96] M. Fiordelli, N. Diviani, and P. J. Schulz. Mapping mhealth research: a decade of evolution. *Journal of medical Internet research*, 15(5):e95, 2013.

[97] D. L. Fixsen, E. L. Phillips, and M. M. Wolf. Achievement place: the reliability of self-reporting and peer-reporting and their effects on behavior. *Journal of Applied Behavior Analysis*, 5(1):19–30, 1972.

[98] R. Fleck and G. Fitzpatrick. Reflecting on reflection: framing a design landscape. In *Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction*, pages 216–223. ACM, 2010.

[99] T. A. Floegel, A. Florez-Pregonero, E. B. Hekler, and M. P. Buman. Validation of consumer-based hip and wrist activity monitors in older adults with varied ambulatory abilities. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, page glw098, 2016.

[100] B. Fogg. *Mobile persuasion: 20 perspectives on the future of behavior change.* Mobile Persuasion, 2007.

[101] B. J. Fogg. Persuasive computers: perspectives and research directions. In *Proceedings of the SIGCHI conference on Human factors in computing systems*, pages 225–232. ACM Press/Addison-Wesley Publishing Co., 1998.

[102] B. J. Fogg. A behavior model for persuasive design. In *Proceedings of the 4th international Conference on Persuasive Technology*, page 40. ACM, 2009.

[103] S. Fox and M. Duggan. *Tracking for health.* Pew Research Center's Internet & American Life Project, 2013.

[104] V. Franklin, A. Greene, A. Waller, S. Greene, and C. Pagliari. Patients' engagement with "sweet talk"–a text messaging support system for young people with diabetes. *Journal of Medical Internet Research*, 10(2):e20, 2008.

[105] L. Fratiglioni, S. Paillard-Borg, and B. Winblad. An active and socially integrated lifestyle in late life might protect against dementia. *The Lancet Neurology*, 3(6):343–353, 2004.

[106] D. P. French, E. K. Olander, A. Chisholm, and J. Mc Sharry. Which behaviour change techniques are most effective at increasing older adults' self-efficacy and physical activity behaviour? a systematic review. *Annals of Behavioral Medicine*, 48(2):225–234, 2014.

[107] J. Frost and B. K. Smith. Visualizing health: imagery in diabetes education. In *Proceedings of the 2003 conference on Designing for user experiences*, pages 1–14. ACM, 2003.

[108] M. Frost, A. Doryab, M. Faurholt-Jepsen, L. V. Kessing, and J. E. Bardram. Supporting disease insight through data analysis: refinements of the monarca self-assessment system. In *Proceedings of the 2013 ACM international joint conference on Pervasive and ubiquitous computing*, pages 133–142. ACM, 2013.

[109] A. C. B. Garcia, A. S. Vivacqua, N. Sanchez-Pi, L. Marti, and J. M. Molina. Crowd-based ambient assisted living to monitor the elderly's health outdoors. *IEEE Software*, 34(6):53–57, 2017.

[110] N. Garrett and E. M. Martini. The boomers are coming: a total cost of care model of the impact of population aging on the cost of chronic conditions in the united states. *Disease Management*, 10(2):51–60, 2007.

[111] D. J. Gladstone, C. J. Danells, and S. E. Black. The fugl-meyer assessment of motor recovery after stroke: a critical review of its measurement properties. *Neurorehabilitation and neural repair*, 16(3):232–240, 2002.

[112] E. T. Gonzalez, A. M. Jones, L. R. Harley, D. Burnham, Y. M. Choi, W. B. Fain, and M. Ghovanloo. Older adults' perceptions of a neckwear health technology. In *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, volume 58, pages 1815–1819. SAGE Publications, 2014.

[113] N. Gorm and I. Shklovski. Steps, choices and moral accounting: Observations from a step-counting campaign in the workplace. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*, pages 148–159. ACM, 2016.

[114] R. Gouveia, E. Karapanos, and M. Hassenzahl. How do we engage with activity trackers?: a longitudinal study of habito. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, pages 1305–1316. ACM, 2015.

[115] E. Grönvall and N. Verdezoto. Beyond self-monitoring: understanding non-functional aspects of home-based healthcare technology. In *Proceedings of the 2013 ACM international joint conference on Pervasive and ubiquitous computing*, pages 587–596. ACM, 2013.

[116] E. Grönvall and N. Verdezoto. Understanding challenges and opportunities of preventive blood pressure self-monitoring at home. In *Proceedings of the 31st European Conference on Cognitive Ergonomics*, page 31. ACM, 2013.

[117] X. Gui, Y. Chen, C. Caldeira, D. Xiao, and Y. Chen. When fitness meets social networks: Investigating fitness tracking and social practices on werun. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 1647–1659. ACM, 2017.

[118] F. Güldenpfennig, F. Nunes, and G. Fitzpatrick. Proxycare: integrating informal care into formal settings. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare*, pages 141–144. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), 2015.

[119] F. Guo, Y. Li, M. S. Kankanhalli, and M. S. Brown. An evaluation of wearable activity monitoring devices. In *Proceedings of the 1st ACM international workshop on Personal data meets distributed multimedia*, pages 31–34. ACM, 2013.

[120] T. B. Hafsteinsdottir and M. Grypdonck. Being a stroke patient: a review of the literature. *Journal of Advanced Nursing*, 26(3):580–588, 1997.

[121] J. Haladjian, Z. Hodaie, H. Xu, M. Yigin, B. Bruegge, M. Fink, and J. Hoeher. Kneehapp: a bandage for rehabilitation of knee injuries. In *Adjunct Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers*, pages 181–184. ACM, 2015.

[122] J. Haladjian, C. Scheuermann, K. Bredies, and B. Bruegge. A smart textile sleeve for rehabilitation of knee injuries. In *Proceedings of the 2017 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2017 ACM International Symposium on Wearable Computers*, pages 49–52. ACM, 2017.

[123] L. Harris, J. DeShazo, and W. Pratt. Diabetes and obesity: can video games help. *Health Informatics: A Patient-Centered Approach. Cambridge (MA): Massachusetts Institute of Technology*, pages 131–50, 2010.

[124] J. A. Harvey, D. A. Skelton, and S. F. Chastin. Acceptability of novel lifelogging technology to determine context of sedentary behaviour in older adults. *AIMS Public Health*, 2016.

[125] S. C. Hayes and N. Cavior. Multiple tracking and the reactivity of self-monitoring: I. negative behaviors. *Behavior Therapy*, 8(5):819–831, 1977.

[126] T. Heart and E. Kalderon. Older adults: are they ready to adopt health-related ict? *International journal of medical informatics*, 82(11):e209–e231, 2013.

[127] P. Heikkilä, A. Honka, and E. Kaasinen. Quantified factory worker: designing a worker feedback dashboard. In *Proceedings of the 10th Nordic Conference on Human-Computer Interaction*, pages 515–523. ACM, 2018.

[128] B. Heinbüchner, M. Hautzinger, C. Becker, and K. Pfeiffer. Satisfaction and use of personal emergency response systems. *Zeitschrift für Gerontologie und Geriatrie*, 43(4):219–223, 2010.

[129] A. Helal, M. Mokhtari, and B. Abdulrazak. *The engineering handbook of smart technology for aging, disability and independence*. John Wiley & Sons, 2008.

[130] S. Hodges, L. Williams, E. Berry, S. Izadi, J. Srinivasan, A. Butler, G. Smyth, N. Kapur, and K. Wood. Sensecam: A retrospective memory aid. In *International Conference on Ubiquitous Computing*, pages 177–193. Springer, 2006.

[131] A. Holden, R. McNaney, M. Balaam, R. Thompson, N. Hammerla, T. Ploetz, D. Jackson, C. Price, L. Brkic, and P. Olivier. Cues: cueing for upper limb rehabilitation in stroke. In *Proceedings of the 2015 British HCI Conference*, pages 18–25. ACM, 2015.

[132] V. Hollis, A. Konrad, and S. Whittaker. Change of heart: emotion tracking to promote behavior change. In *Proceedings of the 33rd annual ACM conference on human factors in computing systems*, pages 2643–2652. ACM, 2015.

[133] V. Hollis, A. Pekurovsky, E. Wu, and S. Whittaker. On being told how we feel: How algorithmic sensor feedback influences emotion perception. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, 2(3):1–31, 2018.

[134] B. Holtz and P. Whitten. Managing asthma with mobile phones: a feasibility study. *Telemedicine and e-Health*, 15(9):907–909, 2009.

[135] K. Huang, P. J. Sparto, S. Kiesler, A. Smailagic, J. Mankoff, and D. Siewiorek. A technology probe of wearable in-home computer-assisted physical therapy. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 2541–2550. ACM, 2014.

[136] E. L. Idler and Y. Benyamini. Self-rated health and mortality: a review of twenty-seven community studies. *Journal of health and social behavior*, pages 21–37, 1997.

[137] S. S. Intille. Ubiquitous computing technology for just-in-time motivation of behavior change. *Stud Health Technol Inform*, 107(Pt 2):1434–7, 2004.

[138] E. Isaacs, A. Konrad, A. Walendowski, T. Lennig, V. Hollis, and S. Whittaker. Echoes from the past: how technology mediated reflection improves well-being. In *Proceedings of the SIGCHI conference on human factors in computing systems*, pages 1071–1080. ACM, 2013.

[139] T. Jenkins, A. Vallgårda, L. Boer, S. Homewood, and T. Almeida. Careful devices. In *Proceedings of the Halfway to the Future Symposium 2019*, page 30. ACM, 2019.

[140] S. M. Johnson and G. White. Self-observation as an agent of behavioral change. *Behavior Therapy*, 2(4):488–497, 1971.

[141] L. Y. Joo, T. S. Yin, D. Xu, E. Thia, P. F. Chia, C. W. K. Kuah, and K. K. He. A feasibility study using interactive commercial off-the-shelf computer gaming in upper limb rehabilitation in patients after stroke. *Journal of rehabilitation medicine*, 42(5):437–441, 2010.

[142] E. B. Kahn, L. T. Ramsey, R. C. Brownson, G. W. Heath, E. H. Howze, K. E. Powell, E. J. Stone, M. W. Rajab, and P. Corso. The effectiveness of interventions to increase physical activity: A systematic review. *American journal of preventive medicine*, 22(4):73–107, 2002.

[143] F. H. Kanfer and L. Gaelick. Self-management methods. *Helping people change*, pages 309–355, 1975.

[144] D. L. Kappen, P. Mirza-Babaei, and L. E. Nacke. Gamification through the application of motivational affordances for physical activity technology. In *Proceedings of the Annual Symposium on Computer-Human Interaction in Play*, pages 5–18. ACM, 2017.

[145] D. L. Kappen, L. E. Nacke, K. M. Gerling, and L. E. Tsotsos. Design strategies for gamified physical activity applications for older adults. In *2016 49th Hawaii International Conference on System Sciences (HICSS)*, pages 1309–1318. IEEE, 2016.

[146] R. Karkar, J. Fogarty, J. A. Kientz, S. A. Munson, R. Vilardaga, and J. Zia. Opportunities and challenges for self-experimentation in self-tracking. In *Adjunct Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers*, pages 991–996. ACM, 2015.

[147] R. Karkar, J. Schroeder, D. A. Epstein, L. R. Pina, J. Scofield, J. Fogarty, J. A. Kientz, S. A. Munson, R. Vilardaga, and J. Zia. Tummytrials: a feasibility study of using self-experimentation to detect individualized food triggers. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 6850–6863. ACM, 2017.

[148] J. F. Karshmer and A. I. Karshmer. A computer-based self-health monitoring system for the elderly living in a low income housing environment. In *International Conference on Computers for Handicapped Persons*, pages 385–391. Springer, 2004.

[149] D. S. Katz, B. A. Price, S. Holland, and N. S. Dalton. Designing for diabetes decision support systems with fluid contextual reasoning. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 625. ACM, 2018.

[150] S. Kaufman. Illness, biography, and the interpretation of self following a stroke. *Journal of Aging Studies*, 2(3):217–227, 1988.

[151] A. E. Kazdin. Reactive self-monitoring: the effects of response desirability, goal setting, and feedback. *Journal of consulting and clinical psychology*, 42(5):704, 1974.

[152] N. Kearney, L. McCann, J. Norrie, L. Taylor, P. Gray, M. McGee-Lennon, M. Sage, M. Miller, and R. Maguire. Evaluation of a mobile phone-based, advanced symptom management system (asyms©) in the management of chemotherapy-related toxicity. *Supportive Care in Cancer*, 17(4):437–444, 2009.

[153] T. Keenan. *Exercise Attitudes and Behaviors: A Survey of Midlife and Older Adults.* AARP Research, 2002.

[154] T. Keenan. *Synthesis of AARP Research in Physical Activity: 1999-2003.* AARP Research, 2004.

[155] C. Kelley, B. Lee, and L. Wilcox. Self-tracking for mental wellness: understanding expert perspectives and student experiences. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 629–641. ACM, 2017.

[156] K. Kilbourn. Weaving the machine. In *2010 4th International Conference on Pervasive Computing Technologies for Healthcare*, pages 1–6. IEEE, 2010.

[157] A. C. King, E. B. Hekler, L. A. Grieco, S. J. Winter, J. L. Sheats, M. P. Buman, B. Banerjee, T. N. Robinson, and J. Cirimele. Harnessing different motivational frames via mobile phones to promote daily physical activity and reduce sedentary behavior in aging adults. *PloS one*, 8(4):e62613, 2013.

[158] V. Kirvesmäki, C. Nygård, R. Rutanen, T. Heinonen, P. Lindfors, and J. Valvanne. A pedometer-based walking program in an assisted-living setting: A pilot study. *Gerontechnology*, 13(3):368–376, 2015.

[159] P. Klasnja, S. Consolvo, and W. Pratt. How to evaluate technologies for health behavior change in hci research. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 3063–3072. ACM, 2011.

[160] P. Klasnja, A. Hartzler, C. Powell, G. Phan, and W. Pratt. Healthweaver mobile: Designing a mobile tool for managing personal health information during cancer care. In *AMIA Annu Symp Proc*, volume 2010, pages 392–6, 2010.

[161] P. Klasnja and W. Pratt. Healthcare in the pocket: mapping the space of mobile-phone health interventions. *Journal of biomedical informatics*, 45(1):184–198, 2012.

[162] T. D. Klassen, L. A. Simpson, S. B. Lim, D. R. Louie, B. Parappilly, B. M. Sakakibara, D. Zbogar, and J. J. Eng. "stepping up" activity poststroke: Ankle-positioned accelerometer can accurately record steps during slow walking. *Physical Therapy*, 96(3):355–360, 2016.

[163] E. Klein. *AARP Bulletin Survey on Exercise*. AARP Research, 2012.

[164] K. Knaving, P. Woźniak, M. Fjeld, and S. Björk. Flow is not enough: Understanding the needs of advanced amateur runners to design motivation technology. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 2013–2022. ACM, 2015.

[165] A. Kollmann, M. Riedl, P. Kastner, G. Schreier, and B. Ludvik. Feasibility of a mobile phone–based data service for functional insulin treatment of type 1 diabetes mellitus patients. *Journal of medical Internet research*, 9(5):e36, 2007.

[166] J. Kopp. Self-monitoring: A literature review of research and practice. In *Social Work Research and Abstracts*, volume 24, pages 8–20. Oxford University Press, 1988.

[167] O. Korn and S. Tietz. Strategies for playful design when gamifying rehabilitation: a study on user experience. In *Proceedings of the 10th International Conference on PErvasive Technologies Related to Assistive Environments*, pages 209–214. ACM, 2017.

[168] S. Krishna and S. A. Boren. Diabetes self-management care via cell phone: a systematic review. *Journal of diabetes science and technology*, 2(3):509–517, 2008.

[169] P. Langhorne, J. Bernhardt, and G. Kwakkel. Stroke rehabilitation. *The Lancet*, 377(9778):1693–1702, 2011.

[170] M. E. Larsen, J. Rowntree, A. M. Young, S. Pearson, J. Smith, O. J. Gibson, A. Weaver, and L. Tarassenko. Chemotherapy side-effect management using mobile phones. In *2008 30th Annual International Conference of the IEEE Engineering in Medicine and Biology Society*, pages 5152–5155. IEEE, 2008.

[171] M. Lawo and P. Knackfuß. *Clinical Rehabilitation Experience Utilizing Serious Games*. Springer, 2018.

[172] G. Lee, C. Tsai, W. G. Griswold, F. Raab, and K. Patrick. Pmeb: a mobile phone application for monitoring caloric balance. In *CHI'06 Extended Abstracts on Human Factors in Computing Systems*, pages 1013–1018. ACM, 2006.

[173] H. R. Lee, W. R. Panont, B. Plattenburg, J.-P. de la Croix, D. Patharachalam, and G. Abowd. Asthmon: empowering asthmatic children's self-management with a virtual pet. In *CHI'10 Extended Abstracts on Human Factors in Computing Systems*, pages 3583–3588. ACM, 2010.

[174] M. L. Lee and A. K. Dey. Reflecting on pills and phone use: supporting awareness of functional abilities for older adults. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 2095–2104. ACM, 2011.

[175] M. L. Lee and A. K. Dey. Real-time feedback for improving medication taking. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*, pages 2259–2268. ACM, 2014.

[176] S. Lee, Y. Kim, D. Ahn, R. Ha, K. Lee, and H. Cha. Non-obstructive room-level locating system in home environments using activity fingerprints from smartwatch. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, pages 939–950. ACM, 2015.

[177] V. R. Lee and M. Briggs. Lessons learned from an initial effort to bring a quantified self meetup experience to a new demographic. In *Proceedings of the 2014 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct Publication*, pages 707–710. ACM, 2014.

[178] A. Lenhart et al. Teens and mobile phones over the past five years: Pew internet looks back, 2009.

[179] B. R. Levy, L. Ferrucci, A. B. Zonderman, M. D. Slade, J. Troncoso, and S. M. Resnick. A culture–brain link: Negative age stereotypes predict alzheimer's disease biomarkers. *Psychology and aging*, 31(1):82, 2016.

[180] B. R. Levy, M. D. Slade, S. R. Kunkel, and S. V. Kasl. Longevity increased by positive self-perceptions of aging. *Journal of personality and social psychology*, 83(2):261, 2002.

[181] I. Li. Designing personal informatics applications and tools that facilitate monitoring of behaviors. *UIST 2009*, 2009.

[182] I. Li, A. Dey, and J. Forlizzi. A stage-based model of personal informatics systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 557–566. ACM, 2010.

[183] I. Li, A. K. Dey, and J. Forlizzi. Understanding my data, myself: supporting self-reflection with ubicomp technologies. In *Proceedings of the 13th international conference on Ubiquitous computing*, pages 405–414. ACM, 2011.

[184] A. Light, T. W. Leong, and T. Robertson. Ageing well with cscw. In *ECSCW 2015: Proceedings of the 14th European Conference on Computer Supported Cooperative Work, 19-23 September 2015, Oslo, Norway*, pages 295–304. Springer, 2015.

[185] J. J. Lin, L. Mamykina, S. Lindtner, G. Delajoux, and H. B. Strub. Fish'n'steps: Encouraging physical activity with an interactive computer game. In *International Conference on Ubiquitous Computing*, pages 261–278. Springer, 2006.

[186] H.-C. Lo, C.-L. Tsai, K.-P. Lin, C.-C. Chuang, and W.-T. Chang. Usability evaluation of home-use glucose meters for senior users. In *International Conference on Human-Computer Interaction*, pages 424–429. Springer, 2014.

[187] L. S. Lo, J. Galloway, B. Ploderer, and D. Perrin. Armbeta: towards accessible wearable technology to quantify upper limb movement and activities. In *Proceedings of the 29th Australian Conference on Computer-Human Interaction*, pages 356–360. ACM, 2017.

[188] A. G. Logan, W. J. McIsaac, A. Tisler, M. J. Irvine, A. Saunders, A. Dunai, C. A. Rizo, D. S. Feig, M. Hamill, M. Trudel, et al. Mobile phone–based remote patient monitoring system for management of hypertension in diabetic patients. *American journal of hypertension*, 20(9):942–948, 2007.

[189] A. Lorenz, D. Mielke, R. Oppermann, and L. Zahl. Personalized mobile health monitoring for elderly. In *Proceedings of the 9th international conference on Human computer interaction with mobile devices and services*, pages 297–304. ACM, 2007.

[190] K. R. Lorig, P. Ritter, A. L. Stewart, D. S. Sobel, B. W. Brown Jr, A. Bandura, V. M. Gonzalez, D. D. Laurent, and H. R. Holman. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical care*, pages 1217–1223, 2001.

[191] K. R. Lorig, D. S. Sobel, P. L. Ritter, D. Laurent, and M. Hobbs. Effect of a self-management program on patients with chronic disease. *Effective clinical practice: ECP*, 4(6):256–262, 2000.

[192] D. Lupton. Quantifying the body: monitoring and measuring health in the age of mhealth technologies. *Critical Public Health*, 23(4):393–403, 2013.

[193] D. Lupton. Self-tracking, health and medicine, 2017.

[194] F. C. Mace and T. R. Kratochwill. Theories of reactivity in self-monitoring a comparison of cognitive-behavioral and operant models. *Behavior Modification*, 9(3):323–343, 1985.

[195] H. MacLeod, A. Tang, and S. Carpendale. Personal informatics in chronic illness management. In *Proceedings of Graphics Interface 2013*, pages 149–156. Canadian Information Processing Society, 2013.

[196] H. MacLeod, A. Tang, and S. Carpendale. Towards personal informatics tools for chronic illness management. *GRAND*, 2013.

[197] J. Maitland and M. Chalmers. Self-monitoring, self-awareness, and self-determination in cardiac rehabilitation. In *Proceedings of the SIGCHI conference on human factors in computing systems*, pages 1213–1222. ACM, 2010.

[198] J. Maitland, S. Sherwood, L. Barkhuus, I. Anderson, M. Chalmers, and B. Brown. Increasing the awareness of moderate exercise with pervasive computing. In *Proceedings of IEEE Pervasive Health Conference*, 2006.

[199] M. Malu and L. Findlater. Sharing automatically tracked activity data: implications for therapists and people with mobility impairments. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pages 136–145. ACM, 2017.

[200] L. Mamykina, E. Mynatt, P. Davidson, and D. Greenblatt. Mahi: investigation of social scaffolding for reflective thinking in diabetes management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 477–486. ACM, 2008.

[201] L. Mamykina, E. D. Mynatt, and D. R. Kaufman. Investigating health management practices of individuals with diabetes. In *Proceedings of the SIGCHI conference on Human Factors in computing systems*, pages 927–936. ACM, 2006.

[202] C. P. Martin-Krumm, P. G. Sarrazin, C. Peterson, and J.-P. Famose. Explanatory style and resilience after sports failure. *Personality and individual differences*, 35(7):1685–1695, 2003.

[203] N. E. Mayo, S. Wood-Dauphinee, R. Coˆte, L. Durcan, and J. Carlton. Activity, participation, and quality of life 6 months poststroke. *Archives of physical medicine and rehabilitation*, 83(8):1035–1042, 2002.

[204] S. Mazilu, U. Blanke, M. Hardegger, G. Tröster, E. Gazit, and J. M. Hausdorff. Gaitassist: a daily-life support and training system for parkinson's disease patients with freezing of gait. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*, pages 2531–2540. ACM, 2014.

[205] S. E. McBride, W.-C. Tsai, C. C. Knott, and W. A. Rogers. Supporting the management of osteoarthritis pain: A needs analysis. In *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, volume 55, pages 286–290. SAGE Publications, 2011.

[206] L. McCann, R. Maguire, M. Miller, and N. Kearney. Patients' perceptions and experiences of using a mobile phone-based advanced symptom management system (asyms©) to monitor and manage chemotherapy related toxicity. *European journal of cancer care*, 18(2):156–164, 2009.

[207] R. M. McFall. Effects of self-monitoring on normal smoking behavior. *Journal of consulting and clinical psychology*, 35(2):135, 1970.

[208] J. McIninch, S. Datta, P. DasMahapatra, E. Chiauzzi, and R. Bhalerao. Remote tracking of walking activity in ms patients in a real-world setting. In *American Academy of Neurology Annual Meeting*, 2015.

[209] S. K. McMahon, B. Lewis, M. Oakes, W. Guan, J. F. Wyman, and A. J. Rothman. Older adults' experiences using a commercially available monitor to self-track their physical activity. *JMIR mHealth and uHealth*, 4(2), 2016.

[210] M. E. McMurdo, J. Sugden, I. Argo, P. Boyle, D. W. Johnston, F. F. Sniehotta, and P. T. Donnan. Do pedometers increase physical activity in sedentary older women? a randomized controlled trial. *Journal of the American Geriatrics Society*, 58(11):2099–2106, 2010.

[211] J. R. McNamara. The use of self-monitoring techniques to treat nailbiting. *Behaviour Research and Therapy*, 10(2):193–194, 1972.

[212] R. McNaney, I. Poliakov, J. Vines, M. Balaam, P. Zhang, and P. Olivier. Lapp: a speech loudness application for people with parkinson's on google glass. In *Proceedings of the 33rd annual ACM conference on Human Factors in Computing Systems*, pages 497–500. ACM, 2015.

[213] A. R. McNeill, L. Coventry, J. Pywell, and P. Briggs. Privacy considerations when designing social network systems to support successful ageing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 6425–6437. ACM, 2017.

[214] C. Megard, S. Bouchigny, A. Martin, R. Goulamhoussen, L. Bertholier, P. Foulon, S. Pouplin, C. Bonnyaud, N. Roche, A. Gelineau, et al. Ergotact: including force-based activities into post-stroke rehabilitation. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, page LBW1811. ACM, 2019.

[215] K. Mercer, L. Giangregorio, E. Schneider, P. Chilana, M. Li, and K. Grindrod. Acceptance of commercially available wearable activity trackers among adults aged over 50 and with chronic illness: a mixed-methods evaluation. *JMIR mHealth and uHealth*, 4(1), 2016.

[216] J. Meyer, J. Fortmann, M. Wasmann, and W. Heuten. Making lifelogging usable: Design guidelines for activity trackers. In *International Conference on Multimedia Modeling*, pages 323–334. Springer, 2015.

[217] A. D. Miller and E. D. Mynatt. Stepstream: a school-based pervasive social fitness system for everyday adolescent health. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*, pages 2823–2832. ACM, 2014.

[218] S. Miller, B. Mutlu, and J. Lee. Artifact usage, context, and privacy management in logging and tracking personal health information in older adults. In *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, volume 57, pages 1027–1031. SAGE Publications, 2013.

[219] S. R. Mishra, P. Klasnja, J. MacDuffie Woodburn, E. B. Hekler, L. Omberg, M. Kellen, and L. Mangravite. Supporting coping with parkinson's disease through self tracking. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, page 107. ACM, 2019.

[220] T. L. Mitzner and K. Dijkstra. Evaluating user centered design of e-health for older adults: Using subjective methods. *International Journal of Computers in Clinical Practice (IJCCP)*, 1(2):24–50, 2016.

[221] P. Mohan, D. Marin, S. Sultan, and A. Deen. Medinet: personalizing the self-care process for patients with diabetes and cardiovascular disease using mobile telephony. In *2008 30th Annual International Conference of the IEEE Engineering in Medicine and Biology Society*, pages 755–758. IEEE, 2008.

[222] K. Moran, H. Wei, D. Monaghan, C. Woods, N. E. O'Connor, D. Zarpalas, A. Chatzitofis, P. Daras, J. Piesk, and A. Pomazanskyi. A demonstration of the pathway system for technology-enabled exercise-based cardiac rehabilitation. 2016.

[223] V. Moretti and B. Morsello. Self–management and type 1 diabetes. how technology redefines illness. *TECNOSCIENZA: Italian Journal of Science & Technology Studies*, 8(1):51–72, 2017.

[224] M. E. Morris, Q. Kathawala, T. K. Leen, E. E. Gorenstein, F. Guilak, W. DeLeeuw, and M. Labhard. Mobile therapy: case study evaluations of a cell phone application for emotional self-awareness. *Journal of medical Internet research*, 12(2):e10, 2010.

[225] M. Mort, C. Roberts, and B. Callén. Ageing with telecare: care or coercion in austerity? *Sociology of health & illness*, 35(6):799–812, 2013.

[226] E. L. Murnane, T. G. Walker, B. Tench, S. Voida, and J. Snyder. Personal informatics in interpersonal contexts: towards the design of technology that supports the social ecologies of long-term mental health management. *Proceedings of the ACM on Human-Computer Interaction*, 2(CSCW):127, 2018.

[227] E. D. Mynatt, G. D. Abowd, L. Mamykina, and J. A. Kientz. Understanding the potential of ubiquitous computing for chronic disease management. *Health Informatics: A Patient-Centered Approach to Diabetes. Health Informatics*, pages 85–106, 2010.

[228] L. Nachman, A. Baxi, S. Bhattacharya, V. Darera, P. Deshpande, N. Kodalapura, V. Mageshkumar, S. Rath, J. Shahabdeen, and R. Acharya. Jog falls: a pervasive healthcare platform for diabetes management. In *International Conference on Pervasive Computing*, pages 94–111. Springer, 2010.

[229] D. Nafus and J. Sherman. Big data, big questions— this one does not go up to 11: the quantified self movement as an alternative big data practice. *International journal of communication*, 8:11, 2014.

[230] R. O. Nelson, D. P. Lipinski, and R. A. Boykin. The effects of self-recorders' training and the obtrusiveness of the self-recording device on the accuracy and reactivity of self-monitoring. *Behavior Therapy*, 9(2):200–208, 1978.

[231] B. B. Neves, R. L. Franz, C. Munteanu, R. Baecker, and M. Ngo. My hand doesn't listen to me!: Adoption and evaluation of a communication technology for the'oldest old'.

In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 1593–1602. ACM, 2015.

[232] F. Nunes and G. Fitzpatrick. Self-care technologies and collaboration. *International Journal of Human-Computer Interaction*, 31(12):869–881, 2015.

[233] F. Nunes and G. Fitzpatrick. Understanding the mundane nature of self-care: Ethnographic accounts of people living with parkinson's. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 402. ACM, 2018.

[234] F. Nunes, N. Verdezoto, G. Fitzpatrick, M. Kyng, E. Grönvall, and C. Storni. Self-care technologies in hci: Trends, tensions, and opportunities. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22(6):33, 2015.

[235] Y. Olsen and J. M. Sharfstein. Confronting the stigma of opioid use disorder—and its treatment. *Jama*, 311(14):1393–1394, 2014.

[236] N. O'Murchu and A. Sigfridsson. Tiy (tag-it-yourself). In *Proceedings of the 8th ACM Conference on Designing Interactive Systems*, pages 57–60. ACM, 2010.

[237] R. Orji and K. Moffatt. Persuasive technology for health and wellness: State-of-the-art and emerging trends. *Health informatics journal*, page 1460458216650979, 2016.

[238] S. B. O'Sullivan, T. J. Schmitz, and G. Fulk. *Physical rehabilitation.* FA Davis, 2019.

[239] J. Paay, J. Kjeldskov, M. B. Skov, L. Lichon, and S. Rasmussen. Understanding individual differences for tailored smoking cessation apps. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 1699–1708. ACM, 2015.

[240] G. Paré, C. Leaver, and C. Bourget. Diffusion of the digital health self-tracking movement in canada: results of a national survey. *Journal of medical Internet research*, 20(5):e177, 2018.

[241] C. Paton, M. Margaret, L. Fernandez-Luque, and A. Y. Lau. Self-tracking, social media and personal health records for patient empowered self-care. *Nursing and Health Professions Faculty Research and Publications*, 2012.

[242] A. Y. Patrick. Baby boomer adoption of healthcare apps. 2016.

[243] S. S. Paul, A. Tiedemann, L. M. Hassett, E. Ramsay, C. Kirkham, S. Chagpar, and C. Sherrington. Validity of the fitbit activity tracker for measuring steps in community-dwelling older adults. *BMJ Open Sport & Exercise Medicine*, 1(1):e000013, 2015.

[244] L. J. Phillips, G. F. Petroski, V. S. Conn, M. Brown, E. Leary, L. Teri, and S. Zimmerman. Exploring path models of disablement in residential care and assisted living residents. *Journal of Applied Gerontology*, page 0733464816672048, 2016.

[245] E. M. Piras and A. Zanutto. Prescriptions, x-rays and grocery lists. designing a personal health record to support (the invisible work of) health information management in the household. *Computer Supported Cooperative Work (CSCW)*, 19(6):585–613, 2010.

[246] A. Pirzadeh, L. He, and E. Stolterman. Personal informatics and reflection: a critical examination of the nature of reflection. In *CHI'13 Extended Abstracts on Human Factors in Computing Systems*, pages 1979–1988. ACM, 2013.

[247] B. Ploderer, J. Fong, A. Withana, M. Klaic, S. Nair, V. Crocher, F. Vetere, and S. Nanayakkara. Armsleeve: a patient monitoring system to support occupational therapists in stroke rehabilitation. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*, pages 700–711. ACM, 2016.

[248] B. Ploderer, W. Reitberger, H. Oinas-Kukkonen, and J. Gemert-Pijnen. Social interaction and reflection for behaviour change. *Personal and ubiquitous computing*, 18(7):1667–1676, 2014.

[249] B. Ploderer, J. Stuart, V. Tran, T. L. Green, and J. Muller. The transition of stroke survivors from hospital to home: understanding work and design opportunities. In *Proceedings of the 29th Australian Conference on Computer-Human Interaction*, pages 1–9. ACM, 2017.

[250] A. H. Pollack, U. Backonja, A. D. Miller, S. R. Mishra, M. Khelifi, L. Kendall, and W. Pratt. Closing the gap: Supporting patients' transition to self-management after hospitalization. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, pages 5324–5336. ACM, 2016.

[251] K. C. Preusse, T. L. Mitzner, C. B. Fausset, and W. A. Rogers. Older adults' acceptance of activity trackers. *Journal of Applied Gerontology*, page 0733464815624151, 2016.

[252] D. Preuveneers and Y. Berbers. Mobile phones assisting with health self-care: a diabetes case study. In *Proceedings of the 10th international conference on Human computer interaction with mobile devices and services*, pages 177–186. ACM, 2008.

[253] J. P. Proença, C. Quaresma, and P. Vieira. Serious games for upper limb rehabilitation: a systematic review. *Disability and Rehabilitation: Assistive Technology*, 13(1):95–100, 2018.

[254] A. Puussaar, A. K. Clear, and P. Wright. Enhancing personal informatics through social sensemaking. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 6936–6942. ACM, 2017.

[255] H. Qian, R. Kuber, and A. Sears. Maintaining levels of activity using a haptic personal training application. In *CHI'10 Extended Abstracts on Human Factors in Computing Systems*, pages 3217–3222. ACM, 2010.

[256] C. Rainville. *2016 Survey on Healthy Behaviors and Well-Being.* AARP Research, 2016.

[257] C. Rainville. *2016 Survey on Physical Activity.* AARP Research, 2016.

[258] S. Raj, J. M. Lee, A. Garrity, and M. W. Newman. Clinical data in context: Towards sensemaking tools for interpreting personal health data. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, 3(1):22, 2019.

[259] S. Raj, M. W. Newman, J. M. Lee, and M. S. Ackerman. Understanding individual and collaborative problem-solving with patient-generated data: Challenges and opportunities. *Proceedings of the ACM on Human-Computer Interaction*, 1(CSCW):88, 2017.

[260] S. Ransiri and S. Nanayakkara. Watchme: wrist-worn interface that makes remote monitoring seamless. In *Proceedings of the 14th international ACM SIGACCESS conference on Computers and accessibility*, pages 243–244. ACM, 2012.

[261] P. Rasche, K. Schäfer, M. Wille, S. Theis, C. Schlick, and A. Mertens. Self monitoring–an age-related comparison. *Proceedings of the Human Factors and Ergonomics Society Europe*, 2016.

[262] P. Rasche, M. Wille, S. Theis, K. Schäefer, C. M. Schlick, and A. Mertens. Activity tracker and elderly. In *Computer and Information Technology; Ubiquitous Computing and Communications; Dependable, Autonomic and Secure Computing; Pervasive Intelligence and Computing (CIT/IUCC/DASC/PICOM), 2015 IEEE International Conference on*, pages 1411–1416. IEEE, 2015.

[263] J. W. Rettberg. *Seeing ourselves through technology: How we use selfies, blogs and wearable devices to see and shape ourselves.* Springer, 2016.

[264] Y. Riche and W. Mackay. Peercare: supporting awareness of rhythms and routines for better aging in place. *Computer Supported Cooperative Work (CSCW)*, 19(1):73–104, 2010.

[265] S. Riggare and K. T. Unruh. Patients organise and train doctors to provide better care. *BMJ*, 351:h6318, 2015.

[266] V. Rivera-Pelayo, V. Zacharias, L. Müller, and S. Braun. Applying quantified self approaches to support reflective learning. In *Proceedings of the 2nd International Conference on Learning Analytics and Knowledge*, pages 111–114. ACM, 2012.

[267] T. E. Roden, R. LeGrand, R. Fernandez, J. Brown, J. E. Deaton, and J. Ross. Development of a smart insole tracking system for physical therapy and athletics. In *Proceedings of the 7th International Conference on PErvasive Technologies Related to Assistive Environments*, page 40. ACM, 2014.

[268] J. Roe, L. Salmon, and J. Twiggs. Objective measure of activity level after total knee arthoplasty with the use of the ‘fitbit’device. *Orthopaedic Journal of Sports Medicine*, 4(1 suppl), 2016.

[269] J. Rooksby, M. Rost, A. Morrison, and M. C. Chalmers. Personal tracking as lived informatics. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*, pages 1163–1172. ACM, 2014.

[270] A. J. Rothman and P. Salovey. Shaping perceptions to motivate healthy behavior: the role of message framing. *Psychological bulletin*, 121(1):3, 1997.

[271] P. Rubel, J. Fayn, G. Nollo, D. Assanelli, B. Li, L. Restier, S. Adami, S. Arod, H. Atoui, M. Ohlsson, et al. Toward personal ehealth in cardiology. results from the epi-medics telemedicine project. *Journal of electrocardiology*, 38(4):100–106, 2005.

[272] R. M. Ryan and E. L. Deci. Intrinsic and extrinsic motivations: Classic definitions and new directions. *Contemporary educational psychology*, 25(1):54–67, 2000.

[273] F. Sailer, M. Pobiruchin, M. Wiesner, and G. Meixner. An approach to improve medication adherence by smart watches. *Stud Health Technol Inform*, 210:956, 2015.

[274] H. Saksono, C. Castaneda-Sceppa, J. Hoffman, M. Seif El-Nasr, V. Morris, and A. G. Parker. Family health promotion in low-ses neighborhoods: A two-month study of wearable activity tracking. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 309. ACM, 2018.

[275] P. Sanches, A. Janson, P. Karpashevich, C. Nadal, C. Qu, C. Daudén Roquet, M. Umair, C. Windlin, G. Doherty, K. Höök, et al. Hci and affective health: Taking stock of a decade of studies and charting future research directions. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, page 245. ACM, 2019.

[276] G. Saposnik, R. Teasell, M. Mamdani, J. Hall, W. McIlroy, D. Cheung, K. E. Thorpe, L. G. Cohen, and M. Bayley. Effectiveness of virtual reality using wii gaming technology in stroke rehabilitation: a pilot randomized clinical trial and proof of principle. *Stroke*, 41(7):1477–1484, 2010.

[277] S. Sawesi, M. Rashrash, K. Phalakornkule, J. S. Carpenter, and J. F. Jones. The impact of information technology on patient engagement and health behavior change: a systematic review of the literature. *JMIR medical informatics*, 4(1):e1, 2016.

[278] A. Schlomann, K. von Storch, P. Rasche, and C. Rietz. Means of motivation or of stress? the use of fitness trackers for self-monitoring by older adults. *HeilberufeScience*, 7(3):111–116, 2016.

[279] H. Schneider, M. Eiband, D. Ullrich, and A. Butz. Empowerment in hci-a survey and framework. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 244. ACM, 2018.

[280] M. Schorch, L. Wan, D. W. Randall, and V. Wulf. Designing for those who are overlooked: Insider perspectives on care practices and cooperative work of elderly informal caregivers. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*, pages 787–799. ACM, 2016.

[281] G. Schreier, D. Hayn, P. Kastner, S. Koller, W. Salmhofer, and R. Hofmann-Wellenhof. A mobile-phone based teledermatology system to support self-management of patients suffering from psoriasis. In *2008 30th Annual International Conference of the IEEE Engineering in Medicine and Biology Society*, pages 5338–5341. IEEE, 2008.

[282] J. A. Serrano, A. Thoms, and P. Weber. Patients initiated timeline marking of events in parkinson's disease: Visualization of time correlation between patients marked events and acquired data from sensors. In *International Conference on Augmented Cognition*, pages 325–334. Springer, 2014.

[283] P. C. Shih, K. Han, E. S. Poole, M. B. Rosson, and J. M. Carroll. Use and adoption challenges of wearable activity trackers. *iConference 2015 Proceedings*, 2015.

[284] J. Shin, B. Kang, T. Park, J. Huh, J. Kim, and J. Song. Beupright: Posture correction using relational norm intervention. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, pages 6040–6052. ACM, 2016.

[285] K. Shinohara and J. O. Wobbrock. In the shadow of misperception: assistive technology use and social interactions. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 705–714. ACM, 2011.

[286] L. A. Simpson, J. J. Eng, T. D. Klassen, S. B. Lim, D. R. Louie, B. Parappilly, B. M. Sakakibara, and D. Zbogar. Capturing step counts at slow walking speeds in older adults: Comparison of ankle and waist placement of measuring device. *Journal of rehabilitation medicine*, 47(9):830–835, 2015.

[287] A. Singh, A. Klapper, J. Jia, A. Fidalgo, A. Tajadura-Jiménez, N. Kanakam, N. Bianchi-Berthouze, and A. Williams. Motivating people with chronic pain to do physical activity: opportunities for technology design. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*, pages 2803–2812. ACM, 2014.

[288] A. Smith. *Older adults and technology use.* Pew Research Center's Internet Project, 2014.

[289] B. K. Smith, J. Frost, M. Albayrak, and R. Sudhakar. Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices. *Personal and Ubiquitous Computing*, 11(4):273–286, 2007.

[290] E. B. Smith, M. M. Desai, M. Slade, and B. R. Levy. Positive aging views in the general population predict better long-term cognition for elders in eight countries. *Journal of aging and health*, 31(10):1739–1747, 2019.

[291] A. Snyder, B. Colvin, and J. K. Gammack. Pedometer use increases daily steps and functional status in older adults. *Journal of the American Medical Directors Association*, 12(8):590–594, 2011.

[292] Y. Sota, K. Yamamoto, M. Hirakawa, S. Doi, and Y. Yamamoto. Support of self-management for chronic kidney failure patients. In *Proceedings of the 2011 Visual Information Communication-International Symposium*, page 6. ACM, 2011.

[293] S. T. Stahl and S. P. Insana. Caloric expenditure assessment among older adults: Criterion validity of a novel accelerometry device. *Journal of health psychology*, 19(11):1382–1387, 2014.

[294] V. Stara, R. Harte, M. Di Rosa, L. Rossi, and G. ÓLaighin. Toward a connected health system for older adults: Lessons learned. In *Advances in Physical Ergonomics and Human Factors*, pages 849–857. Springer, 2016.

[295] Statista. Most popular health and fitness apps in the united states as of may 2018, by monthly active users (in millions), 2018.

[296] K. Stawarz, A. L. Cox, and A. Blandford. Beyond self-tracking and reminders: designing smartphone apps that support habit formation. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 2653–2662. ACM, 2015.

[297] J. Stiensmeier-Pelster and H. Heckhausen. Causal attribution of behavior and achievement. In *Motivation and action*, pages 623–678. Springer, 2018.

[298] C. Storni. Multiple forms of appropriation in self-monitoring technology: reflections on the role of evaluation in future self-care. *Intl. Journal of Human–Computer Interaction*, 26(5):537–561, 2010.

[299] A. Strauss and J. Corbin. *Basics of qualitative research: Techniques and procedures for developing grounded theory* . Sage Publications, Inc, 1998.

[300] T.-H. Tan, M. Gochoo, K.-H. Chen, F.-R. Jean, Y.-F. Chen, F.-J. Shih, and C. F. Ho. Indoor activity monitoring system for elderly using rfid and fitbit flex wristband. In *IEEE-EMBS International Conference on Biomedical and Health Informatics (BHI)*, pages 41–44. IEEE, 2014.

[301] R. Tang, X.-D. Yang, S. Bateman, J. Jorge, and A. Tang. Physio@ home: Exploring visual guidance and feedback techniques for physiotherapy exercises. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, pages 4123–4132. ACM, 2015.

[302] A. Taylor, N. Cable, G. Faulkner, M. Hillsdon, M. Narici, and A. Van Der Bij. Physical activity and older adults: a review of health benefits and the effectiveness of interventions. *Journal of sports sciences*, 22(8):703–725, 2004.

[303] A. Thieme, R. Comber, J. Miebach, J. Weeden, N. Kraemer, S. Lawson, and P. Olivier. We've bin watching you: designing for reflection and social persuasion to promote sustainable lifestyles. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pages 2337–2346. ACM, 2012.

[304] W. G. Thompson, C. L. Kuhle, G. A. Koepp, S. K. McCrady-Spitzer, and J. A. Levine. “go4life” exercise counseling, accelerometer feedback, and activity levels in older people. *Archives of gerontology and geriatrics*, 58(3):314–319, 2014.

[305] K. Tollmar, F. Bentley, and C. Viedma. Mobile health mashups: Making sense of multiple streams of wellbeing and contextual data for presentation on a mobile device. In *2012 6th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops*, pages 65–72. IEEE, 2012.

[306] M. Toriumi, Y. Sugiura, and K. Fujita. An application for wrist rehabilitation using smartphones. In *Proceedings of the 21st International Conference on Human-Computer Interaction with Mobile Devices and Services*, page 65. ACM, 2019.

[307] M. Toriumi, T. Watanabe, K. Fujita, A. Nimura, and Y. Sugiura. Rehabilitation support system for patients with carpal tunnel syndrome using smartphone. In *Proceedings of the 30th Australian Conference on Computer-Human Interaction*, pages 532–534. ACM, 2018.

[308] T. Toscos, K. Connelly, and Y. Rogers. Designing for positive health affect: Decoupling negative emotion and health monitoring technologies. In *Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare*, pages 153–160. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), 2013.

[309] C. C. Tsai, G. Lee, F. Raab, G. J. Norman, T. Sohn, W. G. Griswold, and K. Patrick. Usability and feasibility of pmeb: a mobile phone application for monitoring real time caloric balance. *Mobile networks and applications*, 12(2-3):173–184, 2007.

[310] W.-C. Tsai, C.-L. Chang, and H. Lin. The design of pain management and creative service for older adults with chronic disease. In *International Conference on Human Aspects of IT for the Aged Population*, pages 201–210. Springer, 2015.

[311] D. o. E. United Nations and P. D. Social Affairs. World population prospects 2019: Highlights, 2019.

[312] K. T. Unruh and W. Pratt. The invisible work of being a patient and implications for health care:“[the doctor is] my business partner in the most important business in my life, staying alive.”. In *Ethnographic Praxis in Industry Conference Proceedings*, volume 2008, pages 40–50. Wiley Online Library, 2008.

[313] P. M. Van Vliet and G. Wulf. Extrinsic feedback for motor learning after stroke: what is the evidence? *Disability and rehabilitation*, 28(13-14):831–840, 2006.

[314] E. D. Vidoni, A. S. Watts, J. M. Burns, C. S. Greer, R. S. Graves, A. Van Sciver, J. R. Black, S. K. Cooper, A. C. Nagely, E. Uphoff, et al. Feasibility of a memory clinic-based physical activity prescription program. *Journal of Alzheimer’s Disease*, (Preprint):1–11, 2016.

[315] E. Villalba, M. Ottaviano, M. T. Arredondo, A. Martinez, and S. Guillen. Wearable monitoring system for heart failure assessment in a mobile environment. In *2006 Computers in Cardiology*, pages 237–240. IEEE, 2006.

[316] E. Villalba, D. Salvi, M. Ottaviano, I. Peinado, M. T. Arredondo, and A. Akay. Wearable and mobile system to manage remotely heart failure. *IEEE Transactions on Information Technology in Biomedicine*, 13(6):990–996, 2009.

[317] A. S. Vivacqua and A. C. B. Garcia. Personal neighborhood networks for senior citizen support. In *Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing*, pages 293–296. ACM, 2018.

[318] L. M. Vizer, J. Eschler, B. M. Koo, J. Ralston, W. Pratt, and S. Munson. "it's not just technology, it's people": Constructing a conceptual model of shared health informatics for tracking in chronic illness management. *Journal of medical Internet research*, 21(4):e10830, 2019.

[319] D. M. Walker, C. J. Sieck, T. Menser, T. R. Huerta, and A. Scheck McAlearney. Information technology to support patient engagement: where do we stand and where can we go? *Journal of the American Medical Informatics Association*, 24(6):1088–1094, 2017.

[320] B. Walsh. *Mobile Health for Independent Living.* AARP Research, 2011.

[321] D. L. Walters, A. Sarela, A. Fairfull, K. Neighbour, C. Cowen, B. Stephens, T. Sellwood, B. Sellwood, M. Steer, M. Aust, et al. A mobile phone-based care model for outpatient cardiac rehabilitation: the care assessment platform (cap). *BMC Cardiovascular Disorders*, 10(1):5, 2010.

[322] P. Wang, G. C.-H. Koh, C. G. Boucharenc, and C.-C. Yen. Designing two-player competitive games for the rehabilitation of upper-limb motor function after stroke. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems*, pages 2201–2209. ACM, 2017.

[323] B. W. Ward. Multiple chronic conditions among us adults: a 2012 update. *Preventing chronic disease*, 11, 2014.

[324] B. Weiner. *Achievement motivation and attribution theory.* General Learning Press, 1974.

[325] B. Weiner. The attribution approach to emotion and motivation: History, hypotheses, home runs, headaches/heartaches. *Emotion Review*, 6(4):353–361, 2014.

[326] P. West, M. Van Kleek, R. Giordano, M. J. Weal, and N. Shadbolt. Common barriers to the use of patient-generated data across clinical settings. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 484. ACM, 2018.

[327] G. J. Westerhof, M. Miche, A. F. Brothers, A. E. Barrett, M. Diehl, J. M. Montepare, H.-W. Wahl, and S. Wurm. The influence of subjective aging on health and longevity: A meta-analysis of longitudinal data. *Psychology and Aging*, 29(4):793, 2014.

[328] L. A. Whitlock, A. C. McLaughlin, M. Harris, and J. Bradshaw. The design of mobile technology to support diabetes self-management in older adults. In *International Conference on Human Aspects of IT for the Aged Population*, pages 211–221. Springer, 2015.

[329] C. J. Winstein. Knowledge of results and motor learning—implications for physical therapy. *Physical therapy*, 71(2):140–149, 1991.

[330] G. Wolf. Know thyself: Tracking every facet of life, from sleep to mood to pain. *Wired Magazine*, 365, 2009.

[331] M. Yamada, S. Mori, S. Nishiguchi, Y. Kajiwara, K. Yoshimura, T. Sonoda, K. Nagai, H. Arai, and T. Aoyama. Pedometer-based behavioral change program can improve dependency in sedentary older adults: A randomized controlled trial. *The Journal of frailty & aging*, 1(1):39–44, 2011.

[332] R. Yang, E. Shin, M. W. Newman, and M. S. Ackerman. When fitness trackers don't'fit': end-user difficulties in the assessment of personal tracking device accuracy. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, pages 623–634. ACM, 2015.

[333] F. Yekeh, J. Kay, B. Kummerfeld, L. M. Tang, and M. A. Allman-Farinelli. Can sal support self reflection for health and nutrition? In *Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction*, pages 134–141. ACM, 2015.

[334] S. Yusif, J. Soar, and A. Hafeez-Baig. Older people, assistive technologies, and the barriers to adoption: A systematic review. *International Journal of Medical Informatics*, 94:112–116, 2016.

[335] D. K. Zondervan, N. Friedman, E. Chang, X. Zhao, R. Augsburger, D. J. Reinkensmeyer, and S. C. Cramer. Home-based hand rehabilitation after chronic stroke: Randomized, controlled single-blind trial comparing the musicglove with a conventional exercise program. *Journal of Rehabilitation Research & Development*, 53(4), 2016.