

The Pennsylvania State University

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**DESIGNING SELF-CARE TECHNOLOGY TO
ENHANCE PATIENTS' PREHABILITATION ENGAGEMENT**

A Dissertation in

Informatics

by

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ABSTRACT

Millions of surgeries are performed in the US annually, and with lifespans growing longer, these procedures are becoming more numerous with every passing year. Traditional rehabilitative interventions are struggling to meet current demands, and researchers have turned to pre-operative interventions, or prehabilitation, to improve patient functions prior to surgeries. However, current prehabilitation research is predominantly conducted from a Health Sciences approach and geared toward understanding and determining effective treatment plans. This approach fails to address problems regarding engagement, accessibility, and scalability. I therefore conduct a series of studies exploring prehabilitation from a Human-Computer Interaction lens to complement these existing studies. HCI is uniquely poised to address these gaps because its techniques can offer comprehension of stakeholders through user-centered studies and design insights regarding targeted tools.

In this dissertation, I explored stakeholder needs, and challenges via mixed-methods approaches. I describe a case study in which I examined the interactions of a complex facial paralysis treatment team that utilizes prehabilitation in its practices; this study results in a detailed clinical workflow model and identifies the key patient challenge of losing motivation to adhere to exercises because of an inability to perceive gradual recovery progress. By synthesizing the results of these studies with self-monitoring and social support theories, I present an understanding of prehabilitation practices and design spaces and identify design opportunities for targeted and effective prehabilitation self-care technologies.

This understanding informed the design of MyFace, a mobile self-care technology intended to aid facial paralysis patients in their prehabilitation. MyFace holistically tracks patients' recoveries and helps them become more aware of gradual improvements. It specifically tracks facial exercise durations and frequencies, user feelings, and visual media over time to allow for

assessment of changes; in addition, the system leverages social support which can contribute to their motivation to sustain self-care contributions. The system shows great promise in promoting users' self-awareness, self-reflection, motivation, and engagement and adherence. This dissertation not only provides support for the novel idea of using visual media feedback to increase prehabilitation motivation and adherence in facial paralysis contexts, it provides support for the adoption of an HCI lens in prehabilitation research to better support high quality prehabilitation and prehabilitation technologies.

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GLOSSARY

| Term | Definition |
|-----------------------|--|
| Appraisal support | Appraisal support includes providing others constructive feedback and affirmations which are useful for the others' purposes of self-evaluation. |
| Emotional Support | Emotional support includes offering others: love, care, trust, and empathy for supportive purposes. |
| Informational Support | Informational support is offering others information intended for the others' problem solving and includes both advice and suggestions. |
| Instrumental support | Instrumental support is the offering of services and aid which will assist others in need. |
| Physical Therapy | Physical therapy is a process for the treatment of a condition (e.g., injury, disease, deformity, etc.) which employs physical methods (e.g., exercise, massages, heat treatments, etc.) instead of surgeries or medications. |
| Prehabilitation | Prehabilitation is preoperative care to improve post-operative outcomes by preparing patients for surgical stresses. Prehabilitation can be viewed as the first part of the rehabilitation care continuum, which occurs between the time of diagnosis and the start of acute treatment. It specifically aims to improve patients' postoperative recoveries and decrease morbidities by creating targeted interventions with physical, nutritional, and psychological components. |
| Reactivity Effect | The reactivity effect, or sometimes just reactivity, is a phenomenon in which an individual will change a behavior, or the frequency of a behavior, as a result of increased self-awareness commonly brought about through outside observation or self-tracking. Changes in said behaviors may be negative or positive, but often occur in therapeutic and desirable directions in Health Informatics research. |
| Rehabilitation | Rehabilitation is postoperative care to restore patient functions after undergoing an invasive intervention. Rehabilitation can include physical therapy, medications, and other components. |
| Self-awareness | Self-awareness refers to an individual's conscious knowledge of his or own motivations, desires, feelings, and character traits. |

| | |
|----------------------|---|
| Self-care | Self-care can broadly be defined as actions which enable individuals to actively participate in the promotion of their health and the management of their own conditions. |
| Self-care technology | In this dissertation, we define “self-care technology” as any technology which is used for patients’ self-care, including: consumer health tracking devices (e.g., Fitbit, Jawbone, Microsoft Band), smartphone applications (e.g., MyFitnessPal, GoogleFit, Apple’s HealthKit), medical devices (e.g., blood glucose meters), and online forums (PatientLikeMe, eHealthForum). |
| Self-monitoring | Self-monitoring refers to self-observing behaviors which include a form of self-directed logging of factors, typically for the purposes of understanding a certain condition or behavior in order to make beneficial changes. |
| Self-reflection | Self-reflection refers to an individual’s self-directed meditation or concentrated thought about his or her self, including his or her actions and behaviors, motivations, and character traits. |
| Social Support | Social support is provided by family members, friends, or other people who help an individual during his or her times of need; these people help to provide a broader perspective regarding challenges and often seek to promote the individual’s in crisis self-image. The effects of this social support enhance an individual’s quality of life and offer resistance against adversity during crises. Social support can be broadly generalized into the following four categories: emotional support, instrumental support, informational support, and appraisal support. |

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DEDICATION

To my parents, my advisor, my committee, my friends, and all people helped me to make this happen, thank you for all your support and love. I will forever appreciate this journey.

Chapter 1

Introduction

Millions of surgeries are performed in the US annually, and numbers are trending upwards. Traditional rehabilitative interventions are struggling to meet current demands, and researchers have turned to pre-operative interventions, or prehabilitation, to improve patient functions prior to surgeries. Research regarding prehabilitation is predominantly geared toward understanding and determining effective treatment plans, but researchers have only just begun to examine how to design or utilize prehabilitation specific technologies in a manner which would not disrupt workflow or harm patient-clinician interactions. My motivation for conducting the research in this dissertation was to determine how to leverage technological interventions to better support high quality prehabilitation care by facilitating clinicians and patients in their processes and roles. One promising avenue for promoting prehabilitation quality of care is by supporting and utilizing patient self-care management of pre-surgical activities to thus reduce reliance upon limited prehabilitation specialists. The field of Human-Computer Interaction (HCI) is uniquely poised to design prehabilitation technologies, as it has designed technologies for problems which are themselves found during prehabilitation processes; for example, HCI holds great promise for supporting patients via the design of self-care technologies which promote physical activities, nutrition, mental health, and chronic condition management. Notably, prehabilitation had not been examined from an HCI lens prior to studies which contribute to the body work within this dissertation.

1.1 Motivation

Over 50 million inpatient surgeries, and a similar number of outpatient procedures, were performed in the United States of America in 2010 alone (Surgery Statistics). As healthcare improves and enables larger portions of the populace to live longer, greater numbers of individuals will likely require surgeries and thus be at greater risk for perioperative complications and postoperative declines in functional capacity; this will greatly burden both individuals and society with healthcare costs and losses of productivity. Research shows that perioperative complications increase healthcare costs (Vonlanthen et al., 2011), mortality risks (Wilson et al., 2010), postoperative complications (Robinson et al., 2013) hospital stays, and functional recovery times (Lawrence et al., 2004). Traditionally, researchers have tried to improve patient postoperative recovery using rehabilitation, and tremendous amounts of attention from both technical and healthcare perspectives have been drawn to this area. However, despite the commonality of surgery and the availability of technical resources, postsurgical patients, especially elderly patients with comorbidities, typically experience a 20-40% reduction in both physiological and functional capacities; recovery to preoperative capacities, if ever achieved by a patient, could take several months of rehabilitation (Gillis et al., 2014; Christensen et al., 1982; Lawrence et al., 2004; Mayo et al., 2011). If these challenges remain unaddressed, they would exacerbate the already troubling shortages of both clinicians (Bodenheimer et al., 2013) and hospital beds that is encouraging the early discharge of postoperative patients to make space for new surgical patients (Daly et al., 2001).

Unfortunately, postoperative solutions are proving insufficient for promoting patient postoperative health, and novel solutions must be explored. Contemporary researchers have begun to examine how to enhance an individual's functional capacity prior to the individual's surgery to increase his or her tolerance to impending physiological stresses. This process, known as prehabilitation (Carli & Zavorsky, 2005; Gillis et al., 2014), aims to improve patients' postoperative

recoveries and decrease morbidities by creating targeted interventions with physical, nutritional, and psychological components (Gillis et al., 2014; Silver & Baima, 2013; Barnes et al., 2016; Valkenet et al., 2011). This shift of focus from reactionary (i.e., rehabilitative) to preventative (i.e., prehabilitation) healthcare presents an inherently complex research problem. Studying prehabilitation requires us to account for a patient's multiple conditions, physiological changes, medications and side effects, and any factor which could inhibit or hinder his or her surgical success. This itself is exacerbated by the fact that patients with poor physical function are the most in need of prehabilitation to raise their baseline levels of health to acceptable parameters for surgery. Notably, the prehabilitation process may even be able to avert the need for surgical interventions for certain patients. Prehabilitation thus represents an important opportunity to improve patients' physical and psychological health outcomes, reduce healthcare costs, and decrease hospital readmissions, as these factors have significant effects on patient survival outcomes (Silver & Baima, 2013; Debes et al., 2014; Tzeng et al., 2014; Carli & Scheede-Bergdahl, 2015; Dietz et al., 1980).

During the prehabilitation intervention period, patients are discharged to their homes and are expected to follow their prehabilitation prescriptions and to self-monitor their daily exercise, food consumption, and stress levels. Prehabilitation thus heavily relies upon patient at-home self-care. Patient self-care can be defined as follows:

"[Self-care] refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious [self-care] encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established." (Barlow, et. al 2002)

Such self-care activities can be burdensome to patients, and high burden rates are known to lead to low adherence and engagement in similar contexts (Choe et al., 2015). Currently, researchers use phone calls and self-reports to maintain patient engagement to prehabilitation

prescriptions (Gillis et al., 2014; Silver & Baima, 2013; Barnes et al., 2016; Halloway et al., 2014), but despite these researchers' efforts to encourage and engage patients, engagement is notably low (Gill et al., 2003-67%; Carli et al., 2010-intense exercise-16%; Matassi et al., 2014-79%). These low or variable rates are especially troubling in prehabilitation contexts as the majority of time spent treating prehabilitation patients, and thus the largest contributor to their prehabilitation success, is their performing of self-care (e.g., prescribed exercises, dietary changes, etc.) within their home (Zhu et al., 2018).

Despite the significance of these adherence and engagement challenges in prehabilitation, definite causes for these low rates remain uncertain, and the available literature has largely lacked a firm understanding of how to empower patients to sustain their contributions to their treatment processes to benefit their health. This lack in part stems from the bulk of prehabilitation literature having been written from a health science perspective, but this perspective may fail to explore and address problems such as engagement, adherence, motivation, accessibility, and scalability of care practices. These shortcomings of the health science perspective, however, can be complemented by the existing Human-Computer Interaction literature regarding related contexts.

The Human-Computer Interaction perspective can alleviate the problems of adherence, engagement, low motivation, accessibility, and scalability by addressing the challenges patient and clinician encounter, and support effective and accessible self-care management. HCI researchers have thoroughly examined how technologies can promote physical activities (Consolvo et al., 2008; Rabbi et al., 2015a; Gouveia et al., 2015), nutrition (Thomaz et al., 2015; Rabbi et al., 2015b), and mental health (Bardram et al., 2013; Doherty et al., 2012; Rennick-Egglestone et al., 2016) specifically to understand and increase users' adherence (Bentley et al., 2013; El-Nasr, 2015; Gulotta et al., 2016) and motivation (Kim et al., 2013). However, prehabilitation has only begun to be studied from an HCI lens, and research on self-care technology to support prehabilitation patients is practically nonexistent.

Related HCI research cannot be used as a direct substitution for dedicated prehabilitation studies, however; prehabilitation differs from related HCI health behavioral change intervention design and deployment studies in that it is not a long-term behavioral intervention aimed at encouraging physical activity or monitoring nutritional changes. The goal of prehabilitation is to raise baseline levels of health to acceptable surgery parameters, so that patients may have a better chance of survival or even negate the need for surgery. This is especially necessary for patients with chronic conditions, like obesity or heart disease. Although HCI literature cannot be a direct substitution owing to these differences in inherent goals, HCI's extensive literature regarding "self-care technologies" offers invaluable insights for building a foundation for prehabilitation self-care interventions. "Self-care technologies" can be defined as any technologies used for patients' self-care including: consumer health tracking devices (e.g., Fitbit, Jawbone, Microsoft Band), smartphone applications (e.g., MyFitnessPal, GoogleFit, Apple's HealthKit), medical devices (e.g., blood glucose meters), and online forums (PatientLikeMe, eHealthForum).

This dissertation examines prehabilitation from an HCI lens and employs user centered design approaches to support the exploration and design of targeted prehabilitation support technologies. This work intends to facilitate cost-effective self-care technologies which will improve prehabilitation processes by reducing clinician burdens, increasing patients' engagement, improving accessibility, and ensuring care quality is maintained. This work offers a synthesis of prehabilitation research with an HCI perspective to expand critically understudied perspectives and processes within the field of prehabilitation.

1.2 Dissertation Statements

Prehabilitation motivation and engagement can be improved by enhancing individuals' self-awareness and self-confidence by designing effective feedback methods which utilize and

display their own self-monitoring data. This dissertation's claims are summarized in the following statements:

Understanding current prehabilitation practices and design spaces can allow us to recognize design opportunities for targeted and effective prehabilitation self-care technologies. Recognizing that the prevailing health science lens of the majority of prehabilitation research is insufficient for addressing current prehabilitation challenges which reduce efficacy and patient benefits, I postulate that an HCI lens would complement the existing literature and identify new opportunities. Having conducted the prehabilitation research using an HCI lens, I identify novel opportunities and challenges and offer solutions and interventions which appear to be effective. Therefore, the adoption of an HCI lens in prehabilitation research does complement the existing literature and improve our understanding of how to facilitate prehabilitation patients and clinicians.

1.3 Research Questions and Approaches

The overall objective of this study is to design a self-care application to address the needs of prehabilitation patients and their healthcare providers; in doing so, I will also provide support for the adoption of an HCI lens in prehabilitation research. To verify the goal of this dissertation, I examined the following research questions (RQs) through a mixed-methods approach:

- RQ1: What challenges do patients experience during pre-surgical care and interventions?
- RQ2: What challenges do prehabilitation healthcare professionals (HPs) face, and how do they respond?
- RQ3: How do members of a prehabilitation team for Facial Paralysis (FP) collaborate amongst themselves and with patients?

- RQ4: How should we design self-care technology to support patients with facial paralysis in their prehabilitation?

To answer RQ1 and RQ2 and understand the current landscape of prehabilitation and its associated challenges, I conducted two exploratory studies to gather both patients' and healthcare professionals' perspectives and experiences. My goal for these two studies was to build a more comprehensive understanding of the design space for prehabilitation than was available in the literature, and for this, in-depth explorations of patients' and healthcare professionals' needs, challenges, and perceptions were necessary. Results from these two studies indicate that generalized prehabilitation programs, even those specific to one treatment (e.g., knee replacement, cancer care, facial paralysis, etc.) will only be viable as a foundation for care planning and that care plans must be individualized to ensure needs are met and sufficient outcomes achieved. Likewise, findings indicate that different prehabilitation healthcare professionals may experience different challenges depending upon idiosyncratic workflow differences. Realizing the inherent variability within prehabilitation as a field of study, I narrowed my focus to a specific prehabilitation context—facial paralysis prehabilitation—to constrain variables.

To address RQ3, I conducted a formative case study to closely observe how a multidisciplinary care team for facial paralysis collaborates with their prehabilitation patients to facilitate prehabilitation success. This narrow study regarding workflow and team interaction (i.e., including the patient as a team member) provided a strong foundation for the comprehension of idiosyncratic needs in this one prehabilitation clinic and allowed me to better understand needs which may be generalizable. Notably, I identified an opportunity to address a key motivational challenge (i.e., patient inability to perceive gradual progress) within this prehabilitation context by extrapolating the healthcare professionals' successful motivational strategies (e.g., showing patients visual proof of progression) and designing an intervention to allow patients to more broadly benefit. This formative study thus informed the design and development of the MyFace system, a

self-care technology to help people with facial paralysis track their prehabilitation progress. This project begins to answer RQ4 by providing promising results in an early deployment study. By focusing on enhancing patient self-care motivation through facilitating self-awareness and self-reflection via visual media, I demonstrate that prehabilitation motivation and thus adherence may be improved. This supports the notion that the adoption of an HCI lens in prehabilitation research will provide novel insights and identify hitherto unrecognized opportunities.

1.3.1 Two Exploratory Studies

The first exploratory study, which was aimed at answering RQ1, explored prehabilitation challenges faced by patients and identified opportunities for technological interventions by conducting a qualitative study of public online posts from 154 users on a popular health forum; each user was a patient who had discussed perioperative experiences on the forum. Using this data, I identified categories of patients' needs and challenges during perioperative care with a particular emphasis on preoperative needs and challenges. The results of this exploratory study helped me identify design opportunities and guidelines from a patient-centered perspective.

The second exploratory study, which was aimed at answering RQ2 and complementing the first study, provided a clear comprehension of healthcare professionals' needs and perspectives. User-centered stakeholder understandings are crucial for a technology's adoption, but prehabilitation literature lacked such understandings; I therefore conducted semi-structured interviews with 12 prehabilitation healthcare professionals (HPs) to offer descriptions of care challenges, how they responded to those challenges, and their perspectives regarding suitable and effective technologies. These data assisted me in fostering highly collaborative prehabilitation processes via tailored prehabilitation tools which meet HPs' needs and expectations. I identified technological supports for clinical assessing and tailoring, informing patients to promote care

collaboration, and engaging and monitoring patients' at-home activities as significant prehabilitation technology design opportunities.

1.3.2 Formative Case Study

My decision to focus on prehabilitation for facial paralysis was informed by the following considerations: 1) prehabilitation for facial paralysis is a relatively understudied and under-documented form of prehabilitation; 2) while conducting the study to answer RQ2, apparent differences that warranted further research were noted between facial paralysis prehabilitation healthcare professionals and other prehabilitation healthcare professionals (e.g., the facial paralysis healthcare professionals described higher adherence rates); 3) facial exercises often play crucial roles in patients' recoveries and can even negate the need for surgery just be faithful adherence and execution; 4) facial exercise intensity is relatively minimal, relatively convenient (i.e., performable anywhere with only a mirror), and low risk for injury or harm; 5) facial appearance is a significant factor for everyday interactions and patients with abnormal facial appearances may be more self-aware and more motivated to complete prehabilitation to facilitate normal interactions than other prehabilitation patients; and 6) facial paralysis prehabilitation is an ideal study choice to further our understanding of patient involvement in complex healthcare teamwork, as patient collaboration with multiple healthcare professionals can be critical to health outcomes.

With these facts in mind, I devised a study to collaborate with the facial plastic and reconstructive surgeon and her care team (i.e., speech language pathologist, physical therapist, ENT nurse, and neurology residency doctor) at the neurology department in Hershey Medical Center. This formative case study investigated how the multidisciplinary care team collaborates amongst their members and with patients; this study incorporated the often-overlooked patient's role within healthcare workflow modelling, as patients' at-homes actions were predominantly responsible for

prehabilitation success at the site. I conducted 20 clinic observations and 11 interviews to ultimately describe facial paralysis treatment workflow and its associated challenges. Findings were synthesized into a workflow model and possible solutions were proposed to notable challenges; for example, I identified that promoting data sharing capabilities with the care team and fostering patient motivation through self-monitoring of visual media to be significant areas for technological support.

1.3.3 The MyFace System

Informed by the two exploratory studies and the case study noted above, I designed, developed, deployed and evaluated the MyFace system (Figure 1) to study the efficacy of a self-care technology with visual media self-monitoring and social support functions intended for tracking facial paralysis recovery progress. The MyFace system was intended to holistically track patients' recovery progression and help them to be more aware of gradual improvements. It accomplished this by tracking facial exercise durations and frequencies, user feelings, and visual media (i.e., videos and specifically posed photographs) over time to allow for assessment of changes via comparison of older versus newer visual media. In addition, MyFace employed a social support approach; existing facial paralysis tools rarely support self-monitoring and sharing functions with healthcare professionals or friends and families, despite these support functions having potentially significant roles in enhancing patients' motivation (Face2Face; Zhu & Carroll, 2018b). These social elements offer patients vital informational and emotional support which can contribute to their motivation to sustain self-care contributions during prehabilitation (Cheskin & Donze, 2001). Finally, noting that patients may be self-conscious about their abnormal facial movements and thus be less receptive to sharing, I designed MyFace with proper privacy protection

options embedded within the system design itself to allow patients full control over who could access their personal and sensitive data.

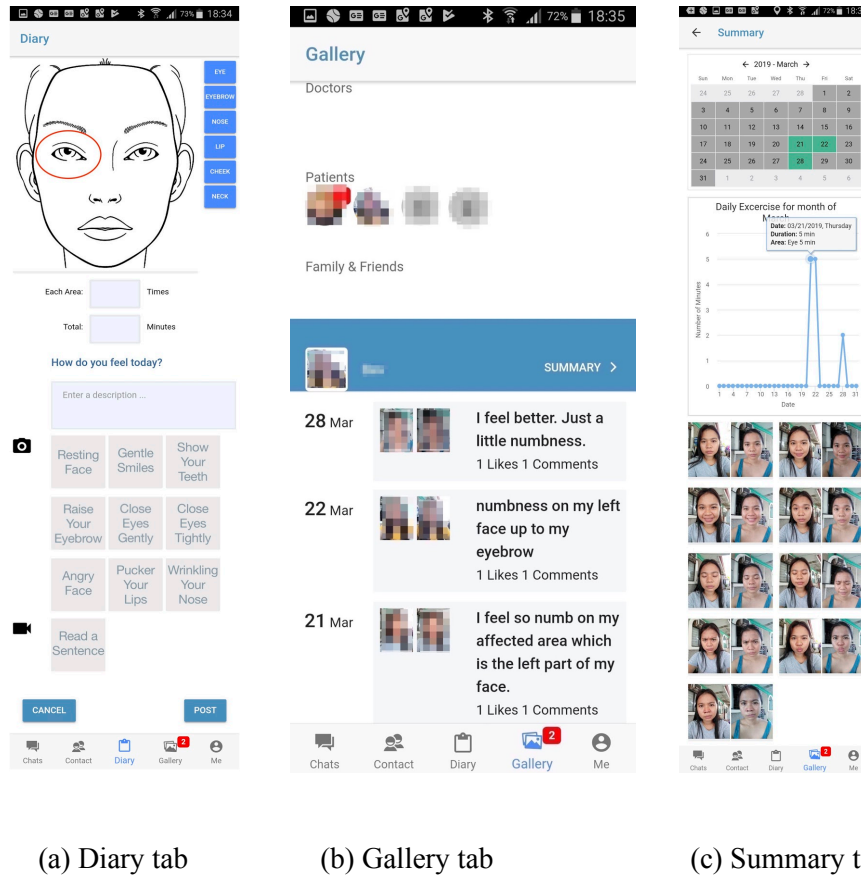


Figure 1: Components of the MyFace system. Daily self-tracking (a), gallery display of chronological photo organization (b), facial exercise summary and photo comparison (c).

Noting the importance of patient self-monitoring and sharing functions with HPs, friends, and family members, as well as the difficulties in utilizing these techniques to foster these tools' benefits, I designed MyFace with real-time communication functions which allow patients to add and message their friends, family, and clinicians. In addition to these real-time communication features, I designed MyFace to include a diary function to assist patients in self-tracking their facial exercises, associated feelings, videos of facial expressions in motion, and 9 photos with different

facial expressions. Patients may open their diary and MyFace will display feedback in its “Gallery” section, which has materials sorted by date, and its “Summary” section, which offers an easy comparison between the patients’ first and latest diary entries. This feature in particular was informed by the studies aimed at answering RQ2 and RQ3, as a common problem mentioned in these studies was that patients could not perceive their gradual process and thus would lose motivation to adhere to care plans and prescriptions. This “Summary” feature thus allows patients to concretely see recovery progression (see Figure 1) which they might otherwise not perceive. In addition, the aggregated facial paralysis progression summary can provide patients with a holistic view of how many days they exercised in a month (i.e., in a calendar view) and exercise duration times (i.e., displayed in a line graph). I evaluated the MyFace system through a 30-day field deployment study with 11 FP patients; user self-reports show great promise regarding improving self-awareness, self-reflection, and thus motivation and exercise adherence through concretely demonstrating gradual recovery progress via the system.

1.3.4 Summary of Research Questions and Approaches

Table 1: A summarization of the research questions of this dissertation, as well as the studies I conducted to answer these research questions.

| | Research Questions | Approaches |
|---|--|--|
| 1 | What challenges do patients experience during pre-surgical care and interventions? | Exploratory Study - Forum analysis of patient prehabilitation challenges (Chapter 3). |
| 2 | What challenges do prehabilitation healthcare professionals face, and how do they respond? | Exploratory Study - Interview study with healthcare professionals regarding care challenges and technology opportunities (Chapter 4). |
| 3 | How do multidisciplinary Facial Paralysis treatment team members | Formative study - In-situ clinic observations and interviews with facial paralysis care team and their patients to synthesize facial paralysis treatment |

| | | |
|---|--|--|
| | collaborate amongst themselves and with patients? | workflow model and identify the design space (Chapter 5). |
| 4 | How should we design self-care technology to support prehabilitation patients with facial paralysis? | Design, development, and deployment study of MyFace (Chapter 6). |

1.4 Contributions

I discuss the following contributions in this dissertation: 1) empirical findings, 2) design and implementation of an artifact; 3) guidelines for prehabilitation research. Specifically, this research generated:

1. A preliminary exploration of prehabilitation through a user-centered lens to understand and chronicle prehabilitation stakeholders' (i.e., healthcare professionals and patients) perspectives, which adds to the body of HCI healthcare research. I provide an empirical description of prehabilitation stakeholders' challenges, how they respond to said challenges in real world circumstances, potential barriers for technological adoption, and future directions for adoptable tailored prehabilitation tools.
2. A case study of how to design technological support for a specific prehabilitation case. Based on empirical evidence (in-situ clinical observations and semi-structured interviews), I offer a Facial Paralysis Treatment Model for mapping the design space of technologies to encourage and support patients with facial paralysis in their recoveries. This work advocates for a perspective shift regarding the incorporation of patients' active roles in healthcare collaboration, and it identifies that promising research opportunities for Human--computer Interaction research include: (1) facilitating collaboration and communication through self-monitoring with visual media for patients' perception of progress and sharing capabilities with carers, and (2) expanding the current scope of complex healthcare team collaboration research.

3. The design, implementation, deployment and evaluation of a mobile--based self--care technology intended for tracking behaviors of prehabilitation patients with facial paralysis. This study provides direct support for both the claim that facial paralysis patients' motivation and thus adherence to care plans may suffer from an inability to perceive their gradual recovery progress, and the notion that data feedback in the form of first versus last diary entries with visual media can improve self-reflection and self-awareness, and thus motivation. This work also provides weaker support for the notion that the MyFace system, through its features, can increase FP prehabilitation patient adherence to exercise prescriptions and thus sustain their contributions and collaboration towards their own recoveries.
4. A set of design guidelines for self-care technology based on empirical findings (i.e., synthesized from forum analysis of prehabilitation patients, semi-structured interviews with healthcare professionals, and the MyFace deployment study). These design guidelines for prehabilitation self-care technologies include: 1) finding visual representations that can convey valence information, 2) Increase self-awareness of self-monitoring progression through showing progression, providing means of comparison, and providing performance progression tracking, 3) enabling social support, and 4) protecting user privacy. Perhaps most importantly, creating persuasive performance feedback that can motivate patients' self-tracking behaviors and enhance their self-reflection can help researchers and designers in creating self-care technologies which promote prehabilitation engagement.

1.5 Dissertation Overview

Chapter 1: Introduction. Chapter 1 includes my interests and motivations for designing a healthcare technology which promotes and facilitates patients' pre-surgical activities; my

dissertation statements, research questions, and the approaches I used to answer these research questions are outlined therein.

Chapter 2: Related Works. Chapter 2 summarizes the background for prehabilitation, discusses several empirical investigations of self-care technologies in HCI and Health Informatics research, and briefly examines how self-care technology can benefit prehabilitation. Moreover, I include the theoretical underpinnings of my dissertation research and highlight the aspects of these theories that are most relevant to the design of the MyFace System. In particular, I cover the theoretical background of self-monitoring and social supports.

Chapter 3: Exploratory Study; Understanding Challenges in Prehabilitation for Patients. Chapter 3 discusses the first exploratory study I conducted for this dissertation. It explores prehabilitation challenges faced by patients and identifies opportunities for technological interventions through a qualitative forum analysis study of an online health forum posts from 154 users.

Chapter 4: Exploratory Study; Experts' Perspectives on Care Challenges and Technological Opportunities. Chapter 4 discusses the second exploratory study I conducted for this dissertation. This study aims to provide a clear comprehension of healthcare professionals' needs and perspectives. Using user-centered design, I identify design considerations, challenges, and opportunities, therefore providing a foundation for understanding prehabilitation stakeholders which is crucial for the adoption of novel technologies.

Chapter 5: Formative Case Study; A Case Study of Multidisciplinary Care for Facial Paralysis Patients. Chapter 5 discusses a case study regarding care practices for facial paralysis

patients in prehabilitation. I chose to investigate facial paralysis in-depth for the reasons listed in section 1.3.2. This formative case study specifically investigates how a multidisciplinary care team collaborates amongst its members and with patients, thus building upon my foundational knowledge regarding how to effectively design self-care technology which addresses both patients' and care team members' needs.

Chapter 6: Design and Evaluation of MyFace System. Chapter 6 includes documentation of the design, deployment, and evaluation of a self-care technology for supporting patient-clinician communication and data collection and organization in the context of FP prehabilitation. The design of this system was informed by findings from the other works within this dissertation. I report on the qualitative and quantitative results of this study, and note how MyFace appears to successfully motivate patients in self-tracking their progression and reflecting upon their progress.

Chapter 7: Contributions and Opportunities for Future Work. Chapter 7 offers a summary of the contributions made during the work of this dissertation and notes further opportunities for future work to expand upon my findings, methodologies, and artifacts.

Chapter 2

Related Work

I have provided in this dissertation strong support for the notion that prehabilitation is a crucial component of patients' postoperative recoveries. However, tools which are designed to support prehabilitation and which utilize strategies that enhance short-term engagement, have yet to be explored fully in the field of HCI and health informatics.

This chapter provides: 1) a brief overview of prehabilitation (i.e., including the key differences between prehabilitation and similar techniques such as rehabilitation and physical therapy) and habilitation spectrum technologies; 2) definitions for self-care technology and explorations of how persuasive strategies and clinical workflow modelling can be used to aid in the design of novel self-care technologies geared toward increasing prehabilitation patients' engagement and adherence; and 3) discussion regarding key theories (e.g., self-monitoring, reactivity, social support, etc.) used in this dissertation's body of work for designing self-care technologies which nudge people towards behavioral changes.

2.1 Background on Prehabilitation

Patients with both poor physical functions (e.g., comorbidities, like obesity or diabetes) and psychological ailments (e.g., depression or anxiety) before their surgeries are more vulnerable to postoperative complications (Hollenbeak et al., 2006; Hulzebos et al., 2003). In addition, recovery periods after invasive surgeries often involve long periods of physical inactivity which might cause losses in patient muscle mass (Bajotto et al., 2006), deconditioning (Kortebein et al., 2009), disabilities (Silver, 2014), decubitus ulcers (Walton-Geer et al., 2009), myocardial infarction, wound infection, urinary infection, and nerve injury (Bamgbade et al., 2007). These

factors can decrease quality of life (Baldwin et al., 2009) and result in longer than necessary hospitalizations (Valkenet et al., 2011), early retirements (Silver, 2014), and increased morbidity and mortality risks (Valkenet et al., 2011). Previous studies suggest that applying exercise-based interventions could optimise a patient's preoperative physical functions before stressful surgeries, which in turn might improve postoperative outcomes or increase viable surgical options in those patients who have borderline fitnesses for specific surgeries (Reeve et al., 2016; Barnes et al., 2016; O'Doherty et al., 2013; Topp et al., 2002). In particular, some prehabilitation research has gained noteworthy acceptance for using physical function and self-rated health status as predictors of postoperative morbidities and mortalities in various patient groups (Thombs et al., 2008; Tosteson et al., 2007; Cesari et al., 2008; Makary et al., 2010; Silver, 2015). However, low engagement rates to prehabilitation intervention impede broader delivery.

2.1.1 History of Prehabilitation

Prehabilitation can be viewed as the first part of the rehabilitation care continuum, which occurs between the time of diagnosis and the start of acute treatment (Silver, 2015). The interventions used during the surgery waiting period may continue after the surgery, and even persist throughout a patient's lifetime. Habilitation services are defined as "health care services that help a person keep, get back or improve skills and functioning for daily living that have been lost or impaired because a person was sick, hurt or disabled (Glossary of health insurance and medical terms)." Prehabilitation is not a new concept. The word was coined in the 1940's by the Medical Division of National Headquarters for the Selective Service, and it was primarily concerned with increasing the number of men who could be accepted to serve in the Army by correcting remediable ailments prior to their military physical examinations (Rowntree et al., 1942). During that time, prehabilitation interventions included lodging, hygiene, recreation, nutrition, physical training, and

education (Br Med J, 1946). Gradually, professionals in healthcare services started to notice opportunities to prepare patients for their upcoming procedures and medical stressors, as well as opportunities to research novel and meaningful interventions (Silver, 2015). Currently, prehabilitation interventions have mostly been studied from the Health Science perspective in a variety of contexts, including patients awaiting joint replacements (Rodgers et al., 1998; Rooks et al., 2006), coronary artery bypass grafts (Arthur et al., 2000; Hulzebos et al., 2003; Alkarmi et al., 2010), abdominal surgeries (Gillis et al., 2014), cancer (Sekine et al., 2005; Silver & Baima, 2013), as well as others.

As noted above, Health Science prehabilitation research has focused primarily on program efficacy for specific populations, but studying efficacy and making comparisons between different programs can be quite difficult owing to a great deal of heterogeneity between programs (i.e., even programs intended for the same purpose) (Hijazi et al., 2017). Instead of focusing on the efficacy of heterogeneous programs, I advocate for the careful study of prehabilitation processes to understand why they are so heterogeneous and what we as a field can do to assist stakeholders. Prehabilitation researchers have rarely, if ever, described how clinicians respond to challenges of prehabilitation care provision; they furthermore have rarely used user-centered approaches to focus on how to effectively integrate technologies into prehabilitation processes. My work has begun to fill these gaps by exploring and describing prehabilitation stakeholders' unique needs, challenges, and opportunities to facilitate prehabilitation technology designers in creating novel, tailored tools for stakeholders.

2.1.2 Habilitation Spectrum Technologies

Rehabilitation technologies (i.e., collaborative systems (Bagalkot & Sokoler, 2011a; Bagalkot & Sokoler, 2011b), game-based rehabilitation software (Bird et al., 2016), prostheses,

wheelchairs (Vanderheiden et al., 1987), networked locomotion system (Yano et al., 2000), etc.) are rapidly advancing in medical research (Patel et al., 2012), but few technological interventions are predominantly designed for prehabilitation; that is not to say that prehabilitation does not utilize technological tools, like internet telehealth communication software (Doiron et al., 2018) or wearable fitness devices (Rumer et al., 2016), just that pre-existing technologies are adopted into practices rather than novel prehabilitation tailored tools. Recent studies on prehabilitation technology use have shown some success in using wearable fitness tracking devices (e.g., accelerometers, gyroscopes, Fitbits, heart rate monitors, etc.) and sensors to monitor and record quantifiable patient health data (Rumer et al., 2016; Beg et al., 2017; Sathe et al., 2018; Singer et al., 2017; Cuadros al., 2017). One such study coupled a customized commercially available web-based telehealth tool with telephone calls and Fitbits to enable remote monitoring, although exercises were still initially taught in clinics (Singer et al., 2017). Researchers have also recently discussed the potential of using text messages or digital applications to facilitate physical activity changes in preoperative programs (Michard et al., 2017). However, we reiterate that these tools have largely been applied or customized commercially available devices intended for other purposes, and designs for prehabilitation specific tools are much scarcer in the literature. This lack of tailored tools might stem from the short duration of prehabilitation and the fact that it is often considered a part of rehabilitation (Silver, 2015) (i.e., it is part of the rehabilitation care continuum, but prehabilitation HPs may have different needs and challenges than rehabilitation HPs, see Section 2.1.3).

I believe that this lack of stakeholder-tailored tools contributes to troubling adherence rates in prehabilitation, as I know that incorporating stakeholders into early design phases for healthcare technologies is crucial for tool success (Zhu et al., 2016); despite the extensive research into prehabilitation (e.g., exercise, dietary, and psychological interventions (Gillis et al., 2014)) and the numerous patient benefits (Valkenet et al., 2011; Silver et al., 2013), adherence and efficacy remain

lower than expected in research settings (i.e., 67% (Gill et al., 2003)). Results are likely worse in non-research settings, especially when the patient alone conducts prehabilitation (e.g., 16% in-home adherence (Carli et al., 2010)). HPs currently maintain prehabilitation adherence via phone calls and self-reports (Gillis et al., 2014), but the lack of subjective and objective measures obfuscates how patients perform prehabilitation in their homes. Accounting for prehabilitation stakeholders' actual needs, rather than adopting readily-available related tools, may aid in raising these poor adherence rates.

One promising avenue of research for improving prehabilitation adherence is the use of self-monitoring devices; self-monitoring technologies are potentially viable tools for prehabilitation, as they show promise in related contexts, especially for chronic condition management (Vogeli et al., 2007; Mamykina et al., 2008; Hallberg et al., 2016; Adams et al., 2017). However, many of these tools are designed for chronic disease monitoring and often rely on long-term behavioral changes (Klasnja et al., 2011), which can be challenging for patients to achieve (Twardella et al., 2006). Moreover, these tools lack design considerations for patient pre-surgical stresses, medication changes, tensions between patients and HPs, motivational strategies, etc. (Zhu et al., 2018); relying upon such health tools might be unrealistic or unwise for most prehabilitation programs, especially for pre-surgical patients with short and limited time to improve health to meet surgical parameters. This work offers the perspective of both patients and clinicians' and considers their challenges and responses; therefore, it can assist the design of tailored adherence and monitoring tools for prehabilitation.

2.1.3 Differences Between Prehabilitation and Related Care

As we mentioned in Section 2.1.2 for a review of habilitation technologies, there were many tailored and purpose-built rehabilitation and physical therapy technologies, however, the

same technologies do not exist, or have only recently been made, for prehabilitation specifically. Prehabilitation is closely related to both rehabilitation and physical therapy, key differences exist between the three which may alter stakeholder needs. The following list will briefly describe some of the general differences between these related care programs:

1. Prehabilitation is characterized by a short, predetermined set of time for preparing patients for impending surgeries (Silver, 2015), whereas physical therapy and rehabilitation generally have access to longer durations with less constricting goals (e.g., meeting surgical parameters vs. improvement);
2. Prehabilitation is generally proactive and preventative, whereas physical therapy and rehabilitation tend to be reactive;
3. Contemporary prehabilitation practices are relatively new and experts generally garner expertise through experience and research, whereas physical therapy and rehabilitation are relative more established with, in some cases, dedicated academic coursework or training which can offer expertise (see Chapter 4 for further discussion);
4. Prehabilitation and rehabilitation can both contain physical therapy as components (i.e., although prehabilitation may include more components than typical rehabilitation, see Figure 2), but prehabilitation patients undergo prehabilitation prior to surgeries (i.e., and any potential complications), whereas rehabilitation patients must perform activities post-surgeries and thus be affected by surgical challenges;
5. Prehabilitation patient motivation to adhere to care plans for proactive health purposes requires foresight regarding potential complications and post-surgical challenges, whereas rehabilitation patients may be motivated to improve merely by their current experiences;
6. Prehabilitation requires patients and their clinicians to find a balance between their acute surgical needs and their chronic needs (e.g., make a decision regarding how a patient's chronic condition medication might affect preparation for impending surgeries) (Zhu et al.,

2018), whereas similar (e.g., acute surgical) needs may or may not exist in physical therapy or rehabilitation; and

7. Prehabilitation success for reaching surgical goal parameters relies upon patient self-tracking and adherence to at-home exercises, which often accounts for the most health care time spent by any prehabilitation stakeholder (chapter 5; Zhu et al., 2018), whereas patients in physical therapy or rehabilitation may be less able to perform activities alone (e.g., because of surgical complications).

Through identifying just these factors, significant differences should be apparent in regard to goals, time, and abilities, but identifying how these differences affect stakeholders requires dedicated user-centered and workflow studies which did not exist prior to the work conducted in this dissertation; as a result, and exploration of what tools do exist for these two related health contexts may still serve as a foundation for understanding general needs for prehabilitation tools.

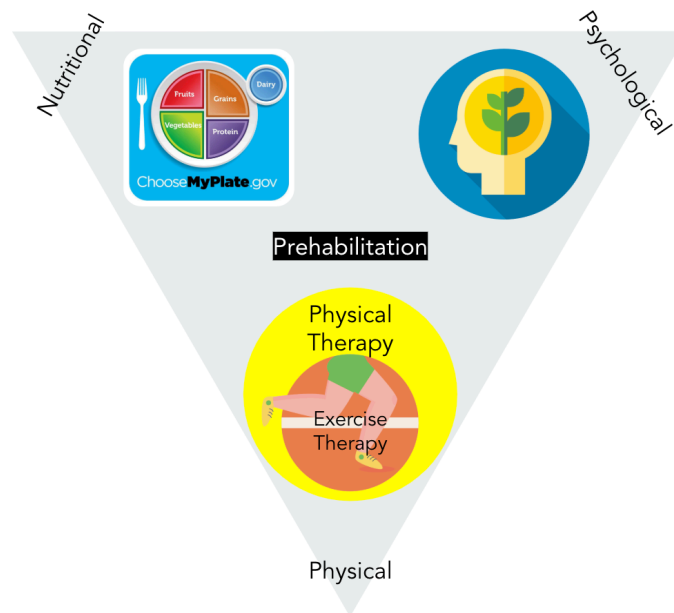


Figure 2: Different components of prehabilitation and their relations to physical therapy.

2.2 Self-Care

Self-care can broadly be defined as actions which enable patients to actively participate in the promotion of their health and the management of their own conditions. A patient undergoing self-care often utilizes expert knowledge, but the patient is the one who actively commits to and performs self-care activities. Self-care or self-management approaches have been employed via a wide variety of delivery formats (e.g., lectures, books, and audio or visual tapes, group discussions, reward systems) for the management of a many issues, including: drug problems, chronic diseases such as asthma, emotional problems such as anger, psychological problems such as depression, sleep problems such as insomnia, stress, and lifestyle (Barlow et al., 2002). In addition to these formats self-care technologies, which are tools which promote a patient's ability to engage in self-care, both through maintenance (i.e., by promoting healthy habits, adhering to treatment regimens, self-monitoring) and management (i.e., responding to symptoms or ailments as they occur) (Saber et al., 2011), have been employed. Such self-care tools can include: medical devices, smartphone applications, tablet applications, internet applications, desktop applications, television applications, and sensor-based technologies (Nunes et al., 2015). Notably, the poor design of a self-care technology can lead to a mismatch between user expectation and user experiences (Nijland et al., 2008). This is significant, because the goal of self-care technologies is to encourage users to make behavior changes through education, persuasion and social interactions rather than through deceptive or coercive means. Therefore, a mismatch between expectation and experience could significantly damage user trust and thus acceptance of a platform.

2.2.1 Contemporary Self-care Technology in Greater Depth

Contemporary self-care technologies are often inspired by persuasive technology design principles. One prior study which aimed to increase user engagement to persuasive technologies provided a design strategy with the following eight components: 1) present users with abstracted, not raw, data; 2) have unobtrusive methods of data collection; 3) present the data in such a fashion as to allow the user to be comfortable with others intentionally or unintentionally viewing it; 4) create a design aesthetic which appeals to specific users; 5) employ positive reinforcement and reward techniques; 6) provide the user control over who has the abilities to both access and manipulate said user's data; 7) incorporate prior data into trends and histories and demonstrate how these relate to user goals and lifestyle changes; and 8) provide a device which is comprehensive with regards to the ability to measure all possible user behaviors and activities (Consolvo et al., 2009). If these factors do increase engagement to a persuasive technology, though, they might not necessarily encourage initial user acceptance of said technology. Together, factors such as perceived usefulness, perceived ease of use, subjective norm, and healthcare knowledge may account for a user's acceptance and use of internet-based self-care applications (Or et al., 2011). Furthermore, attention must be paid to the complex contexts of the factors involved in the design of a technology; each technology or approach will involve intricate relationships between different individual actors, in various settings, and using different amounts and kinds of resources (Nunes et al., 2015).

In addition to using persuasive technology design principles, many self-care technological interventions promote health behavioral changes by measuring an aspect of the desired behavior to change (e.g., time asleep, step counts, heart rate during exercise) and then feeding the data back to users to increase self-awareness. Health systems like this help facilitate self-monitoring, offer effective feedback, and increase user self-awareness through reflection upon activity. My work

builds upon prior work regarding self-care technologies for the promotion of health and health behavioral change. Table 7 (See Appendix E: Current Self-care Technologies) offers a summary of self-care technologies and their measured aspects, and it specifically describes two dimensions of work: 1) technology platform, and 2) persuasive strategy. Technology platform refers to the sensing platform employed to collect data and provide feedback, and persuasive strategy refers to the strategy or strategies employed to create change.

Note that most existing self-monitoring technologies rely on wearable sensing technologies or continuous manual input; both of which are undesirable for long-term monitoring. Wearable sensing imposes physical burdens and manual tracking imposes mental burdens, so it is likely that only the highly motivated or those in serious need of data will commit to these burdens. There is thus an opportunity to design and create unobtrusive self-monitoring technologies which do not require users to wear or remember anything. Unfortunately, there is a lack of data regarding how to guide users through the choice of a self-monitoring technology which fits best with his or her individual needs and motivations; currently no standardized measure exists which accounts for the trade-offs made between and amongst different modes of tracking, which offer different levels of user burden as well as data accuracy.

2.2.2 Using Workflow Modeling to Assist Self-Care Technology Design

Proper design for delivering self-care health interventions through persuasive technologies is of the utmost importance. According to one model, internet-based interventions can be observed and evaluated on the following nine components: the user, environmental factors which influence the user, website use, support, website characteristics, behavior change, symptom improvement, mechanisms of change, and treatment maintenance (Ritterband et al., 2009). These components may be applicable to non-internet reliant interventions, and if they are, ethnographic research

techniques like direct observation might prove useful in the modeling of workflow which can aid in the adoption of informatics systems and tools (Unertl et al., 2006). Workflow modeling is a well-suited method for designing self-care technology to support patient-clinician interactions in clinical settings; thus, workflow modeling is well-suited for improving patients' adherence to treatments and health outcomes, as both are correlated with patient-clinician interaction and communication (Stewart et al., 1999). However, owing to the facts that clinicians often only have use of certain types of patient data (Zhu et al., 2016) and concerns regarding excessive patient-generated data (PGD) affecting patient treatment and PGD being subject to HIPAA laws (Deering et al., 2013; Zhu et al., 2016), HPs may be reluctant to adopt these self-care technologies (Marcu et al., 2013). To be clear, clinicians' reluctance stemming from these key issues can affect the adoption of self-care technologies (Zhu et al., 2016), and each of these issues needs to be considered to successfully utilize self-tracking and PGD for collaboration.

To combat clinicians' concerns, I have adopted ethnographic approaches to first understand stakeholders' needs and interpret potential causes for said concerns; ethnographic research is effective for understanding healthcare practices in related contexts (Blandford et al., 2015; Furniss et al., 2014), and it has provided key insights in my own prehabilitation research (see chapter 5). Ethnographic approaches typically employ structured observations to provide novel insights during health research (Carthey, 2003); for example, one observational study on communication in hospitals discovered communication challenges (e.g., potential preferences for interruptive communication) which might be addressable via supporting communication tools for information exchanges (Coiera & Tombs, 1998). Such studies can also provide clinical workflow insights (Unertl et al., 2006). Researchers have used observations, sometimes in conjunction with interviews, to explore clinical workflow in the following contexts: health information technology adoption and its effects on workflow (Unertl et al., 2006; Zheng et al., 2010), information flow in care for chronic disease patients (Unertl et al., 2009), EMR use in Emergency Departments (ED)

(Chen, 2010), physical therapy consultations (Ni et al., 2011), cognitive behavior therapy for insomnia (Zhu et al., 2017), breast cancer (Unruh et al., 2010), and complex healthcare (Amir et al., 2015). Workflow comprehension is necessary because clinical inefficiencies, medical errors, and missed data can result from clinical informatics tools which are designed with poor workflow comprehension (Unertl et al., 2009).

Notably, no workflow models had been created for FP treatment teams using prehabilitation prior to the work in this dissertation. Furthermore, although Amir et al. (Amir et al., 2015) recognize the importance of incorporating patient needs into treatment plans, they do not address how patients collaborate with HPs in healthcare teams. In addition, Unruh et al. discover how clinical spaces are not equipped or designed for patient collaboration (Unruh et al., 2010). Such findings are significant, as patients' satisfaction with and perceived quality of patient-provider communication correlate with patient compliance (Ong et al., 1995); furthermore, the effects of empowering patients and increasing their abilities to involve themselves in their own healthcare have long been known to positively affect their health outcomes (Greenfield et al., 1985). As a result, one of the studies which contributes to this dissertation sought to include often-ignored patient work and roles into workflow modelling to better ensure the needs, challenges, and opportunities of all major treatment stakeholders were accounted for and described; in this work, I advocate for the further incorporation of patient work into workflow modelling, especially considering that patient roles and efforts in the FP prehabilitation context were critical to the health outcomes of the study site (see chapter 5).

Thus, in addition to the contributions of my research within this dissertation, I advocate for a change in perception regarding the research of patient activities in their own healthcare; I argue that designing useful self-care tools requires comprehension of workflow from both clinicians' and patients' data. To reduce new healthcare technologies' negative outcome risks, clinicians and patients should be consulted during early design processes (Blandford et al., 2012; Zhu et al., 2016).

Noting ethnographic studies' successes, I use mixed-method approaches with clinicians' and patients' input in this dissertation to both understand technology associated challenges and opportunities and build adoptable self-care technologies.

2.3 Theories

2.3.1 Self-monitoring and Reactivity Theory

Most people lack a thorough understanding of themselves and how things can affect their lives. This is partly because people have limited memories and there is far too much for us all to remember. Furthermore, it can be difficult for individuals to accept themselves as they really are, and they actively suppress thoughts which trouble their conscious minds and possibly repress similar thoughts unconsciously (Wilson et al., 2004). However, observing the self more carefully (as through self-monitoring) allows an individual to construct personal narratives which may enable him or her to better acquire meaningful self-knowledge (Wilson et al., 2004). Self-monitoring emerged in social psychology as a description of personality and behavior in the 1970s; a self-monitoring individual was an individual who would gauge his or her expressions and actions and manage his or her behaviors in social situations (Snyder, 1974). In essence, the self-monitoring individual attempted to control how he or she was perceived by others by changing his or her actions. Research has shown that the self-monitoring process, which includes therapist instructions, training, self-recording devices, and self-monitoring responses, leads to the change in the frequency of desired behaviors (Nelson & Hayes, 1981). The term “self-monitoring” in this dissertation refers to:

“an assessment procedure that involves data collection made by the client primarily within naturalistic settings... Self-monitoring has generally served two functions within behavior therapy. The first is an assessment function for which accuracy is an important

consideration. In addition, self-monitoring may also be utilized as part of treatment due to its reactive effects on those behaviors being monitored. These reactive effects tend to occur in the therapeutically desired direction (i.e., undesirable behaviors decrease in frequency while desirable behaviors increase in frequency).” (Korotitsch & Nelson-Gray, 1999)

Self-monitoring design principles are often used in self-care technologies and sensing applications because these tools: 1) provide a source of data, and 2) self-monitoring is often employed as a therapeutic strategy. These principles are useful in therapeutic circumstances because they typically cause reactive behavioral changes. Reactivity is a phenomenon whereby an individual will alter his or her performance or behavior due to an increase in his or her self-awareness, often derived from the practice of self-monitoring; in Health Informatics, researchers try to drive this effect to occur in desirable and therapeutic directions, and as a result provide patients benefits via behavioral changes (Korotitsch & Nelson-Gray, 1999; Mattila et al., 2008). Reactivity, as an effect, occurs when people deliberately self-observe their behaviors and become aware of how their behaviors compare to norms or their own standards of acceptability (Kazdin, 1974). Thus, self-monitoring can effectively increase self-awareness and lead to behavioral changes which facilitate healthy and beneficial behaviors in patients. However, an individual’s beneficial behavioral changes from self-monitoring may stop once an individual ends his or her tracking; tracking engagement is thus one of the most useful measures for determining the efficacy of any self-monitoring tool.

The key to success for employing self-monitoring and reactivity lies in making an individual aware of his or her own problems so that he or she can then fix those problems through behavioral changes. To do this, individuals often need to reflect upon their experiences and data to gain further self-development. Technology can offer significant support to user reflection by providing informational resources (Fleck et al., 2010) such as tools for recording and sharing data. However, reflective thought requires more than just supporting memory through recording and sharing data; individuals must engage meaningfully with their data, analyze it, and draw significant

judgments (Mamykina et al., 2008). Self-monitoring can be improved by coupling it with other theories intended to support behavioral changes (e.g., goal-setting (Locke et al., 2002), providing feedback, etc.); designing appropriate feedback and data visualizations is especially important, as they allow individuals to draw meaningful inferences and bring awareness to unrecognized problems. Refer again to Table 7 (See Appendix E: Current Self-care Technologies) for a more comprehensive view of theories used and coupled with self-monitoring in self-care technologies.

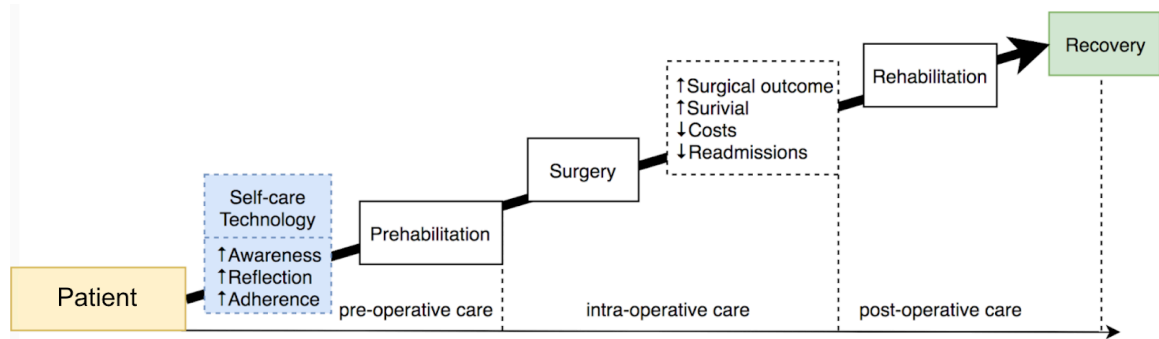


Figure 3: How self-care technology can be introduced into the perioperative care continuum.

Note that despite widespread interest in self-care technologies throughout HCI research, self-care technologies which focus on prehabilitation management are rare; this is troublesome because self-care technology is promising for encouraging patient adherence to prehabilitation prescriptions. As a result, this dissertation explores prehabilitation processes from both patients and clinicians' perspectives and addresses the gap in the literature to investigate prehabilitation from an HCI lens; it further proposes a novel technological way of facilitating prehabilitation engagement by providing a tangible artifact in a particular niche (i.e., facial paralysis) of prehabilitation treatment. Figure 3 shows how self-care technologies which utilize self-monitoring theory can be introduced into the perioperative care continuum. Such an approach may help improve surgical outcomes and survival rates and decrease healthcare costs and hospital readmission rates. It is important to remember that these technologies, and by extension

prehabilitation itself, will not remove the need for rehabilitation, but they will complement it by addressing pre-operative health.

2.3.2 Social Support Theory

Social support can be broadly generalized into the following four categories: emotional support, instrumental support, informational support, and appraisal support (Heaney & Israel, 2008). Social support has positive effects on individuals' physical, mental and social health. Social support is provided by family members, friends, or other people who help an individual during his or her times of need; these people help to provide a broader perspective regarding challenges and often seek to promote the individual's self-image during these times of personal crisis, thus enhancing the individual's quality of life and resistance against adversity. Heaney & Israel note that in one's informal networks, family tends to provide long-term emotional support and friends and neighbors tend to provide short-term support, whereas in one's formal network, healthcare professionals tend to provide information support (Heaney & Israel, 2008). Prior research suggests that social support has a direct effect on health (House et al., 1988), because it helps reduce feelings of stress and thus promotes positive mental and physical effects (Gurung, et al., 1997; Uchino, 2004; Heaney & Israel, 2008).

2.3.2.1 Patient Social Support

Social support can be a significant factor in patient recoveries and health processes. For example, patients who are supported by family members and friends are correlated with reduced hospital readmission rates (Schwarz & Elman, 2003) and significantly higher rates of self-care behaviors (Wang & Fenske, 1996). Social support is known to play a significant role in health

behavioral changes (Skeels et al., 2010). Individuals who have access to specifically emotional support are facilitated during both difficult recovery processes and challenging health behavioral changes (Hartzler & Pratt, 2011; Li et al., 2014; Newman et al. 2011). One study regarding exercise persistence in women after a rehabilitation program even indicated that social support was the only factor examined which predicted persistence (Moore et al., 2003).

Individuals' abilities to adopt healthier behaviors, as well as their health-related risks, are in part affected by the structures of their social networks (Christakis & Fowler, 2008) and in part by the type of person offering support. Notably, patients with experience from managing similar health-related conditions are valuable resources (Hartzler et al., 2010), as patient peer-provided support and expertise significantly differ from the medical expertise healthcare professionals can offer (e.g., patient peers may have first-hand experiential knowledge which healthcare professionals cannot provide) (Hartzler & Pratt, 2011); these differences between patient peer and healthcare professional expertise may also relate to how patients themselves operationalize and contextualize their experiences, share health strategies and illness trajectories, and form support groups with unified comprehension of the management of a shared condition (Huh & Ackerman, 2012). Note that the benefits of peer social support in healthcare contexts can be reciprocal in nature; individuals will adapt tracking strategies to better offer and receive support (Chung et al., 2017). Therefore, healthcare researchers need to consider the following elements of patient social support: 1) what kind of social support is being provided, 2) who is providing the support, and 3) how that support is being provided.

2.3.2.2 Social Support Technologies for Health

Contemporary technologies which leverage social influences to aid behavioral changes in health contexts generally pursue the following three strategies: 1) facilitating peer-to-peer

interaction (e.g., social support and competition); 2) leveraging social support from friends and family members; and 3) utilizing peer modeling (e.g., using peers' successes in similar health contexts) (Klasnja & Pratt, 2012). Technological interventions which incorporate social features can aid individuals in achieving their health goals (Chung et al., 2017) and motivate users to employ self-tracking tools (Newman et al., 2011). In addition to these technologies, researchers have explored the roles and use of both internet-based and social media-based social support in health contexts.

Online Social Support: from 2012 to 2012, 72% of internet users had searched for health-related topics online (Fox & Duggan, 2013), making it a significant informational support tool; in addition, internet users are approaching online communities for health related social and especially informational support. Online support communities exist for health topics including but not limited to: changing lifestyle for weight management (Maitland & Chalmers, 2011; Li et al., 2014), eating disorders (Pater et al., 2016), depression (Li et al., 2016), breast cancer (Vlahovic et al., 2014), bone marrow transplants (Farnham et al., 2002), diabetes (Greene et al., 2011), etc. Online social support is thus significant for exchanges of peer experiences, asking and receiving answers to health questions, and acquiring constructive feedback from peers who share concerns and goals (Greene et al., 2011). Social influence from peers and social ties within programs may be key drivers for engagement in (Poirier & Cobb, 2012) and may reduce attrition rates from (Richardson et al., 2010) internet-based health interventions.

Social Media as Social Support: although social media may not have been designed to specifically provide social support for health-related conditions, social media users have appropriated these media (e.g., Facebook, Instagram, etc.) for seeking health-related emotional and informational support, bolstering motivation and accountability (Newman et al. 2011). Although some social media users post their health data to these social media to create a private archive for their life events (Zhao et al., 2013) and personal challenges (Andalibi et al., 2017), some users also

use social media sites (i.e., Instagram) to exchange experiences and stories, seek support, and connect with peers who share a condition in relatively positive and supportive communities (Andalibi et al., 2017); in these communities, posts which seek support garner more comments and personal narratives, stories involving personal illness, and mentions regarding concerns over personal appearances tend to attract the most positive support (Andalibi et al., 2017). These social media communities and the social support they offer may be strengthened via the sharing of visual media, with videos allowing for greater personal and contextual data sharing opportunities with viewers (Huh et al., 2014a), and images offering the beneficial sharing of difficult to express emotions (Andalibi et al., 2017). In addition to the benefits of novel media sharing capabilities, social media sites offer users who share their health related goals a sense of accountability to these goals which may make them more committed (i.e., potentially even in the absence of feedback from others) (Epstein et al., 2015); however, this benefit may only apply to scenarios in which users choose to share their goals, as the automatic posting of goals onto social media sites (i.e., Facebook) actually decreased user willingness to make new goals (Munson et al., 2015). Interestingly, social media semi-anonymous or anonymous posting capabilities may also facilitate more disclosure of sensitive experiences which may improve emotional well-being (Andalibi et al., 2017), but social media may also expose users to negative health (e.g., pro-anorexic) sentiments (Chancellor et al., 2016) and comments of a negative nature (Andalibi et al., 2017).

Research regarding incorporating social media into actual clinical practices is limited, but rehabilitation researchers determined that involvement with and understanding of stakeholders (e.g., stakeholders) was critical for adoption (Tatla et al., 2015). With these factors in mind, I designed MyFace by utilizing stakeholder understandings developed during prior (Chapter 4 & 5; Zhu et al., 2018a; Zhu et al., 2018b) research to facilitate both personal diary and archiving and social media sharing behaviors for social support.

Chapter 3

Exploratory Study: Understanding Challenges in Prehabilitation for Patients

This chapter presents summarized results from an exploratory study aimed at understanding patients' pre-surgical challenges (RQ1) and uncovering opportunities for computing to support areas which promote pre-surgical patients' well-being.

3.1 Introduction

Little has been done to understand what challenges surgical patients face, especially for patients with multiple chronic conditions (MCC). MCC patients often require increased medical attention during surgical care, including pre-surgery preparation to improve baseline levels of health parameters (i.e., prehabilitation), and management of surgical complications (i.e., during the entire surgical care continuum, including rehabilitation). Effective preparation and management in surgical care is key to improved health-care outcomes, including reduced costs, decreased readmissions, and increased survival. However, most surgical care relies upon patients' self-preparation, and engagement to such programs is often problematic, even at the risk of serious medical consequence. I conducted a qualitative study of online health forum posts to better understand from a patient-centered perspective surgical care for chronic conditions patients, distinguishing categories of surgical needs and challenges, and identifying opportunities for technological interventions to better support surgical care for patients with MCC.

Rehabilitation is well recognized and prominent in prior research (Patel et al., 2012; Silver, 2015) and operative care is predominantly a matter of medical specialists and protocol. Therefore, opportunities for researchers to find novel patient-centric healthcare improvements are more promising for prehabilitation than other care options. I chose MCC patients for this research

because many already utilize components of prehabilitation to prepare for impending surgeries. Although our results will discuss the full spectrum of surgical care, our primary focus will be the novel opportunities of prehabilitation interventions. I further focus our attention on how surgical patients with MCC describe their information needs before and after surgical interventions to identify these opportunities.

I collected and analyzed data from a popular public online health forum. I collected 602 threads from 154 unique users; each user was a patient with MCC and discussed surgical experiences on the forum. Prior researchers have examined online health peer support communities to understand online eating disorders (Pater et al., 2016), depression (Li et al., 2016), breast cancer (Vlahovic et al., 2014), bone marrow transplants (Farnham et al., 2002), and weight management (Maitland et al., 2011) etc. Forum data offers ease of access to extensive quantities of patient self-reports which reveal their concerns towards healthcare, including information patients might withhold from clinicians (Lim et al., 2016), and concerns which are better answered or addressed by patient expertise rather than just clinician expertise (Hartzler et al., 2011). Furthermore, this method allows for greater exploration of the issue and at lower costs when compared to other methods (e.g. interview studies). Therefore, our results will aid HCI and health informatic designers in creating new prehabilitation opportunities with patient-centered design.

Contribution

In this preliminary study I contribute: 1) An empirical description of MCC patients' experiences through perioperative care stages. 2) A set of practical requirements for the design of patient-centric surgical preparation applications. 3) A brief discussion of the interrelatedness of physical, emotional and chronic conditions issues. For example, I note the cascading nature of MCC patients' problems and needs and recommend designing interventions which are capable of

addressing a variety of needs over differing durations. 4) To our knowledge, we are the first to analyze patient prehabilitation requirements for HCI design from a patient-centered perspective. Our study is timely and examines underexplored research areas. I explore both MCC patients and perioperative practices with a focus on the possibility of utilizing technologies in prehabilitation. Our findings act as a preliminary exploration of prehabilitation challenges and opportunities for broader implications in the fields of HCI and Health Informatics.

3.2 Contemporary Chronic Conditions Research

Global health levels are generally declining (Scaglione et al., 2004), and nations like the U.S. and U.K. are experiencing increases in preventable diseases (Finucane et al., 2011), including chronic conditions (e.g., heart disease, cancer, diabetes, stroke, and arthritis). Over 50% of U.S. adults have at least one chronic condition (DC), and 80% of U.S. adults who are over 65 years old have multiple chronic conditions. CC are the leading causes of mortality and disability in the United States (Centers, 2016). With heart disease and cancer, both chronic conditions, accounting for almost half of all deaths (DC). Designing technology aids in patient-clinician collaboration and care management can be difficult (Chung et al., 2016), but effectively designed technologies can significantly affect a patient's ability to collaborate with clinicians, often in new, transformative ways (Andersen et al., 2011).

Research discussing surgical care for patients with MCC is limited, and current works regarding self-care technologies focus on one specific CC (Vogeli et al., 2007), such as diabetes (Mamykina et al., 2008), hypertension (Hallberg et al., 2016), and chronic pain (Adams et al., 2017), etc. A few works have also explored how to support patient health management, such as by exploring the role of caregivers for patients with long-lasting or intensive needs (Kaziunas et al., 2015; Miller et al., 2016), how video blogs enrich social support for YouTubers with CC (Huh et

al., 2014a), and some of the undesirable events during inpatient stays (Halder et al., 2016). However, notable research has shown that healthy individuals react differently to social incentives than those with prior conditions (Chen et al., 2017), so direct comparisons between healthy caregivers and MCC patients who might act as their own self-carers in managing their diseases may be unsound. Also, these works do not directly focus upon surgical care for patients with chronic conditions or how we as HCI designers adopt or respond to their challenges during short-term health interventions.

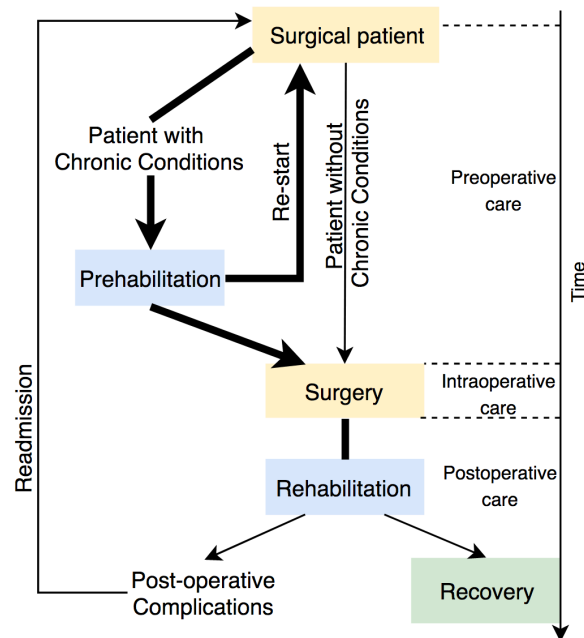


Figure 4: This chart explores the branching pathways through which patients progress during the stages of perioperative health. Note that surgical patients either move forward to their surgeries (if they do not have significant conditions preventing them from doing so), or attend a prehabilitation program until they are qualified for surgery; if they did not reach their goal parameters, they would postpone surgery and restart the whole prehabilitation process. Time is on the right edge to indicate which stage the patient is going through.

Furthermore, MCC patients are often more in need of prehabilitation than healthier patients to raise their baseline levels of health to surgery parameters and to increase their survival outcomes (see Figure 4). Patients with multiple conditions and prior treatments may experience difficulties preparing for and recovering from surgeries (Vogeli et al., 2007), especially while they are also

suffering from physical, emotional, and social changes that affect their quality of life and care (Huh et al., 2014a). Because patients with chronic conditions must necessarily have lifelong medical attention to treat and manage the pervasive effects of their conditions (Wagner et al., 2001), technologies which are designed to support individuals with chronic conditions tend to rely upon changing long-term behaviors (Klasnja et al., 2011). Long-term behavioral changes are often difficult for individuals to achieve (Twardella et al., 2006), so relying upon these intensive techniques may be unrealistic in practice, especially for patients with MCC. Surgical patients usually have fixed amounts of time to increase their baseline health to surgery parameters. I see opportunities for HCI researchers to investigate how to design effective interventions to help MCC patients improve over short periods. Our work differs from prior works by focusing on how MCC patients themselves respond to new or changing burdens and challenges with surgical experiences, while also identifying opportunities for designing technological interventions.

Healingwell

Forum data is abundant, offers more diverse data than similar low-cost interview studies, is publicly available, and often written by anonymous patients unless unmasked by the patients themselves. Anonymous people can be more open about potentially embarrassing or stigmatized topics, including medical conditions (Marx et al., 2001). As such, analyzing forum data is an ideal and low-cost means of collecting a wide range of data to explore broad themes. Healingwell is one of the several popular online health fora designed for sharing blogs, videos, newsletters, articles, resources, and question and answer threads, with over 2.7 million posts, 305k threads, and 153k registered members to date; this tremendous amount of activity makes it ideal for examination.

3.3 Dataset and Data Analysis

I conducted a qualitative study examining the surgical behaviors of MCC patients on Healingwell, an online health forum. I chose Healingwell because this forum is publicly available (Bruckman, 2002), which means there are no requirements for registration to access threads. However, because our data often lacked patient demographic information, I did not perform demographic analyses. Before reporting this work, I considered the potential risk versus benefit of publishing patients' stories, due to the sensitive nature of chronic condition management, and as technology designers who are informed about digital privacy, I have shortened the quotes to what is essential to demonstrate a claim, and removed identifiable information. To further protect anonymity, I revised misspelled words, expanded acronyms, and capitalized initials, doing so within brackets '[]', so that these quotes are not entirely the same. I filtered the posts, and only utilized those from patients with MCC regarding surgeries.

The dataset was first filtered based on the 19 chronic conditions (Chronic Conditions list) listed by the Center for Medicare and Medicaid Services [CMS]. I applied a fuzzy search to find chronic conditions posts throughout the entire forum. Specifically, I constructed a chronic condition keyword-dictionary (CCKD) by tokenizing the words in the list provided by CMS. For example, the CCKD keywords include the 19 listed CC: chronic, Alzheimer, arthritis, osteoarthritis, etc. The surgery keywords include: bypass, surgery, surg, op, pre-op, post-op, etc.

To limit noise in the data, each user in the dataset needed to have posted at least 3 times in at least 2 different categories. For this paper, the assumption is that if a user posted in more than one CC related category, the user is a potential individual with MCCs. To limit acute conditions in our data, length of time between the first and last posts needed to exceed 365 days. This yielded 1406 unique users and 16031 threads. I then narrowed our focus by using surgery-related words for a secondary filtration. However, users might post for their families, friends or pets, which could

cause misclassifications. I extracted subjects from each post, based on the logic that the main subject of the post is the most frequent subject in the post. For example, if in a post the top 3 most frequent subjects are: “he”, “they” and “it”, which are mentioned 10, 3, and 2 times respectively, then ‘he’ is the most frequently mentioned subject. I mark these posts and request a researcher to determine if the post is eligible for our study.

Our final dataset included 154 unique users and 602 threads, spanning from 7/2005 to 11/2016. Among 602 threads that met our criteria, the category with the most posts in our dataset is prostate cancer, which has 228 posts, and the least discussed condition is Alzheimer’s disease with 7 (See Figure 5). I organized our dataset in alphabetical order by the username, and from the most recent post to the oldest post. I assigned each thread a unique identifier (e.g., Q#) for our reference. Using thematic analysis (Braun, 2006), I qualitatively analyzed the initial posts of these threads to answer our research questions. Because surgical care and MCC patients are relatively underexplored topics in HCI, I focus on providing a rich description of the variety of needs of these individuals and the complexities of their problems. As such, I focus on qualitative analyses, rather than quantitative relationships.

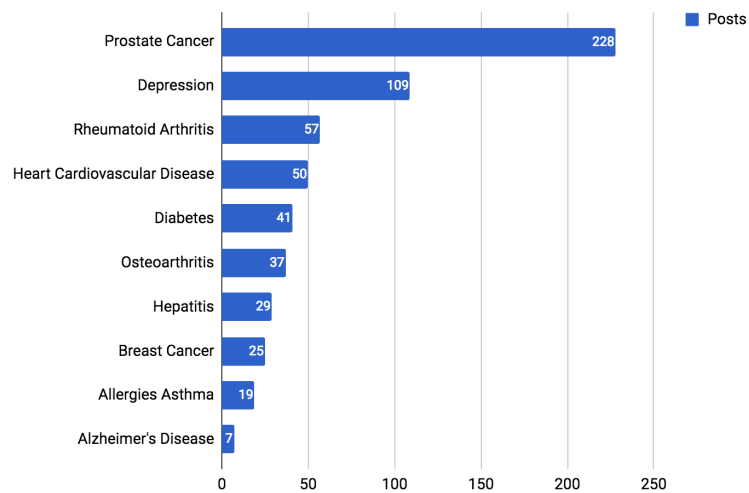


Figure 5: Chronic condition discussion distribution based on number of posts.

Surgical Patients with MCC: I narrowed the analysis in this manner for two reasons. First, studying surgical care requires us to account for a patient's chronic conditions, stress, medications and side effects, and any factors which could hinder his or her surgical success. Oftentimes, MCC patients are the most in need of prehabilitation to raise their baseline levels of health to acceptable parameters for surgery. Therefore, I was primarily interested in determining how MCC patients behaved regarding surgeries (i.e., including all surgical behaviors, from preoperative to postoperative), and I needed to ensure our sampling specifically captured data from these patients with discussions of surgery. Second, the Healingwell forum covers broad and varied aspects of health (e.g., beauty, men's and women's health, dental health, children's health, etc.), so to utilize its vast data, filtration was necessary.

Data Analysis Methods. I was interested in what actions users performed during their posts, what surgical challenges users with MCC faced, and how users' needs, challenges, and opportunities evolved with the progressive stages of surgery. Based on our interests, I used thematic analysis (Braun, 2006) to qualitatively analyze the 602 threads on Healingwell over the 11 years which met our two criteria. These threads consisted of an original post, often but not always followed by replies made by other users; these posts were primarily text-based. Initially, two researchers first read 20% of the posts to understand the types of behaviors and discussions which existed to determine a starting point. The first researcher then examined the entirety of the postings thematically. Our thematic analysis consisted of one round of coding by one researcher, which emerged iteratively. The researcher first read through a thread, attempting to broadly define the contents, while also making note of specific examples of more narrow subsets. Users were not assessed longitudinally, so only examples of behaviors, needs, etc., are determined, not frequency or prevalence. After this initial categorization process was completed, the code was examined and refined. The following section is a rich discussion of how chronic conditions patients interact with

online health forum, their specific surgical challenges, and opportunities for technology to assist these individuals.

3.4 Results

Below, I discuss the collected data in terms of our research questions, including patient prehabilitation challenges, postoperative complications, and patient-perceived challenges for social interaction.

3.4.1 Patients' Prehabilitation Challenges

A patient's pre-existing conditions may interfere with his or her eligibility for surgery. Prehabilitation differs for patients who have MCC from those who do not in two major ways: First, patients with MCC need to increase baseline functionality to sufficient surgery levels. Second, MCC patients must deal with pre-operative complications which may co-occur with their conditions.

3.4.1.1 Balancing Chronic Conditions Against Acute Needs

MCC patients' conditions often fluctuate; they may need to constantly track or monitor their symptoms and make adjustments in response to changes. Therefore, the fact that a common theme in our research was that patients needed to get their parameters under control should not be surprising (e.g., this was common among patients with diabetes and obesity). However, some patients found it difficult to control their chronic conditions when facing imminent surgeries, as their medications could conflict with their surgeries. Patients may thus have to choose between

risking their lives to have surgery, or risking their lives by discontinuing medications. In one case, a patient with diabetes underwent a minor surgery one year prior to posting. During his previous surgery, the clinician used a Dextrose drip even though he had knowledge of the patient's pre-existing condition. The patient was instructed not to take his medication for blood sugar control during the intra- and post-operative period. However, after weighing the risks, the patient took the medication as soon as he got home. He posted online because he would soon have another surgery, and it would require him to stay in the hospital for days. His pre-existing health problems made routine surgeries more complicated than they could be. Because of his prior experience, he expected complications and wanted to minimize risks for those complications, thus he sought online information support. *"I will be having major surgery in less than 2 weeks. I know that they use some kind of Dextrose/glucose saline drip and that this will cause my [blood sugar] to skyrocket."* [Q322]

3.4.1.2 Maintaining Health with Chronic Conditions

Chronic health problems and sudden or unexpected changes in health can postpone or disqualify patients for surgeries. For example, a patient with high blood pressure and a heart muscle problem was expected to have a surgery to remove a growth from her uterus. However, her "current" electrocardiogram result showed that the electrical activity of her heart had changed drastically from her previous tests. As result of the fluctuation in her health caused by her chronic condition, her *"... [Primary Care Physician] said no surgery until they find out what has caused the changes."* [Q41] Therefore, the clinician would not proceed with the surgery until she stabilized her chronic condition.

3.4.1.3 Inconsistent Engagement to Care Plans

Similarly, patients who were newly diagnosed (e.g., with diabetes) did not always adhere to their care plans. This caused some patients to postpone their surgeries. One notable patient indicated that she knew what she was supposed to do to maintain her health, but she did not do it. This type of behavior is consistent with the low engagement rates of prehabilitation reported in prior academic and field studies (Carli, 2010). *“When I need surgery on my neck, with diabetes out of control certainly no surgery of any kind. I am so angry with myself. I know that I could eat better and do more exercise.”* [Q369]

Patients in our data also displayed frustration with the constant intrusion of their chronic conditions into their lives, including how it affected surgical and perioperative care. This frustration led some patients to seek distractions by altering elements of their lifestyles, behaviors, and health management. Some patients discuss that distractions make them feel better despite their diseases. *“Feels hopeless lots of times, but when around people and distracted, I feel pretty good. Better than i have in a long time.”* [Q514] However, the pleasure of distractions is momentary, for example, as long as a vacation. *“We had a wonderful time [during vacation] ... We just forgot totally about [prostate cancer] ... Ok, now I’m back and I do have to deal with stuff.”* [Q99] Once the distraction ends, however, the patient still needs to take up their disease related responsibilities. As noted in the data above (i.e., Q369), some patients already do not maintain their recommended exercises and prescriptions to pursue healthier lifestyles.

3.4.1.4 Psychological Changes

Prior to surgery, patients in our data set sometimes experienced serious psychological changes, and their frustrations or anxieties sometimes affected surgical eligibility, hindered

healthcare opportunities, and physically manifested as new symptoms. For example, one patient noted that he was afraid to go see an orthopedic surgeon to have a surgery performed on his torn meniscus. Although the patient noted that the surgery was both common and relatively short (i.e., a “day surgery”), the patient had had negative experiences with prior unrelated surgeries, and thus found it difficult to stay positive. *“If I don’t get [this anxiety] in check then my asthma could flair. I’ve had bad painful experiences with surgeries...”* [Q79].

Also, patients with a history of failed treatments can even develop psychological comorbidities, such as depression. Multiple procedures can leave patients demoralized and fatigued, and patients may consider if their life in that form is worth living; they may give up hope for future treatments, or even develop suicidal thoughts which prevent them from seeking further medical assistance for their problems. As a result, these psychological problems may prevent patients from further seeking and receiving the healthcare they need. *“Been through tons of medical stuff, 19 surgeries, so many procedures, I can’t count; constant pain, and feeling worthless and without value.... I just don’t want to live anymore.”* [Q313]

This is a significant problem, because many patients from our data had anxiety or fears about undergoing surgeries and procedures for reasons such as side-effects, scarring, or changes in quality of life. One 47-year-old patient who had had type 1 diabetes since she was 2 years old noted that after years of being healthy with diabetes, her condition worsened (i.e., she was diagnosed with “non-proliferative diabetic retinopathy”), but on top of this, she also had been experiencing neuropathy and carpal tunnel syndrome. Although she was approved for surgery on her hands, in which her conditions caused a stinging sensation, she could not undergo surgery because she would have panic attacks when she went to the clinic. *“I was not able to get the surgery and probably won’t because I am afraid I won’t heal properly.”* [Q219] Even in cases where patients are informed about the procedure and have been assured that risks are minimal, they may still feel anxious.

3.4.1.5 Adjusting Drug Regimens

Pre-surgical patients are often told to change or stop medications prior to their surgeries because of potential complications. For instance, a patient with rheumatoid arthritis and a high BMI was in need of a hysterectomy. Her womb had thickened and was leaning permanently on her bladder, causing constipation and cramps. She had her ovaries removed and used high doses of Humira, Mobic and Prednisone on daily bases, and at the time of the post she was controlling her condition. However, her upcoming surgery made her need to stop using Prednisone and Humira. Thus, she sought information support online for alternative solutions. *“I have to wean off prednisone and humira to have the surgery.”* [Q182]

In contrast to patients like Q182, who need to stop prescription medications, other patients need to add medications to prepare for surgeries. However, patients from our data note feeling anxious about adding new medications to their routines, which may already require multiple medications. As noted above, surgery can postpone patients from taking necessary medications if there can be potential complications; clinicians may need to add non-prescription supplements as substitutions until after surgeries. One patient noted that she needed to be on a specific drug for neuropathy. However, her neurologist had to wait to allow the usage of the medication because it might interfere with the patient’s upcoming foot surgery. Therefore, the patient could not be put on her needed treatment regimen until after the surgery, and a substitution was made using over the counter supplements. *“My neurologist added 1200 of fish oil to the aspirin until my surgery is done then I will start Coumadin therapy.”* [Q502]

3.4.1.6 Failure to Meet Expectations

Patients can become frustrated or overwhelmed when presented with new burdens, including new medications, procedures, symptoms, and continued appointments. If MCC patients perceive consistent failures or have negative treatment experiences with clinicians over time, then they may become frustrated with their healthcare. One patient noted that that he had been following the advice of multiple clinicians over a period of years. He had experienced multiple mental health diagnoses and surgeries, for which he was prescribed a variety of medications which never seemed to solve his problems or gave him terrible side effects. *“I am tired of playing ‘pill roulette.’ I usually get the opposite reaction of what the medicine is supposed to do...”* [Q213]

3.4.1.7 Lack of Guidance

Throughout surgical care, clinicians present patients with new information regarding diagnoses, prognoses, and treatment options. Much of this information can be confusing for some patients, at least those in our dataset. For example, one patient was diagnosed with breast cancer, depression and had a family history of diabetes. She would like to have a regular blood glucose meter testing to keep informed about her condition, and she was instructed to eat normally before the test, but because of her family history of diabetes, her diet contains few carbohydrates. Therefore, her diet may have made the results unreliable. Echoing sentiments from prior work suggesting that healthy people respond differently to social incentives than patients with conditions (Chen, 2017), our data suggests that standard procedures for healthy people cannot always be applied to MCC patients. *“Also, I had later read that this test requires carbohydrate intake for a few days prior to the test, but as I was not told that, I ate normally.”* [Q591] Moreover, patients may be given various test results, but they may be unable to comprehend them. Insufficient

guidance and explanation can inhibit patients from comprehending their illnesses and care. *“At the end of the report it states... ‘Impression: Diffuse Atherosclerotic changes with no hemodynamically significant stenosis identified.’ So I’m not sure what to make of it.”* [Q390] Even when information is abundantly available, patients may still have unanswered questions about their conditions and health. *“After reading for days about pre-diabetes, I find myself more confused and scared...Does anyone have info (books, websites, apps) on good diets for active women with ‘pre-diabetes’?”* [Q2] This post demonstrates the patient’s awareness of his or her current condition, and that he or she is actively performing self-care through participating in promoting his or her own health and managing his or her conditions (Levin, 1983).

3.4.1.8 Limitations of Prehabilitation for Chronic Conditions

Some chronic conditions are not appropriate for, or create difficulties for patients to benefit from, prehabilitation. Optimism for any opportunities should be tempered, as chronic conditions like respiratory ailments, can hinder a patient’s ability to perform or adhere to sufficient prehabilitation exercises. Furthermore, a dietary restriction like gluten intolerance or an allergy can limit nutrition based pre-operative improvements, and pain can prevent patients from receiving enough sleep. Many medications which manage patients’ diseases can cause pre-operative complications which make surgery difficult or dangerous. For example, one patient noted that surgery (i.e., percutaneous closure) would be especially dangerous for her, despite it potentially being a viable way to treat her ailment. This is because she suffered from rheumatoid arthritis, and had to use medications which weakened her immune system. Therefore, her risk of postoperative infection would be greater than average. In these cases, treatment options may be limited to lifestyle changes. *“I have an autoimmune disease (rheumatoid arthritis) so my immune system is suppressed by injections...”* [Q502]

3.4.2 Patients' Postoperative Complications

Surgeries can have drastic effects on patients' lives. Complications, like psychological and physical impairments, can result from the procedures, but other complications could result from medications, the hassles of previously failed surgeries and readmission, and insufficient accommodations.

3.4.2.1 Postoperative Physical Complications

Surgeries can lead directly to a variety of complications. For example, surgeries may successfully address a patient's problem and still cause infection. These infections can be severe, and may even necessitate further surgical intervention. One 21-year-old patient with cardiovascular disease required a sternotomy during a procedure. However, after the sternotomy, he experienced an infection around the lower sternal wire. Another surgery was required to remove the sternal wire and to remove a portion of his bone which had become infected as a result of the sternotomy. *"[D]uring the surgery a little part of bone was to be removed because it became soft because of high infection."* [Q30]

After their surgeries, patients may once again face pain, discomfort, altered behaviors, and difficulty performing routine tasks. These effects may be permanent, or they may be addressable with rehabilitation. If rehabilitation is possible, it may require an indefinite amount of time and exercise, and yet may still not return a patient's functioning to pre-operative levels (Gillis, 2014). One patient with osteoarthritis noted that he or she had surgery 3 months prior to the date of the post. The patient was still experiencing post-operative complications, such as swelling and pain, despite adhering to rehabilitative exercises. *"I did all the required therapy as it's my only*

dependable hand. I'm continue to do the exercising with hope that my finger will get back to some normalcy." [Q473]

3.4.2.2 Postoperative Medication Complications

Depending upon the patient and the surgery, some medications will need to be taken for the remainder of the patient's life, whereas others will have a definite use duration. Specific durations depend upon patient needs and treatment plans. However, in some instances, the patient may need to sacrifice comfort for health when deciding whether to continue or discontinue certain medications. One patient, for example, noted experiencing a great deal of pain post-surgery. To treat the pain, the patient used opioid painkillers. However, the painkillers caused opioid constipation which made the patient afraid of developing further complications (i.e., an impaction). Thus, the patient ceased medication. *"I stopped taking [painkillers] the day after discharge because none of the stool softeners or laxatives were working so I made the decision to bear the pain to avoid an impaction."* [Q366]

3.4.2.3 Emotionally Worn Down by Procedures

Prior to surgeries, patients may feel anxious, overwhelmed, frustrated, or depressed. Patients may be uncertain what effects their conditions will have upon their future. Postoperative complications and challenges which result from failed surgeries can thus have further detrimental and frustrating effects on patients, and they may become dissatisfied if they perceive that they are healing more slowly than they would like. Frustration over results can even result in patients choosing to cope with their problems rather than risking another failed surgery. *"I am tired of*

having repair surgeries and the “down” time associated with them. So far I have had 7 surgeries associated with [rheumatoid arthritis] (broken bones count due to meds weakening bones).” [Q74]

After surgery, patients may feel frustrated in their inability to do certain things, isolated as they recover, overwhelmed with their new health statuses, or even discontented with their rate of healing. As one 29-year-old patient with breast cancer and depression noted, postoperative challenges can create a feedback loop of mental and physical unhealthiness. “[P]ain causes depression. Depression causes pain. Pain causes impulsive behavior, horrible thoughts.” [Q24]

3.4.3 Patient-perceived Challenges for Social Interaction

Patient needs are not constant throughout the stages of surgical care; they are often intermittent and changing. The struggles of these patients with their surgeries and chronic conditions create cascading and persistent negative effects on patients’ social relations. As a result, patients in our dataset often sought support, as well as information, when they posted online. Furthermore, these posts often revealed a variety of tensions with clinicians, family, and others around them.

3.4.3.1 Tensions Between Patients and Care Collaborators

Stress from surgery causes negative interactions between patients and their care collaborators. Thus, persistently affecting patient social interactions.

1. **Patient helplessness.** After failed surgeries and treatments and ineffective medications, patients can become so frustrated that they believe no clinician can help them. This patient helplessness can be generalized, or it can be specific to a certain symptom or ailment. Patients can become depressed and feel like they are beyond all hope of any possible treatment, and in

- some cases, that can hinder their search for help. *“I’m searching and searching for ways to feel better and it seems the harder I try, the worse it gets!”* [Q300]
2. **Dissatisfaction with clinicians.** Patients note a variety of factors which cause them to feel dissatisfied with their clinical care, including but not limited to: the distance to specialists, the need for multiple visitations or to see multiple specialists, the unavailability of a specific clinician, a lack of clear and comprehensive information during the healthcare process, and even the perceived loss of autonomy. Patients note that clinicians do not communicate clearly enough the expected outcomes of treatments. A 64-year-old patient with prostate cancer was dissatisfied with his first clinician because the clinician gave him expectations which differed from actual outcomes. The patient believed that he was not able to find another clinician in the same hospital due to political issues. *“The chief was not happy. He was cold with me, disinterested”* [Q197] Patients do not always follow the recommendations of clinicians. Due to their chronic conditions, patients in our dataset often saw numerous clinicians, and any two clinicians could have arrived independently at differing diagnoses and prognoses. This in turn could result in patients searching for even more opinions. Multiple patients noted that finding a reliable and knowledgeable clinician was difficult. In fact, patients are in many cases searching for second opinions regarding subjects (e.g., treatment options) they discuss with their clinicians. Second opinions can come either from other clinicians or from other patients; this is consistent with prior research regarding patient vs. medical expertise seeking (Hartzler, 2011). *“[I] would like to hear from real women, not statistics”* [Q589]
 3. **Antagonism.** Some patients felt that their clinicians held views or had practices which were antagonistic towards their health and recovery. For instance, some patients believed that clinicians would not listen to their opinions or believe them about their problems because of their histories with drug abuse or psychological illness. Furthermore, other patients believed that clinicians would purposefully suggest more costly and unnecessary procedures so that the

hospital or the clinician would receive more money. *“He is in cahoots with my [urologist]. Seems they all want some of my blood and cash.”* [Q132] Interestingly, some patients noted that their clinicians were reluctant to offer them risky or unproven treatments and medications, as the clinician or hospital did not want to be liable for any problems. *“He wants a cardiologist to sign off on me - and I don’t even have a cardiologist. Basically, he wants no responsibility for it!”* [Q174]

3.4.3.2 Tensions with Family

Patient surgical care affects more than just the patient; it also affects the patient’s family and friends. Oftentimes, surgeries and medical ailments are a source of worry for patients’ loved ones. These people provide support, offer information, and help the patient to attend appointments and throughout recovery. For example, younger patients may cause financial burdens for their legal guardians. A 21 years old patient with depression and multiple illnesses noted feeling frustrated about the trouble she and her condition caused for her family. *“I cause my parents so much pain, suffering. They have to spend so much money they don’t have.”* [Q27] On the other hand, legal guardians can have their recovery affected by caring for their children. Legal guardians may not be able to rest, perform physical therapy, or adhere to certain postoperative recommendations if they are responsible for others. Furthermore, surgeries can often permanently change an individual. These changes may negatively affect previously close relationships between friends or spouses. Sometimes, these changes are a source of frustration, while other times they drive people apart. *“I CANNOT get better in the face [of] his anger because I am sick and REFUSE to get better.”* [Q53]

3.5 Opportunities for Future Research

In the previous section, I described MCC patients' surgical challenges, which illuminated issues significant for the design of technological interventions aimed at enhancing patient surgical care. Our design implications are focused on pre-surgical care, including providing guidance for MCC patients in altering lifestyles, investigating well-being, and supporting collaboration and communication.

3.5.1. Provide Guidance for CC Patients in Altering Lifestyles

Chronic conditions can be managed effectively and relatively inexpensively through altering lifestyles (e.g., smoking cessation, increased exercise, dietary changes) (Fight Chronic Conditions). These preventative strategies heavily rely upon patient self-care, such as through the management of symptoms, treatments, emotions, and lifestyles as part of everyday living (Nunes et al., 2015). Self-care is often guided and assisted by formal and/or informal carers (Nunes et al., 2015). These strategies also utilize elements which can be ascribed to the health belief model, which examines the behaviors and attitudes of individuals to explain and predict health related behaviors; this model suggests that patients will perform certain health activities if they have perceived benefits (Becker, 1974), and we see patients in our data similarly trying to perform healthful behaviors, but not having sufficient guidance to do so in the results section. Designers need to provide new ways to keep patients informed and provide guidance.

Personal informatics studies in HCI and health informatics have attempted to improve means of summarizing and visualizing large quantities of information to help people better acquire self-knowledge (e.g., Bentley et al., 2013; Epstein et al., 2014). These works have potential to apply to the particular example of surgery patients with MCC, but caution is needed before applying

findings from non-highly burdened demographics to demographics such as MCC patients undergoing surgeries. Research shows that self-monitoring technology can complement prehabilitation management, as it offers both therapeutic and assessment opportunities (Korotitsch & Nelson-Gray, 1999). The self-monitoring process as a whole, including therapist instructions, training, self-recording devices, and self-monitoring responses, leads to changes in the frequency of desired behaviors (Korotitsch & Nelson-Gray, 1999; Nelson & Hayes, 1981). According to Social Cognitive Theory (SCT), self-monitoring is a part of self-regulation, which allows individuals to focus upon long-term positive outcomes while enduring shorter-term negative experiences (Glanz et al., 2008); therefore, professionally guided self-monitoring may quell negative emotions and experiences associated with, for example, new diagnoses or complications, by offering a means to better health through goal-setting and self-knowledge. Self-trackers often assume that their tracking data is an objective means to identify and understand situations so that actions may be taken quickly and effectively; this belief and these trackers' actions may be intertwined with feelings of self-control and empowerment (Ayobi et al., 2017; Swan et al., 2009).

Opportunities for Future Research: self-monitoring is a step towards understanding one's problems. For MCC patients, designers should consider including the following recommendations: First, consult healthcare professionals or follow the National Guideline Clearinghouse (The National Guideline Clearinghouse) for specific condition management. Second, consider including medications, associated reaction tracking, and medical self-assessment questionnaires in any technology's design. Third, consider the target population's data literacy. Because the majority of MCC patients are older adults, designers should consider providing the most important information in a minimalistic style (Carroll, 1990). Fourth, allow for easy sharing and user discussion. For example, many MCC patients seek help in the form of discussions on Healingwell as well as many other online discussion fora. Discussions may increase confidence and self-awareness of current stages, as well as promote reactivity, which can aid in changing or

maintaining targeted behaviors. In addition to the above suggestions, enabling self-monitoring data sharing (Zhu et al., 2016) can also help clinicians identify which patient cases are inappropriate for prehabilitation. Designers should consider utilizing the benefits of self-monitoring technology, because such technologies can not only improve patient prehabilitation experiences, but also potentially be used to guide rehabilitation for similar purposes (Silver et al., 2015).

3.5.2. Supporting Collaboration and Communication

Consistent with findings from prior health peer support research (Hartzler et al., 2011), collaboration happens spontaneously among prehabilitation patients, clinicians, and third parties. For example, clinicians check patient progress and collaborate with dietitians and kinesiologists to adjust patients' treatments, and patients often receive social support from families and friends (Berry et al., 2017). In fact, most of the posts in our data set sought either peer or information support from online communities, which is consistent with prior peer health support research (Heaney et al., 2008). Patients in our data flocked to online health fora, so community elements may be significant for these patients' health outcomes. In our data, patients shared progress and success with others, and drew inspiration from the progress and success of other patients. Peer supporters are significant for inspiring, informing, and encouraging patients when they are anxious, depressed, or uncertain.

Many patients from our data also sought informational support from peers because they were confused, unclear about a topic, or they wanted to know more about the information clinicians briefly introduced to them. Established literature suggests that patients often seek a different expertise from patients than they do clinicians (Hartzler et al., 2011), but our data suggests that part of the process of patients seeking information results from insufficient clinician communication. Clear communication is key for patient-clinician collaboration. During typical healthcare

processes, clinicians might expect patients to clearly communicate such things as prior health histories, current symptoms, and health related activities, yet they may not always reciprocate by informing patients about care management plans, medication and treatment options, or even treatment risks. As demonstrated by examples throughout our results, current clinical practices can sometimes fail to equip patients with the necessary knowledge or support to be active participants in their healthcare. As a result, patients in our data set expressed a variety of tensions with clinicians, such as dissatisfaction with care, beliefs that their clinicians were acting antagonistically, or feelings that no clinician could help them.

Opportunities for Future Research: designers should consider patient needs regarding information seeking and sharing, support, and the management of multiple needs over multiple surgical stages. However, the target patient demographic is already struggling with multiple burdens from chronic diseases. We must be careful not to overburden them with new tasks (e.g., manual tracking). It may be beneficial to make self-care a more collaborative endeavor. When patients engage in self-care, it is often coupled with clinician collaboration, but the patients are the ones committing to and performing necessary actions (Nunes et al., 2015). Encouraging clinician participation in self-care, such as by sending prompts to ask clinicians to provide instruction on self-care activities, or by adding clinicians as moderators (Huh et al., 2014b), is important for the success of this practice. Benefits of this recommendation might include data consistency regarding clinician-accepted protocols (Zhu et al., 2016), and a clinician presence to which the patient is accountable which could be beneficial for engagement (Zhu et al., 2017). In addition, designers should be aware of the changing social contexts which also influence the way patients adopt medical technology (O et al., 2015). In the long term, if patients can be provided with clear and manageable goals with concrete effects on their health, they may more deeply develop autonomy over their health outcomes, thus limiting the need for clinician guidance in future health issues.

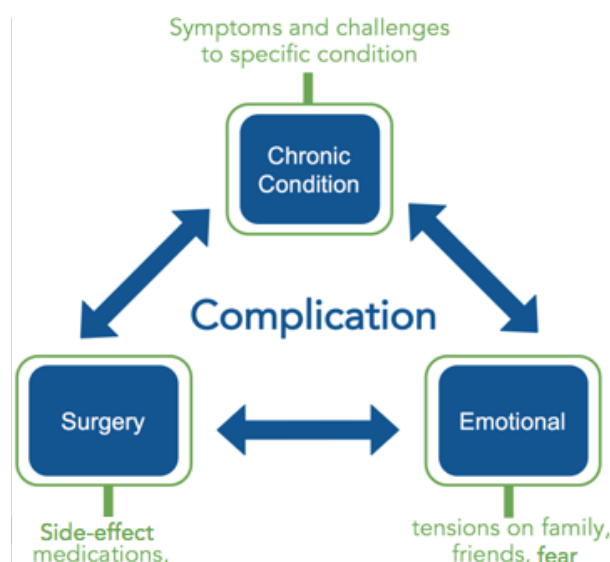


Figure 6: Theoretical interrelated mode of complications.

3.5.3. Addressing Interrelated Challenges

Up to this point in our paper, we have separated patient needs to illuminate the range of challenges and to aid in discussion of potential recommendations; in actuality, however, these needs are often interrelated. A more thorough examination of patient needs may be necessary to benefit patients. Surgical patients with MCC often face complications and challenges which stem from across three orders. Although simplified from the complex reality of CC management, we present a more holistic model of MCC patients' surgical care needs (Figure 6). First, MCC patients experience the primary complications of their chronic conditions, which includes symptoms and challenges specific to the condition. Next, secondary complications arise from their need for surgeries, and can include psychological changes, new medications, and side-effects to new medications. Finally, patients may experience tertiary emotional and social complications, which include tensions with family, friends, and career peers which result from the above complications. This theoretical interrelated model of complications demonstrates the degrees of complications a patient may experience, and it should illustrate the interrelatedness of these issues. A more

complete model may include a holistic interpretation of habilitation (i.e., the inclusion of post-operative and rehabilitation related complications), but such a model is beyond the scope of this work, and further research regarding this theme should be conducted.

As patients may have a variety of interrelated levels of complications, technology for these patients should be capable of addressing each level of complication independently while promoting overall well-being. Separation of needs is necessary, as not all needs will have the same time spans, but each need must be addressed to promote overall well-being, which requires HCI researchers to consider interrelated challenges in future works. For patients with multiple orders of complications, treating one problem without considering how the effects will cascade into other complications would be unwise. The interdisciplinary nature of prehabilitation could be better understood by utilizing existing theories to explain why patients will take action to prevent or control illnesses, including (the health belief model (Becker, 1974)), to understand their intentions to perform behaviors (the integrated behavior model (Montano & Kasprzyk, 2015)), and improved by using positive design for patient psychological well-being.

3.6 Chapter Summary

This exploratory study provides a patient-centered understanding of how MCC patients characterize their information needs before and after surgeries, with an eye towards the challenges they encounter during current practices. Patients with health problems prior to their surgeries are often ill-prepared to face the impending stresses of their procedures and they may experience long lasting or permanent complications. Rehabilitation can sometimes help, but it is inefficient for clinics and insufficient to address global trends. Thus, solutions like prehabilitation are necessary. However, currently little research discusses pre-surgical patients with MCC, or their surgical needs and challenges. Furthermore, research on how to incorporate novel assistive technologies into the

care process of these patients is also lacking. To address these gaps, we qualitatively analyzed publicly available data from an online health forum. We determined that needs, challenges, and opportunities are not static throughout surgical healthcare. New problems, such as anxiety in pre-operative waiting periods or new required medications after a surgery, can either be acute and short-term, long-term and indefinite, or permanent. MCC patients also often face multiple levels of complications, including primary complications from their chronic conditions, secondary complications which result from surgeries, and tertiary complications which result from the complications from those surgeries. Each of these needs must be addressed in different ways and for different lengths of time, but they are all interrelated for patient whole health.

Furthermore, posters in our data set expressed a variety of tensions with clinicians and peer supporters. Some posters were dissatisfied with care, some believed their clinicians were acting antagonistically, and others believed that no clinician could help them. Clinicians and peer supporters however, are significant for inspiring, informing, and encouraging patients when they are anxious, depressed, or uncertain. In fact, the majority of posts in our data set were seeking either information or support from online peers. As such, we see that technologies might be best if they address patient needs regarding information seeking and sharing, supporting, and the addressing of multiple specific needs over multiple specified time spans. Many of these activities could be incorporated into devices for better collaboration between patients and clinicians, and even peers. However, the target patient demographic is already struggling with multiple burdens from chronic diseases. We must be careful not to overburden them with new tasks (i.e., entirely manual self-tracking) and we should endeavor to help reduce burdens. Further research into these important topics will be necessary to address global trends in health.

Chapter 4

Exploratory Study: Experts' Perspectives on Care Challenges and Technological Opportunities

This chapter presents a summary of results from a second exploratory study aimed at understanding healthcare professionals' prehabilitation challenges (RQ2) and how they respond to said challenges in real-world practice. I uncover and present opportunities for computing to support the promotion of tool adoption by healthcare professionals.

4.1 Introduction

Millions of surgeries are performed in the US annually, and numbers are trending upwards. Traditional rehabilitative interventions are struggling to meet current demands, and researchers have turned to pre-operative interventions, or prehabilitation, to improve patient functions. However existing literature primarily discusses efficacy or the use of commercial' sensing devices, and lacks a clear comprehension of healthcare professionals' (HPs') needs and perspectives. User-centered stakeholder understandings are crucial for a technology's adoption, but prehabilitation literature lacks such understandings.

As mentioned in Chapters 1 and 2, researchers lack a firm understanding of prehabilitation stakeholders' challenges, needs, and expectations because user-centered approaches for regarding these stakeholders is limited; to our knowledge, only patient perspectives have even been examined (Zhu et al., 2018c; Ferreira et al., 2018), but that leaves a gap regarding HPs' perspectives. Prehabilitation differs from similar techniques, like rehabilitation and physical therapy, in key ways (see 2.1.1 and 2.1.2); therefore, we should not expect prehabilitation providers to have exactly the

same needs as rehabilitation providers. Despite these differences, we note that technologies used in prehabilitation (e.g., accelerometers, gyroscopes, Fitbits, heart rate monitors, other wearable sensors and monitors (Rumer et al., 2016; Beg et al., 2017; Sathe et al., 2018; Singer et al., 2017; Cuadros et al., 2017;)) are rarely designed specifically for prehabilitation; indeed, they are often adopted or customized commercially available or consumer health tools which were predominantly designed for other purposes and stakeholders. Noting that adoption of stakeholders' in early design phases for technologies is significant for tool success (Zhu et al., 2016), we believe that the differences between intended stakeholders for these devices and the prehabilitation stakeholders who adopt them hinder successful tool utilization. Therefore, to promote successful tool design and adoption in prehabilitation, we answer through this work the following research questions:

- What challenges do prehabilitation HPs face, and how do they respond?
- What are HPs' perspectives regarding adoptable technologies for prehabilitation?

Being a multimodal, multidisciplinary intervention (Minnella & Carli, 2018), prehabilitation can require heavy collaboration amongst team members; owing to the necessity of patient at-home exercise prescriptions for prehabilitation success, collaboration must also occur between patients and HPs. Noting both the heavy collaborative emphasis and the dearth of tailored prehabilitation technologies, we identify this as an ideal area for HCI research to facilitate collaboration amongst healthcare professionals and with patients. However, the literature has a startling lack of user-centered studies for prehabilitation and its stakeholders (Zhu & Carroll, 2018a), despite their input being crucial for successful technology adoption (Abrams et al., 2004). We therefore conduct a formative study through semi-structured interviews with 12 HPs to understand their needs and challenges as stakeholders in this collaborative care and thus facilitate prehabilitation technology design. Through synthesizing expert stakeholders' perspectives, our work provides HCI designers practical requirement analysis regarding which kinds of tools might be suitable for prehabilitation processes. Our works' main contributions to the field are:

1. Examinations of prehabilitation through a user-centered lens to understand and chronicle HP stakeholders' perspectives, which adds to the body of HCI healthcare research.
2. Descriptions of HPs' perspectives regarding prehabilitation challenges, how HPs respond to said challenges in real world practices, potential barriers for technological adoption, and future directions for adoptable tailored prehabilitation tools.

4.2 Method

We conducted 12 semi-structured phone interviews with HPs; interviews ranged from 30 to 90 minutes based on HPs' discussions with the researcher. HPs participated voluntarily, and were not compensated for interviews. The university's Institutional Review Board (IRB) approved this work.

4.2.1 Participant Recruitment and Interviews

To answer how HPs respond to complex patient challenges, we performed a qualitative interview study to build an understanding of our stakeholders and gain insights regarding contexts and their specific needs. The study's inclusion criteria for HPs necessitated that they have experience researching prehabilitation, or providing patients real-world prehabilitation services; both require highly specialized training. Note that because our inclusion criteria requires participants to have experience either as prehabilitation providers or researchers, some of our participants' works may be cited within our work; for anonymity reasons, we cannot specifically say which works, if any, but we assure readers that none of our participants had prior knowledge of their works' inclusion.

We first sent recruiting emails to addresses which were found in popular prehabilitation publications and recruited 7 participants; these 7 HPs were then interviewed. We then used word-of-mouth referrals at the end of each interview to recruit 5 additional participants. In total, we sent 32 recruiting emails and recruited 12 participants. For confidentiality, we assigned HPs identifier codes (i.e., C#). Participants' roles can be categorized as surgeons (C1, C2, C3, C6), C3's research assistant (C4), exercise experts (C5, C7, C8, C9), therapists (C10, C12), and a nurse (C11). Among the 12 participants, C2, C10, C11, and C12 belong to one Facial Nerve Clinic which was purpose-built approximately 2 years ago to treat facial paralysis patients in a prehabilitation program. C3 and C4 are researching prehabilitation for pancreatic cancer patients together. Table 2 shows our HP participants' occupations and which patient population they primarily focused on.

All interviews were done via phone for consistency and ease of participation; questions were designed to explore HPs' perceptions about care processes, treatment challenges, and technology support needs, etc. Interview questions included as Appendix A: Interview Guide for Clinicians.

Table 2. Prehabilitation healthcare professionals' information. Note that HPs who share the same number in the clinic section are members of the same clinic.

| ID | Occupation | Patient populations | Clinics |
|-----|---|-----------------------------------|----------|
| C1 | Gastrointestinal oncologist | Elderly & cancer patients | Clinic 1 |
| C2 | Facial plastic and reconstructive surgeon | Facial nerve palsy patients | Clinic 2 |
| C3 | Pancreatic cancer oncologist | Cancer patients | Clinic 3 |
| C4 | Surgical oncology researcher | Cancer patients | Clinic 3 |
| C5 | Behavioral management and exercise science researcher | Elderly patients | Clinic 4 |
| C6 | Surgical oncologist | Elderly & cancer patients | Clinic 5 |
| C7 | Exercise physiologist | Elderly & osteoarthritis patients | Clinic 6 |
| C8 | Exercise oncologist | Cancer patients | Clinic 7 |
| C9 | Exercise physiologist | Knee replacement patients | Clinic 8 |
| C10 | Speech language pathologist | Facial nerve palsy patients | Clinic 2 |
| C11 | Otorhinolaryngology nurse | Ear, nose and throat patients | Clinic 2 |
| C12 | Physical therapist | Facial nerve palsy patients | Clinic 2 |

4.2.2 Data Analysis

With consent, we collected HPs' prehabilitation recruiting materials, program plans, exercise handouts, instructions, exercise logs, and educational slides for training HPs in their facilities. All interviews were audio-recorded and transcribed to aid inductive thematic analysis (Braun & Clarke, 2006). To be precise, we obtained themes emerging from the first three interviews via open coding. The primary researcher organized these themes into a table of themes and sample quotes which defined the themes. Then, the primary researcher and secondary researcher discussed and refined the themes. Later, the primary researcher read and coded the remaining nine interview transcripts. Both researchers studied the data and identified patterns for semantic themes, and axial coding was applied to the themes to make categorizations and understand relationships. Themes irrelevant to our research goals were discarded. Finally, these themes were mapped and became the following high-level subthemes: 1) HPs' care challenges, and how HPs respond to challenges, 2) technologies and tools, and 3) aversions.

4.3 Results

In this section, we first report challenges that our HPs' encounter during their care practices, and how they respond to those challenges. We then report their perspectives regarding future directions for suitable technologies for potential adoption into prehabilitation programs. Finally, we report on their beliefs and potential aversions to adopting novel technologies in their practices.

4.3.1 Healthcare Professionals' Responses to Challenges in Care Practices

HPs' face 3 major challenges during daily practices: accurately assessing and tailoring prehabilitation programs for typically non-ideal surgical candidates; adequately informing patients during limited visit times; and encouraging patient engagement during programs. In the following subsections, we describe these challenges, and HPs' responses, in more detail.

4.3.1.1 Tailoring Prehabilitation for Non-Ideal Surgical Candidates via Assessments

Prehabilitation, itself a coping strategy for non-ideal surgical candidacy, is typically a 6-8-week program designed to improve patients' health prior to surgery to reduce recovery times and post-operative complications. Half of our HPs directly say that either all or most of their surgical patients, if not all surgical patients, could benefit from prehabilitation, but that it is most beneficial for non-ideal surgical candidates with poor physical functions (e.g., old, frail, chronic/comorbid diseases, etc.). C1 describes specifically his patients as: *"generally older...usually quite frail. They have a lot of medical problems, a lot of comorbid illness..."* HPs note that prehabilitation has few risks (i.e., the same risks as exercise), but patients (e.g., those with cardiac conditions) might need tailored plans to participate.

Prehabilitation HPs are not typically patients' primary physicians, so primary physicians may be consulted to understand patients; however, questionnaires, surveys, and other measures (e.g., frailty, Western Ontario McMaster University Assessment, Beck Depression Scale, MOS-36, SF-36B2 standard, weight, vital signs, etc.) are typically the first tools used to form patient baselines based on specified functions and patient perceptions. These tools are supplemented with physical examinations. C7 notes, *"there's a number of paper and pencil assessments, as well as I think it's important to... measure functional ability."* These data are key to understanding patient

needs and providing tailored, effective care. C8 notes, *“evaluation results indicate what the deficits are and what they would most benefit from...”* However, the variety and number of available measures may cause HPs difficulty choosing and implementing what measures might be most effective. HPs cope by choosing context-specific measures with apparently good predictive capabilities.

In addition to consultations and validated measures, HPs can use specialized equipment to objectively measure patient conditions beyond more typical objective data (e.g., weight, height, etc.). For example, C9 notes, *“We used a handheld isokinetic device to measure their strength using torque... to check like leg extensions and leg curls.”* C9 further notes using pressure plates to objectively measure baseline gait and gait improvements as follows: *“The plate was designed to where they would step on it... with their bad leg, and then the second time around the track... with their good leg... we could tell how much favoring of the good leg... and how they would try to keep some weight off of the bad leg. As their strength improved they used their bad leg more...”* C9 is here describing a research project which aimed to determine one program’s efficacy. Specialized tools like isokinetic devices and pressure plates are not always used in our HPs’ prehabilitation.

Baselines help HPs tailor care based on general multi-component frameworks, but extant academic and commercial frameworks might not meet patient variability. C8 notes, *“if [prehabilitation is] cookie cutter, then everybody gets the exact same prescription... one person walks in with a lung missing, and another person walks in really healthy... there is a need for individualization...”* Personalized care is often necessary, and includes changing plans (e.g., delaying surgery, tailoring for patient goals and progress, etc.) and meeting patient needs (e.g., physical limitations, chronic illnesses, distance from care, etc.). C8 notes tailoring from a framework as follows: *“So we work with a systematic approach and then individualized within the framework... there are five modes of exercise that we consider [aerobic activity, strength training, flexibility exercises, balance exercises, and rest] ... their evaluation and safety leads us to what we*

prescribe. So we do a test... to understand their aerobic capacity and if it's clear that they are really debilitated... then we might give them aerobic activity... If they feel worse or more [tired] after they exercise... Just take it easy until their next round of exercise... and see how they feel at that point."

Note that assessments continue throughout care.

4.3.1.2 Mediating Excessive Patient Information Needs through Handouts

After HPs' tailor patient plans for, they need to explain these plans and patients' roles therein. Their first challenge is explaining all relevant information in a limited amount of time. C1 states, *"I don't have the time in clinic I talk to them for an hour about the cancer and about the surgery... I don't have the ability to also talk to them about which exercises to do and which nutrition parameters to improve..."* HPs cannot focus on just prehabilitation; time must also be spent discussing the patient's condition and the rest of the care plan. All of this information may be difficult for patients to fully grasp at one time. C1 adds, *"Most of the patients are mostly quiet... they don't ask questions... the biggest thing they ask is what to eat and nutritional support. The second biggest thing is how to prepare for surgery."* Note that patients may not ask questions during clinical visits, thus further exacerbating information needs.

Our HPs try to inform their patients to the best of their abilities in the limited clinic time of visits, but they also provide handouts with key information. C1 states, *"We try to have general guidelines for walking, and increasing the fitness, and stair climbing, and basic things that most people can do... for nutrition... for smoking cessation, for sugar control... Beyond that it becomes very hard, and I want to be able to cater to each person individually... I go over everything with them, I talk to them, I give them brochures and booklets..."* These typically paper-based handouts are fairly typical of our HPs' prehabilitation programs, although the information shared will differ based on the specifics of the programs (e.g., knee replacement programs provide different exercise

handouts than facial paralysis programs). Notably, C4 incorporated a pre-developed resistance band exercise program, which had its own videos and website explaining the exercises, into a prehabilitation program; these reference materials were also provided to the patients. C4 describes, *“The doctor who developed [the exercise] program developed a video to show people how to do the exercises. So I do give people a DVD or a website where they can go look at the videos.”* Note that these videos were not tailored to the prehabilitation program, but rather to the exercise program which was incorporated.

4.3.1.3 Understanding and Fostering Patient Engagement via Tools

HPs do not know their program adherence or drop-out rates and lack objective ways to track either. Adherence estimates vary from 10% [C5] to 80% [C8] and drop-out estimates vary from 9% [C8] to 30% [C7]. HPs note that determining adherence is hard because patients self-report at-home work. C9 says, *“I really couldn’t tell you [if patients follow prescriptions] because two of the days they would be at home... you don’t know if they just self-reported and said that they did.”* HPs say patients report dropping out due to low motivation, poor health habits, lack of time, and not noticing benefits. C10 says, *“Some... say they didn’t notice a change... [or] they’re too busy. Those are the two biggest excuses or reasons I hear.”*

HPs promote engagement via: phone calls, patient activity logging, consumer health tracking devices, social support, and demonstrating progress via videos or photos. Phone calls for example are used to check on patients, exchange information, and promote accountability. C4 notes, *“I think that knowing that someone’s going to call and they’re going to have to say oh I did or didn’t do it, makes them more inclined to do it.”* Patient self-logging is also used to promote engagement and better understand adherence, but compliance can be low. C1 notes, *“I ask them to keep a log of how much they walk every day and how many times... compliance is poor... like 10%*

or 20%.” In addition to patient self-logging, participants also have access to consumer health tracking devices to gather certain data. C4 notes, “*we have the pedometer, but that’s really it... [an associate] used activity monitors in preoperative settings... but I don’t think anybody in our group used it for prehabilitation study.*” Finally, HPs have tried to capitalize on research regarding the effects of social support on health outcomes and engagement to care plans. C3 says, “*the researcher [that] designed that study really felt like a lot of the benefit came from the social aspect of the exercise...our idea behind exercising with a buddy was that we were trying to maintain a little bit of that.*” C3 thus describes implementing social support in the form of an “exercise buddy” in the hopes of improving patient adherence.

Finally, we note that C2, C10, C11, and C12 are members of one interdisciplinary team at a purpose-built Neurology clinic which specializes in a multi-component otolaryngology disorder (i.e., ear, nose, throat, head, and neck disorders ranging from hearing loss to cancer) care; they offer treatments such as prehabilitation, surgeries, and rehabilitation. Owing to unique circumstances, patients require and have access to much longer prehabilitation. However, long durations lead to a unique motivational challenge compared to other, shorter programs. HPs at this clinic try to sustain patient motivation over lengthy care plans by demonstrating to patients their progress; this process is aided by videos and photos which can be referenced in the clinic. C12 notes, “*after a couple of months, she was saying how frustrated she was... it was so hard to do and making progress... I pulled out her video and showed her... and she made dramatic improvement. She was impressed herself when she saw the video and saw what she looked like then and what she looked like now. And that really helps to keep the patient motivated to continue to work...*” Note that HPs are not using videos to motivate patients directly, but as tools to correct patients’ faulty perceptions about improvement over time; the demonstration of this unperceived progress is what our HPs believe motivates patients.

4.3.2 HPs' Perspectives on Future Directions for Adoptable Technologies

Although HPs discuss many factors which limit novel technology adoption, they offer a few suggestions for technology and tools which they would find useful. Themes for these technologies include: informing and instructing through tailored patient reference materials, telehealth, and life coaching; increasing patients' adherence through feedback, accountability, social and informational supports; and measuring, interpreting, and sharing data regarding intended activities.

4.3.2.1 Instructional tools

Participants note that technologies could be instituted to improve collaboration with patients through facilitating communication and education. For example, they note that educational references could be improved (e.g., by using more prehabilitation specific video references of exercises). C1 suggests, *"ideally I would do more decent education through... websites or through videos or... personalized to them not just generic."* C1 expands upon this idea as follows: *"if you had some sort of a way to communicate... if they had questions about nutrition then I send them a link to one of the videos I have about nutrition... a lot of hospitals are using text messaging apps that allow the patients to text the team..."* Therefore, C1 is suggesting both more tailored (i.e., less generic) and more varied forms of patient reference materials, as well as more accessible patient means for communicating with HPs (e.g., applications and text messages).

HPs also suggest that "life coaching" may improve prehabilitation education practices, especially in terms of scalability of services. C9 notes, *"let's say we turned the Skype on every day at 1:00 and they turn theirs on. The coach would talk to a hundred of them. We have them all do the same exercises at the same time. That would be a way to do a hundred people in one [session]."*

HPs thus believe that telehealth and coaching could be employed in conjunction to reach multiple patients at one time.

In addition, HPs note that telehealth could allow for sharing relevant data between clinic visits, thus allowing patients to inform HPs. C8 describes one potential automated tool as follows: *“it would be amazing to... have a device that gives momentary analysis data for a quick question, like ‘how tired are you on a scale of one to ten...’ Or, have something come up that just says, ‘Do you have a symptom you want to report at this moment?’ And they can just checklist, fatigue and pain...”*

4.3.2.2 Adherence tools

Drawing upon their years of experience providing and researching prehabilitation, our HPs provide their opinions on what technologies might contribute to or improve patients’ adherence to prescribed prehabilitation programs. Themes regarding such adherence tools include: setting reminders to do activities or to remind patients of progress; providing positive and negative feedback mechanisms; fostering accountability during patient at-home activities; supporting patients; providing data sharing and communication channels.

Automation. HPs suggest that wearable sensing technologies, activity monitors, and remote monitoring tools may reduce patient burden while providing objective medical data. C1 describes, *“activity monitors that automatically upload... they don’t have to remember to put something on or send it or anything like that. And so the ideal thing is just remote monitoring without any... work by the patients.”* In this instance, C1 notes that both the automatic uploading of data and the ability to wear sensory technologies reduce a patient’s burdens during the tracking of his or her data, and suggests that reducing patient burdens in these areas may improve adherence.

Reminders. HPs note that patient reminders to fulfill prescriptions may promote adherence and engagement. C4 says, *“I think that maybe if they had reminders on their phone if they use any, it would help them [to keep participating].”* Note that C4 suggests phone-based reminders, but is aware that not all patients use phones. C2 suggests the following application reminder: *“I think an app will help just because they have that daily reminder... set reminder for exercises today or [ask] ‘hey how are you feeling about this today...’ a reminder to not forget about it, to keep doing it... or [remind them] ‘hey, see where you are if you made benefits,’ they can... look at videos from six month ago and [now and]... evaluate themselves.”* C2 is suggesting two reminders, one for prescriptions and the other to remind patients about their baselines in the hopes that improvements might motivate them.

Feedback. HPs suggest that patient at-home feedback mechanisms may aid adherence and engagement. C8 describes coupling collected data with feedback as follows: *“we could be using monitors that are wearable, but that information is made much more usable by incorporating it into a system where [patients] get feedback.”* HPs also suggest offering negative as well as positive feedback. C1 notes, *“I don’t know how well it would work for [prehabilitation] but... people have these [smoking cessation] apps and text messages... when you admit that you smoked a cigarette, it reminds you smoking causes cancer... you need negative feedback in addition to positive...”* C1 is suggesting that automated negative feedback systems in other health contexts may be suitable for prehabilitation. The potential to use text messages, specifically in contrast to emails, is further discussed by C8 as follows: *“People read their texts. They’re a quick way to communicate... if we’re going to use these commercially available [sensors], we’re going to have to now do feedback. Now what’s interesting is that the feedback is programmed... it’s not actually a real person...”* Note that C8 here is describing an automated text response for a weight loss system, which is similar to C1’s discussion of automated smoking cessation systems; therefore, HPs believe that this potential feedback mechanism might be a good avenue for automation to improve adherence while

potentially reducing human burden. Feedback might also clarify patient prescriptions and allow HPs to respond to patient non-adherence if coupled with remote monitoring. C8 notes, *“the first way is by giving them feedback about their amounts of activity... But giving people specific instructions about their step goal is a very basic way of ensuring that you are clear about what their “prescription” is... The second level is that objective level to be monitored. In order to be able to say... ‘It looks like you’re not walking at all. Are you feeling okay?’... if someone has been walking regularly, but they start walking less, it’s very likely that something’s wrong...”* C8 is suggesting that remote monitoring could allow HPs to tailor care and respond to patients’ distress at-home to improve adherence. In addition, remote monitoring or phone calls might foster patient accountability. As C4 states, *“...knowing that someone’s going to call and they’re going to have to say ‘oh I did or didn’t do it,’ makes them more inclined to do it. Or if I call... and they say, ‘I haven’t done anything since [the last call]’ I say, ‘it’s okay if you miss sometimes just do some tomorrow and you will get back on track’... that helps them to continue.”*

Support. In addition to the instructional benefits of information support tools and techniques discussed in 4.2.1, HPs believe that providing information, social, and emotional support might also improve adherence. For example, HPs believe that increased social support (e.g., exercise buddies) during exercises may increase adherence. C4 says, *“... those who have a spouse that are willing to be a part of [the exercise program is] much more likely to stay with it...”* However, HPs do not believe physical colocation is necessary for patients to benefit from social exercise; they note that telehealth could enable patients to exercise as a group. C4 describes a scenario as follows: *“if people are willing to do a video call, I would be able to observe them doing the exercises... we can get bunch of people doing them together...”* In addition to these social supports, C2 would like to incorporate mental health specialists to support patients during long programs. C2 states, *“[Patients]... see a lot of specialists, but that doesn’t help the way they feel... one thing we are going to do... is get a support group with psychologists, a therapist, and a social*

help psychologists, to... get people with them meet each other, talk about how they are feeling because they really really need that..." C2 thus identifies a need for responding to prehabilitation patients' emotional and mental health as well as physical health; note that such a holistic approach might require diverse interdisciplinary collaboration.

Interaction. HPs describe interacting, or their desire to interact, with other HPs throughout our results, but they also note the importance of interacting and communicating with patients; however, they note that these necessary interactions may cause challenges. C12 explains one challenge sharing data between HP team members as follows: *"We only have access to our equipment. It would be nice if we had some shared equipment so that whenever we upload those files... everybody has access..."* C12 is describing difficulty collaborating with HPs caused by data storage on dislocated pieces of clinical equipment. HPs also point to problems storing patient generated data for record-keeping and collaboration. C2 describes an example as follows: *"these patients will come in and say... 'look when I have recorded myself on my iPhone,' so they show it to us... they don't share it for their chart or anything... we use it a lot for parents to record their children doing facial movement so we can see if they are doing abnormal movement..."* C2 notes that patients may want to share their data with HPs to improve diagnoses and care but the clinic does not collect this data directly. Patient generated videos and photos are not stored directly in an EMR for future reference; instead, HPs make notes of their observations while viewing patient data sources and store those notes in patients' files. To facilitate patients in sharing relevant and meaningful data, C2 also discusses the potential use of patient at-home questionnaires as follows: *"a way to communicate with us and they come in and say, 'hey I have been following this on my app and I notice that I'm really still having a hard time with this every day,' or... 'I do pretty well until I get stressed out and then this is what happens...' it helps them communicate what they're going through at home..."* Note that C2 is suggesting questionnaires and an application which

would allow patients to find patterns and trends in their tracked data to improve interactions and collaboration with HPs in the clinic.

4.3.2.3 *Measurement tools*

We have discussed the validated measures, wearable sensors, and other measures used by our HPs in prior sections, but we note that they have several suggestions regarding: objective and subjective measurement tools and synthesizing/triangulating data sources.

1. **Objective assessments for clinical efficacy of care.** In addition to detecting patient at-home prescription adherence, HPs suggest using quantitative tools to understand both patient baseline and patient improvement from prehabilitation. One suggestion from C8 follows as such: *“So what we really need is to have a fairly robust suite of sensors... to understand... things underneath, in the shoe to understand pressure... inclinometers to understand the extent to which somebody is standing, versus sitting... accelerometers. And... we probably need to understand respiration... [and] temperature. And if there is a way to detect blood counts without... taking a blood sample...”* C8 is describing a comprehensive suite of sensory tools to more completely and automatically detect factors for one prehabilitation program. Such a suite, C8 believes, may allow HPs to detect intended activity (e.g., physical activity during prescribed exercises) and patient health instead of just isolated quantitative measures (e.g., steps taken). C9 describes a similar desire with a clinical focus as follows: *“... if you had the ability to set up infrared cameras and video tape them walking. Then, we also used little balls that you attach to each joint... we could tell if they limped. It would show up in the computer program as a limp, and then after surgery did the limp go away?”* Note that C9 is describing using objective tools to understand the efficacy of a given surgical care plan (i.e., prehabilitation, surgery, and

- rehabilitation). In both cases, C8 and C9 are describing medical grade tools for precise measurements.
2. **Subjective Measurements for Patient Perception of Efficacy.** Although HPs note utility of objective data, they feel that subjective data like patient perceptions of care can be equally or more important. C2 states, *“some of the questionnaires... [are] about how this is affecting their life... research shows that [facial paralysis] decreases quality of life... patients will isolate themselves... being able to follow how they are doing really helps us... know if anything that we are doing is actually making a difference... [if] all your scores say that you feel terrible, and I do a big surgery... and I say, ‘man that’s the best result I can get, you look fantastic...’ do patients actually feel that too?... or am I putting them through all this without making a meaningful difference for the patient?”* For HPs like C2, objective data do not determine if a program is successful for a patient. C2 wants to know if a patient feels that care is beneficial, and wants to measure patient perceptions between clinic visits; patient perceptions ultimately determine whether C2 believes a patient’s care plan has been effective.
 3. **Triangulating Objective and Subjective Measures.** Objective and subjective data both have significance for our HPs in different contextual circumstances; therefore, HPs suggest that mixed method approaches to monitoring are important. C8 states, *“all objective monitor data tells us this person should be increasing their activity, increasing the weights they’re using or increasing their steps... but the patient reported outcomes tell us that they feel... fatigued or in they’re in pain... It’s got to be combined, it’s got to be a mixed approach because you have to meet people right where they are. And there could be a whole variety of reasons why somebody is feeling fatigued.”* C8 thus believes that synthesized measures, or holistic health monitoring, is not only necessary to understand patients’ experiences, but also their physiological responses to prescriptions. C8 further clarifies the need for synthesizing objective and subjective sources as follows: *“researchers just throw those [false patient self-report] data out... what are you*

going to do? Call the person and say, 'hey you lied...' That's not exactly going to... win any point with the subject... what ends up happening is... You triangulate around three things. The objective monitors, the fitness changes, or strength changes... And the self-report changes. So if you get all three, then you feel like, okay, I really have a change." C8 thus notes how one form of data can be reinforced or invalidated based on independent measures; although objective measures are useful for understanding what a patient needs, and subjective measures are useful for understanding how a patient feels, both are needed to understand a patient's health.

4.3.3 Projected Aversion to Technology Adoption

Prehabilitation programs contain primarily older adults, and our HPs feel that older adults may not use, have access to, or adopt "common" technological tools (e.g., smartphones). C3 states, *"we were not using iPad, just because a lot of patients are elderly... we felt like they would be intimidated by the iPad and not want to participate."* Moreover, participants are also ambivalent about adopting new technologies, as they may reduce patient care quality. C8 notes, *"if the answer is that we're giving them technology and then ignoring [the patient], that's not going to work..."* Note that HPs like C8 concerned that technologies which reduce patient-provider interactions could negatively affect care quality. Another concern is that although commercially available tools may be cost-effective and readily available, they may not be ideal for prehabilitation or may not ideally measure intended activities. C7 explains, *"the pedometer is to measure physical activity throughout the day. We're more concerned, did the person do their prescription? So the pedometer wouldn't really necessarily pick that up."* In other words, a pedometer can only record how many steps a patient might take, but it will not tell a clinician if the patient has performed his or her prescribed exercises. Finally, HPs note that HIPAA laws restrict to whom and what kinds of data are shared.

C2 describes one data sharing tool challenge as follows: *“something that they are going to share with us that... might have some personal information, then absolutely [it needs to be approved by the law]. That’s where we kind of got into some difficulties because I want to be able to see their results.”* C2 is thus describing how merely having patient tracking data capabilities is insufficient because of strict personal data policies.

HPs use the existing tools which best fit their momentary needs. HPs may provide patients dietary supplements, informational handouts, exercise equipment like dumbbells, activity monitoring or sensing tools, and paper-based self-tracking logs. Our HPs thus offer their patients options and use the methods to which patients respond best. C3 notes, *“we offered them an option to submit their journals by email but for the most part people were doing them on paper.”* However, paper-based logging may be preferred by HPs for other reasons than just their patients’ preference; HPs may utilize paper-based logging because of the relative value of current sensing technology data. C5 explains, *“No matter what you do, you’re relying on the patient’s memory because, unless you have them strapped to something that records nonstop, which you really don’t, everything is self-report.”* Therefore, when our HPs use sensing data, the data are often treated as indirect or imprecise indicators of potential activity; these data are supplemented by patients’ manual logs to allow for corroboration and clearer comprehension of patient activity.

4.4 Discussion

Prehabilitation offers opportunities to improve pre-surgical patients’ physical and psychological health, reduce health provision costs, decrease hospital readmissions, and increase post-surgical survival outcomes (Carli & Scheede-Bergdahl, 2015; Silver et al., 2013). However, prehabilitation lacks user-centered studies for HP stakeholders, despite such studies being key for successful tool design (Zhu et al., 2016); thus, prehabilitation tool designers may lack

comprehension of HPs' needs and expectations. Our work offers one of the first user-centered studies regarding requirement analysis for prehabilitation HPs. We identify and explore the challenges for which they most desire solutions, as well as their perceptions about tool adoptability.

Our results indicate that the challenges for which HPs most desire solutions are related to patient at-home work, especially regarding patients' abilities and motivations to collaborate in care. HPs want primarily monitoring and motivational tools which can facilitate their roles as instructors and consultants during patients' at-home work, thus allowing patients to become more accountable; notably, existing literature seems to suggest that prehabilitation patients also feel that greater guidance would better allow them fulfill their collaborative prehabilitation roles (Zhu et al., 2018). These findings are significant because the majority of a patient's prehabilitation work is typically conducted unsupervised while at their homes (Bousquet et al., 2018). If patients are not prepared for, or do not adhere to, their prescriptions, outcomes will be less than optimal. These circumstances make this research area ideal for HCI studies. To foster collaboration between patients and HPs via technology, our work discusses the needs of HPs during the following four higher-level processes.

4.4.1 Technological Supports for Assessing and Tailoring

In order to respond to patient variability and provide quality care, HPs must assess patients using questionnaires, surveys, context-specific measures, verbal assessments, and occasionally specialized equipment to form baselines. These baselines allow our HPs to tailor care from a generalized multimodal prehabilitation framework to meet patient needs. We note that establishing a baseline to tailor programs is one of the areas in our results which contains the most unique challenges. Key challenges in this stage of care may be consistent with other care contexts, and includes: clinical time constraints, potential reductions in face-to-face consultation times, and too numerous existing tools (e.g., varied assessment measures, validated scales, specialized objective

measurement equipment). Therefore, we suggest looking for technological solutions to address these challenges; dedicated ethnographic workflow studies, which are promising for discovering technological opportunities in related healthcare areas (Beg et al., 2017), might be ideal for understanding how to design tools for these issues. Based on our results, we tentatively suggest synthesizing and consolidating validated scales and measures (e.g., auto-population of measures from assessment devices with overlapping data), and allowing for patients to complete forms at home (i.e., by reducing medical knowledge complexity in forms) may be viable research avenues. However, HPs should be incorporated into early design phases for grading tools to promote adoption (Zhu et al., 2016); for patients completing forms at home, existing tools (e.g., patient portals) might be able to support such practices, but patient-generated data sharing will need to meet strict HIPAA laws and policies.

Another key issue our HPs discuss regarding tailoring care plans is heterogeneity, which is apparent in many prehabilitation aspects. Prehabilitation programs use commercially available and generalized tools and frameworks (Strong for Surgery), but these fail to meet highly variable patient needs. Patient demographics for our HPs are variable, but they tend to be older, frailer, and have comorbid or chronic illnesses; if these patients were not in poor condition, they might not even need prehabilitation to meet surgical requirements. This patient variability requires a holistic assessment of health and similarly comprehensive care plans (e.g., balancing acute needs vs. chronic illnesses (Zhu et al., 2018)). We thus believe that generalized prehabilitation programs, even those specific to one treatment (e.g., knee replacement, cancer care, facial paralysis, etc.) will only be viable as a foundation for care planning. Care must be individualized to ensure needs are met and sufficient outcomes achieved. Currently, this customization work utilizes HPs' expertise, and cannot easily be replaced by automation or technology. Instead, designers should design tools which facilitate HPs during their unique care processes. Of further note, the need to respond to

patient variability may hinder researchers' abilities to compare efficacy among different prehabilitation programs.

We also note that prehabilitation providers are diverse, interdisciplinary, and not necessarily formally trained for prehabilitation. None of our participants, whom we deem experts because of their experience providing or researching prehabilitation, have been formally trained in prehabilitation provision. This creates two research opportunities: 1) understanding how to foster collaboration in diverse clinical prehabilitation teams via technology, and 2) synthesizing a holistic account of prehabilitation care provision strategies to aid new providers in the absence of formal training. Our findings show preliminary patterns; for example, therapists and researchers participants desire more apt sensing tools, whereas doctors and surgeons want remote monitoring. As for the second opportunity, we hope that this work can help to build and promote a foundation for provider needs.

4.4.2 Informing Patients to Promote Care Collaboration

Informing and instructing patients begins in the clinic, but time constraints exacerbate how much information can be shared between HPs and patients and can hinder patient interaction; this finding is consistent with existing literature (Zhu et al., 2016). HPs also note that most patients do not ask enough questions during visits, and this may in part result from the patients receiving too much information at one time; it might also result from clinical workspaces being poorly designed for supporting patient collaboration in healthcare processes (Unruh et al., 2010; Zhu & Carroll, 2018b). This challenge is currently addressed by sending patients home with references and allowing them to call the clinic with questions. In addition to our HPs' suggestions in our results, we believe that providing patients a scaffolding (e.g., a list of potential questions they should ask their HPs) prior to or even during visits may facilitate discussion and collaboration within the clinic.

Clarifying and supporting at-home activities is necessary to further promote prehabilitation because these activities often constitute the most time and effort spent in prehabilitation (i.e., clinical visits are relatively short and infrequent in comparison to daily at-home prescriptions); therefore, success is likely determined by the amount of prehabilitation work patients conduct at home. As key as these at-home activities are to prehabilitation success, researchers should dedicate time towards ethnographic observation studies of patients performing prehabilitation in their homes. In addition, designers and researchers of clinical workspaces and relevant technologies should examine how to promote and facilitate patient collaboration and specifically question asking within prehabilitation contexts.

4.4.3 Engaging and Monitoring Patients in Care Collaboration

The area with the most HP suggestions in our dataset is patient at-home adherence and engagement; one of the biggest challenges for this is that HPs are currently unaware of their programs' adherence and drop-out rates and rely on estimations. Rate estimates vary widely in our small sample, a finding which is consistent with prior healthcare research (e.g., prehabilitation adherence in research settings at 70% (Gill et al., 2003) compared to at-home rates of about 16% (Carli et al., 2010). This shows an opportunity for technological interventions to support precise measurements for these rates. HPs find accurately measuring patient adherence difficult, in part because a significant portion of care occurs within the patient's home, unsupervised. HPs have tried to create an atmosphere of accountability for patients through self-monitoring (i.e., logging) and sensing technologies (e.g., pedometers) as well as telehealth communication between visits (i.e., phone and video calls). However, manual self-monitoring relies upon patient honesty and memory, and HPs find that commercially available sensing technologies may not accurately measure intended activities (i.e., pedometers cannot show if a patient performed prescribed modular

activities). Systems for gait analysis (Sathe et al., 2018) or those which triangulate from multiple data sources may be more beneficial to HPs than simple sensing devices. Readers should remember that owing to the fact that prehabilitation is an underexplored medical research area, many of our HPs are also researchers. The authors believe that absolute values (i.e., sensor measurements) tend to be sought by researchers looking to gauge program efficacy, whereas impressionistic values (i.e., patients' self-reports) appear more relevant to clinicians. Therefore, system designers should be project-specific when conducting prehabilitation research or work.

Our HPs note success in motivating patients by demonstrating progress via visual media, but they still lack the means to determine if such acts lead to greater engagement or adherence; these techniques are also limited to clinics because HPs must record patient videos on institutional devices (i.e., owing to restricted protections for patients); sharing such media outside of clinics is often a grey area (i.e., HIPAA laws impose challenges regarding how and what kinds of data are shared). Current practices thus may fail to motivate patients at critical times (i.e., when low motivation prevents exercise adherence at-home). These techniques may not be apt for shorter programs, but existing literature does suggest that humans in general often fail to perceive even drastic changes during relatively short time spans (Levin et al., 2000), and that older adults' abilities to perceive subtle changes decline with time (Yang et al., 2017); these techniques thus may still be suitable for older patients.

HPs note that they may be better able to respond to patient adherence problems if they adopt remote monitoring tools (Singer et al., 2017) for patients' actual behaviors, and that they may benefit from adopting sensing technologies designed for program-specific, targeted activities. Future research needs to explore how to make low-cost targeted prehabilitation technologies as well as the effects these tools have on HPs' time and burdens. We should not expect HPs to adopt remote monitoring tools and techniques which increase their burdens without some form of

compensation; such tools should either reduce burdens elsewhere in HPs' workflows to free already utilized time, or these HPs' monitoring activities should be compensated (Zhu et al., 2016).

4.4.4 Addressing Projected Aversions

Finally, we note that our HPs are weary of using novel technologies primarily because of concerns that older patients may not adopt them. One contribution of this paper is providing HP stakeholder perspectives to identify perceived barriers to allow for tool designs which overcome them; we feel that HPs' aversions to potential tools are key to understanding how to design tools which will be adopted. We note that despite their concerns HPs' still suggest that text messages may be a viable tool for monitoring and feedback. Therefore, our HPs are themselves receptive to technological solutions and they must further believe that even their perceived-to-be technologically adverse patient population might adopt simple tools. However, we believe that our participants' perceptions regarding older adults' technology preferences may be incorrect, and that these programs can effectively incorporate more complex technological tools. We note that preliminary feasibility studies of internet telehealth communication software in prehabilitation for older adults is promising (Doiron et al., 2018). To facilitate incorporation of such tools, an educational module on the use of telecommunication software could be incorporated into the in-clinic exercise teaching component of prehabilitation, and similar references to those for exercises may be distributed for technology use. In addition, we should look into avenues of breaking HPs' presuppositions regarding older patients. Researchers and designers may also explore ways to explicitly raise questions regarding older patients' technology preferences with HPs prior to or during clinic visits, or create older adult personas for technology adoption based on real-world data.

4.4.5 Future Work and Limitation

Our study uses a small, non-random sample (N=12) owing to the short supply of prehabilitation experts. Our work also uses experts from varied programs intended for different purposes and without standardized operations between said programs. As a result, our study provides a general overview of prehabilitation and may miss vital data for more specific prehabilitation examinations. Furthermore, this paper focuses on HPs' perspectives and is biased towards a clinical understanding of prehabilitation. Patients and/or other stakeholders' perspectives should be considered; for example, related health research shows the importance of design opportunities for caregivers (Kaziunas et al., 2015). We also note that owing to prehabilitation's need for tailored care plans, studies comparing programs, even those for the same treatments, may face challenges from heterogeneity. Further research should be conducted towards specific programs and the needs of their HPs. Although we offer a foundation for designers to create tailored prehabilitation technologies, we urge them to incorporate stakeholders into the early design stages for tools to further promote adoption and efficacy. We recommend potentially inviting stakeholders from a program to design workshops to ensure needs are fully met, but designers could consider synthesizing our HPs' perspectives with patients' perspectives if stakeholders are hard to incorporate.

4.5 Chapter Summary

Prehabilitation is a promising research avenue for responding to current and future healthcare needs, but tools designed for prehabilitation are rare. We note that user-centered studies regarding prehabilitation experts' needs and current expectations are also lacking in the literature. To address this gap, we employ user-centered interviews with 12 experts to explore their current

practices and perspectives; we identify their care provision challenges, the techniques they use to respond to those challenges, what technology is currently being used and where, and what kinds of technology might be desired by HPs to aid future practices. Using participants' responses, we identify prehabilitation assessment as a potentially significant area for technological facilitation; in addition, we identify training and adherence technologies for patient at-home work as the areas for which our experts most desire technological assistance. Our study takes a user-centered approach to understand which specific technologies within these themes might be adopted and which might not meet expectations. Further research in this vein will be necessary to fully comprehend the vastly heterogeneous field of prehabilitation and to design novel tools intended to facilitate its processes and HPs, but this work represents a crucial first-step towards user-centered design for prehabilitation technologies.

Chapter 5

Formative Case Study: A Case Study of Multidisciplinary Care for Facial Paralysis Patients

In this chapter, I present the summarized results from a formative case study aimed at answering the following: How do members of a prehabilitation team for Facial Paralysis (FP) collaborate amongst themselves and with patients? This study offers a response to RQ3.

5.1 Introduction

Peoples' faces can drastically affect how others perceive their intelligence, fitness, competency, and other significant traits (Zebrowitz & Montepare, 2008); facial appearance is therefore one of the most important factors governing our everyday interactions. However, approximately 127,000 people per year acquire facial paralysis (FP) (Bleicher et al., 1996), like synkinesis, Bell's Palsy, Ramsay Hunt Syndrome, etc. (Shafshak, 2006; Teixeira et al., 2011), which can affect their facial appearances. Over half of FP patients may experience psychological distress and withdraw socially because of their FP (Kosins et al., 2007). FP affects life functions as well as quality of life; FP can cause drooling, inability to chew food, inability to express oneself clearly, and blindness (i.e., from inability to close eyes) (Brach & VanSwearingen, 1999), etc.

FP treatment typically uses: physical therapy, Botox injections, surgery (Shafshak, 2006; Teixeira et al., 2011), and/or electrical stimulation therapy (Tuncay et al., 2015). Because FP treatments often use invasive interventions (e.g., surgery), FP treatments can be seen as prehabilitation (e.g., our site's healthcare professionals consider FP therapy prior to invasive interventions "prehabilitation"). Prehabilitation is preoperative care to improve post-operative

outcomes by preparing patients for surgical stresses (Gillis et al., 2014; Zhu et al., 2018). The same FP physical therapy may be continued after invasive interventions, and can thus also be rehabilitation. Rehabilitation is relatively well-studied, but prehabilitation has only recently become active in healthcare research; rehabilitation and prehabilitation are often studied in conjunction (Nielsen et al., 2010).

In part owing to the varied causes of FP and its complex treatment plans, FP care teams can include multiple specialists (e.g., surgeons and therapists). FP treatment efficacy is a well-studied though inconclusive to controversial (e.g., physical therapy efficacy (Brach & VanSwearingen, 1999) vs. (Teixeira et al., 2011), and electrical stimulation efficacy (Diels, 2000) vs. (Tuncay et al., 2015)) topic, but little is known about how healthcare professionals (HP) collaborate to provide FP treatment. This comprehension gap for complex team dynamics in FP treatment workflow and collaboration hinders our abilities to design adequate, scalable, and efficient support technologies (Unertl et al., 2009). Therefore, we must study these processes from all collaborators' perspectives, including the patients', to facilitate novel designs. Prior research does show that active patient roles (i.e. rather than the passive roles of traditional acute illness care) can benefit certain forms of long-term care (Holman & Lorig, 2000), but patients' active roles have only recently begun to be examined, and patient at-home activities are often treated as separate from treatment roles (i.e., general health management or information work) (Unruh et al., 2010). Our work differs from this perspective, as patient at-home activities are not merely health management or information work; they are often the main form of FP treatment, the factor most expected to lead to progress, and thus inseparable from patient care collaboration. This work begins to fill those crucial gaps regarding understanding potentially complex prehabilitation team workflow, though we note that our strict observation of only clinical settings limits knowledge about patient at-home work and roles. We examine technology's role in collaborative workflow interactions through 20 sessions of clinical observations and 11 total interviews with HPs and

patients to uncover how HPs in one multidisciplinary FP treatment team (i.e., including a surgeon, a nurse, and two therapists) collaborate with themselves and patients. We ask the following research questions:

- How do multidisciplinary FP treatment team members collaborate amongst themselves and with patients?
- What is this team's typical workflow like, and what technological insights can we gather by studying said workflow?

Our work adds to the HCI literature by exploring patient-provider communication and care-team coordination research in multidisciplinary healthcare contexts. We believe that medical services can encourage and strengthen health outcomes by mediating patients' and HPs' mutual efforts and service exchanges. We use user-centered approaches to contribute the following to workflow, care-team coordination, and complex healthcare team collaboration research:

1. Synthesized observation and interview data in a Facial Paralysis Treatment Model, (i.e., in-depth descriptions of HPs' and patients' collaboration). By beginning to incorporate patients' collaborative roles and contributions into clinical workflow models, we notably become advocates for a perspective shift regarding patients' active roles in healthcare collaboration.
2. Identification and discussion of challenges through the FP Treatment Model for HPs (e.g., EMR related challenges) and patients (e.g., motivational challenges regarding perception of progress), and potential ways to facilitate collaboration and communication (e.g., self-monitoring with visual media for patients' benefits, etc.). These challenges may be relevant for designing technologies in other multidisciplinary healthcare collaboration settings, and it may further identify the need to expand the current scope of complex healthcare team collaboration research.

5.2 Methods

We conducted real-world observations during 20 FP clinical visitations (i.e., 7 initial and 13 return visits; 9 males, 11 females) and semi-structured interviews with 11 participants (i.e., 4 HPs and 7 patients involved in the visits). This research was approved by the university IRB.

5.2.1 In-situ Observations

Observations were conducted in a university-affiliated teaching hospital's Neurosurgery department at Hershey Medical Center from 12/2016 to 4/2018. At the end of 2016, C1 started a new subsidiary of the neurology department to test the efficacy of combined FP treatments. The new clinic was only open the second and fourth Fridays a month. Shortly after, HPs noted successes and saw increased patient treatment demand (e.g., site patients usually wait more than 3 months for initial appointments). The clinic experienced many setbacks, like the lack of a standardized plan and understaffing. Physical therapy is a well-studied FP treatment option, but these HPs' attempt to design a structured series of treatments incorporating prehabilitation, rehabilitation, Botox injections, and surgeries is novel. They chose to collaborate with us (i.e., "the IT people") in hopes that we could assist their processes with technological support. This formative case study is the first step toward understanding their problems and helping to facilitate their processes, although, we feel this work is applicable to other contexts. Over a year and half, the first author made a total of 7 trips (i.e., each 3-4 hours) to the site. After observing 20 FP sessions, the recurrence of similar themes in the sites' patient data were noted. Observations lasted from 25 to 90 minutes, varying based on if a patient was a new or return patient, FP treatment methods, and the patient's comprehension. For each session, the observer stood in the corner of the exam room, taking detailed

notes of patient-provider interactions and treatment processes. Conversations were not recorded due to their sensitive nature. Observation data were digitized at the end of each trip.

5.2.2 Semi-structured Interviews

We designed interview questions based on an initial understanding gained from our observations. We used phone interviews for all semi-structured interviews; this was mostly for patient comfort and openness, which we hoped would increase participation. We used a mixed-methods approach for the following reasons: 1) we wanted to gather patients' FP prehabilitation perspectives after they had a few months of experience with their exercises and to capture nuanced data which might have been missed during observations; 2) HPs are in an authoritative role during clinical visits, and we wanted to better capture patient collaboration contributions, which can easily be overlooked; and 3) we wanted to check our observations for internal validity by interviewing FP professionals and patients and collecting corroborating discussion for our model.

5.2.2.1 Interviews with Healthcare Professionals

Interviews ranged from 30 to 50 minutes, varying based on the conversations between the researcher and the HP. Figure 7 shows our HP participants' information and how they collaborated to provide services. HPs were not compensated for interviews or observations. The site's FP team is comprised of 5 HPs, of which we recruited 4 through convenience sampling. We did not get a response from the resident doctor supervised by the surgeon we worked with. The inclusion criterion for professionals necessitated that they have experience providing care for FP patients, and said experience requires highly specialized training. Table 3 shows our HP participants' demographic information. Interview questions for these professionals were designed to facilitate

an understanding of their reasoning behind each step of the treatment process, their technology support needs, and the challenges they currently face (see Appendix A: Interview Guide for Clinicians).

Table 3. Facial paralysis clinician's information

| ID | Specialty | Supports Needs |
|----|---|--|
| C1 | Facial Plastic and Reconstructive Surgeon | Store, organize, and share photos |
| C2 | Speech language Pathologist | Record, store, organize and share videos |
| C3 | Neurology Nurse | EMR |
| C4 | Physical Therapist | Record, store, organize and share videos |

5.2.2.2 Interviews with Patients.

We restricted patient recruiting to patients present at our observations. We obtained consent during these observations to contact them for the interview study. We contacted all patients and asked if they would participate in follow-up interviews; we received no responses. We contacted them again and offered \$20 as compensation. Only 7 agreed to be interviewed. Each interview lasted from 40 to 60 minutes. Table 4 shows patient participants' demographic data. We designed questions to guide patients to discuss FP treatment experiences (see Appendix B: Interview Guide for Patients).

Table 4. Facial paralysis patient participants' demographic information

| ID | Age | Sex | Occupation | Diagnosis | Since Diagnosis | Therapy Duration | Exercise Frequency | Exercise Duration |
|----|-----|-----|-------------------|------------------------------------|-----------------|------------------|--------------------|-------------------|
| P1 | 51 | M | Truck driver | Bell's palsy, paralyzed from Tumor | 1 year | 1 year | Daily | 10-15 min |
| P2 | 35 | F | Nurse | Ramsay Hunt | 4 years | 2 years | Daily | 15 min |
| P3 | 63 | F | Daycare provider | Bell's palsy | 6 years | 2 years | 3-4 times per week | 30-45 min |
| P4 | 49 | F | Medical Assistant | Bell's palsy | 1.5 years | 6 months | Daily | 25 min |
| P5 | 59 | F | Self-employed | Bell's palsy | 6 years | 4 years | Inconsistent | Inconsistent |
| P6 | 61 | M | Professor | Bell's palsy, Ramsay Hunt | 1.5 years | 6 months | Daily | 45 min |
| P7 | 39 | F | School Teacher | Paralyzed from Tumor | 1.5 years | 3 months | Daily | 10-15 min |

5.2.3 Data Analysis

With HPs' consent, we collected copies of all the materials they used during patients' visitations. These materials included: The House-Brackmann facial nerve grading scale (House, 1985) for characterizing the degree of FP, the Sunnybrook facial grading scale (Ross et al., 1996) for assessing patient facial movement outcomes, Botox injection locations and amount graphs, an evaluation of volitional movement sheet, facial massage and exercise handouts, and the patient final report template. All interviews were audio-recorded and transcribed to facilitate analysis. To ensure participant confidentiality, we assigned unique participant identifiers to note participant roles (i.e., C# to denote a HP, and P# to denote a patient).

To understand how multidisciplinary teams collaborate and their associated challenges, we first established the FP workflow model based on our clinical observations. Interview data were used to check for model consistency (i.e., by checking what participants said about treatment against what was observed) and then analyzed for later synthesis. We analyzed transcripts using grounded theory (open coding). 2 researchers independently read and coded 50% of the transcripts and extracted 754 quotes from patients, and 371 from HPs. We subjected these quotes to axial coding to identify patterns and relationships to form high-level themes and subthemes. Researchers discussed discrepancies, and once agreement was reached, framework categories were revised and expanded, thus creating the final coding scheme for our FP workflow model (Figure 7). Interview data were then integrated into the model. This approach allowed us to understand the core components of FP in practice and finalize our model. Prior healthcare workflow modeling studies (Chen, 2010; Zhu et al., 2017; Ni et al., 2011) were used as external validity measures. These models were not directly adaptable to our work, as their described higher-level activities are insufficient for the complex, multidisciplinary FP team in our context, and further do not place adequate emphasis on patient collaborative activities.

5.3 Results

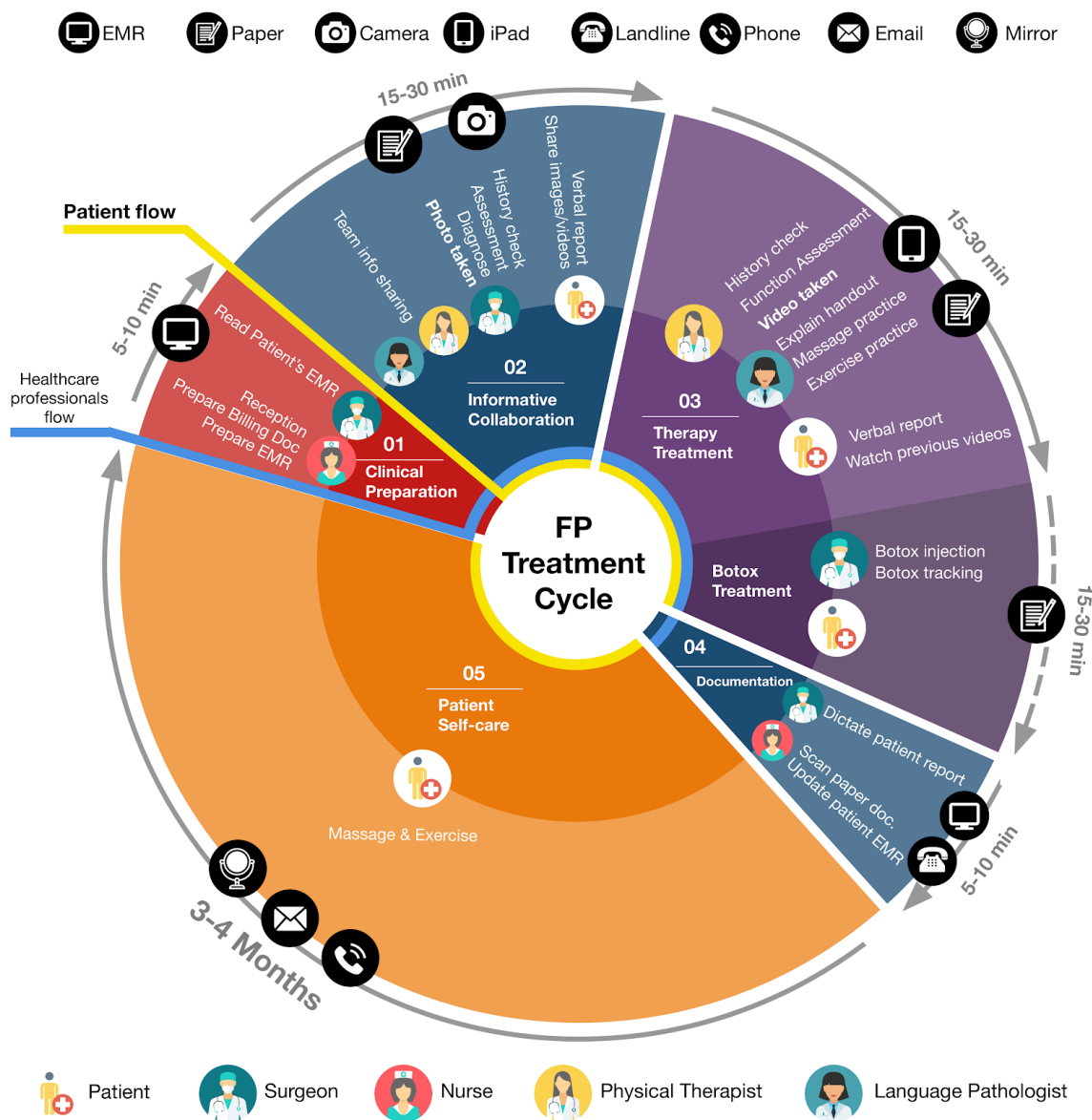
We present an overview of the multidisciplinary nature of the FP team, our FP workflow model, and detailed explanations of challenges associated with each stage of the model below.

5.3.1 Multidisciplinary Care Overview

Our site's FP treatment relies on multidisciplinary specialists and collaboration. Collaboration begins at intake (discussed in a later section). C3 explains to patients that *"there's gonna be different providers coming in at the same time so that they can all hear the history and be there when the Dr. is doing her examination so that they all have their input. The patient doesn't have to come back for multiple appointments to see each one..."* Having all HPs present at this time is a move to be efficient for the HPs who can get all of the relevant patient data at one time, as well as for the patients. As P7 describes it, *"You have a lot of people staring and they all took their turn. It felt like they were all taking notes, definitely working with each other to understand what was going on and have the correct diagnosis."* In addition to being efficient, this team visitation thus can act to reassure patients and increase their confidence regarding treatment outcomes.

C1 describes a typical process as follows: *"when [patients] meet me, they meet with facial therapist, and work with the facial therapist that day and they start a program of facial prehabilitation with the therapist...learn how to do exercises at home."* Each HP has an individual treatment role to play, but they must also work together to determine what needs treated and how. This is confirmed by C4 who says, *"I think among the three of us, we pretty much kind of have this agreement of we know what needs to be treated and what doesn't."*

Figure 7. This figure shows the typical timeframe and workflow stage breakdowns for hospital visits with HPs. Note that therapy sessions are typically monthly. Healthcare participants are shown within stages where they are present, and tools used during stages are noted. The yellow inner path represents patient progression, and the light blue inner path represents that of HPs. Time not shown to scale.



5.3.2 Facial Paralysis Treatment Workflow

Our FP workflow consisted of the following five higher level activities: clinical preparation, informative collaboration, treatment, documentation, and patient self-care (Figure 7).

1. **Clinical Preparation.** Clinical preparation consists of at-clinic activities prior to a patient's visit and extend until the patient meets with therapists or a doctor. This stage thus includes patient communication with HPs about appointment confirmations, intake activities, and early healthcare provider assessments in the form of reading the patient's EMR 5-10 minutes before the visit begins.
2. **Informative Collaboration.** Informative collaboration includes activities which inform HPs about a patient and aid medical decision making. A surgeon checks patient history verbally during a visit, records progress and conditions via photos, and makes diagnoses and treatment decisions. This is collaborative, as patients inform HPs directly.
3. **Treatment.** Treatment begins with therapists providing patients instructional exercise handouts, explaining exercises, and then showing patients how to move specific muscles; wearing gloves they touch patients' facial muscles, if necessary, to demonstrate. The next step varies based on patient needs and conditions. They may receive Botox injections, undergo surgery, or end with therapy. Depending on the patient, visit durations vary from 25-90 minutes. Patients visit the surgeon every 3 or 4 months, and they visit therapists (without the surgeon) about once per month with each visit usually scheduled for 1 hour of physical therapy.
4. **Documentation.** Documentation included the collection and integration of photos/videos, grading scales, and summary reports from the visit into the patient's EMR.
5. **Patient Self-care.** Patient at-home activities mainly refer to therapy exercises, massages, and stretches as prescribed by therapists. Patients may also seek information, either by

communicating with healthcare professions or via other sources, and monitor their progress. In the following section, we describe each of the stages in greater detail.

5.3.3 Stage 1: Clinical Preparation

Our site's clinical preparation is mostly conducted by C3, a neurology nurse, whose job includes intake, Electronic Medical Record (EMR) updating, and paperwork. For new patients, C3 first verifies that the patient's data is in the hospital's system. C3 notes that about a week before new patients' visits, *"I make sure that we have [patient] history... that the patient will either have sent to us or bring with them [their tests] on the day of their visits on CD so that we can load it electronically into their [EMR]. I do that... before the clinic to make sure that Dr. has everything..."* C3 ensures that EMRs have all the patient data that HPs need during care. Patients must arrive 15 minutes prior to scheduled appointments so that they can verify and update EMR data. C3 also collects new data (i.e., patient weight and vital signs), and explains the care process. If C3 finds data is missing, C3 performs the paperwork to retrieve the sensitive data.

Scheduling initial appointments is often the first patient challenge, as it requires another doctor's referral and long waiting periods. Unfortunately, care delays can limit patients' treatment options. P2 states, *"I needed to have a nerve regrafting, but I was outside of the one-year window... I kept saying that to the neurologist, but they were not listening or very helpful in that area."* Even though P2 was aware of her care needs and windows, a late referral prevented a surgery which may have restored functioning. Delays may also arise from the complicated nature of treatment. C1 explains that cancer patients *"have appointment after appointment... with bunch of different doctors and scans and biopsy... I rarely meet them far enough ahead of time to do anything for that."* Any life-threatening factors are prioritized before FP.

5.3.4 Stage 2: Informative Collaboration

Informative collaboration occurs between all HPs and a patient, and includes activities which aid medical decision making. Patient history is checked and then the surgeon performs a visual assessment using validated grading scales (i.e., House-Brackmann facial nerve grading scale (House, 1985) for characterizing the degree of FP, and Sunnybrook Facial Grading Scale (Ross et al., 1996) for assessing facial movement outcomes). C1 says, *“those are suggestive measures that I grade as a provider and give to the patient...I am trying to get [them] prehabilitated enough to do Botox therapy or things like that.”* Therapists assess patients again later using a physical therapy scale which measures muscle strength and symmetry of facial motion. HPs also use verbal assessments for qualitative reports.

5.3.4.1 Visual data as references

Symptoms may not occur during in-person visits. HPs note that patients can demonstrate their, or their children's, symptoms through personal photos or videos. C1 notes that *“[Patients] kind of show it to us...a lot for parents to record their children doing facial movement...”* Visual media are integral for patient assessment, as the surgeon and therapists use photos and videos taken at the hospital as references. C2 says, *“[videos and photos are] very important to us because it's the only way we can really monitor progress at this point... We can tell by, if we have a video at baseline and then a video after treatment.”* Although photos and videos are key for progress assessing, HPs experience difficulty organizing and collecting patient videos.

5.3.4.2 Tailored treatment plans

Patients' diagnoses and assessments, in conjunction with HPs' collaboration and patient self-reports, contribute to HPs' medical decision making. Careful team examination and concordant patient need comprehension are key for effective treatments. C1 notes that *"[if] there's no way they can control [their muscles], and if the therapist says they are just not making any progress...we make [injections] sooner and, weaken muscle so they can participate in the program and the care."* Decisions, treatments, and exercises are patient tailored and often dependent upon their progress, symptoms, and goals; HPs may prioritize returning functions which allow patients to use common facial expressions (e.g., if the patient wants to be able to smile again, therapists will first assign exercises which facilitate smiling).

5.3.4.3 Informative Collaboration Challenges

Informative collaboration challenges include: treatment duration, visual media usage, and video storage and access.

1. **Treatment duration challenges.** The often-lifelong treatment duration coupled with limitations in restoring functioning to pre-ailment conditions can be devastating for patients. P4 says, *"[the therapist is] telling me I'm gonna have to do these [exercises] for the rest of my life, I was devastated. I thought that this crap was gonna be done and over with and I was gonna be able to move on."* These challenges are sufficiently recognized at our site that the HPs have considered adding new support staff to alleviate patients' psychological stress. C1 notes, *"we are going to get a support group with psychologists, a therapist, and a social help psychologist, to get [patients] meet each other, talk about how they are feeling. They're feeling they're the only ones going through this."*

2. **Visual media usage challenges.** Sharing visual media can be challenging in healthcare. HPs use videos and photos to monitor progress, but they also share these data with patients to demonstrate their progress, especially when they have trouble perceiving their progress. Our site's HPs thus motivate patients by demonstrating their progress via visual records. However, the surgeon and the therapists use different devices (i.e., the surgeon takes photos with a departmental camera, therapists take videos of patients in therapy with a departmental iPad). The surgeon can also upload patient photos to EMRs, but therapists cannot upload videos.
3. **Video storage and access challenges.** Technical issues cause therapists to use a commercial iPad application with limited functions; it does not provide a way to export or organize videos. Moreover, when iPad storage is full, videos must be deleted before taking new ones. HPs thus lose vital references because patient videos are only stored on this specific device. This limitation can hinder collaboration between HPs by limiting patient video access to whoever has the device at the time. Inaccessibility and the inability to share data among the team leads to segregation of the patient's data, and thus causes difficulties if a HP needs to share or use aggregated data. Furthermore, because of the inability to export large videos, our site's HPs do not collect patients' personal videos. HPs cope with this challenge by transcribing what they see into notes and uploading these notes to the patient's EMR.

5.3.5 Stage 3: Treatment

Treatment begins with 15-30 minutes therapy sessions, followed by Botox if needed. Injections cause soreness which is managed by holding ice packs on injection sites; this makes therapy difficult for patients, so this order facilitates care.

5.3.5.1 Physical Therapy

Physical therapy includes facial massages and exercises and is the site's most common FP treatment. Handouts (e.g., facial exercises, massage instructions) are provided and practiced in therapy sessions. Therapists start sessions by checking patient progress, asking if any changes need addressed, and then teaching patients to loosen and stretch muscles. There are 12 different massage sets. One massage is instructed as follows: *"Pinch the muscles on the lower jaw bone by using the side of the pointer finger and the thumb. Pinch and roll the muscles on the sore area. Repeat 10 times, and twice daily."* Massages and stretches are patients' first step for managing FP symptoms. Patients are also taught how facial muscles interact to produce movement. This is followed by exercise instruction and practice; there are 19 sets of exercises. One example is as follows: *"Bring the lower lip forward into a pout, hold it about 3 seconds and release. Repeat 20 times a day. The more practice the better."* Patients must sit in front of mirrors to receive key feedback regarding targeted muscles and necessary movement amounts during exercises. In therapy sessions, mirror feedback is reinforced by therapist verbal feedback. If therapists feel a patient's progress from exercises is sufficient, they will instruct the patient to target new muscles with new exercises.

Treatment plans often rely on therapy progress. C2 states, *"therapy is really what we're hoping to see the most improvement in function to come from..."* Patient progress also affects scheduled surgeon appointments, as therapists delay the surgeon's next patient visit if progress is unsatisfactory. Therapy in its own right is thus emphasized in this FP treatment program, but it is also expected to improve post-surgical results. C1 notes, *"it is very very important that these patients do prehabilitation with...therapists ahead of time so that they can maximize their benefit from my surgery...if they don't do the treatment afterwards...they might as well not do the surgery."* FP therapy exercises are treated both as prehabilitation and rehabilitation, though patients may never have surgery. Other locales offer more treatment options (e.g., electrical stimulation therapy),

but our site does not. C1 notes, *“people will use [electromyography] where they put needles in the face and then have them do the exercises, but patients really don’t like that and it’s not shown to be any better...”*

5.3.5.2 Botox and Surgery

Botox and surgery are viable FP treatments, but our site’s HPs do not typically see these as therapy replacements. HPs even suggest therapy can be more beneficial as its effects are permanent, whereas Botox wears off. Patients who need Botox will often receive injections every 3-4 months, as nerves may misfire and cause muscles to spasm again. In some cases, Botox is used earlier in treatment to treat muscle spasms and allow patients to perform therapy. P5 explains, *“[Surgeon] recommended the therapy in conjunction with the Botox so that when I was doing [exercises]... to keep [muscles] from spasming... [and make] them stronger.”* Botox thus facilitates patients’ therapy exercises.

HPs note that even with Botox, therapy will not benefit some patients, although surgery might. C1 notes, *“[if] the therapist says there is no way they’re going to...activate the muscle or nerve...I’ll do a [different] surgery...that doesn’t require them to relearn how to use muscles and nerves...”* C1 here describes altering plans based on therapist expertise. One surgery may have been planned during an initial visit, but therapy progress affects which surgery is ultimately done. Furthermore, surgical pre-requisites (e.g., in effective surgical windows, low complication risks) must still be considered.

5.3.5.3 Treatment Challenges

Treatment challenges include: patient comprehension of instructions and handouts, and patient sense of treatment progression.

1. **Instruction and comprehension challenges.** HPs note flaws in their instruction. During in-person therapy, therapists can explain what patients need to know to perform exercises, but handouts are the only at-home reference. Some patients may find comprehending text-based resources difficult, and blind patients may experience difficulties from being unable to use mirror feedback. HPs suggest that video references may help some of these patients. C2 notes, *“I think the biggest help at this point would be...a video of a non-patient demonstrating how to do the exercises so a patient could have an example.”* Note that C2 suggests a non-patient example because of HIPAA concerns. Moreover, attending visits may be difficult for patients to maintain because of visit frequency and treatment duration. Such patients may maximize benefits by referencing recordings.
2. **Progression challenges.** Physical therapy is a long process, as nerve recovery can take up to a few years; even when patients can attend visits and achieve success, they may plateau in their progress. C2 explains, *“When I feel like they’ve been doing the exercises... if they make a plateau in their progress, that’s typically when we say, let’s try Botox or surgical interventions.”* If a patient plateaus, other treatment options may need to be used to achieve further progress.

5.3.6 Stage 4: Documentation

HPs begin documentation during a patient’s visit, as they make assessment notes and record videos and photos for patient baselines and progress monitoring. C4 notes, *“[Recording*

patient videos] establishes a baseline. We actually use that in writing up our initial evaluation. I'll go back over the video many times just to record what I'm seeing in the video." HPs use estimations, structured notes, and grading systems to quantify patients' progress; these data are used in later visits to look at longer term patients' outcomes. After patients leave, HPs summarize visits and dictate final reports using a voice message storage system. Voice recognition software analyzes reports which are outsourced to a secure hospital collaboration company for transcription. Final documentation includes: patient history, current condition, 12-point review of systems GRED (Review of systems GRED), medications, allergies, social history, family history, physical examination, assessment, treatment plan, and follow up dates. HPs in the system can easily access FP HPs' notes, reports, and updates.

5.3.6.1 Documentation Challenges

Using departmental devices and non-standardized recording practices can be challenging when documenting patient progress.

1. **Challenges of using departmental devices.** Data retrieval challenges revolved primarily around the shared nature of departmental devices for video or photographic patient recording. C4 notes, *"If I want to look at the video myself, I have to go find the iPad. It's a departmental iPad...I have to go find it...and bring it back and then...take it back. Sometimes when I'm seeing the patient it's not available because somebody else is using it...if we [had the video] on a hard drive, it's readily available. I will probably use it way more than I do now. It's also difficult to...[o]rganize them on an iPad so that you can quickly find what you want."* Sharing the same iPad for all patient videos limits accessibility to patient data and hinders healthcare providers' abilities to organize and find targeted data. This problem is exacerbated by our site's HPs'

inability to copy and store patient videos to dispersed hard drives (owing in part to security concerns).

2. **Standardization challenges.** Notably, the lack of team-wide access to patient data contributes to collaboration challenges which are exacerbated by unstandardized recording practices and patient measures. For example, physical therapists and speech therapists use scales which do not match across the healthcare spectrum. This is ineffective and causes extraneous and repetitive assessments (e.g., both a surgeon and therapists check patients' history and facial movements).

5.3.7 Stage 5: Patient Self-care

Patient at-home activities (i.e., primarily prescribed face massages and exercises) serve as an extension of what is learned during therapy sessions. Patients can pick 2-4 targeted areas from the available practice sets, repeat their exercises the required number of times, and perform their sets 2-3 times per day; HPs suggest for patients to do exercises in the morning (i.e., while brushing their teeth and already in front of a mirror), then once during the day, and once before bed. C2 states, “[Try] a couple of different times where they’re feeling different levels of rest because at the end of the day when they’re really tired, it’s hard to control synkinetic muscles.”

5.3.7.1 Online References

Patients actively search for relevant information, sometimes even before a diagnosis is confirmed by HPs. P4 for example notes, “I just looked on the internet and it gave exercises...I looked at YouTube videos from people that had Bell’s Palsy and looked at what they were doing. I looked up massage for Bell’s Palsy and the Botox for Bell’s Palsy. I tried to look up as much as I

could find. Anything that gave me a little glimpse I went after it on the internet.” For patients like P4 (i.e., a medical assistant) who are aware of their conditions and can understand what is medically necessary for treatment, the internet can be a valuable resource prior to diagnosis; such patients can facilitate treatment processes by performing exercises early in their care.

5.3.7.2 Self-monitoring for personal assessment

Patients may also use at-home self-monitoring to assess progress. P5 notes, *“[I took photos to] try to track the progress and see how much it has improved...just see the difference...when I first started going to her it was totally different than it is today.”* Patient self-assessments, whether from photos or based on memory, may lead to feelings of plateauing; plateaus may be actual (i.e., confirmed by HPs) or apparent, given the slow and gradual progression coupled with daily exposure during exercises.

5.3.7.3 Patient Self-care Challenges

Many challenges appear to occur during patient at-home self-care, including: patient-provider communication, time and effort demands, accessibility of exercise tools, and perceptions of plateaus or regression during recovery.

1. **Patient-provider communication challenges.** Patients at our site can contact HPs via phone calls, email, and a patient portal regarding treatments. However, there are limits to what can be discussed, and how. As C2 notes, *“if they email me with questions, I can’t email them back. I can return a phone call, but I can’t include any diagnosis or patient information within an email.”* Patient data is sensitive and protected, so security limits communication options.

2. **Time and effort demand.** 4 patients discuss problems setting time aside for exercises; exercise demands may cause them to lapse in their therapy or to quit altogether. P6 notes, *“Doing the exercises consistently is a real big problem. Because it’s demanding. You have to set aside some time. And it is boring...”* 3 patients also note shifting from preventative care (i.e., exercising to prevent and lessen symptoms) to reactive care (i.e., responding to symptoms that reemerge after inconsistent maintenance). P7 notes, *“if I’m feeling really good I get a little bit lazy with [exercises]. I do them more frequently when I’m feeling symptoms of dry eye or my face feels saggy.”*
3. **Tool access requirement.** Patients need to have access to a mirror to accurately perform exercises and respond to feedback, but mirrors are not always available. C2 explains, *“Because they have to [use mirrors], you have a biofeedback, they have to have a means of monitoring because we’re not very good at using the proprioceptive skills of our body to monitor where our mouth is moving or where our body is moving in such small movements.”* Furthermore, the constant need to learn new facial exercises during therapy may cause patients to rely on reference materials like exercise handouts; handouts are currently paper-based, and patients may not always have quick or easy access to them. These inconveniences may contribute to inconsistent exercising.
4. **Progress plateaus and regression.** Even strongly motivated patients may stop treatment early if they plateau. C4 notes, *“They made a lot of progress in the beginning but then it really slowed down...changes were much more subtle, and they elected to stop...they felt like they were at a point where they could manage. But they weren’t...”* When patients stop activities early, HPs at our site discuss seeing symptoms reappear (e.g., unintentional eye rolls while closing an eye).
5. **HPs’ patient at-home challenges.** The most significant HP challenge for patient at-home activities may be that patients are not accountable to HPs during at-home activities; patients

may choose whether to conduct their activities, and HPs will only be able to respond to their decisions if the effects are noticed during visits. Even if HPs ask patients to record their activities, reports may not be accurate. C1 notes, “[P]atients don’t report very correctly, even if you ask them to write down when they’re doing the therapy, when they’re not, they don’t do them very well.” Our site’s HPs lack effective means to monitor FP patient prescription adherence, gauge patient motivation and feelings toward treatments, provide specialist vetted videos of exercises for patient reference, or remind patients to perform prescriptions. Likewise, healthcare providers do not have effective and secure means of sharing patient progress via videos or photos (which are only stored on hospital devices) outside of patient visits.

5.4 Discussion

Our FP treatment workflow model advances HCI workflow, both in the breadth of team members and in the complex healthcare context. We note the following differences between our work and closely related works: 1) our team is consistent, not loosely formed (Lee et al., 2012); 2) our team is focused on long-term, as opposed to short duration care (Chen et al., 2011); 3) our team does not work in high-risk care (i.e., Emergency Departments (Lee et al., 2012; Chen et al., 2011); 4) our complex team shares characteristics of the FLECS teams of Amir et al. (Amir et al., 2015), but team structure is not flat (e.g., patient activities are key, and therapist expertise affects surgeon plans) and care plans are somewhat integrated; and 5) we include space for patient work, which can be crucial for progress (Zhu et al., 2018). Despite these differences, we reaffirm known findings in related works, especially those related to EMR challenges (i.e., multimedia data support needs (Chen, 2010; Lee et al., 2012; Ratib et al., 2003; Zhang et al., 2017)). Our study thus offers novel insights, as well as further confirmation of known challenges. In addition to using our workflow model as foundation for incorporating patients into clinical workflow design and research, we see

strong potential for further improvements in areas such as improving adoption of multimedia data support in EMRs, using visual media to improve FP treatment processes, and designing tools to further support patients as collaborators.

5.4.1 Multimedia Data Support for EMRs

Data collection, data storage and organization, and data sharing are 3 key HP challenges; we discuss these with regard to service provision, technology trends, and possible future study directions.

1. **Data Collection.** HPs rely on visual media to assess and motivate patients, but unstandardized data collection tools (e.g., therapists use an iPad, surgeon uses a camera, patients share personal media with phone applications, etc. (Zhu et al., 2016)) restrict all parties' access to key data. HPs must rely on transcriptions (i.e., create transitional artifacts (Chen, 2010)) for clinical and patient visual media, thus hindering patient-provider collaboration.
2. **Data Storage and Organization.** After data is collected, HPs face storage, organization, and retrieval challenges. Multimedia data needs to be recorded for each patient and every visit, but the departmental iPad has limited storage space for videos, and videos cannot be uploaded to EMRs. HPs also found data organization difficult, as there were no easy means to search for or show patients visual media on separate hospital devices. Multimedia data centralization onto separate registered devices led to three access and retrieval challenges: 1) HPs could not use stored data to demonstrate patient progress if the device was in use or non-portable, 2) HPs could not rewatch the videos to make transcriptions for documentation while the device was in use, and 3) vital references may be deleted to allow new media storage.

3. **Data Sharing.** Policies limit HPs' data access and sharing. During visits, HPs share information regarding exercise and anatomy through handouts and direct demonstrations. However, there is limited support for patients in their homes (i.e., HPs cannot share data in asynchronous and distributed manners). Vice versa, patients' shared information about their at-home activities cannot be extracted to aid future treatment decision making.

Implications. Centralized patient data challenges from storage on separate departmental devices could be solved by increasing funds, or changing policies; however, others (i.e., adopting multimedia capable EMR, or sharing patient data in general) may require developing a secure technical infrastructure for standardized data sharing between patients and HPs. Notably, our site's HPs once required patients to self-monitor, but they no longer do so because they felt the logs were unreliable. However, C1, C2, and C4 expressed desires to collect quantitative data for number and type of exercises performed, as well as qualitative data for patient perceptions and feelings about exercise efficacy. Patient portals are one existing infrastructure, but portal services offer limited patient collaboration potential. For contexts like FP care, where patient roles are so heavily emphasized and integrated into care plans that HPs change treatments and services based on patient collaboration, a secure infrastructure for data exchanges is needed. Further study regarding designing clinical spaces to promote patient collaboration is warranted.

5.4.2 Supporting Patients with Visual Media

Patients' abilities to collaborate and benefit from FP treatment are bottlenecked by 3 challenges: plateauing, lost motivation, and lack of comprehension. We suggest that visual media could help patients sustain their contributions.

1. **Sensing Progression.** Plateauing is often a deciding factor in care decisions, it affects patient motivation and exercise adherence, and it is a challenge of the treatments

themselves. Progress plateau is discussed in similar contexts (e.g., recovery after arthroplasty (Zhou et al., 2015), recovery following stroke (Demain et al., 2006), etc.); however, discussion of patient plateau perceptions and their responses to said perceptions are scarcer. We note that our site's HPs suggest that patient perception of plateauing is one of the most common reasons patients give for stopping exercises early. This is troubling, as patients note difficulty seeing the often slow, gradual progress made during long treatments. If patients stop early, symptoms may reappear. Patients may thus benefit from visually monitoring and referencing progress over time. Given how key patient plateau perceptions in FP treatment are, and how little they seem to be discussed in related works, further research is needed.

2. **Maintaining Motivation.** FP exercises may not be bodily taxing, but patients describe them as cognitively and time demanding (i.e., requiring concentration). Patients typically perform exercises once per day, and thus fail to meet prescriptions. Patients need mirrors for exercise biofeedback, and this limits how, when, and where exercises can occur. Moreover, owing to the consistent targeting of new muscles, patients need to frequently reference new exercise handouts. 3 patients also claim that the benefits of Botox, frequent time and effort demands, and tool and new exercise requirements, caused them to lose exercise motivation.
3. **Enhancing Comprehension.** Our results show many comprehension challenges which can occur during FP treatment. Challenges may stem from patient abilities or from how data is shared. For example, our site's therapists suggest that text-based handouts may not be ideal for sharing and demonstrating exercises. HPs suggest that videos for at-home reference may be beneficial. Importantly, we note that our site's therapists are integral for clarifying some of patients' common comprehension challenges. As such, we feel it necessary to emphasize that technology should not be seen as a replacement for skilled HPs, but as a

way to facilitate healthcare processes; this is consistent with other work regarding how technology can make space for “quality care” (Zhu et al., 2017)

Implications. We see strong opportunities for visual media to facilitate FP treatments and patients in their collaboration. Notably, visual references instead of text-based handouts would likely improve comprehension and successful exercise, and patient self-monitoring with visual references could directly work as a tool to sustain motivation and continued exercise by demonstrating self-recorded progress (i.e. similar to reactivity (Korotitsch & Nelson-Gray, 1999), but maintaining a behavior change instead of creating a new one). Visual media has been used in self-monitoring to understand behavioral causes for medical symptoms, but this application is largely to aid medical decision making (Smith et al., 2007); our suggestion is novel, as its intended effect is to keep patients aware of their progress and encourage motivation and adherence. Future works could conduct controlled experiments regarding the design, implementation, and testing of visual media aids in FP contexts, especially on their effects on patient motivation and engagement.

5.4.3 Increasing Adherence through Collaboration

HPs at our site claim that FP prehabilitation adherence is high though unknown; direct comparison may be unsound, but this contrasts with low at-home adherence rates for intensive prehabilitation exercise programs (Carli et al., 2010). If perceptions are accurate, the following may contribute to higher site adherence (though further research into these factors’ effects is needed): 1) patient motivation, 2) strong therapist support, and 3) combined therapy and Botox treatments. Although patients’ motivations may waver during plateaus, they have strong motivations to return lost functions. This motivation is in part social, as facial functions affect their daily social interactions. Literature suggests that health motivations that are based on social interaction or appearance may actually be stronger motivators than health-based motivators (Cheskin & Donze,

2001). Therefore, FP prehabilitation may have in-built social motivators not present in other programs. In addition, our site's HPs offer strong informational and emotional support. Support, communication, and collaboration from HPs are correlated to adherence in general health outcomes (Zhou et al., 2015). Finally, typical prehabilitation programs do not always have multiple stages of effective treatment. Because FP HPs can use Botox injections to get patients over their therapy plateaus, patients may stay engaged in treatment longer than other programs. Although this discussion is based upon our findings and existing literature, direct confirmations are beyond the scope of this work; comparative research should be conducted.

FP treatment is a personal, challenging, and complex process which requires great effort from multidisciplinary specialists and patients. This process is mediated by clinical objects (e.g., videos and photos) and active patient engagement (i.e., patient at-home collaboration). It further relies upon person-to-person interactions and communication because of the strong need to collaborate and reach collective outcomes. This form of healthcare emphasizes and amplifies all parties' accountabilities to the process and outcomes. FP patients cannot be passive actors like they could be in traditional acute illness care; patients must maintain motivation, adhere to exercises, and perform their collaborative roles. However, neither HPs' or patients' needs are being met to facilitate their collaboration fully. HPs for example, lack objective measures for determining if patients are engaged; they rely on experience and perceptions. In the case of patients, they often need to change exercises as they progress through therapy, but they are only instructed how to perform these exercises once (i.e., during their monthly therapy visits). Patients thus need more at-home guidance, support, and reference materials. This work only begins to provide insights into this complicated collaborative process and how technology affects it. Future works could more thoroughly examine specific aspects and include extended care collaborators (e.g., family, friends, etc.) to flesh out our basic model.

5.4.4 Limitations and Future Work

Our study was conducted in a clinic, and it is site specific and likely biased towards our participants. Moreover, we had a small sample size, which limits our ability to generalize findings to FP treatment at other locales. Although our case study focuses on the needs of one multidisciplinary healthcare team, we believe our findings can apply to other complex healthcare team contexts, especially those with significant patient responsibilities (i.e. physical therapy). Our lack of in situ (i.e., at-home) patient observations limits our ability to fully track actual patient work, but such observations require obtrusive, resource-intensive study beyond the scope of this work. Our preliminary data indicate that exercise behaviors and patient responses vary and change over time, and future study is necessary to determine subtle changes in actual patient work. Despite this limitation, the inclusion of preliminary patient work data in workflow modeling contributes significantly to workflow modeling practices. We also note that significant informal carer data was scarce in our dataset. Future studies could use more diverse sampling from multiple clinics and more HPs and patients, in situ patient observations, and more direct interaction with informal carers to improve upon our preliminary model. However, as an exploratory study aimed at determining challenges and opportunities for technology use in FP treatment, we offer valuable in-depth insights. We encourage others to consider potential factors (e.g., hospital size, funding, technology availability, etc.) which may potentially affect idiosyncratic workflows and challenges for further studies. HPs and patients experience and understand FP treatment challenges differently; future works could also explore if greater common ground between HPs and patients leads to better clinical outcomes.

5.5 Chapter Summary

Facial paralysis treatment, as demonstrated by our workflow, requires collaboration between various HPs and their patients. Our study uses clinical observations and semi-structured interviews with HPs and patients to provide an in-depth description of FP care workflow and identify challenges for patient-provider collaboration. We find that visual media are essential to FP care; these references are used for assessing and demonstrating patient progress, as well as documenting visit summaries. Our work identifies patient perception of progress and plateauing to be two of the most significant challenges which may lead patients to stop performing exercises. We suggest the addition of self-monitoring with visual references as a potentially strong opportunity for facilitating patients' motivation to perform their collaborative roles by adhering to their exercises. This work adds to the growing body of HCI research for technologically facilitating patient-provider communication and collaboration.

Chapter 6

Design and Evaluate of MyFace System

In this chapter, I present a summary of results from a deployment study aimed at understanding how we should design self-care technology to support patients with facial paralysis in their prehabilitation? (RQ4). This study explores the design and evaluation of the MyFace system, a self-care technology with visual media self-monitoring and social support functions intended for tracking facial paralysis recovery progress; this system is designed based on stakeholder understandings developed from the research discussed in Chapters 3-5. Results of a 30-day deployment with 11 participants show promise in facilitating users' self-awareness of recovery progress, self-reflection on recovery journeys, motivation, and engagement and adherence to health-related behaviors. In addition, user cases in which participants received and offered social support via the MyFace system are reported. MyFace features and their roles in facilitating participants' motivation, engagement, adherence, and social support are discussed; notably, users describe garnering self-awareness of progress via displays of latest vs. earliest visual media, self-reflection from chronological displays of data, and motivation from self-awareness and hope. Opportunities for improved designs which better assist users are offered as design implications.

6.1 Introduction

Peoples' faces can drastically affect how others perceive their intelligence, fitness, competency, and other significant traits (Zebrowitz & Montepare, 2008); facial appearance is therefore one of the most important factors governing our everyday interactions. However, approximately 127,000 people per year acquire facial paralysis (FP) (Bleicher et al., 1996). Facial paralysis not only affects facial appearance, which causes over half of FP patients to experience

psychological distress and withdraw socially (Kosins et al., 2007; Lindsay et al., 2010), it also affects basic life functions including: eating (i.e., being unable to close lips, drooling, and altered sense of taste), drinking (i.e., being unable to form a seal around lids or straws), hearing (i.e., sound hypersensitivity on the affected side), vision (i.e., decreased tearing, loss of blinking control on the affected side, inability to close eyelid), and speaking (i.e., slurred speech) (Brach & VanSwearingen, 1999), etc.

Facial paralysis can be defined as a loss in strength of facial muscles that typically results from damages (i.e., permanent or temporary) to the facial nerve (i.e., the seventh cranial nerve); this nerve also affects saliva production, taste, and tearing of the eyes, so when it no longer functions as it should, facial muscles function improperly and typically cause either partial paralysis (e.g., affecting movement of the eye or mouth) or paralysis of the side or even both sides of the face (Facial palsy; Prendergast, 2013). Causes for FP include but are not limited to viral infections (i.e., bell's palsy, ramsay hunt syndrome), bacterial causes (i.e., lyme disease, ear infection), surgeries (i.e., removal of acoustic neuroma, facial nerve tumor, or parotid gland), traumatic injuries, rare genetic syndromes, and strokes (Facial palsy).

To quicken patients' recoveries, improve their functions, and reduce risks for secondary conditions, FP treatment typically employs physical therapy (i.e., facial exercises, electrotherapy, massages and thermotherapy, etc. (Teixeira et al., 2011)), Botox injections, surgeries (Shafshak, 2006), and/or electrical stimulation therapy (Tuncay et al., 2015). A systematic review of physical therapy for bell's palsy treatment efficacy shows that patient-tailored facial exercises can help patients with moderate or chronic paralyses to improve facial functioning and that these exercises may also reduce secondary conditions in acute paralysis case (Teixeira et al., 2011). Generally speaking, different surgeries and treatments may be recommended to patients during different time frames (e.g., see UW health). At my prior study location (see Chapter 5), healthcare professionals prefer treating FP patients with facial exercises prior to invasive techniques like surgery or Botox;

FP physical therapy can thus be a component of prehabilitation as well as an alternative to surgery. However, at least for my prior case, such pre-surgical care techniques heavily rely upon patient at-home self-care for success.

Regardless of care techniques delivered, healthcare professionals often rely upon visual media (e.g., photos and videos) to demonstrate to patients their treatment efficacy and where treatments are failing, as well as to provide data for medical decision making (Lindsay et al., 2010; Teixeira et al., 2011). However, image-based patient records create new clinical workflow challenges, including visual media data collection, storage, and organization; these workflow challenges nudge clinicians towards using workarounds to treat the symptoms of the workflow issues, which may lead to reduced patient at-home exercise progression tracking and sharing (i.e., because sharing such data would just exacerbate the original workflow challenges) (Zhu et al., 2018b, chapter 5). Despite these challenges, image-based diaries are promising tools for both easing visual media collection, storage, and organization burdens and supporting patients' motivations (Zhu et al., 2018b, chapter 5).

In addition to using data collection, storage, and organization tools to support patients' motivations by easing their burdens, researchers and designers may also choose to utilize social support, which can be a significant factor in patient recoveries and health processes; patients who have social support are correlated with reduced hospital readmission rates (Schwarz & Elman, 2003) and significantly higher rates of self-care behavioral changes (Wang & Fenske, 1996; Skeels et al., 2010). FP prehabilitation is an ideal area for social support exploration, as health motivations that are based on social interaction or appearance may actually be stronger motivators than health-based motivators (Cheskin et al., 2001). That is to say, because the face is so important to everyday social interactions and the fact that these patients suffer from facial paralysis, FP prehabilitation may have in-built social motivators which can benefit from social support.

To better understand how image-based systems with social support functions can aid FP patients in their recoveries, I designed and developed MyFace using user-centered approaches and stakeholder understandings garnered from my prior works as a scaffold for the design (Zhu et al., 2018b, chapter 5). My prior research indicated that healthcare professionals can effectively utilize visual media (e.g., photos and videos) to demonstrate gradual improvements during recoveries to their patients; these healthcare professionals indicated that showing patients their progress in this manner improved patients' motivation to adhere to collaborative health endeavors (e.g., facial exercises, massages, etc.). With this in mind, MyFace is designed to holistically track patients' recoveries and help them become more aware of their gradual improvements. It specifically tracks facial exercise durations and frequencies, user feelings, and visual media over time to allow for assessment of changes; in addition, the system leverages social support to promote patient self-care engagement. We conducted a 30-day deployment study with 11 participants to evaluate system efficacy. Participants reported that the MyFace system did improve self-awareness of progress, self-reflection, motivation, and adherence and engagement while also providing opportunities for efficient social support. This work is conducted to answer the following research questions:

- How does MyFace aid patients with facial paralysis?
- What can we learn from this deployment study regarding the design of self-care technologies which support facial paralysis patients in their prehabilitation?

This work offers an example of how to enhance patient engagement in prehabilitation self-care, which prior healthcare science research identifies as a significant factor in treatment efficacy and health outcomes for related health contexts (Horwitz & Horwitz, 1993); unfortunately, rates for engagement and adherence in prehabilitation are typically low or variable (e.g., Gill et al., 2003-67%; Carli et al., 2010-for intense exercise-16%; Matassi et al., 2014-79%). This study provides support for the novel ideas of adopting an HCI lens in prehabilitation research and for using visual media feedback to increase patient motivation and adherence in facial paralysis contexts. This study

demonstrates that the adoption of an HCI lens in prehabilitation research better supports high quality prehabilitation and prehabilitation technologies via demonstrating early promise in using HCI principles to design technologies for FP prehabilitation tools. With this work, I contribute the following to the field of HCI and health informatics:

1. The design, and evaluation of a mobile--based self--care technology intended for tracking behaviors of prehabilitation patients with facial paralysis.
2. A small-scale evaluation of the MyFace system which demonstrates promise in effectively promoting patient self-awareness of progress, self-reflection, motivation, and engagement and adherence.
3. Empirical understandings of how an image-based diary and visual summary system can be designed to give patients' a sense of progression (i.e. by allowing the patient to identify concrete improvements, thus facilitating patient confidence in recovery and motivation to engage with self-care).

Our study emphasizes the need for tools designed specifically for patient prehabilitation self-care, and provides direct support for both: 1) the claim that facial paralysis patients' motivation and thus adherence to care plans may suffer from an inability to perceive their gradual recovery progress, and 2) the notion that data feedback in the form of before versus after diary entries with visual media can improve self-reflection and motivation to engage with self-care. This work also provides weaker support for the notion that the MyFace system, through its features, can increase FP prehabilitation patient adherence to exercise prescriptions and thus sustain their contributions and collaboration towards their own recoveries.

6.2 MyFace System Design

Informed by the two exploratory studies and the case study noted in Chapters 3-5, I designed, developed, deployed and evaluated a mobile application called MyFace; this study explores the efficacy of a self-care technology with visual media self-monitoring and social support functions intended for tracking patient facial paralysis recovery progress. The MyFace system was intended to holistically track patients' recovery progression and help them to be more aware of their gradual improvements to spark self-awareness and foster motivation to engage and adhere to their collaborative health endeavors. MyFace allows users to track facial exercise durations and frequencies, their feelings, and their health-related visual media (i.e., videos and specifically posed photographs) over time; this allows users to assess changes by comparing their older visual media against their newer visual media. In addition, MyFace employs a social support approach; existing facial paralysis tools rarely support self-monitoring and sharing functions with healthcare professionals or friends and families, despite these support functions having potentially significant roles in enhancing patients' motivation (Zhu & Carroll, 2018c). These social elements offer users vital informational and emotional support which can contribute to their motivation to sustain self-care contributions during prehabilitation (Cheskin & Donze, 2001).

6.2.1 Design Rationale

6.2.1.1 Support Visual Data Exploration for Patients

MyFace's first intended goal is to increase patients' self-reflection and motivation to adhere to their prehabilitation treatment plans. To do so, I utilized self-monitoring theory and a modified application of the reactivity effect in the design of MyFace. Prior work (see Chapter 5) identified strong opportunities for visual references to facilitate FP patients' comprehension and self-

reflection. Patient self-observing with visual references were identified as tools for potentially sustaining motivation to continue treatment by demonstrating self-recorded progress. Such an effect would be similar to reactivity (Korotitsch & Nelson-Gray, 1999) in that individuals would alter their performance or behavior due to improved self-awareness from the practice of self-monitoring; however, unlike reactivity in which users create new behaviors, my intended design would be used to maintain behaviors. To accomplish this, MyFace asks users to take photos and videos to form a "diary" and record text-based contextual explanations. MyFace also organizes visual data collected from the "diary" into a "gallery," which manages data by storing it in chronological order; this ordering is intended to provide patients with easy data comparison opportunities to promote their visual data exploration and retrospectively reflect upon their data in the provided "summary."

6.2.1.2 Design for Social Support for Health Benefit

Based on prior work (see Chapter 5), patients have strong motivations to return lost functions. These motivations are in part social, as facial functions affect their daily social interactions. Literature suggests that health motivations that are based on social interactions or appearances may actually be stronger motivators than health-based motivators (Cheskin et al., 2001). In social network and social support theory (Heaney & Israel, 2008), social support is known to provide positive effects on individuals' physical, mental and social health. Notably, social support differs based on the nature of the supporter. For example, in a patient's informal network, family tends to provide long-term emotional support, and friends and neighbors tend to provide short-term support; however, in his or her formal network, health care professionals tend to provide information support (Heaney & Israel, 2008). Therefore, I built MyFace with social support functions to facilitate both by allowing users' to invite members of their own support networks

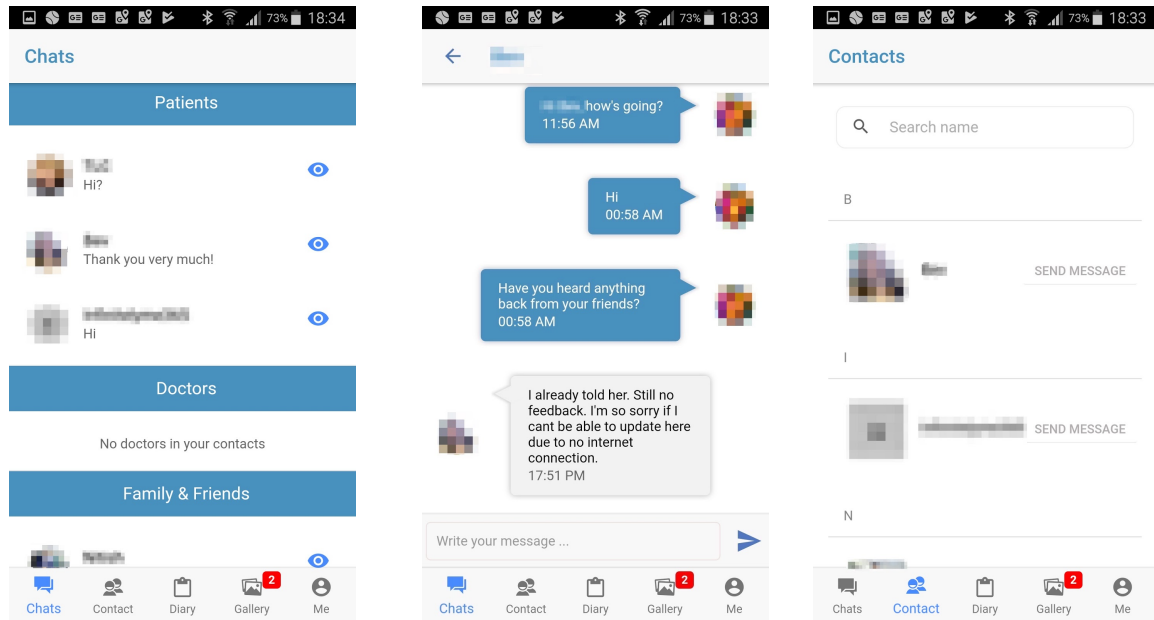
based on 3 different categories (i.e., patients, doctors, family and friends). I thus built a sharing function into the design to allow users to easily share their self-tracking data with individuals of their own choosing to get support; this is intended to contribute to patients' treatment engagement.

6.2.2 MyFace Design Elements

The MyFace system consists of 4 main components: 1) real-time communication and sharing; 2) privacy control; 3) self-tracking with visual media; and 4) contextual data exploration and management with data comparisons.

1. **Real-time Communication and Sharing.** During clinical visits, healthcare professionals share information through handouts and direct interactions with their patients, but there is limited support for patients in their homes (i.e., when patients encounter problems at-home, they cannot easily get information from authorities in real-time); in addition, patients' collected data about their at-home activities cannot easily be extracted to aid healthcare professionals' treatment decision making (see Chapter 4). Noting the importance of both informational support from clinicians and emotional support from patients' support groups (i.e., friends and family members), as well as the difficulties in utilizing tools to foster associated benefits, I designed MyFace with real-time communication functions. Patient users can add and chat with 3 categories of supporters (i.e., friends and family, healthcare professionals, and other patient peers); users can do this by using the "contacts" tab and searching for usernames (Figure 8).
2. **Self-tracking with Visual Media.** Users can use the "diary" feature as a data collection mechanism to self-track their facial exercises, associated feelings, 9 photos with different facial expressions, and videos of facial expressions in motion (see Figure 9a). To minimize manual tracking burdens, users do not need to fill out all of the data requested by the diary. The design allows for any content collected within the system to be posted and shared. In addition, to help

patients stay engaged with their exercise routines, MyFace includes a reminder function in the profile page (see Figure 11a); users can set up to 3 reminders to do facial exercises per day and will be notified when the predetermined exercise time occurs (see Figure 11b).



(a) Chat feature. Note that a blue eye icon indicates this person has permission to view the user's gallery. An eye icon with a cross indicates that there is no permission to view the user's gallery.

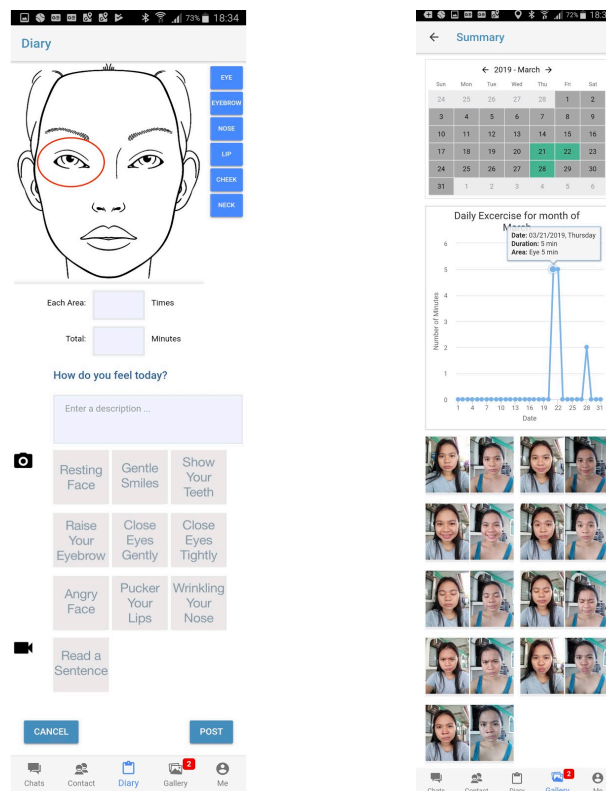
(b) Message feature. Users can leave a message or communicate in real-time with each other.

(c) Contacts feature. By searching for names, users can add other users.

Figure 8: MyFace screenshot showing chat, messaging, and contacts features.

3. **Contextual Data Exploration and Comparisons.** When a user posts a diary, MyFace will display feedback in its “gallery” section (see Figure 10a). This “gallery” has materials sorted by the closest date (i.e., chronological order). By clicking on the top part of another individual's profile photo, the “gallery” section will display their gallery on the bottom if the user has permission (see Figure 10a). Users can click the post to see details in the individual's post or diary (Figure 10b); users' support group members with adequate permission to access the users' visual data can provide their support by liking or commenting under the the post (see Figure 10b). The “summary” section (see Figure 9b) offers a calendar view, a line graph, and a photo

comparison. This aggregated facial paralysis progression summary can provide patients with a holistic view of how many days they exercised in a month (i.e., in the calendar view) and exercise duration times (i.e., displayed as the line graph). The photo comparison is offering an easy comparison between the patients' first and latest diary entries. It supports users' facial expression exploration and comparison of older versus newer facial photos. This feature in particular was informed by chapter 5, as a common problem mentioned in these studies was that patients could not perceive their gradual process and thus would lose motivation to adhere to care plans and prescriptions. This “Summary” feature thus allows patients to concretely see recovery progression (Figure 9b) which they might otherwise not perceive.

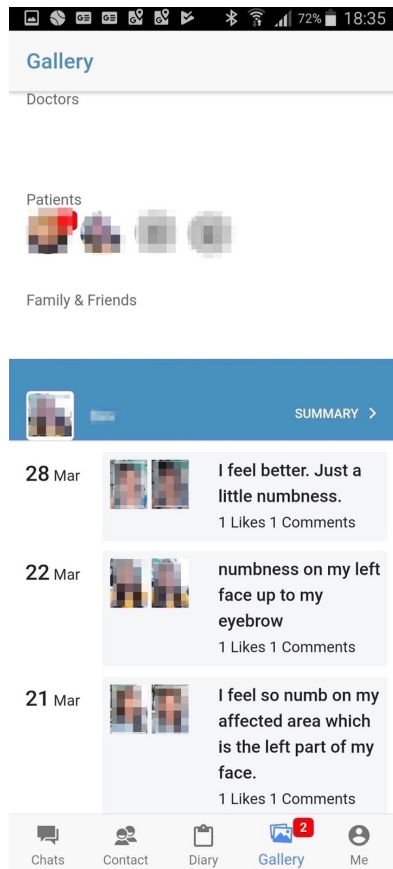


(a) Diary feature. Allows self-tracking for facial exercises, associated feelings, photos, and videos.

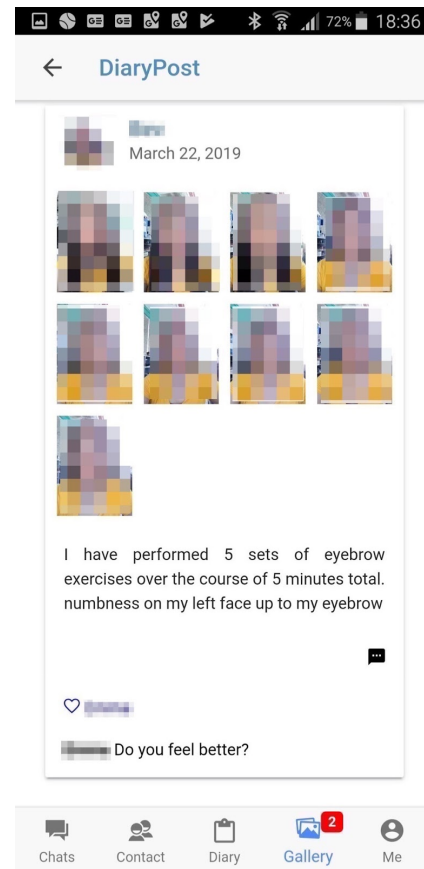
(b) Summary feature. Allows user to view exercise frequency and provide before and after photo comparison.

Figure 9: MyFace screenshot for diary and summary page.

Note b* I received permission from the user to display her photos in this study.



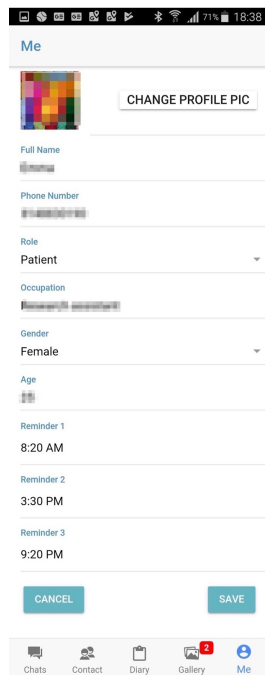
(a) Gallery feature. Allows user to view posts in chronological order.



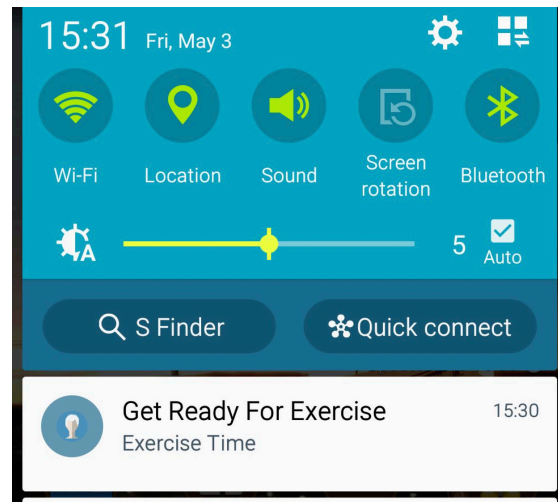
(b) Example of individual posts, user can like and comment below the post.

Figure 10: MyFace screenshot showing the gallery, and example of an individual's post page.

4. **Private Data Sharing.** Noting that patients may be self-conscious about their abnormal facial movements and thus be less receptive to sharing, I designed MyFace with privacy protection options embedded within the system design itself. This allows users to have full control over who can access their personal and sensitive data. The eye icon shown on the left side (see Figure 8a) indicates whether or not permission has been granted for viewing, liking and commenting on a user's posted visual media data.



(a) Profile display. Allows for consolidation of user information and for setting reminders.



(b) Notification message. Message sent as a result of a reminder.

Figure 11: The profile page allows users to set up to 3 reminders to encourage them to stay consistent with their treatment routines.

6.2.3 Implementation

I implemented the MyFace mobile application with ionic framework and NodeJS. Ionic is used to build the frontend UI. A backend server also stores users' data and serves user requests implemented in NodeJS. I chose ionic to implement the mobile application frontend because ionic makes cross-platform development very easy, and thus broader audiences with different smartphone systems can be targeted. The look and feel of this application's UI can be defined using HTML5, CSS, and Javascript. The frontend code can also be automatically generated for different platforms, such as Android and iOS, in the future. The ionic application is essentially a small website running in a browser shell that has access to the native platform layer. The MyFace

application is hosted in the university department server. The NodeJS server handles user management (i.e., signup and login) and data storage (i.e., it stores users' data and shares data with permitted users). Note that users' uploaded data were saved both locally and remotely. This prevents users who log in with the same account across different devices from needing to download their personal data repeatedly.

6.3 Deployment Study

To understand how MyFace aids patients with facial paralysis in their recoveries, I conducted a remote deployment study with 11 participants recruited online. Recruitment in the manner was necessary owing to the difficulty of finding facial paralysis patients locally. The study was approved by the Institutional Review Board (IRB).

6.3.1 Participant Recruitment

I originally recruited 37 participants via social media platforms (i.e., Instagram and Facebook) using convenience sampling (i.e., by searching for people who have posted with keywords like “facial paralysis,” “Bell’s palsy,” and “Ramsay Hunt,” etc.). However, only 11 participants (all Female) completed the deployment study (see Table 5). Participants were distributed globally and included members from diverse ethnic groupings. Due to the study’s goal of understanding how technology aids patients with facial paralysis in preparing specifically for their upcoming surgeries, I only recruited users who had undergone invasive facial procedures, had scheduled such procedures, or had been suggested surgical interventions by their healthcare professionals. Inclusion criteria for the study were: 1) users must be at least 18 years old, 2) users must speak English and be able to provide consent, 3) users must have an Android phone and data

plan, 4) users must have undergone, been suggested to undergo, or be planning to undergo a minimally invasive procedure, and 5) users must have been putting some effort into their collaborative health endeavors prior to the minimally invasive procedures. Due to the sensitive nature of this study's materials, I specified that to protect their privacy, I would delete all photos and videos users provided and uploaded once the study was completed. Data from participants who withdrew early were deleted immediately once their decision to withdraw was confirmed. Each participant who completed the entirety of the study was compensated with a \$100 USD gift card.

6.3.2 Study Procedure

I organized the study procedure into four main components: 1) a pre-study qualification questionnaire, 2) a tutorial on how to use MyFace, 3) the deployment of MyFace, and 4) a post-study interview.

6.3.2.1 Pre-study Qualification Questionnaire.

In the pre-study qualification questionnaire (see Appendix C: MyFace Pre-qualification Questionnaire), I asked for participants' demographic information (see Table 5) and health backgrounds in detail. Their ages range from 25 to 51 (mean = 35.3). The majority of participants (n=8) are healthy individuals, and facial paralysis happened primarily on their right sides (n=8). 4 have scheduled a surgery at some point, and 7 were suggested to undergo a surgery by their healthcare providers. In addition, all of the participants are enthusiastically seeking treatment and conducting self-care behaviors between their visits with healthcare professionals.

Table 5: MyFace participants' demographic information.

| ID | Time Zone | Age | Sex | Health | Side | Duration | Life Impacts | Surgery |
|-----|-----------|-----|-----|----------------------------|-------|----------|--|-----------|
| P1 | GMT-4 | 30 | F | Healthy | Right | 1 year | Depressed; inability to close eyes | Scheduled |
| P2 | GMT-7 | 51 | F | Healthy | Right | 14 month | Self-confidence; eat & drink; inability to close eyes | Scheduled |
| P3 | GMT-5 | 39 | F | Autoimmune disease, asthma | Right | 1 year | Self-confidence; speak, losing eyesight, | Scheduled |
| P4 | GMT+1 | 32 | F | Overweight | Right | 8 months | Self-confidence; taste, blink, vision, hearing, | Suggested |
| P5 | GMT-5 | 26 | F | Healthy | Left | 3 months | Self-confidence; eating; speaking; blink; inability to close eyes; hearing | Suggested |
| P6 | GMT+1 | 41 | F | Healthy | Right | 1 year | Self-confidence; drooling; eat and drink; unable to close eye | Suggested |
| P7 | GMT-5 | 35 | F | Overweight | Right | 1 month | Depressed; social anxiety; shameful; vision; eat & drink; | Suggested |
| P8 | GMT+9 | 37 | F | Healthy | Right | 13 years | Depressed; vision; eat & drink; | Scheduled |
| P9 | GMT+8 | 35 | F | Healthy | Left | 2 year | Depressed; eat & drink; inability to close eyes | Suggested |
| P10 | GMT+1 | 25 | F | Healthy | Left | 7 months | Self-confidence; drooling; eat & drink; hearing; speaking; inability to close eyes | Suggested |
| P11 | GMT-5 | 37 | F | Healthy | Right | 3 months | Self-confidence; speech; drooling; | Suggested |

6.3.2.2 Tutorial.

I informed all interested parties of the study goals, the study scope, and the study procedures before acquiring their consent. After participants provided their consent, I then sent them the link to the MyFace application on the Android Play Store download page; the instructions (see Appendix F: MyFace Instructions) and a 3-minute YouTube video

(http://youtube.com/watch?v=yhhf_UWE97E) were provided to the participants to demonstrate how to use the MyFace system, and included topics like: adding friends, sending messages, recording for the diary and posts, setting reminders, viewing post history, and comparing before and after photos in the summary page.

6.3.2.3 Deployment.

After the tutorial, participants started to use MyFace in their natural settings for 30 days. I asked each participant to at least make one diary post every week during the deployment study. I felt that a 30-day deployment would be sufficient to understand participants' reactions to using this tool and enable me to iteratively revise the design. I wanted to ensure that everyone posted at least weekly so that they could see their first and latest photos for their comparison. To test the social support aspect of the application, I invited all participants to share the MyFace application with their family, friends, and care providers. During the deployment period, I sent friend requests to all participants and informed them that they could ask me anything over the application if they needed help. 4 of the participants approved me as their friend and provided me the permission to view their self-monitoring photos for facial paralysis (see Figure 8a). I was able to like and comment on these 4 users' posts, and thus provide to them social support via the system.

6.3.2.4 Post-study Interview.

To evaluate the system, I held a semi-structured interview upon the completion of the 30-day deployment period. Interviews ranged from 35-55 minutes in duration, and were audio recorded and transcribed to facilitate analysis. After the experiment concluded, the application remained available for users to continue their access to their data. Example interview questions included the

following: 1) What situation makes you want to/not want to use the MyFace application?; 2) What do you like the most/least about MyFace, and why?; 3) How did the MyFace application contribute to your recovery?; 4) How did the MyFace application improve your quality of life?; 5) What kind of information that you want to find online do you need the most for your recovery?; and 6) How did sharing affect your feelings and actions?; etc. (see Appendix D: Interview Guide for MyFace).

6.3.3 Data Analysis

For confidentiality purposes, I assigned each participant a unique ID code (i.e., P#) to denote them as participants. All interviews were audio-recorded and transcribed to aid inductive thematic analysis (Braun & Clarke, 2006). To understand how participants react to MyFace, I first established properties of what they said without relying on existing theories (i.e., open coding) for all of the transcripts. Next, I organized these themes into a table of themes and sample quotes which defined the themes. Then, I read and coded all of the transcripts, and identified, analyzed, and reported patterns for semantic themes. Later I applied axial coding to the themes to make categorizations and understand relationships among subthemes, generating and refining high-level categorical codes using an inductive approach. Themes irrelevant to my research goals were discarded. Finally, these themes were mapped and became the following high-level themes: 1) motivation for use, 2) feature evaluations, 3) adherence and engagement, 4) social support, 5) social media during recovery, 6) tensions with healthcare professionals, and 7) design suggestions. Each theme is discussed with examples and context from users' interviews.

6.4 Results

To understand patients' quotations, we provide this section to detail contextual information regarding participants' reports for varied experiences regarding medical treatments and responses to the MyFace system. Contextual information is summarized in Table 6. For example, patients report having used a variety of treatments, with steroids and antivirals being the most commonly prescribed treatments; note that only P10 describes being prescribed facial exercises, whereas the 7 other participants sought online information and performed facial exercises through self-initiated self-care. 6 participants also discuss having felt tensions with their healthcare professionals and care. Participants described their recoveries ranging from 60%-95%, indicating that most users felt that they had achieved higher levels of recovery. Most users report that they either have not had surgeries, do not want surgeries (i.e., are surgically-averse), or have postponed their surgeries, and others emphasize that they no longer feel that surgery is necessary for their recovery.

Table 6: MyFace Interview results summary regarding selected questions, including: 1) participants' treatment types and frequencies, 2) patient perceptions of recovery relative to pre-condition functioning, 3) whether users asked their support groups to use MyFace, 4) if users experienced any conflicts with their healthcare providers, 5) whether users thought that they needed surgery after their various other treatments for their conditions, and 6) if users would recommend MyFace to others. Y indicates “yes,” and N denotes “no.”

| ID | Treatment (Frequency) | Recovery | Invites | Conflict with doc. | Need for Surgery | Re-commend? |
|----|--|----------|---------|--------------------|------------------|-------------|
| P1 | Acupuncture (once per week); facial exercise (20 minutes per day); Dietary change | 95% | Husband | N | Reversed | Y |
| P2 | Steroids & antiviral (7 days); facial exercise (2-3 times per week) | 75% | - | Y | Postponed | Y |
| P3 | Steroids & antiviral (14 days), Electro-acupuncture & acupressure massage (3 times per week) | 90% | - | N | Reversed | Y |
| P4 | Steroids (14 days); Facial massage (10 min per day) | 70% | - | N | Considering | Y |

| | | | | | | |
|-----|---|-----|-----------|---|-----------------------|---|
| P5 | Steroids & antiviral (10 days); acupuncture (twice per week) | 95% | - | Y | Unnecessary | Y |
| P6 | Steroids & antiviral (10 days); facial exercise and massages (3-4 time per week) | 70% | Therapist | Y | Surgically- averse | Y |
| P7 | Antiviral (7 days); Electro-acupuncture (5 times per week); Chinese herb; Dietary change; multivitamin; | 60% | - | Y | Surgically- averse | Y |
| P8 | Antiviral (14 days); facial exercise and massages (2-3 time per week); Dietary change | 70% | - | Y | Postponed | Y |
| P9 | Facial exercise (10 minutes per day); multivitamins | 50% | 3 Friends | - | Considering | Y |
| P10 | Steroids & antiviral (7 days); facial exercise (10 minutes per day) | 90% | - | N | Unnecessary | Y |
| P11 | Steroids & antiviral (7 days); acupuncture (once per week); facial exercise (20 minutes per day) | 90% | - | Y | Unnecessary | Y |

Note that participant engagement levels with MyFace were relatively acceptable, as can be seen in Figures 12 and 13, and that all users report that they would recommend for others with FP to use the MyFace system (see Table 6). In total, users created 78 posts, with an average of 7 posts per user, and users logged a total of 1277 minutes using the system, with the average time spent on the application being 6 minutes. This indicates a relatively positive response, despite only 3 users reporting having invited members of their social network to use the MyFace Application; this may imply that users felt they had more use for MyFace's non-social support features. Note, however, that MyFace use was not consistent (see again Figures 12 and 13). Participants' MyFace use drops significantly after the first few days before stabilizing. I believe the initial spike during the first few days can be attributed to registration and exploration of the application, whereas the stabilized usage times are largely a result of diary use (i.e., the most used function). Very short time usages may represent participant use of reminder notifications.

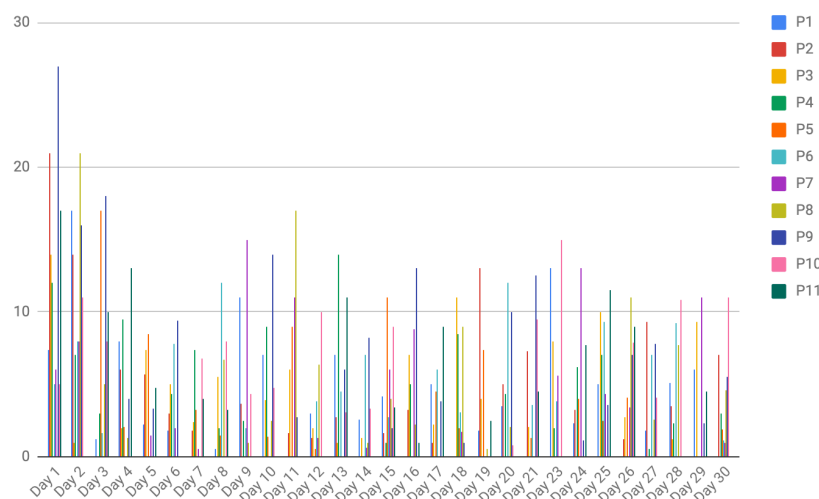


Figure 12: MyFace usage durations for participants. The total number of posts was 78, with the average for posts being 7. Participants' total time spent on the application is 1277 minutes, with the average time spent on the application each visit being 6 minutes; time spent on the application for each visit ranged from 11 seconds to 27 minutes.

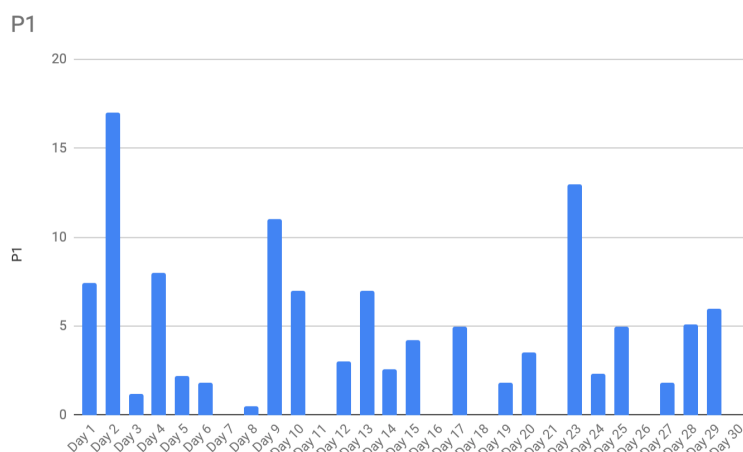


Figure 13: MyFace Usage duration breakdown for P1. The Y-axis unit is minutes. Note that P1's engagement is relatively high. Longer time durations might be the result of generating posts or messaging others, and shorter time usages may represent her checking posted photos or being notified by exercise reminders.

The main body of the results are organized into the following major subsections: 1) motivation for use, 2) evaluation of features, 3) MyFace benefits to adherence as an engagement tool, 4) social support use, 5) exemplar cases, 6) social media usage during recovery processes, 7) tensions with healthcare professionals, and 8) suggested design improvements. Each of these main themes will be discussed using stakeholder users' quotes to provide context and depth.

6.4.1 Motivations for Using MyFace

MyFace users discuss two broad themes regarding motivation to use the system: 1) to use the system as a diary for self-care, and 2) to use the tool to supply others with social support. Notably, self-care motivated users also were motivated to use MyFace for mentally therapeutic benefits.

6.4.1.1 MyFace as a Self-help Artifact

Self-logging and self-monitoring behaviors were common motivations for use. P4 describes using the system to self-track personally initiated facial exercises as follows: *“[I] read a lot of stories, and some of them mentioned that facial massage and exercise are very helpful, every time when I read stories like that, it kinds of remind me that I probably should do some exercise... So I would use the MyFace, cause it’s a neat tool for record[ing] exercise diaries.”* In this sense, P4 is describing MyFace’s intended use as a self-logging tool. Similarly, P5 described wanting to use the system to self-track treatment progress with an emphasis on treatment efficacy; P5 stated the following: *“[I] would use the MyFace app after my acupuncture session, cause I kind of want to keep track of my treatment. I want to see whether it really helped my face. I actually saw a lot of results since I started using MyFace. I use to take before and after photos as she went to stimulate my facial nerves in the clinic. So now I just use MyFace to take photos after my sessions...”* P5 adds that she wanted to keep a record for personal reflection and describes this motivation as follows: *“I think to have like a progression as a record is kind of like keeping a reminder for myself like this is how I came through... I think it's important for like your personal... just like 'OK today*

you can close your eyelids, that's really cool.' Making that progress and not like driving yourself crazy is kind of the only reason I record it..." This reminder of P5's progress serves a motivational purpose.

Users also note wanting to use the tool for more therapeutic intentions. P6 describes motivations for using the tool as follows: *"a couple of things [motivated me to use MyFace] I think, one is you know just by recording something you kind of get it off your chest... I think that by recording it, makes me realize this is a disease, and I am tracking my progression of the disease, it's kind of getting some of those feelings out and it's very mentally therapeutic in that way..."* Self-logging through MyFace thus helps P6 feel better about her condition. This sentiment was also expressed by P7, who noted feeling shame about her condition. P7 stated, *"I think [MyFace] definitely helped me to stay in good spirits. I think it definitely helps... clear up a lot of the shame around it... when I realize people are researching this helped me to have a correct understanding of the disease. This's a great way to using technology to maybe tell myself 'this is just a documentary of my condition of my disease. It's nothing to be ashamed of.'"* Users in the sample group may feel ashamed of their conditions and appearances because of the relative rarity of these conditions. The existence of MyFace may itself offer a sense of normalcy.

6.4.1.2 MyFace as an Artifact to Help Others

In addition to their self-care intentions, users also note that the social features of MyFace can help support others. P1 states, *"I wanted to... inspire a lot of people who also faced Bell's palsy or facial paralysis... to stay positive. And I put those pictures out even though it was so discomforting, even though it was very heart breaking sometimes to see... And that was the biggest thing to me to help somebody out because people were helping me with this very very scary process..."* This sentiment is fairly prominent within the sample population. MyFace users who

were inspired by others' who had shared their stories online want to help in much the same way. P4 states, *"I want to share it all... because I know a lot of other people are affected, they just want to know what's gonna happen to them... I want to help people to know about facial palsy and my experience because I've looked myself and I've seen different various people heal from it, and I think that kind of stories made me feel better..."* This sentiment may have existed prior to use of the MyFace system, as it will be discussed in relation to general social media sharing motivation, but it is worth noting that social support has in this instance led to empathy and a willingness to reciprocate support. This may be especially significant considering the rarity of FP patients.

6.4.2 MyFace Feature Evaluation

This section discusses how users perceive MyFace's features, including those for data collection, data organization and feedback, and social support, facilitates their recovery processes.

6.4.2.1 Data Collection

MyFace users employed MyFace data collection features primarily for self-tracking purposes. P8 describes her data collection practices as follows: *"when I finish my exercise, or after I massaged my face I'll remember to log it into MyFace, cause you know there is a nice calendar view, and I always try to push myself to put some effort in this every week. Or when I feel my face a little bit tighter, I would try to take some photos, and go to the summary to check if my face gets any worse."* Note that P8 is collecting data both after her exercises and massages and during symptomatic episodes. In addition, her data collection helps her to keep records of her facial paralyses (i.e., as she has had multiple episodes); she notes, *"I like to recording myself. So [I like the] gallery... cause I can see what I recorded, and when I took these pictures. [MyFace] helps me*

to have a sense of track record of my journey. If bell's palsy attacks me again I will have a better record." In addition, for collecting data for self-tracking purposes, users also report using the system for self-experimentation purposes. P6 describes one example as follows: *"I have a friend who is a massage practitioner and she just get her qualification. She uses a scraping technique... that [is] supposed to promote blood flow which is supposed to promote healing. I asked her to use MyFace, cause she wants to take sort of my before and after pictures and see if it has any effect... we both want to see what would happen cause it supposed to be able to help."* P11 describes using MyFace's before and after photo comparison collection to look for results from exercise techniques she finds online. In both cases, these users were attempting to use the data collection tools of the system to determine if treatments produced beneficial results (i.e., they were testing efficacy of treatments through self-experimentation). In particular, P7 notes that the MyFace data collection features made her old data collection habits obsolete; she states, *"No [Instagram] don't have [a collage feature], it's a separate app. That you just collage these together, I could put a filter on everything... now I don't use it anymore, if I want to post my before and after photos now, I would just take a screenshot of the photos in summary, cause it shows my before and after, it's very convenient."* P7 no longer requires the use of external collage applications, as her data is automatically summarized and organized when it is collected.

6.4.2.2 Data Organization and Feedback

All 11 participants in this study report enjoying the chronological, before and after, organization and feedback scheme used within the MyFace system; in other words, all users enjoyed both the summary and gallery. P3 notes, *"The photos are organized by date, which I always think make the most sense to me... and I think it's really neat that MyFace can help me create before and after photos to kind of help me see how effective the acupuncture was over time. It is*

also kind of organized them as my face progresses... I kind of can tell when things got better.” Note that P3 is describing how MyFace data organization works in tandem with data collection to facilitate self-tracking, self-awareness, and self-reflection in recovery and treatment processes. P10 describes MyFace’s organization as opposed to her own prior to MyFace use as follows: *“I kinda did the same organization [as MyFace], I just shovel all my photos in chronological order, and I had several different facial expressions, I probably have like 6 so I could flip through and compare how was my face doing over time. Exactly like what you did in MyFace, I was surprised when I first saw the gallery and summary, this is exactly what I was doing, it was really helpful since it was all automatic, it saved me lots of time.”* Together the positive reception to the scheme and the independent convergence of actual user strategies with MyFace design may indicate that this feature was well-developed from stakeholder understandings. To be clear, though, not all users developed this organizational strategy prior to using MyFace. P5 notes, *“I really like the way MyFace organizes them, cause most of my photos ends up sitting in my phone albums... I have a bunch of different photos and videos... I wish I could use MyFace earlier, so that all my photos and videos can be organized this way. Because the only reason I'm keeping it is to remember... what it looks like and how far I've come, so arrange them by date in MyFace is quite convenient for me to look back. It's easy to reference back when it happened, so if I ever want to look at it again it's there.”* In this instance, P5 is highlighting that the MyFace organization scheme facilitates self-reflection. In addition to facilitating self-reflection, P11 further notes that the organization can potentially facilitate social support via supporting the clear sharing of experiences; she states, *“I've just downloaded [my old photos] from my phone to a folder, and labeled [it] as bell's palsy photos, like by category... I'm probably just leave them there even after I heal, they are probably just sitting there. That's why I prefer how MyFace organize them, it's much clearer that way, and very easy for me to access them, or show them to my friends later.”*

6.4.3 MyFace as an Engagement tool

MyFace primarily facilitates self-awareness and self-reflection to motivate patients to adhere to exercises and massages. It further supports patients' adherence by providing in-built reminders. Users report that both were effective for promoting adherence behaviors.

6.4.3.1 Facilitating Self-awareness and Self-Reflection

MyFace users report that perceiving subtle recovery processes is challenging without aid, and that the MyFace system does aid in the perception of those improvements; this suggests that MyFace facilitates self-awareness in users. P3 notes, *"Yes [MyFace] sure did [help me record my recovery process]... when you're experiencing it, you don't really see the changes at times, because you still see yourself as initial onset like the day one... or it's really hard to see, like sometimes [the photos] would capture... a twitching... you don't feel it, but you actually can see visually the change."* Note that here P3 is highlighting how her condition affects both her visual perception and her tactile perception, as she reports that she cannot necessarily feel twitches as they occur; she reports that the MyFace system helps her to capture and perceive what she cannot see or feel during her daily life. P10 notes the following: *"I think it was useful for me to be able to look back... to see that I could like I had the tiniest bit of uplift in the corner of my mouth. I was very excited to see that in one of the comparison photos... I was literally [spending] 5 minutes on the summary page and [studying] each movement photos, I was obsessed... so I can tell what's really going on. And the day I saw the photo that showed wrinkles appear on my forehead I was so excited. That's like a milestone for me."* For P10, the comparison photos and summary thus offered her concrete feedback which demonstrated what she believed to be actual subtle recovery, thus improving both self-awareness and mood.

In addition to improving self-awareness, MyFace facilitates self-reflection upon that improved self-awareness. P4 states, *“I think [MyFace] did [help me in my recovery process]... now I can say take a picture and have a look back... later on I can have a look on how I was feeling, just to remind myself... this [is] how [it] was, and this [is] how it is now, and how far I have gone, you know.”* P4 is describing how her photos allow her to be aware of changes over time, both for her physical appearance and her feelings; she notes that this self-reflection likely helped her during her recovery processes. P10 describes her beliefs as follow: *“Yes [MyFace helped motivate me during recovery]. definitely, just cause as soon as I started to see any kind of progress in the photos, I would know that 'this is working.' They are really important, and I still look back at them actually now, and literally yesterday with my mom, and I'm going like 'oh my god, I really was ill.’”* Note that P10 describes benefits from MyFace use during her earlier recovery processes as well as in her current processes, indicating potential benefits from continued usage; she also describes an instance of herself sharing her self-reflection with her mother in a social circumstance.

6.4.3.2 Motivation through Self-awareness and Self-reflection

The MyFace system primarily motivates users through demonstrating their progress via visual media feedback; this raises their self-awareness and self-reflection and offers the potential for behavioral changes. P9 notes, *“I can't see any movement on my face [before using MyFace], every day I stared at the mirror, I get very frustrated. Since I started [using] the app, I took a lot of photos and videos, and after time, I can see a very little improvement, it means I am getting good.”* P9 here describes her challenge in perceiving subtle improvements over time prior to using the MyFace system, which she notes is frustrating; the MyFace system facilitated her self-awareness of subtle recovery progress and promoted a more positive self-image. P11 discusses her own mood changes as follows: *“I just think using MyFace... made me excited like I was getting*

better over time, they made me more positive I guess, and not feel like depressed about it, that I was making progress even if it was small. That helps, like even little bit progress you can see, you know there is a hope...” Even small improvements may serve as significant motivators when individuals are made aware of those improvements, as they offer hope which may further stimulate motivation and adherence. P2 notes, *“by documenting my progress [in MyFace], I am able to see how much I improved, and also knowing that other people are out there that have experienced it and have done the same things that I've done, and some worked some haven't, it makes me cherish every little improvement I had, and motivated me to try to exercises every day.”* Here, P2 is describing self-reflective and comparative behaviors which are facilitated by both MyFace’s visual media feedback features and social media (i.e., other sufferers’ experiences); these aspects work in tandem to provide support which she reports motivated her to better adhere to exercises.

6.4.3.3 Exercise Adherence Improvements via Reminders

In addition to leveraging self-awareness, MyFace allows users to set reminders, notifications, or alarms to increase adherence to facial exercises and massages. P1, P2, P6, P7, P9, and P10 all directly state that these features helped them to better adhere to their exercises or massages. P2 states, *“The reminder is very useful too, I often forget to do the massages, since I set all the reminders, I think I am doing the massages more often, but I can’t say that I do it every time when I get the notification.”* Note that although P2 may not perfectly adhere, she does report performing more massages than she otherwise would without using the MyFace system. P6 described her experiences as follows: *“Sometimes I just forget [to do face exercises], I think with everything that I suppose do every day... But I was doing more exercises after using MyFace, cause you know, I can set reminders, and then I will get notifications like ‘oh it’s exercise time’... [Prior to using MyFace] I did 2 or 3 times a week I remember. They advise you should do [exercises]*

everyday... But after using MyFace I am able to do it almost every day.” Therefore, self-reported adherence rates appear to be significantly closer to suggested rates. In addition to these reminders, P1 also suggests that the summary feature helped her to remind her to adhere to exercises; she notes, *“The summary really remind me when I did exercises, and when I did not...”*

6.4.4 MyFace as a Social Support Tool

MyFace serves to increase awareness of FP sufferers’ challenges in their social circles and generate social support which can motivate these individuals to continue working toward recovery. P2 states, *“[My family and I] have talked about little things, I show them my photos and tell them like 'this is me in the beginning... and this is the progress that I've made.' And I will answer their questions. MyFace was really handy for explain[ing] my situation... I can just show them MyFace so at least those photos explain how it has been.”* P2 here describes how sharing her MyFace photos can keep her social support circle informed of progress and setbacks if they occur; this acts as both a social support facilitator and an informational support for the social circle. The MyFace system can also allow socially supportive commenting which offers reassurances to users. P6 describes such a situation as follows: *“I think [sharing my MyFace] did [open conversations with my friend] ... I felt really self-conscious about [my condition]. But my friend commented, you know she reassured me that I still looked fine, and that definitely gave me a bit of a confidence boost...”* P6 here describes gaining confidence from this social support despite feeling self-conscious about her condition. This confidence may itself boost motivation, but motivation may also be derived from the act of sharing one’s processes and progress with social networks. P1 describes, *“[Sharing with family and friends] really motivated me to do more, it motivated me to keep working and it really gave me a different type of push. This push comes from just [seeing] my family is there to support*

me, I know that I am not alone.” Note that P1 is not describing any socially supportive actions; the observable reminder of a social support network is providing P1 with motivation to push herself.

In addition to acquiring social support through MyFace, users have used the system to offer support to others with similar conditions. P3 notes, *“I was able to share... a lot of pictures and stuff, like where people [are] really shy about sharing ... because everybody is like 'oh you look so great,' then I will tell them 'well this is what I used to look like.' So it really helps them as well, then they are more open to share.”* Here P3 is describing how she used MyFace to demonstrate her progress and inspire more openness in others. This may again contribute to offering FP sufferers a sense of normalcy which promotes further sharing in a social support feedback loop.

6.4.5 Exemplar Cases of Interrelated Feature Benefits

So far, we have discussed how MyFace works to motivate users via facilitating social support, promoting self-awareness and self-reflection, and providing reminders. We have thus far isolated user quotes based on these primary themes, but the MyFace system employs these features in a synthesized manner, and quotes about the system typically discuss these themes in tandem. For example, P3 states, *“I think [MyFace] was helpful because it also allows me to see... you don't really see your progression, so when you look back at pictures or video then you are like 'oh wow, oh yeah, I am coming along,' so in that sense it does help a lot to boost my confidence that I can overcome this. In the past, after a year of treatment, even I took so many selfies, I never able to compare so many different faces so closely. I did try to make some before and after photos, and I try to use similar light and angle, but none of my previous photos give me such a clear visual comparison. For the first time, I can see how much better my lip on the right can move upward than a month before. This inspire me to keep on trying to get to 100 percent recovery, you know to be consistent with the treatment...”* This quote illustrates that, at least for P3, the challenge of

perceiving and being aware of her gradual recovery was facilitated by the use of MyFace's strict before and after visual media feedback scheme; she further states that it was this clear self-awareness of her progress which boosted her confidence and motivated her to adhere better to her treatment. In addition to these features working in tandem, P6 describes how these features also work in tandem with her social support; she notes, "*[Myface] helped me to see my progression week by week, and remind me I need to do exercises, and it let me talk to my friend easily... if I saw she was commenting me like 'oh I think your lip [has] improved since last week,' I can just talk with her via the app immediately. When I saw the comparison photos, I did see some improvement since the beginning, so it's kind of reassuring what my friend said earlier and gave me that confidence boost.*" Note that P6 describes data feedback, reminders, self-awareness and self-reflection, and social support being facilitated by the MyFace system; all of these factors work together to reassure her that she is making progress.

6.4.6 Exploring Participants' Social Media Use

This section explores participants' behaviors and attitudes towards using social media for support during their facial paralysis treatments and recoveries. It includes their motivations, effects of use, challenges, and preferences in limited contexts.

6.4.6.1 Motivations for Interacting and Sharing online:

Users discuss the following four broad motivations for interacting with their patient peers through online social media: 1) information support seeking, 2) appraisal support seeking, 3) emotional support seeking, and 4) social support providing. P2 describes her experiences with a Facebook social support group as follows: "*There's a really good [Facebook group]... you just*

explain yourself and what's happened with you, and then you've got 15, 20 people coming in and giving you their experience, and what they've tried... it was probably the Facebook support group that told me more so about the acupuncture and the Botox instead of a doctor. So, if I hadn't been on that particular group, I might not have known those options were out there for me." Note that P2 is emphasizing interactions which directly informed her of treatment options that she would have otherwise not known were available; this again may highlight a lack of information support from healthcare professionals. Furthermore, P8 states, *"positive comments helped me, because I've only got [good] comments so far luckily. And those comments definitely like encouragement kind, like 'keep going'. And it makes me feel that I'm accepted and nothing is wrong with me. So I think those parts helps me a lot."* Here P8 notes receiving affirmations in the form of positive comments which helped her feel accepted; this comment thus highlights how P8 receives both appraisal and emotional support which helps her in her recovery processes from positive comments online. Interestingly, P8 seems to imply that she may not have felt accepted prior to receiving those comments. These forms of online support may be facilitated by the nature of sharing online. As P2 notes, *"I like messaging and chatting. I guess exposing yourself but you're not totally exposing yourself you're able to say what you want to say but you don't have the eyes glaring at you, or kind of putting you under the Microscope. You're able to just you know get it out there and not feel exposed."* P2 is highlighting how the semi-anonymous nature of online sharing helps her to not feel stigmatized. Together, P8's and P2's quotes seem to highlight that some facial paralysis patients will feel stigmatized in social situations, but online media can still support these individuals who do feel stigmatized. Finally, much like participants who use MyFace to share their journeys and support others, participants use social media for the same purposes. P3 states, *"I have so many people reaching out to me for advice and support. And like you know and asking me about this, whether to get acupuncture or get help... it affected me in the sense of like it just kind of makes it let go of my life. Share my photos and my story because you know there are other people who need*

it.” The act of sharing for P3 not only provides others with social support (e.g., information and emotional in just this comment), it helps her to reflect upon her own experiences and “let go” of her experiences; this indicates that P3 is herself experiencing catharsis via supporting others and thus receiving her own benefits from these supportive actions.

6.4.6.2 How Reading Peer Experiences Affects Motivation

MyFace users report seeking out online sources of patient peer related experiences; they note that reading these patient peers’ stories can affect their own motivation during treatment and recovery processes. P11 explains, *“[The information I most looked for,] it's been seeing people that have... like a person at you know at their worst, and then seen them recovered, like knowing there was a time, like this is day 4, and then this them recovered at day 30... I sort of scoured YouTube for different people that have sort of gone through the journey of that... Just to know that you're not going to be stuck like that forever. Cause you feel like you're going to be stuck like that forever...”* Note that P11 is describing her own self-directed scouring of internet sources to discover patient peers’ stories of recovery; she notes that reading these stories of recovery have a reassuring and motivational effect for her. This reassurance stems from both garnering a better understanding of expectable outcomes and seeing that patient peers with similar conditions have recovered. However, stories of successful recoveries are not the only peer experiences to be found online, and stories which offer negative views toward recovery can become demotivational. P7 describes her experiences with such negative stories as follows: *“other people's stories could make you feel like hopeless, like somebody else posted online that they have this for four years, and still struggle with it, so you're like oh could this go on for four years ten years, you are like, hearing these stories were awful. It's scary how long it can go.”* Whereas positive stories of recovery offer reassurances and hope (i.e., misguided or not), negative stories exacerbate these individuals’ fears and

uncertainties. P6 and P10 directly state similar feelings towards these negative peer stories, indicating that this is not an isolated incident or attitude. Interestingly, time relative to diagnosis may play a role in the severity of effects when reading peers' stories. P10 notes, *"when you're in the first four weeks of it, the last thing you want to read is about somebody who's had it for three years..."* P10's quote seems to indicate that exposure to negative peer experiences relatively early in the treatment process may be worse than exposure to said experiences later in the treatment processes; this finding may again suggest that there is a lack of informational support regarding expectations during these patients' early treatment stages which makes them more susceptible to uncertainty and demotivation from peer experiences.

6.4.6.3. Online Informational Support Challenges

P2, P4, P5, P6, P7, and P11 all directly stated that using online tools (e.g., Google, YouTube, health websites, etc.) helped to support their self-directed information seeking behaviors and thus their recovery processes. For example, P11 states, *"I googled on YouTube Bell's Palsy and then a lot of different facial exercise things come up.... Cause that's one thing keeps come up in the Internet search. I just try to Google some different facial exercises and I watch the videos and then I sort of pick the video I like and use that one."* Note that P11 is describing searching for, learning, and performing facial exercises on her own, independent of healthcare professionals' prescriptions; such self-care activities were facilitated via online information support from YouTube, Google, and online health websites. These resources offer valuable information for facial paralysis patients, but utilizing it independent of healthcare professionals' input can be challenging. P2 and P6 both indicate that they had to perform critical thinking and choose what they deemed to be valuable for their own recovery processes amongst all of the information available online. P6 notes, *"Internet is definitely tricky, when you search something, you can see how many pages*

showing up, and some of it can be absolutely nonsense, you have to filter through them because you know something can be damaging, I'm sure if you google some kind of remedies to serious illnesses, some of the things you get will be actually wrong." P6 is thus identifying a challenge regarding overabundant information and a lack of medical expertise or guidance. This again may indicate a lack of information support from healthcare professionals during early facial paralysis treatment.

6.4.6.4 Social Support Preferences

Users report experiencing a variety of social support (e.g., in-person, online, from friends or family, from strangers, from patient peers, etc.), but users also note distinct preferences for certain types of social support. For example, despite all of our participants having social media accounts which share their facial paralysis journeys, P4, P8, P10, and P11 note preferences for in-person social support from friends and families. P4, for example, notes the following: *"I don't get much support [online]. I don't need much support from them to begin with. I have support from my friends, you know and I'm trying to stay positive. and you know people, I could see that people care, this online world, I'm not looking for support from there. It's very distant, and I weight the support from my friends and family more."* P4 here discusses the relative worth of her social supporters, and suggests that online support is less meaningful than the support of people she knows in her real-world social circles. P10 describes her experiences interacting with patient peers online as follows: *"For Instagram, I mean I've commented on a few other people's Bell's Palsy photos and I've said 'I hope you get better soon...' even though they do [comment] on my post it's kind of feel [alienated], I mean I don't have much feeling reading those comments from strangers, the support come from my friends and family is more meaningful to me."* P10's quote is especially interesting here because it indicates that she values the social support of her friends and family above social

support provided from online patient peers, as reading comments from these online “strangers” is in some form “alienating.” This may indicate that a lack of social context or shared experiences is partially responsible for these preferences. Furthermore, users may also prefer speaking to patient peers in-person as opposed to online. P8 describes her willingness to join a facial paralysis support group as follows: *“Definitely [I am open to meet people who share my condition]. If there's any kind of like a group or something, like real, I would [definitely] go, but I don't think there's any around here.”* Note that P8 is implying a difference exists between real-world support groups and online support groups, and indicating a desire for real-world groups as online support groups are not constrained to physical locations.

6.4.7 Tensions with Clinicians

The literature suggests that patients with long-standing cases of paralysis are often told by healthcare professionals that there is little they can do to provide further improvements (Lindsay et al., 2010). This is consistent with our participants’ perceptions regarding their care providers and services. It highlights the potential need for greater information and emotional support by exploring their accounts of care experiences. If accurate, this would be especially troubling considering that participants note making recovery progress while using the MyFace system, indicating that their actions, even in long-standing cases, may have provided tangible improvements to their facial movements.

6.4.7.1 Variability in Treatment

Participants note that facial paralysis is a variable condition and treatment recommendations are not currently standardized or consistent. P6 describes her feelings regarding

Bell's palsy as follows: *"Most [Bell's palsy] cases are what they called I think is idiosyncratic... they don't know exactly what causes it. I think medically it is a virus which attacks the facial nerves and effectively paralyzes the facial nerves... depending on severity of the virus, and severity of the first impact that quite often affects kind of recovery time and chance for a full recovery."* This quote emphasizes the perception that facial paralysis is highly variable and may indicate that healthcare professionals with which P6 has consulted may not be experts in facial paralysis specialties; at the very least, this indicates a possible tension. This tension may be more apparent in the following quote from P2: *"[E]ach doctor I went to didn't know enough about it. They're like 'Well I think it's too soon for you to try doing stuff because that could cause more damage'... I found online exercises and they seem to help but now that it's been a year later I've gone to a different doctor and they're like 'Well now it's too long I don't think it would give you a little effect if you try now...' So there's lots of varying. They just don't know enough about it to give me proper suggestions, like when you should do it, and when you shouldn't do it, if you should or if you shouldn't. So that's been a little frustrating."* Note that this variability in treatment and perceived lack of healthcare professionals' awareness regarding facial paralysis is frustrating for P2; this may exacerbate other frustrations caused by dealing with the condition itself. In any case, participants perceive that healthcare professionals (i.e., not specialists) may not be equipped with the expertise to help them in their recoveries.

6.4.7.2 Affordability and Access

This lack of expertise may be particularly troubling for patients, as specialists may be limited or not covered by insurance. P5 explains her experiences trying to acquire an appointment with a specialist as follows: *"[T]he hardest thing for me was getting hold of an EMT, an ear nose and throat doctor. We don't have a lot of them... in our hospital... it took a really long time to see*

the person. And when you see a specialist like that and it's hard to be able to get in contact with them again to ask all of the questions or get a second opinion... by the time I saw the next [specialist] I had my hearing back because I lost my hearing temporarily... I finally got to ask him all my questions, but it almost felt like by then everything [had] just become like easier to manage. And I was like, 'Well I wish I could have asked you this like a month ago when I was actually upset.'” Note that P5 is expressing that her information support needs were not met in a timely fashion by her healthcare services, as by the time she saw a second specialist to consult about a new symptom, she had already recovered from that symptom and learned to better manage her condition. Limited specialists may not be inherent to just facial paralysis treatment, but this issue may frustrate patients if other healthcare professionals appear unable to offer sufficient expertise in a timely fashion (i.e., as may be suggested by section 6.4.8.1). In addition, affordability may be a concern for patients trying to access specialist care or specialized treatments. P2 notes, *“I wanted to try acupuncture but for me it's too expensive... in order to get any kind of effect out of it you have to do it pretty regularly. I just couldn't afford it. And it's not covered by my insurance. So I didn't get to do that, but that is one of the big things on the support group they suggest is acupuncture.”* Whether or not acupuncture is an effective treatment for facial paralysis, P2 is highlighting that she was unable to afford a treatment which was perceived to be effective in a group of patient peers.

6.4.7.3 Perceived Lack of Support

Finally, participants also note perceiving a lack of both information and emotion support from some of their healthcare professionals. For example, P6 states, *“[M]y doctor basically didn't give me anything. You have to find all information out yourself... the problem with the Internet is that you have to... do more research into verifying your sources, whereas if you go... to a medical*

professional... it's probably a lot more reliable... I would have preferred to have a lot more... access to some medical support rather than just having to rely on the internet." In P6's case, she supplemented her own perceived lack of information support by using online resources, but utilizing these resources required her to filter information; because P6 lacks medical expertise, she has concerns about the reliability of this information and would prefer more guidance from her healthcare professionals. In addition, P11 discusses her perception of her care as follows: *"I don't feel that my doctor cared about me, you know he was like 'oh it's not that big of a deal, whatever here is the medicine.' So I guess I just want to somehow even it's just a like, or acknowledge that you're going through some hard thing... at the time I was pretty depressed. And then they throw you on the steroid that are very hard on your emotions, and you have a paralyzed face..."* Note that P11 is describing a desire for more emotional support from her doctor, as she believes her condition had made her depressed during her initial diagnosis. This indicates that she felt her doctor had not considered how the condition was affecting her mentally, which she believes would be exacerbated by side-effects of her prescribed medications.

6.4.8 Design Suggestions for Improvements

Although user response to the MyFace system were generally positive, users do offer suggestions for improvement of the system. These suggestions include fixes for problems during use and features which they desire from their personal interactions with using online resource for support.

6.4.8.1 Data Collection Hassle

Despite MyFace facilitating self-awareness and thus motivating adherence, P1, P3, P6, P8, and P11 feel that the current data collection demands can be tedious. This data collection hassle prevents users from logging information on a daily basis. P8 notes, *“Maybe [I don’t want to use MyFace] when I don’t want to log so much information, you know it takes time. Oh I don’t use MyFace everyday if that’s help. Cause I don’t see myself getting any better every day, so what’s the point to use it every day, right? I usually use it once or twice a week.”* Here P8 is describing logging all of her information (i.e., including photos, videos, and contextual data), and P6 described similar feelings; however, the most recurring theme regarding data collection hassles was that taking 9 strictly regulated photos a day was too much work. As P3 notes, *“I think the instructions on what face you should make is like 9 pictures per post, I can’t just use the selfies I took during the day, cause I have to follow the instruction on which facial expression to put in here. It’s not very convenient for me to use every day.”* Interestingly, this example emphasizes that P3 was taking photos of herself which were not intended for the MyFace system, which suggests a willingness to take photos of herself; this may indicate that, for some users, the hassle was not actually in taking the 9 required daily photos, but with taking photos of the 9 highly-specific poses daily. Therefore, users ask for either being allowed to use photos taken without the specified poses, or suggest using the MyFace system weekly or twice a week instead of daily. P11 highlights another potential avenue for future designs as follows: *“I would have probably taken a video every day and not just the pictures, because it’s interesting to me now to look back and see the video that I did take how my face was moving. And I think I would like to see more video about my face. I think it’s more interesting.”* Note that P11 is describing how she might record her data differently if she could do things again; she describes videos as being both more interesting and more informative than the pictures, of which she would take fewer.

6.4.8.2 Data Organization

Although user responses to the MyFace data organization and feedback scheme were primarily positive, two users did note suggestions. For example, P4 states the following: *“I like what you had now, organize by date it’s very clear. However, ... I would like to see a slideshow, maybe like a time-lapse video... just [putting] one before photo and one after photo did not show the finer granular of my progression... if one day I am 100% healed, I want to see how I progressed...”* Note that P4’s focus in this quote is self-reflection after she has healed; she wants a time-lapse to display her gradual progress in an efficient format. The addition of a time-lapse visual media display may thus offer greater self-reflection after a patient has achieved his or her full recovery, but it may not be an effective replacement for the current scheme. P7, for example, describes a suggestion for collages as follows: *“[For collages I want] the grossest looking to be the first... I usually put photos of how bad it was that first... It’s like there’s a shock value to that... when people saw me they are like ‘oh you don’t look bad’ or ‘you look really nice,’ but they did not see me when I first diagnose with this, so if I just did yesterday to today, it wouldn’t be as much of a difference, but if I put my first facial palsy photo with me now, people would know what I went through.”* Although P4 is suggesting a collage, this example emphasizes that using the patient’s first and latest photos together offers a quick and efficient way of demonstrating progress; furthermore, this quick comparison may facilitate social support by efficiently sharing a patient’s progress with his or her social network.

6.4.8.3 Data Storage and Sharing

Two users note data storage issues which could be improved. The first, P3, describes her issue as follows: *“I did not like the fact that I can only put 1 video there [in the MyFace gallery],*

I think it's very limited..." Note that MyFace does not currently allow for multiple video uploads; this issue may not allow for all users' ideal data collection means, as P11's quote in section 6.4.8.1 suggests. In addition, P11 also states the following: *"I wish all my photos can load to [MyFace], so I can show [a recently diagnosed colleague] my full recovery."* MyFace does not allow users to upload their prior photos; the current design thus makes P11's sharing to support her colleague more difficult as it creates a disparate collection of P11's recovery processes and experiences.

In addition to P11's sharing challenges, both P4 and P10 note that they desire a method of sharing their MyFace data to other social media platforms. P4 specifically states, *"I guess if you can make whatever I posted in MyFace also post on my Instagram and Facebook, I would like to use it more often, cause I can't use MyFace to share."* In this instance, P4 is treating MyFace as primarily a data collection and recording tool; she believes MyFace is currently limited in its sharing abilities, which is a concern regarding MyFace's social support intentions. P10 highlights this as follows: *"I suppose if you can have some kind of like a share button so I can share my post with my mom or on Instagram, or some kind of support, I guess."* Note that P10 is not requesting automatic transfer of data from the MyFace system to her social media or social network; she is requesting a button to enable sharing at her discretion, suggesting that control over what is shared and with whom is important.

6.4.8.4 Informational Support

MyFace system, users were asked to discuss what informational needs might be supported by technology. Regarding specifically MyFace, P10 was confused as to how to perform facial exercises; she suggested the following: *"Maybe put some kind of exercise instruction you want us to do somewhere, so I know what to do... I just go ahead did what my therapist taught me. Oh, and if I need to do all exercises at once, you know, the eye, cheek, lip and neck you had there. I just*

don't know what you want me to do there." Note that MyFace does not currently provide medical advice or information regarding the performance of facial exercises; it merely allows for the recording of facial exercises, which caused P10 confusion. In addition, P6 describes her confusion regarding the MyFace "doctor" tab as follows: *"when I saw MyFace has the doctor category I was expecting some sort of medical support or involvement, but I guess you have to ask your own doctor to join it, but I don't really know any facial palsy doctors, so."* Similarly, P8 requests, *"I guess maybe [recommend] doctors around me?"* These instances represent a desire for healthcare professionals' input.

More generally, users feel like their informational needs regarding basic symptom progression and expectations, treatment options, and exercise instructions are not being met during facial paralysis treatment. P5 notes, *"The information I needed the most was understanding like the different stages... when it first happened, I looked up like how long does this normally take to heal? And then as I kept looking, so like little bits of information that helped me out that weren't really explained by my doctor."* Note that P5 describes supplementing her own comprehension via self-directed online explorations. Her desire to understand progression and her actions regarding self-directed online study are common in the sample population, which emphasizes the need for better informing patients of expectable outcomes. P2 suggests the following, *"I'd like to know or at least with these other people does it get better... Is there a possibility it could get better, or am I where I'm going to be for the rest of my life? That really helps talking to the people who've been through every stage everything from just being diagnosed seven years, and this is what's going on."* Note that P2 is highlighting the potential to supplement expectations by interacting with patient peers and hearing their stories from different stages of care and progress; this may indicate that patient peer information is particularly useful for helping others understand expectable outcomes.

6.4.8.5 Emotional Support

In addition to informational support, users suggested that technology could better facilitate their emotional support. For example, P1 states, “[W]hen I got diagnosed, I didn't know anything about it. I would love to see more inspirational pages around Bell's palsy, like some resources that people can use and go to.” Note that although P1 is asking for resources regarding Bell's palsy, she uses the word “inspirational;” therefore, a link likely exists between facilitating information support and facilitating emotional support in this instance. In addition, P3 discusses how emotional support could be facilitated as follows: “I'm very thankful that I had a lot of emotional support from my family members... but even if I had someone who kind of reached out to me during that time... saying, 'Hey I've had [Bell's palsy] too, don't worry,' or something... it would just kind of be more reassuring, it would have been more effective.” Note that P3 is describing how peer patient support would likely be more effective at reassuring her than her own family's support; this suggests that connecting patient peers from different stages of progression would not only facilitate informational support as noted above, but also facilitate emotional support.

6.5 Discussion

6.5.1 Patient Perception and Motivation

MyFace is a tool which utilizes self-monitoring and social support to bolster user motivation and thus adherence; the design of this tool was informed by prior research which suggests that, in facial paralysis prehabilitation, patient belief in personal progress plateauing and imperception of recovery progress are two of the key causes for patients to stop adhering to prescribed activities (see Chapter 5). Patient progress plateaus (i.e., where patient recovery progress appears to stop being made) are known in the literature from similar health contexts, especially

during rehabilitation (e.g., recovery after arthroplasty (Zhou et al., 2015), recovery following stroke (Demain et al., 2006), etc.). My findings (see Chapters 5 and 6) suggest that FP prehabilitation patients also feel demotivated once they feel that their progress has plateaued. Note that patients will feel demotivated regardless of whether or not the plateau in progress is real or only perceived; their perception of the plateau is what affects their motivation.

Patient perceptions are not perfect; literature suggests that humans often fail to even perceive drastic changes during short time spans (Levin et al., 2000), and my research (i.e., Chapters 5 and 6) indicates that facial paralysis patients fail to perceive subtle and gradual changes in their own faces during their long recovery processes. This faulty perception leads to “perceived plateaus” which may not be actual plateaus in treatment processes. MyFace was developed to facilitate patients in perceiving their own progress and thus overcoming these perceived progress plateaus so that they can stay engaged with a treatment and continue to receive benefits. The results of this deployment study are promising and demonstrate patient self-reported success regarding adherence improvements; if such success is verified via further study, it would highlight that the adoption of an HCI lens in prehabilitation research can benefit one of the biggest challenges in prehabilitation research and delivery (i.e., adherence).

6.5.2 Motivational Features

User responses to MyFace in this deployment study were overwhelmingly positive regarding such features as data organization (i.e., chronological order), data feedback (i.e., before and after photo comparisons), and exercise reminders; these are the factors which users indicated helped them to become self-aware of their progress, reflect upon their recoveries, improve their motivation, and adhere to their processes. The reported success of these features likely indicates that their design is well-informed by patient stakeholder understandings developed in prior research

(i.e., Chapters 3 and 5), as incorporating stakeholder understandings in early design phases can be crucial for developing well-received healthcare technologies (Zhu et al., 2016). In particular, it should be noted that the chronological organization of patient data facilitated their reflection, as it presented them with an efficient way to reflect upon their own progress over time. The side-by-side before and after photo comparisons using standardized poses likewise offered a quick way to see actual changes in a concrete manner; as P7 noted, using the first and the latest photos offers a “shock value” which facilitates self-awareness. Even if the changes are small, users still report being motivated by making any progress, as the progress gives them hope that they can still recover further. This self-awareness of making progress, and the hope for continued progress, is likely the main driver for patient motivation to adhere to activities, although reminders are effective tools for facilitating user engagement as well (Consolvo et al., 2014).

6.5.3 Social Support Features

In addition, these features, MyFace was designed to provide social support by connecting users with user-determined members of their social circles. Although MyFace’s use a social media-like platform was limited, users who did share their MyFace data with others on the platform did receive some social support. Notably, P6 expressed that the system better allowed her to keep her friend who was providing instrumental support (i.e., a face scraping technique) informed of her progress and changes, as well as emotional support. More commonly, users would share their photos with others outside of the MyFace system (i.e., by showing these photos to others on their personal devices, rather than connecting these others to their MyFace accounts). This might due to MyFace is a research study, and user population is very small. Moreover, users’ choice to share data in this fashion may be a reflection of the preferences for in-person sharing with friends and families, but these actions still facilitate social support by informing the users’ social networks

without hassling the non-users to create their own MyFace accounts. MyFace thus facilitates social support by acting both as a social media tool and a reference and sharing tool for in-person interactions, but it also acts itself as a social support tool for users; that is to say, MyFace offers users social support by allowing them to share their own experiences with others, thus potentially providing them some catharsis. Merely articulating their personal experiences in online support groups is known to provide patients cathartic benefits (Buchanan & Coulson, 2007), and MyFace users discuss similar benefits from sharing their own experiences to support other FP sufferers; in fact, it is noteworthy that this act of sharing to support others was a major motivation for some users to begin using MyFace in the first place. Allowing users to constructively share their own experiences with other FP sufferers may provide meaningful mental and emotional benefits in their own recovery processes. Further studies should be conducted to ascertain the potential cathartic effects of sharing in specifically FP patients' recoveries.

6.6 Design Implications

6.6.1 Logging Burden

One of the most consistent user challenges regarding the MyFace system was data collection and logging hassle. Users report that taking 9 strictly posed photos per day in addition to logging contextual details may require too much effort; this is a significant finding considering that all users prominently used social media to share their FP journeys prior to using MyFace, and thus might represent a best-case scenario for implementing self-logging of personal visual media. Simply stated, if this population feels that the current number of photos is too many, then populations which are less prone to taking their own photos and using social media may respond worse. Users report that they did not always record their photo sets on a daily basis, opting instead

for weekly or twice weekly photo logging, and some suggest taking fewer photos altogether or allowing the use of non-posed “selfies.” Requiring users to log photos less often may be viable, but I designed the MyFace photo set to clearly demonstrate symptoms, and I am uncertain if using fewer or non-posed photos will offer the same reported successes.

Despite the high logging burden of the current MyFace design, it may still prove useful for purposes other than self-logging. Teixeira et al. note that randomized trials for major Bell’s palsy treatment options are still necessary for determining effective treatments; they note that such studies need to measure features including facial appearance, facial movements, and functions, preferably using visual media as a blind for outcome assessors (Teixeira et al., 2011). With this in mind, the current tedious iteration of the MyFace system may be better suited for clinical testing of facial paralysis treatments to determine efficacy than for self-logging; after all, the system allows for careful, standardized, and concrete data collection involving the indicated features. In addition, users report using the tool to log photos after performing new exercises or trying new treatments to determine if these behaviors or treatments had any effects upon their conditions, thus providing support for MyFace use in this way.

6.6.2 Organization Opportunities

Although MyFace’s organization scheme was primarily well-received, users did offer valuable suggestions for improvements. Notably, the before and after photo comparisons were intended to promote self-awareness, and the chronological organization structure was intended to benefit self-reflection, but users request potential alternatives. One suggestion was to allow for a time-lapse of all photos to show finer-grained progress over time. Such time-lapse displays may more efficiently show progress than chronological photo displays, but they may also reduce shock value; this might result in losing some self-awareness in exchange for self-reflection opportunities,

and as such may be particularly better-suited for after a patient has completed his or her recovery. If a patient has recovered and reached an actual plateau in progress, then self-awareness of changes will no longer be a priority, but self-reflection may still offer benefits. In addition, collage displays were also suggested; collages may offer a viable in-between (i.e., between before and after photo displays and time-lapse displays) solution for demonstrating finer-grained improvements over shorter times, but the ideal collage structure would need to be determined via further research.

6.6.3 Data Storage and Sharing Improvements

Users also offer suggestions for MyFace data storage and sharing capabilities, which I believe are the areas which represent the most opportunity for improvements which facilitate social support behaviors. Notably, MyFace video storage is currently limited to one video per user; this does not meet some users' preferences for self-logging and it may also limit their self-reflection. P11 in particular noted that videos are "more interesting" than photos; videos offer opportunities for observing and reflecting upon dynamic facial movements which photos cannot offer, but MyFace the inability to store multiple videos reflects again MyFace's bias toward design for self-awareness as opposed to self-reflection. MyFace facilitates both, but it encourages posed photos to clearly demonstrate changes in facial symptoms, which is intended primarily to encourage self-awareness; however, a video with a constant focal point and standardized poses might offer similar benefits for comparison while easing user data collection burdens (i.e., recording once as opposed to taking 9 different photos). In addition to this storage issue, MyFace cannot facilitate the chronological uploading of visual media users have collected prior to using MyFace; this may further hinder self-reflection opportunities by having parts of a user's recovery journey separated from one another, and it may also hinder MyFace's application as a reference and sharing tool. If sharing does offer users cathartic benefits, this may be a significant problem, and it may also

provide context for the last user data sharing suggestion to allow users to easily share their MyFace data to their social media accounts. If such sharing is made possible, however, lessons from related literature regarding user autonomy should be considered; specifically, just like automatically updating Facebook with user goals may decrease goal-setting behaviors (Munson et al., 2015), automatically sharing user data to social media accounts may have unforeseen negative effects. Further study on this matter may be warranted.

6.6.4 Supporting Informational and Emotional Needs

This deployment study also identifies that users report that their informational and emotional needs are not being met by their current healthcare service providers; users' self-described self-care, online knowledge seeking, social media sharing, and support group seeking behaviors also support the notion that these users are fulfilling their own needs outside of clinical contexts. Perhaps unsurprisingly, users have suggested that MyFace provide medical information (e.g., facial exercises, locality-based specialists and clinics, etc.), but MyFace is not intended to provide such information. MyFace, as a tool, cannot and should not replace healthcare professionals' expertise, it should only facilitate high quality care and recovery (Zhu et al., 2017). MyFace may however be better designed to facilitate peer experience sharing. Patients seek different expertise from patient peers than they seek from healthcare professionals (Hartzler et al., 2011), and in this study that peer-derived expertise typically supplements comprehension of reasonable expectations regarding users' condition and recover progression and potential treatments. Notably, users state that experiences with successful outcomes tend to be motivational, whereas experiences with negative outcomes tend to be demotivational.

6.6.5 Designing for Hope

With this in mind, designs for a system to store successful stories and share these positive experiences in users' early recovery processes might prove beneficial to patient motivation and adherence to care; hope is, after all, a powerful motivator and coping strategy in similar rehabilitation contexts (Lou et al., 2016). Furthermore, selectively hiding negative experiences, especially during users' early recovery processes, might prove equally beneficial for promoting hope. This would represent a tricky ethical situation, as it could lead to false hopes, but benefits from adhering to potentially helpful treatments may outweigh the negative effects caused to patients by dwelling on potential negative outcomes. Designing to promote health in this way would be similar to designing technologies for distracting patients with chronic conditions to promote mental and emotional health during long recovery periods where patients have little else to actively do (Zhu et al., 2018c).

6.6.6 Designing to Better Facilitate Informal Carers

Despite showing promise in facilitating social support, MyFace did not in all cases attract users' social networks to join; this is especially troubling considering the participants' preference for support from family and friends. If the success of the MyFace system to help patients stay motivated to adhere to their practices represents design based on thorough patient stakeholder understandings, then the inability to consistently attract family and friends to join represents a design which was not so thoroughly informed by informal carer stakeholder understandings; family and friends become informal carers when they provide support to a patient in his or her recovery. Unfortunately, studies exploring informal carers' needs and experiences are relatively scarce, owing in part to these informal carers' activities typically belonging to the private spheres of

individuals' family lives (Hoffmann & Rodrigues, 2010). What information is available regarding informal carers typically relates to informal carers for chronic diseases (e.g., cancer (Thomas et al., 2002; Payne et al., 1999), strokes (Lou et al., 2016), etc.) or elderly patients (Mazurek et al., 2017); in either of these cases, patients will have suffered either physical or cognitive declines. With these declines, informal carers may need to provide care work (i.e., practical tasks involving helping patients with care burdens) and emotional work (i.e., managing patient emotions) (Thomas et al., 2002). I would hazard against directly applying stakeholder understandings of informal carers in these works to FP informal carers, as although FP patients may experience physical symptoms, they do not typically require physical care in all patients; from the findings of this MyFace deployment, users typically sought more emotional work from their informal carers, thus indicating a potential difference in these groups of informal carers. More work should be conducted to ascertain these differences and thus to provide improved tool designs which attract and meet the needs of informal carers for FP.

6.6.7 Limitations

This study is primarily limited by the user population and by a lack of observational evidence to support user claims of behavioral changes. The user population was recruited via convenience sampling (i.e., owing to the rarity of disease sufferers) from online social platforms, and may represent highly motivated, highly social, technologically savvy individuals. All users were female, which may not capture potential gender differences, and most users reported being close to achieving full recoveries, meaning early care user needs may not be accounted for. The sample size may also not account for all experiences regarding healthcare professionals' informational support practices. This deployment's findings are however promising, and further studies and especially observations are warranted to account for these limitations.

6.6.8 Takeaways

This study identifies the following key takeaways:

1. FP user data feedback in the form of before and after photos facilitates motivation and adherence to prescribed activities.
2. Chronological displays of user data are intuitive and effective at facilitating self-reflection in users.
3. Users report that especially their information needs are not being met, resulting in them seeking out their own information online.
4. Hope is a contributing motivator facilitated both by reading patient peers' successes and from concretely being made aware of personal progress.
5. Users desire a complete documentation of their history to allow for fuller self-reflection after recovering and to enable more effective sharing of their stories, which may offer cathartic benefits.
6. Users ascribe higher value to social support from family and friends and may prefer in-person social support from patient peers.

I further identify the following two opportunities for healthcare social support tools which employ strategies similar to MyFace: 1) identify and design tools based on informal carer stakeholder comprehension to attract, maintain, and support these carers in providing social support, and 2) design for hope, potentially by selectively utilizing and emphasizing positive patient peer stories while hiding negative experiences; however, users should still be able to share their own negative experiences for the potential cathartic benefits, and designs for such considerations must be further explored.

6.7 Chapter Summary

Informed by the two exploratory studies and the case study noted in Chapters 3-5, I designed, developed, deployed and evaluated the MyFace system. This study explores the efficacy of using visual media self-monitoring and social support in a self-care technology intended for tracking facial paralysis recovery progress. Deployment occurred over a 30-day period with 11 participant users. Users used the MyFace system to holistically track their recovery progression and help themselves to become more aware of their gradual improvements; they specifically tracked facial exercise durations and frequencies, feelings, and visual media (i.e., videos and specifically posed photographs) over time to allow for assessment of changes via comparison of older versus newer visual media. Evaluation of these self-tracking features demonstrates promise in successfully motivating users to engage with and adherence to exercises, massages, and treatments. In addition, MyFace shows promise in facilitating social support for users; this is significant, as existing facial paralysis tools rarely support self-monitoring and sharing functions with healthcare professionals or friends and families, despite these support functions having potentially significant roles in enhancing patients' motivation. Examples of participants receiving and offering social support utilizing the system are reported, and opportunities for cathartic sharing are noted. Design implications are offered for specifically improving the current design of MyFace, although such implications will be applicable to other designers who seek to make similar tools using self-monitoring and social support strategies.

Chapter 7

Contributions and Opportunities for Future Work

In this final chapter of my dissertation, I provide a summary of my contributions and the limitations made during the work of this dissertation; I also note opportunities for future work to expand upon my findings, methodologies, and artifacts.

7.1 Summary of Prior Chapters

In **chapter 1**, I described how my motivation for conducting the research within this dissertation was to determine how to effectively leverage technological interventions to better support high quality prehabilitation care via facilitating clinicians and patients in their processes and roles and through supporting patient at-home self-care. Remember that self-care is defined as, “[the] ability to monitor one’s condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life.” With these facts in mind, I emphasize two important challenges for designing self-care technology: 1) facilitating the monitoring of one’s condition, and 2) supporting the cognitive, behavioral and emotional responses necessary for one to maintain a satisfactory quality of life. This chapter also introduces how the adoption of an HCI lens in prehabilitation research complements the existing literature and improves researchers’ and designers’ comprehension of how to facilitate prehabilitation patients and healthcare professionals.

In **chapter 2**, I provided: 1) a brief overview of prehabilitation (i.e., including the key differences between prehabilitation and similar healthcare techniques like rehabilitation and physical therapy) and habilitation spectrum technologies; 2) definitions for self-care technology

and explorations of how persuasive strategies and clinical workflow modelling can be used to aid in the design of novel self-care technologies geared toward increasing prehabilitation patients' engagement and adherence; and 3) discussion regarding key theoretical backgrounds (e.g., self-monitoring, reactivity, social support, etc.) used in this dissertation's body of work for designing self-care technologies which nudge people towards behavioral changes. I argued that enhancing reactive effects from self-monitoring and supporting engagement by facilitating social support were essential when designing self-care technologies for prehabilitation.

In **chapter 3**, I provided a patient-centered understanding of how patient stakeholders characterize their information needs both before and after surgeries; this understanding particularly emphasizes the challenges they encounter during current care practices. Towards this goal, I qualitatively analyzed publicly available data from an online health forum. I determined that needs, challenges, and opportunities are not static throughout surgical healthcare. I identified and explored the following: 1) how new problems, like anxiety in pre-operative waiting periods or new required medications after a surgery, can either be acute and short-term, long-term and indefinite, or permanent; 2) how patients often face multiple levels of interrelated complications (i.e., primary complications from their conditions, secondary complications resulting from surgeries, and tertiary complications resulting from the complications or responses to said surgeries) which contribute to their holistic health, as well as the need to address each in different ways and for different lengths of time; and 3) the variety of tensions patients reported with their clinicians and peer supporters, including dissatisfaction with care, perceived antagonistic tendencies from clinicians, and patient perceptions of helplessness. Note that despite these tensions clinicians and peer supporters remain significant factors for inspiring, informing, and encouraging patients when they are anxious, depressed, or uncertain; in fact, the majority of posts in the data set were seeking either information or support from online peers. As such, I identified that technologies might be more effective if they accounted for patient needs regarding information seeking and sharing, social supporting, and the

addressing of multiple specific needs over different time spans. Many of these activities could be incorporated into devices for better collaboration between patients and clinicians, and even peers.

In **chapter 4**, I describe how I conducted the second of my exploratory studies to gather healthcare professionals' stakeholder perspectives and experiences and form a more complete comprehension of the current landscape of prehabilitation and its associated challenges. This study utilized semi-structured interviews with 12 experts and identified their care provision challenges, the techniques they used to respond to those challenges, what technologies are currently being used and where, and what kinds of technology might be desired by HPs to assist with future practices. Using participants' responses, I identified prehabilitation assessment as a potentially significant area for technological facilitation; in addition, I noted that training and adherence technologies for patient at-home work were the areas for which our experts most desired technological assistance. This study used a user-centered approach to understand which specific technologies within the identified themes might be adopted and which might not meet expectations. Further research in this vein will undoubtedly be necessary to fully comprehend the vastly heterogeneous field of prehabilitation and to design novel tools intended to facilitate its processes and HPs.

In **chapter 5**, I explored prehabilitation within the narrow context of facial paralysis; this context was chosen specifically because prehabilitation for FP often plays a crucial roles in patients' recoveries, and patient involvement in complex healthcare teamwork can be critical to their health outcomes. As a result, facial paralysis prehabilitation was an ideal study area for examining how to implement technology which supports patient-clinician interactions, as well as how to support patients' engagement to at-home prehabilitation activities. Facial paralysis treatment, as demonstrated by the resulting workflow model of the study, requires collaboration between various HPs and their patients. This study used clinical observations and semi-structured interviews with HPs and patients to provide an in-depth description of FP care workflow and identify challenges for patient-provider collaboration. I identified how visual media are essential to

FP care; these references are used for assessing and demonstrating patient progress, as well as documenting visit summaries. This work identified patient perception of progress and plateauing to be two of the most significant challenges which may lead patients to stop performing exercises. In this work, I suggested the addition of self-monitoring with visual references as a potentially strong opportunity for facilitating patients' motivation to perform their collaborative roles by adhering to their exercises. This work added to the growing body of HCI research for technologically facilitating patient-provider communication and collaboration.

In **chapter 6**, informed by the two exploratory studies and the case study noted in Chapters 3-5, I designed, developed, deployed and evaluated the MyFace system. This study explored the efficacy of using visual media self-monitoring and social support in a self-care technology intended for tracking facial paralysis recovery progress. Deployment occurred over a 30-day period with 11 participant users. Users used the MyFace system to holistically track their recovery progression and help themselves to become more aware of their gradual improvements; they specifically tracked facial exercise durations and frequencies, feelings, and visual media (i.e., videos and specifically posed photographs) over time to allow for assessment of changes via comparison of older versus newer visual media. Evaluation of these self-tracking features demonstrated promise in successfully motivating users to engage with and adherence to exercises, massages, and treatments. In addition, MyFace showed promise in facilitating social support for users; this is significant, as existing facial paralysis tools rarely support self-monitoring and sharing functions with healthcare professionals or friends and families, despite these support functions having potentially significant roles in enhancing patients' motivation. Examples of participants receiving and offering social support utilizing the system are reported, and opportunities for cathartic sharing are noted. Design implications are offered for specifically improving the current design of MyFace, although such implications will be applicable to other tool design which utilize self-monitoring and social support strategies.

7.2 Limitations

This section will provide a summary of the limitations of each of the studies I conducted for the body of this dissertation. Note that each study method offers its own unique benefits and limitations and that no one method offers an ideal outcome; researchers who wish to utilize methods contained within this study should first understand these methods' tradeoffs and how the methods themselves affect the results prior to choosing to utilize the methods or mixed-methods approaches I have described.

Chapter 3, I noted that patient demographic information was not collected from the online health forum because the forum did not require users to publish their demographic information. Although this may have limited the ability to understand potential correlations, the primary focus was not to understand patient demographics; it was to provide an understanding of their interpretations and experiences in regards to prehabilitation. Also, to ascertain patient perceptions, the study relied upon patient self-reports; although self-reports are accurate portrayals of subjective experiences, they cannot be independently validated or compared directly with data from quantitative analyses. The methods also precluded me from conducting follow-up interviews with forum users. Moreover, the participants in this study were likely digitally literate individuals, and not representative of people who do not use technology for health information. Therefore, the results of the study should be treated cautiously, and should not be extended beyond the realm of patient-perceptions for a technologically literate population. Furthermore, the chosen forum of study was also intended for patient sharing, rather than medical expertise sharing, which may have biased the results towards patient information seeking and social support.

Chapter 4, I used a small, non-random sample (N=12) owing to the short supply of prehabilitation experts. This work also recruited experts from varied programs intended for different purposes and without standardized operations between said programs for the same reason.

As a result, this study provided a general overview of prehabilitation which may have missed vital data regarding more specific prehabilitation contextual examinations. Furthermore, this study focused on HPs' perspectives and was biased towards a clinical understanding of prehabilitation. Patients and/or other stakeholders' perspectives were absent and warranted further examinations; for example, related health research shows the importance of design opportunities for caregivers (Kaziunas et al., 2015) which were not explored in the conducted study. I also noted that owing to prehabilitation's need for tailored care plans, studies comparing programs, even those for the same treatments, may face challenges from heterogeneity. Further research was called for to better explore the contexts of specific programs and the needs of their HPs. Although this work offered a foundation for designers to create tailored prehabilitation technologies, I urged them to incorporate stakeholders into the early design stages for tools to further promote adoption and efficacy. I recommended potentially inviting stakeholders from a program to design workshops to ensure needs are fully met, but designers were also advised to consider synthesizing my findings regarding HPs' perspectives with other findings regarding patients' perspectives if stakeholders were hard to incorporate.

Chapter 5's discussed study was conducted in a single clinic; it was likely site specific and biased towards the participants. Moreover, the sample size was small, which limited my ability to generalize findings to FP treatment at other locales. Although this case study focused on the needs of one multidisciplinary healthcare team, I believe the findings could be applied to other complex healthcare team contexts, especially those with significant patient responsibilities (i.e. physical therapy). One of the more significant limitations of this work was that it lacked in situ (i.e., at-home) patient observations, which limited my ability to fully track actual patient work; such observations require obtrusive, resource-intensive study which were beyond the scope of the original work. However, preliminary data did indicate that exercise behaviors and patient responses vary and change over time, and future studies were suggested to more fully determine subtle

changes in actual patient work; furthermore, despite this limitation regarding in situ behaviors, the inclusion of preliminary patient work data in workflow modeling contributed significantly to workflow modeling practices. I also noted that significant informal carer data was scarce in my dataset. Future studies with more diverse sampling from multiple clinics and more HPs and patients, in situ patient observations, and more direct interactions with informal carers were suggested to improve upon my preliminary model. However, as an exploratory study aimed at determining challenges and opportunities for technology use in FP treatment, this work offered valuable in-depth insights. I encouraged others to consider potential factors (e.g., hospital size, funding, technology availability, etc.) which may potentially affect idiosyncratic workflows and challenges for further studies.

Chapter 6, this study was primarily limited by the user population and by a lack of observational evidence to support user claims of behavioral changes. The user population was recruited via convenience sampling (i.e., owing to the rarity of disease sufferers) from online social platforms, and may have represented highly motivated, highly social, technologically savvy individuals. All users were female, which may not have captured potential gender differences, and most users reported being close to achieving full recoveries, meaning early care user needs may not have been accounted for. The sample size may also have failed to account for all experiences regarding healthcare professionals' informational support practices. This deployment's findings were however promising, and I suggested that further studies and especially observations were warranted to supplement gaps left by these limitations.

7.3 Opportunities and Future Works

The goals and agendas of my long-term research plans are broadly intended to facilitate prehabilitation stakeholders in providing and receiving high quality prehabilitation care, most

notably in the context of facilitating patient at-home self-care collaboration engagement and adherence. Although I've demonstrated promising results in combatting key challenges associated with these goals within the works presented in this dissertation, my research also identifies areas which need more thorough exploration as well as new opportunities for future works. I present the following summary of future research directions, noting that 1-3 are patient-centric, 4-7 emphasize healthcare professionals, and 8-12 explore more holistic healthcare directions:

1. **Promoting Patients' Psychological Well-being:** Patients' physical incurable conditions are not the only factors which need to be managed or stabilized. Patient psychological changes through perioperative care deserves further examination and researcher attention. For example, patients' stresses regarding their conditions and surgeries can cause anxiety and/or depression throughout the perioperative period. In an effort to feel “normal”, patients may “distract” themselves by changing their environments (e.g., vacations, online) or behaviors (e.g., being more sociable). Therefore, to design effective prehabilitation technology, researchers might need to utilize more **positive design strategies** (Desmet & Pohlmeier, 2013); that is to say, we should consider designing to increase patients' positivity and address hopelessness. To do so, we need to focus on activities and interactions that are intrinsically fun and meaningful. Maintaining health through exercise and nutrition may in some cases lessen the negative effects of certain conditions while improving general well-being, but these lifestyle changes may seem like long-term burdens with an indefinite payoff for some patients. “**Distractions**” may be a viable means of treating patient anxiety, improving patient morale, and potentially encouraging patients to keep maintaining their health.
2. **Using Visual Media to Increase Motivation:** In my prehabilitation case study, I saw strong opportunities for visual media to help patients sustain their contributions by helping them regarding perceived plateauing, lost motivation, and comprehension gaps. I noted that visual references instead of text-based handouts would likely improve comprehension and successful

exercise, and patient self-monitoring with visual references would directly work as a tool to sustain motivation and continued exercise by demonstrating self-recorded progress (i.e. similar to reactivity (Korotitsch & Nelson-Gray, 1999), but maintaining a behavior change instead of creating a new one). Visual media has been used in self-monitoring to understand behavioral causes for medical symptoms, but this application is largely to aid medical decision making (Smith et al., 2007); my suggestion was novel, as its intended effect is to keep patients aware of their progress and encourage motivation and adherence. Future works could conduct controlled experiments regarding the design, implementation, and testing of visual media aids in other prehabilitation contexts, especially on their effects on patient motivation and engagement.

3. **Articulating Social Support:** Patients are able to be supported in their abilities to connect with peers and collaborators to gain stakeholder expertise and support, and their acts of merely articulating their personal experiences in online support groups is known to provide patients cathartic benefits (Buchanan2007). MyFace users discussed similar benefits from sharing their own experiences to support other FP sufferers; in fact, it is noteworthy that this act of sharing to support others was a major motivation for some users to begin using MyFace in the first place. Allowing users to constructively share their own experiences with other FP sufferers may provide meaningful mental and emotional benefits in their own recovery processes. Further studies should be conducted to ascertain the potential cathartic effects of patients' experience sharing in specifically FP patients' recoveries.
4. **Consolidating Validated Scales to Support Assessing:** In order to respond to patient variability and provide quality care, healthcare professionals must assess their patients using various qualitative and quantitative data to form baselines. These baselines allow these HPs to tailor care from a generalized multimodal prehabilitation framework to meet their patients' needs. Due to the variety of the measures, I have tentatively suggested consolidating validated

scales and measures (e.g., synthesizing useful surveys and questionnaires; autopopulation of measures from assessment devices with overlapping data), and allowing for patients to complete forms at home (i.e., by reducing medical knowledge complexity in forms) as potentially viable research avenues. However, HPs should be incorporated into early design phases for grading tools to promote adoption and efficacy (Zhu et al., 2016).

5. **Tailoring Treatment Plans for Heterogeneous patients:** Patient population heterogeneity is apparent in many prehabilitation aspects. This patient variability requires a holistic assessment of health and similarly comprehensive care plans for each individual (e.g., balancing acute needs vs. chronic illnesses (Zhu et al., 2018)). Generalized prehabilitation programs, even those specific to one treatment (e.g., knee replacement, cancer care, facial paralysis, etc.) will only be viable as a foundation for care planning. Future work should be conducted towards specific programs to ensure needs are met and sufficient stakeholder outcomes are achieved.
6. **Increasing the Value of Data Through Triangulation:** One big opportunity for HPs to adopt technological support is presented in the fact that they are currently largely unaware of their patients' adherence to the care programs; patient adherence and drop-out rates currently rely on estimations, which presents an obstacle which may undermine both HPs confidence in prescribing activities and researchers' comprehension of prehabilitation program efficacy. Owing to the fact that prehabilitation is an underexplored medical research area, many of the HPs interviewed in my studies were also researchers, which offered valuable insights into tools which might be suitable for adoption. Notably, systems for gait analysis (Sathe et al., 2018) or those which triangulate from multiple data sources may be more beneficial to help HPs and patients to make sense of their data than simple sensing devices. I believe that absolute values (i.e., sensor measurements) tend to be sought by researchers looking to gauge program efficacy, whereas impressionistic values (i.e., patients' self-reports) appear more relevant to HPs for

providing care. Therefore, future system designers should be project-specific when conducting research regarding aiding HPs and patients in making sense of their data.

7. **Support Prehabilitation Interventions in Clinical Practice:** Further work must be done to promote the growth and efficiency of prehabilitation interventions in clinical practice. One way to do this would be to continue the adoption of my HCI approach and use this HCI perspective to continue examining where, when, and how technology might address needs. Example research questions which may need further exploration include: *Why do patients choose to engage or disengage with their prehabilitation programs?*; *What are the determining factors that could lead to changes?*; and, *how can patient-level information could improve quality of care?*. My dissertation research only just begins to answer these questions in limited contexts. Also, future studies could consider solutions from the perspective of HPs and caregivers, such as by exploring *how clinicians solve problems when recommended surgeries conflict with patients' pre-existing conditions*, or *how technology can facilitate patient-clinician communication under these contexts*.
8. **Addressing Interrelated Challenges:** In Chapter 3, I presented a theoretical interrelated model of complications (Figure 6), which demonstrates the degrees of complications a patient may experience; it should also more clearly illustrate the interrelatedness of these issues. Future work should build a more complete model, perhaps by including a more holistic interpretation of habilitation (i.e., the inclusion of post-operative and rehabilitation related complications). If this line of research is pursued, researchers should remember that technology for these patients should be capable of addressing each level of complication independently while promoting overall well-being. Separation of needs is likely necessary, as not all needs will have the same time spans, but each need must be addressed to promote overall well-being.
9. **Supporting Patient-clinician Collaboration and Communication:** Support, communication, and collaboration from HPs are all correlated to patients' adherence in general health outcomes

(Zhou et al., 2015). However, patients also seek significant support from peers (see 3.4.3, 5.3.7 and 6.4.7). In some instances, this is because they were confused, unclear about a topic, or they wanted to know more about the information which HPs did not offer. However, clinicians in my studies also noted that most patients did not ask enough questions during visits. These findings might result from clinical workspaces being poorly designed for supporting patient collaboration in healthcare processes (Unruh et al., 2010; Zhu & Carroll, 2018b). As a result, patients my research have expressed a variety of tensions with HPs (see 3.4.3 and 6.4.7). Researchers of clinical workspaces and relevant technologies should examine how to promote and facilitate patient collaboration and specifically question asking within prehabilitation contexts (e.g., frequently asked question lists); they should also explore incorporating informational tools to be used prior to surgical interventions, such as by describing medical procedures (e.g., including pros and cons, alternatives, potential complications, etc.). Encouraging HP participation in prehabilitation patient at-home care might potentially benefit patient-clinician collaboration; this may promote both data consistency regarding clinician-accepted protocols (Zhu et al., 2016) and engagement by adding an HP as an authoritative presence to which the patient is accountable (Zhu et al., 2017).

10. **Addressing the Needs of Complex Carer Collaboration:** Prehabilitation is a personal, challenging, and complex process which requires great effort from multidisciplinary specialists (i.e. surgeons, therapists, dietitians, exercise experts, etc) and patients. This process is mediated by clinical objects (e.g., assessment, prescription, handout, and videos, etc) and active patient engagement. It further relies upon person-to-person interactions and communication because of the strong need to collaborate and reach collective outcomes. This form of healthcare emphasizes and amplifies all parties' accountabilities to the process and outcomes. FP patients, for example, cannot be passive actors like they could be in traditional acute illness care; these patients must maintain motivation, adhere to care plans, and perform their collaborative roles.

However, neither HPs' or patients' needs are being met to facilitate their collaboration fully. HPs for example, lack objective measures for determining if patients are engaged; they rely on experience and perceptions. In the case of patients, they often need to change exercises as they progress through therapy, but they are only instructed how to perform these exercises once (i.e., during their monthly therapy visits). Patients thus need more at-home guidance, support, and reference materials. My work only begins to provide insights into this complicated collaborative process and how technology affects it, and I note the following 5 research opportunities: 1) understanding how to foster collaboration in diverse clinical prehabilitation teams via technology, 2) synthesizing a holistic account of prehabilitation care provision strategies to aid providers from different perspectives, 3) helping patients to sustain their contributions, 4) examining specific aspects and including extended or informal care collaborators (e.g., family, friends, etc.), and 5) exploring if greater common ground between HPs and patients leads to better clinical outcomes.

11. **Reduce Burden of Technology Adoption:** Stakeholders noted that they may be better able to adopt technology if the adoption burdens are low. Future research needs to explore how to make low-cost, targeted prehabilitation technologies, as well as the effects these tools have on HPs' time and burdens. Researchers should also explore more fully how to lower tracking burdens for patients. Furthermore, we should not expect stakeholders to adopt remote monitoring tools and techniques which increase their burdens without some form of compensation (Zhu et al., 2016); such tools should either increase patients' self-reflection and confidence in the care, and/or reduce burdens in HPs' workflows to free time which is already being utilized.
12. **A Secure Infrastructure for Data Exchanges:** Adopting multimedia capable EMRs and sharing patient data in general may require developing a secure technical infrastructure for standardized data sharing between stakeholders. Patient portals are one existing infrastructure,

but portal services offer limited patient collaboration potential. For contexts like FP care, where patient roles are so heavily emphasized and integrated into care plans that HPs change treatments and services based on patient collaboration, a secure infrastructure for data exchanges is needed. Further study regarding designing clinical spaces and communication infrastructure to promote patient collaboration is warranted.

7.4 Summary of Contribution

This dissertation has presented my key contributions to the interdisciplinary fields of HCI and Health Informatics; these contributions include: 1) empirical findings regarding prehabilitation stakeholders' challenges, how they respond to said challenges in real world circumstances, and design guidelines for self-care technology design based on a deployment study; 2) design and deployment of the MyFace system, a self-care technology that facilitates patient motivation and self-reflection; and 3) methodological guidelines for approaching prehabilitation technology design. Below, I will expand upon these listed contributions in greater detail.

7.4.1 Empirical Findings of Work in this Dissertation

This dissertation offers empirical findings from both qualitative (e.g., forum analysis, in-situ clinic observations, semi-structured interviews) and quantitative (e.g., questionnaires, log analysis) experiences. Many of these findings were instrumental for the design of the MyFace system, others offer the literature a plethora of user-centered stakeholder experiences and perspectives; my chronicling of these perspectives and experiences offers the literature key insights into stakeholder needs, challenges, opportunities, responses to technologies, and design implications and suggestions for future works. HCI and Health Informatics researchers are

encouraged to take these understandings provided by my research and design improved, tailored self-care prehabilitation technologies which further enhance patient engagement and health outcomes.

1. **Prehabilitation Challenges of Patients with Chronic Conditions:** A patient's pre-existing conditions may interfere with his or her eligibility for surgery. Patients must respond to their situations holistically, accounting for and controlling a variety of interrelated physiological, mental, and social challenges to facilitate effective prehabilitation (see Chapter 3). These challenges include: a lack of guidance, balancing chronic conditions against acute needs, physical risks prior to surgery, inconsistent adherence to care plans, adjusting drug regimens, psychological stresses, holistic life challenges, tensions between patients and care collaborators, and tensions with family.
2. **Interrelated Model of Prehabilitation Complications:** Based on my review of the literature and my exploratory studies (see Chapter 3), I proposed a design framework that maps the design space of prehabilitation complications (Figure 6). Surgical patients with MCC often face complications and challenges which stem from across three orders. First, MCC patients experience the primary complications of their chronic conditions, which includes symptoms and challenges specific to the condition. Next, secondary complications arise from their need for surgeries, and can include psychological changes, new medications, and side-effects to new medications. Finally, patients may experience tertiary emotional and social complications, which include tensions with family, friends, and career peers which result from the above complications. This theoretical interrelated model of complications demonstrates the degrees of complications a patient may experience, and it should aid future researchers and designers in their prehabilitation research and designs.
3. **Experts Perspectives on Adoptable Technologies:** HPs have offered suggestions for technologies and tools which they would find useful (see Chapter 4). Themes for these

- technologies include tools for: 1) informing and instructing through tailored patient reference materials, telehealth, and life coaching; 2) increasing patients' adherence through feedback, accountability, social and informational supports; and 3) objective and subjective measurement tools for triangulating data sources, interpreting, and sharing data regarding intended activities.
4. **Facial Paralysis Treatment Model:** Based on empirical evidence (i.e., in-situ clinical observations and semi-structured interviews), FP workflow consisted of the following five higher level activities: clinical preparation, informative collaboration, treatment, documentation, and patient self-care (Figure 7). Each stage has its own unique challenges and opportunities. I note that visual media are essential to FP care; these references are used for assessing and demonstrating patient progress, as well as documenting visit summaries. My work (see Chapter 5) also identifies patient perception of progress and plateauing to be two of the most significant challenges which may lead patients to stop performing exercises. It further advocates for a perspective shift regarding the incorporation of patients' active roles in healthcare collaboration, and it identifies that promising research opportunities for HCI and Health Informatics research include: 1) facilitating collaboration and communication through self-monitoring with visual media for patients' perception of progress and sharing capabilities with carers, and 2) expanding the current scope of complex healthcare team collaboration research.
 5. **Design Guidelines for Prehabilitation Engagement:** Drawn from the results of the MyFace evaluation study (see Chapter 6), I explore key design implications for improved self-care technology designs, including: 1) finding visual representations that can convey valence information; 2) Increase self-awareness of self-monitoring progression through showing progression, providing means of comparison, and providing performance progression tracking; 3) enabling social support; and 4) protecting user privacy.

7.4.2 Design and Implementation

Through the design, development, implementation, and evaluation of the MyFace system, I created an artifact which can contribute to both the fields of HCI and Health Informatics, as well as to practical care provision for FP prehabilitation. I demonstrated that a mobile--based, self-monitoring application which leverages social support can facilitate facial paralysis patients' self-care motivation and engagement to prehabilitation treatment. Through this deployment study, I provide direct support for both the claim that facial paralysis patients' motivation and thus adherence to care plans may suffer from an inability to perceive their gradual recovery progress, and the notion that data feedback in the form of first versus last diary entries with visual media can improve self-reflection and self-awareness, and thus motivation. The MyFace system is one of the first healthcare systems to leverage self-monitoring and self-logging of visual media and social support for the purpose of enhancing patients' prehabilitation engagement. This work also provides weaker support for the notion that the MyFace system, through its features, can increase FP prehabilitation patient adherence to exercise prescriptions and thus sustain their contributions and collaboration towards their own recoveries. In addition, I provide evidence that before and after photos can demonstrate to patients subtle, gradual recovery progression which may not be perceived under normal circumstances; this offers a significant contribution to HCI and Health Informatics, as I demonstrate means to enhance patients' self-logging and promote a form of reactivity.

7.4.3 Guidelines

7.4.3.1 Methodological Guidelines for Approaching Prehabilitation Technology Design

By adopting an HCI lens to approach prehabilitation healthcare research and demonstrating promising results from doing so, I have made contributions to healthcare research methodologies. To understand the current landscape of prehabilitation and to provide technological support to its associated challenges (i.e., engagement, accessibility, and scalability), I conducted exploratory studies to build a more comprehensive understanding of the design space for prehabilitation than was available in the literature, and for this, in-depth explorations of patients' and healthcare professionals' needs, challenges, and perceptions were necessary. Realizing the inherent variability within prehabilitation as a field of study, I then narrowed my focus to a specific prehabilitation context—facial paralysis prehabilitation—to constrain variables. This narrow study regarding a multidisciplinary care team for facial paralysis workflow and team interaction (i.e., including the patient as a team member) provided a strong foundation for the comprehension of idiosyncratic needs in this one prehabilitation clinic and allowed me to better understand needs which may be generalizable. Notably, this formative study also informed the design and development of the MyFace system, a self-care technology which helps users with facial paralysis track their prehabilitation progress. The MyFace deployment study provided promising results by focusing on enhancing patient self-care motivation through facilitating self-awareness and self-reflection via visual media. I demonstrate that FP prehabilitation motivation and thus adherence may benefit from the adoption of these techniques. This success supports the notion that the adoption of an HCI lens in prehabilitation research will provide further novel insights and identify hitherto unrecognized opportunities.

7.4.3.2 Design Guidelines for Prehabilitation Engagement

From the above-mentioned experiences, I offer design guidelines to inform the designs of further self-care technologies; the following guidelines can be used to in research for designing and evaluating technological supports which aim to enhance patient prehabilitation engagement:

1. **Finding Visual Representations that can Convey Valence Information:** Researchers need to involve stakeholders early in technology design processes (e.g., through direct observation of stakeholders' workflow) to understand what visual representations are useful under their specific health conditions and leverage stakeholders' experiences regarding prevalent visual representations and media (e.g., photos, videos, etc.).
2. **Increase Self-awareness of Self-monitoring Progression:** Examples for this include: 1) showing progression (e.g., chronological history of past activities, current statuses, etc.) which allow stakeholders to conduct self-experimentation and observe if treatments produced beneficial results; 2) providing means of comparison (e.g., before and after) which create persuasive performance feedback that can motivate patients' self-tracking behaviors and enhance their self-reflection; and 3) providing activity level performance progression tracking (e.g., line/bar graph, calendar view, etc.) to give stakeholders a more holistic view of self-monitoring behaviors.
3. **Enabling Social Support:** Researchers need to enable communication among stakeholders to facilitate the provision of emotional support, instrumental support, informational support, and appraisal support.
4. **Protecting User Privacy:** Proper privacy protection options and choices need to be provided to all stakeholders due to the sensitive nature of patient privacy and data protection. Offering choices may also provide greater autonomy over privacy controls.

HCI and Health Informatics researchers are encouraged to utilize these guidelines in the creation of future technologies intended to support prehabilitation engagement and adherence.

7.5 Conclusion

Prehabilitation motivation and engagement can be improved by enhancing patients' self-awareness and self-confidence through the design of effective feedback methods which utilize and display their own self-monitoring data. Understanding current prehabilitation practices and design spaces can allow us to recognize design opportunities for targeted and effective prehabilitation self-care technologies. Recognizing that the prevailing health science lens of the majority of prehabilitation research is insufficient for addressing current prehabilitation challenges which reduce efficacy and patient benefits, I postulate that an HCI lens would complement the existing literature and identify new opportunities. Having conducted my prehabilitation research using an HCI lens, I identify novel opportunities and challenges and offer solutions and interventions which appear to be effective. Therefore, the adoption of an HCI lens in prehabilitation research does complement the existing literature and does improve our understanding of how to facilitate prehabilitation patients and clinicians in their roles and processes.

As I summarize and conclude this dissertation research, I want to highlight a potential challenge which has been prevalent throughout the studies which comprise its body; individuals like to know how their conditions are changing and progressing, patients want to see that they are improving, and healthcare professionals want for their patients to ask questions and to share their experiences and data for medical decision making purposes, but despite shared goals, these groups experience a troubling communication disconnect. For example, both patients and healthcare professionals note that the other party often fails to properly inform them (i.e., healthcare professionals are largely unaware of how patients engage with prehabilitation prescriptions at-home

but desire this information, and patients lament that their healthcare professionals fail to provide sufficient information regarding treatment plans and options). Both groups seem to be assuming that they are providing the other with sufficient information, but neither may in fact be meeting the other's expectations; this may be detrimental to care practices in prehabilitation and elsewhere. Unfortunately, factors which seem obvious to patients may not in fact be obvious to overworked healthcare professionals, and things which may seem obvious to healthcare professionals may not be easily understood by patients with limited medical expertise. As a somewhat neutral third-party, it may be up to us as health information designers to further explore how to alleviate this vexing problem in patient-clinician interaction and communication; our technology designs must put healthcare professionals and patients on equal informational footings. Future studies are encouraged specifically to meet the needs of every stakeholder in every niche of prehabilitation care.

Appendix A

Interview Guide for Clinicians

Interview Guidelines for Clinicians

(Questions may slightly change)

Thank you for agreeing to give this interview. We are conducting a study to learn the general process of prehabilitation, how patients engage with the program, and how clinicians and researchers are involved in the program. So, I will ask you a few questions about your experiences in providing or researching prehabilitation. Would it be ok to begin recording now?

[Begin Recording]

Just to confirm, it's okay that I audio-record our conversation, correct? [Wait for response]

You may refuse to answer any questions if you feel uncomfortable. You may stop this interview at any time.

1. Can you tell me your area of expertise?
2. What is a typical prehabilitation process like?
 - a. Can you give me one example on how you practice prehabilitation?
 - b. What prehabilitation instructions do you provide?
 - c. How are these instructions delivered?
 - d. What is your rationale for providing such information?
3. Do you employ surveys / questionnaires during the prehabilitation program?
 - a. [If yes] What kind of surveys, and why?
 - b. [If No] What you use instead?
4. What is the difference between prehabilitation & rehabilitation?
5. What are the risks in participating in prehabilitation?
 - a. What are the risks if a patient does not follow the prehab programs?
 - b. How closely must patients follow your suggestions?
6. How you decide who should participate in prehabilitation, and why?
 - a. What medical conditions are best/worst served by prehabilitation, and why?
7. How might a patient's disease affect prehabilitation?
 - a. How do prehabilitation suggestions vary among different patients?
8. What types of patients are more likely to follow the prehab program, and why?
 - a. What are some reasons patients reported to stop participating in prehabilitation?
 - b. What are the patient prehabilitation adherence/success rates?
 - c. How do you encourage and motivate patients during the prehabilitation program?
 - i. What is the result?
9. Is there any challenges in patient-clinician communication?
10. How do you define "success/failure" in prehabilitation?
11. What technologies are you currently using for prehabilitation?
 - a. For what purpose (data collection, monitoring, adherence)?
 - b. What kind of data do you want to collect from a patient?
 - i. Why, and in what format?
 - ii. How could patient-collected data aid in your medical decision making?

- c. How patients collect their own data during the prehab period?
 - i. What kind of tools do you usually suggest patients use for data collection?
 - ii. How have patients shared data with you in the past?
 - iii. What would be an ideal way of sharing data collected by patients with you?
- 12. What kind of support do patients seek (informational, emotional, social)?
- 13. How could technology aid you in the prehabilitation process?
 - a. Are there any tasks, challenges, or burdens which could be addressed using technology?
- 14. Do you have any questions for me?

Is there anything else you'd like to tell me that is relevant and that we have not already covered?
Thank you very much,

Appendix B

Interview Guide for Patients

1. Could you tell me about yourself? Some background information, your age, occupation, etc.
 - a. What condition you have?
 - b. How long you have it?
 - c. How did facial paralysis affect your quality of life, and how do you deal with it?
 - d. What kind of invasive interventions will you have or had, and what is the expected outcome?
 - e. How did therapy or Botox help your with this condition?
2. How did you started to do facial exercise?
 - a. How long have you been doing the exercise?
 - b. What exercise or massages do you practice at home?
 - i. What was your exercise experience like, can you describe your general experience with the exercise? (Specific details)
 - ii. Are there any challenges for consistently doing those exercises at home, can you describe a scenario in which you experienced some difficulty?
 - iii. Have you ever stop/ miss exercising?
 1. If so, why you stopped?
 - iv. So, in summary, what are the things you like or dislike about the exercise program?
3. Can you describe a scenario in which encourage you keep going?
 - a. What was the benefit you gain from exercise?
4. What have you learned from the clinical consultation and therapies?
 - a. Did the prehab program lead you to change any aspect of your behavior?
 - i. [If yes] What have you changed?
 - ii. [If no] End.
5. Do you track your changes over time (i.e., photos or videos)?
 - a. [If yes] How do you track your progress and changes over time?
 - i. How do you organize your tracking data (i.e., photo/video)?
 - ii. What are the challenges for monitoring your long-term improvement?
 - b. [If no] End.
6. Did you talk about the exercise program with anyone (i.e., friends, family, clinician, etc)?
 - a. [If yes] What did you talk about? [If no] End.
 - b. Is there anybody who helps you to keep exercise?
7. What information you share with your doctor during the surgical clinic visit/preoperative visit?
 - a. What information you gain from doctors are the most useful to you, and why?
8. Do you share your experiences (i.e., photo/video) with others?
 - a. [If yes] How do you use/share those photos and videos?
 - i. What are the challenges of photo sharing?
 - b. [If no] Why or why not?
9. How do you reflect on your photos?
 - a. How often?

- b. What do you think when you reflect on your progress photo/video?
- 10. How could technology aid you in the recovery process?
 - a. Are there any tasks, challenges, or burdens which could be addressed using technology (i.e., enhancing remote patient-clinician communication, monitoring improvements, reminding you doing exercise, store educational videos, etc.)?
- 11. Do you have any questions for me?

Appendix C

MyFace Pre-qualification Questionnaire

1. Are you at least 18 years old?
 - a. Yes [Proceed]
 - b. No [Cease]
2. Can you read and speak English?
 - a. Yes [Proceed]
 - b. No [Cease]
3. Do you have a smartphone?
 - a. Yes, an Android [Proceed]
 - b. Yes, an iPhone [Cease]
 - c. Yes, a phone not specified [Cease]
 - d. No, I don't have a smartphone [Cease]
4. Do you have a data plan?
 - a. Yes [Proceed]
 - b. No [Cease]
5. Have you ever had, scheduled, or been suggested a surgery by your doctor for facial paralysis?
 - a. Yes, I have had a facial paralysis surgery before. [Proceed]
 - b. Yes, I have scheduled a facial paralysis surgery with my doctor. [Proceed]
 - c. Yes, my doctor suggested that I should have a facial paralysis surgery. [Proceed]
 - d. No, I haven't. [Cease]
6. Have you tried any alternative treatments before having facial paralysis surgery?
 - a. Yes [Proceed]
 - b. No [Cease]
7. Which treatment methods did you try?
 - a. Physiotherapy
 - b. Acupuncture
 - c. Massage
 - d. Botox
 - e. Other (please specify) _____
8. Which side of your face is paralyzed?
 - a. Right
 - b. Left
 - c. Both
9. How is your health in general?
 - a. Healthy
 - b. Not healthy (Please specify) _____

Thank you very much for your participation!

Appendix D

Interview Guide for MyFace

1. Could you tell us about yourself?
 - a. Your age?
 - b. Your health conditions?
 - c. Which side did the episode affect (one side; both side)?
 - d. How long have you had bell's palsy/facial paralysis?
 - e. Which treatment methods did you try?
 - i. Treatment frequency?
 - f. What worries you the most?
 - i. drooling?
 - ii. inability to chew food?
 - iii. inability to talk clearly?
 - iv. inability to close eyes?
 - v. other?
 - g. How has this affected your life?
 - h. How much do you think you have recovered percentage-wise?
2. Tell me a situation that has made you want to use the MyFace app.
 - a. Tell me a situation that made you not want to use the app.
 - b. What do you like the most about MyFace, and why?
 - c. What do you like the least about MyFace, and why?
3. What did you hope that you would achieve by using MyFace?
 - a. Can you describe your general experience using the app? (Specific details)
4. Do you feel the app contributed to your recovery?
 - a. if so, how?
 - b. if not, end.
5. How do you feel regarding the usage of MyFace?
 - a. Which function (e.g., gallery, summary, etc.) did you like the most, and why?
 - i. How often and when do you use the app, and what are the things you capture?
 - ii. How does this function benefit you?
 - iii. What do you like the most about (the gallery, summary, etc)?
 - b. Which function do you think is not useful, and why?
 - c. Do you feel like using MyFace improved the quality of your exercises?
 - d. Were there any unexpected challenges in using the app?
6. Can you describe a scenario in which you experienced some difficulty?
 - a. What do you find most frustrating/problematic about the app?
 - b. Have you ever experienced confusion regarding the system design? Which functions were confusing?
7. Have you given permission to anyone (e.g., family and friends, doctors, etc.)? For what reason?
 - a. To whom would you give permission to view your diary? Why?
 - b. Was it useful? What kind of information do you think is appropriate for others to view (e.g., images, videos, texts, etc.)?
 - i. Did this aid you in your conversations (e.g., with family, friends, doctors, etc.)?

8. Do you think using the app helped you to more reliably and consistently exercise?
 - a. If so, how?
 - b. If not, can you think of anything that might have helped you do so?
9. Did MyFace improve your life?
 - a. How much did this app improve your quality of life/treatment?
10. Have you shared your FP journey on social media?
 - a. [If yes] What motivates you to share your FP journey on social media?
 - i. How did sharing affect your feelings and actions?
 - ii. What kind of support are you are receiving from others on social media?
 - iii. Can you tell me a case that meant something to you, either negative or positive?
 - b. [If no] End
11. What kind of information do you need the most for your recovery and that you want to get online?
12. How do you think we can improve the MyFace App?
13. Would you recommend to others who also have facial paralysis to use this app?
 - a. [If yes] Why?
 - b. [If no] Why not?
14. Do you have any questions for me?

Appendix E

Current Self-Care Technologies

Table 7: Summaries of behavior change interventions, including both commercially available applications and HCI literature. I have divided technology platform into 4 subcategories based on: 1) what types of data it collects (activity measure), 2) what they use for data collection (measured by), 3) the project platform, and 4) forms of feedback.

| Project | For | Technology Platform | | | | Persuasive Strategy |
|--------------------------------------|-----------------------|---|--|----------------------------------|--|--|
| | | Activity measured | Measured by | Platform | Forms of Feedback | |
| Fitbit | General Health | Calories, exercise, heart rate, sleep, step, weight | Wearable sensing, Manual tracking | Stand-alone website mobile phone | Count (Location) Graph Textual Stylized Representations | Self-monitoring Feedback Goal-setting Social comparison Reward |
| Samsung Health | General Health | Calories, step, heart rate, sleep, stress, water intake | Wearable sensing, Manual tracking | mobile phone | Count (Location) Graph Textual Stylized Representations | Self-monitoring Social comparison Goal-setting Feedback |
| Apple HealthKit | General Health | Activity, mental health, nutrition, sleep, reproduction health, body measurements | Wearable sensing, Manual tracking | mobile phone, Apple Watch | Count (Location) Graph Textual Stylized Representations | Self-monitoring Feedback Goal-setting Social comparison Reward |
| GoogleFit | General Health | Step, heart rate, calories | Wearable sensing, Manual tracking | Mobile phone Android watch | Count (Location) Graph Textual Stylized Representations | Goal-setting Self-monitoring Feedback Reward |
| MyFitnessPal | Food Journaling | Calories, food tracker, water intake, exercise | Manual tracking, Barcode scanner | Mobile phone website | Count (Location) Graph Textual Stylized Representations | Self-monitoring Feedback Goal-setting Social comparison |
| Breakaway (Jafarinaimi et. al, 2005) | Behavioral Monitoring | Sitting time | Embedded sensing (Weight sensor) | Dynamic sculpture near desktop | Physical changes in sculpture | Self-monitoring Feedback |
| Fish'n'Steps (Lin et al., 2006) | Physical Activity | Step | Wearable sensing (Pedometer) | Public Kiosk Website | Growth and activity of an animated character, fish in a fishtank | Goal setting Reward Feedback Gamification |
| ViTo (Nawyn et. al, 2006) | Behavioral Monitoring | TV watching, Activity level | Embedded sensing (PDA & accelerometer) | PDA application TV screen | Completion of games through physical activity | Feedback Gamification |

| | | | | | | |
|---|----------------------------|---|--|----------------------------|---|---|
| MyExperience (Froehlich et. al, 2007) | Travel behavior | Visit frequency, travel time | Manual tracking, In situ questionnaire when phone would be stationary for 10 minutes | Mobile phone | For research purposes | Self-monitoring Research Educational |
| MentalCare* (Farzanfar et. al, 2007) | Mental Health | Medication intake, clinical office visit attendance | Manual tracking | Computer telephony system | Telephone Linked Communications (TLC) | Self-monitoring Feedback |
| Shakra (Anderson et al., 2007) | Physical Activity | Activity level (stationary, walking, driving) | Wearable sensing (Mobile phone) | Mobile phone | Count (Location) Graph | Self-monitoring Social comparison Feedback |
| Diab-Memory (Kollmann et. al., 2007) | Diabetes | Blood glucose level, injected insulin dose, carb intake, physical activity | Manual journaling | Web portal Mobile phone | Count (Location) Graph | Self-monitoring Feedback Visualization Reminder |
| MAHI (Mamykina et al, 2008) | Diabetes | Blood glucose value, photo of food intake | Manual journaling | Mobile phone | Educator feedback on each journal entry | Self-monitoring Educational Goal-setting Feedback |
| Ubifit (Consolvo et al, 2008) | Physical Activities | Cardiovascular exercise, strength training | Wearable sensing Manual journaling | Mobile phone | Textual | Self-monitoring Goal-setting Reward Feedback Visualization |
| Wellness Diary (Mattila et al., 2008) | Wellness management | Blood pressure, exercise, fat%, feeling, health event sleep, step, stress, weight | Manual tracking, Wearable sensing Mobile phone Pedometer Blood pressure meter | Mobile phone | Graph Textual | Self-monitoring Feedback |
| Telemedical home care (Pinsker, et. al, 2008) | Chronic disease management | Blood pressure, blood glucose, intake of medication, physical activity | Manual tracking | Mobile phone PC/Web portal | Graphics Reminders | Feedback Self-monitoring Visualization |
| Diabetes self-care (Preuveneers, et. al, 2008) | Diabetes | User location, blood glucose level | Manual tracking, wearable sensing | Mobile phone | Graphics Textual | Feedback Visualization Recommendation for medication intake Professional-coaching |
| edairy (Aarhus et. al, 2009) | Pregnancy with Diabetes | Blood glucose level, video consultations, insulin dose | Manual tracking sent to hospitals | Web portal | Graphic Textual Professional | Feedback Visualization Educational Professional-coaching |
| Managing Asthma (Holtz & Whitten, 2009) | Asthma | Peak air flow reading | Manual journaling | Mobile phone | Textual | Self-monitoring Feedback Reminder |

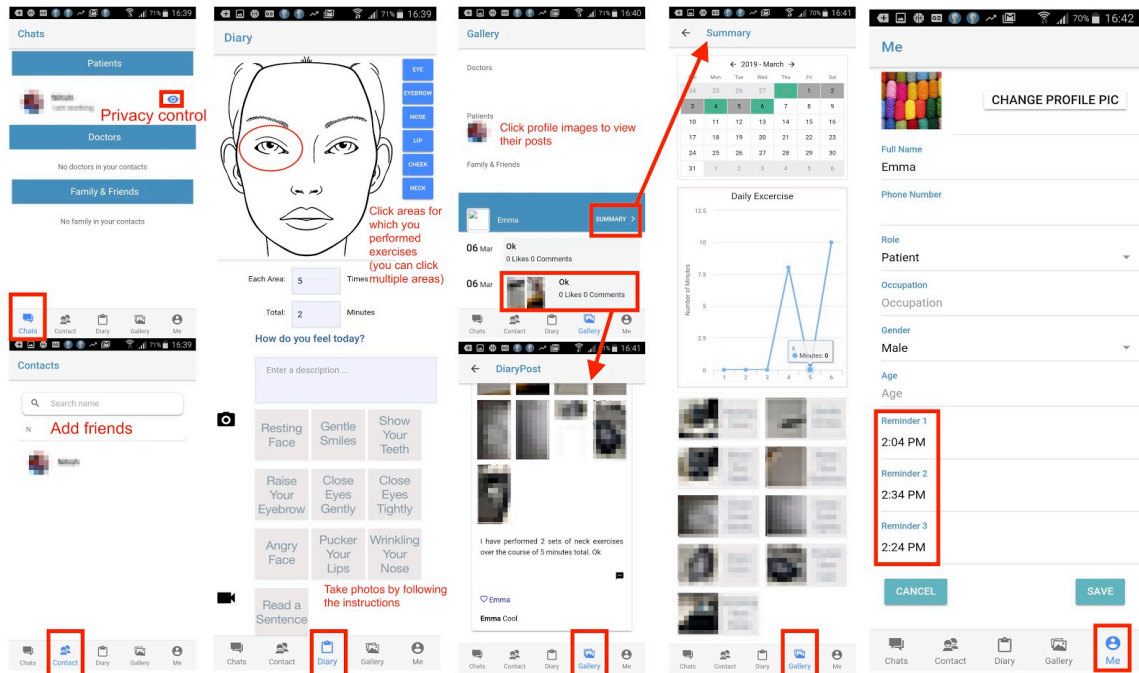
| | | | | | | |
|---|--|---|---|--|--|--|
| Dementia (Yasuda, et. al, 2009) | Dementia | Mental state | Health professionals | PC platform | Video prompts textual | Feedback Reminder |
| ChocolateBroccoli (Glasemann, et. al, 2010) | Diabetes | Carb intake | Manual journaling | Mobile phone | Textual Graphic | Educational Self-monitoring Gamification Visualization |
| Jog Falls (Nachman, et. al, 2010) | Diabetes | Physical activity, energy, diet, health data | Manual journaling, wearable sensing | Mobile phone | Textual Graphic | Professional-Coaching Feedback Recommendation |
| Asthma management (Yun, et. al, 2010) | Asthma | Peak air flow, Air quality index, meal time, stress report | Manual journaling | Web platform Can use text to input data | Graphic Textual | Self-monitoring Feedback Visualization |
| TiY (O'Murchu, et. al, 2010) | Diabetes | Blood sugar level, insulin injection, can add photos to entries | Manual journaling | Mobile phone | Graph Textual | Self- monitoring Visualization |
| Fibromyalgia (Camerini et. al, 2011) | Fibromyalgia management | Available time, pain, sex, age, localization | Manual entry | Web platform | Video Textual | Tailored-health Professional-Coaching Recommendation |
| Chronic Kidney Failure Care (Sota, et. al, 2011) | Chronic Kidney Failure Management | Blood test results | Manual entry | Mobile phone | Graphic textual | Self-monitoring Visualization |
| COPD (Taylor, et. al, 2011) | Chronic Obstructive Pulmonary Disease Management | Physical exercise, pulse | Video conferencing software | Internet based | Video conferencing | Educational Self-monitoring Socialization |
| Lullaby (Kay et. al, 2012) | Sleep | Temperature, light, motion, sound | Sleep sensor, capture and access system | Access aspect is mobile (tablet or mobile phone) | Graph Audio Stylized representations | Self-monitoring Feedback Visualization |
| SilverCloud (Doherty et. al, 2012) | Depression | Pre and post-treatment assessment, mood, personal journaling | Manual entry | Web | User profile Graph Textual | Self-monitoring Feedback Goal-setting |
| Persuasive sensing (Chatterjee et. al, 2012) | Diabetes | Sleep, steps, blood glucose level, weight | Wearable sensing | Mobile phone | Textual (text messages) Weekly health newsletter | Professional-Coaching Personalization Feedback |
| Best intentions (Toscos, et. al, 2012) | Children's health (Diabetes) | Blood glucose level | Wearable sensing | Mobile phone | Textual (text messages sent to parents) Graph | Parent-monitoring of child's health Visualization |

| | | | | | | |
|--|--|--|---|-------------------------------|---|--|
| Health Mashups (Bentley et al., 2013) | Health management | Weight, sleep, step, location, food intake, pain, mood | Manual journaling Wearable sensing | Mobile phone | Textual Graphs | Self-monitoring Visualization Reminder Trend-finding |
| Asthma diary (Craven et. al, 2013) | Asthma | Pulse, peak air flow, mood | Manual journaling, Wearable sensing | Mobile phone | Graph Textual Stylized Representations Oral from health care professional | Self-monitoring Visualization Professional-monitoring |
| MoEN (Kim et. al, 2013) | Mobile user engagement | Satisfaction | Manual entry | Mobile phone | Research data | Research Trend-finding Educational |
| MONARCA (Bardram et. al, 2013) | Mental Health - Bipolar disorder | Mood, physical activity, medication intake | Manual journaling | Web portal Mobile phone | Textual Graph | Self-monitoring Feedback Visualization |
| MONARCA 2.0 (Frost et. al, 2013) | Mental Health- Bipolar disorder | Mood, physical activity, medication intake | Manual journaling | Web portal Mobile phone | Textual Graph Oral from health care professional | Self-monitoring Feedback Visualization Professional-feedback |
| BP@Home (Kusk, et. al, 2013) | Blood pressure management | Blood pressure | At-home blood pressure measuring sensor | Mobile tablet Mobile phone | Textual Graph Stylized representations Professional | Self-monitoring Visualization Social comparison Feedback Professional-coaching |
| COPDTrainer (Spina, et. al, 2013) | Chronic Obstructive Pulmonary Disease Management | Exercise monitoring measurements | Wearable sensing Manual entry | Mobile phone | Professional Textual Graph | Professional-Coaching Feedback Visualization |
| SleepTight (Choe, 2015) | Sleep | Time went to bed, sleep quality, times woken up during the night | Wearable sensing Manual tracking | Mobile phone | Graph Textual Stylized representations | Visualization Reminder Self-monitoring Feedback |
| MS Tracker (Ayobi et. al, 2017) | Multiple Sclerosis (MS) management | Physical activity, mental state | Manual tracking | Mobile phone | Textual Graph | Self-monitoring Visualization |
| MyBehavior (Rabbi et. al, 2015) | General health management | Physical activity, diet behavior | Manual entry, Wearable sensing | Mobile phone | Graph Textual Stylized representations Personalized health suggestions | Personalized feedback Self-monitoring Visualization Recommendation |
| Habito (Gouveia et. al, 2015) | Physical Activity management | Physical activities | Wearable sensing | Mobile phone | Textual | Self-monitoring Goal-setting Feedback Visualization |
| Omni-track (Kim et. al, 2017) | Tracking | Changes according to | Manual journaling Wearable sensing | Mobile phone | Graph Textual | Flexibility Customization |

| | | | | | | |
|--------------------------------------|---|--|-------------------|--------------|--------------------------|--|
| | | what the users wants (ex. Mood, physical activity, food, etc.) | | | Stylized representations | Self-monitoring |
| TummyTrials (Karkar et. al, 2017) | Irritable Bowel Syndrome (IBS) management | Food intake, reaction to food | Manual journaling | Mobile phone | Textual | Self-experimentation Visualization Self-monitoring |

Appendix F

MyFace Instructions



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- Zhu, H., Moffa, Z., Wang, X., Abdullah, S., Julaiti, J., & Carroll, J. (2018c, May). Understanding Challenges in Prehabilitation for Patients with Multiple Chronic Conditions. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare* (pp. 138-147). ACM.

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I am receiving my Ph.D. in Informatics from Pennsylvania State University under the supervision of Dr. John M. Carroll. I utilize user-centered design and consumer-driven approaches to explore how to design technologies which nudge people towards positive behavioral changes (e.g., improving engagement and adherence behaviors) through understanding stakeholders' experiences, workflow, and challenges. Thus far, my work can largely be divided into the following categories: 1) empowering stakeholders, and 2) improving processes. During my projects, I have focused on understudied or high-need research populations (e.g., older adults, patients, complex healthcare team members, students), and utilized human-centered design methods to address challenges regarding data production, sharing, and comprehension, as well as stakeholder interactions.

Selected Publications

1. Zhu, H., Moffa, Z., & Carroll, J. (2019). A Clinical Workflow Case Study: Untangling Challenges in Facial Paralysis Treatment Interactions. In 2019 ACM Conference on Computer Supported Cooperative Work and Social Computing. Under Review
2. Zhu, H., Moffa, Z., & Carroll, J. (2019). Prehabilitation: Care Challenges and Technological Opportunities. In 2019 ACM Conference on Computer Supported Cooperative Work and Social Computing. Under Review
3. Zhu, H., Wang, H., & Carroll, J. (2019, June). Creating Persona Skeletons from Imbalanced Datasets - A Case Study using U.S. Older Adults' Health Data. In Proceedings of the 2019 Conference on Designing interactive systems (DIS'19). To Appear
4. Zhu, H., Chen, J., Wang, H., Almoaiqel, S., Matera, F., Wang, X., ... & Carroll, J. (2019, January). Day Re-construction: Understanding How College Students Manage Their Time Through Self-monitoring. In Proceedings of the 52nd Hawaii International Conference on System Sciences.
5. Zhu, H., & Carroll, J. M. (2018, October). Healthcare Opportunities: Experts' Perspectives on Integrating Technology into Prehabilitation. In Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing (pp. 149-152). ACM.
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