

Understanding Challenges in Prehabilitation for Patients with Multiple Chronic Conditions

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ABSTRACT

Little has been done to understand what challenges surgical patients face before surgery. Specifically, patients with multiple chronic conditions (MCC) often require prehabilitation—pre-surgery steps to improve baseline levels of health parameters required for surgery. Prehabilitation can improve health-care outcomes, reduce costs, and decrease readmissions. However, prehabilitation can be challenging for MCC patients since they need to balance chronic conditions with surgical preparation. Unsuccessful prehabilitation adherence can result in serious medical consequences including postponed surgeries and post-operative complications. In this work, we explore prehabilitation challenges faced by patients with MCC and identify opportunities for technological interventions by conducting a qualitative study of online health forum posts from 154 users. Using this data, we identified categories of patients’ needs and challenges during prehabilitation. Based on our findings, we propose design recommendations to better support prehabilitation for patients with MCC.

CCS CONCEPTS

• **Human-centered computing** → **Interaction design**;
Interaction design process and methods; User centered design;

KEYWORDS

Perioperative care; prehabilitation; rehabilitation; surgery; chronic condition; forum.

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1 Introduction

Over 100 million inpatient and outpatient procedures were performed in 2010 in the United States [2]. With lifespans growing longer, these procedures are becoming more numerous with every passing year [18]. Perioperative complications (i.e., complications which encompass the entirety of the surgical health spectrum, including preoperative, operative, and postoperative) increase healthcare costs, mortality risks, and postoperative complications [52, 54], and prolong hospital stays and functional recovery times [30]. Clinicians have tried to improve patients’ postoperative recoveries with rehabilitation. However, postsurgical patients, especially patients who are elderly or with comorbidities (e.g., chronic conditions/CC), experience 20–40% reductions in both physiological and functional capacities, and recovery to preoperative capacities is rarely achieved [15, 21, 30]. Current rehabilitation solutions, thus, are insufficient to promote patient postoperative health. Researchers must explore and examine the entire spectrum of surgical care to discover opportunities for improvement. Toward this goal, we focus on themes beyond just the effectiveness of prehabilitation programs. We specifically chose MCC patients for this study because they are likely to experience losses in functionality after surgeries, and thus could greatly benefit from prehabilitation. Furthermore, prehabilitation for MCC patients presents a more pressing set of needs with different lengths of time as compared to healthier patients or CC management alone.

Healthcare researchers have begun to examine how to enhance individuals’ functional capacities prior to surgeries to increase their tolerances to impending physiological stresses; this process, known as prehabilitation [21] helps patients to qualify for surgeries, improves their postoperative recoveries, and decreases morbidities [21]. The ideal prehabilitation program has not been defined, but it will likely contain multiple components; current prehabilitation programs utilize targeted interventions with physical (e.g., by increasing exercise duration and frequency), nutritional (e.g., by restricting sodium and caloric intakes), and psychological components (e.g., by teaching relaxation exercises) [7, 21, 45, 49]. Prehabilitation requires patient collaboration with clinicians and/or third parties. For example, clinicians check patient progress and adjust patients’ treatments before surgery, and patients often receive social support from families and friends. The following research questions guide our work to both help provide HCI researchers and designers analysis regarding patients’

challenges and in locating opportunities to reduce surgical complications through prehabilitation using patient-centric approaches: 1) What are the pre-surgical challenges for surgical patients with MCC? 2) What social challenges do MCC patients experience during pre-surgical care and interventions?

To answer our research questions, we collected 602 threads from 154 users on a popular public online health forum; each user was a patient with MCC and discussed surgical experiences on the forum. We explore both MCC patients and perioperative practices with a focus on potentially using technologies in prehabilitation. Our paper expands upon recent HCI works involving MCC management and prehabilitation. We offer the following contributions: **1)** We conduct a preliminary exploration of prehabilitation challenges and opportunities for MCC patients. MCC patients often face unique challenges during prehabilitation. Our paper offers evidence that the competing demands of managing chronic illness can be exacerbated by necessary surgeries. **2)** We provide an empirical description of perceptions and experiences from MCC patients regarding preoperative care. For example, patients found balancing between the needs of chronic conditions and preoperative care difficult, and felt anxious about taking new medications for surgeries when they were already on medications. **3)** Based on our findings, we provide design recommendations for patient-centric surgical preparation applications. We specifically focus on what HCI researchers should consider when designing technological interventions aimed at enhancing prehabilitation.

2 Related Work

2.1 History of Prehabilitation

Prehabilitation--which occurs between diagnosis and the start of acute treatment--is the first part of the rehabilitation care continuum [44]. Interventions used during this waiting period may continue after a surgery, and persist throughout a patient's lifetime. The word "prehabilitation" was coined in the 1940's by the Medical Division of National Headquarters for the Selective Service; it was primarily concerned with increasing the number of men who could serve in the Army by correcting remediable ailments prior to military physical examinations [43]. During that time, prehabilitation interventions included lodging, hygiene, recreation, nutrition, physical training, and education [48]. Gradually, healthcare services professionals recognized opportunities to prepare patients for upcoming procedures and medical stressors, as well as to research novel interventions [44]. Contemporary medical research into prehabilitation has focused primarily on efficacy for specific conditions, such as coronary artery bypass grafts [6], abdominal surgeries [21], cancer [45], and other diseases. Healthcare research has not yet focused on how to integrate technologies into prehabilitation from a patient-centric perspective. Our findings can act as an expansive overview of opportunities to help organize and address MCC patients' prehabilitation needs through technology.

2.2 Surgical Spectrum Technologies

Habilitation services are "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 [1]." Technologies that assist habilitation include both prehabilitation technologies (i.e., those aimed at improving patient functional capacity prior to surgery), and rehabilitation technologies (i.e., those aimed at helping patient postoperative recovery). Currently, HCI offers no mobile health interventions aimed at prehabilitation specifically. In contrast, rehabilitation technologies (e.g., prostheses, wheelchairs, game-based rehabilitation software [10], etc.) are rapidly advancing in medical research [41], but few technological interventions are predominantly designed for prehabilitation, perhaps because of the short duration of prehabilitation and that it is often considered a part of rehabilitation [44]. Owing to inherent differences between the goals and challenges of rehabilitation (i.e., recovery) and prehabilitation (i.e., prevention), technologies designed for one will not necessarily be suited for the other. Also, engagement rates to prehabilitation vary drastically (e.g., research settings: around 70% [20]; in-home 16% [13]), despite prehabilitation being an important opportunity to improve patients' survival outcomes, and reduce healthcare costs [21, 45]. Prior research fails to fully describe patient prehabilitation challenges or causes for engagement variability. Our work aims to fill the gaps from a patient-centered perspective by exploring patients' prehabilitation challenges, and identifying opportunities for designing technology to support patient-clinician collaboration.

2.3 Opportunities for Prehabilitation

Patients with poor physical functions (e.g., MCC, like diabetes) or psychological ailments (e.g., depression or anxiety) experience difficulties preparing for surgeries [51], especially while they are also suffering from physical, emotional, and social changes that affect their quality of life and care [25]. Pre-existing conditions also make them more vulnerable to postoperative complications than healthier patients [27]. Thus, MCC patients are often more in need of prehabilitation than healthier patients to raise their baseline levels of health to surgery parameters and increase survival outcomes (see Figure 1). Exercise-based interventions prior to stressful surgeries could optimize preoperative physical functions, and thus improve postoperative outcomes and increase surgical options for patients with borderline fitness for specific surgeries [7]. Notably, physical function and self-rated health status (i.e., a form of self-monitoring data) could be used as predictors of postoperative morbidities and mortalities in various patient groups [36, 44]. However, research discussing prehabilitation for patients with MCC is limited, and works regarding self-monitoring technologies focus on one specific CC [51], such as diabetes [37], hypertension [23], and chronic pain [5], etc. Because patients with chronic conditions (e.g., conditions that last over 3 months which cannot be cured with medication [3]) must necessarily have lifelong medical attention to treat and manage the pervasive effects of their conditions [53], technologies which are designed to support individuals with chronic conditions tend to rely upon changing long-term behaviors [28]. Long-term behavioral changes are often difficult for individuals to achieve [47], so relying upon these intensive techniques may be unrealistic, especially for surgical patients with MCC who usually

have fixed amounts of time to increase baseline health to surgery parameters. We see opportunities for HCI researchers to investigate how to design 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.

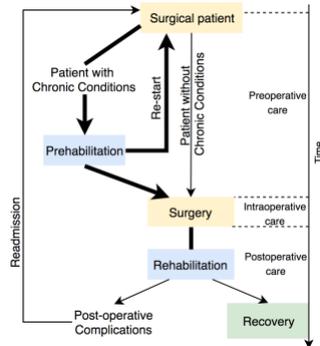


Figure 1: This chart explores the branching pathways through which patients progress during the stages of perioperative health. Note that for elective surgery, patients either move forward to their surgeries (if they are not impeded by significant conditions), or attend a prehabilitation program until they are qualified; 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.

3 Method

We conducted a qualitative study examining the surgical behaviors of MCC patients on HealingWell, a popular online health forum designed for sharing blogs, videos, newsletters, articles, resources, and question-answer threads. Prior researchers have examined online health peer support communities to understand online eating disorders [42], depression [32], breast cancer [50], and weight management [35] 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 [34] and concerns which are better addressed by patient expertise rather than clinician expertise [24].

3.1 Data Collection

HealingWell is publicly available [12]; there are no requirements for registration to access threads. Before reporting this work, we 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. We thus shortened the quotes to what is essential to demonstrate a claim and removed identifiable information. To further protect anonymity, we revised misspelled words, expanded acronyms, and capitalized initials, doing so within brackets '[]', so that these quotes are not entirely the same. We filtered the posts, and only utilized those from patients with MCC regarding surgeries. The dataset was first filtered based on the 19 chronic conditions [4] listed by the Center for Medicare

and Medicaid Services (CMS). We applied a fuzzy search to find chronic conditions posts across the entire forum. Specifically, we constructed a chronic condition keyword-dictionary (CCKD) by tokenizing the words in the list provided by the CMS. For example, the CCKD keywords include the 19 listed CC: alzheimer, arthritis, asthma, atrial fibrillation, autism, cancer, chronic kidney disease, chronic obstructive pulmonary disease, depression, diabetes, heart failure, hepatitis, HIV/AIDS, hyperlipidemia, hypertension, ischemic heart disease, osteoporosis, schizophrenia and other psychotic disorders, stroke. The surgery keywords include: surgery, 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. By filtering data to only include patients with greater than a year of post activity, we select for posters who have chronic-level time spans for conditions and potentially require chronic care. This yielded 1406 unique users and 16031 threads. We then narrowed our focus by using surgery-related words for a secondary filtration, and we did this 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 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, we were primarily interested in determining how MCC patients behaved regarding surgeries (i.e., including all surgical behaviors, from preoperative to postoperative), and we 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 filtration was necessary to identify data relevant to the scope of this paper.

Some users might post for their families, friends or pets, which could cause misclassifications. We used Natural Language Processing technique (Part of speech tagging) to extract 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. We 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. We organized our dataset in alphabetical order by the username, and from the most recent post to the oldest post. We assigned each thread a unique identifier (e.g., Q#) for our reference.

3.2 Data Analysis

We are interested in what actions users performed during posts, what preoperative challenges users with MCC faced, and how users' needs, challenges, and opportunities evolved with the progressive stages of surgery. Because prehabilitation and MCC patients are relatively underexplored topics in HCI, we focus on providing a rich description of the variety of needs of these

patients and the complexities of their problems. As such, we focus on qualitative analyses, rather than quantitative relationships. To answer our research questions, we used thematic analysis [11] to qualitatively analyze the initial posts of threads while excluding replies. Because some threads did not have replies to initial posts, and because replies occurred over varying time spans (i.e., both pre- and post- surgery), we chose to standardize the factor of time in our sampling by collecting only data from initial posts rather than including inconsistent longitudinal data from varying timescales when available.

Posts were primarily text-based. Initially, two researchers determined a starting point by reading 20% of the posts to understand the types of behaviors and discussions which existed. The first researcher then examined all of the postings thematically. 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 an online health forum, their specific surgical challenges, and opportunities for technology to assist patients.

4 Result

4.1 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. Patients must respond to their situations holistically, accounting for and controlling a variety of interrelated physiological, mental, and social challenges to facilitate effective prehabilitation.

4.1.1 Lack of Guidance. Throughout prehabilitation, clinicians present patients with diagnosis, prognosis, and treatment option information which can be confusing for some patients. 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. *"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] Echoing sentiments from prior work suggesting that healthy people respond differently to social incentives than patients with conditions [14] our data suggests that standard procedures for healthy people cannot always be applied to MCC patients.

Moreover, patients may be given various test results, but they might be unable to comprehend them. For instance, *"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] Insufficient guidance and explanation can inhibit patients from comprehending their illnesses and care. Even when information is 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 condition, and that he or she is actively performing self-monitoring, participating in promoting his or her own health, and managing his or her conditions [31].

4.1.2 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. Perhaps unsurprisingly, patients needing to control their health parameters (e.g., hypertension) was a common theme throughout the posts. 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]

4.1.3 Risk Prior to Surgery. Chronic health problems and sudden or unexpected changes in health can postpone or disqualify patients for surgeries. Thus, surgical interventions require stable conditions. 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. Some chronic conditions make it especially difficult for patients to perform health-promoting activities, such as exercising and dieting. Optimism for any opportunities should be tempered, as chronic conditions like

respiratory ailments or even medications to treat a condition, 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. For example, many medications which manage patients' diseases can cause pre-operative complications which make surgery difficult or dangerous. 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]

Patients with MCC may experience conflicts between symptoms of their MCC and the activities necessary to stabilize their health. One 31 year old poster had Crohn's disease and asthma. She was on blood thinners, which prevented her from having a liver biopsy to confirm whether she had fatty liver disease. At the time, she had roughly 3 months to lose at least 10 pounds to avoid the liver biopsy. Her chronic conditions inhibited extensive dietary plans and exercise routines. She was not able to diet because her prior dieting had caused her to have Crohn's related obstructions, and her asthma required her to use an albuterol inhaler before any workout. *"If it is a fatty liver, losing some weight can make a big difference, and I may be able to avoid the liver biopsy."* [Q55] She realized that components of prehabilitation potentially could have negated the need for procedures and surgeries. Other opportunities for prehabilitation to reduce surgery risks and aid recovery have been recognized in our dataset, although rarely. For example, prior to operations, patients increased physical exercise and altered eating habits. One poster noted that he was struggling to maintain his weight and health prior to his surgery, and his increased exercise was specifically aimed at reducing post-operative surgery recovery times by improving his pre-operative health. *"Just got done with my 3 miles on the treadmill, which I've been doing about 5-6 days a week. I'm hoping this last 5 weeks or so of increased activity will make for an easier recovery."* [Q411]

4.1.4 Inconsistent Adherence 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 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 [13]. *"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] Frustration led patients in our dataset to seek distractions by altering lifestyles, behaviors, and health management. Some note 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, the patient must resume their disease related responsibilities. As noted in the data above (e.g., Q369), some patients already do not maintain recommended exercises and prescriptions to pursue healthier lifestyles.

4.1.5 Adjusting Drug Regimens. Pre-surgical patients are often told to change or stop medications prior to surgeries because of potential complications. One 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, was controlling her condition. However, her upcoming surgery required her to stop using Prednisone and Humira, and she sought alternative solutions online. *"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, others 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 needing to be on a specific drug for neuropathy, but her neurologist had to wait to allow her to use it 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]

4.1.6 Psychological Changes. Prior to surgery, patients 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 being afraid to see an orthopedic surgeon to have a surgery for 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].

Frustration. Patients can also 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]

Anxiety. Anxiety 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.

Depression. 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]

4.1.7 Holistic Life Challenges. Individuals' surgical challenges affect more than just their physical health; they create or exacerbate emotional and social challenges and can alter patient lifestyles. For example, a patient undergoing life-changing surgeries may no longer be able to enjoy social events or activities which they find meaningful. *"It is just over a week until my surgery. Starting to get somewhat apprehensive about certain aspects. Whilst I am not that nervous about the surgery, I am certainly nervous about the recovery and pathology afterwards, (and of course, the dreaded catheter). One of my main worries, although it may seem trivial to some, is my ability to return to competitive sport. This is a way of life for me. Will I still be able to continue this lifestyle in the future, or will the break make that impossible? I want to climb Mt Kilimanjaro next year. Will that still be possible?"* [Q193]

4.2 Communication & Social Challenges

Patient needs are not constant throughout prehabilitation; 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.

4.2.1 Tensions Between Patients and Care Collaborators. Stress from impending surgeries causes negative interactions between patients and their care collaborators, thus persistently affecting patient social interactions.

Patient helplessness. Accumulation of diagnoses, prior treatments, and ineffective medications cause patients to feel frustrated, and might causes them to believe that no clinician can help them. *"I am tired of having repair surgeries and the "down" time associated with them."* [Q74] This patient helplessness can be generalized, or it can be specific to a certain 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 and treatment with future ailments. *"I'm searching and searching for ways to feel better and it seems the harder I try, the worse it gets!"* [Q300]

Dissatisfaction with clinicians. Patients note various factors which cause them to feel dissatisfied with clinical care, including but not limited to: distance to specialists, need for multiple visitations or to see multiple specialists, unavailability of a specific clinician, lack of clear and comprehensive information during the healthcare process, and even perceived loss of autonomy. Patients note feeling 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] Patient dissatisfaction from prior encounters and treatments might also contribute to patients not seeking or receiving needed treatments and interventions; this may be especially true for patients with chronic conditions, as they must receive lifelong care to manage their conditions.

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 believed 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 [24]. *"[I] would like to hear from real women, not statistics"* [Q589]

Lack of Trust. Some patients felt that their clinicians held views or had practices which were antagonistic towards their health and care. 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/unproven treatments and medications, as the clinician/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]

4.2.2 Tensions with Family. Patient pre-operative 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. *"I've not managed to rest [my shoulder] as recommended. I have two kids and no help."* [Q19] Furthermore, surgeries can often negatively affect previously close relationships between friends or spouses. For example, family may feel stressed about balancing daily responsibilities with supporting the patient. *"Tomorrow [Husband] will have surgery... [Work] has taken all of my time, focus, and energy. [Husband] has had to do all his pre-op details himself."* [Q204]

5 Discussion & Design Implications

In the previous section, we highlighted a variety of prehabilitation challenges related to patients with MCC. We now turn to five discussion points regarding themes HCI researchers and designers could consider when designing technological interventions aimed at enhancing patient prehabilitation. These points include: helping patients monitor nuanced changes, promoting patients' psychological well-being, supporting collaboration and communication, addressing interrelated challenges, and disseminating information about prehabilitation to the general public.

5.1 Monitoring Nuanced Changes

The experiences patients posted on the forum illuminate the challenges they faced in a wide variety of contexts and provide us with design insights into how HCI researchers might be able to address prehabilitation related problems. Based on our results, MCC patients are required to balance chronic conditions with their acute surgical needs. For example, patients may need to adjust drug regimens for their impending surgeries, as well as stabilize their pre-existing conditions. However because of the

complexity of managing their conditions and their lack of clinical expertise, certain patients in our dataset found it difficult to make an informed decision about adjusting regimens. Prior research demonstrates that long-term lifestyle changes can manage and stabilize chronic conditions (e.g., increased exercise [19], dietary changes [17]), but such solutions take time greater than the current period allotted for prehabilitation to show such results. Furthermore, some conditions made it difficult to adhere to prescribed exercises. In extreme cases, a patient's conditions may prevent them from being able to benefit from prehabilitation. For example, respiratory ailments can hinder a patient's ability to perform sufficient prehabilitation exercises.

Monitoring of subtle changes is necessary to ensure that clinicians are properly informed about patients' conditions. This will enable clinicians to better plan for surgery and post-operative procedures tailored to individual patients. Monitoring may also help patients better understand and manage their conditions through increased self-knowledge, identify instabilities in their conditions, and determine potential drug interactions or reactions. This is especially true if patients enact self-monitoring [33]. Self-monitoring technology can complement prehabilitation management because it offers both therapeutic and assessment opportunities [29]. Furthermore, because many chronic medical conditions co-occur with both sub-clinical and clinical mental illness [46], self-monitoring can be used in conjunction with techniques like Cognitive Behavioral Therapy to better address patients' holistic health. The self-monitoring process --- including therapist instructions, training, self-recording devices, and self-monitoring responses --- can lead to changes in the frequency of desired behaviors [29, 39]. According to Social Cognitive Theory (SCT), self-monitoring is part of self-regulation, which allows individuals to focus upon long-term positive outcomes while enduring shorter-term negative experiences [22]. Professionally guided self-monitoring, thus, might be helpful in addressing negative emotions and experiences associated with prehabilitation. Self-monitoring data sharing [55] can also help clinicians identify which patient cases are inappropriate for prehabilitation.

5.2 Promoting Psychological Well-being

Patients' physical incurable conditions are not the only factor which needs to be managed or stabilized. Patient psychological changes through perioperative care was a recurring theme in our dataset, although we refrain from making quantitative analyses regarding behavior frequencies. We believe this theme deserves further examination and researcher attention. For example, patients' stresses regarding their MCC and surgeries can cause anxiety and/or depression throughout the perioperative period. Current prehabilitation practices include psychological components for this reason, such as by providing relaxation and breathing exercises [21]. However, our results show that many patients seek *"distractions"* to give themselves emotional breaks from procedures and conditions throughout the care process. In an effort to feel "normal" (i.e., unburdened by chronic conditions), patients may distract themselves by changing their environments

(e.g., vacations) or behaviors (e.g., being more sociable). This often results in inconsistent care practices.

However, to design effective prehabilitation technology for MCC patients, researchers might need to utilize more positive design strategies [16]; 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. We need to consider both challenges and strengths in conjunction for pre-surgical MCC management. 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.



Figure 2: The interrelated levels of complications.

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 2). 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 [8]), to understand their intentions to perform behaviors (the integrated behavior model [38]), and improved by using positive design for patient psychological well-being.

5.4 Supporting Collaboration & Communication

Many patients from our data sought support from peers. In some instances this is because they were confused, unclear about a topic, or they wanted to know more about the information clinicians briefly introduced to them. Prior literature suggests that patients often seek a different expertise from patients than they do clinicians [24], but patients in our data set reveal that tensions between the patients and their clinicians may contribute to the behavior to seek differing expertise. As a result, patients in our dataset 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. In essence, clinical practices sometimes failed to equip patients with the necessary knowledge or support for patients to be active participants in their healthcare, despite communication and collaboration being significant factors in promoting prehabilitation health. Established literature [24] suggests that collaboration happens spontaneously among patients, clinicians, and third parties. In our case, clinicians check patient progress and collaborate with dietitians and kinesiologists to adjust patients' treatments, and patients often receive social/information support from families, friends, or online communities [9].

To foster communication and collaboration and improve prehabilitation care, we will here discuss some themes designers should consider when designing prehabilitation technologies for MCC patients. Patients in our data underwent sometimes drastic emotional and psychological changes during their care. Designers could pay attention to and account for these emotions and psychological changes in relation to perceived pre-surgical challenges. Because patients often sought extra information from peers after consultations with their clinicians, designers could also incorporate 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.). However, patients might also be supported in their abilities to connect with peers and collaborators to gain both patient and clinician expertise and support. Encouraging clinician participation in prehabilitation care, such as by sending prompts to ask clinicians to provide instruction on self-monitoring activities, or adding clinicians as moderators [26], might also potentially benefit prehabilitation; this could promote both data consistency regarding clinician-accepted protocols [55] and engagement by adding a clinician presence to which the patient is accountable

[56]. In addition, designers should be aware that changing social contexts also influence the ways patients adopt medical technology [40], and be careful to consider how MCC patients social contexts may affect adoption. In general, when conducting research for prehabilitation, researchers should be mindful of patients' actual and perceived interrelated needs.

Limitations

We did not collect patient demographic information because some users did not publish their demographic information online. However, our primary focus is not to understand patient demographics, but to understand their interpretations and experiences in regards to prehabilitation. To ascertain patient perceptions, we rely upon patient self-reports, and although self-reports are accurate portrayals of subjective experiences, they cannot be independently validated or compared directly with data from quantitative analyses. Our methods also precluded us from conducting follow-up interviews with forum users. Moreover, the participants in this study are likely digitally literate individuals, and not representative of people who do not use technology for health information. Therefore, our results should be treated cautiously, and should not be extended beyond the realm of patient-perceptions for a technologically literate population. The prevalence of prehabilitation challenges reported in our dataset is also likely only representative of general MCC patients undergoing surgery, as our research likely depicts the most interesting cases. Furthermore, the challenges and needs we describe may not necessarily be exclusive to only MCC patients. Our chosen forum of study was also intended for patient sharing, rather than medical expertise sharing, which may have biased our results towards patient information seeking and social support.

6 Conclusion

We argue that prehabilitation is an important opportunity to improve patients' survival outcomes in the spectrum of habilitation services. Understanding challenges associated with prehabilitation can help HCI researchers and designers to better provide technological support to patients in need of surgery. In this work, we chose to examine patients with MCC to help us understand their prehabilitation challenges. Our results show that patients with MCC perceived an array of difficulties, such as balancing chronic conditions against surgery needs, stabilizing conditions prior to surgeries, inconsistencies in adhering to care plans, a lack of guidance in making adjustments, etc. We then discussed some potential directions for designing technological solutions to address these challenges. Our work provides a patient-centered understanding of how MCC patients characterize their information and support needs before surgeries. Our findings can act as a preliminary exploration of technology supported prehabilitation for MCC patients and inform future prehabilitation technology designs in the fields of HCI and Health Informatics.

Future Work: We have presented data showing that a wide array of factors can influence MCC patients' prehabilitation behaviors, including the symptoms of their conditions and their support structures, but future research is needed to answer questions such as, *"Why do patients choose to engage or*

disengage with their prehabilitation programs?" and *"What are the determining factors that could lead to changes?"* Our work is an initial exploration of this topic, as well as why prehabilitation remained relatively underutilized in our data set. Future work could also investigate how patient-level information could improve quality of care, by incorporating interviews, observations, and longitudinal studies to understand prehabilitation in specific disease management. Also, future studies could consider solutions from the perspective of clinicians 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. Future studies could also practically utilize findings, such as by forming design and deployment studies, feasibility and efficacy tests, and efficiency iterations.

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