"I'm Done with Cancer. What am I Trying to Improve?": Understanding the Perspective of Prostate Cancer Patients to Support Multiple Health Behavior Change

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ABSTRACT

Research suggests a lifestyle with specific diet, physical activity, and smoking cessation may prevent the progression and recurrence of non-metastatic prostate cancer. Adopting this lifestyle often requires multiple health behavior changes. While health behavior change is well-explored in HCI, the current context differs from past work. It has implications for how technology could support health behavior changes in this specific context. We provided prostate cancer patients with a website, text messages, and activity trackers to understand their experience with health behavior change interventions. Two focus group interviews conducted after the study revealed specific issues regarding these interventions. We found that patients interpreted the recommendations based on their existing understanding of healthy lifestyle and that the inability to measure cancer progression made health behavior change more challenging. Our findings also indicate a gap between the expectation of the researchers and the patients regarding technology. These results have implications for design of technology-enhanced interventions to support health behavior change in other similarly constrained contexts.

CCS CONCEPTS

• **Human-centered computing → Empirical studies in HCI**;

KEYWORDS

Prostate cancer, health behavior change, Fitbit

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1 INTRODUCTION

Medical recommendations for healthy living are almost universally familiar: maintain a healthy diet, get regular exercise, do not smoke, get good sleep, and stay well-hydrated. Medical research as well as human-computer interaction (HCI) focuses on helping people to adopt these behaviors either proactively as preventive measures, or to treat or manage a health condition such as diabetes, obesity, or heart disease. Recent medical research suggests that adopting some very specific health behaviors may prevent the progression and recurrence of non-metastatic prostate cancer [41]. This is especially significant, since prostate cancer is the second leading cause of cancer death among men in the US [47]. While this is an area of ongoing research, current evidence suggests that this is another chronic disease that may be managed with specific lifestyle changes.

However, there are important aspects of this specific context that distinguish it from other areas of health behavior change that have been explored previously. Most notably, the recommended behaviors are *much* more specific than in other cases, and include:

- Building 3 or more hours of vigorous aerobic exercise per week [28]
- Replacing saturated fats with vegetable oils and eating 1 serving of oil-based salad dressing or nuts per day [45]
- Eating 1 serving of cruciferous vegetables per day [44]
- Eating at least 2 servings of cooked tomatoes per week [11]
- Eating at least 2 servings of fish per week [11]
- Avoiding all processed meat [46]
- Avoiding single vitamin or mineral supplements without consulting with a doctor [30]
- Avoiding all tobacco products [27]

Having such specific behavior targets as these is considerably different from many common contexts for health behavior change. On

one hand, having concrete goals can be very helpful for behavior change. On the other hand, having such specific recommendations, and so many of them, could make adherence especially difficult. In addition, the context of behavior change here is significantly different from other health conditions such as diabetes and obesity, where behavior change recommendations are more obviously tied to those specific medical conditions.

In this study, we set out to understand how patients with prostate cancer engage with the behavior change recommendations. Researchers running a medical study provided 37 prostate cancer patients with a website, text messages, and activity trackers aimed at supporting them in adopting these recommended behaviors. After completing the study, two focus group interviews were conducted with 14 men (eight men in the first focus group and six men in the second focus group) to understand their experiences attempting to adopt these behaviors. The interviews revealed that participants struggled with aspects of this type of behavior changes due to a mismatch between their preconceptions about a healthy lifestyle and the recommendations of the study. There was also a gap between the intentions behind technology provided to participants and their usage of that technology. These results inform the design of future tools to support behavior change in this and similar contexts.

2 BACKGROUND AND RELATED WORK

Prostate cancer is the second leading cause of cancer death among men in the US [47]. The American Cancer Society estimated 174,650 new diagnoses and 31,620 deaths from prostate cancer in 2019 in the US [47]. In this section, we discuss relevant literature for health behavior change in the context of prostate cancer.

2.1 Recurrence and Progression of Prostate Cancer

Prostate cancer originates from uncontrolled growth of cells in the prostate gland. It can then spread to other parts of the body. If the cancer has not spread, then that stage is called "non-metastatic cancer" which includes the tumor stages *T1-T3a* [47]. Though prostate cancer can be treated in these stages, existing literature suggests that about 15-40% of patients diagnosed with this cancer can experience recurrence within 5 years of the surgery for radical prostatectomy [22]. However, research also suggests that specific lifestyle factors may lower one's risk of lethal prostate cancer [41]. Since these lifestyle factors involve specific diet, physical activity and smoking cessation, in most cases, patients need to change multiple behaviors in order to adopt these recommendations. In Section 3.1 we discuss those specific health behaviors in detail.

2.2 Support for Cancer Patients

A cancer diagnosis has major impact on the lives of the patients and their families. Past work has explored providing different types of support for patients diagnosed with cancer. For instance, several studies have explored the relation between social support and quality of life for patients diagnosed with cancer during the first year of diagnosis [15, 17]. Jacobs et al. developed a "cancer journey framework" that details their participants' experiences with breast cancer [24]. This framework takes a holistic perspective on patients' journeys to support them during the treatment phase. Health behavior change is mentioned in the context of patients' desires to be healthier (rather than for reducing probability of recurrence). In another study, Moradian et al. reviewed the effectiveness of Internet-based interventions for managing physical symptoms related to chemotherapy for cancer treatment [38].

A cancer diagnosis comes with physical implications, social implications, as well as psychological implications. These past literature highlight the broad variety of issues and challenges that cancer patients encounter. However, they do not engage health behavior change with the target of preventing the progression or recurrence of cancer. As we show in this work, there are important differences in how patients engage with health behavior change and what their motivations are in the context of cancer treatment.

2.3 Supporting Cancer Patients in Health Behavior Change

Though the primary concern for many of the interventions for cancer patients is informational and emotional support, studies have also been conducted for supporting health behavior change of patients diagnosed with cancer. Bantum et al. studied the effectiveness of a web-based workshop with cancer survivors, to help them identify a behavior that they would like to change [6]. Trained facilitators then worked with participants to develop action plans to support accomplishing their desired goal. This context differs considerably from ours: participants each chose their own goal for a behavior to change. By contrast, in our study, there were multiple goals, these were specified by the study, and the motivation for accomplishing those goals was tied to the likelihood of progression and recurrence of prostate cancer.

Accomplishing behavior change in this context can be difficult. Literature suggests that the awareness of participants about the risk and benefits associated with the recommended behavior serves as a precondition for health behavior change, helping to improve their motivation [5]. Perhaps most relevant, a study was conducted to study the impact of an activity tracker and a web-based application, called *RiseTx*, on reducing sedentary behavior among prostate cancer survivors [48]. The study asked participants to set a step goal for 3,000 steps higher than their baseline step count established at the beginning of the study. Patients in that study changed their behavior, however, lacked sustained engagement. While the population studied is similar to our target population, many of the other details are different. First, we are targeting multiple behaviors. Prior research suggests that multiple health behavior change might be perceived as highly demanding and might fail to address any single behavior in sufficient depth [42]. Additionally, the physical activity goals in our intervention are based on hours of vigorous aerobic exercise, rather than step counts.

2.4 Health Behavior Change for Other Medical Conditions

A plethora of studies have been conducted on health behavior change. However, the majority of these studies are focused on behavior change for health conditions like diabetes [37, 40], obesity [3, 10], and asthma [25, 51]. Other studies on health behavior change consider healthy living [9], increasing physical activity [34, 35], reducing alcohol consumption [33] or smoking cessation [4] as their health behavior change goals. While findings from these literature

provide guidance for designing technology-enhanced interventions, the target behavior and the context is significantly different from that of prostate cancer. The goal of health behavior change for prostate cancer is reducing the risk progression and recurrence, which is a long-term outcome. However, the goal of health behavior changes like smoking cessation or reducing alcohol consumption has a near-term outcome (i.e. improving the quality of life), in addition to a long-term outcome (increasing life expectancy).

In this work, we focus on health behavior change to reduce the likelihood of prostate cancer recurring, which has some properties that distinguish it from these other contexts. In particular, the patients are all men, the majority of them are older (prostate cancer is rare below age 40 and relatively common by age 60 [47]), and they are not necessarily living lifestyles that would be considered unhealthy. In addition, the recommended behaviors (listed in the introduction) are very specific and different from the contexts of other medical conditions. Past literature suggests that specific goals might be difficult to achieve depending on circumstances [19].

2.5 Self-Tracking to Support Behavior Change

Past work also suggests that involving self-tracking technology positively influences performance with health behavior change. Participants of a study that explores the impact of self-tracking for health behavior change commented that tracking provides structure and motivation that helps adherence to a recommended lifestyle [9]. However, this study used photographic journaling of diet and exercise so that the users can reflect on their health behavior. This is different from our context because the goal for our participants is to change very specific health behaviors rather than just reflecting. Additionally, findings from prior research also suggested that tracking provides a sense of competition that leads to increased motivation and engagement [23]. Prior work also showed that tracking helps to increase awareness about lifestyle among the participants [16]. While in retrospect developing custom self-tracking technology seems like an obvious component for this study, these studies were all published since 2014, when the current study was designed.

Past work has also identified some ways that self-tracking can be problematic. Several studies have reported that users perceive tracking as time-consuming and burdensome [13, 18]. Past work has also suggested that users without prior experience with self-tracking lose engagement over time and perceived the visualized data as difficult to understand [43].

The presence of a health-care provider leads to a sense of obligation for the patients and that might lead to improved performance with tracking as well as with health behavior change [31]. However, Bellg et al. found in their study that adherence to modified health behavior starts to decline as soon as the severity of the health condition is subsided or contact with health-care provider ceases [7]. Another important issue to consider for digital self-tracking is the age of the person tracking. Prostate cancer is diagnosed more often in men of age 60 and older and is rare before the age of 40 [47]. Perhaps unsurprisingly, surveys show that older adults tend to be less comfortable with technology, which may further limit the value of self-tracking in this context [2].

These implications from recent work on self-tracking suggests that there is some potential for self-tracking to support patients diagnosed with prostate cancer in adopting the recommended health behaviors, however, there may also be issues with the target population (age, past experience tracking) that decrease the likelihood that self-tracking will be effective. Further, the burdens of manual self-tracking would be amplified if multiple behaviors are being tracked. However, considering the technology available at the time of the intervention design, in 2014, we decided to make some of the benefits of self-tracking available, while limiting the burden. We discuss about the available technology in 2014 in Section 3.1.

Together, past work indicates that the experiences and needs of prostate cancer patients in attempting to change behaviors for reducing the risk of recurrence of prostate cancer is an interesting and unexplored area. The results from this effort contribute to a broader literature that covers technological support for health behavior change. In the next section, we present the description of the method employed in this study.

3 METHOD

This work reports on focus group data collected from participants of a pilot study named Prostate 8 (P8) [29]. The findings of this pilot study will be used in the design of a larger study that involves technology-enhanced tools for self-tracking to support health behavior change of patients diagnosed with prostate cancer. The P8 study used technology-enhanced tools and resources for targeted health behavior change as an intervention component of a randomized controlled trial (RCT). Past work tells us that some specific health behaviors can help reduce the progression and recurrence of non-metastatic prostate cancer [41], and the P8 study contributes to that literature. The aim of the focus groups was to understand the perspectives and experiences of the patients in adopting these recommended health behaviors.

In this section, we first give a brief overview of the larger P8 study to provide context for interpreting results from the focus group interviews. Next, we describe the data collection and analysis of the focus group interviews, that are reported in this paper.

3.1 Procedure: The Prostate 8 (P8) Study

The P8 study was a novel pilot feasibility study originally designed in 2014. It was a randomized controlled trial conducted by medical researchers to understand how men with non-metastatic prostate cancer would engage in targeted multiple health behavior change with the support of technology that was available at that time. Participants were encouraged to adopt 8 healthy lifestyle goals that prior research found had a relationship with prostate cancer: building 3 or more hours of vigorous aerobic exercise per week [28], replacing saturated fat and animal fats with vegetable oils and consuming 1 serving of oil-based salad dressing or nuts per day [45], consuming 1 serving of cruciferous vegetables per day [44], consuming at least 2 servings of cooked tomatoes or tomato products per week [11], consuming at least 2 servings of fish per week [11] as well as avoiding: all processed meat [46], single vitamin or mineral supplements without consulting with a doctor [30], and avoiding all tobacco products [27].

To support participants in adopting these 8 behaviors, we provided participants with an informational website, a Fitbit One Activity Tracker, a personalized health report, and occasional text messages. While more technology is available now to support tracking

and behavior change, in 2014 self-tracking tools were in a developing phase. For instance, the *Xiaomi* band was launched in July, 2014 [50] and the *Apple Watch* was launched in April, 2015 [20]. However, by 2014, *Fitbit* had launched a number of fitness trackers. Among those, *Fitbit One®* gained more popularity due to it's ease of use, enhanced battery-life and wireless synchronization technology.

Popular mobile applications and websites for diet and calorie tracking in 2014 included: *MyFitnessPal, Lose it, FatSecret, Cron-o-meter*, and *SparkPeople* [8]. While these diet trackers supported a barcode scanner to help the users with tracking, none of them support automated tracking for home-cooked meals. Moreover, the goals provided to participants of the current study were in number of servings, not in calories since the recommendations involves very specific dietary items that could be measured in number of servings, rather than calories. Again, the recommendations focus on very specific target foods rather than their entire diet. The available diet trackers did not provide feedback on specific food items, and were burdensome to use because they required constant manual tracking. As a result, this study was designed with the tools available at that time. We conducted the study with the goal of supporting the participants with health behavior change while at the same time, managing the burden associated with study participation. Next, we discuss the components of this intervention in more detail.

3.1.1 The Prostate 8 Website. To support achieving and sustaining the lifestyle goals, participants had access to a website provided by the study that focused on all eight recommended lifestyle goals. The website also contained an exercise guide, recipes, shopping guides, and a weekly food planner. Additionally, the participants received a health and wellness guide, and a log-in information sheet with passwords for the website. The primary goal of this website was to educate the participants about the eight healthy lifestyle goals. Therefore, the website had static educational content about the recommendations and access to tools. This website did not include communication support or tracking. The primary motivation for using the website for this purpose was its ease of access from any device. The participants can access the website from both their mobile phones and computers. Additionally, websites are faster to develop and easier to maintain and update.

Though the website was based on static educational content, it also had the weekly recipes and blogs that were updated on weekly to bi-monthly basis. To remind the participants about these updates, they were emailed on a bi-monthly basis by the principal investigator about the new recipes and blog topics.

3.1.2 Fitbit One® Activity Tracker. As mentioned previously, researchers asked participants to track their physical activity only. Diet tracking was not included in this study because of the significant burden of manual diet tracking and the mismatch of available tools with the goals of this study. The intervention provided a *Fitbit One®* activity tracker to help support physical activity tracking. The primary goal of using a *Fitbit One®* was to explore whether tracking would help participants in this specific context. Note that the *Fitbit One®* tracked steps and did not track the exact target goal (3 or more hours of vigorous physical activity). At the time we were not aware of a wearable that did track this, and we made the decision that the additional burden on patients would be low (because tracking would be automatic) and there was some chance that the Fitbit would encourage physical activity.

At the baseline visit each patient received the *Fitbit One®* tracker with instructions on using the device and also access to a study-only community group named "Prostate 8" on the *Fitbit* website. Any damaged or lost *Fitbit* devices were replaced by the research team.

3.1.3 Personalized Health Report. Participants also received a personalized health report in printed form at the baseline visit. The report was also emailed to them for ease of access. This report was prepared by comparing their self-reported diet, physical activity and smoking habits with the recommendations. The participants were then classified into "meeting", "almost meeting" and "not meeting" the recommendations. This classification was used to provide targeted guidance on what behaviors patients needed to change and was included in their personalized health report.

3.1.4 The Text Messages. Participants received 4-5 text messages each week from the study. Since more than half of the messages required a response from the participants, too many messages might have been burdensome for them. Among the 83 text messages sent during the entire 12-week study, 11 text messages also asked the participants to complete daily challenges. For instance, the text message sent on day-5 says, *"Aim for 5 servings of fruits and vegetables a day. We will ask you tonight how many servings you ate"*. Therefore, the text messages were mostly sent in the morning, so that the participant could have time to complete those challenges during the day. Twenty-three text messages required short responses, and 7 text messages required answers to quiz questions to foster engagement of the participants. These messages emphasized behavior change techniques such as goal setting, social support, maintaining self-efficacy, improving motivation, etc. The challenges and quizzes in the text-messages were incorporated to reinforce and motivate adoption of the recommendations.

Along with the above mentioned tools, each participant also received one "Actigraph GTX3+ accelerometer". This device was not a part of the intervention. It was used by researchers to observe any changes in physical activity over the course of the study. For measuring and comparing the data, the participants were asked to wear the accelerometer around their waist for seven consecutive days before the baseline visit and at 12 weeks.

3.2 Participants

The recruitment process for the P8 study started in June 2015. 228 men with prostate cancer, who live within a 2-hour drive distance from the study location were assessed for eligibility and screened over phone or in-person for participation. The eligibility criteria for the participants in this study were:

- Men who have non-metastatic prostate cancer in stages $\leq T3$
- On active surveillance or had completed radical prostatectomy at least 3 months prior to enrollment
- Are able to speak and read English
- Are able to walk unassisted
- Are able to navigate websites, fill out forms on the web, communicate by email, and have regular access to the Internet
- Are willing and able to travel to the study location for pre- and post-study blood collection
- Are meeting ≤ 4 of the 8 recommended behaviors

Participants were excluded if moderate-to-vigorous intensity aerobic exercise or blood collection was inappropriate for them. Written informed-consent was obtained before conducting any assessment.

Among the 228 men assessed for the study, 126 men met the inclusion criteria. However, 50 of the eligible participants declined to participate in the study. Therefore, the study had a total of 76 participants. These participants were randomly assigned to intervention arm (N=37) or control arm (N=39). In each of the arms, 32 participants completed the 12-week study. The participants in the intervention arm were then invited over email to participate in the focus group interviews. Note that only the participants in the intervention arm were invited for the focus group interview since the goal of the interview was understanding their experience with the technology in the intervention. The email invitations for the focus group interviews were sent in February 2017 and April 2017. A copy of the consent form, HIPAA, and the bill of rights were sent to the participants with the invitation for their consideration.

From the 32 participants of the intervention arm, 14 participants agreed to participate in the focus group interviews. Four of the participants were in the age range 55-64 years, seven were in range 65-74 years, and three were in the range 75-84 years. The average age of the participants of the focus group interview was 65, compared with an average age of 66 in the intervention arm. Next, we discuss the data collection through the focus group interviews.

3.3 Focus Group Data Collection

The P8 study was a pilot study to evaluate acceptability and feasibility of a health behavior change intervention, in preparation for a larger upcoming RCT. Participants in the intervention group of the P8 study had reported changes in their diet compared to the control group, moving from a median of 3 target goals being met to a median of 5 target goals being met at the 12 week assessment after completion of the study [29].

To understand participants' experiences in this study, researchers conducted two focus group interviews with a total of 14 participants from the intervention arm. The first focus group interview (F1) was conducted in March, 2017 with 8 participants and the second interview (F2) was conducted in May, 2017 with 6 participants. The interviews were conducted by one main interviewer and an additional researcher who asked follow-up questions for clarification or further details if needed. Before starting the interviews, researchers explained the consent form and also informed participants that they could stop their participation at any point. The participants were also informed that they could choose not to answer any of the questions if they did not wish to answer for any reason. They were also asked to complete a short demographic survey.

In the interviews, the participants were asked to discuss their experience, opinion and suggestions about different components of the study. The list of questions that were used to facilitate discussion in the focus group interviews is provided in Table 1.

The whole process of obtaining consent, completing the survey and conducting the main interview took 3 hours for each focus group. The core discussion lasted for 96 minutes for F1 and 104 minutes for F2. The interviews were then transcribed using a paid transcription service that took 24 hours to complete. In the audio recordings of the interviews, it was not always possible to identify the individual who was speaking, and, therefore, our transcripts do not all contain participant-level identifiers. As a result, we attribute quotes in the findings section to the focus group that they came from (F1 and F2), but not to individual participants. Next, we discuss about the data analysis process used in this study.

• Tell us about the changes you made while participating in this study. How did you do it?
• Which components of the study were helpful?
• Was there anything about participating in the study that felt time-consuming or burdensome?
• What would have motivated you to visit the website?
• Would you want to have a forum where you can ask questions to the experts?
• Would you use a tracking system on a weekly basis?
• Did you set your own goals or just work with the goals that the study provided you?
• How many of you used the *Fitbit* website or the app? What motivated you to use it?
• Did anybody use the online community in the *Fitbit* website?
• What was your opinion about the text messages?
• Is there any other feedback that you have about participating in the study or suggestions for us?

Table 1: Questions for facilitating discussion in the focus group interviews

3.4 Data Analysis

We conducted thematic analysis with the data collected from the focus group interviews. We started our analysis by coding the transcripts of the focus group interview discussions. One researcher worked on coding the transcripts and then had weekly meetings with another researcher to discuss the codes. In this process, a total of 450 codes were extracted from the transcripts of the two focus group interviews. However, we disregarded 21 codes from our analysis that were not relevant for the technology-related aspects of the study (e.g. "learned cooking from daughter"). Therefore, we continued our analysis with the remaining 429 codes.

When the coding process was complete, two researchers analyzed the 429 codes together and merged similar codes together. In the first round, 429 codes were grouped into 155 codes. These 155 codes were then written on post-it notes. The researchers continued this process in an iterative manner to identify themes. After all 155 codes were grouped in themes, the researchers reviewed each theme to discuss the codes in that theme to verify consistency within each group, and made adjustments where themes were not consistent. By the end of this process, 19 themes were identified which were then carefully considered for drawing important implications for the design of similar technology-enhanced interventions.

4 FINDINGS

We combined insights drawn from across the 19 themes from the thematic analysis and identified the high-level findings with important implications for design of technology-enhanced health behavior change intervention tools for prostate cancer patients. In addition, we also found themes that support past work on behavior change interventions. In this section, we discuss our findings.

4.1 Patients Applied Prior Health Knowledge

The focus groups revealed that, despite having received information detailing the suspected relationships between the recommended lifestyle changes and progression of prostate cancer, participants in the study fell back on their existing understanding of these lifestyle changes and about prostate cancer even when it did not align with the information provided during the study.

Participants tried to change their health behavior as a part of the study. However, while working to adopt the recommended behaviors, they also incorporated their own prior knowledge about living a healthy lifestyle. Though not related to the recommended lifestyle for preventing the progression of prostate cancer, participants focused on some more commonly targeted aspects of their behavior related to other health conditions like obesity, diabetes, and heart diseases. For instance, a participant in F1 mentioned about a mobile application called "MyFitnessPal", *"...I regularly check into there (the MyFitnessPal app) because I want to see what my sodium level is...It helps me work on my caloric as well as other intakes and such"*. It is important to note here that the participant was using the application for checking his calorie intake even though this application was not a part of the study and the recommendations did not involve calories. Similarly, another participant commented about measuring body fat in the *Fitbit* website, *"The Fitbit scale...it measures body fat, BMI (body mass index)...from your weight and height and stuff"*. Another participant in F1 commented, *"...If you want to eat something and you don't know exactly how many calories it has...and if there's a substitute that would satisfy that same cravings"*. It is notable here that, even though sodium level, body fat or amount of calories were not part of the recommendations in the context of this study, participants tried to combine their existing knowledge of living a healthy lifestyle with the recommended lifestyle changes specifically for prostate cancer.

Keeping track of calories, sodium level, or body fat adds extra burden for the participants while working towards health behavior change. Even though the study did not include diet or nutrient tracking to reduce the burden for the participants and does not require monitoring those data, participants tried to track these values based on their prior understanding of a healthy lifestyle which made the process even more complex for them.

Similarly, participants in the focus group focused more on the default daily goal for step counts in the *Fitbit*, even though the recommendations provided by the study were presented in hours of physical activity per week. As mentioned above in section 3.1.2, we thought that *Fitbit* would be useful in motivating physical activity, but not used as a direct measure of whether they were accomplishing their goal. However, this was not the case. For example, a participant in F1 said, *"Well, Fitbit has a 10,000 step goal...I just used that as default"*. Participants also used their preconceived idea that if someone appears to be fit or thin, he is doing well with his physical activities. As another participant in F2 says, *"...Everybody sitting in here,...,is relatively thin and fit...and I suspect everybody in this room is (physically) active"*. Here again, participants focused on their preconceptions rather than the specific goals they were provided. Also, the *Fitbit* may have been more of a distraction than a motivator, which we did not anticipate.

Another example of applying a preconception relates to participants' understanding of whether or not they should still adhere to the lifestyle recommendations following surgery for radical prostatectomy. The study information they had been provided advised them to adhere to these recommendations even after the surgery, as it was suspected that sustaining these behaviors could help to prevent the cancer from recurring. However, participants in the focus groups, who had already been through the surgery, were under the impression that they no longer needed to adhere to the recommendations. For instance, a participant in F1 commented, *"I had had the surgery. I'm cancer free... so what am I trying to improve?"*. Similarly, a patient in F2 asked, *"A guy has had a radical prostatectomy. He's got no prostate left. What's the difference in terms of prostate health?"*. These reflect the fact that participants falsely assume that after surgery, prostate cancer cannot recur, which decreases their motivation for health behavior change.

To summarize, participants' comments suggest that they are relying on their existing understanding of healthy behaviors and lifestyle, even when lifestyle recommendations for limiting the recurrence of prostate cancer provided in this study differed from that preexisting knowledge. Participants seem to have combined their existing knowledge with the recommendations provided in the study, which may have influenced their interaction with the provided tools as well as their motivation for health behavior change.

4.2 Measuring Adopted Behaviors and Their Impacts

Our second major finding suggests that the participants in the study had a desire to measure their adopted health behaviors and associated impacts of those behaviors on their health and on progression of prostate cancer. As discussed in the previous section, participants were interested in checking their BMI or body fat in their *Fitbit* account, even though these measurements were not relevant to the recommendations in the study. They mentioned that it was motivating for them to see some measurements of their health status to quantify their progress. Further discussion in the focus groups revealed that a major challenge participants encountered in adopting the recommended behaviors in this study is that there was no measurement or other indication of how well they were doing. For instance, a participant from F1 suggested *"...just a healthy to unhealthy scale as you start going down to the unhealthy part, that's a motivation to start doing better"*. This reflects their interest in observing measurements of their health status or lifestyle.

A participant from F1 pointed out the difficulty of focusing on changing a behavior without having an associated measure: *"We talk about food, but we don't talk about weight... is there any consideration about the calorie intake around the cruciferous diet or the prostate cancer so that people have targets in terms of not just the volume that they are ingesting but the total caloric intake that's appropriate for their height or body style"*. These comments, in addition to the comments mentioned in the previous section, reflect that participants wanted concrete physiological measures and targets. Since the participants could not measure how positively or negatively their lifestyle was influencing the progression of cancer, they wanted to map the recommendations with calorie intake and weight so that they could have a better understanding of whether or not their behaviors were having an impact on their health.

Another participant in F1 commented *"Your food, you can measure what you put in, but you can't really measure what you're getting out of it. With Fitbit, like you say, Ah! I'm at 9,830, keep it going. I don't think you see a result like that with food"*. This participant wanted something to measure his progress with the diet goals like he can measure his steps in *Fitbit*. A second, more interesting point is that they wanted to measure the "benefit" they were getting from the recommended diet. It is very difficult to measure the benefits of a specific food especially in the context of measuring the probability of the recurrence of cancer.

Together, these indicate that participants found it challenging to adhere to the recommendations in part because there were not specific physiological measures to show the effects of adopting these behaviors, and also because there was no automatic mechanism for tracking their progress towards the stated goals, as there was with steps using *Fitbit*.

4.3 The Gap in Expectations About Technology Between Participants and Researchers

Participants in this novel pilot study for men with prostate cancer received technology-enhanced tools to support targeted behavior change. However, the focus group interviews revealed a significant gap between the expectation of the participants and the researchers regarding these tools.

As stated earlier, each participant received a *Fitbit One®* activity tracker and were asked to use the *Fitbit* account provided by the research team. The goal was to track whether participants wore the device each day during the study and also to provide some motivation for physical activity. However, some participants in the focus group were dissatisfied with this arrangement, as they were concerned about losing their data after completion of the study. A participant in F1 mentioned that *"...The other thing I found a little annoying is the fact that you (the research team) wanted it on your own Fitbit account, so I couldn't get credited for my own personal account"*. He was annoyed by the fact that they could not use their own *Fitbit* account for this purpose.

Despite describing the role of the *Fitbit* to participants at the start of the study, several participants were unclear about its purpose. They were more concerned about the comfort and aesthetics of the device. For instance, a participant in F1 commented that *"I think the downside of the Fitbit that goes in your pocket is that you change clothes, you leave it in there...try to get a Fitbit that you wear on your arm"*. This feedback is also supported by previous literature where participants reported that comfort as well as accuracy of the tracked data were important factors for them [23].

The researchers provided an online community within the *Fitbit* website expecting that the participants would compare their data with other participants and also share experiences in the community. Past work suggests that comparison and social support helps to increase motivation for behavior change [21]. However, some participants had *Fitbit* competitions with their friends, family and with themselves rather than with study participants. A participant in F1 said, *"I have friends. We compete with steps..."*. Someone from F2 commented, *"That (personal progress) to me is more important than whether or not I climbed more or less stairs than someone else in the group"*. Some participants also mentioned a reluctance to log-in to that online community. A participant in F2 noted, *"There were some group (the online community in the Fitbit website)...And that just didn't work"*. Even though some participants visited the community, they found no one else there with whom to communicate. As a result, they lost interest in using the community.

However, not all of the feedback about using *Fitbit* in this study was negative. For instance, a participant in F1 said *"...I think Fitbit was the critical electronic engagement. This thing keeps talking to me, how many hours do I get 250 steps. The idea of being in competition with yourself, tagging those markers as much as you can...it's compulsive almost"*. However, he goes on to note: *"On the food side, we don't seem to have the same engagement"*. These participants suggested that they would have liked some tool or mechanism that would engage them more with diet like *Fitbit* did for physical activity.

Again, as mentioned earlier, the research team also sent text-messages regularly as a part of the intervention to remind the participants about the recommendations as well as to foster engagement. However, since the participants knew that the text messages were automated, some of them did not feel the need to respond to the messages. In some cases, participants also ignored the text messages. For instance, an F2 participant said *"...I thought it would come at the same time, it was just an automated thing and either I'm motivated or I'm not motivated. And I didn't care"*. From this perspective, the lack of more tailoring behind the automated reminders seems to have made them less effective.

The participants received four types of text messages: suggestion-based, short responses about opinions on recommendations, quiz-like questions, and questions to answer with yes or no. Therefore, a fraction of the text messages required the participants to respond. These were designed both to serve as a reminder as well as to engage the participants more with the information about the recommendations. Though the researchers wanted to foster engagement with the recommendations using the short responses and quizzes, focus group conversation revealed that the participants preferred to respond to the questions with yes or no responses since those take less time and were easier to respond to.

Despite the intention of the researchers to provide participants with several pieces of technology both to support data collection and engagement in the study, participants' experiences with those technology indicate that this did not fully succeed. Instead, participants' existing practices of using *Fitbit*, as well as the reluctance to engage with automated text messages meant that the technology did not play an equally useful role for everyone. Different participants had different expectations from the tools which influenced their interaction with those tools.

4.4 Additional Support for Past Findings

Along with the new findings discussed above, we also found themes that support existing findings in the literature. As a part of the intervention, the participants received text messages as reminders as well as to foster engagement and emails to provide updates about the website. However, they reported that text messages were more effective than emails. For instance, a participant from F1 commented, *"...I get about 2,000 emails a day, so all the emails you sent me were basically just buried in the noise..."*. Email overload has long been an issue in the HCI literature [49]. On the other hand, another F1 participant mentioned, *"...I think some of the texts and motivational texts...were effective"*. Again, a participant in F1 commented

that *"I think texts are more immediate and daily...It's (text messages) in your hand"*. These support the findings of existing literature, which also found that text messages were useful as reminders [51].

Participants also mentioned that an online health community in the study website to share both informational and emotional support would be helpful for their behavior change. For instance, one F1 participant commented, *"I think a forum on a website would be very helpful. Even an anonymous one, just for asking questions"*. This finding supports previous literature on effectiveness of online health communities for behavior change interventions [3, 21].

The focus group interviews also revealed that even when participants did not make significant changes in their health behavior, they became more aware of their lifestyle. For instance, a participant from F2 mentioned, *"I think it's just being aware. Just plain and simple..."*. Past work has also shown that journaling increases awareness about lifestyle [16].

While discussing diet tracking, participants noted that tracking would be difficult since they have to remember to track and in some cases, it might not be feasible to track in a social setting. They also perceived tracking as a burdensome process. For instance, a participant from F2 commented that, *"To me, that's (tracking every meal) asking a lot"*. Diet tracking have also been reported as time-consuming and burdensome in previous literature [9, 18].

5 DISCUSSION

The P8 study examined feasibility and acceptability of a behavior change intervention in men with non-metastatic prostate cancer. Overall, the study demonstrated that men in the target group were interested to try the technology-enhanced tools to support behavior change, and men in the intervention group changed several behaviors in a positive direction, compared to the control arm [**?**].

In the current detailed analysis of the post-intervention focus group data, we uncovered several important themes that correspond to novel opportunities for enhancing interventions like this one. First, the ways that participants applied their existing understanding of healthy behaviors and of cancer indicate that careful thought should go into designing health behavior change intervention to address possible misunderstandings. Next, we need to consider opportunities to better support participants in measuring their progress, which is difficult given the uncertainty of that progress. Finally, there are important opportunities to consider regarding the role of self-tracking in this context.

These observations may increase the likelihood of helping men successfully make behavior changes and sustain them over the long-term. We will be using these to inform a future iteration of the P8 study, that includes more participants and a 24-month intervention. We engage these opportunities and challenges in more depth below.

5.1 Working with Participants' Preconceptions

The focus group interviews showed that participants' prior knowledge about cancer and healthy lifestyles affected their motivation in the study. Most notably, participants indicated their belief that cancer would not recur after going though radical prostatectomy. They also had some existing ideas about healthy lifestyles and behavior change, based on their prior knowledge. These differed from the recommendations provided in this study, to reduce the likelihood of prostate cancer recurring. As we found, these concepts influenced the motivation of participants for health behavior change. These preconceptions need to be addressed directly in the design of interventions and tools that support health behavior change, so that they do not become a barrier for adopting the recommendations.

One approach for dealing with these preconceptions is to design tools that proactively help individuals to break their misconceptions before and during the process of health behavior change. Dynamic content that targets specific preconceptions could be especially useful here. For instance, a chat-bot could check in with participants on their progress. If they have stopped working on some of the behaviors, it could follow up to ask why, with information directed at addressing specific misconceptions. However, one challenge to this approach is that it requires knowing what misconceptions people might have ahead of time. In this case, a hybrid approach might be useful: if a particular misconception is not addressed in the existing system, a human could follow up, and also capture that misconception to update the chat-bot content. Additionally, breaking a deep-seeded concept can be a challenging task in reality.

Another approach is to design tools to support users in mapping their existing concepts with the new recommendations. For instance, perhaps using some other non-cancer disease as an analogue for prostate cancer could be useful for helping patients to understand that it may recur, and that they can take steps to help decrease this risk. One potential issue here is that an analogy in this context might actually add to the confusion. Another issue is that this approach depends strongly on having a good analogy, and certain aspects that might be impossible to map.

5.2 Representing Progress Towards Outcomes

One important issue that came up for our participants is that the inability to measure progress towards the overall goal made it more difficult to adopt the recommendations. Literature also suggests that visible measurements help provide motivation to patients [9, 36]. While in many other types of behavior change, there is an outcome that is more directly measurable (i.e. weight, blood sugar, frequency of headaches), and can show progress (or lack thereof) along the way, in the context of this study, such measurements are difficult.

In case of health behavior change for prostate cancer, the ultimate outcome is whether or not the cancer recurs, and the recommendations are targeted at lowering the probability of that event occurring. The measurement of progression and recurrence of cancer are probabilities, which can already be difficult for people to reason about: an entire research domain exists in the area of risk communication in medical contexts [1]. The challenge here is even greater, because we are asking participants to reason about decreasing a probability, which provides the overall motivation for changing behavior. Communicating a change in probability is an open challenge for this context. A recent study also suggests that adherence to an intervention becomes challenging for participants when that intervention involves probabilistic outcomes [14]. Another study by Kay et al. reported that when the measurement about the status of health involves uncertainty, the tool might be perceived as unreliable by the user [26]. A significant challenge for future work is to develop approaches that effectively and accurately communicate to participants the projected effects of adopting these recommendations in a way that sustains their motivation.

5.3 Better Support for Researchers Deploying Behavior Change Technology

This intervention was part of a pilot study for a randomized controlled trial to study medical outcomes associated with prostate cancer related to these lifestyle changes. In this context, the technology employed in this intervention was the best initial effort of the researchers to support participants in making these changes: the study specified concrete goals and provided support for accomplishing these goals through the website, text reminders and email updates, and activity tracking through *Fitbit*. Despite these efforts, our findings indicate that the technology deployed did not support the participants in accomplishing their goals as well as it could have, and that there was a mismatch between participants' expectations and the support provided by the tools. Past literature suggests that mismatch between the expectation of users and the capabilities of the tools is the most common reason of abandoning health tracking tools [12]. Moving forward, there is an opportunity for the HCI community to provide the medical research community with better tools and guidelines for deploying behavior change interventions. Recent work by Kim, et al. has begun to explore the potential for such systems with flexible self-tracking tools [32]. There is an opportunity to further develop these tools to make it easier for medical researchers to run similar studies in the future.

5.4 The Potential and the Complexity of Self-Tracking

Participants expressed conflicting opinions regarding efficacy of the components of the intervention. One notable topic of disagreement was 'manual self-tracking': some participants wanted to manually track their health behaviors, some would have tracked if the study required it, and some said that they would not use a self-tracking system. Participants also had individual preferences for method of tracking. Some of the participants wanted a paper diary for self-tracking, some wanted to use a tracking website, and some preferred to use smart-phone applications. Preferences for tracking frequency also varied, with some participants wanting to track daily, while others preferred weekly because they felt that tracking might be difficult to commit to and might become burdensome.

Past work indicates that self-tracking and visualization of progress towards health behavior change can improve motivation as well as adherence [9, 36]. Combining the issues about preconceptions, difficulty of measurements related to cancer, and the individual differences with the positive impact of self-tracking on health behavior change, our findings suggest some particular guidelines for manual self-tracking in this context. First, it would be useful for a self-tracking system to help participants understand the recommended lifestyle within a common understanding of health behaviors and how cancer works (i.e. that it can recur). This would be especially useful for pointing out significant differences between the recommendations and their preconceptions. Second, the system should include some representation of the probabilities of recurrence or other metrics of success. This is clearly a difficult space to design in because no guarantees can be made about whether or not cancer will recur in an individual. However, if done well, this could help patients to maintain their motivation. Third, the design needs to consider the conflicting preferences of the participants about self-tracking as well as their individual differences in health conditions. In other words, the solution cannot be a one-size-fits-all approach. Recent work on just in time adaptive interventions (JITAIs) provides some direction for this work [39]. Finally, the system should be designed in such a way that would help the users with managing a huge load of information in this context. Participants are exposed to a large amount of information in this context (and in other contexts for multiple behavior change), and it is not reasonable to assume that they will ingest all of the relevant information. It is also not reasonable to assume that they will voluntarily seek out the information that they did not retain.

6 CONCLUSION

Helping prostate cancer patients to adopt the recommended lifestyle described above has the potential to save many lives. The Prostate 8 pilot trial demonstrated the feasibility and acceptability of using a technology-enhanced intervention to support health behavior change in prostate cancer survivors. Next steps include improving the intervention to better meet patients' individual needs, and to help them change and maintain healthy habits over the long-term.

This in-depth analysis of the post-intervention focus group responses highlights important opportunities for improvement, which can be applied both to this specific study and also more generally to tools that support multiple behavior change. For instance, carefully designed software could help to surface and correct misconceptions, provide clearer feedback on how the adopted behaviors are changing the probability of recurrence, and provide additional feedback and tools to help participants sustain their motivation. There is still more work to be done towards this goal: the challenges described above are definitely not straightforward. However, identifying these challenges is the first step towards solving them.

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