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Using Magic Machines to Elaborate Menstrual Self-Trackers for Women with Endometriosis

MIRIAM AFEWORK

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Swedish title

Utveckling av Hälsoappar med Hjälp av Magic Machines för Kvinnor med Endometrios

Author

Miriam Afework, mafework@kth.se

Supervisor: Madeline Balaam

Examiner: Kristina Höök

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ABSTRACT

Existing self-tracking tools for women concentrate on one's general well-being and keeping track of ovulation and periods.. With around 10% of women worldwide suffering from endometriosis there is an unmet need to leverage self-tracking for women whose cycles are affected by more variables. The disease is enigmatic with an unknown cause and cure and the illness differs for each individual in symptoms and working treatments. It is therefore critical to understand how women can learn about their bodies and how to treat their condition. In this research I work with two sufferers to identify their *secret desires* through a workshop and a series of interviews. Results suggest that women with endometriosis could benefit from experimenting with different habits and make personalized routines to suit their own needs. Finally I present design implications for an existing menstrual app in the form of an add-on. The steps of the add-on tool included three steps. Firstly, choosing variables of one's well being to track (mood, energy, pain etc.), choosing activities for one or more cycles (gluten-free diet, exercising etc.), and lastly viewing an analysis of any changes in the body.

SAMMANFATTNING

Nuvarande self-trackers för kvinnor är centrerade kring användarens allmänna hälsa, ägglossning och menstruation. Cirka 10% av kvinnor i världen lider av endometrios, en vanligt förekommande men okänd sjukdom. Bland många tillgängliga applikationer för kvinnor är få fokuserade på endometrios. Sjukdomen skiljer sig i symptom bland de drabbade. Därför är det viktigt att förstå hur kvinnor själva kan lära sig hur deras menstruationscyklar ser ut och behandla deras egna symptom med hjälp av self-trackers. I denna studie arbetar jag med två kvinnor för att förstå deras behov. Resultaten visar att kvinnor med sjukdomen kan dra nytta av att experimentera med olika vanor för att hitta en personlig rutin. Jag presenterar ett designförslag på ett tillägg till en nuvarande mens-applikation. Tillägget är ett verktyg för att experimentera med olika vanor för att se hur det kan påverka ens välmående. Verket innehöll tre steg: Användaren får välja en eller ett par variabler att studera (humör, smärta etc.) samt en eller ett par rutiner att följa (ny matvana, träningsvana etc.) under en eller flera menscyklar. Därefter får användaren se en analys över hur rutinerna kan ha påverkat kroppen.

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Miriam Afework
KTH Royal Institute of
Technology
Stockholm, Sweden
mafework@kth.se

ABSTRACT

Existing self-tracking tools for women concentrate on one's general well-being and keeping track of ovulation and periods.. With around 10% of women worldwide suffering from endometriosis there is an unmet need to leverage self-tracking for women whose cycles are affected by more variables. The disease is enigmatic with an unknown cause and cure and the illness differs for each individual in symptoms and working treatments. It is therefore critical to understand how women can learn about their bodies and how to treat their condition. In this research I work with two sufferers to identify their *secret desires* through a workshop and a series of interviews. Results suggest that women with endometriosis could benefit from experimenting with different habits and make personalized routines to suit their own needs. Finally I present design implications for an existing menstrual app in the form of an add-on. The steps of the add-on tool included three steps. Firstly, choosing variables of one's well being to track (mood, energy, pain etc.), choosing activities for one or more cycles (gluten-free diet, exercising etc.), and lastly viewing an analysis of any changes in the body.

Author Keywords

Personal informatics; self-tracking; patient generated data;enigmatic disease; endometriosis; participatory design.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION

Self-tracking is the practice of recording information about one's diet, health or daily activities with the ultimate goal of discovering patterns that could be changed to improve one's physical or mental wellbeing [29]. Common ways of self-tracking are through wearable sensors and fitness trackers, but also through self-reporting [2][23]. Out of 90,088 existing health apps in the Apple iTunes store in 2015, 7% were for women's health and pregnancy [18]. Women use period trackers for different reasons, a few being: To be aware of one's well being, understand how the

body reacts to different phases of the cycle (period, PMS, ovulation), to be prepared for one's period and to become pregnant [8]. Epstein found that though many women find menstrual tracking helpful, they are not effective when the predictions are inaccurate. Many also expressed that the apps they use fail to take into account life stages such as pregnancy and menopause [8]

Around 10% of women worldwide suffer from endometriosis [27], a chronic condition characterized by endometrial tissue normally found inside the uterus growing outside it which can manifest itself in pelvic pain, pain during intercourse, infertility etc. Despite its prevalence the causes are unknown, and with individuals having different experiences, the condition remains enigmatic and many women suffer for many years without being diagnosed [14]. Research shows that a lot more variables beyond the start-date of one's periods need to be recorded in order to understand the disease across individuals with the condition [25].

With a relatively high number of sufferers, and with many of them being left in the dark regarding their diagnosis and treatment options, it would increase their incentives to understand and manage their illness through self-tracking. The differing characteristics of symptoms among individuals make it crucial to understand how self-tracking can be used or further developed to provide women with tools tailored for each individual.

The current study explores the main problems that women with endometriosis face, with the aim of understanding how current self-trackers might be further developed to suit them. Specifically I aim to answer "*How can current menstrual self-trackers be developed to cater to the individual needs of women with endometriosis?*".

A magic machines workshop was conducted [1] as well as in-depth interviews with two women. The main contribution of this paper is a design suggestion of an additional functionality for a period tracker. It has been made iteratively with continuous feedback from both participants in the study.

BACKGROUND

In the following section I review prior research in a few relevant areas. I provide some background to endometriosis as well as menstrual etiquette, sexual health education and normalization of pain. I also look into existing online support for sufferers and menstrual self-trackers.

Endometriosis

Endometriosis is a condition where tissue that is normally found inside the uterus grows outside it. The tissue responds to the hormones that trigger menstruation and swell, which causes lesions and cysts to form. Symptoms include severe pelvic pain just before, during or after menstruation, pain during bowel movements and urination as well as during sexual intercourse. Many also experience chronic fatigue, nausea and vomiting, headaches and heavy periods. Endometriosis is the leading cause for infertility where a third of infertile women have endometriosis [6]. There is no cure for endometriosis nor is the cause known however pain medications and hormonal therapy can be effective in relieving pain. Conservative surgery is sometimes performed to alleviate infertility difficulties and eliminate pain, although it is not a guarantee the endometriosis pain will not return [11].

Endometriosis is estimated to affect 1 in 10 women of reproductive age, which constitutes around **176 million** women worldwide [27].

Diagnostic delay

Although the condition is relatively common, women are not diagnosed until many years after symptoms have been detected. One study of 218 women with endometriosis found that the time between the onset of symptoms and diagnosis was 7.96 years in the United Kingdom and 11.73 years in the United States of America [14].

The reasons for the diagnostics delay mentioned in previous studies vary. Some emphasize the roles of women and others the role of the medical practitioner. Although there may be a delay in seeking out help, Hadfield [14] mentions that once women report the symptoms to doctors “the medical practitioner may have difficulty in distinguishing between other causes of pelvic pain and endometriosis”. Another study with in-depth conversations with 20 women highlights the role of doctors in the diagnostic delay [9]. Participants claimed that their pain complaints were normalized where the doctors would suggest that menstrual pain was non-pathological. Denny also mentions the weight of women’s social circles influencing their decision to see a doctor. She found that for some women “family and friends acted as a deterrent, frequently because of their perception of pain in general, and menstrual pain in particular” [9: 42])

Menstrual etiquette and disclosure of pain experiences

Sophie Laws puts forward the term of *menstrual etiquette* which “regulates relations between the sexes, one part of which governs how menstruation should be dealt with and

spoken of” [22: pg. 28-29]. The central element of the menstrual etiquette is that women should aim to keep the topic of their menstruation away from men’s attention. Women are often encouraged by other women to conceal their menstruation whether it be their sanitary wear or mentioning of their menstrual pain.

Participants in Seear’s study all agreed that they would make an effort of concealing the potentially discrediting information about themselves in many different ways. When the information *was* disclosed to selected friends and family, some found that their experience of pain was “redefined and normalised” [28: pg. 1223]. Many of the participants were told by their mothers that the pain was something they should endure while remaining quiet. Comments included that it was their “load in life” and something that they should “put up with” [28: pg. 1223]. Since the people they disclosed the information to were close family or friends, they relied heavily on the interpretations of their pain complaints. When pelvic pain during sex was brought up to partners, some women were met with frustrations with their complaints. When they revealed that sex was painful they were “accused of using their pain as an excuse to withdraw from sex” [28: pg. 1224].

The normalization of women’s pain or negative experience during their cycle might also stem from very early stages in women’s lives when they’re first educated about menstruation. One study showed that women are more likely to obtain knowledge about their menstruation from their mothers, sisters and sources at school, however the information tends to be centered around what happens to the body biologically and how to cope with the practical aspects such as how to use sanitary products [5]. It is focused less on the experience like how to deal with the emotions before and during menstruation. By centering the information around the biological aspects Britton claims that women are treated like a homogeneous group and menstruation as a universal process. “*It creates a gap in knowledge because it stops short of an understanding of collective, shared beliefs and values about the body and of variations in individual experience*” [5: pg. 647].

Online support

Upon diagnosis and treatment, many women commented on the inadequacy of information that was provided by their doctors [16]. They found that they were given information about what the physical implications would be but lacked information about endometriosis in general and at-home treatments such as dietary changes to relieve pain. Support groups were claimed to provide advice on lifestyle modifications however specific groups were not mentioned. At the moment, the online platforms are limited to closed Facebook groups and websites with collections of articles that may be beneficial for women with endometriosis or for family members or friends of women with the illness.

Menstrual self-trackers

Among the tools provided for people who menstruate the majority of the them are centered around tracking the menstrual cycle in order to get clarity on when to expect the period to start and when one would be ovulating and in some cases when you could expect to experience PMS symptoms. **Clue** is a application for tracking the stages in the menstrual cycle [7]. Each day the user is able to enter bleeding flow volume, pain, emotions, energy levels and other data the user themselves choose to track during the month. The user is also able to enter data such as body temperature and exercise which is aimed at making the predictions of the ovulation and period more accurate. It is unlike other period tracking apps since it provides information about all the data you can track, educating the user on the variables that could play a role in the cycle which might not initially be obvious. It shows predictions of the cycle for the coming 3 months, and notifies the user for each step, for example when they could expect to feel PMS symptoms. **Flo** is similarly a period tracking application which is synchronized with the iPhone health app and keeps track of daily walking distances for example [12]. Besides bodily symptoms users can enter their water intake for example. The data is processed to show a “health insights” displaying short articles of what might happen to the body. If the user experiences and enters “dryness”, they would be able to read about how dryness could lessen the chance of becoming pregnant. The third most downloaded menstrual app is **Period Tracker** which is a very simplified version of the previously mentioned [26]. The user can enter data about their physical symptoms, sexual activity and weight/body temperature. The period and ovulation is predicted however no other information is presented like the previously mentioned apps.

One study has through interviews, focus groups and surveys attempted to identify design requirements for self-tracking endometriosis [25]. They explore what data needs to be collected from women suffering both to make self-tracking tailored for them but also for the purpose of characterizing the illness through a standard set of variables. They developed the app **Phendo**, a tracker designed for women with endometriosis which differs from the ordinary apps made for women such as **Clue** and **Flo**. For everyday tracking the questions are more detailed: “What did you eat?”, “What activities were hard to do?” and “What did you do to self-manage?” were a few. Upon registration the user builds their profile by filling out demographic and lifestyle information, if they are diagnosed, what hormone treatments they are currently undergoing, and what foods and exercises improve or worsen their symptoms. On the “insights” page, the past months have been summarized for easier visualization of any patterns in the user’s symptoms.

Another self-tracking app called Flutter also differs from mainstream women’s health trackers since it focuses on women with endometriosis [13]. In the app, users can track

their cycle, but also get advice for pain management and overall health in another part of the app. Furthermore, there is a community where users can share their stories and get feedback from other users of the app through likes and comments. Before registration the user is able to enter their symptoms for self-diagnosis. It includes a detailed list of bodily symptoms to track.

The tools available have a mutual focus on self-tracking with some additions of advice on diets and activities that can help manage or prevent pain. An important question is if the needs of women with endometriosis are met with self-trackers with variables specific for the disease. What do sufferers prioritize in the treatment of their illness, and (how) can that be applied to current technologies?

METHOD

To understand the dimensions of women’s experience with endometriosis, data was gathered through a magic machines workshop and a series of interviews. Results were analyzed and used to design suggestions for an add-on function for menstrual tracking application.

At the starting point of this study, two support groups for women suffering from endometriosis on the social networking site Facebook were intended to be used to gather a larger number of participants (around 6-10) for a workshop. Upon requests to join the Facebook groups, explanations of the purpose of the study was not enough to be invited by administrators. The administrators of the two biggest groups in Sweden “Endometriosis” and “Living with endometriosis” are closed for women who do not suffer from the illness to protect the members. The challenge of finding participants suggests that discussions with women is sensitive. Close social networks were used to understand this. A friend claimed that it is difficult to talk about your pain experiences without it being normalized. She explained that she “gave up complaining about her menstrual pain because her friends just didn’t get it”. Therefore I decided to select two women who were able to comfortably discuss their experiences with me as a researcher and be part of the workshops. I refer to these participants using the pseudonyms Hannah and Demi throughout.

Making magic machines is a way to design experiences that “explore ideas and notions of the unknown” [1: pg. 35]. During short and intense but carefully planned workshops, participants are asked to materialize their ideas in order to expose their underlying personal desires. In the case of the current study, the participants were asked to firstly explore the main concerns of their illness to then use different materials to build a “magic machine” to address this concern.

The title of a magic machine is used to generate specific qualities in the outcomes of the participants’ ideas. “The term magic refers to the desired not-yet understood ability of future technology and machine to its embodiment and

physical interface to the human user” [1: pg. 35]. Even hinting towards the object being “futuristic” would give participants ideas that are largely influenced by current TV and film’s vision of the future (such as public transport above the ground, robot butlers etc.). The workshop was planned as follows:

The Introduction

The introduction is short and aims to mark the beginning of the experience. It serves as a shared social contract with the group of participants which provides an understanding of what the experience will be and what rules the workshop will be conducted under. During the introduction the participants were asked to read and sign a consent form stating that the data collected will only be used in research purposes and personal information regarding their illness will not be shared outside of the current study.

The Prompt

The participants are provided with a prompt that hints at what they are going to do during the workshop. In this study the women were asked to describe what their endometriosis makes them feel like by writing it down on a piece of paper. When finished they would place the pieces of paper in their pocket without sharing what they wrote down with the group.

The Material Switch

Following the prompt, the women were asked to build a machine that respond to those feelings. They were given a selection of materials to do this. In order to avoid any type of hints towards what the objects are expected to look like, I made sure that all materials were of neutral colors to ensure that they did not remind them of existing parts of current products such as boxes, screens or buttons. The materials presented were string, cardboard, candy, aluminum foil, glue sticks and tape.

Presentation

When they seem to be finished with their machines, they were asked to describe what they wrote on the note and how the machine works as well as what it is called.

Discussion

This part of the workshop was where myself and the other participant asked questions about the machine. The machine was taken seriously regardless of how unrealistic or ridiculous it was. They were asked how it would be used, where it would be placed, how it would sound etc. forcing them to improvise the aspects they had not considered during the making segment and to clarify the purpose and functionalities of the machine.

Documentation & Analysis

The women’s presentations of the magic machines were documented and analyzed to find what main problems were tackled using the machines. As a researcher I made an ef-

fort to look into all the functions of the machines and the interpretations that were not directly noticeable by objectively looking at the machine, with emphasis on the ways the machine was magic. Through my analysis I found what they valued the most in the topic of treating their endometriosis, described by Andersen et al as their *secret desires* [1].

RESULT

In this section I present results from the magic machine workshop and a thematic analysis of the machines. Thereafter I explain the design process finally leading up to the design suggestions.

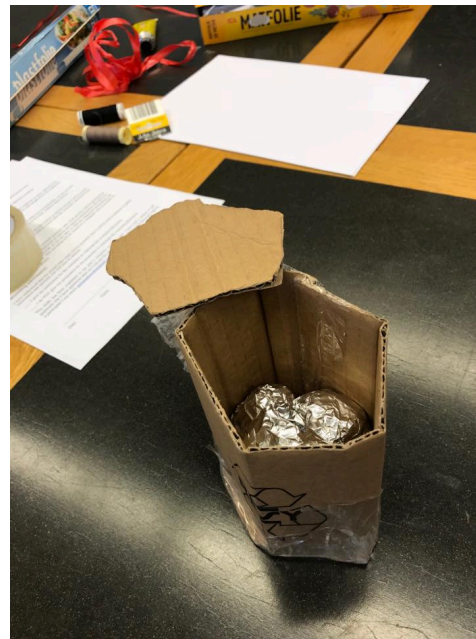


Figure 1: Hannah’s magic machine - The Endo Box

Hannah built a box filled with food pills that she would use anytime she experienced cramps that would magically remove all the pain *immediately* (figure appendix). The box was made out of carton and the food pills were marshmallows wrapped in tinfoil. She explained that the “pills” were made from normal foods she would normally eat because she is very sensitive to any strong pain medication because of her gastric catarrh. Even if medication would work with relieving her pain she describes herself as “not a pill person”. She would ideally like to eat and drink normal everyday foods to relieve any pain, not exclusively her endometriosis. When speaking about her endometriosis she (before being aware of her menstrual pain being a condition) referred to the pain as “the attack”. Sometimes she gets “normal” menstrual cramps with milder pain, but the attack is the really bad pain that leaves her in a fetal position until they are over, unable to pay attention to any other tasks during the day. She says that the food pills would come in handy during the attack where she claims that no medica-

tion can stop the endo pain unless she takes it before the pain starts which is unpredictable.



Figure 2: Demi's magic machine - The Safe Space

Contrary to Hannah, Demi was prescribed hormonal medication a few months back and does not experience severe menstrual pain anymore. Therefore her main concern was the psychological implications. Having to be dependent on her birth control makes her anxious about her future and eventually getting off it and attempting to have a child with her partner. She made the safe space was made using cardboard with the shape of a small sofa (see figure 2). The sofa contained small pieces of paper that contained the answers to everything she wanted to know about her endometriosis. The sofa was wrapped with bubble wrap and marshmallows to symbolize that the information was soft and put forward in a way that makes you feel better. Oftentimes when searching online for information she feels discouraged and “doomed” to living with this illness for the rest of her life. *“Sometimes when I read or even talk about endometriosis it actually makes me cry because it reminds me of the pain I experienced for years up until I started taking hormones”.*

She designed the safe space for her to go and feel supported by other older women who have gone through life and were still able to have children and live a normal life in general. The sofa was surrounded by small women made by tinfoil that were all connected through a red thread. When asked to describe how this space would look in the real world, she said that it could be either a physical room or an online space. She mentioned that she would enter the space when she gets into negative thought loops such as when thinking about possible pregnancies or when she is unsure about what routes to take like changing hormonal medicines.

Analysis

A thematic analysis was used to examine the machines and the workshop discussions to derive design ideas.

The result of the magic machines workshop fostered potential for a few design ideas to be explored. Firstly, Demi's machine presented problems among women with endometriosis that have managed to treat their pain symptoms but still experience anxiety and worry about their future and possible infertility for example. There is potential to build some community for young women who are in their early stages of dealing with the worries of being diagnosed with the illness and would not only benefit from understanding the technicalities of the disease but also receive support from older women who have gone through similar experiences. The need for support from older women might contribute to compassion, sympathy and reassurance that doctors or others without the experience are unable to offer.

Secondly, there is potential to treat the actual pain. TENS machines have been used for menstrual pain by stimulating nerves making it difficult for pain to pass [10]. By understanding the way that pain works specifically for women with endometriosis we can find either physical interaction design ideas or ideas where women could be instructed to locate and understand the different stages of pain and how to handle them.

In this study, I wanted to explore the anxiety both participants expressed regarding the pain. Since Demi had started taking hormones that eliminated her pain but still suffered from the trauma of her past experiences, I went back for an additional interview with her past pain in focus.

From taking me through the steps before and during her period I found that her pain was very similar to Hannah with the exception that she used to faint at times. She went into detail about one particular instance where she says that she had such bad cramps that she was convinced that her ovaries had exploded, and she was taken to the hospital with an ambulance. She felt very anxious before every period and not knowing how bad *“this one would be”*. During her years in high school she said that she would feel particularly worried because if the pain started she would need to spend over an hour getting home to be able to comfortably act on her pain symptoms by crying, laying down etc.

At first glance the endo box seemed to be a description of *working medicine*. However Demi's description of her past experiences resembled Hannah's magic machine, especially the anxiety around when the period would start and how bad the pain would be. Demi expressed that she still feels triggered reading or hearing about others' pain. The commonality between their experiences called for a response that explored the anxiety around these attacks.

Part of the problem with their period pain was the anxiety

of not knowing *when* they would get their periods and possible pain. Hannah found a way to prevent the attack from happening by taking an ibuprofen at the first sign of her period. However her fear is always to get her period in the middle of the night where there is no stopping the pain. Both of them claimed that when the pain has already started, no medication will stop it, you are forced to suffer through it until it is over.

This made me look into how one could prepare the body for a possible attack, and perhaps even prevent it from happening by understanding your cycle and preparing for your period.

DESIGN PROCESS

With Hannah's metaphor of the attack as a starting point, I started looking into the menstruation as a hurricane or other natural disasters that affect houses in different areas differently. Some areas only suffer from a few broken window and other areas are left barely habitable. Should the hurricanes be regular, for example approximately in the beginning of August each year, it would make sense to both prepare your house for the hurricane a couple of days ahead by installing hurricane shutters, bringing any items you may have in your yard and creating food and water supplies for example. It would *also* be important to prepare your house in the long term by getting insurance on your home, making a list of all your possessions and determining if you should replace your roof with a hip roof that is more resilient in case of hurricanes.

It is in a similar way that I believe women should be preparing for their periods and period pain in both the long and short term. Women are currently most likely to obtain knowledge about their menstruations from their immediate family or through sex education in school [5], which is mostly centered around the practical issues that overlooks the individual experiences. When deciding what to do in order to prepare I believe that all preparations should be originating from themselves and their own cycles, to avoid being influenced by other people's ideas of what the experience of periods is. For all women there are dissimilarities in cycle length, PMS symptoms, cravings and pain that require different preparations and amount of attention, and starting from yourself could help women learn about what happens with both their body and mind during their own period - becoming meteorologists for their own bodies.

Learning and preparing the body

An organisation with the aim to improve the lives of sufferers of endometriosis provides information about the illness, information about possible treatments such as surgery and hormones and pain relief and personal stories of sufferers [10]. The pain relief section provides alternatives such as heat treatments, physiotherapy, Transcutaneous Electrical Nerve Stimulator (TENS) machines, pain modifiers (such as antidepressants) and painkillers. NSAIDs, or non steroidal

anti-inflammatory drugs such as Ibuprofen, Voltarol and Ponstan, work by blocking the production of prostaglandins, chemicals in the body that cause pelvic pain and are produced more among women who suffer from endometriosis. NSAIDs are **only** effective before the production of prostaglandins. It is therefore recommended that women with endometriosis use painkillers a couple of days before menstruation. This explains Hannah's description of her attempts of controlling her pain, which would be beneficial information for all sufferers of endometriosis or other menstrual pain .

Other studies show that dietary habits may have an impact on changes in pelvic pain. In one study where 156 women with endometriosis were asked to follow a gluten free diet for 12 months, 75% showed a significant change in pelvic pain symptoms [24]. Another study concluded that a low fat vegetarian diet was associated with decreases in dysmenorrhea duration and intensity as well as PMS symptoms due to the diet's effects on estrogen activity [4].

Looking at ways in which women could potentially be able to decrease pain symptoms by changing everyday habits, the cycle should be viewed as something one would be able to control rather than being a passive observer or a helpless victim. The current self-help apps are focused on keeping track of periods and users have the option of entering data about themselves and be able to read about how that may affect them [7][12], but I think it is necessary that self-tracking apps need to go a step further. Currently the user would need to make conscious efforts of studying the patterns of the cycle. I would like to propose a way to experiment with different habits to make a personalized routine for the menstrual cycle with both long term and short term tasks in order to prepare the body and mind for every period, hopefully with less pain symptoms and anxiety around them.

Endo Clue Solution

Both tracking apps Clue and Flo do not have the right focus for women wanting to not only keep track of their periods but attempt to study their cycle with the aim to control it and their pain. However the changes that are needed are not drastic to the point where a completely new application would be necessary. Therefore the solution I present is an add-on for the self-tracker Clue.

"Find my routine" is the add-on function that allows the user to use one or a few cycles to experiment with different habits and watch how that translates into their physical and emotional well being. Initially, users should track their days without following a routine to record their usual cycles. Thereafter they can design their own routine they might want to try out themselves. A walkthrough is shown below.

Emma is 20 years old and has been struggling with bad period cramps since 8th grade, where she is unable to do eve-

ryday things almost every period. She went to multiple doctors before one suggested that she might have endometriosis. The doctor said that they do not offer surgeries but offered her hormonal therapy. Since she is uncomfortable taking hormones, she has decided to try to treat her pain by herself. One of her friends recommended the new feature on Clue as she herself, found a way to treat her own cramps through heat therapy.

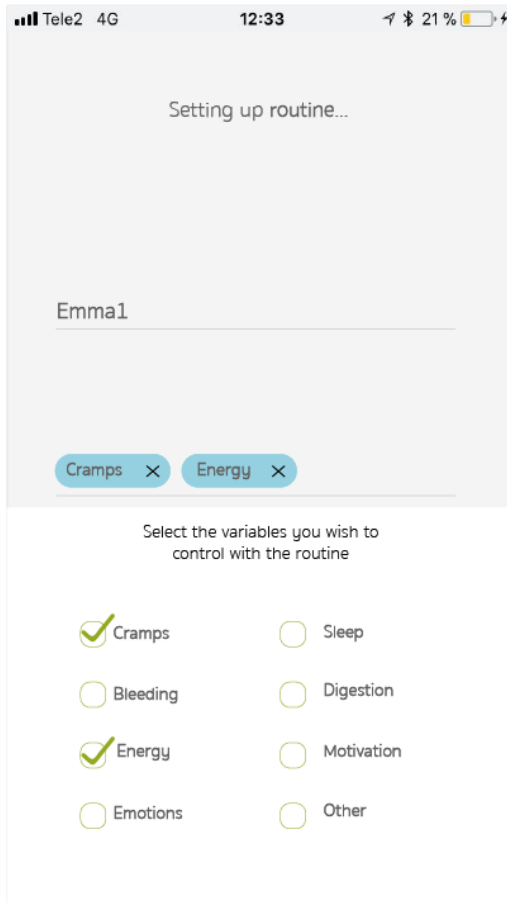


Figure 3: Designing your routine

On the app, Emma fills in what she would like to explore with the app. Besides her period cramps, she has always had terrible energy dips, and wonders if it might have anything to do with her endometriosis. She chooses the two variables in set up of the routine (figure 3).

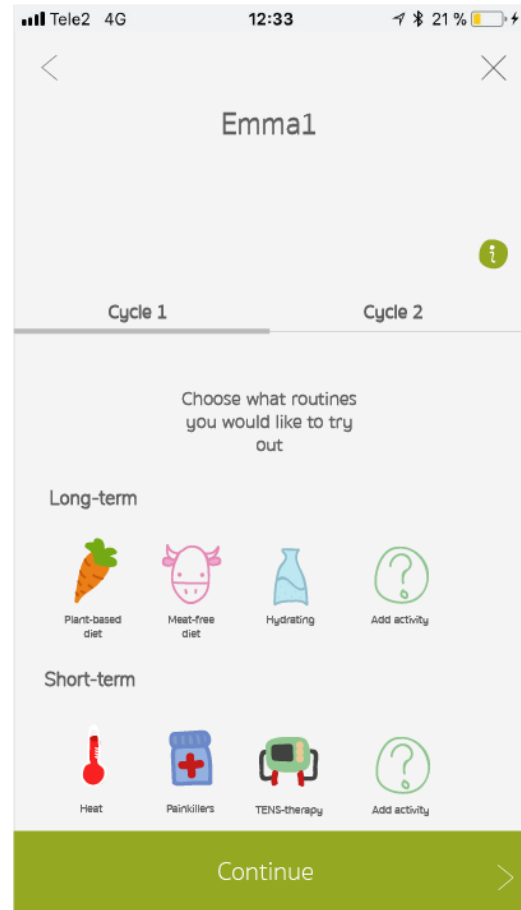


Figure 4: Selecting activities to try out for each cycle

For two cycles she would like to try different routines. During the first cycle she will try drinking 2l of water everyday. Her friend recommended taking yoga and said it might help with the pain, so Emma manually added yoga as an activity once a week. She read in the app that a gluten free diet has shown decreases in pain symptoms, as well as using a heat pillow. She adds gluten free for the whole cycle, and heat therapy for every PMS day up until her period is expected to start, see figure 4 and 5.

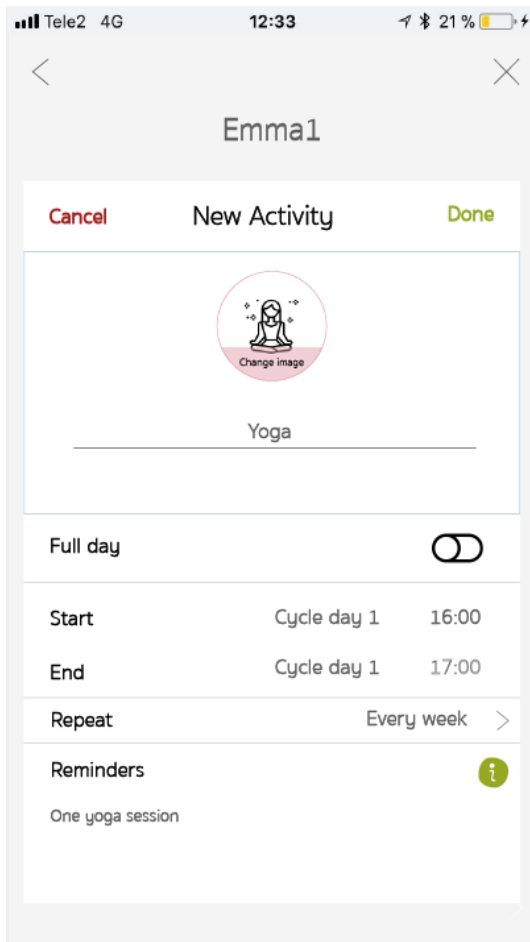


Figure 5: Setting up new activity

For each activity she adds notes in the reminders section that will display on the calendar with predictions, so she doesn't forget her tasks, see figure 6.

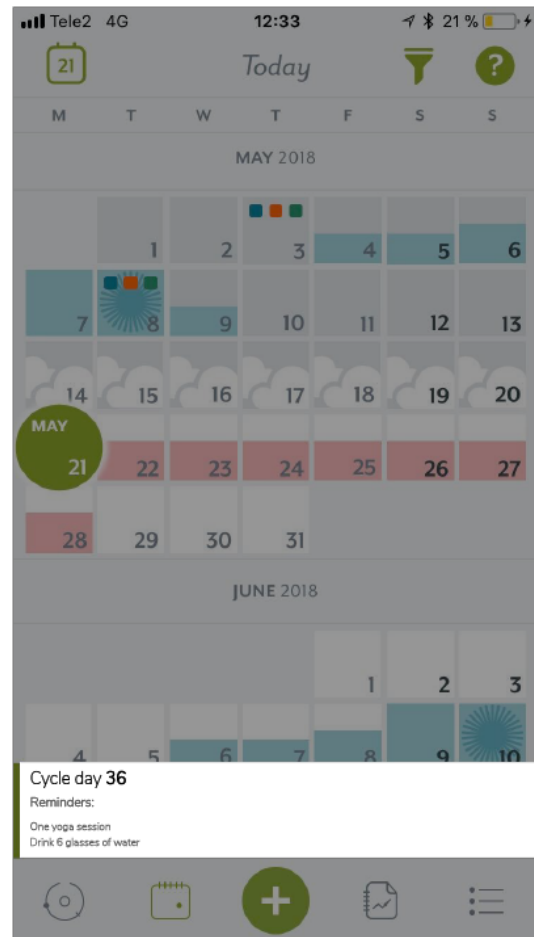


Figure 6: Added reminders to the current Clue calendar

After following her routines and doing her daily tracking (you can currently choose what variables you would like to track on the Clue app. Tracking options include both physical and psychological states such as pain, mood etc.), she is able to view the results of both cycles on the analysis page. "Health insights" shows her the results with some information about why hydration might ease pain for example (figure 7). She is also able to see the results in the form of a diagram for easier visualization (figure 8).

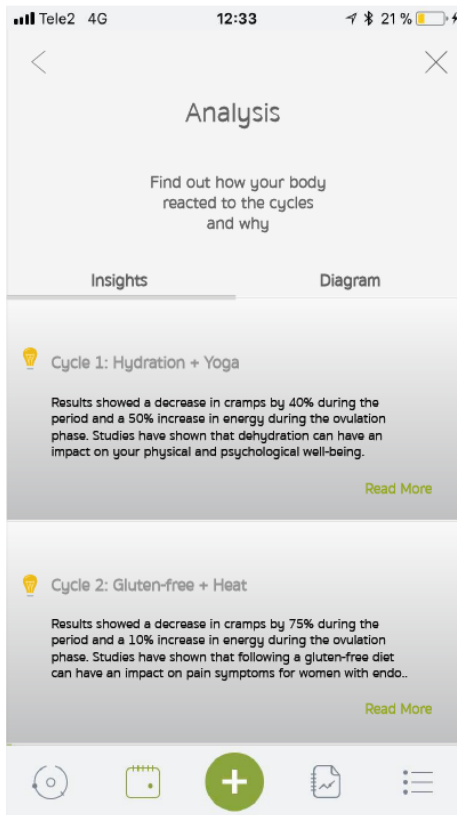


Figure 7: Health insights

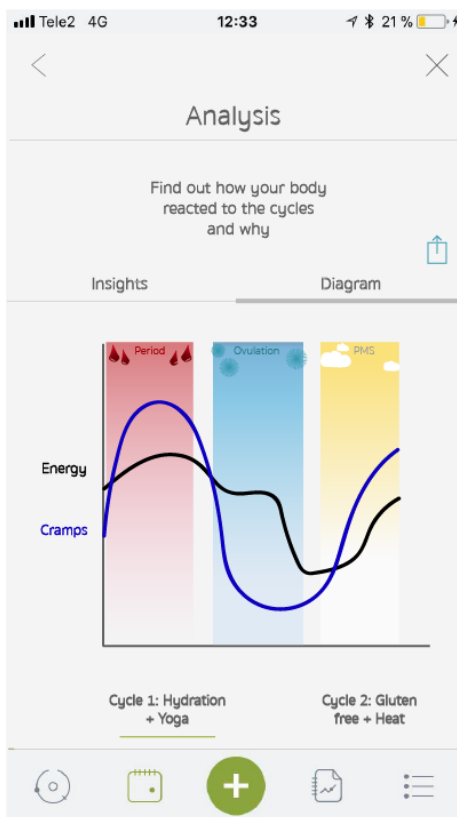


Figure 8: Health insights

Follow-up

Following the sketch of the add-on I went back to a short interview with Hannah to discuss whether this type of functionality would be beneficial since the idea was inspired by her magic machine. The takeaway from that conversation was that she has already made attempts to control her pain by taking Ibuprofen before pain starts and wish she would have known it worked for her sooner. She explained that she is not aware of the dietary changes she could make and would definitely be willing to try this. It would help because she would be able to try out routines she does not know about. *“I don’t know anything about what I can do besides taking painkillers which doesn’t always work either.”* Following this conversation, I thought an addition to this function might be a way of posting their routines attached with the analysis. Currently Clue does not have a community to which the user could share their routines. Therefore the icon added in figure 8 would allow the user to send their results via email, Whatsapp or other applications as such. It could inspire other sufferers to trying out different routines.

DISCUSSION

The findings showed that women with endometriosis could benefit from a tool for both long term and short term planning to prepare the body for potential pain which current self-help apps and trackers do not do. It would be beneficial to provide women with personalized routines based on their own experimenting with different habits - both pre-planned routines grounded in scientific findings and routines they may want to try out themselves perhaps inspired by other women’s stories.

Firstly, I believe that self-trackers being used to understand women’s well being and tracking various phases of the menstrual cycle is a good source of information because it stems from oneself and eliminates the potential normalization of pain which many women experience when disclosing pain to close family and friends or doctors [28]. To some degree, self-trackers also regard the menstrual cycle as an individual experience unlike the information often provided by schools for young women [5]. Therefore, I found it beneficial to develop a prototype of an add-on to an existing self-tracking application.

Even though I managed to find self-tracker apps focused on endometriosis, I still found that it might not cater to women with a preventative agenda of taking control of their own pain.

Both apps Phendo and Flutter have been designed for women with endometriosis. For everyday tracking the questions or tracking variables were more detailed, in Flutter tracking symptoms included many more types of pain to track. Similarly, Phendo asked the users to track variables like their food intake: *“What did you eat?”*, *“What activities*

were hard to do?” and “What did you do to self-manage?” were a few. In both apps they were also able to fill out complementing information about themselves like demographic and lifestyle information, if they are diagnosed, what hormone treatments they are currently undergoing, and what foods and exercises improve or worsen their symptoms.

Though the app is focused on women with endometriosis and their pain experience while taking into consideration that their diet and daily activities might be contributing factors, it lacks the preventative planning aspect. Phendo is a useful tool in research purposes and it *should* be a priority to understand group-level characteristics of the illness. However, filling out what foods and exercises improve or worsen symptoms are what many women are struggling to find out to begin with. In the magic machines workshop, a strong commonality between the two participants were that they both anxiously awaited their period. When the period pain did start, they agreed that there was nothing they could do but suffer through the pain until it was over. No medication, heat pad or anything similar would work. Women with endometriosis or any type of menstrual pain or associated problems need a platform with tools to try out different ways to solve their problems and regain control over their pain independently. Patients interviewed in the Phendo study mentioned that the lack of effective medical treatments lead them to experiment with self-management techniques like drinking less alcohol and exercising to see if it made a difference which it did for some of them. “*I can deal with the pain if I can just know what I’m doing and it does not actively contribute to it.*” [25]. This is reminding of the magic machines workshop discussion where Hannah had actually made attempts and succeeded to get some kind of control over her pain by taking Ibuprofen before the endo pain started, and Demi had made no attempts such as those. It shows that a platform for personalized experimenting might provide women with the guidelines they need to find what routines will work for them in the future.

In addition Epstein’s design implications answered to the current problems women face with menstrual trackers. Firstly, women expressed that menstrual trackers are not effective when they are not accurate. In the case of endometriosis, this would be an additional reason why planning long term routines might be helpful. Secondly, he found that women have different motivations for tracking getting pregnant, avoiding pregnancy, just keeping track of periods - where he proposed that users should perhaps be able to re-configure the interface to suit their goals. An add-on of experimental planning could therefore be beneficial addition to Clue.

LIMITATIONS TO ADD-ON

As with self-trackers of any kind, there are risks and limitations to the end goal of the tracker. In the current study, the aim of the suggested solution is to prevent pain or other

unwanted symptoms by experimenting with different habits. However, it is not guaranteed that the user will eventually find a working routine. Additionally, the routine they may have found might not necessarily work every cycle, which may leave women feeling helpless.

Another risk is that using a self-tracker to find out what the body does and does not respond well to might place the responsibility on the individual. This may cause them to blame themselves if they do not manage to treat their own pain. The problem of pain normalization and lack of knowledge regarding endometriosis is still prevalent, and should be a priority. The responsibility of understanding endometriosis and finding a cure should still be placed on medical research, and listening to and consulting women with endometriosis pain should primarily be in the interest of the medical practitioner. Therefore, the presented add-on should be seen as a complement rather than a replacement for advice from a doctor.

CONCLUSION

The current paper contributes to an understanding of design of menstrual self-trackers with the purpose of catering to women with endometriosis whose end goal is beyond tracking. The findings indicate that there are both long term and short term planning strategies for pain management, some of which women have already attempted to try when the health profession has failed to provide working treatment options. Since endometriosis symptoms vary among individuals it is necessary for women to experiment with different routines to make personalized scheduled designed for each individual. Design suggestions for an add-on was developed for the iPhone application *Clue*.

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