DEPARTMENT: PERVASIVE HEALTH

Designing Apps to Support People With Illness: Using Beneficial Engagement to Avoid an Illness-Centered Experience

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In this piece, Maria Ebling interviews former colleague Michael Rogan about the experiences that led him to enter the field of digital health. Michael is a neuroscientist, mental health clinician, and digital health specialist at Greenphire who focuses on supporting people dealing with serious illness. Maria is the former CTO of a company Michael co-founded, Medaptive Health. They discuss the challenges faced in designing apps to support people with illness, so that tech promotes health as well as care and research compliance without increasing the burden of illness. When life can be filled with reminders of being ill, no one wants to use an app that does nothing but provide more such reminders. Apps need to strike a balance between contributing to this *illness-centered* experience and supporting a more *life-centered* user experience. This balance is of particular importance in supporting participation in disease registries and clinical trials, which are essential for the development of new treatments and are sometimes the only way for people with serious illness to gain immediate access to new and potentially effective treatments. This balance is achieved through implementation of *beneficial* engagement, where the participant experiences a personal net benefit from engaging with the app.

How Did You Identify the Problem of Engagement for People with Serious Illness?

My neuroscience research focused on how adverse events and situations affect neural, cognitive, emotional, and behavioral function. These effects include the development of sensitivity and responsiveness to

danger in the environment, as well as sensitivity to features that confer safety and the more expansive responses that happen when one feels safe. In particular, my work has elucidated the observable fact that responses to danger and to safety are to some degree independent and coexistant. For example, one can have a serious illness that is onerous and likely to be fatal, but at the same time still have experiences of safety within relationships and settings that allow for more expansive feelings of pleasure and satisfaction.

This observation led me to my clinical work with people with serious illness, investigating ways of enhancing people's ability to cope with and ameliorate the danger and adversity of their illness while at the same time fostering the ability to find safety and ease in their life. Having had prior experience as a software developer before beginning my neuroscience studies, I naturally looked for ways to use tech to scale solutions to these issues, and this led me to cofound a digital health company and develop the Medaptive Interactive Study platform (now a part of Greenphire).

People talk about "engagement" in tech and also in health care. What kind of engagement are we talking about with people who have an illness?

The clinical literature talks about *patient engagement* and *patient activation* as general issues that describe how people are involved in their own care, and how they are motivated to act in ways that improve their health and care management. In discussing tech, I am going to refer to users as *participants* rather than patients.

From a behavioral health perspective, there are two aspects to consider. First, we must support people in carrying out the illness-related mental processing and behavioral tasks needed for their care and for their participation in a clinical trial (e.g., tracking and reporting both symptoms and adverse events as well

as managing meds, appointments, and care providers), as well as the emotional burden these present. However, supporting them in illness will not be successful without also supporting people in *not* being illness-centered. This second part allows people to have perspective and agency about how their life is bigger than their illness: that is, a more *life-centered* experience. Finding a balance between these somewhat contradictory goals is essential for maximizing health, good function, quality of life, and good participation in care and research.

The ever-increasing access to the internet and smartphones makes apps obvious candidates for helping with this kind of *beneficial* engagement. Apps are only helpful if they are used, and so part of the challenge is to get participants to engage with the app in a way that supports the important illness-centered tasks without sacrificing life-centered goals. And to be clear, by life-centered I also mean life outside of the apps.

How does this compare to engagement on social media platforms, like Facebook and Twitter?

It is quite different. Social media apps aim to keep your attention as long as possible and have you return as frequently as possible. As we all know, their business model involves driving ad revenue from their sites and selling information about users. The consequences of their success in driving this kind of unbridled engagement have been studied for its unhealthy effects. If sites that aim to support participants with serious illness behaved like social media apps, it would likely lead to an increasingly illness-centered experience, which would negatively affect their mental health and probably lead to abandoning the app altogether—perhaps even contributing to dropout from a trial.

For an app that supports participants in a clinical trial, the research goal is to have people be comfortable returning to the app just often enough and long enough to meet the goals of the trial. The app experience must be both efficient and trustworthy—so they can quickly offload aversive information about their illness as it happens, with confidence that it will be attended to and be impactful. In this way, the app reduces the burden of illness by freeing participants from having to carry this aversive information in mind until conventional appointments with research staff or care providers.

No matter how efficient an app may be, illness-only engagement will tend to be aversive in the long run. Additional outreach and engagement that is more life-centered, beyond what is strictly needed for trial compliance, is actually very useful to maintain beneficial

engagement and compliance. This beneficial engagement can be achieved by shaping additional outreach that gives value to the participants by sharing useful information about how to live better with their condition, lauding their truly altruistic role as "citizen scientists" through their participation, and helping them be connected with others who support them—thereby supporting quality of life and wellness. In this way, participants associate the app with wellness, agency, and efficacy rather than only with the bad news of the illness. Clearly, there is a fine balance that must be reached. And it may be noted that this more *balanced, moderate, and sufficient* engagement strategy puts an unusually high importance on a clean, unambiguous user experience. When building our apps we always stay on the lookout for "speed-bumps"—things that may cause the participant to hesitate or stop in a task. Once a participant who is experiencing the stress of illness leaves the app out of frustration or annoyance, they may never return.

What other ways can you shape the user experience to achieve this kind of beneficial engagement?

For people with serious illness, which is itself usually isolating, it is important to convey that they are not *alone* with a piece of tech. Apps can convey this by sharing with the participant deidentified information about the population using the app, such as the demographics of the participant population, or their stage at diagnosis, or the age distribution. These data show them where they fit in with their peers—others who are on this journey with them.

Participants may also have difficulty with the normal activities of daily living, including their ability to use an app. This difficulty can happen through the course of illness, but also can just be about good days and bad days. Apps can support these participants by allowing them to give someone—a caregiver, friend, or family member—permission to access the app, review the information provided to the participant, and even report information into the app when the participant's condition makes doing so themselves difficult or impossible.

Apps can also help by allowing participants to share information with their support network. Their support network includes their healthcare providers, caregivers, family, and friends—all of whom can use this information to help the participant with decisions about their care and their life.

How do you make it safe for people to provide such personal information?

First and foremost, the participants using these apps have to trust the technology. They may be asked

to share information as part of a clinical trial that they do not share with anyone else in their life. They have to trust the sponsor and the provider of the technology that runs the app.

The way to begin building trust starts with the consent process, the first step in participating in any app that involves personal health information. In our experience, the layered consent approach is the best. Layered consent starts with a summary that is concise and easy to understand and always has a link to more detailed information. The consent process needs to satisfy the participant that they understand the goals and expectations of the study.

Another way that technology can engender trust is to be clear about the relationships and motivations of all involved. Participants need to understand who owns their data and whether their data will be sold to third parties, and if so, under what conditions. The consent process should document this information, and privacy policies and websites can also state this information.

Participants also feel safer and less alone when they know they are seen. Apps can support them by ensuring that the outreach they receive fit their identity and their current condition. Irrelevant information and questions should not be pushed to them. It wastes their time and their attention, and breaks trust.

People also appreciate having help with communicating difficult information clearly. Disease-specific, ontology-based features for self-report of symptoms generate confidence in reporting and also give assurance that the researchers know all about these problems, and want to hear about them.

Do you have any guidance for people working in the health space as they think about participant engagement for their systems?

Engendering beneficial participant engagement is essential because it improves the participant's experience, reduces study/care dropout, and improves data quality. It also requires significant effort on the part of the app designers and content-creators.

Content needs to be fresh and appealing, with a range of both illness-related and health- and wellness-related material. The software driving the app has to be built so it is as easy as possible for the research staff, who likely do not have a background in tech, to compose, schedule, and deliver content. For research, the content creation and delivery workflow also has to have safeguards to ensure that IRB requirements are met.

Methods for gathering patient-reported outcomes through the app need to be efficient, unambiguous, and generate no misfires (questions that do not apply to the participant). The research staff need to keep their questions short and ensure that the possible answers are clear. One approach that can help with this is the use of *ecological momentary assessments* (EMA) for electronic patient-reported outcomes. An EMA is a brief question that appears on the smartphone and can be easily answered so it is answered immediately. EMAs can gather some kinds of information with less burden and greater fidelity.

The technology needs to keep current with the standard findings of behavioral science in shaping outreach. One such example is the use of variable schedules when possible—having content or questions arrive on fixed schedules (say 9 a.m. every day) tends to dull user response. Variable schedules tend to be more successful in keeping people engaged.

The ability to send notifications or alerts about certain important new content is very valuable but must be used carefully. Every notification received can bring the illness to mind. Apps aiming to support people with illness need to consider the added burden of each notification, and the density of the illness-related experience they provide.

Can you give me some examples of apps that use features that support beneficial engagement?

There are some apps out there that have some of these features:

CaringBridge[1] does a good job of reducing the burden of communication. Rather than having to field many inquiries about "How are you doing and how can I help," participants can write a single update and share it with all their family and friends at once. CaringBridge is a nonprofit and makes their business model clear on their website.

The FDA MyStudies App,[2] like the underlying ResearchKit and ResearchStack technologies that it builds upon, supports layered consent and the ability to push information and collect survey data with branching logic that customizes followup to the participant's responses. Interestingly, MyStudies includes an Informed Consent Comprehension Test that participants take to confirm to themselves and the researchers that the consent was properly understood.

The Medaptive Interactive Study platform (now part of Greenphire), also built upon ResearchKit and ResearchStack, supports layered consent and logic-

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[1]https://www.caringbridge.org
[2]https://www.fda.gov/drugs/science-and-research-drugs/fdas-mystudies-application-app-technical-background

driven surveys. It also supports the ability to share multimedia insights with participants, including simple charts summarizing participant responses to a particular survey question, links to external resources, maps, and the like. Participants can enlist caregivers to help with the app, and readily share the information they have entered or have received on the app with care providers and others. It also provides an interface that allows nontechnical research staff to drive a study, with comprehensive content authoring and scheduling options. This functionality has led to a direct registry-to-clinical study path on the same platform, which is easier on participants.

Finally, the NIH is recruiting participants to share their electronic health records and more, to be part of a very broad registry and database, called All Of Us,[3] that will be accessible to researchers for studies. This site is notable for building trust with a very clear, multimedia layered consent process, with embedded phone numbers and email contacts available to answer any questions. The participant is assured that the sponsor will do everything possible to make the consent process clear and valid.

CONCLUDING REMARKS

People with serious illnesses are already burdened by the details of illness in their daily life. This includes the unfortunate circumstance of having the details of illness often dominate their interactions with friends and loved-ones. It is hard to not dwell on these details when everyone is concerned and wants to know "How they are doing."

Having an app intrude in this same way is exactly what developers need to avoid. Instead, tech can uniquely provide excellent ways to help people offload information about symptoms, adverse events, and the accomplishment of self-care tasks onto a smartphone app, as they occur. Offloading this aversive, illness-centered information means participants need not harbor it in mind until a more conventional verbal report during a care visit.

Apps can become welcome tools for people whose lives contain so much that is out of their control, and provide some real agency. Our goal should be tech that gives people access to good information, and helps them take actions that improve their well being. One example is the ability to use app-supported symptom reporting to provide clear and actionable information to care providers. Another is to support people's ability to contribute to science in a way that helps others suffering from the disease, now and in the future, by sharing their experiences. People with serious illness are often quite motivated to do this, and feel great satisfaction with this altruistic activity. The most important goal is to ensure that the app helps people maintain a life-centered focus and not elicit an unhealthy level of participant engagement that moves too far toward an illness-centered focus. Apps need to be flexible so that this balance can be tuned.

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[3]https://allofus.nih.gov/