Beyond sensors: reading patients through caregivers and context

Abstract
Mobile technology for remotely sensing key health indicators about patients receiving long-term or outpatient care continues to become more affordable and more easily embedded, but there remain certain patient variables, especially mental health and adaptive functioning characteristics, that are difficult to automatically detect or problematic to self-report. To address this problem, we are working on technology that integrates input from caregivers (as well as patients) with enhanced context reporting. We describe how leveraging both methods in an application designed for use by PTSD/mTBI patients and their caregivers can potentially lead to more informed clinical care teams, better family engagement of the care process, and potentially better treatment outcomes.

Author Keywords
mental health; sensors; caregivers; personalization; contextual enrichment; PTSD; TBI; information extraction

ACM Classification Keywords

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Introduction

Much attention has been given to self-quantification due to advances in mobile and sensor technology [4]. For example, it is now relatively easy to automate the continuous gathering of factual information about one’s location, fitness behavior, social network updates, and so forth. Furthermore, signal processing and machine learning techniques have enabled technologists to build upon this core set of data to help interpret patterns within, for example to detect activities such as driving or running. While this has certain privacy implications for the public at large, it also provides a unique opportunity to significantly improve certain types of medical care for consenting patients. Medical practitioners can potentially apply remote sensing technologies to longer term, outpatient care beyond weekly/monthly meetings, and understand a patient on a timely and more regular basis.

Despite these emerging capabilities, there are still important metrics that cannot be easily remotely sensed or gathered by devices, yet would be very helpful for clinicians. For example, it is inherently difficult to measure feelings, such as stress, depression, or happiness. It is also hard to assess more subjective measures of behavior, such as displays of anger or level of personal care (showering, shaving, etc.). And there are also measures that involve relationships, such as measuring amount of interaction with family, which are not only difficult to quantify but require input from multiple parties. Other types of medical related measures that can be used as a proxy – for example, glucose monitoring as a proxy for eating habits – can require devices that either make tracking cumbersome for the patient or are themselves not entirely reliable as proxies. While there is innovative research actively looking at how to sense some of these for individuals through novel means, such as mood from voice [2], they can be constrained and may require training to reach acceptable reliability. Patient self-reporting is another option, but this can have limited validity due to under or over reporting, or social desirability bias.

Nevertheless, these measures can be very important in terms of patient monitoring for mental health disorders, such as PTSD and mTBI, and other health issues where understanding the patient’s state of mind is important. For example, PTSD clinicians who treat patients through 10-16 week outpatient treatment program would like to understand patient stress, sleeping behavior, personal care, level of work stress, relationship stress, and other measures throughout that time. Outside of interacting with the patient directly during a weekly care meeting, it is difficult to capture such information. And often the care meeting is far from sufficient because such meetings are short, only involve the patient, and occur well after certain important feelings or behaviors have emerged.

Meanwhile, many of these same patients have family or caregivers that play key roles in their ongoing lives. Caregivers may help the patient cope with various issues, support the patient financially, provide social interaction, and so forth. These caregivers are in a unique position to help understand many of the more difficult measures to automatically sense or self-report. Moreover, it can often be helpful for clinicians to understand the caregiver’s status, since caregiver feelings and behavior can have dramatic effects on patients during treatment and in the future. [3]
We are a multi-disciplinary team actively exploring methods for better quantification and reporting of mental health related measures, such as those described earlier. In doing so, we have designed a system for including caregivers as well as patients in a personalized, family-centered mobile medical care application for patients with PTSD/mTBI. In addition, we are looking at how to further augment some of basic sensor data we expect to be available from patients/families using our application, so that we can more fully understand the context surrounding the information we receive. The overall goal is to empower clinicians with a higher resolution of relevant patient data, while improving the engagement in care by not only the patient and clinician, but by the family. In this paper, we discuss technical approaches to those goals.

**Mobile app for family-centered patient care**

The application, called SupportTeam, aimed at families of patients suffering from PTSD/mTBI, to be used during extended and/or outpatient treatment. The application collects data from all users on a regular basis, and then summarizes input and provides analytics for clinical care staff in a provider portal.

SupportTeam collects data directly from the user, as well as indirectly (e.g., time of day input was provided). Certain data is collected about the person (patient or caregiver); some is just about the patient (second hand via caregiver). Data is collected at various times during the week, sometimes multiple times per day. Data collection is brief and personalized, as discussed below.

The typical “Notification-driven workflow” prompts the user for input via typical smart phone notification systems. If the user acknowledges the notification, he/she is asked a brief series of questions. Patients are asked only about their own feelings or behavior. Caregivers may be asked about both the patient as well as themselves. Each question consists of binary or multiple-choice input, about a range of personally relevant topics, such as: how much stress they feel right now (e.g., SUDS measure), whether they slept well last night, if they ate breakfast that morning and – if so – whether they ate alone. Some of the questions about behavior are meant to be proxies for more complex outcomes, in the same way that GPS measurements about individual mobility can be a proxy for level of social engagement. In addition to Notification-driven mode, SupportTeam also has a “Self-directed workflow” in which users initiate using the app and can browse useful information/resources related to PTSD/mTBI, as well as enter additional information and answer questions.

SupportTeam differs from current approaches aimed at similar audiences in a few important ways. First and foremost, the app is meant for use by caregivers as well as the patient. In general, the importance of caregivers and awareness of their status is generally underestimated in mental health care [3] and their inclusion is not usually supported in the typical clinical care model. Yet caregivers can be an important data source about both the patient, but also about themselves (which in turn, relates to the patient). Furthermore, caregivers are often well motivated to provide regular input, as part of their care/support for the patient, and because they often have limited clinical opportunity to express their feelings or concerns. Thus, we include them in our application as a way of understanding the patient and his environment better. When asking questions of caregivers about patients, we
focus on asking non-judgmental observation questions, to avoid causing awkwardness and stress between family members. For example, we ask caregivers “did you eat breakfast with [the patient]” or “did you spend any time with [the patient] on Sunday”, as opposed to “did [the patient] look depressed yesterday?”

Second, to keep users engaged and focus clinical care, the application is personalized per user, based on user profile and usage behavior. This occurs in multiple ways. One is in terms of the questions that are asked of patients and caregivers. SupportTeam starts by leveraging existing background information (diagnosis, family structure, known issues – such as substance abuse, etc.), as well as information on treatment goals (which it gets from all participants, and potentially clinicians). Based on this information, an initial question bank is identified. However, over time, users may not respond to (or skip) certain questions or they may respond more quickly or provide more interesting data to other questions. Based on this use, the question set continues to be refined until it becomes a set that is not only relevant for the participant, but is reliable in terms of gathering feedback. Refinement of the question bank is accomplished by associating features with each question, and then using features associated with background information and goals, along with usage statistics, to determine the most relevant questions. Furthermore, not all questions are asked with the same regularity; some are more/less frequent than others. Progression towards customized question banks is shown in the figures to the left.

A second type of personalization involves content shown to the user in Self-Directed mode. In this mode, they are exploring information provided by the app about PTSD, treatment options, strategies for coping, and so forth. Once again, relying on background information and user behavior (questions preferred and past information browsed), we show users more relevant information. For example, if a participant shows interest in videos of personal stories or in tools for coping (such as relaxation techniques), the application will show more of those (or ones related to them). To do this, we plan to leverage a combination of classification and recommender techniques, such as collaborative filtering, to model user interest.

**Contextual enrichment**

A third key aspect to SupportTeam involves higher contextual resolution. Every time data is collected, it is also infused with basic context data that is then expanded through an enrichment process. As a result, several additional variables are exposed, so that the SupportTeam Analyzer (a server side process) has a wider view from which to detect significant correlations and compute similar analytical measures. This is then made available to clinicians through the provider portal.

Contextual enrichment is the categorization or translation of base contextual data into various semantically meaningful terms. For example, when a user responds at a particular time of day (which is a base contextual variable) that precise value can then be labeled as morning/afternoon/evening, holiday/non-holiday, weekday/weekend, etc. GPS location data, in its most basic form, is about precise geographical locations; but these can also be viewed in terms of what city or state the user was in, what county, what type of area (rural vs. urban, etc.), and similar such derivations. From this type of feature expansion, we can potentially discover more sophisticated knowledge...
(such as that the user feels more stress on weekends or while at work, or that families are spending more or less time together). For example, SupportTeam data can be expanded so that providers can identify correlations such as the work/stress correlation suggested by the figure below.

Certain types of enrichment, such as knowing that 8:45pm classifies as "evening", can be encoded as simple local rules. Other types, such as knowing the weather on a particular day, require secondary sources (e.g., web sites) to help classify or translate the base contextual value. To facilitate source integration, we combine browser automation tools with traditional information extraction techniques.

**Next steps**

Our next step is to conduct an experimental trial to measure the impact of SupportTeam. The trial will be offered in the context of CBT-based treatment for veterans with PTSD. The primary aim of our study is to understand whether providers understand patients better through our methods. If so, we anticipate that care can be more tailored to the person as well as to their primary system of support—the family, making it both more engaging and effective. Our study will also look at treatment adherence, perception of care, and whether there might be any overall treatment effect.

While SupportTeam focuses on caregiver input and enhanced context, we plan to support the integration of existing sensors, devices, and applications (e.g., fitness tracking apps). Our hope is that methods like those in SupportTeam can complement the significant capabilities of mobile and sensor technology today, by providing access to certain types of measures that remain challenging to read.

This work was funded, in part, by the U.S. Army Medical Research SBIR program, under award W81XWH-13-C-0158.

**References**


