

Understanding Personal Informatics Needs of Unique User Groups

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ABSTRACT

Many philosophers from all corners of the globe have attempted to understand the self, and its relation to the external world. In recent years, this desire for self-knowledge has manifested itself through the use of personal informatics systems, which allow individuals to collect and reflect on data related to their personal lives. The problem is that the designers of these tools need to know the requirements and the context of use before being able to design well. While there have been efforts made in past research to identify common problems that users experience when using personal informatics systems, that research has been focused on large general populations; little heed has so far been paid to the likelihood that different users may use tools differently, such as users whose use of a personal informatics tool is related to a critical health condition. Individuals who have more serious reasons for using personal informatics tools have very different needs than those examined in prior work. The model developed in this work describes the different phases of personal informatics that individuals tracking data related to a critical health condition go through. These three phases are *Situational Understanding*, *Personal Understanding* and *Maintenance*. Design implications are provided based on these phases.

1. INTRODUCTION

Many philosophers from all corners of the globe have attempted to understand the self, and its relation to the external world. The classic Chinese text Tao te Ching claims "Knowing others is wisdom. Knowing the self is enlightenment. Mastering others requires force. Mastering the self requires strength." [10] In recent years, this desire for self-knowledge has manifested itself through the use of personal informatics systems, which allow individuals to collect and reflect on data related to their personal lives. These systems allow people to better understand their behaviour. Once their behaviour is better understood, these systems can help users to change their behaviour, by encouraging them to set and work towards goals.

The problem is that the designers of these tools need to know the requirements and the context of use before being able to design well. While there have been efforts made in past research to identify common problems that users experience when using personal informatics systems, that research has been focused on large general populations; little heed has so far been paid to the likelihood that different users may use tools differently; they may collect different types of data, for different purposes, and have different motivations for doing so. Just as people use spread sheets in many different ways for many different purposes, one might expect personal informatics to be used for many different needs.

There has been little effort towards understanding other groups of personal informatics system users, such as users whose use of a personal informatics tool is related to a critical health condition. Individuals who have more serious reasons for using personal informatics tools have very different needs than those examined in prior work. Some of the stages and phases in existing models are not a good fit for these individuals, and an updated, more accurate model is needed so that designers can accurately design for these individuals and their requirements.

This approach to understanding their requirements involved developing and conducting interviews with people who have more serious needs for personal informatics tools. The results of these interviews have been analyzed using thematic analysis and open coding, and a model has been developed. This model describes the different phases of personal informatics that individuals tracking data related to a critical health condition go through. These three phases are *Situational Understanding*, *Personal Understanding* and *Maintenance*, and will be discussed in greater detail in this paper.

This research provides three main contributions: 1) to identify different types of users based on type of data collection, motivation for collection of data, and problems encountered, 2) to introduce a model for these users that will allow the designers of these systems to better assess the needs of their target population when making decisions regarding a system's functionality, and 3) to provide a conceptual framework for creating new personal informatics tools that are more focused on meeting the needs of these users, and eliminate many of the problems these users experience.

2. RELATED WORK

There are two main areas that influence the work of this research. First, it is important to be familiar with personal informatics tools. While there are a large number of these tools on the market, and many of these tools are quite diverse, it is important to have an overview of what is available. Second, there have been a few works that have developed models of personal informatics tool use.

2.1 Personal Informatics Tools

Personal informatics tools can take a variety of forms – everything from portable tools designed specifically for this purpose to apps that run on an existing mobile phone to Internet websites. These instruments can also take the form of physical, non-digital entities such as a notebook or a form to be completed.

As an exemplar in this space, Fitbit [12] is a company that makes a line of products designed to help individuals get in shape and lose weight. The Fitbit Ultra is a small physical device that can be clipped onto one's belt or pants and measures physical activity

(steps taken, stairs climbed, distance travelled, calories burned). They also offer the Fitbit Aria WiFi Smart Scale – a scale that tracks weight, body mass index (BMI), and percentage of body fat. The data collected by both these devices can be examined using their online and mobile tools, which provide interesting visualizations of the data. A similar tool, myfitnesspal [13], provides much of the same functionality as the Fitbit online tools, but goes a step further by allowing users to track their calorie intake on top of their fitness activity.

In addition to weight loss and fitness tools like the Fitbit product line, there are personal informatics tools for numerous other aspects of life. Mint [14] for instance is a personal financial management website that pulls data from all of an individual's bank accounts, credit cards, investments, loans, and mortgages. This information is visualized online or on a mobile device so that users can track their spending and saving habits, set budgets, and reach their savings goals. There are also tools managing and tracking mood [15], fertility [16], alcohol consumption [17], sleep cycle [18], time management [19], as well as many other types of data. Additionally, many tools allow their users to track a variety of different types of data to provide them with a more comprehensive picture, such as Chart Myself [20], GraphoMatic [21], Daytum [22] or your.flowingdata [23].

2.2 Quantified Self Movement and Models of Use

Personal informatics tools are often quite popular amongst individuals who self-experiment. Individuals who frequently self-experiment express an appreciation of the freedom that comes from the studying of oneself without concern for grants or publishable results or even deadlines [8], and the tools provided by personal informatics systems facilitate this experimentation. They have also come to recognize the value and power of introducing quantification – a longstanding practice in the fields of science and commerce – into their personal lives [11]. This movement has been made manifest in the relatively recent transition from a language-centric description of aspects of human behaviour to the construction of a quantified self, which uses numeric data to describe the human condition.

There has been considerable effort by researchers to break down personal informatics systems into smaller pieces in an effort to increase the usability of systems at each stage. Li, Dey, and Forlizzi [4] outlined a model for these systems based on five stages – *preparation*, *collection*, *integration*, *reflection*, and *action* – with the goal of improving the diagnosis, assessment and mitigation of problems associated with using personal informatics tools. The *preparation* stage encompasses the users' initial decisions about the information they will collect (i.e. what kind of data they are collecting, how they will collect it, and why they are collecting it). As the name implies, users in the *collection* stage are actually collecting the data. In the *integration* stage, the system transforms and prepares the data for users to observe. This is followed by the *reflection* stage, in which users reflect on the results of their data collection. In the final stage, the *action* stage, users choose a course of action based on the knowledge they've gained.

Li et. al. further develop an understanding of reflection by focusing on the types of questions users are asking about their data. These questions can be grouped into two phases of reflection [5]: discovery and maintenance. In the discovery phase, users are still figuring out what their actual goals are and therefore

collect different types of data with the goal of establishing or discovering correlations between them. In the maintenance phase, users reflect on their data to maintain awareness and monitor behaviour, specifically comparing their current state with their goal state.

Li et. al also introduced the concept of cascading barriers through their stage based model; problems in an earlier stage of use impact later stages. Because of this, they have suggested that the best approach to designing these tools is a holistic approach. "Focusing on only one stage ignores the whole experience of the user with the system. While we can take inspiration from different fields to resolve barriers within each stage... creating an effective personal informatics system requires the consideration of all of the system's parts." [4]

Many of these authors decided that the best way to find experienced tool users to participate in their study was by targeting readers and users of personal informatics blogs and forums, i.e. self-experimenters and quantified self individuals. By doing so, they limited their study to users who had enough of an interest in personal informatics and their tools to write about them and share them on the Internet. It follows, then, that users who were new to using the tools, or less enthusiastic about their collections may have been excluded. These personal informatics blogs tend to be written by the self-experimenters and "data nerds" [4] and using them as a recruitment tool precludes the presence of inexperienced and less enthusiastic users in their studies.

Many of these works have successfully identified problems with personal informatics tools, and made design recommendations based on those problems. Those problems, however, were identified by interviewing widely divergent groups of users who had little in common aside from their experience in using these tools. There is reason to consider whether or not all of the identified problems apply to all of the users interviewed. The research outlined in this paper addresses this shortcoming.

3. METHOD

To better understand the usage of personal informatics tools by different types of individuals, interviews were conducted with eight people who collect and reflect on their personal information.

3.1 Recruitment

Participants were recruited using snowball sampling. Eight participants were selected in total, with a primary focus on those with critical health conditions. Three participants were selected who did not have a critical health condition, so that comparisons could be made between the two groups. Table 1 details the individuals who participated in the interview study.

Of the eight participants, two were male and the remaining six were female. Ages of the participants ranged from 19-55, with a mean age of 29 and a median age of 22. Participants had been collecting data for anywhere from two months to 20 years; three participants had been collecting data for less than one year. Only one participant mentioned collecting data relating to more than one aspect of her life; P5 collected seizure and medication data for her epilepsy condition, and tracked food and dietary information for weight loss purposes. Two participants (P4, P5a) used forms provided to them by their doctor as part of a drug study program as their collection tool. Participants P6 and P8 both used more than one collection tool to obtain the data they needed.

Table 1. Table of Participant Information

ID	Health Condition	Data Collected	Duration	Tool
P1	N/A	Amount of money spent on groceries	2 months	Notebook
P2	N/A	Gas mileage, money spent on gas	4 years	Notebook
P3	Low blood pressure	Food and beverages consumed, meal times, hours of sleep, episodes	2 years	Notebook
P4	Migraines	Medication amount/type, episode frequency, effectiveness of medication, pain level	7 years	Form provided by Doctor
P5a	Epilepsy	Episode frequency, effectiveness of medication, episode pain level.	4 months	Form provided by Doctor,
P5b	N/A	Food, beverages consumed, exercise.	2 years	Weight Watchers App for iPhone
P6	N/A	Exercise data (elevation, heart rate, distance, grade, cadence, weight)	2 years	GPS, computer software, weight scale, sports video camera
P7	Fibromyalgia	Episode frequency, pain level, medication type and amount	2 months	Notebook
P8	Diabetes	Blood sugars, carbohydrates consumed, meal bolus, basal insulin, corrective insulin taken	20 years	Insulin meter, test strips, lancing device, Insulin pump, Software Kit, Forms provided by Doctor

3.2 Procedure

Each recruited participant partook in a 30 minute to one-hour interview, either in person or over instant messaging. For interviews conducted in person, participants were asked to bring the tools they used for data collection and/or reflection. Remote participants emailed in pictures of their tools and devices. Each participant was asked a series of questions on three topics. A complete list of questions can be found in Appendix A.

Topic 1: Reasons for Collecting Data. The main goal of this topic was to gain an understanding of the motivation behind each individual's data collection. They were asked questions about the type of data they collected, why they started collecting this data, and what kind of impact this data collection had on their life.

Topic 2: Use of the Collection Tool. The main goal of this topic was to understand each individual's collection tool. The questions were asking about how they use the tools, how often they use them, and how successful the tools are at meeting their needs. The study participants also partook in a think-aloud exercise, in which participants were asked to demonstrate the use of the tools and speak about what they were doing and observations they were making.

Topic 3: Use of the Data. The main goal of this topic was to understand what individuals do with the data once it has been collected. They were asked questions about how they review the data, what triggers them to do this, and what they are looking for when they do review it.

3.3 Analysis Methods

These interviews were recorded, transcribed, and finally analyzed using thematic analysis, affinity diagrams, and open coding [9]. A coding scheme was not determined in advance so that themes from the data could be identified in as much of an unbiased manner as possible as the responses were processed. The coded ideas identified from the interview results were recorded onto post-it notes, and sorted and grouped based on related ideas. This analysis led to the identification of a model of personal

informatics relating to the collection of personal data by individuals living with health conditions.

4. RESULTS

Participants in the study can be divided into two categories. The first category is individuals who collected data that was directly related to a health condition that had been diagnosed by a medical professional. These health concerns were low blood pressure, migraines, epilepsy, fibromyalgia, and diabetes. The second category encompasses all the other participants. Some of their data collection was still health and wellness related, but it was not related to a specific condition. It was related to general health and wellness, such as exercise and fitness, or weight loss. This category also includes individuals collecting financial data and data about vehicles. Representative individuals will be introduced below, and a summary of the findings for each group will be discussed.

Several of the participants were tracking "episodes" related to their health conditions – this term meant something different to each of them. For P3 (Low blood pressure), an episode occurs when she feels dizzy or faints. For P4 (Migraine), an episode is a migraine, and for P5a (Epilepsy) it is a seizure. For P7 (Fibromyalgia), an episode is the twitching and jerking of her arms and legs.

While some participants used their episodes as a reminder to make an entry in their tool, other participants kept to a regular schedule for their data collection. Some participants would enter data at a specific time each day (e.g. P4 (Migraines) enters data every evening before bed) or based on events and activities during the day (e.g. P8 (Diabetes) enters data after every meal, before sleeping and before driving a vehicle.)

4.1 Participants with Health Conditions

Participants with health conditions varied drastically in their understanding of their conditions; participants who were newly diagnosed were very unsure of their data collection, and often

forgot to record information. Participants who have been living with their diagnosis for a longer period of time had more information about their disease than those who were more recently diagnosed.

P7 is a 20-year-old female who has been suffering from fibromyalgia for approximately five years, but was only diagnosed two months before her interview. Her doctor requested she collect data about her pain level, episodes, and medication so they could discuss this data and evaluate whether the medication is working. She explains that fibromyalgia is not a well-understood disease in the medical profession and as such she does not know very much about it.

P4 is a 55-year-old woman who has been experiencing excruciating migraines, some of which have been so painful she has been hospitalized. She was referred to a migraine clinic approximately seven years ago, and as part of this program she keeps a diary of the medications she takes, what kind, how often, and how effective those are, as well as how many migraines she has per day, and the severity of those. She has seen a great improvement in her migraines recently, and now has reduced her neurology visits from two or three times a year to once a year.

P8 is a 34-year-old woman who has had diabetes since she was fourteen years old. She initially began monitoring her insulin by writing down the results of her insulin tests, but transitioned to using a software system that came with a glucose pump that she started using eight years ago.

Individuals who were collecting data because of a diagnosed health concern expressed a desire to manage their diseases, but not necessarily cure them. P7 (Fibromyalgia) said “One of the things my doctor told me was that you just have to manage it.” She is not optimistic that her condition will go away, but is hopeful that she will be able to avoid pain and episodes using medication and eliminating triggers.

For many of the participants the data collection began initially either to assist their doctors in making a diagnosis, or because their doctors required the data to be collected as part of a process of evaluating the success of the treatment. Participants P4 (Migraine) and P5a (Epilepsy) were tracking their data using forms provided to them as part of a drug study or trial medical program. These forms appear to be designed to observe the impact of certain medications and doses on the number and severity of episodes. These forms provide information about the success of the medication at eliminating the symptoms, not necessarily the disease.

4.2 Other Participants

Participants who were collecting data unrelated to any health condition were much more willing to experiment with their data, and saw data collection as more of a journey than a goal. P6 (exercise) has been continually adding new types of data to his collection procedure, and often experiments with the inputs; he will observe a graph of his data from the previous day and then intentionally make changes to his behavior during his next bike ride to see how it impacts his graphs.

P1 is a 19-year-old female who is a student in a university dance program, and is interested in understanding how the amount of money she spends on groceries changes depending on the number of hours she spends doing physical activity during a week. She measures this by keeping a journal of the totals on her grocery bills, and comparing this against recent events involving physical activity.

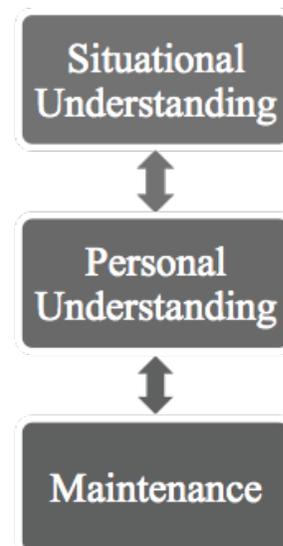
P2 is a 22-year-old male who is a car enthusiast, and keeps a journal in his vehicle where he makes note of the date he filled up his tank, the number of liters he put into the tank, the total cost, and the kilometers he has traveled since the last time he filled up his tank. From this data, he can calculate the gas mileage of his two vehicles. In his interview, he said “I’ll drive a full tank of gas on four wheel drive and I’ll drive a full tank on two wheel drive and I’ll try to compare. The Miata being a standard transmission, I once went a tank of gas with driving around mostly with the clutch in, so I was just idling most of the time, seeing if I could get more kilometers off a tank of gas by just not driving as hard.”

These participants all seemed to have a higher prerequisite level of understanding than those with health conditions. P1 (grocery bills), P2 (gas mileage), P5b (weight loss) and P6 (exercise) all understood, at least generally, the context in which their data collection was occurring. P1 knew that the more exercise an individual did, the more food he /she would consume. Similarly, P2 understood that certain driving habits, road conditions, and vehicle types would have an impact on fuel consumption.

5. Model of Uncertainty Reduction

The findings of this research have led to the development of a model to encapsulate the motivations and behaviors of the participants with respect to personal informatics tool use. The model of uncertainty reduction contains three phases: *Situational Understanding*, *Personal Understanding*, and *Maintenance*. The individual’s placement in a phase is largely determined by the amount of uncertainty he/she has. In this case, uncertainty refers to the lack of understanding by the participant surrounding contextual information (about the condition and its potential causes, symptoms, triggers, and treatments), how the condition impacts them as individuals (which causes, symptoms, triggers, and treatments apply to them personally, and how best to manage those), their data-collection methods (choices of tools, frequency of collection, whether to collect automatically or manually, how to remember to enter data), and their reflection techniques (how often they reflect on the data, what they look for, which pieces of data are important, whether they are interested in trends or outliers, how to best visualize the data for reflection).

Figure 1. Model of Uncertainty Reduction



5.1 Situational Understanding

In this phase, individuals are primarily interested in learning about the situation they are in. There is a high degree of uncertainty in this phase, surrounding their health condition. Individuals in this phase are often inexperienced at using their tools and are beginning to establish a structure for their data collection. P5a (Epilepsy) and P7 (Fibromyalgia) had both been recently diagnosed with conditions they were unfamiliar with. When asked if there was anything she would like to be able to understand about her data that she couldn't, P7 expressed a desire to know more "about the disease. And about the cause." Furthermore, P7 explains that she often forgets to collect the data. She says, "I'll realize my pain level is pretty low. I should be writing that down. Or if it's pretty high and I start to have an episode, then I will write it down. It's pretty much just based on how I feel in the day." Her system is much less reliable than participants who have been collecting data for a longer period of time.

5.2 Personal Understanding

In this phase, there is less uncertainty than in the previous phase. These individuals have gained an understanding of the context of their condition, and are interested in learning more about their place within the condition, and how it impacts them personally. P3 (Low blood pressure) said, "Pistachios are so good, but if I eat more than 10, I feel dizzy and sometimes faint. One of my friends can't eat eggs and cheese together for some weird reason, but when she eats them separately it's fine. It's handy to track that sort of thing because I'm not always able to remember, "Oh, I had 10 pistachios and an apple before." She expresses an understanding of the potential causes of her episodes, and has become more aware of what she needs to be tracking in order to better understand her own situation and how to prevent fainting episodes and dizziness for her personally.

5.3 Maintenance

In this phase, individuals are concerned with maintaining their current behavior; they now are satisfied with the extent to which they understand their condition and their place within it and are able to successfully manage their disease. P8 (Diabetes) said, "Because I've done it for so long and I know what I'm looking for in trends, I know the range I want to be in, I know how to adjust appropriately – it's just the time it takes to do it."

For all the participants with health conditions, the maintenance phase appeared to be the end goal. Once they were able to manage their conditions, they discontinued their active search for more information about their diseases, other possible triggers, different medications, etc. Even though individuals in this phase are no longer changing their behavior, they continue to collect data for two reasons.

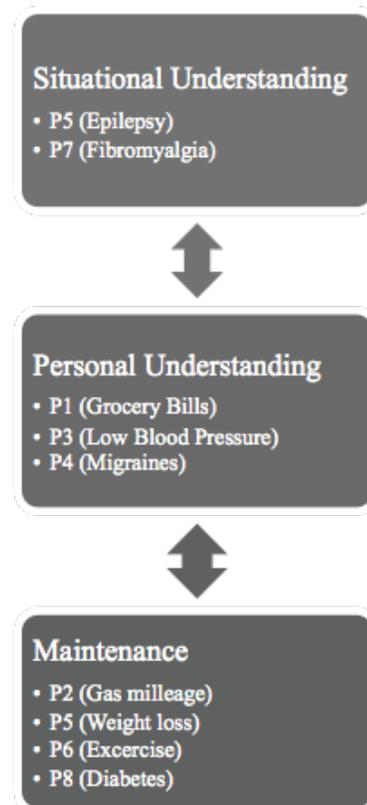
1. **Potential for Future Use.** Some participants continued to collect data so they would have an accurate long-term record in case their circumstance ever changed and they found they needed it. P4 (Migraine) said, "If I felt I was getting bad again, I would have the data to take to my doctor and become an advocate for myself."
2. **Noticing Changes.** Some participants mentioned they would continue to collect data after attaining the maintenance phase so that they would immediately notice any concerning changes or irregularities in their data. P3 (Low blood pressure) expressed a fear of what might happen if she stopped collecting the data. She says "Even just thinking about what can happen to you if you don't watch out for that

sort of thing. So if something goes out of whack, you can catch it quickly and easily and not have to succumb to it completely for the rest of your life." P8 (Diabetes) pays attention to changes in trends on a more regular basis, so she can adjust her insulin as needed. She said, "Once you see trends, so if you're always high at lunch time, lets say you're always a blood sugar of 9 to 11, so you're needing to have a little bit more insulin, then you would type that into your pump that starting about two or three hours ahead of that that you're wanting to up your basal rate a little bit."

Participants who did not collect data because of a health condition were also interested in achieving the maintenance phase, but upon doing so, widened the scope of their data collection. Because the consequences of experimenting with behavior for this group are less dangerous than the consequences of experimenting with behavior (and medication) for the health condition group, they often completed the maintenance phase by voluntarily returning to the situational or personal understanding phases. P2 (Gas mileage) has been collecting only data about his vehicle relating to gas mileage for the past four years, and has gained a reasonable level of insight about the impact of certain behaviors on his gas mileage. He now expresses an interest in expanding the scope of his data collection to provide more information about other areas of vehicle performance. "I would want to have a more comprehensive overall car maintenance history routine schedule... I've never written down when I've done an oil change, I've never written down when I've gotten my transmission fluid changed, I just round off the numbers. So yeah, I would like to start collecting that data."

5.4 Understanding Participants within the Model

Figure 2. Participant Placement within the Model



Situational Understanding. Participants P5a (Epilepsy) and P7 (Fibromyalgia) are currently in the situational understanding phase. P5a is learning about the possible triggers of seizures, causes of epilepsy, and medication options to reduce or eliminate seizures. P7 is learning about the possible triggers of muscle spasms, causes of fibromyalgia, and medication options to reduce or eliminate pain and muscle spasms. She said, “It’s a working diagnosis. I’ve had it for about five years, but it was only diagnosed in January this year... Part of the condition is that (the episodes) could be triggered by stress, but its kind of hard to tell. I’m petty much just learning as I go.” They each know relatively little about their disease, and are gaining background information and context for their data. Neither of them have observed personal triggers, or identified any personalized aspects of the disease yet.

Personal Understanding. Participants P1 (Grocery bills) and P3 (Low Blood Pressure) are in the personal understanding phase. P1 already understands that the more exercise one does, the more food he/she will consume. She is now interested in understanding the relationship between her physical activity and her food consumption at a more personal level. She compares specific events in her own life to her grocery bill amounts and is learning about how her own activities influence her grocery costs. P3 has strong background knowledge about what amounts of nutrients are recommended per day. In her interview, she said “There are all these different theories about how often you should eat, but generally every two to three hours you should be consuming something that’s got a complex carbohydrate in it, along with some protein so you get a quick blast of sugar in your blood, and it also lasts longer because it is broken down with protein. This is good for blood pressure and gives you consistent energy and gets your heart pumping and not having a potassium attack.” She demonstrates a strong contextual understanding, and has now begun observing her own diet and noticing deficiencies and patterns in her routine. “Sometimes I just won’t eat enough or there are some days where I’ve had breakfast and then all I’ve eaten for the rest of the day is some hummus, and that’s not so healthy. And even if you eat a lot of vegetables, they are made of cellulose and its harder to digest than just glucose is, so it takes a lot longer to get that sugar high or increase in that and it’s not that efficient for your blood pressure. I’m trying to improve on that.”

P4 (Migraine) is an interesting case. In her interview she says, “I see a neurologist at the Migraine clinic – it used to be 2-3 times a year, but now only once a year as my headaches are improving. I believe because of that, they are about to kick me out of the program. And that is a good thing.” It would seem that P4 is right on the cusp of transitioning from personal understanding to maintenance. She has identified enough triggers and has come to understand enough about medicinal doses that she has her condition almost completely under control. She will soon discontinue her regular discussions with her doctor to analyze her data, and will simply be collecting data to preserve her record, in case she needs it in the future.

Maintenance. Participants P2, P5b, P6, and P8 are in the maintenance phase. P2 (Gas mileage), P5b (Weight loss), and P6 (Exercise) are not collecting critical health data, nor have they been collecting data as long as P8 (Diabetes). They are only likely to be in the maintenance phase for a short time before they begin adding to their data, and seeking a wider situational and personal understanding. P2 expressed a desire to collect additional information about his vehicles’ performance, and P6 is currently shopping for a new GPS device, which may have different or additional functionality and may provide more data

than his existing one. P8 is collecting health related data and has been collecting data the longest out of any participant. She has been in a maintenance phase for a number of years; she understands her disease (diabetes) to her satisfaction, and she understands the disease’s impact on her personally to an extent that she is able to effectively manage her condition. She monitors her data in case there are any concerning changes in the overall trends of her data, but she understands her condition well enough that she is able to respond to any occasional spikes or drops in her data without too much panic or concern.

6. IMPLICATIONS OF DESIGNING FOR INDIVIDUALS WITH HEALTH CONDITIONS

6.1 Supporting the Situational Understanding Phase

As individuals in this phase are typically uncertain about the big picture of their condition, they are interested in gaining more information about the condition itself. Tools should provide information to the user about observations others have made about the condition, including possible triggers and ways of dealing with the condition. Tool designers may also wish to provide information from medical professionals about the causes and treatments of the condition, and their observations of triggers and solutions.

Individuals in this phase are also often new to the idea of collecting data about their life. A tool designed for this group should be extremely simple and easy to start using right away. It should not require them to collect too much data, nor too detailed of data. The data collection at this phase can be very generic because users do not yet have any idea what parts of it are important to them, or even what they should be looking for from the data. The point of collecting data this early on is twofold: by collecting data from the start, they have this data when they do move to a later phase (and will be able to look back on past data, even if it is less detailed than data they may collect in the future) and collecting data before they need to allows them to adjust to the process of doing so, so that by the time the data is needed, they will be comfortable with the collection process.

Finally, the tool should be extremely flexible; it should allow the user to try out different strategies and methods for collecting the data, as well as different strategies for reflection so the user can gain an understanding of what works for them. Included in this exploration of different options is trying out different collection frequencies, different ways of remembering to enter data (if not done automatically), and different ways of looking at and reflecting on the data.

6.2 Supporting the Personal Understanding Phase

In this phase, users are uncertain about their own relationship with their disease, and how the big picture understanding applies to them personally. They are looking for correlations between pieces of data, and so a tool must allow for the collection of a variety of different types of data. Data collection should be thorough, at least initially, so that all possibilities are considered. Users may be able to eliminate some data over time, as they are able to recognize that there is no important reason for them to be collecting it. Attempts should still be made to make this data collection as easy as possible, and not be a burden on the user, however users in this stage are more committed to their data collection than in the first phase; they understand the importance

of the data collection, and are willing to put in extra effort to acquire it if necessary.

Tools designed for users in this phase should also allow for observations and recommendations to users, specifically about correlations and trends in the data. Study participants at this stage expressed a desire to have a tool that would point out to them the relationships between pieces of data that they might not notice on their own. They are interested in discovering these correlations in this phase, and value the feedback of the tool. Strong visualizations that help identify these trends and correlations are an asset in these tools.

6.3 Supporting the Maintenance Phase

In the maintenance phase, individuals are in the habit of collecting data and are experienced in using their tools. They do not typically have as many problems with forgetting to make an entry, and are not actively seeking new knowledge. If they are observing or reflecting on their data at all, it is to observe changes or to notice if they are regressing in their condition. In this phase, visualizations that draw attention to regressions or consistent changes in condition would be an asset.

Additionally, in this phase the users already know which pieces of data are relevant and of interest to them and which are not. For this reason, the tools should provide more control to the user about what data they are collecting, and the way in which they do it.

7. DISCUSSION & CONCLUSIONS

Based on the findings from this work, it may be desirable to pursue future research in this area. As this research was limited in geographically, as well as limited in scope, it would be beneficial to expand this research by interviewing a wider group of users. This addition to the study may also include interviews with medical professionals to better understand their use of the data they are requesting from their patients.

Additionally, it would be interesting to better understand transitions between phases. There is reason to suspect that there are situations that may occur which would be an impetus for a step backwards in the cycle. If an individual with a critical health condition experiences a change in his/her condition, he/she may have to move backwards a phase or two and work his/her way back down to the maintenance phase. This backwards movement may also be caused by the introduction of a new tool, or new medical advancements that are presented to the individual. One way of examining this would be to revisit this study's participants in a year or two and observe their progress in their condition, as well as in their data collection.

A further area of future work would be to begin designing tools based on the design implications provided in this paper, and evaluating them with actual users with health conditions to assess how well they meet their users needs.

The analyses of the results of this study have shown that individuals who are using a personal informatics tool to better understand and manage a health condition have different needs than the self-experimenter types of individuals studied in the work done by Li et. al. While the staged based model provided by Li. et. al. has been considered quite accurate and successful when describing self-experimenters, it is not necessarily accurate and applicable to other user groups. Individuals with critical health conditions move through a stage-based model of personal informatics, but a model that is human centric, and one in which movement through the model is driven by a reduction in

uncertainty. This model describes three different phases of personal informatics that these individuals go through: *Situational Understanding*, *Personal Understanding* and *Maintenance*. Unlike the self-experimenters, individuals with health conditions see the *Maintenance* phase as the clear end goal, and are not interested in intentionally cycling through the model.

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9. Appendix A: Thematic Interview Guide

Topic 1: Reasons for Collecting Data

- What kind of data do you collect about yourself?
- How long have you been collecting this data?
- How do you collect this data?
- Why do you collect this data? [If it is due to health reason, then probe about the health condition to understand what the relationship is between the health condition and the data.]
- In what ways have you collected this data?
- How do you use tools to help you collect/record/store this data?
- Does your lifestyle impact the kind of data that you collect?
- Why did you initially begin collecting this data?
- What impact does this data have on your life?
- Why do you continue to collect this data?
- How would your life be different if you weren't collecting this data?
- If you had to sum up in one word why you are collecting this data, what would it be? What do you mean by that?

Topic 2: Use of the Collection Tool

- Please show me how you use the tool to collect data.
- Under what circumstances would you collect that data and how often?
- Are there multiple stages or components of your data collection? What are those?
- What observations can you make on this collection process? Are there any problems with it?

- Automated or manual?
- Frequency?
- What triggers a collection?
- Are you collecting everything that you would like to collect? What else would you collect if you could automatically do so?

Topic 3: Use of the Data

- How do you use the data that is collected?
- Do you review the data that is collected?
- When was the last time you reviewed the data? Where were you? Why did you do it? Show me what you looked at, and in what order [think-aloud exercise].
- What techniques do you use to reflect on this data?
- Do you share or discuss this data with someone else? With whom? How? Why?
- What can you learn from it?
- Will/do you change your behavior based on what you are learning?
- Have you previously tried to change your behavior because of what you've learned? To what extent were you successful?
- If you could automate part of this process, or have someone/something help you with this, what would they/it do?
- What problems do you encounter when reviewing past data?
- Do you have any ideas on how to improve the tools you use?
- Are there things you would like to be able to do with the data or understand about the data that you can't?