

USING A SMART MOBILE DEVICE TO LEARN TO LIVE WITH LONG-TERM DISEASE TREATMENT

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ABSTRACT

Dangerous diseases have many kinds of effects on people. The risk of being taken ill or dying is obviously the primary concern for most patients. Challenges of adhering to longitudinal cures, which may require a disciplined regime of living or acceptance of physical discomfort, are lesser-known secondary aspects. If they lead to non-adherence to the cures, they may cause illness or increase the risk of dying. Some groups are particularly at risk, e.g., children and people living in underdeveloped parts of the world. Taking advantage of the advanced level of present mobile phones and the advent of inexpensive, commonly available sensor devices, this paper presents a proposal to implement a platform for drug administration that is accessible, affordable, and relevant for “smart” mobile phones. At the same time as it should work as a mobile learning platform to help users deal more skillfully with their condition. We conclude by outlining an effort towards implementing an executable specification targeting use of the mobile phone as a “boundary object” between the competences of medical aid, technological support and quality of life.

KEYWORDS

Mobility, drug administration, adherence, learning, boundary objects

1. INTRODUCTION

Many types of medical treatment are given as longitudinal cures comprising a combination of drugs. The amount, time and type of drugs that need to be administered may rely on many different factors, such as the stage of the illness, height and weight, the patients’ level of activity or recent food intake, as well as interaction with other drugs.

Numerous patients struggle to keep up with their cures, e.g., children, elders and patients in lesser-developed areas. Failure to adhere to the administration plan for longitudinal treatment of acute illnesses is often critical to the outcome of the cure (Atkins and Fallowfield 2006). We would like in particular to address the issues related to quality of life and outcome expectations from longitudinal cures for children.

Diabetes is a disease where the body's own production of the insulin has stopped or been greatly reduced. Insulin is necessary to allow cells to utilize sugar transported around the body through the blood. Without insulin, the blood sugar (glucose) level will continue to increase, causing various medical problems, and in the end be fatal to the patient. The treatment of diabetes consists of monitoring actual blood sugar level, and injecting insulin using a syringe several times a day. Typically, a diabetic will inject insulin before all meals as well as once or twice each day using a “long-term” type of insulin that provides a base insulin depot in the body. The amount of insulin that is injected is critical. Administration depends on establishing a “mental model” of the relationship between activity, food and medication, which is based on experience. Assessing the effect of food on blood sugar is non-trivial because different types of food contain different amounts of sugar and is transformed into blood sugar at very different rates.

A common objective will be to develop procedures that combine medical data, which are necessary or useful to adjust the dosage of drugs that comprise the cure, and patient parameters more generally. Different parameters will be requested depending on the illness, bearing in mind that we want our approach to be valid for other chronic diseases as well. Some of the parameters will be truly context-dependent, however, and their range and significance will in relevance and number vastly surpass the context-dependent data that we have seen alluded to for horizontal applications (Schmidt, Beigl et al. 1999), e.g., blood sugar level and time of measurement, food intake and time of eating, physical exercise as well as time period and exercise level, heart rate, blood pressure and body temperature, cross-medication, even with non-prescription drugs sleeping pattern, weight (loss) and body

composition, etc. In the specification below, which illustrates our approach, the first three of these are explicated.

2. RELATED RESEARCH

There has been some work done previously in the area of insulin-dosage calculations algorithmically (Pacini and Bergman 1986). Pacini and Bergman use a model that they call the minimal model (MINMOD) to evaluate the metabolic control of glucose. The problem for our objectives of supporting children, is that the input variables do not make sense at all to the patient, and even if they did, they would not be able to collect the data.

Islam et al. have expanded the minimal model with additional equations to implement an algorithm, which is still relatively simple, but comprises even more variables that have to be determined by professional doctors (Islam, Leech et al. 2007). However, some of the insulin sensitivity parameters can also be defined by studying computer simulated glucose profiles and this is an opportunity that needs to be considered. Another algorithm, proposed by Fisher is more adapted to a situation such as ours (Fisher 1991). It is still based, however, on a much too theoretical analysis of the control of blood glucose level and the interaction between the glucose and insulin. It is based on the presence of three plasma glucose samples and although the author acknowledges that the meals are really important for predicting the glucose level, it does not pragmatically consider what sort of food a diabetic is eating. Without knowing (by heart) the glycemic index of a composite meal, which is almost impossible to do manually even if the table of glycemic indices for each ingredient were available, it would be difficult to give a prediction of the individual response.

3. IMPLEMENTING A BOUNDARY OBJECT

It seems clear that in order to work properly under the conditions that we have outlined above, a device needs to satisfy several requirements. It needs to be robust and easy to use. It has to be sufficiently fast and power efficient. However, we need to go beyond that in order to arrive at a solution that will work for many diverse groups, and hostile and barren conditions in ecological terms (a football pitch as well as the rural environment of South-Africa) and can tie together the concerns of multifarious user groups, such as the parents of a kid with diabetes on one hand, and his friends on the other.

Dedicated devices, which serve specialist-functions, are of course one category of medical equipment that we need to look at, but considering that we are targeting children, this cannot be the limit of our scope. We need to look at the opportunities that exist to integrate heterogeneous devices in order to increase the capacity of cell phone-based healthcare solutions. Therefore we are also going to try to “make medical” much simpler and more available equipment, such as sports’ heart-rate monitors, by inputting their data to the mobile phone application that we propose to develop. Such devices are precise (Treiber, Musante et al. 1989), robust and readily available where more advanced medical apparatus is not.

Not only are the different user groups likely to be having different viewpoints on the services offered by the technology, but also the viewpoint of one might be exactly the driving force behind non-adoption or erroneous usage on behalf of another user group’s viewpoint.

For the reasons sketched above, we have looked at the notion of a *boundary object* as one way of informing the design of a tool that can compile and enforce a sufficiently strict administrative regime for medical cure adherence. For now, we are going to keep our scope to the harnessing of diabetes with insulin, with particular concern for children since they are less likely to keep track of nutrition, level of activity and insulin dosages themselves.

In previous IS (Information Systems) literature, the notion of a boundary objects has had mainly analytical purchase (Star and Griesemer 1989). Therefore, it is a novel contribution of this paper to draw inferences from the usage of the concept for design purposes. There is very little literature on boundary objects as a design component, except “after-the-fact” as one discovers the role such objects have come to play (Henderson 1991). Instead, what we are going to try to do in this paper is to use it as a proactive means of eliciting the design ideas (rather than only mediating them).

The problem that we face in designing a smart tool for our purposes is similar to the one described by Star and Griesemer (1989), in particular because the internalization of the algorithm, which models insulin’s role in the metabolism, e.g., is such an integral part to actually using it. Learning and

motivation goes hand in hand, and the boundary object as a perspective on knowledge therefore becomes very useful.

“The creation of scientific knowledge depends on communication as well as on creating new findings. But because these new objects and methods mean different things in different worlds, actors are faced with the task of reconciling these meanings if they wish to cooperate (Star and Griesemer 1989)”

In the terminology of Star and Griesemer, actors inhabit different social worlds, and when they encounter the knowledge interest of parties “from elsewhere” they re-interpret their agenda to fit better with their own. They then try to control action, which is related to the agenda through the object. This is the process of *translation*. As a concept, it fits with our select domain, which is populated by parents, doctors and children with diabetes. Doctors need to treat many patients efficiently, and look twice only at the exceptional situations. The parents will seek stability and predictability for all family members, while the average kid with diabetes is more likely to want to live life just like his or her friends. Doctors and parents can use *coercion* to maintain the dominant perspective of their own interpretation of the situation (Gasson 2005), but this option is generally quite limited. In general, the dominant “gatekeeper” or any given “obligatory point of passage” must take into account the interests of all parties. In the next paragraphs we are going to outline “the design of a gatekeeper” by means of a boundary object.

A boundary object is an (analytic) concept of phenomena that “inhibit several intersecting social worlds (Star and Griesemer 1989). Boundary objects cannot be static or standardized, in the sense that there must be room for them to fill different informational needs in different social worlds. They have to be similar enough to be recognizable as a means of translation across social worlds, however, and

“The creation and management of boundary objects is a key process in developing and maintaining coherence across intersection social worlds (Star and Griesemer 1989).”

We want to focus on the learning aspects. We want to think about it in terms of simple parameters, which can be estimated or measured relatively accurately by the patient. We start with level of activity, along a scale of perceived exertion/effort. Next we want to include a measure of the blood sugar levels, which is absolutely essential for a sufficiently precise administration of insulin. Finally, the nutritional components have to be assessed, e.g., by breaking down by their glycemic indices the components of meals to help the patient anticipate which levels of activity or insulin dosages may become necessary soon. The task is now to make a model with which interaction can be accurately modeled, and then see if it can be implemented to satisfy the requirements of a boundary object.

Our proposal is to make an executable specification, as the first step in the project. We use the declarative programming language Maude. The detailed characteristics of the language are outside the scope of this paper), and we focus only on the so-called *rewriting* rules. Consider, for instance, the rule labeled [activity], which emulates a change in the activity level of the patient and generates an auxiliary message about it to the rest of the system, which can then respond appropriately.

We have specified a module, which (edited for readability) looks like the following:

```
mod CATLA is
  ***( Declarations and help functions removed )

  eq init = < 'steinar : Patient | diabetesType: II,inMsgBuffer: nil,
  outMsgBuffer: nil,
  currentSugar: low, currentActivity: low, currentFood: mid >
  < 'catlasim : SimPick | splist: high ++ high ++ low ++ mid ++ mid ++ mid > .
    --- twice as likely to get high than low, etc., for easy simu only

  ***(Variable declarations removed )

  rl [ sugar ] :
    ***( Similar, but simpler than the one below )
  .

  rl [ activity ] :
    < PATIENT : Patient | diabetesType: DT,
    inMsgBuffer: IMB, outMsgBuffer: OMB,
    currentSugar: CS, currentActivity: CA, currentFood: CF >
    < SIMPICK : SimPick | splist: SPLSET ++ METRIC ++ SPLSET' >
    =>
    < PATIENT : Patient | diabetesType: DT,
    inMsgBuffer: IMB, outMsgBuffer: OMB,
    currentSugar: CS, currentActivity: METRIC, currentFood: CF >
    < SIMPICK : SimPick | splist: SPLSET ++ METRIC ++ SPLSET' >
    msg PATIENT changed(CA, METRIC) activity
  .
```

```

rl [ sugar ] :
    ***( Similar, but simpler than the one above )
.

rl [ sugar-too-low ] :
  < PATIENT : Patient | diabetesType: DT,
    inMsgBuffer: IMB, outMsgBuffer: OMB,
    currentSugar: low, currentActivity: CA, currentFood: CF >
  =>
  ( msg PATIENT increase food )
  < PATIENT : Patient | diabetesType: DT, inMsgBuffer: IMB,
    outMsgBuffer: OMB,
    currentSugar: low, currentActivity: CA, currentFood: CF >
.

rl [ activity-increasing ] :
  ( msg PATIENT increased activity )
  < PATIENT : Patient | diabetesType: DT,
    inMsgBuffer: IMB, outMsgBuffer: OMB,
    currentSugar: low, currentActivity: CA, currentFood: CF >
  =>
  ( msg PATIENT increase food )
  < PATIENT : Patient | diabetesType: DT, inMsgBuffer: IMB,
    outMsgBuffer: OMB, currentSugar: low, currentActivity: CA,
    currentFood: CF >
.

endm

```

For the purpose of illustration in this paper, the two main rewriting rules are [`sugar-too-low`] and [`activity-increasing`]. The former makes sure that a patient *always* is told to increase his food intake (which may mean taking pure sugar or fruit juice to acutely treat a situation which comprises dangerously low blood sugar level). The latter makes sure that we simulate the same instruction given to a patient as a result of self-reporting that the level of activity is increasing. The outcome is similar, but the causes are different.

We can then run a simulation asking the Maude interpreter to find a state in which the patient was instructed to take in more food. The interpreter will according to the specified criteria search the entire state space (if it is finite), and list the number of matching states that we asked for.

```

search in CATLA : init =>* SW:SmallWorld msg P:Qid increase food .

Solution 1 (state 8)
states: 9 rewrites: 162 in 0ms cpu (0ms real) (~ rewrites/second)
SW:SmallWorld --> < 'catlasim : SimPick | splist: high ++ high ++ low ++ mid ++
  mid ++ mid >
< 'steinar : Patient | diabetesType: II, inMsgBuffer: nil,
  outMsgBuffer: nil
  , currentSugar: low, currentActivity: low, currentFood: mid >
P:Qid --> 'steinar
Maude> show path labels 8 .
sugar-too-low

```

Showing the path which lead to the state concludes that the reason was that the blood sugar level had dropped too low. This is something that we believe can be pursued in several planned steps within the project that we have outlined in this paper, in order to develop the specification into a boundary object that can aid the learning of appropriate strategies for diabetes patient which have to rely on simple and mobile, yet “smart” technology. One of the most important aspects of such a model would be to learn to live, and to live well, with being treated under a strict and permanent medical course of therapy.

4. DISCUSSION

This is the first step in the direction of establishing a systematic effort to design an aid to people who have previously been underserved in terms of technological support for adherence to longitudinal medication. Existing technology is too heavyweight and expensive, too intrusive and demands data that mobile users are not in a position to get. We have suggested to see the notion of this technology as a boundary object, in order to find ways around these practical obstacles, and at the same time setting

ourselves up to provide a more pedagogical presentation of the algorithm which prescribes how much and when to take insulin, adjust the activity level or take in more nutrition.

We have seen many examples recently that mobile technology combined with the multifarious perspectives of friends and fellow users, medical consultants etc., have been established as normative and effective implementations in this respect¹. Some of these systems are proven in practice (Prochaska, Velicer et al. 2005). Our project starts from the understanding that such approaches are instrumentally sound, but we wish in addition to develop a pedagogical element on top of that. Thus, the next step will be to assess with users whether the “boundary object” in guise of a running Maude specification can be used as a way of learning more and better how to live under longitudinal administration of drugs. This will give us opportunities to explore the pedagogical outcome of the logical properties of the specification. We hypothesize that the assisted executions of search strategies on basis of the specification, to confirm in principle its potential as a boundary object. It may have to be re-implemented on a user-friendlier platform, in order for the specification to become a fully functional and “live” boundary object, which may make living with diabetes easier. This is the ultimate goal of this project, of course, but in terms of verifying the correctness of the underlying model, Maude is a promising tool.

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¹ <http://www.packitin.org/>