The Stone: Digital support for (un)common issues during pregnancy

Aino Vonge Corry, Tony Gjerlufsen, Jesper Wolff Olsen

Department of Computer Science, Aarhus University, Aarhus, Denmark

Abstract

The availability of both healthcare professional oriented and solely personal information is of great importance to women during their pregnancy. The data constituting this information is currently distributed between many parties which makes it very difficult for the pregnant woman to assess her situation. To address these issues we have pursued the idea of providing each woman with a digital artefact intended as a starting point for the provision of pregnancy support. Secondly the coordination of information between several parties of the health sector suffers from redundancy that could be rectified by simple technical aids. In this paper we describe the challenges found in relation to pregnancies and propose a solution to meet these challenges.

Keywords:

Information Management, Medical Informatics Applications, Pregnancy, Pregnant Women, Diabetes Mellitus, Self Care, Communication, Information Storage and Retrieval, Participatory Design.

Introduction

The scenario we explore concerns provision of support during pregnancies to the women and their care team. This team includes the families of the pregnant women as well as primary and secondary healthcare providers. During her pregnancy the pregnant woman is in contact with several different healthcare professionals in different locations. Many data items are created during the pregnancy, some are valuable and necessary for the healthcare professionals, while others are mostly of interest to the pregnant woman and her family. Many data items are used both by the pregnant woman and the professionals, but with different purposes.

The varying reliability of information available online is a frequent cause of concern [2] to the women. They need reliable and updated information on pregnancy and health to turn to. No matter where the woman is or at which stage of her pregnancy she is in, she should be able to get a reliable answer to her questions and the information the healthcare providers have about her should be updated and shared. As a primary goal we propose to supply the pregnant individual with a digital artefact, mostly for storing and communicating information. We introduce this digital artefact as *the Stone*, not to be thought of as a burden, but to lead one's thoughts away from

the leading contemporary form-factor for portable digital computing; the PDA. In the future the Stone may very well be embodied in a PDA. But taking into account the possibility of it being something else entirely, we have decided to coin an abstract term for contemplating this artefact. The Stone serves the pregnant woman and mother when the child is born, as the main carrier of information to be used in relation to her pregnancy and motherhood. This applies whether she is at home, with healthcare professionals, or with family and friends. That is, the Stone supports the woman in carrying all the information she chooses to collect.

As a secondary goal we see the Stone as an artefact to rectify the inconvenience in relation to redundant work among the professionals. The healthcare providers could improve their communication and make less redundant interviews of and notes on the pregnant woman, utilizing the capabilities of the Stone.

The Stone as a concept is the result of a joint effort between healthcare professionals (including doctors, nurses and midwives at the Skejby Hospital and general practitioners) and the Palcom Project under the 6th European Framework Programme [3]. The Palcom Project aims to research and develop a new perspective on ambient computing denoted palpable computing. 'Palpable' denotes that systems are capable of being noticed and mentally apprehended. Furthermore palpable systems support people in understanding what is going on at the level they choose. Often the default mode is to suggest courses of action rather than acting automatically. Palpable computing complements the unobtrusive effectiveness of ambient computing with a focus on making the means of empowering people intelligible. The two main objectives are to design an open architecture for palpable computing and a conceptual framework to understand the particulars of palpable technologies and their use.

The entire work carried out in relation to the Stone is a direct input to the Palcom Project contributing to the development of the two main objectives.

The paper is organised as follows: After this introductory section, the next briefly presents the different methods and techniques employed during the design process. In the following section we describe the scenario, used primarily to frame our vision and secondly to describe the setting in which our prototype would reside. Before proposing our solution, including a presentation of the currently developed prototype, we introduce the collection of challenges exposed during our work.

Finally we discuss the outcome of the work and findings up until now.

Methods

We have used and employed various techniques and methods during our work process, all to acquire a deeper understanding of the situation at hand and to explore the different problems the women encounter throughout the pregnancy and possible solutions for these. The overall approach is rooted in a *Participatory Design* [4] tradition. Following this tradition we have employed several different methods, one of them being *Dilemma Games* [5], in which we made an attempt to render potentially contradicting goals and elements of practice visible. This was accomplished by inviting a group of healthcare professionals and pregnant women to join us and act through scenarios that should expose dilemmas. Additionally we used elements and techniques from *Artifacts as Triggers [5]* and *Future Laboratory* [6], both methods had the developed prototype as their main focal point. The first method is meant to use artefacts to trigger discussions on a given practice, carried out in cooperation with the end users. The idea behind the second is to bring the practitioners into the laboratory, where they appropriate prototype technologies by working seriously on a particular, authentic job for a prolonged period. In addition we used various types of field work, including ethnographic observations in Department Y at Skejby Hospital, focus on pregnant women with diabetes, ethnographic 'shadowing' of pregnant women, the midwife's and the general practitioner's work practice and interviews.

Scenario

A pregnant woman contacts her General Practitioner (GP) for her first appointment. At the GP she gets a general examination; her blood pressure, height, weight and urine examination. The data is stored in the GP's medical record system. The woman has diabetes, and she is asked to write down all p-glucose measurements. The GP sends an electronic referral to the hospital, including the data from the examination and some other basic information. Because of the diabetes she gets an appointment with the hospital the next day. This and other relevant appointments are noted on her pregnancy notes together with a date for the next consultation at the GP. The GP also initiates a pregnancy journal which is sent to the chosen place of birth and to the midwife clinic.

At the GP, the woman is confronted with the fact that smoking can damage the foetus and is urged to stop smoking. The woman already knew this and has tried to change her smoking habit without success. Changing her life style is not something she finds easy.

The next day the woman goes to the antenatal clinic at the hospital. The doctor interviews her and adds her answers to the medical record at the hospital. The doctor does an ultrasound scan to check that everything is ok. The woman can buys a still photo from the scan and when she gets home she shows the scan picture to her husband and tries to explain to him, what the picture is supposed to show.

Because of her diabetes, she goes to visit the hospital for consultations every two weeks. At these meetings she sometimes gets scanned, sometimes she sees an oculist but every time, the doctor evaluates her state based on her own p-glucose measurements.

In week 12 she has a neck fold ultrasound scan. Based on this she is told that her baby has a very low likelihood of suffering from Down's syndrome. When she gets home, she wants to talk to her husband about it, but she finds it difficult to remember the specifics and he thinks that the information she got was insufficient.

She gets an invitation from the midwife clinic to attend her first meeting with a midwife. She is told to bring a urine sample, and her pregnancy notes. She shows the pregnancy notes to her midwife and they discuss her earlier pregnancy and how the birth was. The midwife writes the relevant data from the consultation on the woman's pregnancy notes. She has had to ask the pregnant woman many of the same questions, the GP has already asked her and a lot of the things she wants to know about her are stored in the EHR (Electronic Health Record), but are not immediately accessible for the midwife. A lot of the information she gets is thus based solely on the pregnant woman's ability to remember details. Sometimes she has to scribble additional information in the margin, because the paper form does not support details out of the ordinary. The woman tells the midwife that her first birth was hard and that she does not want to go through that again. The midwife tries to persuade the woman to take classes in birth preparation, but she does not have the time for it and would rather have a caesarean section.

During the rest of the 40 weeks of pregnancy the woman attends a lot of meetings and is repeatedly asked at lot of the same questions by different parties.

When the woman wakes up one night experiencing labour, she calls the maternity clinic only to discover that she has to wait at home until the labour has reached certain intensity. The pregnant woman and her husband time the contractions as best they can using a watch. After a while they go to the maternity clinic.

The birth is about to take place when they enter the clinic and in the rush, the midwife and the nurse do not have time to read the relevant parts of the pregnancy note. They have to rely on the couple to tell them what they need to know. Unfortunately they both forget that the woman bled too much after the last birth and that immediate action is needed when the child is born. Because of this, the woman loses quite a lot of blood.

Challenges

Most of the challenges described in the above scenario could be met by technical and cultural changes in the health sector. To sieve out the important focus points, we will briefly explicate the main challenges.

- The pregnant woman suffering from e.g. diabetes must attend far more meetings with health personnel than the average pregnant woman, because she needs to hand in her self-measurements.

- The different parts of the health sector suffer from redundancy with respect to information about the pregnancies.
- A pregnant woman, who has e.g. lost a foetus, needs many consultations to convince herself that the baby is fine.
- The pregnant woman knows that she has to change her life style but it is difficult to change habits and remember to, e.g. exercise.
- Information stored in several health information systems, such as EHR systems, the general practitioner's etc. can be relevant to the pregnancy or birth, but they are only taken into account by chance.

Our solution

In order to meet the challenges stipulated above, we propose to supply to the pregnant woman, a network-enabled digital artifact, the aforementioned Stone, for holding and communicating information. Augmenting the pregnant woman with such a device entails some intriguing possibilities. In this position, the Stone could function as a common artifact for person-to-professional as well as inter-person and inter-professional communication.

What we have come to learn from our sessions with healthcare professionals and pregnant women is that for an artifact such as the Stone to make sense, one of the tenets has to be configurability. Some women need a lot of information and assurance. Others need support in maintaining a certain lifestyle, while a whole third group is best left quite oblivious to some of these challenges. On the basis of this, the Stone is built as a modular digital artifact with configurable support for both the pregnant woman as well as for the professionals with regard to the pregnancy. The Stone supports multiple levels of configurability, some of which can only be set up by professionals. Others may be (de)selected by the pregnant woman.

The Stone should be introduced to the pregnant at the first consultation with her GP. Here, it is initialized by the GP and configured to the needs of the specific individual. This happens, taking into account, their conversation as well as the overall patient history. The relevant information from the EHR and other databases is downloaded onto the Stone. This can be accessed by the various professionals and constitutes the common ground for forming the numerous journals and notes used throughout the pregnancy. That way, the midwife can access information stored on the Stone by the GP as starting point for her consultation, thus eliminating both redundancy regarding the various records, but also with regard to asking the pregnant woman the same questions repeatedly.

Other functionalities could be a calendar, enabling the pregnant woman to communicate reservations with her GP and the pregnancy ward, along with functionalities for logging and keeping track of her intake of e.g. alcohol, tobacco and some types of food. Next to these more general functionalities, the Stone will also support more special issues with regard to some pregnancies; e.g. diabetes. The GP could install a module on the Stone, able to connect wirelessly to a blood sugar reader, reading its measurements and communicating them directly to the EHR. This way, the pregnant diabetic would not need the bi-weekly p-glucose consultation. A further functionality could be support for prenatal breathing exercises. This could be in the form of some audible or visual signaling, or it could be in the form of vibration from, for instance, a mobile phone which the Stone communicates with. Along with these, GP configurable functionalities, one could imagine the Stone holding a host of user configurable functionalities, the obvious examples being the choice of various information sources. Of course, this could be sanctioned by the GP, but once that has happened, it could be up to the woman herself, whether she wants those information sources visible. Another example could be a media library, which could hold images and video clips from her various consultations, e.g. the ultra sound scans, along with her own private ones. At last, one could also imagine the Stone being configured with a text writing mechanism using the calendar as basis for a private pregnancy diary. This could in turn be associated with the media library, if enabled, to provide images in the diary.

All of these small elements will be tied together in the Stone, enabling them to communicate with external sources and each other where necessary. To allow for this rather complex and dynamic inter-communicating conglomeration of digital entities, we suggest utilizing the future PalCom open architecture.

The PalCom Open Architecture

The Open Architecture is the technical nucleus of the PalCom project. From the point of view of this paper, it facilitates inter-communicating *services* and *assemblies*, running on a common platform – the PalCom *runtime environment*. What follows below is a rather technical, though exemplified, description of a PalCom implementation of the envisioned concept.

A *service* which, at this level, can be seen as the smallest unit of description is among others described as being a remotely accessible, discoverable, context-free entity. Thus, packaging the various base functionalities used in this scenario, e.g. calendar, blood sugar monitoring etc., as services, will enable them to discover- and communicate with each other regardless of context, or as in this case; some predetermined overall functionality. This gives, in this scenario, the necessary freedom to ensure that the Stone can be configured entirely to the needs of the pregnant woman, also when these needs change throughout the pregnancy. This configurability is not only relevant with regard to the communicating functionalities internally on the Stone, but also the various external devices utilized; it enables the dynamic change of one, normally used device, into another merely having the same functionality.

Such *services* can be composed into an *assembly*. This mechanism orchestrates the flow of information between the inter-operating services and manages their overall structure, providing a single uniform interface of functionality to the surrounding world. An example is how a mobile phone can be seen as an assembly consisting of various services; namely keypad, display, memory, GSM, and camera services.

Both *services* and *assemblies* are running on top of the PalCom *runtime environment*, supplying a common, hardware

Blood sugar
reader

independent platform along with base functionality for com-

Figure 1: The Stone being extended with a blood sugar reader
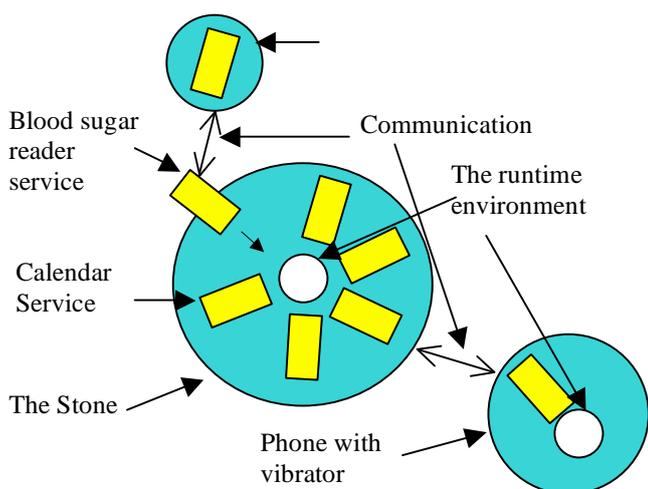
munication and security.

Using this framework, the different functionalities presented for the user of the Stone, e.g. a calendar functionality, a diabetes logging functionality etc. can be constructed as services and combined as assemblies. Further, the blood sugar reader from the above example will have a service running, enabling it to communicate with and integrate into the context given by the Stone. Similarly, the telephone will, it is assumed, have the PalCom runtime environment, enabling the transfer of a service for utilizing its vibrator functionality. All of these will then be composed into assemblies, according to their differing input and output needs. For example, the diabetes blood sugar logging service needs to communicate with a service running on an external blood sugar reader, capable of returning its readings. Further, it needs to be aware of the date and time to associate this with a given blood sugar reading, hence communicating with a calendar service. Similarly, all of the functionalities presented to the user, would communicate to a single common display service, capable of rendering the functionalities, actions and data visible to the user. Given this modularity, one could easily imagine simply changing display service in the Stone assembly from the service running natively on the Stone to one running on the living room television. This way enabling the person to better show to the family, e.g. the ultra sound scan video mentioned earlier.

Current status

At present, we have implemented a horizontal prototype embodying some of the concepts of the Stone. It basically consists of a Java application running on a PDA with wi-fi and Bluetooth capabilities. Our initial efforts have mostly been centered on creating an artifact for triggering further discussions during our workshops [5].

The Java application can be seen as a simulated assembly, consisting of a number of simulated services of different functionality.

Further, we have written a small service, also in Java, for a Nokia 6630 telephone, capable of controlling the phones vibrator functionality. Currently, this just means that the service

executes a predetermined vibration sequence on the phone in order to guide the pregnant woman when she is performing her breathing exercises. In the future, the service will be programmed to continually communicate with the Stone, allowing the user of the Stone to structure these exercises on the fly. The service is located on the PDA Stone, which can connect to any smartphone and transfer the service, enabling the phone to support the breathing exercises from the scenario.

The services implemented on the PDA Stone are:

- *A diet monitoring service*. This service functions as support for the pregnant woman in monitoring her intake of various substances. This could be some types of food, alcohol or tobacco. Supporting the pregnant woman in monitoring her intake of these, may help her keep track of them, maybe according to some pre-set limits or purely as a motivator for a healthier pregnancy. This service is used as a proof-of-concept on entering data into the Stone.

- *A breathing exercise support service*. This service enables the pregnant woman, via Bluetooth, to discover and connect to some specific telephones in the vicinity. This done, it can transfer a small vibrator service, which is mentioned above, to the phone. This service is a proof-of-concept on connecting to and communicating with external devices.

- *A media service*. This is for managing and viewing various media types, e.g. pictures and video. Currently it is only able to play video and show pictures, already on the PDA. The media service could hold pictures and video from ultra sound scans etc., as well as private pictures and video clips. In a PalCom envisioned future, the Stone will be able to communicate with, for example, a camera or camera phone to retrieve pictures and video relevant for storage on the Stone.

- *A calendar service*. This service resembles a regular calendar, with all its uses. Further, events and data from the other services are associated with a date, enabling the pregnant to access them date-wise, rather than type-wise, through the calendar. For example, at one date, there may be a diet entry regarding something she ate, along with a media entry with a picture of her tummy. Another day may hold a reminder for an appointment for an ultra sound scan along with the video recorded at that session. In the future, the calendar service will play an even more central role to the stone, enabling the reservation of various appointments through the Stone. This can be relevant both from the pregnant woman's, as well as from the professionals' side.

In the near future, the prototype will be extended to cover, amongst others, connection to and communication with EHR, along with a blood sugar reader. This will enable us, through the prototype, to take blood sugar measurements and communicate them directly to EHR.

At present, the prototype is not utilizing the PalCom Open Architecture, but as elements of this near some state of com-

pletion, we plan on gradually moving the prototype's functionality.

Evaluation

We have, up until now, had several workshops with the associated healthcare professionals. During the pre-prototype workshops, we worked with a piece of concrete as artifact for use in dilemma games and for triggering discussions – hence *the Stone*. This was, as mentioned earlier, to avoid people fixing on the idea of a PDA as the only host for a possible future implementation. The results from these sessions had more of an abstract nature, focusing on the context of the Stone, as this was more domestic and graspable than the Stone itself to the participants. As the prototype became ready, we presented it and integrated it into our work. This brought with it, some more specific ideas and discussions regarding the Stone and its future functionality. Up until now, our workshops have mostly evolved around trying to confirm or invalidate various ideas and conceptions regarding the Stone, some of which are presented in this paper. In the near future, we plan on hosting a more in-depth future lab, using the working prototype of the Stone as the main artifact.

Conclusion

In this paper we have highlighted the challenges in the healthcare system regarding pregnancies. These were found together with healthcare professionals and pregnant women by general field work, Dilemma Games, Future Laboratories and other Participatory Design methods. Five main challenges were found: Pregnant women suffering from e.g. diabetes must attend far more meetings than the typical pregnant woman; the healthcare sector suffers from redundancy with respect to information about the pregnancies; pregnant women need more information and reassurance that the foetus is healthy; information already existing in other systems is relevant for the pregnant woman; and it can be hard to change the lifestyle during pregnancy.

We have proposed a solution for improving the support for pregnancies using a digital artifact. The Stone can store relevant information singled out either by the pregnant woman or the professionals; it can communicate with a choice of devices i.e. other computers, displays or mobile phones or it can help the woman improve her lifestyle during the pregnancy, if needed.

From discussions with pregnant women and healthcare professionals, one common concern was brought to our attention. Excessive information would confuse the involved persons rather than helping them. We have chosen to include as much information as possible in the Stone and supply well designed views of the data, making the information easy to comprehend. In daily use, only the most important information will be visible, however the users have the possibility of extending the views to contain more or/and new information.

Another subject of discussion was the redundancy of information exhibited by repeated queries to the pregnant woman from different parties. This is ideally something that should be solved by a general change in the healthcare sector. If we could make all information available in the EHR and make the EHR available from everywhere, redundancy would not be so common. Since this is not an option today, we have chosen to base our solution on the Stone as information carrier, even if this is not the optimal solution.

Generally it is important to note that the Stone we have presented in this paper is by no means a final design, more a brick on the road.

It is our belief that with the right support, pregnancies and births can become a better experience for pregnant women.

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Address for correspondence

Tony Gjerlufsen, Department of Computer Science, University of Aarhus, Aabogade 34, DK-8200 Aarhus N, Denmark. Phone: +45 8942 9301. Mobile phone: +45 4112 1609. e-mail: tonz@daimi.au.dk