

Palpable Time for Heterogeneous Care Communities

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ABSTRACT

This paper describes an ongoing design experience conducted in the Neonatal Intensive Care Unit for Premature Newborns. The specificity and the delicateness of such a setting provided the opportunity for reflecting on how the different stakeholders perceive, interpret and use time in their different activities connected to their specific relation with the neonatal ward and the activities taking place there.

The design concept of Palpable time sets this difference in focus to initiate a communication model aiming at supporting these needs. The value of this concept is that all members of the care community are entitled to act as equal partner in taking care of the baby. Therefore, this implies the idea of a horizontal organization in which all members are equally valued, where the stakeholders interact according to their preferences from a time-space perspective. The system must handle roaming between spaces, devices and physical nets. Furthermore, it enables the users to configure emerging properties of their choice to propagate these to themselves and others. Managing and matching the heterogeneity of these different needs and profiles. Palpable Time supports the creation and the consolidation of a Care Community around the Neonatal Ward. Today the concept is explored through an early prototype used as a springboard for further development.

Keywords

Ambient computing, care community, palpable time, premature newborns

INTRODUCTION

The necessity of making the technology pervasive, distributed and embodied makes the applications, in most of the cases invisible for the user. In doing this, functions become opaque and unclear. A certain degree of ‘visibility’ or a good balance between ‘visibility’ and ‘invisibility’ of technologies should complement this lack of control as perceived by the user.

Furthermore, the emphasis on the possibility to configure applications and tools through these ambient system

solutions might be further investigated introducing also the notion of ‘deconstruction’ as means to enter the system and manipulate it. This paper puts in the same fashion focus on the complementary properties presence and absence.

As a consequence these systems should support the continuous attribution and negotiation of meaning through interaction. In order to examine these aspects we look at an evolutionary approach to ambient computing, considering what might be the thresholds to overcome the actual boundaries and problems.

In this paper we will address this investigation considering the notion of time as experienced in a particular domain, the Intensive Care Unit for Premature Newborns at “Le Scotte” hospital in Siena; exploring the concept of Palpable Time to support active negotiation of time between the diverse actors. Our aim is to create, with time as a mediator, a space of presence for sharing and interpreting events connected to the care of premature newborns. This system as we envisioned it, will pose on a community of actors constructed by both real and digital elements to dynamically create ecologies of entities. This in order to exchange information in such a way that it creates meaning for the different users; trying to bridge the cultural and political gaps between all stakeholders active in this particular setting.

PRESENCE WITH ABSENCE

Much work in “technology-mediated presence” has moved away from its original and widely assumed focus of “being there” towards a wider concept of “perceptual illusion of non-mediation” [5]. Halloran [3] offers an intriguing and complementary definition of “presence” that introduces the notion of “acceptance”. He suggests that “presence” can refer to “existential definitions of a thing based on how we invite and accept it as a part of our lifeworld”. This definition makes intuitive a scenario like the feeling of the authority in the work place, that even if not co-located biases the activity of the workers. Key elements of this scenario are the “illusion” of a mediated co-presence, the “accessibility” to culturally mediated systems of values, a compelling sense of sharing values and rituals with other people, the understanding of the semantics conveyed by the environment through perceptual stimuli designed ad hoc. Notwithstanding the articulated reality of the concept of “presence”, many current approaches to design systems mediating the sense of presence continue to be focused on the creation of a perceptual and sensory-motor immersion

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in non proximal or virtual environments. Nevertheless, perceptual immersion per se does not necessarily result in rich presence experiences. Sensorial realism is certainly an important influence on presence, but even a system, which perfectly mediates sensory perception, would not automatically induce a strong, continuous sense of presence. On the contrary, it may be associated with low engagement and alienation. Conversely, very basic communication technologies, such as chat rooms, can create strong and sustained experiences of presence, despite the poorness of sensorial realism. Expectations, lack of familiarity, limited prior experience, and limited cognitive schemas can dampen the sense of “presence”. Other factors like time pressure and stressful tasks pull attention away from other non-task related current sensory stimuli (virtual or real), potentially reducing the experience of physical presence [4].

THE NEONATAL INTENSIVE CARE UNIT

Valuable and peculiar features depicted the setting and the environment we observed. Critical and challenging activities define the Neonatal Intensive Care Unit (NICU) of the Siena Hospital.



Figure 1: The Neonatal intensive care unit

The Neonatal ward is divided into two units: the intensive care unit and the para-intensive care unit where newborn are moved when out of risk. All infants enter the NICU under different circumstances, there could be 24-weeks newborns or more, term infants requiring special aid for respiration or feeding. Generally admissions to the NICU are often occurring under emergency conditions related to the delivery or to the pregnancy while the infant’s health status and emergent needs determine the types of procedures and care needed. At the admission infants are placed on a preheated bed where the medical staff start to continuously monitor the infant’s heart rate, respiratory rate, oxygen saturation, body and incubator temperature and blood oxygen levels. These are non-intrusive methods of monitoring allowing the continuous assessment of infant’s

condition. The premature newborns are used to require complex medications, umbilical tubes, and intubations.

The basic problem regarding neonatal intensive care is that the baby should be as close to the mother as possible but at the same time the baby cannot survive outside the controlled environment of the incubator. Premature newborns could have many health status complications and need repeated medical examinations (i.e. for sight, hearing and motor-physical concern) to monitor their progress. When critical activities have to be performed medical personnel has to limit the access for visitors. Nurses and physicians are demanded to carry on critical interventions while preserving a safe environment for the children.

Being able to see your baby within the incubator can be a very intimidating experience without any kind of support or help to interpret and explain the setting and the current health situation of the child [8]. Parents usually don’t have the opportunity to meet the staff before the admission and they actually don’t know how critical the situation could become. Therefore, restrictions in visiting hours are set to provide and maintain a safe and quiet environment to perform these potentially critical procedures.

Actors as isolated individuals in the care work

Different actors intervene in the care of the premature newborns from the moment of the delivery.

The admission in the Neonatal Intensive Care Unit makes the parents feeling alienated and not more (or not yet) in control of the situation. They are completely immersed in their new situation where they seldom receive all the support they need.

Medical staff members take care of the children trying to supply them with all their needs and dealing with any possible problems or complications. There is one neonatal doctor in charge of a new admitted child, looking after the newborn until leaving the ward. The medical personnel share the same workspace but they do not share the same work: different actors have their own specific competencies, their own tasks and their own time in which they perform their duties. Each physician, nurse and therapist perceives, interprets and organizes their time in respect to the activity within the neonatal ward.

Parents try to get involved in the work carried out by the medical staff, but they are easily confused due to the stressful situation and their lack of knowledge about what is going on. As a consequence, each actor tends to carry out their own tasks, without sharing their information and experience with the other actors such as family and colleagues with a different organizational position. Social, cultural and political constraints currently inhibit the creation of a real care community.

PALPABLE TIME ENABLING THE CARE COMMUNITY

The vision of Palpable Time emerges from a concern for active support for the development of an egalitarian community around each premature newborn, including the

different actors involved in the process of taking care of the child. Therefore Palpable Time provides a stage where different actors regardless of formal role and power in the health care organization, can interact on equal terms, disregarding social and organizational status.

The concept depicts how the different stakeholders perceive, interpret and organize their time in connection to the neonatal ward. It addresses assemblies of people, devices and settings through time, supporting “remote presence” among members of a physically distributed Care Community.

In doing this, Palpable time becomes the setting of meaningful daily events that different members of a Care Community (child, parents, nurses, doctors, therapists) can share with others. Actors define “communication windows” to exchange vocal or textual messages, videos or intimate “signs of presence” (smell, heart beat, breathing, vocalism and tactile); utilizing connectivity between different communication devices with different input/output information resolution.

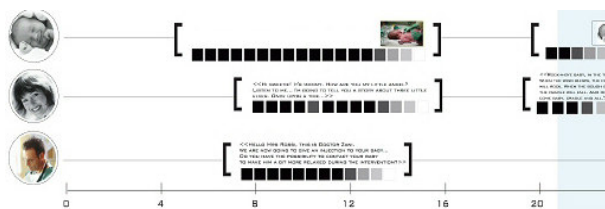


Figure 2: visualization of the Palpable time windows.

Palpable Time embodies the role of meaning mediator among actors, devices and settings and in parallel supplies the stakeholders and actors with the means to enable meaningful interaction to cross-organizational positions and social status. In this sense Palpable time can be understood as being based on concepts of heterogeneity and boundary objectness [2].

An exemplar scenario

In order to explore the potentiality within this concept we developed different scenarios. Below follows one example of those to better explain one typical setting and situation.

Sonja is in the hospital to visit Caterina, as usually she has brought the Palpable time audio link in order to be able to have a more physical sense of presence and intimacy with her baby in the incubator. During the visit, Doctor Zani and a nurse enter the room and explain that they have to do some treatment on the baby that was postponed earlier because a set of test had been delayed. The treatment involves various steps that will appear overly dramatic to the mother, so Zani has decided that it is better if Sonja does not see the treatment, getting to understand that Caterina was not a normal baby is still hard for Sonja. On the other hand it is better for Caterina if she can be calmed down and comforted by her mother during the treatment. Zani, the nurse and Sonja discuss what is going to happen, Sonja suggests that she can take the Palpable time audio

link with her to the next room and talk and sing for the baby during the treatment. In this way the treatment proceeds smoothly in cooperation between the four parties.

Even though the care community consists of equal partners, there are things that some of them do not want or need to see.

As our scenario pointed out above, the setting of our design work provides new input to the concept of presence. We would not like to create an illusion of being somewhere else, or provide users with push-pull like systems. The specific notion of presence in our work leads to the two extremes presence complemented with absence.

THE PALPABLE TIME PROTOTYPE

An early prototype of the Palpable Time System is being developed. By exploring the prototype together with families and medical staff we aim to co-construct properties, functionality and values of the concept.

The prototype presents itself as a repository of informational requests that has their own life cycles, represented in the prototype as “communication windows”. When two or more “communication windows” match, an information exchange as well as interaction between actors can be performed. The different users of Palpable Time announce the wish to interact with other actors. These requests can be time, space and data resolution specific.

From a web interface the different users can propagate these requests to other users sharing the same palpable time setting, i.e. the care community. In the creation of a “communication window” specific properties can be set, for instance the richness of shared or requested data.

In most ambient applications as much bandwidth as possible is wanted by the system, here it might be the opposite due to the specific setting where Palpable Time is supposed to operate. This flow of information between the different actors can be regulated and constrained depending on the situations, the needs and the expectations of the actors themselves. For example, even if a real-time video and audio stream is available hardware-wise from an incubator it may be better, as described in the above scenario, to limit the data to audio only.

The prototype aims at exploring how humans, devices and applications negotiate availability, communication requirements and possible artifacts to mediate the interaction. As some actors most probably move between different spaces and setting during time a number of roaming situations must be supported in a final system; both between networks and between devices.

Technical description of the prototype

The prototype is today based upon standard client-server components and implemented around MySQL, an Apache web server running on a Debian Linux system. Furthermore a Java server with clients is used to handle specific tasks. A user (doctor, parent etc) propagates either

the availability of an information source or the request for some information utilizing a common web interface. These activities can be of a synchronous or asynchronous nature.

A mother can for example request information about the physical condition of her premature born child. The request propagates through the system and a doctor at the ward can respond to this request while being at the computer. The mother is notified and can access the information. The doctor can therefore open up a synchronous time window, for example two hours, during an afternoon with less activity, if a parent at the same would like to discuss some issues regarding the situation they can connect to the open time-window and initiate for example a voice communication. This is today handled by Java applications that interact with the Sql server where information about these different information sources and requests are stored.

DISCUSSION

Our concept of Palpable Time elaborates on a new challenging view of presence complemented with absence. The concept addresses scenarios of fundamental lack of presence caused by the premature birth. The isolated environment in the incubator is necessary for the child's survival, thus absence is a basic condition for the prematurely newborn and the mother. But with the help from the palpable time technology the premature baby and mother can regain some of the intimate presence that normal children and mothers have. When the child was in the mother's uterus they experienced a close intimacy and they were able to communicate, to react to each others movements, to be aware of the other's diurnal rhythm: the mother could sing for the child, tell stories etc. Palpable Time provides the possibility to open up an intimacy window enabling the mother and the child to extend their intimacy beyond their separation.

Furthermore in the premature birth scenario, presence has to be balanced with the considerations for how painfully aware the mother has to be of all the details of the treatment. In that way we also have situations where total presence is not desirable, but has to be complemented with "absence", that is some means for filtering the physical presence with alternative ways of participation in a situation. The idea of collaborative presence and absence allows, for example, an actor to be physically absent while fully present in taking care and collaborating. The effect of this is directly graspable in the Neonatal Intensive Care setting. When the mother is present the child is calmer and more relaxed.

The medical staff usually tries to saturate the sensorial channels of the child with massages and perfumes in order to balance the painful sensation during some treatments [1]. By allowing the mother to be remotely present through intimate communication (smell, heart beat, breathing, vocalism) [4] the child could be more relaxed and safe during medical interventions.

The evaluation of the Palpable Time has just started. Simulations have been tried out in the lab and the concept has been submitted to a continuous process of discussion and refinement with stakeholders. Our scenarios based on the idea of a care community seem promising and interesting for our stakeholders. In particular, users appreciate the idea that the parents (and the mother in particular) can participate actively in the treatment and that mother and child independently can establish an intimacy enabled by technology. It is, however, important to acknowledge that these scenarios and the idea of a care community depends on deep organizational changes, as well as deep changes in the professional culture at the hospital. This implies the idea of a horizontal organization in which all members are equally valued and where the stakeholders interacts according to their preferences and availability from a time-space perspective.

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