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Exploring Mobile Information Systems for Adolescent Cancer Patients

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Abstract¹

Adolescent cancer patients have to deal with many dependencies and obligations. Very often they are torn out of their social environment and become isolated because of changing therapy cycles and different treatment locations. This causes significant social and economic damages. The objective of this article is to present the first steps of an empirical exploration of the possibilities of mobile IT-support for communication and coordination for this target group during treatment and aftercare. Special emphasis is put on the effects of mobile systems on the patient's perceived quality of life. The background here fore is a four-month field experiment conducted together with the cancer station of the hospital of Heidelberg University. We focus on particularities of and challenges for mobile information systems for patients in Germany and outline necessary future research aspects in this field.

1 Diagnosis of the problem situation

Cancer diseases are after cardiovascular diseases the second most frequent causes of death in Germany. Every year approx. 338.000 people are confronted with the diagnosis "cancer" (Deutsche Krebshilfe 2003), out of these approx. 1800 are children/adolescents under 15 years (Arbeitsgemeinschaft Bevölkerungsbezogener Krebsregister in Deutschland 2002). Cancer among adolescents is considered as a chronic disease (Pfefferbaum 1990, p. 555). It is important that the affected adolescents can have an as normal as possible physical and psychological development since this can be an important step towards a successful coping with the disease (Kyngäs et al. 2000).

The treatment (e.g. in the case of leukaemia) usually lasts two years and consists of several different stages. During the different stages the patient migrates between locations: Permanent hospital phases, ambulant/day hospital phases and home care phases. In some stages of the treatment cycle patients have to be isolated because the chemotherapy has weakened their immune systems. Extensive medication plans, different physicians, many different consultation appointments and strong side-effects very often demand too much from the patient and its family. The adolescent is excluded from important social events in his social network (Rowland 1990, p. 535). Additionally many patients retreat into their shells because the physical changes of their bodies make them feel fragile and unattractive (Adams-Greenly 1990, p. 563).

These aspects show the importance of patient interaction with their existing social networks but also the relevance of developing new social contacts, for instance with other patients. Additionally it becomes evident that adolescent cancer patients have to deal with many coordination problems (medical appointments, medication plans, etc.), not to mention control and reminder issues that parents have to deal with. Another challenge emerges from the patients' migrations between contexts /locations (school, hospital, etc.). These insights deliver several starting points for ICT-support in general and for mobile IS-support in particular.

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2 A Mobile Information System for Adolescent Cancer Patients

2.1 General conditions and requirements for an ICT-Solution

Frequently changing locations/contexts determine patients as nomadic users that require ubiquitous access to relevant information and ubiquitous communication possibilities. It is known from innovation research (e.g. (Rogers 1995)), that a successful innovation (in this case a mobile IS for patients) has to have a relative advantage (subjectively perceived advantages), it should be compatible with the values, attitudes and demands of a potential user and its environment, it should be easy to use (comprehensive and manageable), triable and observable.

A potentially fruitful approach is a mobile system that follows his user everywhere or that the user always carries along. Since mobile phones are widely spread among adolescents such a system could be based on mobile phones. This would be pragmatic especially given the already existing adaptation of the target group to mobile phone usage.

2.2 Mobile radiotelephone services and healthcare

A system based on pulsed radiation (such as GSM/UMTS mobile radiotelephone service) has to deal with some problems in the context of hospitals. In many hospitals and medical practices the use of mobile phones is restricted or prohibited (Otto/von Mühlendahl 2003, p. 26) because of potential disturbance of vital medical equipment (Goslich 2003). However, in reality this prohibition is often handled less restrictively.

Impacts of high-frequency magnetic fields (as caused by mobile phones) on the human health are addressed very controversially in academia and practice. Especially new often inconsistent or contradictory research results cause frequently explosive discussions (Berg/Breckenkamp/Blettner 2003). Potential adverse health effects are assigned to thermic effects of radiation, but also athermic effects are suspected. A final evaluation of the biological risks of emissions caused by mobile phones is currently hardly possible (Maes/Haumann 2002, p. 31). The broad usage of cellular phones exists only a couple of years; therefore further research especially on the long-term effects is still necessary before scientifically profound evaluations can be made.

Mobile phones can cause technical disturbances of sensitive medical equipment (e.g. cardiac pacemakers) (Goslich 2003). Correct shielding against magnetic fields and sufficient distance (radiation loses intensity squared to the distance between sender and receiver) to medical equipment are said to be sufficient for avoiding disturbances (Bundesamt für Strahlenschutz 2003).

Several types of wireless communication have already entered the healthcare system (Campbell/Durigon 2003, p. 233). Some hospitals use already WLAN, location-based services (e.g. for emergency calls) and transmission of medical data directly to the clinic bed or from the ambulance to the hospital are currently being explored (Goslich 2003). In the following we will develop a scenario for mobile IS usage of adolescent cancer patients.

2.3 A Scenario

Markus Fiedler (fictitious name) has been diagnosed with cancer a couple of years ago. The apprentice has recently completed his second therapy cycle. When he is on his way he has always all his medical data in his pocket: a smartphone contains all important information about his disease and allows him to keep contact with his hospital, family and friends.

Several times a day the device is beeping. By this sound the smartphone reminds him to take his medicine. All important data, diagnostic findings (e.g. blood parameters) and a pain / side-effect diary are on his device and accessible anytime and from any place. Frequently changing schedules and appointments can easily be administrated. Markus' autonomy and independence are increased and mistakes reduced.

The smartphone allows him to use several communication channels (E-Mail, Instant Messaging, SMS and MMS). Thus he can easily maintain contact with his social network, other patients of school mates.

Following we describe a system that is intended to realize the previously outlined scenario.

2.4 The applied system

The hardware chosen for this study is a smartphone, a combination of a PDA, a digital camera and a tri-band mobile phone, distributed by O2 Deutschland GmbH & Co. OHG (figure 1).


	<p>Hardware: XDA II (distributed by o2 Germany GmbH & Co. OHG); Operating System: Microsoft Pocket PC. Features: Tri-Band, 32 MB working storage, SD I/O-Slot, Java-capable, GPRS-, WLAN-, IR- & Bluetooth-capable, built-in camera, etc. Applications: MS Office (Pocket), MMS, SMS, Internet-Browser, E-Mail-Client, ...</p>
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Figure 1: The applied mobile device XDA II with technical specifications

The PDA- and camera-functionalities can be used separately from the phone unit allowing usage of the device independently from the permission to use a mobile phone in certain areas. The device can be used as an internet access device, displaying ordinary internet pages with its browser and allowing sending and receiving e-mails, and with an extension it is WLAN-compliant. User dialogs can be made via a touch-screen, using either a virtual keyboard or handwriting recognition. There are plenty of applications available for pocket pc devices, most of them being similar to pc desktop applications. For the support of adolescent cancer patients especially the coordination tools (calendar, diary, notepad) and communication tools (sms, e-mail, instant messaging) are of major interest and their usage in the field study will be consequently analysed in more detail.

3 Research Design

The research object „mobile information systems for patients“ is very new and hardly investigated. Valid results and insights in this field do not exist yet. Therefore an explorative research design is applied in the following study in order to grasp deeper insights into this domain. Since general theories about the research object do not yet exist, the research process can hardly start from a theoretical background. Stating and validating hypotheses as common in an empirical-analytical research designs cannot be applied here. The intension of this research is the design of reality. According to Ulrich very often the research process starts „...in practice, is focused on analyzing the context of use and ends in practice“ (Ulrich 1981, S. 19), this research can be classified in this tradition.

The field study was conducted together with the university hospital in Heidelberg. Based on a 4-month pre-phase with 5 test users exploring the possibilities of the devices and services without limitations the actual field study was designed and conducted with 16 patients in a 4-month period from February to May 2004. Table 1 shows the allocation of patients along gender and diagnosis.

The individual process of using and evaluating technology and innovations depends strongly on the social environment. Also the resistance of the hospital staff towards the electronic devices had to be overcome. Hence selected hospital staff and selected parents resp. relatives were equipped with devices as well. However they are not included in the following analysis.

	Gender		Overall
	male	female	
leukaemia	2	2	4
bone tumour	3	1	4
lymphoid cancer	2	1	3
other tumour	2	0	2
mucoviscidosis	0	3	3
Overall	9	7	16

Table 1: Gender and Diagnosis of the Participants in Field Study (Source: (Knebel/Leimeister/Krcmar 2004)

3.1 Introduction of Smartphones

Users will only be able to evaluate the smartphone after a longer period of use. This process can be influenced significantly during the introduction phase since basic attitudes are formed then (Döhl 1983, S. 200). Consequently the analysis of the introduction phase is of major importance in this study. In order to explore the potential support and benefit of mobile information systems for cancer patients, interventions (i.e. tasks the user had to accomplish in his daily context) were designed for supporting the self coordination and communication. For motivating and supporting the use of the devices additional events were organized, for example support meetings, user meetings, on-the-spot-support, etc. The services and applications used in this explorative study were freely available and

merely configured for the current requirements; no specially developed software was applied. For a detailed overview of the actions conducted in the introduction phase see (Knebel 2004).

3.2 Interventions: Tasks for the users

The purpose of the interventions/tasks can be assigned to two topic areas: self coordination and communication support for keeping up the patient's social network.

Self coordination: During a therapy a patient has to deal with extensive schedules and medication plans that change very often. Also a close observation of the patient's state of health is crucial. Adolescent patients and their parents are frequently swamped with this necessary monitoring. The use of an XDA in order to coordinate these different tasks can help to keep appointments and supports a well-organized and central data management of all data concerning appointments and medication treatment. Also parents will be relieved from their duty to remind their children continuously of making and keeping appointments and of taking medicine, also because of the available reminder functionalities. A further result can be the improvement of patient compliance, the reporting of the patient's health status over the time.

Services applied in this context were a calendar function for managing appointments and medication plans, a contact list, a task list for daily to-dos and also a patient's diary for protocolling pain and health conditions. Introducing the digital management of appointments and the diary was done by giving specific tasks to the test users. They were told to enlist all appointments with doctors and taking their medicine and activate the reminder function for these tasks. The handling of the device and its functionalities was explained in detail in a training provided for the users. The users were also provided with printed information.

Communication support (for maintaining contact to the social network): Spending a lot of time in hospitals – often far away from home – and being isolated due to their health state makes it difficult for young people to stay in contact with their peer groups. Building up a new network or community of “peer sufferers” can help to push the cure process and improve perceived quality of life (see Chapter 1). Thus the purpose of using an XDA in this context is to enrich the possibilities to stay in contact with family and friends. The reduction of inhibitions of the patients and their communication partners as well as the possibility to get in contact with persons easily, quickly and irrespective of the location is also a positive effect caused by the use of the mobile device. Services such as E-Mail, MMS, SMS and ICQ were used in this context. The participants were told to explore these communication possibilities and use them for their daily concerns. Restrictions were a cost limit of 100 € per device and month. Using the device as a telephone was prohibited particularly to support the use of alternative services. Most participants knew these service from their private mobile phones or home PCs. Creating, sending and receiving SMS and E-Mails as well as creating a new E-Mail account was also explained in the initial trainings. Additionally the users received print material with detailed information.

4 Preliminary Empirical Results

Before handing out the devices the users had to fill out an extensive questionnaire. Existing knowledge of the users plays a major role for „learning“ about new devices and systems (Agarwal/Venkatesh 2002), therefore the participants were asked about their technical competence and affinity, their PC and mobile phone usage behaviour and their experiences with managing appointments and medical documentation. Functions and applications of the XDA are very similar to those for PC and mobile phones. An estimation of the existing technical competence was deduced from the stated use of PCs and mobile phones. 14 out of the 16 test persons did have a mobile phone that was used at least once a day by 11 of the persons. All of the users had access to a computer at home. 14 used the computer once a week, 12 at least once a day. Internet and E-Mail were the most frequently used services followed by computer games, applications and chat resp. ICQ (for detailed results see (Knebel/Leimeister/Krcmar 2004)).

In the following we will focus particularly on the use of the appointment management (calendar / reminder functionalities), the patient diary as well as on the available communication services.

Self coordination: According to the statements of the patients and the evaluation of the medical staff in the hospital the self coordination of the adolescents improved significantly by using the mobile devices. The central data storage and appointment management in one device helped to avoid mistakes and confusions when managing different important appointment. The mobile device led to a more precise observance of and compliance with appointments.

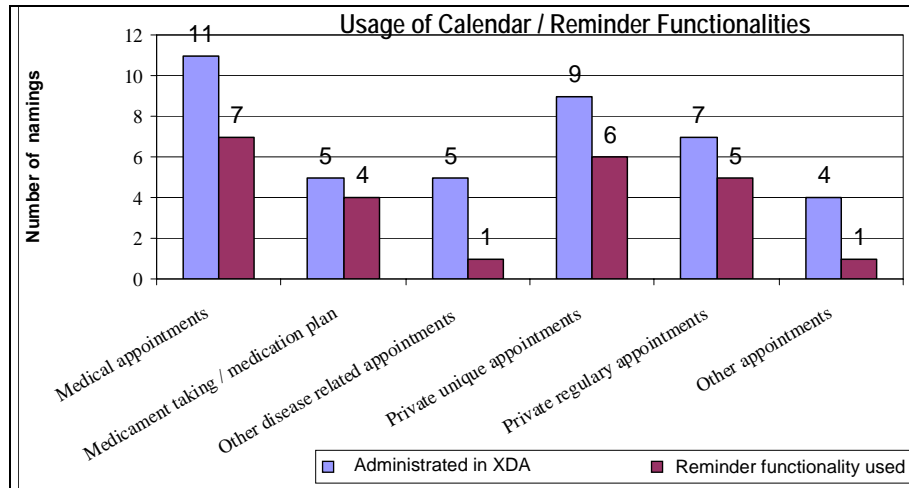


Figure 2: Usage of calendar and reminder functionalities (n=13), (Source: (Knebel/Leimeister/Krcmar 2004))

The electronic patient diary was not well accepted among the patients (see figure 5 in the appendix). Writing a diary was often seen as of little help and considered laborious. From a medical point of view using a diary can be a great help during the treatment process when used consequently and continuously. Physicians hope to get more valid insights into cause-effect-chains during treatment, data they usually cannot receive since patients are not monitored when they leave the hospital. Thus they expect to gather deeper insights into the compatibility of single and combined therapeutic actions over the time. But since there was no immediate benefit for the patients using the diary they abandoned it wherever possible.

From the empirical exploration of mobile information systems for the self coordination of patients the result can be drawn that mobile services and applications together with mobile device are appropriate to support young people with chronic diseases in managing their self coordination.

Communication support: The intensity of use of the communication means varied a lot among the participants. All in all SMS received the highest relevance in the target group. SMS was used in particular to get in contact spontaneously or to organize ad-hoc meetings. In contrast E-Mail was used for transmitting large amounts of content. Instant Messaging allowed the most versatile use, e.g. for communicating about the disease or current feelings. However, only few people communicated over this channel because most of them were not very familiar with it.

Especially encouraging is that computer-mediated communication was very popular among the participants and apparently among young people in general (see figure 3 in the appendix). It is also remarkable that anonymity in the communication was not important to the users. It is known from other research that computer-mediated communication lowers barriers (see e.g. (Döring 2003)) to talk to other people or to start a conversation. The communication via chat of the participants of this study focused on friends, while SMS were also sent to family and other patients. Astonishingly hardly any computer-mediated communication took place between physicians and patients.

Computer-mediated communication is an essential part of the communication structure of young people, more than it is the case among other age groups. For keeping and supporting this communication structure even in the case of a severe chronic disease, the access to computer-mediated communication is very important. When desktop PCs were available the use of a mobile device took a back seat due to the lesser ease of use. However, in most situations, e.g. in hospitals or rehabilitation centres, desktop PCs were not available. Then a mobile device offered new ways of communication and coordination – the mobile device became an enabler for the patients. Another advantage was that different communication applications and services were integrated in a single device and an immediate access was possible.

Overall aspects: The independence of location for usage was considered the most valuable aspect of the mobile information system. Using the device was considered fairly easy, only the keyboard was often perceived as too small. The device and its services were regarded as an immense help, although they did not make the patients feel better when it came to dealing with the physical aspects of their disease. The acceptance of the device and its usage among family and hospital staff as well as among the participants was fairly high and the hospital staff worked as promoters for the field study.

It is difficult to evaluate whether the use of similar mobile information systems makes economical sense for patients on the basis of this study. Services such as the appointment management (calendar) and contact management can hardly be valued in a monetary way and compared with the initial and operating costs caused by the system. The initial costs of such a system are fix and relatively high for a private person while variable costs can be influenced by usage. Costs for internet use can be reduced by using a WLAN card where/whenever WLAN access points are available. In this experimental setting the costs for self-coordination were zero / not existent and the costs for communication support were manageable.

5 Outlook: Chances and Challenges of Mobile Services and Devices for Patients

The aspects self-coordination and communication support for patients seem to bear promising further research potential. Broadening the focus beyond these aspects and target group opens the chance to analyse the use of mobile services and devices in the hospital environment in general. The need for further research in this area however holds some challenges and limitations. Until now there are still no reliable and transferable empirical results in this area.

Additionally these first empirical results from an ongoing research project do not include the effects of specially designed software solutions; especially the used patient diary was suboptimal and did not meet the users' requirements. Further applications could be very valuable for patients and medical staff: online group calendaring, resource management or medical information repositories.

Limitations emerge from the prohibition of mobile phone use in some hospitals; they limit the use of such systems in many hospital areas. Additionally it remains to be seen whether WLAN extensions are capable to overcome the restrictions mobile phones are facing. Aspects of data security and privacy are of great importance in the context of medical data and hospitals. New applications and services must always meet current legal restrictions, even when some legal aspects in Germany are still "under construction".

This research explores first potential application areas of mobile information systems for patients. Due to the small number of not representatively selected users and the short period covered in the study the results have to be understood as a first step towards empirically substantiated research in this area. There is a need for broader verification of the findings as well as a need for longitudinal studies in order to be able to assess the sustainability of mobile systems for patients and for mobile systems in healthcare.

The exploration of mobile devices for patients is only the first step within in a wide field of possible scenarios in the health sector resp. hospital sector. The health sector opens many possibilities for improvement of communication, coordination and collaboration of different actors. Other possible scenarios and fields where mobile devices and services could be promising refer to the cooperation of different medical actors or the cooperation between medical service providers and health insurances

By the time of the conference we hope to be able to present further results from the usage of several developed software applications for patient self-documentation and different groupware functionalities such as automated calendaring services with the hospital or individual patient record access.

6 Appendix

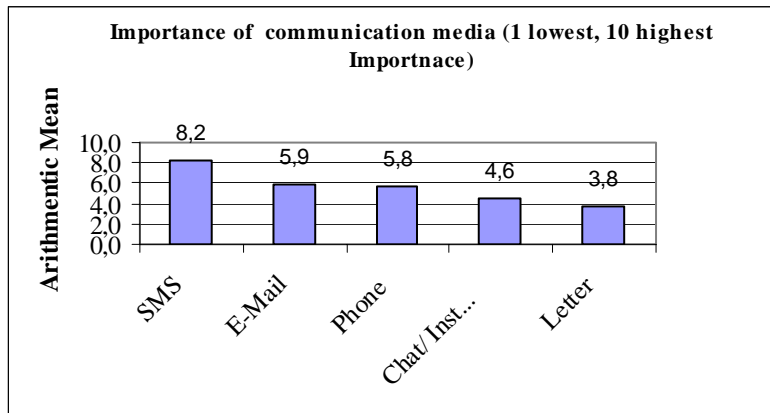


Figure 1: Importance of communication means: Mean (n=9), (Source: (Knebel/Leimeister/Krcmar 2004))

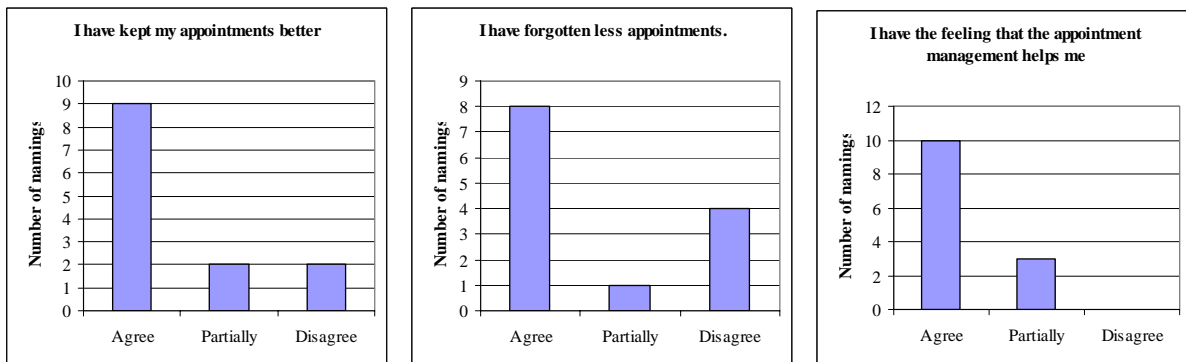


Figure 2: Keeping appointments and perceived benefit of appointment management (n=13), (Source: (Knebel/Leimeister/Krcmar 2004))

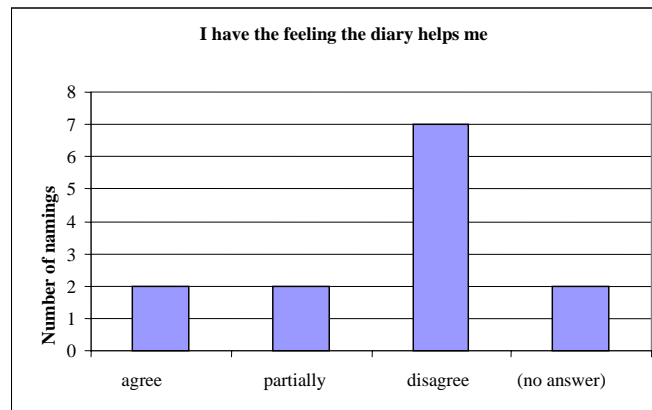


Figure 3: Perceived support of the diary (n=13), (Source: (Knebel/Leimeister/Krcmar 2004)).

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