

A case study of an interaction design approach to pervasive healthcare

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ABSTRACT

We conducted a survey in a dermatology outpatient clinic to identify issues related to user experience, usability and learnability, looking at outpatients as users and the dermatology clinics as a service. The results showed that there were no problems with the quality of the medical care in line with current practices and guidelines. However, patients expressed the wish that they had received more information and more personal support regarding their condition. There were also strong correlations between the outpatients feeling confident, comfortable, and them having a positive experience of the clinics. Learnability, usability, and user experience were also strongly correlated with other questions. These results indicate the positive potential of an interaction design approach based on personalised and pervasive services as means to improve healthcare in a dermatology clinic.

Author Keywords

Interaction Design; Dermatology Clinics; Ambient Assisted Living; Pervasive healthcare.

ACM Classification Keywords

Applied Computing: Life and medical sciences: Health care information systems.

INTRODUCTION

Healthcare costs and caring for long term conditions such as chronic diseases and ageing are a heavy burden on the public purse. It makes sense to encourage and support patients into adopting better lifestyles to improve their condition, and into practicing better self-care to ensure medication compliance which will then, in turn, reduce their demand on health services (notably visits to the hospital clinics, and interaction with staff for routine issues). Furthermore, rather than regular visits to the clinics, we posit that patients would prefer to carry on with their normal life and have minimum disruptions due to their condition. Patients should also have

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more choice and control over their care and be given opportunities to build expertise on doing so [14].

Background

Pervasive Healthcare System (PHS) is a decentralised, preventive and assistive approach to the delivery of healthcare services [3]. It is a system for self-managed care and medication compliance, which is particularly suitable for chronic diseases with low to medium risks but high impact on Quality of Life (QoL). Behaviour and health condition monitoring, support for the user's awareness of condition, improvements to user's QoL, minimally-intrusive provision of healthcare, and connection with healthcare professionals are all mentioned in the literature as key feature of PHS [1,15]. However, most work reported, focuses on system integration, data collection and processing, context modelling and detection of anomalies [1,15,16]. An alternative is to focus on interaction design and user experience issues. It is in line with what has been advocated in the literature [4, 7], and in particular the importance of usage, learnability and aesthetics as elements of design of a PHS [2].

Motivation

Long term and chronic medical conditions are significant constraints on patients, in particular those conditions that are detrimental to the quality of life (QoL) of individuals. For this study we chose to focus on psoriasis. Psoriasis can be physically and emotionally debilitating and is not just affecting the patient's appearance and image, it interferes with daily routines, causes psychological distress, and disrupts social relationships [13]. The condition has also significant impact on the patient close relatives, its psychological effects extending to the close family [9].

Current therapy for severe cases is based on a holistic approach that aims to improve the patient's overall lifestyle and well-being [17]. It is now accepted that a successful management of psoriasis depends on assessing and treating both the physical, and the psychological aspects of the condition, and on an understanding of the link between the two [8,10]. It requires a certain level of personalisation of the combination of therapies and the correct timing of their administration. Hence the relevance of the work presented hereby: as its overall aims are to improve various aspects of the patient daily life with a better user experience (UX) of the clinics and improve medication compliance with an assistive PHS.

This paper reports on the survey we did of Outpatients that visited the clinic of the Department of Dermatology at the Royal Victoria Infirmary Hospital (RVI) in Newcastle upon Tyne (UK), as part of a project called Patient Care Quality Improvements (PCQI). We investigated how they perceived and experienced their medical care and their visits during the clinics. These form only part of the issues patients face when caring for their condition and wellbeing, in most scenarios of long term conditions, patients manage much of their healthcare independently as part of their daily routines [7]

PRELIMINARY INVESTIGATIONS

This investigation was the first part of the project. The aim was to determine specific area(s) of the hospital and clinics that could be target for interaction design (IXD) improvements. To do so we observed an outpatient visit pathway and had our observation validated by 2 senior hospital nurses and 2 doctors who described our observed pathway as a typical outpatient visit.

In a typical visit pathway, difficulties arise at the following stages of the outpatient walkthrough: (1) initial finding of the hospital; (2) parking space; (3) finding the dermatology outpatient reception area; (4) waiting time for consultation is not clearly indicated; (5) finding the pharmacy; (6) waiting time indications at the pharmacy are misleading; (7) Waiting area for pharmacy is not suitable; (8) Car park time limit is not sufficient. There are two points in the pathway that were identified where outpatients are visibly unhappy (as also reported from staff observation), during waiting times in an outpatient visit (typically 60-70% of visit length): (1) waiting for the consultation, (2) waiting at the pharmacy. Indeed, waiting time is of particular concern, as it affects the mood of the outpatient which can have detrimental effect on their condition just before consultation. It is a known fact that uncertainty about the waiting time and the procedure at the clinics have a negative effect on the patient experience [12]. These results are of particular importance, considering that stress and bad mood negatively affect the condition of psoriasis sufferers.

We also distributed a preliminary questionnaire with 60 questions to 10 medical and paramedical staff at the RVI, to investigate if they were aware of any issues related to the care given to outpatients. We report here, the most relevant results – those that indicate some issues. They are (scaled -2, 2): (1) Whenever patients make a mistake regarding how they care for themselves, they can recover easily (average -.25, standard deviation 1.281); (2) Whenever a patient makes a mistake regarding how they take their prescriptions, they can recover easily (avg -.142, std .899); (3) Prescriptions give instructions that clearly tell patients how to fix mistakes if they make any (avg -.875, std .991), and; (4) Patients like taking the prescription(s) (avg -.285, std .487).

These preliminary results indicate that the following issues need addressing: (1) Instructions and support for patients that make mistakes in taking/applying their prescription(s); (2) Ease of recovery for patients, from a mistake in

taking/applying their prescription(s); (3) The dislike patients have of taking their prescription(s).

OUTPATIENT SURVEY

Following our preliminary results, we decided to move onto a more thorough investigation via a comprehensive survey of outpatients. We designed a questionnaire to investigate the patient experience during an outpatient clinic, some medical data was also collected in the form of background outpatient information (e.g. age, duration of conditions, length of time as an outpatient), DLQI (Dermatology Life Quality Index) and HADS (Hospital Anxiety and Depression Scores) questionnaires [10,18]. The questionnaire was divided into three parts: (1) Background Questions, (2) Effectiveness, Efficiency, Affect and learnability and, (3) Usability and User Experience. It was made up of 95 questions. Apart from the validated DLQI and HADS parts, the remainder of the questionnaire focused on Usability and UX issues, more specifically questions were related to: (1) Effectiveness, (2) Efficiency, (3) Affect, (4) Learnability, (5) Experience, (6) Context and (7) Usability.

Survey Participants

We have surveyed outpatients suffering from psoriasis at the clinics of the Department of Dermatology at the RVI from February to December 2016. N= 101, 53F, 48M, Average age 47 (std 15), average disease duration 247 months (std 204), average visit frequency 7 per annum (std 1), mean Psoriasis Area & Severity Index - PASI 7 (std 7). PASI 1-3 indicates mild disease, 4-9 is moderate and 10 and over is severe [11].

Aim

The aim of the was to identify which questions were most effective in recognising the issues and identify the outpatients who would benefit most from different clinic IXD solutions, to enhance their UX and improve their disease management. We focus in this paper on questions that have correlated with others, as possible indication of their importance. However, future work will be needed to determine if the correlation is coincidental or causal. Having identified the most discerning questions the aim would be to reduce the number of questions to around 20-30. Questions were designed as bi-polar scaled questions (5 intervals Likert scales), with the exception of those that had a yes/no answer. The full questionnaire is available online as a PDF at: www.bsalem.info/PCQI_Questionnaire.pdf.

Method

Over the duration of the survey (between February and December 2016), when the outpatient had their appointment at the clinics they were presented with the possibility to participate voluntarily in the survey via an explanation sheet. If they accepted to take part, they were then given instructions as how to fill the questionnaires handed to them, they were also informed of the financial compensation they would be entitled to for the returned questionnaire (GBP 15). They were allowed to fill the questionnaire at their own time

and pace, due to its length. The study was approved by the NHS ethic committee for the North East of England.

The questionnaire response data are reported as descriptive statistics, with some of the questions not reported as no significant or relevant problem were identified. In order to discover which questions were the most discerning, we first looked at questions where the mean answer was 30% or more different to the optimal answer. We then ran a correlation analysis of the questions to identify questions that are potentially indicative of important issues that relate healthcare, UX, and IxD. We also looked at the remainder of the answers and report on those that are relevant to this study.

RESULTS

Our primary objective is to identify issues that have a detrimental effect on the interaction and the experience that outpatients have of their clinics. These are not necessarily limited to effects in terms of medication, medical or psychological well-being, but also in terms of their experiences and their interactions with the RVI staff.

Descriptive Statistics

We report on the cohort of outpatient responses to our questionnaires presenting the questions grouped by questionnaire sections, indicating the ideal answers, avg. and std. of each answer. We focus on the questions are relevant to the scope of this paper. Here we regroup the questions according to what they might indicate.

Background Questions A

The average DLQI average score was **7.1666**, with a standard deviation (std) of **7.3902**. First, the average score, indicates that as a cohort, the surveyed outpatient conditions have moderate effect on their life (we interpret the DLQI score with the following rule: 6 – 10 moderate effect on patient's life. Second a larger std is a clear indication that we have surveyed a varied cohort of subjects, across the range of condition severity and impact on their lives.

Background Questions B

We calculated the HADS out of five questions for Anxiety (13, 15, 17, 19 & 25) and five questions for Depression (14, 16, 20, 21 & 24). We used a similar approach to Bjelland [5] and the surveyed outpatient cohort, gave an average score of **1.7678** for Anxiety and **2.7313** for Depressions. Both are below the threshold for the presence of either conditions. Although the average score for Depression is noticeably higher. This is a result that was expected, as psoriasis is known to trigger depression.

Other Background Questions

I have been given help with strategies on how to deal with the impact of my condition on my physical well-being: Yes 55.71%, No 44.29%;

I have been given help on strategies on how to deal with the impact of my condition on my Psychological well-being: Yes 32.88%, No 67.12%;

I have been offered the possibility to self-manage my condition at home: Yes 70.00%, No 30.00%.

The answers are indicating that not all outpatients are given helpful information about how to care their condition, a fact that could have consequences in terms of QoC.

Descriptive Statistics

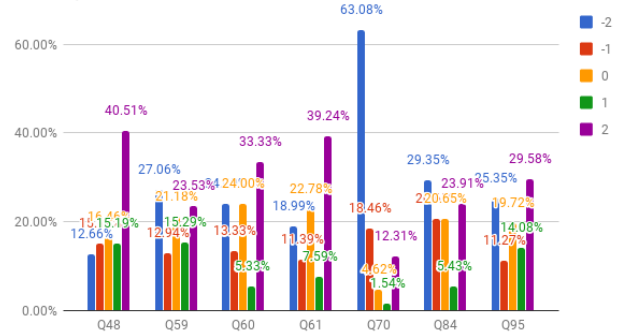


Figure 1. Descriptive Statistics for selected responses

Effectiveness, Efficiency, Affect & Learnability (questions are 5 intervals scale, for all interval values see figure 1):

Q48 *Would you want extra information* Definitely 12.66%... Not at all 40.51%; Meaning that 59.49% of participants would like extra information.

Q59 *I changed my lifestyle to suit my condition* Significantly 27.06%... Marginally 23.54%

Q60 *I changed my lifestyle to suit my regular usage of prescription creams* Significantly 25%... Marginally 33.33%;

Q61 *I changed my lifestyle to suit my regular usage of prescription tablets/injections* Significantly 18.99%... Marginally 39.24%;

Answers to questions 59, 60 and 61 indicate that outpatients' lifestyles are affected by their conditions.

Q70 *I needed to learn a lot of things before I could get going with using the prescription injections* Strongly disagree 63.08%... Strongly agree 12.31%; The results indicate that the outpatients perceive the usage of prescription injections as difficult and requiring training.

Q84 *When at the clinics, I have spoken to other outpatients* Strongly disagree 29.35%... Strongly agree 23.91%; The answers indicate that the outpatients have a clear tendency to ignore their peers and potentially do not benefit from their support.

Q95 *During visits to the outpatient clinic, I can only go through a process without being able to change events or their order* Strongly disagree 25.35%... Strongly agree 29.58%. The outpatients have a clear tendency to believe they are not in charge and have to follow a process.

Analytical Statistics

In this section, we report on analytical statistics we have run on the responses collected. We present correlations between answers that are either **significant** or **highly significant**. We also indicate if the effect is **Small**, **Medium** or **Large**. A desired correlation between answers would be **highly significant** with a **Large** effect. We considered the results to be **significant** where such a probability was equal or less than 5% (e.g. ≤ 0.05) and, **highly significant** when the probability was equal or less than 1% (e.g. ≤ 0.01). The effect size was qualified according to Cohen [6] guidelines: $0.1 < |r| < .3$ **small** effect, $0.3 < |r| < .5$ **medium** to moderate, $|r| > .5$ **large** to strong.

All questions were subject to a Pearson correlation r test. Those tests that yielded significant or highly significant results were then subject to scatterplot visual inspection for the detection of linear association, if any. Those pairs of questions which yielded significant to highly significant results and whose scatterplots showed some linear association are presented in the next section. In other words, we present in the next section questions that correlate with other in a statistically meaningful way.

Correlations with a Large Effect

I did finish the course of my prescription injections and I think that I will need the support of a nurse to be able to use the prescriptions I was given: $r(16) = -.634$, $p < .01$, $r^2 = .40$, large effect

In essence the outpatient who finish the course of injections do not need support. But what about those who did not finish the course?

When I arrive at the clinic I am greeted by the staff and:

1. While in the consultation room I can raise all sort of issues that are relevant to my condition: $r(93) = .586$, $p < .01$, $r^2 = .36$, large effect.

2. The order of events, from arriving at the hospital until leaving it, is logical and well-ordered: $r(93) = .586$, $p < .01$, $r^2 = .34$, large effect

The order of events, from arriving at the hospital until leaving it, is logical and well-ordered and Overall I have a positive experience of the clinics at the RVI: $r(94) = .521$, $p < .01$, $r^2 = .27$, large effect.

I feel confident during my clinic visits and Overall, I have a positive experience of the clinics at the RVI: $r(93) = .675$, $p < .01$, $r^2 = .45$, large effect.

There is a strong correlation between staff greeting the outpatient, the outpatient being able to raise all sorts of issues that are relevant to their condition, and the logic and order of event during their visit. This is rather unexpected and highlight the key role greeting and welcoming outpatient can have on their visit. There is also a strong correlation between the order of events during a visit and the positive experience outpatient have. Finally, there is a strong correlation between

outpatient confidence level and their overall positive experience

Correlations with a Medium Effect

There are medium effect correlations between the following issues:

The feeling that the outpatient treatment is useless **and** the fact that their condition is itchy, sore, painful or stinging. There is also a medium correlation **with** how embarrassed the outpatient has felt.

The outpatient feeling that their treatment is useful **and** them understanding how to treat their condition.

The outpatient finishing the course of their prescription creams **and** them having difficulties getting to the RVI **and**, finding the order of events logical and well ordered. There is also a medium effect negative correlation **with** the outpatient being focused on their psoriasis during their appointment.

The outpatient confidence in using their prescription medicines **and** their lack of understanding on how to treat their condition. There is a similar correlation **with** lack of help given to the outpatient on strategies to deal with their condition's impact on their physical well-being. Finally, a similar correlation occurs **with** the lack of offer to self-manage their condition.

The outpatient speaking to other outpatient when at the clinics **and** them having casual conversation with the staff, being greeted by the staff, **and** them having an overall positive experience of the clinics.

The outpatient feeling confident during their clinic visits **and** them having an overall positive experience of the clinics.

The correlations indicated that the following questions: *In general, I feel confident in using the prescription medicines to take care of my condition, I always feel uncomfortable while being at the hospital, and Overall, I have a positive experience of the clinics at the RVI* are correlated with a noticeable number of questions. They respectively relate to **feeling confident**, **feeling comfortable** and **positive experience**.

Six Questions (e.g. *I did finish the course of my prescription creams*) about **learnability** are strongly correlated with other questions. In similar fashion seven questions (e.g. *When at the hospital, I have had casual conversations with NHS staff*) about **Usability** and **User Experience** are also strongly correlated.

These results clearly vindicate the validity of our approach, and our attempt to identify issues related to UX, usability and learnability, looking at the outpatient as users and the clinics as a service.

DISCUSSION

The descriptive statistics show that while there are no shortcomings in the service delivery of medical care at the RVI clinics, following current health guidelines and

regulations. However, there are definitively avenues for improvements in the outpatient experience. We have identified those answers that are noteworthy as either having an effect on the service delivery (of medical care) on the usability (e.g. self-care and consultations) or on the UX (e.g. clinic visits).

Looking at the analytical statistics, there are two types of correlations reported in the preceding sections that are worth further investigation and that will form the basis of our proposed follow-up work.

The first type is the “Logical Outcome”. These are correlations that make sense immediately, such as outpatient having difficulties getting to the hospital and their condition making it difficult for them to do sports. These two answers identify outpatient that have difficulties to perform physical actions such as walking, however there is a need to further investigate to find out if this is a direct effect of their condition and if so why isn't there a correlation with PASI or the location of the condition.

The second type is the “Unexpected result”, these are correlations that were not expected and highlight issues that were not predicted. These have the potential to trigger the discovery of new effects and new directions of improvement in care delivery at the clinics. A good example is the respondents overall positive experience of the clinics correlated to being given strategies on how to cope physically and psychologically with their condition correlated with. The experience of the clinics is also correlated to the confidence felt in using prescription medicine. Another example is the respondents being greeted by the clinics staff, which is correlated to them raising all sort of issues that are relevant to their condition during consultations. It is also correlated to the respondents finding the order of events from arriving at the hospital until leaving it logical and well ordered.

This study does have some limitations. To participate patients needed to be able to consent and read and write, which exclude significant intellectual disability. We also do not have information on more finely graded variation on IQ or educational level, which could have an impact on some elements of the study (e.g. ability to self-manage medications). We also did not collect data on other health conditions, employment status, close family, etc. which could impact on the outpatient abilities. However, we can state that our typical surveyed outpatient wishes that they have more information about their condition and care, as well as more personal support. Their confidence level, perception of comfort, as well as their positive experience of the clinics, are correlated with their medical care. Engagement with the outpatient at the clinics is also of relevance – after all, it is known that patient engagement during clinics leads to better medical outcomes [13].

CONCLUSION

We have identified areas in the psoriasis clinics at the RVI hospital that are correlated to the outpatient UX as well as self-management of their conditions. These findings raise promising issues, notably the potential for IxD to address some of the clinic's design and to provide support and assistance to the outpatient in their daily lives. Considering that currently in the NHS (UK National Health Service), patients essentially get the same clinic organisation regardless of their individual needs, these findings highlight the true potential for personalised clinic experiences and personalised medical care. It seems very likely that patients will benefit from more personalised and configurable IxD solutions for both self-care (e.g. daily care routines and condition management) and clinic structure (e.g. organisation, pathway, waiting times). An assistive PHS present in the outpatient's daily life seems a very good candidate solution to realise the potential benefits of personalised and configurable clinics and of continuously assisted and supported self-care. Although, assessing the health outcomes of the implementation of a system such as a PHS will require subjects to use the technology for extended periods of time [9].

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