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2014

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Abstract

Compliance relating to eHealth websites has tended to consider issues around ethics, safety, privacy and trustworthiness. However, from an adherence point of view that acknowledges the care seekers role in accessing and applying the advice they receive, it is important to evaluate whether the eHealth site is designed to assist adherence. This paper reports a study involving the review of a paediatric online system for treating urinary incontinence in children that was found to provide accurate treatment advice but that advice was only adhered with 50% of the time. While many factors will influence patient (in)decision and behaviour, in the study reported in this paper we conducted a heuristic evaluation of this incontinence program and review of its functionality which was compared with the six most highly accessed eHealth websites. The study found that the incontinence program performed well from a usability perspective and provided numerous recommendations for further improvement of the system with the intention that this will increase compliance with the treatment advice. The evaluation approach used can be applied to measure other eHealth advisory systems.

Keywords: eHealth, Compliance, Adherence, Paediatric Healthcare, urinary incontinence.

1   INTRODUCTION

EHealth is the process of providing health care by electronic means, in particular over the Internet. It includes teaching, monitoring (e.g. physiological data), and interaction with healthcare providers, as well as interaction with other patients afflicted with the same conditions (Pretlow, 2000). The introduction of eHealth represented the promise of information and communication technologies to improve health and the health care system (Oh et al., 2005). There are over 50 value definitions of eHealth (Alvarez, 2002). For our purposes, eHealth is the convergence point where health and technology meet and through a series of activities help the user generate an outcome. The outcomes of eHealth can include increased patient health outcomes, increased knowledge, improved quality of life and improved efficiency in healthcare – improved access and resources utilisation.

This study is concerned with evaluating a paediatric eHealth system with the particular intention of identifying and addressing any technology issues that may impede compliance with the advice. In the past 15 years, eHealth has been increasingly adopted in paediatrics (Cushing, 2010). In paediatrics, eHealth is more complex because communication with children of differing ages requires additional considerations and the users of eHealth can be the parent, guardian and/or child.

This paper reports a study involving the review of a paediatric urinary incontinence online system that was found to provide accurate advice but that advice was only complied with 50% of the time. While many factors will influence patient (in)decision and behaviour, this study sought to discover:

1) What elements of the technology design may potentially impede or encourage adherence.
2) Recommendations for changes to the existing system
3) A set of design principles and recommendation that can be applied to evaluate other eHealth advisory system.

Through this evaluation process, we offer a set of design principles and features based on successful advisory eHealth systems that can be used to evaluate and improve other systems. In the following two sections we briefly review compliance and introduce the program. Section 4 presents our methodology for identifying a good design for an advisory eHealth system. Results, recommendations and conclusions follow in section 5, 6 and 7, respectively.

2   COMPLIANCE

Compliance with advice provided by an eHealth website can be seen as a two-way street or a two-sided coin. The focus has typically been on the need for eHealth websites to comply with various quality criteria set by international organisations such as the American Medication Association (AMA) and specific Internet focused medical associations such as the British Healthcare Internet Association (BHIA), Health on the Net Foundation (HON) and the Internet Health Coalition (2000).

Hernandez-Borges et al. (2003), for example, conducted a study of 363 web pages with paediatric information investigating the degree of site compliance with the quality criteria set by the AMA, BHIA and HON. They found overall 60.2% compliance with HON but low compliance for privacy, confidentiality and commerce. They noted a moderate, significant correlation between the number of inbound links and website compliance with quality criteria. However, the number of daily visits to a site did not correlate with compliance. Looking from the paediatric professional perspective, Kind and Silber (2004) conducted a review of the eHealth Code of Ethics developed by the Internet Health Coalition (2000) which included the principles of: candor, honesty, quality, informed consent, privacy, professionalism in online health care, responsible partnering and accountability. Their insightful review of these principles identified eHealth situations not covered by the code of ethics and raised issues concerning physician-patient online communication and equity. Kind and Silber (2004) concluded with a call to paediatricians as professionals to ensure that "philosophical reflection" is undertaken and that they are proactive in taking responsibility for policy development in these areas.

As in the above examples, issues around ethics, safety, privacy and trustworthiness have been the focus of studies and concern from parents, medical practitioners and society in general, prompting calls for discussion, tighter regulations and enforcement of compliance by site developers and owners. The other side of the coin concerns whether the intended user of the site is compliant with the medical advice given by the system. Increasingly the medical community prefer the use of the term "adherence", where compliance is doing what you are told and adherence is more of a shared responsibility concept (Katz and Hawley, 2013). We will not distinguish between the two. Gajdosic (1991) states that "when referring to the paediatric population, compliance primarily means the extent to which the parent or primary caregiver of the child adheres to or follows through with the prescribed treatment regimen". Adherence can include "performing exercises, adhering to restrictions, keeping appointments, or seeking recommended services" (p.74). Little attention has been given to the responsibilities of the eHealth consumer (particularly if the consumer is a minor), or even if any such responsibility exists.

3   URINARY INCONTINENCE

Urinary incontinence (bedwetting and daytime wetting) is a topic that is very common in children but rarely discussed, due to the stigmatising nature of the condition. The management of urinary incontinence has been shown to follow an evidence-based algorithm that includes the child's medical history and calculations using their data. A team from the Children's Hospital at Westmead (CHW) with the help of IT specialists and web designers have developed a proof of concept, personalised tool for treating incontinence in children.

The tool assesses the child by asking 15 questions about the child and his/her bladder and bowel function and can be used either by parents or the child him/herself, the latter requiring that every question is stated in a child friendly language. The website also provides background information for each question helping the user understand the nature and reasons of the questions. Based on the data entered into the system, the program diagnoses the child's condition and provides personalised advice that includes six possible treatments. Figure 1 shows the page that appears once the assessment has been completed. As shown, the page includes links to the "treatment plan" and the "time and volume chart" (T&V chart) that assess the child and provide treatment they should follow.

The patient's general practitioner (GP) is involved in the process and will be informed about the children's response and the treatment advice given, this means that the GP will be able to access their patient's data including: questions and answers, treatment advice and follow up questions and treatment, and to monitor their patient's progress.

Sometimes the children's advised treatment may include medication for which the system will advise the parents to consult their general practitioner and provide them with a printable letter addressed to their doctor that will explain in detail the rationale for recommending the medication and the child's data collected from the system that supports the advised treatment. The GP will also be notified via email or fax that the patient has been advised to consult him. The GP has access to their patient's data at all times. When the child consults the GP, it is the doctor's responsibility to assess the patient to determine how appropriate the treatment is and prescribe and monitor the medication use if appropriate. He/she can also contact the specialist research team for further advice.

So far a proof of concept program has been tested with 10 children who were referred to the CHW continence service who were awaiting their appointments. Each child or their parents had the opportunity to use the system for a period of four months, with data collected at the beginning and end of the trial period to evaluate the success of the program. Results from the ethics approved pilot study found that the program provided accurate diagnoses and appropriate treatment advice and was well received by the parents, children and general practitioners. However, up to 50% of the advice given for treatment was not followed by the families; this implies that there may be some areas of the system that can improve to help increase treatment adherence. While we acknowledge that compliance is a complex issue, this study seeks to remove technical hurdles before dealing with the more difficult social factors.

4 METHODOLOGY

Adherence is associated with motivation and design factors can influence engagement with eHealth (Hardiker and Grant, 2010). Analysing the feedback given by the families, comparing the website to other successful eHealth websites and analysing the website from a web design and human computer interaction perspective were the key steps undertaken to evaluate and improve the website and potentially increase compliance with the treatment advice.

The process had the following three steps.

1. Identification of:
    a. Interface aspects for usability, such as human computer interaction and design trends for eHealth website.
    b. Other successful eHealth advisory systems to determine their features.
2. Comparison of our website with other health advisory websites via:
    a. Description of each of the sites.
    b. Review of data collected from our pilot study.
    c. Heuristic evaluation of each of the sites.
    d. Comparison of all sites based on the features identified in 1(b).
3. General discussion of findings and specific recommendations for the next version.

For steps 1(a) and 2(c) we used Sommerville's (2010) six general principles that apply to all user interface designs, together with different perspectives on critical success factors in user interface design (Horsky et al., 2012, Paap, 2001,Turner et al. 2013) and various articles and eHealth website case studies (Lubberding et al., 2013, Gough et al., 2006, Kreps and Neuhauser, 2010, Ruland, 2013, Zajicek, 2004) to comprise a set of design principles and features for comparing each website.

The websites chosen as part of step 1(b) were determined using the following four step process:

1. Google search including terms such as eHealth, medicine online, health information and symptoms checker.

2. Selection of websites according to their position in Google search.

3. Analysis of the descriptions of the websites to ensure that the highest ranked websites matched the intention of the eHealth definition and included functionalities that can be compared with our website.

4. Using Quantcast (2013) to identify the importance of the website.

Based on the time frame of the study, the top six were selected: WebMD (2013); MedlinePlus (2013); MedicineNet (2013); Mayo Clinic (2013); Patients Like Me (2013) and PubMed (2013). These sites are easily accessed and well known. Due to space constraints further clarification of step 1 and the results of steps 2(a) and 2(b) are not provided in this paper. The full report may be obtained from the authors.

5 RESULTS OF COMPARATIVE EVALUATION

The results of our heuristic evaluation are summarized in Table 1. From a user interface design perspective our website performed well achieving 22/30, only four points away from the highest score that was for Patients Like Me (2013) with a score of 26/30. For user familiarity our website was weaker on the navigation bar element which most of the other sites did have. This is a feature that is planned to be included in the next version (it was left out for cost reasons). Consistency was not an issue as the website has been created to be simple and consistent in each of the areas that were analysed. Maintaining that consistency should be kept in mind when improvements are done to the system. Similarly, the simplicity of the system and the effort made to avoid any confusion and unnecessary actions, gives the system a high score for minimal surprise.

Principle	Our site	WebMD	Medline	Medicine Net	Mayo Clinic	Patients Like Me	PubMed
User Familiarity	4	5	4	4	3	5	4
Consistency	5	4	3	4	4	5	2
Minimal Surprise	5	4	4	4	4	5	4
Recoverability	3	4	4	4	4	4	3
User Guidance	3	5	3	3	4	4	4
User diversity	2	2	4	2	4	3	3
Total	22	24	22	21	23	26	20

Table 1.   *Summary Usability Scores. Each principle was measured and scored as follows: User Familiarity -Buttons use common words (2), Interface doesn't change during the different iterations (2), Navigation bar (1); Consistency - Question layout (1), Button layout (1), Logo Layout (1), Background (1), Question format (1); Minimal Surprise - Button predictability (2), Links open what they state (3); Recoverability-Undo Facility (1), Confirmation of actions (1), Question review   (1), Question navigation (1), Return functions to important pages (1); User guidance –Manuals (1), Tutorials (2), Help System (2); User diversity- Font size change (2), Dynamic size website for mobile   (2), Children's Version (1), bonus marks for language support, blind or deaf user capabilities.*

Of concern in the usability of our website are the scores for recoverability, user guidance and user diversity. Recoverability is low because of the inability to go back and review/change questions. During each session, the patients can go back to previous questions and change them. However, once all the questions are completed, they are asked to confirm, and then recoverability is lost. The purpose of this is to stop patients changing their answers, which would then influence their treatment recommendations. This sort of model is used in diet apps such as MyFitnessPal, so that people can't change their weight once entered. This is a deliberate feature. User guidance was provided in the form of additional information buttons, but the pilot revealed that few users made use of these button and more pictures were requested. Parents also had difficulty using the time and volume chart; a common complaint even when patients are seen face to face. This suggests that other means of collecting data for the time and volume chart (which collects information on when a child voids and drinks and the volume of the void and drink within a 24 hour period) should be developed. As the users for the system are limited in number and hand-picked currently, understandably user diversity has not been a factor in the design with the exception of handling both parent and child interaction. Ours is the only system of the seven analysed that targets and supports children. There are other paediatric sites that target children. Our site is innovative because it is the only program that addresses diagnosis, treatment, monitoring and feedback with interaction with medical staff.

Table 2 is a summary and overview of how the different functionalities and characteristics found in the different websites are present across the different systems. One of the issues of comparing the websites chosen is that the purpose of some of these websites is for education (c.f. 5.2, 5.3 and 5.6); developing an online community (c.f. 5.1, 5.4, 5.5) and our website's purpose is for treatment. Due to these differing aims, we do not evaluate if any of the sites were fit for purpose. The collective functionality is used for comparison and consideration only.

Our website is focussed on a very particular medical condition. Other specific sites exist, for example for cancer (Lubberding et al, 2013) or diabetes (Pacaud et al, 2012), but these sites were not accessible for comparison. In addition to inaccessibility, as they are specifically for other medical conditions and have a smaller number of users making them less suitable when seeking to extract features that make a site widely accepted. For that reason we chose to compare our advisory tool with some of the most successful and complete eHealth portals around the world.

The functionality checklist was comprised of all functionalities found in the collection of reviewed systems. While all functionalities do not apply to all websites, if a site has a good user interface design score and high functionality, the website generally receives a high number of unique visitors per month (Compete, 2013, Quantcast, 2013). Some functionalities were targeted as high potential

because they help with user engagement and provide the user with a level of security that the information that they are receiving is trustworthy. These functionalities are: User sharing experience; Input from real doctors; Privacy policy; Mobile version; Free; Symptoms checker; Medication information; Links for more information in different formats; Progress tracking. These functions should be considered for relevance and a cost-benefit analysis conducted to determine if they are worthwhile additions. At time of publication, various backend issues affecting availability have been addressed, a mobile version now exists and progress tracking is planned for next version.

FUNCTIONS/ CHARACTERISTICS	Our site	Web MD	Medline Plus	Medicine Net	Mayo Clinic	Patients Like Me	Pub Med
User sharing experience	NO	YES	NO	YES	YES	YES	NO
Interactive characters	NO	NO	NO	NO	NO	NO	NO
Input from real doctors	YES	YES	YES	YES	YES	YES	YES
Information from medical journals and sources	NO	YES	YES	YES	YES	NO	YES
Privacy Policy	YES*	YES	YES	YES	YES	YES	YES
Mobile version	YES*	YES	YES	YES	NO	YES	YES
App for mobile	NO	YES	NO	NO	YES	NO	YES
App for tablet	NO	YES	NO	NO	YES	NO	YES
Free	YES	YES	YES	YES	YES	YES	FREEMIUM
Magazine	NO	YES	NO	NO	NO	NO	NO
Symptoms checker	YES	YES	YES	YES	YES	YES	NO
Pet Health	NO	YES	YES	YES	NO	NO	NO
Medication Information	YES	YES	YES	YES	YES	YES	YES
MedTerm Dictionary	NO	NO	YES	YES	NO	NO	NO
Area for medical professionals	NO	YES*	NO	NO	YES	NO	NO
Testimonials	NO	YES	NO	YES	NO	YES	NO
Children Version	YES*	NO	NO	NO	NO	NO	NO
Newsletter	NO	YES	YES	YES	YES	NO	NO
Language Support	NO	NO	YES	NO	NO	NO	NO
News	NO	YES	YES	YES	NO	YES	NO
Links to more information in different formats	NO	YES	YES	YES	YES	YES	YES
Progress Tracking	YES	YES	NO	YES	NO	YES	NO

Table 2.   Summary Functionality Checklist.

6   RECOMMENDATIONS AND FUTURE WORK

Many of the participants in the pilot study had recommendations for the system. For example, one participant suggested the following: 1) more advice about medication history and whether medications should be stopped; 2) improved clarity of T&V chart and whether it was essential to use it; 3) more pictures; 4) an app with reminders to drink, etc.; 5) more opportunities to record current medication use and; 6) changes so that the treatment plan takes existing medications into account. Suggestions 1, 5 and 6 are already addressed in the next version.

Based on the comparison with other sites, we have made a number of the recommendations for the next version. These recommendations are summarised here. They have been grouped thematically. We indicate with ☑the changes already planned and/or implemented since this study.
Access
   1) App or mobile version to improve accessibility and portability of the system ☑. Done
   2) Time and volume chart access: the time volume chart is a functionality of the system used to DETERMINE THE PHYISIOLOGICAL FUNCTION OF CHILD'S BLADDER by measuring their FLUID INTAKE AND URINE OUTPUT. After the first assessment there is a downloadable version of this document for parents to fill in between assessments. When the second assessment is started, the user must enter the data from the document into the system.

It would be much easier for the user if they can access this chart from their computers or mobile devices at any time they need to fill in the information. This would make compliance with the process easier.

3) Google search engine optimization requiring the site to have its own URL, ideally one that is associated with one of the prestigious organisations involved in this project. This can also enhance credibility and trust of the system. ☑ Will be done when trial is over.

Appearance

1) Overhaul of the children's version that will allow them to follow the process with minimal or no assistance from an adult, but always letting the parents know through notifications and emails what the children are doing in the website.

2) Background of the website should be less distracting. While the pictures of children and families are colourful, the other websites analysed had simple and plain backgrounds that attract the user to what is really important which is the information not to the background.

3) Position of important elements: tools like www.clicktale.com can provide different functions such as heat maps or mouse movement that shall help the system position the elements in a better shape and will also help the website treat user interface design elements not covered by these research such as focus points or scroll reach (Clicktale, 2013).

Content

4) Addition of sources of information to the links to more information in different formats to add to further verification and trustworthiness.

5) Trustworthy information certificate: complying with the eight principles of the HON Code of Conduct (HONcode) is an excellent way of showing the patient that the information provided by the website is trustworthy.

6) Inclusion of testimonials as there can be a big impact on the patient's perception of a diagnosis and treatments when they hear of the experiences of other patients (Leung, 2011). A few testimonials could be visible from the home page and a complete list should be accessible.

7) User sharing experiences through blogs and social networks (Eysenbach, 2008), or leaving comments to the testimonials suggested in 6). Possibly questions could be posted that could be answered by other parents/patients or by the medical team. Some monitoring is likely to be needed to ensure the content is appropriate and not misleading.

8) Addition of medication information. As was found in the pilot, and further reported by the paediatrician and in the literature (McMahon and Forehand, 2005), parents generally try to avoid medication. Linking to a reliable and up to date database about the recommended drugs (e.g. composition, dosage, contraindications/side-effects, etc.) may reduce parental apprehension and help them feel more empowered to make choices. Other specialists, general practitioners and/or paediatricians associated with the patient could find the information valuable.

Navigation/Interaction

9) Navigation bar for the website could help improve the user familiarity with the system and make the functionality more accessible and visible. ☑.

10) Question countdown would help the user know how much the assessment has been covered and how much is still to be completed. It provides feedback and keeps the user in control.

Evaluation/Monitoring/Maintenance

11) Transaction log file analysis can track user actions, such as whether certain buttons are clicked, how long the user stays at a certain point, where errors are made and the type of error. This information can be used to improve the site (Han, 2011). ☑ This data already collected.

12) User interface and functionality oriented feedback form for pilot participants as another method to capture feedback and improve the site and experience. ☑Current version has this.

13) Finally, the framework used in this project could be used to evaluate improvements to the system over time and to suggest further changes to the system.

7 CONCLUSIONS

The paediatric urinary incontinence program has been built on top of a very robust algorithm capable of diagnosing and advising treatment with just the information entered by the user. Despite its accuracy, users were often unwilling to follow all the recommended treatment. This study sought to understand how the system's usability features and functionality compared to those found in some highly used sites. The program scored well in the design principles evaluation but was missing many of the functionalities found in other advisory systems. However, the other websites served a different function (to provide information) whereas program's main function is to diagnose and treat, therefore some of the assessment items may not be relevant. Also we have not been able to explore accuracy of diagnosis or level of adherence on the other sites.

In this paper we measured the technological and design features of a paediatric urinary incontinence website against the top most accessed eHealth websites. As next steps we will consider how well our advisory system could or should follow a *persuasive systems* design (Oinas-Kukkonen and Harjumaa, 2009) and human issues around compliance in the medical and psychology-based literature to improve and measure compliance. For example, we see a parallel in the monitoring of un(der)used disposable items, such as cotton swabs (in our case unused buttons), and daily journals that have been used to measure compliance with non-technology-based home programs (Gajdosik, 1991). We believe that improvements in compliance will only occur when human factors and issues such as trust and empowerment are adequately embodied in the system together with technology enhancements as suggested in this paper.

EHealth systems which provide patient specific treatment advice and a tailored treatment plan that is co-managed with the patients GP are just emerging. While technology may advance rapidly, the development and implementation of therapeutic interactive technologies can not advance rapidly due to the requirement of lengthy clinical trials and high initial development costs (Caldwell et al., 2013). As a result, information on these emerging systems is limited and their widespread use is still a thing of the future. This paper offers a glimpse of one system that is in the process of gaining funding for extensive clinical trials and also provides an initial set of design principles, eHealth website features and scores against which other emerging eHealth advisory and treatment management systems can be compared.

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