Interactive Journal of Medical Research

Impact Factor (2022): 2.0
Volume 8 (2019), Issue 2 ISSN 1929-073X

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Metadata Correction: Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study

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Related Article:

Correction of: http://www.i-jmr.org/2019/2/e12999/

(Interact J Med Res 2019;8(2):e14352) doi:10.2196/14352

The authors of “Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study” (Interact J Med Res 2019;8(2):e12999) wish to change the corresponding author from Hatan Hisham Mortada to Hattan A Aljaaly. The phone number and email address have been updated accordingly.

The correction will appear in the online version of the paper on the JMIR website on June 19, 2019, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article also has been resubmitted to those repositories.

Submitted 11.04.19; this is a non–peer-reviewed article;accepted 12.04.19; published 19.06.19.

Please cite as:
Mortada HH, Alqahtani YA, Seraj HZ, Albishi WK, Aljaaly HA
Metadata Correction: Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study
Interact J Med Res 2019;8(2):e14352
URL: http://www.i-jmr.org/2019/2/e14352/
doi:10.2196/14352
PMID:31219047

Viewpoint

Artificial Intelligence in Clinical Health Care Applications: Viewpoint

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Abstract

The idea of artificial intelligence (AI) has a long history. It turned out, however, that reaching intelligence at human levels is more complicated than originally anticipated. Currently, we are experiencing a renewed interest in AI, fueled by an enormous increase in computing power and an even larger increase in data, in combination with improved AI technologies like deep learning. Healthcare is considered the next domain to be revolutionized by artificial intelligence. While AI approaches are excellently suited to develop certain algorithms, for biomedical applications there are specific challenges. We propose six recommendations—the 6Rs—to improve AI projects in the biomedical space, especially clinical health care, and to facilitate communication between AI scientists and medical doctors: (1) Relevant and well-defined clinical question first; (2) Right data (ie, representative and of good quality); (3) Ratio between number of patients and their variables should fit the AI method; (4) Relationship between data and *ground truth* should be as direct and causal as possible; (5) Regulatory ready; enabling validation; and (6) Right AI method.

(Interact J Med Res 2019;8(2):e12100) doi:10.2196/12100

KEYWORDS

artificial intelligence; deep learning; clinical data; Bayesian modeling; medical informatics

Introduction

The idea of artificial intelligence (AI) has a long history. Since the 1950s there have been several revolutionary promises of AI replacing human work within a few decades. It turned out, however, that reaching intelligence at human levels was more complicated, which led to several “AI winters,” where interest in AI disappeared [1]. Currently, we are experiencing a renewed interest in AI, fueled by an enormous increase in computing power and an even larger increase in data generation. In combination with improved algorithms that allow training of deep neural networks, several high-tech companies have reached successes in performing tasks that are close to human or even beyond human performance: playing games like chess and Go, image recognition and computer vision, natural language processing, machine translation, and self-driving cars are just a few examples.

Health care is considered the next domain to be revolutionized by AI [2-5]. In addition to many academic efforts, companies are also getting involved. IBM has developed Watson for several health applications, such as Watson for Oncology and Watson for Genomics, and there is a large number of start-ups addressing all possible aspects of the health continuum [6,7].

Artificial Intelligence

The term *artificial intelligence* is used to indicate development of algorithms that should execute tasks that are typically performed by human beings and are, therefore, associated with intelligent behavior. AI makes use of a variety of techniques, such as deep learning, but also probabilistic methods like Bayesian modeling [8,9]; for definitions, see He et al [2]. Colloquially, the term is applied to a machine that mimics cognitive functions, such as learning and problem solving [2,4,10,11].

Use of Artificial Intelligence Methods in Health Care

It is clear that health care has numerous needs that could benefit from solutions developed with, or by embedding, artificial intelligence [2,4,8]. In this brief article, we focus on the contributions AI can make to clinical health care, a domain that poses new and sometimes unique challenges to the application of AI. In the next sections, we discuss some important challenges and provide our recommendations on how to deal with them.

While radiology imaging was first in delivering digital data, digital pathology is a more recent revolutionary development [4,12,13]. In addition, for many years, hospitals have been digitizing their medical patient records [14]. Hence, a large and ever-increasing body of reasonably annotated clinical data has been collected: partially structured data in machine-readable formats, such as those from medical imaging, and partially unstructured data in natural language. As in other industrial sectors, it is expected that this *big data* movement can be leveraged to transform health care and drive unprecedented improvements in quality of patient diagnostics, treatment, care, and clinical outcome. Expected results range from identification of individuals at high risk for a disease, to improved diagnosis and matching of effective personalized treatment to the individual patient, as well as out-of-hospital monitoring of therapy response [15]. Although these opportunities and this potential are widely acknowledged, it is important to understand what can be delivered in practice with the current state-of-the-art AI technologies and which applications require further advances in AI to become feasible.

Artificial Intelligence Methods: Supervised or Unsupervised Learning; Knowledge-Based or Data-Driven?

Multiple AI technologies are available to choose from [2,9,16]. Algorithmic learning-based AI can be performed in a supervised mode; this means that a *ground truth* label is available for every data sample, which guides the AI effort and is based on domain knowledge. It will be obvious that the correctness of *ground truth* labels is a prerequisite for good performance of an AI solution. The alternative, unsupervised mode, is when no *ground truth* is available and only similarities can be found with a yet undefined meaning [2,16].

Machine learning traditionally involves a human to determine features of the data, using domain knowledge. In contrast, deep learning allows finding such features from the data *by itself*. The features are subsequently used in various models. Some of those can be knowledge-based models in which new deep learning-defined features are integrated according to knowledge [17,18]. The current interest in AI from industry comes from the recent breakthroughs in data-driven approaches, such as deep learning, and their applicability in industrial applications such as speech recognition, machine translation, and computer vision. Still, it is expected that combining data-driven and knowledge-based approaches will bring AI to the next level, much closer to human intelligence [17,18].

Artificial Intelligence for Well-Defined Narrow Tasks: Radiology Imaging and Digital Pathology

One of the more studied and successfully executed AI opportunities is in imaging. For example, AI technologies can be applied to problems such as distinguishing cell nuclei or certain cell types present in a tumor sample on a histopathology slide, using slide images obtained with a digital pathology scanner [19-21]. Such images are made with consistent equipment and acquired in a controlled fashion, generating images consisting of uniform data and providing very good representations of the phenomena to be modelled. The problem domain is limited. For instance, in the training process, the AI system gets as input raw images with associated labels for different cell types that are provided by a pathologist. The pathologist is providing a *ground truth* , based on existing expert knowledge (eg, on the different cell types or architecture present in the tissue slide). Deep learning has been applied to this problem and AI technologies already outperform manually crafted tissue analysis technologies [16,20,22,23]. It is expected that they will soon be on par or better than a human pathologist on certain well-defined histology feature recognition and measurement tasks, though not yet for clinical interpretation.

Artificial Intelligence for Wider Purposes: Coupling Patient Clinical Data to Clinical Outcome

On the other hand, research projects are ongoing using multimodal data (ie, a combination of datasets of a different data type), for example, to enable prediction of prognosis of a patient or clinical outcome after a certain treatment. One may, for example, use medical imaging data combined with histopathology and clinical laboratory data and even lifestyle data to try to predict survival, risk of rehospitalization within a certain number of days, etc. Such projects remain challenging and have typically been proven not to be very successful [5,24]. IBM's Watson for Oncology claims to integrate all available cancer patient data and disease information for improved diagnosis and therapy decision making. In 2013, the MD Anderson Cancer Center started using IBM Watson technology to increase effective treatment of cancer patients; however, the project was stopped in 2017 because it "did not meet its goals" [25,26]. In contrast, the concordance with respect to clinical interpretation of single-modality genome sequencing data using Watson for Genomics versus a clinical genomics expert group was reportedly quite good, between 77% and 97%, depending on the type of identified genomic mutations [7].

The most difficult challenge for AI in the coming years will be to move from successful narrow domains into wider-purpose, multimodality, data systems. A promising approach here is not to find one methodology to address every problem but to separate the wider-purpose AI goal into smaller goals. In this approach, subgroups of the data may be processed separately with suitable AI methods to provide meaningful, clinically relevant output. For example, for cardiac ultrasound images, one could zoom in to develop an algorithm with deep learning to measure left ventricular volume; or for pathology slide images, one could zoom in to develop an algorithm for recognition and quantification of a specific cell type (eg, lymphocytes). To increase chances at success, it is important to determine a well-defined, focused, and clinically relevant question for an AI project that can be adequately answered with the available data.

The conclusion of this section is that a relevant and well-defined clinical question should come first.

The Relationship Between Patient or Sample Numbers and Data Variables

Many AI techniques, especially deep learning, rely on the availability of large datasets or *big data* [15]. Sometimes domain knowledge can help to create additional data derived from the data that are available. It is important, however, to distinguish the type of data that is needed. In games, such as chess and Go, it is easy to artificially synthesize additional data of the right type to increase the size of the dataset. With respect to medical and histopathology imaging, large amounts of data are available since samples are defined on an image pixel basis. Using this type of data, with relatively few images one can create millions of annotated samples with drawing tools. It is relatively easy to further augment every sample with artificially generated variations (eg, mirror copies, rotated versions, modified intensities, and modified colors) without consequences for the annotation.

In contrast, in clinical health care the type of data typically is a pathology or radiology report from a patient, associated with a clinical annotation such as diagnosis or response to therapy. In this case, the number of samples is generally equal to the number of patients. The annotation is often more difficult, as it requires an expert physician to provide the *ground truth* . When using multimodal data to find parameters that, for example, predict clinical outcome, despite all digital records and digital health devices, there are not enough data. The number of patients for which the necessary multimodal data are available is, in general, the limiting factor for using AI methods on such combined data sources to create a valid algorithm for risk prediction, diagnosis, or a therapeutic decision. When the number of patients of a specific defined disease (sub)type is low, the often-heard strategy is to extend a study to include more patients, even all patients worldwide, which requires addressing various legal and technical barriers. However, this is still likely to fail in reaching the required patient number; with efforts to increase the number of patients for inclusion in data analysis, the amount of variation per patient, including many unknown features and variables, tends to grow as well, leading to uncontrolled data variation. This is caused by the large variation in human individuals: their DNA (ie, just think of the 3 billion base pairs and the near-infinite combinations of genomic variations), their lifestyle, family medical history, use of medication, etc. Moreover, patients are never treated in exactly the same manner in the various hospitals, bringing in many additional variables. It is a well-recognized issue in clinical trials run by pharma companies [24]. The challenge is to minimize such unwanted variables in the patient or sample set to analyze. Much of this uncontrolled variation is not recorded or, at best, only in a very noisy way. The number of unknown parameters that may have influenced the outcome, especially if its measurement lies many years after the diagnosis and treatment, is typically underestimated. Examples of failure of AI methods caused by these issues include many genome-wide association studies aimed at identification of clinically useful genomic risk factors for complex diseases and genomic studies aimed at identification of biomarkers for cancer diagnostics and treatment decisions [27].

Similar challenges are present in other domains, but solutions in those areas can be invoked that are not possible in the health care domain. In natural language processing, Google Translate is a well-known example. When it started, translations were of very poor quality and heavily criticized, but Google decided to keep the service up and running; online feedback was used to collect a large amount of translation data, enabling continuous improvement of the performance of the translation algorithm [28].

In summary, for applying AI to multimodal patient data, the number of patients from whom the complete set of multimodal data is available is frequently too limited to address the *curse of dimensionality*. In the scientific community, dimensionality reduction remains an active research area [29-31]. In clinical application areas for AI, it remains the main challenge to address. The first solution lies in reducing data modality and bringing the number of variables (*P*) on the right level in relation to the number of patients or samples (*N*) for which a *ground truth* is available. The desired solution will reduce high-dimensional data to biologically sound knowledge-based features. Introducing knowledge-based computational approaches is expected to provide a way forward to reduce model freedom and handle high-dimensional data [32].

The conclusion of this section is that the ratio between the number of patients and their variables should fit the AI method.

Insufficient Data Quality and Many Subjective Parameters

For the patient data that is available, it turns out that this data is usually neither 100% complete nor 100% correct. For example, diagnoses are not always complete or correct, or they were not correctly entered into the digital domain. The main diagnosis is, in general, reasonably well-documented; however, side diagnoses and complications that arise, for example, during hospital admission or in the home setting, as well as treatment details are less-accurately or not documented [5]. For many clinical variables, such as diagnoses, the *ground truth* comes from a physician's judgement and cannot be objectively measured or quantified. For example, it is documented that histopathology diagnoses differ to a varying extent among pathologists that diagnose the same slide [33-35]. As a consequence, datasets may be incomplete and noisy, and presumed *ground truths* may not always be correct.

The conclusion of this section is that the right data (ie, representative and of good quality) needs to be obtained.

Causal Relations Versus Correlations: A Role for Bayesian Reasoning

Any data-driven approach on data for which the ratio of number of patients (ie, samples) to variables is too low can lead to multiple spurious correlations [36]. This means that the data suggest a correlation between two factors, but this is purely due to chance and there is no underlying explanation or causal relationship. In machine learning, this can easily lead to overfitting and finding of irrelevant correlations [16,37]. Also, for clinical implementation, any interesting correlation (eg, a feature or combination of features associated with increased disease risk) needs to be clinically validated at high cost, where lack of causality generally results in very low success rates. Therefore, turning an algorithm, based on correlations, into a successful proposition will, in general, be easier if causal relations underlie the found correlations. Knowledge-based reasoning techniques, such as Bayesian network models, can reduce the number of spurious relations and overfitting problems by using existing knowledge on causal data relations to eliminate noisy data [11,14]. As an additional advantage, Bayesian models can deal very well with uncertainty and missing variables, which is the rule rather than the exception in clinical data [11]. Not a coincidence, with respect to patient data interpretation, Bayesian models reason the way a medical doctor does [38].

The conclusion of the section is that the relationship between data and *ground truth* should be as direct and causal as possible.

Validation of Artificial Intelligence-Based Solutions

For many of the success stories of AI, a robust and reliable result is usually not necessary. For a free translation service, the consequence of a wrong decision is at most a dissatisfied customer. Improvements of those services could happen relatively quickly because many of those AI applications are deployed in the field and iteratively improve their performance on the basis of new data, thus learning from their mistakes. In sharp contrast to most of these consumer or lifestyle solutions based on AI, every clinical application, be it hardware or software, requires a thorough clinical validation in order to be adopted by the professional clinical community for use in patient care, such as diagnostics or treatment decisions, and must be approved by regulatory authorities [24]. The requirements for clinical validation will be more stringent when errors or mistakes can have greater consequences. In a clinical trial, it needs to be demonstrated how accurately the developed AI solution performs compared to the clinical standard (eg, sensitivity and specificity of a diagnostic test). Still, it is not completely clear whether good performance of an algorithm is acceptable if the solution is a “black box” and not transparent and rationally explainable [2]. On top of that, it is not obvious what proper validation of a continuous learning-based solution implies. An important issue is that because of lack of transparency, deep learning-based “black box” algorithms cannot be easily improved, in contrast to, for example, Bayesian models that are based on a transparent structure. Initial attempts to tackle this challenge are on the way [39].

Have AI-based solutions already been approved for clinical use? The earlier mentioned Watson for Oncology system operates as a “black box” and its advice could not be clinically validated [26]. On the other hand, in 2017 it was claimed that the first deep learning-based algorithm, which identifies contours of cardiac ventricles from a magnetic resonance imaging (MRI) image to calculate ventricular volume, was validated and approved by the US Food and Drug Administration (FDA) for performing the calculation faster than a clinician [40]. Obviously, this system’s scope is far more restricted than Watson’s; the unimodal imaging data that were used were directly and causally related to the *ground truth* provided during every image analysis by the clinician. Also, it can be considered a measurement algorithm and does not include a clinical interpretation claim. Clinical validation and obtaining regulatory approval are much more difficult for those algorithms for which such an interpretation claim is added [4].

Several new solutions are ready or able to perform continuous (ie, incremental) learning [41]. However, within current regulations, an AI system for clinical applications should be “frozen” and can, therefore, not learn online and immediately apply its new knowledge. Rather, it needs to have an offline validation of the obtained “frozen” model on an independent series of patient or sample data. Following a next continuous-learning cycle, the validation process needs to be repeated again prior to renewed implementation of the model. Ideally, new clinically acceptable ways to shorten validation tracks for digital applications in a patient-safe manner should be found; it is expected that special procedures will be put in place to facilitate regulatory approval of updated algorithms. In line with this, the FDA is actively developing a strategy to deal with AI-based software solutions [42]. Maximal use of existing knowledge in transparent and causal model algorithms, as in Bayesian modeling, is expected to facilitate both clinical validation and obtaining regulatory approval, both for unimodal as well as for multimodal data.

The conclusion of this section is that procedures must be put in place to facilitate algorithms to be regulatory ready and to enable validation.

Methods to Use

Technology-wise, numerous methods from the domain of AI have been explored for the development of clinical applications [8,11,16,43]. Some have been more successful than others, mostly depending on application type. For automating pathology diagnosis using tissue slide images, deep learning has proven to be an appropriate technology. When dealing with more general multimodal problems, such as predicting clinical outcomes, patient assessments, and risk predictions, other methods that often include domain knowledge are likely to be more appropriate choices. Probabilistic methods using knowledge representation are increasingly used and enable reduction of the number of influencing variables, determining *sensible* features or latent variables. Probabilistic Bayesian modeling is well-suited to deal with complex biological (eg, “omics” data, such as genomics and transcriptomics data) as well as medical and clinical data; it is finding its way into diagnostic applications as well as drug development [9,44-49]. However, where knowledge is lacking, knowledge-agnostic AI approaches become valuable; Bayesian reasoning networks are thought to have high potential for use in combination with deep learning, combining the best of two worlds in Bayesian deep learning [17,18,50].

The conclusion of this section is that the right AI method must be used for the problem.

Recommendations for Use of Artificial Intelligence Methods to Develop Clinical Applications: The Six Rs

In view of the challenges related to the use of AI for health care and biomedical applications, we believe it will be of value to have some guidelines when designing a study. They may also serve to facilitate communication between scientists involved in AI and medical doctors. From the discussion above, we have extracted six basic recommendations.

1. Relevant and well-defined clinical question first. Data analytics without domain knowledge can be applied in the health care domain, but at high risk of getting clinically irrelevant outcomes. For every new AI project, the clinical questions should be well-defined and reviewed with clinical experts. The outcome of the analysis should also be reviewed for clinical and/or biological sense.
2. Right data (ie, representative and of good quality). Carefully define the dataset that is needed to answer the clinical question. A clinical dataset with *ground truth* should be sufficiently clean and reliable. Be aware of hidden variation between samples that is not visible in the dataset. The dataset should be appropriate for the question at hand as well as representative for the population under study.
3. Ratio between number of patients and their variables should fit the AI method. To obtain useful results, ensure working with adequately large datasets (ie, numbers of patients or samples) for the AI method to be used, and reduce patient variables where possible. Use domain knowledge to limit spurious correlations.
4. Relationship between input variables and predicted output variable, as the dependent value, should be as direct and causal as possible. The clinical question should as closely as possible relate the *ground truth* to the data. Hence, finding new pathology features that best distinguish between two different pathology diagnoses can be successful; using lifestyle information to predict 10-year survival might not.
5. Regulatory ready; enabling validation. Upfront, consider how a certain solution can be validated and pass regulatory requirements. Consider how using domain knowledge could speed up the validation process, for instance, by breaking up the AI system into smaller AI systems. This effectively excludes systems that iteratively change by continuous learning.
6. Right AI method. Use the right method for the question at hand. Data-driven methods can be used if the data available allows it, and knowledge-based methods can be applied if there is knowledge available but not enough data; a mixture of the two, combined in a wise manner, may be highly productive for development of clinically applicable health care solutions.

Privacy Issues

Driven by the *big data* analysis developments in health care, new privacy regulations were recently implemented in Europe—General Data Protection and Regulation (GDPR) [51]. To protect privacy, individuals control their own personal data, and explicit informed consent is required for access to the data and use in AI. This regulation is expected to make it more difficult to share patient data between multiple medical centers and with companies involved in development of AI solutions.

Key Takeaways

While AI approaches are excellently suited to develop algorithms for analysis of unimodal imaging data (eg, radiological or digital pathology images), for clinical (ie, patient-related) applications, major challenges lie in the usually limited patient or sample numbers (*N*). This is in comparison to the number of multimodal variables (*P*) due to patient variation, inadequate *ground truth* information, and a requirement for robust clinical validation prior to clinical implementation. Artificial Intelligence solutions that combine domain knowledge with data-driven approaches are, therefore, preferable over solutions that use only domain knowledge or are fully data driven. We introduce the following 6R model to keep in mind for AI projects in the biomedical and clinical health care domain:

1. Relevant and well-defined clinical question first.
2. Right data (ie, representative and of good quality).
3. Ratio between number of patients and their variables should fit the AI method.
4. Relationship between data and *ground truth* should be as direct and causal as possible.
5. Regulatory ready; enabling validation.
6. Right AI method.

Acknowledgments

We wish to thank Rien van Leeuwen and Ruud Vlutters for their valuable contributions and Ludo Tolhuizen for thorough reading and providing valuable suggestions.

Conflicts of Interest

All authors are regular employees of Royal Philips, Eindhoven, The Netherlands.

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Abbreviations

AI: artificial intelligence
FDA: US Food and Drug Administration
GDPR: General Data Protection and Regulation
MRI: magnetic resonance imaging

Edited by T Rashid Soron; submitted 03.09.18; peer-reviewed by A Davoudi, M Lang, X Shen; comments to author 08.10.18; revised version received 18.01.19; accepted 31.01.19; published 05.04.19.

Please cite as:
van Hartskamp M, Consoli S, Verhaegh W, Petkovic M, van de Stolpe A
Artificial Intelligence in Clinical Health Care Applications: Viewpoint
Interact J Med Res 2019;8(2):e12100
URL: https://www.i-jmr.org/2019/2/e12100/
doi:10.2196/12100
PMID:30950806

Original Paper

Differences in the Level of Electronic Health Literacy Between Users and Nonusers of Digital Health Services: An Exploratory Survey of a Group of Medical Outpatients

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Abstract

Background: Digitalization of health services ensures greater availability of services and improved contact to health professionals. To ensure high user adoption rates, we need to understand the indicators of use and nonuse. Traditionally, these have included classic sociodemographic variables such as age, sex, and educational level. Electronic health literacy (eHL) describes knowledge, skills, and experiences in the interaction with digital health services and technology. With our recent introduction of 2 new multidimensional instruments to measure eHL, the eHL questionnaire (eHLQ) and the eHL assessment (eHLA) toolkit, eHL provides a multifaceted approach to understand use and nonuse of digital health solutions in detail.

Objective: The aim of this study was to investigate how users and nonusers of digital services differ with respect to eHL, in a group of patients with regular contact to a hospital outpatient clinic. Furthermore, to examine how usage and nonusage, and eHL levels are associated with factors such as age, sex, educational level, and self-rated health.

Methods: Outpatients were asked to fill out a survey comprising items about usage of digital services, including digital contact to general practitioner (GP) and communication via the national health portal sundhed.dk, the eHLQ, and the eHLA toolkit, as well as items on age, sex, education, and self-rated health. In total, 246 patients completed the survey. A Mann-Whitney test was used to test for differences between users and nonusers of digital services. Correlation tests described correlations between eHL scales (eHEALSs) and age, education, and self-rated health. A significance level of .0071 was used to reject the null hypothesis in relation to the eHEALSs and usage of digital services.

Results: In total, 95.1% (234/246) of the participants used their personal digital ID (NemID), 57.7% (142/246) were in contact with their GPs electronically, and 54.0% (133/246) had used the national health portal (sundhed.dk) within the last 3 months. There were no differences between users and nonusers of sundhed.dk with respect to age, sex, educational level, and self-rated health. Users of NemID scored higher than nonusers in 6 of the 7 dimensions of eHLQ, the only one which did not differ was dimension 2: *Understanding of health concepts and language.* Sundhed.dk users had a higher score in all of the 7 dimensions except for dimension 4: *Feel safe and in control*. The eHLA toolkit showed that users of sundhed.dk and NemID had higher levels of eHL with regard to tools 2, 5, 6, and 7. Furthermore, users of sundhed.dk had higher levels of eHL with regard to tools 3 and 4.

Conclusions: Information about patients’ eHL may provide clinicians an understanding of patients’ reasons for not using digital health services, better than sociodemographic data or self-rated health.

(Interact J Med Res 2019;8(2):e8423) doi:10.2196/ijmr.8423

KEYWORDS

health literacy; computer literacy; questionnaires; telemedicine; consumer health informatics

Introduction

Background

The ongoing extensive digitalization of health services worldwide may be considered an advantage for many people, as the use of information and communications technology (ICT) ensures greater availability of services and better contact to health service professionals [1].

In line with this development, in Denmark, public services are highly digitalized, and citizens communicate with public authorities via a digital portal. This includes electronic communication via a national email service called patient’s digital mailbox (e-Boks) [2]. Only people who are not able to access computers or use the digital services can be exempted from this (currently 8.9%) [2]. Digital access to all public services is governed by the national identification system NemID. In total, 98% of the population above 15 years has access to NemID [3]. Since 2009, the national health portal sundhed.dk has facilitated citizens’ access to the national, regional, and local health care services, their communication with health professionals, and their access to health-related information [4]. The access to nonperson-specific information about health services and the health-related information is publicly available, but access communication that includes personal data, for example, clinical data and communication with one’s general practitioner (GP) for renewal of drug prescriptions, requires a personal log-in using the NemID log-on. Public authorities communicate with citizens via e-Boks to send information letters from hospitals, including the outpatient clinic referrals.

This increasing tendency toward mandatory digital communication with public services, including health care services, as is seen in Denmark, calls for attention to a problem: how can we include citizens who are not able to take advantage of the new digital opportunities and obtain the full benefits of digitalization?

Previously, reasons for not using digital services or technologies were considered to be that users lack access to, have resistance to, or reject using the digital services as they do not find it beneficial [5].

This simplified view has been challenged in recent years by studies that explore, in detail, the reasons for not using digital health services. A recent review identified several key barriers to successful adoption of digital health interventions [6]. These barriers were related to both personal attributes such as agency, motivation, personal life experiences, and values, and the context, that is, the health care providers’ approach to engaging and recruiting users, as well as the quality of the solution. In alignment with this, a Danish study, which examined why older people (aged above 58 years) use public digital services, identified that motivation, convenience, and skills were important factors for adopting digital solutions [7]. Two recent qualitative studies support this finding and also show that the patients’ context and condition may also influence their preferences. The first of the 2 qualitative studies is a Danish study based on 10 patients with more than 1 chronic condition (multimorbid patients), which argues that patients’ motivation to use ICT is positively related to the burden of their disease [8]. The other study from the Netherlands, including 17 patients with a chronic heart disease, reveals several other important factors for patients choosing to use an electronic health (eHealth) portal: a more personal contact to a coach, self-perceived computer skills, and factors related to how the platform is introduced and used [9].

In a newly published study with 201 informants examining the willingness to use eHealth portals, authors found that the willingness to use a health portal was related to younger age, higher self-rated health, an education level above high-school level, higher acculturation status, higher computer literacy, and adequate health literacy [10].

All these studies point to a complexity of reasons for adoption and use of digital health services, of which many relate to the individual’s knowledge, skills, perception, and experiences, including trust and motivation, but also relate to the way health professionals introduce new technologies [11].

Electronic Health Literacy

In 2015, Monkman and Kushniruk proposed a new model of Consumer Health Information System adoption [12]. In this model, they combine an understanding of the usability of the products with the users’ eHealth literacy (eHL)—a model which is in alignment with the suggestion by Kayser et al that it may be important to address users’ eHL to achieve design solutions that suit the user’s needs and capabilities better [13]. This calls for further investigation of the role of eHL as a means to understand the adoption and usage of digital health services in the context of the user interacting with the services and technology.

The original concept of eHL or digital health literacy was introduced in 2006 by Normann and Skinner [14], and it highlights the users’ competence needed to engage with digital health services. Using the Normann and Skinner model and the related instrument, eHL scale (eHEALS), a positive correlation between information-seeking behavior and eHL has been demonstrated, for example, in 31 patients with rheumatoid arthritis in the Netherlands [15], 2371 parents of children with severe conditions in the United States [16], and in several thousand consumers in Israel [17]. The latter also reported that there was no relation between self-reported health and eHL [17].

eHL has also been shown to correlate positively with the users' educational level but correlate negatively to age [15,18].

Although these studies have linked eHL to digital behavior, their findings were mainly based on the eHEALS instrument that directly evaluates information-seeking behavior on the internet in relation to health.

Even though eHEALS is still a widely used tool [19-22], it does not provide sufficient understanding of the individual's interaction with digital services and technology. In 2011, van der Vaart [15] already called for the need of a new understanding of eHL after the internet had been turned into a more dynamic Web 2.0 media. Moreover, in 2017, Griebel et al pointed to the need of new ways to describe eHL with a broader view on the digital health consumer perspective [23].

With the development of 2 new tools, we have introduced a new understanding of people's eHL, including knowledge, skills, perceptions, and experiences in relation to their usage of digital health services and health technology. One measure, the eHL questionnaire (eHLQ), is developed as an instrument to access the 7 dimensions of the eHL framework (eHLF), which describes users' knowledge, skills, perception, and experiences in relation to digital health services and health technologies [24].

The 35 items of eHLQ emerged from a condensation of more than 450 statements that constituted the fundament for the development of the eHLF. In this way, the final items capture a somewhat higher-order assessment of the respondent's understanding and engagement in health information, which is more suitable for the intended usage as a psychometrically sound and valid instrument and is not intended to act as an inventory [24].

The other instrument, the eHL assessment (eHLA) toolkit, examines eHL by combining specific elements from health literacy and digital literacy as both self-reported and performance tests [25].

Objectives

With this new multifaceted approach, we are able to contribute to a better understanding of how users differ from nonusers of digital services, not only with respect to personal attributes such as age, sex, educational level, and self-rated health but also with a particular focus on the individuals' knowledge, skills, perception, and experiences with digital health services.

Consequently, our research question is how can a multifaceted evaluation of individuals' eHL be used to understand usage and nonusage of digital health services and how are usage and eHL related to age, sex, educational level, and self-rated health?

Methods

Study Design

We used a quantitative cross-sectional study design, collecting data using Danish versions of the eHLQ and eHLA instruments, both validated in a Danish population. In total, 246 patients diagnosed with diabetes, other endocrine conditions, and/or gastrointestinal diseases were included. The patients were consecutively enrolled when visiting the outpatient clinic at the Gentofte Hospital, Denmark, between November 2015 and March 2016.

Patients were excluded if they were under the age of 18, had insufficient cognitive functions, or did not understand Danish. The distribution of the questionnaire containing the 2 instruments was undertaken by the nurses at the outpatient clinic, who also assessed whether the respondent had sufficient cognitive functions to participate. In some cases, the nurses also judged from an ethical perspective that the patients, for reasons not stated in the protocol, should be excused from participation in the study (see Figure 1). Patients either filled out the questionnaire in the waiting room or completed it at home and returned it in a prepaid envelope. Patients did not receive reminders.

A total of 553 patients were given the questionnaire to complete. Of these, 246 filled in and returned the questionnaire, whereas 307 did not respond, resulting in a response rate of 44.4% (246/553; Figure 1).

Questionnaires

The questionnaire battery contained eHLQ, eHLA, and questions concerning the patient's sociodemographics, digital behavior, and self-rated health.

The questionnaire battery also included questions about whether informants were exempted from using e-Boks, had used their NemID within the previous 6 months, and whether they had logged into sundhed.dk within the previous 3 months. Finally, questions about the informants' communication with their GP were included.

Educational Level

The demographic variable education was aggregated to 4 levels:

1. *Comprehensive school* equivalent to International Standard Classification of Education 2011 (ISCED-2011) levels 1 and 2 or European Qualifications Framework (EQF) level 2.
2. Short education equivalent to ISCED and EQF levels 3, 4, and 5.
3. Medium education equivalent to ISCED and EQF level 6.
4. Long education equivalent to ISCED and EQF levels 7 and 8 [26,27].

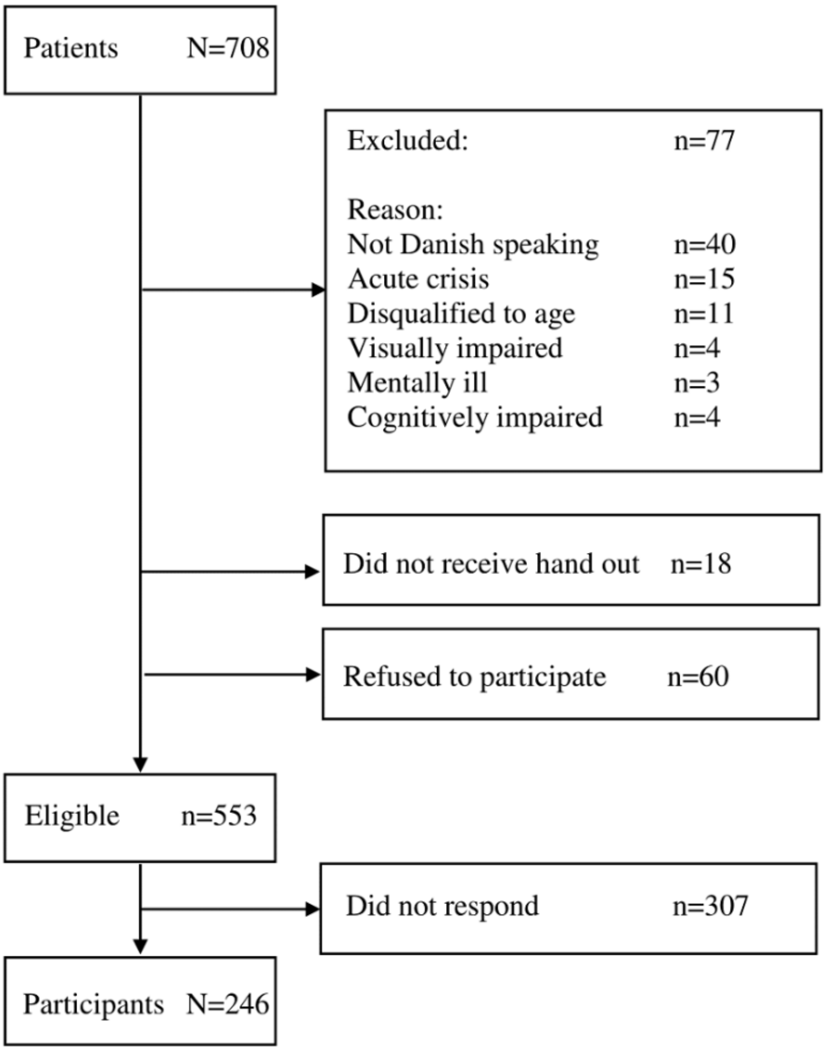
Self-Rated Health

The levels reported in eHLQ and eHLA were correlated to self-rated health, which was measured on a 5-point Likert scale from excellent to poor [28,29]. For the statistical evaluation, the scale was reversed so that *excellent health* was given the highest score (5) and *poor health* the lowest score (1).

Sociodemographic Data

The participants' sociodemographic characteristics are provided in Table 1. The mean age was 56.5 with a range from 18 to 89 years.

Figure 1. Flowchart for inclusion of patients in the study.



Electronic Health Literacy Questionnaire

eHLQ is a validated and psychometrically sound instrument that comprises 35 items covering 7 dimensions: (1) *using technology to process health information*, (2) *understanding of health concepts and language*, (3) *ability to actively engage with digital services*, (4) *feel safe and in control*, (5) *motivated to engage with digital services*, (6) *access to digital services that work*, and (7) *digital services that suit individual needs* [30]. Dimensions 1 and 2 describe the patient's individual competence, dimensions 3 to 5 describe the interaction between the patient and the digital services, and dimensions 6 and 7 characterize the patient's experience with digital systems or services. Each of the first 5 dimensions contains 5 items, whereas dimension 6 has 6 items and dimension 7 has 4 items. Each item has 4 options, *strongly disagree*, *disagree*, *agree*, and *strongly agree*, which yield 1 to 4 points, respectively.

Electronic Health Literacy Assessment Toolkit

eHLA is a validated and psychometrically sound instrument that contains 4 (1-4) health literacy tools and 3 (5-7) digital literacy tools. The tools describe (1) *functional health literacy*, (2) *self-assessed health literacy*, (3) *familiarity with health and disease*, (4) *knowledge of health and disease*, (5) *digital familiarity*, (6) *digital confidence*, and (7) *digital incentives* [25].

The eHLA comprises 44 items: 10 items in tool 1 (*functional health literacy*), 9 items in tool 2 (*self-assessed health literacy)*, 5 items in tool 3 (*familiarity with health and disease*), 6 items in tool 4 (*knowledge of health and disease*), 6 items in tool 5 (*digital familiarity*), 4 items in tool 6 (*digital confidence*), and 4 items in tool 7 (*digital incentives*). Tools 1 and 4 are performance tests. In tool 1, *functional health literacy*, 1 point is given for each correct answer, and in tool 4, *knowledge of health and disease*, 2 points are given for each correct answer and 1 point for opting out. The remaining 5 tools have a 4-option scale. In tool 2, the scale ranges from *very difficult* to *very easy*, in tool 3, the score ranges from *noknowledge* to *full knowledge*, in tool 5, from *notat all familiar* to *completely familiar*, and in tool 6, from *very unconfident* to *very confident*. The items in tool 7 are assessed on a scale ranging from *strongly disagree* to *strongly agree*.

Table 1. The distribution of sociodemographics and self-rated health.

Total	Statistics (N=246), n (%)
Sex	
Female	137 (55.7)
Male	109 (44.3)
Education	
Comprehensive school	19 (7.2)
Short education	70 (28.5)
Medium education	84 (34.1)
Long education	65 (26.4)
Self-rated health	
Poor	8 (3.3)
Less well	61 (24.8)
Well	108 (43.9)
Extremely well	59 (23.9)
Excellent	9 (3.7)
Patients' condition	
Diabetes	92 (37.4)
Other	154 (62.6)

Statistical Analyses

Descriptive statistics are reported as means and interquartile range for age, educational level, and self-rated health. Differences in scores between male and female and users and nonusers of sundhed.dk and NemID were tested using the nonparametric Mann-Whitney test. Differences between users and nonusers of sundhed.dk and NemID with respect to sex were tested using Pearson Chi-square test. We tested for correlation among eHL and age, educational level, and self-rated health. We interpreted the strength of the correlation in accordance with Brace (weak ≤±.2, ±.3 to .6 moderate, strong ≥±.7) [31]. A Bonferroni correction was made for univariate analyses for each of the 2 tools relating sociodemographic factors to each of the tools' 7 dimensions (alpha/number of hypotheses→.05/7=.0071) [32].

Ethics

The research complied with the Helsinki declaration, and the study was approved by the Danish Data Protection Agency (2012-58-004 under the capital Region of Denmark local record number HGH-2018-021 I-suite 06245). Information about the survey was given to the patients in accordance with the inclusion criterion, and written informed consent was obtained beforehand from all the participants.

Results

Use of Digital Services Among Outpatients

The results showed that 142/246 (57.7%) of the outpatients were in contact with their GP via email or econsultation on the GP's website. The use of NemID was widespread: 234/246 (95.1%) patients had used it in the previous 6 months to communicate with public authorities, access home banking or a Web portal for citizens.

A total of 133/246 (54.1%) patients had visited sundhed.dk within the previous 3 months; the majority of patients used the website to access their own eHealth record (Figure 2).

There was no difference between males and females (*P*=.87) age (*P*=.22), self-rated health (*P*=.09), or educational level (*P*=.29) between users and nonusers of sundhed.dk. Users of NemID had a lower mean age 56 (45-68) years versus 67 (54-82) years (*P*=.01) and higher score of self-rated health, 3.0 (2-4) versus 2.2 (2-3) (*P*=.001), than nonusers. There was no difference in educational level between users and nonusers of NemID (*P*=.14), and there were no differences in usage between males and females (*P*=.68).

Percentages in Figure 2 are calculated on the basis of 133 users of sundhed.dk.

In total, 202 patients of the 234 patients with nemID (86.3%) had activated the functionality of receiving an email notification when an official institution sent a letter to the e-Boks. Only 6.4% (15/234) patients were assisted by friends or family in the use of different features in the digital mailbox. A total of 4.5% (11/234) patients were exempted from using the mandatory digital mailbox.

In dimensions 1, 3, 5, 6, and 7, scores of eHLQ dimensions were higher for users than for nonusers for both NemID and sundhed.dk. In dimension 2, *understanding of health concepts and language*, users of sundhed.dk but not users of NemID scored significantly higher, and in dimension 4, *feeling safe and in control*, only NemID users but not sundhed.dk users scored higher than nonusers (Table 2).

Results from the eHLA toolkit showed that users of sundhed.dk and NemID scored significantly higher in tools 2 (*self-assessed health literacy*), 5 (*digital familiarity*), and 7 (*digital incentives*). In addition, users of sundhed.dk also scored significantly better in tool 3 (*familiarity with health and disease*), and users of NemID scored significantly better in tool 6 (*digital confidence*; Table 3).

Figure 2. The participants' (N=133) use of functionalities on sundhed.dk. eHealth: electronic health; GP: general practitioner.

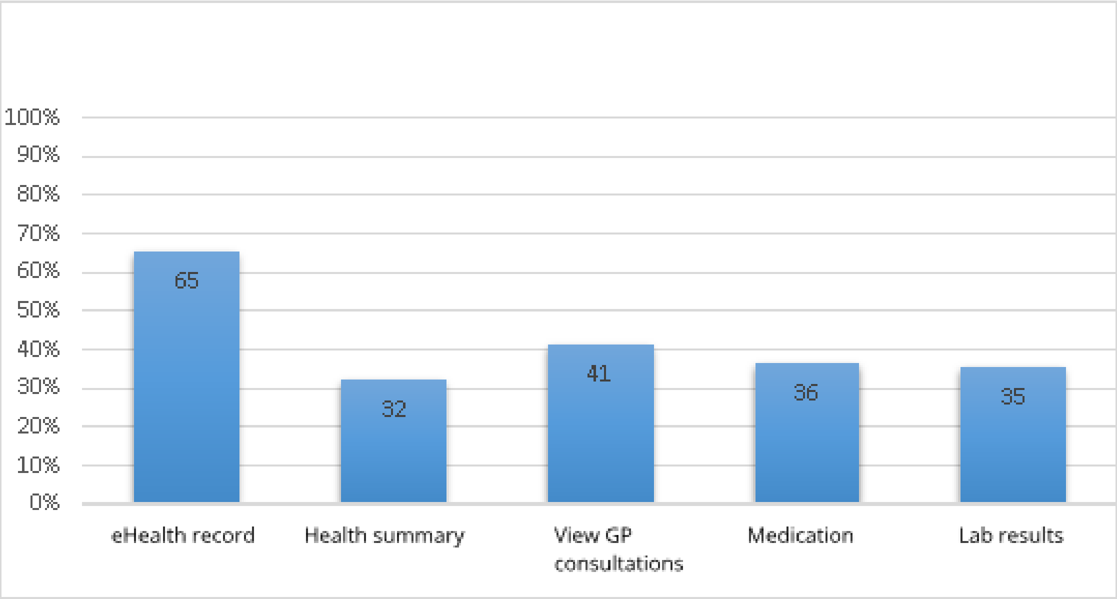


Table 2. Differences in the 7 dimensions in electronic health literacy questionnaire between users and nonusers of sundhed.dk and NemID.

Dimension name in eHLQ[a]	Mean	Users of sundhed.dk			Users of NemID		
		Yes/No, N	Mean (IQR[b])	*P* value	Yes/No, N	Mean (IQR)	*P* value
1. *Using technology to process health information*	2.7	Yes, 132	2.9 (2.6-3.4)	<.001	Yes, 230	2.8 (2.4-3.2)	<.001
		No, 94	2.5 (2.2-3.0)		No, 8	1.5 (1.0-2.0)	
2. *Understanding of health concepts and language*	3.1	Yes, 132	3.2 (3.0-3.6)	.004	Yes, 230	3.2 (2.8-3.4)	.56
		No, 94	3.0 (2.6-3.4)		No, 8	2.9 (1.9-3.8)	
3. *Ability to actively engage with digital services*	3.0	Yes, 132	3.1 (2.8-3.6)	<.001	Yes, 230	3.0 (2.6-3.6)	<.001
		No, 94	2.8 (2.4-3.4)		No, 8	1.6 (1.0-2.0)	
4. *Feel safe and in control*	2.8	Yes, 131	2.9 (2.6-3.2)	.58	Yes, 228	2.9 (2.6-3.2)	.003
		No, 93	2.8 (2.5-3.2)		No, 8	2.1 (1.6-2.6)	
5. *Motivated to engage with digital services*	2.7	Yes, 131	2.9 (2.6-3.4)	<.001	Yes, 229	2.8 (2.4-3.2)	<.001
		No, 95	2.5 (2.0-3.0)		No, 9	1.6 (1.2-2.0)	
6. *Access to digital services that work*	2.7	Yes, 133	2.8 (2.3-3.0)	.007	Yes, 231	2.7 (2.3-3.0)	.001
		No, 95	2.6 (2.2-3.0)		No, 9	2.0 (1.7-2.5)	
7. *Digital services that suit individual needs*	2.6	Yes, 130	2.7 (2.3-3.0)	.005	Yes, 226	2.6 (2.3-3.0)	.001
		No, 93	2.4 (2.0-3.0)		No, 9	1.7 (1.0-2.0)	

[a] eHLQ: eHealth literacy questionnaire.

[b] IQR: interquartile range.

Table 3. Differences in the 7 tools in electronic health literacy assessment between users and nonusers of sundhed.dk and NemID.

Tool in eHLA[a]	Mean	Users of sundhed.dk			Users of NemID		
		Yes/No, N	Mean (IQR[b])	*P* value	Yes/No, N	Mean (IQR)	*P* value
1. Functional health literacy	9.5	Yes, 120	9.5 (9-10)	.75	Yes, 207	9.5 (9-10)	.89
		No, 86	9.4 (9-10)		No, 8	9.5 (9-10)	
2. Self-assessed health literacy	3.3	Yes, 123	3.3 (2.9-3.7)	.004	Yes, 217	3.2 (2.9-3.6)	.007
		No, 93	3.1 (2.8-3.3)		No, 11	2.8 (2.6-3.2)	
3. Familiarity with health and disease	3.1	Yes, 124	3.3 (3.0-3.8)	.006	Yes, 221	3.1 (2.6-3.8)	.58
		No, 95	2.9 (2.4-3.8)		No, 10	3.0 (2.8-3.4)	
4. Knowledge of health and disease	9.7	Yes, 119	9.9 (9-12)	.01	Yes, 213	9.6 (8-11)	.41
		No, 92	9.3 (8-10)		No, 10	10.1 (8-12)	
5. Digital familiarity	3.5	Yes, 125	3.7 (3.5-4.0)	<.001	Yes, 220	3.6 (3.5-4.0)	<.001
		No, 95	3.2 (2.8-4.0)		No, 12	1.7 (1.0-2.3)	
6. Digital confidence	3.4	Yes, 129	3.6 (3.3-4.0)	.02	Yes, 225	3.5 (3.3-4.0)	<.001
		No, 92	3.3 (2.8-4.0)		No, 8	1.7 (1.0-2.3)	
7. Digital incentives	3.5	Yes, 133	3.6 (3.3-4.0)	.005	Yes, 230	3.5 (3.0-4.0)	<.001
		No, 93	3.3 (2.8-4.0)		No, 8	2.0 (1.3-2.8)	

[a]eHLA: eHealth literacy assessment.

[b]IQR: interquartile range.

Relation Among Electronic Health Literacy Questionnaire, Electronic Health Literacy Assessment and Age, Sex, Education, and Self-Rated Health

Age is weakly and negatively correlated to eHLQ dimension 3 (*ability to actively engage with digital services*; Table 4). Using the Mann-Whitney test, we did not find any differences between the eHLQ scores for males and females. Educational level was weakly and negatively correlated to dimensions 4 (*feel safe and in control*) and 6 (*access to digital services that work*; Table 4).

Patients' self-rated health showed a positive, weak correlation with 4 of the 7 dimensions: 1 (*using technology to process health technologies*), 3 (*ability to actively engage with digital services*) 5 (*motivated to engage with digital services*) and 6 (*access to digital services that work*).

Three of the 7 eHLA tools were associated with age: tool 6 (*digital confidence* was moderate, negative correlate). Tools 5 (*digital familiarity*) and 7 (*digital incentives*) showed a weak negative correlation. Educational level was weakly and positively correlated with tools 4 (*knowledge of health and disease*) and 5 (*digital familiarity*). Self-rated health was weakly and positively correlated with 2 (*self-assessed health literacy*), 5 (*digital familiarity*), 6 (*digital confidence*), and 7 (*digital incentives;*Table 5). The Mann-Whitney test for differences between sexes revealed a significantly higher score for males than females in tool 5 (*digital familiarity*, P=.005).

Table 4. The correlations among dimensions for electronic health literacy questionnaire and age, education, and self-rated health.

Dimension name in eHLQ[a]	Age		Education		Self-rated health[b]	
	Coefficient	*P* value	Coefficient	*P* value	Coefficient	*P* value
1. *Using technology to process health information*	−.12	.01	0.09	.08	0.16	.002
2. *Understanding of health concepts and language*	−.02	.61	0.14	.01	0.1	.05
3. *Ability to actively engage with digital services*	−.23	<.001	0.09	.08	0.18	.001
4. *Feel safe and in control*	−.01	.8	−.17	.002	0.08	.12
5. *Motivated to engage with digital services*	−.10	.03	0.04	.46	0.23	<.001
6. *Access to digital services that work*	−.07	.1	−.14	.005	0.14	.005
7. *Digital services that suit individual needs*	−.09	.05	−.08	.13	0.13	.01

[a]eHLQ: eHealth literacy questionnaire.

[b]Self-rated health: 1=poor health, 5=excellent health.

Table 5. The correlation between tools in electronic health literacy assessment and age, education, and self-rated health.

Tool in eHLA[a]	Age		Education		Self-rated health[b]	
	Coefficient	*P* value	Coefficient	*P* value	Coefficient	*P* value
1. Functional health literacy	−.08	.13	.16	.01	.05	.45
2. Self-assessed health literacy	−.05	.31	<.001	.95	.18	.001
3. Familiarity with health and disease	.08	.09	.11	.05	.03	.62
4. Knowledge of health and disease	.11	.02	.15	.007	.03	.60
5. Digital familiarity	−.25	<.001	.22	<.001	.25	<.001
6. Digital confidence	−.34	<.001	.13	.02	.20	<.001
7. Digital incentives	−.17	<.001	.11	.04	.20	<.001

[a] eHLA: eHealth literacy assessment.

[b] Self-rated health: 1=poor health, 5=excellent health.

Discussion

The introduction of the 2 new, recently validated multidimensional measures of eHL, eHLQ and eHLA toolkit, allows us to examine patients' digital behavior from a multifaceted approach, offering a better understanding of whether knowledge, skills, perception, or experiences are related to usage of digital services. As described in the following, this offers a richer understanding than just judging the users' capabilities on the basis of their sociodemographic data such as age, sex, educational level, and self-rated health.

Usage of Digital Services

The lack of a difference with respect to age and sex between the users and nonusers of the digital health service sundhed.dk corresponds with the findings of Siren and Stellefson [7,33].

We did find a difference in age between users and nonusers of the public digital service NemID. This may be explained by the relatively high adoption of NemID in the Danish society; consequently, those not using NemID are mainly excluded because of high age and disabilities. The latter is also supported by the finding that nonusers also had a lower score of self-reported health. Whether this relatively small but vulnerable group of 5% can benefit from digital inclusion remains to be investigated, but the health professionals should be aware of this particular group.

Here, multidimensional measures such as eHLQ and eHLA can add to our understanding of areas that might need to be addressed, as discussed in the following.

Although 95% of the participants in the study use NemID to access digital services, less than 60% of the participants have been in contact with their GP electronically or have taken advantage of the functions available on sundhed.dk. This could be explained by the fact that some NemID services, for example, the electronic mailbox for communications from public authorities, are mandatory to use, whereas electronic contact to one's GP and use of the portal sundhed.dk are voluntary.

The conflicting results in the literature regarding the association among eHealth usage and users' age, sex, or educational level may be explained by the context and research question. A study where the actual usage is reported as in this study may differ from studies where the focus is on, for example, the users' willingness to use a health portal or a medical record, such as reported by Trubitt et al, which found an association with age and education. This is in contrast to our finding that there were no differences between users and nonusers of sundhed.dk with respect to age and education [10].

Electronic Health Literacy and Usage of Digital Services

In general, users of NemID and sundhed.dk scored higher in most dimensions of the eHLQ. Moreover, users tended to score higher in 4 of the 7 eHLA tools for both sundhed.dk (tools 2, 3, 5, and 7) and NemID (tools 2, 5, 6, and 7). It should be noticed that sundhed.dk users had a higher score in the eHLQ dimension 2 as well as 2 of the 4 health literacy tools in eHLA, whereas the 2 other tools in eHLA that related to functional tests did not differ. This suggests that the users of sundhed.dk, because of their better understanding of the health-related language and concepts, are better equipped to understand the information and interact with the services in the health portal.

The assumption that health literacy is a determinant of the usage of the digital health services can be supported by the finding that NemID users did not differ from nonusers with respect to eHLQ dimension 2 and the eHLA tools 1, 3, and 4, which indicates that usage of other public digital services is not related to the users' health literacy.

It is noteworthy that we did not find any differences in scores for the eHLQ dimension 4 (*feeling safe and in control*) between users and nonusers of sundhed.dk. This contrasts with our findings for users of NemID; here, a difference was found. An interpretation of this finding could be that although trust has no significance for the decision to use eHealth technologies such as the health portal sundhed.dk, the relatively few nonusers of NemID may have concerns about safety because of a lack of insight into how the services function.

Our finding is in accordance with Siren and Knudsen [7], who also found that the feeling of being safe and in control is not in itself a significant factor for using digital health services. It can be speculated whether being a patient in the health care sector makes people more trusting when they access and use health services.

Electronic Health Literacy in Relation to Sociodemographic Data

The eHL level only differed between males and females with respect to 2 of the eHLA tools, but it did not differ in any of the dimensions in the eHLQ.

It is of particular interest that the digital tool 5 (*digital familiarity*) in the eHLA toolkit showed a higher score in males compared with females. This is in accordance with the findings of Hargittai et al, who measured digital literacy in college students using a scale that has inspired the construction of this tool [34].

Scales of eHLQ and eHLA that relate to digital skills showed significant negative correlations with age. This may reflect that people of older age generally have more problems finding information, which may contribute to less motivation to engage with technology [15]. Moreover, an increased need of health services by elder individuals may give rise to a feeling that the services are not sufficiently suited to their needs. This was reflected in a negative correlation between age and eHLQ dimension 7 (*access to digital services that suit individual needs*; P=.05); however, it was not significant after a correction for multiple comparisons using Bonferroni.

For the eHLQ dimensions, educational level was weakly, negatively correlated with dimension 4 (*feel safe and in control*) and dimension 6 (*access to digital services that work*). The negative correlation in dimensions 4 (*feel safe and in control*) and 6 (*access to digital services that work*) may be because of a general skepticism toward digital services. The finding that people with a higher educational level tend to have less trust is in alignment with a recent study from a European Union (EU) project evaluating an eHealth solution, the Health Monitor, with both patients and health professionals. In this study, health professionals tended to have more concerns about data privacy than lay people [18].

In contrast to the negative correlation between the 2 eHLQ dimensions and 2 of the eHLA tools; tool 4 (*knowledge of health and disease*) and tool 5 (*digital familiarity*) were positively correlated with the educational level. This finding is inconclusive, as several of the other tools within both health literacy and digital literacy are not related to educational level.

Although studies based upon eHEALS point to an association among eHL and age and educational level [15-17,35], our data are, apart from the negative correlation between age and the digital scales, not conclusive. Combined with our finding, that age and educational level do not differ between users and nonusers of sundhed.dk, this suggests that other factors may contribute to the adoption of eHealth service usage.

Electronic Health Literacy and Self-Rated Health

Most interestingly, eHLA's tool 2, which was derived from the European Health Literacy Survey HLS-EU, had a positive correlation with self-rated health similar to earlier reports in relation to the full HLS-EU instrument [36]. As self-rated health is often positively associated with health literacy [37], it would be expected that those tools and dimensions that are related to health literacy would also be positively correlated with self-rated health. Interestingly, eHLQ dimension 2 (*understanding health concepts and language*) as well as 3 of the 4 health literacy tools (1, 3, and 4) in eHLA did not exhibit such a correlation. However, 4 of the eHLQ scales as well as the 3 digital literacy tools in eHLA demonstrated such a correlation.

This may reflect that people who perceive their own health to be good are more engaged in information and technology and are more motivated than those with poor self-rated health. This is in contrast to Neter and Brainin (2012) who examined the relation between self-rated health and eHL in an Israeli population study and to Milne et al (2015) who examined the relation between perceived health and eHL in patients with lung cancer. This may be explained by differences in the instrument used to assess the self-reported health as well as measurements of eHL [17,38].

Limitations of the Study

A limitation of the study is that it is an observational study conducted in an outpatient clinic in a Danish region where people in general have a rather high sociodemographic profile with respect to income and education.

It should also be noted that the data about digital behavior build on self-reported information and not data acquired from the systems. This may introduce a bias.

Another limitation is the mandatory usage of NemID in Denmar, which may have resulted in a selected population for this investigation compared with other countries with a lower degree of digitalization.

Using 2 instruments, each with 7 scales in the evaluation, may have resulted in a multisignificance problem, where we can have obtained type I error. We have accommodated this by applying the Bonferroni correction. On the other hand, this may have introduced a risk of type II error because of insufficient power of the study caused by the sample size [32]. Further studies that are designed to test our findings, with enough power, are necessary before further conclusions can be drawn.

Conclusions

Our results contribute to the growing knowledge about which factors are important for use of digital health services. Our data show that there were no significant differences between users and nonusers of the digital health service sundhed.dk with regard to age, sex, or educational level. Therefore, these factors alone cannot be used to guide health professionals to understand their patients' adoption and usage of sundhed.dk. However, significant differences were identified between users and nonusers in almost of all the tools of eHLA and eHLQ dimensions. This supports the notion that skills, motivation, and experience of health and digital services are related to the adoption and usage of technology [6,7].

The results emphasize that multifaceted measurements of eHL may be able to capture the factors important to the adoption of digital health services and thereby serve to guide health professionals to better understand and support their patients to obtain the full benefits of the increasing digitalization of the health care sector.

Further studies are needed to identify how the tools or the underlying dimensions can be best used to inform the clinicians and facilitate that more patients take advantage of digital health services and technologies and benefit from the ever-expanding evolution of digital health.

Acknowledgments

The authors would like to thank the nurses at the outpatient clinic at Gentofte Hospital for their help with data collection and all the patients willing to participate and complete the questionnaire. The authors also wish to thank Thanks Steen Ladelund for the initial statistical discussions. The authors thank Ms. Emily Duminski for helping in preparing the manuscript for submission. AK is a PhD fellow at the Danish Multiple Sclerosis Society and is also supported by the Innovation Fund Denmark.

The University of Copenhagen owns the IPR to eHLA. Together with Deakin University, Melbourne, Australia, they also own the IPR of eHLQ. eHLA can be obtained via a free license from the University of Copenhagen. eHLQ can be licensed for free for noncommercial use from either the University of Copenhagen or Deakin University.

Authors' Contributions

KAH, AK, DO, SEN, LK, MER, and GF participated in the design of the study. KAH and SEN handled the collection of data. MER in collaboration with GF collected the patients’ clinical data from eHealth records. Management of data was supported by KAH, AK, DO, and LK. KAH, LK, and DO performed the statistical analysis supported by AK and Steen Ladelund. KAH drafted the first version of the manuscript assisted by DO. LK and AK wrote the second draft assisted by DO. MER and GF contributed in interpreting the data, results, and in the discussion. All authors critically revised the text and read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

e-Boks: Patient’s digital mailbox
eHEALS: eHealth literacy scale
eHealth: electronic health
eHL: eHealth literacy
eHLA: eHealth literacy assessment
eHLF: eHealth literacy framework
eHLQ: eHealth literacy questionnaire
EQF: European Qualifications Framework
GP: general practitioner
ICT: information and communications technology
ISCED: International Standard Classification of Education

Edited by G Eysenbach; submitted 14.07.17; peer-reviewed by E Neter, B Xie; comments to author 24.11.17; revised version received 08.03.18; accepted 07.02.19; published 05.04.19.

Please cite as:
Holt KA, Karnoe A, Overgaard D, Nielsen SE, Kayser L, Røder ME, From G
Differences in the Level of Electronic Health Literacy Between Users and Nonusers of Digital Health Services: An Exploratory Survey of a Group of Medical Outpatients
Interact J Med Res 2019;8(2):e8423
URL: http://www.i-jmr.org/2019/2/e8423/
doi:10.2196/ijmr.8423
PMID:30950809

Original Paper

EasyDetectDisease: An Android App for Early Symptom Detection and Prevention of Childhood Infectious Diseases

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Abstract

Background: Infectious diseases often lead to death among children under 5 years in many underdeveloped and developing countries. One of the main reasons behind this is an unawareness of disease symptoms among mothers and child caregivers. To overcome this, we propose the EasyDetectDisease mobile health app to educate mothers about the early symptoms of pediatric diseases and to provide them with practical advice for preventing the spread of such diseases in children under 5 years. The EasyDetectDisease app includes detailed knowledge of infectious diseases, including the corresponding symptoms, causes, incubation period, preventive measures, nutritional guidelines such as breastfeeding, video tutorials of child patients, and video guidelines by pediatric health experts to promote child health. It also provides information on the diagnosis of the infectious diseases based on symptoms.

Objective: The objective of this study was to evaluate the usability (eg, ease of use, easy detection of disease, functionality, and navigation of interfaces) of the EasyDetectDisease app among mothers of children under 5 years of age.

Methods: Two health sessions, held in Pakistan, were used to evaluate the usability of EasyDetectDisease by 30 mothers of children under 5 years. The app was evaluated based on various quantitative and qualitative measures.

Results: The participating mothers confirmed that they were able to diagnose diseases accurately and that after following the instructions provided, their children recovered rapidly without any nutritional deficiency. All participating mothers showed an interest in using the EasyDetectDisease app if made available by governmental public health agencies, and they suggested its inclusion in all mobile phones as a built-in health app in the future.

Conclusions: EasyDetectDisease was modified into a user-friendly app based on feedback collected during the usability sessions. All participants found it acceptable and easy to use, especially illiterate mothers. The EasyDetectDisease app proved to be a useful tool for child health care at home and for the treatment of infectious diseases and is expected to reduce the mortality rate of children under 5 years of age.

(Interact J Med Res 2019;8(2):e12664) doi:10.2196/12664

KEYWORDS

infectious diseases; mHealth; causes of death

Introduction

Overview

Child health care is one of the foremost priorities in the world. However, it is an undeniable truth that millions of children's lives are affected each year by disease. Infectious diseases have been regarded as a major cause of morbidity and mortality in children under 5 years of age, according to a recent report by the World Health Organization (WHO) [1], 83% of the global deaths of children under 5 years are caused by infectious diseases and malnutrition. According to another recent WHO report [2], around 5.6 million (60%) children died before reaching their fifth birthday in 2016 [2], out of which 3.6 million deaths happened in 10 South Asian and African countries. Out of these 3.6 million children, almost half of the deaths occurred in 5 countries (ie, Nigeria, the Democratic Republic of the Congo, India, Ethiopia, and Pakistan). Pakistan is one of the developing countries that is facing the challenge of a high child mortality rate because of infectious diseases. The mortality rate was 78.8 in 2016 [3], with a 40% ratio of infectious diseases in Pakistan [4].

A mother is considered to be a sick child's first health care provider at home. Various studies have been conducted in Pakistan to show a strong correlation between maternal education and lower child mortality [5]. These studies examined health-seeking behaviors, specifically the education level of the mother and its effects on child mortality [5]. It was identified that the behavior of mothers who had a better understanding of childhood diseases and were accustomed to using modern health care services was quite distinct from those who had no knowledge of childhood diseases. Therefore, maternal education can be regarded as an important contributor to child health development and can be used to overcome the abovementioned issues.

In Pakistan, however, to the best of our knowledge, very little effort is being made to educate mothers about pediatric infectious and noninfectious diseases. It has been found that a lack of child health awareness, inadequate maternal education, improper access to medical facilities, and a lack of exposure to smart technology and mobile health (mHealth) tools are some of the key causes behind child mortality in Pakistan [6-8]. In this paper, we focused on maternal education, child care awareness, and provision of mHealth tools as potential solutions for reducing the mortality rate of children under 5 years. In particular, we present the mHealth app EasyDetectDisease to educate mothers about childhood infectious diseases. The EasyDetectDisease app provides information on the diagnosis of infectious diseases based on symptoms, the prevention of the spread of such diseases, nutritional recommendations for children under 5 years, as well as sick patients' tutorials and guidelines formulated by pediatricians.

Global Death Estimates for Children Under 5 Years by Cause and Sex (2000-2015)

This subsection provides the estimated statistics of global deaths by cause and sex of children under 5 years while focusing on the statistics for Pakistan. Updated data of children under 5 years has been retrieved from the WHO and United Nations International Children's Emergency Fund (UNICEF) websites; specific information has been extracted and presented in tables.

According to the WHO's Global Health Observatory, globally, 15,000 children died every day in 2016 (5.6 million per year) [9] and 16,000 died per day in 2015 (5.9 million per year) [10]. Globally, under 5 years deaths declined to 5.6 million in 2016 from 12.7 million in 1990 [11]. Table 1 shows the figures for deaths by cause and sex of children under 5 years since 2000 (see Multimedia Appendix 1 for complete data).

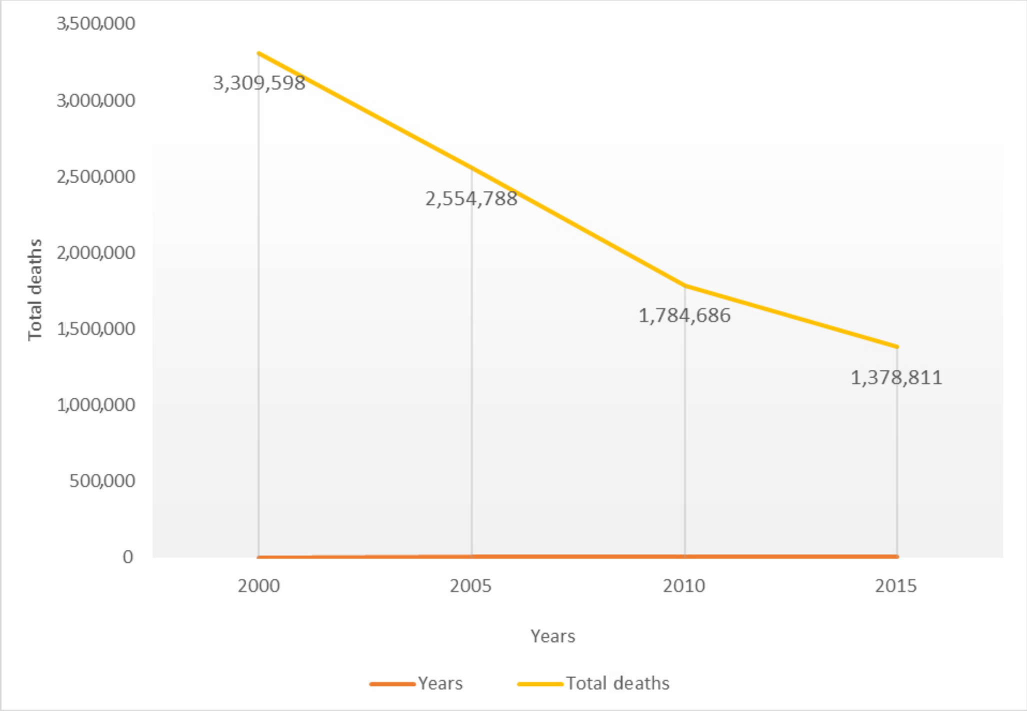
It can be observed from Table 1 that the ratio of deaths due to infectious diseases is higher than other kinds of diseases. The total number of deaths caused by infectious and parasitic diseases declined from 3,309,598 in 2000 to 1,378,811 in 2015 [12]. Figure 1, based on the data from Table 1, shows the decline in deaths caused by infectious and parasitic diseases.

Globally, most countries achieved remarkable progress in the reduction of deaths among children under 5 years during the period of 2000 to 2015. However, it is still expected to reach 5 million deaths by 2025 [13], according to the WHO, and 97% of them would be in the developing regions of the world, including Pakistan, and due to infectious and parasitic diseases such as pneumonia, diarrhea, and inappropriate nutritional conditions [11]. If the current trends continue and appropriate measures are not taken, it is expected to reach a total of 69 million global deaths, that is, 4.6 million deaths per year, by 2030 [3]. Moreover, only 5 countries would be responsible for more than the half of these deaths, that is, India for 17% of deaths, Nigeria for 15% of deaths, Pakistan for 8% of deaths, the Democratic Republic of the Congo for 7% deaths, and Angola for 5% of deaths [3].

Table 1. Deaths by cause and sex of children under 5 years of age (2000-2015): global statistics.

Year	2000		2005		2010		2015	
	Male	Female	Male	Female	Male	Female	Male	Female
Population (thousands)	307,365	288,056	314,316	293,895	327,383	305,647	340,696	318,471
All causes	3,125,021	3,023,960	2,573,082	2,443,545	2,067,721	1,943,638	1,726,318	1,582,772
Communicable, maternal, perinatal, and nutritional conditions	2,613,990	2,573,705	2,107,444	2,037,486	1,606,145	1,538,904	1,293,035	1,209,656
Infectious and parasitic diseases	1,675,701	1,633,897	1,296,962	1,257,826	906,321	878,365	705,280	673,531
Respiratory infections	703,758	729,592	598,657	595,634	495,105	486,014	389,846	370,367
Maternal conditions	0	0	0	0	0	0	0	0
Neonatal conditions	122,311	115,293	112,414	104,739	108,504	101,210	105,356	98,276
Nutritional deficiencies	112,220	94,924	99,411	79,287	96,215	73,314	92,553	67,482
Noncommunicable diseases	296,596	285,550	269,893	256,698	255,631	240,535	246,338	227,590
Malignant neoplasm	20,978	16,204	19,968	15,572	20,604	15,684	21,155	16,042
Other neoplasm	1557	1404	1410	1340	1749	1551	1779	1591
Diabetes mellitus	1343	1399	1149	1184	1015	1041	874	885
Endocrine, blood, and immune disorders	35,753	31,327	34,870	29,505	35,466	28,493	37,397	27,851
Mental and substance use disorders	0	0	0	0	0	0	0	0
Neurological conditions	11,423	8292	10,747	8086	10,085	7995	9545	7916
Sense organ diseases	0	0	0	0	0	0	0	0
Cardiovascular diseases	31,539	25,723	27,031	21,784	23,824	19,130	20,714	16,764
Respiratory diseases	31,611	28,215	25,740	21,118	22,662	17,819	20,490	15,333
Digestive diseases	18,479	20,786	16,015	19,123	13,979	17,066	12,166	15,005
Genitourinary diseases	12,058	10,541	10,995	9226	10,364	8486	9823	7743
Skin diseases	2123	2994	2084	3128	2119	3473	2307	3897
Musculoskeletal diseases	0	0	0	0	0	0	0	0
Congenital anomalies	119,252	130,087	109,316	117,983	103,514	111,222	99,896	105,862
Oral conditions	0	0	0	0	0	0	0	0
Sudden infant death syndrome	10,479	8579	10,569	8647	10,250	8576	10,192	8700
Injuries	214,436	164,704	195,745	149,362	205,945	164,199	186,944	145,526
Unintentional injuries	203,682	154,364	187,073	141,177	196,940	155,988	176,700	136,424
Intentional injuries	10,754	10,340	8672	8185	9005	8212	10,244	9102

Figure 1. Decline in deaths due to infectious and parasitic diseases among children under 5 years of age.



Death Estimates for Children Under 5 Years by Cause in Pakistan (2000-2015)

Pakistan is ranked sixth among 22 high disease–burden countries and is facing the challenge of high communicable diseases with a 40% ratio [4]. The leading causes of under 5 years deaths include premature birth, pneumonia, diarrhea, and malaria. The total number of deaths caused by various diseases is depicted in Figure 2 to assess the top 20 most dangerous infectious diseases [14].

In Figure 2, we can see that the ratio of deaths due to acute respiratory infections (cause 9) was quite high in 2000. This decreased gradually until 2008. Prematurity (cause 10) increased rapidly after 2008, and even now, it is the most dominant cause of death. Birth asphyxia (cause 11) was high in 2002, that is, ranked third, but it was controlled by 2006. After 2006, birth asphyxia again prevailed and the number of deaths associated with it continued to increase until 2012. The number of deaths due to diarrheal diseases (cause 3) increased by the mid 2000s but was controlled in 2008, although a minor increase was seen in 2009 and 2010 and it persisted as a major cause of under 5 years child mortality in Pakistan. Sepsis (cause 12) was ranked as the fifth major cause of death by 2005, and then, the number of corresponding deaths increased higher than diarrheal diseases in 2015. Deaths due to cause 13 (other group 1) diseases, cause 17 (injuries), cause 16 (other communicable diseases), cause 15 (congenital anomalies), cause 5 (tetanus), cause 7 (meningitis), cause 4 (pertussis), cause 6 (measles), cause 8 (malaria), and cause 2 (HIV/AIDS) were prominent in Pakistan, as reported by the WHO. The death rate of children under 5 years (variable name “rufive”; the data for rufive was retrieved from the WHO website and is shown in Table 2 and the figures) is depicted in Figure 3.

Figure 2. Estimates for causes of death among children under 5 years of age in Pakistan (2000-2015).

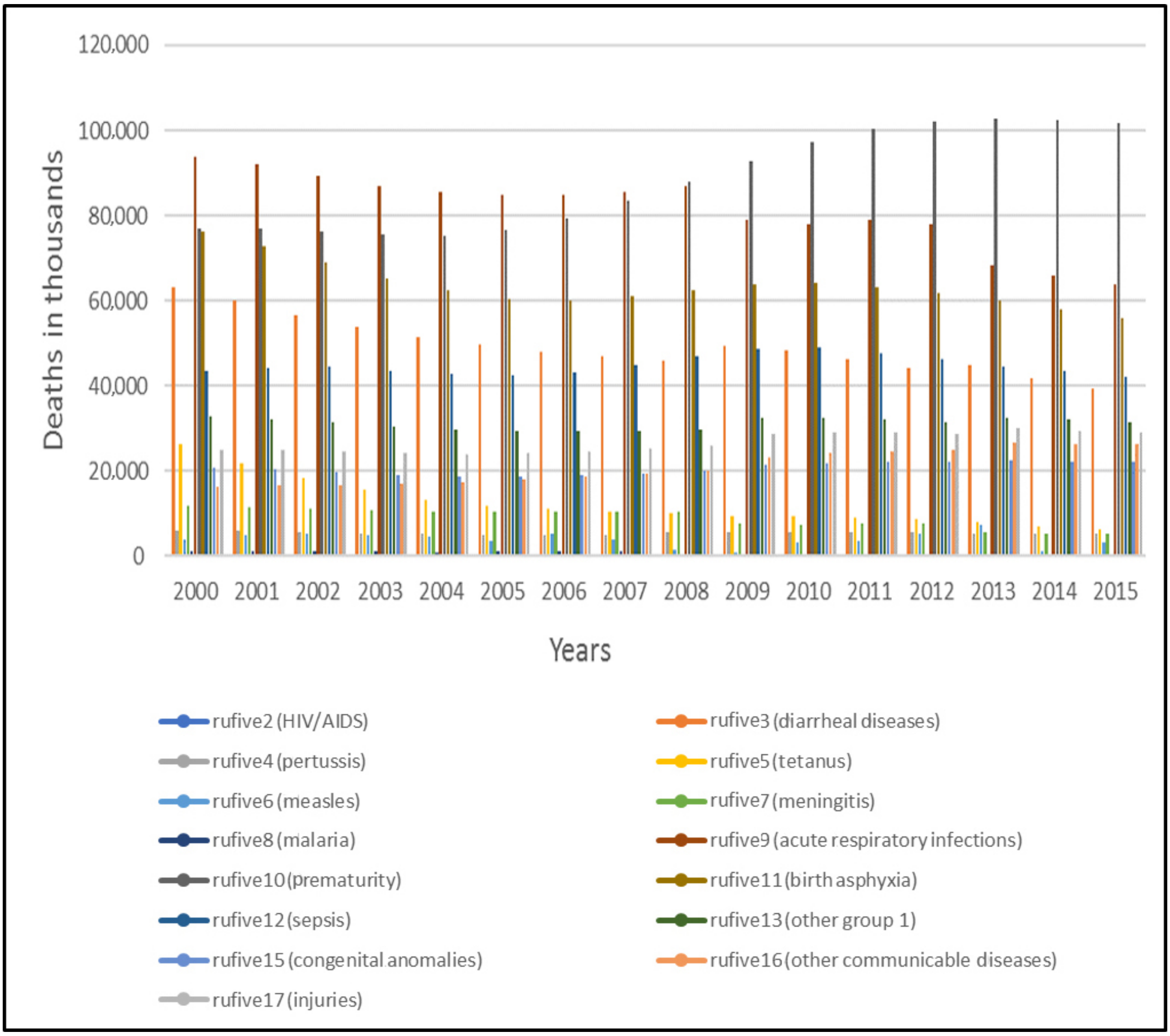
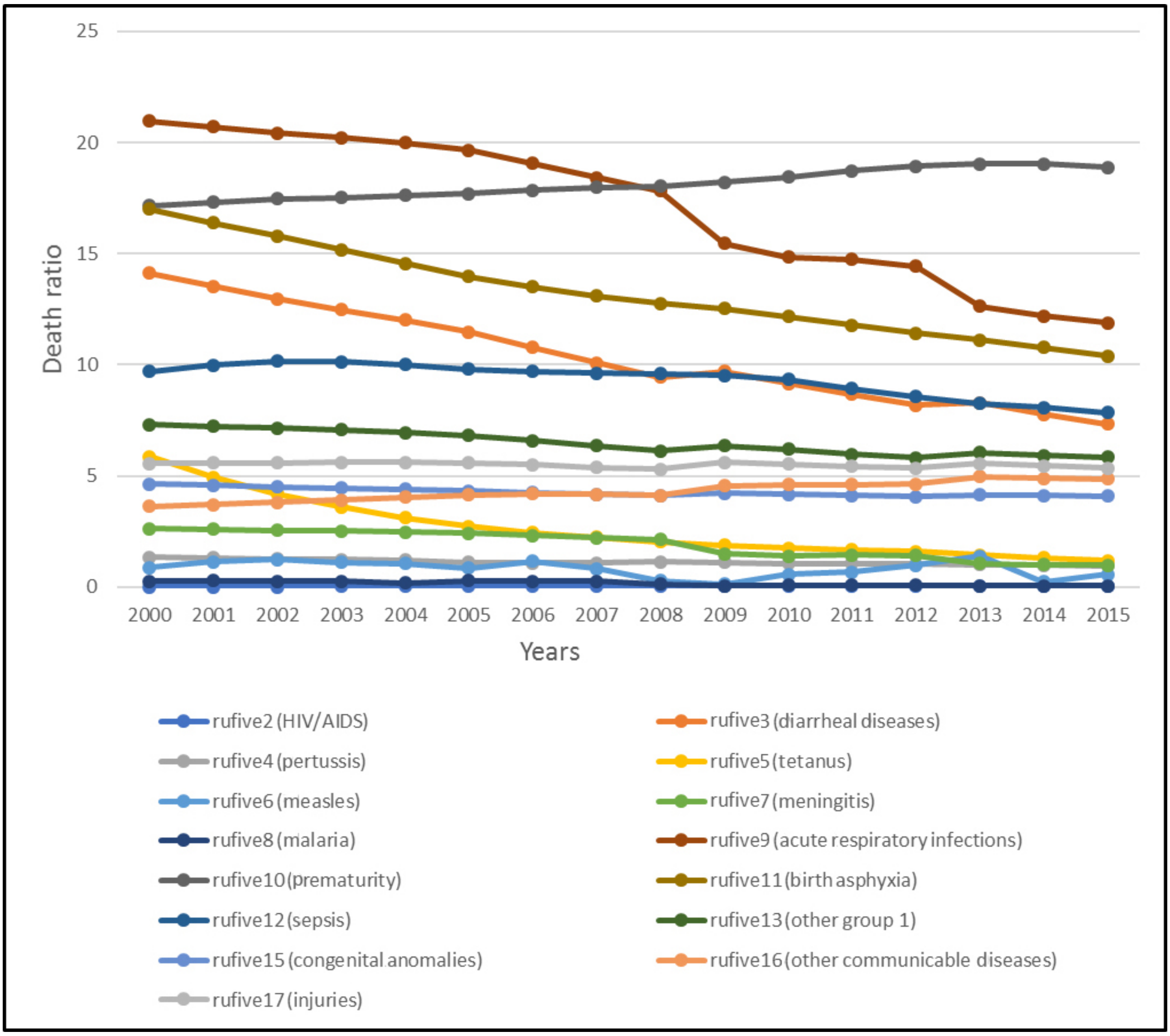


Table 2. Deaths by cause and sex of children under 5 years of age (2000-2015): statistics for Pakistan.

Year	2000		2005		2010		2015	
	Male	Female	Male	Female	Male	Female	Male	Female
Population (thousands)	10,399	9703	10,441	9610	11,609	10,791	12,792	11,871
All causes	264.1	233.2	234.7	201	253.5	216.7	233.2	195.7
Communicable, maternal, perinatal, and nutritional conditions	229.7	205.9	200.1	174.9	210.8	184.2	189.8	162.2
Infectious and parasitic diseases	62.8	64.5	47.3	47.2	42.6	44.6	33.6	35.3
Respiratory infections	43	50.9	40.5	44.3	37	41	31.1	32.8
Maternal conditions	0	0	0	0	0	0	0	0
Neonatal conditions	122.5	89.4	111.3	82.4	129.6	97.2	123.2	92.6
Nutritional deficiencies	1.3	1.1	1.1	1	1.6	1.4	1.8	1.4
Noncommunicable diseases	21.1	15.8	20.6	14.7	26.5	19.6	27.7	20.4
Malignant neoplasm	0.9	0.5	1	0.6	1.3	0.8	1.6	1
Other neoplasm	0.1	0.1	0.1	0.1	0.1	0.2	0.2	0.3
Diabetes mellitus	0.1	0.1	0.1	0.1	0.1	0.2	0.1	0.2
Endocrine, blood, and immune disorders	0.9	0.9	0.9	0.9	1.4	1.4	1.6	1.6
Mental and substance use disorders	0	0	0	0	0	0	0	0
Neurological conditions	0.5	0.4	0.6	0.5	0.8	0.8	0.9	1
Sense organ diseases	0	0	0	0	0	0	0	0
Cardiovascular diseases	0.9	0.2	1	0.2	1.3	0.3	1.4	0.3
Respiratory diseases	4.7	2	5.2	2.1	6.4	2.7	6.6	2.8
Digestive diseases	1.1	0.6	1	0.5	1.5	0.8	1.4	0.9
Genitourinary diseases	0.7	0.3	0.8	0.3	1.1	0.5	1.2	0.5
Skin diseases	0.1	0.4	0.1	0.5	0.2	0.8	0.2	1
Musculoskeletal diseases	0	0	0	0	0	0	0	0
Congenital anomalies	10.8	9.9	9.9	8.7	11.5	10.3	11.7	10.2
Oral conditions	0	0	0	0	0	0	0	0
Sudden infant death syndrome	0.4	0.4	0.6	0.5	0.7	0.7	0.9	0.8
Injuries	13.4	11.5	13.3	10.8	16.2	12.9	15.7	13.2
Unintentional injuries	12.8	11	12.9	10.4	15.3	12	14.7	12.1
Intentional injuries	0.6	0.6	0.4	0.4	0.9	0.9	1	1

Figure 3. Death rate of children under 5 years of age due to various causes in Pakistan (2000-2015).



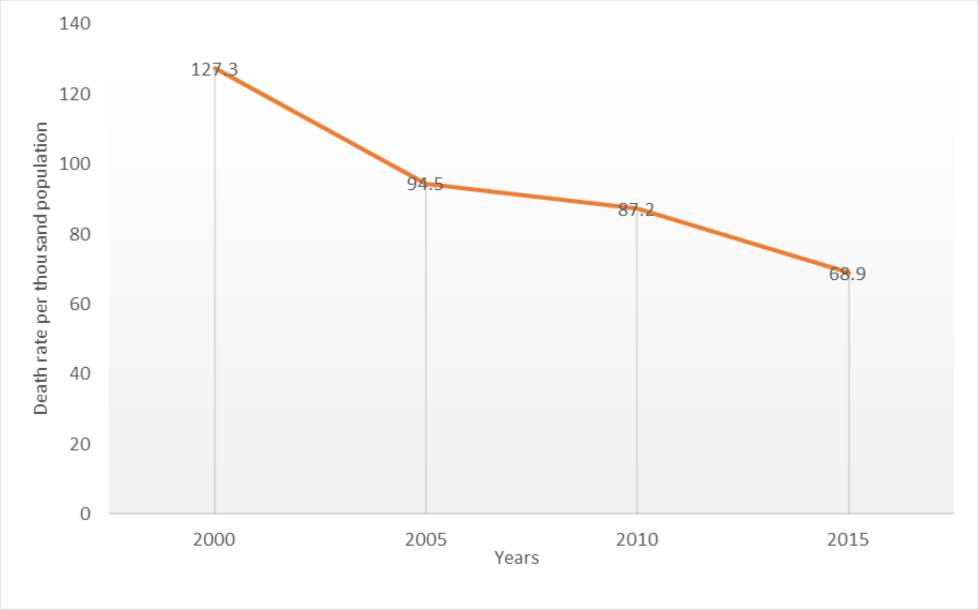
Pakistan's Estimated Under 5 Years Deaths by Cause and Sex (2000-2015)

According to the WHO, deaths among children under 5 years of age in Pakistan because of contagious diseases are higher than those linked to noncontagious diseases [11]. In Pakistan, the number of deaths caused by infectious diseases was 352,000 in 2015 [10]. Table 2 shows the figures for deaths of Pakistani children under 5 years by causes and sex (see Multimedia Appendix 1 for complete data).

We can see from Table 2 that the infectious disease death ratio is higher than other categories of diseases. The total death rate due to infectious and parasitic diseases declined from 127.3 per 1000 children in 2000 to 68.9 per 1000 children in 2015 [12]. Figure 4, based on data from Table 2, shows a decline in the death rate of children in Pakistan due to infectious and parasitic diseases.

Pakistan has achieved remarkable progress in the reduction of deaths among children under 5 years during the period of 2000 to 2015, as shown in Figure 4. Despite achieving progression in the fourth goal (*Reduce Child Mortality*) of Millennium Development Goals, 4.6 million child deaths per year is projected for the period of 2016 to 2030, and Pakistan is expected to be responsible for 8% of these deaths [3]. These numbers are quite alarming and require preventive measures to be taken.

Figure 4. Decline in child death rate caused by infectious and parasitic diseases in Pakistan.



Related Works and Motivation

mHealth is an area of electronic health that deals with health aids via mobile phones [15-16]. The most common practice of mHealth is the use of smartphones to educate users about health care services [17]. To the best of our knowledge, no research focusing on minimizing the mortality of children under 5 years using mHealth-based maternal education in Pakistan has been conducted before.

It has been observed that most Pakistani mothers are not aware of diseases, their prevention, and child care at home [18]. Mothers in Pakistan mostly use homemade remedies instead of providing proper medical care to their children. Such actions often lead to disease severity or even death of the child in the worst-case scenarios. To promote child health, the government of Pakistan periodically initiated various health care programs. In 2010, working with the Ministry of Health, nongovernmental organizations (NGOs) and UNICEF launched Maternal, Neonatal and Child Health [19] and the national Expanded Program on Immunization programs to overcome the problems of diseases, to monitor the health of mothers and children, and to promote child development [20]. The School Health Program by the United Nations Educational, Scientific and Cultural Organization (UNESCO) was also launched in 2010 to promote health activities in schools [21]. In 2012, the National Integrated Development Association Pakistan launched the Health and Nutrition Program to provide awareness about mother and child care and to educate about childhood diseases and other epidemics through active community participation [22]. In 2015, the Prime Minister of Pakistan initiated the PM's National Health Program to provide people of lower socioeconomic status with free medical treatment [23]. In 2016, the Al Khidmat Foundation and the Maternal and Child Health Center initiated 1800 free mHealth camps all over Pakistan to train mothers on maintaining their own and their children's health [24]. In 2017, Save the Children, an NGO, also participated to save children from disease by training lady health workers (LHWs) from different regions of Pakistan to educate young mothers and to minimize health issues [25]. The School Health Program for Pakistan commenced in 2017 to promote physical activities for children in schools, to control the consumption of snacks and junk food, and to increase the consumption of fruits and vegetables for a sound body and mind [26].

Approach and Contributions

All the awareness efforts and education programs mentioned above were time limited to a few days or weeks. Similarly, online child health awareness and health promotion sessions are held globally, but they are of limited duration and participants usually have to pay for attending these sessions. The proposed EasyDetectDisease app, conversely, provides a long-term solution based on the following features:

- Symptoms detection
- Diseases awareness
- Nutrition awareness
- Promotion of breastfeeding
- Explanatory tutorials of live patients
- Video guidelines about diseases by pediatric health experts.

EasyDetectDisease provides a means to mothers for diagnosing the early symptoms of infectious diseases in their children. This kind of early detection of symptoms can prevent serious attacks of diseases. The app provides complete awareness about the most frequently occurring diseases in children under the age of 5 years. The EasyDetectDisease app would be a free-of-cost service, made available through governmental health agencies and app stores.

Methods

Overview

This section describes the main design stages of the EasyDetectDisease app development. We started off by collecting health care–related data from different websites and local health institutes. The app was designed and developed based of the collected data. Next, its usage was evaluated by a sample group of end users. Here, we explain these stages one by one.

Data Collection

We gathered data on the diseases highlighted in the WHO and UNICEF websites and by The Children's Hospital (CH) and the Institute of Child Health Multan (ICHM) in Pakistan. After gathering the data, 3 pediatric health experts from CH and ICHM examined the data for coherency and accuracy. The collected data were then sorted according to the instructions of experts and inserted into the app after final approval of the doctors.

App Design

The EasyDetectDisease app consists of 7 modules: diagnostic test, diseases, prevention, nutrition, video guidelines, video tutorials, and report, as depicted in Figures 5 and 6. Each 1 of these 7 modules has its own functionality and purpose. The EasyDetectDisease app is bilingual and provides content in the Urdu language for Pakistani users and English for international users. The user-friendly interface has been developed to facilitate both literate and illiterate mothers in Pakistan.

According to the UNESCO data, Pakistan ranked 135th (out of 150) in literacy in 2016 [27]. According to the latest economic survey of Pakistan, the literacy rate of Pakistan has declined by 2%, from 60% in 2015 to 58% in 2017 [28]. Female literacy rate in Pakistan is 49%, which is very low compared to male literacy rate [28]; therefore, the app also provides text to speech (TTS) for mothers who cannot read Urdu but can understand it.

Figure 5. Modules of the EasyDetectDisease app in English.

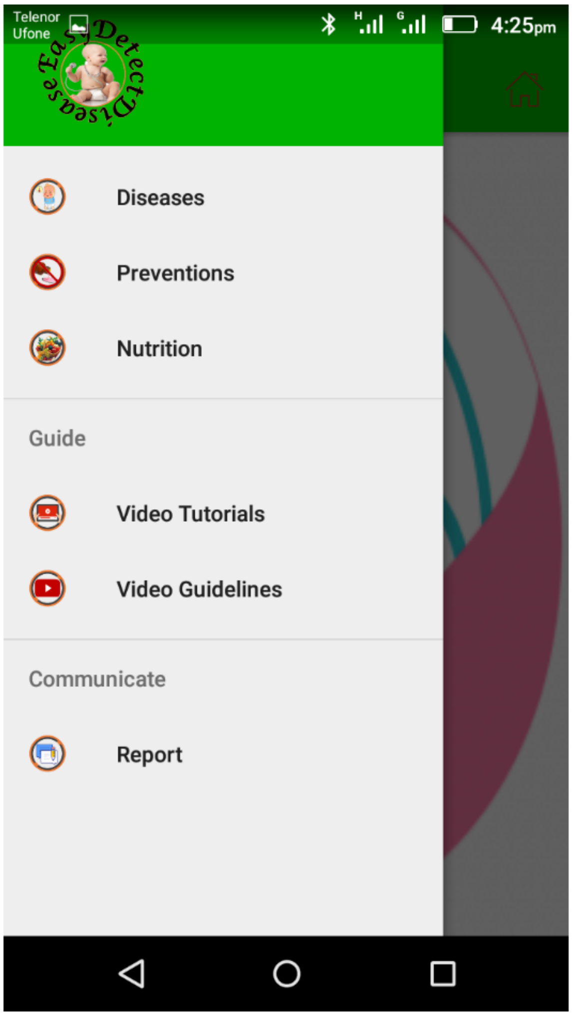
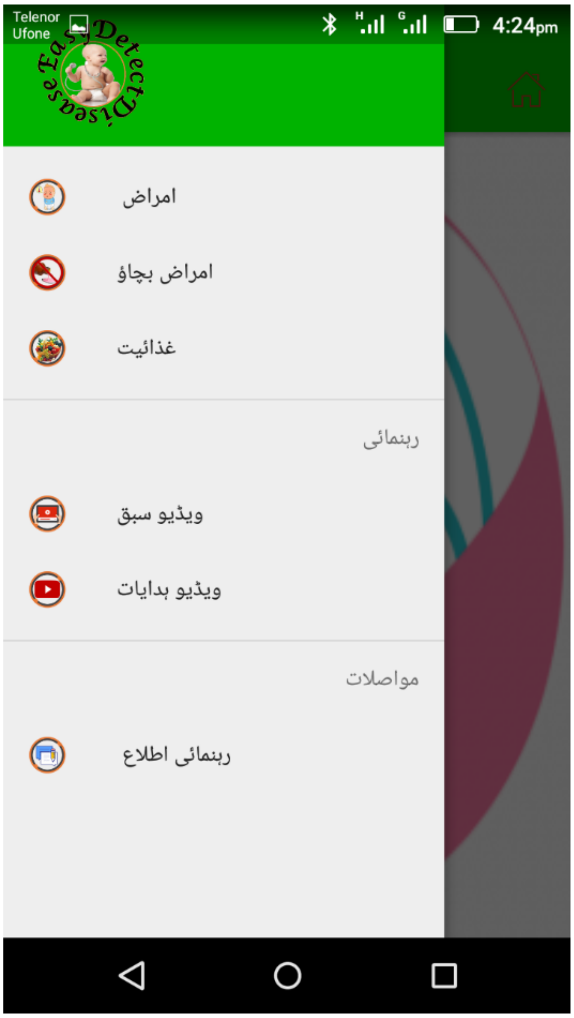


Figure 6. Modules of the EasyDetectDisease app in Urdu.



Diagnostic Test

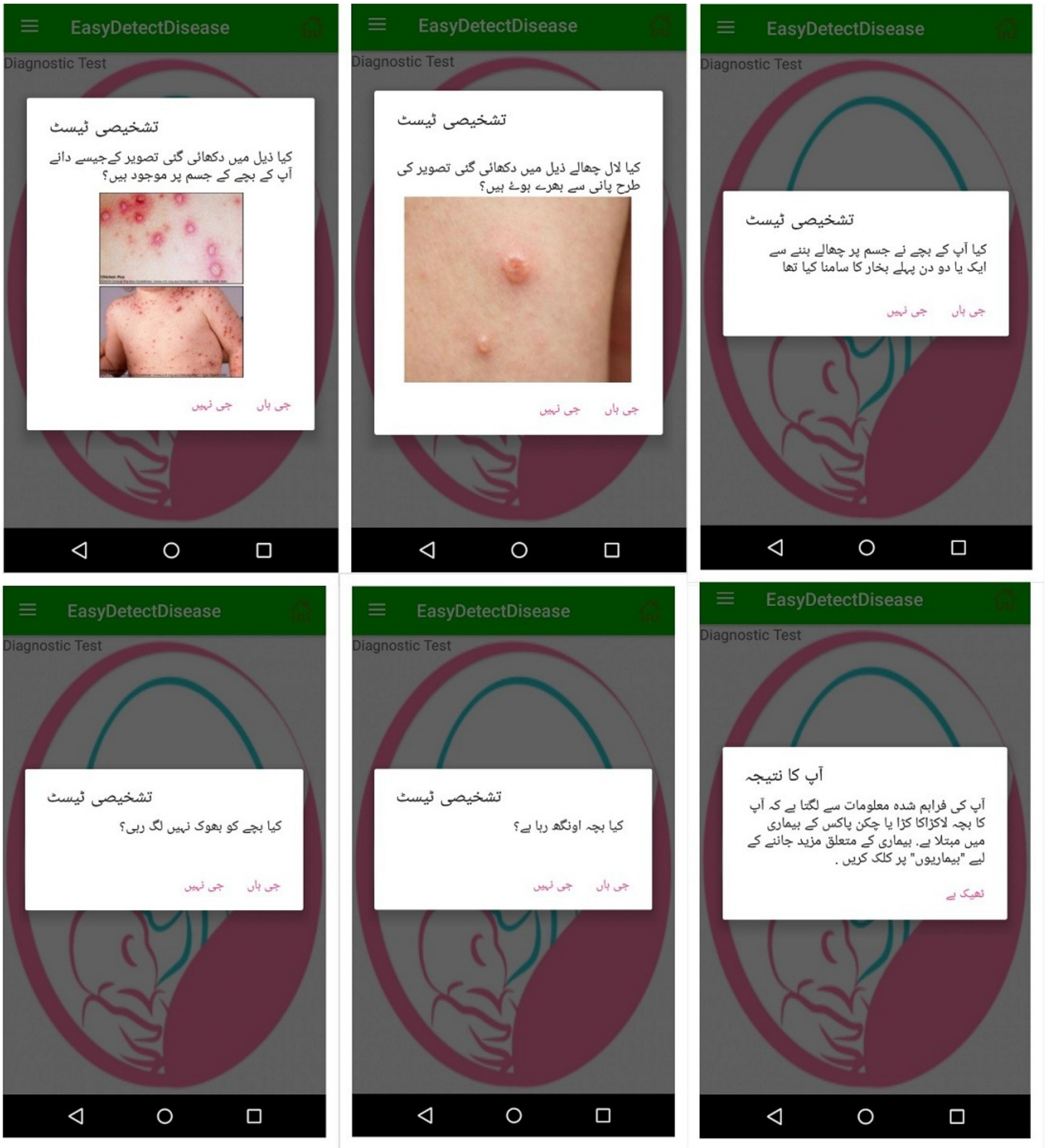
The diagnostic test module allows the mother to detect the disease from its early symptoms. The module detects the symptoms of the sick child by asking some questions from the mother while showing her pictures of sick children.

The text of these questions is also read by the TTS. This module provides easy navigation between interfaces, and the foremost task for the mother is to select the language, and then, the user interface guides her to further navigate the app. The diagnostic test interface in Urdu and English is shown in Figures 7 and 8, respectively.

Diseases

This module provides a detailed description of infectious diseases and some noninfectious diseases, their spread, incubation period, causes, child care at home, and medical advices. For example, if a child is suffering from anaphylaxis and his/her mother chooses anaphylaxis from the list of diseases as shown in Figure 9, the EasyDetectDisease app will show her a virtual patient to highlight the symptoms, give an overview of the disease, indicate the signs of danger and affected areas, incubation period of disease, and medical advice (see Figure 10).

Figure 7. Diagnostic test interface of the EasyDetectDisease app in Urdu.



تشخیصی ٹیسٹ

کیا ذیل میں دکھائی گئی تصویر کےجیسے دانے
آپ کے بچے کے جسم پر موجود ہیں؟

تشخیصی ٹیسٹ

کیا لال چھالے ذیل میں دکھائی گئی تصویر کی
طرح پانی سے بھرے ہوئے ہیں؟

تشخیصی ٹیسٹ

کیا آپ کے بچے نے جسم پر چھالے بننے سے
ایک یا دو دن پہلے بخار کا سامنا کیا تھا

تشخیصی ٹیسٹ

کیا بچے کو بھوک نہیں لگ رہی؟

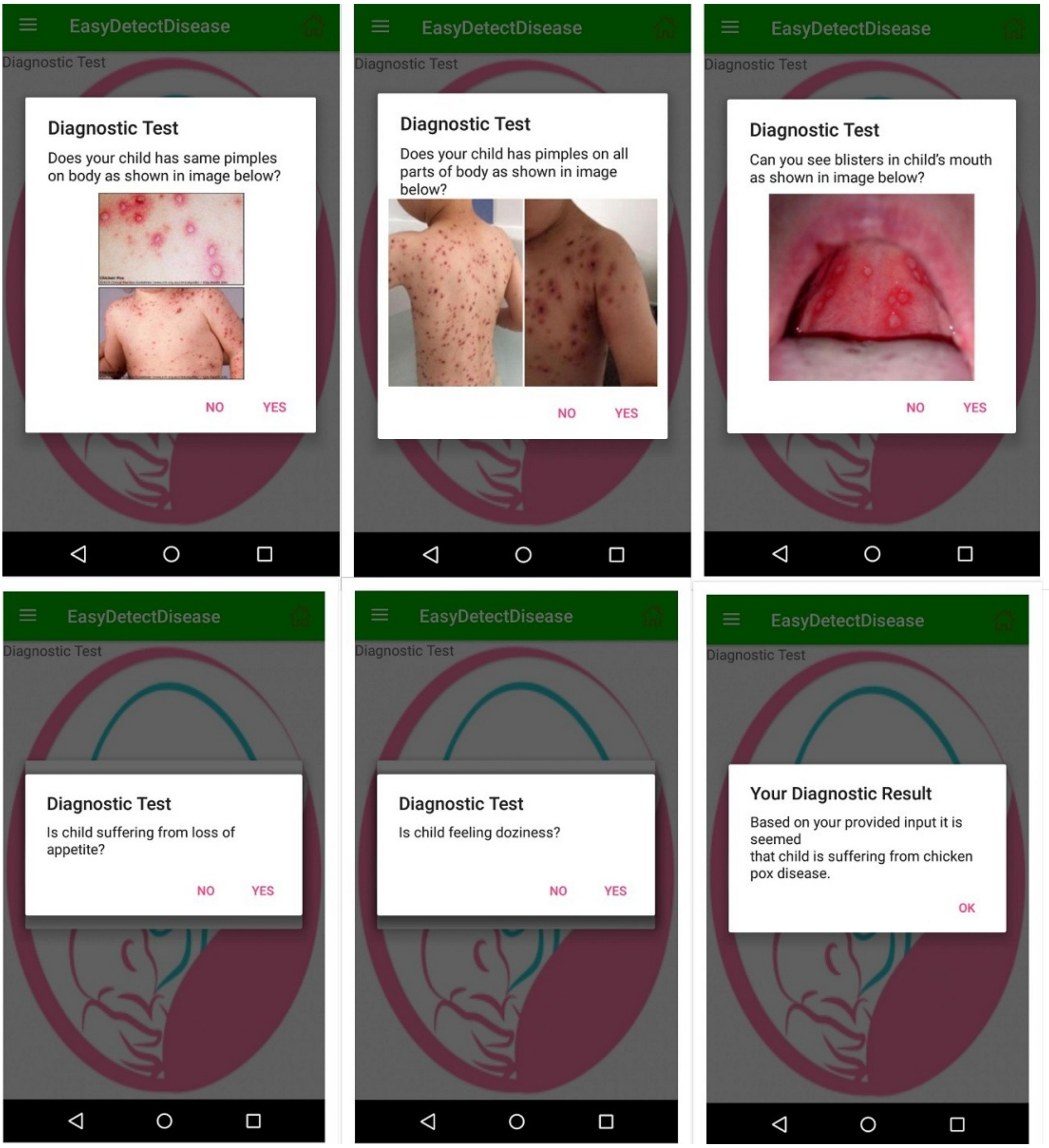
تشخیصی ٹیسٹ

کیا بچہ اونگھ رہا ہے؟

آپ کا نتیجہ

آپ کی فراہم شدہ معلومات سے لگتا ہے کہ آپ
کا بچہ لاکڑاکا کڑا یا چکن پاکس کے بیماری
میں مبتلا ہے. بیماری کے متعلق مزید جاننے کے
لیے "بیماریوں" پر کلک کریں .

Figure 8. Diagnostic test interface of the EasyDetectDisease app in English.



Diagnostic Test

Does your child has same pimples on body as shown in image below?

Diagnostic Test

Does your child has pimples on all parts of body as shown in image below?

Diagnostic Test

Can you see blisters in child's mouth as shown in image below?

Diagnostic Test

Is child suffering from loss of appetite?

Diagnostic Test

Is child feeling doziness?

Your Diagnostic Result

Based on your provided input it is seemed
that child is suffering from chicken pox disease.

Figure 9. List of diseases.

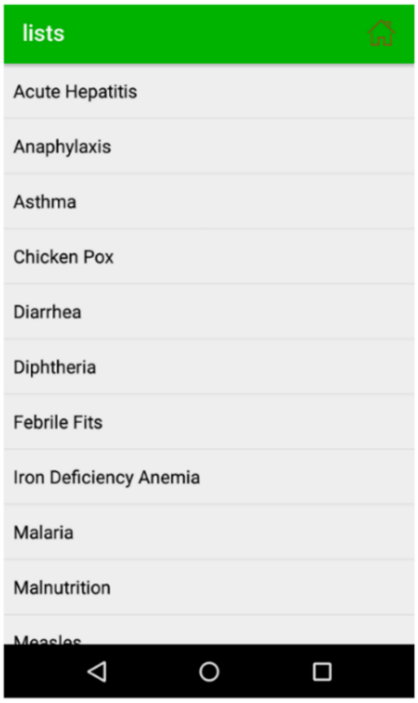
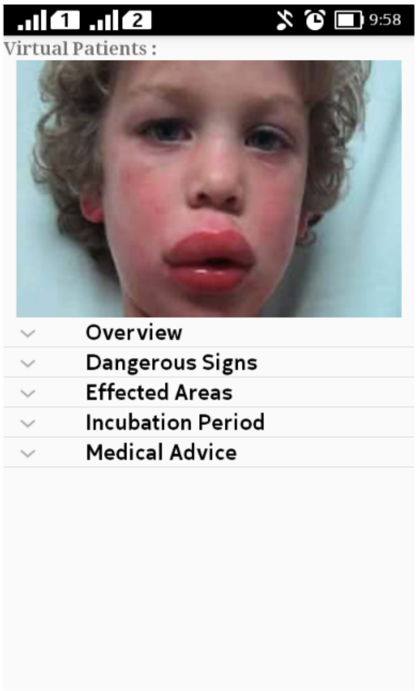


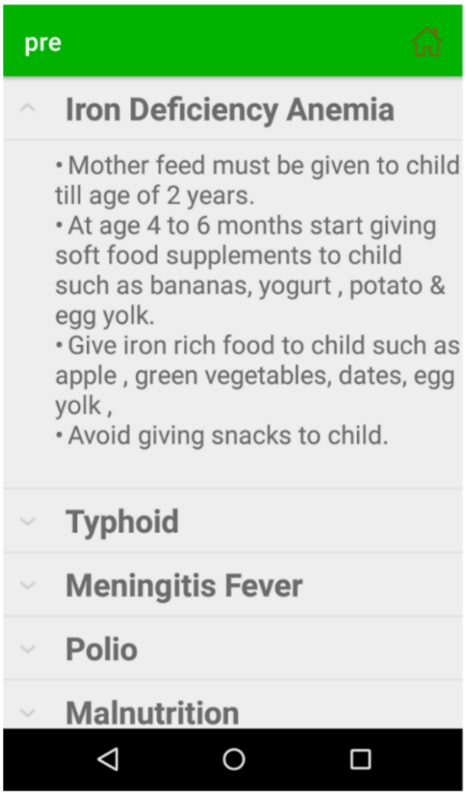
Figure 10. Disease description.



Prevention

The prevention module provides the mother with guidelines on how to prevent common diseases such as acute hepatitis, anaphylaxis, asthma, chicken pox, diarrhea, diphtheria, febrile fits, iron deficiency anemia (IDA), malaria, measles, meningitis, mumps, pertussis, tetanus, and urinary tract infection; the do's and don'ts when the child is suffering from a certain disease; guidelines on how to maintain cleanliness; and information on the kinds of medicine that should be avoided during specific infectious diseases and can result in emergency situations (eg, death). For example, Figure 11 shows the prevention instructions for patients with IDA according to age; it highlights iron-rich foods and instructs to avoid junk food to prevent the severity of IDA. If the child is suffering from measles, the EasyDetectDisease app educates the mother on the use of the measles using measles, mumps, rubella (MMR) vaccine for prevention, and it defines the possible schedule of MMR vaccine so that the child can be cured from measles (see Figure 12).

Figure 11. Disease prevention in English.



Iron Deficiency Anemia

- Mother feed must be given to child till age of 2 years.
- At age 4 to 6 months start giving soft food supplements to child such as bananas, yogurt , potato & egg yolk.
- Give iron rich food to child such as apple , green vegetables, dates, egg yolk ,
- Avoid giving snacks to child.

Typhoid

Meningitis Fever

Polio

Malnutrition

Figure 12. Disease prevention in Urdu.

خسرے سے بچاو کا طریقہ

خسرے، ممز اور روبیلا[ایم ایم آر] کی ایک ھی ویکسین ھوتی ھے۔ اپنے ڈاکٹر سے رابطہ کیجئے اگر آپ دونوں نے حفاظتی ٹیکہ نہیں لگایا

آپکے بچے کو خسرہ، ممز اور روبیلا[ایم ایم آر] کا حفاظتی ٹیکہ لگانا ضروری ھے۔ اس کے دو ممکنہ شیڈیول ھیں:

- بارہ مہینے اور اٹھارہ مہینے یا
- پندرہ مہینے اور چار سے چھھ سال کا عرصہ

چکن پاکس سے بچاو کا طریقہ

کن پیڑے یا ممپس سے بچاو کا طریقہ

گردن توڑ بخارکےلیے گلاس ٹیسٹ

دمہ کیلئے کنٹرولر ادویات

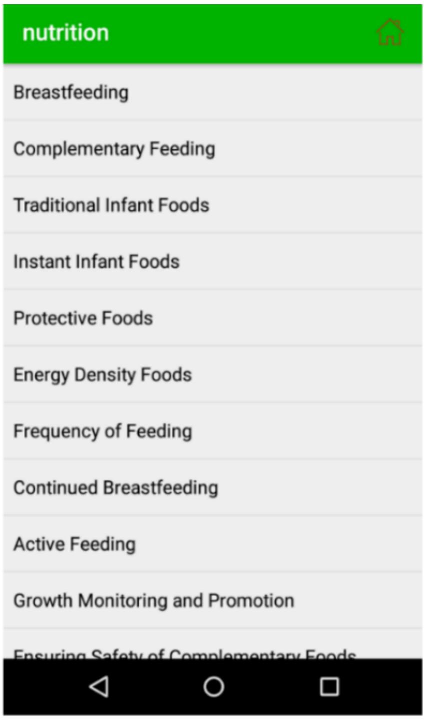
Nutrition

This module provides the nutritional guidelines to mothers. It contains dietary instructions for pregnant mothers and a nutritional guide for breastfeeding mothers (ie, feeding guidelines for newborn babies and feeding instructions for babies aged 6 to 9 months, 9 to 12 months, or 12 to 24 months). It provides details on complementary feeding, traditional infant foods, instant infant foods, protective foods, and energy-dense foods, and it instructs to monitor the growth of the child by using measuring scales. The topics of nutritional guidelines are listed in Figure 13, and Figure 14 shows the nutritional instructions for a child aged 9 to 12 months.

Video Guidelines

The video guidelines module consists of instructional videos recorded by pediatric health experts from CH and ICHM. In these videos, doctors educate mothers about the symptoms and prevention of diseases and provide clinical advice. For example, if a child is suffering from acute hepatitis, the pediatrician highlights the signs and symptoms of acute hepatitis before disease attack and after disease attack, causes and risk factors of acute hepatitis, its incubation period, nutrition during the disease period, prevention methods, care at home, and medical advice (see Figure 15).

Figure 13. Nutritional guide in English.



Breastfeeding

Complementary Feeding

Traditional Infant Foods

Instant Infant Foods

Protective Foods

Energy Density Foods

Frequency of Feeding

Continued Breastfeeding

Active Feeding

Growth Monitoring and Promotion

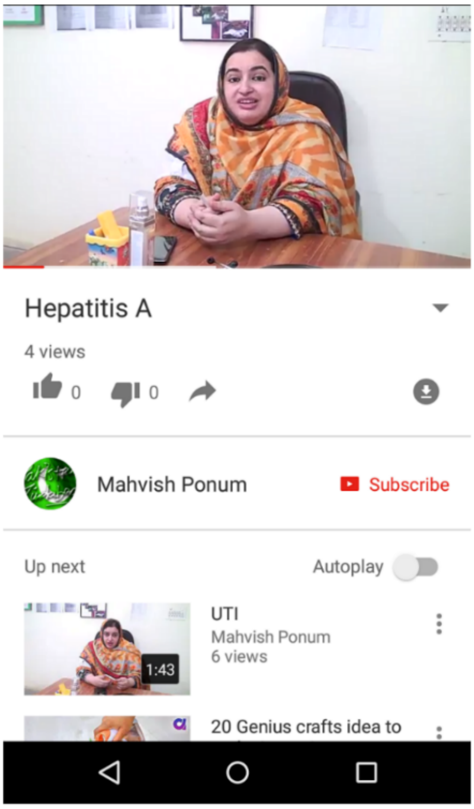
Ensuring Safety of Complementary Foods

Figure 14. Nutritional guide in Urdu.

9 سے 12 ماہ کی عمر تک اضافی غذائیں

- بچے کو مناسب مقدار میں چاول، گندم، مکئی، آلو، دلیہ، مچھلی، دالیں، مٹر، دودھ، دہی، پنیر، مکھن، گوشت، مرغی، انڈہ، گہرے سبز پتے والی سبزیاں، ٹماٹر، گاجر، پھل اور چکنائی والی غذائیں دیں۔
- بچے کو گھریلو غذا کے چھوٹے چھوٹے ٹکڑے دیں تا کہ وہ باآسانی کھا سکے۔
- بچے کو دن میں کم از کم تین سے مرتبہ غذا دیں۔
- مقدار کو بتدریج آدھے پیالے تک بڑھائیں۔

Figure 15. Video guidelines.



Video Tutorials

This module contains the recorded videos of actual patients affected by various diseases to practically teach mothers about the symptoms of diseases. This module also contains videos on how to make oral rehydration solution and samoji, how to use a nebulizer, etc. Figure 16 shows a list of videos about child patients with diarrhea, febrile seizure, chicken pox, and many more diseases. When a mother clicks on a specific disease, the complete guide related to that disease is provided to her by showing the affected children.

Report

This module allows mothers to report all those diseases that are not described well in the app or are difficult to understand. This module is primarily based on an algorithm that monitors the reports from users about diseases. If the algorithm gets 3 reports about a specific disease, then it automatically replaces the content of that disease with easier to understand material to facilitate enhanced comprehension.

Usability Evaluation

Overall, 2 health sessions were conducted in 2 different communities with the help of LHWs to evaluate the app’s usability (see Figure 17).

A total of 30 mothers were recruited from 2 different communities since the recommended number of participants for a usability evaluation is at least 10 [29]. According to the record kept by the LHWs, 30 mothers with ill children were called to attend the health sessions. None of these mothers had used the EasyDetectDisease app previously and most of them had their own smartphones. The app was installed on their cell phones and they were asked to use it. It was observed in the study that all those mothers who had a secondary level of education or higher used the app easily, without any help. Moreover, mothers with a primary level of education also performed well compared to illiterate mothers. The illiterate mothers were provided with a demonstration before they used the app. An explanatory usability session was conducted to explain the app’s features and its usage. It was observed that all the illiterate mothers learned how to use the app after the first explanatory session. Later, they were provided with the app to diagnose their children’s diseases in the second session where they used the app without any assistance.

Figure 16. Video tutorials.

Figure 17. Mobile health sessions.

After all the mothers became familiar with the diseases and their symptoms, which they could find in their children, they were provided a questionnaire (see Multimedia Appendix 1). The facilitator helped all mothers fill out the questionnaire. During the evaluation of the app, the facilitator recorded and observed the interaction of each mother with the app interface. She also noted their suggestions and comments regarding the app. At the end of the session, usability statements were evaluated on a scale of 3, ranging from strongly agree to disagree. In addition, 8 qualitative questions were asked to understand the practical effectiveness and benefits of the EasyDetectDisease app:

1. Does the user interface provide easy navigation?
2. Does the diseases module provide detailed knowledge of infectious diseases?
3. Does the prevention module provide necessary preventive measures to avoid diseases?
4. Does the nutrition module provide useful nutritional guidelines to mothers?
5. Does the video guidelines module provide complete details about diseases?
6. Do video tutorials contain useful information?
7. What is the app's best feature?
8. Which feature of the app needs improvement?

Results

This section provides details of the evaluation outcomes of the EasyDetectDisease app and the participants' feedback.

Evaluation Outcomes

The mothers of 30 ill children used the app and diagnosed the disease their child had. The ratio of the most and least common diseases was derived from the diagnostic test. The percentage of disease occurrence is shown in Table 3.

The highest number of cases were reported for diarrhea; this was diagnosed in 30% (9/30) of the children. The second major disease was chicken pox (6/30, 20%). Similarly, pertussis (4/30, 13%) and typhoid (4/30, 13%) were diagnosed as the third major diseases. The least common diseases were febrile fits and mumps (1/30, 3% for each).

After diagnosing the diseases, mothers were advised to explore the details of the disease and to follow the guidelines. They read about the symptoms and preventive measures of the disease, nutritional guidelines, and medical advice, and followed the video guidelines of the pediatric health expert. In the next meeting, each mother was asked, "What kind of health improvement did you notice in your child after using the EasyDetectDisease App?". Most of the mothers answered that they followed all of the instructions of the app, and that they noticed that their child recovered quickly without any visible signs of weakness in the body. They did not find any dietary deficiency in their children after following the nutritional instructions.

Participants' Feedback

This subsection provides the results of the diagnostic module usability questionnaire and qualitative feedback from the mothers.

Diagnostic Module Usability Questionnaire Results

The diagnostic module questionnaire results were very positive. All participants diagnosed diseases accurately based on the symptoms. Most responses were recorded as 1 (strongly agreed). All participants strongly agreed to the statement "I liked using the EasyDetectDisease App." All mothers found the app to be easily navigable, easy to use, and easy to understand. Very few mothers faced navigation errors because of their unfamiliarity with the app and touchscreen phones, but in the second health session, they were all able to navigate through the app.

Qualitative Feedback

When asked about the positive and qualitative aspects of the EasyDetectDisease app, mothers generally liked its simplicity and ease of use. One mother commented that using the app required no training as it was really easy to use. Most of the mothers reported that the app provides easy health guidelines. One mother said:

> *App does not need any skill to start, as I just started the app and it itself guided me what to do.*

Many mothers were of the view that the disease diagnosis does not require much time as the app quickly diagnoses the disease after getting the symptoms. One mother said:

> *I liked the reporting feature as it automatically converts the text into easy to understand visuals.*

One mother suggested that this app should be available as an built-in feature in all smartphones.

Table 3. Percentage of disease occurrence.

Diseases	Frequency, n (%)
Chicken pox	6 (20)
Diarrhea	9 (30)
Febrile fits	1 (3.3)
Iron deficiency anemia	2 (6.7)
Measles	3 (10)
Mumps	1 (3.3)
Pertussis	4 (13.3)
Typhoid	4 (13.3)
Total	30 (100)

Discussion

Principal Findings

Development of a mobile app that can be used in a cross-cultural environment with low resources is challenging, as it requires iterative testing and adaptation. The EasyDetectDisease app has been developed and updated iteratively based on feedback from end users.

The EasyDetectDisease app provides a user-friendly approach for disease diagnosis, description, symptoms, prevention, and nutrition, medical advices, tutorials featuring ill patients, and video guidelines by the pediatric health experts to promote in-home child health care. Our goal of teaching illiterate mothers about infectious diseases common in children under the age of 5 years was achieved successfully since their progress can be judged from the 2 pilot health sessions during which they used the app without any assistance. All mothers appreciated easy navigation, effectiveness, free-of-cost availability, and usefulness of EasyDetectDisease. Moreover, all mothers found the app to be very useful for their child care, and all of them agreed to use it if made publicly available.

To support the varying levels of education among mothers, many ideas were discussed (eg, adding more diseases, easiest interfaces, hint screens for illiterate mothers, and more video guidelines) that would be helpful for future implementations. Mothers with a low level of education preferred to have the app in the local languages of Pakistan. Awareness among mothers can play a vital role in reducing the mortality rate of children under 5 years. If EasyDetectDisease is made available at governmental public health agencies across Pakistan, there would be a need to educate and train mothers on some of its functionalities via governmental mHealth sessions or mHealth programs for its adaptation.

Limitations

The EasyDetectDisease app's current version is in its initial state, and it only contains limited and the most common infectious diseases that each child may face in his/her childhood. This app does not contain directions on dosage or medicine that may lead to death. This app is not an alternative for any medical procedure. In fact, this is an educational app that can be used to train mothers to diagnose the illness of their child at home and to immediately provide first aid by reading or listening to the guidance instructions. The awareness among mothers can prove to be the best contribution to reducing the mortality rate of children under 5 years.

Information on more diseases and additional education topics related to breastfeeding promotion, pregnancy guidelines for safe and healthy births, and noninfectious diseases will be added in the next version of the app. This app is bilingual, but in future implementations, more local languages will be added to enhance the acceptance of EasyDetectDisease in all parts of Pakistan.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Mortality ratios and usability questionnaire.

[RAR File, 31MB - ijmr_v8i2e12664_app1.xlsx]

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Abbreviations

CH: Children’s Hospital
IDA: iron deficiency anemia
LHW: lady health workers
mHealth: mobile health
MMR: measles, mumps, rubella
NGO: nongovernmental organization
TTS: text to speech
UNESCO: United Nations Educational, Scientific and Cultural Organization
UNICEF: United Nations International Children's Emergency Fund
WHO: World Health Organization

Edited by G Eysenbach; submitted 31.10.18; peer-reviewed by A Hussain, MT Mahmood; comments to author 21.11.18; revised version received 23.11.18; accepted 26.02.19; published 14.05.19.

Please cite as:
Ponum M, Hasan O, Khan S
EasyDetectDisease: An Android App for Early Symptom Detection and Prevention of Childhood Infectious Diseases
Interact J Med Res 2019;8(2):e12664
URL: http://www.i-jmr.org/2019/2/e12664/
doi:10.2196/12664
PMID:31094329

Original Paper

Clinical Impact of a Digital Dose Counter Pressurized Metered-Dose Inhaler on Uncontrolled Asthma: Cross-Sectional, Observational, Surveillance Study

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Abstract

Background: In India, control of asthma with persistent symptoms remains a clinical enigma with likely incriminating factors including non- and pseudoadherence to the inhaled corticosteroids and long-acting beta2-agonists. The United States Food and Drug Administration guidance recommends the use of dose counter pressurized metered-dose inhalers (pMDIs) with further mechanisms to track adherence and pseudoadherence in real-world settings.

Objective: Digital dose counter pMDIs (dpMDIs) offer simplified, reliable tracking of individual “actuated” dosages with “END” display at completion of the labelled therapeutic aerosol spray. The translational impact on symptom persistence with likely unwarranted exposure to the “Step up” strategy is often prevented if not treated, as in the cases of “pseudo” severe asthma. To further assess the real-world acceptance and clinical impact of dpMDIs in bronchial asthma including poorly controlled or uncontrolled bronchial asthma cases, a noninterventional observational study was performed.

Methods: This cross-sectional, retrospective, case cohort, observational study—the Drug Utilization Surveillance—of dpMDIs in bronchial asthma was conducted in September 2016 in an outpatient setting in India. The retrospective analysis was initiated and conducted as per the International Conference on Harmonization Good Clinical Practice principles and Declaration of Helsinki, following approval from the local ethics committee and registration in the Clinical Trial Registry of India.

Results: Consecutive cases of moderate-to-severe asthma with poor control (n=4575), diagnosed as per the Global Initiative for Asthma symptom scale at baseline and follow-up, were included. Patients under treatment using dpMDIs were enrolled from 500 centers across India and assessed by respiratory care specialists. Baseline asthma control was assessed as partly controlled (n=4575) or poorly controlled (n=2942). Per protocol analyses showed that asthma was well controlled with dpMDIs at 8 weeks in 92.7% of the cases (2727/2942, *P*<.001). Adverse events (n=106, 2%) of mild-to-moderate intensity were reported. Nebulization was required in two patients with episodic breathlessness who were discharged with no consequent sequelae. Post hoc analyses for patients with baseline poorly controlled asthma who “switched” exclusively to dpMDI monotherapy or a combination with xanthines or long-acting beta2-agonists showed a “well controlled” asthma status in 85.9% (500/582, *P*=.04), 95.4% (395/414, *P*=.048), and 80.3% (106/132, *P*=.28) of the cases, respectively. The patient acceptability criteria for an “empty” canister was well correlated with the clinical strategy to identify and avoid pseudoadherence in poorly controlled or difficult-to-treat asthma cases, especially in patients who “switched” exclusively to dpMDIs (n=582) and demonstrated responses of “Use till twenty dose display” (65/156, 41.6%), “Use till END display” (83/156, 53.2%), and “Use till LAST spray” (8/156, 5.1%).

Conclusions: dpMDIs offer simple, accurate, and reliable tracking of non- and pseudoadherence while highlighting incremental asthma-control rates in severe and pseudosevere asthma cases before risk assessment for further “add-on” therapy

Trial Registration: Clinical Trials Registry - India CTRI/2018/06/014595; http://www.ctri.nic.in/Clinicaltrials/pmaindet2.php?trialid=24583

(Interact J Med Res 2019;8(2):e13530) doi:10.2196/13530

KEYWORDS
asthma; drug utilization surveillance; pseudoadherence; xanthines; anti-asthmatic agents

Introduction

Bronchial asthma continues to be a serious global health challenge with an estimated global prevalence of 300 million people, where most cases remain poorly controlled [1-3].

Problem Statement

Patient-reported asthma control worldwide, especially in India and China, remains remarkably low, varying from 0% to 50% [4,5]. The correlation of the patient-reported satisfaction scores and the Global Initiative for Asthma (GINA) symptom scale for asthma control reveals disproportionate or alarming rates of partly controlled (48%-60%) or uncontrolled (18%) asthma, especially in patients receiving background inhaled corticosteroid and long-acting beta2-agonist (ICS/LABA) combination inhaler therapies [4,6,7]. Asthma control is a complex and multiparametric issue that is largely affected by not only physiological and environmental parameters, but also the psychological state of patients and their cultural and socioeconomic background [8]. In the Indian subcontinent, the clinical issues of patient-reported social stigma, habituation, tolerance, and adverse events with inhaler therapies are often perceived to be complex and perplexing for primary care physicians.

Despite the enumeration of these likely confounding variables or concomitant risk factors, asthma control continues to remain an elusive goal, regardless of the availability of new devices or therapeutic strategies including biologics or anti-Ig E therapy [9-12].

The pressurized metered-dose inhaler (pMDI) has been the most widely used inhaler over the past 40 years and a value-added proposition, unlike the dry-powder inhaler. The pMDI offers incremental lung-deposition rates, especially in patients with severe asthma or poor inspiratory flow rates. However, in most cases, they provide little information on the “remaining” medication or therapeutic dosages in the canister [13]. This uncertainty leads to pMDI overuse beyond the stated labelled number of dosages, and the patient inhales little or “tail” sprays containing only propellant. The clinical implications of this are huge, with the patients often dealing with persistent symptoms or exacerbations requiring further investigations or unwarranted approach with advanced therapies or bronchodilators. Ogren found that up to 40% of patients believe they are taking their asthma medication when they are actually activating an empty or nearly empty pMDI [14]. Similarly, an epidemiological survey (B Singh, MD, personal communication, 2016) conducted across India seconded the viewpoint of most pulmonologists in highlighting patients’ persistence with the conventional pMDIs till the “last” spray, creating a false perception that they are actually receiving medication, which leads to pseudoadherence and related complications [15].

International Recommendations

The United States Food and Drug Administration took cognizance of these twin challenges of non- and pseudoadherence, especially with pMDI devices used to deliver ICS/LABA combinations, and recommends the use of dose counter pMDIs to track nonadherence accurately and reliably through individual dosage movement or actuation, with “lockout” mechanisms to avoid inhalation of the tailed sprays [16]. However, the use of “lockout” mechanisms may not be clinically relevant when delivering formulations with dual use such as maintenance and rescue medications.

Digital dose counter pMDIs (dpMDIs) offer simplified, reliable tracking of individual “actuated” dosages with END display that signifies the onset of pseudoadherence or “empty” sprays containing propellant only. The translational impact on symptom persistence with likely unwarranted exposure to the “Step up” strategy is often prevented if not treated, as in the cases of “pseudo” severe asthma (ie, Step 3 Asthma control cases receiving Step 4 care).

Objective

In line with the global and local epidemiological burden of uncontrolled or partly controlled asthma, which varies from 58% to 60% for patients on the current standard of care [4,7], the real-world utilization and impact of dpMDI initiation or “switch” was evaluated in this retrospective, observational, drug-utilization clinical study.

Methods

This cross-sectional, retrospective, case cohort analysis—the Drug Utilization Surveillance study (Clinical Trials Registry - India CTRI/2018/06/014595)—of dpMDIs was performed in patients with bronchial asthma after obtaining approval from the local ethics committee, with registration in the Clinical Trial Registry of India. Patients were enrolled from 500 outpatient centers that utilized the GINA symptom scale for assessing asthma control in patients on dpMDIs across India in September 2016. The study was conducted as per the principles of International Conference of Harmonization for Good clinical practice and Declaration of Helsinki while ensuring confidentiality of patient identifiers before analyses.

Consecutive case records for patients with bronchial asthma exposure to dpMDIs were collated for analyses with follow-up information on the asthma control status for at least 8 weeks. Primary analyses for clinical cases were performed to assess the asthma control status with symptomatic assessment using the GINA symptom scale for daytime symptoms, night-time symptoms, activity limitation, and use of rescue medications for at least 8 weeks with dpMDIs. As per the GINA scale, asthma control was defined as well controlled, partly controlled, or uncontrolled, with total scores of 0, 1-2, and 3-4, respectively, at baseline, 4 weeks, and 8 weeks (follow-up). Clinician assessment or review of the inhalation technique, including patient feedback on the use of dpMDIs at 4 weeks, was also analyzed.

Efficacy Parameters

Primary analysis, post hoc analyses, and interaction tests were performed for well-controlled asthma overall, in newly diagnosed cases, and in poorly controlled asthma cases at baseline, respectively. Statistical analyses for categorical and numerical data were carried out by the Fisher exact test and Student *t* test, using QuickCalcs GraphPad Prism (version 7.05; San Diego, CA), with two-tailed *P* values<.05 considered statistically significant.

Safety Parameters

Descriptive statistics were used for assessment of the incidence of treatment-emergent adverse events at 8 weeks.

Results

A total of 4575 consecutive cases of moderate-to-severe asthma with uncontrolled status, as assessed by respiratory care specialists, of at least one GINA symptom at baseline and follow-up were enrolled. Patients included were under treatment with dpMDIs from 500 centers across India. Asthma control status was categorized as partly controlled (n=4575) or uncontrolled (n=2942) at baseline. Per protocol analyses were performed for patients with uncontrolled asthma, as evaluated by the GINA symptom scale at 8 weeks. Baseline demographics are presented in Table 1. More patients were on formoterol/budesonide combination treatment (n=3791, 73%) than on salmeterol/fluticasone combination treatment (n=1404, 27%).

Clinical records were available for 4575 cases, with further per protocol analyses conducted for patients with at least two follow-up visits (n=2942, uncontrolled asthma status at baseline), as highlighted in the patient disposition chart (Figure 1).

Asthma control status at 4 and 8 weeks was categorized as well controlled, partly controlled, or uncontrolled as per the available GINA assessment total scores for daytime, activity limitation, night-time symptoms, and use of rescue medications in the last month. The baseline and follow-up symptoms were assessed as uncontrolled, partly controlled, or well controlled based on the GINA assessment scale for symptom and rescue medication use (Table 2).

Table 1. Demographics and clinical characteristics at baseline.

Parameter	Value
Asthma control, n (%)	
Partly controlled	4575 (100)
Uncontrolled	2942 (64.3)
Characteristics of patients with uncontrolled asthma	
Gender, n (%)	
Male	2114 (71.9)
Female	828 (28.1)
Age, mean (SD)	49.5 (15.9)
Body weight, mean (SD)	62.8 (13.2)
Newly diagnosed, n (%)	1234 (41.9)
Poorly controlled, n (%)	1708 (58.1)
Exacerbation history, n (%)	135 (4.6)
Baseline medications, n (%)	
Antibiotics	24 (0.8)
Bronchodilator syrup	200 (6.8)
Oral steroids	218 (7.4)
Inhaled corticosteroids/long-acting β2 agonist	1194 (43.9)
Xanthines	110 (4.0)
Leukotriene receptor anatagonist with or without antihistaminic agents	55 (2)
Other combination	1359 (50)
No therapy	514 (17.5)

Figure 1. Patient disposition flow chart to digital dose counter pMDIs at baseline. LTRAs: Leukotriene receptor antagonists, LAMAs: Long-acting muscarinic antagonists, pMDIs: pressurized metered dose inhalers.

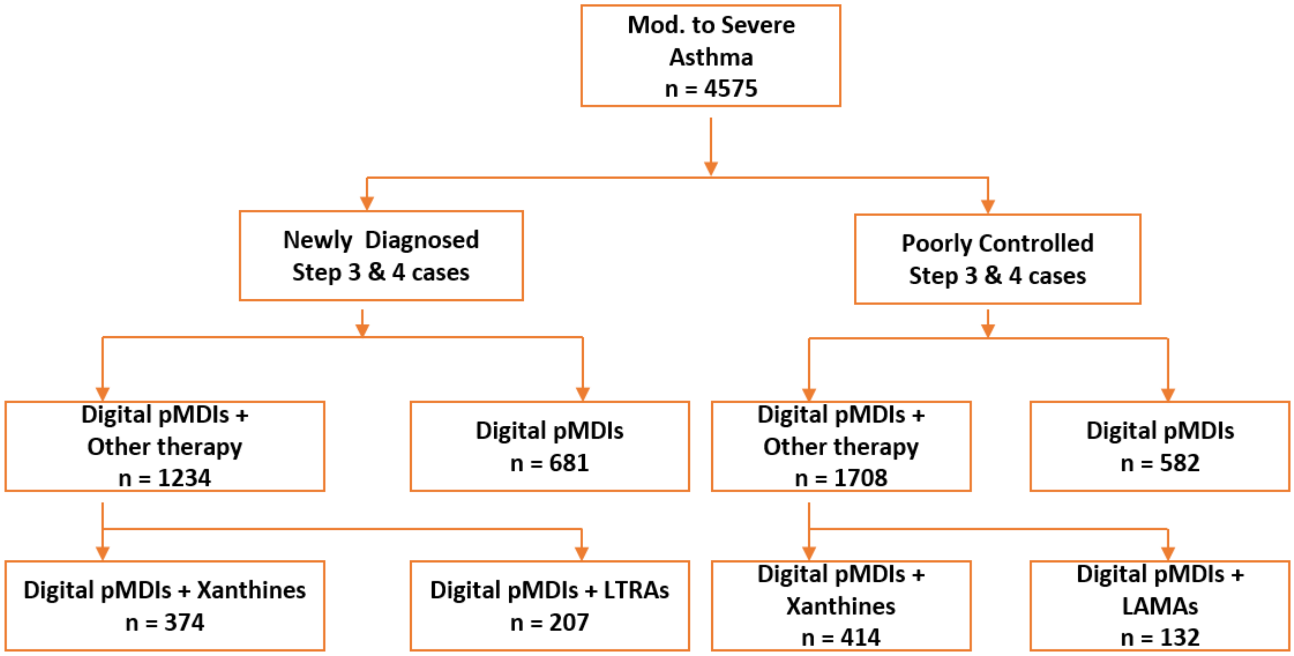

Table 2. Patient symptom assessment scores for well-controlled, partly controlled, or uncontrolled asthma at every visit. The scores are marked as Yes (1) and No (0). Total scores of 3-4, 1-2, and 0 at each visit indicate uncontrolled, partly controlled, and well-controlled asthma, respectively.

Global Initiative for Asthma symptom scale	Score
Daytime asthma symptoms >2 times/week	1/0
Activity or exercise limited by asthma	1/0
Waking at night due to asthma	1/0
Rescue medication (number of times/month)	1/0

Efficacy

Primary analyses based on clinical assessment for daytime, night-time, activity limitation symptomatology showed that a “well-controlled” status was observed in 92.7% cases (2701/2942, *P*<.001), 95.9% (1184/1234, *P*<.001), and 90.3% (1563/1708, *P*<.001) of the overall cases, newly diagnosed cases, or poorly controlled cases at baseline, respectively (Table 3).

Clinician assessment of patient acceptability and use of dpMDIs at 4 week was categorized as “Use till twenty dose display” (n=430, 33.4%), “Use till END display” (n=765, 59.4%), and “Use till LAST spray” (n=92, 7.3%).

Post hoc analyses for newly or poorly controlled cases receiving dpMDIs with or without concomitant therapy were further performed for patients with well-controlled asthma.

Well-controlled asthma was observed in 97.6% (365/374, *P*=.01) and 97.6% (202/207, *P*<.001) of patients with newly diagnosed asthma receiving xanthine and LTRAs, respectively.

Similarly, in the poorly controlled group at baseline, who “switched” exclusively to dpMDIs, the clinical response rates for well-controlled asthma was significantly high at 85.9% (500/582, *P*=.04) at 8 weeks. In the baseline poorly controlled group receiving dpMDIs with xanthines or long-acting muscarinic antagonist (LAMAs), the response rates for well-controlled asthma at 8 weeks were significant at 95.4% (395/414, *P*=.048) and 80.3% (106/132, *P*=.28), respectively.

Assessment of the “switch” group for dpMDIs by the health care specialists at 4 weeks showed the following responses: “Use till twenty dose display” (n=65, 41.6%), “Use till END display” (n=83, 53.2%), and “Use till LAST spray” (n=8, 5.1%).

Safety Outcomes

Adverse events (n=106, 2%) of mild-to-moderate intensity involving tremors (n=34, 0.7%), palpitation (n=10, 0.2%), mouth ulcers (n=10, 0.2%), and oral candidiasis (n=9, 0.2%) were reported. Nebulization was required in two patients with episodic breathlessness, who were discharged with no consequent sequelae.

Table 3. Well-controlled asthma status at 8 weeks overall, in the newly diagnosed group, in the poorly controlled group, and in the uncontrolled group at baseline.

Patient population	Bronchial asthma cases, n (%)	Well-controlled asthma at 8 weeks, n (%)	*P* value
Baseline partly controlled asthma (overall) — dpMDI[a]/combination	4575 (100)	3955 (86.4)	<.001
Baseline uncontrolled asthma — dpMDI/combination	2942 (64.3)	2701 (92.7)	<.001
Baseline newly diagnosed			
dpMDI/combination	1234 (58)	1184 (95.9)	<.001
dpMDI/xanthine	374 (17.6)	365 (97.6)	.01
dpMDI/LTRA[b]	207 (9.7)	202 (97.6)	.001
Baseline poorly controlled			
dpMDI/combination	1708 (69.8)	1563 (90.3)	<.001
dpMDI/xanthine	414 (16.9)	395 (95.4)	.048
dpMDI/LAMA[c]	132 (5.4)	106 (80.3)	.28
dpMDI monotherapy	582 (23.8)	500 (85.9)	.04

[a] dpMDI: digital dose counter pressurized metered-dose inhalers.

[b] LTRA: leukotriene receptor antagonist.

[c] LAMA: long-acting muscarinic antagonist.

Discussion

This real-world, cross-sectional, retrospective study highlights the clinical impact and utilization of dpMDIs in the management of uncontrolled asthma. The well controlled asthma rates of 92.7% (2727/2942, $P<.001$), 95.4% (394/414, $P=.048$), and 85.9% (500/582, $P=.04$) at 8 weeks for overall group and clinical cases who ‘switched’ from conventional pMDIs to dpMDIs with Xanthines or alone, respectively, provides the first data point on clinical response rates with any dpMDIs for asthma cases predominantly on ICS/LABA combination. There is sparse literature on similar studies; a postapproval, prescription event, clinical study conducted with analogue dose indicator pMDIs that included 13,464 patients on salmeterol/fluticasone (EVOHALER*) treatment for Reversible Obstructive Airway Disease reported a response rate of 62% [17].

Severe asthma remains largely uncontrolled when the differential diagnosis involves conditions that may mimic asthmatic symptoms (eg, extrathoracic hyperresponsiveness syndromes and vocal cord dysfunction) or comorbidities that may worsen disease control (eg, allergic or nonallergic rhinitis, chronic rhinosinusitis with or without nasal polyps, bronchiectasis, and gastroesophageal reflux); when the condition is investigated with little recognition or connection with possible incorrect inhaler techniques; or when treatment adherence is poor, including non- or pseudoadherence observed in most clinical cases, which often leads to severe or a difficult-to-control asthma state.

Nonadherence and Difficult-to-Control Asthma

The REALISE (REcognise Asthma and LInk to Symptoms and Experience) Asia survey based on the GINA assessment scale suggested that the questionnaire for asthma control highlighted the disparity in the rates of the well-controlled status (only 53.2%), and most patients (86%) were nonadherent to maintenance therapy with aerosols, making them highly susceptible to developing persistent symptoms or progressive disease. Timely reminders or active counselling plays a critical role in improving or building treatment adherence for optimal control or prevention of exacerbations [18]. This was further highlighted by Krishnaprasad in a noninterventional, prospective, observational, single-arm study involving moderate-to-severe asthma cases requiring ICS/LABA inhalation. Telephonic monitoring conducted for 124 patients to assess asthma control utilizing the GINA assessment questionnaire highlighted consistency in the “well-controlled” asthma status (84%) at 1 year for treatment of adherent patients utilizing conventional pMDIs without dose counters [18-19]. However, in most real-world settings, outside the realms of controlled research framework, monitoring the patient for adherence remains a difficult proposition to assess and review, as suggested by the GINA.

Pseudoadherence and Difficult-to-control Asthma

Our results and patient descriptors highlight the pertinent need for an inhalation device or strategy to address the likely behavioral or device-related risk factors that may be observed, such as old age, a history of noncompliance, socioeconomic variables, or cognitive deficits, for continued benefits especially in severe asthma or pseudo-severe asthma cases due to “intermittent” or pseudo-adherence when faced with responsive symptoms [20].

The clinical response or well-controlled asthma rate of 90.3% in the poorly controlled group on dpMDIs with other therapy shows significant credibility to the overall “therapeutic” impact of these devices in the real-world management of severe asthma before further prescribing “Step up” or Single Maintenance and Rescue Therapy, which are likely to expose patients to systemic side effects of high-dose inhaled corticosteroids.

Post hoc analyses for poorly controlled patients with Step 3 Asthma control who "switched" exclusively to dpMDI monotherapy showed a "well controlled" asthma status in 85.9% (500/582, P=.04), of the cases, respectively. This finding further consolidates the rationale of the therapeutic role of these devices for symptomatic or pseudo-severe asthma cases. This was seconded by the high rates of compliance and feedback by patients using the dpMDIs correctly till the END display, thereby avoiding the ill-effects of pseudoadherence.

The lack of a significant response to dpMDIs with LAMAs in this study may be precluded by the small sample size and a lack of investigation or understanding of the underlying pathophysiologic basis involving eosinophilic inflammation or fraction exhaled nitric oxide response scores for continued response to the background ICS/LABA combination.

Study Limitations

The findings are limited by the retrospective nature of the analyses, which lacks a control for comparative assessment. However, to our knowledge, the results are the first to highlight the incremental or translational benefits of dpMDIs in patients with difficult-to-treat or pseudo-severe asthma, which is often treated with continued or high-dose inhaled corticosteroids.

Conclusion

The dpMDIs offer a simple, accurate, and reliable solution to tracking non- and pseudoadherence in real-world settings, thereby preventing morbidity or mortality associated with such obstructive airway diseases. By tracking the effects of the use of both preventer (controller) and reliever (rescue) medications, the digital pMDI will engage and empower patients in their self-care, leading to improved adherence while enabling real-time monitoring of medication use and symptom flare-ups by caregivers and the health care community.

The dpMDIs also remain a clinically important, yet relevant strategy that delivers optimal responses in therapy-resistant severe asthma while endorsing the concept that they “treat” pseudo-severe asthma while preventing severe asthma management with biologics or xanthines.

Acknowledgments

DUSS investigators: Dr Abdul Gashi, Dr Sunil Mehta, Dr Murali C P, Dr Gopal D Bahurpi, Dr Anand Madhukar Londhe, Dr Arun Kumar, Dr Abdul Rahiman, Dr Smrithesh S MD, Dr Paul P Kallumkal, Dr Thriprayar Subramaniam Ramaswamy, Dr Jobi Paul Poulose, Dr George Mathew, Dr Shreeja K M, Dr NabeelDr Binoy Mathai, Dr Abhilash Chako, Dr Shaji Abdul Gafoor, Dr Basheer vawther, Dr Bobin Joseph, Dr Jayasree, Dr C Ravindran, Dr A K Sing, Dr C K Chand, Dr Gopalkrishnan, Dr Vishwas Dashputra, Dr Abhishek Gaurkar, Dr Jayant Dhande, Dr Rose Kamal Puri, Dr K D Tibrewala, Dr Jeevanandam, Dr Jeyaganesh D, Dr Gopinath , Dr C Sukunar, Dr PL Saravanana, Dr Sudhir M Shet, Dr Mahesh Kumar Poddar, Dr Bharat Bhushan Jindal, Dr Ashwani Kumar Mittal, Dr Siddhartha Sonkar, Dr Ashok Solanki, Dr Govind Swarup, Dr Haresh Patel, Dr O R Ansari, Dr Sanjay Kalaan, Dr P C Bhanu, Dr D P Sarkar, Dr Satish Agarwal, Dr Sreejith S R, Dr Ajay Gupta, Dr N Murangam, Dr Janaki Jhiagarajar, Dr Mathaw, Dr K Krishnamoorthy, Dr Y Rubam Mores, Dr Gopal Subramaniyan, Dr Sajeev Vasudevan, Dr Revathy, Dr R Narasimhan, Dr B Kalaikovan, Dr, Amit Oza, Dr Deepak Gaba, Dr Ananita Gupta, Dr Vinayak Kale, Dr Jitendra Agarwal, Dr P S Shajahan, Dr Anand Mandhaniya, Dr Sachin Verma, Dr Dinesh Jain, Dr D S Goel, Dr Jaspreet Singh, Dr Aditya Mahamankar, Dr Akhilesh Kumar Singh, Dr G RaviKumar, Dr Mahendra Kumar Jaiswal, Dr M K Pal, Dr Akhilesh Kumar Singh, Dr Smriti Singh, Dr Kamal Kumar, Dr B Dhamodaran, Dr Vijay Kr, Dr Kuldeep Singh Chauhan, Dr Rajnish Dahuja, Dr Kaleem Ahmed, Dr Rakesh Jain, Dr Rahul Doshi, Dr Dinesh Lokhande, Dr, Joseph Pratheeban J, Dr Thilagar S, Dr, Yasar Arafat, Dr M Mohammed Rafi, Dr V Srinivasan, Dr M Gopinath, Dr Rajneesh Srivastav, Dr Sailesh Srivastava, Dr Virendra Bahadur Srivastava, Dr Rajesh Kumar, Dr A R Yadav, Dr Imran Aziz, Dr Abhijit T Sotgir, Dr Siddharth Ved Prakash, Dr Raj Kumar Gupta, Dr Naresh Khare, Dr Rakesh Strivastava, Dr Pankaj Gupta, Dr Ashish Garg, Dr Mukesh Agarwal, Dr Rahul Yakmi, Dr Ajay Kumar Chaudhary, Dr P K Dhawan, Dr Prashat Upadhyay, Dr Akshay M Nakrani, DrAnand Amesange, Dr Janardhan Bandi, Dr Ashish Kumar Gupta, Dr Vikas Goel, Dr Anup Srivastava, Dr Atul Vadgaonkar, Dr Umesh Ramdas Aher, Dr Shaji P S, Dr Cherian Joseph, Dr M Mallikarjuna Reddy, Dr Shah Abrar, Dr T Raja, Dr Tuman U S Krishanan, Dr Nilay Thakore, Dr Mustufa Rangwala, Dr Umesh Chandra, Dr Ajay Tari, Dr O N Pandey, Dr Sanjay Tripathi, Dr Amar Modi, Dr Amit R Agrawal, Dr Aziz K S, Dr Shine Shukoor, Dr K Lokesh, Dr Nitesh P, Dr Prasanna Kumar T, Dr Charu G, Dr C Ramesh Bagu Reddy, Dr Vasundhara Rahul, Dr D D Changkaksh, Dr Abdul Mateen Athar, Dr Somashekar A R, Dr Rajeev Lochana, Dr Siddalingayya R Hiremath, Dr Vishwajith S M , Dr Veda Prakash A, Dr Sheetal Chauvaria, Dr Manjunath P H, Dr S A Narayana Prasad, Dr Nitin Mahaja, Dr Vishal Gandhi, Dr K S Nagar, Dr Deepak Bhambe, Dr Arindam Chatterjee, Dr Anurag Agarwal, Dr Sanjay Kumar Bharti, Dr Manish Kumbmare, Dr Yoginder Gupta, Dr Archana Kabra, Dr Rameshwar A Walkad, Dr Rahul Uttamrao Deshmukh, Dr Shaikh Anees, Dr Swapan Sarkar, Dr Amartyadeep Pal, Dr Abhijeet Joshi, Dr Arun Kumar Singh, Dr Manoj Kumar Pal, Dr Ajay Yadav, Dr Pankaj K Barg, Dr Suraj Purshotam.

The authors would like to thank Dr Deepak Talwar (Noida, India) for technical guidance in manuscript development and acknowledge Dr Prashant Katke (Mumbai, India) and Dr Hanmant Barkate (Mumbai, India) for providing technical expertise in statistical analyses.

Conflicts of Interest

None declared.

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Abbreviations

dpMDI: digital dose counter pMDIs
LAMA: long-acting muscarinic antagonist
LTRA: leukotriene receptor antagonist
pMDI: pressurized metered-dose inhalers
REALISE: REcognise Asthma and LInk to Symptoms and Experience

Edited by G Eysenbach; submitted 29.01.19; peer-reviewed by I El Akkary, D Dalan; comments to author 27.02.19; revised version received 13.03.19; accepted 24.03.19; published 07.05.19.

Please cite as:
Guleria R, Korukonda K, DUSS Investigators
Clinical Impact of a Digital Dose Counter Pressurized Metered-Dose Inhaler on Uncontrolled Asthma: Cross-Sectional, Observational, Surveillance Study
Interact J Med Res 2019;8(2):e13530
URL: http://www.i-jmr.org/2019/2/e13530/
doi:10.2196/13530
PMID:

Original Paper

Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study

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Related Article:

This is a corrected version. See correction statement: http://www.i-jmr.org/2019/2/e14352/

Abstract

Background: Although plastic surgery has been gaining a lot of popularity recently, there seems to be limited perception and a poor understanding of this field by both medical professionals, including medical students, and the general public. This might alter referral patterns as well as medical students' choice to pursue a career in plastic surgery.

Objective: The purpose of this study was to assess knowledge and perception of plastic surgery among medical students and to explore the influencing factors underlying particular beliefs.

Methods: Data for this cross-sectional study were collected between August 22 and December 22, 2017. The questionnaire was formulated on the basis of our own study objectives and from available questionnaires with similar objectives. It was composed of 14 questions divided into three main parts: demographics, the specialty of plastic surgery, and media involvement and its effect on plastic surgery. The study was conducted via an online questionnaire among medical students in all years at King Abdulaziz University Hospital, Jeddah, Saudi Arabia. Data were considered significant at $P<.05$. All analyses were performed using SPSS, version 20.

Results: A total of 886 medical students participated in this study. We achieved a response rate of 56.79%. The mean age of the participants was 21.2 years. The mean awareness score was 9.7 (SD 4.2) for female students and 8.3 (SD 4.2) for male students ($P<.001$). The condition most commonly known to be treated by a plastic surgeon was burns (70.3% of responses).

Conclusions: Medical students do not have adequate awareness of plastic surgery, and early exposure to this specialty may enhance their awareness.

(Interact J Med Res 2019;8(2):e12999) doi:10.2196/12999

KEYWORDS

plastic surgery; perception; knowledge; medical students; media; King Abdulaziz University; Jeddah; Saudi Arabia

Introduction

Plastic surgery is well defined as the specialty concerned with restoration, reconstruction, and enhancement of the function and appearance of body structures that are missing, defective, damaged, or misshaped. It includes both reconstructive and cosmetic surgery [1]. According to the American Society of Plastic Surgeons, nearly 17.1 million cosmetic procedures and 5.8 million reconstructive procedures were performed in 2016 alone; this represents an increase in cosmetic procedures of

132% since 2000 [2]. Despite this growth in the field, there seems to be limited perception and a poor understanding of this specialty by medical professionals, including medical students, and the general public [3].

Even though plastic and reconstructive surgeons require extensive surgical training and technical skills, they are mostly known for performing cosmetic surgeries [4]. An Indian study reported that plastic surgery is poorly understood in the medical community, as 12% of the participants thought that plastic and cosmetic surgeries were the same [3]. Similarly, a recent study conducted by Fraser et al [5] concluded that medical students have a skewed perception that is largely influenced by television. As these students go on to become practicing physicians, their misconceptions regarding plastic surgery may negatively affect the specialty by altering patient referral patterns and their decision to pursue a career in plastic surgery.

The number of Saudi plastic surgeons is relatively low in comparison to that in other parts of the world: Recent statistics showed the percentage of plastic surgeons in Saudi is 0.5% compared to 15.6% in the United States, 12.6% in Brazil, and 6.4% in China [6]. Therefore, this study aimed to measure the level of awareness about plastic surgery among medical students in Saudi Arabia in order to improve their perception and maybe their interest in plastic surgery as a choice in their specialty.

No data are available in the literature about medical students' knowledge and perception of plastic surgery in Saudi Arabia. The purpose of this study was to assess knowledge and perception of plastic surgery among medical students in Saudi Arabia and to explore the influencing factors underlying particular beliefs.

Methods

Study Design and Data Collection

This cross-sectional study was conducted via an online questionnaire at King Abdulaziz University Hospital in Jeddah, Saudi Arabia. The survey was hosted freely on the Google survey webpage, and the link was sent by two randomly chosen representatives from each year (second to sixth year) who volunteered to distribute the questionnaire online via WhatsApp, wherein they had a master list of students' names and their contact information. Participants were chosen via a multistage stratified random sampling method. Stratification considered gender and educational year (second to sixth). A total of 886 medical students participated in the study. The data were collected from August 22 to December 22, 2017. All participants were informed about the demands of the study, and those who agreed to participate were enrolled. Participants who refused to participate or failed to complete the questionnaires were excluded.

Questionnaire Variables

The questionnaire was formulated on the basis of our own study objectives and from available questionnaires with similar objectives [7-9]. Both content and face validity were assessed by two experts. Internal consistency reliability was assessed using Cronbach alpha. The questionnaire was composed of 14 questions divided into three main parts: demographics, the specialty of plastic surgery, and media involvement and its effect on plastic surgery. The first part included age, gender, educational level, and academic grade point average (GPA). The second part aimed to assess medical students' knowledge about plastic surgery. The total score for awareness was 21 and ranged between 1 and 21; a higher score indicated more awareness about plastic surgery. The final part involved questions aimed at determining the role of media in students' perceptions of plastic surgery.

Ethical Considerations

This study was approved by the Institutional Review Board and the Research Ethics Committee of King Abdulaziz University in Jeddah.

Statistical Methods

Descriptive statistics were used for the baseline characteristics of all respondents, the frequencies and percentages of respondents who had chosen other specialties, the sources of information regarding plastic surgery, and the conditions treated by plastic surgery. The Student *t* test was used to compare the mean difference in awareness scores of all respondents according to different variables. A one-way analysis of variance test was used to compare the mean awareness score among participants across decisions regarding plastic surgery and the level of education. The Spearman correlation test was used to determine the correlation between the score achieved and age, educational level, and academic GPA. A Chi-square test generated *P* values according to different variables for participants who chose the plastic surgery specialty. Data were considered significant at $P<.05$. All analyses were performed using SPSS, version 20 (IBM Corp, Armonk, NY).

Results

Participants

A total of 886 medical students participated in the study, yielding a response rate of 56.79% (886/1560). The mean age of students was 21 years, and 50% were females. Students were from different levels of medical school—25.6% were in their final year—and 66% of the students had a GPA between 4.5 and 5 (Table 1).

Among the sample, 65.8% of the students had not yet decided on their career specialty, 11% had chosen to pursue a career in plastic surgery, and 22.7% had chosen a different specialty (Figure 1).

Knowledge of Plastic Surgery

The mean awareness score was 9.7 (SD 4.2) for female students and 8.3 (SD 4.2) for male students ($P<.001$). Those who had been exposed to a surgical discipline had a higher score (mean 10.4, SD 4.4) than those who had no exposure (mean 8.5, SD 4.1; $P<.001$). Students who had not decided on their career specialty had a lower score (mean 8.4, SD 4.1) than those who had chosen plastic surgery or any other specialty ($P<.001$). Sixth-year medical students had an awareness score of 10.5, which was higher than that of second-, third-, and fourth-year students ($P<.001$; Table 2).

Table 1. Summary of characteristics and responses of participants.

Characteristics and responses	n (%)
Gender	
Female	440 (49.7)
Male	446 (50.3)
Educational level	
2nd year	156 (17.6)
3rd year	220 (24.8)
4th year	188 (21.2)
5th year	95 (10.7)
6th year	227 (25.6)
Academic GPA[a]	
<2.5	1 (0.1)
2.5-2.99	7 (0.8)
3-3.49	29 (3.3)
3.5-3.99	103 (11.6)
4-4.49	252 (28.4)
4.5-5	494 (55.8)
Exposed to medically themed television	
No	325 (36.7)
Yes	561 (63.3)
Exposed to a surgical discipline	
No	648 (73.1)
Yes	238 (26.9)
Made a decision about choosing plastic surgery	
Yes	102 (11.5)
No	39 (4.4)
Other specialty	162 (18.3)
Not decided	583 (65.8)

[a] GPA: grade point average.

Figure 1. Specialty preferences among participants.

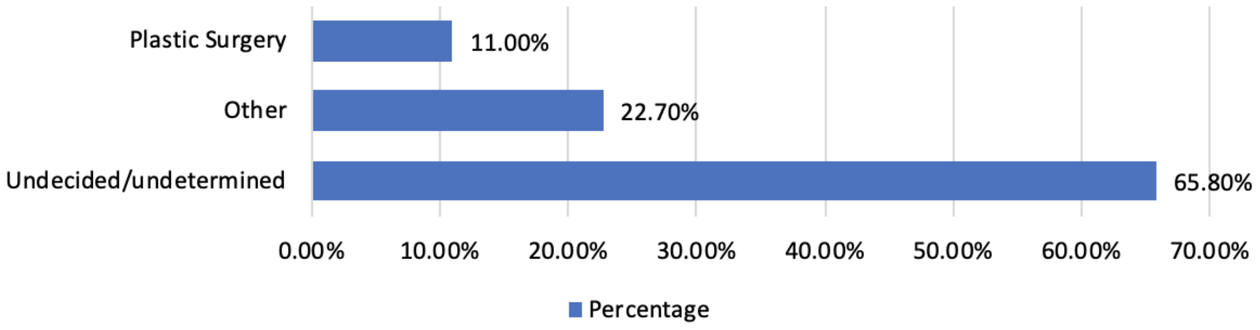

Table 2. Achieved scores across various factors.

Factor	n	Mean score (SD)	P value
Gender			<.001[a]
Female	440	9.73 (4.178)	
Male	446	8.30 (4.196)	
Exposed to medically themed television			<.001[a]
Yes	561	10.01 (4.029)	
No	325	7.29 (4.060)	
Exposed to a surgical discipline			<.001[a]
Yes	238	10.42 (4.296)	
No	648	8.49 (4.110)	
Wants to be a plastic surgeon			.07[a]
Yes	102	9.73 (4.446)	
Other specialty or not determined	784	8.92 (4.213)	
Made a decision regarding plastic surgery			<.001[b]
Yes	102	9.73 (4.446)	
No	39	9.59 (4.278)	
Other specialty	162	10.67 (3.984)	
Not decided	583	8.39 (4.138)	
Educational year			<.001[b]
2nd year	156	6.95 (4.011)	
3rd year	220	8.66 (4.008)	
4th year	188	8.84 (4.087)	
5th year	95	10.01 (4.304)	
6th year	227	10.49 (4.092)	

[a] By Student *t* test.

[b] By analysis of variance.

Burns were most commonly known to be treated by a plastic surgeon (70.3% of students), followed by rhinoplasty (67.6%) and breast reduction or enhancement (66.6%). The conditions least known to be treated by plastic surgeons were injuries to the nerves of the hands and legs (12.1% of students), tendon injuries of the hand (12.3%), and bedsores (13%) (Table 3).

Role of Media in Perceptions

Of the students in the sample, 63.3% had been exposed to medically themed television programs. Their awareness scores were higher (mean 10, SD 4) than those of students who had not been exposed to these programs (mean 7.3, SD 4.1; *P*<.001; Table 1) The most commonly mentioned source of information was the internet (54.4%), followed by the television (44.7%; Table 4).

Spearman rank correlation was performed to test the correlation between the achieved score and age, academic year, and GPA (Table 5). There was a significant correlation between the score and age (*P*<.001; *r*=0.18). There was also a significant correlation between the score and academic year (*P*<.001; *r*=0.27), which indicates a weak positive correlation between the score and both age and academic year. There was no statistically significant correlation between the GPA and the achieved score (*P*=.45).

Table 3. Conditions treated in plastic surgery. Frequency refers to the number of students who were aware of the conditions treated in plastic surgery.

Condition	Frequency, n (%)
Burns	623 (70.3)
Rhinoplasty (nose job)	599 (67.6)
Breast reduction or enhancement surgeries	590 (66.6)
Botox	555 (62.6)
Cleft lip and palate (congenital)	536 (60.5)
Eyelid tears and cuts over the face	483 (54.5)
Congenital anomalies of ear and nose	460 (51.9)
Liposuction (fat aspiration)	456 (51.5)
Abdominoplasty (tummy tuck)	404 (45.6)
Fractures of the jaw and face	402 (45.4)
Hair transplantation	353 (39.8)
Sex-change surgery	352 (39.7)
Finger amputations	229 (25.8)
Diabetic foot wounds	153 (17.3)
Fractures of the hand	123 (13.9)
Bedsores	115 (13.0)
Tendon injuries of hand	109 (12.3)
Injuries to nerves of the hands and legs	107 (12.1)

Table 4. Sources of information regarding plastic surgery.

Source	Frequency, n (%)
Internet	482 (54.4)
Television	396 (44.7)
Friends	316 (35.7)
Snapchat	240 (27.1)
Instagram	234 (26.4)
Personal encounter	174 (19.6)
Twitter	127 (14.3)
Other	122 (13.8)
Teaching sessions	120 (13.5)
Magazines	87 (9.8)
Personal experience	86 (9.7)
Clinical rotations	81 (9.1)
Workplace	77 (8.7)
Facebook	26 (2.9)

Table 5. Spearman correlation test for the correlation between achieved score and age, educational level, and academic grade point average (N=886).

Variable	Correlation coefficient (*r*)	*P* value
Age	0.182	<.001
Educational level	0.267	<.001
Academic grade point average	0.025	.45

Discussion

Principal Findings

A total of 886 medical students participated in this study. The mean age of the participants was 21.2 years, and half of them were female. Almost 66% of the students had a GPA above 4.5/5. The mean awareness score was 8.3 (SD 4.2) for male students and 9.7 (SD 4.2) for female students (P<.001). The condition most commonly known to be treated by a plastic surgeon was burns (70.3% of responses), followed by rhinoplasty (67.6% of responses). As plastic surgery is a unique specialty that deals with everything from head to toe, it has no organ system of its own. Our data show that medical students lack a proper understanding of the specialty of plastic surgery. These findings are consistent with those of other studies that defined plastic surgeons as cosmetic surgeons only or did not recognize the surgeries that are commonly performed by plastic surgeons, such as hand surgery and cleft palate surgery [9,10]. Interestingly, these misconceptions are also held by other groups, including the public, primary care physicians, and residents [7,8].

Students in our study believed that plastic surgeons most commonly treat burns (70.3%), perform rhinoplasty (67.7%), and perform breast-reduction and enhancement surgeries (66.6%). In contrast, in a study from Pakistan, the perception was that plastic surgeons most commonly perform hair transplant surgery (89.9%), followed by facial scar surgery (88.0%) and rhinoplasty (83.4%) [11]. However, in a study performed in India, burns were the most frequently named condition (20.4%), but at a much lower percentage than that observed in our study (70.3%) [4]. Adeyemo et al [12] reported that the most commonly named procedures were liposuction (88.2%) and hair transplant surgery (84.4%); in contrast, liposuction was named by only 53% of our study participants. A similar study conducted in Pakistan among college students found that the internet was the main source of information about plastic surgery (88%) [11], which is in agreement with the results of our study (54.4%).

The revolution in various forms of media and social networking channels has made the conditions treated by plastic surgeons more recognizable. Medically themed series such as Grey’s Anatomy and House seem to be significantly associated with better awareness of plastic surgery among the students in our study. The internet and social media are considered a rich source of information for plastic surgery, as the majority of students identified them as their sources of information. Considering new trends in social media and the advertisements that serve to educate students about cosmetic surgery, the use of the internet and social media tools to promote a more accurate and realistic portrayal of medicine should be strongly advocated.

Medical students' perceptions about the different surgical disciplines may increase as they progress through their clinical years. Students in their final year in this study had significantly more knowledge about plastic surgery than their younger peers. Although medicine and surgery were considered essential in shaping the educational foundation of the students, their lack of knowledge about plastic surgery may have a negative impact on their chances of obtaining a residency in this field. Plastic surgery is an extremely competitive specialty, and it is mandatory for students who wish to pursue a residency position in this field to be involved in extracurricular activities that include electives and related research.

In our study, female medical students were more knowledgeable and aware of the discipline of plastic surgery than male students. This could be explained by the positive correlation between the awareness level and the GPA, as female students had a statistically significant higher GPA. In our study, we also found that 14.5% of male students wanted to pursue a career in plastic surgery compared to only 8.4% of female students, consistent with the findings of a study conducted in Riyadh, which showed that male medical students were more interested in plastic surgery as a specialty than female students [13]; this finding is in agreement with previous published articles in countries with cultural similarities such as Turkey and Jordan [14,15].

Specialty selection might vary according to gender, as shown in a study by Alshahrani et al: Family medicine was the most preferred specialty for women among Saudi medical students [16].

To our knowledge, this study is the first of its kind in Saudi Arabia to assess the perception and knowledge of medical students about plastic surgery. Many different modalities may improve awareness of this specialty. Self-explanatory brochures about this specialty and its different disciplines have been advocated as a tool to increase awareness. We recommend that future studies asses if there are any social or cultural components to the awareness score and analyze medical students’ interest of pursuing a carrier in plastic surgery.

Limitations

Although our sample size was much larger than that reported in any other article in the field [4,5,11] and the study achieved its aim, there were some limitations that need to be highlighted. First, our study was cross-sectional, covered a short interval time, and was conducted at a single institution. In addition, there is a possibility that the responses and level of awareness are not representative of all medical students in Saudi Arabia. Second, response bias may have occurred because of the moderate overall response rate (56.79%), which was particularly affected by some students’ refusal to participate or failure to complete the questionnaire. This could be attributed to the lack of interest and time, which resulted in the exclusion of these students from the study.

Conclusions

Medical students do not have adequate awareness of plastic surgery. Early exposure to this specialty may enhance their awareness. Internet and social media channels are rich sources of information and their use as educational tools should be encouraged.

Acknowledgments

We would like to thank Aseel Khayyat, Sarah Alnakhli, Naif Alansari, Muaz Bazuhair, Ebtihaj Al Amoudi, Mohammed Almatrafi, Amjad Ghandurah, and Ghada Almohammdi for their collaboration and support in data collection.

Conflicts of Interest

None declared.

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Abbreviations

GPA: grade point average

Edited by G Eysenbach; submitted 30.11.18; peer-reviewed by F Alahdab, K Miller; comments to author 05.01.19; revised version received 28.02.19; accepted 24.03.19; published 03.04.19.

Please cite as:
Mortada HH, Alqahtani YA, Seraj HZ, Albishi WK, Aljaaly HA
Perception of Plastic Surgery and the Role of Media Among Medical Students: Cross-Sectional Study
Interact J Med Res 2019;8(2):e12999
URL: http://www.i-jmr.org/2019/2/e12999/
doi:10.2196/12999
PMID:30942694

Original Paper

Orthopedic Surgeons' Perspectives on the Decision-Making Process for the Use of Bioprinter Cartilage Grafts: Web-Based Survey

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Abstract

Background: Traumatic and degenerative lesions in the cartilage are one of the most difficult and frustrating types of injuries for orthopedic surgeons and patients. Future developments in medical science, regenerative medicine, and materials science may allow the repair of human body parts using 3D bioprinting techniques and serve as a basis for new therapies for tissue and organ regeneration. One future possibility is the treatment of joint cartilage defects with in vivo 3D printing from biological/biocompatible materials to produce a suitable cell attachment and proliferation environment in the damaged site and employ the natural recovery potential of the body. This study focuses on the perspectives of orthopedic surgeons regarding the key factors/determinants and perceived clinical value of a new therapeutic option.

Objective: This study aimed to determine the knowledge and expectations of orthopedic surgeons regarding the clinical use of bioprinted cartilage.

Methods: The survey, conducted anonymously and self-managed, was sent to orthopedic surgeons from the Catalan Society of Orthopedic and Traumatology Surgery. In accordance with the method devised by Eysenbach, the Checklist for Reporting Results of Internet E-Surveys was used to analyze the results. The following factors were taken into consideration: the type and origin of the information received; its relevance; the level of acceptance of new technologies; and how the technology is related to age, years, and place of experience in the field.

Results: Of the 86 orthopedic surgeons included, 36 believed the age of the patient was a restriction, 53 believed the size of the lesion should be between 1 and 2 cm to be considered for this type of technology, and 51 believed that the graft should last more than 5 years. Surgeons over 50 years of age (38/86, 44%) gave more importance to clinical evidence as compared to surgeons from the other age groups.

Conclusions: The perspective of orthopedic surgeons depends highly on the information they receive and whether it is specialized and consistent, as this will condition their acceptance and implementation of the bioprinted cartilage.

(Interact J Med Res 2019;8(2):e14028) doi:10.2196/14028

KEYWORDS

orthopedic surgeons; online survey; 3D bioprinting; cartilage; graft

Introduction

Background

The cartilage is a specialized connective tissue that does not contain nerves, blood, or lymphatic vessels and is formed by the differentiation of mesenchymal cells. It is flexible and composed mainly of extracellular matrix that contains chondrocytes. Defects on the articular cartilage do not heal spontaneously and tend to develop into osteoarthritis, which in turn alters the articular function and can cause disability and progressive loss of quality of life [1]. The exact incidence of symptomatic lesions of cartilage in the general population is unknown. In some large epidemiological studies, cartilage lesions have been observed in 5%-11% of diagnostic arthroscopies in predominantly young adults with joint pain [2]. However, injuries are often focal chondropathies, resulting in matching injuries on the opposing surface such as in meniscus or ligament injuries to the knee. They are also related to misalignments of the axis articulating load. Two types of techniques are used for the treatment of symptomatic lesions of cartilage: the reconstructive techniques have been in use since the 1950s and the regenerative techniques are newly introduced in tissue engineering [3]. Current surgical procedures [4] such as microfracture surgery, mosaicplasty, and allografting have limited efficacy [5], and none of them are significantly more successful than the others [6]. More innovative surgical treatments from the past few years, including autologous chondrocyte implantation and matrix-induced autologous chondrocyte implantation [7], which require a previous surgery to obtain the cells, have markedly improved the outcomes of chondral defect treatments [8] but often, the resulting repairing tissue is of low performance, and surgery only delays the onset of degeneration and osteoarthritis [8].

The development of regenerative medicine and tissue engineering–oriented techniques may contribute to the knowledge of the field of joint injuries. This, in turn, could lead to better articular disease treatment techniques and resolve the clinical problem of healing critical size articular osteochondral defects [9].

The key elements of tissue engineering are tissue-forming cells, structural scaffolds, and signaling molecules, the combination and application of which result in a functional tissue construct to promote tissue healing and regeneration [10]. Tissue engineering strategies typically aim to homogenously distribute biological factors such as cells and growth factors throughout a biomaterial matrix [11].

Autologous chondrocytes could be an obvious choice for regeneration of articular cartilage injuries. However, traditional treatments based on chondrocytes have identified several drawbacks of such chondrocytes: (1) they have a low rate of proliferation; (2) although it is easy to isolate them, the number of obtainable cartilage cells is limited; and (3) there are implications for morbidity of the donor site. Consequently, the use of other cell types for different tissue engineering applications such as stem cells [12] (embryonic, mesenchymal, cord blood stem cells, obtained from adult tissue, or induced pluripotent stem cells [13]) are the future for treatment.

Regenerative medicine [14] and tissue engineering [15] are current approaches aimed to solve these problems. These new possibilities could drive the paradigm shift from symptomatic treatment [16] in the 20th century to healing treatment of the 21st century [17,18].

Bioprinting [19], defined as a real-time disposition of structural biomaterials and live cells to create tissues and organs that imitate the characteristics of the injured tissue/organ, is moving forward very quickly, but because the process of obtaining tissues by using this technique depends on many factors, several technological needs must be met beforehand.

In an animal study, Di Bella and collaborators [20] used a 3D printer of a hand *in situ*. 3D printing, an innovative bioprinting technology, allowed the surgeon to use tissue engineering techniques at the time and place of need, using the hand-held printer Biopen. This instrument, with separate cartridges for each biomaterial, allows the surgeon to set the different layers right on the cartilage. Furthermore, it does not require a computed tomography scan, as the surgeon can use the Biopen directly where it is needed [21]. No studies in humans have been published, but according to the authors, it will not take long for the results to be obtained. As researchers develop bioprinted grafts, the knowledge of clinician priorities will facilitate their refinement and implementation.

Implementation research [22] seeks to resolve a wide range of issues found in the process of clinical application. The goal is to understand how and why the researchers' new suggestions are understood in the clinical sphere and find the best approaches to develop them [23]. In previous research [24] focusing on orthopedic surgeons, the information aspect was highlighted. Therefore, this study will focus on the information received, with the aim of understanding the surgeons' process of decision-making and to identify their expectations regarding the ideal bioprinted cartilage graft.

Aim

This study aims to understand how orthopedic surgeons make clinical decisions and to assess their knowledge and opinion on this topic as well as their needs concerning the bioprinted cartilage graft.

Two main goals were set: (1) to obtain a better understanding of the orthopedic surgeons' decision-making process, and, by using this knowledge, to understand which factors would drive surgeons to use the graft on the treatment of cartilage lesions and (2) to identify surgeons' expectations regarding the use of grafts and the key factors to be addressed for surgeons to consider implantation of such grafts on a patient. Hence, the overall purpose was to define the ideal scenario and characteristics of the graft for successful implantation.

Methods

Contextualization of Research and Ethical Approval

This survey and its questions were defined in the context of both a previous qualitative study [24] about the barriers and facilitators in the clinical use of bioprinted cartilage, which had derived conclusions from semistructured interviews and focus groups with orthopedic surgeons, and a literature review. Both these approaches helped identify the most pressing issues, on which this survey was focused.

Approval was obtained from the Committee of University Research from a University of Vic - University Central of Catalonia (registration number 28/2017).

Participants of the study were informed that the survey was anonymous and notified about the average completion time, and all information mentioned in the survey was credited to its source. The results were stored on a university-owned website, with private access for the authors.

Survey Design

Before the final version of the survey was sent, a trial version was sent to 17 orthopedic surgeons to ensure that both the subject and the instructions were understood and to measure the average time for completion. After the results were obtained, some changes were introduced in the survey: questions that asked to rate agreement were scored on 10 possible scores instead of 5 possible scores, adding more options; the writing of the questions and answers was edited; and more specific questions were added.

The final questionnaire, with 25 self-managed questions, allowed identification of the decision-making patterns of orthopedic surgeons. The constituent elements of the questionnaire are configured in five domains: (1) demographic questions, (2) information and knowledge of 3D printing, (3) knowledge about the graft's qualities, (4) knowledge about the expectations for this new technology, and (5) scientific evidence and clinical trials.

Sample Population

The Col·legi de Metges de Barcelona (the Medical Association of Barcelona) has 1081 currently active orthopedic surgeons registered, including 906 men (83.8%) and 175 women (16.2%). Of the members, a total of 849 also belong to the Catalan Society of Orthopedic and Traumatology Surgery (SCCOT), which is a nonmandatory affiliation. An email was written to all SCCOT surgeons, asking them to participate in the study, with a survey link. Of these, 72 emails were returned to the sender (the email address was wrong), and 777 orthopedic surgeons received the email.

In Spain, orthopedic surgeons can develop their work in the public and private sector at the same time. The specialization in sports orthopedics is not separately regulated. Because the survey was anonymous, we could not determine how many of the respondents were from the academic field.

The survey was voluntary, had no incentives, consisted of only one page, and allowed for review of the answers before sending. Answers could be easily obtained and homogenized, as they were in the same order, level, and presentation within all instances, which reduced the error margin and facilitated data retrieval.

The response rate was 11% (86/777). The average time to completion was 15.43 minutes. The survey was kept active until a sufficient number of answers were collected.

The calculation of the size of the finite sample was obtained using the Murray and Larry [25] formula. Configured with a margin of error of 10%, a confidence level of 95%, and a population of 777, the resulting sample size was 85.57 people.

Statistical Analysis

IBM SPSS Statistics software for Windows, version 21.0 (IBM Corp, Armonk, New York), was used to analyze the answers of the survey. The Kolmogorov-Smirnov test was used to evaluate the homogeneity of the data. A descriptive analysis with the distribution of frequencies, averages, and SDs was conducted. A comparative analysis was conducted using the Kruskal-Wallis test, Mann-Whitney *U* test, and Chi-squared distribution. The results have been presented following the Checklist for Reporting Results of Internet E-Surveys [26].

Results

The results have been categorized into two blocks: the information that affects the decision-making process of orthopedic surgeons and the qualities that a graft should ideally have, to be implanted in patients.

Demographic Data

Participants were first asked about their gender, age, experience, and type of hospital where they practiced surgery (Table 1).

Hospitals in Spain can be classified as low, medium, or high complexity depending on the type of technology they use and the type of medical assistance they offer. Research and teaching are conducted at medium- and high-complexity hospitals.

Information Linked to the Decision-Making Process of Surgeons

The main aspect of implementation research is evaluating and determining the level of information specialists need to acquire in order to implement the new technology. To obtain a better understanding of the information orthopedic surgeons depend upon to make decisions, answers have been classified by type and origin of the information, relevance, level of acceptance of new technologies, and how the technology is related to age, place, and years of experience.

Information Received

Participants were asked if they had received any type of information related to new medical applications and 3D printing (Table 2).

Almost 70% of the surveyed participants reported that they have received information related to new medical applications and 3D printing via any medium. They considered themselves updated in the medical applications of new technologies as per their own perception.

Table 1. Demographic data of the participants (N=86).

Demographic	Surgeons, n (%)
Gender	
Women	32 (37)
Men	54 (63)
Age	
<40 years	27 (31)
40-50 years	14 (16)
>50 years	45 (52)
Years practicing medicine	
5-15 years	33 (38)
15-30 years	28 (33)
>30 years	25 (29)
Performing surgical activity	
Yes	80 (93)
No	6 (7)
Work placement	
Hospital of low complexity	16 (19)
Hospital of medium complexity	34 (40)
Hospital of high complexity	36 (42)

Table 2. Information received and new technologies updates.

Source of information	Value
Have you received any kind of information, through any means, about the latest progress on 3D printing? n (%)	
Yes	60 (70)
No	26 (30)
Do you consider yourself up to date regarding new 3D printing technologies emerging in the medical field?	
Reported scores (range)	2-10
Mean (SD) score	6.88 (1.66)

Information Relevance

From the previous question, the relevance of the information was analyzed. Relevance was determined by the effect information had in making surgeons feel more and better informed.

To evaluate the relevance, the source of information was analyzed. We analyzed whether those who had received information (by any medium; n=60) considered themselves better informed than the rest and whether those who had received information from specialized companies (n=20) had more knowledge than those who had not received any such information (Table 3).

Crossing the two variables from the previous Table 3 showed that participants who received information by any means considered themselves more knowledgeable (*P*=.001) than those who had not received any kind of information. Of the former, those who had received information from companies who are developing these technologies perceived their knowledge to be higher than that of the rest (*P*=.006). In addition, participants informed by specialized companies showed higher self-perceived knowledge (mean 6.95, SD 1.76) than those who received information via other sources (mean 6.27, SD 1.99).

Regarding the bioprinted cartilage graft specifically, participants who received information on the medical application of 3D printing (n=60) and considered themselves informed (mean 6.27, SD 1.99) were asked how specific and from which source the information they had received on bioprinted cartilage was (Table 4).

Of the 60 participants who received general information on 3D printing, only 27 (45%) knew about bioprinted cartilage, and the information had been acquired from their colleagues (18%) or the scientific literature (27%).

Table 3. Level of self-perceived knowledge on 3D printing in relation to the information received (N=86).

Source of information	Surgeons, n (%)	Mean (SD)	Z [a]	P value
Have you received any kind of information, through any means, about the latest progress on 3D printing?			**–3.225**	**.001**[b]
Yes	60 (70)	6.27 (1.99)		
No	26 (30)	4.69 (1.73)		
Have you been informed by a specialist company about 3D technology?			**–2.746**	**.006**[b]
Yes	20 (23)	6.95 (1.76)		
No	66 (77)	5.44 (2)		

[a] Mann-Whitney *U* Test.

[b] $P<.01$.

Table 4. Means of learning about bioprinted cartilage among participants who received information on 3D printing (Question: If you have received any 3D printing information regarding bioprinted cartilage, through which channel was it? N=60).

Means of learning	Surgeons, n (%)
Through other colleagues	11 (18)
I read a lot of new research	16 (27)
I read a little new research	2 (3)
I have no information about it	30 (50)
I'm not interested in it	1 (2)

Level of Acceptance of New Technologies

To determine if there was a relationship between the relevance of the information received and the acceptance of new technologies, we analyzed the acceptance level of the bioprinted cartilage graft among participants who had higher self-perceived knowledge (20/86) and had received the information from specialized 3D companies (Table 5).

Regarding the perception or ease of acceptance of the bioprinted cartilage graft, there was a significant difference between participants who were informed by specialized companies and those who were not (P=.02). The more information the participants had, the higher was the level of acceptance. Of those who had not received any specific information, no significant conclusion could be deducted (P=.08).

Relation to Demographic Data

To define if the process of decision-making by orthopedic surgeons could be linked to their demographic data, three variables were analyzed: age, years of experience, and place of experience (Table 6).

Considering self-perceived knowledge, the only difference identified was in the age of the participants. Participants aged over 50 years (38/86) considered themselves to be significantly more informed on new technologies than those of other age groups (P=.05). No differences were observed regarding the place and years of experience.

Table 5. Surgeons' acceptance of the use of bioprinted cartilage grafts for their patients, according to the source of information (Question: If the researchers/biotech industry could give us a cartilage graft made with bioprinting, would you think about the convenience of using it in your patients? N=86).

Source of information	Surgeons, n (%)	Mean (SD)	Z [a]	P value
Have you been informed by a specialized company about 3D technology?			**–2.254**	**.02**[b]
Yes	20 (23)	8.40 (1.53)		
No	66 (77)	7.53 (1.69)		
Have you received information, through any means, about the latest progress on 3D printing?			**2.736**	**.75**[b]
Yes	60 (70)	7.65 (2.38)		
No	26 (30)	7.92 (1.41)		

[a] Mann-Whitney *U* test.

[b] $P<.05$.

Table 6. Influence of demographic data of orthopedic surgeons on the knowledge of new technologies (Do you consider yourself up to date regarding new technologies emerging in the medical field? N=86).

Demographic	Surgeons, n (%)	Mean (SD)	χ^{2a}	*P* value
Age			**3.6**	**.05**[b]
<40 years	28 (33)	6.5 (1.79)		
40-50 years	20 (23)	7.2 (1.85)		
>50 years	38 (44)	7 (1.45)		
Years practicing medicine			**3.5**	**.18**
5-15 years	33 (38)	6.42 (1.88)		
15-30 years	28 (33)	7.14 (1.55)		
>30 years	25 (29)	7.2 (1.38)		
Work placement			**0.07**	**.96**
Hospital of low complexity	16 (19)	6.94 (1.48)		
Hospital of medium complexity	34 (40)	6.91 (1.65)		
Hospital of high complexity	36 (42)	6.83 (1.79)		

[a] Kruskal Wallis test.

[b] *P*<.05.

Analysis of the Qualities of the Archetypal Bioprinted Cartilage Graft

The second goal of this study was to identify the qualities of the ideal cartilage graft for application by the orthopedic surgeons in relation to patient characteristics, type of lesion, and perceived difficulties of their use.

Factors Determining the Ideal Graft

The essential characteristics of the bioprinted graft that were analyzed to identify the suitable age of the patient for the implantation, ideal size of the lesion, and duration of the graft. Participants were also asked to choose the most relevant of five suggested qualities (Table 7).

Regarding the age of the patient, 50% of the participants would not implant the graft on patients aged over 70 years, whereas 42% of them did not consider age to be a delimitating factor. Most of them (62%) considered the ideal size of the injury to be between 1 and 2 cm for implantation of a bioprinted cartilage graft. However, 27 (31%) of participants would consider such grafts for lesions over 3 cm. Almost all participants would reject a graft that lasted less than a year. Moreover, 51 of them (59%) said they would not recommend the graft to the patient unless it lasted more than 5 years.

Of the suggested qualities, the two most often selected (78%) were duration of the graft and patient safety (no side effects to general health). One less-often selected quality was ease of implantation, only considered by 50% of the participants.

Perceived Difficulties

The link between the perception in relation to the difficulties and the type of hospital was examined to determine if perceived difficulties were related to surgeons' place of work or whether it was the individual perception of the orthopedic surgeon (Table 8).

Table 8 shows the number of answers depending on the type of hospital and the percentage that each subpopulation represents in relation to the type of hospital.

The main difficulties considered by orthopedics in low-complexity hospitals were outcome uncertainty (ie, lack of clinical trials that prove successful outcomes) and authorization issues by the hospital management. In medium-complexity hospitals, surgeons shared these worries, although to a lesser extent. In high-complexity hospitals, however, the main issue was patient safety, followed by outcome uncertainty.

Table 7. Determining factors of the archetype graft (N=86).

Factor	Surgeons, n (%)
To what extent do you consider the patient's age to be a limitation in the use of bioprinted cartilage?	
I do not see any age limitation	36 (42)
Under 20 years of age	7 (8)
Over 70 years of age	43 (50)
To what extent do you consider the size of the cartilage injury to be a limitation?	
<1 cm	6 (7)
1-2 cm	53 (62)
>3 cm	27 (31)
What minimum duration would the implant need to have for you to recommend it to your patients?	
<1 year	6 (7)
1-5 years	29 (34)
>5 years	51 (59)
What are the most significant variables that you ask for in a bioprinted cartilage, before deciding to use it on your patients? (multiple choices possible)	
Durability in time	67 (78)
Safety for the patient	67 (78)
Good clinical results	58 (67)
Affordable price	54 (63)
Reliable evidence	55 (64)
Ease of surgical implementation	43 (50)

Table 8. Perceived difficulties with bioprinted cartilage according to place of work (What problems/difficulties do you perceive for its use/work placement? Multiple choices possible)

Difficulty	Surgeons, n (%)	Surgeons in hospitals of low complexity[a], n (%)	Surgeons in hospitals of medium complexity[b], n (%)	Surgeons in hospitals of high complexity[c], n (%)
Uncertainty in results	61 (71)	11 (18)	23 (38)	27 (44)
Authorization by the hospital	50 (58)	11 (22)	16 (32)	23 (46)
Patient safety	46 (53)	10 (22)	16 (35)	30 (65)
Hard to handle	38 (44)	6 (16)	15 (39)	17 (45)
Waiting time	37 (43)	8 (22)	13 (35)	16 (43)
Surgical difficulties	31 (36)	7 (23)	9 (29)	15 (48)

[a] 16 surgeons were from hospitals of low complexity (19% of the 86 participants).

[b] 34 surgeons were from hospitals of medium complexity (40% of the 86 participants).

[c] 36 surgeons were from hospitals of high complexity (42% of the 86 participants).

Relevant Variables To Use

Once the qualities of the graft were defined, their consequences on the patient’s life were highlighted, from pain reduction to improvement in the quality of life (everyday life satisfaction). Participants were also asked about the need for clinical trials. These data were crossed with the source of information, via any medium or specialized companies, and with the age of the surgeon, as it was previously observed that it was the only relevant demographic variable (Table 9) [23].

No significant differences were observed in terms of the importance of pain reduction, which was considered by all participants as a necessary requisite. Surgeons who had received information via any medium were more pessimistic regarding the positive effects or positive impact the bioprinted cartilage graft could have on the patients’ quality of life (*P*=.03). Surgeons who had received information via specialized companies were more optimistic than the rest (*P*=.03).

Table 9. Correlation of variables for the use of a bioprinting cartilage, the need for clinical trials, and age of surgeons.

Variable	Number of surgeons (%)	Mean (SD)	Z [a]	P value
To what extent do you consider the alleviation of the patient's pain one of the main characteristics of the new implant?				
Have you been informed by a specialized company about 3D technology?			**–0.435**	**.66**
Yes	20 (23)	8.9 (9.96)		
No	66 (77)	8.44 (1.83)		
To what extent do you that this technology could have beneficial effects and/or a positive impact on the quality of life of patients?				
Have you received information, through any means, on the latest progress in 3D printing?			**2.244**	**.03**[b]
Yes	60 (70)	7.53 (1.67)		
No	26 (30)	8.27 (1.25)		
Have you been informed by a specialized company about 3D technology?			**2.237**	**.03**[b]
Yes	20 (23)	8.45 (1.07)		
No	66 (77)	7.60 (1.63)		
To what extent do you think evidence of clinical trials is needed to be able to implement the bioprinting cartilage in daily clinical use?				
Have you received information, through any means, about the latest progress in 3D printing?			**-0.5**	**.62**
Yes	60 (70)	8.78 (1.71)		
No	26 (30)	8.77 (1.53)		
Age			**9.825**	**.007**[c]
<40 years	28 (33)	8.65 (1.87)		
40-50 years	20 (23)	8.35 (1.18)		
>50 years	38 (44)	9.16 (1.58)		

[a] Mann-Whitney *U* test.

[b] *P*<.05.

[c] *P*<.01.

Most of the participants highlighted the need for clinical trials, irrespective of the source of information. When the need for clinical trials and the age of the surgeons were crossed, it was clear (*P*=.007) that the age group >50 years in surgeons considered scientific evidence through clinical trials to be most necessary.

Discussion

Recent Research

There are a few studies published on the perspective of orthopedic surgeons on the bioprinting cartilage, since it is not yet on the market, but there is research on 3D printed medical implants [27]. This study presents an overview of the characteristics that implants should have as well as surgeons' knowledge of the decision-making process and their expectations and requirements, a thorough understanding of which is necessary to facilitate implementation of the new technology. This technological adoption requires a proactive role, both from the point of view of orthopedic surgeons and health policies, since it will represent a change in the decision-making process of surgeons and the coverage of health benefits [28].

Recent studies represent a significant advance in the clinical translation of human cartilage and the appropriate surgical procedure. The focus of the research is on the biofabrication of biomaterials that maintain the biocompatibility and biodegradability of the original cartilage while increasing the efficiency of cell growth [29]. Mohanraj et al [30] suggested that the presence of an inflammatory environment is more likely to jeopardize the in vivo success of repairers of cartilage derived from mesenchymal stem cells. Using these cells, Yamasaki et al [31] examined the regeneration of articular cartilage and subchondral bone in artificial corpses.

Although researchers are moving forward in all fields of cartilage bioprinting, we have not been able to find working groups publishing the issues of implementation, and therefore, knowledge of orthopedic surgeons on this topic is scarce.

In our previous research [24], which identified the barriers and facilitators for the bioprinted cartilage use and this new approach, we validated the conclusion that orthopedic surgeons should receive information of higher quality from reliable sources, thus enabling the implementation of the bioprinted cartilage, and that researchers should consider what surgeons believe the cartilage graft should be like.

Implications and Explanation of the Findings

The results of this study show that the information received impacts the decision-making process of orthopedic surgeons in a complex and diverse way, as it depends on several variables: the type and origin of the information and its relevance to their demographic data. Previous research [24] found that the amount and quality of the information received was one of the main barriers for the implementation of new technologies. The sample analyzed here shows that orthopedic surgeons lack the specific knowledge of 3D printing as applied to cartilage (Table 4), where 50% of the survey participants who admit to being informed in an unspecific way have almost zero knowledge about it. In contrast, the 20 participants who had been informed by specialized companies considered themselves both better informed and more accepting of new technologies.

Therefore, it could be argued that specialized companies should work closely with orthopedic surgeons to help them acquire more specialized knowledge [32], as shown in Table 3. Another interesting fact is that specifically informed surgeons are more optimistic about the benefits and positive impact of the bioprinted cartilage graft on the quality of life of patients. The origin of the information impacts the level of acceptance and expectations of new technologies, both of which are required for ensuring a wider and easier implementation [33] and are key factors in finding a possible solution to osteoarthritis and improving the life of patients (Table 9). The only variable that is significantly linked to the level of up-to-date knowledge among surgeons is their age: Surgeons aged over 50 years considered themselves better informed. Quite often, the extrapolation of clinical studies to the real world is obstructed by the lack of knowledge of a key factor—the people who will have to implement it.

The second set of goals was to analyze the factors that would provide the ideal context and qualities of an archetypal bioprinted cartilage graft as well as factors perceived as difficulties. The characteristics listed on the survey were size of the lesion, duration of the graft, and age of the patient (Table 7), although more characteristics could possibly have been added. The ideal lesion size preferred by most surgeons was between 1 and 2 cm. A long durability was the most required quality in a graft, which was at least 5 years by 59% of the participants. It could be assumed that if the intervention were proven to be simple and noninvasive, this requisite would not be as important. Since this information is not available, orthopedic surgeons expect a long duration for grafts, predicting possible future reinterventions. The age of the patient presents some debate, as 50% believe that age over 70 years in patients is a limitation, whereas 42% do not consider age a factor. This could be explained by the increased life expectancy of over 70 years in the population. Further research could determine if this difference is a consequence of uncertainty or if it could change with time and experience (Table 7). Surprisingly, 43 of the 86 surgeons believed that the ease of implantation of the graft was not a decisive factor for its use.

For the perceived difficulties in the use of the bioprinted cartilage graft (Table 8), six options were provided, two of which—outcome uncertainty and patient safety—were emphasized by surgeons. Logically, surgeons need positive results from clinical trials in patients before using this technique. As the other answer suggested, issues regarding the implantation and manipulation of the graft were less important, and although they were mentioned in some cases (as the technique is not known yet), they were rated well below the other issues. It is important to highlight this difficulty from the surgeons' viewpoint: They try to offer solutions to the perceived difficulties but are not able to visualize the graft. Orthopedic surgeons are constantly learning and using new surgical techniques, and they are used to the learning curve. Therefore, as long as there is clinical evidence of the effectiveness of a technique, surgical difficulties are not a deterrent, because surgeons believe they will learn the technique in time.

It was expected that other difficulties linked to practical aspects, such as the hospital management's authorization to use the technique and the wait time for the graft, would be linked to the type of hospital. Therefore, in medium-complexity hospitals, authorization is less problematic than either of the two abovementioned aspects: There is not as much bureaucracy involved in medium-complexity hospitals as in a high-complexity hospital, and new technologies are more easily accepted than they are in smaller hospitals. Finally, the need for clinical trials is one of the main difficulties for implementation of the technique (Table 9), as almost all survey participants required clinical evidence (the average, in every case, was higher than 8 on a scale of 0-10). A significant finding was that surgeons who asked for more evidence were aged over 50 years, probably ranked higher in the hospital structure, and had both greater responsibility and more decision-making power.

Strengths and Limitations

The present study should be interpreted in the context of its limitations. The initial proposal planned to cover the entirety of the Spanish territory, through the Spanish Society of Orthopedic and Traumatology Surgery and the Spanish Society of the Knee, and English-speaking specialists through the International Cartilage Research Society, but it was not possible to receive authorization from these societies to send the survey. Our coverage of only a small population is a big limitation, as is the low response rate. In addition, there could be a bias, since the participants who answered the survey were probably more interested in the application of new technologies. Finally, the Chi-squared test might provide inexact results when the values input are small.

Conclusions, Recommendations, and Future Directions

The process of decision-making is based on precise information of quality, provided by companies specializing in the medical application of 3D printing. This variable seems essential to the acceptance of new technologies. The ideal graft, as described by surgeons, could provide important insight to researchers, at least in the initial stages of development, to satisfy the expectations of surgeons. Implementation research should focus on two variables: ensuring communication flows from researchers to surgeons and ensuring that the opinions of orthopedic surgeons regarding the qualities and issues of the grafts reach researchers, which would help them implement the bioprinted cartilage graft with success.

Acknowledgments

We thank the Catalan Society of Orthopedic and Traumatology Surgery, and specially its President, Pere Torner, for the help provided to distribute the survey. We also thank Ismael Cerdà for reviewing the survey and Marina Mustieles for her help in the translation of this text.

This study has not been funded by any institution or organization.

Authors' Contributions

ASV conducted the study and data analysis with the help of MY and FLS. The other authors contributed to the writing and editing of the manuscript. All authors read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

SCCOT: Catalan Society of Orthopedic and Traumatology Surgery

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Edited by G Eysenbach; submitted 15.03.19; peer-reviewed by C Di Bella, S Prasad, T Jiang; comments to author 03.04.19; revised version received 16.04.19; accepted 02.05.19; published 15.05.19.

Please cite as:
Salvador Verges À, Fernández-Luque L, López Seguí F, Yildirim M, Salvador-Mata B, García Cuyàs F
Orthopedic Surgeons' Perspectives on the Decision-Making Process for the Use of Bioprinter Cartilage Grafts: Web-Based Survey
Interact J Med Res 2019;8(2):e14028
URL: http://www.i-jmr.org/2019/2/e14028/
doi:10.2196/14028
PMID:31094326

Original Paper

“As If Neck Injuries Did Not Exist”: An Interview Study of Patients’ and Relatives’ Perceptions of Web Information on and Management of Whiplash Injuries in Sweden

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Abstract

Background: If purposefully designed, patient information can help individuals make well-founded health care decisions. This study was initiated to improve the information on whiplash injuries found in the national health care portal Healthcare Guide 1177, operated by the Swedish government.

Objective: The objective of this study was to describe the thoughts of patients and relatives on (1) information about whiplash injuries presented in the portal and (2) the Swedish health care system’s management of whiplash injuries.

Methods: A total of 5 interviews were conducted with patients (n=10) who had experienced a whiplash injury and with relatives (n=3) of such patients. The interviews were taped, transcribed verbatim, and analyzed by means of conventional content analysis.

Results: The following two themes emerged from the latent content analysis: (1) confidence and trust in the public health care system and (2) a disappointment with health care encounters.

Conclusions: We found that most of the study participants felt distress due to insufficient information; respondents perceived a discrepancy between the public health care system's authority and the information provided. The Web information on whiplash injuries may greatly impact patients' care decisions as well as their physical, mental, and social well-being. We would recommend detailed patient information on whiplash injuries, with less emphasis on psychology and more data on pathophysiology, prognosis, and treatment.

(Interact J Med Res 2019;8(2):e9881) doi:10.2196/ijmr.9881

KEYWORDS

self care; patient participation; health communication; patient portals; patient education handout; patient satisfaction; whiplash injuries; neck pain; chronic pain

Introduction

Background

Whiplash injury is an umbrella term for a type of trauma involving a sudden distortion of the neck, or an acceleration-deceleration injury. The injury mechanism is a forward and upward movement of the chest or the torso with great force, which creates a compression of the lower cervical spine. Simultaneously, there is an unphysiological so-called double curvature of the neck where the lower segments are in hyperextension and the upper joints are in flexion. The neck and head then move into extension, after which the head is thrown forward. Whiplash trauma is most common in traffic collisions [1] and also frequently occurs in sports, which accounts for approximately 10% of all neck injuries [2] (eg, ice hockey [3] or other contact sports [4]). The incidence of whiplash injury is estimated to be 3 out of 1000 inhabitants per year in Sweden [5], Western Europe, and North America [1]. A whiplash trauma can cause several different injuries. Symptoms include head and neck pain, radiating symptoms [6], and a multitude of other symptoms often referred to as whiplash-associated disorders (WADs). About half of the patients with WADs have persistent pain and disability [7]. However, there are still conflicting views on etiology and pathophysiology [8], and so, whiplash injury remains a controversial subject, ranging from its definition to complex medical and legal issues [9,10].

Web-Based Patient Information

Patient information is critical to the health care sector. If purposefully designed, this information can support patients in making well-founded decisions about their care, thereby facilitating patient-focused care. In Sweden, patient information is mainly found at the Healthcare Guide 1177, a national portal for health care advice and information [11]. The guide's explicit aim is to increase access to health care, strengthen the patient's role, and improve public health by offering the general public both in-depth information and access to the health care system. The content is quality assured in collaboration with experts. Access to information can be gained via the home page by clicking the heading entitled *Facts & Advice*. This loads a Web page with 40 broader medical areas listed in alphabetical order. Locating and clicking on *Joints, Muscles & Bones* will load an alphabetical list of more detailed conditions where *Whiplash Injury* is included. More practically, the same information can always be accessed by using the portal's search field found at the top of the home page. The information analyzed in this study includes sections for injury mechanisms, symptoms and diagnosis, and treatment and care (Multimedia Appendix 1), which are the main headings found in all condition-specific information at the portal.

It is not unusual for patients to be dissatisfied with the information they have been given because the information often fails to consider individual needs in a satisfactory way [12]. Whether patient information works well (ie, provides the material needed for good patient decision-making) is dependent on, among other things, inclusion of end users during the design process (Textbox 1) [13,14].

With highly debated issues like whiplash injuries [9,10], it is important to involve patients in the design of patient information, so that their ideas and needs can be incorporated. This way, the information compiled can be made more relevant to the target group [15].

Study Aims

By focusing on respondents' perceptions, this research aims to describe how patients and relatives perceive (1) information about whiplash injuries found on the the Swedish national Web-based portal for health care advice and information (version 2012-12-07-2016-06-21; Multimedia Appendix 1) and (2) the public health care system's management of whiplash injuries. The goal was to contribute to the improvement of such patient information.

This study was initiated because of acknowledged shortcomings in the guide's information about whiplash injuries—the editor of the Healthcare Guide 1177 had received several requests from different parties for a general update of the information and extended an invitation to the corresponding authors' research group to provide the suggested update. The information was updated in collaboration with the corresponding author (2016-06-22) before this study was published.

Textbox 1. Variables influencing the quality of patient information according to Bunge et al [13]. Patients' participation is included in the last variable development process.

- Content of information and meta-information
- Quality of evidence
- Patient-oriented outcome measures
- Presentation of numerical data
- Verbal presentation of risks
- Diagrams, graphics, and charts
- Loss- and gain-framing
- Pictures and drawings
- Patient narratives
- Cultural aspects
- Layout
- Language
- Development process

Methods

Study Design

With the aim of describing how patients and relatives perceive Web information about and the health care system's management of whiplash injuries, we set out to engage focus groups [16] for interviews and to assess the resulting data through qualitative content analysis. Content analysis allows for the interpretation of underlying meaning(s) by penetrating the respondents' choices of phrases and words in relation to context [17].

Recruitment

Respondents were purposely recruited with one distinct criterion for inclusion—anyone who was part of the target audience of the Healthcare Guide 1177. Other inclusion criteria included: (1) experienced a whiplash injury in the past, or is the relative of someone with a previous whiplash injury and (2) a willingness to share experiences and perceptions of the patient information found on the guide with a researcher. We chose to engage members of a patient organization with the aim to obtain rich and relevant data. Patient communities tend to have an ongoing exchange of experiences, reflection, and knowledge accumulation. This awareness of relevant issues in the field made the respondents better prepared to discuss the pros and cons of the patient information, compared with the average person or nonengaged individuals [18]. Study participants were contacted via four Swedish patient-driven organizations representing the interests of people with neck injuries (the Swedish Neck Injury Organization; the Rights of Persons With Neck, Back, and Brain Injuries to Assessment and Diagnosis After Trauma; the Swedish Association for Survivors of Accident and Injury; and the Trigger Point Association). The associations were asked to randomly gather names of patients and relatives. To a group of about 100 patients and relatives recruited by the associations, we sent an information letter and a consent form, through which 52 individuals agreed to participate by returning the signed consent form. An email invitation to a focus group interview was sent to 28 individuals from this group who could be reached by email. Finally, the respondents were those who were able to attend the interviews, until we estimated that saturation was reached.

The first interview served as a pilot. Two respondents participated and the interview was held using the same question template as in the subsequent interviews. We chose to include the first interview in our material as it worked well and produced answers relevant to the study objective. The matters of importance emerging in the pilot interview remained consistent in all 5 interviews. Already in the first couple of interviews, the participants' perceptions converged on a limited number of matters, with new participants confirming and adding their own experiences on already existing matters. This, in our view, suggests that the number of respondents, however small, was nevertheless sufficient to produce adequate results.

Study Participants

The 13 study participants, 9 women and 4 men, were aged between 35 and 74 years, and 10 of them had had a whiplash injury. Time elapsed since diagnosis varied between 6 to 28 years.

Data Collection

Data were collected in the autumn of 2015 in Stockholm. A total of 5 interviews were held within a month. Semistructured interviews were used (key questions and discussion), one of which took the form of a focus group with several participants. Three interviews with groups of 2 (patients), 1 (relative), and 7 (patients) participants were held by telephone for geographical reasons and 2 interviews were held in physical meetings with 1 (patient) and 2 (relatives) participants. The physical meeting interviews were held at a primary health care center in Stockholm, Sweden, in a comfortable, simply decorated conference room. Respondents who came to a physical meeting interview were offered coffee or tea and sandwiches. There was no other compensation or reimbursement.

We used a simple question template (Multimedia Appendix 2) that corresponded to the headings in the existing patient information at the Healthcare Guide 1177 and asked broadly about perceptions of information on injury, perceptions of injury, and perceptions of care. Questions were phrased in a way that made it possible for the respondent to give his or her view on many different aspects of the text such as "How did you perceive the information at 1177.se?" At the start of each interview, respondents were asked to take about 20 min to reread the text for better recall. The interviews were 60 to 90 min long and were taped with a sound recording device. At the end of each interview, one of the researchers summarized what was discussed and asked if anything was missed. Each interview was transcribed and printed.

Three researchers held the interviews (2 present at each interview), 1 family physician (male), 1 psychotherapist and medical student (male), and 1 physiotherapist and linguist (female), the latter with many years of professional experience in sociolinguistics.

Data Analysis

The interviews were followed by a step-by-step conventional content analysis, where all meaningful interview text units are extracted and condensed into codes, after which the codes are grouped into subthemes defined by Graneheim and Lundman [19] as "threads of meaning running through the condensed text." Finally, the subthemes were abstracted into overall themes. The psychotherapist and physiotherapist coded all 5 interviews together, aligning differences in assessment. Latent content was labeled as subthemes and themes to capture the essence of the respondents' descriptions [17]. The themes emerged toward the end of the analysis. The quotes were translated from Swedish to English by the first author and then reviewed by a native English proofreader.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki [20]. Before commencing data collection, ethical permission was granted by the Ethical Review Board in Stockholm (2015/1629-31/5). The respondents' privacy was guaranteed by confidentiality during the entire study. The patient organizations were informed both orally and by email about the study and its terms and purpose. Each organization provided the same information to potential participants individually. All the respondents gave their written consent after being informed of the study aim, of their rights, and that participation was voluntary in all aspects. Each interview began only after the moderator reminded the respondent or respondents of the recordings.

Results

Overview

The respondents are referred to as R1 to R13 and as *she* throughout the text below. No significant differences were found between patients and relatives as both groups contributed in a similar way to each of the codes and subthemes.

Overall, 4 subthemes were developed inductively from 11 codes (13 codes in all). Two main themes, confidence and trust in health care and disappointment with health care contacts, were identified from the subthemes (Textbox 2). A total of 3 codes were excluded from further analysis (Table 1) as they did not relate to the research question.

Subthemes

1. A Bridgeable Knowledge Gap in Swedish Health Care

Respondents overwhelmingly expressed a general lack of basic knowledge in health care about causes and mechanisms of WADs. Neither 1177.se nor health care guidelines offered adequate facts or recommendations for problem management in the respondents' view. As a result, patients and the public were more ignorant than initially thought, considering the abundance of knowledge available today. The lack of adequate management and a diagnosis was evident to several respondents:

> *From what I know today, my feeling's that the guide is lacking in several places....There's nothing at all here—how to care for, about what can come from this type of injury!* [R12, 45-year-old relative]
>
> *For me...it's been such a long stretch. In the beginning...there was like, no process to begin with to investigate whether I had a neck injury.* [R11, 52-year-old patient]

Important facts not conveyed by the health care system were that even mild force can cause injuries and that being less physically active right after the accident may be beneficial. Moreover, one respondent said that listing symptoms in a primary care consultation did not "ring any bells" and resulted only in the advice to take a paracetamol.

Some had concluded that there lacked awareness of this group of patients in the Swedish health care system, since adequate care existed only outside of it. One respondent described never being presented with a proper diagnosis, only "late symptoms after a motor vehicle collision," which she found hurtful and signaling a lack of interest in finding where the injury was located. For another, it had taken a long time just to get the information that it was a neck injury and years to get it documented.

According to another respondent, the phrasing of content found on 1177.se threw suspicion on affected individuals. She had interpreted the main message of the information on the portal to be that, after an accident, an injured person may find it pleasant to remain idle at home, which was improbable in her view. Overall, several respondents had their symptoms assessed as being mainly psychological. One respondent suggested that it may not be plain to the eye as to what was wrong, such as with a broken leg, and one had contacted a psychiatrist to fend off the hypothesis from health care professionals that the health issues faced by her relative were related to mental illness:

> *And the only one who tried to explain to NN what causes her to have these different symptoms...was really Dr NN. Because the others mainly offered her...well...that she had psychological...* [R13, 74-year-old relative]

Conversational therapy was proposed to provide symptom relief. The respondents reflected that this advice was unhelpful since talking to someone could not heal an injury:

> *Instead...they started to talk about...how she should go to a place for people who were burned out. So now she would travel tens of kilometres back and forth every day. And she..."I can feel I'm not burned out, that's not the problem"...* [R13, 74-year-old relative]

One respondent worried about the consequences of the public's view since the picture painted by 1177.se was that whiplash injuries tended not to be serious.

Several respondents suggested ways to provide symptom relief or prevention. Suggested strategies for higher quality and safer care included adequate information, pain medication, nerve blocks for pain treatment, cervical spine bracing, paid sick leave for a sufficient period of time, referral to therapists specialized in treating neck distortion, and help on learning to accept physical limitations and adjusting activity levels accordingly.

2. Lack of Patient Safety

Respondents found that patient health and well-being could have been at risk if they had used 1177.se as a guide, either because of lacking information or a tendency to downplay or trivialize symptoms and concerns associated with whiplash injury. Several respondents found that basic information had been omitted. This would have kept patients and relatives unprepared and was a burden for them:

> *It would be a good thing if the Healthcare Guide could list the many similar problems you get initially, so you'll understand that if this happens to you it's part of the picture and you're not the only one.* [R2, 57-year-old patient]
>
> *I would believe it until I...couldn't believe it anymore...and that's dangerous!* [R7, 44-year-old patient]

Textbox 2. Main themes crystallized from the interviews.

- Confidence and trust in the health care system
- Disappointment with health care contacts

Table 1. Overview of the content analysis results.

Examples of meaning units	Codes[a]	Subthemes
"I've had a wonderful doctor who's supported and helped me, and who had a personal interest in this type of injury, but many people with these injuries get doctors who don't care and don't take these things seriously at all. In my experience, the knowledge and interest of physicians out at the primary care centres varies and is a bit of a game of chance." [R2, 57-year-old patient]	There are knowledge gaps	A bridgeable knowledge gap in the Swedish health care system
"I was given advice from two people who declared me an idiot and...gave me a psychiatric diagnosis on the phone! Because I didn't have anything broken in my neck!" [R7, 44-year-old patient]	Psychologizing from health care	
"I so reject this argument that I expected to feel worse. What, why would I? I mean, I expected to feel better for a year. That was always my hope, that "this will get better, this will get better."...In the end, you might accept it, but it's not because of that that you get chronically ill, that you expected it." [R3, 48-year-old patient]	My experience is questioned	
"Well, I've gone through about all of these treatments. But I think it's important to get medication, to reduce the pain. As soon as possible, that is." [R3, 48-year-old patient]	Examples of purposeful care or self-care	
"It was very hard to get any help. Our daughter sought help at the primary health care centre. But there was nothing wrong with her. They took X-rays and there was nothing wrong—that is, according to the doctors. But it turned out, since she's been to NN, where we did this upright MRI, she has a lot of injuries. [...] Regular health care, there's not a lot of help to get." [R13, 74-year-old relative]	Develop adequate guidelines for investigation!	
"It says you should seek care at once if you have a lot of neck pain or headache after an accident. But I think some people haven't had a lot of pain in the beginning, but the symptoms come later on!" [R4, 49-year-old relative]	Patient information is lacking	Lack of patient safety
"Let's see what else I wrote. Vertigo, here, that vertigo can also be from anxiety. It doesn't have to be. There may be injuries. There are actually quite delicate structures up there." [R3, 48-year-old patient]	Downplaying from the health care system	
"How they describe that there are nerve fibres that transmit information...you really understand that there are things that can be injured. I find that this has improved!" [R3, 48-year-old patient]	Patient information is sufficient	The health care system as an authority
"The ones who must be informed are relatives and those in the periphery. Personnel at the social insurance agency, employers, colleagues, neighbours!" [R1, 35-year-old patient]	Patient information has an important role	
"And she has been active, as much as she could, given the injuries. So she didn't...She's really pretty tough. She's been training and has tried to be active. She has dogs so she's out a lot in the woods and fields. But the sort of help that you got at that pain unit...There's no difference if you've got neck pain or shoulder pain or knee pain. Everyone had to do the same thing. So...they considered her as...like she wasn't interested! When she couldn't manage!" [R13, 74-year-old relative]	Feelings of abandonment	Lack of help and support
"These...interest groups, there's really an immense amount of knowledge there." [R3, 48-year-old patient]	Peer support is valuable	

[a] Three codes were excluded from the analysis as they did not relate to the research question: how I/my relative was injured, my/my relative's symptoms, and my economy.

All respondents felt negative effects to the neck from a whiplash injury were downplayed in the patient information or by the health care system. The message in the patient information was that nearly everyone recovered, which did not correlate with the reality that many patients suffer from chronic symptoms. Health care contacts had said no injury could occur from a whiplash accident, although many experienced this. One respondent interpreted this to mean that health care personnel had no desire to investigate what was really wrong. Another respondent saw risk in the message to be physically active as soon as possible, as this may aggravate symptoms:

> *I'm thinking if there would be a ligament tear, this would need some rest to get a chance to heal.* [R10, 52-year-old patient]

The view was that there was a lack of expert knowledge and seriousness in the information available to patients, which meant people may seek care outside the public health care system. When to seek care after a whiplash injury was discussed. The patient information advised that if the symptoms did not decrease, or if there was substantial neck pain, to consider seeing a physician. Otherwise, patients were instructed to wait 2 weeks. This, it was pointed out, could create insurance difficulties for the individual because insurance agencies require that an injury be addressed within a few days or 72 hours. Respondents felt the patient information should advise a professional medical assessment at the slightest suspicion of injury.

3. The Health Care System as an Authority

Several respondents shared views of medical and health care in terms of competence and reliability. The Healthcare Guide could be relied on; therefore, it was an important tool for obtaining information. One respondent allegorically described the significance of the Healthcare Guide as a bible. If someone's child was sick, she said, there are always things you need to look up and then you turn to 1177.se. Also, the respondents felt Web-based patient information had an important role as an educational forum for the public. This was said to be even more important than informing patients and their families as it contributed to a general awareness in society. Several found positive aspects to the content of the patient information (eg, the possible symptoms of a neck distortion were well described). They found the version evaluated in the study to be better than previous ones and more comprehensive:

> *I rely on the Healthcare Guide as an instrument, so it's actually quite important...* [R1, 35-year-old patient]
>
> *Had I gotten injured now today, and had turned to reading 1177, I'd have told myself..."this is going to be OK. I'm going to get well and I don't have to dig into this. I don't have to seek healthcare. This'll pass!"* [R7, 44-year-old patient]

The respondents implied a trust in the public health care system and seemed to lack a critical view on the adequateness of instructions. For example, one respondent was treated in 20 sessions with no sign of improvement; however, she continued another 10 or 15 sessions. Later, she learned one might respond to some treatments and not others. Another respondent had felt pressured by the health care system to work more than her health allowed. Though it had felt wrong and better to care for her body, she granted the health care system an expert role. In this context, advice was followed regardless of outcome; the health care system seemed to hold an absolute mandate for assessment:

> *I was given the advice not to wear a cervical collar—and really I thought it was so stupid. I, like, walked around and—aaaah—instead of maybe being able to hold it together for a while.* [R3, 48-year-old patient]
>
> *Live life as normal, I was told. And you do follow what the doctor and the physiotherapist say to the dot.* [R10, 52-year-old patient]

4. Lack of Help and Support

Several respondents perceived a lack of support from health care contacts. One respondent described feeling exposed and terribly alone following the accident; another respondent reported that next to no one had acknowledged that deteriorating mechanical properties could be a consequence of a neck sprain:

> *Um, and a lot of things like that, that makes me react when I see the text, a lot of glossing over saying it's psychological, that the problems you have are psychological.* [R3, 48-year-old patient]
>
> *Yes, it's called FMRI. I've had 2 independent assessments showing the exact same thing. But this wasn't really taken seriously by the doctor and so on. It's said it's not scientific!* [R8, 68-year-old patient]

Moreover, it was said that 1177.se addressed individuals with other types of discomfort. Chronic problems were mentioned, but the text left one respondent with the impression that the intended target group did not include people in her situation. Help and support from peers rather than professional carers was described by several to have been helpful and empowering. Explanation and advice from peers helped respondents get oriented in the health care system, learn about treatment or know what questions to raise. All respondents described a struggle to find effective treatment and a more manageable situation for themselves or their relatives.

> *You can do stuff only you get so sensitive to strain, if you don't have any recuperation time. This is the most misunderstood of all things. Namely that...not that you can't walk, can't lift, can't laugh or whatever it might be. You can do everything. Only you're so sensitive to strain.* [R6, 53-year-old patient]
>
> *So she was admitted to hospital. And no one wanted to look into it. She was hidden at a medicine ward. The kidney unit! Where all sorts of doctors were consulted. But no one wanted to deal with it. Instead...We chose ourselves or we decided together. That there won't be any care. It'll only get worse, and...And then I took her home in the same state as when she came in. She rode an ambulance back in full cramps again.* [R12, 45-year-old relative]

Themes

Two main themes crystallized from the interviews, *confidence and trust in the health care system* and *disappointment with health care contacts* (Textbox 2). The main themes characterize the conflicting views on the patient information; the respondents' needs and expectations and their experiences were in poor agreement with what the health care system had offered and the context of whiplash injuries described at 1177.se. In several cases, respondents found the facts (eg, about the type and severity of the condition) presented by the health care system to be misleading.

1. Confidence and Trust in the Health Care System

The examples of cognition and behavior from the respondents revealed the long-term confidence and trust that characterized their relationship with the health care system. The respondents indicated an active participation in their care and no fear after the accident that they may be misled by the carer. They had felt secure and put themselves in the hands of the carer or health care as an institution, as one does in a trustful relationship. Important components of trust in a health care consultation are expectation and beliefs about the context, attributes of professionals, and the asymmetry of power between the carer and patient even if the relationship is voluntary.

All respondents, following the accident, acknowledged the health care system's responsibility in providing recommendations. The patient information was seen as valid. Many facts had been excluded or omitted, which became clear later as respondents gradually gathered knowledge of the subject. They had not questioned the initial view of the situation, but felt surprised, perplexed, or misled when faced with the discrepancies between the briefing from health care encounters and the result of their rehabilitation. This was most likely a consequence of the general high regard for and trust in the competence of the health care system. In parallel, the recommendations available on 1177.se as to when one should seek care were vague, according to several people, and this instigated concern. It risked leaving to the patient or relative to decide what management action to take. It would have had negative consequences for the individual who sought advice if this advice had been acted upon. These opinions can be interpreted as requests for the health care system to assume greater responsibility, when phrasing definitions and in decision-making. It follows that respondents see the health care system as an agent qualified to set standards in the field. It also indicated that the role of the health care system strongly influenced the individual's decisions:

> *There's a risk among those who are injured, they remain at home waiting for 2 weeks...because it says so on the Healthcare Guide.* [R2, 57-year-old patient]

2. Disappointment With Health Care Contacts

Respondents reported that their care had been inadequate in several ways and that very little or nothing had been done by the health care system to address it. Care management was below the standards they had expected, so they were disappointed—in the patient information description of whiplash as a minor injury, in their meetings with health care personnel, and in treatment outcomes. They felt let down in their situations and by the health care system. Given the seriousness of their problems, the likelihood that these individuals had set up *too narrow* parameters of an acceptable outcome was small. Most likely, they would have been content with partly helpful management; however, they had been deeply disappointed.

Several respondents described poor or inadequate management by the health care system compared to the management of other conditions. These descriptions ranged from risk-filled advice at 1177.se to wait and not obtain a medical assessment immediately following the accident to a lack of further investigation or referral to a more knowledgeable professional. The time span reflected this in several cases: sometimes many years passed until symptoms were traced to a neck injury or it was documented by the health care system:

> *Neurologists know surprisingly little. They have no interest in trying to solve the puzzle of what it's all about. Orthopaedists have no interest either. It's as if neck injuries didn't exist in this country. That's my experience.* [R12, 45-year-old relative]

> *It has taken me 15 to 20 years...I did not receive this information, not from the Healthcare Guide nor the Swedish healthcare.* [R2, 57-year-old patient]

We found that respondents perceived a breach of contract on the part of the health care system. First, they felt that the health care system had unloaded the responsibility of early management following a whiplash accident to the patient or relative. Second, health care had frequently failed to provide a basic level of help that is expected from a carer, summed in the often-cited Hippocratic oath to *console always, relieve often, and cure occasionally*. Instead, patients' and relatives' problems were ignored or bandied back at them:

> *No one here in Sweden ever acknowledged or cared for that.* [R6, 53-year-old relative]

Discussion

Principal Findings

The following 4 subthemes arose from the data: a bridgeable knowledge gap in the Swedish health care system, lack of patient safety, the health care system as an authority, and lack of help and support. A total of 2 main themes were identified that were significant for the respondents' perceptions: confidence and trust in the health care system and disappointment with health care contacts. The themes revealed a gap between respondents' needs and expectations and what the health care system had offered.

Comparison With Previous Work

The majority of respondents reported that the type and severity of whiplash-associated disorders is trivialized at 1177.se. Respondents' negative perceptions are fueled, for example, by the general psychologizing of discomfort. Although this is essentially a consequence of knowledge gaps and the omission of relevant facts in the information made available to patients via the health care portal, we suggest that the simplified presentation may have relevance. Linguistically, text can build group identity in the way content is selected and presented and the group is addressed and consequently handled. A communication strategy may make one group invisible by not mentioning it or refer certain behavior and values to another [21], as when respondents felt they were considered idle by the health care system. A possible influential factor may have been the Healthcare Guide's editorial choices for a superficial structure (eg, syntax and word choice). Swedish county councils strive continually to write plainly [22], tailoring language for recipients, with the aim to support patients' equal rights to participate in their own care. Patient information is recommended to suit the reading skills of 12-year-olds [13,23,24]. Such negative spillover from oversimplified presentation could be lessened by including in the patient information that the text is limited, general, and not for everyone (Textbox 3).

Textbox 3. Insights gained from the process of performing and analyzing the interviews and recommendations for those involved in designing patient information.

- Use comprehensive and detailed information, as this can be very helpful in a serious health situation
- Include a statement that the text is limited, general, and not for everyone to avoid an element of exclusion of some readers or the impression that matters discussed are trivialized
- Include the target group(s) in the process of designing information to make the content relevant to readers

In this study, the perceived rejection from the side of the health care system caused great distress, as manifested in the respondents' comments. When seeking help, the individual always exposes themself and their vulnerabilities to some extent to the carer or to the health care system. This demonstration of trust is most often accompanied by the expectation that others will respond to this openness in a responsible way. This has been described by Logstrup [25] as an *ethical demand*, which can be met or refused. For example, respondents clearly want more facts or all the available medical facts, especially of mechanisms behind the symptoms. The perceived lack of information caused misconception and worry. It is relevant to highlight earlier research focused on carer-patient communication for chronic conditions, where attempting to meet the patient in patient information has been discussed in terms of honesty. For example, among patients with cancer, honesty from carers is seen as helpful in making a serious health situation more real [26]. In another study on information for patients with cancer, the authors found that detailed information about a bad cancer prognosis does not cause more distress or diminish quality of life [27]. This indicates that even information conveying serious health issues can, in a complete and clear presentation of known facts, be helpful to the patient or relative. However, patient satisfaction with Web-based information in computer-based environments is, as of yet, not extensively researched. Brown et al [28] found that the overall desired elements of an electronic communication portal were frequent updates and detailed medical information rather than a presentation of the *big picture*. This was among American current and potential intensive care unit (ICU) patients and their family members. Rather than designing patient information by outlining matters of concern, the results in this study support the recommendation to use information-rich texts.

Brown et al [28] also found that preferences varied significantly by age, sex, ethnicity, and previous experience with ICU hospitalization. As for the management of chronic disease, Kruse et al [29] explored in a systematic review the shared characteristics of portals that receive favorable responses from patients and providers and elements that patients and providers believe need improvement. The authors concluded that there are varied attitudes among patients and caregivers toward the use of patient portals. The most prevalent positive attribute was found to be carer-patient communication, and the most prevalent negative perceptions were security and user-friendliness. Our results were homogeneous with regard to what patients expressed versus what relatives expressed. This must, however, be interpreted with care, as earlier research has found differences in patients' and family members' information needs [30].

Patient organizations are found by respondents to be valuable alternative sources of information. It is well known that copatients who have the same health issues can have a positive influence on patient empowerment, by providing skills, knowledge, and self-awareness [31]. Copatient narratives have also been shown to affect patient decisions on treatment [13], which can be beneficial or counterproductive to the patient. Both perspectives indicate a need to include the patient collective in a professional context if health care is to gain from peer support in treatment outcomes.

Limitations

All the individuals participating in the interviews are members of a patient organization, and it may be that nonmembers with a whiplash injury in the past and their relatives face problems and challenges that members do not. In addition, 2 of the respondents worked in health care, which means that they can describe the patient or relative perspective with a greater understanding of the health care system. This may negatively impact the transferability of results. Finally, our study addresses the Swedish public health care context. However, though the results cannot be generalized to everyone experiencing whiplash, they can be of use in developing patient information, given the similarity of responses. There are frequently appearing common denominators. Another limitation is the difference in the number of participants between sessions. Group interaction is likely to have been more pronounced in the interview with 7 respondents than in the others. However, apart from the number of respondents, the interview format was the same and the nature of data collected did not differ across interviews.

Strengths of this work include the close relationship between participants' descriptions that strengthens data credibility, the diversity of perspectives among the researchers, and coding results from consensus, which improves distinctness and subsequently the quality of the analysis.

Conclusions

We found that most of the study participants felt distress due to insufficient information; respondents perceived a discrepancy between the public health care system's authority and the information provided. The Web information on whiplash injuries may greatly impact patients' care decisions as well as their physical, mental, and social well-being. We would recommend detailed patient information on whiplash injuries, with less emphasis on psychology and more data on pathophysiology, prognosis, and treatment.

Acknowledgments

The authors would like to thank the individuals and organizations who generously shared their time and experiences for the purposes of this project. The Academic Primary Health Care Centre, Stockholm County Council, provided funding for BCB.

Authors' Contributions

GB and CS analyzed and interpreted the patient data. GB was a major contributor in writing the manuscript. All authors held interviews and read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Patient information from the Healthcare Guide 1177.

[PDF File (Adobe PDF File), 136KB - ijmr_v8i2e9881_app1.pdf]

Multimedia Appendix 2

Interview question template.

[PDF File (Adobe PDF File), 60KB - ijmr_v8i2e9881_app2.pdf]

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Abbreviations

ICU: intensive care unit
WADs: whiplash-associated disorders

Edited by G Eysenbach; submitted 18.01.18; peer-reviewed by J Amann, C Bolling, S Atanasova, A Cyr; comments to author 14.08.18; revised version received 29.11.18; accepted 25.01.19; published 21.05.19.

Please cite as:
Bernhoff G, Saripanidis C, Bertilson BC
"As If Neck Injuries Did Not Exist": An Interview Study of Patients' and Relatives' Perceptions of Web Information on and Management of Whiplash Injuries in Sweden
Interact J Med Res 2019;8(2):e9881
URL: https://www.i-jmr.org/2019/2/e9881/
doi:10.2196/ijmr.9881
PMID:31115342

Original Paper

Using Virtual Reality to Improve Antiretroviral Therapy Adherence in the Treatment of HIV: Open-Label Repeated Measure Study

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Abstract

Background: Nonadherence to HIV medications is a serious unsolved problem and is a major cause of morbidity and mortality in the HIV-positive population. Although treatment efficacy is high if compliance is greater than 90%, about 40% of people with HIV do not meet this threshold.

Objective: This study aimed to test a novel approach to improve medication adherence by using a low-cost virtual reality (VR) experience to educate people with HIV about their illness. We hypothesized that people with HIV would be more likely to be compliant with the treatment following the 7-minute experience and, therefore, should have decreasing viral load (VL), increasing cluster of differentiation 4$^+$ (CD4$^+$) cell counts, and improved self-reported adherence.

Methods: We showed the VR experience to 107 participants with HIV at a county hospital in Los Angeles, California. Participants were asked to self-report how often they take their medications on a Likert-scale. The self-reported question (SRQ) was given before and at least 2 weeks after the VR experience. We also compared VL and CD4$^+$ cell counts before and on average 101 days after the experience. VL and CD4$^+$ were obtained per the clinic's standard care protocol. Two-tailed paired *t* tests were performed on the initial and follow-up SRQ scores, VL, and CD4$^+$. We restricted the CD4$^+$ analysis to participants who had a pre-CD4$^+$ below normal (defined as 500 cells/mm^3). To reduce the possibility that VL were trending down and CD4$^+$ were trending up regardless of the VR experience, 2 serial VL and CD4$^+$ obtained before the experience were also compared and analyzed. Immediately following the VR experience, participants were given a 4-question Likert-type postexperience questionnaire (PEQ) that assessed their opinions about the experience.

Results: SRQ scores improved from pre to post experience with high significance ($P<.001$). VL decreased from pre to post experience by 0.38 $\log_{10}$ copies/mL (95% CI 0.06-0.70; $P=.02$). In contrast, the 2 serial VL obtained before the experience showed no statistically significant changes. There was also a statistically significant increase in CD4$^+$ (95% CI –3.4 to –54.3 cells/mm^3; $P=.03$). Analysis of the PEQ revealed that VR was comfortable for almost all of the participants and that most participants believed the experience to be educational and that it would improve their medication adherence.

Conclusions: The findings suggest that the low-cost VR experience caused an increased rate of antiretroviral therapy adherence that resulted in a decrease of VL and an increase of CD4$^+$. Further studies are required to explore the duration of this effect and whether these results are generalizable to other treatment settings and populations.

(Interact J Med Res 2019;8(2):e13698) doi:10.2196/13698

KEYWORDS

HAART; technology; virtual reality; medication adherence; viral load; education

Introduction

Background

HIV is a serious medical illness with significant morbidity and mortality. Advances in treatment have continued to progress with improved regimens both in terms of efficacy and tolerability and in terms of convenience in the form of combination medications in a once- or twice-daily pill known as highly active antiretroviral therapy (HAART). Adherence to HAART has been shown to be correlated with survival [1,2] and quality of life [3]. Primarily because of HAART, HIV is now widely regarded as a chronic and manageable infection [4]. Treatment efficacy, defined as a decrease in viral load (VL), is highly correlated with an almost perfect adherence rate to HAART of at least 90 to 95% [5,6]. However, about 40% of HIV-positive patients have adherence rates to HAART below 90% [7,8].

Several factors have been identified that correlate to poor medication adherence including homelessness [9-11], comorbid mental illness [12,13], and active substance use [14,15]. In addition, health literacy has been shown to be an independent predictor for HAART adherence [16,17]. A survey of Medicare patients revealed that 34% of English-speaking and 54% of Spanish-speaking respondents had inadequate or marginal health literacy [18]. Compounding to this challenge, a study found that although physicians frequently believe that they are using nontechnical terms when communicating with their patients, they actually used nontechnical language in only 12% of encounters [19]. Moreover, a study of audiotaped encounters between patients and physicians revealed that there was a discussion about the patient’s degree of understanding in only 2% of the encounters [20]. These data suggest that changes to how patients are educated about their illness may be needed to optimize medication adherence rates.

Virtual reality (VR) has recently emerged as an effective tool in several branches of medicine [21-26]. Recent advances in VR head-mounted displays (HMDs) have made their use increasingly comfortable, affordable, and immersive [27]. VR radically differs from most other media because it can create a level of immersion that produces a feeling of presence—a “sense of being there” [28]. Due to this distinct experiential quality, VR can augment learning with an immersive experience. In addition, VR has been shown to improve learning outcome gains [29-31], and, compared with educational videos, VR has been shown to increase engagement, positive emotions, and remembering of the presented information [32,33]. In fact, an increasing number of classrooms are utilizing VR technology to provide unique and effective educational experiences for their students [34,35].

Objectives

In light of this trend, the aim of this study was to investigate the effects of an educational VR experience on HAART adherence in people with HIV. Specifically, people with HIV were enrolled at a county clinic to undergo an interactive VR experience that educates them about the importance of HAART adherence. The participants were asked to self-report how often they take their HAART medications on a Likert-scale. To verify the self-reported compliance, pre- and post- HIV VL and CD4$^+$ cell counts were obtained from the participants’ digital chart. In addition, second pre- VL and CD4+ were obtained to detect any trends before the VR experience. Participants also completed a post experience questionnaire (PEQ; Multimedia Appendix 1) that assessed their immediate reaction to the VR experience with regard to its novelty, comfort, educational value, and perceived effectiveness.

Methods

Participants

From February to September 2018, 107 HIV-infected participants were recruited from Olive View-University of California, Los Angeles (UCLA) Medical Center’s HIV clinic in Los Angeles, California. To enroll, participants had to be diagnosed with HIV, be on HAART, be at least 18 years of age, be fluent in English or Spanish, and have no major uncorrectable problems with vision or hearing. There were no selection criteria for initial VL, CD4$^+$, or HAART regimen. Participants were continuously recruited from the clinic until the study’s predetermined time for access to the clinic elapsed. The institutional review board at Olive View-UCLA Medical Center approved the study. Each participant signed a written informed consent. There were no financial incentives for enrolling in the study.

Interventions

A 7-minute interactive 3-dimensional educational VR experience was created that illustrates a simplified version of the mechanisms of immune cells, HIV, and antiretroviral medications. We used a Dell Windows Mixed Reality HMD. Research assistants helped place the HMD on the participants’ head and adjusted it for optimal clarity and comfort. Participants required no training before the VR experience. The English and Spanish versions of the VR experience had different narrators but otherwise all participants had the same VR experience.

The narrator begins by introducing a virtual person with HIV named Dave and explaining that Dave is made up of cells. A magnifying glass moves to show Dave’s skin cells (Multimedia Appendix 2). The experience then virtually transports the participant into one of Dave’s arteries. Red blood cells can be seen traveling through the artery when a single rod-shaped bacterium swims nearby (Multimedia Appendix 3). For dramatic visual effect, the bacterium is seen releasing green particles representing poison into the artery. Intense music ensues when a white blood cell (WBC) chases the bacterium, which it eventually engulfs (Multimedia Appendix 4). A single HIV then enters the scene, gets inserted into the WBC, and makes many copies of itself until the WBC bursts (Multimedia Appendix 5). With no WBCs around, many bacteria swim freely and release the green poisonous particles. The artery gradually turns green, signifying that Dave is sick (Multimedia Appendix 6). The scene resets and the narrator says, “Let’s see what happens when Dave remembers to take his medications.” Hopeful music plays and the narrator encourages the participant to press a button to release “a dose of life-saving medication.” When the participant presses the button, medication in the form of gold particles enters the artery and creates a shield around the WBC (Multimedia Appendix 7). HIV again tries to attack the WBC but gets repulsed by the shield. The participant is asked to press the button several more times to give more medication as more HIV attempt to attack the WBC (Multimedia Appendix 8). In conclusion, the narrator explains that although Dave feels fine, he is required to continue taking his medications to keep the shield active.

Data Collection

Participants were asked to self-report how often they take their medications on a Likert-scale. This SRQ was asked just before the VR experience and again at least 2 weeks post experience. The initial SRQ was asked in a face-to-face interview, while the follow-up was asked either by phone or with another face-to-face interview. Immediately following the experience, a PEQ was administered.

VL and CD4$^+$ cell counts were drawn as per standard clinic protocol. Both the treating physician who ordered the labs and the laboratory were blinded as to which patients were enrolled in the study. Post-, pre-, and second pre-VL/CD4$^+$ were recorded from the participants' digital chart. Given that blood concentrations of HIV ribonucleic acid are expected to decrease rapidly in the first 2 weeks after HAART initiation [36,37], post-VL/CD4$^+$ were defined as the first labs that were obtained at least 14 days post experience, whereas pre-VL/CD4$^+$ were defined as the most recent labs that were obtained before or on the same day as the experience. Finally, second pre-VL/CD4$^+$ were defined as the most recent labs that were obtained before the pre-VL/CD4$^+$. All identifying information was removed to protect the privacy of the participants. Demographic data obtained from each participant were age, gender, and primary spoken language.

Data Analysis

All analyses were performed by use of IBM SPSS software, version 22. The raw VL were converted to a logarithmic scale because of the large variance in the data. Spearman correlation was performed on the initial SRQ scores and pre-VL. A 2-tailed paired *t* test analysis was performed to compare the initial and follow-up SRQ scores. A 2-tailed paired *t* test was also performed to compare pre- to post-VL, and pre- to post-CD4$^+$. To assess for the possibility that the VL were decreasing even before the VR experience, a 2-tailed paired *t* test was performed on the second pre-VL and pre-VL. For the CD4$^+$ analysis, only participants who had below normal pre-CD4$^+$ (defined as 500 cells/mm^3) were included. Participants who did not have pre-VL, second pre-VL, or post-VL were excluded from this analysis. Finally, the PEQ was correlated with age using Spearman correlation.

Results

Descriptive statistics were computed and compiled in Table 1. There were no significant gender- or age-related differences in terms of SRQ scores or VL. Out of 107 participants, 28 were excluded because 11 did not have a second pre-VL and 17 did not have a post-VL recorded by the time data collection has concluded. There were no demographic differences between the 28 excluded participants and the remaining 79 participants.

Out of the 79 participants, 4 did not complete the initial SRQ correctly and therefore were excluded from SRQ statistics. Of the remaining 75 participants, 69% (52/75) were identified as high adherers (score 5/5 on Likert-scale), 15% (11/75) as medium adherers (score 4), and 16% (12/75) as low adherers (score <4). A total of 8 participants did not complete the follow-up SRQ because they were both unreachable by phone and were unavailable for follow-up face-to-face interviews. Out of 67 participants who completed the follow-up SRQ, 90% (60/67) were identified as high adherers, 6% (4/67) as medium adherers, and 4% (3/67) as low adherers. The initial SRQ scores were shown to be correlated with pre-VL (n=75, r_s=0.316; *P*=.006). Likewise, the follow-up SRQ scores were shown to be correlated with post-VL (n=65, r_s=0.549; *P*<.001). SRQ scores improved very significantly (95% CI .24-.70, *P*<.001) from pre to post VR experience. Table 2 summarizes participants' transitions from pre to post SRQ. There were not enough data to analyze statistical differences between the 2 modalities used to collect the SRQ (face-to-face and phone interviews); however, other studies suggest that they should be highly correlated [38-40].

Comparison of pre-VL to post-VL showed an average decrease of 0.38 $\log_{10}$ copies/mL (95% CI 0.06-0.70; *P*=.02). On the other hand, analysis of second pre-VL and pre-VL showed no statistically significant changes (95% CI –0.40 to 0.24; *P*=.62; Figure 1). The difference between these 2 measurements was highly significant (*P*=.01). The medians for second pre-, pre-, and post-VL were all 0.

When taken as a whole, there was no statistically significant difference in pre- to post-CD4$^+$. However, when only participants who had a pre-CD4$^+$ below normal (defined as 500 cells/mm^3) were included in the analysis, there was a statistically significant increase from pre- to post-CD4$^+$ (95% CI –54.3 to –3.4; *P*=.03). Conversely, there was no significant CD4$^+$ count difference between second-pre and pre-CD4$^+$ (95% CI –56.2 to 42.6; *P*=.78). The medians for second pre-, pre-, and post-CD4$^+$ were 285, 301, and 323, respectively.

On average, the pre-VL were drawn 60 days (SD=74) before the VR experience. A total of 10 participants had their pre-VL drawn on the day of the VR experience, thereby accounting for this non-normal distribution. The post-VL were drawn on average 101 days (SD=62) after the VR experience. The average interval from second pre-VL to pre-VL was 141 days (SD=90).

None of the questions on the PEQ were significantly correlated with age. None of the participants reported that the VR experience was uncomfortable. Only 2 participants disagreed that they learned something new about their immune system, HIV, or their medications. Finally, 100 participants (94%) agreed or strongly agreed that they are more likely to take their medications because of the VR experience (Table 3).

Table 1. Demographic characteristics of the overall sample and the analyzed group. There were no statistically significant group differences in gender, age, or language.

Demographics	Overall sample (N=107), n (%)	Analyzed group (n=79), n (%)
Gender		
Male	83 (77.6)	59 (75)
Female	24 (22.4)	20 (25)
Age (years)		
18-39	31 (29.0)	25 (32)
40-49	29 (27.1)	21 (27)
50-59	34 (31.8)	26 (33)
60+	13 (12.1)	7 (9)
Language		
English	100 (93.5)	74 (94)
Spanish	7 (6.5)	5 (6)

Table 2. Number of patients transitioning from low, medium, or high adherence groups in the pre self-reported question (SRQ) to the post SRQ (n=67). High adherence was defined as SRQ score 5/5; medium adherence was defined as SRQ score 4; low adherence was defined as SRQ score <4.

Self-Reported Questionnaire adherence score	Post low, n (%)	Post medium, n (%)	Post high, n (%)	Total, n (%)
Pre low	3 (4)	1 (1)	8 (12)	12 (18)
Pre medium	0 (0)	3 (4)	6 (9)	9 (13)
Pre high	0 (0)	0 (0)	46 (69)	46 (69)
Total	3 (4)	4 (6)	60 (90)	67 (100)

Figure 1. The change log10(VL) from before to after the virtual reality experience was significant (green, P=.02). On the other hand, the change from the 2 viral loads prior to the experience was nonsignificant (orange, P=.62). The difference between the 2 measurements is highly significant (P=.01). VL: viral loads.

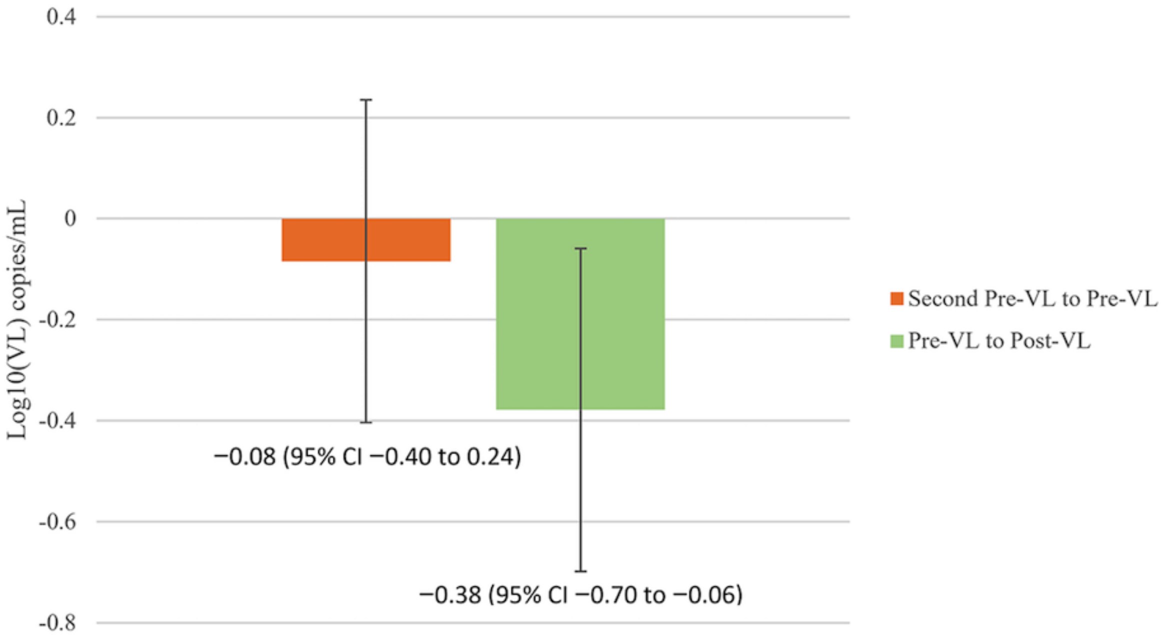

Table 3. Responses to the Postexperience Questionnaire (PEQ). Question 1: Virtual Reality is a new experience for me; Question 2: The experience was comfortable; Question 3: I learned something new about my immune system; Question 4: I am now more likely to take my HIV medications. N=106.

Post-Experience Questionnaire	Question 1, n (%)	Question 2, n (%)	Question 3, n (%)	Question 4, n (%)
Agree or strongly agree	91 (86)	105 (99)	92 (87)	100 (94)
Strongly disagree, disagree, or neutral	15 (14)	1 (1)	14 (13)	6 (6)

Discussion

Principal Findings

When taken together, several points of evidence strongly suggest that participants indeed were more compliant with their HAART medications because of the VR experience: (1) the SRQ scores were correlated with VL, (2) the SRQ scores improved from pre to post experience, (3) the VL decreased from pre to post experience but not from serial VL obtained before the experience, (4) the CD4$^+$ cell counts improved from pre to post experience but not from serial counts obtains before the experience, and (5) almost all participants (94%) answered on the PEQ that they are more likely to take their medications because of the VR experience.

Limitations

Although these preliminary results are promising, a number of limitations need to be addressed. First, the study did not randomize participants and no controls were used. Future studies should ideally use a placebo-controlled design. Second, the study was conducted only at a county clinic and therefore may not necessarily be generalizable to other settings or populations. Third, the VL and CD4$^+$ counts were obtained as per the clinic's standard of care. A superior study would control the timing of the blood draws to more thoroughly account for extraneous variables in the data. Fourth, the duration for which increased HAART adherence is maintained is unclear. A longitudinal study with more participants would allow for more robust statistical analyses. It would also be worth testing whether repeating the experience every few months can maintain improved compliance over time. Finally, collecting further demographic data on, for example, health literacy, homelessness, substance use, and comorbid mental illness could yield interesting correlations that may help advise which subpopulations would be most likely to benefit from the VR experience.

Conclusions

This study suggests that patient education using VR is effective for increasing HAART adherence. If the results are confirmed, VR's effectiveness and relative low cost offers a great opportunity for clinics to implement a simple solution that may improve both the morbidity and mortality of their patients. Future studies should attempt to generalize the results to other settings, populations, and illnesses—especially those in which patients feel healthy and may not feel the need for taking their medications as scheduled. Compared with other traditional media platforms such as videos, VR is more immersive and thus has a greater positive emotional impact, which can improve engagement and learning. VR is rapidly becoming more accessible, affordable, and immersive, and more studies are needed to further explore opportunities for using this maturing technology for improving peoples' lives.

Acknowledgments

No external funding sources were used. The VR hardware and accessories were purchased by the authors. The VR experience software was created by the primary author. The data were collected by volunteer research assistants. Participants were not compensated monetarily.

Authors' Contributions

OL designed the research study, created the VR experience, and authored the article. OL and RD performed the research. KK and OL analyzed the data.

Conflicts of Interest

OL may decide to patent some aspects of the software he developed. RD and KK declare no conflicts of interest.

Multimedia Appendix 1

Postexperience questionnaire.

[PDF File (Adobe PDF File), 135KB - ijmr_v8i2e13698_app1.pdf]

Multimedia Appendix 2

Dave's skin is made up of cells.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app2.pdf]

Multimedia Appendix 3

A bacterium swims inside an artery.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app3.pdf]

Multimedia Appendix 4

A white blood cell engulfs the poison-producing bacterium.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app4.pdf]

Multimedia Appendix 5

HIV enters the white blood cell, makes copies of itself, and causes the cell to explode.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app5.pdf]

Multimedia Appendix 6

Without the white blood cells, bacteria can produce poison without deterrence.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app6.pdf]

Multimedia Appendix 7

The medication produces a shield around the white blood cell.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app7.pdf]

Multimedia Appendix 8

HIV cannot penetrate the medicated white blood cell.

[PDF File (Adobe PDF File), 1MB - ijmr_v8i2e13698_app8.pdf]

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Abbreviations

CD4+: cluster of differentiation 4+
HAART: highly active antiretroviral therapy
HMD: head-mounted display
PEQ: post experience questionnaire
SRQ: Self-reported question
UCLA: University of California, Los Angeles
VL: viral load
VR: virtual reality
WBC: white blood cell

Edited by G Eysenbach; submitted 14.02.19; peer-reviewed by K Fortuna, M Kwasny, S Zheng; comments to author 28.04.19; revised version received 14.05.19; accepted 17.05.19; published 20.06.19.

Please cite as:
Liran O, Dasher R, Kaeochinda K
Using Virtual Reality to Improve Antiretroviral Therapy Adherence in the Treatment of HIV: Open-Label Repeated Measure Study
Interact J Med Res 2019;8(2):e13698
URL: http://www.i-jmr.org/2019/2/e13698/
doi:10.2196/13698
PMID:31223117

Original Paper

Perceptions of Food Hypersensitivity Expertise on Social Media: Qualitative Study

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Abstract

Background: Seeking and sharing information are the primary uses of the internet and social media. It is therefore vital to understand the processes individuals go through when engaging with information on these diverse platforms, especially in areas such as health- and risk-related information. One important element of such engagement is evaluating and attributing expertise to others.

Objective: This study aimed to explore how meanings around expertise in relation to food allergy and intolerance (food hypersensitivity) were constructed by 2 groups of social media users: (1) those who use platforms for reasons relating to food hypersensitivity and (2) those seen as experts by this community.

Methods: Survey participants were asked open-ended questions to identify potential experts in food hypersensitivity issues on social media and to discuss their reasoning for their choices (n=143). Subsequently, 8 adult social media users with experience of managing food hypersensitivity and 5 participants designated as experts by those users took part in email interviews. Survey and interview data were analyzed thematically using Braun and Clarke’s approach.

Results: Judging expertise on social media is a complex and multifaceted process. Users might be judged as experts through their professional background or their experience living with food hypersensitivities. How users behave on social media and the traces of their Web-based activity can influence how others will see them. Such considerations are both measured and moderated through the social media community itself. Findings highlighted how social media often act as a supportive information tool following a diagnosis, but this also raised concerns regarding the scenario of patients not being able to access suitable vetted information.

Conclusions: This work has implications for understanding how users perceive expertise on social media in relation to a health concern and how information assessments are made during the management of risks. Findings provide practical insights to both medical and organizational stakeholders involved in the support of those living with life-changing conditions, such as food hypersensitivities.

(Interact J Med Res 2019;8(2):e10812) doi:10.2196/10812

KEYWORDS

social media; food allergy; food hypersensitivity; celiac disease; food intolerance; interviews as topic; qualitative methods

Introduction

Background

In today's digital age, people attend to the information they encounter on social media; seeking and sharing health-related information is a common practice [1-3]. However, in situations where there is the possibility of negative health consequences, it is important that people are acting on accurate and reliable information. Judgments about the expertise of the source are an important part of this, and it is, therefore, important to know what the heuristics for judging expertise are in the context of social media [4]. One such situation with potential negative consequences to health is food hypersensitivity—conditions associated with the need to avoid specific foods that cause adverse reactions [5]. By gaining an insight into perceptions of expertise in food hypersensitivity on social media and from the perspective of those living with hypersensitivity and those deemed to be experts in this area, we can further shed light on the dynamics of expertise on social media in relation to food, health, and risk. A greater understanding of the factors that affect an individual's perceptions of expertise online may have implications for agencies and organizations that support people with health concerns.

Food Hypersensitivity

Food hypersensitivity occurs in people who experience reproducible adverse symptoms when consuming specific foods and denotes both food allergy and nonallergic food hypersensitivity, for example, food intolerance and celiac disease [6]. Living with food hypersensitivities involves constant risk assessments surrounding the food one consumes. This is especially the case when eating outside the home [5,7-9]. Those with food intolerance wish to avoid repeatable adverse reactions to food, such as bloating, constipation, vomiting, and diarrhea. Celiac disease is an autoimmune disease caused by the immune system reacting to the protein gluten (found in the cereals wheat, barley, and rye), which leads to similar adverse reactions, but it can have long-term consequences if undiagnosed, such as anemia, fatigue, and weight loss [10]. Individuals who are allergic to certain food items must avoid consuming allergens that could lead to a reaction called anaphylaxis (associated with breathing difficulties, sudden drop in blood pressure, and which may be fatal). Given these characteristics of food hypersensitivity, this is an ideal domain within which to explore attributions of expertise on social media because misinformation may have significant consequences [11,12]. The aim of this study was to explore how social media users and perceived experts in food hypersensitivities on social media construct meanings around expertise. To this end, we will first consider how expertise can be defined and interpreted, how internet users seek information on social media, the cues they use to assess potential expertise, and how they validate the information they encounter.

Defining Expertise

When attempting to define expertise, experts typically have comprehensive and authoritative knowledge in a specific area [13]. They are well regarded by their peers, relay accurate and reliable information, and have gained extensive knowledge through their experience [14]. Being an expert is normally considered a good thing to be respected or cited in relation to one's area of expertise [15]. Expertise is largely an attribution; someone is usually considered an expert because others see them as experts [15]. Expertise typically encompasses assessments of credibility, trustworthiness, believability, and accuracy of information [16]. Expertise might be assessed through academic qualifications, years spent in a specific role, or experience [17]. The importance of experience, however, highlights how distinctions between experts and lay persons can be flexible and dynamic, for example, if a lay person has experience in a certain area [18]. Expertise is contextually valuable; an individual may know a lot about specific contexts and situations (eg, from their life experiences) but little outside of that environment [18]. Whether expertise on specific social media platforms holds true for expertise in other contexts (eg, offline or through different platforms) is worth consideration; Sternberg and Frensch [15] note "experts in one place or one time are not necessarily considered to be experts in another place or another time."

Seeking Information from Experts on Social Media

Seeking and sharing information are primary uses of the internet and social media [12,19-21]. In comparison with more traditional media, social media allow users to communicate in a reciprocal way, exchanging knowledge, sharing opinions, or challenging information from others [22]. Social media encompass a variety of internet-based platforms that use the technological advances of Web 2.0, associated with collaboration and user-generated content [23]. Some social media sites are designed explicitly to enable and encourage interactions, such as Facebook and Twitter. Others embody some functions of social media (eg, posting, commenting, liking, and sharing) but where this is not the primary purpose of the site, such as forums, chat rooms, and comments systems following Web-based news articles or published media (eg, blogs). Health information seekers can readily connect with those who share similar health concerns [24,25]. In fact, information circulated among peers, especially those perceived to be similar, may be more influential than formal expertise [25,26]. Social media can offer access to other people living in similar circumstances, and as a result, those managing health conditions often turn to their social media peers for help, perhaps for emotional peer support, for example, from other parents of allergic children [8,27]. This instant and supplementary access to other perspectives contrasts with information provision practices within a more formal medical setting.

Web-based information-seeking practices can be dependent on individual characteristics or motivations of the user. Metzger and Flanagin [16] highlight how the level of accuracy an information seeker is aiming for, their *accuracy goal* [28], will vary when using the internet. When using social media, for example, information seeking might be quite casual, where accuracy in the information is less crucial (eg, searching for ideas on Pinterest), or purposeful, where getting the correct information is important (eg, around a medical concern). Information in line with current beliefs tends to be noticed and valued more, with discrepant information more likely to be disregarded, even when opposing arguments are well argued and evidenced [29].

Thriving groups of users with specific health concerns exist on social media, for example, users with diabetes on Facebook [1] and food allergic and intolerant individuals on Twitter [30]. Those with health concerns are sharing experiences as well as gaining independence and self-sufficiency through the internet [3]. For people caring for loved ones, social networking platforms and forums comprising people in similar circumstances can be a source of reassurance and support [24]. However, having many *authors* of relevant information on social media can pose difficulties for credibility assessments because the origin and development of a source can become difficult to authenticate [16]. A lack of verification systems or formal gatekeepers and the fact that, in most cases, any user can publish or post information on the internet mean that it is important to understand how people assess the credibility of the information they encounter [2,16,20,31]. In light of this, we now turn to consider the cues used to assess information on the internet. Metzger and Flanagin [16] provide a useful framework for considering the kinds of cues that could affect perceptions of expertise in terms of source, author, and message assessments.

Source Assessments

In internet research to date, source has often referred to the websites that present information; *source* and *site* are often used interchangeably. Cues to credibility provided by the source of information have included the following: design, navigability, absence of errors, links to other reputable sources (or academic citations), evidence of sponsors, or whether the site makes money from advertising or product promotion [16,32-34]. In a review of several studies about Web-based health information seeking, Cheever and Rokkum [35] highlight how testimonials or comments from other users on Web content are increasingly being used to assess the credibility and veracity of Web-based content. However, in the realm of social media, a *source* is more challenging to define. It might refer to the platform user profiles are held on (eg, Facebook, Twitter, or Instagram), but user profiles themselves might be seen as separate sources, as they hold much of the information to be considered a site in their own right (eg, their own Web address, content, and layout). Research around website assessments of credibility are likely to relate to certain sources such as blogs, but the multidimensional nature of social media does not translate so easily: a platform that might be considered credible by users may not necessarily always contain credible sources of information although familiarity with a specific platform may give a user better tools to make assessments about the information or users within [36,37].

Author Assessments

Certain characteristics of the authors of Web-based material can help other users assess the expertise of the published information. Metzger and Flanagin [16] highlight factors such as the author's qualifications, reputation or professional association, available contact information, and lack of commercial motives. Social media allow us to make quite detailed judgments about individuals we encounter, as users leave traces of their Web-based activity. For example, having many followers on one's social media accounts or having forum answers ranked highly by other members could be potential signals of expertise [38]. Similarly, the reactions of others may have some bearing on how individuals judge the expertise and reputation of social media accounts; shares, retweets, comments, and likes can be used as indicators to affirm how others see sources of information on the internet [38,39].

Often in the absence of an official or qualified source, users with experiential knowledge or *situated understandings* may be mobilized to offer additional insights on an issue [40]. People with long-term illnesses may become expert in their particular condition based on experience and specific contexts that relate to their health concern [18]. Cues relating to shared and lived experience can lead to a sense of collective trust. For example, parents of children with a newly diagnosed food allergy were seen drawing on the expertise of other parents they knew had gone through the same sorts of issues [27]. In another example, users of a multiple sclerosis (MS) support forum were seen to share experiences and treatments in addition to (what was considered) static Web-based advice monitored by the professional MS bodies [41].

There are several cues that may be used to infer the credibility of the Web-based content: clarity of writing, accuracy, presence of bias, recency of information, and supporting evidence [16,32-34]. In the realm of Web-based health information, the use of medical discourse holds high social status and legitimacy [42], increases a user's social credibility, and is often a cue to expertise. Furthermore, using community terminology (such as abbreviations and acronyms) as well as presenting information as factual are also ways of performing expertise [43-45]. Cues of a social nature that are attached to social media posts, such as comments, likes, and shares, are likely to play a significant role in how users make message assessments, for example, whether they accept or trust the information provided or wish to participate in the discussion themselves [35,39,46].

Objectives

In this study, we investigate how users construct meanings around expertise on social media in the area of food hypersensitivity. We explore the construction of expertise from 2 user perspectives: (1) social media users who are food hypersensitive (FH) or parents of FH children and (2) perceived experts in food hypersensitivities within the FH social media community.

Methods

Design

Initial exploratory data were obtained from open-ended qualitative questions on a Web-based survey relating to social media use for FH concerns [12]. These data were combined with subsequent in-depth qualitative email interviews. In total, 13 email interviews were conducted with 8 FH adults and parents of FH children who use social media (hereafter referred to as FH participants) and 5 perceived experts in food hypersensitivity on social media. Given the focus of the study, we knew participants were confident to engage online; social media users are likely to be technologically able, and access to the internet would not be an issue. Email interview techniques were chosen here, as they are particularly appropriate when participants are asked about something that they are unlikely to have explicitly considered before [47,48]. The approach gives participants time to contemplate questions. We were able to explicitly ask participants to consider their responses before replying, as well as provide examples from their own social media activities if it helped them get their point across or jog their memory. The ability to review responses sets this approach apart from many other forms of qualitative data collection and can provide more articulate responses and richer, more focused data [48]. This study was exploratory in nature, and to avoid restricting the narrative of interview discussion, social media were considered in a broad sense. This allowed participants to discuss perceptions relating to their understanding of their own social media use. Thus, participants could refer to various types of social media, as outlined in the introduction, such as well-known platforms themselves (eg, Twitter, Facebook, and Instagram) or chatroom websites and online support groups.

Participants

From the survey, 143 participants completed 2 open-ended questions. Table 1 shows the demographic details and social media use descriptives relating to this sample. Overall, 2 groups of interview participants were recruited. One consisted of FH social media users who identified potential experts in food hypersensitivity within their social media networks. This sample of users was recruited from the survey and had given permission to be recontacted for this follow-up study; these participants are not included in the 143 participants mentioned previously [12]. Table 2 shows the demographic characteristics of interview participants. Another sample comprised users identified by the FH participants as experts in relation to food hypersensitivity. From respondents on the previous FH survey, 98 potential experts were identified; this list contained multiple duplicates, and following inclusion criteria for accounts managed by individuals (as opposed to larger organizations) and those contactable through social media or public email addresses, a list of 30 potential experts was created. From this list, 16 users were randomly selected and invited to participate; 5 took part. The professions and backgrounds of experts varied, comprising a health journalist and writer, food policy official, FH travel writer, social media discussion group moderator, and FH recipe blogger. There were 4 female experts and 1 male expert. The data collection period for the survey was January to March 2017, and for the email interviews, April to May 2017.

Table 1. Demographic characteristics for survey participants.

Descriptive	n (%)
Female	131 (91.61)
Male	10 (6.99)
Preferred not to say	2 (1.40)
Age (years)	
18-24	9 (6.29)
25-34	36 (25.18)
35-44	44 (30.77)
45-54	31 (21.68)
55+	23 (16.08)
Education level	
University degree	85 (59.44)
Commercial/technical diploma	32 (22.38)
Secondary education	22 (15.38)
Prefer not to say	4 (2.80)
FH[a] adults	92 (64.34)
Parents of FH children	51 (35.66)
Diagnosis[b]	
Allergy	64 (44.76)
Celiac disease	59 (41.26)
Intolerance	86 (60.14)
Speed of reaction	
Immediate	47 (32.87)
From 1 hour	36 (25.17)
1-24 hours	47 (32.87)
>24 hours	13 (9.09)
Reaction causing allergen[c]	
Peanuts	39 (27.27)
Nuts	28 (19.58)
Cow’s milk	48 (33.57)
Gluten	81 (56.64)
Eggs	29 (20.28)
Fish	4 (2.80)
Crustaceans	7 (4.90)
Molluscs	7 (4.90)
Soya	18 (12.59)
Celery	1 (0.70)
Mustard	4 (2.80)
Lupin	3 (2.10)
Sesame	14 (9.79)
Sulfur dioxide	5 (3.50)
Other	27 (18.88)

Descriptive	n (%)
Social media use	
Facebook	135 (94.41)
Twitter	73 (51.05)
Instagram	50 (34.97)
Pinterest	56 (39.16)
Snapchat	21 (14.69)
YouTube	73 (51.05)
TripAdvisor	63 (44.06)
Tumblr	6 (4.20)
Support groups	71 (49.65)
Comment forums	33 (23.08)
Other	4 (2.80)
Frequency of use	
<Less than 1 hour	33 (23.08)
1 hour (approximately)	50 (34.97)
2 hours (approximately)	31 (21.68)
3 hours (approximately)	10 (6.99)
4 hours (approximately)	3 (2.10)
>4 hours	16 (11.19)

[a] FH: food hypersensitive.

[b] Individual may have more than 1 type of diagnosis.

[c] Individual may experience reactions from more than 1 allergen.

Table 2. Demographic characteristics for food hypersensitive interview participants.

Descriptive	n (%)
Female	7 (87.50)
Male	1 (12.50)
Age (years)	
18-24	0 (0)
25-34	3 (37.50)
35-44	4 (50.00)
45-54	0 (0)
55+	1 (12.50)
Education level	
University degree	7 (87.50)
Commercial/technical diploma	1 (12.50)
FH[a] adults	4 (50.00)
Parents of FH children	4 (50.00)
Diagnosis[b]	
Allergy	5 (62.50)
Celiac disease	3 (37.50)
Speed of reaction	
Immediate	5 (62.50)
From 1 hour	2 (25.00)
1-24 hours	1 (12.50)
24 hours +	0 (0)
Reaction causing allergen[c]	
Cow’s milk	2 (25.00)
Nuts	3 (37.50)
Eggs	1 (12.50)
Gluten	3 (37.50)
Peanuts	1 (12.50)
Social media use	
Facebook	8 (100)
Twitter	5 (62.50)
Instagram	3 (37.50)
Pinterest	3 (37.50)
Snapchat	1 (12.50)
YouTube	5 (62.50)
TripAdvisor	4 (50.00)
Tumblr	0 (0)
Support groups	5 (62.50)
Comment forums	4 (50.00)
Other	0 (0)
Frequency of use	
<1 hour	2 (25.00)

Descriptive	n (%)
1 hour (approximately)	4 (50.00)
2 hours (approximately)	2 (25.00)

[a] FH: food hypersensitive.

[b] Individual may have more than 1 type of diagnosis.

[c] Individual may experience reactions from more than 1 allergen.

Materials

The open-ended questions from the larger FH social media use survey that formed part of this analysis asked participants to identify any social media accounts they considered expert in FH issues and discuss their reasoning for recognizing these sources as experts [12]. The subsequent email interview schedules covered questions relating to typical use of social media and aspects of accounts that may be considered as cues to expertise (Multimedia Appendix 1). Questions were informed by the literature and were checked and clarified with the research team and other colleagues to minimize the possibility that participants would require clarification or explanation, which would have unnecessarily increased the number of email exchanges. FH participants were asked questions around their reasons for highlighting specific users as experts. Questions to experts asked participants to reflect on their own expertise and their thoughts on being perceived as an expert by other users. The schedules were intended as guides to the interview structure with a degree of question flexibility for follow-ups on relevant information. Separate email invitations and consent forms were developed for each group.

Procedure

As mentioned previously, open-ended responses were included from a previous survey study; these asked participants to consider potential experts in FH issues on social media and provide some reasons for their choices. Participants from this survey study, who agreed to take part in the email interviews and provided informed consent, were emailed the first set of interview questions. Similar to face-to-face interviews, subsequent questions followed up on the aspects of previous responses and asked for elaboration or further explanation, as well as providing the next schedule questions. On completion, a final debriefing email was sent to thank participants for taking part and to give further information about the study. Due to the longer duration of email interviews, a £20 Amazon voucher (equivalent to US $25.33, Can $ 33.62, AUS $36.39) was given to interviewees as compensation for their time and to thank them for participating. On average, there were 5 email exchanges (ie, email sent and responded to) with each participant, a minimum of 3 and maximum of 7. Typically, each interview email included 2 or 3 questions (with probes) for participants to respond. Email interactions were anonymized and saved as Microsoft Word documents to facilitate analysis. Pseudonyms replaced names of individuals referred to in the interviews. Names of organizations were retained. Participants were able to use their preferred internet-enabled device to respond at a time and place that suited them.

Ethics

Email interview participants were asked to give consent by typing their name and date in the final section of the email information sheet to confirm they understood the study information. An email interview approach itself can resolve some ethical considerations associated with typical face-to-face interviews; participants must actively click to send responses, and this arguably acts as a second phase of consent—the risk of participants inadvertently sharing something is much lower. Data security and confidentiality remained paramount. Data were stored on secure password-protected university servers, and names or associations linked to participants were removed from transcripts. Approval to contact participants from the previous survey study was granted by the University of Bath ethics committee (reference: 16-146), and approval for this project was also granted by the same committee (reference: 17-004).

Analysis

An in-depth qualitative thematic analysis was conducted, following the guidelines set out by Braun and Clarke [49,50]. Early stages of analysis featured thorough familiarization with dataset content and development of initial codes (eg, through annotation of interesting elements relevant to the research questions). Following initial descriptive first-order coding, codes were grouped into more specific second-order codes, which were used to develop overall themes. Final themes were reviewed and refined to ensure that they appropriately explained their content and considered as much of the data as possible. The number of interviews analyzed would be considered appropriate in line with typical email interview samples of 5 or more participants [51]. Guest et al [52] note, when coding for overarching themes, a sample of 6 interviews can be sufficient to enable the development of meaningful themes and beneficial interpretations. However, the addition of 143 shorter but detailed open-ended answers to questions relating to the reasoning behind judgments of expertise for FH social media sources complemented this more in-depth sample. Furthermore, the homogeneity of our sample (the FH concerned) and clear aims surrounding perceptions (of expertise) further support the suitability of our sample size [52].

Results

Thematic Analysis

In outlining findings, we discuss observations across and within groups to develop a clear narrative that highlights associations and overarching concepts relating to perceptions of expertise in food hypersensitivity on social media. In quoting from interview participants and survey respondents, FH demographic information is also highlighted: FH *Adult* or *Parent* of an FH child; sensitivity as *Allergy*, *Celiac*, or *Intolerance*. Interviewees are denoted by an *I*, and survey respondents with an *S*, both followed by their participant number. Perceived expert interviewees are represented by an *E* and participant number. Overall, 4 main themes were identified in the data: (1) discerning traditional expertise on social media, (2) expertise acquired through lived experience, (3) cues to expertise in social media content, and (4) cues to expertise afforded by social media practices.

Discerning Traditional Expertise on Social Media

There was clear recognition across the data that 1 marker of expertise on social media was a qualified professional (often a medical professional). Participants highlighted how using an official title (eg, dietitian) or job description on the internet increased the likelihood of attributions of expertise. Claims of qualifications were similarly unproblematically equated with having expertise. Those working for or associated with experts within the field were also considered more credible, as well as links to research outputs:

> *To consider them an expert they would either be working within the field of allergy or involved in research.* [I4-Parent-Allergy]
>
> *Dietician is a protected title in the UK.* [S74-Adult-Celiac]
>
> *Published academic, so I would consider trustworthy.* [S9-Adult-Intolerance]

Participants often noted how they had met perceived experts in an offline capacity (eg, at conferences or events) or that an expert was, in fact, their own or their child's doctor or nurse:

> *I know some of the doctors quoted from our time at the allergy clinic.* [S37-Parent-Allergy]
>
> *I follow immunologists or doctors I have heard about from Anaphylaxis Campaign or Allergy UK.* [S119-Parent-Allergy]

Many of the judgments of expertise here are based on attributes outside the realms of social media. Here, expertise is not extrapolated from what the perceived expert user is *doing* online, but rather from the markers of expertise associated with them such as qualifications, publications, and external relationships. Social media are not an influencing factor in their possession of expertise, which would also presumably exist as a perception through patient and peer assessments in the offline world. In contrast, without the influence of a social media network, one might assume the expertise of nonqualified individuals discussing FH issues (as will be discussed in our next theme) would not stretch much farther than their personal, physical networks.

Traditional sources of expertise formed a benchmark against which users sought to discern the credibility of social media information. Social media information was scrutinized by comparison with traditional materials more likely to have been checked and evidenced with scientific backing or recommended by qualified health professionals:

> *Social media gives a platform to people who can say almost anything they like. When I was first diagnosed...I noticed there were a lot of contradictory information. As I was given an information pack by the NHS I used this as level 1 point of reference and compared what I found on the internet to this so I could sort the facts from the hearsay.* [I6-Adult-Celiac]

Furthermore, and as I6 highlights previously, receiving a new diagnosis heightens uncertainty and concern about the trustworthiness of information needed to manage hypersensitivities on a daily basis:

> *There are too many groups that people use as a platform for personal preferences, views and experiences. It can be daunting for somebody newly diagnosed to know what is what.* [S7-Parent-Allergy]
>
> *I think people new to the world of allergy struggle to see what is correct and what isn't.* [I8-Adult-Allergy]

However, it was often the perceived shortcomings in the support from qualified professionals that led FH individuals to seek support elsewhere:

> *However, my personal experience...is you get your diagnosis, you go away with your list of foods and your left to it. Yes you have a follow up appointment with the dietician 6 months after and can call for advice. But I feel you are just left to work the rest out.* [I1-Parent-Allergy]
>
> *Those coming fresh to social media looking for answers after getting short shrift from their GP etc. are more likely to fall into the trap laid by self-styled experts.* [E2]

The recently diagnosed patient sought information that could be trusted at a time of vulnerability and uncertainty. The acknowledgment of professional titles, qualifications, and experience with experts outside the realms of social media were key markers of expertise online. Thus, the locations and boundaries of expertise begin to be defined: signifiers of traditional medical expertise were valued around the process of diagnosis.

Expertise Acquired Through Lived Experience

The concept of expertise developing through experience featured strongly for both FH participants and perceived experts. Having lived (or cared for someone) with food hypersensitivity conveyed expertise in managing the condition:

> *Having easy access to people who have already been through it who share this knowledge may mean people are seen to be "expert" sources of information* [I5-Adult-Celiac]

The nature of expertise that living with FH conveys is associated with day-to-day living, for example, managing a child's allergy at school, appropriate places to eat out, or guidance on eating out in other countries. Such postdiagnosis day-to-day expertise is not seen as being available from the medical community but rather from those whose expertise stems from their personal encounters with the issue. These experts can be accessed through social media:

> *You can't get more expert than someone who appreciates and lives with the strains, stresses, worries of an allergy; and I feel that Facebook support groups provide this. Medical professionals know the "medical" bit but they don't deal with the day to day living.* [I1-Parent-Allergy]

The role of charities seemed to occupy a middle ground in terms of the expertise attributed to them. The provision of good advice was valued but could be associated with a lack of emotional resonance though being run by those who had personal experience of FH accorded greater credibility:

> *Gov and charities are a good source but their content lacks emotion and passion.* [S52-Adult-Celiac]
>
> *They're not run by professionals but others in similar situations and have been through the diagnosis etc!!! Often more helpful than the medical profession and I belong to the medical profession.* [S85-Parent-Allergy]

Although perceived benefits of information from those with experience was clear, there was also an appreciation that the information provided was a function of differences in the ways FH individuals approach their condition or differences in their conditions (eg, reaction severity or types of allergy or intolerance). Those who have lived with a food hypersensitivity for several years and feel confident in their lack of reaction, for instance, may take certain consumption risks:

> *Variations in the way some people may take "risks" could create some confusion particularly to those who have just been diagnosed.* [I5-Adult-Celiac]

Having said that, there was not an unthinking or automatic acceptance of the advice given by those deemed as experts by experience. There was some acknowledgment that the experience of different reactions to the same allergen (eg, cow's milk allergy vs lactose intolerance) could be associated with information that may be inappropriate. Therefore, it was not food hypersensitivity, in general, that conveyed expertise but rather it was having the "same condition" (S140-Adult-Celiac) and the "same intolerances" (S28-Parent-Allergy). This demarcation of expertise was also evident from the perspective of the experts themselves. One such participant, an experienced FH mother, outlined the boundaries of her expertise explaining that she would avoid handing-out health advice and rather point people in the direction of medical professionals:

> *I share my own experiences but never give medical advice—I always refer to a doctor or official resource...I would say I am an "expert" parent in the sense that I have experience managing allergies day-to-day, and can advise on issues such as handling school and nursery.* [E2]

The online FH community were accorded a role in helping to moderate the kinds of information being shared and ensure that it was appropriate and credible. For example, a weekly Twitter discussion hour around allergy matters, #AllergyHour, was 1 location where this occurred:

> *I often join in with...#allergyhour where you can ask anything allergy-related and someone will have experience to share. There is a tremendous support network on Twitter. We very much see ourselves as an allergy family.* [E4]

Information would be subject to a process of social validation. By asking other individuals experienced in managing FH concerns their opinion on specific matters or by others sharing the knowledge they had gained from expert sources elsewhere (eg, in managing children's allergies, eating out, recipes, or recommendations for medical advice or treatment), communities became a trusted site of knowledge. Members of these social media communities were more confident to use information or attribute expertise if it had been vetted or accepted by other trusted users:

> *They are other parents in the same boat sharing information which they have either learned themselves or sharing information from doctors, health visitors, dieticians.* [S109-Parent-Allergy]

Thus, there were 2 pillars that buttressed those seeking credible information on social media: (1) information about the experience of living with food hypersensitivity and (2) medical information. Social media support postdiagnosis was viewed as legitimately sought and provided in relation to the experience of living with food hypersensitivity, although it was recognized by some at least that this may be inappropriate because experiences of food hypersensitivity varied greatly. Those who had been accorded as experts on social media were reticent to give medical information and noted the pitfalls of doing so.

Cues to Expertise From Content

The first 2 themes have primarily considered attributions of expertise located in the characteristics of that person: their qualifications or experience. However, the nature of the information being posted or available on social media was also a marker of potential expertise. For example, the relevance and novelty of social media communications served as cues to expert status:

> *I don't tend to share material or news which is already "doing the rounds" or has been shared widely already by others—I'll trust that my followers will already have seen it.* [E1]
>
> *Posts relating to current issues. They give out useful information that is updated.* [S100-Adult-Allergy]

Expert information needed to be factually correct, and this was signified by links to research journals, official publications, or trusted sources:

> *I share from credible sources, but in all cases I read the article or link on the Tweet to make sure I am reposting something which is accurate, share interesting materials/facts/research.* [E3]
>
> *If someone had credible information backed up with scientific research that was a) new to me and b) working, that would be great.* [S51-Adult-Celiac]
>
> *Information is based in fact and scientific evidence.* [S34-Parent-Allergy]

In contrast, those who did not give evidence for their claims or were promoting information users felt had no medical or research backing were not viewed as credible:

> *In what way might you consider someone on social media as non-expert?* [Researcher]
>
> *People who claim they cured their allergy with simple lifestyle changes such as buying a salt lamp. Or people pedalling Vega tests which have no medical backing whatsoever.* [I4-Parent-Allergy]
>
> *People who don't know what IgE mediated allergy is or do not know the difference between lactose intolerance or CMPA. People who think someone with CMPA can have a little dairy and be okay.* [I3-Parent-Allergy]

Some did not expand on the grounds of how they would make their judgment but simply stated the nature of the content that they would attend to: it needs to be *accurate*, *relevant*, and *evidenced*.

User profile information was also seen to contain certain markers that users may use to assist them in assessments about the information presented there. One such example was the number of followers:

> *People like the collectiveness. They, subconsciously perhaps, believe if lots of other people are following/believing someone there is safety in numbers and it must be true.* [I3-Parent-Allergy]
>
> *I think they became to be seen as an expert by blogging originally and then creating the website and Facebook group. This has then attracted a large number of followers and so then people consider it as expert/knowledgeable simply because of the number of followers and it becomes self-fulfilling.* [I3-Parent-Allergy]

However, others took the opposite view, seeing follower numbers as a warning sign rather than a sign of expertise:

> *I fear a lot of people equate lots of followers with knowledge or expertise.* [E4]
>
> *There is definitely fake authority imbued by someone who has tens of thousands of followers—for instance some celebrities or self-styled food gurus. Social media makes it easier for these people to have a voice.* [E2]

Thus, the number of followers associated with content may be seen as a potential heuristic for assessing the accuracy and relevance of information; the following may itself act as a form of evidence. However, there are concerns if this following is not indicative of more traditional expertise or clear lived experience.

Cues to Expertise Afforded by Social Media Practices

In addition to considerations around the nature of the information available on platforms, participants noted how the way users behaved or performed on social media may be a marker to expertise. Some participants noted that the degree of interaction in social media engagement was pertinent to judgments about expertise:

> *I look for accounts that interact with other people...I don't have a lot of time for accounts that only retweet other people's tweets* [E4]
>
> *I think the perception is due to the fact I respond to tweets, correct factual errors, I am quite vocal.* [E3]

The practice of deferring to other users considered to have more expertise in an area and being open to feedback were also seen as markers of expertise:

> *I also look for non-qualified people who defer to qualified people—always a good sign.* [E1]
>
> *The two bloggers I referred to in my previous responses tend to offer advice and welcome feedback rather than making statements they believe to be fact.* [I6-Adult-Celiac]

The option on social media platforms to tag other users within posts and thus draw them into discussion supported these engaged interaction practices, and such exchanges are readily visible in the history of related posts or feeds. Similarly, evidence of connections with key FH stakeholders served to warrant credibility or expertise. These connections included relationships with associated charities, businesses, or organizations:

> *[The Facebook group moderator] talks directly to companies and gains assurances that certain products are completely nut free. This has led to the Facebook group being very popular as lots of people value [their] knowledge and the contacts [they] have.* [I2-Adult-Allergy]
>
> *I follow immunologists or doctors I have heard about from anaphylaxis campaign or allergy UK.* [S119-Parent-Allergy]

A mark of trusted expertise was brokering the content supplied by relevant external stakeholders, or to put this another way, the credibility of the content was enhanced when it was mediated by a trusted expert. Conversely, some noted that people may attempt to align themselves with the official profiles of organizations to project a greater sense of legitimacy. The ability to include and link to others on social media affords users who may not have expertise the possibility of enhancing their presentation of authenticity:

> *The individuals have yet to demonstrate themselves in the arena, the audience have yet to form a view on whether they are credible and borrowing from the reputation of others can ease this.* [E3]

In short, features such as liking, sharing, replying, and tagging on social media sites provide ways that users can observe the behaviors, attitudes, reputations, and level of engagement of accounts they wish to make assessments about. At the same time, FH participants noted that such features can assist in less authentic users attempting to portray a certain level of credibility or expertise within social media networks. This final point highlights how the affordances of social media platforms can, on the one hand, hinder the efforts of FH users seeking support online, but, at the same time, may support the FH community in moderating inappropriate information, for example, through calling out, tagging, or publicly warning others about posts.

Discussion

Principal Findings

In exploring how those managing food hypersensitivity and perceived experts constructed meanings around expertise, we identified 4 themes. The first and second themes were associated with the location of expertise: either being valued as an expert in a more traditional manner (eg, through qualifications and professional knowledge) or acquired through experience managing food hypersensitivity. Both forms of expertise were valued, and traditional expertise was most often unchallenged and taken for granted. The third theme highlighted the specific cues to expertise in social media content. Users were seen to attend to various markers of expertise in the FH realm, such as evidenced, accurate, and relevant posts. The final theme considered the effect of social media practices or behaviors. Expertise may be assigned if a user is seen to engage with the FH social media community as well as draw on and interact with other potential expert users.

A key cross-cutting issue related to the concerns felt around the time of diagnosis for FH individuals and parents. Several participants across both FH participants and experts emphasized the importance of patients being able to get access to correct information, and this was not always guaranteed when using social media. It is a paradox that social media provide important perspectives postdiagnosis about managing the condition—perspectives that are not available through traditional medical channels often instrumental in diagnosis—and yet they cannot be unproblematically taken on board—cues to expertise have to be found and interpreted. A medical background or qualification was a taken-for-granted factor in defining expertise in the FH area. However, in the absence of expert knowledge, we see experienced FH patients and carers offering advice through social media about the day-to-day management of avoiding allergens. Research looking into internet use in patient-practitioner relationships has suggested that it would be beneficial for both parties if physicians used their knowledge to guide patients to approved sources [53], and this may help reduce anxieties surrounding users taking advice that may not correspond with medical opinion [54].

Social media were seen as providing a *treasure trove* of nonprofessional expertise [41] and highlighted the value placed on experiential knowledge or *situated understandings* [40]. However, participants were often clear to stress that they would frequently take information read on social media and consider it in line with more official (eg, National Health Service) materials and their own knowledge. It is not simply the case that social media information is considered as credible as more traditional media sources [16], it sometimes was used as a source on top of, and to complement, traditional materials. This finding has also been seen in parents of children recently diagnosed with food allergy; parents used websites, journal articles, and online support groups to quickly improve their food allergy health literacy [27]. This time-dependent need for finer assessments of credibility and expertise is something we do not feel has been clearly demonstrated in the literature. Nonetheless, Metzger and Flanagin's [16] observations around receiver characteristics such as past experience, reliance, and prior knowledge are associated with this, but the focus here is more on experiences as a patient with food hypersensitivity as opposed to experience as a social media user per se.

Interview discussions demonstrated clearly defined groups of FH users on various social media platforms (eg, Twitter discussion participants or members of Facebook support groups) and supportive groups similar in nature to those recognized by Broome et al [27], Greene et al [1], and Hamshaw et al [30]. Groups supported fellow users when information or advice was needed, and drawing on and deferring to the knowledge of others (even when considered an expert yourself) was considered a highly regarded trait in someone supporting the community. A similar finding is presented by Lovatt et al [37], where use of caveats relating to one's level of expertise was key to the development of trust in online breast cancer forums. Trusted familiar users (either traditional or experience experts) on social media were imbued with the ability to convey social validation such that their reactions to other users acted as a benchmark of status or believability. In a similar way to Metzger et al's [29] findings around the use of social information pooling (such as reliance on testimonials, reviews, or ratings), social validation was conveyed here in FH users' liking, sharing, or commenting on posted messages, which demonstrates a form of rating for the social media post itself. However, as suggested by the name, *social* media perceptions of credibility can involve a much more social assessment—users can partake in 2-way interactions, question authors of original content, and ask advice of other trusted users—thus, highlighting variance with typical observations relating to Web-based credibility assessments associated with sources that are more static. The credibility of expert knowledge was also visible within social media sources such as Twitter discussion groups such as #AllergyHour and Facebook support groups. Again, a factor that sets social media cues to expertise apart from those associated with typical Web sources was the level of engagement expected to validate expertise; for example, taking part in discussions, challenging misinformation, and being available to comment, was also noted as encouraging trust through social media by Lovatt et al [37]. This further highlights an affordance of social media and a different way that expertise can be assessed through the internet in a more hands-on fashion because of communication capabilities of these platforms.

When considering research around the more static forms of Web-based media such as websites and assessments of their credibility, findings may relate to social media, but the multidimensional nature of these platforms was not always seen to translate very easily. Frameworks relevant to assessments of Web-based information, such as those presented by Metzger and Flanagin [16] and Fogg et al [32], must now move further to account for the more complex nature of social media information. Users are assessing information that blurs the boundaries between source, message, and author—does one assess the post itself or the platform it resides on? Does the post come directly from the poster or has it been *shared* or quoted from elsewhere? Although our findings highlight many credibility cues suggested by frameworks, such as information recency, accuracy, and relevance, as well as author qualifications or credentials, and absence of commercial motives, it is clear that social media do not fit these molds well. Furthermore, platforms such as Twitter offer users regular real-time updates (through hashtags) on matters of interest, but because of the limited (although recently extended) character capacity for tweets, credibility assessments are more challenging. Social media posts often do not have the space to give as much detail as a website might to suggest expertise (eg, references, evidence, and associations with reputable organizations). Recent research has shown that links to other sources of evidence in social media posts can promote a sense of credibility [12]; however, the extent to which this can be considered the same as references or evidence cited within Web-based sources needs to be considered.

Limitations

The interview sample was only a small number of social media users. However, it did consist of an array of FH concerns, from FH adults, parents of FH children, allergic and celiac, as well as those who make a living around food hypersensitivity (eg, writing about it or working for support organizations). However, the addition of 143 shorter yet detailed answers to questions relating to reasoning behind judgments of expertise for FH social media sources strongly enhanced the more in-depth interview sample. Several potential experts in the health care sector on social media were targeted during recruitment, and although 3 individuals did give informed consent, they did not respond during our interview timescale. Thus, we were not able to consider this perspective. Participants who had given informed consent and sent the first phase of interview questions were sent a reminder email if responses were not received within a reasonable time frame (approximately 1-2 weeks). Further reminders were not sent to avoid harassing participants who may have decided they no longer wished to take part in the email interview. Moreover, the gender split of the study sample could be considered imbalanced. Such an outcome has frequently been seen in the associated literature [5,55-57] and may be due to the more common primary caregiving role of females in managing a child’s food hypersensitivity. Unfortunately, the nature of sampling for a narrow population (individuals managing food hypersensitivity) limits the level of control over such considerations.

The email interview approach gave participants a high level of control over their data; they could consider replies, gather information, and add to previous responses. This reflection time slows down the research process, and the lack of face-to-face contact means participants can more easily ignore or forget about questions. Reminders proved useful in some cases, but it was difficult to know when to start and stop prompting. Compared with face-to-face interviews, developing rapport with participants was more challenging because of lack of social cues. Participants had their own communication styles, and we needed to adapt to these. Creating an interview schedule also presented additional issues. There is little opportunity to prompt participants, and confusing questions might lead to withdrawal. It was essential that questions were clear and likely to promote rich detailed responses. We also encouraged participants to be as detailed in their responses as possible. Thus, email and face-to-face interviews need to be viewed as distinct research approaches, each requiring a slightly different set of skills [58].

Conclusions

This study has begun to unpick factors associated with constructions of expertise on social media, specifically in the area of food hypersensitivity. Traditional perceptions of expertise, such as formal qualifications, remain a taken-for-granted sign of expertise; however, it was acknowledged that those living with food hypersensitivity could be seen as experts through their lived experience. There appear to be several cues to FH expertise on social media, including those typically anticipated such as factual and appropriate information and evidence. The 2-directional (*social*) nature of social media highlighted how social validation cues, such as likes, shares, follows, comments, and communication with other reputable sources or users, could aid in the assessments of expertise in a different way to more static forms of Web-based media.

Future work would benefit from exploring constructions around expertise on social media from the perspective of those considered traditional experts and how experiential expertise is considered here. This study suggests that more support may be needed in relation to living with food hypersensitivity, especially following diagnosis. Exploring approaches that encourage the mutual support of traditional and experienced patients and carers in managing health concerns (eg, online) could prove valuable. Understanding the processes involved in social media information assessments could help support groups to design interventions to improve the information evaluation skills of social media users; such applications could prove vital, as people increasingly turn to Web-based sources for help and support in relation to their health. Practical and actionable implications from the study findings may include the following:

1. Providing further support for those with food hypersensitivity following diagnosis. This may be through additional and subsequent contact with their medical diagnostic team.
2. Instigate online platforms that could foster mutual support from medical professionals and those who have experience managing food hypersensitivity on a day-to-day basis, for instance, more tailored forums or chat rooms, which could be closed to the public and moderated.
3. Develop the provision of training for medical professions in use of social media. For example, in how to promote one’s own expertise but also manage impressions given to the expertise of other users on social media (eg, through their own practices or that of other users). A stronger understanding of these issues would also enable practitioners to empower their patients in managing such concerns.
4. Stakeholders not only need to consider the accuracy of the information they post on social media but also the degree they evidence their posts. In addition, relevance was seen as a key issue here, meaning stakeholders may need to

consider how they tailor their communications to target certain audiences.

Acknowledgments

The authors would like to thank the contributions made to the development of this research project from Coeliac UK, Allergy UK, and Fiona Begen for assistance in participant recruitment. Funding for this project was provided by the Food Standards Agency (England, Wales, and Northern Ireland), grant number FS305013, and the Asthma, Allergy and Inflammation Research Charity. The funders provided support in the form of a PhD studentship for RJTH but did not have any additional role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Authors' Contributions

RJTH designed and conducted the reported study and produced the written manuscript. JB and JG assisted in the study design and provided detailed comment and amendments to various manuscript versions. JSL assisted in the study planning and also provided feedback on the various versions of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Email interview schedules.

[PDF File (Adobe PDF File), 66KB - ijmr_v8i2e10812_app1.pdf]

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Abbreviations

FH: food hypersensitive
MS: multiple sclerosis

Edited by G Eysenbach; submitted 18.04.18; peer-reviewed by R Chandrasekaran, K Tamura; comments to author 27.09.18; revised version received 31.03.19; accepted 31.03.19; published 28.06.19.

Please cite as:
Hamshaw RJT, Barnett J, Gavin J, Lucas JS
Perceptions of Food Hypersensitivity Expertise on Social Media: Qualitative Study
Interact J Med Res 2019;8(2):e10812
URL: http://www.i-jmr.org/2019/2/e10812/
doi:10.2196/10812
PMID:31254334

Publisher:
JMIR Publications
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