What's to Learn from Unvalidated Sources of Health Information?

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Abstract—Unvalidated Sources of Health Information (USHI) have been very successful in spite of the risk they pose to the health and well-being of their users. Our goal is to present a framework for the future study of USHI that studies the basic factors responsible for its success so as to enable the creation of better strategies to curb their use. Such studies leading to the identification of the components of USHI's success can be useful in improving the design of other less adopted consumer healthcare systems. To achieve this goal, we suggest the "reverseengineering" of various information technology (IT) adoption and success theories to identify the actionable components of their antecedents with respect to USHI that can be directly useful to designers of IT artifacts. We also speculate on several potential benefits of such research beyond addressing the threat USHI represents.

Keywords—unvalidated health information; health IT adoption; antecedents of IT success

I. INTRODUCTION

In this era of abundant and accessible health information especially through health portals and websites, Unvalidated Sources of Health Information (USHI) like health information presented through social network sites (SNS), blogs, forums, private websites and the likes, also pervade the web. Many times, the information on these platforms are incomplete, incorrect, outdated or plainly misleading and can be perilous to their consumers [1]. Patients, relatives of patients, or friends of patients utilize these platforms for a plethora of reasons ranging from guidance on major and minor health decisions to the desire for support from other users [30]. Support, as used here, could be emotional, social or financial and is usually gained by patients through the sharing of information concerning their personal health challenges, asking questions or sharing of their experiences with other users [12].

A key reason given in literature for the increasing use of USHI by patients for guidance on their health decisions is that patients trust that contributors to the USHI they use are knowledgeable in their area of interest [1, 13, and 16]. Some other reasons given for the use of USHI are (1) the pleasure derived from the process (2) the quickness of responses when compared to searching, and (3) the ease of the process [16].

When patients identify with the experiences shared by other users of USHI, they tend to believe in the possibility of extrapolating lessons from such experiences to similar cases especially theirs. Unfortunately, experience is seldom accurate as it is created by linking fragments of thoughts and events together in the bid to understand and explain their causes. Even when they are accurate, the conditions that created them are not necessarily reproducible [17]. Reliance on other patients' experiences as a guide to health decisions is therefore not encouraged. This "habit" continues to thrive nonetheless [5]. A classic example of its success is the major reduction in visits to pediatric centers as parents now rely mainly on internet-based health information which are in many cases wrong and unsafe [1].

The publicly available guidelines for identifying trustworthy sources of health information on the web are hardly used [1]. A study involving an unvalidated non-health related decision support systems (DSS), highlighted "Complacency" as a major reason for continued use [3]. However, USHI can have fatal consequences and unlike DSS, its source of information is usually an individual or a community of people with varied levels of knowledge (and sometimes interests) whose accuracy may not have been verified. Therefore, even though USHI have become a primary source of decision support for their users [25], they differ from normal DSS and the reasons why people use unvalidated DSS might not hold for USHI. Here, we propose a study of USHI giving reasons why such studies will be beneficial and providing a roadmap for its pursuit.

II. WHY ARE USHI IMPORTANT?

Research has shown that persuasive use of social networks and other related platforms can be used to drive people's private goals which may be positive or negative [6-10]. Nevertheless, the use of social networks, forums, and blogs, as platforms for USHI has continued to thrive in the healthcare sphere [18]. As a consequence, the health risks that the consumption of inaccurate health information portends, is a source of concern to stakeholders in the healthcare industry [1, 2, 19, 20]. Sometimes these inaccurate health information are ensconced in the content to deliberately mislead people [1, 3], however, oftentimes they are not (at least not deliberately) [1].

III. SOME INTERESTING QUESTIONS USHI'S SUCCESS POSE

A. On Privacy

The low adoption rates of other key health information systems like the Personal Health Record (PHR) is a topical issue for the research community who have identified several factors as possible causes [21]. Ordinarily, the privacy concerns of users are a constraint to the adoption and use of health websites, especially those requiring them to share personal health information [11]. Why are users' privacy concerns not deterring their use of USHI?

B. On Provider Endorsement

Provider endorsement and their continued engagement with consumer health informatics applications (CHI) – information systems directed at consumers to help them actively participate in their own care, has been identified as a major determinant of patients' adoption and sustained use of CHIs especially in the cases of Personal Health Records (PHR) [21, 22], however, in many USHI, users are not linked to providers [1]. Why is the lack of provider endorsement not a crippling challenge for USHI?

C. On Usability

One major use of the internet by seniors is to source health information [25]. This may imply that the usability issues that plague PHRs, have less severe effect on seniors (and younger adults) when the sourcing of healthcare information from the web is concerned (sometimes from USHI).

D. On Information Quality

Researchers have traditionally considered the quality of information to be defined by its accuracy, relevance, completeness, presentation and currency [25]. Consumers are expected to prefer information that possesses positive amounts of these factors [24, 25]. Interestingly, USHI's success contradicts these beliefs on information quality. Thus, it questions the sufficiency of objective methods of measuring information quality in predicting the adoption and success of IS.

These are only some of the questions that the success of USHI poses to the research community. Some others concern the identification of design factors that engender users' positive perception. Could the simplicity of the content, which is usually written in layman's terms, be an enabling factor? Is there an appealing design structure they employ? Also, understanding the characteristics of the adopters of these systems may provide useful insights to reasons for their vulnerability and how to curtail them or positively use them to improve other CHIs.

IV. GUIDE TO STUDYING USHI

We propose the use of IT Adoption and Success theories to guide our understanding of USHI. However, unlike other research that attempt to predict the adoption or success of technologies based on predefined constructs (antecedents), we argue that the most useful studies on USHI will be those that attempt to "reverse-engineer" its success, going even beyond standard antecedents with a view to identifying key components that inform those antecedents which in turn result in the success of the technology. This approach as proposed by Benbasat and Barki [26] for the technology acceptance model is believed to be able to help generate actionable information on how to "create" the antecedents to the desired success of information technology artifacts. Some applicable theories that can be reverse-engineered are:

A. Theory of IS success

This theory identifies information quality, service quality and system quality as the prerequisites for the success of any information system (IS) [27]. Using this theory as a guide in order to identify the components of its antecedents will help us understand what features of USHI make users perceive them as providers of quality information, quality health IT systems, and quality service.

B. Technology Acceptance Model

This theory predicts that users are likely to adopt a technology if it is perceived as easy to use and useful [30]. USHI succeed in these areas. Understanding what makes them appear useful and usable to their users with the goal of recreating the causes of these perceptions in other CHIs will be a beneficial research route.

C. The Task – Technology Fit theory

This theory posits that a technology will succeed to the degree in which it helps the user to perform their tasks [29]. The likelihood of success or "fit" of a technology is determined by the task characteristics, the individual and the technology's characteristics. Studying the components of these antecedents to fit, from the perspective of the user, might help us understand how to design online health IS that fit tasks.

While there are other pertinent theories that can be used to decipher the reasons for the success of USHI (like the Elaboration Likelihood Model – which can provide explanations on the persuasiveness of its content, or theories on Trust that can help us understand the antecedents of users' trust in these systems), the goal of such pursuits will be to help us understand how these antecedents can be "created" or "destroyed" for an IS [14, 15].

V. WHAT DO WE HOPE TO FIND?

A. Results that will inform design

The PHR as an example, have not enjoyed high levels of adoption or usage. Insights as to why USHI has been successful despite the risk of adopting their contents will help guide the designs of other CHIs.

B. Results that will inform policy

The success of USHI showcases an amount of trust in such systems. Understanding the causes of trust for these systems will help policy makers create strategies to undo such trust.

Such a study will not only line-up with Benbasat and Barki's proposal for a focus on the "left side" of TAM but

extend it to other theories. It will highlight the capacities of theories to be used to trace-out components of their antecedents that can guide designers and IT managers in their creation of IT artifacts.

A practical contribution of extracting the components of the antecedents is the provision of scientifically realized, actionable and practical results to designers.

The proposed approach will also open up the current delineations of accepted methodologies in research.

This paper therefore starts the discussion on harnessing positive insights from the challenges USHI constitutes. The aim is not only to help provide new strategies for tackling these challenges, but also to encourage the use of the insights garnered for the improvement of the designs of other CHI applications. Its depth is limited, thus, we hope that future studies would involve empirical tests to validate the propositions made here.

VI. CONCLUSION

In this paper, we have presented the motivation and roadmap for an exploratory study into the success of USHI. Existing literature shows that USHI is widely used and a need to control this use exists. However, how USHI can be successful while other health platforms struggle or fail is in itself an enigma, and unraveling this enigma can help us curtail its adoption. We, therefore, encourage that future research endeavors on successful sources of low quality health information can "reverse engineer" existing theories to extract the components of the antecedents of success of such USHI. It is our hope that the results of such research endeavor will guide policymakers in their attempts to discourage the use of USHI. We also contend that such studies will generate valuable insights that can be adapted to other CHIs in order to improve their acceptance and usage.

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