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Exploring Online Health Information Seeking in Scotland

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Abstract. Online Health Information Seeking (OHIS) has become an area of increasing interest over the last decade. The Internet has enabled the democratisation of health information as knowledge which was previously exclusive to health professionals has now become open access for all. The activity of OHIS has also revealed a digital divide in terms of those who access the Internet for health information. The prevalence of OHIS and the impact it has on patient outcomes and the relationship between health professional and patient is the focus of an on-going body of research outlined in this paper.

1 Introduction

Health information which is available online is changing how patients interact with health professionals. Much research focuses on the minefield of unregulated information and the impact this has on patient outcomes, positive and negative. However, it is vital to consider the impact on the health professional as this information has the potential to alter the relationship between patient and health professional as the patient becomes more empowered through OHIS. Recruitment of health professionals is in crisis. Short consultations and the changing landscape of healthcare have reduced the attractiveness of frontline healthcare [1].

In a recently published National Framework, The Scottish Government [2] encourages digital participation at a local level in the hope that the Scottish people are presented with the opportunity to benefit from the wide range of information, goods, and services accessed via the Internet. The particular focus is on improving digital participation among groups who are less likely to access the Internet, the elderly and low-income households [3]. These groups stand to benefit most from reduced-price goods and other benefits, which the Internet can provide. Internet use at home has been steadily increasing in Scotland. From 2007 to 2013 the percentage of adults accessing the Internet for personal use has risen 17.1 points (62.7% in 2007 to 79.8% in 2013) [3]. This compares with a 15-point increase of Internet use among adults in the United States for the same period (71% in 2007 to 86% in 2013) [4]. The increase in internet use at home results in people being able to engage in a range of online activities, potentially impacting on people's lives. Information available which relates

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to health and well-being is one area in which the Internet is becoming increasingly important.

Scotland has a health service that is free at the point of need. As the population increases, the health of the nation continues to be an area of concern for the Scottish Government and the National Health Service (NHS) in Scotland. Internet use has enabled patients to access search engines, online symptom checkers, and health information sites to contribute to positive health outcomes for themselves or a loved one. This digitally literate population is described as "health seekers" [5].

Patient OHIS is not intended to replace physician care but to support it as health professionals also seek information online during a consultation as they include patients in the diagnostic process [6]. However, OHIS and user contributed health information is encouraging patients not to adhere to physician advice [7], to which health care professionals must adapt [8]. The online health seeker expects convenience, to be a partner in decision-making, and almost instant service in all aspects of their health care [9]. However, the health seeker must pass through a series of complex processes in order to access and utilise health information [10]. Barriers in language, information and communication technologies (ICTs) knowledge, or the ability to weigh up sources and formulate a reasoned perspective can all limit the positive outcomes of health seeking online. Trust has also been identified as a key barrier to improving the online health information-seeking experience [11].

Online Health seekers differ from offline health seekers by age, income and education [12]. Those accessing health information online are affluent, well-educated adults [13]. These differences are known as the digital divide [14-16]. Therefore issues surrounding the digital divide, focusing on eHealth literacy, are also important.

By identifying patient OHIS activities, the needs of the patient can be further understood. Technology has provided access to previously exclusive information and therefore it is important that the health professional be aware of how this information could potentially influence patient decisions. Knowledge of patient OHIS must be based on empirical data that is specific to the time and cultural context.

2 The Prevalence of Online Health Information Seeking in Scotland

Generating a baseline of the prevalence of OHIS among Scottish patients provides an important starting point in understanding how OHIS impacts healthcare. It is not necessarily appropriate to rely on data from secondary sources, other cultures or general Internet use surveys. To investigate this, an exploratory study of online health seeking behaviour in Scotland identified the number of patients who were influenced to seek further medical advice offline as a result of online health information seeking [19]. The attitudes patients have towards this information were also identified.

The study involved a convenience sample of 571 patients who responded to a self-completed questionnaire based on the Pew Internet and American Life Project [4]. Responses were predominantly on a nominal scale. Data were analysed using Statistical Package for the Social Sciences (SPSS). Findings revealed a total of 68.4% (379/554) of patients had previously used the Internet to acquire health information. A

total of 25.4% (136/536) of patients consulted the Internet for health information regarding their current appointment on the day surveyed; 34.6% (47/136) of these patients were influenced to attend their appointment as a result of that online health information. With reference to the impact of the information on their health 43.2% (207/479) of patients stated the health information helped improve their health and 67.1% (290/432) indicated that they had learned something new. A total of 34.0% (146/430) of patients talked to a health professional about the information they had found and 90.0% (376/418) reported that the information was useful. In total, 70.4% (145/206) of patients were concerned about obtaining health information online from reliable sources. A total of 67.1% (139/207) of patients were concerned that a health site may sell their personal information, yet only 6.7% (36/535) checked the privacy policy of the site visited. However, 27.9% (55/197) of patients were not concerned about their employer finding out what health sites they visited, whereas 37.5% (78/208) were concerned that others would find out. The full study can be accessed online [19].

3 The Power Exchange Between Health Professional and Patient

It is argued that OHIS has the potential to impact the interaction between patients and health professionals [12, 19]. Specifically how, and to what degree this occurs is unknown. Patients are engaging in OHIS to meet their personal health needs, but they do not necessarily discuss this with a health professional [17-20]. In order to explore this impact a pilot study, the second stage of this programme of research, was developed in an attempt to identify how the democratisation of medical knowledge through the Internet creates new levels of empowerment and agency for patients as well as breaking down traditional barriers by shifting the balance of power from health professional to patient. The health professional/patient relationship is persistently asymmetrical [25]. The focus during this phase of the research is on the health professional's experience of OHIS.

Following ethical approval from NHS Grampian, a series of unstructured qualitative interviews were conducted among health professionals (n=13). The focus of these interviews was to identify issues encountered during a typical patient consultation in relation to patient OHIS and the impact this has on the health professional. This was an exploratory study seeking to identify themes that will inform subsequent research. Therefore unstructured interviews were most appropriate as this method allows the interviewee to direct the conversation [22] and results in less arbitrary interviewing allowing the interviewee to tell their story [23, 24]. In this context this approach is particularly apt as the health professionals were sharing privileged information about their experiences with patients.

After an initial briefing and question the health professionals were given the opportunity to elaborate with minimal contribution from the interviewer. No confidential information was disclosed, however, this is a topic that some health professionals may not be comfortable with. The question asked was 'In the context of a typical consultation, what is your experience of patient online health information seeking?'

Interviews lasted approximately 20 minutes and were recorded using a dictaphone. The recordings were later transcribed and imported into Nvivo as word documents. A conceptual framework analysis, as proposed by Miles and Huberman [23], was conducted using Nvivo in order to identify themes of power and efficacy in relation to patient and health professional interaction around OHIS. Miles and Huberman [ibid] recommend reducing the data, displaying the data and then drawing conclusions. This process was followed and the data were reduced by extracting relevant sentences and pasting them into a new document [26]. Themes were identified relating to; time spent discussing online health information; tension experienced during this process; trust in the health professional over the information; terminology as patients lacked digital or health literacy; and finally trouble when confrontation can occur.

3.1 Preliminary Findings

Preliminary analysis of the interview data indicated that most health professionals see the merits of increased patient OHIS. They largely accepted this as a part of their consultation process. Respondent 2 stated:

“Doctors attune themselves wherever they are to their circumstances and I am sure that people working in that environment are good at dealing with that” (R2)

However, some health professionals felt undermined by patients who present information during consultations that they found on the Internet. Trust was a key concept here:

“...quite a few times there have been minor symptoms which patients interpret online. Quite difficult for me to shake off as it often feels like patients think we are contradicting online information. Sometimes there is a lack of trust” (R5)

“People have extraordinary faith in the information they find on the Internet” (R6)

“...frustrated with patients who are difficult to convince.” (R5)

“...frustrating...can lead to conflict in the consultation. No trust or respect” (R3)

On the other hand respondent 1 stated the following:

“I have been here quite some time so I have quite a good relationship with some of the patients so it may be that they are trustworthy of your opinion and so if I say ‘I don’t think it is that and here is why’, then that is fine” (R1)

Although OHIS is seen as a largely positive activity, it is clear from the interview data that most health professionals spend some portion of a consultation discussing online health information. Existing research indicates that information presented during consultations as a result of patient OHIS can result in longer consultations [17]. In addition health professionals are often presented with information that they do not know themselves [17]. Health professionals indicated that they often search

for appropriate sources of information with a patient during a consultation. The following extracts highlight this:

“Sometimes patients bring data that you have no idea about...I have just been honest about that and tried to educate myself about that” (R5)

“Patient needs are diverse and therefore treatments equally so. In this sense a snapshot of [OHI] is not particularly helpful and it serves to confuse rather than help. Therefore time is spent fixing this during a consultation” (R6)

“...appointments are longer than 10 years ago as information giving is now built into consultation” (R6)

“...spend a long time persuading someone that they do not have something” (R3)

“...in a large % of consultations I will go online with the patient and point out a website that might be useful to them and ask them to go away and look at it and then come back” (R1)

Some respondents indicated a concern for the type of information patients were accessing and highlighted this as a potential cause of conflict in the consultation:

“The other kind of internet behaviour I would be very cautious about is the patient forum. It tends to be people with undiagnosed medical problems and they get onto forums and convince themselves they have something and they want a label for it and some of these things can be a bit toxic really and can cause difficulty ” (R2)

“...they [patients] come armed...” (R6)

Further to this, concern was expressed about patient ability to interpret appropriate information and actually possess the relevant level of literacy to understand it:

“...multi-disciplinary input for a patient...they come to you with almost an information overload. When problems are so complex the Internet stops being helpful at that point” (R1)

“The question usually is do I have this thing rather than what is thing. Pointing out reliable sources – forums are a problem and patients can think they have a side effect and join with collective in thinking they have it” (R5)

These preliminary findings support current discussion in the field of health communication and highlights the need for improvements in how health professionals mediate patient OHIS [17, 18, 20, 21].

4 eHealth Literacy: A Comparative Approach

Preliminary findings from the exploratory study outlined above indicate that digital health literacy is a concern for health professionals and patients alike [18, 20]. In general digital literacy is an issue that presents access issues for general Internet users across various socio-economic groups. This digital divide highlights certain characteristics that predispose affluent groups to enhanced digital literacy skills. When complex medical terminology is added to this in an OHIS context, the problem of access to health information via the Internet is further compounded [16].

Finland and Scotland are often identified as sharing certain social and health characteristics. With populations of similar size, comparison between the two in regards to digital health literacy is an interesting prospect. The authors and a partner in the University of Oulu, Finland, are to investigate levels of digital health literacy among patient populations, in a comparative study.

5 Conclusion

The impact of OHIS on health professionals and patients is a multi-dimensional issue that needs to be understood at the macro and micro level. Patient experience appears to be held above the plight of the health professional as the digital culture brings Dr Google further into the consultation space. The findings at this stage of this programme of work suggest that online health information-seeking behaviour influences offline health-related behaviour among the population surveyed.

The first study in the series provides support for the growing phenomenon of an empowered, computer-literate, health information consumer, and the impact of this phenomenon must be considered in the context of the patient-health professional dynamic. Patient attitudes to online health information seeking were focused on issues relating to trust, reliability, privacy, and confidentiality. This study provided a baseline of the prevalence of online health information seeking in the Grampian region of Scotland.

Preliminary findings from the second study, which focuses on the experience of health professionals in relation to patient OHIS, has shown that health professionals are adjusting their consultation style and spending time justifying diagnoses and treatment options as a result of patient OHIS.

Patient experience is not to be overlooked in this context, however, this particular topic has received much attention within the field across cultural, social and economic divides. It is important to conduct a Scotland specific study as assumptions of a universal experience should not be made. Therefore a further qualitative study will be conducted identifying the patient experience of presenting information found online during a consultation. By continuing this programme of work the authors strive to contribute to the overall understanding of the impact of OHIS on healthcare.

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