



E-Health

Haematology patients and the internet – The use of on-line health information and the impact on the patient–doctor relationship

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ABSTRACT

Objective: Patients access on-line health information (OHI) to better understand their health. We aimed to determine which demographic factors influence OHI use. We also explored how OHI is used and subsequent implications to the patient–doctor relationship.

Methods: We distributed a self-administered questionnaire to 202 haematology out-patients.

Results: 62.3% used the internet and 54.3% used OHI. Higher education, ($P < 0.001$, OR 34.62, 95% CI 5.20–230.66) and household incomes of £15 000–25 000 ($P = 0.023$ OR 4.8 95% CI 1.236–18.59) were positively associated with OHI use.

Those reassured after reading OHI had improved trust in their specialist ($P < 0.001$, OR 52.1, 95% CI 12.3–221.1), improved confidence during consultations, ($P < 0.001$, OR 23.0, 95% CI 2.8–188.2) and were improved decisions makers ($P = 0.008$, OR 13.6, 95% CI 4.1–45.7). Those with increased trust in their haematologist also had improved confidence ($P < 0.001$, OR 6.2, 95% CI 2.2–17.3) and improved decision making ability ($P < 0.001$, OR 13.6, 95% CI 4.7–39.4). 74.6% of patients did not share OHI with their haematologist.

Conclusions: Two-thirds of participants were exposed directly or indirectly to OHI. OHI affects patients' view of their health and influences behaviour during consultations.

Practice implications: Haematologists could facilitate patients using OHI by recommending high quality websites and act supportively when patients share OHI.

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1. Introduction

Doctors are the primary health information source for their patients [1–4]. The British Department of Health (DOH) urges doctors to provide accredited information to promote patient participation in joint healthcare decisions [5]. Health information can empower patients and well-informed patients comply better with treatment and enjoy superior outcomes [6–9]. However patients feel they receive inadequate information and desire further reassurance, and this motivates patients to seek additional health information [1,10]. The internet has emerged as an excellent health information resource for patients [11]. The internet is more than a computer network. Vast communities are formed providing

users with intellectual, psychological, and social support [12]. Anyone can publish on-line without permission, a key feature of the internet's popularity [12]. However, this is a fundamental weakness with little regulation of on-line material [13].

On-line health information (OHI) has several unique features; round the clock availability, access to interactive on-line supportive communities, access to expert and alternative opinions [1,2,10,14]. 73% of British adults use the internet each day, equating to 20 million more since 2006 [15]. 43% of the British population access OHI, this is especially popular amongst those aged 24–34 [15]. 6.75 million worldwide health related searches are being performed daily on Google alone [16]. OHI has helped transform patients from passive receivers into active consumers of health information [2,14]. The internet has changed the dynamics of the patient–doctor relationship, this relationship largely determines the quality of care patients receive [6]. Previously the relationship was didactic, doctors made decisions and patients silently complied [17]. Patients and healthcare professionals have advocated a shift to 'mutual participation', whereby power and

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responsibility are shared [17]. This has been interpreted by some as reducing influence and threatening the medical professions authority [18]. Patients can now access information which doctors themselves rely upon with the advent of the internet [19].

Historically doctors disliked patients using OHI, concerned about unreliable and poor quality information [18,20]. Inaccurate, biased and non-evidence based information can confuse and misinform patients [21,22]. Healthcare Internet Ethics, Health On The Net Foundation, and Internet Healthcare Coalition combined to develop the e-health code of ethics to protect those utilizing OHI [20]. However, with little internet regulation this code cannot be enforced [20]. Furthermore OHI can potentially harm patients through self-diagnosis or self-medication [2]. An estimated \$15–20 billion is generated annually from prescription medications being sold on-line directly to the public [23].

Patients consider themselves good appraisers of OHI [6,24] but many lack sufficient appraisal skills and misinterpret OHI [1,25]. DISCERN is a validated method for non-experts to appraise the quality of written health information [26]. When objectively assessed using DISCERN scores, few websites relating to bowel disease and paediatric cancers achieve high quality scores [27,28]. High quality websites are often too complex for the lay person to comprehend [29]. These factors can produce unrealistically high expectations amongst patients.

Several national general populations studies have identified factors associated with greater use of OHI; being Caucasian [2,30–32], female [10,30,33–35] younger [10,24,34], wealthier [24,31,32,35] and highly educated [10,24,35]. However, these factors are not universal [33,35], and some associations are weakening over time [30,34]. Nonetheless the 'digital divide' still exists, individuals with lower levels of education, the elderly and ethnic minorities access less OHI [36,37].

Several studies have examined patients use of OHI, particularly amongst oncology patients for whom urgent complex decisions are necessary at a time of emotional distress [38]. However, of all malignancies haematological cancers are the least well understood by patients and OHI could potentially help these patients [39]. Prior to starting chemotherapy haematology patients must understand the risks and benefits of treatments, in addition to understanding side effects in order to give informed consent. This can be overwhelming, especially if patients enrol onto trials or seek alternative options [40]. Few studies have investigated haematology specific OHI. One qualitative study of a newly designed haemophilia websites highlights the potential benefits of OHI [41]. Appealing aspects to patients included; unrestricted availability, educational value, and features of on-line social networking with other patients. One study used DISCERN to objectively measure the quality of OHI for patients who had their spleen removed [42]. Worryingly websites in general contained less than 50% of the information that should be given to patients undergoing splenectomy. In addition websites were written using language too complex for the lay person to understand.

Only Laurent et al. have assessed the use of OHI by haematology patients at their tertiary specialist centre in Belgium [43]. Their findings may not be widely generalizable to non-specialist centres and little insight into the patient–doctor relationship was gained from their study. We aimed to determine which demographic factors influence the use of OHI amongst our haematology patients. We also aimed to examine how patients access and utilize OHI, and to identify any effects to the patient–doctor relationship.

2. Method

A self-administered questionnaire was distributed to consecutive adult haematology clinic patients at our non-specialist centre, The Royal Sussex County Hospital, Brighton, UK. Participants had a

wide range of conditions including leukaemia, lymphoma, myelofibrosis, myelodysplasia, myeloma and various anaemias. Patients were not asked to provide their diagnosis. Informed consent was obtained from all participants. We aimed to recruit 150 participants after a minimum sample size of 94 was calculated (calculated using; $N = 4\sigma^2(z_{crit})^2 / \text{over } Ds^2$). σ being the assumed standard deviation for the sample, and D is the total width of the expected confidence interval [44].

The questionnaire was developed considering previous research investigating OHI. Social deprivation was derived from post-codes by calculating index of multiple deprivation (IMD) scores [45,46]. IMD scores combine; income, employment, health, education, housing, environment and crime [47]. The inclusion criteria was ≥ 18 years of age. The exclusion criteria were; inability to read and write in English. The study was approved by our Institutions Research and Development Board and the National Research and Ethics Committee (approval code 12/WM/0323). Prior to data collection, face validation was performed by piloting the questionnaire, see Appendix 1 for the final questionnaire.

Data was analyzed using SPSS for windows (version 20, SPSS Inc, Chicago, IL). Mann–Whitney U test compared average ages and binomial test compared gender ensuring the study sample represented the clinic population. An initial univariate analyzes identified demographic factors associated with internet or the use of OHI (Chi-squared or Fisher's exact test). Significant factors were entered into a multiple-regression model. Chi-squared or Fisher's exact test identified associations between participants attitudes and actions following the use of OHI.

3. Results

202 questionnaires were distributed with a response rate of 81%. No differences existed between the study and clinic populations (age $P = 0.62$, gender $P = 0.403$). 37.7% (95% CI 33.8–41.6; $n = 57$) of participants did not use the internet due to; no interest ($n = 23$), had never used a computer ($n = 23$), cannot afford a computer ($n = 5$), and no access ($n = 5$). Table 1 summarizes the characteristics of internet and OHI users. 62.3% of the sample was internet users (95% CI 58.4–66.2; $n = 94$). Age, education, job status and income were entered into a multiple-regression model. Increasing age was associated with less internet use ($P = 0.03$, OR 0.91 95% CI 0.84–0.99). Higher level of education was associated with greater internet use, university graduates had the strongest association ($P = 0.04$ OR, 19.83 95%CI 2.57–152.89). Job status and income lost significance in the multiple-regression model ($P = 0.517$ and $P = 0.688$, respectively).

OHI was used by 54.3% (95% CI 50.2–58.4; $n = 82$) of participants. In addition, 22 non-internet users had someone look up OHI for them, therefore 68.9% of all participants were exposed to OHI. Education, job status, income, and age were associated with OHI use on univariate analysis. Education remained significant in the multiple-regression model, university graduates had the strongest association with OHI use ($P < 0.001$, OR 34.62, 95%CI 5.20–230.66). The highest household incomes ($>£75,000$) were not associated with greater OHI use ($P = 0.99$). However the £15,000–25,000 group used significantly more OHI ($P = 0.023$, OR 4.8, 95%CI 1.236–18.59). Job status did not influence OHI use amongst the employed, unemployed or retired, however home-makers used less OHI ($P = 0.008$, OR 0.008 95% CI 0–0.27). Age lost significance ($P = 0.579$) in the multiple-regression model.

Few participants fully trusted (9.9%) or distrusted (1.3%) OHI. 85.7% did not know about e-health codes or appraisal methods. 18.3% strongly agreed and 64.6% agreed it was easy to locate OHI, only 6.1% disagreed. Only 17% ($n = 14$) recalled which websites they visited, NHS websites ($n = 25$), Macmillan ($n = 6$), and Wikipedia ($n = 5$) were the 3 most popular websites. Fig. 1 illustrates the

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