

TITLE: AN EXPLORATORY STUDY IN BREAST CANCER OF FACTORS INVOLVED IN THE USE AND COMMUNICATION WITH HEALTH PROFESSIONALS OF INTERNET INFORMATION

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ABSTRACT

Objective: To study the impact of the spontaneous use of Internet on breast cancer patients and on their relationship with health professionals.

Methods: A mixed methodology was used. Two questionnaires were designed through three focus groups, and then administered to 186 patients and 59 professionals in order to assess: (1) patients' use of Internet for health-related information, and 2) the impact of this information on patients' psychological outcomes and on their relationship with professionals.

Results: Patients spent more time looking for illness-related information after diagnosis, using interactive communities more than static information websites. Patients and professionals disagreed about the use of Internet in terms of the knowledge it provides, and its psychological impact. The main barrier reported by patients regarding the sharing of online information with their professionals was the belief that it would damage their relationship.

Conclusions: Both professionals and patients have a protectionist conception of the therapeutic relationship. This attitude tends to dismiss the positive impact that the use of Internet and the new communication tools may have in cancer patients. New resources should provide an "Internet Prescription" and modes of interaction to facilitate a more open digital communication.

KEYWORDS

Breast cancer; oncology; Internet Prescription; therapeutic relationship.

INTRODUCTION

People with life-threatening illnesses such as cancer commonly search for health information and support from other sources than the medical staff [1]. In recent years, there has been a significant increase in the number of people seeking health-related information on Internet [2,3], with 70-97% of patients doing so on a daily basis [4,5]. In addition, the use made of online resources has also changed, evolving from an initial need for information towards a need to stay connected to cope with the disease [6]. This change has promoted a shift from spontaneous use of Internet towards more targeted applications, as well as a greater involvement of professionals in the provision of psychosocial services [7,8]. Thus, the impact of Internet on patients and on their relationships with healthcare providers has become an important study subject [9,10].

To date, major discrepancies exist in this regard. Some studies have associated Internet use with a deeper knowledge of the disease and increased optimism [5,11]. However, online information may not always be reliable, and the variability in the quality, readability and accuracy of contents increases the possibilities of a negative impact on patients [12]. Indeed, some studies have suggested that online information may lead to greater confusion, worries, and distress [13,14]. Therefore, although the impact of Internet on patients' knowledge of the disease and emotional distress has been widely explored, published results are contradictory, with other areas such as patients' illness-related hope remaining unexplored.

In turn, there is also a growing interest among oncology health professionals to use Internet and social media [15]. However, only a scarce minority of them already use these resources for professional purposes [16]. Moreover, most health providers have doubts about the emotional and behavioral impact of non-professional-guided use of Internet. Newnham and colleagues [17] noted that 75-91% of practitioners thought that Internet searches may harm patients' emotional state. In effect, although many professionals have acknowledged some positive effects of spontaneous Internet use, apparently they do not consider it to be sufficient to meet patients' needs [18]. In addition, the disagreement between patients and practitioners regarding their perceptions of Internet may have consequences for the therapeutic relationship [10]. Despite these caveats, online health resources like "Smart patients", provide an opportunity for practitioners to collaborate with patients towards recovery [19], changing their interactions and enabling patients to play a more active role in their health [6]. However, a lack of communication between the two parts regarding Internet use still exists [20].

The aim of this study was to study the spontaneous use of Internet and its impact on patients following breast cancer diagnosis, placing special emphasis on the patient-professional relationship. We hypothesized that health-related Internet use would significantly increase after diagnosis, and that patients would spend more time in interactive online communities than on static websites. Moreover, and building upon previous studies, we anticipated a disagreement between professionals' and patients' perceptions of the use of Internet and its impact on patients' knowledge of the disease, their hopes regarding the illness, their cancer-related worries, and their levels of emotional distress.

METHODS

Design

We have developed a mixed methods research design [21]. Therefore, this study collected both qualitative and quantitative data in two phases within a sequential exploratory design [22].

This approach was selected because we were interested in understanding the personal experience of patients with the use of internet, and how it affected their relationship with health professionals treating them. In order to achieve this kind of understanding, first, two focus groups were conducted with breast cancer patients and another one with practitioners; data collected from these focus groups was transcribed and analyzed.

Second, the results from the qualitative data were used to adapt previous questionnaires which were administered to a representative sample of patients and professionals. Thus, focus groups permitted to look for emerging themes related to the use of internet and its impact on patient-professional relationship, and to integrate them into subsequent questionnaires. This second phase allowed us to have access to a bigger sample with the potential to confirm or reject our previous hypothesis.

As we stated before, qualitative data helped us to better understand the personal experience of patients, focusing on how it is narrated. In turn, quantitative data helped us to achieve a larger sample in order to generalize results [21]. Finally, following Denzin and Lincoln [23], who clearly recommended that researchers employing mixed methods should be explicit about their paradigms, we share a constructivist standpoint [24,25].

Participants

In the first phase, a convenience sample of 13 women with breast cancer were consecutively recruited in an oncological hospital in Barcelona metropolitan area, and invited to participate in two focus groups. Inclusion criteria were (a) diagnosis of breast cancer at least one month earlier, and (b) having searched for illness-related information online. In turn, patients were excluded if they (a) reported not using Internet ($n = 4$), (b) had never searched for illness-related information online ($n = 3$), or (c) reported impaired cognitive performance ($n = 1$). Convenience sampling was also used for the professionals' focus group in order to have an interdisciplinary and representative sample that had daily contact with breast cancer patients. Eight practitioners were recruited: an oncologist, a radiotherapist, a medical radiologist, a gynecologist, three nurses, and a psycho-oncologist.

In the second phase, 296 women meeting the same inclusion criteria from focus groups were recruited from four hospitals in northeastern Spain. Patients attending routine visits with professionals were invited to enter the study if they met the inclusion criteria. Those who accepted were interviewed by a psycho-oncologist and signed an informed consent. Regardless of their participation, patients with significant distress were offered psychological care. Among the women recruited, 60 did not reply, 37 reported not searching illness-related information online, 12 did not complete the questionnaire, and one declined to participate. The final sample therefore comprised 186 participants. Similarly, a representative sample of 93 professionals was also recruited **at the same hospitals** to participate in the online questionnaire in the service meetings. Thirty-four finally did not reply, and the final sample comprised 59 participants. The study was conducted in accordance with the Declaration of Helsinki, and approval was granted by the ethics committees of all hospitals (approval number: PR012/12).

Instruments

Focus groups

The topics raised in these groups were: (a) reason and time of Internet use; (b) type of information searched; (c) its psychological impact; and (d) communication barriers between patients and professionals. As said, these themes were integrated into the two subsequent questionnaires described below.

Patients' questionnaire

This instrument assessed two main factors: Internet use, and Internet impact. The Internet use part was based on the self-report questionnaire by Fogel and colleagues [26], together with relevant

topics published in The European Citizen's Digital Health Literacy report [27]. It comprised two categories: (a) time spent looking on Internet; and (b) source of online information, including static websites and interactive resources. In turn, the impact of Internet information section included items developed to assess: (c) psychological domains (i.e., awareness/knowledge, hope, cancer-related worries and emotional distress); and (d) therapeutic relationship (i.e., agreement on the impact of Internet use, discussion of Internet information, and communication barriers).

Professionals' questionnaire

This tool assessed practitioners' perceptions of the use and impact of online information on patients in the same terms as those described for the patients' version. It was adapted from the self-report questionnaire by Helft, Hlubocky and Daugherty [28]. It included questions regarding whether they had felt intimidated while discussing and clarifying the information patients found online.

Thematic and statistical analysis

The qualitative analysis was performed using thematic analysis [29], while statistical analyses of quantitative information were performed using IBM SPSS v.21 [30]. Intention-to-treat (ITT) multilevel linear models (MLM) were used to analyze questionnaire data, and Likelihood ratio test guided the modelling process for nested models. The agreement between answers of patients and professionals was assessed with Cohen's linear weighted kappa (k).

RESULTS

From the thematic analysis of focus groups, nine categories were extracted from patients' and eight from professionals' groups (see Table 1). These findings were used to adapt previous questionnaires and to design new ones, leading to the obtention of the quantitative results below, which are reported in order to emphasize the most generalizable results [21].

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Sample characteristics

Of the 296 patients who met the inclusion criteria, 186 completed the questionnaires. Age was the only significant difference between patients who entered the study and those who did not (participants were younger). Patients' characteristics are summarized in Table 2.

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The online questionnaire for practitioners was sent to 93 participants, and 59 completed it (44 women, 15 men). The professional sample comprised oncologists ($n = 13$), radiotherapists ($n = 10$), surgeons ($n = 8$), nurses ($n = 8$), palliative care doctors ($n = 4$) and other specialties ($n = 16$). The average experience was 13.9 years (SD = 10; min-max 0-41). There were no significant differences between professionals who completed the questionnaire and those who did not.

Internet use

Patients were asked about the amount of time spent looking for illness-related information before and after diagnosis, as well as after active treatment completion. The MLM for the effect of time was built parsimoniously. The covariance structure that best fitted the data was heterogeneous first-order autoregressive for level 1, and diagonal for level 2, while the residual plots did not reveal obvious deviations from normality and homoscedasticity. A quadratic trend was observed for participants' scores, which improved the fit of the model, as did setting both intercept and slope as random. Variance was found in intercept ($\text{Var}(u_{0j}) = 6.46, p < .001$) and slope ($\text{Var}(u_{1j}) = .54, p = .012$), while covariation between them was also observed ($\text{Cov}(u_{0j}, u_{1j}) = -.73, p < .001$).

A statistically significant effect for time was found ($b = -1.04$, $p = .001$, $95\%CI = -1.63 - - .44$), with Internet use increasing from an average of 1.51 hours ($SD = 4.46$) per week before diagnosis to 2.80 hours ($SD = 3.16$) afterwards, and then slightly decreasing to 2.61 hours ($SD = 6.514$) after active treatment. On the other hand, although patients reported their preference for static medical information websites (50.5%) rather than interactive resources like social networks (26.9%), the reported time spent on these latter resources (6.83 hours/week; $SD = 9.56$) almost tripled the time spent on static websites (2.3 hours/week; $SD = 2.55$). This difference was significant as shown by a second MLM for which the best fit was achieved with a heterogeneous first-order autoregressive matrix again, and fixed intercept and slope ($b = 3.74$, $p = .001$, $95\%CI = 1.60 - 5.88$). Finally, when patients and professionals were asked what proportion of patients they thought looked for online information, no agreement was observed ($k = -.044$): most patients estimated a rate of between 75-100%, and professionals a rate of between 51-75%.

Impact of Internet

Psychological impact

When both groups were asked if online searches improved patients' knowledge and awareness about cancer, the vast majority of patients reported an increase (69.6%), or no impact (21.2%) (see Table 3). In contrast, physicians declared that online information considerably reduced patients' awareness or knowledge of their illness (86.5%). Thus, no significant agreement was found ($k = -.017$).

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Another indicator explored referred to the worries that online information could generate. Again, disagreement was found ($k = .037$), as most patients reported either a decrease in their illness-related worries (39.4%), or a lack of effect (32%), whereas professionals thought that online information increased worries (86.4%).

Regarding the impact of online information on patients' distress, groups disagreed as well ($k = .052$), since patients reported that it had no impact (36.6%) or made them feel slightly more distressed (33.1%), while most professionals thought that information definitely increases distress (67.8%).

Finally, when patients and professionals were asked about the effect of online information on patients' hope about their illness, differences were also found ($k = -.055$). In this case, patients declared no change (54.3%) or greater hope (28%), while for professionals online information either reduced patients' hope (37.7%) or lacked effect (37.7%).

Therapeutic relationship

As shown in Table 4, the two groups were also asked how frequently they discussed online information during their medical appointments. Again, no agreement was found ($k = .001$), as patients declared they never (42.5%) or sometimes (22.6%) shared the information with their physicians, while these stated that they always (40.7%) or usually (28.8%) discussed such information. Finally, when patients and professionals were asked whether they had difficulties discussing online information with the other group, no agreement was found ($k = -.001$): most patients (45.2%) declared no difficulties, but 47.5% of professionals reported problems in this regard. The barriers reported by patients who have difficulties ($n = 102$) primarily focused on the belief that sharing information would damage the therapeutic relationship (83.4%).

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Finally, when physicians were asked whether they felt intimidated by discussing Internet information with patients, 45.6% of them reported never having felt intimidated; 38.6% rarely; and 15.8% sometimes.

DISCUSSION

Online health resources are encouraging patients to take a more active role in their healthcare, and at the same time enabling professionals to support patients' capacity to take decisions regarding their health [10,13,31]. Consequently, the use of Internet and its impact on patients and their relationship with practitioners have become important challenges that health systems need to address [2,10].

With respect to present study, qualitative data helped us to understand the phenomena and make themes emerge, while quantitative data allows us draw conclusions that may be generalized to the population of interest more easily. As hypothesized, we found that the use of Internet as a source of health information significantly increased after the cancer diagnosis and extended through the survival phase, in line with previous findings [13,32], and indicating possible unmet needs. Moreover, even though our patients reported preferring the use of static information websites, indeed they spent more time in interactive communities, indicating a desire to stay connected [32].

We also expected a disagreement between professionals and patients regarding the use of Internet and its impact on several psychological domains. Our findings confirmed this hypothesis, revealing that patients felt their searches increased their knowledge and awareness of the disease without affecting their hope, emotional distress or illness concerns, much as other studies have found [5,13,31]. In contrast, professionals reported that the use of Internet increased patients' doubts, confusion and misinformation, deriving in emotional distress and worries. These professional statements have also been reported in similar studies [17]. **One potential and highly reported reason for this discrepancy is that professionals may fear a "leveling effect", in which the expertise of the doctor is subverted, and promote a paternalistic model also with digital information [6].** Indeed, recent studies conclude that it is important for practitioners to seriously consider patients' ability to access, understand and use illness-related online information [14,32,33]. **It is striking that health professionals seemed to distrust the quality of available information online and disclaim the validity of the wealth of expert resources that are available to their patients in sites such as Cancer.Net.**

Another major obstacle in physician-patient interactions is the lack of communication regarding the use of Internet. Although most patients in our study (45.2%) declared no difficulties discussing online information, a majority of them reported never (42.5%) or rarely (21%) sharing and discussing online information with their professionals, which is consistent with previous publications [20]. The reason for such apparently contradictory finding may be that their difficulties are related to patients' beliefs about the damaging effect that the disclosure would have on the therapeutic relationship, instead of difficulties in the communication per se, confirming the barriers posed by the protectionist nature of the therapeutic relationship [20,34]. However, our data suggested practitioners never (45.6%) or rarely (38.6%) feel intimidated when patients ask about information acquired online.

Finally, regarding professionals, the vast majority of our sample reported always (40.7%) or usually (28.8%) discussing online information with patients, although they do not encourage its use. Similar studies reported analogous professional attitudes in other countries [18]. All these findings stress the importance of fostering the healthcare relationship, especially considering how valuable is for patients receiving the support of their physicians [35].

A number of limitations need to be mentioned. First, the study involved only breast cancer patients, what may restrict the generalizability of the results to other samples. Second, the influence of sociodemographic variables was not analyzed, as it was not the focus of this research. Finally, the use of Internet before the illness was assessed *ex post facto*. We acknowledge the possible recall bias that the use of this method may entail.

Conclusions

New online health resources are updating the relationship between patients and professionals, increasing patients' participation in their health. The present results reveal the existence of a protectionist conception of the therapeutic relationship, in both professionals and patients, with the latter avoiding sharing information to safeguard the therapeutic alliance. In turn, professionals tend to minimize the potential benefits of Internet, while maximizing its risks with regard to reducing hope and increasing worries and emotional distress. Thus, physicians avoid encouraging the use of online health resources, while patients avoid sharing this information with them. This current digital gap needs to be addressed, since it is holding back the advantages of Internet for health – that is, the promotion of patients' empowerment, self-responsibility and autonomy, its support for social connection, and its ability to provide valuable knowledge [10,13,31].

DATA AVAILABILITY

The data of this study are available from the corresponding author upon reasonable request.

CONFLICT OF INTEREST STATEMENT

Declarations of interest: none.

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AUTHORS CONTRIBUTIONS

All authors contributed to the study conception and design. Material preparation and data collection were performed by Cristian Ochoa-Arnedo, Nuria Casanovas-Aljaro, Enric C. Sumalla, María Lleras de Frutos, Agustina Sirgo, Ana Rodríguez, Gloria Campos¹, Yolanda Valverde. Data analysis was performed by Aida Flix-Valle, Anna Casellas-Grau, Noémie Travier, Joan Carles Medina. The first draft of the manuscript was written by Aida Flix-Valle, Nuria Casanovas-Aljaro, Olga Herrero. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

ETHICAL APPROVAL

The authors assert that all participants gave their informed consent prior to their inclusion in the study. All procedures conducted complied with the ethical standards of the relevant institutional committees on human experimentation, and with the Helsinki Declaration as revised in 2008.

INFORMED CONSENT

Informed consent was obtained from all individual participants included in the study.

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