Contents lists available at ScienceDirect





International Journal of Medical Informatics

journal homepage: www.elsevier.com/locate/ijmedinf

Surrogate health information seeking in Europe: Influence of source type and social network variables



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ARTICLE INFO

Keywords: Internet Health information seeking Social network theory Surrogate seeking

ABSTRACT

Objectives: Health information seeking on behalf of others is an important form of social support by which laypeople provide important sources of information for patients. Based on social network theory, we analyze whether this phenomenon also occurs in offline sources. We also seek to learn more about the type of relationships between information seekers and patients, as research to date indicates that surrogate seeking mostly occurs in close relationships between the seeker and the patient.

Methods: Using a large-scale representative survey from the 28 member states of the European Union (N = 26,566), our data comprise all respondents who reported seeking health information online or offline (n = 18,750; 70.6%).

Results: Within the past year, 61.0% of the online health information seekers and 61.1% of the offline health information seekers had searched on behalf of someone else. Independent of the information channel, surrogate seekers primarily searched for health information for family members (online: 89.8%; offline: 92.8%); they were significantly less likely to search for information on behalf of someone with whom they had weaker ties, such as colleagues (online: 25.1%; offline: 24.4%). In a multilevel generalized linear model, living together with someone was by far the most relevant determinant for surrogate seeking, with differences between countries or Internet activity being less important.

Conclusion: These results support the assumptions of social network theory. Implications are discussed, especially with regard to the provision of adequate health information.

1. Introduction

Health information seeking on behalf of others (i.e., surrogate seeking) is a common phenomenon, and one's personal environment and face-to-face communication with other laypeople are important sources of information for patients [1]. Findings from the US report that about two-thirds of online health information seekers also act as surrogate seekers [2,3]. The benefits of surrogate health information seeking may be significant, as health-related information needs and content have increased worldwide in recent decades [4].

Family members and friends who "seek information on behalf or because of others" [5] often trigger behavior change or influence patients' health-related decisions [2,6]. For patients, information from their social network can represent an important alternative to oftenrushed medical professionals, and may assist patients in coping with the variety and complexity of health information [5,7]. For health policymakers, surrogate seekers may represent an important channel for otherwise hard-to-reach populations, who have only limited access to

health information or low media literacy [2].

Despite the clear importance of social variables for health information seeking, health information seeking models such as the theory of motivated information management [8], the comprehensive model of information seeking [9] or the risk information and processing model [10] primarily concentrate on the influences of demographic characteristics, individual psychological variables (e.g., risk perception, subjective norms, control beliefs, or personal experience), or content criteria on information-seeking behavior [11,12].

To date, social network theory [13] has only played a minor role in explaining surrogate health information seeking. Carter et al. [14] included a persistent lack of knowledge about the safety and effectiveness of care recipients' medicines as one predictor of the information seeking intentions of caregivers, and Oh [15] applied the comprehensive model of information seeking [9] to caregivers of cancer patients and their contexts. However, neither study concentrated on the role of social relationships and related characteristics for information seeking.

The aim of the present study was therefore to analyze the

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http://dx.doi.org/10.1016/j.ijmedinf.2017.04.006

Received 29 September 2016; Received in revised form 3 April 2017; Accepted 7 April 2017 1386-5056/ © 2017 Elsevier B.V. All rights reserved.

importance of social characteristics as determinants of surrogate seeking. Social network theory "shifts the focus of the study from the individual to his or her relationships with others" [13]. As a result, we wanted to know who health-related information was being sought for. Research in social science, health science, and evolutionary psychology suggests that, of all relationship types, family members are most likely to receive social support. Human beings are more likely to support those with whom they have strong ties than those with whom they have weak ties [16]; the majority of caregivers are relatives [17] and genetic relatedness has been found to increase the likelihood of helping someone who is ill [18].

This assumption about the importance of strong ties for health information seeking is supported by the fact that surrogate seekers of cancer patients are mostly family members: most commonly spouses or partners, but also adult children, siblings, or other relatives [19]. Furthermore, one of the predictors for the health-related information seeking are recent health concerns for a family member [20]. This leads to our first hypothesis:

H1. Surrogate seeking is more likely to be on behalf of family members than for friends or colleagues.

According to social network theory, surrogate health information seeking mostly depends on the relationship between the seeker and the patient, and can be regarded as an expression of caring and concern about the patient [5]. Social and relationship-related variables such as being married, a parent, or a caregiver, or having a close relationship with someone with a chronic or serious medical condition have been described as reliable positive predictors of surrogate health information seeking online [15,3]. These assumptions are supported by the fact that surrogate seekers are more likely to share a household with others (albeit not necessarily the patient; [2] and to have strong relational ties with the patients they are searching on behalf of [5].

The influence of the demographic characteristics of age and gender on surrogate seeking also seems to be based on social factors. Adults aged 35–64 [2,3] were most likely to report engaging in surrogate seeking behavior, with surrogate seeking being least likely in the youngest and oldest adults. Several studies about the partners of cancer patients have reported that female carers are more likely to use the Internet for health-related information than male carers [21,22,15]. The characteristics of both being middle-aged and female are associated with a higher rate of giving social support [17,23,24]. In contrast, media-related characteristics—such as media literacy or frequency of internet use—that are frequently cited to explain differences in general online activities [25,26] seem to be less important. Instead, it seems that, as long as people have access to the Internet, they are just as likely to seek out health information for others as those who are more media literate or active [3].

In light of these findings regarding the impact of these characteristics on carer behavior, we expect that:

H2. Relationship-related factors (e.g., living together) should be more relevant for surrogate seeking than demographic (i.e. age, gender, education, country) or media-related characteristics (i.e., internet usage).

Most studies on surrogate seeking are solely based on online health information seeking [5,2,15,3] and do not analyze offline health information seeking. If it is true that media-related factors are not relevant [3], it is very likely that surrogate seeking is not limited to online information or a certain country and similar predictors should be relevant for online and offline surrogate seeking. Therefore, we want to know:

RQ1: Does surrogate seeking also occurs in an offline context?

RQ2: Are there differences between countries?

RQ3: Are there differences between offline and online surrogate seekers and interactions of the information source type with social, demographic, and media-related characteristics?

2. Methods

2.1. Data source

Our analyses are based on the Flash Eurobarometer 404 on "European Citizens' Digital Health Literacy" [27]. This telephone survey was conducted within the "eHealth Action Plan 2012-2020" of the European Commission. The data set, questionnaires, and documentation about the sampling method are publicly available. The field work was conducted on September 18–20, 2014. The samples for each country were generated by regionally stratified random digit dialing on both fixed landlines and mobile phones and are representative for the populations of EU residents aged 15 and older in each country. The total sample comprises 26,566 residents of the 28 EU member states ($n \approx 1000$ per country, except for Cyprus, Luxembourg, and Malta, where $n \approx 500$). See Bachl [28] for a more general analysis of this data set. In our analysis we focus on the subsample of health information seekers (n = 18,750): respondents who searched for any health-related information during the last 12 months, online or offline, for themselves or for others.

2.2. Measures

Extensive descriptions of all variables, basic descriptive analysis, and cross-tabulations are documented in a report by the European Commission [27]. We therefore focus on presenting the relevant variables for our research questions. Question numbers given in parentheses refer to the original full-length questionnaire.

2.2.1. Health information seeking

General health-related Internet use was measured using the question "Within the last 12 months, have you used the Internet to search for health-related information? This could include information on an injury, a disease, illness, nutrition, improving health, etc." (Q2). Response categories comprised five sub-categories of "Yes" (denoting different approximate frequencies) and "No, never." Respondents who selected any of the five "Yes" categories were categorized as healthonliners. Respondents who answered "No, never" reported never using the Internet for health-related purposes during the last 12 months or who did not have Internet access were then asked whether they had searched for health-related information using any other source types within the last 12 months. Response categories comprised five subcategories of "Yes" (denoting different approximate frequencies) and "No, never." Respondents who selected any of the five "Yes" categories were categorized as health-offliners.

2.2.2. Surrogate information seeking

Health-onliners and health-offliners were asked "When trying to find information on health, on behalf of whom do you usually search for this type of information?" Response categories were "yourself," "spouse or partner," "child(ren)," "other family," and "friends, colleagues" (Onliners: Q7, Q11, Q15, Q19; Offliners: Q27). Health-onliners answered this question for four different domains of health-related information—general information, health problems, second opinions, and treatments (Q3). These responses were aggregated for our analysis, because there were no differences between the response patterns for the four domains.

For our analyses, responses to the questions about surrogate information seeking were combined in the following two categories: The first category contained those who sought information for themselves only (henceforth, *self-seekers*) and the second contained those who sought information on behalf of someone else from at least one domain or source (henceforth, *surrogate seekers*). The surrogate seeking category included both people who had sought information only on behalf of others (i.e., surrogate seekers only) as well as those who had sought information both for themselves and for others [2].

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