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Health literacy and its effects on well-being: How vulnerable healthcare service users integrate online resources

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Abstract

Purpose – This study develops a better understanding of how online health community (OHC) members with different health literacy (HL) levels benefit from their participation, through the analysis and comparison of their resource integration (RI) processes. It investigates through a RI lens how the vulnerability of community members - captured as their level of HL - affects the benefits they derive from participation.

Methodology - Quantitative and qualitative methods were used to investigate effects of healthcare service users' vulnerability. Data were collected about their profiles and levels of HL. Furthermore, 15 in-depth interviews were conducted.

Findings - The study demonstrates how low levels of HL act as a barrier to the integration of available online health resources. Participation in OHCs appears less beneficial for vulnerable users. Three types of benefits were identified at the individual level: (1) psychological quality-of-life, (2) physical quality-of-life and (3) learning. Benefits identified at the community level were: (1) content generation and (2) participation in the development of the community.

Originality/value - This study has implications for the understanding of how service users' activities affect their own outcomes and how the vulnerability of users could be anticipated and considered in the design of the community.

Keywords Transformative service research, Quality-of-life, Online health communities, Resource integration, Health literacy

Paper type Research paper

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Introduction

Participation in online health communities (OHCs) may benefit individuals because these communities are an important source of informational, emotional and social support (Yao *et al.*, 2015), whereas these types of support are known to improve well-being (Rosenbaum and Massiah, 2007; Rosenbaum and Smallwood, 2013; Yao *et al.*, 2015). A recent article in the British Medical Journal states that “*people have the right to be actively involved in their healthcare, and should be provided with high-quality, culturally appropriate and timely information, support and services, allowing them to be knowledgeable about, and to participate in their health in different ways*” (Synnot *et al.*, 2018, p. 1). OHCs could play an important part in achieving this. It has even been suggested that OHCs could be a “safe place” for vulnerable healthcare service users (Parkinson *et al.*, 2017).

However, patients’ use of OHC content can also be problematic. Content created by community members often remains unvalidated (White and Dorman, 2001). Furthermore, creation and use of this content are affected by situational (e.g., stress and anxiety) and competence-related factors (Rubenstein, 2015). Additionally, given the lack of non-verbal cues, the information may be misinterpreted or misused by some community members (White and Dorman, 2001).

Benefitting optimally from participation in OHCs requires the integration of available resources. These resources can be informational (advice, teaching, referral), emotional (empathy, encouragement, caring), companionship (chatting, humor/teasing) or relational (e.g., a relational bond between members) (Yao *et al.*, 2015). Resource integration (RI) requires that several activities (Hilton and Hughes, 2013; Laud *et al.*, 2015) take place to co-create value (Leclercq *et al.*, 2016; Peters, 2016). Not all users are equally able or willing to integrate resources made available on the community, while some are more vulnerable than others. Vulnerability implies that a user “*is unable to accomplish his or her goal in a consumption*

situation because of being powerless, out of control, and so forth” (Baker *et al.*, 2005, p. 7). Consequently, vulnerable users generally experience less favorable service outcomes (Bone *et al.*, 2014), or even negative effects on their well-being (Anderson *et al.*, 2013; Hibbert *et al.*, 2012; Parkinson *et al.*, 2017; Sharma *et al.*, 2017).

Transformative service research (TSR) stresses the need to better understand the relationship between vulnerability and service outcomes such as well-being (Anderson and Ostrom, 2015). Vulnerability levels are expected to partially explain why identical offerings may have different outcomes for different individuals (Anderson *et al.*, 2013; Hollebeek *et al.*, 2016). It is thus highly relevant to compare vulnerable users' RI processes with those of other users and clarify the role the service provider potentially plays in this process (Parkinson *et al.*, 2017).

In this study, vulnerability will be studied as health literacy (HL), an important concept in healthcare. HL is defined by the World Health Organization (WHO) as: “*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information and ways which promote and maintain good health*” (Nutbeam, 2008; Otal *et al.*, 2012, p. 965). Low HL is a major challenge for the sector, as HL may directly impact health (İlgün *et al.*, 2015). Thus, the present study is guided by the following research question: How do OHC members with a low level of HL benefit from their participation in the community compared to members with higher levels of HL?

The study contributes to TSR by developing a better understanding of how vulnerable users integrate online health resources (McColl-Kennedy *et al.*, 2017a), and focusing on consequences of their vulnerability in terms of the individual's well-being and benefits for the community (Anderson and Ostrom, 2015). By learning how these processes differ between vulnerable and non-vulnerable users, it is possible to establish how to help vulnerable users to benefit more from their participation in the community.

A contribution is also made to the literature on online communities. Most existing research considers there to be a direct relationship between participation in online communities and service users' outcomes (Yao *et al.*, 2015). However, users co-determine the outcomes through their RI activities (McColl-Kennedy *et al.*, 2017a), which, in turn, are affected by their HL. Considering a direct relationship between participation to OHCs and users' outcomes may therefore be underestimating the complexity of the relationship between being a member of an OHC and getting benefits from participation.

The remainder of the article is organized into four sections. First, literature on OHCs and RI is reviewed. Studies on consumer vulnerability and HL are also discussed. Then the methodology is presented. Next, findings are presented. Finally, the conclusion includes a discussion, the main contributions at theoretical and managerial levels, a discussion of the limitations, and avenues for future research.

Literature review

OHCs and benefits for users

From the 2010s onwards, researchers focused increasingly on patients' use of OHCs (Bender *et al.*, 2011; Bender *et al.*, 2013; Ginossar, 2008; Hwang *et al.*, 2012; Nambisan, 2011; Rodrigues *et al.*, 2016; Setoyama *et al.*, 2011a). An OHC is "*a group of people using telecommunications with the purpose of delivering healthcare and education, and/or providing support, and covers a wide range of clinical specialties, technologies and stakeholders*" (Demiris, 2006, p. 179). Most research on online communities focused on motivations for the creation of, and for participating in, such communities, and on the activities of patients and other users on such platforms. Some studies also focused on the consequences for patients.

Most OHCs in a cancer context were created for fundraising and awareness purposes (Bender *et al.*, 2011). However, groups containing the greatest number of user-generated contributions were support-oriented groups (Bender *et al.*, 2011). It has been suggested that

health organizations could use OHCs to increase patient empowerment (van der Eijk *et al.*, 2013; Winkelman and Choo, 2003). Online communities are also created to share experiences, exchange knowledge and improve expertise about specific pathologies (van der Eijk *et al.*, 2013). In addition, given the fragmented nature of the healthcare system, online communities may be used to improve collaboration between various stakeholders and to bridge geographical distances (van der Eijk *et al.*, 2013).

Many different motivations to participate in online communities have been identified. OHCs can be used to interact and find support that patients cannot obtain in their 'offline' lives (McLaughlin *et al.*, 2012). Some patients use OHCs to gather information they would not be able to obtain from healthcare professionals, who are often perceived as too busy (Rupert *et al.*, 2014). Breast cancer patients use online communities during treatment to obtain information and suggestions for symptom management (Bender *et al.*, 2011).

Studies investigating patient behavior on OHCs found that they mainly exchange health related information and experiences (Willis *et al.*, 2014) while also providing and/or receiving support (Welbourne *et al.*, 2013). Although differences exist between communities, five principal content categories were identified: generic support, experiential knowledge, treatments / procedures, medication, and management of conditions (Chen, 2012).

The type of online behavior patients display is related to their motivations for joining the OHC. People looking for emotional support are more inclined to participate actively (through posting), whereas people looking for information will not post but rather read other members' posts and stories (Welbourne *et al.*, 2013). Next to the need to join the community, self-efficacy and personal characteristics such as reciprocity, altruism, and empathy (Zhang *et al.*, 2017) were found to affect patient participation in OHCs (Sun *et al.*, 2014). Social identity and trust also influence participation through the development of empathy (Zhao *et al.*, 2013).

Several studies investigated barriers to OHC use, such as privacy concerns, or a lack of trust and awareness, but also insufficient self-efficacy (Antheunis *et al.*, 2013; Bender *et al.*, 2013).

Finally, some studies investigated benefits of OHC participation. In their review of social media use in healthcare, Merolli *et al.* (2013) identified five major categories: (1) participation on the platform, (2) social interactions, (3) disease-specific knowledge, (4) psychological impact, and (5) effects on the physical condition. OHC participation is also associated with benefits such as quality-of-life improvement (Idriss *et al.*, 2009; Smailhodzic *et al.*, 2016) and lower perceived severity of the disease (Idriss *et al.*, 2009). Yao *et al.* (2015) demonstrated that social support received on online communities affect the patient's quality-of-life in all three dimensions: physical, psychological and existential. The physical domain of quality-of-life "*reflects a person's most problematic physical symptoms, such as fatigue or pain*" (Yao *et al.*, 2015, p. 371). Psychological quality-of-life involves the absence of "*feelings of depression, nervousness, sadness and fear of the future*" (Yao *et al.*, 2015, p. 371). Hence, support received on the OHC also improves mental health (Setoyama *et al.*, 2011b).

Participation can also increase empowerment through the utility of obtained information, defined as satisfaction with the usefulness of an information source. Information can be useful in four dimensions: relevance; novelty, credibility, and comprehensibility, (Johnston *et al.*, 2013).

Next to effects on patients at an individual level, participation in OHCs can also affect relationships with health professionals by leading to a more egalitarian communication. It can also decrease the rate of switching between doctors and/or lead to a more harmonious relationship (Smailhodzic *et al.*, 2016).

To conclude, motives for joining and/or participating in OHCs were frequently studied, and many benefits have been identified. However, most studies focused on the online platform

and the patient's or professional's online behaviors and benefits. Little is known about how patients' vulnerability affects the benefits they obtain.

Benefits of OHCs: the role of RI

RI is a prerequisite for value co-creation (Leclercq *et al.*, 2016) and defined as “a series of activities performed by an actor” (Payne *et al.*, 2008: 86) in which the service user is considered the resource integrator. Anything intangible or tangible are potential resources, but they only become resources when they are used in an activity by a service actor (Peters *et al.*, 2014), as Vargo and Lush stated (2008, p.8): “*value creation is always uniquely and phylogenomically determined by the beneficiary*”.

This implies that value creation strongly depends on the service user's ability to integrate available resources (Kleinaltenkamp *et al.*, 2012). Consequently, people having access to the same resources might not get identical benefits given the diversity of abilities and capabilities of these actors and their un/willingness to integrate those resources.

Furthermore, RI is widely recognized to be context dependent. The stages and practices that make up the RI process are expected to differ from one context to another. For instance, in the context of co-creation previous studies conceptualized the RI process differently. In the context of a service network, Akaka *et al.* (2012) identified three practices: (1) accessing, (2) adaptation and (3) integration. Accessing refers to “attain(ing) resources via relationship in network”, adaptation refers to “fitting of resources with available assortment” and (3) integration refers to “fitting of resources in unique context” (Akaka *et al.*, 2012, p. 34). Whereas Laud *et al.* (2015), taking a social capital perspective, proposed three other practices: (1) mobilization (willingness to exchange resources in the eco-system), (2) internalization (transforming explicit knowledge into tacit knowledge) and (3) transformation (creating new resources by assimilating existing ones). Studying customers' RI, Plé (2016) found different outcomes including (1) successful integration which leads to value co-creation, (2) mis-

integration (accidentally or intentionally) which may lead to value co-creation or value co-destruction, or (3) no integration (accidentally or intentionally) which may also lead to value co-creation or co-destruction. These different outcomes stress the context-dependent nature of the RI process and the importance of research to be grounded within a specific context.

In the context of online communities, Jayanti and Singh (2010) empirically studied the process through which members transform resources acquired on an online community into actions, which allowed them to solve their problems. They used Pragmatic Learning Theory, which focuses on the “*transformation of knowing embedded in individual actions to (experiential) knowledge for behavioral responses*” (Jayanti and Singh, 2010, p. 1059). Three steps were identified in the transformation process (Figure 1) (Jayanti and Singh, 2010): first, individuals experience an issue (a question) that forces them to look for a solution (an answer). This step is labeled “noticing problems”. Second, the individual mobilizes knowledge available on the community through an inquiry process. Finally, if the inquiry is successful, it expands the individuals’ action repertoires and the individual may be able to solve the problem. The first and last steps occur, according to these authors, at the individual level, whereas the second step occurs at the collective level (i.e., in the community). Through RI, participation in OHCs can be beneficial for individual members (Anderson *et al.*, 2013; Ostrom *et al.*, 2015) and for the community itself (Ostrom *et al.*, 2015). At the individual level, the integration of the resources available online help users at the physical and the psychological level. Finally, learning is considered a source of service users’ well-being (Anderson *et al.*, 2013).

Low health literacy as a source of vulnerability

The concept of vulnerability emerged in the late nineties. Brenkert (1998) emphasizes that everybody could, in some way, be vulnerable in the marketplace. Vulnerability must be taken into consideration, because it makes individuals less likely to realize maximum value from consumption (Edwards *et al.*, 2018).

In a consumption context, consumer vulnerability was defined as “*a state of powerlessness that arises from an imbalance in marketplace interactions or from the consumption of marketing messages and products. It occurs when control is not in an individual’s hands, creating a dependence on external factors (e.g., marketers) to create fairness in the marketplace. The actual vulnerability arises from the interaction of individual states, individual characteristics, and external conditions within a context where consumption goals may be hindered and the experience affects personal and social perceptions of self*” (Baker *et al.*, 2005, p. 134). Through this definition, the authors emphasized that vulnerability is multidimensional, because it occurs when the consumer (1) is powerless, (2) does not have control and (3) is dependent in a consumption situation (Anderson *et al.*, 2013; Baker *et al.*, 2005). These three conditions occur because of individual characteristics (biophysical and/or psychological), individual states (such as mood and/or motivations) and external conditions (such as distribution of resources, discrimination and/or repression). Consequently, vulnerable consumers are not able to reach or sometimes even to define their goals (Baker *et al.*, 2005).

In TSR, understanding how to guide the most vulnerable consumers is a key priority (Anderson and Ostrom, 2015; Anderson *et al.*, 2013; Rosenbaum *et al.*, 2011) because vulnerability can strongly affect consumer outcomes and well-being (Shi *et al.*, 2017). For instance, it was demonstrated that consumer literacy in finance affects well-being (Mende and Van Doorn, 2015). Furthermore, the level of literacy might be a key source or driver of service exclusion. Despite the importance of this vulnerability issue, little attention has been devoted to its study. Several recent studies call for a further investigation of this issue, and of the drivers and mechanisms that help to enhance service inclusion (Rosenbaum *et al.*, 2018) and maximize value realization during any consumption experience (Edwards *et al.*, 2018).

Low literacy levels were identified as a key source of vulnerability. Literacy refers mainly to the ability to read and write, and solve problems in everyday life (Ishikawa and Yano,

2008). Low HL can be considered a risk factor that needs to be managed in the healthcare process (Nutbeam, 2008). Patients with limited HL make less use of established criteria to evaluate health information (Diviani *et al.*, 2016). Additionally, Yin *et al.* (2012) stress that those patients rely more on professionals' knowledge. In this conceptualization, HL acts as a mediator between health and clinical decision making (Baker, 2006). High HL can act as a lever enabling people to have greater control over their health and life. HL is defined by the WHO as “*the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health*”.

The most common definition refers to functional HL, and refers to “*basic reading, writing and literacy skills, as well as the knowledge of health conditions and health systems*” (Chinn, 2011, p. 61). Functional literacy is the basis on which other skills can be developed (Nutbeam, 2008). Everyday reading and writing skills might not be adequate in the – much more complex - healthcare context (Ishikawa and Yano, 2008), however. The HL concept evolved from a narrow perspective towards a broader one, while several researchers consider it to be multidimensional (Ishikawa and Yano, 2008; Sørensen *et al.*, 2012). Two additional components have emerged: communicative HL and critical HL (Nutbeam, 2008). Communicative HL is defined as “*advanced skills that allow a person to extract information, derive meaning from different sources of communication, and apply new information to changing circumstances*”. Critical HL refers to “*advanced skills for critically analyzing and reflecting on information or advice received and using information to exert greater control over life events and situations*” (Heijmans *et al.*, 2015, p. 42).

Alternative HL dimensions have been proposed: fundamental, science, civic, and cultural literacy (Zarcadoolas *et al.*, 2005). Whereas fundamental literacy appears similar to functional HL, science literacy refers to the skills associated with understanding science and

technology, whereas civic literacy refers to the ability to “*become aware of the public issues and to become involved in the decision-making process*” (Zarcadoolas *et al.*, 2005, p. 197). Finally, cultural literacy refers to “*the ability to recognize and use collective beliefs, customs, world-view and social identity in order to interpret and act on health information*” (Zarcadoolas *et al.*, 2005, p. 197).

Despite their importance, these HL definitions are known to ignore the dynamic aspect of literacy and approach it as static rather than as a process. Therefore, more recently Sørensen *et al.* (2012) have proposed an integrated model that covers the different steps in the process, i.e., accessing (to seek, find and obtain), understanding (to comprehend), and appraising (to interpret, filter, judge and evaluate) health information, and using (to communicate and apply) that information for decision making (Sørensen *et al.*, 2012, p. 1480). This model can be applied to three domains: (1) healthcare, (2) disease prevention and (3) health promotion.

The interest in HL can be explained by the important consequences of low HL on healthcare users’ outcomes. These consequences, identified in prior studies, were classified into six categories (see Table 1). The first category which low HL could affect, i.e., preventive healthcare behaviors, includes all activities a patient could undertake related to the management of their health, to prevent or to manage a disease (e.g., adherence to medication, information seeking, self-management activities, etc.). Among ‘health behaviors’, ‘participation in health management’ and ‘adherence or non-adherence to medication’ (Fransen *et al.*, 2012; Paschal *et al.*, 2016) are the most frequently cited categories.

Insert Table 1 about here

Despite the large number of studies conducted on the consequences of low HL, reliability and validity of these studies are judged to be moderate (Berkman *et al.*, 2011). The reason for this negative evaluation is that these studies have been conducted on small samples and suffer from a lack of representativeness. Secondly, the statistical tests used to perform the

analyses ignored important control factors. There is a need to understand the factors that might act as moderators or mediators in the relationship between HL and health outcomes (Berkman *et al.*, 2011).

In the present study, low HL is considered a source of vulnerability. Absence or low HL levels are expected to make the navigation along the patient's journey more challenging and riskier.

Methodology

The present study aims to develop a better understanding of how OHC members with different HL levels benefit from their participation in OHCs through the analysis and comparison of their RI processes. Therefore, a study was conducted on a French OHC for patients with breast cancer. The platform launched in June 2014, and had more than 2,000 members at the time of data collection. The WHO emphasizes that cancer is one of the main causes of death worldwide. In 2012, 14.1 million people learned that they were suffering from cancer. Breast-, lung- and genital- cancers are the most frequent forms. Moreover, cancer does not only affect an individual's physical health, but also social, psychological and economic aspects of his/her life. Next to facilitating the sharing of information and experiences, the platform under investigation aims to inform patients about relevant events and service providers close to their geographical location. The content is not accessible to non-members. The community is extensively moderated by the community manager (who is also its founder and an ex-patient).

Two methods of data collection were used: a survey and in-depth interviews. In both cases, a convenience sample was used. The survey constituted the first step. The survey aimed to measure community members' level of literacy and learn about their disease and their demographic profile. Information about their age, their level of participation in the community, the duration of their membership and the stage of their disease was collected. Additionally, respondents were asked to indicate if they accepted to participate in the second part of the

research. A link was published on the platform and in a newsletter by the administrator. Given privacy concerns and based on an agreement with the community, a convenience sampling strategy was used. The researchers could not directly contact the members. HL was measured using the scale developed by Heijmans *et al.* (2015), which consists of 14 items, because it measures the three components of HL: functional, critical and communicative.

The survey was available for two weeks. During this period, one hundred questionnaires were completed and the data were analyzed using SPSS. A factorial analysis has been performed. Two dimensions were identified (Table 2): (1) functional HL and (2) advanced HL. Functional HL is related to the most basic level of “*reading and writing skills to obtain, understand and use factual health information*” (Heijmans *et al.*, 2015, p. 42). Advanced HL grouped communicative and critical HL skills. Both measures have acceptable levels of reliability (see Table 2).

Insert Table 2 about here

A two-step cluster analysis was used (Sarstedt and Mooi, 2014). Respondent groups were identified that were similar regarding their HL levels. The two identified factors were used as clustering variables. No a priori knowledge regarding the expected number of clusters was available. Two clusters were obtained. The solution’s reliability was assessed by testing its stability. The database was split and the clustering solutions were compared (Sarstedt and Mooi, 2014). No changes were observed between the two solutions.

To assess the validity of the solution, the groups were compared on the two clustering variables: (1) functional and (2) advanced HL. Two t-tests were conducted (Sarstedt and Mooi, 2014). The two groups were significantly different regarding their levels of functional (see Table 3) and advanced HL (see Table 4).

The first cluster grouped respondents with a higher level of both functional and advanced HL. They were classified as “knowledgeable members”. The second group was

composed of members with a lower level of both functional and advanced HL. They were classified as “novice members”.

Insert Tables 3 and 4 about here

An e-mail was sent to 25 among the 50 community members who had shown interest in participating in our study. However, despite their willingness to participate many of these members were not available. In this specific context of breast cancer, many of the members were either still under treatment or at convalescence period which means that they felt weakened or unable to be interviewed. Ultimately, 15 members of the community were interviewed (Table 5). The objective was to understand how knowledgeable and novice members benefit from their participation in OHCs. Interviews were conducted by Skype or by phone. A qualitative design suited the objective of gaining a deep understanding of a process and human interactions (Gephart, 2004). Additionally, through qualitative research researchers learn how respondents experience a phenomenon, rather than imposing predefined scientific concepts (Gephart, 2004; Yin, 2010). A semi-structured interview guide was used during data collection. Questions addressed the respondents’ activities on the platform, the types of resources they obtained by participating in the OHC, and how they used resources to solve the problems they encountered.

Among the respondents, between 30 and 69 years of age, six were considered “knowledgeable” and nine “novices”. As breast cancer mainly affects women, only one respondent was male. The respondents had to be members of the community for at least three months. Data were collected until redundancy was reached (Malhotra *et al.*, 2010). People in different stages of the disease were part of the sample (see Table 5). Among the respondents, ten were in treatment and five were in remission. Regarding membership duration, three respondents were considered as newcomers who recently joined the community, seven respondents were members for at least six months and five respondents were members for more

than a year. Membership duration and frequency of visiting the community are cross-tabulated in Table 6. Interviews lasted between 70 and 100 minutes.

Insert Table 5 about here

Insert Table 6 about here

The qualitative data were analyzed through content analysis (Mayring, 2000). To systematize this analysis, a coding scheme was developed (Miles and Huberman, 2003). The categories were defined before the data collection. However, the procedure was iterative, some codes were modified or sub-categories were added based on the collected data (see Appendix 1). The codes in italics emerged from the data analysis. Regarding the RI process, stages were renamed for the sake of clarity. A multi-stage categorization and coding process was used in this study at different levels, as suggested by Mayring (2000).

Second, all data were entered into NVivo 11 software through which an analysis was performed to facilitate the interpretation of the findings. The NVivo database supports searches, improving the coding and classification of the data as themes and patterns emerge. Third, the author team adopted an insider/outsider coding method (Gioia *et al.*, 2013). An “insider” author, who worked in the field, coded the data, then two other authors, who had not worked in the field, acted as “outsiders” by reviewing and criticizing the schema during the coding process. Collective discussions and regular meetings ensured team alignment.

After coding the data, a matrix was used for thematic analyses. This matrix helped to identify: (1) each step of the integration process, (2) the strategy (strategies) used by the members, (3) the difficulties encountered by the members during each step and (4) the perceived benefits of the RI process.

Two strategies were used to validate the interpretations. Firstly, data were triangulated by using multiple sources of information (Yin, 2010). “*With data triangulation the potential problems of construct validity can be addressed because the multiple sources of evidence*

essentially provide multiple measures of the same phenomenon” (Yin, 2009, p. 43). The patients, but also other stakeholders involved in the patients’ journeys were interviewed. Additionally, the patient organization provided descriptions of each patient’s journey and of each actor’s role. Secondly, the interviewed patients had different journeys and different characteristics. In such a way, complementary evidence was obtained (Yin, 2010).

Results

Integration of online resources

The community is perceived by its users as a source of informational support, emotional support and companionship. Emotional support involves sharing happiness or sadness, showing concern and encouragement, providing hope and confidence, and expressing blessings and congratulations. Informational support is related to giving others information related to treatment or how to cope with symptoms, such as clarifying the problem or offering suggestions. Finally, companionship consists of chatting, teasing, group meetings, or other social activities (Yao *et al.*, 2015). To make them valuable, each of these resources must be integrated by the community member. The terms ‘resources’, ‘online resources’ or ‘information’ are used in this section to refer to the three types of support that were identified on the online community.

Once a resource had been acquired online, three steps in the process could be recognized: (1) sense-making, (2) resource evaluation and (3) experiencing. The process and the strategies used, i.e., how members reach the objectives related to each step, are summarized in Figure 2². First, to make sense of the resources they have identified online, members may use one of the following three strategies:

² The main stages of the RI process are presented in full-lines whereas the facilitators and/or inhibitors of RI are presented in dotted-line boxes.

- (1) Using personal knowledge: using knowledge and awareness of their own body and situation.
- (2) Fixing boundaries: considering that the information provided by the healthcare professional is always the most relevant and reliable.
- (3) Avoidance: avoiding content that seems to be too complicated.

Second, to evaluate an online resource, three possible strategies were identified:

- (1) Use of other sources of information, such as books or recognized websites.
- (2) The frequency with which the information is confirmed on the OHC.
- (3) Looking for social support: the member will discuss the online information with individuals in their care network.

Finally, once the resource has been evaluated, three ways to experience it have been identified:

- (1) Integration: the member uses the resource 'as is'.
- (2) Adaptation: the member resolves his/her problem, but the resource is first adapted to his/her situation. For example, Member 6 read on the community that some other members did not eat before chemotherapy to avoid side-effects. This member had difficulties imagining not eating. Therefore, she decided to eat light before a treatment. It appears that this was beneficial for her, as the side-effects were less severe as compared to the first session.
- (3) Discard: Despite a “positive” evaluation, the resource is not used to solve the member’s problem. This happens, for example, when it is not possible to benefit from the resource in their geographical area.

Insert Figure 2 about here³

Novice and knowledgeable members were also compared regarding how they go through the RI process.

Comparing the RI processes of knowledgeable vs. novice members

Sense-making

The analysis revealed that novice members are less likely to go through the first step. This can be explained in various ways:

- (1) Novice members tend to avoid content that seems too complicated, whereas knowledgeable members tend to establish first whether it can be used. Consequently, novice members tend to stop the process more prematurely than knowledgeable members, as they consider themselves unable to manage the resource. Knowledgeable members appear more confident in their ability to evaluate and in their awareness of their own condition as it can be illustrated by the following example. One member told us that she read about the positive impact of doing sports during the treatment. However, due to problems she had with her arm, she could not participate in sports. This resource was therefore not applicable to her situation. The member was asked how she identified interesting resources and how she decided to evaluate them or not. She replied: *"It depends, there is some advice that I will directly apply and other that I will never apply. How I choose? That is personal, I know myself"* (Member 3, knowledgeable).
- (2) Avoidance is less likely to be used by knowledgeable members who will try to take into consideration all the resources they find on the community. On the one hand, the most vulnerable members directly renounce to use resources that may be too complicated to understand. Novice members reported that they did not even read posts wherein other members speak about their medical condition or experience. This can be illustrated by the following quote: *"I am only interested in things that are not scientific. (...) I am interested in useful things as long as they do not affect the treatment"* (Member 4, novice).

(3) Finally, the last strategy (fixing boundaries) was only mentioned by knowledgeable members. Member 13 (knowledgeable), reported *"I also had information in my cancer center. So, when the information was not the same, I focused on what was advised in my center"*. It can be explained by the fact that novice members tend to avoid medical related health information considering that they do not need to compare the doctor's information with the information from other sources, such as the community.

Resource evaluation

How novice members vs. knowledgeable members evaluate online health resources was compared (Table 7). Differences emerged regarding (1) how they are used and (2) how they are combined.

Insert Table 7 about here

The first strategy *"looking for social support"* is effortful. It implies discussing/sharing the information with (1) the other members on the community by asking additional information and/or (2) with the medical team. In general, patients will discuss a resource with a medical professional if applying it requires to take drugs or if there is doubt as to how it will affect the effectiveness of the main medical treatment (e.g., chemotherapy, radiotherapy). Only four out of nine novice members used this strategy, compared to five out of six knowledgeable members. Members with low HL perceive the medical team as being *"under time pressure"*. The following quote illustrates this finding: *"I never ask the opinion of my oncologist, because I see him enough. I will not try to get in touch with him outside appointments. (...) And they don't have time"* (Member 4). It thus appears that if novice members would like to get social support from the healthcare professionals and from peers, they are less likely to use this mechanism. The few novice members who used this strategy for resource evaluation all

mentioned that they did it because their medical team was open to discussion and gave them the opportunity to ask questions during the appointment.

Differences between novice and knowledgeable members were observed regarding the extent to which other sources of information were used and how this strategy was used (Table 7). Among novice members (nine respondents), three reported to use this strategy compared to six among knowledgeable members (out of six respondents). Additionally, whereas novice members tend to consider the Internet as the main “other source of information”, knowledgeable members also reported to use “offline” tools, such as books. Many novice members reported avoiding the use of additional information sources because they did not want to be distracted. They tried not to increase the number of information sources to avoid a risk of information overload and confusion. The data revealed that the last strategy, “recurrence”, is the least frequently used strategy by both knowledgeable (three respondents) and novice (two respondents) members. The only novice member who mentioned this strategy used it alone, whereas the two knowledgeable members used it in combination with other strategies.

Finally, a difference also emerged regarding the extent to which the strategies for resource evaluation are combined. Indeed, most novice members will focus on only one strategy whereas knowledgeable members will tend to combine different strategies. This can be explained by the fact that combining two or more strategies is perceived as more effortful for novice members than for others.

Data analysis emphasized that novice members are less likely to go through the second step of the RI process. Even if the resource appears interesting for solving a problem, they encounter difficulties in finding the right strategy for evaluating it. They also perceive some strategies as consuming too much ‘time and energy’ to apply it.

Experiencing

There are three options when patients reach this last stage: they implement the resource as it is (integration), they implement the resource by adapting it (adaptation) to their own situation or they discard it (see Table 8). Most of the novice members never reach the stage of ‘experiencing’. Most of them stop earlier in the RI process. Indeed, among the nine novice members interviewed, only three really integrate online resources whereas all six knowledgeable members go successfully through the entire process.

Integration refers to the use of the resource as it is, and this is the most common experiencing strategy identified in the data. Adaptation is more effortful. Surprising is that the member who mentioned this strategy was a novice. Looking at more personal and/or network factors, it appears that this member has a medical team that is open to discussion and giving her the opportunity to ask questions during medical appointments. This support could explain her ability to reflect and to adapt a resource to her own situation despite her lack of HL.

Insert Table 8 about here

To summarize, regarding the RI process it appears that novice members encounter difficulties in doing it. In a breast cancer context, low HL seems to strongly affect the abilities to adopt the right approaches or strategies to integrate resources. For example, for sensemaking novices tend to “over-use” avoidance and to constrain themselves by fixing very strict boundaries. Most of the time, RI seems to require too much effort for these members. In the next sub-section, the effects of online RI at the individual and community levels will be discussed.

Outcomes of participation in online communities

Benefits from participating in OHCs were identified at two levels: (1) at the individual level (Table 8) and (2) at the community level (Table 9). They are explained in the next sub-sections.

At the individual level

At the individual level, participation in the online community can positively affect the member psychologically and physically, but also members' learning (see Table 9).

Regarding effects at the psychological level, it appears that it is important for members to get in touch with people in a similar situation: "*we are not so unusual, there are so many people living with cancer*" (Member 12). Almost all members reported benefits at the psychological level, as they were almost immediate, whereas getting benefits at the physical level required to go through the RI process. Regarding benefits at the psychological level, differences between novice vs. knowledgeable members were not identified. This can be explained by the immediacy of this type of benefit compared to benefits at the physical or community level.

Going through the RI process allows members to deal with the symptoms and side effects of the treatment (such as pain and tiredness) thanks to the resources acquired on the community. Many examples of such benefits were identified (Table 9). The benefits can result from the application of advice regarding supportive care (such as cures or doing sports). It can also concern the side effects of the treatment, such as when and how to apply nail polish to avoid losing nails. Differences were observed between novice and knowledgeable members. Indeed, six novice members among the nine interviewed reported this type of benefits whereas five knowledgeable members among the six interviewed reported benefits at the physical level. This could be explained by the difficulties encountered by novice members during the first two phases of the RI process. Most novices failed in completing the entire process, because they were not able to apply the right strategies.

Finally, participation in the OHC allows members to learn new things. Members acknowledged that they became more knowledgeable as a result of acquiring and processing information. During their membership, they learned that different forms of breast cancer exist, which helped them to better organize information they retrieved. Learning does not always

require going through the entire RI process. Even when the process was prematurely stopped, OHC members recognized that it already increased their understanding. Members who never used a resource acquired on the community also mentioned this benefit. Clear differences existed again between the two groups. Only three of the novices reported learning as a benefit from participation in OHCs, compared to four of the knowledgeable members. In addition, the data emphasized that the knowledge acquired by the novice members was more basic (e.g., distinguishing between different cancer types – Table 9). At the opposite end, the type of knowledge acquired by knowledgeable members could be qualified as “advanced”.

At the community level

Participation in OHCs and the effective use of acquired resources can benefit the community itself. Two types of benefits were identified at community level: (1) content generation and (2) participation in the development of the community (see Table 10).

Insert Tables 9 & 10 about here

The data show that benefits at community level generally emanate from knowledgeable members. Indeed, most members who mentioned that they had created content and/or participated in the development of the community through RI were knowledgeable (four out of five).

Discussion and conclusion

Discussion

The present study aimed at developing a better understanding of how OHC members with different HL levels benefit from participation in OHCs through the analysis and comparison of their RI processes. To achieve this objective, the RI processes of vulnerable healthcare service users and other healthcare service users were compared. In-depth interviews allowed to identify how and when user vulnerability, captured by low HL, affects the RI process and its outcomes at the individual user and the community levels.

Jayanti and Singh (2010) suggested that further research investigate the barriers to RI. In this study, low HL was considered a major barrier to RI. In this study, low literate members encountered more difficulties in integrating resources and, consequently, reported fewer benefits from participation in OHCs. A second barrier to the integration of online resources was identified: the lack of availability of the service offering. Some members indeed identified the resources, made sense of others' experiences, and evaluated the resources, but were unable to effectively use them because there was no suitable service offering in their geographical area. It has been suggested that limited availability of service offerings in remote geographical areas may affect healthcare service users' quality-of-life (Anderson *et al.*, 2013).

Once a resource was identified in the community, two steps were identified in the RI process for value co-creation: sense-making and resource evaluation (Figure 3). Regarding resource evaluation, novice members were more likely to use a 'negative' strategy, i.e., avoidance. They avoid to be influenced by information they may not understand or manage.

Regarding resource evaluation, three strategies were found to be used by community members: (1) use of other sources of information, (2) the citing frequency (referring to the number of times a resource is mentioned on the community) and (3) looking for social support from peers or from healthcare professionals. It was found that novice members are less likely to use these strategies and use them differently compared to knowledgeable members. Given the high risk of information overload in online communities, the low level of HL of novice members seem to be a key hindrance for combining different sources of information. While others are more prone to look for social support to overcome this issue, novice members are less likely to solicit any support or advice from professionals as they perceive them as very busy people.

Previous studies showed that people with low HL tend to limit their information seeking activities (von Wagner *et al.*, 2009), which is in line with the finding that novice members try

to limit the number of information sources. They seem to distrust their skills to manage and evaluate large amounts of information. This may be a strategy to avoid the risk of information overload. Finally, research on the consequences of HL stresses that people with low HL tend to avoid questioning a professional's decision and prefer to let the decisions up to professionals (Yin *et al.*, 2012). Additionally, less literate people are reluctant to ask questions to healthcare professionals (Johnson *et al.*, 2010). The data showed that novice members were less likely to discuss online information with health professionals. The results are thus congruent with previous studies.

Previous studies showed contradictory results regarding the benefits of participation in online communities (Rosenbaum and Smallwood, 2013; White and Dorman, 2001; Yao *et al.*, 2015). In the present study, it was found that benefits of online social support depend on the extent to which the online resources can indeed be integrated by the members affected by low HL.

To conclude, novice members appear to show more difficulties to effectively use sense-making and resource evaluation strategies. The application of each strategy seems to require much more effort for them, which explains the difference in terms of RI with knowledgeable members. This is in line with Sweeney *et al.* (2015), who have shown that the perceived difficulty of an activity decreases the likelihood that this activity is performed by the patient.

Benefits for the community through content generation and member participation in the development of the community have also been identified. The effects of participation in online communities at the community level had rarely been investigated (Pendry and Salvatore, 2015). In the context of wedding planning, Leal *et al.* (2014) demonstrated that participants in virtual communities may continue to create content (even after the wedding) for the purpose of helping others. Dholakia *et al.* (2009) found similar results in studies among users of a problem-solving virtual community. Pendry and Salvatore (2015) demonstrated that in some cases participation

in online discussion forums may affect participants' civic online behaviors. These findings can be compared with members taking part in the development of the community. The results are thus in line with previous studies regarding the effect of participation in online communities for individuals and for the community itself.

Insert Figure 3 about here

Theoretical contribution

This study contributes to TSR by enhancing our understanding of how service users' activities affect their well-being (Anderson et al., 2013). It has become clear that most resources acquired online do not have value in themselves. Users need to integrate them before value can be created and their well-being improved.

Moreover, this research focused on a 'nonprofessional' context. Whereas prior research focused on relationships between professionals and healthcare service users' well-being, this study focused on resources acquired beyond interactions with healthcare professionals (Beirão *et al.*, 2017). In the context of an OHC, both creation and use of its content are affected by situational and competence-related factors (Rubenstein, 2015). It was shown how these factors can have negative effects on users' outcomes (White and Dorman, 2001).

In line with Parkinson *et al.* (2017), this research also contributes to the emerging domain of TSR at the intersection of vulnerable healthcare service users and online third places (Rosenbaum and Smallwood, 2013). Third places are traditionally physical places such as coffee shops, where consumers can meet. However, they can also be non-physical places, such as online communities (Parkinson *et al.*, 2017). The present research suggests, however, that some vulnerable healthcare service users are less able to benefit from online third places due to their lack of skills and knowledge. As vulnerable healthcare service users face additional challenges, it is important to identify what type of challenges they encounter and how this

affects their outcomes (Rosenbaum *et al.*, 2018; Sharma *et al.*, 2017). In this article, difficulties encountered by vulnerable members during the RI process were investigated.

By investigating HL as a barrier to RI, this article addresses an important gap in the literature regarding how to design services for the inclusion of vulnerable consumers (Rosenbaum *et al.*, 2018) and help them to optimize value creation for them (Edwards *et al.*, 2018). According to our findings, healthcare professionals may play an important role, in the case of low HL, by showing readiness to listen to those patients' inquiries, dedicating time to answer their (non-medical) questions and being open to discuss information brought from these online communities. This could imply extending the roles and activities of healthcare professionals, especially in a cancer context where support is found to be critical. Vulnerable users encounter more difficulties in terms of online information processing and obtaining support. Without contributions from medical professionals their RI could be compromised, which could affect their well-being and quality-of-life negatively.

Through this research, a contribution was made to the literature on online communities. Most existing research considers there to be a direct relationship between participation in online communities and the user's outcomes (Yao *et al.*, 2015). This research shows that benefits from participation in OHCs mainly depend on the RI process, in line with McColl-Kennedy *et al.* (2017b). In addition, existing literature stressed the importance to better understand the barriers to RI especially in the context of online communities (Jayanti and Singh, 2010). Therefore, this study investigated how HL acts as a barrier of the integration of online resources, and explored the conditions under which this process could be mitigated especially for low HL patients. In addition, the particularity of the cancer disease context makes this study unique as these patients are fundamentally vulnerable because of the nature of their disease, making them physically, psychologically and socially disadvantaged. In this context, most patients tend to use these platforms motivated by negative emotions like anxiety, stress

or loneliness, or depression compared to other online communities in which people participate because of more positive motives, such as enjoyment, pleasure or to enhance social interactions, etc. It is therefore expected that the integration of resources from health online communities would be different from other types of online communities. Furthermore, given the severity and high risks associated with cancer, the integration of resources from related online communities is expected to be different from the integration process from online communities about less severe or serious diseases. Although OHCs could offer much support to cancer patients, how these resources are integrated may affect the quality-of-life of these vulnerable patients negatively or positively. Findings also show that these patients are double penalized for low HL levels. The lower their HL levels, the more they are at a disadvantage to benefit from this OHC. In this specific context, the role of health professionals appears crucial as they are expected to play a complementary role to the OHC in monitoring the integration of resources by low HL patients. The absence of such support will put these patients, i.e., their well-being, at risk.

Managerial implications

The results show that vulnerable healthcare service users are less likely to benefit from their participation in OHCs. Based on the strategies used by vulnerable OHC members, managerial recommendations can be made to (1) designers of online communities, (2) healthcare professionals and (3) public institutions. First, service practitioners need to be aware that some healthcare service users are more vulnerable than others, which may affect their experience and service outcomes (Rosenbaum *et al.*, 2017). Actions should thus be implemented to help health professionals better assess HL levels. Thus, they could adapt their discourse, behaviors and attitudes. Vulnerable patients appear less likely to ask questions about OHC information to health professionals. However, when the health professional is perceived to be open to discussion, this barrier can be better managed. In such a way, inequalities between vulnerable

healthcare service users and others could be diminished. Given the increasing use of shared medical records by all healthcare stakeholders, it would be interesting to include information about HL levels in these files.

OHC members frequently use other sources of information for triangulation purposes. However, the most vulnerable ones sometimes avoid this strategy, because they fear to be distraught by too much information. Community designers may facilitate using this strategy by suggesting links towards reliable websites or reference books that might facilitate the choice for the most relevant references. OHC members also discuss information they find on the community with their medical team. However, some members, due to their low level of understanding of the topic, tend to use this strategy less often. Community designers could develop tools for them, encouraging them to involve their medical teams in the management of their health. This could be done in different ways. Firstly, it might be interesting to proactively sensitize professionals in hospitals to the potential value of these platforms and their potential benefits to patients.

It is generally difficult to control patients' use of online platforms. Therefore, policy makers should reflect on the role of professionals in the interconnected world and think of mechanisms that facilitate the integration of these OHCs in healthcare ecosystems. For instance, while in some countries the duration of medical consultations decreases, in the specific context of chronic diseases and more precisely in the context of cancer, allowing medical professionals to extend consultation times for these patients is highly recommended. This would put less pressure on professionals, which could positively impact their predisposition to listen and respond to patients' inquiries. However, as face-to-face encounters remain the most common in the cancer context, extending duration of consultation would not be feasible. Given the limited time, this would affect the number of daily appointments that medical teams might schedule and therefore the number of patients that they could serve. Accordingly, using

assistive technologies would be of great help in such a context, for instance using an OHC on which patients and medical teams could interact could facilitate interventions and support from professionals when needed.

Furthermore, many countries appear to take an erroneous approach, using ad campaigns to demonize these peer-to-peer platforms, and prevent patients from online medical information use. Instead, policy makers should invest in educating patients on how to critically use these platforms and how to approach these online resources. Communication that emphasizes the importance to involve professionals and seek their support to answer questions would be more beneficial. As it is difficult to completely prevent or prohibit the use of unfit online health resources, educating people to better understand medical information also seems crucial. Education involves learning to focus on relevant and reliable sources of information. It is also necessary to educate people how to navigate health-related online content. Thus, low HL users may then be better prepared to use the resources they will have acquired online. Furthermore, at ultimate scenario especially for chronic disease, launching a professional or government hosted online communities could help prevent misuse of peer-to-peer online platforms. Even though this might be an expensive solution, for specific diseases like cancer, where patients' well-being could be compromised and the patient experience could be affected with what is shared online, professionally hosted communities could help to reduce risks, and increase trust in online communities. Designing dedicated communities, managed by professionals, will help to better monitor them. In the case of pure peer-to-peer platforms, strengthening the presence and involvement of professionals is strongly encouraged. This could be facilitated by technology. Chatbots could for instance be used to increase interaction with professionals, when having questions, and to provide more appropriate and personalized support.

Limitations and avenues for future research

Findings were based on the analysis of information from multiple sources. Even though the suggested guidelines for qualitative research were respected, this research remains largely exploratory in nature. First, data were collected among members of one OHC. Each community has its own objectives and design, which may affect how members handle the RI process. For example, some communities are managed by a healthcare organization (such as a cancer treatment center). The information provided on this type of social media platforms may be perceived as more reliable by the members and/or these members may feel more at liberty to discuss the content of the social media with the medical team. It could thus be interesting to compare the RI processes between communities that have different characteristics.

Members participated in the study on a voluntary basis. Consequently, they may not be fully representative of all community members. The patients who responded to the survey and who accepted to take part in the interview might be the most frequently participating members and/or those who get most benefits from their participation in the community. Therefore, additional insight might be obtained when people who left the community would also be interviewed. In addition, a longitudinal design would help develop a more detailed understanding of the sequences of the three RI practices that were identified, as this process may be non-linear.

This study mainly focused on support *received* by OHC members. However, most respondents also *provide* support to other members. It would be interesting to study to what extent the effects of both, social support received and provided, influence the outcomes for the members and for the online community (Yang *et al.*, 2017).

In addition, exploring the patient's *network* would be very insightful in this context. Interviewing their medical team, family and friends could enrich the results. Situational or individual factors might affect the RI process. For example, users with more social support from family and friends could be more inclined to discuss the information found on the online

community within their network. Some may be reluctant to discuss information with unfamiliar people, like other community members, due to personality traits or out of fear to disclose personal information on the Internet.

HL seems to be highly relevant when it comes to OHC use in cure and care contexts for cancer patients. However, OHCs are equally important for many other diseases and even for prevention purposes. Even in case of less risky diseases, low HL could hinder patients in dealing with online resources. With the proliferation of peer-to-peer platforms, fake information and unreliable content are increasingly available, which puts health and well-being of patients at risk. For example, in the case of the corona virus epidemic, in the absence of well-organized and reliable campaigns from professionals and policy makers, online platforms became more powerful and took over the institutions' role in providing information, advice and support. Citizens' reactions (e.g., panic) to OHC content are likely to be influenced by their level of HL. Accordingly, studying HL further in various contexts may make sense.

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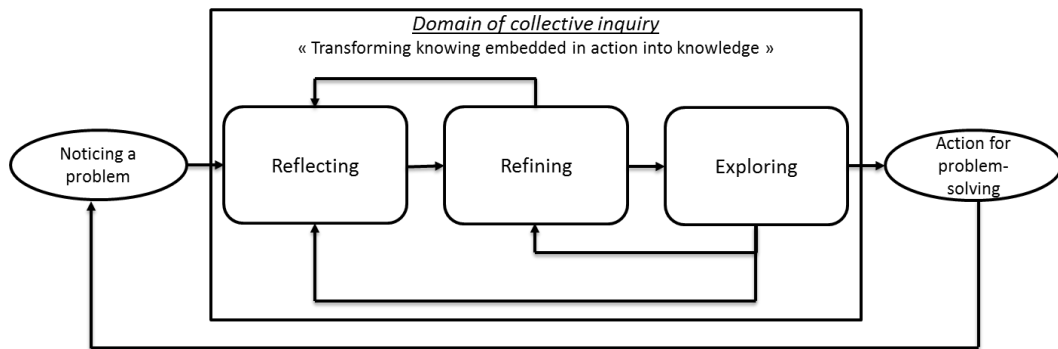


Figure 1: Process of resource integration based on the inquiry-action framework developed by Jayanti and Singh (2010)

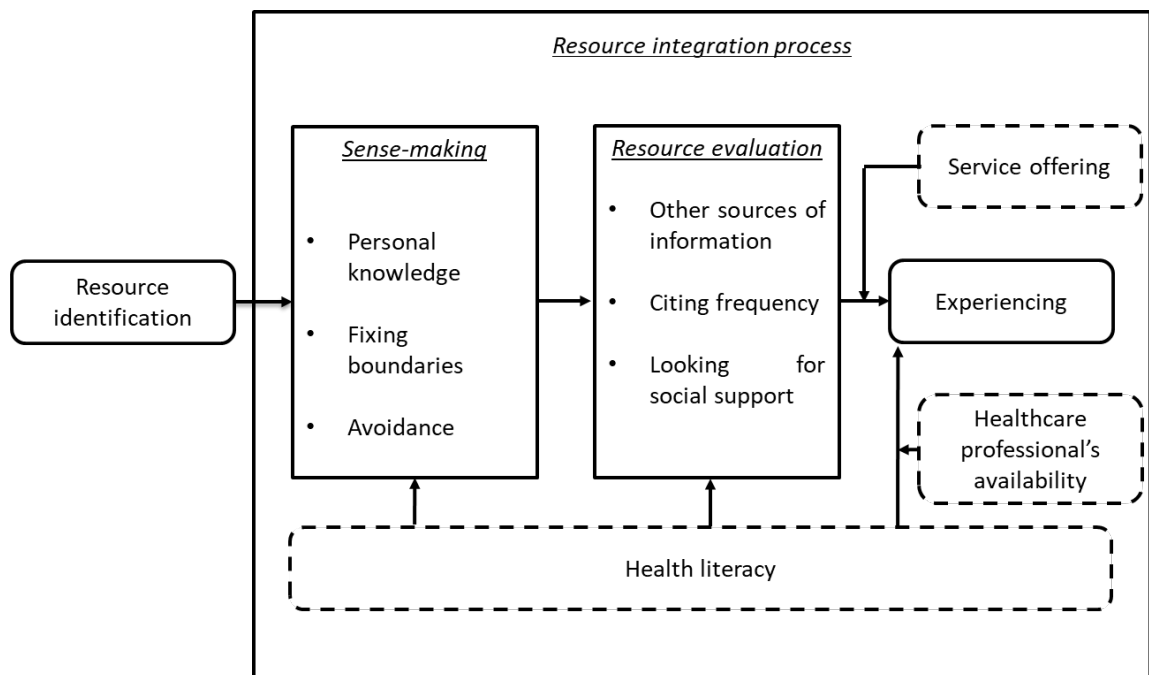


Figure 2: The process of resource integration

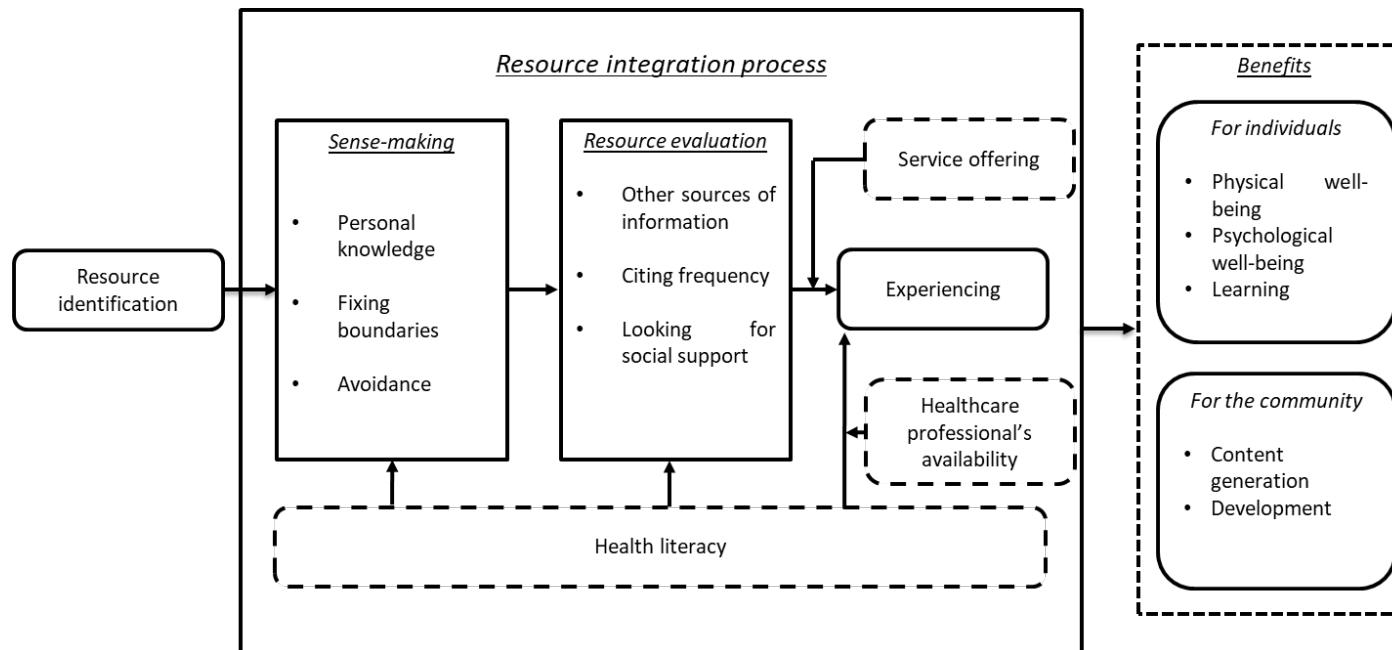


Figure 3: The process of resource integration and its consequences

Category of consequences	Examples	Selected references
Preventive health behavior	Active provider choice, cancer risky behavior, emergency department use, knowledge about the factors associated with cancer (smoking, diet, obesity), self-reported lifestyle risk-factors (associated with cancer).	White <i>et al.</i> (2008), Diviani <i>et al.</i> (2016), Adams <i>et al.</i> (2013), Ueno <i>et al.</i> (2013)
Healthcare behavior	Self-care activities, self-management activities, medication and non-medication adherence, use of active ingredient information, information seeking	Lee <i>et al.</i> (2016), Miller-Matero <i>et al.</i> (2016), Geboers <i>et al.</i> (2014), Husson <i>et al.</i> (2015).
Health outcomes	Morbidity, likelihood to receive the adequate care, likelihood to be readmitted	Heijmans <i>et al.</i> (2015), Miller-Matero <i>et al.</i> (2016)
Patient-healthcare provider relationship	Perceived information provision, satisfaction with information provision, not feeling like a partner	Verkissen <i>et al.</i> (2014), Otal <i>et al.</i> (2012)
Quality-of-life	Health-related quality-of-life, physical well-being, mental well-being	Lee <i>et al.</i> (2016)
Patient's skills or perceived skills	Self-efficacy, knowledge about the disease, attitude/beliefs towards the disease	Lee <i>et al.</i> (2016), Federman <i>et al.</i> (2013), Mantwill and Schulz (2017)

Table 1: Consequences of low HL

Results of the factor analysis					
In reading instructions or leaflets from hospital, pharmacies or on the community, how often do you find	Factors			Descriptive statistics	
	Advanced HL	Functional HL	Reliability	Mean	SD
Characters and words that you do not know		.860	0.88	3.83	0.78
That the content is too difficult		.925			
That you need a long time to understand them		.910			
That you need someone to understand them		.721			
Since being diagnosed / when you were ill, how difficult is it for you to:					
Collect information from various sources	.500		0.84	2.88	0.72
Apply the obtained information to your daily life	.785				
Consider whether the information is applicable to your situation	.815				
Consider the validity and the reliability of the information	.900				
Check whether the information is valid and reliable	.900				

Table 2: Results of the factor analysis

Clusters	N	Mean	SD	t	Sign.
Knowledgeable members	45	4.24	.67	5.430	0.000
Novice members	55	3.50	.70		

Table 3: Results of the t-test on functional HL

Clusters	N	Mean	SD	t	Sign.
Knowledgeable members	45	3.53	.40	14.439	0.000
Novice members	55	2.35	.41		

Table 4: Results of the t-test on advanced HL

Members #	Level of HL	Stage of the disease	Age
1	Knowledgeable	Remission	53
2	Novice	In treatment	48
3	Knowledgeable	In treatment	69
4	Novice	Remission	59
5	Novice	In treatment	54
6	Novice	In treatment	30
7	Knowledgeable	Remission	58
8	Novice	In treatment	43
9	Novice	In treatment	57
10	Novice	Remission	54
11	Knowledgeable	Remission	50
12	Knowledgeable	In treatment	49
13	Novice	In treatment	38
14	Knowledgeable	In treatment	54
15	Novice	In treatment	56

Table 5: Sample description

		Frequency of connection				Total
		Between one and two times a week	Between three and four times a week	Between five and six times a week	Everyday	
Membership duration	> 3 months and < 6 months	1	1	0	1	3
	> 6 months and < 1 year	0	1	3	3	7
	More than 1 year	1	1	0	3	5
Total		2	3	3	7	15

Table 6: Membership duration and frequency of connection of the respondents

	Novice		Knowledgeable	
	Number of respondents	Examples of quotes	Number of members	Examples of quotes
Looking for social support	4 (out of 9)	If the solution suggested is more medical, I will ask my physician's opinion. (...) I can freely ask questions. If it is something that it not dangerous or medical, he will say that I can try. But if it is potentially dangerous, he will give a clear advice. (Member 6)	5 (out of 6)	<i>“When there is advice about food that may affect the treatment, I will always ask the medical team's opinion. I want to avoid doing something bad.”</i> (Member 3)
		A member read on the community that doing sports was very good even during the treatment. But he was skeptical and decided to look for support among his medical team. <i>“Sports I discussed with my doctor. He said that it was better to go swimming. I think I will do that”</i> . (Member 2)		A member read on the community that she could use a natural product for hair coloration immediately after the chemotherapy. She looked for more information about it and finally decided to ask the question to somebody in the cancer center <i>“I also discussed it with professionals. Like for the hair coloration, I discussed it with the social-hairdresser.”</i> (Member 14)
		<i>“When I find some information, often I will ask my oncologist's opinion.”</i> (Member 8)		
		The member read about another member's experience with Sophrology. It helped her a lot. Member 13 thus decided that it could also be of interest for herself. <i>“Regarding Sophrology, I talked with the radiologist. She told me that it might help, but that I should be careful because there are a lot of scams. People may abuse our vulnerability, for example regarding the costs of the session”</i> (Member 13).		
		<i>“No... I don't discuss it with my oncologist or with the nurses. I think they don't have time... They will not appreciate it...”</i> (Member 4)		
Other sources of information	3 (out of 9)	Recently I wanted to have more information about the post-cancer follow-up. I read that people had exams every six months. (...) I search on the community and through a link suggested on the network, I simply find the information. (Member 5)	5 (out of 6)	<i>“About the hormone therapy for example, some discussions encouraged me to go further in my research. I read articles about experiments in Canada and in Germany, for example.”</i> (Member 3)
		<i>To be sure of the information, we also try to check it on other websites or on another network”</i> . (Member 6)		<i>“Yes, I also check the information on other websites, but I also try to use an institutional website, as a matter of reliability.”</i> (Member 12)

Recurrence	2 (out of 9)	<i>"I had problems with the hormone therapy. I was admitted to emergency because of the treatment. And I decided to quit until the next appointment with the oncologist. Somebody also advised that on the network. Thus, it reassured me (...)"</i> . (Member 15)	2 (out of 6)	<i>"When I get an answer, I will always privilege the solutions suggested by multiple members."</i> (Member 7)
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Table 7: Resource evaluations of novice vs. knowledgeable member

Dimension	Experiencing Examples of quotes
Integration	<p>"For example, for the nail polish, I searched on the community the brand that was suggested and for a shop. That way, I was sure that it was a reliable sales outlet." (Member 5, Novice) (The member had read on the community that using nail polish during chemotherapy reduces the risk of nail loss. To experience this resource, she looks on the community for a brand of nail polish to avoid taking a product that was unreliable).</p> <p>Member 11 read about many positive experiences about doing a cure after the treatments. She decided to apply this solution for herself. "I would never have thought of doing a cure after the treatment. But it really helps me to cope with the pain" (Member 11, Knowledgeable)</p> <p>"Recently somebody posted a video about practicing Pilates. (...) And I tried Pilates and it is true that it helps (...) even if it is hard to start, because we are not physically fit. And to see other people doing the same is reassuring and motivates to continue doing it." (Member 15, Novice)</p>
Adaptation	<p>"It also helps during chemo. Because for the first session, I didn't know how it was working so I ate a lot before. Because I thought that, after, I would be sick. But it was horrible, because I had nausea. Then I read on the network that some members fasted before the session. Then I tried eating very light the day before the chemo. (...) But I didn't want to fast, because I really like to eat (...) And it is true that the side effects were less hard to support. (...)". (Member 6, Novice)</p>
Discard	<p>"For example, some members mentioned acupuncture as potentially helpful, but there was no help offered close to my home". (Member 13, Novice)</p>

Table 8: Experiencing

Type of benefits	Examples of quotes	
	Novice members	Knowledgeable members
Psychological	“(…) at the psychological level it is very important. I get a lot of psychological support on the community. (…) We have the impression to be there for somebody. It helps to see that we are not alone”. (Member 4)	“We can speak about all the topics, without taboo (…) Especially for people who are alone. And even with family you cannot speak about everything when it is about cancer”. (Member 7)
	“Sometimes we are lost. For example, when hair falls out it is disastrous. And people who are not sick say that it will grow back, but the patient hates to hear that. But people sharing the same experience rather give advice on how to deal with it and emotional support”. (Member 9)	“For example, I posted a message because I had pain. Of course, I knew that nobody was able to make a diagnostic. But to know that others had the same pain. (…) It was reassuring”. (Member 12)
	“It also helps, at the psychological level, to know that there is always somebody to answer your questions, that you are not alone”. (Member 8)	“For example, I had information about hair loss. And it helped me because I was prepared. (…) It helped me psychologically”. (Member 14)
Physical	“It also helps during the chemo. Because for the first session, I didn't know how it was working, so I ate a lot before. Because I thought that after I would be sick. But it was horrible, because I had nausea. Then I read on the network that some members fasted before the session. Then I tried eating very light the day before the chemo. And it is true that the side effects were less difficult to support. (…)” (Member 6)	“Yes, because the program in which I took part really helps me at the physical level. When I go there I am tired, but it helps me to manage the pain”. (Member 1)
	“It also helps me to cope with the side effects. For example, I did sports as it was recommended on the community. (…) But practicing sports helps me to cope with the tiredness”. (Member 8)	“For example, I tried phytotherapy and it helps me a lot at the physical level. (…) For example, I also needed to find something to replace the sports that I had to quit. And the community helped me to find something. It helps me to deal with the level of pain”. (Member 3)
	“For example, thanks to the advice to apply a lotion on my nails, I will not lose them”. (Member 13)	
Learning	“Now I pay more attention to what I am saying, to the words I use to speak to people. (…) Because I know that I already shocked some people”. (Member 3)	“It also allows me to discover new therapies. Even if I don't use them, it is nice to know that there exist solutions”. (Member 7)
	“Thanks to the community, I became a little bit more knowledgeable. (…) when you are alone, like me, you need to become a little bit smarter to be able to ask specific questions to the physicians. If you ask very specific questions, they cannot avoid giving you an answer”. (Member 5)	“I learned a few things on the network like the importance of supportive care”. (Member 7)

Table 9: Benefits of participation in health-related online communities at the individual level

Types of benefits	Examples of quotes
Content generation	“When I try something that somebody on the community advised me, I always post a feedback on the community. I think it is nice to share with other people”. (Member 1)
	“When I find interesting addresses, I share them with other members (...). It is also our job to add information, to enrich the network. (Member 14)
	“I shared the information I got at the social-hairdresser. She gave me the name of a 100% natural dye”. (Member 14)
Development of the community	“For example, I read something about the PETSCAN on "increasing my knowledge" and I asked additional information from members on the community. And when I received this information, I said to the community manager that this information was missing in the section "enrichir mes connaissances"”. (Member 3)
	“By participating to a race for people with cancer, I met a woman who is creating accessories for people with cancer. I took the information and I suggested to add this comment in the “Neighborhood resources”. (Member 7)
	“I informed myself about the lymphoedema and I developed a section on the topic with the community manager”. (Member 10)

Table 10: Benefits of participation in health-related online communities at the community level

Appendix 1

Codes	Sub-codes
Resources	
	Information
	Emotional support
Resource integration process stages	
	<i>Sense-making</i>
	<i>Resource evaluation</i>
	<i>Experiencing</i>
Individual benefits	
	Physical well-being
	Psychological well-being
	<i>Learning</i>
Benefits for the community	
	<i>Content generation</i>
	<i>Development</i>
Strategies	
	<i>Other sources of information</i>
	<i>Citing requery</i>
	<i>Social support</i>
	<i>Personal knowledge</i>
	<i>Fixing boundaries</i>
	<i>Avoidance</i>
Barriers	
	Health literacy
	<i>Service offering</i>
	<i>Healthcare professional's availability</i>

Table 11: The coding scheme