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Sharing is caring: the everyday informal exchange of health information among adults aged fifty and over

Martijn Huisman, Daniël Biltereyst, and Stijn Joye.

Introduction. Most studies on information behaviour focus on individual behaviour, predominantly seeking, scanning and avoiding. This paper explores sharing, the understudied informal exchange of health information in everyday social settings.

Method. Forty qualitative in-depth interviews were held with adults in the age range of fifty to eighty in Flanders, the Dutch-speaking northern part of Belgium.

Analysis. Thematic data analysis was carried out to identify and single out sharing behaviour. Using a grounded analysis approach, data findings were compared with and placed within the literature and conceptual frameworks.

Results. The study finds that health information sharing is a common and frequently occurring type of health information behaviour, embedded in everyday social and supportive interactions. The sharing of knowledge, experiences and advice takes place intentionally and in a

premeditated fashion, as well as spontaneously and unintentionally when opportunities arise. Respondents observe and learn from others about health conditions, although the doctor remains the foremost expert.

Conclusions. Driven by social motivations, sharing plays an important role in the acquisition, exchange and circulation of health information. This suggests that more attention should be paid to the social, collective and collaborative aspects of information behaviour, specifically everyday information sharing.

Introduction

Traditionally, information behaviour research has focused on the seeking, scanning, and avoiding of information by individuals and their use, or non-use, of information (Case and Given, <u>2016</u>; Johnson and Case, <u>2012</u>; Talja, <u>2002</u>; Talja and Hansen, <u>2006</u>; Wilson, <u>2010</u>). Although situated within information behaviour studies as individual activities, information seeking and other types of information acquisition are embedded in daily social life (Talja, <u>2002</u>; Almehmadi et al., <u>2014</u>) and its '*interactive networks of social relationships*' (Veinot, <u>2009</u>, p. 2329), thus are inherently social by nature. Cline (<u>2011</u>) argues in this context that everyday social interactions play an important role in health management and the dissemination of health information. Past research has shown that people tend to prefer the easiest way of acquiring

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information, which is usually by asking others (Case and Given, <u>2016</u>; McKenzie, <u>2003</u>). Interpersonal conversations are a common source of obtaining health information (Dutta-Bergman, <u>2004</u>; McKenzie, <u>2003</u>), in fact often the preferred way due to its immediacy and opportunities for feedback and social support (Johnson and Case, <u>2012</u>; Liu et al., <u>2019</u>; Wilson, <u>1997</u>). Collaborative information behaviour, including sharing, has thus been described as common and a natural aspect of information engagement (McKenzie, <u>2003</u>; Rioux, <u>2005</u>; Savolainen, <u>2007</u>; Talja and Hansen, <u>2006</u>). For instance, people not only seek out information for themselves, but also on behalf of others (Fox and Jones, <u>2009</u>; Rioux, <u>2005</u>; Veinot, <u>2009</u>). In this paper we argue that to ignore social, collective and collaborative aspects is to miss out on important facets of (health) information behaviour (McKenzie, <u>2003</u>; Talja, <u>2002</u>). Our article examines the sharing of health information in everyday social interactions among adults aged fifty to eighty. Does sharing translate into caring in the context of health information?

Pilerot (2012) suggests that the study of information sharing is carried out along the lines of '*unifying dimensions*' (p. 563), such as shared demographics or experiences. We explore information sharing from two unifying dimensions, namely age (adults over fifty) and health. As humans get older and the body and mind age, the likelihood of physical, mental and cognitive ailments and limitations increases (Friemel, 2014), making health a relevant and recurring topic of conversation for many older adults (Williamson, 1998). Williamson found, for instance, that the information needs of 202 Australians aged sixty and over centred primarily upon health, particularly among those who experienced health issues. Health has become an important field of study in the twenty-first century, for people are increasingly expected to take an active role in their health management and participate in treatment decision-making processes (Dutta-Bergman, 2004; Johnson and Case, 2012). With greater individual health responsibility, health information becomes more important if not crucial (Johnson and Case, 2012), making the study of health information behaviour both pertinent and meaningful.

To date, few studies have examined health information sharing, let alone among older adults (Liu et al., <u>2019</u>). In response to a lack of research, our paper examines the everyday sharing of health information among the growing demographic group of adults aged fifty and older. The following research question is addressed: what kind of health information-sharing behaviour takes place among Flemish adults aged fifty to eighty and with what outcomes and results? It should be noted that we study information sharing in everyday social settings outside the walls of the medical establishment and professional discourses: sharing health information with a physician falls outside the scope of this research. The following sections draw upon information behaviour and communication studies to outline the social, communicative and health contexts in which health information sharing is embedded and takes place.

Background

Health information behaviour

Information behaviour is a sub-discipline which emerged from the field of library and information science (Case and Given, 2016). Information behaviour as an umbrella concept consists of both active and passive modes of information engagement and use. Wilson (2000) defines information behaviour as 'the totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use' (p. 49). A large body of research exists, which is discussed in works by Wilson (1999), Godbold (2006), Case and Given (2016), and Johnson and Case (2012) among others. Within information behaviour studies, the study and issue of health takes a unique place as it distinguishes itself as a crucial aspect of life. Health information can improve quality of life and potentially save lives, whereas a lack of information or the wrong information can have damaging and dramatic effects (Johnson and Case, 2012; Li et al., 2018). Compared to general information behaviour, health information behaviour is more personal, private and sensitive (Greene, 2009; Li et al., 2018) and with greater emotional impact considering the health-related decisions and consequences (Wilson, 1997). Furthermore, uncertainty, stress and coping are prominent phenomena in the context of health information behaviour, as feeling unwell or being diagnosed with illness might give rise to concern and feelings of anxiety and fear (Brashers, 2001; Brashers et al., 2004; Wilson, 1997).

Information behaviour studies have traditionally covered three *usual suspects*, namely seeking, scanning and avoiding information. First, seeking, also called searching, is by far the most studied, as exemplified by the

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work of Wilson (<u>1997, 1999, 2000</u>). It is defined as the intentional, goal-oriented act of actively finding information in response to a perceived need or want (Case and Given, <u>2016</u>; Johnson and Case, <u>2012</u>; Wilson, <u>2000</u>). Secondly, scanning, also known as information encountering or information exposure (Case and Given, <u>2016</u>), is defined as the non-purposeful and unintentional acquiring of information through exposure to routinely used sources of information, both interpersonal and mediated (Niederdeppe et al., <u>2007</u>; Hornik et al., <u>2013</u>; Kelly et al., <u>2010</u>). Scanning behaviour plays a significant role in how we engage with information, as scanning takes place more often than actively seeking out information (Niederdeppe et al., <u>2007</u>; Hornik et al., <u>2013</u>; Kelly et al., <u>2010</u>). Third, avoiding is a common and purposeful non-seeking behaviour (Case and Given, <u>2016</u>) with various underlying psychological, situational and motivational influences. Avoiding information can help to resist overexposure or information overload (Bawden and Robinson, <u>2009</u>). Within the health context, avoiding might limit anxiety levels, help users to remain optimistic, and maintain boundaries between health and daily life (Barbour et al., <u>2012</u>).

Health communication and information behaviour studies have traditionally focused on individual, formal and planned health information engagements, such as interactions between patients and physicians or individuals seeking information on the Internet (Case and Given, <u>2016</u>; Johnson and Case, <u>2012</u>; Liu et al., <u>2019</u>; Talja, <u>2002</u>). Health information is also obtained, exchanged, circulated and used in informal face-to-face and mediated everyday life interactions (Cline, <u>2011</u>). Health information is, in other words, shared.

Health information sharing

Sharing can be understood as a communicative activity and as a label within information behaviour research for a type of information behaviour (Pilerot, 2012). As an activity, sharing refers to interactions in which health information is exchanged, typically within a dyad such as physician-patient, partner to partner or parent to child (Johnson and Case, 2012; Savolainen, 2017). Importantly, by using the term exchange the reciprocal and multidirectional nature of information sharing is recognised (Savolainen, 2017) and emphasised as fundamental to human interaction (Wilson, 2010). Although subject to increasing attention in recent years (Case and Given, 2016), sharing remains an understudied and underdeveloped information behaviour concept that is 'relatively unexplored' (Wilson, 2010, Abstract), although considered a 'promising research area in health communication' (Liu et al., 2019, p. 1824). Savolainen (2017) suggests that a limited amount of work has been done as information sharing is difficult to define and delineate. It is challenging to study as it takes place in everyday ordinary life and is often implicit, unstructured, and interwoven into social contexts, activities and interactions (Cline, 2011; Veinot, 2009). Furthermore, the individual concepts of information and sharing carry a wide array of meanings, without consensus about their definition or how to operationalise and study them (Case and Given, 2016; Pilerot, 2012; Savolainen, 2017). Pilerot (2012) talks about a 'prevailing conceptual multitude and vagueness' (p. 559), while Savolainen (2017, Discussion, para. 3) suggests that the multiplicity of meanings makes information sharing a 'multi-faceted communicative phenomenon'.

Information sharing has been studied in a variety of disciplines, chiefly exploring the professional and formal collaboration of co-workers and sharing of information within academic, business and industrial environments (Almehmadi et al., 2014; Case and Given, 2016; Pilerot, 2012; Savolainen, 2017; Talja, 2002; Talja and Hansen, 2006; Wilson, 2010), but to a limited extent in the context of health (Johnson and Case, 2012; Veinot, 2009). These studies have focused on who is sharing, what is being shared, and the location or place where the sharing takes place (Pilerot, 2012). Within the realm of health, studies have largely explored information sharing processes between patients and physicians or between physicians and medical teams (Johnson and Case, 2012; Veinot, 2009; Wilson, 2010). Since the emergence of Web 2.0 and digital platforms which facilitate uploading and sharing health information (Lin et al., 2016; Li et al., 2018), researchers have investigated online and face-to-face interactions as complementary social settings in which information is exchanged (Savolainen, 2017). Recent studies have increasingly focused on the online sharing of health information (De Choudhury et al., 2014), particularly the facilitating role of social media platforms (Dong et al., 2019; Li et al., 2018; Zhang et al., 2016).

The everyday sharing of health information in face-to-face settings has received little attention (Liu et al., <u>2019</u>), even though the social life of older adults probably takes place outside of the digital sphere (Friemel, <u>2014</u>) and family members and friends were respectively the first and third most used sources of information for Australians over the age of sixty (Williamson, <u>1998</u>). Moreover, past research found that as many as two-thirds of Internet users talk to others about health information obtained online (Fox and Jones, <u>2009</u>). While

little research has been carried out about interpersonal face-to-face health information sharing interactions (Case and Given, 2016; Johnson and Case, 2012; Liu et al., 2019; Veinot, 2009), these studies do clearly underwrite that health information sharing is a common aspect of daily life. Pettigrew (1999) found that the information needs of senior customers at a foot clinic were satisfied by casual small talk and chatting about life with the clinic staff. Fu et al. (2017) and Liu et al. (2019) found that interpersonal communication was an important source of health information for respectively chronic patients and older adults in rural China. Liu et al. (2019) suggest that the likelihood of sharing health information depends on individual levels of health knowledge, the ability to communicate information to others, and the quantity and quality of relationships in which information might be shared. To gain a deeper understanding and properly contextualise the sharing of health information, we turn to the integral concepts of self-disclosure and support.

Self-disclosure

Wilson (2010) suggests that the social context (i.e., the relationship between sharer and receiver) and the nature of the information decides the likelihood of information being shared. He argues that information sharing most likely takes place when there is a perceived positive risk and reward outcome, i.e., low or acceptable risk and high benefit. When thinking about personal health information, these considerations carry additional weight. Sharing one's personal health status requires openness and involves vulnerability as well as potential risks and negative outcomes, for example when divulging dangerous or taboo health conditions to family members or employers (Greene, 2009; Wilson, 2010). In the context of serious and chronic health conditions, self-disclosure has been found to be an important strategy to manage personal health-related information (Checton and Greene, 2015). Self-disclosure can be understood as an interaction between at least two people whereby one deliberately discloses personal information (Greene, 2009), expecting reciprocity (Savolainen, 2007; Wilson, 2010) and hoping for disclosure, encouragement and/or support from the other person (Lin et al., 2016). Linked to thinking out loud, catharsis (i.e., expressing, venting), as well as seeking help and support, self-disclosure has been found beneficial to physical and mental well-being (Checton and Greene, 2015; Greene, 2009; Hawkley and Cacioppo, 2010; Lin et al., 2016; Luo et al., 2012).

The health disclosure decision-making model (Greene, 2009; Checton and Greene, 2015) suggests that the decision to share health information depends on the nature of the information and an assessment of the potential information receiver. People are more likely to share when there is social proximity and the other person is trusted (Greene, 2009; Lin et al., 2016; Wilson, 2010), confirming that relational quality (i.e., degree of closeness) or tie-strength (Granovetter, 1973, 1982; Haythornthwaite, 1996) is decisive in deciding to self-disclose. Further considerations to self-disclosing health information include the perceived level of availability, approachability, discreetness and being non-judgemental of the potential information receiver (Checton and Greene, 2015; Greene, 2009; Veinot, 2009). Finally, the anticipated relevance to the other (Almehmadi et al., 2014) and the support which can be expected are important factors in assessing the benefits and risks of disclosing health information (Greene, 2009; Checton and Greene, 2015).

Support

Besides understanding and encouragement, people hope to receive support when they self-disclose about their health (Johnson and Case, 2012; Veinot, 2009). Seeking support is a coping strategy employed by individuals in stressful situations (MacGeorge et al., 2011), such as acute and chronic health problems (Brashers, 2001; Veinot, 2009). Support comes in various ways but can be divided roughly into informational and emotional support (Johnson and Case, 2012). The former refers to attempting to understand and control one's environment and health condition, while the latter relates to coping, self-esteem, and expressions of acceptance, care, solidarity and connectedness (Goldsmith and Albrecht, 2011; Johnson and Case, 2012; MacGeorge et al., 2011).

Past research shows that health is embedded in supportive interactions, which are 'verbal and nonverbal behaviour produced with the intention of providing assistance to others perceived as needing that aid' (MacGeorge et al., 2011, p. 317). Supportive interactions take place in everyday settings within social networks and might involve partners, family members, friends, neighbours, co-workers and other acquaintances (Cline, 2011; Goldsmith and Albrecht, 2011), with relatives recognised as the most important providers of support (MacGeorge et al., 2011). Goldsmith and Albrecht (2011) argue that supportive

interactions can enhance individuals' health in multiple ways. First, supportive interactions can be conducive to obtaining and sharing health information, finding proper health care, and determining treatments to pursue (Dutta-Bergman, 2004; Liu et al., 2019; Talja and Hansen, 2006; Veinot, 2009). Secondly, feedback and social control can promote healthy behaviour and the avoidance of health risks (Dutta-Bergman, 2004). Third, effective supportive conversations can communicate acceptance, understanding, and validation, thus enabling the sharing of thoughts, experiences, and emotions (Dutta-Bergman, 2004; Goldsmith and Albrecht, 2011) to relieve stress, stimulate adjustment to the health problem, and even aid in resisting and recovering from illness (MacGeorge et al., 2011; Johnson and Case, 2012). Supportive interactions and outcomes are thus integral to understanding health information sharing and self-disclosure patterns.

Having discussed and contextualised health information sharing and the mechanisms of self-disclosure and support, we now turn to the study design before examining in detail the sharing of health information in everyday social interactions among Flemish adults over the age of fifty.

Study design

Forty in-depth, semi-structured interviews were conducted between April and September 2015 with Flemish adults between the ages of fifty and sixty-four and sixty-five and eighty years old. The age range reflects the larger research project about health news and communication in relation to ageing that this study forms part of. The age cut-off at sixty-five (based on the Belgian retirement age) and the distribution of respondents into age groups were deliberate so as to be able to compare pre- and post-retirement respondents. In doing so, we recognise the heterogeneous nature of people in this age range and the possible vast differences between individuals in terms of health information behaviour. A heterogeneous group of respondents was recruited, not only in terms of age, but also gender and education in order to prevent sample bias. Respondents were all living in or around the city of Ghent in the east of Flanders. They were recruited with the help of local service centres and the organisation OKRA (Open, Kristelijk, Respectvol en Actief [Open, Christian, Respectful and Active]), the largest Flemish association for older adults, by distributing paper surveys. The youngest respondent was fifty-one years of age, the oldest eighty years old, with an average age of sixty-four years, nine months. Eighteen men and twenty-two women participated, with a small tendency towards higher (higher-education (HE); bachelor/master/university degree) and middle (middle education (ME); higher secondary education) education compared to lower (lower education (LE); no degree, primary and lower secondary education) education levels (HE: 35%, ME: 37.5%, LE: 27.5%). Contrary to other health information behaviour research, we did not focus on patients diagnosed with a specific health condition but on the demographic of adults aged fifty and older. Respondents therefore included both diagnosed patients as well as healthy, undiagnosed individuals.

The interviews were conducted using a predefined topic list (Mortelmans, 2013), keeping the questioning as open as possible to fully investigate respondents' attitudes to health and their information behaviour. This stimulated extraordinarily rich conversations and garnered a wealth of insights. The interviews covered the following topics: 1) definitions of health, illness and health information, 2) sources and use of health information, and 3) Alzheimer's disease, sleeping disorders and diabetes as health information cases. All interviewees signed an informed consent form in which the research project and its aims were explained, in which they consented to being recorded and confidentiality was guaranteed. The interviews were recorded, transcribed verbatim and analysed qualitatively. After a thorough first reading of the transcripts and a literature review, we employed semi-open coding by using the NVivo 12 software to identify, single out, and code the relevant parts of the transcripts (Mortelmans, 2013). The coding book was refined through axial coding to narrow down and focus the data until saturation was reached and a final coding frame emerged. Inspired by the grounded theory approach (Glaser and Strauss, 1999) we developed grounded analysis, making ongoing comparisons between the findings from the data and their viability and place within conceptual frameworks and the literature.

The following sections present and discuss the findings of our explorative study of health information sharing among older Flemish adults. Seven themes emerge from the data, namely sharing in everyday life; collaborative sharing behaviour; online sharing; types of information; trust and reliability; outcomes and limitations. Quotes by respondents have been extracted from the transcripts, translated from Dutch into English by the authors, and anonymised to guarantee respondent anonymity.

Results

Sharing in everyday life

Respondents explicitly and implicitly related that health is part of everyday life and social interactions as the body and mind age. Health naturally becomes a conversation topic as people start to suffer from lifestyle diseases (e.g. diabetes) and other health conditions and discomforts related to ageing.

On Saturday we talked with friends about health and being ill. From my age everyone starts to decline. If you are in your sixties, you come into contact with others with problems. (Male, 68, HE)

McKenzie (2003) and Liu et al. (2019) suggest that information can be shared spontaneously and acquired unintentionally, for example when a conversation unexpectedly turns to the topic of health. From our interviews it appears that sharing often takes place spontaneously in social settings as part of everyday interactions, without a premeditated purpose. A polite how are you doing? can turn into a prelude to a conversation in which health is discussed and information is acquired incidentally.

It is a natural thing, like when someone asks you, 'How are you doing? Are you still having troubles?' That is how it starts. (Male, 69, LE)

Health information is also shared intentionally (Liu et al., <u>2019</u>; McKenzie, <u>2003</u>), often taking the shape of asking advice and guidance from patients with relevant experience or someone with a professional background and experience in healthcare. These individuals might serve as trusted sources of valuable and reliable health information.

There are people who know I have diabetes. When they also suddenly start to suffer from diabetes, they ask what diabetes does to me, how I manage it, what I have to do. (Male, 79, LE)

We asked respondents specifically about their knowledge of Alzheimer's disease and diabetes, and how they had learned about these illnesses. Respondents indicate that their knowledge mostly comes from the experiences of others, particularly partners, family members, friends and co-workers. These experiences are not only discussed orally, but often simply observed. This resonates with the study by Veinot (2009), who describes how social proximity to individuals with HIV/AIDS leads to unintentionally acquiring information through exposure, particularly when those with HIV/AIDS talk about their health, experiences and feelings. Similarly, respondents observe and learn through exposure to other people suffering from health conditions.

I will never take sleeping pills. Because I know what my wife takes every day. (Male, 76, LE)

I have known several people with Alzheimer's and yes... that stays with you. It sticks. (Male, 79, LE)

No one in our family has ever had diabetes. I cannot say anything about it. (Female, 71, LE)

Conversely, as the last two quotations illustrate, respondents with little or no knowledge about Alzheimer's or diabetes explicitly state that the reason that they lack knowledge is that they do not personally know anyone suffering from it. In other words, there is a lack of social proximity to an example through which they can acquire knowledge about these health conditions. This suggests the importance of social networks and interactions in spreading health information through experiences as well as observation and monitoring.

Collaborative sharing behaviour

Health information sharing not only takes place in social interactions, but also in the form of collaborative information acquisition. Particularly among partners, relatives, and close friends, illness and not feeling well can lead to what Talja and Hansen (2006, p. 114) call '*collaborative information behavior*' and what Rioux (2005) describes as information-acquisition-and-sharing: health information obtained from mediated sources that is shared with and passed on to others. The passing on of health information particularly takes place

towards older adults who do not use the Internet and are thus limited in the amount of information available to them. As the youngest of five children, the following respondent seeks out information for her older sisters:

We are with five at home and I am the only one who uses a computer. The others are not familiar with it because of their age, so for them it is difficult to find enough information. They rely on me to print out and pass on information. (Female, 55, LE)

Another respondent's sister made him aware of polyps running in the family, which could develop into cancerous tumours. The sister reported her experiences and diagnosis to her brother, who promptly went to the specialist to be checked.

My elder sister passed on information from the specialist, who said to take good care and have it checked out as these things run in the family. So I used that information to have a colonoscopy... (Male, 64, HE)

Online sharing

Only a few respondents mention using the Internet to share health information and experiences. Sharing in everyday face-to-face conversations seems to take place among both male and female respondents regardless of age and education level. From the interviews it appears that younger and higher-educated respondents are more likely to use the Internet for health (information) purposes, which is consistent with past research (Friemel, 2014). Among the few respondents who use the Internet to talk about their health status, two patterns of use can be distinguished. First, some use the chat function of social media platforms (e.g., *Facebook Messenger*) or instant messaging applications such as *WhatsApp* to stay in touch with family, friends and other acquaintances, sometimes sharing a health update and/or inquiring about the health status of the conversation partner. Secondly, on rare occasions, respondents share with and acquire information from strangers or distant acquaintances. The following study participant learned about an alternative breast cancer treatment from someone she had met years before:

I learned from an American woman on Facebook that she had had a very different treatment, and then I wondered why we didn't do that here in Belgium. It was about radiation treatment, which they do after the operation over here and in America during the operation. So I learned about it on Facebook from someone I met before while travelling. (Female, 54, HE)

However, the vast majority of respondents do not use the Internet and social media to share health information, instead preferring face-to-face interaction to the anonymity of the Internet (again pointing out the social aspect of health information sharing) and/or lacking the necessary computer and Internet access and skills.

Types of information

Health information shared by respondents in social interactions comprises information about health and illness on the one hand, and (practical) information about products, medicine, treatments, insurance and reimbursement on the other.. The majority of information shared revolves around symptoms and possible treatments, as this kind of knowledge can help others who are struggling with health issues.

My sister has lymphoma cancer. When I visit her I tell her about the symptoms. We talk about the possible consequences. It gives me a good feeling to know that she can talk about it with someone. (Female, 66, LE)

Importantly, health information sharing is not limited to the exchange of facts, but also includes the exchange of experiences, support and advice. Personal or first-person experiences (experienced by the person sharing) and third-person experiences (from someone not part of the conversation) appear to be the most frequently exchanged types of health information. While first-person experiences are personal stories of self-disclosure, third-person experiences might also take the character of gossip.

Support, one of the desired outcomes of health information sharing, comes in many ways depending on the context and individual needs, ranging from practical help to lending an ear to the problems of others. Limited to communicative support, simply asking how someone is doing can in itself be supportive when going through challenging times.

I am quite a social person. If someone has a problem and they come to me, I will talk to them. Try to reassure them a bit. I am not a doctor, but it always helps to listen so that they can get something off their chest. (Male, 58, LE)

The above respondent is conscious of his social role and offers those in need a chance to talk about their health problems, thus engaging in supportive conversations (MacGeorge et al., 2011). This corresponds with the argument by Savolainen (2007, Literature review, para. 2) that information sharing in non-work contexts often draws upon '*kindness as a social institution*' within social interactions and networks. Support also comes in the form of empathy and letting the other person know that you are trying to understand his or her situation, for example by looking up information.

I want to support her, so I will look up information about what it is and what you can do about it. To understand what it is like, for example when the partner of a friend would suffer from Alzheimer's. (Female, 52, ME)

Health information sharing can also take the form of advice, for instance about lifestyle, homemade treatments, over-the-counter products, and innocent and light health problems such as a cold. Importantly, when it comes to serious health conditions, medical treatments, and prescription medication, the most important advice given by respondents in social interactions is to talk to a doctor.

No, no, no, I will not give any advice. I will say they have to go to the doctor! (Female, 68, ME)

This suggests that respondents not only monitor and evaluate their health status, but also that they have corresponding information attitudes and behaviour, with the doctor being the first point of contact in case of serious health problems.

Trust and reliability

Whether health information sharing takes place online or offline, in a premeditated way or spontaneously, trust is a decisive factor when it comes to sharing health information. While it is beyond the scope of this paper to examine the concept in more detail, trust appears a central aspect for respondents to both sharing information and determining the reliability of information shared by others.

If you talk to someone about your health, it is because you trust that person. I will not talk about my melanoma with a stranger who has had melanoma, because I don't know her. I talk to people I know and trust. (Female, 70, HE)

Interestingly, respondents employ various strategies to establish trust and appraise the reliability of health information shared in social contexts. Primarily, social proximity and the nature of the relationship underpin considerations of self-disclosure as well as placing trust in other people and the health information they share.

When we have friends visiting us, we know them well and we know the value of the information they give. (Male, 66, ME)

Trust is also generated when someone speaks from experience, i.e., being an experienced patient or having a professional background in healthcare. Health information is deemed reliable by respondents when it is shared by someone who has first-hand and relevant experience, rather than third-party experiences or gossip. Furthermore, respondents mention that they compare and validate health information obtained from others by comparing it to their own experiences, particularly in the case of chronic health conditions.

You know when you start a conversation to what extent those people have the experience, or are talking gossip... I will trust people who are active in the medical sector more. (Male, 65, ME)

Lastly, respondents rely on the power of numbers, reasoning that information is more reliable when it is shared and circulated by more than one person.

I listen to different opinions. When you have for example five people who say the same thing, then I think that information is reliable. (Female, 62, LE)

On a critical side note, we can see how the latter strategy might be a reason why modern phenomena such as fake news and (health) misinformation seem to thrive and continue to circulate and be shared: if enough people repeat it, it might be considered reliable and true.

Outcomes

Outcomes of health information sharing can be grouped into two categories: 1) engagement in other types of information behaviour, and 2) personal health management. Information sharing does not stand on its own but is linked to other information behaviour. People often respond to information not only by seeking out more information, but also by sharing or spreading that information by telling others or by documenting it (Godbold, <u>2006</u>). Health information sharing can be a prelude to other types of information behaviour, as well as the result of other types of information behaviour. Exposure to health news on television might lead to sharing that information with someone at a later date. The following respondent encountered information about melanoma in the media and turned it into advice for her daughter:

I heard in the media about the Day of Melanoma. I told my daughter that she has a lot of freckles and birthmarks on her back. That she shouldn't forget about Melanoma Day, as you can have yourself checked for free... (Female, 70, HE)

Conversely, the interviews detail how exposure to shared health information in social settings triggers purposeful health information acquisition, in particular seeking out health information on the Internet. This respondent remarks that casual conversations about health sometimes make her actively seek for health information.

People talk a lot. Sometimes there are things which you use to find more information, finding out that it could be relevant. Those talks are like triggers which makes you seek information. (Female, 64, ME)

The motivation to follow up on shared health information varies from satisfying a curiosity to gaining a better understanding and being able to support someone.

Health information sharing might also help respondents to make sense of their health situation and seek solutions and ways to cope. Newly diagnosed patients might need guidance and seek out support and advice from experienced patients. The following respondent, recently diagnosed with ulcerative colitis, received guidance from an experienced patient, which got him on his way to coping with his inflammatory bowel disease:

I visited that man who also had it, on the first day I was able to. I learned from him what I should do and not do. In terms of diet, and in terms of managing stress. (Male, 51, ME)

Perhaps the most valuable and desirable outcome of health information sharing, receiving and sharing information with others might contribute to filling gaps in knowledge and experience so that individuals can better cope with their health problems.

Limitations

While sharing health information ostensibly has its benefits, it also has its limits. Respondents indicate that information shared in casual interactions is seldom considered serious or proper medical advice or reason to take action beyond visiting the physician. Conversations about health quite often motivate and trigger respondents to visit their doctor.

Maybe I am quite conservative. Even if friends would suggest, 'try this and you will have less pain', I will never do that. But I would ask my doctor about it. Tell him that someone advised me to try this or that. (Female, 65, ME)

Another limitation of health information sharing lies in the fact that respondents recognise that they are not doctors, and that their own knowledge and experiences are limited. They are careful about sharing and giving advice to others and are careful with the information they receive from others, particularly when it comes to serious health conditions and treatments.

I can talk about my own experiences. Or answer if others ask me what might be wrong. But I always say that I am not a doctor, that what I know comes from my own experiences. (Female, 77, HE)

Some people tell me what kind of medication they take. I listen to them, but I don't use the information. I will not go to my doctor and ask if I can also get it. (Male, 58, LE)

One step further is declining to neither talk and share about health with others at all, nor to listen to the health stories and experiences of other people. Beyond the scope of the present research, we intend to explore this non-sharing of health information in a separate study.

Discussion

Our explorative study finds that health information sharing is embedded in everyday social interactions, confirming Cline's (2011) argument that everyday exchanges of health information and support are rooted in social contexts and in the realities and norms of individuals engaging in those interactions. While very few respondents use the Internet and social media to upload and share health information, the majority shares and exchanges health information and experiences in everyday interpersonal social settings. The social aspect of health information sharing is emphasised by the fact that respondents explicitly and implicitly state that much of their knowledge about health and illness comes from observations and the experiences of others. Respondents often seem to learn from others about health conditions such as Alzheimer's disease and diabetes, whereas knowledge is more limited or even lacking in the absence of social proximity to individuals suffering from such conditions. This suggests not only that personal relevance and social proximity can precede information acquisition, but also that sharing is an important source of health information. Similar to information scanning (Niederdeppe et al., 2007; Hornik et al., 2013), we find information sharing to be a common and frequently occurring type of health information behaviour.

The sharing of health information refers both to the transferring of factual messages (e.g., I take X when I have a headache), as well as social contexts of communication in which health features (e.g., How are you doing?) as a way of building and maintaining relationships (Savolainen, 2017). Sharing takes place both intentionally and premeditatedly (self-disclosure) as well as spontaneously and unintentionally when the opportunity arises. This implies that the health disclosure decision-making model by Greene (2009) can only partly explain health information sharing, for the model explicates intentional sharing alone. Both the literature review and the interviews suggest that spontaneous and non-planned instances of health information sharing might be explained within the context of supportive interactions, i.e., informational and emotional support to cope with health problems (Johnson and Case, 2012). While intentional sharing is more like the purposeful information behaviour of seeking information, information shared spontaneously in interactions and acquired unintentionally is more similar to scanning behaviour and exposure. In sum, health information sharing can be both intentional and unintentional, more or less goal-driven, explicit and implicit, and take on the character of collaborative information behaviour.

Johnson and Case (2012) make a distinction between effective and extended social networks. The former consists of strong ties, i.e., partners, family members, friends and others who are close, while extended networks are made up of casual acquaintances and those further away, also called weak ties (Granovetter 1973, 1982; Haythornthwaite, 1996). Our study shows how health information is mainly self-disclosed and shared with strong ties, as they are deemed trustworthy, reliable, accessible and able to assist and support. Greene (2009) calls this information relational in nature, as there is a familial, friendship or other social bond in play underlying the disclosure and sharing of health information. Only occasionally, at least among the

respondents in this study, information is shared with or obtained from strangers or weak ties, i.e., individuals outside of the close circle of relatives and friends.

While health information sharing takes place commonly and frequently, we find that the centrality of the physician on the one hand and respondents recognising the limitations of their own knowledge on the other hand are limiting factors of health information sharing. The doctor seems to have a moderating and controlling position, as respondents evoke the expertise and authority of the physician and appear aware of implicit expectations of what it means to be a good and responsible patient: go to the doctor when something is wrong. Besides innocent suggestions to for example drink tea to sleep better, respondents are careful about giving health advice or acting upon advice received from others, instead (advising them to) visiting the doctor. Despite increased emphasis on individual responsibility and taking an active role in health management and decision making, respondents thus appear to largely rely on their doctor, who remains the first and foremost trusted health expert.

Finally, our findings not only suggest the importance of interpersonal communication in sharing health information, but they also echo Rioux's (2005) concept of information acquiring-and-sharing. We find that different types of health information behaviour overlap and/or lead to one another. Information acquired purposefully (seeking) or accidentally (scanning) might be shared at a later moment with someone else. Conversely, health information shared and obtained in interpersonal settings might trigger individuals to look up more information, usually on the Internet. The interpersonal sharing of health information is often complementary to mediated and digital sources of information, rather than exclusive. Sharing information after all means to exchange that which was previously acquired through interpersonal and/or mediated sources (Rioux, 2005; Talja and Hansen, 2006). Indeed, 'The health knowledge repertoire built by health information seeking and/or scanning is a prerequisite for health information sharing behavior'. (Liu et al., 2019, Health information seeking, scanning and sharing, para 1). Health information sharing is thus in and of itself inexplicably linked to other (mediated) sources of information as well as other types of information behaviour. It makes health information sharing part and parcel of the spectrum of health information behaviour and what we might call the eco-system of health information, that is, health information sharing bridges different types of individual information behaviour (seeking, scanning) as well as interpersonal and mediated sources and channels of information.

Conclusions

Sharing seems to equal caring when it comes to health information. Whereas seeking and scanning are usually individual health information behaviour, health information sharing is driven more by social and altruistic motivations (Liu et al., 2019), with sharing of experiences and advice taking place within everyday supportive interactions. Health as an important conversation and sharing topic in informal everyday social settings points to the importance of social networks and having people around to share with and find support. Johnson and Case (2012) and Liu et al. (2019) note that the quality and quantity of relationships in the interpersonal environment has implications for health attitudes and behaviour. Particularly in the autumn of life, people are faced with bereavement and the loss of partners, family and peers, limiting the amount of close and supportive relationships. An insufficient social network can lead to insufficient support, deteriorating health, and a bigger reliance on and need for medical support (Luo et al., 2012). From a health information behaviour perspective, our study thus underscores the importance of policies aimed at preventing social isolation and loneliness among older adults (Hawkley and Cacioppo, 2010; Luo et al., 2012).

In terms of limitations, the aforementioned difficulty in defining and demarcating information sharing due to how embedded it is in daily social interactions applies to this exploratory study. Future studies might be able to further define and conceptualise (health) information sharing. Due to space constraints, we could not explore in full detail all aspects of everyday information sharing in the context of health, such as reasons to not share. We hope that our exploration will lead to future studies offering deeper and richer insights in (health) information sharing behaviour and outcomes. Such studies might expand the scope to other geographic areas and demographic groups, such as younger adults or adolescents. A quantitative study could moreover shed light on individual and group differences by looking at variables such as age, gender, education, health status and media use and their impact on information sharing. Sharing plays an important role in the acquisition, exchange, and circulation of health information, making health information sharing an important type of information behaviour. While it is admittedly challenging to study the multifaceted concept and activity that is information sharing (Pilerot, 2012; Savolainen, 2017), this should not be reason to ignore it outside of professional contexts. We suggest that more attention be given to the phenomenon of everyday information sharing, by recognising the social, collective and collaborative aspect of information behaviour, thus broadening the scope of information behaviour studies beyond the usual suspects of seeking, scanning, and avoiding. Future research into the health information behaviour of (older) adults might increasingly focus on online sharing, for the older generations of the future are likely already online today and finding and sharing health information and experiences there.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest. No ethical issues had to be addressed.

About the authors

Martijn Huisman (corresponding author) is a PhD candidate at the Health, Media & Society research centre within the Department of Communication Sciences of Ghent University, Korte Meer 11, B-9000 Gent, Belgium. His research interests include health communication and health information behaviour. He can be contacted at <u>martijn.huisman@ugent.be</u>

Daniël Biltereyst is Professor in media studies at the Department of Communication Sciences of Ghent University, Belgium, in addition to being Director of the Centre for Cinema and Media Studies. His contact address is <u>daniel.biltereyst@ugent.be</u>

Stijn Joye is an Associate Professor at the Department of Communication Sciences, Ghent University, Belgium. His research interests are in the field of international communication with a focus on mediated suffering. He can be contacted at <u>stijn.joye@ugent.be</u>

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