

To share or not to share: an explorative study of health information non-sharing behaviour among Flemish adults aged fifty and over

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Introduction. *This study explores health information non-sharing behaviour in everyday social settings and interactions. The novelty and relevance of the study lies in the fact that it explores a common yet understudied information behaviour, as very few studies have examined information non-sharing.*

Method. *Forty qualitative in-depth interviews were held in Flanders, the Dutch-speaking northern part of Belgium, with adults between the ages of fifty and eighty.*

Analysis. *A contextual framework was drawn from information studies and health information and communication research, consisting of the concepts of health orientation, information avoidance, uncertainty management, to help understand health information non-sharing. Thematic analysis was employed to identify reasons for non-sharing behaviour.*

Results. *Seven key themes or reasons emerge for health information non-sharing behaviour; health as a non-topic, avoid being labelled as ill, individual responsibility, avoid burdening others, lack of trust in others, lack of trust in the internet, and avoiding information overload.*

Conclusions. *This study is not only more nuanced than earlier work on sharing behaviour, but also leads to new questions about outcomes of health information non-sharing. The findings further illuminate 'non-information behaviour' within information studies, while also offering insights relevant to health communication researchers and healthcare practitioners.*

Introduction

Information sharing in interpersonal communication is described as 'natural' and 'highly social' (Rioux, [2005](#)), often drawing upon 'kindness as a social institution' (Savolainen, [2007b](#), Literature review, para. 2). It is characterised as 'common' (Case and Given, [2016](#)) and occurring 'regularly, even spontaneously' (Raban and Rafaeli, [2007](#)). However,

sharing information within social everyday interactions as a type of information behaviour has been explored in only a handful of studies, leaving it relatively underdeveloped as a theoretical concept (Huisman et al., [2020](#); Case and Given, [2016](#); Cline, [2014](#); Liu et al., [2019](#); Pilerot, [2012](#); Savolainen, [2017](#); Wilson, [2010](#)). Even fewer studies have examined the non-sharing of information, a type of '*non-information behaviour*' (Manheim, [2014](#)) or '*information non-seeking*' (Martinez, [2014](#)), which is why it is explicitly mentioned as an avenue of information behaviour which has not been properly understood (Rioux, [2005](#); Savolainen, [2017](#)). As non-sharing might lead to a '*state of knowledge disadvantage*' (Manheim, [2014](#), Analysis, para. 18) or even information poverty (Case and Given, [2016](#); Chatman, [1996](#); Manheim, [2014](#)), it is relevant to study and understand this type of (non-)information behaviour. Further, understanding health information non-sharing behaviour is important for the way individuals deal with and respond to information as an essential part of how they deal and cope with health issues (Ek and Heinstrom, [2011](#)). To address the above mentioned knowledge gap, this contribution explores the non-sharing of health information among adults within the age range of 50 to 80 years in Flanders, the Dutch-speaking northern region of Belgium.

Health information has the potential to improve quality of life, and even save lives, by enabling people to make sense of their health condition and properly and effectively deal with health problems (Huisman et al., [in press](#); Johnson and Case, [2012](#)). Insufficient, incorrect, and incomplete health information can on the other hand increase uncertainty, misunderstandings, and ignorance, and lead to negative outcomes (Brashers, [2001](#); Dutta-Bergman, [2004](#); Johnson and Case, [2012](#); Li et al., [2018](#); Wilson, [1997](#)). In comparison with general information behaviour, health information behaviour is therefore more personal, private, and sensitive (Li et al., [2018](#)), and also because health problems might be surrounded by guilt, stigma, and taboo (Greene, [2009](#); Johnson and Case, [2012](#); Rains, [2014](#); Veinot, [2009](#)). Besides mediated sources of health information such as traditional media and the internet, everyday interpersonal interactions have been found to play an important role in the dissemination and circulation of health information (Huisman et al., [2020](#); Chae and Quick, [2015](#); Cline, [2011](#), [2014](#); Dutta-Bergman, [2004](#); Johnson and Case, [2012](#); Liu et al., [2019](#); Wilson, [1997](#)). In a previous contribution, we found sharing to be a common and frequently occurring type of health information behaviour embedded in everyday social and supportive interactions. We therefore concluded that health information sharing plays an important

role in the acquisition, exchange, and circulation of health information (Huisman et al., [2020](#)). Here, we expand upon those findings and on the limited amount of literature and empirical studies available by investigating reasons for non-sharing behaviour in everyday social settings. The research question answered in the present work is therefore as follows:

What are the reasons for health information non-sharing behaviour among adults aged fifty and older in everyday informal social interactions?

By way of thematic analysis (Boyatzis, [1998](#)) of forty qualitative interviews, we arrive at themes (reasons) linked to health information non-sharing behaviour. To make sense of these themes, the following sections review the literature and construct a contextual framework consisting of relevant concepts from information studies and health information and communication research.

Literature review

Sharing information

Sharing is described in the literature as a type of information behaviour (Case and Given, [2016](#); Pilerot, [2012](#); Savolainen, 2017). The field of information behaviour concerns itself with how people actively and passively engage with and use information (Wilson, [1997](#)). Information behaviour is, as Wilson ([2000](#)) puts it, *'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). The research field has mostly examined seeking, scanning, and avoiding as the most common information behaviour (Case and Given, [2016](#); Johnson and Case, [2012](#)). Sharing has received comparatively limited attention, in part because it is challenging to study as a *'multi-faceted communicative phenomenon'* (Savolainen, [2017](#), Discussion, para. 3), surrounded by *'prevailing conceptual multitude and vagueness'* (Pilerot, [2012](#), p. 559).

Health information sharing processes typically take place within the offices of doctors and in hospitals between patients and physicians as well as among medical personnel, but it also takes place outside of the patient-physician encounter in everyday settings between partners, relatives, friends, and other acquaintances (Cline, [2014](#); Johnson and Case, [2012](#); Robinson, [2014](#); Savolainen, [2017](#); Veinot, [2009](#); Wilson, [2010](#)). However, compared to formal or planned interpersonal and mediated health information behaviour, health information behaviour in everyday informal social settings

such as sharing and non-sharing have received limited attention (Cline, [2014](#)). In this contribution, we understand sharing as a communicative activity in everyday social interactions in which health information is exchanged. Importantly, the term exchange denotes and emphasises the reciprocal and multidirectional nature of information sharing, which is fundamental to human interaction (Liu et al., [2019](#); Savolainen, [2017](#); Wilson, [2010](#)). In other words, we understand sharing as a two-way exchange of information, although it is possible that one-way transmissions of information occur in daily life (e.g., a person sharing health information without receiving information back). Health information sharing is not limited to information and facts, but also includes the exchange of experiences (first-person and third-person), support, and advice (Huisman et al., [2020](#)). When people share health information and experiences with others, they primarily seek understanding, empathy, encouragement, and support (Johnson and Case, [2012](#); Robinson, [2014](#); Veinot, [2009](#)).

The few studies which have examined interpersonal, face-to-face informal (health) information sharing found that sharing is an everyday aspect of life and a common type of health information behaviour (Huisman et al., [2020](#); Case and Given, [2016](#); Cline, [2014](#); Johnson and Case, [2012](#); Liu et al., [2019](#); Veinot, [2009](#)). Cline ([2014](#)) therefore argues that *'everyday messages play highly significant roles in influencing health, health behavior, and health outcomes.'* (p. 466). In our previous study we indeed found that respondents' knowledge of health and illness came to a large extent from observations, everyday interactions, and the experiences of others (Huisman et al., [2020](#)). This concurs with health communication research which suggests that interpersonal communication is a common and important source of health information and support (Cline, [2011](#), [2014](#); Dutta-Bergman, [2004](#); Johnson and Case, [2012](#); Liu et al., [2019](#)). Further, Fox and Jones ([2009](#)) conclude that the *'social life'* of health information is *'robust'*, with two-thirds of internet users talking to others (e.g., partners, relatives, friends) about health information obtained online. But what about the other third? What about individuals who do not want or cannot talk about their health and share information with others? And what are their reasons for not sharing?

Non-sharing

Scant attention has been paid in the information behaviour literature to the phenomenon of non-sharing behaviour in everyday social settings, even less so with regards to health

information. Moreover, the few available studies arrive at different and sometimes contradictory findings. Synthesising her studies on the information worlds of poor people, Chatman (1996) found that the non-sharing of information could be explained by various factors, namely secrecy, deception, risk-taking, and situational relevance. Secrecy and deception are deliberately employed as '*self-protecting mechanisms*' (p. 197) by individuals who mistrust others with regards to their interest and ability to handle confidential information as well as or to provide useful information. Moreover, secrecy and deception help individuals to protect themselves against unwanted exposure and maintain a personal, private space. With risk-taking, Chatman (1996) refers to the evaluation by individuals of the value of information, the level of trust in others, and the risks involved in sharing that information; such risks in the context of health are discussed further on. Situational relevance as an explanation for non-sharing refers to a lack of information relevance, that is, an absence of interest in the information as it is not deemed useful for application to some problem or context.

Chatman's (1996) study of 55 residents of a retirement community in the United States is particularly instructive. Chatman concludes that residents recognised that there was often a price to pay for communicating openly about their health condition and wellbeing. As the retirement community only accepted individuals who were in relatively good health and ambulatory, the community dwellers feared being forced to leave the complex due to deteriorating health and needing care. Residents therefore opted to not talk with anyone about their physical and mental health problems and concerns, their struggles with aging, and the isolation and loneliness they experienced. They did their best to appear healthier than they were and purposely did not seek out health information to appear to be doing and coping with health issues well. Further, respondents did not share information as they felt that others could not be trusted to keep the information confidential or because they simply did not want to bother others. Last, residents opted to not share as they recognised that exchanging health experiences and information might lead to a need for sympathy and support, which was deemed an undesirable form of dependency and becoming responsible for other residents.

Talja (2002) suggests that non-sharing behaviour is not always the result of a conscious choice to withhold information, keeping distance to others, or due to a lack of social contacts. She found that non-sharing occurred in a Finnish academic research community at large in situations when the group simply could not provide any relevant information or

documents to one of its members. Haas and Park ([2010](#)) argue that withholding information, which they define as the *'intentional failure to share potentially useful information with others'* (p. 873), is not only the result of individual interests. In their study of life scientists, they found that the social context and professional environment, particularly the influence of information behaviour (i.e., sharing or withholding) by other scientists, influenced individual considerations to share or not share information with colleagues.

Almehmadi et al. ([2014](#)) observed the information behaviour of female Saudi Arabian academics. Their respondents withheld information from each other out of a sense of being in constant competition, particularly with regards to publishing papers. However, on the intersection of their professional and private lives, respondents avoided exposing others to certain information for a variety of reasons. They did so mainly to respect the feelings of others and to not upset them, to avoid information overload, and because they thought others would not be interested in the information. Interestingly, the information that was not shared was largely health-related, such as individual health status and information about health conditions like obesity and cancer. Because others around them did not request health information, respondents choose to not share such information. Almehmadi et al. thus conclude that the decision to share or not to share health information is the result of a conscious consideration and of keeping the feelings, wishes, and (information) needs of others in mind. Finally, Liu et al. ([2019](#)) argue that health information might not be shared when individuals lack sufficient quality relationships (i.e., relationships with a degree of closeness and intimacy fostering trust and openness) or possess insufficient health knowledge and abilities to share information.

So far, we have reviewed the literature on sharing and non-sharing of health information and situated them within the field of information behaviour. Given the scarcity of theoretical work and empirical data, the following sections discuss concepts which help to contextualise our empirical findings.

Health orientation

In their work on health information seeking, Johnson and Case ([2012](#)) note that, *'some people seem to think as little as possible about the state of their health, and the consequences of their behaviour. For others (particularly the elderly), health is constantly on their minds—health becomes their life'* (p. 8). As humans age, their attitudes, behaviour, lifestyles, and

needs tend to differentiate and become more dissimilar (Settersten, [2017](#)). Likewise, health attitudes and orientations and health information behaviour might differ in the later stages of life. For instance, some individuals proactively pursue healthy lifestyles, while others are more passive and prefer to put responsibility in the hands of their physician (Dutta-Bergman, [2004](#); Ek and Heinstrom, [2011](#); Johnson and Case, [2012](#)). Attitudes, beliefs, motivations, and behaviour towards health and health information are captured by the concept of health orientation (Dutta-Bergman, [2004](#); Johnson and Case, [2012](#); Van der Rijt, [1996](#)). Dutta-Bergman ([2004](#), [2005](#)) suggests that health orientation consists of four indicators: health consciousness, health information orientation, health-oriented beliefs, and health activities. For this contribution, we limit ourselves to health information orientation, which Dutta-Bergman ([2004](#)) defines as the '*extent to which the individual is willing to look for health information*' (p. 275). For instance, individuals with high levels of health orientation are likely to be motivated to engage in healthy lifestyles and educate themselves by actively seeking out health information (Chae and Quick, [2015](#); Dutta-Bergman, [2004](#), [2005](#)). Conversely, individuals with low levels of health orientation might not be interested in seeking out health information and may avoid it as much as possible (Barbour et al., [2012](#)).

Different levels of health orientation are not just reflected in the extent to which individuals engage with or avoid health information, but also in how and through which channels and sources such information is acquired (Chae and Quick, [2015](#); Dutta-Bergman, [2004](#)). Individuals with high levels of health orientation might make use a broad range of information sources, including the internet as well as mediated and face-to-face interpersonal conversations. These are recognised by Dutta-Bergman ([2004](#)) as active communication channels, for they require an active role to communicate, obtain and process information. Besides not seeking and avoiding or ignoring health information, individuals with low health orientations are more likely to obtain health information incidentally via passive communication channels such as television and radio (Chae and Quick, [2015](#); Dutta-Bergman, [2004](#)), which do not require individuals to take up an active role. Extending these findings to sharing and non-sharing in everyday social interactions, the literature suggests that higher levels of health orientation relate to an increased propensity to share health information (Dutta-Bergman, [2004](#); Robinson, [2014](#)).

Previous studies have formulated various patient and health consumer typologies which help concretise the concept of health orientation. Ferguson (1991; as cited in Johnson and

Case, [2012](#)) proposes three types of health consumers, namely the passive patient, the concerned consumer, and the health-active, health-responsive consumer. Passive patients are likely to face their health problems with resignation and a greater likelihood of giving up as they feel that they can do little if anything to improve their health. Concerned consumers follow their physicians' advice, occasionally asking questions or seeking a second opinion. Health-active, health-responsive consumers are motivated and assertive individuals who demand the best healthcare and health outcomes, thus exhibiting a high health orientation. In a study of 319 elderly respondents in the Dutch city of Rotterdam, Van der Rijt ([1996](#)) found four different health (information) attitudes, namely fatalism, unconcern, internal control, and preventative orientation. Older adults with a fatalist outlook believed that staying healthy relied on good luck and accidental circumstances, while illness was considered unavoidable and the result of bad luck and fate. Unconcerned respondents did not worry about their health and stated that they were not afraid to become ill. Respondents labelled as internal control believed they were responsible for and in control of their health. When they fell ill, they argued that it was their own fault and the result of not having sufficiently cared for themselves. The persons found to having a preventive orientation did all they could to remain healthy by trying to stay fit, regularly visit their doctor, and follow advice for a healthy lifestyle (Van der Rijt, [1996](#)). Last, individuals who actively scan their surroundings for health threats and seek out information to cope with health issues are deemed monitors, while individuals who are likely to avoid or distract themselves from health information in order to avoid anxiety and stress are called blunters (Case et al., [2005](#); Case and Given, [2016](#); Ek and Heinström, [2011](#); Johnson and Case, [2012](#); Sairanen and Savolainen, [2010](#)).

The concept of health orientation and the above discussed typologies highlight individual differences in attitudes, beliefs, motivations, and behaviour towards health and health information. We expect that different levels of health orientation are linked to individual considerations and tendencies to either share or not share health information with others in everyday life. More specifically, we expect that individuals who do not share health information are likely to have lower levels of health orientation and fit the typology of unconcerned (Van der Rijt, [1996](#)) and passive patients (Ferguson, 1991; cited in Johnson and Case, [2012](#)) and generally tend to be blunters rather than monitors (Case et al., [2005](#)).

Information avoidance and uncertainty management

Information avoidance and uncertainty management theory help to explain underlying motives to engage with or avoid and, by extension, share or not share health information. While humans have generally held information acquisition and increasing one's knowledge in high esteem (Case et al., [2005](#); Case and Given, [2016](#)), and the need to understand ourselves and our world might be rooted in our very being (Maslow, 1963), we can also purposefully avoid information. People tend to avoid, ignore, or discard information that does not fit with or contradicts pre-existing convictions and knowledge (Case and Given, [2016](#)), particularly when it comes to information about unhealthy habits and preventable health conditions (Case et al., [2005](#)). Health information is avoided as it can raise concerns and increase levels of anxiety, fear, and stress (Brashers, [2001](#); Case et al., [2005](#); Manheim, [2014](#); Martinez, [2014](#)). Sometimes people prefer not to know that their health and well-being are at risk or that they are part of a risk group, as this can be experienced as threatening (Case et al., [2005](#); Manheim, [2014](#)). Barbour et al. ([2012](#)) found that individuals avoid health information so that they can remain hopeful, deny the seriousness of their health condition, cope, maintain boundaries, or because they want to act at a later time (Martinez, [2014](#)). Finally, resisting overexposure (i.e., information overload) and managing inaccurate, flawed, or contradictory information are reasons to avoid health information (Barbour et al., [2012](#); Bawden and Robinson, [2009](#); Manheim, [2014](#)). To avoid information, individuals might employ various strategies, ranging from escape (satisficing and ceasing to search and obtain information) to reduction (filtering and narrowing of search) and omission (avoidance of search) (Manheim, [2014](#); Savolainen, [2007a](#)).

Looking at avoiding behaviour in more depth, Sairanen and Savolainen ([2010](#)) distinguish between comprehensive and selective avoidance. Comprehensive avoidance describes the general unwillingness to access any source which potentially offers undesirable health information. Comprehensive avoidance is mainly driven by a need to shield oneself from negative emotions (Sairanen and Savolainen, [2010](#)) and of avoiding the need to act (Maslow, 1963). Applied to everyday health information non-sharing, individuals might for example avoid certain individuals if they know that health is likely to be a conversation topic. Selective avoidance describes the behaviour of individuals who prefer to avoid rather than expose themselves to information. Yet, they are *'willing to seek and receive some information to manipulate uncertainty to*

suit their needs' (Sairanen and Savolainen, [2010](#), Empirical findings, para. 4). This type of avoidance likely occurs during engagements with information, such as encountering unpleasant or unreliable information on the internet or in interpersonal interactions. Related to health information, non-sharing, selective avoidance might for example lead to changing the topic of conversation from health to something else.

A key aspect of health information behaviour which sets it apart from general information behaviour is managing uncertainty. Being ill, particularly when one is diagnosed with an acute, chronic, or fatal illness, possibly leads to uncertainty and feelings of anxiety and fear (Brashers, [2001](#); Wilson, [1997](#)). This uncertainty is reflected in people's health information behaviour. Maslow ([1963](#)) notes in this context that '*we can seek knowledge in order to reduce anxiety and we can also avoid knowing in order to reduce anxiety*' (p. 122).

Uncertainty management theory explains health information avoiding behaviour by proposing that individuals seek or avoid information to manage emotional responses and deal with uncertainty (Brashers, [2001](#)). People might reduce uncertainty by seeking information, but they can also avoid information to maintain uncertainty. This suggests that seeking, avoiding, sharing and non-sharing as various modes of information behaviour are related to expressions of uncertainty management in the context of health (Barbour et al., [2012](#); Brashers, [2001](#); Sairanen and Savolainen, [2010](#)).

Self-(non-)disclosure

The concept of self-disclosure helps to further make sense of health information non-sharing. Sharing often involves self-disclosure, which is an important strategy to manage personal health-related information, particularly concerning serious and chronic health conditions (Checton and Greene, [2015](#); Greene, [2009](#)). Self-disclosure is an interaction whereby one person intentionally reveals personal information to the other (Greene, [2009](#); Lin et al., [2016](#); Zhang, [2017](#)). While self-disclosure has been linked to positive outcomes such as catharsis, reflection, seeking help and support (Derlega et al., [2000](#); Greene, [2009](#); Lin et al., [2016](#); Rains, [2014](#); Zhang, [2017](#)) and improved physical and mental well-being (Checton and Greene, [2015](#); Greene, [2009](#); Hawkley and Cacioppo, [2010](#); Lin et al., [2016](#); Luo et al., [2012](#); Zhang, [2017](#)), self-disclosure can also pose a barrier to sharing health information as it requires opening up and being vulnerable. Health issues can be accompanied by embarrassment, guilt, self-blame, shame, stigma, and taboo (Derlega et al., [2000](#); Greene, [2009](#);

Johnson and Case, [2012](#); Rains, [2014](#); Veinot, [2009](#)), thus raising the bar and making it difficult to self-disclose. Individuals might also forego self-disclosure to not upset and make others worry, and because self-disclosure can lead to social rejection (such as conflicts with relatives, friends, and employers) and in the worst case ridicule and abandonment (Chatman, [1996](#); Derlega et al., [2000](#); Greene, [2009](#); Rains, [2014](#); Wilson, [2010](#)).

The health disclosure decision-making model by Greene ([2009](#)) suggests that the first step to self-disclosure consists of an assessment of the health information that might be divulged. Symptoms, prognosis, stigma, and relevance of the information are evaluated at this stage. An appraisal of the potential information receiver is the second step (Checton and Greene, [2015](#); Greene, [2009](#)). Self-disclosure is more likely when there is social proximity (i.e., a degree of closeness and intimacy), a high amount of trust between conversation partners (Chatman, [1996](#); Greene, [2009](#); Lin et al., [2016](#)), and when the person considering sharing perceives a low risk and a high benefit of doing so (Wilson, [2010](#)). Indeed, as Manheim ([2014](#)) notes, '*individuals calculate the costs and benefits of threatening information*' (Analysis, para. 12). Perceived availability, approachability, discretion, being non-judgemental, and the anticipated response and expected support are further considerations when deciding to self-disclose or withhold health information in everyday social interactions (Chatman, [1996](#); Checton and Greene, [2015](#); Greene, [2009](#); Veinot, [2009](#)). In the third step, the individual evaluates his or her ability to self-disclose and to share in a way that leads to desired and satisfactory results and outcomes (Greene, [2009](#)). In short, the health disclosure decision-making model explains the mental process and steps which people go through when consciously deciding to self-disclose (share) or withhold (not share) personal health information. It should be noted that the health disclosure decision-making model does not cover all health information sharing, as health information is not always personal; it can for example take on the form of advice or third-party information and gossip, which might lower or remove self-disclosure considerations.

Taken together, the concepts of health orientation, information avoidance, uncertainty management, and self-(non-)disclosure form the contextual framework and theoretical background to interpret and understand this study's findings pertaining to health information non-sharing behaviour. Health orientation refers to the general attitude of individuals towards health and health information, while information avoidance and uncertainty management explain underlying tendencies and

motivations to avoid health information and, presumably, not share information. Further, the health disclosure decision-making model describes and explains when individuals do share or not share personal health information with others. As such, the concepts drawn together herein describe different aspects of (non-)sharing which help to make sense of health information non-sharing behaviour.

Study design

As part of a qualitative audience research project about health news, information, and communication in relation to ageing, we conducted forty semi-structured, in-depth interviews with Flemish adults between the ages of fifty and eighty. A heterogeneous respondent group was recruited in terms of age, gender, and education level to prevent sample bias. The average age of the respondents was 64.9 years, with the youngest fifty-one and the oldest eighty years old. Eighteen men and twenty-two women participated, eleven of whom were labelled as lower educated (LE; no degree, primary and lower secondary education), fifteen as middle educated (ME; higher secondary education), and fourteen as higher educated (HE; bachelor's degree and master's or university degree). The group of respondents consisted of both diagnosed patients as well as health consumers without any diagnosed conditions. All respondents were living in or around the city of Ghent, Belgium, and were recruited through paper surveys.

The interviews were conducted between April 2015 and September 2015 using a predefined topic list (Mortelmans, [2013](#)). Before the interview, interviewees signed an informed consent to guarantee confidentiality and agreed to the interview being recorded. In the interviews, respondents were asked about different ways of obtaining and dealing with health information, ranging from actively searching to accidentally encountering and avoiding information. Sharing and non-sharing were discussed largely in terms of information outcomes, that is, of what respondents did with health information they obtained and knowledge they possessed. Respondents were asked, for example, if they talked about health with others, if they shared health information with others, and with which goals and outcomes. All interviews were recorded, transcribed verbatim and analysed qualitatively following a thematic analysis approach (Boyatzis, [1998](#)). After a thorough reading, the interview transcripts were semi-open coded in the [NVivo 12 software](#) to identify and single out relevant passages of the conversations (Mortelmans, [2013](#)). The coding book was subsequently refined by narrowing down and focusing (axial coding) until data saturation was reached

and a final coding framework emerged. From this coding framework in turn emerged themes related to health information non-sharing behaviour. The following section presents the results of the analysis. All respondent quotes have been extracted from the interviews, translated from Dutch into English by the authors, and anonymised to guarantee respondent anonymity.

Results

From the interviews and their analysis emerge seven distinct themes, which can be viewed as reasons for health information non-sharing behaviour. They are 1) health as a non-topic, 2) avoid being labelled as ill, 3) individual responsibility, 4) not burdening others, 5) a lack of trust in others, 6) a lack of trust in the internet, and 7) avoiding information overload.

1. Health as a non-topic: 'We don't talk about health'. While sharing health information and experiences appear to be perfectly normal for many respondents (Huisman et al., [2020](#)), for some it is a non-topic which is rather not talked about. These respondents seem to manage their health in a quite passive and reactive way; they only act when something is wrong by visiting their physician. They tend to not look up much or any health information and do not want to talk about health with others. In fact, they are prone to avoid health information, not wanting to be confronted with bad news and negative health stories.

Not so much in the family. Let us say there is less talk about that kind of things.' (Male, 58, LE)

If there is a problem we go to the doctor, take the medication that is needed, and hope that it will be resolved. (Male, 76, LE)

Note how the above respondents shift their usual perspective of 'I' to 'we' and 'family' when they talk about health as a topic of conversation, underscoring the inherent social nature of health information (non-)sharing. Interestingly, the respondents who share these sentiments and deem health a non-topic are overwhelmingly male and lower educated. This suggests that lower educated males are more likely to have a passive or lower health orientation, which translates to health as a non-topic and health information non-sharing behaviour.

2. Avoid being labelled as ill: 'I am not my illness'.

Respondents indicate they do not disclose and share health information to avoid being labelled as ill, be treated differently, and to avoid stigma. The following respondents found in the past that people tended to react differently to them and see and

label them as patients. In response, these interviewees became wary of sharing health experiences and information:

I had a cardiac arrest a long time ago, so I had to recover from that. When people know that about you, they look at you differently. They really look at you differently. (Female, 52, ME)

It is not a taboo, but the fact that someone is labelled as sick... I think that is not necessary. You do not change when you have diabetes. But most people respond differently when you have an illness. (Female, 64, ME)

Respondents mention that they sometimes employ strategies to actively hide their health afflictions, such as minimising the symptoms of their condition so that it is not noticed by others (Rains, [2014](#)) and simply not informing others about their health afflictions. Echoing the findings of Chatman ([1996](#)), respondents thus occasionally engage in secrecy to not disclose and share their health status and information.

3. Individual responsibility: 'I am not a doctor'. Respondents of different ages and levels of education adamantly state that they do not want to talk about their health with others, nor listen to and talk about the health problems of others. They contend that everyone is responsible for his or her own individual health and that every person and body is different and requires an individual, professional approach, which in their opinion can only be provided by a physician and not by laypersons like themselves. They therefore believe that one should go to a doctor and not discuss (share) health with others who cannot really be of help.

You can talk about your health situation with a doctor, but not with me. It is your own responsibility. Make your own plans, but do not talk to me about it the whole time. I am not a doctor. (Female, 67, ME)

Your body is not my body. Bodies are different, and every person is different. To get good information, you need to visit the doctor. (Female, 78, LE)

These opinions not only originate in the argument mentioned above, but also more generally in older adults' preference and habit to rely on their physician for advice, diagnosis, and treatment. Seeing the doctor as the ultimate medical authority, these respondents appear to prefer to avoid and not share health information with others in everyday life as much as possible.

4. *Avoid burdening others: 'I do not want to worry others'*. Almehmadi et al. (2014) found that not wanting to burden others and keeping their feelings in mind were important reasons to withhold and not share health-related information. Respondents in our study also indicate not wanting to bother and burden others with their health experiences and issues, believing it to be unnecessary or unwanted to talk about health all the time. The following 79-year old respondent, who lived in a home for the elderly, remarks, for instance, that since health problems are part of daily life for most people of her age, she does not want to talk about it:

Nowadays everyone has problems. There are some very old people here. There are people in their 90s, someone became 100 years old. I do not want to bother them. And what advice can you give those people? (Female, 79, HE)

While sharing might figuratively speaking be linked to caring, non-sharing in this context also means to care about others, that is, by evaluating the relevance of information and keeping in mind others' situation and information needs and wishes.

5. *Lack of trust: 'I do not trust others in matters of health'*. Respondents employ various strategies to appraise health information exchanged in everyday conversations. They determine whether others can be trusted, i.e., whether that person has a reputation of trust and being knowledgeable by for example having a professional medical background and/or relevant health experiences. Overreactions and wrong advice are reasons to not divulge one's health condition and information and to stay away from people who give poor advice. A lack of trust and credibility might lead to information shared in social interactions being discarded, not being open and willing to listen to the health experiences of others and refusing to share any health information with others.

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)

You have a cold and they say you are dying. You should not inform yourself by talking to such people and you certainly should not believe them. (Female, 64, ME)

Experienced patients with chronic health conditions, such as the below respondent living with rheumatism, indicate that even family and friends are often simply not knowledgeable enough to talk to (share) about their health, let alone get advice from them:

Advice from friend and relatives I take with a grain of salt. They are not specialists. If they say to me, 'Why don't you try this?', I think, 'Sure, I have been living with rheumatism for forty years, so what are you talking about?' (Female, 68, ME)

Trust and reliability thus play an important role in everyday social interactions and the exchange of health information. Specifically, they relate to self-disclosure (evaluation of risk and benefit, social proximity, anticipated response), as well as to avoiding untrustworthy and unreliable sources of health information.

6. *Lack of trust: 'I do not trust the internet'*. Most respondents do not use the internet to share health information, preferring face-to-face interactions over the anonymity of the internet or lacking the necessary computer and internet access and skills. Some study participants are opposed to sharing and reading health experiences online, believing these might be coloured and embellished out of commercial motives or to seek attention. Further, in the health information sharing context respondents appear to dislike the anonymity of the internet, as it undercuts the sense of trust and reliability established within offline, face-to-face social networks and interactions. Thus, anonymity, found in past studies to be an important factor in encouraging digital self-disclosure (Rains, [2014](#)), is perceived by respondents as a barrier to self-disclosure and health information sharing. Besides the aspects of trust, reliability, and anonymity, interviewees mention that sharing health information and experiences online often leads to negative outcomes, such as people playing doctor and egging each other on.

Those forums are ridiculous. Sometimes I accidentally click on a wrong link and end up on a forum where people give each other... they play doctor. It is ludicrous. That would be the last place where I would get information from. (Female, 55, LE)

It is such a chatter and egging each other on. Like, 'I have this and I did this, you should take care about this and do that'. That is really not for me, those wild tales. I do not trust them. Everyone just wants to tell their own story. It doesn't help me.' (Female, 59, HE)

Only a few respondents were active on social networking sites such as Facebook, but they all stated that they would never trust any health information appearing there nor take any action.

Thousands of people suffer from something different. On Facebook you read for example a lot about

sleeping pills. I will never take those. Or vitamins. No, no, no. I will never take up on those kinds of things, never ever. (Male, 51, ME)

I certainly will not trust any [health information] on there. If you see what they put up there every day... (Male, 58, LE)

Remarkably, the statements above about the Internet and Facebook all come from respondents on the lower end of the age spectrum in our study, being respectively 51, 55, 58, and 59 years old. Their opinions suggest that they have reached a certain level of computer-, Internet-, health-literacy which enables them to confidently appraise health information sources and denounce the chatter and playing doctor on social media and forums where health information and experiences are shared and discussed by laypersons.

7. *Avoiding information: 'I want to avoid too much negative information'*. Too much information can have adverse effects such as information overload, anxiety, and stress (Barbour et al., [2012](#), Bawden and Robinson, [2009](#)). Respondents indicate that they frequently avoid health information to ward off information overload. Moreover, they mention that they do not want to burden themselves with health information to avoid hypochondriac thoughts and to keep negative health stories and news out of their lives.

You are so overwhelmed with information, about health and other things. I try to put things in perspective and consult with someone who is really knowledgeable. (Female, 52, ME)

I don't have to know everything about things I am not confronted with in my immediate environment. I do not have to become a walking encyclopaedia. (Female, 65, ME)

Respondents not only try to avoid health information on the internet and from other media channels, but also by minimising and avoiding health as a topic of conversation in interpersonal interactions. As such, they are less open and willing to engage in the exchanges of health information in everyday informal interactions.

Discussion

Whilst our previous study found that everyday informal sharing behaviour plays a prominent role in the acquisition, exchange, and circulation of health information of Flemish adults between the ages of fifty and eighty (Huisman et al., [2020](#)), the present explorative work nuances these findings with seven themes or reasons for non-sharing behaviour. These

reasons are 1) perceiving health as a non-topic; 2) avoid being labelled as ill; 3) deeming health an individual responsibility; 4) avoid bothering and burdening others; 5) a lack of trust in others; 6) a lack of trust in the internet; and 7) avoiding information. In part, these themes correspond with the work by Chatman ([1996](#)), who found secrecy, deception, risk-taking, and situational relevance to be important factors in the non-sharing of information. For instance, avoid being labelled as ill involves secrecy and perhaps deception, although the latter was not discussed in our interviews. Avoiding bothering and burdening others as well as avoiding information appear to be examples of Chatman's situational relevance, while a lack of trust in others and the internet can be related to Chatman's notion of risk-taking; evaluating the value of the information, the level of trust in others, and the risks involved in sharing that information.

Due to a persistent lack of theoretical and empirical literature, we constructed a contextual framework by linking health information non-sharing behaviour to various concepts from information and health communication studies. Underwriting the link between health orientation and health information behaviour (Dutta-Bergman, [2004](#), [2005](#)), we find that respondents with lower levels of health orientation seem more likely to avoid or ignore health information altogether. Instead of looking up information and talking (thus sharing) about it with others, they prefer to limit their health information experiences to going to the doctor when they are concerned or experiencing health problems. This confirms our expectation that individuals who do not share health information are more likely to be passive or unconcerned individuals, rather than pro-active health-responsive (Ferguson, 1991; cited in Johnson and Case, [2012](#); Van der Rijt, [1996](#)). Different levels of health orientation thus appear linked to, and to some extent explain, individual considerations and tendencies to either share or not share health information with others in everyday life.

Furthermore, health orientation relates to the two themes that do not match Chatman's ([1996](#)) findings: health as a non-topic, and deeming health an individual responsibility, as well as the seventh theme, avoiding information, given that health orientation describes the attitudes, beliefs, motivations, and behaviour of individuals towards health and health information (Dutta-Bergman, [2004](#); Johnson and Case, [2012](#)). In other words, deeming health an individual enterprise and a topic to avoid stems from respondents' perceptions of and attitudes towards health, and thus they are part of, and follow, respondents' health orientation. The findings also indicate that information avoidance, uncertainty management, and self-disclosure play roles in the social life (i.e., interpersonal

exchange and circulation) of health information, including non-sharing. That is, avoiding and not talking with others about health matters (health as a non-topic) can be a form of uncertainty management, while not trusting others or the internet to share health information with links back to self- (non-) disclosure.

From an overarching perspective, our findings suggest that respondents not only have various reasons to not share, but also that they employ various filtering and withdrawal strategies (Manheim, [2014](#); Savolainen, [2007a](#)) towards health information in everyday settings. Filtering strategies are used to filter out useless and unreliable health information circulating in social networks, such as information which comes from individuals who are deemed untrustworthy. Withdrawal strategies help to limit the daily amount of health information or avoid it altogether, including information exchanged in everyday social interactions. These strategies appear to be employed consciously by respondents to serve multiple purposes, ranging from self-protection and keep health private (Chatman, [1996](#)) to avoiding stigma and being labelled ill, as well as reducing uncertainty and information overload.

In terms of relevance and implications, the present study not only contributes to the understudied and underdeveloped field of (health) information non-sharing behaviour in everyday life, but also adds to the growing body of literature that more generally deals with information non-seeking (Martinez, [2014](#)) or non-information behaviour (Manheim, [2014](#)). The non-sharing of health information might result in individuals missing out on beneficial information (Chatman, [1996](#); Martinez, [2014](#)), which in turn may contribute to an overall lack of health information and knowledge (Case and Given, [2016](#); Chatman, [1996](#); Manheim, [2014](#)). This information poverty (Chatman, [1996](#)) can in turn lead to negative health outcomes, for as Martinez ([2012](#)) reminds us, '*what may begin as an information disparity can quickly translate into a health disparity*' (p. 714). Reasons for health information non-sharing and non-disclosure are thus important, especially when they impact health decision making processes, behaviour, and outcomes. While self-disclosure has been found beneficial to physical and mental wellbeing (Checton and Greene, [2015](#); Greene, [2009](#); Hawkey and Cacioppo, [2010](#); Lin et al., [2016](#); Luo et al., [2012](#); Zhang, [2017](#)), non-disclosure can lead to a lack of social support (Cline, [2014](#)) and tensions and stress accumulating, thus reinforcing negative feelings and emotions (Rains, [2014](#)) and potentially resulting in physical and psychological issues (Zhang, [2017](#)). This might be even

more salient among older adults, who, as they age, are likely to experience loneliness and social isolation as they lose people around them to share health experiences with. The seven themes related to non-sharing found herein might therefore be of interest to health communication researchers and healthcare practitioners engaged in countering loneliness among older adults and stimulating healthy ageing and participation in society. As using and responding to information is an essential part of dealing and coping with health issues (Ek and Heinström, [2011](#)), a better understanding of differences in health information behaviour might contribute to the development and enhancement of health communication practices and the design and tailoring of health information messages. This, in turn, might positively influence people's wellbeing.

Conclusion

Expanding on our previous work on health information sharing, the present study finds seven themes or reasons why Flemish adults between the age of fifty and eighty choose to withhold rather than disclose, and not share rather than share, health information and experiences with relatives, peers, and others in everyday informal social interactions. The findings contribute to further illuminating non-information behaviour (Manheim, [2014](#)) within information studies, while also offering insights relevant to health communication researchers and healthcare practitioners.

Naturally, the present findings should be considered in the light of the limitations of the study. The study sample was restricted in the number of respondents and, because of the enquiry being embedded in a larger research project, consisted of a population characterised by a wide age range. Given the explorative nature of this contribution, however, we do not deem the latter to be a significant hindrance. Further, the qualitative character of our fieldwork did not allow for a representative quantitative analysis, such as the one carried out by Van der Rijt ([1996](#)), to establish health orientation typologies and link these directly to information non-sharing behaviour. A quantitative follow-up study might be able to link health orientation to variables such as age, gender, education, social relationships, and health status to gain deeper insights into which individuals are likely to share health information and which do not. Furthermore, a quantitative study could be useful to test, refine, and possibly expand on the seven themes found herein. As little research has been carried out about non-sharing behaviour in everyday informal social settings, future studies might extend the field beyond the health context and to

other demographic groups. Finally, it will be both interesting and relevant to explore outcomes of non-sharing: do non-sharers, for instance, experience information poverty and different health and health information outcomes than people who do share? Regardless of the study limitations and the questions left open for future study, the present work demonstrates that health information non-sharing is a pertinent type of health information behaviour, worthy of attention and inquiry.

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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.

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Note: A link from the title is to an open access document. A link from the DOI is to the publisher's page for the document.

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