

TO SHARE OR NOT TO SHARE

AN EXPLORATIVE STUDY OF HEALTH INFORMATION NON-SHARING BEHAVIOUR AMONG FLEMISH ADULTS AGED 50+

Martijn Huisman, Stijn Joye, & Daniël Biltereyst / ICA 2020



FOLLOW UP TO ICA 2019 PRESENTATION

SHARING IS CARING
THE EVERYDAY INFORMAL EXCHANGE
OF HEALTH INFORMATION AMONG ADULTS AGED 50+
Martijn Huisman, Daniël Biltereyst, & Stijn Joye / 26.05.2019



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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.

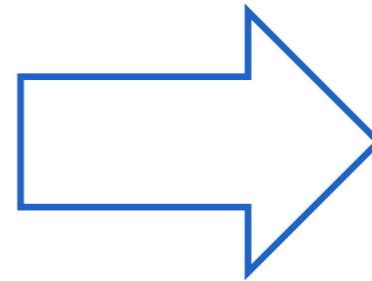
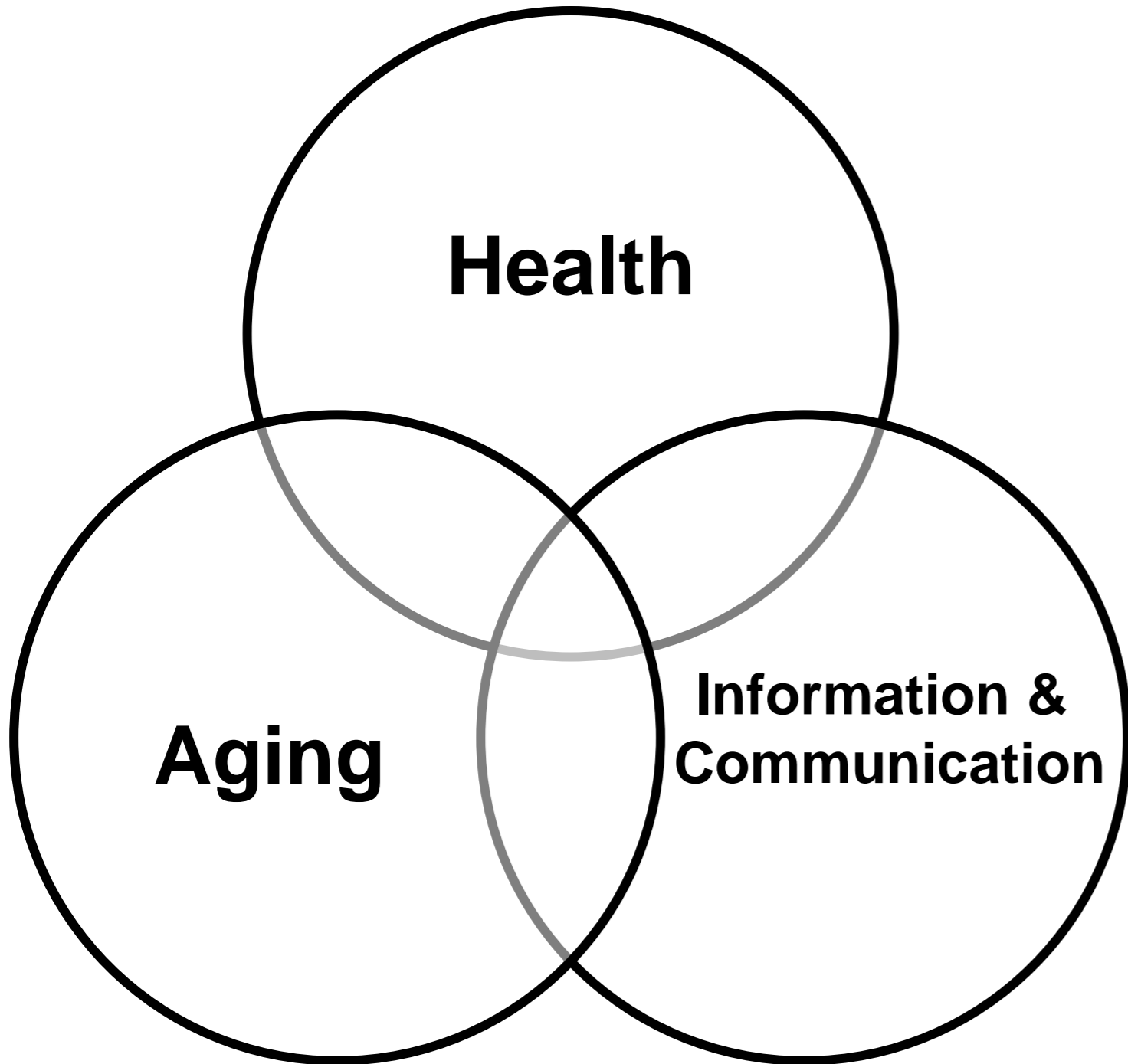
Conclusions. Driven by social motivations, sharing plays an important role in the acquisition, exchange and circulation of health information. This suggests that more attention should be paid to the social, collective and collaborative aspects of information behaviour, specifically everyday information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



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URL: <http://informationr.net/ir/25-1/paper848.html>





Information behaviour

“The totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use.”
(Wilson, 2000, p. 49)



INFORMATION BEHAVIOR

- Traditionally, information behaviour research has focused on the **seeking, scanning, and avoiding** of information.
- Health information is obtained, exchanged, circulated, and used in informal **face-to-face and mediated** everyday social interactions. **Health information is, in other words, shared.**
- Sharing is an understudied and underdeveloped information behaviour concept that is **'relatively unexplored'** (Wilson, 2010), although considered a **'promising research area in health communication'** (Liu et al., 2018; Case & Given, 2016).

NON-SHARING

- Even fewer studies have examined the non-sharing of information → explicitly mentioned in past work as an **avenue of information behaviour which has not been properly understood** (Rioux, 2005; Savolainen, 2017).
- Most studies have explored **information non-sharing processes** among academics and professionals (Almehmadi, Hepworth, & Maynard, 2014; Haas & Park, 2010; Talja, 2002).
- These studies arrive at **different and sometimes contradictory findings**.
- Little is known about **health information non-sharing behaviour** (Liu et al., 2018).

RESEARCH QUESTION

What are reasons for health information non-sharing behaviour among Flemish adults aged 50 to 80?

STUDYING HEALTH INFORMATION NON-SHARING

- Given the scarcity of theoretical work and empirical data, we employ a theoretical framework which brings together the concepts of **Health orientation**, **Avoiding and Uncertainty Management**, and **Self-disclosure**.

Health orientation

- **Attitudes, beliefs, motivations, and behaviours towards health and health information** (Dutta-Bergman, 2004; Johnson and Case, 2012; Van der Rijt, 1996); some individuals proactively pursue healthy lifestyles, others tend to have more passive health attitudes.

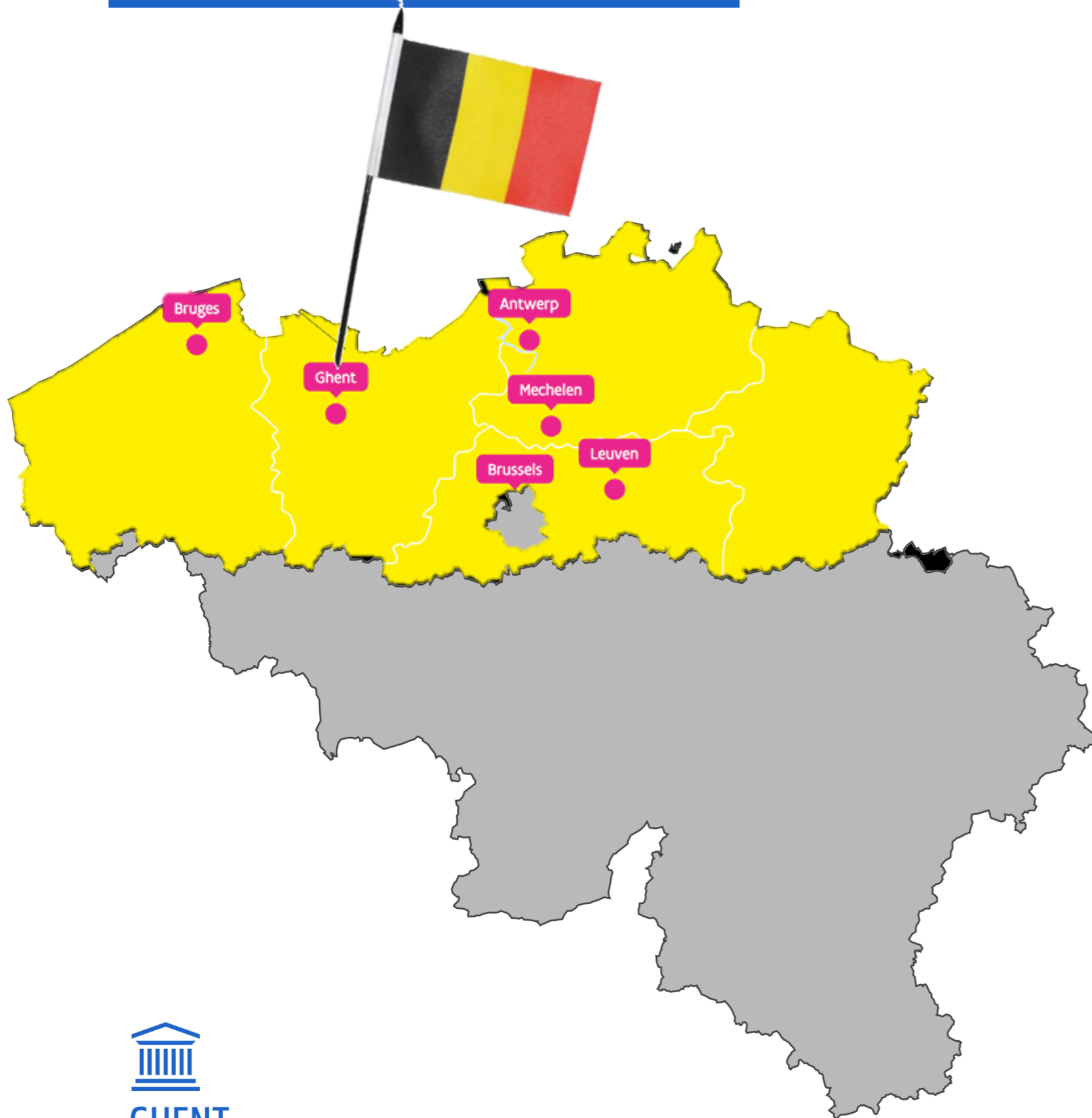
Avoiding and Uncertainty Management

- **Individuals might reduce uncertainty by seeking information, but they can also avoid information to maintain uncertainty.** Health information might be avoided as it might increase levels of anxiety, fear, stress, and uncertainty.

Self-disclosure

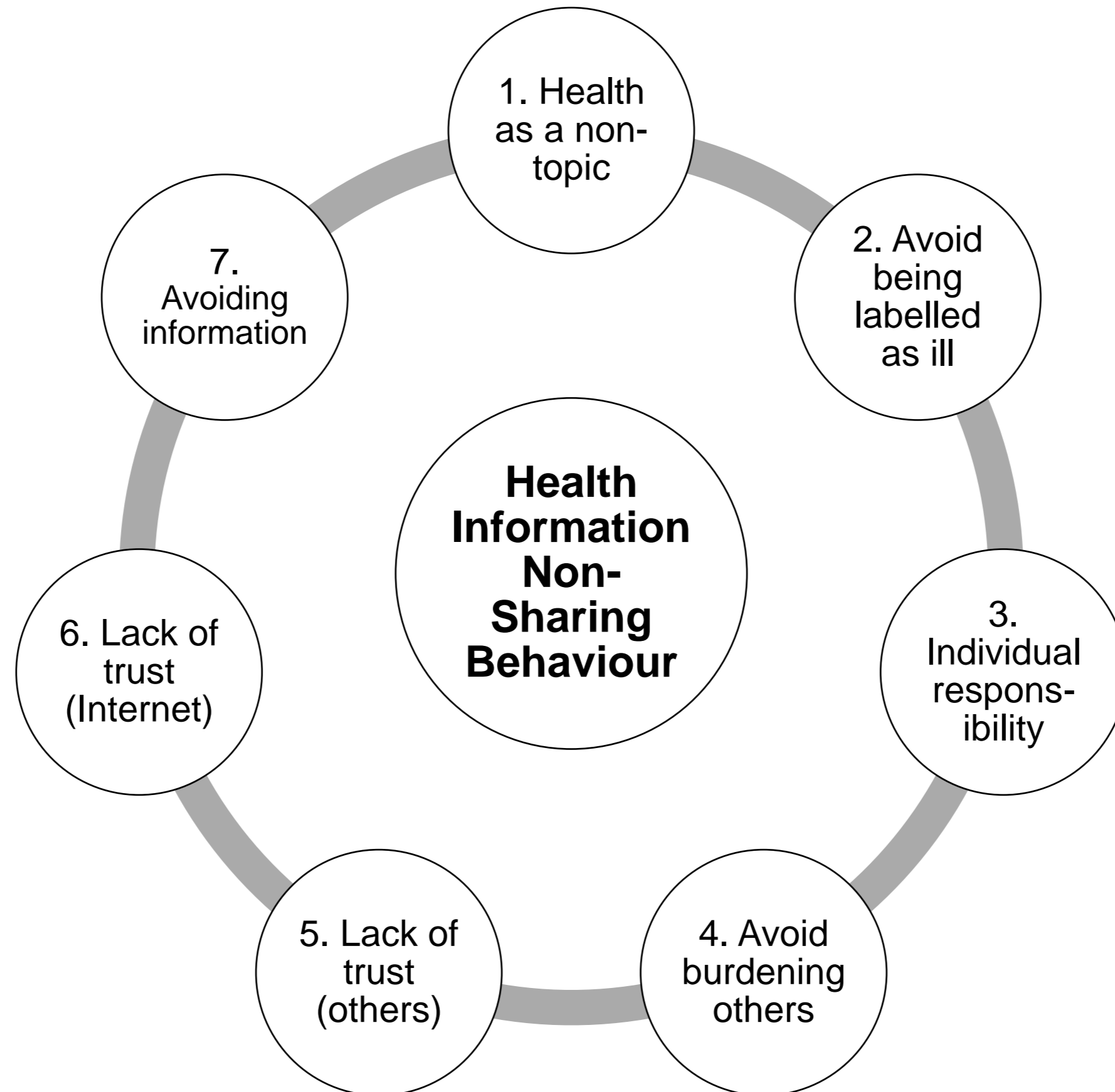
- Sharing often involves **self-disclosure, which is an important strategy to manage personal health-related information**, particularly concerning serious and chronic health conditions (Checton & Greene, 2015; Greene, 2009).
- Individuals might forego self-disclosure to not upset and make others worry, 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 (Derlega et al., 2000; Greene, 2009; Rains, 2014; Wilson, 2010).

DATA & METHOD



- 40 in-depth **qualitative interviews**
- Ghent, **Flanders** (Belgium)
- Middle-aged adults (**50-64**) & older adults (**65-80**)
- **Heterogeneous group:** age, gender, & education
 - Youngest participant 51 y.o., oldest 80 y.o. (group average 64.9)
 - 18 men / 22 women
- **Diagnosed** health conditions as well as **healthy** individuals

RESULTS: SEVEN SHARING THEMES



1. HEALTH AS A NON-TOPIC: 'WE DON'T TALK ABOUT HEALTH'

- While sharing health information and experiences appeared perfectly normal for many respondents, for some it is clearly **a non-topic which is not talked about**.
- The respondents who considered health as a non-topic were **typically male and lower educated**. This might suggest that lower educated males are more likely to have **a passive or lower health orientation**, which translates to health being a non-topic and health information non-sharing behaviour.

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

“As long as we don’t have ill people in our family, there is little said about it.”
(Male, 64, LE)

2. AVOID BEING LABELLED AS ILL: 'I AM NOT MY ILLNESS'

- Not share health information to **avoid being labelled ill and treated differently**, as well as to **avoid stigma**.
- Older adults employ various strategies to cover up their health afflictions to avoid stigma, such as **minimizing the symptoms of their condition** so that it is not noticed by others (Rains, 2014) and **not informing others about their health afflictions**.

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

3. INDIVIDUAL RESPONSIBILITY: 'I AM NOT A DOCTOR'

- Respondents of different ages and levels of education adamantly stated that they did not want to talk about their health with others, nor listen to and talk about the health problems of others.
- They argued that **everyone is responsible for his or her own individual health**, and that **a doctor should be visited and consulted in the case of health concerns and problems**.

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

4. AVOID BURDENING OTHERS: 'I DO NOT WANT TO WORRY OTHERS'

- Almehmadi et al. (2014) found that **not wanting to burden others and keeping others' feelings in mind** were important reasons to withhold and not share health-related information.
- We too find that people do not want to bother and burden others with their health experiences and issues, believing that it is **unnecessary and/or unwanted to talk about health issues all the time.**

5. LACK OF TRUST: 'I DO NOT TRUST OTHERS IN MATTERS OF HEALTH'

- **A lack of trust and credibility** appear to lead to
 - Health information shared in social interactions being discarded;
 - Not being open and willing to listen to the health experiences of others;
 - Refusing to share any health information with others.
- Respondents determine whether others can be trusted, i.e., whether that person has a reputation of trust and is knowledgeable, by considering if the other has a **relevant medical background and/or relevant health experiences**.

*"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)*

6. LACK OF TRUST: 'I DO NOT TRUST THE INTERNET'

- The vast majority of respondents does **not use the Internet to share health information**, instead **preferring face-to-face interactions** over the anonymity of the Internet and/or lacking the necessary computer and Internet access and skills.
- Anonymity, found in past studies to be an important factor in encouraging digital self-disclosure (Rains, 2014), is perceived by respondents in our study as a **barrier to self-disclosure and health information sharing**.

“Those forums, they 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.”
(Female, 55, LE)

7. AVOIDING INFORMATION: 'I WANT TO AVOID TOO MUCH NEGATIVE INFORMATION'

- Respondents clearly indicated that they avoided health information to **avoid information overload**. They did not want to burden themselves with health information to **avoid hypochondriac thoughts** and to **keep negative health stories and news out of their lives**.
- **Respondents also attempt to minimize and avoid health as a topic of conversation in interpersonal interactions.** This desire to minimize health in everyday life contributes to health information non-sharing behaviour.

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

CONCLUSIONS & TAKEAWAYS



7 themes why respondents refrain from sharing health information in everyday social settings and interactions



Confirms link between health orientation and health information behaviour (Dutta-Bergman, 2004; 2005), **respondents with lower health orientations appear to avoid or ignore health information altogether and, by extension, not share.**



The concepts of avoiding behaviour, Uncertainty Management, and self-disclosure appear relevant as respondents employ various filtering and withdrawal strategies (Savolainen, 2007a) **towards health information in everyday social settings.**



While sharing often takes place spontaneous and unplanned (Huisman et al., 2020), **it appears that non-sharing is generally the result of conscious choices to not share health information.** (cf., health disclosure decision-making model by Greene, 2009).



Self-disclosure of personal health issues is beneficial to physical and mental wellbeing (Checton & Greene, 2015; Greene, 2009; Hawkley & Cacioppo, 2010; Lin et al., 2016; Luo et al., 2012; Zhang, 2017), **while non-disclosure can lead to tensions and stress accumulating, thus reinforcing negative feelings and emotions** (Rains, 2014) **and potentially resulting in physical and psychological issues** (Zhang, 2017).



THANK YOU

Martijn Huisman

martijn.huisman@ugent.be

www.ugent.be

<http://hmsoc.ugent.be/>

 Ghent University

 @ugent / @HMS_UGent

 Ghent University

