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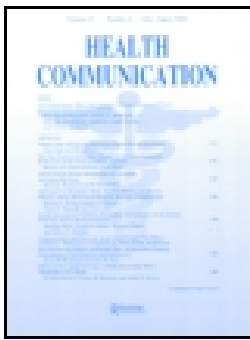
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Contextual Health Information Behavior in the Daily Lives of People with Type 2 Diabetes: A Diary Study in Scotland

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ABSTRACT

Changes in lifestyle can have positive effects on treating type 2 diabetes (T2D), like sporting or healthy eating. Therefore, a person diagnosed with T2D is often advised to make healthy choices throughout the day, in addition to other interventions such as medication. To do this, he or she needs health information to support decision-making. Literature describes ample categorizations of types of (health) information behavior and theoretical models that explain the factors that drive people to search for, encounter or avoid information. However, there are few longitudinal studies about triggers and factors in daily life that affect health information behavior (HIB). This study was set up to identify triggers, actions and outcomes for active, passive and avoidant HIB situations in daily life among Scots with Type 2 diabetes (T2D) to identify points of attention for communication strategies. Twelve participants took part in a four-week diary study. Every day, participants received an online diary form to describe active, passive or avoidant HIB situations. Data collection resulted in 53 active, 120 passive and 25 avoidant diary entries. Seven active HIB contexts (e.g., experiencing symptoms, cooking dinner, sports training) and five passive HIB contexts (e.g., home, work, medical facility) were identified. Four motivations for avoidance were found (e.g., time constraints, no health trigger). These results can be used to supplement the theoretical models of health information behavior. Furthermore, health professionals can use these results to support their clients with T2D in the self-management of their health, by guiding them to trustworthy sources of health information and lowering barriers for searching health information.

Introduction

Being diagnosed with type 2 diabetes means your body becomes resistant to insulin or does not produce sufficient insulin. Over time, diabetes can cause blindness, kidney failure, heart attacks, stroke and lower limb amputation (World Health Organization, 2016). Type 2 diabetes, often termed ‘adult-onset diabetes’, is most often diagnosed later in life, although it is also becoming more prevalent among adolescents and children (Abbasi et al., 2017; Dabelea et al., 2014). There is not one clear cause for T2D. Most often, it is caused by a combination of genetic factors like family history of diabetes and lifestyle factors such as obesity and physical inactivity (World Health Organization, 2016). It is estimated that more than 400 million people around the globe have diabetes type 2 and it is expected that these numbers will continue to rise (Chatterjee et al., 2017).

T2D has a tremendous impact on one’s life and lifestyle. Since unhealthy lifestyles are a risk factor for T2D, drastic measures to change one’s lifestyle can have positive effects on treating the disease (Diabetes Prevention Program Research Group, 2018; Uusitupa, 1996; Wing et al., 1985; Tuomilehto et al., 2001; Wolf et al., 2004). Therefore, many treatment and intervention programs focus, besides medication, on lifestyle interventions such as (a combination of) improving physical activity and adopting healthy eating habits (e.g., Agurs-Collins et al., 1997; American Diabetes Association, 2004; Franz et al., 2015).

Providing health information to people with T2D is an important aspect of these interventions (Beck et al., 2019), to support them in making healthy food choices or managing their blood sugar levels. Providing health information is hereby seen as a more or less top-down process: the information given by the health professional will do something to the individual who receives the information (Griffin et al., 2002). However, people with T2D do not only receive health information from medical professionals. They can access a multitude of other sources with lifestyle and disease-related information and take different actions based on the information they obtain. This is called the bottom-up process (Griffin et al., 2002). A major risk is that people tend to prefer information that match their personal beliefs (Hart et al., 2009; Nickerson, 1998), or not check the reliability of a health source (Eysenbach & Köhler, 2002), which might lead to misinformation. Furthermore, people may choose not to search for information or to avoid receiving information that is important for their health. In this study, we want to examine the different health information behaviors of people with T2D that occurs in their daily lives.

Health information behavior

The way in which people interact with information is termed information behavior. It is defined as “information seeking as

well as the totality of other unintentional or passive behaviors, as well as purposive behaviors that do not involve seeking, such as actively avoiding information” (Case, 2012). When information behavior concerns health-related topics, we speak of Health Information Behavior (HIB). Lambert and Loisel (2007) describe how HIB is mostly studied in three different contexts: (1) when there is a health-threatening situation, (2) during medical decision-making situations, and (3) in situations that involve behavior change or preventative behavior. Various studies describe different strategies of information seeking behavior (see Table 1), whether or not related to health-related topics. While these studies give different labels to the type of information seeking behavior, they can all be traced back to one of the following three: active, passive or avoidant behavior. For the purpose of this study, we will from now on refer to this as health information behavior.

Active HIB is viewed as a conscious and goal-oriented action (Anker et al., 2011). Lambert et al. (2009a, 2009b) and Wilson (1997) differentiate between wanting to know about a topic (intense information seeking, active search) or wanting to *more* about a topic (complementary information seeking, ongoing search). Passive HIB means that someone encounters information without consciously searching for it (Wilson, 1997). Lambert et al. (2009a, 2009b) and Wilson (1997) make distinctions between unintentional information seeking (fortuitous information seeking, passive search), having limited interest in obtaining new information (minimal information seeking) or finding information about a relevant topic while searching for something else (passive attention). Avoidant HIB is the conscious decision *not* to search for health information even when knowing that the information is available (Case, 2012; Sairanen & Savolainen, 2010). Reasons why people may opt to avoid information are: (1) it threatens one’s beliefs, thereby creating cognitive dissonance and mental discomfort (Case et al., 2005; Gaspar et al., 2016), (2) fear for the information and the consequences of knowing (Chae, 2015; Jepson & Chaiken, 1990), and (3) a need to resume to normality (Germeni & Schulz, 2014) in which people don’t usually search for health information. If people feel they will not benefit from the information (Sweeny & Miller, 2012), lack personal or interpersonal resources to manage the threat or feel socially excluded (Brashers et al., 2004; Howell et al., 2014; Howell & Shepperd, 2017), they are more prone to avoid information.

Models of health information behavior

Many scholars have tried to capture the factors that trigger individuals to engage in health information behavior in coherent models and frameworks. The underlying assumption of most models is that information seeking is goal-driven (e.g., Afifi & Weiner, 2004; Byström & Järvelin, 1995; Johnson & Meischke, 1993; Kahlor, 2010; Ramirez et al., 2006): Various factors (e.g., personal, situational, social, cultural) will make an individual aware he or she is missing certain information, whereupon he or she then wants to fill that knowledge gap by searching for information. These models explain the set of factors that lead up to information seeking behavior. However, while they describe how personal, social or contextual factors can influence information behavior, we lack insights into everyday life situations in which an interplay of these different factors encourages individuals to search for or avoid health information, or create opportunities for them to encounter health information. Furthermore, getting health information is one thing, but what do people do with the information acquired?

Analyzing HIB in daily life

There are several studies that attempt to map daily life situations in which health information occurs and the channels that people with specific health conditions use for searching information. However, most studies applied a single qualitative method, like surveys or interviews (Dubbeldam et al., 2018; Fanos & Johnson, 1995; Longo et al., 2010; Yang, 2012). These studies are useful to identify which strategies people use and why they choose these strategies, but they do not provide in situ and in-moment data of health information behavior nor the influences of and the interplay between contextual and personal factors. One study took a different approach, in the form of a diary study: van Velsen et al. (2012) conducted a diary study on citizens’ use of mass media during an Enterohemorrhagic Escherichia Coli (EHEC) outbreak. Comparisons between the active and passive diary entries show that there were large differences in the number of diary entries (239 passive versus 24 active) and in their health information topics. Studies such as this one, illustrate how a closer look into the daily life situations of people seems promising in uncovering some of the main triggers for HIB in daily life.

Table 1. Categorizations of (health) information behavior.

Information behavior	Lambert et al. (2009a, 2009b)	Griffin et al. (1999)	Wilson (1997)	Germeni and Schulz (2014)	Longo et al. (2010)
<i>Active</i>	Intense information seeking	Nonroutine/Systematic*	Active search	Seeking information	Active information seeking
	Complementary information seeking	Nonroutine/Heuristic*	Ongoing search		
<i>Passive</i>	Fortuitous information seeking	Routine/Systematic*	Passive search		Passive receipt of information
	Minimal information seeking	Routine/Heuristic*	Passive attention		
<i>Avoidance</i>	Guarded information seeking			Avoiding information	

*Systematic or heuristic refers to the level of cognitive processing that one performs on the information obtained. Systematic means in-depth while heuristic means superficial processing.

Research question

In this study, we will apply the diary study method to elicit a fine-grained understanding of HIB situations among people with type 2 diabetes. While there is a lot of theory available about health information seeking, an explorative study about situations in daily life in which HIB occurs will provide a practical perspective that can supplement the existing literature. This is especially valuable for T2D patients. As T2D is partly a lifestyle illness, people need to make healthier choices throughout the day to treat this disease. Health information can help them to make these choices, especially when this information is given to them at these crucial decision-making moments.

Our main research question is thus: *What are the triggers in daily life that affect the health information seeking behavior (active, passive or avoidance) and its outcome of people with type 2 diabetes?*

Figure 1 shows the theoretical framework that serves as the basis for this study, which is based on the study of Longo et al. (2010). A person experiences a trigger in his or her daily life context upon which he or she applies one of three HIB strategies: actively seeking for information, passive reception, or active avoidance. Then, in the case of active or passive information behavior, a person must decide (1) whether or not to act on this information and (2) if so, how. The results will provide useful insights for health and patient organizations to better align their communication strategies with the needs and

daily context of their target group, and will allow us to enrich our theoretical HIB models.

Method

Recruitment area

Participants were recruited in the area of Dundee, Scotland. It is one of the five largest Scottish cities and has almost 150,000 inhabitants. About 66% of the population is of working age and about 24.8% has a higher education degree (Dundee City Council Information and Research Team, 2018). About 22.4% of the inhabitants (>16 years) smoke and there were around 225 hospitalizations in this city in 2017/18 due to diabetes-related issues (National Health Service Tayside, 2018). Between 2014 and 2018, there have been on average 525 newly diagnosed T2D patients every year, of which the majority was 51 years or older (Information Governance National Health Service Tayside, 2019). Recruitment took place by advertisements in local newspapers, posters in and around the city of Dundee, the university's news page and through a Diabetes e-mail list from Diabetes UK. Participants were eligible if they met the following criteria: (1) being diagnosed with type 2 diabetes, (2) fluency in English, (3) willingness to provide informed consent, and (4) no cognitive impairments that could hinder participation.

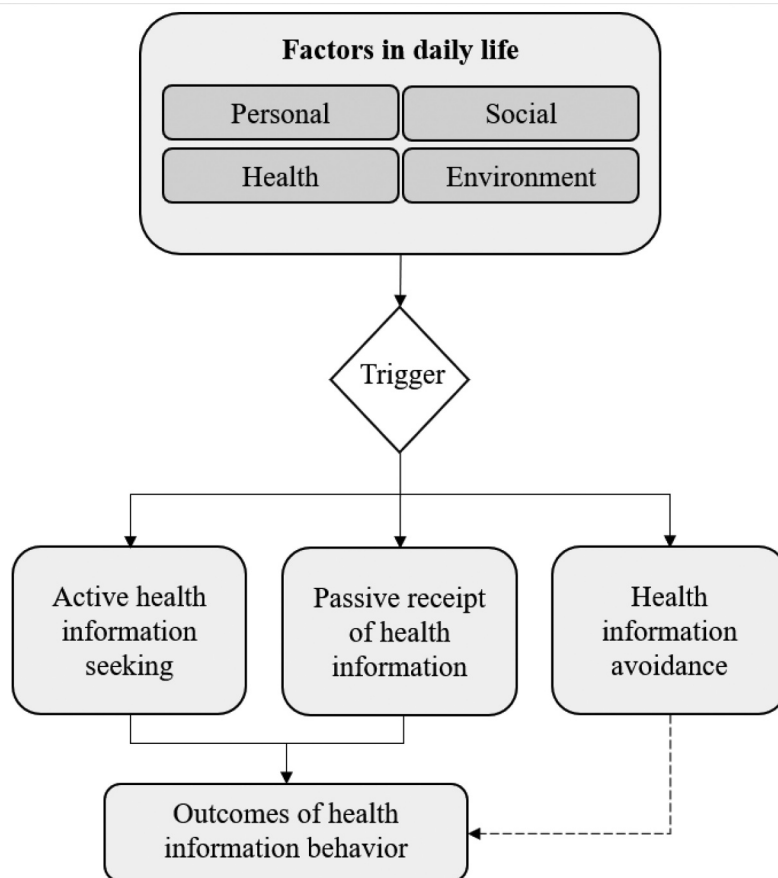


Figure 1. Proposed framework for health information behavior strategies of people with T2D, adapted from the theoretical framework of Longo et al. (2010).

Participants

Thirteen people with T2D agreed to participate, of which one person dropped out. In total, seven women (58.3%) and five men (41.7%) took part, with an average age of 54.8 years. A complete overview of their demographics is shown in Table 2, including their health literacy (the knowledge and skills of an individual to seek, understand and use health information to maintain or improve one's health (Peerson & Saunders, 2009), assessed via the scale by Chew et al. (2004). This health literacy scale was chosen as it is a short scale (three items) that does not heavily increase the workload of participants. A high health literacy score indicates that a person feels capable of understanding and correctly interpreting health-related information.

Data collection

We performed a diary study between July and August 2018, in which participants were requested to complete a diary entry each day. This method is very suitable for eliciting detailed descriptions of everyday life situations (Hektner et al., 2006; Larson & Csikszentmihalyi, 2014; Robinson, 2002). The diary study lasted for four weeks. Diary forms were offered via an online survey tool and started with an entry question to determine if participants performed active, passive, or avoidant HIB. The entry question in the diary forms was inserted as a cue for participants to think about health information they sought, read or watched that day. Based on their answers, they were directed to the form for active, passive or avoidant HIB, so we could tailor the questions for each of the types of HIB. This was not so much done for automatic classification purposes, but

rather to make sure we only asked the questions that were relevant for the specific behavior. Figure 2 below illustrates the routing. Pre-and post-study sessions were organized for briefing and de-briefing about the study. This was done face-to-face in individual or group sessions, depending on the participants' preferences and scheduling options.

Study procedure

All participants took part in a briefing session in which they received basic information about the study, completed a demographics questionnaire, and received instructions on how to complete the diary forms. Then, participants received a link via e-mail to an online diary form at 7 pm every day for 28 days. If the diary form was not completed that evening a reminder was sent the following morning at 11 am. After four weeks, the participants were invited to a debriefing session for a general discussion and evaluation of the diary study.

Ethics

Ethical approval was granted by University of Dundee Ethics Committee. Participants were notified that participation is voluntarily and that they could quit the study at any time. All participants signed an informed consent before the start of the study in which they confirmed voluntary participation and agreement to the use of their anonymized data for scientific publications. Participants were reimbursed for their time with amazon vouchers that had a total value of £100 pounds.

Data analysis

Although the diary entries were automatically categorized as active, passive, avoidant or other, two researchers (MB and LvV) independently reviewed and, if necessary, recoded the diary entries. If the participant noticed an information gap or need and took the initiative to search for health information search, the diary entry was classified as active. If the initiative was with other people or if participants encountered health information through mass media or books, or when they found health information they did not search for, the diary entry was classified as passive. Information received during regular checkups and visits to health professionals was also classified as a passive situation. Visits and checkups that were irregular were classified as active. Avoidant health situations were

Table 2. Demographics of participants.

ID	Gender	Age	Education	Living situation	Health literacy
01	F	61	Higher vocational	With spouse	4
02	F	61	Higher vocational	Alone	4
03	M	54	Higher vocational	With spouse	3.3
04	F	50	Vocational	With Friend/Family	3.7
05	M	70	Vocational	Alone	2
06	M	63	Vocational	With spouse	3
07	F	58	Higher vocational	With spouse	3.7
08	F	53	Higher vocational	With spouse	3.3
09	M	55	Vocational	With spouse	2.3
10	F	51	Vocational	With spouse	3.3
11	F	40	Higher vocational	Alone	3.3
12	M	42	Vocational	Alone	4

The health literacy scale ranges from 0 (low) to 4 (high).

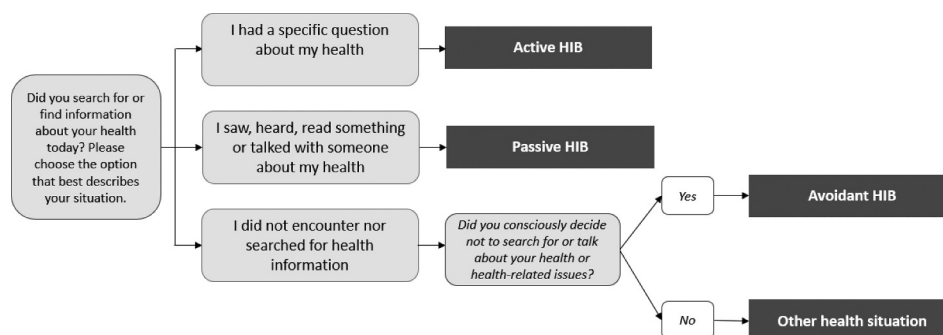


Figure 2. Routing within diary forms (HIB = Health Information Behavior).

classified as such when participants made a conscious decision not to search for health information or when they stated that they were too occupied with other activities to search for health information. Situations in which no HIB situations occurred were excluded from the data set. While reviewing the diary entries, it became clear that participants sometimes filled out a diary form for passive HIB, while actually describing an active HIB situation. After review, it was decided to regroup thirteen passive HIB situations under active HIB situations and to regroup four active situations under passive HIB situations. In addition, there were 34 diary entries in which participants mentioned they did not seek, encounter or avoid health information, but that there was a health incident or situation in which they had to think about their health. Upon reviewing these situations, two more diary entries were added to active HIB situations. One could argue that there is variation in the attention that people show while, for example, watching television, browsing the internet or doing both activities simultaneously (Brasel & Gips, 2011; Hawkins et al., 2006; Holmes et al., 2012). However, since it is not possible to measure the exact attention that a person devotes to focusing on a medium passively, we considered all passive health information seeking as being equal in this study.

The data obtained was treated as open-ended survey data. We opted for thematic analysis of the data, following the five stages of Pope (2000). The familiarization stage was done while preparing the dataset. For the second stage, we divided the data based on type of HIB (active, passive or avoidant). Then, we clustered the data on one of the four main themes: (1) sources and topics of health information for both active and passive HIB situations; (2) factors of active HIB situations; (3) factors that influenced passive HIB situations; and (4) motives for avoidant HIB situations. This was done iteratively by researchers MB and LvV until both agreed upon the clustering of the data. Next, for the indexing stage per theme, we further analyzed the data and clustered them based on specific themes. For theme 1, we grouped the data based on health information topic, such as 'nutrition' or 'blood sugar levels'. The same was done for the channels of health information. For theme 2, we distilled the triggers, actions and outcomes that influenced participants to seek health information, their actions and the outcomes (if available). For theme 3, we elicited personal, social, environmental and medical factors that affected passive HIB situations. For theme 4, we identified the motives for participants to avoid HIB. Every stage was iteratively done by researchers MB and LvV until both agreed with the grouping of the data. During the last phase, mapping and interpretation, we created tables and flowcharts to visualize the data.

Results

A total of 198 diary entries was collected in which HIB was described. In 53 diary entries, participants actively searched for health information, in 120 entries they passively encountered health information situations, and in 25 entries they consciously avoided searching for or absorbing health information. Additionally, there were 119 situations in which no HIB was reported.

Sources & channels

During both active (49.1%) and passive (27.5%) HIB situations, the Internet was a popular source for health information. People found information on diabetes-specific websites ($n = 23$), social media ($n = 13$), or health/medical websites ($n = 11$). In five situations, only a search engine (e.g., Google) was mentioned. Diabetes-specific websites are dedicated to diabetes-related matters. Health/medical websites are dedicated to health in general, like hospital websites or the National Health Service (NHS) website. Several participants used social media, especially Facebook, as a source for health information. Table 3 provides a complete overview of the sources and corresponding topics of health information, as well as the device used for seeking/encountering health information.

Active HIB

In addition to Internet searches, participants mentioned in thirteen situations (24.5%) other types of sources in active HIB situations, such as glucose meters, e-mails and food packaging labels. For example, when participants were shopping for groceries, they checked food product labels for their nutritional values. Conversations were described twelve times (22.6%) during active HIB situations, 50% of which were conversations with health professionals. There was only one situation in which a participant used a book, magazine or newspaper to actively search information. Television or radio programs were not listed as sources.

Passive HIB

In 50% of the passive HIB situations, people encountered health information by talking to other people. The participants discussed their health with family members (e.g., spouses, partners, children, relatives), health professionals (e.g., diabetes nurse, diabetes chiroprapist, hospital/practice nurse, GP, pharmacist) and friends. Books, magazines or newspapers were passive sources of health information in 8.3% of the passive HIB situations, of which newspapers were most common ones. The category 'Television programs' appeared in 5.8% of the situations, most of which were BBC programs. In nine situations, participants encountered health information though solicited e-mails from diabetes websites, such as reading about a low-carb program or noninvasive glucose testing.

Health information topics

Seventeen topics of health information were identified (see Table 4). The topic "nutrition" was the most frequent topic in active and passive HIB situations. The topic "blood sugar levels" (BSLs) had, at first glance, a similar frequency between active and passive HIB situations. However, when taking the relative occurrence into account (15.1% active vs 5.8% passive HIB situations), this topic was more common in active than in passive HIB situations. Furthermore, the table shows that in active HIB situations, participants reported searching for health information about symptoms after experiencing some health issues. The topic "symptoms" did not occur frequently in passive HIB situations. Two topics ("health information

Table 4. Descriptions and frequencies of health information topics of people with T2D.

Health information topics	Explanation	Frequency	
		Active	Passive
Nutrition	Participant(s) searched for or discussed with other the nutritional values of food products	16	25
Blood sugar levels	Participant(s) checked their blood sugar levels with glucose meters or discussed their blood sugar levels with others	8	7
Symptoms	Participant(s), when experiencing physical complaints or discomforts, searched for an explanation of their symptoms	10	4
Treatment	Participant(s) wanted more information on the treatment plans or searched for alternative treatment options	2	10
General T2D	Participant(s) searched for information on diabetes in general or discussed this topic with other people	2	15
Disease/condition	Participant(s) wanted more information on a specific health condition	4	7
Physical activity	Participant(s) searched information on physical exercises or sports activities	2	8
Diagnostic process	Participant(s) received information before undergoing medical tests	0	6
Medical results	Participant(s) received the results from the medical tests, such as blood results	0	1
Medication	Participant(s) searched for information on side effects or preparation of medication	5	8
Research	Participant(s) read research articles on their personal and general health conditions	1	10
Negative feelings	Participant(s) thought or talked about negative feelings, such as anxieties, insecurities or stress they have because of their illness	0	2
Health information source	Participant(s) searched for a new source for health information, specific for their health condition	1	0
General health themes	Participant(s) read articles, watched television programs and talked with others about general health topics that are not related to their own chronic illness	1	7
Medical equipment	Participant(s) encountered or searched for information on medical equipment (i.e. glucose meters, compression socks)	0	6
Finances	Participant(s) discussed about their health in order to receive financial compensation for health costs they made	0	2
Personal health status	Participant(s) engaged in health information activities to create a summary of their health	1	0
Unspecified	Participants mentioned that they searched for, or encountered health information but did not specify the health topic or theme	0	2
Total		53	120

source” and “personal health status”) were only found in active HIB situations. Five topics (“disease/condition”, “medical results”, “negative feelings”, “medical equipment” and “finances”) were only found in passive HIB situations.

Daily life situations

Active HIB

The participants brought forth seven types of triggers that led to active HIB: (1) experiencing health issues or symptoms, (2) cooking dinner or having a meal, (3) preparing for sports training, (4) starting a diet program, (5) experiencing feelings of anxiety, concerns or frustration, (6) changes in medication, and (7) other. Figure 3 shows the triggers, actions and outcomes of these active HIB situations.

Experiencing health issues or symptoms. In most active HIB situations (n = 16), participants experienced a health issue or symptom which triggered them to search for more information about that health condition. This was done by searching online (n = 6), contacting a medical professional (n = 4), talking to friends of family members (n = 4) or checking their BSLs (n = 2). For example, one participant 06 reported: “I start my Saturday very early 0400 hrs. and as soon as I woke I knew there was something wrong. very light headed, almost to the point of dizziness. I felt very sick, a feeling I am not used too at all”. He checked his blood sugar levels which were lower than usual, but still normal. He took no further action. Participant 11 was experiencing nerve pain and talked to her spouse about it. She decided to contact a medical professional. In four situations, participants decided to follow the advice they found online and after checking BSLs, which was lower than expected, decided to inform their spouse or decided to wait before undertaking actions to see if the problems subsided.

Cooking dinner or having a meal. In twelve active HIB situations, preparing for, or having a meal was a trigger for participants to actively search for nutritional values of foods or calorie contents (n = 9), check their BSLs (n = 1), talk to their family or friends (n = 1) or search online (unspecified) (n = 1). For example, participant 10 wrote: “I was at home making tea and I had to calculate how many carbs were in my spaghetti Bolognese I was making”. She checked her carb book and programmed the information in her glucose meter that tells her how much insulin she has to take. In two situations, participants mentioned they experienced difficulty with finding the correct answer regarding the nutritional values of food products. Other outcomes of these situations were that participants ate something extra because the BSLs were too low, bought food or felt annoyed because a food product seemed quite healthy, until checking the product’s nutritional values.

Sports training. Preparing for a sports training or physical exercise was a trigger for participants to engage in HIB to maintain stable blood sugar levels (n = 7). In four situations, participants checked their BSLs before exercising. The results of checking their blood sugar levels affected the outcome of that situation. If the blood sugar levels were normal, they could resume their daily activities (n = 1). However, if the levels were low (n = 3), they had to take protective measures, such as eating fast-acting carbs, canceling sports activities or informing their spouse about their low blood sugar levels. For example, participant 10 intended to go for a run and checked her BSL’s before the training: “I wanted to go for a run so had to check my levels of blood sugar to ensure they were high enough. I wasn’t feeling great so didn’t think they were high enough”. The glucose levels were too low for her to exercise which made her feel disappointed. In a later situation, the same participant forgot to eat a pre-workout snack. She checked

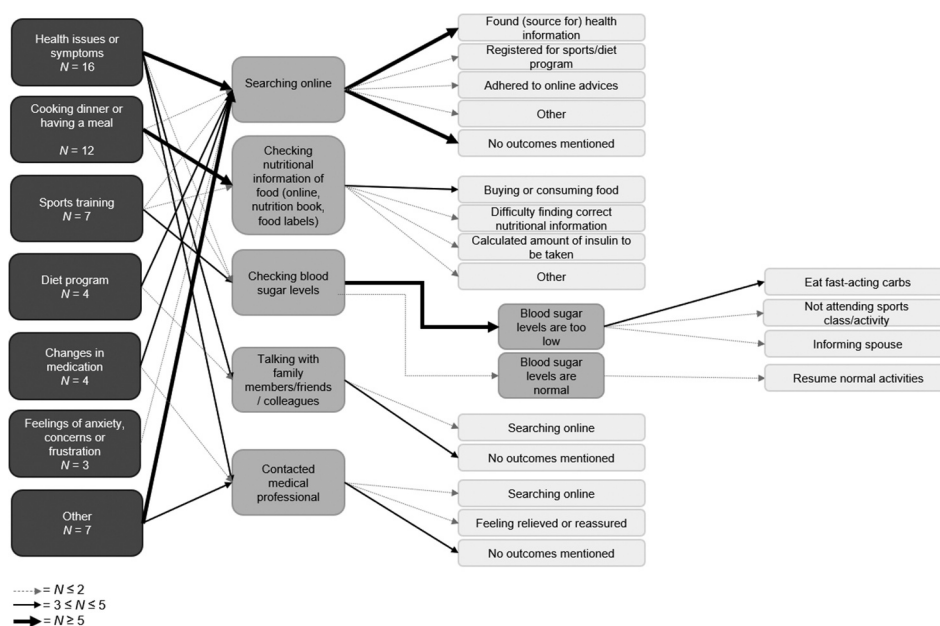


Figure 3. Overview of triggers, actions and outcomes of active health information behavior situations.

her BSLs, which were too low, but still decided to run and compensate for the low BSLs by eating two glucose tablets.

Diet program. Four participants just started a diet program or were thinking about joining one ($n = 4$) which led them to search for health information. Participant 06 wrote down the following: “Taking a milk shake diet (.) I wondered what would happen to my blood sugar”. They searched online for more information about the diet ($n = 3$) or discussed their diet with friends or family members ($n = 1$). Participant 07 was waiting for an appointment and thinking about an e-mail to register for a low-carb program she received: “In a police station, killing time while waiting to be interviewed”. She searched some additional information online about the program, after which she decided to join the program. As she stated: “Good to double check and make me feel more confident”.

Changes in medication. In four situations, changes in medication caused participants to search for health information. Participants were prescribed new medication and searched online for more information on the drugs and their effectiveness ($n = 2$). In two situations, they contacted a GP to change medication. Participant 12 reported: “Medication comes in liquid form and I wanted to change to tablets. So had to discuss with my GP”. In one situation a participant contacted her diabetes nurse to receive more information on medication usage for an upcoming medical procedure. She felt relieved afterward.

Feelings of anxiety or worries. In three situations, participants felt anxious, sad or stressed by hearing information from family members of friends. This caused them to search online for information that would make them feel at ease. For example, participant 01 had “a discussion with family about whether having type 2 diabetes shortened your life span”. She felt “quite sad and anxious” and therefore searched more information online. In another situation, participant 07 heard from a friend who also has diabetes

how her health had declined. This made the participant feeling worried about one’s own health, so she started searching on Google and visited multiple health and diabetes-specific websites. No specific outcomes were mentioned in all three situations.

Other. There were seven situations that occurred only once or twice. Participant 03 was searching a sports activity to become more physically fit: “At home, on tablet – searched for cheap form of exercise to improve health and wellbeing”. He registered for an introductory sports class. A few days later, the same participant searched online to know more about the health benefits of that particular sports activity. Another participant had to prepare for surgery and contacted a medical professional on how to manage blood sugar levels whilst fasting. Also, one participant used an online tool to create a summary of his health condition and problems in order to request financial support for people with a chronic illness or disability. Another participant wanted to compare prices of alternative medicines. Lastly, there was one participant who was worried about any potential foot problems and wanted to know more about the prevalence of foot amputations. He searched online and also checked this with his diabetes nurse during a regular checkup.

Passive HIB

Five different contexts were identified in which people with T2D encountered health information: (1) home environment, (2) work environment, (3) medical facility, (4) social eating context and (5) other. In addition, there were nine situations in which the specific context was not specified.

Home environment. The home environment was mentioned in 50 passive HIB situations. In fifteen (30%) of these situations, people encountered health information by reading or listening to the news. Participant 01 reported: “It was a TV programme researching whether fasting has a significant effect

on reducing blood sugar levels”. Participant 05 was watching BBC Breakfast in the morning in his dining room, when he heard about a new glucose meter, the Libra meter. Other activities via which they encountered health information included general internet activities ($n = 11$), conversations with friends and family ($n = 9$), checking their e-mails ($n = 5$), browsing social media ($n = 4$), watching television programs ($n = 3$) and conversation with health professional ($n = 1$). In two situations, the activities were unspecified. In ten situations, participants acted based on the information they found. For example, participant 05 passed the information about the Libra meter to a family member, who is also a diabetic.

Work environment. The work environment was described in 13 passive HIB situations. In six (46.2%) of these situations, participants conversed with colleagues about their health. Participant 04 was discussing with a colleague her diabetes medication on the work floor. She described this as “awkward as it was open plan with no privacy”. However, she did mention that “the more I talk about diabetes with friends/colleagues the less I am embarrassed about it”. Participant 10 was chatting to a regular customer at work and discussed a problem she had with regulating blood sugar levels while running. She liked talking about this topic with someone else who had similar experiences and understands this problem. Other health information activities at work were checking their e-mail ($n = 4$) and general internet activities ($n = 1$) or browsing social media ($n = 1$). There is one specific action mentioned after encountering health information. Participant 10, who was discussing exercising with a customer, decided to sign up for a running competition.

Medical facility. Thirteen passive HIB situations occurred in or around medical facilities. In six (46.2%) of these situations, participants went to the hospital or clinic for a routine health checkup. Participant 07 went to the diabetes nurse’s office for a regular health checkup: “Somewhat anxious, then relieved when I found out my test results”. Other activities were follow-up appointments ($n = 5$). Lastly, some participants encountered health information while having to wait for an appointment ($n = 2$). Participant 03 was browsing online and read an online article on his mobile phone he encountered. In another situation participant 08 was conversing with the staff nurse on the day ward, while waiting for a medical procedure. In five situations, specific actions were described after encountering health information. For example, participant 03, who was reading an online article while waiting for the appointment, discussed the contents of the article with his diabetes nurse.

Social eating context. There were thirteen passive HIB situations in which people had a drink or meal with family members and/or friends. In eight (61.5%) of these situations, participants went out to a restaurant, pub or café. In five (38.5%) situations they stayed at their friends’ or partner’s house. For example, participant 01 was having coffee with a friend in a garden center while taking about her health: “Talking with a friend about the everyday impact of diabetes on our lives”. Participant 02 was displeased because of a discussion on suitable foods for

a type 2 diabetic during a dinner with relatives: “Frustrated”. The son said this (the poached salmon) was an unhealthy meal and that he was fed up of people interfering with his father’s meals. The son had been a nurse and he knew all about nutrition and he knew best what was good for his father. He organized all his meals and his father should have taken his allotted meal from the fridge and microwaved it. In another situation, participant 11 was at a friend’s barbecue. During the barbecue, a discussion arose about her blood sugar levels. In only one situation a specific action was taken. Participant 11 and her partner ate too much during a dinner, which led both of them to feel unwell. She decided to check both their blood sugar levels.

Other. There were 21 passive HIB situations in which other contexts described than those previously mentioned. In six (28.6%) situations participants mentioned an exercising environment, such as the gym or taking a walk in the park. Participant 12 talked to a fitness instructor at his gym. He felt nervous but said he “looked forward to making positive steps regarding fitness”. In six (28.6%) shops and businesses in the town were described, such as the barber, cinema or local pharmacy. In four (19%) situations, participants described passive HIB situations that took place at their friend’s or partner’s house. Lastly, there were five (23.8%) other contexts that emerged from the data, such as the university, health offices or while driving in the car. In five situations the participants described a specific action they took based on the information they found. For example, participant 12, who talked to his fitness instructor, decided to use the information he received to make a fitness exercise program. In five situations, the participants did say they took actions but did not further describe these actions in detail.

Unspecified. There were 10 passive HIB situations in which the context of the participant was not specified. In seven (70%) of these situations, participants described that they were on their mobile phones, browsing through social media or checking their e-mail. In two (20%) situations, they were talking to a friend or family member and in one situation, a participant watched a television program with a friend. Participant 02 found through social media an article: “For most people exercising at a target heart rate is the best way to increase fitness and strength over time. Article explained how to measure target heart rate”. She saved the article to read later.

Avoidant HIB

There were 25 situations in which the participants consciously decided not to search for health information. We identified four reasons for this decision: (1) time constraints, (2) lack of a health cause, (3) negative feelings (i.e. stress, worries), (4) other. In ten (40%) situations, participants were too busy with work, chores around the house or other activities to think or worry about their health. As participant 06 wrote: “Too busy finishing off refitting a new bathroom no time to think about health issues”. Participant 07 mentions how she keeps herself occupied with other tasks to refrain from worrying about her health. She wrote down in their diary: “Just too busy as per usual. I find when I am busy non-stop I simply don’t have time

to worry about health issues. It is 22:30 right now and I am only just getting down to my emails”. The second reason for avoiding health information is when participants had little to no health problems and thus had no need to search for information ($n = 6$, 24%). They describe how they “have nothing to search for”, or that they know the reason of a health issue: “My blood sugar is low while being on a diet so did not need to question my health today”. The third reason is that participants feel that thinking about their health or diabetes affects their mood negatively ($n = 5$, 20%). Participant 04 wrote that he does “not wanting to obsess about my diabetes”, and participant 11 wrote: “Sometimes I feel I think too much about my health and it affects my mood”. Finally, in the ‘other’ category ($n = 3$, 15%) a number of reasons were mentioned that only occurred once. These were: technical barriers (no access to WiFi), going on holidays, and “taking a day off from thinking about my medical problems”.

Discussion

In this study, we analyzed the health information behavior (HIB) of people with T2D, with a focus on uncovering active, passive, and avoidant HIB. To this goal, we utilized a longitudinal approach with daily diaries for data collection. As such, this study is among the first to describe in detail HIB situations in the daily lives of people with T2D by being able to identify contextual and personal factors that trigger these situations. To this goal, we used an in-situ qualitative method, a diary study, which provides the full picture of HIB, including the interplay between personal and contextual factors. We found that (1) people with T2D tend to find health information through passive reception, (2) that there are distinctive differences between the contexts in which active and passive HIB occur, and (3) that people with T2D have multiple reasons for avoiding health information behavior.

Our findings can improve health information behavior models and frameworks for people with a chronic disease (such as T2D). Although several studies (e.g., Longo et al., 2010; Wilson, 1997, 1999) mention the presence of passive HIB, our study showed that passive HIB situations were actually much more frequent than active and avoidant HIB situations. This is understandable, as research on education and continuous learning stress how informal or incidental learning in the workplace or learning-on-the-job, is essential for employees to perform well on the job (Ellinger, 2005; Eraut, 2004). Instead of learning-on-the-job, people with T2D have to learn by living their daily routines on how to better cope with their illness. Whereas employees have resources like coworkers, organizational activities guidance by superiors to incidentally learn new information or skills, people with T2D make use of resources like family and friends, mass media channels, routine checkups and support from peers with T2D or health professionals. We therefore recommend researchers to consider all three types of HIB (active, passive and avoidance) when investigating health information behavior. In addition, this study gives detailed descriptions of contexts in which people with T2D passively receive and share health information. Current models of HIB imply that passive HIB is, similar to active HIB, somewhat of

a linear process: There is a context in which a need arises that leads to information seeking behavior (active or passive). While this is often true for active HIB, our results suggest that passive HIB is more intertwined with daily life. People don’t just encounter the information, but also share this with others. This sharing of information is currently lacking in the prevailing HIB models, but might make for a valuable extension. More research is necessary to better understand how passive receipt of health information emerges from daily life, and if and how people act upon this information. The relationship with emotions is also potentially interesting here, since experiencing negative emotions (e.g., by reading negative health information) can affect one’s ability to reason logically (Blanchette & Leese, 2011). Furthermore, this study is among the first that describes reasons for health information avoidance for people with T2D. Golman et al. (2015) describe how information avoidance is generally driven by (1) hedonic considerations (e.g., preventing disappointment, negative feelings) or (2) strategic consequences (e.g., preventing having to take responsibility, preventing demotivation). Of course, reasons given for not seeking information (e.g., being busy) could also be a method for people to ignore their situation. This study found some evidence for both categories – such as anxieties and postponing health information seeking behavior – but this topic needs to be further explored in future studies.

Next, our results can support the development of communication strategies of patient organizations. The results show that the factors related to eating and nutrition shaped most active and passive HIB situations. People search for and discuss diet programs, the nutritional value of food products, pre-workout snacks and meals with family members or friends. They use various tools to gain information, such as apps, calorie-books and websites. In these situations, there was often a strong social element. This does not come as a surprise, as eating has always been heavily intertwined with a social component. Fischler (2011) describes how humans have a strong tendency to eat together and suggest that eating together can actually help people to better regulate their eating habits. Research on interventions to improve self-management for people with T2D mention how social support is an important factor in managing type 2 diabetes (La Fisher et al., 1998; Mayberry & Osborn, 2012), as complementary tools in lifestyle and medical interventions (Fisher et al., 2005). Recent interventions focus on the role of the community health workers (Hargraves et al., 2012; Otero-Sabogal et al., 2010; Spencer et al., 2011), peer support groups (Heisler et al., 2010; Qi et al., 2015; Smith et al., 2011) or group visits to health professionals (Burke & O’Grady, 2012; Davis et al., 2008; Reitz et al., 2012). Van Dam et al. (2005) found that these types of social support are more effective than the role of family and friends. However, the study of Norris et al. (2010) found that the impact of self-management interventions for people with T2D sharply declines after the interventions end. Potentially, there lies a role for the social network of people with T2D. After the end of interventions by health professionals the guidance is transferred to the social network of patients to support and motivate them.

Study limitations

While we elicited a high number of diary entries during the study we should bear in mind that these were derived from twelve participants. This urges us to treat these results carefully. We recommend that replication studies in various cultural contexts be undertaken to increase the sample size and control for cultural factors. Secondly, while this was a longitudinal study with a high ecological validity, we did not examine the link between attention and recall. An experimental research, for example, using eye-tracking technology, could be used to study this connection (Bol et al., 2016). Thirdly, the diary study itself affected people's information seeking behavior. In the debriefing session, some participants mentioned that the diary study made them think about their health and in some cases caused them to search for more information. Effective solutions to prevent this behavior are currently not yet available, since this would involve a great intrusion in the privacy of participants (e.g., tracking internet activities or observing in daily life for a longer period of time). These effects are therefore inevitable in this type of social research. Last, in this study we did not take into account the stage of illness the participant was in. This can give valuable insights into why people search for certain topics or (do not) search for health information. For example, people who have recently been diagnosed with T2D may tend toward to more information seeking to better understand their illness than seasoned T2D patients. Future studies can shine more light on the matter of how the length of coping with T2D can affect HIB. We would recommend that such studies be conducted with a larger sample size in order to better distill (significant) differences between groups.

Conclusions

By analyzing active, passive and avoidant health information behaviors, this study provides a detailed overview of various daily life situations in which people with T2D are occupied with health information. By combining these three perspectives, our study shows how especially food and nutrition are important aspects in the daily lives of people with T2D and that family and friends play a large role in many HIB situations. We recommend that practitioners and researchers add passive and avoidant HIB to their current HIB models. Health professionals can use these results to optimize health information provision to their clients with T2D by considering the causes and motivations for active and avoidance HIB and contexts in which people can passively receive health information.

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The authors declare no conflict of interest.

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