Practices related to diabetes information in a group of Finnish adults living with Type 1 diabetes

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Introduction

About half a million out of 5.5 million inhabitants in Finland have diabetes, and of these 50,000 have Type 1 diabetes (Finnish Diabetes Association, n.d.). However, research on diabetes-related information behaviour among persons with Type 1 diabetes is scarce (Kuske et al., 2017). This abstract presents some first results from an exploratory, small-scale, qualitative study of Finnish adults with Type 1 diabetes, focussing on their diabetes information practices concerning certain information or sources. McKenzie (2003) identified four modes of information practices named 'active seeking', 'active scanning', 'non-directed monitoring' and 'by proxy'. Niemelä (2006, 163) added 'information avoidance' to these four modes.

Methodology

We conducted semi-structured interviews by using a translated version of the interview guide developed by Ryan and Webster (2020), available at `https://bit.ly/3FroBWn`. The questions covered which diabetes data and information and sources were either used or avoided, and how information behaviour changed with age. Participants were recruited through, e.g., advertisements via the Finnish Diabetes Association, and through information on the website of the researchers' university. We obtained oral informed consent and permission to record the interviews, which were conducted in 2020–2021 through video communication. Analysis was mainly deductive. Despite repeated advertising, only six people volunteered to participate. These were four women and two men born between 1952 and 1998. All participants had Type 1 diabetes; three had been diagnosed in childhood or adolescence, two in their 20s, and one at the age of 50.

Results

Sources for Diabetes-related Information

All informants currently use a sensor and software that automatically monitors their blood glucose levels. The sensor's app can also record carbohydrate intake, exercise and other information that can be used for self-management. General diabetes-related information was obtained mainly through formal sources, including health professionals, the magazine and website of the Finn-

ish Diabetes Association, and leaflets. Medical websites such as HealthVillage. fi and Terveyskirjasto.fi (Health Library) were also popular. Some also used scientific journal articles or weekly magazines. Peers were mainly contacted through Facebook groups for diabetics, whereas interpersonal communication with laypersons seldom occurs.

A couple of interviewees specified that physicians or diabetes nurses give them needed basic information on disease management, or when new devices are to be used. Expert information was perceived most valuable. Disappointment in the expertise also occurred, however; one participant with long experience of diabetes sometimes had to teach the physician how diabetes actually works.

Internet information was mostly searched on Google. However, one person thought that it is difficult to find anything this way, and another thought that most of the retrieved information is unfortunately not trustworthy. Facebook groups for Type 1 diabetics were used by half of the participants. Peer support and having access to the experience of living with Type 1 diabetes by a large number of people were mentioned as the positive sides of these.

Information Practices

We categorised interaction with sources as belonging to any of the five modes of information practices. Urgently needing information ("…I got this enormous need to get all kinds of information…") or acquiring possible sources ("…especially in the beginning I borrowed books from the library…") are categorised as 'active seeking', whereas less active monitoring ("…it's true in fact that, that I follow that only a little…") or active listening are categorised as 'active scanning'. Serendipitous encountering ("…you can stumble upon something you did not know about…") is then categorised as 'non-directed monitoring'. Passively obtaining information ("…it has been more the other party that has been the one giving information…") or being recommended sources by health professionals can be categorised as 'by proxy'. In addition, avoidance of information or sources occurred especially if they were not perceived as needed, useful, trustworthy or related to self-management; half of the informants said that they avoided information on Type 2 diabetes. Facebook groups were avoided because of the often negative and snarky discussion climate. A couple of the participants avoided general discussion forums, one even as advised by health professionals following diagnosis.

Information practices obviously change over time: one participant did not have the strength to absorb all information directly after diagnosis, but a month later, and for several months to follow, she actively searched and read

all available information, but after that she mainly monitored information. Another interviewee mentioned that in the beginning, she needed information to build a knowledge base to be able to manage her disease, but nowadays there is rather a need for specific information.

Discussion and conclusions

Health professionals and medical online sources were the most important sources, while peer support was mostly obtained from Facebook groups. Similarly, previous research show reliance on health professionals (Eriks-son-Backa, 2003; Kuske et al., 2017). Sparud-Lundin, Ranerup and Berg (2011) found that although almost 80% of Swedish women with Type 1 diabetes used the internet, about half of them did not use social websites at all. In Spain, little more than half of diabetics used social media daily, and an additional 26% weekly, and Facebook was the most commonly used site (Gimenéz-Pérez et al., 2016).

Information not perceived as useful for self-management was avoided, and information practices varied depending on the current stage of the condition. This is similar to modes of information practices (McKenzie, 2003; Niemelä, 2006). Avoidance of certain information and sources occurred due to prefer-ence for only useful information (cf. Sairanen and Savolainen, 2010), being advised to avoid certain sources, or negative experiences of Facebook groups.

Despite the limited sample in this study, it fills a gap in health information behaviour research. Information and healthcare providers should be aware of possibly changing information needs, practices and reasons for avoidance in order to meet specific needs. Ruthven (2021) proposed a theory of transitions that can be used to examine information behaviour at different stages, and determine what support is needed for transitions. Further studies on larger populations are needed for insights that are more thorough, for example by studying diabetics' information practices in different stages based on transi-tion models.

Acknowledgements

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