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Information avoidance by younger adults with Type 1 diabetes: a preliminary empirical study

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Abstract

Introduction. People with Type 1 diabetes need to collect data to calculate their own insulin doses, and collect information about potential complications. However, information avoidance may be a barrier to such activities.

Method. A preliminary study of information avoidance by younger adults with Type 1 diabetes covered data, information and information channels that they avoid, and adolescence's effects on diabetes information behaviour. Semi-structured interviews with six younger adults with Type 1 diabetes and five healthcare professionals were used to understand their diabetes information behaviours.

Analysis. The understandings were gleaned from thematic analysis of interview transcripts.

Results. Younger adults with Type 1 diabetes may only collect blood glucose data, disregarding other relevant data and information. They may also take 'time off' from collection, and not gather information about potential complications. Some desire more contact with healthcare professionals. Adolescence may involve significant avoidance of data and information.

Conclusions. Observed behaviours speak to 'utility' and 'hedonic drives'. Long gaps between healthcare appointments may exacerbate avoidance, as well as limiting healthcare professionals' opportunities to advise patients. Younger adults with Type 1 diabetes avoid data and information unless they believe these are needed. Frequency of appointments and routes to information could be improved.

Introduction

This paper reports a preliminary empirical study of information avoidance in adults with Type 1 diabetes in Scotland. Over 4.8 million people in the UK have diabetes (Diabetes UK, 2020). Of these, around 10% have Type 1 diabetes, an autoimmune disease that destroys the body's ability to make insulin and hence control blood glucose (Diabetes UK, n.d.-d). Diabetes can lead to long-term 'complications' such as nerve damage possibly leading to amputations, heart attacks, strokes and kidney disease (Diabetes UK, n.d.-a). Diabetes may account for around 17% of UK health expenditure by 2035-36 (Hex, et al., 2012), with complications accounting for a large part of this.

Management of diabetes requires regular blood-glucose monitoring and control, and healthy lifestyles based on suitable diets and exercise. People with Type 1 diabetes generally self-administer insulin via injections or insulin pumps. They may regularly measure blood glucose to calculate required insulin doses. These calculations may need to be adjusted depending on exercise, food and alcohol consumption (UK. National Health Service, n.d.-b), or during periods of illness, when diabetes self-management may need to change significantly (Diabetes UK, n.d.-b)

People with diabetes therefore need to gather and engage with data about their own conditions, and information about healthy lifestyles. However, avoidance of information is common in everyday life (Narayan, et al., 2011). This includes avoidance of knowledge of diabetes-risk (Orom, et al., 2018).

Reported in this paper is the first qualitative study of information avoidance in young adults with Type 1 diabetes, focussing on the types of data and information that may be avoided. It also reports why these types may be avoided; the information channels avoided, and possible improvements to them; and the impact of adolescence on diabetes-related information avoidance. This research adds to empirical knowledge of information behaviours, focussing on people with Type 1 diabetes whose information avoidance is under-researched. It thus adds a further valuable dimension to work on avoidance behaviours and diabetes that stretches back over two decades (Evans, et al., 1999), by studying a known research-gap, i.e. *current* information avoidance by young adults who have a *specific* type of diabetes (Type 1), and hence would benefit from engagement with their own data and with information.

This paper first outlines previous research into health-related information avoidance. It then outlines the research design that comprised data collection by online interview, and thematic analysis of data to address five research questions: three on the use and avoidance of data, information and information-channels; one on features of digital information channels; and one on the impact of adolescence on information behaviours related to Type 1 diabetes. These research questions are:

1. What types of information about diabetes are avoided and used?
2. Why may people avoid data and information about their diabetes?
3. Which diabetes information-channels are avoided and used?
4. How can digital diabetes information-channels be improved to get higher uptake?
5. How did adolescence affect adults' past diabetes-related information behaviour?

Following this, the findings are presented: (1) adults with Type 1 diabetes engage with data, information and information-channels only if they perceive them to be useful, while avoiding sources of misinformation and worry; (2) suggested improvements to information channels centre on improving monitoring systems; (3) avoidance of diabetes data and information is severe during adolescence. This is followed by discussion of the findings in the light of existing knowledge. This preliminary study demonstrates that it would be worthwhile conducting further research in this area, drawing attention to the potential value of a larger longitudinal study that would deploy both qualitative and quantitative approaches.

In this paper, when referring to data and information about diabetes:

- ‘data’ means quantitative data about patients’ own diabetes, such as blood glucose readings, carbohydrate intake, insulin doses, levels of ketones, amounts of exercise.
- ‘information’ means qualitative information on, for example, how to use data, how to maintain health, possible complications.

Literature review

Information avoidance was defined in 2010 as ‘any behaviour intended to prevent or delay the acquisition of available but potentially unwanted information’ (Sweeny, et al., 2010). A later refinement emphasised *active* avoidance, i.e. when there is awareness that the information is available (Golman, et al., 2017).

Information avoidance may arise from hedonic drives, i.e. avoidance of feeling bad, or strategic drives, i.e. desire to gain an advantage (Golman, et al., 2017). Here, people ‘calculate’ whether information avoidance confers ‘advantages’. However, Hertwig and Engel (2016) dismiss such fully ‘economic’ explanations because humans are not purely rational, and may calculate poorly, so it is necessary to understand *how* people make these calculations. More recently, Sharot and Sunstein (2020) have stated that calculations are based on instrumental, hedonic and cognitive utility.

Information avoidance may also be spurred by desired levels of uncertainty (Hertwig and Engel, 2016; Huisman, et al., 2020). Another possible origin is ‘learned helplessness’, a phenomenon in which people learn to behave helplessly to avoid negative circumstances (Peterson, et al., 1993). Also, people may avoid information more if they have ‘non-avoidance’ reasons for doing so (Woolley and Risen, 2021). For example, people may not choose restaurant gift-cards that do not contain calorie information, or choose sugary snacks that do not have labels warning about the dangers of sugar. (In both cases, participants were offered choices between cards and labels containing and not containing the information.) The researchers attribute such choices to ‘cover’, i.e. people being able to attribute such choices to other features or contexts than to the information they wish to avoid.

Much of the research reviewed for this paper covers Type 2 diabetes. This may be because Type 2 is far more prevalent than Type 1 (UK. National Health Service, n.d.-a) There is a range of ‘internal’ factors that may mediate information avoidance in diabetes. These include whether loci of control are internal or external (Chang and Huang, 2020), and maintenance of positive moods, for example by avoiding thinking about the condition (Broekhuis, et al., 2020). Age may also be a factor: adolescents with Type 1 diabetes may rebel against undertaking diabetes tasks (Starkman, et al., 2019). Poor diabetes control may exacerbate information avoidance in adolescents (Starkman, et al., 2019).

General health information avoidance is associated with low health literacy (Chang and Huang, 2020; Hay, et al., 2021) and with low healthcare use (Jones, et al., 2020). Recently diagnosed patients may avoid information due to the shock of diagnosis, or due to having received ‘sufficient’ information at that point (Sheridan, et al., 2020).

As well as internal/psychological factors mediating health information avoidance, external factors may also do so. (See Table 1.)

Factor	Participants and their conditions	References
The power of audiences such as spouses	Adults with Type 2 diabetes	(Anderson, et al., 2016)
The power of audiences: families attempting to control health behaviour	People (ages not stated) with Type 2 diabetes or HIV/AIDS	(Brown and Veinot, 2021)
Racial discrimination	Adult women with Type 2 diabetes	(Gonzales, et al., 2014)
Time constraints	Older adults with Type 2 diabetes	(Broekhuis, et al., 2020)
Absence of ill health	Older adults with Type 2 diabetes	(Broekhuis, et al., 2020)
Debt/income	Adults with Type 2 diabetes	(Houle, et al., 2016)
Lack of WiFi	Older adults with Type 2 diabetes	(Broekhuis, et al., 2020)
Whether people live in rural or urban settings	Adults with diabetes or other health conditions (abnormal uterine bleeding, arthritis, asthma, chronic obstructive pulmonary disease, hypertension, coronary heart disease, skin or other cancer, benign prostate disease, or depression)	(Dean, et al., 2017)

Table 1. External factors affecting information avoidance by people with diabetes

Information needs of people with diabetes

There is a body of literature specifically addressing diabetes patients' self-perceived information needs. For example, people with diabetes may wish for technology that supports decision-making, sharing information with healthcare teams, interpersonal support and choice (King, et al., 2012). Such adults want information on appropriate diets, exercise and avoidance of foot complications (Kalantzi, et al., 2015)

The relative importances of healthcare professionals and the internet have changed over time. For example, healthcare professionals have been seen as reliable information sources by adults with diabetes (Eriksson-Backa, 2003). A decade later, adults with diabetes in a study by King et al. (2012) preferred face-to-face contact with healthcare professionals to electronic resources, even if the participants were interested in using IT. A few years later, adults with diabetes in a study by Kalantzi et al. (2015) were most reliant on their doctors for diabetes information, while over 70% had never used the internet for this purpose. However, two years later still, Kuske et al. (2017) found that that their participants' most frequently reported diabetes information sources were the internet and healthcare professionals (Kuske, et al., 2017). Further 'doctors versus internet' factors include continuity of contact with healthcare professionals (Dovey-Pearce, et al., 2005), and professionals' understanding of poor health literacy, uncontrolled diabetes and multiple complications (Nelson, et al., 2018). Preferences for information sources can vary with age. For example, adults with diabetes who are under 40 are ten times more likely than others to regard the internet as an important information source (Kalantzi, et al., 2015).

A combination of healthcare professionals, social support and technology may be needed to provide optimum outcomes. For example, although use of phone apps may improve blood glucose levels, benefits depend on the frequency of feedback from healthcare professionals (Hou, et al., 2018). In contrast, adults with diabetes may learn about technologies such as glucose sensors from online networks rather than healthcare professionals (Turnbull, et al., 2021). Online systems may not lead to better outcomes (Hirani, et al., 2017), possibly because they need to be co-designed with specific patient-groups (Goff, et al., 2021).

A study of a small number of information avoidance by Finnish adults with Type 1 diabetes was undertaken in 2022 (Eriksson-Backa, et al., 2022). It found that diabetes information may be avoided if it is 'not perceived as needed, useful, trustworthy or related to self-management'.

Objectives

There are limited discussions of information avoidance in reviews of diabetes information-seeking (Kuske, et al., 2017). Research into health information behaviour often covers undifferentiated 'chronic diseases' (for example, Phillips, et al., 2014). Research publications may not state the type of diabetes (for example, Orom, et al., 2018), or may 'mix' diabetes with other chronic conditions (for example Dean, et al., 2017). In much of the research reviewed for this study, either participants' ages were not stated (for example, Orom, et al., 2018), or participants were older adults (for example, Broekhuis, et al., 2020). This highlights the lack of focus on young people with Type 1 diabetes in the literature. Further to these observations about research publications, in contrast to other chronic diseases, Type 1 diabetes requires daily self-monitoring and self-administration of insulin. Hence the factors affecting 'data avoidance' may be specific to Type 1 diabetes.

Technology for monitoring blood glucose levels, and for delivering insulin, has improved in recent years. For example, Libre sensors that 'flash' blood glucose data to an app or meter on the press of a button became available on prescription for people with Type 1 diabetes in Scotland by late 2018 (UK. Insulin Pump Awareness Group, 2018). The current version of these sensors automatically sends blood glucose data to the app every minute. These sensors require one insertion per fortnight, in place of frequent finger-prick testing. The app or meter then highlights the current blood glucose level, as well as showing recent hours' levels. The app can also be used to record carbohydrate intakes and exercise data, which facilitates calculation of insulin doses, and to send data to healthcare professionals. Rather than injections, insulin may be continuously delivered using pumps, thus significantly reducing numbers of insertions.

From the above, there is a research gap: detail of *current* information avoidance by young adults who have a *specific* type of diabetes (Type 1), and hence would benefit from engagement with their own data and with information. This, and the difficulties often experienced by adolescents with diabetes (Starkman, et al., 2019), prompted an empirical study exploring the following research questions:

1. What types of information about diabetes are avoided and used?
2. Why may people avoid data and information about their diabetes?
3. Which diabetes information-channels are avoided and used?
4. How can digital diabetes information-channels be improved to get higher uptake?
5. How did adolescence affect adults' past diabetes-related information behaviour?

Methods

Interviews with people with diabetes were chosen to gather qualitative data on information avoidance. To gain a more complete picture of information behaviour, and to investigate how people with diabetes may be helped to engage with data and information, interviews with a range of healthcare professionals were also used as 'expert' sources.

Two sets of interview questions were developed from the research questions: one for young adults, about the data and information they do and do not gather or engage with, the information channels they use, and changes in their diabetes information behaviour when entering and leaving adolescence. The other set was used to ask healthcare professionals matching questions about their patients' general information behaviours. The question-sets are available online (https://bit.ly/3FroBWn). All processes were approved by the researchers' university's ethics panel, and all participants gave informed consent.

Six younger adults with Type 1 diabetes (Table 2) were recruited via a student support-group at the researchers' university. Due mostly to research question 5, younger adult participants were sought, so that participants would not be asked to recall long-past events. (NB this paper uses 'younger adults' because 'young adult' specifies 'under 25', and two of the participants were aged 27 and 33.) Due to ethical concerns, adolescent participants were not sought. Advertisements sought participants who 'sometimes do not access or use information about their diabetes'. This did not result in recruitment of participants who avoided all diabetes data and information. For example, one occasionally worked for Diabetes UK; another was a student nurse intending to specialise in diabetes. All younger adult participants were white. All were British apart from D05. (His nationality is deliberately not reported.) All but one were in their twenties.

Code	Age	Gender	Age when diabetes was diagnosed
D01	23	F	7
D02	23	M	7
D03	27	M	16
D04	21	F	17
D05	33	M	11
D06	dropped out		
D07	20	M	9

Table 2. Participants: younger adults with diabetes

Five healthcare professionals (Table 3) from a diabetes centre in a local hospital were recruited. The lengths of time they had specialised in diabetes ranged from one year to over 25 years. Two had Type 1 diabetes.

Code	Gender	Professional role around diabetes	Years in this role	Years in any diabetes specialist role	Diabetes Type	Age when diabetes when diagnosed
HCP01	M	Consultant diabetes physician	16	>25 years	none	NA
HCP02	F	Diabetes specialist nurse	20	20	Type 1	13
HCP03	F	Consultant psychiatrist	1	1	none	NA
HCP04	F	GP focussing on diabetes	7	7	none	NA
HCP05	F	Diabetes dietician	2	2	Type 1	25

Table 3. Participants: healthcare professionals

Interviews and analysis

Interviews were conducted between 22 May and 15 June 2020. All were online due to Covid-19. The above-noted distinction between the terms 'data' and 'information' was emphasised at the start of each interview. Interviews were conducted via phone, Skype, Microsoft Teams and Webex. Interviews with younger people lasted on average 33 minutes 50 seconds, ranging from 26 minutes 03 seconds to 48 minutes 50 seconds. Interviews with healthcare professionals lasted on average 45 minutes27 seconds, ranging from 30 minutes 0 seconds to 1 hour 4 minutes 49 seconds. They were recorded on an iPad, Teams or Webex. Recordings were transferred to a secure server, then deleted from local devices. Recordings were manually transcribed by the first author.

Transcriptions were analysed using thematic analysis (Braun, Clarke, and Hayfield, 2019; Braun, Clarke, Hayfield, and Terry, 2019; Braun and Clarke, 2006; Elliott, 2018). Theme development and analysis were undertaken by the first author, in consultation with the second. Themes (Table 4) were derived from familiarity with the data, then used to code it. Coded interview data was then used to generate answers to the research questions.

Theme-code	Interview data placed in this theme	Relevant research questions
01 Data	Data on whether and why people with diabetes do and don't collect and use/interpret quantitative diabetes data.	1, 5
02 Information	Data on whether and why people do and don't collect and use/interpret information around diabetes	2, 5
03.1 Data-kit	Data on hardware and software used by people with diabetes to obtain, store and interpret *data* on their own diabetes.	1, 2, 3
03.2 Info-kit	Data on artefacts and software used by people with diabetes to obtain, store and interpret *information* around their own diabetes. These include books, computers and phones.	1, 2, 3, 4
03.3 Internet	Data on websites and social media used by people with diabetes to access *information* around their own diabetes	1, 3, 4, 5
03.4 Insulin-kit	Data on people with diabetes calculating their own insulin doses, and self-administering insulin	1, 2, 3, 4, 5
04 Diagnosis	Data on experiences of people with diabetes of being diagnosed (including shock and its effects), and the aftereffects of this	1, 2, 3, 4, 5
05 Social and family support	Data on experiences of people with diabetes of support (and lack of support) from family, friends and peers	1, 2, 3, 5
06 HCP support	Data on experiences of people with diabetes of support (and lack of support) from healthcare professionals	1, 2, 3, 5
07 Transitions into and from adolescence	Data on the effects of transitions by people with diabetes from childhood to adolescence, and from adolescence to young and full adulthood.	5
08 Negative emotions	Data on anxiety, worry, depression and similar negative emotions in people with diabetes related to their own diabetes	1, 2, 3, 5
09 Other psychological information	Data on psychologies of people with diabetes	1, 2, 5
10 Other physical illnesses	Data on other health conditions, and how they affect diabetes	1, 2, 4, 5
11 Sorting IA	Data on reducing and ameliorating diabetes-related information avoidance.	1, 2, 3, 4, 5

Table 4. Themes used for coding interview data

Results

Data use and avoidance

Details of the younger adults' data collection practices are in Table 5. They all used Libre sensors to obtain blood glucose data; all but one gathered this data on the Libre phone app. Only one mentioned collecting insulin doses. Two collect data about exercise. Two mentioned measuring ketones. These are substances produced when the body has insufficient insulin, potentially leading to complications (Diabetes UK, n.d.-c)

Participant	How blood glucose data is collected	Other equipment and software used	Collects carbohydrate-intake data	Collects exercise data	Collects ketone data	Other data collected
D01	Libre sensor and app	Insulin pump	Y	N	N	None stated
D02	Libre sensor and app	None stated	Y	Y	Not stated	sometimes records feelings based on blood-glucose levels
D03	Libre sensor and app	Computer Occasional use of finger-prick blood-glucose tests to check accuracy of Libre data	Y - when D03 wishes to calibrate insulin doses	N	Y – if D03 feels unwell or blood glucose is very high	None stated
D04	Libre sensor and app	Carbs & Cals (an app for calculating carbohydrate intake and other nutritional data from amounts of food) Occasional use of finger-prick blood-glucose tests to check accuracy of Libre data	Not stated	Y	Not stated	Insulin doses, meals/food-diary (occasionally)
D05	Libre sensor and meter	None stated	N	Not stated	Not stated	Does not collect insulin doses
D07	Libre sensor and app	Insulin pump which indicates required insulin doses Occasional use of finger-prick blood-glucose tests	Y	N	Y – when ill	Not stated

Table 5. Diabetes equipment used, data collected and not collected by participants

The participants' reasons for collecting and not collecting data centre on perceived need, such as controlling blood glucose levels. For example, D05 stated that eating new foods is a '*nightmare*' that requires close monitoring of blood glucose. An example of lack of perceived need came from D01: '*With exercise … I don't jot that down because I do it every day, it's not frequent that it affects my sugars*'. This behaviour may also be due to avoiding worry or stress. For example, D04 does not collect data when drinking '*because you kind of just want to have fun*'.

HCP01 stated that there are two cohorts of people with diabetes: those that engage with data and information, and those that do not. Three other healthcare professionals explicitly agreed with this statement. All the healthcare professionals agreed that collection of blood glucose data was most common. Four healthcare professionals stated that some patients may collect carbohydrate data. HCP02 stated that patients are likely to collect carbohydrate and insulin data if asked to do so by healthcare professionals. Two healthcare professionals stated that patients may occasionally collect ketone data. One healthcare professional stated that collection of exercise data is very rare.

HCP02 suggested two further reasons for the avoidance of data collection: (1) '*life gets in the way*'; (2) gaps of 4 to 6 months between clinic appointments may mean that patients do not know what to do with their data, so collecting it becomes pointless. Hence HCP02 would like to see her patients at least once a month. HCP01 stated that courses about use of data require attendees to have good English, so may not reach people who need them most. A further issue is that such courses may require five contiguous days away from normal life. Work pressures prevented D05 from attending such courses. In the UK, courses may take place some years after diagnosis, which contrasts with D07's experience of diagnosis in Germany: '*I spent two weeks [immediately after my diagnosis] in a hospital being taught everything that I'd need to know*'.

Information use and avoidance

As with data, the participants avoid information unless they believe they need to know it, for example about diet, travelling, or 'sick-day rules' (Diabetes UK, n.d.-b). Otherwise, they rely on information they have previously gathered. While all participants are aware of potential complications, they prefer not to dwell on these. Two stated that this is because they have good diabetes control, so do need not know details that will only make them afraid.

The participants' reasons for their information behaviours vary. For example, D03 accesses information that is personally and/or professional relevant to him, such as '*new treatments or new developments in technology*'. D01 and D04 do not access most diabetes information, specifically due to the worry it causes. D07 accesses information about travel, precautions, different climates and different activity levels.

The healthcare professionals gave a varied picture of the information their patients access, in addition to the two cohorts mentioned in the previous section. HCP03 stated that many patients do only what they are told by healthcare professionals. However, one healthcare professional stated that patients often look up sick-day rules, while another stated that patients may access information on holidays and driving. Another noted that a few look up technical information, such as how to make 'closed loop' systems in which insulin pumps automatically respond to changing blood-glucose levels.

Information channels

Use of information channels is mixed: the participants prefer 'official' channels, but have a range of attitudes towards Facebook groups focussing on diabetes. Examples of the former include D04's preference for the Diabetes UK and NHS websites, and D03's use of academic resources. Two participants are members of relevant Facebook groups, while another believes that it can be very dangerous to follow advice from Facebook.

Concern about misinformation can be seen in D01's statement that a 'diabetes community' website provides false information, and in D03's statement that some online sources falsely state that cinnamon can cure diabetes. Misinformation was the focus of one of only two statements by participants about printed information, namely D01's statement that books might contain out-of-date information. (The other mention was a book on using diet to control blood glucose.)

The role of interactivity in channel-choice is mixed. For example, D04 prefers to gain information from the non-interactive Diabetes UK and NHS websites, while avoiding Facebook. However, she receives advice from friends via WhatsApp. The picture of interactivity is further complicated because no participants use My Diabetes My Way ('*The Scotland interactive diabetes website to help support people who have diabetes and their family and friends.*') In fact, one participant had not heard of it. However, all healthcare professionals stated that My Diabetes My Way is recommended to people with diabetes, although HCP01 acknowledges that it is hardly used, and HCP05 finds it poorly designed.

The participants' views of healthcare professionals as information sources are also mixed: four praised their healthcare professionals in this context, but D05 did not.

For example D04 stated that she is in frequent email contact with her healthcare professionals. However D05 has been unable to obtain information from his doctors about a very personal condition which is more prevalent in diabetes.

The healthcare professionals agreed that younger patients are more likely to obtain information online, all stating that patients are directed to the Diabetes UK website. However, there was concern that online sources are suboptimal. For example, HCP04 stated that although '*the younger generation undoubtedly use phones, apps, computers much more often … websites aren't really easy to use, they're not necessarily kept up to date*'. Similarly, HCP02 had been so concerned about the quality of diabetes websites that she created her own.

Most healthcare professionals are unaware of the specifics of their patients' use of information channels, but HCP03 may spend significant proportions of appointments discussing this topic with patients. The other healthcare professionals mentioned that patients can use My Diabetes My Way, a website about emotional support, Diabetes UK's website and printed leaflets. However, there was pessimism about the use of these channels. For example, HCP03 stated '*there's a much bigger percentage that … are not, to my knowledge, looking things up*', while HCP05 stated that some patients do not read leaflets.

Both the younger adults and the healthcare professionals noted the personal support available via online channels. For example, D02 stated that the '*main purpose of the Facebook group seems to be to bring people's spirits up*'. HCP03 suggested that '*people are keen to have a sense of not being alone, and have a sense of connectedness*'.

Improving information channels

Four participants suggested improvements to the Libre system. D01 would like it to directly control insulin pumps. D04 would like automatic alerts and replacements when sensors fail. D05 would like the Libre meter to compare body-weight information with insulin doses. HCP05 suggested that the Libre system should record types of exercise.

Other suggestions from the younger adults focussed on online information channels. D01 stated that she would like less negativity on Facebook, while D03 suggested that research information for '*general consumption*' should be clearer and less sensationalist. D02 pleaded for email access to healthcare professionals, to avoid embarrassment during in-person appointments. However, this contradicts D04's good email contact with healthcare professionals. Further, D03 noted that in another region of Scotland, diabetes teams can be emailed by patients. D03 also contrasted the UK with Germany, where '*they consider internet as part of your basic human rights*'. Of the healthcare professionals, only HCP02 mentioned email, stating that her patients often email her data. She finds that matching these data with patients' other activities and data from Libre sensors is '*quite time-consuming*'.

The healthcare professionals gave no suggestions for improving information channels, apart from HCP01's implicit desire for improvements to My Diabetes My Way, HCP02's wish for better diabetes websites, and HCP05's previously noted suggestions for the Libre system.

Adolescence

According to participants' recollections, this period was characterised as very difficult for people with diabetes, who may completely avoid data and information. For example, in his pre-teens, D02 accessed information about his diabetes but then completely lost interest due to trying to make it seem that his lifelong condition was not present. Similarly, D05's 'dip' started when he was 16, before which he '*did everything properly*'. He then '*stopped collecting everything*', started drinking, giving himself incorrect insulin doses, not recording them and generally being '*irrational*'.

Entry into adulthood often reduced information avoidance. For example, after D01's first year of university she realised what might happen to her because of her diabetes, so she began to take more care. This transition may have been eased by her starting to use Libre sensors at that time. However, changes may be due to regional variations in healthcare, according to D07 who moved from England to Scotland around the time he emerged from his 'dip'. Despite a majority of participants reducing their information avoidance on entry into adulthood, this is not guaranteed, according to D03. While living at home, he found it easy to record data. However, this lapsed when he first went to university, eventually leading a period in intensive care. The only mention of parental pressure was by D07 who stated that this did not cause his adolescent information avoidance.

The healthcare professionals confirmed this picture of adolescence. For example, HCP01 stated that adolescents are often unreceptive to all forms of information, while HCP02 suggested that younger adults may begin to take more care. HCP03 suggested that adolescents are rebellious due to wanting not to be different to their friends. She attributed post-adolescent improvement to people starting to make better use of information, in part due to increased internet use.

Discussion

Types of data and information about diabetes avoided and used (RQ1)

The overall picture from younger adults with Type 1 diabetes is that they collect only the data they believe they need to control their *current* condition, i.e. mostly just blood glucose data. This data collection may have been promoted by the advent of facilitative sensors. Younger adults mostly do not collect other data (for example insulin doses, carbohydrate intake) that they cannot or do not use immediately, even though this data might help with dose calculations, and hence help minimise future complications. Data-collection may be paused while people enjoy social occasions, even though collection may take only a few seconds.

A similar picture of information avoidance emerges: participants collect only information believed to be immediately useful, and avoid gathering information that causes worry without adding to immediate benefit, or rely on information previously known and hence potentially out of date or incorrect. Similar practices by older Finnish adults have been reported (Eriksson-Backa, et al., 2022, p. 31). Despite the younger adults' behaviours, healthcare professionals recognise there is a significant cohort of patients who do not engage with data and information. Both data and information behaviours speak to immediate 'utility' (Golman, et al., 2017; Sharot and Sunstein, 2020), and to minimising thinking about the condition (Broekhuis, et al., 2020).

Reasons for avoiding data and information about diabetes (RQ2)

In addition to the 'utility' and 'time off' reasons, there may be long gaps between appointments with healthcare professionals. These may prompt cessation of data gathering. The long gaps, and the high workload reported by one healthcare professional, also suggest that healthcare professionals have limited opportunities to get to know and advise their patients.

The overall picture matches the finding that information avoidance is common (Narayan, et al., 2011). It somewhat fits with the idea of low self-motivation leading to avoidance of monitoring progress towards goals (Webb, et al., 2013). However, all participants had clear wishes to avoid complications, a definite goal, even though their behaviours may not fully support this goal. The picture also fits with hedonic drives (Golman, et al., 2017; Sharot and Sunstein, 2020), and is reminiscent of desires for 'absence of ill-health' (Broekhuis, et al., 2020). D05's inability to attend a course matches these researchers' 'time-pressure', and information avoidance arising from income concerns (Houle, et al., 2016).

The reported behaviours and the reasons behind them raise four practical issues. The first is that the frequency of diabetes appointments is not optimal for preventing 'data avoidance'. The second is that if people with diabetes do not collect at least blood glucose and carbohydrate data, it will be difficult for healthcare professionals to advise on their dose-calculations. The third is that some people cannot take the time needed to learn how to engage with their data. This may call for more flexibility in how such teaching is delivered. The fourth, based on D07's experience, is the question of how soon after diagnosis people with diabetes should be taught how to calculate insulin doses.

Avoidance and use of diabetes information channels (RQ3)

Arguably, the clearest picture emerging from the younger adults in this study is that printed information sources are hardly used, in part because they may become out of date. This matches recent preferences for online channels (for example, Hirani, et al., 2017; Hou, et al., 2018; Kuske, et al., 2017). Facebook is used by participants who are members of relevant groups. However, there was some mistrust of Facebook and other online sources. This is reminiscent of findings by (Eriksson-Backa, et al., 2022, p.32) and by Kim et al. (2020) about the consequences of misinformation. Online channels that informed participants were praised, echoing ideas about utility (Golman, et al., 2017; Sharot and Sunstein, 2020), as were those provided social support, echoing Turnbull et al. (2021). For example, Golman et al. (2017, p. 98) suggest that 'persons at risk of diseases, such as genetic disorders, may be able to lead perfectly happy lives until emerging symptoms or test results force the reality of their situation upon them'. Similarly, Sharot and Sunstein (2020, p. 17) state that 'For example, all else being equal, the less curable a disease (instrumental utility) the worse it would be to learn that one carries it (hedonic utility).' In the results reported above, participants reported avoiding collecting data and information that they did not believe they immediately needed, so that they could avoid fear (e.g. of future complications) and hence impacts on their happiness. Turnbull et al. (2021, p. 9) found that their participants (people with Type 2 diabetes, some of whom could not obtain Libre or other sensors) 'sought information from their personal social networks and diabetes support groups (in person and online).' In summary, people with diabetes use channels that support or inform them, when they can or choose to, and ignore others.

Suggested improvements to diabetes information channels (RQ4)

Suggestions for improvement to information channels clearly concerned improvements to systems for measuring and controlling blood glucose. These improvements would either save time (Broekhuis, et al., 2020) or provide extra utility (Golman, et al., 2017; Sharot and Sunstein, 2020). Other suggestions centre on increased online contact with healthcare professionals, even though this might increase healthcare professionals' workloads, and possibly increase the gaps between appointments. This would risk increasing data avoidance (Dovey-Pearce, et al., 2005; Hou, et al., 2018). However, if overall contact can be increased, this would speak to wishes for information to come from healthcare professionals (Eriksson-Backa, 2003; Kalantzi, et al., 2015; King, et al., 2012; Kuske, et al., 2017). An 'official' online information source, My Diabetes My Way, is not used by all of the participants, one of whom was unaware of it. One of the participants and one healthcare professional reported poor experiences with it. Hence work should be undertaken to improve the appeal and uptake of My Diabetes My Way.

The effects of adolescence on diabetes-related information behaviour (RQ5)

The overall picture, according to all participants' recollections, is that adolescence is a time of extreme diabetes information avoidance. People with diabetes living through adolescence may well want to avoid the difficulties and tasks it brings, to be like their peers. Towards the end of adolescence, access to alcohol can exacerbate the difficulties. As people with diabetes enter adulthood, they tend to leave the adolescent 'dip'. This finding corresponds with those of Starkman et al. (2019). While information avoidance by people with Type 2 diabetes may be induced by families' attempts to control them (Brown and Veinot, 2021), this was not supported by the younger adults with Type 1 diabetes in this study.

Conclusions

This study has responded to a research gap by reporting findings on information avoidance amongst younger adults with Type 1 diabetes. Information channels used and avoided by such adults have been found, along with suggestions to increase their uptake. Some similarities with information avoidance by people with Type 2 diabetes are noted. Participants' recollections of heightened information avoidance during adolescence are reported. Overall, there is similarity with the practices and findings reported for older Finnish adults, possibly suggesting that diabetes information avoidance habits, once formed, may be hard to break – and that the Scottish situation is not unique.

The study has also raised some practical issues regarding diabetes healthcare. Perhaps the most significant is that long gaps between appointments may exacerbate harmful information behaviours. The week-long courses that teach insulin dose-calculations may need some flexibility for those pressured by everyday life. Further issues centre on variations of diabetes support across borders.

In reaction to the issues discussed above, it might be possible for healthcare professionals to educate their patients about the value of collecting and working with data so that they can ameliorate future possible complications. This would presumably call for professionals and patients to meet for longer, and more often, and to be aware of how individual patients collect and work with data and information. Unfortunately, this does not seem immediately practical given the current long gaps between appointments. Alternatively, professionals might signpost patients to Diabetes UK and similar organisations that might be able to provide relevant support and advice. Again, this might not be practical – such organisations can be charities that have limited resources. Another possibility is signposting patients to (online) support groups that are known to give reliable advice and support. An issue here might be ascertaining which groups – and possibly which members – are reliable.

Alternatively, the UK NHS might move to the reported German approach reported by D07. While this might increase 'up-front' costs, hopefully it would reduce the financial (and human) costs of complications. However, we suggest that ongoing reminders and education would also be needed. Similarly, the time between diagnosis and invitations to courses such as 'Dose Adjustment For Normal Eating' might be reduced so that 'good habits' are instilled early. The situation reported by D05, if this has recurred, presumably requires better employment rights.

The participants suggested some technological improvements. The authors are aware that there have been changes to My Diabetes My Way since data was gathered, so perhaps professionals could help their patients use it and any similar systems better.

Concerning adolescence, we very tentatively suggest that professionals might help parents and guardians of children with diabetes prepare for this very difficult period, or at least know that such difficulties may well arise. We are not able to make any specific suggestions about such support. All of these suggestions are very tentative and require further research.

A limitation of this study is the small number of participants. Also, the participants live in a single city, so are affected mostly by that city's diabetes health-care arrangements. As university students, the participants may have similar levels of information skills. Also, the participants are quite similar in age. Older or younger participants may show different behaviours. Similarly, people may develop diabetes in middle age: age at diagnosis and length of time since diagnosis may have a bearing on behaviours. This research specifically concerned Type 1 diabetes: other types (for example Type 2, gestational) may lead to different behaviours.

However, the study has served as a useful precursor to the design of a larger project investigating participants with more varied levels of information skills. In this future work, quantitative data will also be gathered, such as frequencies of use/avoidance of various types of data, information and information channels, along with variations due to data-gathering methods, insulin-delivery methods and age. The authors aim to work with researchers in other countries who are also interested in information avoidance in diabetes. Such work would involve investigating development of interventions to reduce the depth and impact of information avoidance, and increase relevant health information and health data literacy. This work is currently at an early planning stage, so further details are not available at the time of writing.

A longitudinal study would also offer opportunities to chart information behaviour and use over time, allowing for examination of behaviours at different life stages. In the longer term, findings from this study may have relevance for other chronic health conditions. Such a study could also investigate adolescents' behaviours during this period, rather than relying on their later recollections – a further limitation of this study.

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