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Objectives. To improve understanding of how individuals at high risk of type 2 diabetes experience the risk of diabetes, and how these experiences relate to the adoption of physical activity as a protective behaviour.

Design. A qualitative study using semi-structured interview with individuals identified by screening as at high risk for type 2 diabetes.

Methods. Fourteen individuals, aged 40-64, were interviewed twice, with a two-year interval between. Participants' experiences of their risk of diabetes and physical activity were assessed. The transcribed interview data were analysed using inductive qualitative content analysis. Two themes emerged from the data: a threatening risk perception and a rejected risk perception.

Results. The threatening risk perception occurred when the risk was unexpected by the participant, but become internalised through the screening procedure. The threatening perception also involved a commitment to increase physical activity to prevent diabetes. However, short-term anxiety and subsequently emerging hopelessness were also part of this perception. The rejected risk perception involved indifference and scepticism regarding the risk. Here, physical activity behaviour and cognitions appeared to remain unchanged. Rejection also involved difficulties in accepting one's high-risk identity. The rejecting group lacked motivation for increased physical activity, while the other group showed determination regarding increased physical activity, often leading to success.

Conclusions. Perceptions of the risk of diabetes emerged as threatening or as rejected. Participants' perceptions reflected varying and intertwining emotional, cognitive, and behavioural mechanisms for coping with the risk, all of which should be recognised in promoting physical activity among high-risk individuals.
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The study is part of a larger FIN-D2D programme. The results of the data based on patient records have been published previously. However, present study is the first to analyse the qualitative interview data collected as part of the programme. Thus, there is no overlap to declare.

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“I saw what the future direction would be…”

Experiences of diabetes risk and physical activity after diabetes screening

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The statement of contribution

What is already known on this subject?

Diabetes screening has few adverse psychological effects on screened individuals. Diabetes can be prevented by increased physical activity and modest weight loss among high-risk individuals. The evidence on the effects of screening on protective behaviour is limited and inconsistent.

What does this study add?

- High-risk individuals may perceive the risk of diabetes as “threatening”, or may reject the risk altogether.
- Individuals having problems in adjusting to high-risk identification may not be motivated to engage in physical activity for prevention.
- Failure to achieve the outcomes expected from lifestyle changes may lead people with threatening risk perception to a sense of hopelessness.
Experiences of the risk of type 2 diabetes and physical activity

Abstract

Objectives. To improve understanding of how individuals at high risk of type 2 diabetes experience the risk of diabetes, and how these experiences relate to the adoption of physical activity as a protective behaviour.

Design. A qualitative study using semi-structured interview with individuals identified by screening as at high risk for type 2 diabetes.

Methods. Fourteen individuals, aged 40–64, were interviewed twice, with a two-year interval between. Participants’ experiences of their risk of diabetes and physical activity were assessed. The transcribed interview data were analysed using inductive qualitative content analysis. Two themes emerged from the data: a threatening risk perception and a rejected risk perception.

Results. The threatening risk perception occurred when the risk was unexpected by the participant, but become internalised through the screening procedure. The threatening perception also involved a commitment to increase physical activity to prevent diabetes. However, short-term anxiety and subsequently emerging hopelessness were also part of this perception. The rejected risk perception involved indifference and scepticism regarding the risk. Here, physical activity behaviour and cognitions appeared to remain unchanged. Rejection also involved difficulties in accepting one’s high-risk identity. The rejecting group lacked motivation for increased physical activity, while the other group showed determination regarding increased physical activity, often leading to success.

Conclusions. Perceptions of the risk of diabetes emerged as threatening or as rejected. Participants’ perceptions reflected varying and intertwining emotional, cognitive, and behavioural mechanisms for coping with the risk, all of which should be recognised in promoting physical activity among high-risk individuals.

Keywords: type 2 diabetes, experience, perceived risk, physical activity, behaviour change, prevention, screening
Experiences of the risk of type 2 diabetes and physical activity

Several countries recommend targeted or opportunistic screening for early identification of individuals at high risk of type 2 diabetes (Paulweber et al., 2010; Saaristo et al., 2007; Simmons, Echuffo-Tcheugui, & Griffin, 2010). A thorough screening procedure should enable more accurate perceptions of risk, and lead to appropriate further tests and support for prevention (UK National Screening Committee, 2012). Physical inactivity and a poor diet comprise major risk factors for diabetes along with impaired blood glucose, metabolic syndrome, and a family history of diabetes (Paulweber et al., 2010). High-risk individuals can substantially reduce their risk of type 2 diabetes by lifestyle changes that result in modest weight loss and increased physical activity (Tuomilehto et al. 2001). Nevertheless, only 29–42% of individuals with pre-diabetes are currently regarded as sufficiently physically active (Zhou & Mi, 2012; Zhou, Remsburg, Caufield, & Itote, 2012).

The potential for harm from diabetes screening has been extensively examined. Adverse effects, i.e. anxiety, depression, and a decreased quality of life, appear to be minimal regardless of the diagnosis (Adriaanse & Snoek, 2006; Eborall et al., 2007a; Paddison et al., 2011). However, the absence of adverse effects may stem merely from people’s tendency not to regard diabetes as a serious disease (Adriaanse et al., 2002; Eborall, Davies, Kinmonth, Griffin, & Lawton, 2007b; Skinner et al., 2006), or to have a low risk perception, due for example to an optimistic bias (Jones, Roche, & Appel, 2009; Kemple, Zlot, & Leman, 2005; Kim et al., 2007). Overall, it seems that responses to screening tend to be fairly indifferent: screening does not appear to cause emotional distress, nor does a negative screening result cause relief (Adriaanse & Snoek, 2006). Thus, a lack of psychological distress may not indicate successful adjustment to the risk, but rather a tendency to avoid dealing with the risk.

The adoption of a healthier lifestyle has been seen as a favourable effect of diabetes screening. However, few trials have compared screened and non-screened individuals to examine the association between risk screening (especially diabetes screening) and protective behaviour (Deutekom et al., 2010). A recent study found no difference in behavioural intention between
Experiences of the risk of type 2 diabetes and physical activity

screened and non-screened high-risk individuals (Paddison et al., 2011). Minor but inconsistent impacts on lifestyle were found in another study comparing non-screened and screened high-risk individuals (Mai et al., 2007). Similarly, in a recent trial on overweight primary care patients, Grant et al. (2013) examined whether information on a high genetic risk improved prevention behaviours, but did not find differences in behavioural motivation between informed vs. not informed patients. However, cross-sectional studies indicate that in general an awareness of one’s elevated risk of diabetes increases the likelihood of adopting a healthy lifestyle (Okosun, Davis-Smith, & Seale, 2012; Qureshi & Kai, 2008), although others have claimed that people who are aware of their risk do not have intentions to change their lifestyle (Adriaanse et al., 2002; Eborall et al., 2007b; Green, Bazata, Fox, & Grandy, 2007). A recent study (Vähäsarja et al., 2012a) indicated that 74% of high-risk individuals did indeed perceive a need to increase their physical activity after screening. However, the need was not associated with the majority of objective risk factors.

It has been claimed that individuals at risk of diabetes do not to fully translate their personal risk-factors into accurate risk perceptions, even if they do understand the causation of the disease (Claassen et al., 2011; Damman & Timmermans, 2012). A similar tendency seems to apply to translating personal risk-factors into physical activity perceptions (Vähäsarja et al., 2012a, Vähäsarja et al., 2012b, Green et al., 2007). Hivert, Warner, Shrader, Grant, and Meigs (2009) examined previous behavioural efforts and future intentions among at-risk groups with a high and low risk perception, and found no difference between the groups. However, risk perception, in conjunction with positive outcome expectations, is regarded as a prerequisite for adopting protective behaviour (Brewer, Weinstein, & Cuite, 2004; Janz & Becker, 1984; Leventhal, Leventhal, & Cameron, 2001; Schwarzer, 2008; Rogers, 1975). Since type 2 diabetes is highly preventable by lifestyle changes, a correct perception of risk and its relation to behaviour is vitally important (Critchley, Hardie, & Moore, 2012; Grant et al., 2013). Nevertheless, previous studies (see e.g. Kinmonth et al., 2008; Kramer, 2007; Paddison et al., 2009) indicate that the association
between diabetes risk perception and protective behaviour requires further examination. There is also a need to analyse physical activity separately from dietary behaviour, as these two behaviours may involve different risk perceptions.

The present qualitative study was designed to investigate how individuals at high-risk of type 2 diabetes experience the risk of diabetes, and how these experiences are manifested in the adoption of physical activity as a protective behaviour.

**Methods**

*Procedure and participants*

The present study forms part of a larger programme (FIN-D2D) aiming to screen the Finnish population at high risk of type 2 diabetes, and to prevent diabetes by lifestyle intervention in routine primary care settings (Saaristo et al., 2007). The participants’ risk for diabetes was initially assessed via a modified FINDRISC score (Saaristo et al., 2007), followed by oral glucose tolerance tests (OGTT) to check the participants’ risk status. The inclusion criteria for the interview included a high-risk status for diabetes and participation in the FIN-D2D lifestyle intervention. The definition of the high-risk status and the FIN-D2D study protocol are reported elsewhere (Saaristo et al., 2007). Nurses at six primary health care centres in the Central Finland health care district were trained to recruit high-risk individuals (attending their usual appointment with a nurse) for participation in two face-to-face interviews. The nurses shared the contact information of twenty volunteering individuals with the researcher, who then contacted the volunteers by telephone. One of the persons initially contacted refused to participate in the interview. Data from five persons were excluded from the analysis for the following three reasons: not fulfilling the high-risk criteria, being unable to participate in any physical activity, and non-provision of follow-up data (due to withdrawal from the follow-up interview). In total, 28 interviews from 14 participants were included in the analysis. The participants (8 women, 6 men) had an age-range of 40–64 years. Their
height and weight measurements were derived from FIN-D2D baseline data (patient records). Their characteristics are presented in Table 1.

**Interviews**

Interviews were conducted in two stages: after the diabetes screening in 2006 (less than one-year post-screening), and on average two years from the first interview, in 2008. The semi-structured interviews (averaging 90 minutes) were conducted in locations affording complete privacy. Each interview began with a description of the study, and continued with questions on the participant’s demographic information, current health status, and participation in the intervention sessions. We focused on two main themes: (i) participants’ experiences concerning the risk of diabetes, and (ii) experiences concerning physical activity as a protective behaviour. Each question in the interview guide was covered, though not in strict order. The questions were partially repeated from interview I to interview II to assess consistency between the two interview rounds. After the interviewer’s explanations of the study, the participants signed the informed consent form. The Ministry of Social Affairs and Health in Finland gave permission to the National Institute for Health and Welfare to collect the data from health care units. The Institutional Review Board (IRB) of the National Institute for Health and Welfare had approved the FIN-D2D study.

**Analysis**

Each interview was audio-taped and transcribed verbatim as a text file. The analysis involved content analysis (Krippendorf, 1986), applying an inductive analytical approach (Graneheim & Lundman, 2005). These methods were chosen as systematic and objective means to capture the richness of a phenomenon of interest. In the analysis, each interview transcript was regarded as a unit of analysis. The transcripts were read through repeatedly to gain a sense of the interviews as a
Experiences of the risk of type 2 diabetes and physical activity

whole. A meaning unit consisted of a half or a full sentence, or a paragraph containing one idea, episode or piece of information containing the contextual meaning.

The analytical stages involved (i) identifying the meaning units concerning experiences of diabetes risk and physical activity; (ii) condensing the meaning units (deleting all words that were unnecessary for an understanding of the statement), then further condensing the meaning units into a more abstract level; (iii) creating sub-categories by exploring the similarities and differences between the condensed meaning units; (iv) creating main categories; (v) creating themes encompassing the preceding categories. The descriptions of participants’ physical activity levels were compared with the current physical activity recommendation (engaging in moderate-intensity physical activity for 150 minutes/week, or in vigorous physical activity for 75 minutes/week or more, or an equivalent mix of these; see U.S. Department of Health and Human Services, 2008). The data extraction process is presented in Table 2 and Table 3, separately for the two themes.

Findings

Risk experiences following the high-risk diagnosis

We discerned participants’ experiences as falling into two themes: (i) a threatening risk perception (ten participants), and (ii) a rejected risk perception (four participants). The content elements of the threatening risk perception included unexpectedness, internalisation, anxiety, commitment, and hopelessness. In contrast, the rejected risk perception included indifference, scepticism, drifting and a defended identity. The contents of the two themes are presented below (see Tables 2 and 3 for examples of the participants’ expressions).

A threatening risk perception

Unexpectedness
Participants who saw their risk of diabetes as a serious threat expressed the unexpectedness of their awareness of the high risk. Unexpectedness was mostly related to the finding of impaired blood glucose levels, but also to impaired blood lipid levels, and to previously unidentified /non-informed blood pressure levels. Becoming identified as having a high-risk status was often expressed as a shock. Before the screening, most individuals within the threatening risk perception category had been mainly aware of some single risk factors (e.g. overweight, insufficient physical activity, or a family risk for diabetes). However, they had not previously made a serious link between these factors and their health status, let alone a link with diabetes. Unexpectedness was often related to an optimistic bias: many participants, especially those without, but also those with a known family history of diabetes, had believed it would be others who would get diabetes rather than themselves.

Internalisation

The participants’ expressions indicated that the risk had to become internalised to be perceived as a serious threat. Internalisation occurred through several means. Firstly, each participant within the threatening risk perception category described the FINDRISC score as striking. As they perceived it, this was the first time that they had become aware of the significance of each risk factor in terms of a cumulative increase in diabetes risk. The risk score (showing the statistical likelihood of developing diabetes in the future) was described as comprehensible, providing an eye-opening experience to many. Secondly, the risk was internalised through the health examinations and a comparison of the results with the target values. Only two out of ten participants had been fully aware of their elevated risk of diabetes. One had a strong family history of diabetes, whereas the other had a disease for which diabetes had been mentioned as a complication. Regardless of their awareness of the risk in principle, neither had seriously considered the risk until now. A few participants reported having experienced symptoms (e.g. dizziness, or “seeing stars”) before the screening. However, they had assumed the symptoms to be normal or transitory. The tests now
linked these symptoms to the risk of diabetes. Thirdly, internalisation occurred through the interaction with the health professional (in most cases a public health nurse). The participants often indicated that it was the negotiation with the nurse that had brought home an understanding of the risk, through the provision of individually targeted and trustworthy guidance.

Anxiety

Anxiety was typically experienced by participants immediately after the screening. It was particularly related to the threat-scenarios most participants envisaged on the basis of prior experiences of diabetes among family members, relatives, or friends. Anxiety was typically related to the worry of having to start medication, especially injections. For some of the participants, the awareness caused anxiety due to prior experiences of other severe diseases, with a resulting general fear of disease. Some of the participants were also concerned about what they perceived as a diabetes epidemic, and its economic costs to society. A few expressed uncertainties, involving a concern about what the high-risk status might mean, and the changes diabetes might cause in their lives. Some participants became nervous while waiting for further tests. In the longer term, anxiety appeared to be related to the participant’s current health condition. If improvements in health occurred, or if signs of worsening health were lacking, anxiety decreased over time.

Commitment

Becoming aware of the risk was often seen as an opportunity leading to improved health awareness. Participants’ general interest in health issues increased significantly (in many cases starting from almost zero. This was manifested as actively seeking diabetes- and health-related information. Many expressed gratitude at becoming aware of their risk, since it allowed them to act to prevent diabetes. None of the participants perceived their new awareness negatively. Becoming aware was regarded as a chance to re-evaluate one’s lifestyle, often seen as unsatisfactory up to now.
Awareness helped them define their need for change, with change being expected to add both years and quality of life (e.g. physical functional capacity), and further to maintain the freedom to make choices without diabetes-related restrictions.

After the screening, the participants – with one exception – were determined to increase their physical activity levels. One person preferred to change diet only. Before the screening only 2/10 participants within the threatening risk perception group participated in the recommended levels of physical activity. Many participants indicated that they now took responsibility for their own health, having made a clear decision to adopt a physically active lifestyle. Participants mentioned having changed their attitude to physical activity. Unlike before the screening, every activity was now considered beneficial, especially walking. They emphasised principles such as adding physical activity to their everyday activities, starting with modest changes, and choosing the forms of activity that were feasible and enjoyable. Most of the participants did indeed succeed in increasing their physical activity. At the time of the first interview 8/10 were engaging in the recommended levels of physical activity. However, only 5/10 were adhering to these levels at the time of the second interview. The main reasons for relapse were physical or mental health problems, and a lack of time and energy due to work or family commitments.

Engaging in regular physical activity often provided a sense of control over the risk. Most of the interviewees mentioned the importance of constantly monitoring their behaviour and weight status, feeling they could not afford to relapse. Control visits to a nurse or physician strengthened motivation and created a sense of security for most participants. Continuous monitoring was considered especially important among those with limited ability to be physically active.

Hopelessness

Although the majority of the participants were optimistic about preventing diabetes through lifestyle changes, some seemed to have accepted the possibility of diabetes in a fatalistic manner. The risk
Experiences of the risk of type 2 diabetes and physical activity

was sometimes regarded as a “payment” for healthy years so far, and sometimes as an inevitable destiny running in the family. Hopelessness was particularly present after a longer time (i.e. manifested in the second-round interviews only) if participants felt they had made the required changes in their lifestyle, yet were unable to progress. Participants were discouraged when they did not get the health benefits they had expected through lifestyle changes. Their expressions indicated resentment because their efforts had not yielded more favourable outcomes. Some people found a physically active lifestyle more difficult than they had expected. In some cases the participants lost their ability to participate in physical activity due to illness or changes in occupational status. According to the data, all such events can lead to hope being abandoned.

Rejected risk perception

Indifference

Becoming aware of one’s risk status by screening was not described in emotional terms by individuals exhibiting a rejected risk perception. These participants expressed their risk of diabetes as obvious even without any screenings, or they expressed the presumption they would receive a positive OGTT diagnosis. These types of comment indicated that the risk was perceived as non-imminent; the participants did not consider diabetes to be a serious threat, perceiving it as distant and unlikely to occur personally. This group did not describe any negative prior experiences of diabetes. True contact with diabetes as a serious illness appeared to be lacking. Some did indeed mention that they understood diabetes to be a serious disease. However, their sentences often continued with but or however, indicating a tendency to downplay the overall risk.

Scepticism

Scepticism was often related to a perceived lack of proof of risk status due to asymptomacy, and a good general perception of health. Thus, in assessing one’s own risk status, a perception of
improved health could outweigh recently increased body weight. In addition, the risk was regarded sceptically if there was a negative score in the OGTT. On the other hand, if the OGTT showed abnormal glucose levels, this was explained away, for example as having had breakfast before the OGTT, or as having had a fever on the examination day. Furthermore, the risk score was downplayed by questioning its validity: a measure via “such small questions” was seen as a poor indicator of risk. Some of the participants had not comprehended that their overweight was associated with an increased risk of diabetes. For those who believed themselves to be in good general health, the risk assessment from the health professional was perceived as a conflicting phenomenon, producing a dilemma between “common sense” and science.

Drifting

None of the participants within the rejected risk perception category took deliberate steps to increase their physical activity. Initially, they were all insufficiently physically active and showed no determination for increasing their physical activity. They emerged as constantly intending to increase their physical activity levels, but as always encountering problems with adopting and maintaining a physically active lifestyle. The risk of diabetes was not seen as a particular reason for increasing physical activity, nor was the lack of physical activity perceived as a serious health problem. Moreover the motivation for physical activity appeared to be the same as before the screening, i.e. losing weight to improve one’s appearance. Receiving a negative OGTT result was seen as reassuring, indicating no immediate need to increase physical activity. In general, they saw any action to prevent diabetes as irrelevant for the time being. Participants often indicated that they had more important priorities than their own health, such as taking care of family members. There were no indications of an increased interest in diabetes information. None of the participants within this group had adopted regular physical activity by the second interview.
Defended identity

Many phrases used indicated that participants were not prepared to become identified as of the “high-risk” type. To defend their identity, they seemed to use social comparisons, either in an upward direction (identification with healthier people) or a downward direction (identification with vulnerable people). Some of the participants expressed embarrassment – a sense of inferiority at not being as fit as their peers. They also felt ashamed of their unhealthy behaviour, seeing their own behaviour as foolish, given the consequences.

Discussion

We discerned a broad range of emotional, cognitive, and behavioural mechanisms used by participants to cope with their diabetes risk. The data gave rise to two themes: a threatening risk perception, and a rejected risk perception. In general, people at cardio-metabolic risk have been claimed to have a dichotomous conception of risk: they see themselves as either sick or not, without recognising “high risk” as existing on a continuum (Damman & Timmermans, 2012). Responses to a diabetes high-risk status have been described as manifesting “indifference” (Adriaanse & Snoek, 2006). In the present data, only a small minority disregarded the high-risk attribution. Thus the word “indifference” appeared inappropriate to describe the overall experience of the high-risk status.

Within the threatening risk perception group, the diabetes risk initially appeared as something unexpected, regardless of participants’ prior knowledge of their risk factors. This confirms a major challenge related to the prevention of diabetes – that people do not convert their personal risk factors into an accurate perception of risk even if they are broadly aware of the consequences of their lifestyle and other risk factors (Calvin et al., 2011; Claassen et al., 2011; Damman & Timmermans, 2012). This is especially true if none of the classic symptoms of diabetes have appeared yet (Thoolen, Ridder, Bensing, Gorter, & Rutten, 2008). As dysglycemia is known to
Experiences of the risk of type 2 diabetes and physical activity

develop over many years without any noticeable signs of the disease (American Diabetes Association, 2007), the present findings emphasise the importance of initial risk-score testing, which may capture asymptomatic individuals, persons who would not otherwise recognise their need to contact a health centre.

Within the rejected risk perception group, indifference was a typical response to the risk information, as found in previous studies (Adrianse et al., 2003; Eborall et al., 2007b). A high-risk status was expressed as something already presumed but as yet non-imminent. A negative diagnosis and asymptomacy played a major role in scepticism concerning the risk, providing false reassurance, again as found in previous studies (Adriaanse et al., 2002; Eborall et al., 2007b). So far, qualitative studies have addressed false reassurance as a phenomenon decreasing one’s risk perception. However, quantitative studies have not supported these findings (Grant et al., 2013; Paddison et al., 2009). In the present data, the lack of expressions of emotional distress within the rejected risk perception group seemed to reflect a tendency to avoid dealing with the risk (see Thoolen et al., 2008). Such a lack also seemed to reflect inaccurate perceptions of the risk and the disease. The expressions used indicated the difficulty of dealing emotionally with one’s risk status; people were embarrassed by their risk status and they used social comparisons to gain an unrealistically positive view of their situation, increasing hope, and enhancing their self-esteem (Taylor & Lobel, 1989). They also made excuses to explain the risk away (see Eborall et al., 2007b). In addition, they downplayed the risk by taking it for granted, which may imply attempts to avoid negative emotions and to disengage with the risk (Carver & Connor-Smith, 2010).

All in all, it appears that maladaptive coping with a high-risk status may prevent people from becoming engaged with their risk and adopting a physically active lifestyle. As people tend to postpone lifestyle changes until a diabetes diagnosis is confirmed (Parry, Peela, Douglas, & Lawtonic, 2004) it is important to highlight the benefits of early detection, and to encourage people to acknowledge the benefits of setting risk-reduction higher in their priorities. However, as long as
people are not ready to cope with the risk, they may not be receptive to the information provided. Invitations to regular follow-up visits are therefore important, as they allow gradual adjustment to the risk.

In line with previous studies, anxiety – perceived only within the threatening risk perception group – mostly emerged during the screening procedure (see Adriaanse & Snoek, 2006), and was mostly related to prior experiences. Prior experience of diabetes has been shown to have both a negative and a positive effect on cognitions and attitudes (Thoolen et al., 2008). In the present data, prior experiences appeared to increase both the perceived threat, and the motivation to prevent diabetes through lifestyle changes, as there was then no hesitation regarding the seriousness of the risk. Prior experiences also enhanced beliefs in the ability to control diabetes and live with the disease. To improve actualisation of the risk among persons with no prior experiences of diabetes, media accounts of the experiences of celebrities and ordinary people may have a role, helping the general public to identify with persons with diabetes.

The more information people within the threatening risk perception group absorbed, the more receptive to health information they seemed to become, simultaneously becoming motivated towards greater physical activity. Increased knowledge has recently been found to be the most important determinant of successful change in physical activity behaviour among individuals with pre-diabetes. Critchley et al., (2012) did not find that a positive mood, self-efficacy, or motivation were determinants of change; nevertheless, they did act as significant mediators between greater knowledge and behaviour change. In the present data, increased knowledge appeared to play a major role in determining participants’ motivation to increase physical activity. This was indicated through clearly defined expressions indicating a perceived need, a reason, and an intention to change behaviour. These constructs of “change-talk” are considered essential for motivation towards behaviour change (Miller & Rollnick, 2002). In the present data, ability, the fourth component of change-talk (involving self-efficacy), often appeared high, reflecting strong
Experiences of the risk of type 2 diabetes and physical activity
determination. However, the ability was seriously restricted in some cases, mostly due to various
health issues. Within the rejected risk perception group, there were no phrases expressing a clearly
defined need, reason, or desire to increase physical activity levels in order to reduce risk. Instead, a
low ability to perform physical activity was emphasised. According to Deci and Ryan (2012),
people’s understanding of their personal risk will be improved if accurate information is given from
an individual perspective, in a dispassionate way, and without causing needless anxiety. This helps
people to make their own informed choices about their behaviour in a way that supports their
autonomy and self-identity. However, if health authorities do not give people time and a forum in
which to discuss their perceptions, an opportunity to enhance motivation to change will be missed
(Kettunen, Poskiparta, Karhila, & Kasila, 2006).

We see it as important to acknowledge the concept of hopelessness in diabetes prevention.
Hopelessness could occur when people initially had strong expectations regarding the efficacy of
lifestyle changes in diabetes prevention. It is worth noticing that people may overestimate their
ability to adopt a physically active lifestyle (Thoolen et al., 2008). They may further overestimate
the sufficiency of the modifications they have conducted in their behaviour. In addition, people may
have health-problems preventing them from engaging in physical activity regardless of their
motivation. In all of these cases, people who take great responsibility for diabetes prevention, but
who show no significant improvement, would benefit from regular control visits to a health centre,
where support and encouragement can be provided. This could help high-risk individuals to
maintain their positive mood instead of sinking into hopelessness. A positive mood, in turn, may
significantly enhance engagement with protective behaviour (Baruth et al., 2011, Kyrios et al.,
2009) such as physical activity. In counselling, a positive mood could be enhanced, and a sense of
achievement provided, by focusing initially on moderate, short-term behavioural goals rather than
on long-term health outcomes.
Strengths and limitations

Using qualitative content analysis we were able to grasp the richness of the experiences arising from the risk of diabetes. To ensure that the categories reflected the data and that the original content of the expressions was persistent, we constantly moved back and forward between the original data and the condensed categories. All the categories created were internally homogeneous and externally heterogeneous. Coding consistency was ensured by coding the data twice by the first author. Problems concerning the definitions of categories or the categorisation of specific cases were resolved within the research team. We have provided extracts from the transcripts in Table 2 and Table 3 to illustrate emergent themes, so that the reader can assess the trustworthiness of the analysis. Note that the study was based on a small sample and was descriptive in nature. As is usual with qualitative research, caution is required regarding generalisability. It is also worth bearing in mind that personality differences may have affected people’s tendency to express their perceptions and emotions. However, in general, the interviews were informal in nature, and thus encouraged respondents to express their perceptions freely.

Conclusions

A threatening risk perception involved a commitment to change one’s physical activity behaviour, whereas a rejected risk perception involved a weak motivation to change physical activity behaviour. We found that accepting one’s high-risk identification may be awkward for some people. To help people become engaged with their risk-status, accurate and individualised information is required. This should be provided by varied means, serving different ways of comprehending the information. Regular control visits are important, since adjustment to a high-risk status may require time, and people may need a gradual build-up in their motivational readiness to adopt regular physical activity (Norcross, Krebs, & Prochaska, 2011). Once they seem ready to consider change (which may well be for reasons other than risk reduction), they should be provided
Experiences of the risk of type 2 diabetes and physical activity

an opportunity for self-evaluation and for the generation of change-talk. Prompts for regular check-ups are needed, since people unengaged with their risk status may not seek help spontaneously. We found that people for whom screening served as a wake-up call were motivated to change their behaviour. However, they should not be left without regular checks as they may require encouragement when they do not achieve the expected outcomes, or when they are unable to adopt regular physical activity. More research is required to examine the experiences and needs of those who take high responsibility for prevention but who fail to adopt protective behaviour. Future interventions should aim to facilitate change in high-risk individuals’ emotional, cognitive, and behavioural functioning – given that none of these appear to be less important than others with regard to the risk perceptions that encourage changes in physical activity.
References

Diabetic Medicine, 19:406-411.


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Preventing Chronic Disease. 8(6);A130.
Critchley, C., Hardie, EA., & Moore, SM. (2012) Examining the Psychological Pathways to

Damman, OC., & Timmermans, DRM. (2012) Educating health consumers about cardio-metabolic
health risk: What can we learn from lay mental models of risk? *Patient Education and
Counseling, 89*:300-308.

motivational interviewing: A few comments. *International Journal of Behavioural Nutrition

Deutekom, M., Vansenne, F., McCaffrey, K., Essink-Bot, M-L., Stronks, K., & Bossuyt, PMM.

Eborall, HC., Griffin, SJ., Prevost, AT., Kinmonth, AL., French, DP., & Sutton, S. (2007a)
Psychological impact of screening for type 2 diabetes: controlled trial and comparative study
embedded in the ADDITION (Cambridge) randomised controlled trial. *BMJ, 335*:486-489.

Eborall, H., Davies, R., Kinmonth, AL., Griffin, S., & Lawton, J. (2007b) Patients’ experiences of
screening for type 2 diabetes: prospective qualitative study embedded in the ADDITION

Quantity and Quality of Exercise for Developing and Maintaining Cardiorespiratory,
Musculoskeletal, and Neuromotor Fitness in Apparently Healthy Adults: Guidance for

Graneheim, UH., & Lundman, B. (2004) Qualitative content analysis in nursing research: concepts,


Paddison, CAM., Eborall, HC., French, DP., Kinmonth, AL., Prevost, AR., Griffin, SJ., et al. (2011) Predictors of anxiety and depression among people attending diabetes screening: A
Experiences of the risk of type 2 diabetes and physical activity


Experiences of the risk of type 2 diabetes and physical activity


Table 1. Characteristics of the interview participants

<table>
<thead>
<tr>
<th>No.</th>
<th>Risk perception</th>
<th>Participant Sex and age</th>
<th>BMI (kg/m²)</th>
<th>Occupational status Interview I</th>
<th>Occupational status Interview II</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Threatening</td>
<td>M 57</td>
<td>24.7</td>
<td>Disability pension</td>
<td>Disability pension</td>
</tr>
<tr>
<td>2.</td>
<td>Threatening</td>
<td>F 54</td>
<td>34.5</td>
<td>Job alternation leave</td>
<td>Blue collar</td>
</tr>
<tr>
<td>3.</td>
<td>Threatening</td>
<td>M 50</td>
<td>28.1</td>
<td>Unemployed</td>
<td>Blue collar</td>
</tr>
<tr>
<td>4.</td>
<td>Threatening</td>
<td>F 45</td>
<td>37.0</td>
<td>Part-time disability pension</td>
<td>Part-time disability pension</td>
</tr>
<tr>
<td>5.</td>
<td>Threatening</td>
<td>M 64</td>
<td>26.5</td>
<td>Blue collar</td>
<td>Blue collar</td>
</tr>
<tr>
<td>6.</td>
<td>Rejected</td>
<td>F 50</td>
<td>29.0</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>7.</td>
<td>Rejected</td>
<td>M 37</td>
<td>40.7</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>8.</td>
<td>Rejected</td>
<td>F 57</td>
<td>32.0</td>
<td>Entrepreneur</td>
<td>Entrepreneur</td>
</tr>
<tr>
<td>9.</td>
<td>Rejected</td>
<td>M 59</td>
<td>30.0</td>
<td>White collar</td>
<td>Unemployed</td>
</tr>
<tr>
<td>10.</td>
<td>Rejected</td>
<td>F 56</td>
<td>-</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>11.</td>
<td>Rejected</td>
<td>F 57</td>
<td>32.7</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>12.</td>
<td>Rejected</td>
<td>F 50</td>
<td>35.6</td>
<td>Entrepreneur</td>
<td>Entrepreneur</td>
</tr>
<tr>
<td>13.</td>
<td>Rejected</td>
<td>F 40</td>
<td>28.3</td>
<td>Blue collar</td>
<td>Blue collar</td>
</tr>
<tr>
<td>14.</td>
<td>Rejected</td>
<td>M 46</td>
<td>35.5</td>
<td>Blue collar</td>
<td>Blue collar</td>
</tr>
</tbody>
</table>
Table 2. Contents and formation of theme *Threatening risk perception*

<table>
<thead>
<tr>
<th>Examples of the original expressions</th>
<th>Condensed expression</th>
<th>Sub-category</th>
<th>Main-category</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...It was unexpected, as I’ve had problems with glucose before, but it was because of...like alcohol use...” “...I did not realise I was in such a bad state...”</td>
<td>Unexpectedness of the OGTT result</td>
<td>Unexpectedness of the laboratory test results</td>
<td>UNEXPECTEDNESS</td>
<td></td>
</tr>
<tr>
<td>“...Because I know a lot of people who are much more overweight than I am and so they have much higher risks...” “...I haven’t really thought about it that way…that those things would make a difference...”</td>
<td>Unexpectedness of the FINDRISC test result (risk level)</td>
<td>Unexpectedness of the high-risk categorisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“...but when I really saw it… I saw how high I actually scored...” “...as I saw it just like that, as points...showing what the future direction was going to be...”</td>
<td>Synergy of the risk factors conceptualised</td>
<td>Comprehensibility of the FINDRISC score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“...after the blood samples were taken, to be honest, I was a bit frightened...” “...Who knows how long it would have taken ...before I noticed something [family risk]...” “...sometimes I felt very dizzy...but I thought ‘oh well, it will pass...”</td>
<td>Relating personal results to target values</td>
<td>Concreteness of the laboratory test results</td>
<td>INTERNALISATION</td>
<td></td>
</tr>
<tr>
<td>“...I really appreciate the nurse there, that she…she spoke out...” “...but when somebody explained these things to me thoroughly...what it really meant...I got it...” “...the nurse really made me take it seriously...”</td>
<td>Confidence in facts presented by a health authority</td>
<td>Negotiation with a health professional</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Experiences of the risk of type 2 diabetes and physical activity

<table>
<thead>
<tr>
<th>Anxiety at potential complications of diabetes</th>
<th>Anxiety at having to start medication</th>
<th>General fear of diseases</th>
<th>Worry about the consequences of diabetes epidemics</th>
<th>Creation of threat-scenarios</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...yes, it did scare me off...I have…you know…people around me who’ve had their legs cut off and so on...”</td>
<td>“...it was kind of a wake-up call…that I am...in a way]...facing such a serious issue...”</td>
<td>“...I must say, since then I have had this nagging fear in my mind...”</td>
<td>“...how many of us are there…terribly many. I was worried, I must say...”</td>
<td>ANXIETY</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Uncertainty about the future (long-term)</th>
<th>Stress preceding follow-up examinations (short-term)</th>
<th>Uncertainty about the significance of the high-risk status</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...it was quite like when I got this heart attack…had to think quite a while what next...”</td>
<td>“...by the second time I went there, I started feeling a bit anxious...”</td>
<td>“...I didn’t really understand what that stage was...”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Awakened interest in health information</th>
<th>Cognitive re-evaluation</th>
<th>COMMITMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...I guess I’ve had the knowledge before, but, well… I haven’t been tuned in, I suppose...”</td>
<td>“...I was like really starting to reconsider myself....”</td>
<td>“...you had thought that these things did not concern you…that the recommendations are for everyone else...”</td>
</tr>
<tr>
<td>“...this happened at the right stage in my life… It was easy for me to start following these recommendations”</td>
<td>“...I wasn’t just thinking that one day you’ll die anyway, but if you could do something to live a little longer, surely you’d do it...”</td>
<td>“...it would be so nice to be healthy...”</td>
</tr>
<tr>
<td>“...Now I can simply choose what to do or what to eat. I”</td>
<td>“...you don’t just think that one day you’ll die anyway, but if you could do something to live a little longer, surely you’d do it...”</td>
<td>“...it would be so nice to be healthy...”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Desire for a longer life</th>
<th>Desire for a better quality of life</th>
<th>Defined need for change</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...you don’t just think that one day you’ll die anyway, but if you could do something to live a little longer, surely you’d do it...”</td>
<td>“...you don’t just think that one day you’ll die anyway, but if you could do something to live a little longer, surely you’d do it...”</td>
<td>“...it would be so nice to be healthy...”</td>
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<td>“...Now I can simply choose what to do or what to eat. I”</td>
<td>“...you don’t just think that one day you’ll die anyway, but if you could do something to live a little longer, surely you’d do it...”</td>
<td>“...it would be so nice to be healthy...”</td>
</tr>
</tbody>
</table>
realised one day it’ll be too late, if I don’t make the change right now...”

“...if it is still possible to do something, I’ve got to try...”
“...I’d rather try to live so that I don’t have to start injecting myself...”
“...I started to value all the smallest activities. Somehow I understood it’s just like that, as long as I just keep myself away from the sofa...”
“...it’s my attitude now – regularly every day, at least something...”

“...that you’re not that worried anymore... You’ve found out what it’s all about...like eating and exercise and that sort of stuff, you know...”
“... I’m not worried anymore really...you just keep on cycling as long as you can...”
“...I’ve noticed, it’s like, when I’ve gained some weight...you just take your dog out right away...”
“...I think it’s ok now, I’m being followed up...”

“...’cause you’ve been healthy, you think well, there must be some disease that will hit me, too...”
“...I guess I’ll probably get the disease for sure...[strong hereditary tendency]
“... Well, I already made all the changes [behaviour]. They didn’t help. Well...there’s not much else I can do, is there...”

“...I must say I was a bit shocked ’cause I thought I had looked after myself...”
“...and I have done all the things I can do myself...So it has all been for nothing, hasn’t it...”
“...even if you believe...that you yourself can make a difference ... It’s still, you know, quite a difficult thing to do...”

<table>
<thead>
<tr>
<th>Determination for behaviour change</th>
<th>Behavioural implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feasibility of changes</td>
<td>Embedding new behaviour within routines</td>
</tr>
<tr>
<td>Taking responsibility for prevention</td>
<td>Sense of control</td>
</tr>
<tr>
<td>Regular checking offering reassurance</td>
<td></td>
</tr>
<tr>
<td>“Paying” for one’s healthy years</td>
<td>Fatalism</td>
</tr>
<tr>
<td>Resigning oneself to the family history of diabetes</td>
<td></td>
</tr>
<tr>
<td>Perceiving oneself as powerless</td>
<td>HOPELESSNESS</td>
</tr>
<tr>
<td>Resentment towards inefficacy of changed health behaviours</td>
<td>Discouragement</td>
</tr>
<tr>
<td>Complexity of adopting a new behaviour</td>
<td></td>
</tr>
</tbody>
</table>
### Table 3. Contents and formation of theme *Rejected risk perception.*

<table>
<thead>
<tr>
<th>Examples of authentic expressions</th>
<th>Condensed expression</th>
<th>Sub-category</th>
<th>Main-category</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...it’s a bit stupid to fill in this form, ’cause it’s so obvious...” “...I knew it [blood glucose] might be elevated...”</td>
<td>Taking high-risk status for granted</td>
<td>Expectedness</td>
<td>INDIFFERENCE</td>
<td></td>
</tr>
<tr>
<td>“...it is not [diabetes], you know, not a big deal...” “...well, I did realise it somehow, but anyway, it still felt quite distant...” “...you just believe it’s not going to happen to you anyway”</td>
<td>Low perceived severity of diabetes</td>
<td>Non-imminence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“...’cause I haven’t had such...you know...the kind of symptoms that my sugar was in any way...” “...somehow I just feel healthier now [despite increased weight] ...I don’t see the risk as a big issue anymore...” “...it had not occurred to me to think that way, ‘cause the result seemed, you know, seemed quite, quite ok...”</td>
<td>Feeling asymptomatic</td>
<td>Absence of proof</td>
<td>SCEPTICISM</td>
<td></td>
</tr>
<tr>
<td>“...My temperature was up a bit, so I guess that probably had an effect on the values, that they were a bit, you know, elevated...” “...with just a tiny question, they got the points... had a feeling... no one’s passing this test anyway...”</td>
<td>Questioning the validity of the OGTT result</td>
<td>Questioning the test results</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“...I guess I didn’t necessarily understand it that way, that my overweight had any causal connection with getting the disease...” “...I thought well, I could just go and show them I’m healthy...”</td>
<td>Unawareness of the causes of diabetes</td>
<td>Conflicting self perceptions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“...There is not much to change, is there?” “...There’s no clear goal, you just try this and that...” “...I wasn’t anxious or anything, ‘cause there was nothing</td>
<td>Undefined need for increased physical activity</td>
<td>Indetermination</td>
<td>DRIFTING</td>
<td></td>
</tr>
</tbody>
</table>
Experiences of the risk of type 2 diabetes and physical activity

<table>
<thead>
<tr>
<th>Statements</th>
<th>Experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...I’ve been thinking I’d start to do something about it as well [inactivity], whatever, during the spring or summer...”</td>
<td>Non-urgency of implementing change</td>
</tr>
<tr>
<td>“…No, I haven’t notably increased my activity levels…”</td>
<td>Lacking ability</td>
</tr>
<tr>
<td>“…I don’t have the discipline. I would exercise if I only was able to…”</td>
<td></td>
</tr>
<tr>
<td>“…I start going for walks, and then forget it for a week or two…”</td>
<td></td>
</tr>
<tr>
<td>“...I didn’t consider it [diabetes risk], you know, important in my life at that time…”</td>
<td>Irrelevance of prevention (at the time)</td>
</tr>
<tr>
<td>“…If I’d go for exercise, it would be for other reasons than the disease…”</td>
<td>Low prioritisation of prevention</td>
</tr>
<tr>
<td>“…If there’s nothing else to do, then we’ll go for a walk…”</td>
<td>Prioritising important others</td>
</tr>
<tr>
<td>“...it’s not that relevant, you know, my thing [diabetes risk]...”</td>
<td></td>
</tr>
<tr>
<td>“...Somehow I see me when I’m old like my mother who is now 70 years old and perfectly healthy....”</td>
<td>Relating oneself to healthy peers</td>
</tr>
<tr>
<td>“...but he [brother with diabetes], on the other hand, lived a totally different kind of life than I do...”</td>
<td>Social comparison</td>
</tr>
<tr>
<td>“…no way I’m going to become a diabetic, you know...”</td>
<td>DEFENDED IDENTITY</td>
</tr>
<tr>
<td>“…well, I guess I’m as vulnerable as any of my patients are, you know.”</td>
<td></td>
</tr>
<tr>
<td>“…it’s a social pressure, you know…you wish you could be, so to speak, a better person yourself...”</td>
<td>Having a feeling of inferiority</td>
</tr>
<tr>
<td>“…Well, I was ashamed, you know, that am I really that stupid ... that I consciously act like this to get this condition...”</td>
<td>Embarrassment</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>