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EMPIRICAL STUDIES



## Awareness of cardiovascular risk among persons with type 2 diabetes: a qualitative study

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### ABSTRACT

**Purpose:** To describe the process of becoming aware of and acting on personal cardiovascular (CVD) risk in type 2 diabetes (T2D).

**Method:** A purposive sample of 14 persons living with T2D participated in semi-structured, open-ended, in-depth interviews. The interviews were analysed with grounded theory.

**Result:** The analysis identified the core category “Balancing emotions, integrating knowledge and understanding to achieve risk awareness and act on it.” Five categories describe the movement from not being aware of the risk of cardiovascular disease (CVD) to becoming aware of this risk and taking action to reduce it. Persons with T2D need to transform their knowledge and experience of CVD risk and incorporate it in their individual situations. Emotional and existential experiences of CVD risk can lead to awareness about the severity of the condition and contribute to increased motivation for self-management. However, an overly high emotional response can be overwhelming and may result in insufficient self-management.

**Conclusion:** Persons with T2D seemed not to fully grasp their increased risk of CVD or recognize that self-management activities were aimed at reducing this risk. However, their awareness of CVD risk gradually increased as they came to understand the severity of T2D and became more emotionally and existentially engaged.

### ARTICLE HISTORY

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### KEYWORDS

Cardiovascular risk; type 2 diabetes; primary health care; risk awareness; patients' experiences; qualitative

## Background


Diabetes is a chronic metabolic disease affecting about 537 million people worldwide. In Europe, more than one in three cases of diabetes are undiagnosed, and approximately 1.1 million deaths are attributed to it in 2021 (International Diabetes Federation, 2021). The most common form, Type 2 diabetes (T2D), accounts for 90% of all cases. Over the past three decades, the prevalence of T2D has increased dramatically in most countries and at all income levels (American Diabetes Association, 2019; International Diabetes Federation, 2021).

People living with diabetes are at high risk of complications such as retinopathy, neuropathy and nephropathy, and particularly cardiovascular disease (CVD) (American Diabetes Association, 2019; Yang et al., 2021). Individuals with T2D are between two and four times more likely to suffer from CVD than those without diabetes (Kishore et al., 2012; Visseren et al., 2021; Yang et al., 2021). The most common initial manifestations of CVD in T2D are heart failure and peripheral arterial disease (Shah et al., 2015). It is

essential to decrease glucose levels, quit smoking and treat risk factors to minimize the risk of CVD and other diabetes-related complications such as hypertension, hyperlipidaemia and obesity (American Diabetes Association, 2019; Joseph et al., 2022; Low Wang et al., 2016).

Reducing the risk of CVD and other diabetes-related complications and achieving good metabolic control requires self-management. This includes regular physical activity, adopting a healthy diet, losing weight, stopping smoking, maintaining reasonable blood sugar levels, and taking medication to lower levels of glucose and lipids and reduce blood pressure (American Diabetes Association, 2019; Joseph et al., 2022; Swedish National Board of Health and Welfare, 2018). These self-management activities can substantially lower the risk of CVD incidents and mortality (Joseph et al., 2022). However, despite the evidence of the importance of reducing CVD in people with T2D, many individuals with T2D are not achieving sufficient risk factor control. There are also differences in how well the national goals for

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diabetes care are being met in different regions of Sweden (The Swedish National Diabetes Register NDR, 2021).

In Sweden, people with T2D are treated in primary health care centres by general practitioners, diabetes specialist nurses, physiotherapists and dieticians. The nurses often play a key role in coordinating when visits are needed. The aim of care is to optimize secondary prevention for this patient group through self-management, self-management support, and medical treatment to reduce CVD risk and other diabetes-related complications (Adolfsson et al., 2010). However, previous research has shown that health care professionals (HCPs) and patients have differing views about the risk of complications, CVD risk and self-management (Hajos et al., 2011). HCPs say that patients need more information about CVD risk and self-management, while patients say that they do not need more information (Huntink et al., 2015).

To use self-management to reduce their risk of CVD, persons with T2D must first be aware of this risk. Yet they often underestimate it or are unaware of it, especially in situations where they are asymptomatic (Carroll et al., 2003; Price et al., 2009; Vornanen et al., 2021). They lack risk perception, which is described in the literature as not only a general knowledge of risk but also perception of one's own risk in relation to predicted risk, and what one can do to lower the risk (Woringer et al., 2017). The authors of this paper consider that risk awareness involves more than just knowledge and perception and includes an emotional dimension. In the scientific literature, the concept of risk awareness is not often associated with CVD risk in diabetes, and therefore it is sparsely studied and needs to be further investigated.

There are few qualitative studies on how persons with T2D understand and perceive the CVD risk both internationally and in Sweden. This study accordingly sets out to explore the lived experience of people with T2D and the process of their becoming aware of and acting on their personal risk of CVD. It offers valuable knowledge about subjective perspectives on understanding, perceiving, and becoming aware of CVD risk to act to reduce the risk of CVD.

## Aim

To describe the process of becoming aware of and acting on personal CVD risk in T2D and acting on this risk.

## Method

### Design

This study has a qualitative descriptive research design using individual semi-structured interviews that can capture persons' experiences of CVD risk

when they have T2D. We have followed the consolidated criteria for reporting qualitative research (COREQ) checklist.

### Setting

The study was conducted in Region Västerbotten in northern Sweden. This sparsely populated region has large rural areas as well as a few cities. The inhabitants go to primary health care centres (PHCs) for care for their T2D or other conditions. The head of primary health care in the region was informed about this study through an oral and written presentation and consented to the study. Diabetes nurses from six PHCs, three in rural and three in urban areas, were then contacted and informed about the study. The researchers received contact information for persons living with T2D through them.

### Participants and procedure

A purposive sample of fourteen persons, seven women and seven men, with type 2 diabetes living in both urban and sparsely populated areas in northern Sweden participated in the study. The inclusion criteria were having T2D, speaking Swedish, and being able to respond to the questions asked and provide informed consent. There were no exclusion criteria other than not wanting to participate. Prospective participants were first briefly informed about the study by their diabetes nurse. Thereafter a researcher contacted each of them individually and scheduled an interview. Before the interview, participants received information about the study both orally and in writing and had the opportunity to ask questions about the study. Written consent was obtained from the participants, and no one declined to participate. The participants were aged 38 to 83 years. The median age was 63 and their diabetes duration varied from six months to 17 years, with a median of seven years. All participants were treated with various oral pharmaceuticals, and in three cases also with insulin.

### Data collection

The in-depth interviews were based on a semi-structured interview guide with open-ended questions. The interview guide was developed to respond to the aim of the study and underwent minor modification during the data collection process, in accordance with the GT method (Charmaz, 2014). Probing questions were also asked, as well as questions that emerged from previous interviews. Example of questions were: "What do you know about the possible complications of T2D?"; "How did you get your information about CVD risk and other diabetes-related

complications?"; "How serious is T2D in your opinion?"; "What do you know about the link between T2D and increased risk of heart attack and stroke?"; "What do you think about the CVD risk when having T2D?"; "What do you feel when you hear that CVD is a complication of T2D?"; "How and when have the HCPs talked to you about CVD risk?"; "How important is self-management for the future development of CVD?" The interviews lasted between 30 and 60 minutes and were conducted by telephone in 2021 by the first ( $n = 13$ ) and the fifth ( $n = 1$ ) author, both with experience in interviewing and with PhD degree. The interviews were recorded digitally and transcribed verbatim. Only the participant and the interviewer were present during the interviews, which were conducted at times and places selected by the participants.

### **Ethical considerations**

Ethical approval was granted by the regional review board [Dnr. 2018/455–31]. Written informed consent was obtained from all participants, and the participants were informed that they could withdraw their participation in the study at any time. They were also assured that their participation would not affect their ordinary care.

### **Analysis**

The interviews were analysed using constructivist grounded theory (Charmaz, 2014), an approach that requires rich data obtained from the in-depth interviews. Each interview was transcribed verbatim shortly after it took place. Data collection and analysis were done in parallel, that is, the analysis process started immediately after the first interview. During the analysis process, memos, that is, notes of ideas and reflections on the text's content, were written to clarify and reflect on emerging questions and thoughts. The analysis started with reading through the text of each interview several times to understand the whole. Sentences or lines of text that corresponded to the purpose of the study were labelled with codes i.e. initial coding. During the coding process, these codes were constantly compared due to their similarities and differences. Focused coding and categorizing were then used to sort codes into clusters that were re-coded with a more specific focus, with clusters of codes being formed and labelled as subcategories. Thereafter, theoretical coding started, with a search for and description of the relation between the core category and the categories. During the analysis process constant comparison were performed, the categories were reviewed, renamed, and consolidated. The data collection continued until theoretical saturation was achieved,

indicating that no new properties or characteristics of the categories emerged from the data (Charmaz, 2014). The core category, along with its related categories, were described and illustrated by quotations from the interviews. The core category that emerged from data was identified and labelled "Balancing emotions, integrating knowledge and understanding to achieve risk awareness and act on it" and could be traced through most of the data. Finally, our analysis resulted in a model (Figure 1) that visualizes the findings reported and discussed in this manuscript. This model was discussed and confirmed by the authors throughout the entire analysis.

In Grounded Theory, trustworthiness can be described in terms of credibility, originality, resonance, and usefulness. In this study credibility was established by a variation in participants included and conducting constant comparison between the data, subcategories, categories, and core category throughout the entire analysis process. Originality is demonstrated through new conceptual rendering of the data. Resonance was achieved by thoroughly describing the categories and incorporating detailed quotes to verify the results. The results of this study can be useful for both persons living with T2D and HCPs in comprehending the process of risk awareness (Charmaz, 2014).

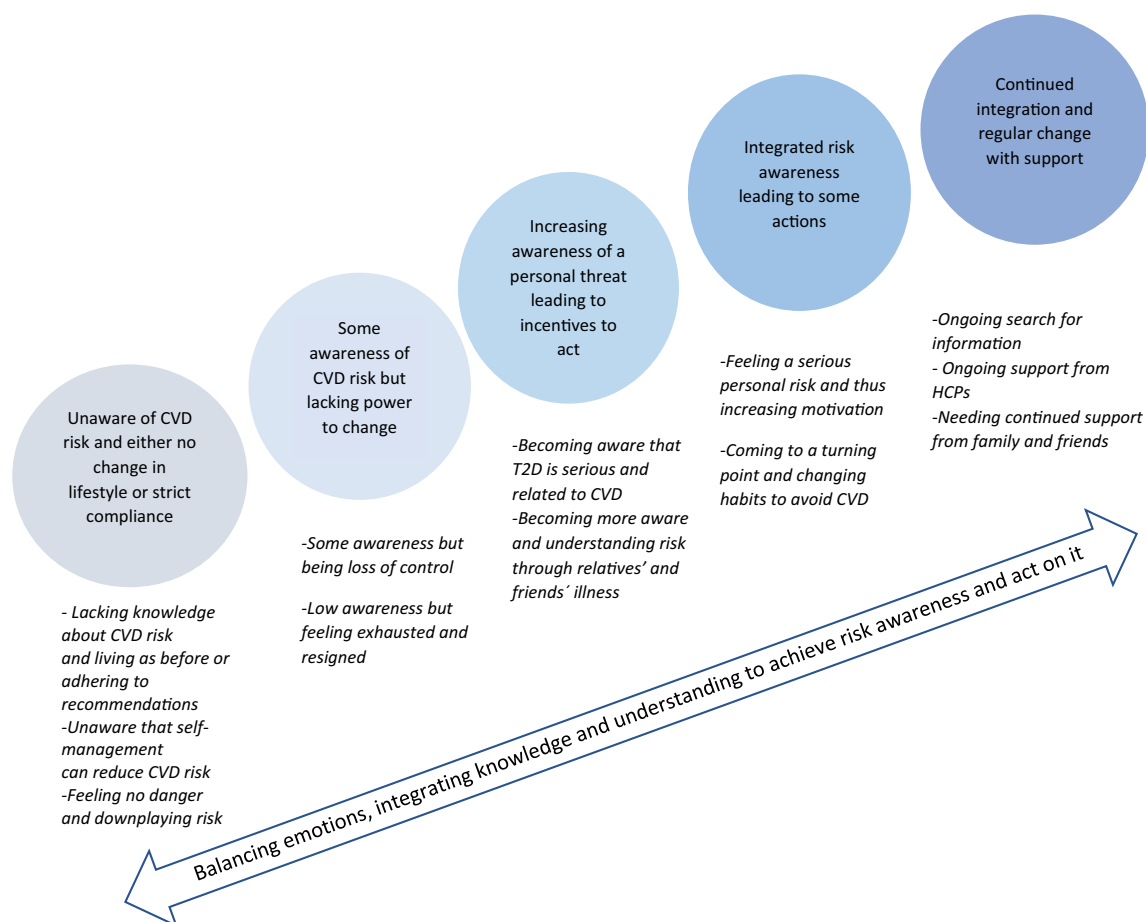
### **Results**

The analysis identified one core category, "Balancing emotions, integrating knowledge and understanding to achieve risk awareness and act on it", with five categories and twelve subcategories that were connected to the core category (Figure 1).

The core category highlighted the process starting from not being aware of the risk of CVD to becoming aware of this risk and then acting on it through adequate self-management. It is important to note that this is a process in which risk awareness increases over time. Persons with T2D needed to transform the knowledge and experiences regarding CVD risk conveyed by HCPs, family and friends and incorporate this into their own individual situation to perform self-management including appropriate activities to reduce CVD risk.

Emotional reactions can be important because they can lead to awareness and insight into the severity of the condition and thus contribute to an increased motivation to perform self-management. However, if the insights come too abruptly and people become too emotionally involved, they may become resigned or find self-management too burdensome. They may then do nothing or hold off on activities to reduce their CVD risk.

The five categories and the subcategories within them are presented below and illustrated using quotations from the interviews.



**Figure 1.** A model describing the personal process of becoming aware of and acting on personal CVD risk in T2D.

### **Unaware of CVD risk and either no change in lifestyle or strict compliance**

This category emerged from the three subcategories described below and shows that most of the participants were unaware of the risk of CVD or that self-management could reduce their risk. Thus, they were not feeling endangered by having T2D.

### **Lacking knowledge about CVD risk and living as before or adhering to recommendations**

Several of the participants said that they did not know anything about CVD and its connection with T2D. Most of the participants also said that their diabetes nurses or physicians had never talked about the risk of CVD.

No one has discussed the risk of heart attack and stroke, or other complications with me. They ask how I'm doing, then talk about my blood sugar values, check my feet, and ask if I need any new aids, like needles or something and then bye, bye (participant 8).

The participants stated that they did not have adequate knowledge about T2D or other diabetes-related complications. Some did report a history of both heart attacks and stroke but said that HCPs had not

discussed the connection between T2D and myocardial infarction or stroke with them. They were thus unaware that these cardiovascular diseases could be linked to their having T2D. They said that the diabetes nurses and physicians talked about CVD as one disease and T2D as another, unrelated disease. The participants also said that HCPs either did not talk about the risk of CVD or downplayed it. While some HCPs had mentioned CVD, they had not done so in a way that made the participant grasp that they themselves were at risk.

The participants described themselves as unaware of the risk of CVD and other complications. They said that they did not understand either the impact of high blood sugar levels and other metabolic values or their connection to CVD and other diabetes-related complications. If the participants had received some information about CVD, the information was experienced as very general, on a group level and unrelated to their personal risk. The participants also said that they were concerned about their CVD risk in the present, but not about eventual CVD risk in the future. They were disappointed that no one had explained the CVD risk in a simple way that they could understand.



The participants thought that constantly changing personnel might explain the failure to provide sufficient information about CVD, for the physicians and diabetes nurses sometimes changed between annual check-ups. Some participants reported that they never had met with a physician for their T2D but had only met the diabetes nurse. However, some participants said that their knowledge had gradually increased over their years of living with T2D. One participant described the importance of HCPs giving them more information about the causes and consequences of T2D. They wanted more information about the CVD risk associated with T2D and were concerned about the fact that they also had other hereditary conditions such as high blood pressure.

### ***Unaware that self-management can reduce CVD risk***

The participants did not fully understand that managing their T2D was crucial to reducing their personal risk of CVD and other diabetes-related complications. They said that they had failed to grasp the link between T2D and CVD because the diabetes nurses talked only about the importance of lowering blood sugar levels, increasing physical activity, and improving their diet, without explaining why these self-management activities were important.

Something you don't find out when you first learn you have diabetes is that you should be physically active. If you move more, you can lower your sugar levels. No one told me this – no, no, not a squeak! All I got was some numbers ... this is what it should be, and this is your blood sugar level, and nothing more. I feel sorry for everyone who has diabetes and has been through the same things as I have because you don't realize how dangerous this is (participant 12).

Some participants stated that they would have managed their illness differently if they had known about the CVD risk at an earlier stage, while others stated that even if they had received information and had known that T2D increases the CVD risk, they would probably not have changed their self-management behaviour immediately. They said that the diabetes nurse had told them what they should do to in terms of physical activity and a restricted diet. A few participants carried out self-management activities only because the diabetes nurses had told them to do so, without asking any questions.

The participants said it was very important to have an opportunity to discuss their personal CVD risk with HCPs, but they had never done so. Several said that the interview meant that they would be asking their diabetes nurses for more information about their risk of CVD and other complications. Some participants said that they wanted to become more involved in conversations about their CVD risk and their self-management activities rather than leaving it all to

the diabetes nurse, who only raised the topic when, changes in medications were needed. At such times, the diabetes nurses mentioned discussions with the physician, but the participants had never been part of these discussions about the pros and cons of medication changes. They speculated that the reason HCPs did not inform them sufficiently about their CVD risk was to avoid scaring them or arousing anxiety.

### ***Feeling no danger and downplaying risk***

Many of the participants did not regard T2D as a serious illness and said that they had no insight into the complications associated with T2D, and thus were not aware of the CVD risk. They did not perceive T2D as an illness that would progress, and so they did not worry about possible future effects. Several stated that they were not there yet but were living in the here and now. The participants also said that they downplayed the severity of T2D because there was not an imminent risk of CVD and other diabetes-related complications. Some stated that they had made no changes to how they lived and did not worry about having diabetes or the risk of CVD risk at all. These participants said that they did not want to consider the seriousness of T2D ahead of time, before they got problems or complications relating to the disease. They also stated that T2D was far less serious than other diseases such as cancer, dementia, stroke, and heart failure. They could see the physical damage caused by those diseases, but they did not want to show their own health problems for other persons and toned down the severity of T2D and the risk of future CVD events.

No, I carry on living just as usual, I'm not losing sleep over this (having T2D). It doesn't affect me at all (participant 7).

### ***Some awareness of CVD risk but lacking power to change***

This category emerged from the two subcategories described below. It shows that participants may have some insight about their risk of CVD but be unable to manage their illness well enough to reduce their CVD risk. They experienced a lack of control, exhaustion, and abandonment.

### ***Some awareness but being loss of control***

Some participants were aware that they had an increased risk for CVD events but did not improve their lifestyle to reduce their risk. They argued that nothing they could do would affect their risk of CVD, and so they did not practise self-management. They knew it was important to change their lifestyle but felt it would be too difficult. Some participants were not motivated to improve their self-management because they did not want to give up their previous habits and did not feel any different regardless of whether their

blood sugars were high or normal. These participants also believed that the illness would be the same now and for ever, and so saw no point in self-management activities.

Other participants were aware of possible complications such as circulatory problems or their vision being affected, but believed it was beyond their power to reduce their risk of getting those complications and so did not take any action. They spoke of the risk of mental breakdown due to pressure and held that it was crucial to maintain a positive view of their life situation and their self-management activities, even if these activities were sometimes suboptimal.

Other participants expressed the hope that more effective drugs would be developed rather than looking at what they personally could do to reduce the risk for future CVD and other complications. Some said that they probably would not live long enough to develop complications like CVD.

You must have a positive attitude to the disease in order to survive, otherwise you break down. You can't go around thinking that the T2D will get worse and worse. Right now, I'm happy that I can eat something and keep the food down and that I can work five hours a day. I can't exercise because I am too tired, but I am happy about what I can do even if I know that my habits are not optimal (participant 9)

### ***Low awareness but feeling exhausted and resigned***

Some participants felt exhausted. They experienced the T2D diagnosis as a threat to their health that caused them to worry about future complications. The risk of CVD was also experienced as an imminent threat. When they had understood their increased risk, they found it too horrible and stressful to contemplate.

They also said that the expectation that they would self-manage to reduce their CVD risk was difficult or impossible to achieve in real life. Some said that they did not have the strength to manage the disease any better than they were doing. They were also anxious about not being able to control this health threat by their self-management activities.

Some participants said that they knew what they should be doing to reduce the risk of complications but were incapable of performing the necessary self-management activities, such as physical activities. They had to choose between their work and physical activities, as they could not do both. This added stress in relation to the risk of CVD since they could not engage in optimal self-management. Some participants mentioned that they had a bad conscience since they could not eat a healthy diet with a lot of vegetables to lower their blood sugar values because they had other conditions such as irritable bowel syndrome or gastroparesis. These participants were

comforted by the fact that they felt well and that the medications seemed to work, and they did not want to think about the CVD risk and their inability to perform self-management.

Participants also described a sense of resignation due to worries about rising blood sugar values and future complications that they could not control. Some said that they felt doubtful about the effectiveness of self-management because they could not be sure that the increased physical activity and improved diet would really reduce their CVD risk. Other participants said they found it difficult to persevere. Even if they followed a healthier lifestyle for a while, they easily reverted to their old habits.

What worries me is that you cannot manage diabetes ... you don't get the blood sugar values down and it gets worse and worse. When you meet the diabetes nurse and she says that your sugar levels are too high, you start to think, "Now ... I have to do something." Then you change a little, but unfortunately it is very easy to fall back into old ways again (participant 2).

### ***Increasing awareness of a personal threat leading to incentives to act***

This category emerged from the two subcategories described below and shows that as T2D become increasingly serious, awareness of the threat to the person's own health also increased. Seeing the consequences of the illness among their relatives and friends could provide an incentive for self-management activities.

### ***Becoming aware that T2D is serious and related to CVD***

Many participants said that when they were initially diagnosed, they did not believe that their illness was serious or lifelong. Some, however, said they had seen the consequences of T2D through their previous work in health care or elder care. Some also said that when you have T2D, you are not aware that something is happening in your body. Others already had signs and symptoms when they were diagnosed with T2D, and when they understood what was wrong, all the pieces fell into place. Over time they became aware that the disease can do great damage in the long run and had come to understand that it is important to keep diabetes-related parameters as low as possible. Other participants said that T2D is a warning sign that something is wrong in your body and that your future life is unpredictable. Some had eventually become aware that T2D and CVD risk were something that concerned them personally. A few had also recognized that they would have to make a lifelong commitment to self-management activities if they were to avoid CVD events, other

complications, and premature death. They reported that this was something in the background that gnawed at them all the time.

Now I see it with completely different eyes; this condition requires a lifelong commitment to yourself. Because I want to live, I don't want a cerebral haemorrhage or blood clot or a heart attack, so I have to shape up (participant 12).

A few participants said that they had recognized that T2D was serious disease at the time of diagnosis, but after a while their sense of a serious threat had diminished. They said that medication had decreased their risk of CVD, and thus they did not think much about the self-management activities.

I felt I was stricter in the beginning, before I was given medications. I used to think that if could eat healthier and take better care of myself, the next time I came in for a check-up they would say ... you don't have diabetes anymore (participant 13).

### ***Becoming more aware and understanding risk through relatives' and friends' illness***

Many participants said that they had relatives who had T2D and therefore they were not surprised that they themselves were also diagnosed with T2D. They said that it was easier to understand the impact of T2D and its connection to CVD risk when relatives and friends were affected, since they could see the impact the disease had on their bodies, including heart attacks, strokes, amputations, and kidney problems. Some participants said that they learned more about the disease in interactions with others with T2D than from the information provided by diabetes nurses and physicians. Some participants also said that when talking about their CVD risk with others, they got useful information and insights into T2D and its complications and new ideas for managing their T2D better. They also said that their present experience of talking about CVD risk with others was giving them food for thought, and that it was an eye-opener that brought the seriousness of T2D into sharper focus. The participants also stated that when their relatives and friends got sick or had complications, they recognized their own CVD risk and wanted to do something about it.

When I was young, I used to hang out with someone who had diabetes and took insulin injections ... He died of diabetes and its complications. He had both a heart attack and a stroke and I thought ... a young man like him can't have a heart attack ... (participant 11).

### ***Integrating risk awareness leading to some actions***

This category emerged from the two subcategories described below and shows the realization that T2D is

a serious illness and CVD a serious threat that must be taken into consideration. It became important to notice changes in one's metabolic balance, and the participants reached a turning point where they were motivated to carry out self-management activities to reduce their risk of CVD and other complications.

### ***Feeling a serious personal risk and thus increasing motivation***

The participants described coming to a turning point where they gradually or immediately understood that T2D was a serious illness and that complications could affect them personally. Those who had come to this realization said that CVD represented a serious threat that they would have to take into consideration when living with T2D. These participants also understood how to reduce their risk for CVD and other diabetes-related complications, and they were also aware of their personal risk. They stated that this knowledge had increased over years of living with T2D and that they were now more observant of changes in their metabolic balance than they had been before. When first diagnosed with T2D, they had not thought much about serious complications such as CVD, but after some years their perception of T2D as a serious disease increased and thus also their motivation for improved self-management. Some participants believed that their CVD risk could be affected by their actions. They were aware of their personal CVD risk, and so they took their medications (e.g., statins and high blood pressure medication), performed self-management activities (i.e., maintaining a healthy diet, engaging in regular physical activity, and stopping smoking). They also said that if all the laboratory values were optimal, they thought that they had very low risk for CVD events, possibly even as low as that of people who did not have T2D. Some of the participants said that when they performed self-management activities, they felt healthier than before their T2D diagnosis, which motivated them to continue with their self-management behaviour. Some participants also had a fear that their illness could progress over time, and this increased their motivation for performing self-management activities.

Yes, it is a serious disease, you can see that it is. In the work I used to do, I saw the consequences of diabetes. You must try to do everything you can to keep your blood sugar and other values down; you cannot ignore it and think that this is nothing, because it can cause very big problems (participant 5).

### ***Coming to a turning point and changing habits to avoid CVD***

Some participants said that if they had not improved their self-management by increasing their physical



activity and eating a healthier diet, it would have been devastating for their health considering the risk of CVD events. They said that even when complications occur, one must find new ways to perform some level of self-management activities to keep all laboratory values and measurements as good as possible. This insight had increased their motivation to manage the disease in an optimal way. Other participants stated that they were motivated to perform self-management by their desire to live longer and see their children and grandchildren grow up. Some saw any reduction in their insulin dose or any loss of weight as a sign of optimal self-management and expressed satisfaction and happiness about it. Some also said that if they did not perform their self-management activities properly, they were aware that their risk for CVD increased. They said they would to what it takes to avoid complications even if this meant increased medical treatment such as starting on insulin.

When I get this confirmation of how much more I can do, every single step becomes easier, and I feel much better than I did before. I get a boost when people do not recognize me (due to my weight loss) (participant 6).

### ***Continued integration and regular change with support***

This category emerged from the three subcategories described below and highlighted the importance of being encouraged by HCPs, family and friends as well as constantly searching for new information to improve their knowledge and their self-management. They felt that they were doing enough in their self-management to reduce their personal CVD risk over time.

#### ***Ongoing search for information***

Some participants said that they had received some information about CVD from HCPs and had been prompted to read more about it in a brochure. They sometimes felt that the information they received from HCPs raised more questions than answers. Some participants said that they felt compelled to search for supplementary information about diabetes and CVD risk on their own in order to understand their illness, self-management, and risks for the future.

There was no one who really talked about risks. All I know about risk probably came from what I have read and understood earlier. No nurse or physician has discussed what I should do to decrease the CVD risk (participant 14).

Other participants were watching medical TV programmes to get answers to some questions regarding diabetes. Some participants also said that their physicians did not understand that they were suffering from complications, and they had to search for information by themselves and give their own suggestions about what to do to fix problems, such as asking for a lipid-lowering

treatment. One participant said that reading an autobiography about living with diabetes had been an eye-opener, because it had made the seriousness of T2D and the CVD risk come alive. The participants who searched for information based on their needs also understood that they had an increased risk of developing CVD. They had also become aware of the importance of being active themselves and said that they had requested or demanded technical aids and better medications in order to postpone CVD and other complications.

No one informs you about innovations [new medications or technical aids;]; you have to discover these innovations yourself and also inquire about them in order to get access to them (participant 3).

Other participants said that they had only received oral information, and that only when they were first diagnosed with T2D. They therefore requested that information about the CVD risk be given again at a later stage. They also indicated that the information should be supplemented with written information and suggestions for reliable web pages with this kind of information so that they could fully understand their risk of CVD.

#### ***Ongoing support from HCPs***

The participants said that they needed guidance and support in order to prevent or postpone CVD and other diabetes-related complications. Some said that they had met knowledgeable and proficient diabetes nurses who had been able to inform and support them in living with and managing T2D in an optimal way. However, the participants also stated that the CVD risk should regularly be discussed with HCPs. They highlighted the importance of diabetes nurses pointing out high metabolic values (e.g., increasing HbA1c values), which motivated them to intensified self-management of their T2D. The participants also said that it was important to continuously be reminded of the risk of CVD and other diabetes-related complications in order to be motivated to continue to manage the disease adequately.

Some participants regarded their HCPs as competent and willing to help them. They said that meeting with a diabetes nurse for regular check-ups made them feel safer since they got to know how the disease was progressing. However, some participants wanted more frequent face-to-face visits, while others felt that an annual visit was enough. Some participants emphasized that it was important to not get all the information about CVD risk at the same time. Others highlighted the importance of HCPs encouraging them to improve their self-management and gradually increase the number of steps per day so that they could see the change, identify improvements in self-management, and know that the diabetes-related values were good enough. They would like to receive

a phone call, email, or SMS from the diabetes nurses at some point between the annual appointments.

The participants questioned why the HCPs used only oral or written information to convey facts about the risk of CVD and other diabetes-related complications. This was not considered a fruitful pedagogical approach because it delivered too much information at once. Instead, they suggested several shorter meetings with a diabetes nurse. They would prefer to discuss their personal risk rather than being given information about the different risks associated with T2D at a population or group level. They also said that they wanted to meet both physicians and diabetes nurses annually to get an opportunity to discuss their own knowledge about the risks associated with T2D, what they could do to prevent or reduce their own risk for CVD events and other complications, and to get ongoing support from HCPs. Lastly, they wanted to discuss their concerns and worries about developing CVD and other complications. They said that this kind of approach would do more for their personal knowledge and understanding than when HCPs presented only facts.

It is important that you have time to reflect on the discussions about CVD risk and other complications between meetings. You have to take it in slowly ... have time to digest the information and discussions about risks ... Otherwise, you feel like a sausage stuffed to bursting ... when you get a whole lot of information at the same time. You just can't take it all in. There's nothing worse than being given a half-hour lecture ... it makes me give up, ... I would just back up and say ... take it easy now (participant 14).

### **Needing continued support from family and friends**

The participants said that support from relatives and friends was important when it came to reducing the risk of CVD because they could facilitate self-management activities such as diet and physical activities being performed as well as possible in a natural environment. Some participants said that it was sometimes difficult to prioritize their self-management because they were used to thinking about other family members first, especially their children. In these situations, it was crucial that their family members understood the need for self-management of T2D and supported them in it. The participants said that family and friends could, for example, join them in a walk or in other physical activities or could help them to make better food choices. They also said that the family could facilitate their self-management by being motivated and positive about adopting healthier eating habits for the whole family, so that the whole family would eat the same meal. Some participants said that it was easy to live with T2D because their spouse also had diabetes. Thus, it was very easy

for them to ask questions about T2D and about the complications related to the illness.

I don't think that I have any major problems. My wife tells me there are some things I should give up, and other things [in my diet] that are better. It's not a big deal, because there have been stricter restrictions in the past compared to what there are today (participant 6).

## **Discussion**

The aim of this study was to describe different stages in the process of T2D patients' becoming aware of and willing to act on their personal risk of CVD. Our results are summarized in a concept model. The core category *balancing emotions, integrating knowledge, and understanding to achieve risk awareness and act on it* highlights the need to find a balance between emotional and existential aspects and knowledge in order to come to insight into the risk of CVD, the severity of the condition and the need for changed habits. The results showed that knowledge and understanding of the CVD risk as well as feeling threatened to the right extent facilitates changes in lifestyle. These factors are also important in the process of achieving risk awareness.

Our study showed that most of the participants were unaware of the association between T2D and CVD or underestimated the CVD risk in T2D, which is in line with other studies (Perreault et al., 2019; Saeedi et al., 2020). According to Saeedi et al. (2020), in a global survey, one in ten persons with T2D did not know about CVD and its risk factors, and about 17% of the respondents reported that they had never discussed T2D and CVD with HCPs. Only one in six considered themselves to be at high risk for CVD, even though the majority of them had at least one risk factor for CVD in addition to T2D. (Grauman et al., 2021). randomly selected people aged between 50 and 64 years old from a Swedish population and asked about their self-perceived risk for CVD. The study showed that the participants with T2D and CVD risk factors tended to disregard these if they perceived their health as good. It appears that some of the participants in our own study knew about the risk of CVD but did not use that knowledge when assessing their own risk. As long as they felt healthy and had no symptoms, they believed there was no danger. Personal assessment of CVD risk is often based on a perception of general health, not on general knowledge of risk factors for CVD (Carroll et al., 2003; Grauman et al., 2021; Price et al., 2009).

Many of the participants in our study said that their diabetes nurses or physicians had never talked to them about the CVD risk. A previous study similarly reported that patients with diabetes and

myocardial infarction stated that they had not received information from their diabetes nurses or physicians about the risk of myocardial infarction (Ångerud et al., 2015). The connection between T2D and CVD is well known in the literature and among HCPs, but if and how it is communicated to persons with T2D is unclear. A systematic review has shown that the way to present cardiovascular risk to patients depends on the purpose of the communication and that both graphical and numerical approaches can be effective. Patients' risk perceptions and their emotional reactions to it can lead to a reduction in risk (Waldron et al., 2011). Saeedi et al. (2020) showed that nurses and physicians have an important role to play in increasing awareness and knowledge of CVD in people with T2D.

Research also shows that by focusing on personal understanding, the HCPs learn to know the person better in terms of their knowledge about their condition, preferences, choices in self-management activities and decision-making. This makes it easier for HCPs to address serious and sensitive issues such as the increased risk of developing complications (Bostrom et al., 2014; Lakerveld et al., 2013; Navar et al., 2019).

It appears that the participants' claim not to have received information about CVD risk may be related to how the information was delivered by HCPs. The information may not have been presented clearly enough, or too much information may have been given at one time. It is therefore important that healthcare professionals encourage people to ask questions and follow up on whether someone has understood the information, possibly by asking them to retell what they heard. Research also shows that the way in which HCPs talk about risk influences patients' decision-making and their awareness of CVD risk, self-management, and medical treatment (van Smoorenburg et al., 2019). Other studies show that persons with T2D want the communication about risk to be related to their individual risk and not to general risk at the group level. The communication should also contain strategies to reduce this risk, as well as a visualization of the individual risk (Price et al., 2009; Webster & Heeley, 2010).

Our results indicate that several of the participants did not seem to fully understand or internalize the information, suggesting that their ability to receive information affects their understanding of it. Reasons for their inability may include previous experiences of similar situations, reduced cognitive ability, cultural background, previous negative care experiences, and preconceived ideas involving themselves or a family member. These aspects can lead to stress and anxiety, which affects the ability to absorb information.

Thus there are many aspects other than knowledge that must be taken into consideration when communicating risk (Alageel et al., 2020).

Our results indicate that HCPs need to become more proficient and clearer when discussing CVD risk with their patients. Some participants in our study did not understand that self-management activities would contribute to reducing their CVD risk. Alageel et al. (2020) report that a patient's lack of understanding of CVD risk may have a negative impact on their engagement with lifestyle changes, decisions about medication, and use of prescribed medication. Our results indicated that those who felt at personal risk of CVD had more motivation to improve their self-management.

Previous research has shown that it can be difficult for the patients to judge their own risks because they may not fully understand the risks and treatment benefits and are unable to balance them (Lipkus, 2007). Patients must thus receive good and adapted person-centred information about possible risks to increase their motivation to adopt an improved lifestyle. A person-centred approach and communication adapted to the patient's individual condition is therefore preferred (Jutterström et al., 2016). Another study shows that turning point transitions, such as the realization that T2D is a serious illness, that you yourself must do something, and finding the willpower to change your lifestyle are helpful in avoiding future complications such as CVD. Turning points include existential and emotional aspects that can increase inner motivation and power for a lifestyle change (Jutterström et al., 2012).

Some participants had some degree of risk awareness but found the threat of CVD so frightening that they avoided thinking about it. Previous research has shown that persons newly diagnosed with diabetes have a variety of thoughts and reactions, ranging from surprise and denial to neutrality and acceptance, and not all of them want to know about long-term complications (Pikkemaat et al., 2019). Their quality of life might be negatively affected if they were confronted with a list of possible complications (Price et al., 2009; Trikkalinou et al., 2017). This finding indicates that it can be difficult to provide information about risk clearly enough to motivate lifestyle changes without frightening people into denial. The patients need to find out more about CVD risks without becoming so paralysed that they cannot cope with the disease. Studies show that an exchange of risk information and opinions about risk between patients and HCPs is important to explore a person's attitudes to risk. It is also important that information about risk be individual, simple, and balanced (Edwards et al., 2002; Navar

et al., 2019). Other studies show that emotional responses to the risk information can have important positive consequences in terms of decision-making processes, behavioural outcomes, and psychological well-being. It is therefore important to talk about the existential and emotional aspects of CVD risk when living with T2D (Ferrer & Klein, 2015; Jutterström et al., 2012). It thus appears that risk communication is an interactive process involving both HCPs and the patient. It is not only the HCPs' knowledge that is important when it comes to communication about CVD risk. It is also essential that the patients' knowledge, beliefs, priorities, and experiences are brought into play and incorporated into strategies to reduce this risk, making the patient feel confident and empowered to achieve their self-management goals (Gidlow et al., 2019).

Our results indicate that people with T2D need to receive support from HCPs and from family and friends to become aware of their CVD risk and make lifestyle changes. Previous research shows that social support is important for both initiation of lifestyle change and for facilitating long-term behaviour changes (Alageel et al., 2020; Baig et al., 2015). The support can take the form of a nurse-led, person-centred group- or individual intervention where persons with T2D discuss T2D from their own perspective (Jutterström et al., 2016). Topics that were discussed in the intervention were whether T2D is perceived as serious or not; the meaning of the diagnosis; illness and self-management; responsibility for self-management, and future prognosis. Results of this person-centred intervention shows that discussions like this can have a positive effect on the patients' metabolic balance, and that individual support is just as effective as group support, and that diabetes specialist nurses should adopt a more person-centred approach to self-management to support patients with T2D (Jutterström et al., 2016).

Our result indicates that becoming aware of the risk of CVD can be seen as a process whereby over time persons with T2D come to understand and respond to the CVD risk with appropriate self-management. This awareness may be problematic at first, but with time it increases and becomes easier to act on. HCPs can support patient's progress towards integration of their illness by discussing risk while offering emotional support and responding to existential issues as well as medical and practical issues. It is thus important that diabetes nurses establish a good, trust-based care relationship, where trust and sensitivity characterize the conversation, and avoid assigning blame. Instead, they should let people "grow" by listening to their experiences and needs. This may promote a positive and supportive environment for persons living with T2D (Stuckey et al., 2015) and is consistent with person-centred care.

## Clinical implications

This study highlights that many people with T2D have not understood that they are at increased risk of CVD. HCPs can use the model in Figure 1 to identify where in the process the person is and to support them as they move towards increased risk awareness. HCPs should inquire about the patient's view of CVD risk and ask about their knowledge about CVD risk, their own abilities, and their willingness to try to prevent CVD events. By using patients' perceptions of CVD, HCPs can more easily understand each person's needs, attitude to self-management, decision-making and motivation to perform self-management in relation to the risk of CVD. The results indicate that person-centred care is needed when meeting persons with T2D in primary healthcare.

## Strength and weakness of the study

One strength of this study is that the participants came from different areas in northern Sweden and included women and men of different ages and with different diabetes duration. Thus we received a multifaceted picture of the perception of CVD risk in persons with T2D. Another strength is that there were different competences that complement each other in the research group. However, due to Covid-19, the recruitment of participants was difficult, which could be seen as a weakness of the study.

## Conclusion

This study clearly shows that some persons with T2D did not understand that they were at increased risk of CVD, although there is clear evidence that this is the case. They also perceived that they had not received information about the CVD risk from HCPs; nor had they understood that their self-management activities were aimed at reducing their risk. However, this study also shows that some participants gradually increased their awareness about the risk of CVD once they understood the severity of T2D and had become emotionally and existentially engaged. This engagement can result in increased motivation to perform self-management now that they understood that these activities are important to decrease their CVD risk, a so-called turning point in self-management. Some persons said they had received no information about CVD risk from HCPs. It is not clear whether this was actually the case, or whether they did not understand or remember the information given. More research about how HCPs communicate CVD risk to their patients with T2D is needed, as well as about how they discuss emotional issues in relation to CVD risk in T2D.



## Abbreviations

CVD Cardiovascular disease  
T2D Type 2 diabetes  
HCP Health care professionals

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Analysis of data: Conducted by LJ, KHÄ, ALS. JO and ML contributed to analysis and interpretation of the results.

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