Experiences of Hypoglycaemia in Adults with Diabetes Mellitus

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Abstract

Aims: To describe adults’ experiences of hypoglycaemia in diabetes mellitus, and the consequences of hypoglycaemia in daily life.

Methods: This study was conducted using qualitative content analysis with an inductive approach. It was performed as a secondary analysis of semi-structured interviews. A total of 29 people participated in the study: 15 with type 1 diabetes and 14 with type 2 diabetes.

Results: The theme that emerged was: Hypoglycaemia is an ever-present risk that manifests itself in different ways. The following categories were identified: Symptoms of hypoglycaemia can appear like a bolt from the blue. Knowledge comes from life experiences. Training and exercise today often have consequences tomorrow. Self-management may be perceived as a feeling of not being free. Family support can provide security in the illness.

Conclusion: Hypoglycaemia is perceived as an ever-present risk that can come like a bolt from the blue, which in turn causes fear and problems in the daily life of people with diabetes. Better support, help and information from specialist nurses is needed. Family members should also be given more knowledge and information, in order to reduce the fear and discomfort of hypoglycaemia.

Keywords: Diabetes Mellitus, Hypoglycemia, Life Experiences, Qualitative

Introduction

Fear of hypoglycaemia often make daily life difficult for people with Diabetes Mellitus (DM) \citep{1,2}. According to the World Health Organisation (WHO), self-management is what individuals do to maintain their own health, and this also involves the prevention of DM \citep{3,4}. National guidelines for diabetes care state how important it is that people with DM receive patient education so that they can handle the extensive self-management of the disease.

DM is described primarily in three main forms: Type 1 Diabetes (DM1), Type 2 Diabetes (DM2) and secondary DM. Swedish national guidelines recommend self-measurement of glucose concentration in both DM1 as DM2. The purpose of these recommendations is to facilitate optimal treatment and to prevent hypoglycaemia \citep{5}.

Experiences of Hypoglycaemia

According to the Swedish National Board of Health, there is some uncertainty regarding the definition of the state of hypoglycaemia \citep{5}. However, it is specified that clinical hypoglycaemia occurs when plasma glucose is below 4.0 mmol / l. Convulsions and coma can occur at values around 1.5 mmol / l and below. Intensive care may be required to terminate hypoglycaemia; if left untreated, it can be fatal. Hypoglycaemia is a relatively common complication of insulin-treated DM, especially in DM1. About a third of people with DM are affected by hypoglycaemia at some time, with loss of consciousness as a result, while one person in thirty suffers frequent hypoglycaemia \citep{6,7}. Rintala et al. \citep{8} dem-
Hypoglycaemia occurred frequently at night, where people with DM woke up with the symptoms, which could lead to a feeling of anxiety and discomfort specifically in connection with nocturnal hypoglycaemia [14]. Lizheng et al. [15] and Shafiee et al. [16] found a significant correlation between an impaired life quality and fear of hypoglycaemia. The experience of hypoglycaemia was compared with feeling as if one was going to die or was described as a state of having an "empty brain" [17]. It is obvious that fear of hypoglycaemia is an obstacle to achieving adequate self-management and quality of life [18]. Zhang et al. [9] also observed that hypoglycaemia could lead to fear in people with DM2. Martyn-Nemeth et al. [18] and Shafiee et al. [16] highlighted the importance of finding strategies for individuals to deal with their fear of hypoglycaemia and for researchers to create solutions.

Good knowledge, awareness and adherence to treatment are prerequisites for a good life despite the disease. The objective of this study is to seek a greater understanding that can serve as guidance in the care of people with DM. Svedbo Engström et al. [19] performed an interview study in order to create a so-called Patient Reported Outcome Measure (PROM). During the analysis of the interviews it became clear that many patients suffered from different aspects of hypoglycaemia. Since the aim of the named study was to find important aspects of living a good life with diabetes, it was beyond the scope of that study to describe the experiences and consequences of hypoglycaemia in more detail. This provided the incentive to analyse these experiences in a single article.

**Aim**

The aim of this study was to describe the experiences and consequences of hypoglycaemia in adults with diabetes.

**Materials and methods**

**Design**

The study was conducted using qualitative content analysis with an inductive approach. It was performed as a secondary analysis, based on interviews for the purpose of creating a patient survey commissioned by the Swedish National Diabetes register (NDR).

**Selection**

In the primary study there were 29 informants: 14 men and 15 women. The study group included 15 people with DM1 and 14 with DM2. See Table 1. The person who was responsible for the primary study submitted by email about 1,000 anonymised pages of transcribed interview material to the authors of this present study. There has also been written correspondence, where parts of the procedure were clarified (described elsewhere).

<table>
<thead>
<tr>
<th>Type of Diabetes</th>
<th>Diabetes mellitus type 1 (n=15)</th>
<th>Diabetes mellitus type 2 (n=14)</th>
<th>Total (n=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (m=54,4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>31-40</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>41-50</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>51-60</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>61-70</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>71-80</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>&gt;80</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes duration years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (±SD)</td>
<td>22,7 (13,9)</td>
<td>13,4 (5,0)</td>
<td></td>
</tr>
<tr>
<td>HbA1c mmol/mol Mean (±SD)</td>
<td>62 (11)</td>
<td>59 (14)</td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin injections</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Insulin pump</td>
<td>7</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Tablets</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
Dietary treatment 0 1 1
Combined treatment 0 8 8

<table>
<thead>
<tr>
<th>Relationship status</th>
<th>Living alone</th>
<th>Cohabitation</th>
<th>Living with parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Cohabitation</td>
<td>10</td>
<td>11</td>
<td>21</td>
</tr>
</tbody>
</table>

Table 1: Study group background data.

**Data Collection Method**

The primary study of Svedbo Engström et al. [19] was based on semi-structured interviews conducted with the support of an interview guide.

**Procedures**

Participants in the study of Svedbo Engström et al. [19] were searched in the diabetes clinics of Dalarna County Council and the Västra Götaland Region. The person responsible for the primary study made personal contact with the units in Dalarna and the quality manager nurse in the Västra Götaland Region. The diabetes nurse at each receiving unit then contacted the person responsible for the primary study, to ask if they were interested in assisting with the recruitment. At the same time, further information and details of this study were given.

After agreement, an information letter with an enclosed consent form was sent to the diabetes nurse. The letters and consent forms were coded to be able to link answers to the correct unit. The diabetes nurse provided information to potential informants and returned consent forms were sent back to the person responsible for the primary study. Based on this consent form, contact was made with informants, where verbal information about the study was given and the date and place for the interview agreed. Interviews were conducted at the informants’ diabetes clinics, with the exception of one of the interviews, which was conducted at a university where the informant was a student. Each interview lasted between 30-120 minutes and was conducted in a private room with only the informant and the interviewer present. The interviews were recorded with a dictaphone and transcribed by a professional secretary [19].

**Ethical Considerations**

Ethical approval for the primary study was received from the regional ethical review board at the University of Gothenburg (ref 565-12). Both written and oral information was given in connection with the request for participation. It was made clear that participation was voluntary and that participation in the study could be discontinued at any time without giving any reasons. This study is based on the Act on Ethical Review of Research Involving Humans [20] and Codex [21], with reference to the meaning of good research in accordance with the Declaration of Helsinki, last revised in October 2013 [22].

**Analysis**

In the present study, the interviews (n=29) were read through several times to achieve a sense of the whole, and to obtain meaningful units that corresponded with the purpose of this study. The meaningful units in the text were marked and transferred to a new document. The condensed meaningful units formed a code of the key words in the text. The meaningful units and the codes were then entered in tables, see Table 2. Codes which represented a common content formed different categories, from which themes and categories were created. These are presented in the results of this study.

<table>
<thead>
<tr>
<th>Meaningful units</th>
<th>Condensed meaningful units</th>
<th>Code</th>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>No 9. … But when that happens, I eat one of those glucose cubes or drink sweet</td>
<td>Eat glucose cube, drink sweet drinks when it happens. Must eat eleven or half past eleven,</td>
<td>Must eat specific times.</td>
<td>Planning and structure.</td>
<td>Self-management may be perceived as not being free...</td>
</tr>
<tr>
<td>drinks. After five minutes, ten minutes it gets better. I’ve checked. Sometimes,</td>
<td>otherwise the signs of low blood glucose...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>maybe that time, eleven o’clock or half past eleven, I have to eat. After half an</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>hour and I don’t eat food, then it’s like that [low blood glucose] …...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nr 3. … Well I guess it’s here that one is afraid to go low… for it’s these low</td>
<td>Afraid to be low.</td>
<td>Fear of low blood glucose</td>
<td>Fear</td>
<td>Symptoms of hypoglycaemia can appear like a bolt from the</td>
</tr>
<tr>
<td>blood glucose-feelings I… am afraid.</td>
<td></td>
<td></td>
<td></td>
<td>blue.</td>
</tr>
<tr>
<td>Nr 13. No, not at all, just if I’m almost happy when I… if I felt [low blood</td>
<td>…becoming almost happy if he knows blood glucose is low...</td>
<td>pleased by low-b...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>glucose]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Examples of the analysis process.
Results

The theme that emerged was: Hypoglycaemia is an ever-present risk that manifests itself in different ways. The following five categories were identified: Symptoms of hypoglycaemia can appear like a bolt from the blue, Knowledge comes from life experiences, Training and exercise today has consequences tomorrow, Self-management may be perceived as not being free, Family support can provide security in the illness. See Figure 1.

**Table 1:** Symptoms of hypoglycaemia can appear like a bolt from the blue

<table>
<thead>
<tr>
<th>Symptoms of hypoglycaemia</th>
<th>Knowledge comes from life experiences</th>
<th>Training and exercise today has consequences tomorrow</th>
<th>Self-management may be perceived as not being free</th>
<th>Family support can provide security in the illness</th>
</tr>
</thead>
</table>
| DM1 “I’ve been very afraid of getting low blood glucose. That’s why I’ve taken less insulin. ... I’ve fainted three times so this has made me afraid of low blood glucose...” [26] I’ve taken less insulin ... afraid to take the amount of insulin I should take” [14].

Knowledge comes from life experiences

The participants felt that they learned over time to live with...
diabetes and about the risks of hypoglycaemia, but it took time to learn. They expressed that knowledge came by learning from mistakes. However, since the level of knowledge and awareness of the general public was too low, it could be dangerous to collapse in a public place due to hypoglycaemia.

DM1 “There’s a shocking number of people who mistakenly believe that they must give me more insulin if I have low blood glucose” [27].

The informants found it valuable to get tips and suggestions from friends about hypoglycaemia, and thought that knowledge about nutrition and the reasons why they got low blood glucose were important in an educational context, for example, in diabetes teams. They also felt it was important for relatives to be included in the visits to the clinic so that they could also get information and learn about blood glucose levels.

DM1 “And it would probably be good if the next of kin can attend and listen and hear a little bit how this works. So that you know how to act if something should happen. If you go into a coma, for example. So that family members know what to do. Or if you get symptoms, and perhaps it’s the first time someone sees something like that, so it can be really tough” [20].

The participants reported experiences of a poor level of knowledge and preparedness of hypoglycaemia among nursing staff. This was when they had been hospitalized and observed the staff’s lack of action and attention associated with hypoglycaemia.

**Exercise and Fitness Today has Consequences Tomorrow**

The participants learned that their blood glucose was affected by different forms of exercise. They described their experiences of the impact on blood glucose. The blood glucose could go low directly or could sink the next day. It was revealed that blood glucose could fall during the night, despite having eaten after exercise. It could be problematic when physical activity turned out to go on longer than first planned, because the blood glucose could fall too much.

DM2 “... then I was all on my own in the forest to get a Christmas tree to bring home. And when I got home, my wife said I looked weird. You have to check your blood glucose, she said. And then it was 2.8. So, I suppose I’d been out for a bit too long. If I’d been out a little longer, it might have become a problem” [5].

The informants also described that the risk of low blood glucose prevented them from exercising and being as physically active as they wished. Instead of taking part in physical activity they therefore chose and preferred to stay at home.

DM1 “If I have one of those days when I just ... I mean when I have low blood glucose I can hardly work out at all, because then it drops even more. It could ... well, that could stop me at times” [28]. Planning and structure was also required to handle blood glucose after exercise. The participants handled the obstacles in their daily lives for example by taking fruit with them. They reported that they always had dextrose with them during exercise, which was perceived as a security and an effective strategy when symptoms associated with physical activity occurred.

**Self-Management Could be Perceived as not Being Free**

Self-management was described as a struggle for a stable blood glucose level and was described as a balancing act, like walking the tightrope. The informants felt that their diabetes and the risk of hypoglycaemia accompanied them throughout the day and it was always on their minds.

DM1 “I mustn’t be too low and not too high. So, you’re constantly balancing between the two. It’s like walking a tightrope. You have to stay up there, so you don’t fall down” [24].

Self-management could be complicated because the participants experienced the confusion associated with hypoglycaemia. This gave a sense of insecurity in terms of the risk of forgetting important things because of this confusion. It was considered important to design and structure life because DM dominated the day. It was important to plan meals, yet hard to never be able to spontaneously eat if someone invited. Planning could be perceived as not being free. It was also expressed that the lack of planning could lead to a sense of panic.

DM1 “Yes, it’s somehow there all the time. You have to think ... you have to plan a little. .... If I’m going out biking or if I should take a walk instead, I have to check my blood glucose and see, yes, I can walk now, or do I need to eat first or. .... Well, I must say that’s something I find quite hard” [20].

The informants expressed that they liked to control their blood glucose frequently. Some had learned that they could feel if the blood glucose was low without the use of meters. Experiences showed that access to a blood glucose meter made them feel safer than the availability of insulin. Others expressed that they had no desire to control blood glucose, but it was constantly on their minds. They relied on their family or friends to signal when it was time to take blood tests. It could mean trouble if they got low blood glucose at work, because this could be practically difficult to manage. Self-management could be awkward to handle in the case of stomach flu because of fluctuating blood glucose. They also expressed concern about other medical conditions such as various infections, since they could cause a sudden drop in blood glucose.
glucose. Self-management could be restricted at work, since it was necessary to regulate and control blood glucose, for example in connection with physical stress which increased the risk of hypoglycaemia.

DM1 “... Because at work, I can’t say that now I have to go and eat ... Then I just have to adjust my needs to ... the company” [3].

The informants tried to avoid hypoglycaemia by always planning what to do next. It was perceived as awkward when friends at work wanted to do something together, and that it did not always work since DM required planning. The insulin pump was considered a good help to avoid low blood glucose. It had an alarm function, and could warn if the blood glucose levels were too low. However, to some extent this gave them a false sense of security, since the insulin pump could raise the alarm too late.

They had learned that they could wake up in the night due to the symptoms of hypoglycaemia, and reported that they controlled their blood glucose levels at nights. Some stated that they set the alarm clock to ring at night to control their blood glucose levels, particularly in connection with consumption of alcohol when, according to experience, blood glucose levels could fluctuate. To avoid sleep disturbance, they chose to check their blood glucose levels before going to bed at night rather than risk being awake wondering over possible low blood glucose.

DM1 “...and then I felt like..., yes, but then I can’t take as much night insulin, because what if I don’t wake up then and it was ... yes, mm. This blood glucose meter is the best thing that has happened” [3]

DM1 “Always at night. Because I wake up when my blood glucose is below a level, I don’t know exactly, but it’s around ... yes, definitely under three. But I’ve also woken up with 1.6 or thereabouts. ....And then I mean it’s really urgent ... but then I’m already sweaty when I wake up. I’ve often dreamt that I’ve eaten something yummy too” [27].

It was perceived as important to always have some dextrose and fruit at hand, and this could give a sense of security. They took dextrose and bananas with them when they were with friends at different events, instead of staying at home.

DM1 “So, you need to eat something quickly. So I always have dextrose with me, then I feel secure. So I have what I call my survival bag with me. That’s where I’ve got my dextrose and a banana” [25].

**Family Support can Provide Security in the Illness**

It was described as important to talk about diabetes and of hypoglycaemia with family, relatives, friends and colleagues, and let them know how they should act if a hypoglycaemic incident happened. Security from family, friends and colleagues, and the fact that they could be of assistance if symptoms of hypoglycaemia occurred, was also important. The informants sometimes felt that it could be hard to ask someone for help, and would therefore find it easier to handle everything themselves. They explained that because of memory problems, they had to tell everything to everyone around them, so that they could intervene in case of hypoglycaemia.

DM1 “If I meet someone new, I usually tell them about my illness, if I know I’ll be meeting this person again. So I tell them that I have diabetes, in case I fall into a coma. I mean it’s good that they know about it” [20].

Some of the participants also felt that they were a burden on their families and relatives because they often needed support to deal with the difficulties of daily life. Others chose not to show people around them if they did not feel well, but tried to handle the situation themselves. The participants felt that the concern of relatives could come in expressions as in anger. It was also disclosed that the demands from their families, relatives and among friends could be perceived as stressful. They felt that children and even grandchildren were involved in DM and the risk of hypoglycaemia, and this was a worry. Sometimes children called for help or assistance, measured blood glucose or gave glucagon when the participants were not awakened.

DM1 “But, how strange you look grandma. Yes, but shall I, shall I check your blood glucose, grandma? He’s sort of learned how to do it... [3].

The informants expressed that their partners had control and could see the symptoms of hypoglycaemia, and then remind them to eat something. They described a concern that their experiences could mean that children needed psychological help to deal with these situations.

DM1 “But if there’s something that doesn’t work, if it’s too high or too low, then you’re not feeling good. And then you’re still supposed to function in a community, a family and ... with children and grandchildren, and all of this. You should be able to take care of the grandchildren” [24].

**Discussion**

The theme that appeared was: Hypoglycaemia is an ever-present risk that manifests itself in different ways. The following five categories were identified: Symptoms of hypoglycaemia can appear like a bolt from the blue, Knowledge comes from life experiences, Training and exercise today has consequences tomorrow,
Self-management may be perceived as not being free, Family support can provide security in the illness.

The analysis showed that hypoglycaemia was described as something unpleasant and sometimes frightening. There were also those who rarely or never experienced any symptoms of hypoglycaemia. However, hypoglycaemia could occur at any time and was therefore perceived as treacherous. Low blood glucose was described by participants in the present study also to be disgusting, nasty, difficult and fraught with a sense of fear, which could be about falling into a coma, fainting or dying. However, experiences of symptoms differed between informants. This is also described by Zhang et al. [9] who reported unpleasant symptoms such as increased hunger, sweating, trembling, palpitations and anxiety. Rintala et al. [8] reported that episodes of hypoglycaemia could be without symptoms, and that the person with DM did not necessarily notice anything.

Those who participated in our study described that their blood glucose was affected by physical activity and described that low blood glucose could surprise them by appearing the next day after training. Hypoglycaemia therefore led to them sometimes dropping out of physical activity in daily life, even though they knew the significance of physical activity. Tomar et al. [11] reported that no reductions in HbA1c were seen, despite increased physical activity, which was believed to depend on the fears and concerns of unpleasant hypoglycemic episodes. It appeared that people adjusted their insulin dose on their own initiative after physical activity to avoid unpleasant blood glucose [11].

Self-management was described as a struggle for a steady blood glucose level within the preferred and recommended reference values and likened to balancing, or walking a tightrope. To deal with this struggle, the analysis showed that planning and structure were of most importance in their own care. Constant planning could provide a sense of not being free, while others experienced that planning was a perquisite for a good daily life. It is obvious that patients with diabetes need individual support in training flexibility. The DAFNE study showed that patients with type 1 diabetes need continuous support in training flexible intensive insulin management, in order to increase their quality of life and decrease their HbA1c without worries about hypoglycemia [23]. From a nursing perspective, Ludvigsson et al. [24] described the importance of support and help to deal with fear and anxiety, where nursing care would be characterized by listening, honesty and knowledge. The results of this study showed that the participants requested support and assistance in regulating their blood glucose. If healthcare does not succeed in helping and reducing fear, there is a possible risk that the patient cannot achieve optimal self-management, which can increase the risk of late complications of DM. Furthermore, the fear could also be due to being alone and not having anyone around that could be helpful. If family, relatives and friends are well-informed, this could provide a sense of security. The participants also felt as if they were a burden on their relatives because of their disease and the ever-present risk of hypoglycaemia. Rintala et al. [8] described that participants saw themselves as teachers for the family, in that they often have responsibility for giving advice and education about hypoglycaemia.

Methodological Considerations

This study was conducted as a qualitative content analysis with an inductive approach, through a secondary analysis with new questions of existing transcribed interview materials. The design was considered appropriate because the intention was to try to create a deeper understanding of people’s experiences. Qualitative text analysis means extracting the characteristics of the content to form prominent categories and themes [25].

The interviews took place between two persons who were physically present. In this way, the interviewer came closer to the informant [25,26]. Respondents who opted not to participate could have done so for various reasons, such as being confronted with something they may have experienced as unpleasant. Another aspect was that the informant might customize responses based on what he or she thought the interviewer wanted to hear [25]. The interviewer was not employed at the units where the interviews took place and had no previous relationship with the informants.

Qualitative research, where data is based on reports and observations, requires understanding and collaboration between researchers and participants. Reality can be interpreted in different ways and therefore text comprehension at a secondary analysis may contain subjective interpretation, despite the fact that great efforts have been made to maintain objectivity in the analysis [25]. However, the analysis was carried out without involving the interpretation of body language or facial expression, and may therefore achieve a higher degree of objectivity. On the other hand, the interpretation could also be hampered by the authors of this study not having met the participants and gained access to the whole range of communication, both verbal and non-verbal.

Reliability is strengthened by both authors reading and reviewing the material, and making comparisons [26]. According to Graneheim et al. [27] the interview material was read and discussed several times to increase the probability that all material was processed. Meaningful units in the text were marked and highlighted. To clarify the context, the surrounding text was included. The meaningful units were coded and formed categories reported in the results. Quotes from the interviews were linked with the results.
The elements that contributed essential information to the purpose of the study were highlighted in the result. The size of this study group may be the strength of this study, because a more content-rich and varied material was obtained due to the larger number of participants, and this could lead to higher credibility [26]. The objective of the primary study was to achieve heterogeneity in the study group, and this also favoured the result of this study in that a variety of experiences appeared. Graneheim et al. [27] define that the number of informants and a heterogeneous component of a study group could help to strengthen the transferability of a study.

Conclusion

Hypoglycaemia is perceived as an ever-present risk that can come like a bolt from the blue, which in turn causes fear and problems in the daily life of people with diabetes. Better support, help and information from specialist nurses is needed. Family members should also be given more knowledge and information, in order to reduce the fear and discomfort of hypoglycaemia.

Funding source

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