



Experiences of alcohol drinking among Swedish youths with type 1 diabetes

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Introduction

In Sweden, drinking alcohol is a culturally accepted and integrated part of society and is, excluding tobacco, the most common drug with which youths experiment.¹⁻³ Youngsters with type 1 diabetes also want to have a social life that sometimes includes alcohol, but they expose themselves to greater risks than their friends when they drink alcohol.

Previous studies have focused on the fact that even modest amounts of alcohol can increase the risk of serious hypoglycaemia for people with diabetes.^{4,5} This may worsen their ability to sense and interpret physical symptoms of hypoglycaemia.⁶ Also, the risk of diabetic ketoacidosis (DKA) increases with alcohol use, because it reduces one's capacity to interpret test results and estimate insulin requirements. Moreover, symptoms of DKA, such as nausea and vomiting, can be put down to a hangover or gastroenteritis.^{7,8}

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Abstract

Background: Alcohol consumption in Europe and North America is greatest in 18–25-year-olds. This behaviour can be seen as a transitional stage from childhood to adulthood, where consuming alcohol is perceived as a typical feature of adult behaviour. Youths often start to consume alcohol when they are 14–15 years of age, and one in five youngsters around 15 years of age report binge drinking. Studies of alcohol consumption among youths with type 1 diabetes have not been undertaken but it is well known that, in these people, alcohol drinking can cause hypoglycaemia and worsen the capacity to feel and interpret the symptoms of hypoglycaemia.

Aim: The overall aim was to explore experiences of alcohol consumption among youths with type 1 diabetes. Another objective was to identify strategies as to how they deal with situations when they drink alcohol.

Methods: Semistructured interviews with ten 18-year-old youths with type 1 diabetes, using Burnard's content analysis method.

Results: This study illustrates that informants strive for security, independence and control. Frequency of binge drinking did not seem to differ from rates in other teenagers. Informants exposed themselves to considerable risks and many had met with serious incidents. Moreover, the result exemplifies how symptoms of diabetic ketoacidosis (such as nausea and vomiting) can easily be misinterpreted as a hangover or gastroenteritis. Informants lacked age-appropriate knowledge about diabetes and the effects of alcohol, but had tested things out themselves; some involved their friends in their diabetes treatment. Moreover, three strategies occurred with the aim of normalisation and security: the 'low-consumption' strategy, the 'ambitious' strategy and the 'rather-high-than-dead' strategy. Fear of hypoglycaemia was a significant concern and the consequence was poor diabetes control.

Conclusion: To increase youths' independence and security, the diabetes care team should provide adequate and relevant information about alcohol. Treatment plans might contain practical steps such as advice about responsible alcohol intake and adjustments of insulin and meals, and could also encourage young people with diabetes to carry diabetes ID and inform friends about hypoglycaemia (and how to handle situations involving alcohol).

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Key words

Alcohol consumption; type 1 diabetes mellitus; interviews; youths

A certain degree of risk supports young peoples' development towards independence, even if this involves poor metabolic control for a time period.⁹ Parents and friends provide important support for the teenager who has to accept living with, and dealing with, diabetes. By involving friends diabetes-related conflicts with parents can be reduced and metabolic control can be improved.¹⁰⁻¹²

Studies of alcohol consumption among youths with type 1 diabetes

have not been undertaken, but studies involving youngsters in general indicate that alcohol use in Europe and North America is greatest among 18–25-year-olds.¹⁻³ Youths usually start to drink alcohol when they are 14–15 years of age.^{2,3} One in five youths around 15 years of age reports binge drinking¹ (defined in women as four or more, and in men as five or more, drinks on the same occasion, over a one-month period¹³). This behaviour can be seen as a transitional stage from



childhood to adulthood, where alcohol consumption is a typical feature of adult behaviour.¹⁴⁻¹⁷ Factors of significance include societal norms, availability of alcohol and the extent to which young people who have reached 18 years of age drink in legally commercial establishments that sell alcohol. Variables such as personality, ability to adapt to situations, choice of friends, gender, ethnicity, parental consumption as well as the parents' and youths' level of education are also significant.^{3,16-21}

To prevent and deal with problems which may arise in connection with young people who have diabetes and who also drink alcohol, it is valuable to consider the reflections of young people with regard to their experiences and strategies. Teaching young people with diabetes about alcohol is a challenge. The topic is sensitive in that it is illegal to drink before 18 years of age. Moreover, for the diabetes care team it seems contradictory on one hand to inform youngsters that alcohol use is illegal before 18 years of age and focus on prevention; but at the same time to provide concrete advice on how to avoid problems in case they should drink it. How young people with diabetes view alcohol consumption is far from clear.

Aim

The overall aim of this study was to explore individual experiences of alcohol drinking among youths with type 1 diabetes. Another objective was to identify their strategies as to how they deal with situations when they drink alcohol.

Methods

Participants

Young people diagnosed with type 1 diabetes who had reached 18 years of age, who had consumed alcohol and who could communicate in Swedish were selected to participate in interviews.

Ethical approval

The subject of these interviews is sensitive because in Sweden it is illegal to procure and supply alcohol to people under 18 years of age. With the permission of the ethics committee (HS 60-05/1421) and the operational director at the Children and Youth Clinic, the caregiver at the clinic gave verbal information about the study. Before the interviews, informants were informed verbally about the study again and gave written consent.

Data collection

The study comprised semistructured interviews that aimed to obtain a deeper understanding of the individual experiences that youths with diabetes have of drinking alcohol. Structuring the interview according to Burnard's content analysis method made it possible to stay close to the original text but also allowed specific categories to be generated.²²⁻²⁴

Interviews began with an opening question to encourage the informants to report their experiences as freely as possible; more focused questions were then asked.²⁵ Interviews concluded with the first author (AL) providing a short description of the interview, whereby informants had the opportunity to raise objections.

Interviews took place during spring 2006 at the informant's clinic, except for one that, at the informant's request, took place at the informant's home. Informants were contacted by telephone by AL who arranged a time for the interviews. Informants were told that they could leave the study whenever they wanted to without any negative effects on the healthcare service they received.

The main areas of interest were: diabetes, experiences of alcohol, knowledge, parents and friends. Each interview was expected to last

approximately 60 minutes and was tape recorded. An interview guide was arranged²⁵⁻²⁷ and used as a checklist at the end of each interview, to ensure that the same data were collected. A pilot interview was conducted, which later became part of the study. Interviews, transcripts and analyses were undertaken by AL (who did not work at the clinic from where informants were recruited).

Analysis

As the study goal was to obtain a deeper understanding of the individual experiences of youths with diabetes who consume alcohol, text analysis followed Burnard's qualitative content analysis.²²⁻²⁴ This method involves a number of key steps:

- Notes were written directly after each interview
- After transcription, the interview text was analysed and re-read several times
- Recurring relevant concepts were identified as units and systematically listed
- Units were then reduced into sub-categories, then condensed further by identifying similarities and differences. This continued for several steps until just six categories remained
- In the final step of latent interpretation, three themes of a more abstract character emerged.

Results

Thirteen youths with type 1 diabetes mellitus were invited to participate in these interviews. Three were unable to participate: one due to multidysfunction; and two because they were of Muslim faith (they could not understand Swedish and did not consume alcohol). All informants gave verbal and written consent before being interviewed. The remaining 10 informants completed the study. Table 1 provides baseline information about the participants; and



the box on page 13 presents key results under the main themes and categories. The informants' desires for independence and normality easily came into conflict with the need for regularity and control.

Parental support and anxiety

Informants seemed to have at least one parent who kept an eye on them, who could intervene if the diabetes or the alcohol consumption got out of hand. Many had some kind of agreement and ritual when coming home, such as announcing their arrival to calm their parents:

'Mom has always been worried and has wanted me to keep it under control, and it is indeed troublesome. She calls when I am with my friends and asks about my blood sugar level and stays awake until I get home. She usually takes the cordless phone with her to the bedroom in case I call. When I get home, I give her a nudge; this is what we usually do. Dad has also said that I cannot drink before I'm 18 but he has been able to sleep.'

Parental anxiety, especially among mothers, peaked when youngsters were out late and were drinking alcohol. Fathers were more rational (informing children that it is illegal to drink before 18 years of age, or giving them diabetes ID to carry, for example).

Friends' support

Relationships with friends played an important role. Many told their closest friends about their diabetes, blood glucose monitoring and what to do if hypoglycaemia was suspected. In particular, male informants handed over the responsibility to keep an eye on them to friends or girlfriends:

'My friends know that they have to check my blood sugar and call an ambulance if I act strange.'

Participant	1	2	3	4	5	6	7	8	9	10
Age	18	18	18	18	18	18	18	18	18	18
Gender	F	M	M	F	M	F	F	M	M	F
Diabetes duration (yrs)	7	6	3	10	7	7	8	9	5	17
Treatment*	PP	PP	PN	PN	PN	PN	PN	PP	PP	PP
HbA _{1c} [†] (%)	9.8	5.0	6.2	10.0	7.3	12.0	9.0	6.0	9.8	9.0
Cigarette smoker	N	N	N	N	N	Y	N	N	Y	Y

*PP, pump; PN, pen. †Guideline level for HbA_{1c} in Sweden is 6%, which corresponds with an average glucose intake of approximately 9 mmol/L.²⁶

Table 1. Baseline data obtained directly from interviews involving 10 youths with type 1 diabetes mellitus, participating in a study about alcohol consumption

'I have been too drunk on occasion and just dropped off, then my girlfriend usually checked my blood sugar, so I try to sleep at her home because it feels safer.'

Control versus loss of control

Informants had concerns when their glucose levels rose or they behaved more unsteadily in connection with alcohol consumption:

'Alcohol itself always lowers blood sugar levels, but soft drinks, juices, and cider raise it. So I thought that one thing makes up for the other and I drink mostly beer which contains a lot of carbohydrates and that increases my blood sugar level. I noticed that alcohol does not reduce my blood sugar level until the day after.'

Many informants reported that they felt bad when they woke up late around lunchtime. Some had reflected that this condition was related to both alcohol consumption and blood glucose levels.

'I noticed that even if you get home late, it is better to get up early to take insulin and get some breakfast. You feel a lot better when you get up after lunch if you have insulin in your body.'

Alcohol consumption

Reported alcohol consumption varied between participants (ranges, 1–10 drinks and 1–8 occasions per

month). Some informants indicated that they had a risk-level consumption that would be classified as binge drinking. Many informants who reported high levels of alcohol consumption also had poorly regulated diabetes. These informants exposed themselves to great risks from high alcohol consumption and had, on several occasions, been involved in serious incidents. Eight informants had experienced ambulance transportation and hospitalisation in relation to 'partying'. Three informants knew that the reason was DKA:

'We were out and I didn't feel well. When I got home, I didn't check myself at all and threw up. The next day I continued to throw up and when my dad came home, I was lying on the floor. He tried to wake me up but I was completely out of it. I had a lack of insulin and ended up in hospital. They said that I had gone into a coma and that I needed potassium, otherwise I would have died.'

This incident was the informant's third DKA. The informant's reflection on this experience was that it must never happen again:

'That must be the last time.'

Four informants had experienced vomiting incidents but did not know the reason:



'I woke up because my whole body was shaking. I threw up and was completely out of it. It felt like I was intoxicated, the body fought to survive, it was really bad. I ended up in hospital. It is the worst thing that has ever happened to me, but I don't think it had anything to do with my diabetes or the alcohol.'

Although the experience may have been frightening, the informant did not link these symptoms to diabetes or alcohol, probably denying or not understanding the reasons for occurrence.

Most informants were anxious about hypoglycaemia but only two had experienced severe hypoglycaemia. In one case, friends were able to stop it; in the other, the informant experienced a serious insulin shock:

'It was last summer when we were at a disco. We drank vodka on the bus because it is so expensive in the bar. Then I didn't recall anything until I woke up in hospital. Two old ladies found me lying in the sand dunes at the beach and understood that I needed help. They saw my insulin pump and called an ambulance.'

The informant was lucky to be found and identified as having diabetes. This quote illustrates the typical alcohol behaviour, where informants binge drink cheap alcohol before going out because they cannot afford to buy it in clubs and bars.

Knowledge

Many informants lacked relevant age-appropriate knowledge and could not recall receiving information about the effects of alcohol; instead, they had to discover it for themselves. The person who spoke to informants about alcohol was usually their diabetes nurse, but conversations usually took place many years after their alcohol debuts. Alcohol-related information focused

Main themes

Dependence versus independence
Control versus loss of control
Security versus insecurity

Categories

Parental support and anxiety
Support from friends
Consumption
Knowledge
Self-care
Strategies

Main themes and categories of results in a study involving ten 18-year-olds with type 1 diabetes mellitus, who consume alcohol

on avoiding hypoglycaemia by reducing insulin dosages and eating more before going to bed:

'If anyone said anything it must have been the diabetes nurse, but it cannot have been so profound because I do not remember anything except that you have to eat more.'

Most of the informants acted on information given without any reflection about the consequences. All informants seemed to focus on how to avoid hypoglycaemia and also knew what to do. Although there was a significant fear of low blood glucose levels, this turned out to be a minor consequence. Instead, hyperglycaemic incidents seemed to be more common. However, in contradiction to the majority, one informant tried different approaches until he found a strategy that worked best:

'You learned that you should eat before and after drinking, regardless of your blood sugar level. So you have really high levels throughout the whole evening and night but never dare take insulin when you party.'

Self-care

Only one of the informants carried a diabetes ID bracelet; the other

nine did not carry such ID, although some had them (at home). While most informants left their insulin pens and glucose meters at home when they went out and 'partied', one informant increased his blood glucose control instead:

'I always take a supply of insulin, a meter and dextrose. I keep a regular check, maybe 3–4 times each evening and try not to sleep alone.'

Five informants used an insulin pump and it emerged that handling this pump had both advantages and disadvantages when drinking alcohol:

'You don't have to think at all because you always have insulin with you and all you have to do is take some now and then when you feel high. On New Year's Eve, the tube must have come off but I didn't notice until it had gone too far and I forgot to test myself because I was so drunk that I vomited on the ambulance guy, it was just bile in the end.'

'I was at my girlfriend's and had disconnected the pump and we went to bed. In the morning I woke up and then vomited. My blood sugar and urine stick were at their highest. My girlfriend called an ambulance and I stayed at the hospital for several days because I had acid poisoning.'

These quotations illustrate that alcohol consumption may decrease the ability of self-care, and just how rapidly an incidence of DKA can occur if an insulin infusion is interrupted.

Strategies

When informants 'partied', they wanted to relax and be like their friends. Some stated that they deliberately did not bother about the rules and didn't allow the diabetes to limit them:



'Why should I have to adapt? If you have an illness that lasts your whole life, you have to make the best of the situation. I do exactly the same as my friends.'

This quote illustrates that one way of coping is to strive for normalisation by behaving like (or worse than) members of their friendship group. There are different ways to cope with the fact that you have a chronic disease that sometimes puts restrictions on the way you live your life. The difficulty of accepting diabetes depends on factors such as personality. A lack of knowledge is another contributory factor and can include poor management and low self-esteem.

The informants' experiences and the information that was gathered during these interviews characterised their strategies. By looking for differences and similarities during the analyses, three different types of strategies emerged:

Low-consumption strategy: Caution was an exception among the participants, most preferred getting drunk. However, one informant had found a self-caring strategy in that she could be together with friends and drink alcohol without risking any incidents:

'I am always extremely careful. It is nice to get slightly tipsy but not too drunk.'

Ambitious strategy: Few informants had methodically tried behaviour strategies to avoid hypoglycaemia. Concern about hypoglycaemia caused frustration because of the need to accept higher glucose levels:

'I have experimented, partly to take the normal amount of insulin, partly to reduce insulin before I drink, but it does not work well because then I get too high. I have noticed that alcohol does not reduce my blood sugar level until the next morning and the day after, so I

thought that what works best is if I eat a lot before drinking and also if I eat something during the evening while I drink and I take some insulin so I don't get high. I reduce the insulin dose at breakfast and lunch the day after, and that usually works just fine.'

Rather-high-than-dead strategy: The strategy that most informants felt safe with, which involved the least possible effort, was to remain on the safe side by reducing insulin doses and eating more. This involved hyperglycaemia for up to a period of 24 hours when the youngsters 'partied':

'When I party, I usually have a high blood sugar level, it is better to be high rather than dead.'

Although informants consumed juices, soft drinks and fast food (snacks, hamburgers and kebabs) throughout the evening and night, very few dared to administer themselves normal insulin doses when they 'partied':

'You don't want to risk it going down during the evening. It is better to get high than risk maybe not waking up at all. You can regulate the sugar the day after.'

Security versus insecurity

Throughout the interviews, the fear of hypoglycaemia was a significant concern. The informants described how *unrest, fear, uncertainty and insecurity* were accentuated by alcohol consumption, especially in connection with bedtime:

'The worst that can happen is that you can go into a coma when you sleep. That can also happen when it is high but then it would be extremely high, so you think first of all, not to be too low.'

'You can never really be totally sure, there is always a risk, especially when you have been drinking alcohol and

then you go to bed. You can quickly drop even though you are high when you go to bed and there is the thought that you can die in your sleep.'

These quotes illustrate that most of the informants had a general fear of hypoglycaemia. Moreover, this fear increased when the informants were going to sleep. In particular, fear increased when they had been drinking alcohol.

Discussion

This study illustrates the informants' strive for security, independence and control. The consequences of this can be seen in the perspective of the transition phase between childhood and adulthood,^{14,15} during which it is hard to accept and live with a chronic illness and where a fight for independence easily conflicts with necessity for control. Our interview findings confirm how relations with people of the same age group can be very important and that liberating oneself from parents can be easier if friends are involved.¹⁰⁻¹²

Informants were aware of the risks of hypoglycaemia and it was precisely the fear of hypoglycaemia that was given as the foremost hindrance for metabolic control.²⁸ Alcohol modifies self-perception into a more relaxed and less self-critical direction;²⁹ when the informants 'partied' they relaxed their checks on their blood sugar levels. The consequences of such actions provide examples of how circadian disruptions with subsequent biological disturbances, together with skipped or forgotten insulin doses, can lead to DKA. Both informants and their relatives had misinterpreted symptoms as hangover or gastroenteritis episodes, which shows how treacherous symptoms such as nausea and vomiting are in connection with alcohol consumption.

The informants demonstrated



the same consumption patterns as healthy youths of the same age with an alcohol debut around 14–15 years of age followed by some years of intensive binge drinking.^{1,2} Variations in the pattern reflect how young people deal with the transition to adulthood:^{15–17} many consumed alcohol at levels which considerably exceeded recommendations.^{1–3} Most of the informants consumed alcohol (vodka) in a manner which must be classified as risk consumption and binge drinking,^{1,2,13} *ie* they met early in the evening in someone's home, drank more than six drinks on one occasion during 1–2 hours before continuing the evening at different pubs and clubs. The main reason for this drinking behaviour is that alcohol is expensive to buy at clubs and the fact that the informants had recently reached 18 years of age and were permitted to buy alcohol.

Informants with the highest alcohol consumption were those who suffered the most incidents and had the highest glycosylated haemoglobin (HbA_{1c}) levels, indicating the possible link between HbA_{1c} level, high alcohol consumption and number of ambulance escorts.

Some informants reflected on the fact that their diabetes control was better before their alcohol debut and they stated a consumption that can be classified as binge drinking.¹³ Worsening of HbA_{1c} levels might be due to risk taking with high alcohol consumption as well as choice of strategies used when 'partying'. Some informants even stated that they had lost control over their metabolic situation.

However, it is far from clear how these factors interact. Studies suggest that factors such as societal norms, availability of alcohol, personality, ability to adapt, and age of debut are important.^{3,15–21} There are many reasons why HbA_{1c} levels increase among teenagers. A certain degree

of risk supports youths' development towards independence even if this involves poor metabolic control during a time period.⁹ Striving for normality was a common issue for informants, but the ways to obtain normality differed, as did the efforts. Some informants experienced normality when doing the same things as their friends (*eg* neglecting diabetes self-care, and leaving insulin pens and glucose meters at home). Another method of normalisation was to make efforts to keep normal blood glucose levels and try to avoid incidents. Lack of knowledge may be a contributory factor and this could also include poor management and low self-esteem.³⁰ Many informants in the study lacked knowledge both about diabetes and the specific effects of alcohol.

Methodological considerations

Regarding generalisation of the findings,^{30,31} this study is the only one to explore the experiences of alcohol use among youths with type 1 diabetes and therefore does not build on earlier studies. The findings cannot be defined with reference to relevant literature and settings or groups.³² Therefore, the conceptual framework of our work has to be defined from other settings and groups, such as studies concerning alcohol habits and consumption behaviour in general.

Our hypothesis is that the findings from this study might be generalised to concern all youths with type 1 diabetes because they all live under the same medical terms, *ie* they can rapidly develop acute medical complications due to their chronic disease and insulin treatment. It is obvious that alcohol consumption can increase the risk of both serious hypoglycaemia and hyperglycaemia. These facts cannot be generalised to non-diabetics.

In the present study, both manifest and latent analyses were made. Results of the latent analyses interpret the categories into more abstract themes. According to credibility (one especially important aspect of trustworthiness) the strengths of this study are that:

- Informants could react to and correct the researcher's summaries
- Alternative categories were critically discussed with an experienced co-analyst throughout the process
- The analytical process followed tested stages of analysis.

According to Polit and Beck²⁷ trustworthiness also includes the question of transferability^{31,32} and refers to 'the extent to which the findings can be transferred to other settings or groups'.

Interviewing is a valuable research technique which provides deep insight into people's lives.³³ However, when using content analysis as this study represents, interpretation involves a balancing act.³⁴ The interpretations made in this study were arrived at on the principle of choosing 'the interpretation that is most easily compatible with psychological arguments of how individuals feel and react in different situations, and with factual arguments, compatible with other known facts'.³⁵

According to the dependability theory,³² these results are necessarily influenced by the fact that the first author is a well-experienced diabetes nurse. Therefore, it was impossible not to interpret the informants' verbal and non-verbal communication – as well as the situation as a whole – in light of the researcher's knowledge, experience, values and empathy.^{34,35} At the same time the researcher tried not to add meaning that was not present into the text.³⁴

Clinical implications

Teenagers want to emphasise their independence and can easily



perceive instruction as tedious. Preventive work must be directed at strengthening protective factors by building young people's self confidence and teaching them how to cope in different situations.³⁰

Information about alcohol should be given on a regular basis, from 11–12 years of age, and be age-appropriate with a focus on prevention. It should also support simple concrete advice that youngsters can understand, namely:

- Carry diabetes ID
- Avoid drinking alcohol on an empty stomach, eat before drinking
- Be careful with strong drinks
- Alternate alcoholic and non-alcoholic drinks
- Tell friends about hypoglycaemia and what they can do to help in an emergency situation
- Check your blood glucose, to become an expert
- Eat more during physical activity, ie dancing, sexual intercourse
- Avoid going home alone and sleeping alone, and eat something before going to sleep
- Beware of nausea and vomiting the day after, which can be symptoms of low insulin.

Conflict of interest statement:

None

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