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CONCEALMENT OF TYPE 1 DIABETES AT WORK – A MIXED-METHOD STUDY

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CONCEALMENT OF TYPE 1 DIABETES AT WORK – A MIXED-METHOD STUDY

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ABSTRACT

Objectives To explore the possible reasons for concealing type 1 diabetes (T1D) at work.

Methods The main set of data came from a cross-sectional survey, the participants of which were 688 wage-earners with T1D. Concealment of T1D was measured by asking respondents have they ever during their working career hidden their diabetes from their a) colleagues and b) line manager. Furthermore, semi-structured interviews (N=20) were conducted to obtain deeper understanding. Questionnaire data were analysed using logistic regression analyses and qualitative interviews with inductive thematic analysis.

Results About 30% of wage-earners with T1D had concealed their condition during their working career from their colleagues and almost 20% from their line manager. Younger age, not disclosing T1D to extended family, feeling an outsider at work and being embarrassed by receiving special attention at work were associated with T1D concealment from colleagues and line managers. Neglecting treatment at work was associated with concealment of T1D from colleagues. From the interviews five main themes related to concealment emerged, expressing fears related to the consequences of telling: 1) being perceived as weak, 2) job discrimination, 3) unwanted attention 4) being seen as a person who uses their T1D for seeking advantages, and 5) losing privacy.

Conclusions Both overemphasis and underestimation of T1D at work by the colleagues or line manager may lead to concealing T1D and are thus harmful to self-management of T1D. The obstacles in disclosing T1D could be diminished by giving adequate information at the workplace about the condition and its significance.

Keywords: Type 1 diabetes; Concealment; Workplace; Psychosocial aspects; Occupational health

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We had a randomly selected large (N=2500) national sample. The remaining sample size, after excluding non-responders, those who had not worked in the past 12 months and those who were self-employed, was 688 employed respondents, allowing statistically reliable results.

- Another strength of our study was the use of mixed methods, or methods of triangulation. Carrying out the interviews after the first stage of analysis of the survey data made it possible to ask the interviewees to comment on the finding that a great proportion of people with type 1 diabetes choose to conceal their condition in the work place. The interviews deepened the understanding of the reasons of concealment that had been asked in the survey and revealed new reasons that were not covered by the survey. Moreover, similar results obtained by different methods increased the validity of the findings.

- The cross-sectional design of our study prevents the interpretation of causality between concealment of type 1 diabetes and independent variables.

- The interviewees did not necessarily report the reasons of their own concealment but their views on why other people choose to conceal their condition.

- All of the measures were self-reported; thus, recall bias may have influenced the results.

- Our results might be extrapolated only to those Western countries, which have same kind of employment legislation and health care systems to Finland.

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INTRODUCTION

Research into the psychosocial aspects of type 1 diabetes (T1D) is growing.[1-3] However, only a few studies have focused on the psychosocial aspects of T1D in working life.[4,5] There are several qualitative studies focusing on e.g. self-management of T1D[6,7] and stigma due to T1D[8,9] where interviews have brought up work-related psychosocial challenges of T1D. However, both quantitative and qualitative research on T1D with working life as the sole focus is scarce. To the best of our knowledge, there are no previous mixed-methods studies on concealment of T1D at work. In this article, concealing refers to intentionally hiding existence, symptoms and management of T1D.

Despite the advances made both in diabetes care and in supporting persons with T1D at work, evidence suggests that many individuals with T1D are not disclosing their condition to their work colleagues and line managers, or do it with caution. Not disclosing T1D or only partially disclosing can affect the individuals' self-management of their condition, and ultimately their health and wellbeing.[6,10] A number of studies report that non-disclosure of T1D at work is related to perceptions of stigma, experiences of discrimination and limited career prospects.[9,11] An important consequence of not disclosing T1D is avoidance of self-managing T1D at work, such as skipping insulin injections.[11] In contrast, disclosure is related to receiving social support at work, having good psychosocial work ability, as well as, relations at work and self-management opportunities at work.[12]

However, whilst quite much is known about disclosure of diabetes, it is not fully understood why some individuals would choose to conceal their T1D condition in the workplace despite important negative consequences associated with poor self-management of T1D at work. The aim of this article is to explore the possible reasons for concealing T1D at work, which goes beyond the individual simply not telling someone that they have T1D.

MATERIALS AND METHODS

Study design

This is a mixed-method study design[13] employing quantitative and qualitative research data collection methods. First, we collected quantitative data on concealment of T1D at work by a questionnaire (N=688) as

part of a larger research project in Finland. Next, we developed topics for a semi-structured qualitative interview schedule using the questionnaire study results and conducted interviews with an independent sample of participants (N=20). The Research Ethics Committee of the Northern Savo Hospital District reviewed and approved the research protocol (18//2010).

Study 1: Questionnaire data

We sent a questionnaire to a random sample of 2,500 Finnish working aged people with T1D drawn from the Medication Reimbursement Register of the Social Insurance Institution of Finland, which holds individual-level demographic and medical information on all the Finns with T1D. In 2011, there were around 40,000 individuals diagnosed with T1D. This random sample, therefore, equalled to 6% of the Finnish population with T1D. From among the respondents, we selected only those who we were in gainful employment during the past 12 months (excluding self-employed) for these analyses (N=688). The questionnaire included items on demographics, diabetes history, diabetes and work, work ability, health, diabetes and current work community, occupational health and safety and diabetes, and occupational health and diabetes.[14]

Measurements

We measured concealment of T1D by asking respondents "Have you ever during your working career hidden your diabetes from your colleagues?" and "Have you ever during your working career hidden your diabetes from your line manager?" The responses were rated separately on a scale 1-3 (never; sometimes; often), and were dichotomized (never vs. sometimes/often) for further analysis. Disclosure to immediate and extended family were measured separately by yes/no options. Work measures included type of work (mental, physical or equally both), employment (permanent/fixed term) and work pattern (regular/irregular). Karasek's[15] job control (9 items) and job demands (5 items) were measured on a scale from 1 to 5 (fully agree to fully disagree). The original indices of job control and job demands were calculated as means of the original items, and the indices were dichotomized with the median as the cutting point. Respondents were asked whether due to their diabetes, they had ever felt like an outsider during their working career (never; sometimes; often); perceived discrimination (never; sometimes; often); were embarrassed by receiving special attention at work (never; sometimes; often); and been prevented from getting a job (yes/no). Respondents were also asked if they had

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ever during their working career neglected their diabetes treatment during working hours (never; sometimes; often) or had difficulty in accepting their T1D status (no; yes, a little; yes, a lot). All these ordinal scale responses were dichotomized (never vs. sometimes/often) for analysis. Demographic and health questions included age (years), gender (male/female), marital status, educational level, duration of diabetes (years), HbA1c level and severe hypoglycaemia events (yes/no).

Statistical analysis

First, two sets of step-wise logistic regression analyses were conducted for concealment of T1D from a) colleagues, and b) line managers, as expressed by odds ratio (OR) and 95% confidence interval. Disclosure to family and all demographic, work and health measures were entered as independent variables (total of 20 variables). Second, a further four logistic regression analyses models were performed. For these additional analyses, respondents were split into age groups based on results of the first two analyses. In the case of concealment from colleagues, the age groups were 18-44 and 45-64 years. In the case of concealment from line manager, the age groups were 18-24 and 25-64 years. The aim of these further analyses was to find out possible differences in explanatory variables between age groups. All analyses were carried out in SPSS for Windows, version 21.0; 2012 (SPSS Inc., Chicago, IL, USA).

Study 2: Interviews

Participants and recruitment

Twenty Finnish working individuals (6 men and 14 women) aged 22-58 years (mean = 39.5, SD= 12.2) participated in this interview study. They were recruited by the diabetes clinic of the department of endocrinology and diabetology in Kuopio University Hospital. The inclusion criteria were diagnoses of T1D, aged between 18-64 years, and in current employment. We used a purposeful sampling frame to ensure variation in the sample by gender, age groups, occupational setting, type of work (physical, mental or equal) and work patterns (regular or irregular work patterns).

A registered nurse at the diabetes clinic identified potential participants by first applying the inclusion criteria to the patient list. Next, the nurse applied the sampling frame to identify a mix of patients. These patients were

then approached by the nurse at their next medical appointment at the clinic. The nurse introduced the study to these potential participants and gave a fact sheet and a contact form to those who expressed an interest to take part in the interviews. The nurse kept in regular contact with the researcher to adjust the sampling frame as required.

The potential participants completed and returned the contact form directly to the researcher (PH) via post. The researcher then contacted them by telephone and gave them further details about the research and the interview (interview topics to be covered, approximate length of interview, audio recording, transcription in service, anonymous reporting) and that taking part was entirely voluntary and participants could withdraw at any time. A suitable time and place were arranged for the face-to-face interviews with those willing to participate. A written informed consent was completed before the interview. No fee was paid for taking part in the study.

Data collection

The topics covered by the semi-structured interview were based on the preliminary results of the questionnaire survey. The topics were the following: diabetes-related and work-related background, experiences of the relations between T1D and work, current work community, and occupational health and safety. In addition, the interviewees were presented with the statistics from the questionnaire data on participants' concealment of T1D and asked to comment on them and discuss possible reasons for concealment. The current article focuses on the themes discussed in this part of the interview.

The aim of the interviews was to elicit narratives of perceived diabetes-related challenges at work. The face-to-face interviews were carried out between March and May 2011 by the main researcher (PH) who is trained in conducting research interviews. Of the 20 interviews, 5 were carried out at the interviewee's home, 4 at the interviewee's workplace and 11 at the interviewer´s office in UEF. The interviews were audio recorded and the interviewer made additional notes on her reflections directly after each interview.

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Transcription and data analysis

The audio recordings were transcribed verbatim by a professional transcription service. The interviewer (PH) checked the transcripts against the recordings and anonymized the data.

The interviews lasted on average 67 minutes (range 37-96 min). An inductive thematic analysis[16] was used to examine the data. The transcripts were read and re-read separately by two members of the research group (PH and VH). First, the researchers picked out the passages that dealt with concealing diabetes and categorized the passages according to the motives ascribed to concealment. After that, they coded the data independently on the basis of the categorization. Then the researchers compared and discussed their decisions, ready to revise the categorization in case of discrepancies. No such discrepancies arose, however.

RESULTS

Study 1: Questionnaire

The characteristics of the 688 respondents are summarized in Table 1. The mean age of the respondents was 36 years, and 47% of them were women. A total of 44% of the respondents were diagnosed with T1D more than 10 years ago. A total of 30% of the respondents had concealed their diabetes during their working career from their colleagues and 18% from their line manager.

Results of the stepwise logistic regression

Of the 20 variables included in the stepwise logistic regression analyses, five variables were retained in the final models. The logistic regression model on concealment from colleagues concluded in five steps (Table 2). Individuals in the 18-44 years age group were more likely to conceal their T1D from their colleagues than older workers during their working career. Not disclosing T1D to the extended family, feeling an outsider at work, being embarrassed by receiving special attention at work and neglecting treatment at work, were all associated with concealment of T1D from colleagues.

The model on concealment from the line manager concluded in four steps (Table 2). The youngest age group 18-24 years were more likely to conceal their T1D from their line managers than the older age groups during

their working career. Not disclosing T1D to the extended family, feeling like an outsider at work and being embarrassed by receiving special attention at work were associated with concealment of T1D from line managers.

In the further analysis, the colleague model in age groups 18-44 years and 45-64 years, as well as the line manager model in age groups 18-24 years and 25-64 years revealed that different variables were associated with concealment of T1D at work in different age groups (Table 3). In the younger group, feeling embarrassed by receiving special attention was a strong predictor of concealment. In contrast, for the older group, feeling an outsider in the work place was the largest predictor.

Study 2: Interviews

All interviews (N=20) discussed possible reasons for concealment of T1D at work. More than half of them discussed their own positive experiences of disclosing but understood why some people may conceal their diabetes at work.

Five main categories of reasons for concealment emerged from the inductive analysis of the interview data. Each of them reflected the interviewees' perceptions of what the consequences of telling at their workplace about their T1D status might be. The first four themes (being perceived as weak, job discrimination, unwanted attention, and being seen as a person who uses their T1D for seeking advantages) anticipated other people´s attitudes and behavior and the fifth reflected the person´s wish to avoid too close intimacy with others. All of the interviewees discussed at least two out of the five identified kinds of reasons of concealment.

The first kind of reason the interviewees thought might lead to concealment was labelled fear of being perceived as weak or fear of losing status among the work-mates. The participants discussed that diabetes is often kept hidden because telling someone about it at work would make that person seem weak and inferior to others. Appearing as weak may be felt as causing loss of status among the work mates. *"You feel you are weak and you*

don´t want to show your weakness to your pack." (Man, 27) Altogether, people were seen as not willing to differ from the others, especially in a negative way. *"It´s perhaps just that I wanted to be like everybody else."(Man, 49)* It was also mentioned that TD1 may be seen as an indication of a more general personal fault. Some interviewees used the social scientific word *stigma* to refer both to losing status among the colleagues and to being at risk of discrimination. *"I think [by not disclosing] you can avoid being stigmatized." (Woman, 53)*

The second kind of reason for concealment told about by the interviewees was related to the fear of discrimination. Several examples were given of the ways in which being open about one´s diabetes could hinder the individual from getting a job or a promotion or could increase the probability of getting laid off. Both young and middle-aged interviewees talked about discrimination: *"If I left this job, I don´t know if, due to my diabetes, I could get a new job. This thought is absolutely horrifying!" (Woman, 29)*. Some interviewees mentioned possible reasons for discrimination: a person with T1D might be seen as one who is often on sick leaves or is prone to accidents and who is "*in the end more expensive.*" (Woman, 40)

Reluctance to receive special attention was the third category of reasons for concealment that emerged in the interviews. The interviewees gave examples of the ways in which other people had made a fuss, been overprotective or patronizing after hearing about the interviewees' diabetes. Irrespective of whether this had been benevolent or malevolent, it was felt as awkward. Lack of up-to-date knowledge about diabetes was seen as the main reason for overprotection. *"My colleagues might come every two hours to ask how I feel and if I am okay. If they see me buying chocolate, they might go and tell my supervisor that my blood sugar is swinging." (Woman, 29)*

Fear of being seen as a person who uses their T1D for seeking advantages was yet another category of reasons for concealment brought up by the interviewees. The special arrangements, such as taking regular meal breaks to manage diabetes were sometimes not understood as necessary, as some people did not know about the seriousness of the illness. It might be that people are mixing up type 1 and type 2 diabetes and there is a real lack of understanding of T1D. *" I feel that some of my colleagues thought that diabetes is just a pretext to being*

allowed to have meal breaks every four hours. As if it was only something I´d like to have although it was

something I had to have. There is no reason for envy." (Woman, 26)

The final category of reasons for concealment was related to losing privacy i.e. a perception that illnesses are private matters that should only be disclosed to close people. The wish to keep the illness to oneself was seen as understandable especially when the relations between workmates are distant, when the worker has not quite made the illness as a part of their identity, and when the person is generally reserved as a person. *"...Of course, illness is always a personal matter, and not everybody wants to make it public."* (Woman, 51) *"... Not everything is everybody´s business."* (Man, 26)

In connection with discussing the reasons for concealment, the interviewees usually mentioned the risk associated with hypoglycaemia events if nobody around knows how to deal with it. *"There´s a real risk of losing your life if you get a hypoglycaemia and nobody knows. You might even die in the worst case."* (Woman, 49) Also self-management of TD1 – having regular meal breaks, measuring blood glucose levels, injection, and visits to a doctor - was seen as difficult for one who tries to conceal their condition.

When asked in what kind of workplace disclosing one´s illness, the interviewees emphasized openness, trust and mutual caring of each other as important factors. Also the habit of evaluating the worker on the basis of how they do their job instead of their personal features was mentioned as creating a safe atmosphere for telling.

DISCUSSION

As far as we know, this is a first population-based study to report figures of concealment of T1D from colleagues and line managers at work places. In this article, concealing refers to intentionally hiding the existence, symptoms and management of T1D. In our survey results, about one in three had sometimes or often concealed their T1D from their colleagues and one in five from their line manager during their working career. This is noteworthy, because colleagues may be the first ones to notice a hypoglycaemic event and to offer help

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when needed [8]. In addition, the line manager can support a worker with T1D to manage their condition effectively at work if they knew about a worker's T1D status.[6]

Young workers were more likely to have concealed their T1D than older ones from both colleagues and line manager. This could be interpreted as indicating harsher competition for jobs and proceeding in a career between younger workers in the current working life. It is also obvious that young adults being in the beginning of their working career have more to lose than older people. Although the effect of fear of discrimination did not reach significance in the quantitative part of the study, the theme of discrimination was often brought up by the interviewees – young and older alike. There are no previous studies concerning concealment of T1D among young workers.

We found by regression analysis that those who had not disclosed their T1D to their extended family were more likely to conceal their condition from colleagues and line manager. This suggests that some workers may choose to keep their condition hidden from everyone outside their closest circle of people, which was also discussed in the interviews. In addition, those who felt like an outsider at work due to their T1D were more likely to conceal their condition from colleagues and line manager. In the same line, some of the interviewees said that unopen and strained working relationships at work make it difficult to reveal one's T1D. This emphasizes the importance of the quality of relationships in the work place.[7,17] If working relationships are strained and there is little interpersonal trust or a negative workplace climate then workers are more likely to conceal their condition at work.[6] Employers and managers have an important role in developing an inclusive working environment.[17] Thus, they should take working relationships into account when developing workplace practices.

Although openness with employers could be encouraged, it is important to remember that disclosure of one´s chronic condition is a highly private and confidential decision[17,18], and there should be no pressure to do it. In Finland, an employer can ask an applicant about their health status during a job interview only if there is a legal reason to do so i.e. if a health condition may potentially impact job safety.[19] In addition, the Non-discrimination Act (1325/2014) [20] promotes equality and prevent discrimination in the workplaces.

Embarrassment caused by receiving special attention at work due to T1D was associated with concealment of T1D from colleagues and line manager. The theme "unwanted attention" was also found in the interviews. Giving special attention was seen as an overreaction to the risks related to the condition. On the other hand, some of the interviewees felt that the risks related to T1D could be underestimated, which could result in seeing a person with T1D as one who uses their condition for seeking unwarranted advantages. As far as we know, there are no previous studies reporting this kind of results.

In general, concealment of T1D from colleagues was associated with neglecting self-management of T1D at work. If a person conceals their T1D from a colleague, it is difficult to self-manage their condition effectively at work place. This may lead to keeping blood sugar levels higher than optimal to manage at work as found in a previous study from U.K.[7] We reported in our previously published study that work-related diabetes distress, such as worry and exhaustion in reconciling work with T1D, was strongly associated with keeping blood glucose level high at work.[14] In addition, it has been shown that young workers with T1D experience time pressure at their work and therefore they sometimes neglect or delay self-management activities at work.[5] As both concealment and time pressure among young workers with T1D hinder their self-management activities at work, special attention should be focused on supporting them for avoiding long-term complications and diminishing of work ability.

One of the often discussed reasons for concealing one´s T1D at the work place was fear of discrimination, which could restrict one´s career development and even lead to unemployment. This supports a previous qualitative study that also found those with T1D, who did not disclose their condition at work, gave the reason as fear of being discriminated against, which could harm their working career.[9] Our findings also relate to the finding of the study of Polish seafarers with T1D, who were not allowed to work at sea, and who concealed their condition from health care and from their colleagues and worked on seagoing vessels.[21] Another frequently mentioned reason for concealing one´s T1D was reluctance to appear as a weaker or inferior person than the others. A similar result has previously been obtained among adolescents, young adults and adults with T1D.[9,22,23]

Both above-mentioned reasons for concealment, fear of discrimination and fear of being seen as weak, can be subsumed under the term "stigma". Social disadvantages of poor health are often described with the concept of stigma, i.e. disqualification of full social acceptance.[24] Health-related stigma may lead to anticipated or actual experience of stereotyping, exclusion, blame, and discrimination.[25,26] Although T1D has not been considered an outstandingly stigmatized condition, it is nevertheless somewhat stigmatizing.[9,22,27] Additionally, a lack of adequate knowledge of T1D causes transposition between T1D and type 2 diabetes and a new type of stigmatization including the conception that the condition is self-inflected.[8,9,28]

Strengths and limitations

This is the first study to have investigated concealment of T1D at a national level. One of the strengths of the study was the randomly selected large (2,500 subjects) national sample. The remaining sample size, after excluding non-responders, those who had not worked in the past 12 months and those who were self-employed, was 688 employed respondents, allowing statistically reliable results.

Another strength of our study was the use of mixed methods, or methods of triangulation.[29] This had several benefits. Carrying out the interviews after the first stage of analysis of the survey data made it possible to ask the interviewees to comment on the finding that a great proportion of people with T1D choose to conceal their condition in the work place. The interviews deepened the understanding of the reasons of concealment that had been asked in the survey and revealed new reasons that were not covered by the survey. Moreover, similar results obtained by different methods increased the validity of the findings.

A number of study limitations need to be considered. Firstly, this study was cross-sectional and therefore the interpretation of causality is not possible. In the interviews, the interviewees did not necessarily report the reasons of their own concealment but their views on why other people choose to conceal their condition. Moreover, all of the measures were self-reported; thus, recall bias may have influenced the results. In addition, our results might be extrapolated only to those Western countries, which have same kind of employment legislation and health care systems to Finland.

Conclusion

Concealment of T1D at work was common enough to warrant serious attention. On the basis of our findings it could be concluded that both overemphasis and underestimation of the consequences of T1D in the work place may lead to concealing and are thus harmful to self-management and reconciling work and T1D. Both overemphasis and underestimation are based on a lack of objective knowledge. The obstacles to telling about diabetes could be diminished by giving workmates and supervisors adequate information about the illness and its purport. However, the fear of discrimination is difficult to overcome if there is a real risk of losing opportunities because of illness.

Young workers were more likely than older ones to conceal their T1D in their work community. Concealing is especially harmful for their health as they have a long working life ahead of them. Thus, special attention should be focused on supporting young workers with T1D.

CONTRIBUTORSHIP STATEMENT

P.H., L.M., K.R., and V.H designed the study and planned the data collection. P.H. and F.M. researched the survey data, performed the statistical analyses, and wrote and edited the manuscript, P.H. and V.H. researched the interview data, performed the thematic analyses, and wrote and edited the manuscript, L.M. and K.R helped to interpret the results and edited the manuscript. All authors have read this manuscript, and the requirements for authorship have been met. V.H. is the guarantor of this work. She had full access survey and interview data in this study. She takes responsibility for the integrity of the data and the accuracy of the data analysis.

COMPETING OF INTERESTS

There were no potential conflicts of interest relevant to this article.

ETHICS

The Research Ethics Committee of the Northern Savo Hospital District reviewed and approved the research

protocol (18//2010).

DATA SHARING

The datasets generated during and/or analysed during the current study are not publicly available due to other

ongoing research projects using the material but are available from the corresponding author on reasonable

request.

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Table 1. Characteristics of the participants

	N=688
Gender (*n = 684*)	
Women	318 (46.5)
Men	366 (53.5)
Mean ± SD age, years (*n = 681*)	35.4 ± 12,2
Education (*n = 688*)	
Basic education (only high school or vocational course)	155 (22.5)
Vocational school	237 (34.4)
Technical or vocational college, or university of applied sciences	196 (28.5)
University	100 (14.5)
Last HbA$_{1c}$ level* (*n = 678*)	
≤60 mmol/mol (≤7.5%)	230 (33.9)
61–70 mmol/mol (7.6–8.5%)	233 (34.4)
71–80 mmol/mol (8.6–9.5%)	156 (23.0)
≥81 mmol/mol (≥9.6%)	59 (8.7)
Duration of diabetes (*n = 685*)	
0–5 years	165 (24.1)
6–10 years	221 (32.3)
11–15 years	266 (38.8)
≥16 years	33 (4.8)
Type of work (*n = 683*)	
Mental work	290 (42.5)
Physical work	171 (25.0)
Mental and physical work (equally)	222 (32.5)
Mean ± SD length of employment, years (*n = 652*)	8.5±9.5
Type 1 diabetes concealed	
From colleagues (*n = 683*)	203 (29.7)

From line manager (*n = 686*)	123 (17.9)

Data are *n (%)* except where indicated. Missing data were excluded.

*Self-reported.

Table 2. A logistic regression analysis of concealment of type 1 diabetes to colleagues or line manager during the respondent´s working career

	Colleagues (n=594)		Line manager (n=596)	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Age		0.019		0.004
18-24	3.77 (1.42-9.97)	0.008	4.23 (1.38-12.95)	0.011
25-34	3.65 (1.39-9.56)	0.008	2.68 (0.88-8.23)	0.084
35-44	3.23 (1.24-8.95)	0.017	1.79 (0.55-5.81)	0.332
45-54	1.78 (0.61-5.18)	0.288	1.23 (0.34-4.47)	0.754
55-64 (ref.)	1		1	
Non-disclosure to extended family				
Yes	5.24 (2.06-13.35)	0.001	4.41 (1.72-11.32)	0.002
No (ref.)	1		1	
Feeling an outsider at work				
Yes	2.47 (1.58-3.84)	<0.001	2.51 (1.52-4.14)	<0.001
No (ref.)	1		1	
Embarrassed by receiving special attention				
Yes	1.99 (1.33-2.96)	0.001	1.81 (1.13-2.91)	0.014
No (ref.)	1		1	
Neglected treatment of diabetes at work				
Yes	1.59 (1.01-2.48)	0.044	-	-
No (ref.)	1		-	-

Missing data were excluded.

Table 3. Four further logistic regression analyses of concealment of type 1 diabetes to colleagues or line manager during the respondent´s working career. For these additional analyses, respondents were split into age groups based on results of the first two logistic regression analyses models.

	Concealment from colleagues in the age group of 18-44 years (n=466) OR (95% CI)	p-value	Concealment from line manager in the age group of 18-24 years (n=154) OR (95% CI)	p-value
Embarrassed by receiving special attention				
Yes	2.23 (1.46-3.40)	<0.001	3.16 (1.52-6.60)	0.002
No (ref.)	1		1	
Feeling an outsider at work				
Yes	2.20 (1.36-3.55)	0.001	-	-
No (ref.)	1		-	-

	Concealment from colleagues in the age group of 45-64 years (n=128) OR (95% CI)	p-value	Concealment from line manager in the age group of 25-64 years (n=442) OR (95% CI)	p-value
Duration of diabetes				
0-10 years	3.79 (1.22-11.83)	0.022	-	-
>10 years (ref.)	1		-	-
Feeling an outsider at work				
Yes	8.84 (2.71-28.91)	<0.001	4.16 (2.35-7.38)	<0.001
No (ref.)	1		1	
Non-disclosure to extended family				
Yes	42.27 (6.26-285.51)	<0.001	3.82 (1.40-10.42)	0.009
No (ref.)	1			

Missing data were excluded.

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (p. 1 and 2)
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found (p. 2)
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported (p. 4)
Objectives	3	State specific objectives, including any prespecified hypotheses (p. 4)
Methods		
Study design	4	Present key elements of study design early in the paper (p. 4-5)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection (p. 5-7)
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants (p. 5 and 6-7)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (p. 5-6)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group (p. 5-6)
Bias	9	Describe any efforts to address potential sources of bias (p. 5)
Study size	10	Explain how the study size was arrived at (p. 5)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why (p. 6)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (p. 6)
		(*b*) Describe any methods used to examine subgroups and interactions (p. 6)
		(*c*) Explain how missing data were addressed (p. 20-23)
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (p. 4-6 and 8-9)
		(b) Give reasons for non-participation at each stage (p. 5-6)
		(c) Consider use of a flow diagram (not applicable)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (p. 6, 8, 20)
		(b) Indicate number of participants with missing data for each variable of interest (p. 20-23)
Outcome data	15*	Report numbers of outcome events or summary measures (p. 8-9)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (p. 5-6, 8-9 and 22-23)
		(*b*) Report category boundaries when continuous variables were categorized (p. 5-6)

		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (p. 8-9 and 23)
Discussion		
Key results	18	Summarise key results with reference to study objectives (11-14)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias (p. 14)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence (p. 14)
Generalisability	21	Discuss the generalisability (external validity) of the study results (p. 14)
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based (p. 16)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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CONCEALMENT OF TYPE 1 DIABETES AT WORK IN FINLAND - A MIXED-METHOD STUDY

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CONCEALMENT OF TYPE 1 DIABETES AT WORK IN FINLAND– A MIXED-METHOD STUDY

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ABSTRACT

Objectives To explore the possible reasons for concealing type 1 diabetes (T1D) at work.

Methods The main set of data came from a cross-sectional survey, the participants of which were 688 wage-earners with T1D. Concealment of T1D was measured by asking respondents have they ever during their working career hidden their diabetes from their a) colleagues and b) line manager. Furthermore, semi-structured interviews (N=20) were conducted to obtain deeper understanding. Questionnaire data were analysed using logistic regression analyses and qualitative interviews with inductive thematic analysis.

Results About 30% of wage-earners with T1D had concealed their condition during their working career from their colleagues and almost 20% from their line manager. Individuals aged 18-44 years age were more likely to conceal their T1D from their colleagues than older workers during their working career. Not disclosing T1D to the extended family OR 5.24 (95% CI 2.06-13.35), feeling an outsider at work OR 2.47 (1.58-3.84), being embarrassed by receiving special attention at work OR 1.99 (1.33-2.96) and neglecting treatment at work OR 1.59 (1.01-2.48), were all associated with concealment of T1D from colleagues. The youngest age group 18-24 years were more likely to conceal their T1D from their line managers than the older age groups during their working career. Not disclosing T1D to the extended family OR 4.41 (1.72-11.32), feeling like an outsider at work OR 2.51 (1.52-4.14) and being embarrassed by receiving special attention at work OR 1.81 (1.13-2.91) were associated with concealment of T1D from line managers. From the interviews five main themes related to concealment emerged, expressing fears related to the consequences of telling: 1) being perceived as weak, 2) job discrimination, 3) unwanted attention 4) being seen as a person who uses their T1D for seeking advantages, and 5) losing privacy.

Conclusions Both overemphasis and underestimation of T1D at work by the colleagues or line manager may lead to concealing T1D and are thus harmful to self-management of T1D. The obstacles in disclosing T1D could be diminished by giving adequate information at the workplace about the condition and its significance.

Keywords: Type 1 diabetes; Concealment; Workplace; Psychosocial aspects; Occupational health

STRENGTHS AND LIMITATIONS OF THIS STUDY

- A total of 688 employed respondents participated in our national study, allowing statistically reliable results.

- Another strength of our study was the use of mixed methods, or combination of quantitative and qualitative methods. Carrying out the interviews after the first stage of analysis of the survey data made it possible to ask the interviewees to comment on the finding that a great proportion of people with type 1 diabetes (T1D) choose to conceal their condition in the work place. The interviews deepened the understanding of the reasons of concealment that had been asked in the survey and revealed new reasons that were not covered by the survey. Moreover, similar results obtained by different methods increased the validity of the findings.

- The cross-sectional design of our study prevents the interpretation of causality between concealment of T1D and independent variables.

- The interviewees did not necessarily report the reasons of their own concealment but their views on why other people choose to conceal their condition.

- All of the measures were self-reported; thus, recall bias may have influenced the results.

- Our results might be extrapolated only to those Western countries, which have same kind of employment legislation and health care systems to Finland.

INTRODUCTION

Research into the psychosocial aspects of type 1 diabetes (T1D) is growing [1-3]. However, only a few studies have focused on the psychosocial aspects of T1D in working life [4,5]. There are several qualitative studies focusing on e.g. self-management of T1D [6,7] and stigma due to T1D [8,9] where interviews have brought up work-related psychosocial challenges of T1D. However, both quantitative and qualitative research on T1D with working life as the sole focus is scarce. To the best of our knowledge, there are no previous mixed-methods studies on concealment of T1D at work. In this article, concealing refers to intentionally hiding existence, symptoms and management of T1D.

Despite the advances made both in diabetes care and in supporting persons with T1D at work, evidence suggests that many individuals with T1D are not disclosing their condition to their work colleagues and line managers, or do it with caution. Not disclosing T1D or only partially disclosing can affect the individuals' self-management of their condition, and ultimately their health and wellbeing [6,10]. A number of studies report that non-disclosure of T1D at work is related to perceptions of stigma, discrimination and limited career prospects [9,11]. An important consequence of not disclosing T1D is avoidance of self-managing T1D at work, such as skipping insulin injections [11]. In contrast, disclosure is related to receiving social support at work, having good psychosocial work ability, as well as, relations at work and self-management opportunities at work [12].

However, whilst quite much is known about disclosure of diabetes, it is not fully understood why some individuals would choose to conceal their T1D condition in the workplace despite important negative consequences associated with poor self-management of T1D at work. The aim of this article is to explore the possible reasons for concealing T1D at work, which goes beyond the individual simply not telling someone that they have T1D.

MATERIALS AND METHODS

Study design

This is a mixed-method study design[13] employing quantitative and qualitative research data collection methods. First, we collected quantitative data on concealment of T1D at work by a questionnaire (N=688) as part of a larger research project in Finland. Next, we developed topics for a semi-structured qualitative interview

schedule using the questionnaire study results and conducted interviews with an independent sample of participants (N=20). The Research Ethics Committee of the Northern Savo Hospital District reviewed and approved the research protocol (18//2010).

Study 1: Questionnaire data

We sent a questionnaire to a random sample of 2 500 Finnish working aged people with T1D drawn from the Medication Reimbursement Register of the Social Insurance Institution of Finland, which holds individual-level demographic and medical information on all the Finns with T1D. In 2011, there were around 40,000 individuals diagnosed with T1D. This random sample, therefore, equalled to 6% of the Finnish population with T1D. From among the respondents, we selected only those who we were in gainful employment during the past 12 months (excluding self-employed) for these analyses (N=688). The questionnaire included items on demographics, diabetes history, diabetes and work, work ability, health, diabetes and current work community, occupational health and safety and diabetes, and occupational health and diabetes [14].

Measurements

We measured concealment of T1D by asking respondents "Have you ever during your working career hidden your diabetes from your colleagues?" and "Have you ever during your working career hidden your diabetes from your line manager?" The responses were rated separately on a scale 1-3 (never; sometimes; often), and were dichotomized (never vs. sometimes/often) for further analysis. Disclosure to immediate and extended family were measured separately by yes/no options. Work measures included type of work (mental, physical or equally both), employment (permanent/fixed term) and work pattern (regular/irregular). Karasek's [15] job control (9 items) and job demands (5 items) were measured on a scale from 1 to 5 (fully agree to fully disagree). The original indices of job control and job demands were calculated as means of the original items, and the indices were dichotomized with the median as the cutting point. Respondents were asked whether due to their diabetes, they had ever felt like an outsider during their working career (never; sometimes; often); perceived discrimination (never; sometimes; often); were embarrassed by receiving special attention at work (never; sometimes; often); and been prevented from getting a job (yes/no). Respondents were also asked if they had ever during their working career neglected their diabetes treatment during working hours (never; sometimes;

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often) or had difficulty in accepting their T1D status (no; yes, a little; yes, a lot). All these ordinal scale

responses were dichotomized (never vs. sometimes/often) for analysis. Demographic and health questions

included age (years), gender (male/female), marital status, educational level, duration of diabetes (years),

HbA1c level and severe hypoglycaemia events (yes/no).

Statistical analysis

First, two sets of step-wise logistic regression analyses were conducted for concealment of T1D from a)

colleagues, and b) line managers, as expressed by odds ratio (OR) and 95% confidence interval. Disclosure to

family and all demographic, work and health measures were entered as independent variables (total of 20

variables). Second, a further four logistic regression analyses models were performed. For these additional

analyses, respondents were split into age groups based on the statistical significance of the differences in

concealment between the groups. In the case of concealment from colleagues, the age groups were 18-44 and

45-64 years. In the case of concealment from line manager, the age groups were 18-24 and 25-64 years. The aim

of these further analyses was to find out possible differences in explanatory variables between age groups. All

analyses were carried out in SPSS for Windows, version 21.0; 2012 (SPSS Inc., Chicago, IL, USA).

Study 2: Interviews

Participants and recruitment

Twenty Finnish working individuals (6 men and 14 women) aged 22-58 years (mean=39.5, SD=12.2)

participated in this interview study. They were recruited by the diabetes clinic of the department of

endocrinology and diabetology in Kuopio University Hospital. The inclusion criteria were diagnoses of T1D,

aged between 18-64 years, and in current employment. We used a purposeful sampling frame to ensure variation

and balance in the sample by gender, age groups, occupational setting, type of work (physical, mental or equal)

and work patterns (regular or irregular work patterns). However, more women volunteered than men.

A registered nurse at the diabetes clinic identified potential participants by first applying the inclusion criteria to

the patient list. Next, the nurse applied the sampling frame to identify a mix of patients. These patients were

then approached by the nurse at their next medical appointment at the clinic. The nurse introduced the study to

these potential participants and gave a fact sheet and a contact form to those who expressed an interest to take part in the interviews. The nurse kept in regular contact with the researcher to adjust the sampling frame as required.

The potential participants completed and returned the contact form directly to the researcher (PH) via post. The researcher then contacted them by telephone and gave them further details about the research and the interview (interview topics to be covered, approximate length of interview, audio recording, transcription in service, anonymous reporting) and that taking part was entirely voluntary and participants could withdraw at any time. A suitable time and place were arranged for the face-to-face interviews with those willing to participate. A written informed consent was completed before the interview. No fee was paid for taking part in the study.

Data collection

The topics covered by the semi-structured interview were based on the preliminary results of the questionnaire survey. The topics were the following: diabetes-related and work-related background, experiences of the relations between T1D and work, current work community, and occupational health and safety. In addition, the interviewees were presented with the statistics from the questionnaire data on participants' concealment of T1D and asked to comment on them and discuss possible reasons for concealment. The current article focuses on the themes discussed in this part of the interview.

The aim of the interviews was to elicit narratives of perceived diabetes-related challenges at work. The face-to-face interviews were carried out between March and May 2011 by the main researcher (PH) who is trained in conducting research interviews. Of the 20 interviews, 5 were carried out at the interviewee's home, 4 at the interviewee's workplace and 11 at the interviewer´s office in UEF. The interviews were audio recorded and the interviewer made additional notes on her reflections directly after each interview.

Transcription and data analysis

The audio recordings were transcribed verbatim by a professional transcription service. The interviewer (PH) checked the transcripts against the recordings and anonymized the data. The interviews lasted on average 67

minutes (range 37-96 min). An inductive thematic analysis [16] was used to examine the data. The transcripts were read and re-read separately by two members of the research group (PH and VH). First, the researchers picked out the passages that dealt with concealing diabetes and categorized the passages according to the motives ascribed to concealment. After that, they coded the data independently on the basis of the categorization. Then the researchers compared and discussed their decisions, ready to revise the categorization in case of discrepancies. No such discrepancies arose, however.

RESULTS

Study 1: Questionnaire

The characteristics of the 688 respondents are summarized in Table 1. The mean age of the respondents was 36 years, and 47% of them were women. A total of 44% of the respondents were diagnosed with T1D more than 10 years ago. A total of 30% of the respondents had concealed their diabetes during their working career from their colleagues and 18% from their line manager. In total, 16% of the respondents reported having concealed their diabetes during their working career from both their colleagues and line manager alike.

Results of the stepwise logistic regression

Of the 20 variables included in the stepwise logistic regression analyses, five variables were retained in the final models. The logistic regression model on concealment from colleagues concluded in five steps (Table 2). Individuals in the 18-44 years age group were more likely to conceal their T1D from their colleagues than older workers during their working career. Not disclosing T1D to the extended family, feeling an outsider at work, being embarrassed by receiving special attention at work and neglecting treatment at work, were all associated with concealment of T1D from colleagues.

The model on concealment from the line manager concluded in four steps (Table 2). The youngest age group 18-24 years were more likely to conceal their T1D from their line managers than the older age groups during their working career. Not disclosing T1D to the extended family, feeling like an outsider at work and being embarrassed by receiving special attention at work were associated with concealment of T1D from line managers.

In the further analysis, the colleague model in age groups 18-44 years and 45-64 years, as well as the line manager model in age groups 18-24 years and 25-64 years revealed that different variables were associated with concealment of T1D at work in different age groups (Table 3). In the younger group, feeling embarrassed by receiving special attention was strongly associated with concealment. In contrast, for the older group, feeling an outsider in the work place was the strongest association with concealment.

Study 2: Interviews

All interviews (N=20) discussed possible reasons for concealment of T1D at work. More than half of them discussed their own positive experiences of disclosing but understood why some people may conceal their diabetes at work.

Five main categories of reasons for concealment emerged from the inductive analysis of the interview data. Each of them reflected the interviewees' perceptions of what the consequences of telling at their workplace about their T1D status might be. The first four themes (being perceived as weak, job discrimination, unwanted attention, and being seen as a person who uses their T1D for seeking advantages) anticipated other people´s attitudes and behavior and the fifth reflected the person´s wish to avoid too close intimacy with others. All of the interviewees discussed at least two out of the five identified kinds of reasons of concealment.

The first kind of reason the interviewees thought might lead to concealment was labelled fear of being perceived as weak or fear of losing status among the work-mates. The participants discussed that diabetes is often kept hidden because telling someone about it at work would make that person seem weak and inferior to others. Appearing as weak may be felt as causing loss of status among the work mates. *"You feel you are weak and you don´t want to show your weakness to your pack." (Man, 27)* Altogether, people were seen as not willing to differ from the others, especially in a negative way. *"It´s perhaps just that I wanted to be like everybody*

else."(Man, 49) It was also mentioned that T1D may be seen as an indication of a more general personal fault. Some interviewees used the social scientific word *stigma* to refer both to losing status among the colleagues and to being at risk of discrimination. *"I think [by not disclosing] you can avoid being stigmatized." (Woman, 53)*

The second kind of reason for concealment told about by the interviewees was related to the fear of discrimination. Several examples were given of the ways in which being open about one´s diabetes could hinder the individual from getting a job or a promotion or could increase the probability of getting laid off. Both young and middle-aged interviewees talked about discrimination: *"If I left this job, I don´t know if, due to my diabetes, I could get a new job. This thought is absolutely horrifying!" (Woman, 29)*. Some interviewees mentioned possible reasons for discrimination: a person with T1D might be seen as one who is often on sick leaves or is prone to accidents and who is "*in the end more expensive.*" (Woman, 40)

Reluctance to receive special attention was the third category of reasons for concealment that emerged in the interviews. The interviewees gave examples of the ways in which other people had made a fuss, been overprotective or patronizing after hearing about the interviewees' diabetes. Irrespective of whether this had been benevolent or malevolent, it was felt as awkward. Lack of up-to-date knowledge about diabetes was seen as the main reason for overprotection. *"My colleagues might come every two hours to ask how I feel and if I am okay. If they see me buying chocolate, they might go and tell my supervisor that my blood sugar is swinging." (Woman, 29)*

Fear of being seen as a person who uses their T1D for seeking advantages was yet another category of reasons for concealment brought up by the interviewees. The special arrangements, such as taking regular meal breaks to manage diabetes were sometimes not understood as necessary, as some people did not know about the seriousness of the illness. It might be that people are mixing up T1D and type 2 diabetes and there is a real lack of understanding of T1D. *" I feel that some of my colleagues thought that diabetes is just a pretext to being allowed to have meal breaks every four hours. As if it was only something I´d like to have although it was something I had to have. There is no reason for envy." (Woman, 26)*

The final category of reasons for concealment was related to losing privacy i.e. a perception that illnesses are private matters that should only be disclosed to close people. The wish to keep the illness to oneself was seen as understandable especially when the relations between workmates are distant, when the worker has not quite made the illness as a part of their identity, and when the person is generally reserved as a person. *"…Of course, illness is always a personal matter, and not everybody wants to make it public."* (Woman, 51) *"… Not everything is everybody´s business."* (Man, 26)

In connection with discussing the reasons for concealment, the interviewees usually mentioned the risk associated with hypoglycaemia events if nobody around knows how to deal with it. *"There´s a real risk of losing your life if you get a hypoglycaemia and nobody knows. You might even die in the worst case."* (Woman, 49) Also self-management of T1D – having regular meal breaks, measuring blood glucose levels, injection, and visits to a doctor - was seen as difficult for one who tries to conceal their condition.

When asked in what kind of workplace disclosing one´s illness would be easy, the interviewees emphasized openness, trust and mutual caring of each other as important factors favoring disclose. One interviewee said it would be helpful if the workers were always evaluated on the basis of how they do their job instead of on the basis of their personal features.

DISCUSSION

As far as we know, this is a first population-based study to report figures of concealment of T1D from colleagues and line managers at work places. In this article, concealing refers to intentionally hiding the existence, symptoms and management of T1D. In our survey results, about one in three had sometimes or often concealed their T1D from their colleagues, one in five from their line manager and one in six from both colleagues and line manager during their working career. This is noteworthy, because colleagues may be the first ones to notice a hypoglycaemic event and to offer help when needed [8]. In addition, the line manager can support a worker with T1D to manage their condition effectively at work if they knew about a worker's T1D status [6].

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Young workers were more likely to have concealed their T1D than older ones from both colleagues and line manager. This could be interpreted as indicating harsher competition for jobs and proceeding in a career between younger workers in the current working life. It is also obvious that young adults being in the beginning of their working career have more to lose than older people. Although the effect of fear of discrimination did not reach significance in the quantitative part of the study, the theme of discrimination was often brought up by the interviewees – young and older alike. To the best of our knowledge, there are no previous studies concerning concealment of T1D among young workers.

We found by regression analysis that those who had not disclosed their T1D to their extended family were more likely to conceal their condition from colleagues and line manager. This suggests that some workers may choose to keep their condition hidden from everyone outside their closest circle of people, which was also discussed in the interviews. In addition, those who felt like an outsider at work due to their T1D were more likely to conceal their condition from colleagues and line manager. In the same line, some of the interviewees said that unopen and strained working relationships at work make it difficult to reveal one's T1D. This emphasizes the importance of the quality of relationships in the work place [7,17]. If working relationships are strained and there is little interpersonal trust or a negative workplace climate then workers are more likely to conceal their condition at work [6]. This has been confirmed in a Danish study among workers with type 2 diabetes [18]. Employers and managers have an important role in developing an inclusive working environment [17]. Thus, they should take working relationships into account when developing workplace practices.

Although openness with employers could be encouraged, it is important to remember that disclosure of one´s chronic condition is a highly private and confidential decision [17,19], and there should be no pressure to do it. In Finland, an employer can ask an applicant about their health status during a job interview only if there is a legal reason to do so i.e. if a health condition may potentially impact job safety [20]. In addition, the Non-discrimination Act (1325/2014) [21] promotes equality and prevent discrimination in the workplaces.

Embarrassment caused by receiving special attention at work due to T1D was associated with concealment of T1D from colleagues and line manager. The theme "unwanted attention" was also found in the interviews.

Giving special attention was seen as an overreaction to the risks related to the condition. On the other hand, some of the interviewees felt that the risks related to T1D could be underestimated, which could result in seeing a person with T1D as one who uses their condition for seeking unwarranted advantages. As far as we know, there are no previous studies reporting this kind of results.

In general, concealment of T1D from colleagues was associated with neglecting self-management of T1D at work. If a person conceals their T1D from a colleague, it is difficult to self-manage their condition effectively at work place. This may lead to keeping blood sugar levels higher than optimal to manage at work as found in a previous study from U.K [7]. We reported in our previously published study that work-related diabetes distress, such as worry and exhaustion in reconciling work with T1D, was strongly associated with keeping blood glucose level high at work [14]. In addition, it has been shown that young workers with T1D experience time pressure at their work and therefore they sometimes neglect or delay self-management activities at work [5]. As both concealment and time pressure among young workers with T1D hinder their self-management activities at work, special attention should be focused on supporting them for avoiding long-term complications and diminishing of work ability.

One of the often discussed reasons for concealing one´s T1D at the work place was fear of discrimination, which could restrict one´s career development and even lead to unemployment. This supports a previous qualitative study that also found those with T1D, who did not disclose their condition at work, gave the reason as fear of being discriminated against, which could harm their working career [9]. Our findings also relate to the finding of the study of Polish seafarers with T1D, who were not allowed to work at sea, and who concealed their condition from health care and from their colleagues and worked on seagoing vessels [22]. Another frequently mentioned reason for concealing one´s T1D was reluctance to appear as a weaker or inferior person than the others. This kind of reluctance to give an impression of weakness has previously been obtained among adolescents, young adults and adults with T1D [9,23,24].

Both above-mentioned reasons for concealment, fear of discrimination and fear of being seen as weak, can be subsumed under the term "stigma". Social disadvantages of poor health are often described with the concept of

stigma, i.e. disqualification of full social acceptance [25]. Health-related stigma may lead to anticipated or actual experience of stereotyping, exclusion, blame, and discrimination [26,27]. Although T1D is not necessarily considered a very stigmatizing condition by the general public, people with the condition nevertheless feel stigmatized by it [28,29]. In some societies, e.g. China, the stigma is especially high [11]. Additionally, a lack of adequate knowledge of T1D causes transposition between T1D and type 2 diabetes and a new type of stigmatization including the conception that the condition is self-inflicted [9,30].

Strengths and limitations

To our knowledge, this is the first study to investigate concealment of T1D at a national level. One of the strengths of the study was that 688 employed respondents with T1D participated in our study, allowing statistically reliable results.

Another strength of our study was the use of mixed methods, or combination of quantitative and qualitative methods. This had several benefits. Carrying out the interviews after the first stage of analysis of the survey data made it possible to ask the interviewees to comment on the finding that a great proportion of people with T1D choose to conceal their condition in the work place. The interviews deepened the understanding of the reasons of concealment that had been asked in the survey and revealed new reasons that were not covered by the survey. Moreover, similar results obtained by different methods increased the validity of the findings.

A number of study limitations need to be considered. Firstly, this study was cross-sectional and therefore the interpretation of causality is not possible. In the interviews, the interviewees did not necessarily report the reasons of their own concealment but their views on why other people choose to conceal their condition. The interviews were carried out only in one city, which can be considered as a limitation in our study. However, Kuopio is a middle sized city and located middle in Finland and the demographics of this city is similar to other cities in Finland. Moreover, all measures were self-reported; thus, recall bias may have influenced the results. In addition, our results might be extrapolated only to those Western countries, which have same kind of employment legislation and health care systems to Finland.

Conclusion

Concealment of T1D at work was common enough to warrant serious attention. On the basis of our findings it could be suggested that both overemphasis and underestimation of the consequences of T1D in the work place may lead to concealing and are thus harmful to self-management and reconciling work and T1D. Both overemphasis and underestimation might be diminished by increasing up-to-date- knowledge about the condition among the workmates and supervisors. However, the fear of discrimination is difficult to overcome if there is a real risk of losing opportunities because of illness.

Young workers were more likely than older ones to conceal their T1D in their work community. Concealing is especially harmful for their health as they have a long working life ahead of them. Thus, special attention should be focused on supporting young workers with T1D.

CONTRIBUTORSHIP STATEMENT

P.H., L.M., K.R., and V.H designed the study and planned the data collection. P.H. and F.M. researched the survey data, performed the statistical analyses, and wrote and edited the manuscript, P.H. and V.H. researched the interview data, performed the thematic analyses, and wrote and edited the manuscript, L.M. and K.R helped to interpret the results and edited the manuscript. All authors have read this manuscript, and the requirements for authorship have been met. V.H. is the guarantor of this work. She had full access survey and interview data in this study. She takes responsibility for the integrity of the data and the accuracy of the data analysis.

COMPETING OF INTERESTS

There were no potential conflicts of interest relevant to this article.

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ETHICS

The Research Ethics Committee of the Northern Savo Hospital District reviewed and approved the research protocol (18//2010).

DATA SHARING

The datasets generated during and/or analysed during the current study are not publicly available due to other ongoing research projects using the material but are available from the corresponding author on reasonable request.

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Table 1. Characteristics of the participants

	N=688
Gender (*n = 684*)	
Women	318 (46.5)
Men	366 (53.5)
Mean ± SD age, years (*n = 681*)	35.4 ± 12,2
Education (*n = 688*)	
Basic education (only high school or vocational course)	155 (22.5)
Vocational school	237 (34.4)
Technical or vocational college, or university of applied sciences	196 (28.5)
University	100 (14.5)
Last HbA$_{1c}$ level* (*n = 678*)	
≤60 mmol/mol (≤7.5%)	230 (33.9)
61–70 mmol/mol (7.6–8.5%)	233 (34.4)
71–80 mmol/mol (8.6–9.5%)	156 (23.0)
≥81 mmol/mol (≥9.6%)	59 (8.7)
Duration of diabetes (*n = 685*)	
0–5 years	165 (24.1)
6–10 years	221 (32.3)
11–15 years	266 (38.8)
≥16 years	33 (4.8)
Type of work (*n = 683*)	
Mental work	290 (42.5)
Physical work	171 (25.0)
Mental and physical work (equally)	222 (32.5)
Mean ± SD length of employment, years (*n = 652*)	8.5±9.5
Type 1 diabetes concealed	
From colleagues (*n = 683*)	203 (29.7)

From line manager (*n = 686*)	123 (17.9)

Data are *n (%)* except where indicated. Missing data were excluded.

*Self-reported.

Table 2. A logistic regression analysis of concealment of type 1 diabetes to colleagues or line manager during the respondent´s working career

	Colleagues (n=594)		Line manager (n=596)	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Age		0.019		0.004
18-24	3.77 (1.42-9.97)	0.008	4.23 (1.38-12.95)	0.011
25-34	3.65 (1.39-9.56)	0.008	2.68 (0.88-8.23)	0.084
35-44	3.23 (1.24-8.95)	0.017	1.79 (0.55-5.81)	0.332
45-54	1.78 (0.61-5.18)	0.288	1.23 (0.34-4.47)	0.754
55-64 (ref.)	1		1	
Non-disclosure to extended family				
Yes	5.24 (2.06-13.35)	0.001	4.41 (1.72-11.32)	0.002
No (ref.)	1		1	
Feeling an outsider at work				
Yes	2.47 (1.58-3.84)	<0.001	2.51 (1.52-4.14)	<0.001
No (ref.)	1		1	
Embarrassed by receiving special attention				
Yes	1.99 (1.33-2.96)	0.001	1.81 (1.13-2.91)	0.014
No (ref.)	1		1	
Neglected treatment of diabetes at work				
Yes	1.59 (1.01-2.48)	0.044	-	-
No (ref.)	1		-	-

Missing data were excluded.

Table 3. Four further logistic regression analyses of concealment of type 1 diabetes to colleagues or line manager during the respondent´s working career. For these additional analyses, respondents were split into age groups based on results of the first two logistic regression analyses models.

	Concealment from colleagues in the age group of 18-44 years (n=466) OR (95% CI)	p-value	Concealment from line manager in the age group of 18-24 years (n=154) OR (95% CI)	p-value
Embarrassed by receiving special attention				
Yes	2.23 (1.46-3.40)	<0.001	3.16 (1.52-6.60)	0.002
No (ref.)	1		1	
Feeling an outsider at work				
Yes	2.20 (1.36-3.55)	0.001	-	-
No (ref.)	1		-	-
	Concealment from colleagues in the age group of 45-64 years (n=128) OR (95% CI)		Concealment from line manager in the age group of 25-64 years (n=442) OR (95% CI)	
Duration of diabetes				
0-10 years	3.79 (1.22-11.83)	0.022	-	-
>10 years (ref.)	1		-	-
Feeling an outsider at work				
Yes	8.84 (2.71-28.91)	<0.001	4.16 (2.35-7.38)	<0.001
No (ref.)	1		1	
Non-disclosure to extended family				
Yes	42.27 (6.26-285.51)	<0.001	3.82 (1.40-10.42)	0.009
No (ref.)	1			

Missing data were excluded.

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (p. 1 and 2)
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found (p. 2)
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported (p. 4)
Objectives	3	State specific objectives, including any prespecified hypotheses (p. 4)
Methods		
Study design	4	Present key elements of study design early in the paper (p. 4-5)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection (p. 5-7)
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants (p. 5 and 6-7)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (p. 5-6)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group (p. 5-6)
Bias	9	Describe any efforts to address potential sources of bias (p. 5)
Study size	10	Explain how the study size was arrived at (p. 5)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why (p. 6)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (p. 6)
		(*b*) Describe any methods used to examine subgroups and interactions (p. 6)
		(*c*) Explain how missing data were addressed (p. 20-23)
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (p. 4-6 and 8-9)
		(b) Give reasons for non-participation at each stage (p. 5-6)
		(c) Consider use of a flow diagram (not applicable)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (p. 6, 8, 20)
		(b) Indicate number of participants with missing data for each variable of interest (p. 20-23)
Outcome data	15*	Report numbers of outcome events or summary measures (p. 8-9)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (p. 5-6, 8-9 and 22-23)
		(*b*) Report category boundaries when continuous variables were categorized (p. 5-6)

		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (p. 8-9 and 23)

Discussion

Key results	18	Summarise key results with reference to study objectives (11-14)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias (p. 14)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence (p. 14)
Generalisability	21	Discuss the generalisability (external validity) of the study results (p. 14)

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based (p. 16)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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CONCEALMENT OF TYPE 1 DIABETES AT WORK IN FINLAND - A MIXED-METHOD STUDY

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CONCEALMENT OF TYPE 1 DIABETES AT WORK IN FINLAND– A MIXED-METHOD STUDY

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ABSTRACT

Objectives To explore the possible reasons for concealing type 1 diabetes (T1D) at work.

Methods The main set of data came from a cross-sectional survey (response rate 49.3%), the participants of which were 688 wage-earners with T1D. Concealment of T1D was measured by asking respondents have they ever during their working career hidden their diabetes from their a) colleagues and b) line manager. Furthermore, semi-structured interviews (N=20) were conducted to obtain deeper understanding. Questionnaire data were analysed using logistic regression analyses and qualitative interviews with inductive thematic analysis.

Results About 30% of wage-earners with T1D had concealed their condition during their working career from their colleagues and almost 20% from their line manager. Individuals aged 18-44 years age were more likely to conceal their T1D from their colleagues than older workers during their working career. Not disclosing T1D to the extended family OR 5.24 (95% CI 2.06-13.35), feeling an outsider at work OR 2.47 (1.58-3.84), being embarrassed by receiving special attention at work OR 1.99 (1.33-2.96) and neglecting treatment at work OR 1.59 (1.01-2.48), were all associated with concealment of T1D from colleagues. The youngest age group 18-24 years were more likely to conceal their T1D from their line managers than the older age groups during their working career. Not disclosing T1D to the extended family OR 4.41 (1.72-11.32), feeling like an outsider at work OR 2.51 (1.52-4.14) and being embarrassed by receiving special attention at work OR 1.81 (1.13-2.91) were associated with concealment of T1D from line managers. From the interviews five main themes related to concealment emerged, expressing fears related to the consequences of telling: 1) being perceived as weak, 2) job discrimination, 3) unwanted attention 4) being seen as a person who uses their T1D for seeking advantages, and 5) losing privacy.

Conclusions A considerable proportion of wage-earners with T1D are concealing their diagnosis often because of feelings associated with stigma. Both overemphasis and underestimation of T1D at work by the colleagues or line manager may lead to concealing T1D and may thus be harmful to self-management of T1D. The obstacles in disclosing T1D might be diminished by giving adequate information at the workplace about the condition and its significance.

Keywords: Type 1 diabetes; Concealment; Workplace; Psychosocial aspects; Occupational health

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- A total of 688 employed respondents participated in our national study, allowing statistically reliable results.

- A strength of our study was the use of quantitative and qualitative methods where the survey identified the prevalence of T1D concealment and the interviews deepened the understanding of the reasons for concealment.

- The cross-sectional design of our study prevents the interpretation of causality between concealment of type 1 diabetes and independent variables.

- All measures were self-reported; thus, recall bias may have influenced the results.

- Our results might be extrapolated only to those Western countries, which have similar employment legislation and health care systems to Finland.

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INTRODUCTION

Research into the psychosocial aspects of type 1 diabetes (T1D) is growing [1-3]. However, only a few studies have focused on the psychosocial aspects of T1D in working life [4,5]. There are several qualitative studies focusing on e.g. self-management of T1D [6,7] and stigma due to T1D[8,9] where interviews have brought up work-related psychosocial challenges of T1D. However, both quantitative and qualitative research on T1D with working life as the sole focus is scarce. To the best of our knowledge, there are no previous mixed-methods studies on concealment of T1D at work. In this article, concealing refers to intentionally hiding existence, symptoms and management of T1D.

Despite the advances made both in diabetes care and in supporting persons with T1D at work, evidence suggests that many individuals with T1D are not disclosing their condition to their work colleagues and line managers, or do it with caution. Not disclosing T1D or only partially disclosing can affect the individuals' self-management of their condition, and ultimately their health and wellbeing [6,10]. A number of studies report that non-disclosure of T1D at work is related to perceptions of stigma, discrimination and limited career prospects [9,11]. An important consequence of not disclosing T1D is avoidance of self-managing T1D at work, such as skipping insulin injections [11]. In contrast, disclosure is related to receiving social support at work, having good psychosocial work ability, as well as, relations at work and self-management opportunities at work [12].

However, whilst quite much is known about disclosure of diabetes, it is not fully understood why some individuals would choose to conceal their T1D condition in the workplace despite important negative consequences associated with poor self-management of T1D at work. The aim of this article is to explore the possible reasons for concealing T1D at work, which goes beyond the individual simply not telling someone that they have T1D.

MATERIALS AND METHODS

Study design

This is a mixed-method study design [13] employing quantitative and qualitative research data collection methods. First, we collected quantitative data on concealment of T1D at work by a questionnaire (N=688) as part of a larger research project in Finland. Next, we developed topics for a semi-structured qualitative interview

schedule using the questionnaire study results and conducted interviews with an independent sample of participants (N=20). The Research Ethics Committee of the Northern Savo Hospital District reviewed and approved the research protocol (18//2010).

Study 1: Questionnaire data

We sent a postal questionnaire to a random sample of 2 500 Finnish working aged people with T1D drawn from the Medication Reimbursement Register of the Social Insurance Institution of Finland, which holds individual-level demographic and medical information on all the Finns with T1D. Random sampling was carried out using the uniform function of SAS for Windows 9.2 (SAS Institute Inc, Cary, NC, USA). In 2011, there were around 40,000 individuals diagnosed with T1D. This random sample, therefore, equalled to 6% of the Finnish population with T1D. The response rate from the random sample was 49.3%. There were no incentives for taking part in the study. From among the respondents, we selected only those who we were in gainful employment during the past 12 months (excluding self-employed) for these analyses (N=688). The questionnaire included items on demographics, diabetes history, diabetes and work, work ability, health, diabetes and current work community, occupational health and safety and diabetes, and occupational health and diabetes [14].

Measurements

We measured concealment of T1D by asking respondents "Have you ever during your working career hidden your diabetes from your colleagues?" and "Have you ever during your working career hidden your diabetes from your line manager?" The responses were rated separately on a scale 1-3 (never; sometimes; often), and were dichotomized (never vs. sometimes/often) for further analysis. Disclosure to immediate and extended family were measured separately by yes/no options. Work measures included type of work (mental, physical or equally both), employment (permanent/fixed term) and work pattern (regular/irregular). Karasek's[15] job control (9 items) and job demands (5 items) were measured on a scale from 1 to 5 (fully agree to fully disagree). The original indices of job control and job demands were calculated as means of the original items, and the indices were dichotomized with the median as the cutting point. Respondents were asked whether due to their diabetes, they had ever felt like an outsider during their working career (never; sometimes; often); perceived

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discrimination (never; sometimes; often); were embarrassed by receiving special attention at work (never; sometimes; often); and been prevented from getting a job (yes/no). Respondents were also asked if they had ever during their working career neglected their diabetes treatment during working hours (never; sometimes; often) or had difficulty in accepting their T1D status (no; yes, a little; yes, a lot). All these ordinal scale responses were dichotomized (never vs. sometimes/often) for analysis. Demographic and health questions included age (years), gender (male/female), marital status, educational level, duration of diabetes (years), HbA1c level and severe hypoglycaemia events (yes/no).

Statistical analysis

First, two sets of step-wise logistic regression analyses were conducted for concealment of T1D from a) colleagues, and b) line managers, as expressed by odds ratio (OR) and 95% confidence interval. Disclosure to family and all demographic, work and health measures were entered as independent variables (total of 20 variables). Second, a further four logistic regression analyses models were performed. For these additional analyses, respondents were split into age groups based on the statistical significance of the differences in concealment between the groups. In the case of concealment from colleagues, the age groups were 18-44 and 45-64 years. In the case of concealment from line manager, the age groups were 18-24 and 25-64 years. The aim of these further analyses was to find out possible differences in explanatory variables between age groups. All analyses were carried out in SPSS for Windows, version 21.0; 2012 (SPSS Inc., Chicago, IL, USA).

Study 2: Interviews

Participants and recruitment

Twenty Finnish working individuals (6 men and 14 women) aged 22-58 years (mean = 39.5, SD= 12.2) participated in this interview study. They were recruited by the diabetes clinic of the department of endocrinology and diabetology in Kuopio University Hospital. The inclusion criteria were diagnoses of T1D, aged between 18-64 years, and in current employment. We used a purposeful sampling frame to ensure variation and balance in the sample by gender, age groups, occupational setting, type of work (physical, mental or equal) and work patterns (regular or irregular work patterns). However, more women volunteered than men.

A registered nurse at the diabetes clinic identified potential participants by first applying the inclusion criteria to the patient list. Next, the nurse applied the sampling frame to identify a mix of patients. These patients were then approached by the nurse at their next medical appointment at the clinic. The nurse introduced the study to these potential participants and gave a fact sheet and a contact form to those who expressed an interest to take part in the interviews. The nurse kept in regular contact with the researcher to adjust the sampling frame as required.

The potential participants completed and returned the contact form directly to the researcher (PH) via post. The researcher then contacted them by telephone and gave them further details about the research and the interview (interview topics to be covered, approximate length of interview, audio recording, transcription in service, anonymous reporting) and that taking part was entirely voluntary and participants could withdraw at any time. A suitable time and place were arranged for the face-to-face interviews with those willing to participate. A written informed consent was completed before the interview. No fee was paid for taking part in the study.

Data collection

The topics covered by the semi-structured interview were based on the preliminary results of the questionnaire survey. The topics were the following: diabetes-related and work-related background, experiences of the relations between T1D and work, current work community, and occupational health and safety. In addition, the interviewees were presented with the statistics from the questionnaire data on participants' concealment of T1D and asked to comment on them and discuss possible reasons for concealment. The current article focuses on the themes discussed in this part of the interview.

The aim of the interviews was to elicit narratives of perceived diabetes-related challenges at work. The face-to-face interviews were carried out between March and May 2011 by the main researcher (PH) who is trained in conducting research interviews. Of the 20 interviews, 5 were carried out at the interviewee's home, 4 at the interviewee's workplace and 11 at the interviewer´s office in UEF. The interviews were audio recorded and the interviewer made additional notes on her reflections directly after each interview.

Transcription and data analysis

The audio recordings were transcribed verbatim by a professional transcription service. The interviewer (PH) checked the transcripts against the recordings and anonymized the data. The interviews lasted on average 67 minutes (range 37-96 min). An inductive thematic analysis[16] was used to examine the data. The transcripts were read and re-read separately by two members of the research group (PH and VH). First, the researchers picked out the passages that dealt with concealing diabetes and categorized the passages according to the motives ascribed to concealment. After that, they coded the data independently on the basis of the categorization. Then the researchers compared and discussed their decisions, ready to revise the categorization in case of discrepancies. No such discrepancies arose, however.

RESULTS

Study 1: Questionnaire

The characteristics of the 688 respondents are summarized in Table 1. The mean age of the respondents was 36 years, and 47% of them were women. A total of 44% of the respondents were diagnosed with T1D more than 10 years ago. A total of 30% of the respondents had concealed their diabetes during their working career from their colleagues and 18% from their line manager. In total, 16% of the respondents reported having concealed their diabetes during their working career from both their colleagues and line manager alike.

Results of the stepwise logistic regression

Of the 20 variables included in the stepwise logistic regression analyses, five variables were retained in the final models. The logistic regression model on concealment from colleagues concluded in five steps (Table 2). Individuals in the 18-44 years age group were more likely to conceal their T1D from their colleagues than older workers during their working career. Not disclosing T1D to the extended family, feeling an outsider at work, being embarrassed by receiving special attention at work and neglecting treatment at work, were all associated with concealment of T1D from colleagues.

The model on concealment from the line manager concluded in four steps (Table 2). The youngest age group 18-24 years were more likely to conceal their T1D from their line managers than the older age groups during

their working career. Not disclosing T1D to the extended family, feeling like an outsider at work and being embarrassed by receiving special attention at work were associated with concealment of T1D from line managers.

In the further analysis, the colleague model in age groups 18-44 years and 45-64 years, as well as the line manager model in age groups 18-24 years and 25-64 years revealed that different variables were associated with concealment of T1D at work in different age groups (Table 3). In the younger group, feeling embarrassed by receiving special attention was strongly associated with concealment. In contrast, for the older group, feeling an outsider in the work place was the strongest association with concealment.

Study 2: Interviews

All interviewees (N=20) discussed possible reasons for concealment of T1D at work. About a half of them had first-hand experience of concealing. Of those who had not concealed their diabetes, most of them understood why some people may choose to conceal. More than half of the interviewees discussed their own positive experiences of disclosing.

Five main categories of reasons for concealment emerged from the inductive analysis of the interview data. Each of them reflected the interviewees' perceptions of what the consequences of telling at their workplace about their T1D status might be. The first four themes (being perceived as weak, job discrimination, unwanted attention, and being seen as a person who uses their T1D for seeking advantages) anticipated other people´s attitudes and behavior and the fifth reflected the person´s wish to avoid too close intimacy with others. All of the interviewees discussed at least two out of the five identified kinds of reasons of concealment.

The first kind of reason the interviewees thought might lead to concealment was labelled fear of being perceived as weak or fear of losing status among the work-mates. The participants discussed that diabetes is often kept

hidden because telling someone about it at work would make that person seem weak and inferior to others. Appearing as weak may be felt as causing loss of status among the work mates. *"You feel you are weak and you don´t want to show your weakness to your pack." (Man, 27)* Altogether, people were seen as not willing to differ from the others, especially in a negative way. *"It´s perhaps just that I wanted to be like everybody else."(Man, 49)* It was also mentioned that TD1 may be seen as an indication of a more general personal fault. Some interviewees used the social scientific word *stigma* to refer both to losing status among the colleagues and to being at risk of discrimination. *"I think [by not disclosing] you can avoid being stigmatized." (Woman, 53)*

The second kind of reason for concealment told about by the interviewees was related to the fear of discrimination. Several examples were given of the ways in which being open about one´s diabetes could hinder the individual from getting a job or a promotion or could increase the probability of getting laid off. Both young and middle-aged interviewees talked about discrimination: *"If I left this job, I don´t know if, due to my diabetes, I could get a new job. This thought is absolutely horrifying!" (Woman, 29).* Some interviewees mentioned possible reasons for discrimination: a person with T1D might be seen as one who is often on sick leaves or is prone to accidents and who is "*in the end more expensive.*" (Woman, 40)

Reluctance to receive special attention was the third category of reasons for concealment that emerged in the interviews. The interviewees gave examples of the ways in which other people had made a fuss, been overprotective or patronizing after hearing about the interviewees' diabetes. Irrespective of whether this had been benevolent or malevolent, it was felt as awkward. Lack of up-to-date knowledge about diabetes was seen as the main reason for overprotection. *"My colleagues might come every two hours to ask how I feel and if I am okay. If they see me buying chocolate, they might go and tell my supervisor that my blood sugar is swinging." (Woman, 29)*

Fear of being seen as a person who uses their T1D for seeking advantages was yet another category of reasons for concealment brought up by the interviewees. The special arrangements, such as taking regular meal breaks to manage diabetes were sometimes not understood as necessary, as some people did not know about the seriousness of the illness. It might be that people are mixing up type 1 and type 2 diabetes and there is a real

lack of understanding of T1D. *" I feel that some of my colleagues thought that diabetes is just a pretext to being allowed to have meal breaks every four hours. As if it was only something I´d like to have although it was something I had to have. There is no reason for envy." (Woman, 26)*

The final category of reasons for concealment was related to losing privacy i.e. a perception that illnesses are private matters that should only be disclosed to close people. The wish to keep the illness to oneself was seen as understandable especially when the relations between workmates are distant, when the worker has not quite made the illness as a part of their identity, and when the person is generally reserved as a person. *"...Of course, illness is always a personal matter, and not everybody wants to make it public." (Woman, 51)* "... *Not everything is everybody´s business." (Man, 26)*

In connection with discussing the reasons for concealment, the interviewees usually mentioned the risk associated with hypoglycaemia events if nobody around knows how to deal with it. *"There´s a real risk of losing your life if you get a hypoglycaemia and nobody knows. You might even die in the worst case." (Woman, 49)* Also self-management of TD1 – having regular meal breaks, measuring blood glucose levels, injection, and visits to a doctor - was seen as difficult for one who tries to conceal their condition.

When asked in what kind of workplace disclosing one´s illness would be easy, the interviewees emphasized openness, trust and mutual caring of each other as important factors favoring disclose. One interviewee said it would be helpful if the workers were always evaluated on the basis of how they do their job instead of on the basis of their personal features.

DISCUSSION

As far as we know, this is a first population-based study to report figures of concealment of T1D from colleagues and line managers at work places. In this article, concealing refers to intentionally hiding the existence, symptoms and management of T1D. In our survey results, about one in three had sometimes or often concealed their T1D from their colleagues, one in five from their line manager and one in six from both

colleagues and line manager during their working career. This is noteworthy, because colleagues may be the first ones to notice a hypoglycaemic event and to offer help when needed [8]. In addition, the line manager can support a worker with T1D to manage their condition effectively at work if they knew about a worker's T1D status [6].

Young workers were more likely to have concealed their T1D than older ones from both colleagues and line manager. This could be interpreted as indicating harsher competition for jobs and proceeding in a career between younger workers in the current working life. It is also obvious that young adults being in the beginning of their working career have more to lose than older people. Although the effect of fear of discrimination did not reach significance in the quantitative part of the study, the theme of discrimination was often brought up by the interviewees – young and older alike. To the best of our knowledge, there are no previous studies concerning concealment of T1D among young workers.

We found by regression analysis that those who had not disclosed their T1D to their extended family were more likely to conceal their condition from colleagues and line manager. This suggests that some workers may choose to keep their condition hidden from everyone outside their closest circle of people, which was also discussed in the interviews. In addition, those who felt like an outsider at work due to their T1D were more likely to conceal their condition from colleagues and line manager. In the same line, some of the interviewees said that unopen and strained working relationships at work make it difficult to reveal one's T1D. This emphasizes the importance of the quality of relationships in the work place [7,17]. If working relationships are strained and there is little interpersonal trust or a negative workplace climate then workers are more likely to conceal their condition at work [6]. This has been confirmed in a Danish study among workers with type 2 diabetes [18]. Employers and managers have an important role in developing an inclusive working environment [17]. Thus, they should take working relationships into account when developing workplace practices.

Although openness with employers could be encouraged, it is important to remember that disclosure of one´s chronic condition is a highly private and confidential decision [17,19], and there should be no pressure to do it. In Finland, an employer can ask an applicant about their health status during a job interview only if there is a

legal reason to do so i.e. if a health condition may potentially impact job safety [20]. In addition, the Non-discrimination Act (1325/2014) [21] promotes equality and prevent discrimination in the workplaces.

Embarrassment caused by receiving special attention at work due to T1D was associated with concealment of T1D from colleagues and line manager. The theme "unwanted attention" was also found in the interviews. Giving special attention was seen as an overreaction to the risks related to the condition. On the other hand, some of the interviewees felt that the risks related to T1D could be underestimated, which could result in seeing a person with T1D as one who uses their condition for seeking unwarranted advantages. As far as we know, there are no previous studies reporting this kind of results.

In general, concealment of T1D from colleagues was associated with neglecting self-management of T1D at work. If a person conceals their T1D from a colleague, it is difficult to self-manage their condition effectively at work place. This may lead to keeping blood sugar levels higher than optimal to manage at work as found in a previous study from U.K [7]. We reported in our previously published study that work-related diabetes distress, such as worry and exhaustion in reconciling work with T1D, was strongly associated with keeping blood glucose level high at work [14]. In addition, it has been shown that young workers with T1D experience time pressure at their work and therefore they sometimes neglect or delay self-management activities at work [5]. As both concealment and time pressure among young workers with T1D hinder their self-management activities at work, special attention should be focused on supporting them for avoiding long-term complications and diminishing of work ability.

One of the often discussed reasons for concealing one´s T1D at the work place was fear of discrimination, which could restrict one´s career development and even lead to unemployment. This supports a previous qualitative study that also found those with T1D, who did not disclose their condition at work, gave the reason as fear of being discriminated against, which could harm their working career [9]. Our findings also relate to the finding of the study of Polish seafarers with T1D, who were not allowed to work at sea, and who concealed their condition from health care and from their colleagues and worked on seagoing vessels [22]. Another frequently mentioned reason for concealing one´s T1D was reluctance to appear as a weaker or inferior person than the others. This

kind of reluctance to give an impression of weakness has previously been obtained among adolescents, young adults and adults with T1D [9,23,24].

Both above-mentioned reasons for concealment, fear of discrimination and fear of being seen as weak, can be subsumed under the term "stigma". Social disadvantages of poor health are often described with the concept of stigma, i.e. disqualification of full social acceptance [25]. Health-related stigma may lead to anticipated or actual experience of stereotyping, exclusion, blame, and discrimination [26,27]. Although T1D is not necessarily considered a very stigmatizing condition by the general public, people with the condition nevertheless feel stigmatized by it [28,29]. In some societies, e.g. China, the stigma is especially high [11]. Additionally, a lack of adequate knowledge of T1D causes transposition between T1D and type 2 diabetes and a new type of stigmatization including the conception that the condition is self-inflicted [9,30].

Strengths and limitations

To our knowledge, this is the first study to investigate concealment of T1D at a national level. One of the strengths of the study was that 688 employed respondents with T1D participated in our study, allowing statistically reliable results.

Another strength of our study was the combination of quantitative and qualitative methods. This had several benefits. Carrying out the interviews after the first stage of analysis of the survey data made it possible to ask the interviewees to comment on the finding that a great proportion of people with T1D choose to conceal their condition in the work place. The interviews deepened the understanding of the reasons of concealment that had been asked in the survey and revealed new reasons that were not covered by the survey. Moreover, similar results obtained by different methods increased the validity of the findings.

A number of study limitations need to be considered. Firstly, this study was cross-sectional and therefore the interpretation of causality is not possible. Second, the response rate was only 49%. However, the respondents represented working-aged Finns with T1D as the sample was not biased in terms of demographic distributions.

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There was a small difference in the gender distribution between the respondents and non-respondents (proportion of women participating more than men). The distributions of the age groups and residential provinces were similar in both groups (dispersion about 2%). The final sample represented workers from different organizations and occupations (31). In recruiting for the qualitative interviews, more women volunteered than men and we had to stop data collection as we reached the end point for the recruitment period. This can be considered as a limitation, although women´s overrepresentation is usual in this kind of research (32). In the interviews, the interviewees did not necessarily report the reasons of their own concealment but their views on why other people choose to conceal their condition. The interviews were carried out only in one city, which can be considered as a limitation in our study. However, Kuopio is a middle sized city and located middle in Finland and the demographics of this city is similar to other cities in Finland. Moreover, all measures were self-reported; thus, recall bias may have influenced the results. In addition, our results might be extrapolated only to those Western countries, which have same kind of employment legislation and health care systems to Finland.

Conclusion

Concealment of T1D at work was common enough to warrant serious attention. On the basis of our findings it could be suggested that both overemphasis and underestimation of the consequences of T1D in the work place may lead to concealing and thus may be harmful to self-management and reconciling work and T1D. Both overemphasis and underestimation might be diminished by increasing up-to-date knowledge about the condition among the workmates and supervisors. However, the fear of discrimination is difficult to overcome if there is a real risk of losing opportunities because of illness.

Young workers were more likely than older ones to conceal their T1D in their work community. Concealing may be especially harmful for their health as they have a long working life ahead of them. Thus, special attention should be focused on supporting young workers with T1D.

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CONTRIBUTORSHIP STATEMENT

P.H., L.M., K.R., and V.H designed the study and planned the data collection. P.H. and F.M. researched the survey data, performed the statistical analyses, and wrote and edited the manuscript, P.H. and V.H. researched the interview data, performed the thematic analyses, and wrote and edited the manuscript, L.M. and K.R helped to interpret the results and edited the manuscript. All authors have read this manuscript, and the requirements for authorship have been met. V.H. is the guarantor of this work. She had full access survey and interview data in this study. She takes responsibility for the integrity of the data and the accuracy of the data analysis.

COMPETING OF INTERESTS

There were no potential conflicts of interest relevant to this article.

ETHICS

The Research Ethics Committee of the Northern Savo Hospital District reviewed and approved the research protocol (18//2010).

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DATA SHARING

The datasets generated during and/or analysed during the current study are not publicly available due to other ongoing research projects using the material but are available from the corresponding author on reasonable request.

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Table 1. Characteristics of the participants

	N=688
Gender (*n = 684*)	
Women	318 (46.5)
Men	366 (53.5)
Mean ± SD age, years (*n = 681*)	35.4 ± 12,2
Education (*n = 688*)	
Basic education (only high school or vocational course)	155 (22.5)
Vocational school	237 (34.4)
Technical or vocational college, or university of applied sciences	196 (28.5)
University	100 (14.5)
Last HbA$_{1c}$ level* (*n = 678*)	
≤60 mmol/mol (≤7.5%)	230 (33.9)
61–70 mmol/mol (7.6–8.5%)	233 (34.4)
71–80 mmol/mol (8.6–9.5%)	156 (23.0)
≥81 mmol/mol (≥9.6%)	59 (8.7)
Duration of diabetes (*n = 685*)	
0–5 years	165 (24.1)
6–10 years	221 (32.3)
11–15 years	266 (38.8)
≥16 years	33 (4.8)
Type of work (*n = 683*)	
Mental work	290 (42.5)
Physical work	171 (25.0)
Mental and physical work (equally)	222 (32.5)
Mean ± SD length of employment, years (*n = 652*)	8.5±9.5
Type 1 diabetes concealed	
From colleagues (*n = 683*)	203 (29.7)

From line manager (*n = 686*)	123 (17.9)

Data are *n (%)* except where indicated. Missing data were excluded.

*Self-reported.

Table 2. A logistic regression analysis of concealment of type 1 diabetes to colleagues or line manager during the respondent´s working career

	Colleagues (n=594)		Line manager (n=596)	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Age		0.019		0.004
18-24	3.77 (1.42-9.97)	0.008	4.23 (1.38-12.95)	0.011
25-34	3.65 (1.39-9.56)	0.008	2.68 (0.88-8.23)	0.084
35-44	3.23 (1.24-8.95)	0.017	1.79 (0.55-5.81)	0.332
45-54	1.78 (0.61-5.18)	0.288	1.23 (0.34-4.47)	0.754
55-64 (ref.)	1		1	
Non-disclosure to extended family				
Yes	5.24 (2.06-13.35)	0.001	4.41 (1.72-11.32)	0.002
No (ref.)	1		1	
Feeling an outsider at work				
Yes	2.47 (1.58-3.84)	<0.001	2.51 (1.52-4.14)	<0.001
No (ref.)	1		1	
Embarrassed by receiving special attention				
Yes	1.99 (1.33-2.96)	0.001	1.81 (1.13-2.91)	0.014
No (ref.)	1		1	
Neglected treatment of diabetes at work				
Yes	1.59 (1.01-2.48)	0.044	-	-
No (ref.)	1		-	-

Missing data were excluded.

Table 3. Four further logistic regression analyses of concealment of type 1 diabetes to colleagues or line manager during the respondent´s working career. For these additional analyses, respondents were split into age groups based on results of the first two logistic regression analyses models.

	Concealment from colleagues in the age group of 18-44 years (n=466) OR (95% CI)	p-value	Concealment from line manager in the age group of 18-24 years (n=154) OR (95% CI)	p-value
Embarrassed by receiving special attention				
Yes	2.23 (1.46-3.40)	<0.001	3.16 (1.52-6.60)	0.002
No (ref.)	1		1	
Feeling an outsider at work				
Yes	2.20 (1.36-3.55)	0.001	-	-
No (ref.)	1		-	-
	Concealment from colleagues in the age group of 45-64 years (n=128) OR (95% CI)		Concealment from line manager in the age group of 25-64 years (n=442) OR (95% CI)	
Duration of diabetes				
0-10 years	3.79 (1.22-11.83)	0.022	-	-
>10 years (ref.)	1		-	-
Feeling an outsider at work				
Yes	8.84 (2.71-28.91)	<0.001	4.16 (2.35-7.38)	<0.001
No (ref.)	1		1	
Non-disclosure to extended family				
Yes	42.27 (6.26-285.51)	<0.001	3.82 (1.40-10.42)	0.009
No (ref.)	1			

Missing data were excluded.

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (p. 1 and 2)
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found (p. 2)
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported (p. 4)
Objectives	3	State specific objectives, including any prespecified hypotheses (p. 4)
Methods		
Study design	4	Present key elements of study design early in the paper (p. 4-5)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection (p. 5-7)
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants (p. 5 and 6-7)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (p. 5-6)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group (p. 5-6)
Bias	9	Describe any efforts to address potential sources of bias (p. 5)
Study size	10	Explain how the study size was arrived at (p. 5)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why (p. 6)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (p. 6)
		(*b*) Describe any methods used to examine subgroups and interactions (p. 6)
		(*c*) Explain how missing data were addressed (p. 20-23)
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (p. 4-6 and 8-9)
		(b) Give reasons for non-participation at each stage (p. 5-6)
		(c) Consider use of a flow diagram (not applicable)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (p. 6, 8, 20)
		(b) Indicate number of participants with missing data for each variable of interest (p. 20-23)
Outcome data	15*	Report numbers of outcome events or summary measures (p. 8-9)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (p. 5-6, 8-9 and 22-23)
		(*b*) Report category boundaries when continuous variables were categorized (p. 5-6)

		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (p. 8-9 and 23)

Discussion

Key results	18	Summarise key results with reference to study objectives (11-14)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias (p. 14)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence (p. 14)
Generalisability	21	Discuss the generalisability (external validity) of the study results (p. 14)

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based (p. 16)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.