

Diabetes-related stigma affects the quality of life of people living with diabetes mellitus in Switzerland: implications for healthcare providers

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What is known about this topic

- Recent studies reported that persons living with diabetes (PWD) experience stigma (discrimination and stereotypes) due to their health condition.
- Surveys suggest that PWD affected by discrimination report lower scores of well-being, experience higher levels of distress and score lower in quality of life.

What this paper adds

- This study establishes experienced and perceived stigma of PWD living in Switzerland and thus, provides an insight into the situations in which PWD feel discriminated against and the perceived stereotypes.
- Findings suggests that stigma impacts the quality of life of those PWD affected – mediated by psychological distress and depressive symptoms.
- The paper gives insight into the important role of perceived stigma in this dynamic.

Introduction

A recent powerful statement published first in *Diabetes Voice* – the International Diabetes Federation's journal – highlights from a global perspective in frank

Abstract

There is a growing body of scientific evidence that stigma represents a reality for many people living with diabetes (PWD). However, little is known about the impact of experienced stigma. Against this background, the present study aimed to establish, by means of an in-depth consideration of the situation in Switzerland, whether and how experienced and perceived stigma impact the quality of life of those PWD affected. In this cross-sectional study, an anonymous paper-and-pencil self-administered questionnaire (SAQ) was used for data collection. The SAQ drew on a qualitative elicitation study and was distributed in 2013 to the readers of a Swiss journal destined to people living with diabetes. Data were analysed using descriptive statistics and structural equation modelling. The sample included 3347 people (response rate of 16%) with type 1 and 2 diabetes, aged 16–96. Respondents who reported higher levels of perceived stigma reported higher levels of psychological distress ($\beta = 0.37$), more pronounced depressive symptoms ($\beta = 0.33$) and less social support ($\beta = -0.22$). Higher psychological distress ($\beta = -0.29$) and more pronounced depressive symptoms ($\beta = -0.28$), in turn, predicted lower quality of life. Findings suggest that stigma should be considered as an additional predictor of quality of life in PWD. Therefore, healthcare providers should support PWD's fight against stigma. Especially, social workers are called to engage in advocacy to reduce discrimination against PWD and claim equal chances for them. They are also called to develop and implement interventions to correct stereotypes about PWD.

Keywords: diabetes, discrimination, quality of life, stereotypes, stigma

and unadorned words that 'the violation of human and social rights of people with diabetes is widespread' (Benedetti 2014, p. 338). These violations range from the most basic right to survival to stigma and discrimination in various contexts of everyday

life. In the perception of the dedicated advocate, these discriminations are 'still broadly diffused' (Benedetti 2014, p. 339) and, what seems worse to him, stigma is passively accepted and even 'not fully perceived' by a significant number of people living with diabetes.

According to Goffman, stigma is a personal attribute or mark that has a discrediting effect and leads to its bearer being treated differently (Goffman 1975). This fundamental dynamic is also central to the latest theoretical conceptualisations of stigma. Link and Phelan conceive stigma as the result of a process involving five interrelated components: First, human beings identify and 'label' human differences. Which differences are selected, considered relevant and labelled are the results from a social selection and definition process. Second, the labelled differences are linked with stereotypes, leading to the attribution of negative, undesirable characteristics to the labelled individual. Third, the linking of negative attributes to individuals or groups facilitates the (discursive) separation between stigma bearers ('them') and the 'normal' majority ('us'). Fourth, the bearers are discriminated and lose their social status. The fifth and last component involves the exercising of power: failing the corresponding resources and influence, the above process has no consequences (Link & Phelan 2001, 2006). For those stigmatised, these dynamics result in stereotypical attributions, accusations, unjustified unequal treatment, rejection, exclusion and/or status loss (Browne *et al.* 2013).

Stigma can be viewed and studied from different perspectives. This results in various concepts. In the present study, 'perceived stigma' means the perception of stereotypes linked with labelling. 'Experienced stigma' – also referred to in literature as 'enacted stigma' (Bunn *et al.* 2007) – means the discrimination and exclusion experienced by those affected (see, e.g. Alonso *et al.* 2008). 'Discrimination' signifies the unequal treatment – yet above all the disadvantaging, ignoring or exclusion – of a person on account of personal characteristics revealing their affiliation with a certain group but bearing no factual relevance. Thus, discrimination exists when unequal treatment occurs despite a comparable set of facts. Discrimination also exists, however, if equal treatment occurs despite a non-comparable set of facts (Pärli 2009).

In recent theoretical models, 'stigma' and 'discrimination' are closely interrelated. Discrimination is seen as the endpoint, that is, as the visible manifestation of stigma processes (Link & Phelan 2001, Pescosolido *et al.* 2008).

To date, experiences of stigma and discrimination of people living with diabetes (PWD) have rarely

been studied. Diabetes was long considered a health condition entailing no stigma (Schabert *et al.* 2013). In recent years, eventually, this perception has been revised. In part, this is due to studies that reported PWD's experiences of unjustified unequal treatment in the labour market already many years ago. Studies on this aspect – the only one to have been investigated in more detail so far – clearly suggest that due to their condition PWD experience instances of not being employed, losing their job, not being promoted, not being granted a pay rise, or experiencing difficulties with insurances (Songer *et al.* 1989, Robinson *et al.* 1990, Griffith & Moses 1993, Petrides *et al.* 1995, Tak-Ying Shiu *et al.* 2003) – also in Switzerland (Nebiker-Pedrotti *et al.* 2009). Furthermore, qualitative studies published in recent years indicated that PWD experience unjustified unequal treatment and exclusion due to their diabetes also in other contexts of their lives: They show that PWD experienced being avoided or excluded and having to provide a medical certificate when renewing their driver's license (Broom & Whittaker 2004). Other experiences include travel restrictions, broken friendships and restrictions against becoming an adoptive parent (Browne *et al.* 2013).

PWD indicated negative attributions. Thus, type 2 PWD reported being perceived as 'weak' (Tak-Ying Shiu *et al.* 2003) 'fat', 'lazy', or 'slothful', or as 'overeaters' or 'gluttons'. Other stereotypes depicted PWD as 'poor people', as 'not terribly intelligent', or as 'bad persons' (Browne *et al.* 2013). PWD, moreover, are blamed for their health condition. Such accusations are perceived by type 2 diabetics, but are also documented for people living with type 1 diabetes (Vishwanath 2014). Furthermore, PWD injecting insulin have experienced being mistaken for drug users (Tak-Ying Shiu *et al.* 2003).

Given the scarce knowledge (Schabert *et al.* 2013), further research is required in order to reduce the gap between the awareness of activists and the contribution social science is able to make. Scholars call for studies that investigate in depth and from the perspective of those affected the contexts of life where stigma and discrimination take place (Browne *et al.* 2013, Benedetti 2014). As the extant research has disregarded stigma and discrimination, the investigation of the consequences of these experiences failed to take place. However, drawing on data from 17 countries, the recent Diabetes Attitudes Wishes and Needs 2 (DAWN2) study (Peyrot *et al.* 2013) is able to provide first insights: 19.2% of the surveyed PWD reported being discriminated against due to their diabetes. The respondents affected by discrimination reached lower scores in psychological well-being, reported higher

levels of psychological distress and scored lower in quality of life. Furthermore, they reported a negative impact on several aspects of their lives including their financial situation; relationship with family, friends and peers; leisure activities; and work or studies (Wens *et al.* 2013). The interrelations contoured in these findings require extensive research. Consequences of stigma should be investigated in detail and considering the complexity at stake. Notably, the interrelation of stigma and quality of life should be explored and modelled.

The variation in experienced stigma by PWD across countries reported by the DAWN2 study point to the need of refined analyses also with regard to different local contexts. This need for investigation is even more accentuated in countries that were not included in the DAWN2 study and do not even have basic data available. Among them is Switzerland, where epidemiological data are scarce. As Switzerland has no disease-specific registers, even exact information about the prevalence of diabetes is not available. According to the most recent approximation, in the year 2011 overall prevalence in the adult population was 4.9% (4.2% in women; 5.7% in men) (Huber *et al.* 2014) compared with 6–7% in Europe (International Diabetes Federation, European Region, & Diabetes Foundation of Ireland 2004). The Swiss Diabetes Association assumes that there were 500,000 PWD in Switzerland, among them 40,000 type 1 diabetics (Swiss Diabetes Association, 2014).

Nonetheless, there are first findings regarding experiences of stigma and discrimination of PWD in Switzerland that illustrate perceived and experienced stigma in an array of contexts (Raemy & Gredig 2013) reaching far beyond the context of labour market and work-related insurances (Nebiker-Pedrotti *et al.* 2009). The investigation of the impact of stigma and discrimination and a tentative model of the complexity in question can draw from these results as well as from the well-corroborated findings on the impact of stigma related to other health conditions such as HIV/AIDS or mental health disorders (see, e.g. Berger *et al.* 2001, Corrigan & Watson 2002, Bunn *et al.* 2007, Mak *et al.* 2007, Stuber *et al.* 2008).

Against this background, the present research study aimed to establish, considering in depth the current situation in Switzerland, whether experienced and perceived stigma impacts the quality of life of those affected.

It was hypothesised that experienced and perceived stigma would impact the quality of life of PWD. It was further hypothesised that low self-esteem, psychological distress, depression and a perceived lack of social support would be mediating

factors – as visualised in Figure 1. In detail, this included the assumptions that (i) respondents who report higher levels of experienced and perceived stigma would report lower self-esteem, higher levels of psychological distress, more pronounced depressive symptoms and less perceived social support; and (ii) respondents who report lower self-esteem, higher levels of psychological distress, more pronounced depressive symptoms and less perceived social support would also indicate a lower global quality of life.

Methods

Design and data collection

The present study combined methods of qualitative and quantitative social research and followed a sequential explorative design (Creswell 2009, p. 206ff). The initial, qualitative study established – *inter alia* – the contexts of discrimination and the stereotypes perceived by PWD. For this purpose, problem-centred interviews (Witzel 1985) were conducted using a maximum variation sample (Patton 2002) involving 30 women and men with types 1 and 2 diabetes, aged 20–76, living in German- or French-speaking Switzerland, and having differing educational levels. Interview data were analysed using theoretical coding (Strauss & Corbin 1996). Among other things, data analysis allowed establishing 33 specific situations in which PWD had experienced stigma at least once in their life, such as, for example, being denied access to their envisaged professional training, being denied life insurance or being removed from an executive position. It also permitted attributing these situations to seven specific contexts: education, employment, military service, mobility, taxation, insurance, leisure activities and social contacts. Data also provided insight into the perceived stigma as respondents delivered accounts on the stereotypical attributions they have become aware of at least once in their life, such as, for example, being seen as weak-willed, lazy, or having an impaired work performance (for full report of the findings of the qualitative study see: Raemy *et al.* 2012).

The data further provided a basis for compiling a list of stereotypical attributions perceived by respondents.

The quantitative study presented below was designed as a cross-sectional analysis among PWD in Switzerland. Based on the results of the qualitative study, it used the insights gained on experienced and perceived stigma among PWD to develop tools for standardised data collection. Data were gathered

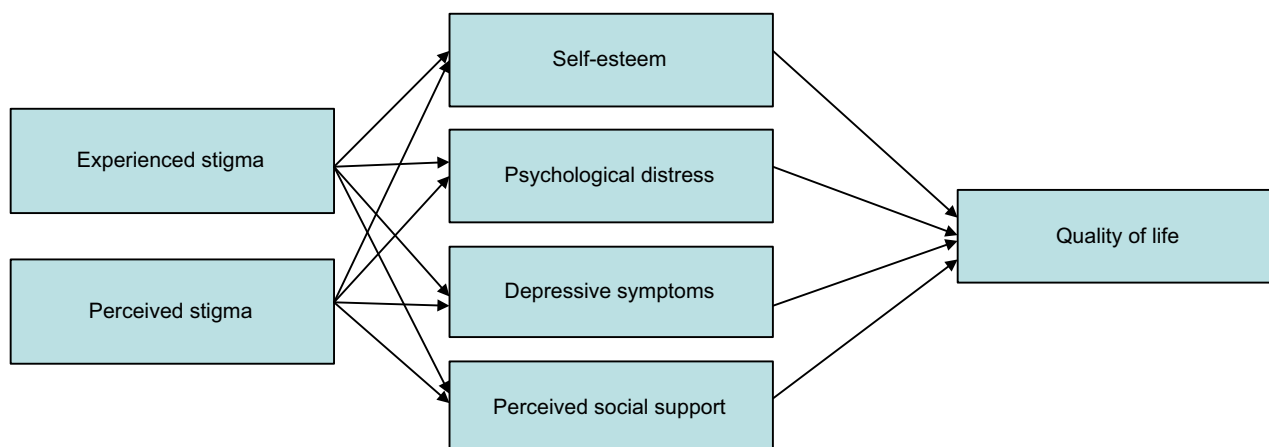


Figure 1 Model of the hypotheses on the impact of experienced and perceived stigma and quality of life.

using an anonymous, self-administered paper-and-pencil questionnaire.

Operationalisation, measures and the construction of the questionnaire

Independent variables

To survey PWD's experiences of stigma, two series of formative single-item indicators were elaborated (Diamantopoulos & Siguaw 2006). The first series of indicators served to capture experienced stigma. It determined situations in which PWD had experienced unjustified unequal treatment, disadvantage or exclusion due to their health condition. For each situation known from the preliminary qualitative study, an item was developed. This series encompasses 33 items. It is formulated so that each question takes the form of the first part of a sentence, which is then meaningfully complemented by each of the items to form a complete interrogative sentence. For instance, the question 'Have you ever experienced...' was followed by the item '...that your superiors removed you from an executive position due to your diabetes?' Four response categories were provided: 'Yes', 'No', 'Doesn't apply because I never held an executive position' and 'Doesn't apply because I didn't have diabetes at the time'.

The second series of indicators served to capture the perceived stigma, that is, the stereotypical attributions perceived by PWD. This series encompasses 26 items. Here, too, the question is introduced by the first part of sentence, which is then complemented by each of the items to create a complete question. For instance, the question 'Have you in the past felt that...' was followed by the item '...people think

that diabetics have themselves to blame for their illness?' The response categories were 'yes' and 'no'.

To verify whether this instrument could validly capture experiences, the interview partners of the qualitative study were asked to answer the questions of both indexes. Their responses were then compared with the views expressed in their interviews. Comparison revealed that the constructed instruments reflected both the experiences and the perception of PWD.

The indexes were constructed to survey the situations and contexts in which the respondents experienced unequal treatment (lifetime prevalence). The instruments, however, deliberately did not survey the frequency with which the experience of a certain situation repeats itself. Situations vary significantly, with some occurring daily, while others are once-in-a-lifetime events. One-time experiences, however, may be just as crucial for a person's way of life, may weigh more heavily as regards equal opportunities, and may have a far greater formative influence (on a career choice, for instance) than daily experiences that, although inappropriate and impairing, may have no far-reaching consequences (for instance, interfering with one's eating habits). Given the current state of research, it seems more important to capture situations and contexts of unequal treatment than the frequency with which they are experienced. Capturing all factors would have significantly increased the complexity of the instrument.

Intermediate and dependent variables

In order to measure self-esteem, psychological distress related to diabetes, depressive symptoms, and the perceived social support as well as the quality of life, we used instruments that have proved valid in

former studies and – if ever possible – offered a German and/or French version. The overview of the measures used is provided in Table 1. In the tested model, the global aspect of quality of the WHOQOL-BREF was considered.

The questionnaire also gathered information on the type of diabetes, the respondent's age at the time of diagnosis and various socio-demographic features (age, gender, education level, occupation, professional status, marital status, type of household, city size and nationality).

The questionnaire was structured so that the indicators of experienced and perceived stigma featured in third and fourth place and thus appeared in the area where respondents could be expected to be most focused (Költringer 1993, Scherpenzeel & Saris 1997).

Two identical versions of the questionnaire (German and French) were prepared. The original version was in German. In order to obtain an equivalent French version, the original German questionnaire was translated into French, with the outcome being verified using a back-translation procedure.

The same layout was used for both versions and aligned with a data-input software. Each page was marked to enable secure data scanning.

Finally, a pre-test involving a sample of 220 members of the Swiss Diabetes Association was used to verify the comprehensibility and usability of the questionnaire.

Data entry and analytic strategy

Questionnaires were scanned individually and stored as image files. The files (with the exception of the comment field, which partly contained personal details identifying the respondent) were recorded by Electronic Paper, a specialised company, using TELE-Form OCR software and saved as Microsoft Excel files. Data were imported into IBM SPSS Statistics 22.

First, the variables included in the model were analysed using descriptive statistics. Second, the correlations of these variables with diabetes-related and socio-demographic variables were determined using bivariate and multivariate analyses. Third, the hypothesised causal paths were analysed using structural equation modelling. Thereby, the variables mentioned in the model were included along with diabetes-related and socio-demographic variables that were correlated with them (diabetes type, gender, age, time spent living with diabetes and area in which respondents lived). All variables were entered into the equation at once. For the analysis, the independent variables were entered as metric continuous variables expressing the number of situations or stereotypes PWD reported ranging from 0 to 33 or 26 respectively; variables that were measured on a nominal level were transformed into dummy variables with the values 0 and 1. The variable labels displayed in the tables and graphs relate to the value 1 (e.g. the

Table 1 Overview of the measures for the intermediate and dependent variables in the model and their internal consistency

| Intermediate variables Measure | N items | Response scale | Range | Cronbach's alpha | Source |
|---|---------|----------------------|-------|---------------------|--|
| Self-esteem Rosenberg's self-esteem scale (SES) | 10 | 4-point Likert scale | 10–40 | 0.84 | Deutsch and Gäbler (2006) Rosenberg (1965) |
| Psychological distress Problem Areas in Diabetes scale (PAID) | 20 | 5-point Likert scale | 0–80 | 0.95 | Bundesärztekammer, Kassenärztliche Bundesvereinigung, & Arbeitsgemeinschaften der Wissenschaftlichen Medizinischen Fachgesellschaften (2012) |
| Depressive symptoms Patient Health Questionnaire (PHQ-9) | 9 | 4-point Likert scale | 0–27 | 0.85 | Löwe <i>et al.</i> (2002) |
| Perceived social support Fragebogen zur Sozialen Unterstützung (F-SozU) | 14 | 5-point Likert scale | 14–70 | 0.94 | Fydrich <i>et al.</i> (2009) |
| Dependent variable Quality of life WHOQOL-BREF | 24 | 5-point Likert scale | 0–100 | | Angermeyer <i>et al.</i> (2000) |
| Global | 2 | | | – | |
| Domain physical health | 7 | | | 0.82 | |
| Psychological domain | 6 | | | 0.82 | |
| Domain social relationships | 3 | | | 0.68 | |
| Domain environment | 8 | | | 0.83 | |

value of the variable 'gender' was 0 for male and 1 for female. In consequence, in the results the variable is labelled 'female gender').

Structural equation modelling was performed using AMOS. Analysis was performed by means of the asymptotically distribution-free method, which allows including variables without normal distribution. As structural equation modelling requires complete data sets and given that 12 variables were entered into the model, missing data could have entailed the exclusion of a number of participants and a potential bias. In order to avoid exclusions, multiple imputation as suggested by Lüdtke *et al.* (2007) was performed.

The description and interpretation for the results assume – based on Cohen (1992) and newer thoughts by Durlak (2009) – that in this context, a standardised regression coefficient of ≥ 0.2 in size is to be considered as weak, ≥ 0.3 as moderate and ≥ 0.50 as strong. Standardised regression coefficients < 0.2 are considered to be negligible and were dropped from the final model.

Sampling

As mentioned above, to date there is no national register for diabetics living in Switzerland. Neither the total number of PWD living in this country nor their characteristics have been described. Given this situation, random sampling is virtually ineffective and a quota sample impossible. Hence, a convenience sample of PWD living in German- or French-speaking Switzerland was used.

To reach the largest possible number of PWD in various life situations as directly as possible – that is, independently of third parties or intermediaries (healthcare providers, counsellors, etc.) – private individuals subscribing to the magazine *d-journal* (in German) and *d-journal romand* (in French) were contacted. These magazines are the only diabetes-specific magazines available in Switzerland. They are published by the Swiss Diabetes Association and available to the general public. At the time of the survey (2013), the journals had 25,398 subscribers, of which 21,154 were private individuals. The latter included all members of the Swiss Diabetes Association, PWD as well as people who are not affected, and interested members of the general public. The questionnaire and the pre-addressed, postage-paid response envelopes were sent out with the October 2013 German and French issues of the journal. The questionnaire included information about the study, a confirmation of anonymity, the affirmation that participation was voluntary and instructions. The

questionnaire also included the participant's declaration that they agreed on the inclusion of their data in the study. In accordance with national legislation in force at the time, an ethics approval was not needed.

Results

Respondents

Due to the chosen form of contact, neither reminders nor repeat delivery of the documents was possible. A total of 3401 questionnaires were returned, corresponding to a response rate of roughly 16%, as expected under these circumstances (Diekmann 1995). The study included data of 3347 PWD. Data from participants with less than 16 years of age and questionnaires filled in by proxies were excluded. The analyses include 1479 (45.2%) women and 1791 (54.8%) men. Among those disclosing their diagnosis, 1352 (42.3%) had type 1 and 1841 (57.7%) had type 2 diabetes. The respondents were aged 16–96. The mean age was 64.4 years and the median was 67. The median age at the time of diagnosis was 45 years. The time respondents had lived with (diagnosed) diabetes ranges from less than a full year to 76 years. On average, respondents had lived with diabetes for 21 years. The median lifetime with diabetes was 19 years. Table 2 displays the description of the sample in terms of the key diabetes-related and socio-demographic features of the survey participants.

Experienced and perceived stigma

The respondents reported experienced stigma in all situations listed in the questionnaire. The most frequently reported incidents referred to unequal treatment in the context of taxation (denied deduction for medical expenses), military service (declared unfit for service) and insurances (denied life insurance; denied supplementary health insurance). The full overview of situations in which interviewees encountered discrimination is provided in Table 3. Respondents also reported having heard every stereotype against diabetics listed in the questionnaire. Among the most frequently perceived were those that diabetics were old and overweight, have a terrible disease or have themselves to blame for their illness. An overview of the perceived stigma respondents encountered is provided in Table 4.

Bivariate analyses show that experienced stigma was significantly associated with diabetes type, gender, age and the lifetime spent with diabetes. Perceived stigma was associated with gender, age and lifetime spent with diabetes. None of the other socio-

Table 2 Diabetes-related and socio-demographic characteristics of participants (*N* = 3347)

| Variable | Descriptor | <i>N</i> | % | <i>N</i> |
|----------------------------|---|----------|------|----------|
| Gender | Female | 1479 | 45.2 | 3270 |
| | Male | 1791 | 54.8 | |
| Diabetes type | Type 1 | 1352 | 42.3 | 3193 |
| | Type 2 | 1841 | 57.7 | |
| Age | 16–25 years | 108 | 3.4 | 3159 |
| | 26–35 years | 144 | 4.6 | |
| | 36–45 years | 218 | 6.9 | |
| | 46–55 years | 448 | 14.2 | |
| | 56–66 years | 646 | 20.4 | |
| | 67–75 years | 934 | 29.6 | |
| | 76–85 years | 573 | 18.1 | |
| | >85 years | 88 | 2.8 | |
| Level of formal education | No school-leaving certificate | 10 | 0.4 | 3265 |
| | Primary school | 145 | 4.4 | |
| | Compulsory education | 305 | 9.3 | |
| | Grammar school, high school, vocational baccalaureate college | 154 | 4.7 | |
| | Teacher training college | 110 | 3.4 | |
| | Apprenticeship, college of trade and industry (full time) | 1299 | 39.8 | |
| | Advanced professional training | 571 | 17.5 | |
| | Higher professional college | 243 | 7.4 | |
| | University/university of applied sciences | 428 | 13.1 | |
| | University studies | 57 | 1.5 | |
| Employment situation* | Unemployed | 50 | 1.3 | 3913 |
| | Retired | 1701 | 43.5 | |
| | Unable to work | 158 | 4.0 | |
| | Performing housework | 685 | 17.5 | |
| | Director | 169 | 12.2 | |
| | Executive or senior management | 339 | 24.5 | |
| | No executive or senior role | 873 | 63.2 | |
| Marital status | Unmarried | 518 | 16.0 | 3239 |
| | Married | 1924 | 59.4 | |
| Type of household/housing* | Registered partnership | 54 | 1.7 | 3636 |
| | Widowed, divorced, separated | 743 | 22.9 | |
| | Single | 812 | 22.3 | |
| | With partner | 2188 | 60.2 | |
| | With children | 467 | 12.8 | |
| Area | With relatives | 124 | 3.4 | 3347 |
| | In an institution | 45 | 1.3 | |
| | German-speaking Switzerland | 2487 | 74.3 | |
| Nationality | French-speaking Switzerland | 860 | 25.7 | 3282 |
| | Swiss | 3128 | 95.3 | |
| | Other | 154 | 4.7 | |

*Multiple answers possible.

demographic variables were significantly associated with experienced or perceived stigma.

Description of the variables in the model

Experienced stigma

Respondents reported their experience with unjustified unequal treatment due to diabetes in all of the situations captured in various degrees. Roughly one-

third of respondents (31.5%) said they had never experienced any form of discrimination mentioned on the questionnaire. However, 68.5% reported having been discriminated due to their health condition.

The number of situations in which respondents had experienced diabetes-related discrimination allows for an estimation as to whether the experiences of the affected PWD are restricted to one situation in one context or expand over more than one

Table 3 Overview of situations and contexts in which people living with diabetes have experienced unjustified unequal treatment or exclusion and proportions of respondents reporting the respective experience

| Context* | N [†] | n [‡] | % [§] |
|--|----------------|----------------|----------------|
| Leisure activities and social contacts | | | |
| Unjustified unequal treatment by friends and acquaintances | 3139 | 379 | 12.1 |
| Having to constantly justify oneself when eating out with friends | 3144 | 767 | 24.4 |
| Prevented from practising one's preferred sport | 2453 | 385 | 15.7 |
| Denied access to bars, clubs, restaurants, etc. | 2886 | 32 | 1.1 |
| School | | | |
| Exclusion from school trips and excursions | 1430 | 103 | 7.2 |
| Workplace | | | |
| Forsaking a career goal against one's will | 1956 | 221 | 11.3 |
| Denied access to one's envisaged professional training | 1851 | 161 | 8.7 |
| Rejected as a job applicant | 2090 | 167 | 8.0 |
| Removed from an executive position | 1773 | 67 | 3.8 |
| Removed from an executive position due to hypoglycaemia | 1798 | 41 | 2.3 |
| Recommended to have particular working hours | 2476 | 91 | 3.7 |
| Relieved of interesting professional duties and responsibilities | 2492 | 106 | 4.3 |
| Declined promotion | 2463 | 87 | 3.5 |
| Work colleagues showing fear and restraint | 2584 | 369 | 14.3 |
| Work colleagues interfering with eating habits | 2602 | 482 | 18.5 |
| Prompted to give notice | 2460 | 81 | 3.3 |
| Termination of employment | 2481 | 65 | 2.6 |
| Termination of employment and advised to apply for incapacity benefit | 2481 | 74 | 3.0 |
| Prompted to seek early retirement | 2478 | 118 | 4.8 |
| Military service | | | |
| Declared unfit for military service at recruitment | 753 | 252 | 33.5 |
| Declared unfit for civil defence service at recruitment | 800 | 106 | 13.3 |
| Discharged from the military | 819 | 197 | 24.1 |
| Required to pay military service exemption tax despite willingness to do military service | 885 | 272 | 30.7 |
| Required to pay military service exemption tax despite willingness to do civil defence service | 911 | 210 | 23.1 |
| Mobility | | | |
| Special treatment at airport security checks | 2488 | 578 | 23.2 |
| Required to provide a medical certificate to retain a driver's license | 2456 | 327 | 13.3 |
| Tax | | | |
| Denied deduction of medical expenses by tax authorities | 2865 | 1090 | 38.0 |
| Insurance | | | |
| Denied life insurance | 1576 | 451 | 28.6 |
| Denied loss-of-income insurance | 1529 | 190 | 12.4 |
| Denied per diem (daily benefits) insurance | 1687 | 223 | 13.2 |
| Denied supplementary health insurance | 1927 | 509 | 26.4 |
| Termination of supplementary health insurance | 2472 | 70 | 2.8 |
| Pension fund imposed benefits provision | 2216 | 258 | 11.6 |

*Multiple answers.

[†]Number of respondents in the respective situation/position while having diabetes.[‡]Respondents reporting such an experience.[§]Proportion of respondents with the respective experience.

(expansion of stigma). An analysis of the expansion shows: 21.4% of respondents reported experiencing one, 12.3% two such situations. The remaining respondents mentioned experiences in several situations. Among those who had experienced unjustified unequal treatment ($n = 2245$), the median experience was three situations.

Perceived stigma

Respondents' reports of perceived stereotypical attributions linked with the label 'diabetic' confirmed all of the stereotypes offered in the questionnaire. Only 15.6% of respondents ($n = 516$) reported not perceiving any of the mentioned attributions. The number of perceived stereotypes allows capturing the density of

Table 4 Overview of stereotypical attributions to people living with diabetes respondents have perceived and frequencies of reports

| Item* | N [†] | n [‡] | % [§] |
|---|----------------|----------------|----------------|
| <i>I have in the past felt that ...</i> | | | |
| ... people think that people with diabetes are 'poor souls' | 3234 | 1227 | 37.9 |
| ... people think that people with diabetes deserve pity | 3222 | 1216 | 37.7 |
| ... people think that diabetics have a terrible disease | 3206 | 1370 | 42.7 |
| ... friends or acquaintances think that people with diabetes need special attention | 3190 | 1119 | 35.1 |
| ... people think that diabetics use their illness as a pretext to gain some kind of benefit | 3208 | 402 | 12.5 |
| ... people think that people with diabetes are simulating or feigning their illness | 3219 | 360 | 11.2 |
| ... people think that people with diabetes are often off-sick due to their illness | 3184 | 641 | 20.1 |
| ... people think that diabetes impairs the (work) performance of diabetics | 3196 | 1289 | 40.3 |
| ... people think that people with diabetes are unable to cope with a heavy workload | 3180 | 1002 | 31.5 |
| ... people think that people with diabetes damage their organisation's/company's image | 3128 | 120 | 3.8 |
| ... people think that people with diabetes are invalids | 3180 | 357 | 11.2 |
| ... people think that people with diabetes have a deficit | 3160 | 721 | 22.8 |
| ... people think that people with diabetes are disabled | 3171 | 574 | 18.1 |
| ... people think that people with diabetes are a risk factor | 3167 | 1208 | 38.1 |
| ... people think that diabetics and their health costs are a burden for the taxpayer | 3188 | 903 | 28.3 |
| ... people think that people with diabetes are 'rare birds' | 3170 | 264 | 8.3 |
| ... friends and acquaintances think that diabetics are not one of them | 3185 | 124 | 3.9 |
| ... people mistakenly believe that diabetics are junkies | 3157 | 475 | 15 |
| ... people give diabetics injecting insulin in public strange looks | 3127 | 1726 | 55.2 |
| ... people think that diabetics are worth less than non-sufferers | 3172 | 333 | 10.5 |
| ... people think that diabetics are lazy | 3172 | 280 | 8.8 |
| ... people think that diabetics are old and overweight | 3191 | 1526 | 47.8 |
| ... people think that diabetics are gluttons | 3174 | 717 | 22.5 |
| ... people think that diabetics are weak-willed | 3189 | 544 | 17.1 |
| ... people think that diabetics have themselves to blame for their illness | 3192 | 1260 | 39.5 |
| ... people with diabetes are perceived solely as diabetes sufferers | 3172 | 875 | 27.6 |

*Multiple answers.

†Number of respondents.

‡Respondents reporting such a perception.

§Proportion of respondents reporting such a perception.

perceived stigma. The number of perceived stereotypical attributions varies widely. A considerable array was evident, ranging from the perception of one attribution to 26 attributions. The median number of perceived stereotypes was three.

Quality of life

The average score reached by the respondents on the general aspect of their quality of life was 71.95 (theoretical maximum being 100). The median and mode were 75. In total, 43.7% of the respondents reached a score of 75. About 24.0% of the respondents scored higher, and 10.4% scored the maximum. Of the respondents, 17.6% scored below 50. Bivariate analyses show that the quality of life score was associated with diabetes type, gender and area (German-/French-speaking). None of the other socio-demographic variables were significantly associated with the quality of life score.

The description of the other variables included in the model is displayed in Table 5.

The impact of experienced and perceived stigma on the quality of life

The analysis shows that perceived stigma predicts psychological distress ($\beta = 0.37$), depressive symptoms ($\beta = 0.33$), and perceived social support ($\beta = -0.22$). The coefficient for self-esteem was below the cut-off of 0.20. Also, none of the coefficients for experienced stigma were above the cut-off (the largest was 0.17 for the prediction of psychological distress). In other words, analysis evidences that the intermediate variables are significantly determined by perceived stigma. Notwithstanding, perceived and experienced stigma are strongly correlated ($r = 0.53$). However, self-esteem, psychological distress, depressive symptoms and the perceived social support had strong correlations.

Quality of life, in turn, is predicted by the level of psychological distress ($\beta = -0.29$) and the severity of depressive symptoms ($\beta = -0.28$). However, it turns out that quality of life is not determined by self-

Table 5 Description of the variables self-esteem, psychological distress, depressive symptoms, perceived social support and quality of life

| Variable | <i>n</i> | Scale | Min./max. | Range | Mode | Mean | SD | Median |
|---------------------------------------|----------|-------|-----------|-------|------|------|------|--------|
| Self-esteem (SES) | 3347 | 1–40 | 1/40 | 39.0 | 35 | 32.3 | 5.5 | 33.0 |
| Psychological distress (PAID) | 3347 | 0–100 | 0/97.5 | 97.5 | 5 | 21.4 | 17.1 | 17.5 |
| Depressive symptoms (PHQ-9) | 3347 | 0–27 | 0/27 | 27.0 | 0 | 4.8 | 4.2 | 4.0 |
| Perceived social support (F-SozU) | 3347 | 1–5 | 1/5 | 4.0 | 5 | 4.0 | 0.8 | 4.1 |
| Quality of life, global (WHOQOL-BREF) | 3347 | 0–100 | 0/100 | 100.0 | 75 | 71.8 | 17.4 | 75.0 |

esteem ($\beta = 0.09$) or perceived social support ($\beta = 0.10$) (see Table 6 and Figure 2). Both were highly significant, but this was due to the large sample size.

The model further considered the diabetes-related and socio-demographic variables which were correlated with the variables in the model (experienced stigma, perceived stigma, self-esteem, psychological distress, perceived social support and quality of life) on a bivariate level. Analysis evidences that experienced stigma is dependent on the respondents' age ($\beta = -0.40$) and the time spent living with diabetes ($\beta = 0.33$). The younger the respondents are, the larger is the array of situations and contexts in which they had experienced unjustified unequal treatment and exclusion. And the longer respondents had been living with diabetes, the larger the expansion of experienced stigma. The density of perceived stigma also proves to be dependent on the respondents' age ($\beta = -0.32$): the younger the respondents, the higher the number of stereotypes they had perceived. Age was also a predictor of the perceived social support: The older, the lower the perceived social support. Finally, the respondents' age correlated strongly with type 2 diabetes ($r = 0.55$). However, none of the other diabetes-related and socio-demographic variables turned out to impact the variables in the model (see Table 6).

Discussion

As the modelling in the present study reveals, stigma is a predictor of the quality of life of PWD: The path leads from perceived stigma to the level of psychological distress and the severity of depressive symptoms to the general quality of life.

However, two related hypotheses were not fully confirmed. The first hypothesis is refuted in the aspect that the experienced stigma did not prove to be a predictor of the intermediate variables of quality of life. The path departs solely from the perceived stigma. However, perceived and experienced stigma are highly correlated.

The second hypothesis was only partially confirmed: General quality of life is predicted by the level of psychological distress and the severity of depressive symptoms. However, it is not determined (in noteworthy strength) by self-esteem or the perceived social support. These variables are strongly correlated with psychological distress and depressive symptoms and seem, if so, to influence the quality of life in a rather indirect way, namely mediated through the two confirmed predictors (see Table 6).

These findings may be interpreted as evidence that perceived stigma has a negative impact on the general quality of life independent of a tangible experience of discrimination in a specific situation. The perceived stereotypes seem to exert an influence over PWD even when they had not actually experienced unjustified unequal treatment prior to the time of the survey. The confrontation with the stereotypes mentioned above is not limited to any certain context. PWD can be exposed to the uncharted stereotypical attributions and insinuations in several contexts of their life – so to say anywhere and anytime – and may have encountered them even before they were diagnosed. This study report displays the stereotypes that were perceived by the participants. And it shows that the perception of these negative and derogative stereotypes is associated with higher level of psychological distress, more severe depressive symptoms and lower levels of quality of life.

The imputation that PWD are to blame for their diabetes; the allegation that PWD burden the health system as well as the misconception of PWD as 'junkies' are also reported in recent summaries of the state of research on stigma and recognised as the stereotypes that play out in the stigma process (Schabert *et al.* 2013). The ascriptions which characterise PWD as weak-willed, gluttonous, overweight and elderly persons whose behaviour is to blame for their condition are part of the public stigma that Browne *et al.* (2013) refer to in their qualitative study on perceived social stigma.

The correlation of perceived stigma on the one hand and psychological distress and depressive

Table 6 Results of structural equation modelling (considering diabetes-related and socio-demographic characteristics)

| Regressions variables | Standardised regression weights | P |
|--|---------------------------------|--------|
| Experienced stigma ← Age | -0.399 | <0.001 |
| Perceived stigma ← Age | -0.321 | <0.001 |
| Experienced stigma ← Time spent living with diabetes | 0.328 | <0.001 |
| Perceived stigma ← Time spent living with diabetes | 0.092 | <0.001 |
| Perceived stigma ← Type 2 diabetes | 0.048 | 0.037 |
| Perceived stigma ← Female gender | 0.046 | 0.007 |
| Experienced stigma ← Type 2 diabetes | -0.094 | <0.001 |
| Experienced stigma ← Female gender | -0.121 | <0.001 |
| Self-esteem ← Experienced stigma | -0.067 | 0.002 |
| Psychological distress ← Experienced stigma | 0.166 | <0.001 |
| Depressive symptoms ← Experienced stigma | 0.156 | <0.001 |
| Perceived social support ← Experienced stigma | -0.073 | 0.002 |
| Self-esteem ← Perceived stigma | -0.176 | <0.001 |
| Psychological distress ← Perceived stigma | 0.367 | <0.001 |
| Depressive symptoms ← Perceived stigma | 0.331 | <0.001 |
| Perceived social support ← Perceived stigma | -0.220 | <0.001 |
| Depressive symptoms ← Age | 0.023 | 0.291 |
| Psychological distress ← Age | -0.006 | 0.776 |
| Self-esteem ← Age | -0.152 | <0.001 |
| Depressive symptoms ← Female gender | 0.105 | <0.001 |
| Depressive symptoms ← Type 2 diabetes | 0.099 | <0.001 |
| Perceived social support ← Living in German-speaking area | 0.068 | <0.001 |
| Depressive symptoms ← Living in German-speaking area | -0.008 | 0.646 |
| Psychological distress ← Living in German-speaking area | -0.176 | <0.001 |
| Self-esteem ← Time spent living with diabetes | 0.047 | 0.021 |
| Psychological distress ← Time spent living with diabetes | -0.138 | <0.001 |
| Perceived social support ← Time spent living with diabetes | 0.037 | 0.087 |
| Perceived social support ← Age | -0.201 | <0.001 |
| Depressive symptoms ← Time spent living with diabetes | -0.106 | <0.001 |
| Perceived social support ← Type 2 diabetes | -0.093 | <0.001 |
| Perceived social support ← Female gender | 0.018 | 0.286 |
| Psychological distress ← Type 2 diabetes | 0.029 | 0.178 |
| Psychological distress ← Female gender | 0.052 | <0.001 |
| Self-esteem ← Type 2 diabetes | -0.029 | 0.192 |
| Self-esteem ← Female gender | -0.087 | <0.001 |
| Self-esteem ← Living in German-speaking area | 0.130 | <0.001 |
| Quality of life ← Self-esteem | 0.093 | <0.001 |
| Quality of life ← Psychological distress | -0.285 | <0.001 |
| Quality of life ← Depressive symptoms | -0.275 | <0.001 |
| Quality of life ← Perceived social support | 0.104 | <0.001 |
| Quality of life ← Female gender | 0.004 | 0.785 |
| Quality of life ← Age | -0.094 | <0.001 |
| Quality of life ← Time spent living with diabetes | -0.034 | 0.037 |
| Quality of life ← Type 2 diabetes | -0.044 | 0.017 |
| Quality of life ← Living in German-speaking area | 0.077 | <0.001 |
| Correlations variables | Coefficient | |
| Age ↔ Time spent living with diabetes | 0.197 | |
| Age ↔ Type 2 diabetes | 0.546 | |
| Type 2 diabetes ↔ Time spent living with diabetes | -0.318 | |
| Female gender ↔ Age | -0.157 | |
| Female gender ↔ Time spent living with diabetes | -0.050 | |
| Experienced stigma ↔ Perceived stigma | 0.530 | |
| Psychological distress ↔ Depressive symptoms | 0.658 | |
| Self-esteem ↔ Depressive symptoms | -0.515 | |
| Self-esteem ↔ Psychological distress | -0.407 | |
| Depressive symptoms ↔ Perceived social support | -0.328 | |
| Psychological distress ↔ Perceived social support | -0.249 | |
| Self-esteem ↔ Perceived social support | 0.373 | |

$N = 3347$, Method ASE, SRMR = 0.067, GFI = 1.0, AGFI = 0.999; CMIN = 6.720; $df = 6$; adj. $R^2 = 0.397$.

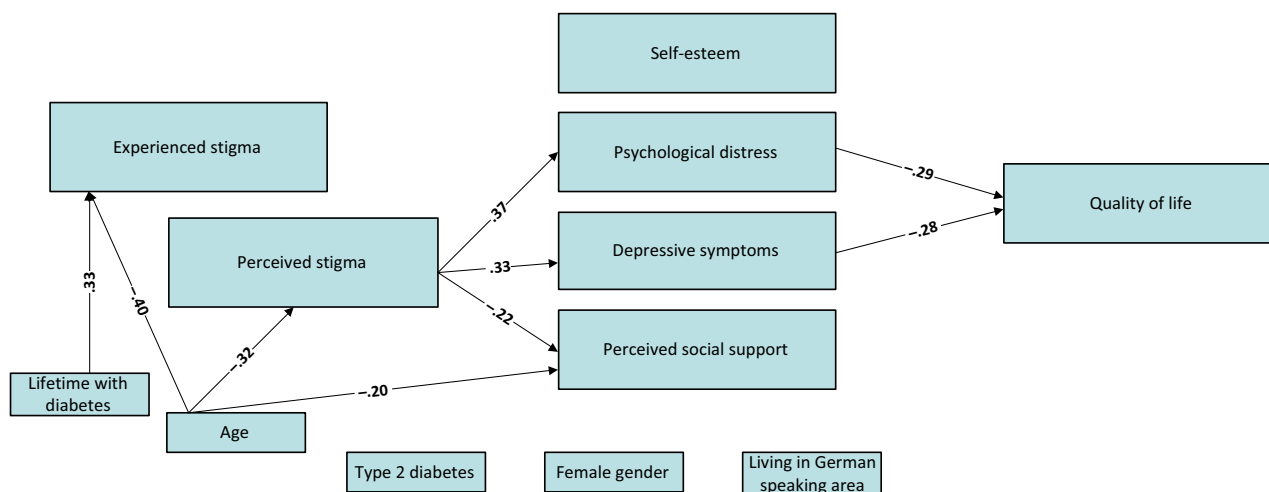


Figure 2 Visualisation of the results of the structural equation modelling (SEM).

Note: $N = 3347$; diagram shows paths where standardised regression coefficient $|\beta| \geq 0.20$.

symptoms on the other hand is all but specific to PWD. Rather, this correlation reflects an interrelation which evolves also in people living with other diseases or impairments if they perceive stigma. A recent synthesis also shows that people being stigmatised due to another disease report more severe depressive symptoms and psychological distress (Stuber *et al.* 2008).

As with all studies, the present one also has certain limitations. Capturing unequal treatment relies on self-reports, which may introduce some bias. Moreover, the retrospective capturing of experiences over a lifetime may mean that less obvious forms of unequal treatment are forgotten or not remembered and hence remain under-reported. Moreover, a longitudinal design would have allowed for a strictly causal interpretation of the effects identified in structural equation modelling. Given the scarce epidemiological findings on PWD in Switzerland, the study was impelled to gather a convenience sample. The response rate was low although it was on the expected level for an anonymous survey without an option for reminding the target persons (Diekmann 1995). Sampling strategy and response rate could entail a sampling bias. Nonetheless, the comparison with the most recent epidemiological estimates (Huber *et al.* 2014) shows that the proportion of men and women in this study's sample (women: 45.2%; men: 54.8%) is very close to that in the sample used for the estimation of prevalence of diabetes in 2011 (women: 45.7%; men: 54.3%). Also, the distribution of age groups seems to be similar. In our sample, 70.9% of the participants were over 56 years, while in the other study 73.7% were more than 59 years old

(Huber *et al.* 2014). In our sample, younger PWD and PWD type 1 are possibly overrepresented.

However, the study also has particular strengths. It includes a large sample of 3347 PWD living in Switzerland, a country with assumedly 500,000 people affected. Moreover, by the specific measurement and the separate consideration of experienced and perceived stigma, the study provides a particular insight into the dynamics under investigation.

This study reveals that stigma – especially the exposure to negative stereotypes – does not only raise questions relating to equal treatment and justice but it also shows that negative stereotypes have a potential to impair the quality of life of PWD. The situation sketched in this study demands change.

However, times when PWD simply tended 'passively to accept' (Benedetti 2014) stigma seems to be over. The results also reveal that the younger generation of surveyed PWD recognise stigma as such – they reported more perceived and experienced stigma than the older generation of surveyed PWD. Younger PWD no longer seem to view unequal treatment as inevitable concomitants of their health condition or to normalise or even internalise the stereotypical attributions as inherent to their disease. This indicates a potential to scandalise the impacts of stigma. For PWD this is a positive point of departure for their fight for equality of chances and against stigma, unjustified unequal treatment and exclusion. One possible way to attain these goals is legal action. However, relating to the legal situation in Switzerland, an expert report commissioned by the Swiss Diabetes Association highlights the restrictions of legal action given the fragmentary anti-discrimination legislation in this

country (Pärli 2009). Legal action would require that PWD self-identify as 'disabled' persons. Yet, as the qualitative elicitation study evidences, this self-identification is contested and in many cases rejected. Delicately, a self-identification as 'disabled' would actually implicate the acceptance of one of the stereotypes that make part of the perceived stigma and as such may fuel the negative dynamics shown here. Against the background of this study, there is not only a need for strategies against manifest discrimination. In particular, stereotypes and public stigma have to be addressed. The stereotypes have to be rejected and action has to be taken in order to change prevailing negative beliefs relating to PWD. One of the major challenges will be to balance the tension between interventions and messages destined to prevent type 2 diabetes and actions taken to change the image of people living with this condition.

From a professional intervention perspective, healthcare providers are called to support PWD's initiatives and fight against stigma. They should also contribute to a change of cultural beliefs about diabetes and PWD. Specific interventions will have to be developed and tested. Design and development (Fraser *et al.* 2009) can draw, for example, from the lessons learnt in the fight against stigma for people living with HIV/AIDS (Grossman & Stangl 2013).

Social workers are in a particular good position to engage in advocacy, to call for equality of chances and justified unequal treatment of PWD in cases where this is an individual need. Thus, the scope of social work interventions should be widened beyond counselling and assisting PWD in their adjustment of lifestyle changes and adherence to diabetes management recommendations in order to improve the patients' medical conditions and reduce complications (Ayalon *et al.* 2008). According to social work's 'person in environment' perspective, the focus should be wider and not only centre on PWD alone but also include their social environment and the way how PWD are treated because of their health condition. For this aim to be achieved, social work professionals should partner with people living with diabetes and their organisations in order to agree on, adapt existing, develop new and finally implement interventions to reduce stigma with joint forces. A national programme on diabetes would be a supportive context for this endeavour.

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