

# BMJ Open Experiences of food abstinence in patients with type 2 diabetes: a qualitative study

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## ABSTRACT

**Objective:** People with type 2 diabetes often report pressure to abstain from many of life's pleasures. We tried to reconstruct these patients' sense of pressure to better understand how people with diabetes make sense of, and integrate, these feelings into their life.

**Design, setting and participants:** A secondary analysis of narrative interviews with 14 patients with type 2 diabetes who are part of a website project.

**Main outcome measures:** Grounded theory-based analysis of narrative interviews, consisting of open, axial and selective coding.

**Results:** People with type 2 diabetes felt obliged to give up many pleasures and live a life of abstinence. They perceived a pressure to display a modest culinary lifestyle via improved laboratory test results and weight. Their verbal efforts to reassure and distance themselves from excessiveness indicate a high moral pressure. With regard to the question of how to abstain, food and behaviour were classified into healthy and unhealthy. Personal rules sometimes led to surprising experiences of freedom.

**Conclusions:** People with diabetes have internalised that their behaviour is a barrier to successful treatment. They experience an intensive pressure to show abstinence and feel misjudged when their efforts have no visible effect. Taking into account this moral pressure, and listening to patients' personal efforts and strategies to establish healthy behaviours, might help to build a trusting relationship with healthcare providers.

## INTRODUCTION

Type 2 diabetes is a prototypic disease where lifestyle factors influence the onset and course of the illness—even more so than medical and pharmacological interventions do. Consequently, doctors are looking for ways to motivate their patients towards a healthier lifestyle and patients are struggling to better control their condition.

We know from innumerable studies that, for many people living with diabetes, the disease imposes lifelong self-discipline

## Strengths and limitations of this study

- This narrative interview study was not led by pre-defined questions but was open to those aspects the participants considered meaningful.
- Following principles of 'theoretical sampling', we were able to conduct a secondary analysis of an extensive data set collected for a website project. Through careful interplay of open, axial and selective coding, an in-depth look was possible.
- Given the normative dimension of abstinence, there is a chance of social desirability in the interviewees' answers and in their account of presenting themselves as disciplined and moderate.

regarding diet, exercise and medication, and often results in a complete lifestyle change.<sup>1–4</sup> Moreover, several studies have reported diabetes results in social stigmatisation by peers, healthcare professionals and the media.<sup>5 6</sup> As a consequence, people with type 2 diabetes often report a reduced health-related quality of life.<sup>7</sup>

The paradigm of diabetes management focuses now on empowering the affected person through knowledge of managing the disease successfully and by improving their quality of life. This implies a collaborative approach in chronic care with the patient as a full partner in healthcare decision-making; this replaces traditional authoritative relationships with healthcare staff.<sup>8 9</sup> Although this approach is widely acknowledged, it is not yet an integral part of daily practice and, as Elissen *et al*<sup>10</sup> put it, medical professionals 'are talking the talk of patient participation, but are far from walking the walk'.

One reason for this shortcoming may be that health professionals are not fully aware of what it is like to live with the disease—the many challenges patients experience and how they reconcile them. For diabetes in

particular, these challenges have an impact on almost all areas of life. Therefore it is necessary to give people the unrestricted opportunity to frankly report on their experience with this illness, and to analyse their accounts in an open and sensitive way. This study makes use of a large sample of narrative interviews conducted for the German website <http://www.krankheitserfahrungen.de>, part of the <http://www.dipexinternational.org> online network.

As suggested by grounded theory, we took a non-predetermined approach to data analysis and soon became aware that most interviewees felt a strong pressure to give up their former life and to abstain from nearly all pleasures. In the study presented here, we tried to reconstruct this feeling as a dominating patient with diabetes experience so as to come to a better understanding of how people with type 2 diabetes make sense of and integrate these pressures into their life. We used grounded theory also with the aim to learn more about causal factors for this feeling, including the role of doctors and medicine, seen from the patient's perspective.

## METHODS

### Context and setting

The study presented here is a secondary analysis of narrative interviews conducted for the website <http://www.krankheitserfahrungen.de>. This website is based on the idea and methods of the British <http://www.healthtalkonline.org>. It contains sequences from narrative interviews about the experiences of people suffering from chronic conditions. The German and British projects are both part of DIPEX International (<http://www.dipexinternational.org>). The main goal of the DIPEX project is to give patients the opportunity to learn from each other and to have access to free information distinct from that provided by medical experts or internet sources that are economically motivated, for example, to sell medical products.

The purpose of this study was to reconstruct the experiences of people with type 2 diabetes, including the role of doctors and medicine seen from the patient's perspective. In order to take an in-depth look at experiences the participants considered meaningful, our analysis followed the principles of grounded theory.<sup>11</sup>

### Participants

The complete database consisted of 35 narrative interviews with patients having diabetes. Following a maximum variation sampling strategy that aims to provide a wide selection of experiences, the participants were recruited considering factors such as background, age and gender with the assistance of primary care practices, self-help groups, local clinics and local communities, for example, an Islamic centre.

### Data collection

Interviews for <http://www.krankheitserfahrungen.de> were conducted by qualified interviewers one-to-one either in the participant's home or in a department of the University. All interviews were conducted in German. A narrative interview technique was employed so that participants could freely express what they considered important. The interview began with a section in which an open question invited the participants to relate their stories—from the moment they first suspected something was wrong with their health. Prompts and probes were used, when appropriate, to elicit further information. All interviews were digitally recorded (either videotaped or audiotaped), pseudonymised and transcribed verbatim.

### Analysis

In grounded theory studies, data analysis is performed simultaneously with data collection and consists of three steps: open, axial and selective coding.<sup>11</sup> After reading all interviews, a randomly selected interview from our database was coded *openly* line by line in order to structure the data and to generate first assumptions about the content of the interviews. This process was facilitated by the analytic software ATLAS.ti. Theoretical memos, covering ideas about the data and remarks on recurrent topics of the interviews, were written during the whole analysis and guided the development of hypotheses. Following the concept of theoretical sampling, other interviews were selected from our dataset to draw minimal and maximal contrasting comparisons to further develop our hypotheses, and to integrate them into a larger theoretical framework. In our study, this was the topic of abstaining, which was present in most of the interviews and relevant to nearly all other topics. *Axial* coding was used to refine our preliminary concepts into more abstract categories and to explore the relationship between the categories. With *selective* coding, we connected the categories finding one 'story line' or theme. Overall, the main theme was the interviewee sense of obligation to live an 'abstinent' life. Analysis ended when saturation of concepts had been reached.

### Ethics

All participants gave prior written consent.

## RESULTS

### Participants and key themes

We started the analysis with an interview chosen at random, that of Nadim (male, 35 years, [table 1](#)). A preliminary analysis led to the hypothesis that, in diabetes, being overweight plays an important role in the illness experience. On the basis of a memo written during the coding of the first interview, we chose Anna (female, 42 years), who also worried about weight and diet. She felt rejected by her doctors who, in her view, seemed to assume she was lazy as she did not lose weight.

**Table 1** Sample of interviewees and reason for selection

Person	Time of diagnosis and medication	Short characteristic	Reason for selection
Nadim (P32) ♂; 35 years	11 years ago; oral medication, long-acting insulin	Nadim changed his lifestyle radically after a heart attack; participated in a diet programme and fasting during Ramadan, which led to an intense experience of community and a successful weight loss	Weight problems/support from others
Anna (P30) ♀; 42 years	18 years ago; oral medication	Anna thinks her doctors always assume her to be lazy; does not lose weight although struggling very hard; husband and children wanting her to cook 'unhealthy' food	Feels disapproved of by doctors/ feels that having to abstain is unfair
Margaret (P21) ♀; 67 years	8 years ago; oral medication	Margaret feels having to abstain from little pleasures is unfair especially since she always has been slim while some overweight friends are not diabetic	Distancing oneself from those who indulge themselves
Thomas (P16) ♂; 57 years	3 years ago; no medication	Thomas gets compliments from the doctor for good laboratory values after abstaining from former habits, including eating unhealthy food and having beer as part of his group's activities	Radical change of lifestyle
Iris (P20) ♀; 54 years	7 years ago; oral medication	Iris wants to improve her lifestyle at her own speed and has tried some new activities such as caring for her body by swimming; makes her feel proud of herself	Individual rules of how to abstain
Lisa (P22) ♀; 52 years	6 years ago; Insulin	Lisa discovered that her blood sugar rises more when eating foods high in fat than those high in sugars	Individualised experience and explanation of eating habits and laboratory values
Katharine (P15) ♀; 73 years	3 years ago; oral medication	Katharine explains her weight problem as a genetic disposition and distances herself sharply from other overweight people	Distancing oneself from those who indulge themselves
Peter (P8) ♂; 73 years	3 years ago; oral medication	Peter struggles with the desire to have emotionally important food, for example, chocolate; is happy that he can 'admit' having a glass of red wine from time to time	Rules that fit personal needs/ feeling approved by the doctor
Luise (P1) ♀; 51 years	11 years ago; first oral medication, now insulin	Luise feels resigned to being overweight by doctors; seems to her like a 'death sentence'	Feeling resigned to being overweight and laboratory values
Klaus (P2) ♂; 64 years	5 years ago; oral medication	Klaus since diagnosis feels that 'every pleasure like his Sunday roast is forbidden; is tired of the repetition of this advice during each medical consultation	Feeling that having to abstain is unfair
Jonathan (P3) ♂; 57 years	10 years ago; oral medication, sometimes long-acting insulin	Jonathan considers eating and being overweight is a result of living in a family of the after-war-generation; bullying also leads to eating out of frustration	Weight problems/no support from others
Max (P6) ♂; 52 years	25 years ago; oral medication and long-acting insulin	Max describes his wife as a 'second will' and warning signal when he eats too much; often 'escapes' from the rules to have a 'nice party'	Wanting external restrictions
Katy (P27) ♀; 65 years	24 years ago; insulin	Katy supposes that the only way to change lifestyle would be if her doctor would exile her on a lonely island where she can no longer be tempted by unhealthy food	High laboratory values; even if she eats next to nothing
Maria (P29) ♀; 65 years	32 years ago; insulin	Maria was disappointed and felt neglected when her doctor told her that her laboratory values do not always have to be perfect	Feeling that doctors do not care/ being ambitious about having good laboratory values

In parallel, we selected Margaret (female, 67 years), who reported that she had always been slim and received a lot of approval from her doctor for having almost normal laboratory values. [Table 1](#) shows how we continued to select further interviews, in order to find

minimally and maximally contrasting cases, and after considering additional attributes such as age and gender.

Saturation was reached after having included 14 of 35 interviews. The final sample comprised eight women

and six men, with a mean age 57.6 (range 35–73) years; duration of illness ranged between 3 and 32 years. For the purpose of illustration, we provide translated sequences from our interviews in the following chapters.

A key theme of all interviews was the strongly felt pressure to abstain (*‘verzichten’* in German) from culinary treats and other pleasures. We detected four subcategories that helped to generate a complete picture and a deeper understanding of the experience of *‘verzichten’*: (i) the pain of abstaining from former pleasures; (ii) moral pressure to prove abstinence instead of excessiveness; (iii) how to abstain and (iv) abstention as freedom.

### The pain of abstaining from former pleasures

While elevated glucose levels were usually not perceptible, abstention from culinary favourites was painfully evident and affected a patient’s sense of well-being, resulting in permanent feelings of hunger and thoughts about eating, sometimes enhanced by insulin. Abstention related to, for example, emotionally significant favourite dishes and sweets. While other people of her age would enjoy a communal, ‘well-deserved’ pleasant meal, Margaret, for example, felt excluded from such social events having instead only ‘dry crisp bread’ (box 1, quote 1). Using strong words, Klaus (box 1, quote 2) expressed his impression that for people with diabetes every treat is ‘generally’ forbidden.

Feasts are a particular challenge. Not only are they centred around eating, they can also revitalise positive feelings from the past. In Peter’s narrative (box 1, quote 3), we witness a highly emotional struggle resisting and yearning for familiar culinary pleasures. Parties and ceremonies represent a further threat that can undermine efforts to change behaviour. Consequently, interviewees often felt excluded from social activities or unable to participate, as in the case of Thomas (box 1, quote 4), in order to resist any temptations.

### Moral pressure to prove abstinence instead of excessiveness

Nearly all interviewees felt evaluated by visible and measurable criteria, such as appearance and body weight, respectively, or laboratory values. This evaluation took place mainly in the medical area but also in the interviewees’ social environment. Those with poor values feared moral condemnation for a supposed lack of discipline even if they had tried hard to change their behaviour but without visible effect. The fear of being morally discredited was apparent during the interviews to such an extent that nearly all interviewees emphasised that they lived moderately and distanced themselves from all forms of self-indulgence (box 2, quotes 1 and 2). Several interviewees confessed to have eaten unhealthy food from time to time, characterising their behaviour as occasional lapses, hoping to receive forgiveness (box 2, quote 3).

### Box 1 The pain of abstaining from former pleasures

*Margaret, 67 years, P21:318, 65–269*

And, as the doctor just said, you need to abstain from really any (stutters) any kind of white-, um, wheatbread stuff and (...) well, I thought, that’s hard, well, you’re not going to do (this)... And just now with my retirement I was really looking forward, actually, to those afternoon coffee treats. (...) Yes, and these, well, a colleague also told me so, don’t take it so seriously and so on, but I really pulled this through. Yes, with cake. But I find it difficult, yes. Munching some kind of crisp bread in the afternoons.

*Klaus, 64 years, P2:055*

Honestly, you are then handed from one seminar on nutrition to the next: they always tell the same stories, I am not to drink beer anymore, I am not to eat any pork knuckle, oh, my Sunday roast is forbidden, and, and, and, oh, everything is forbidden, this is so on principle, that is just the other end of the scale, I am not allowed anything, I’m just going home, they can kiss my ass, they achieve just the opposite of what is aimed for.

*Peter, 73 years, P8:0646–0652*

There’s chocolate bunnies and stuff like that for the children all over the place for Easter, of course, you know, and that certainly means temptation, I had, just now for Easter, my wife had bought chocolate bunnies, and I hadn’t really registered that. One of them, um, was made of dark chocolate, and I (laughs) I had read just before this that dark chocolate would be better for diabetics, if one *had* to have chocolate, that is, and then my wife said: “Yes, because—the kids don’t like this anyways, so this is for you.” Then I (clears his throat), well, for two weeks (laughs) I looked at this bunny and then I really went for it, bit off the ears at the top, and then, of course, this is also a fond memory, when I had eaten bunnies more often, but then one has to, um, overcome one’s inner weaker self and resist. Then one has to put this aside and at a later time another piece.

*Thomas, 57 years, P16:0826–0828*

Oh well, it starts with much-loved habits, um, with my group of regulars, for instance, where one always went to and used to have a couple of pints down the pub (...) I want to lose weight, I um, I do not go out to eat, I don’t go to the pub. This just doesn’t work for me, I don’t have what it takes, y’ know, ‘cause, it just doesn’t make sense, umm, just so, um, on one hand count the three carbohydrate units and on the other, um, eat a plate heaped full in a pub, or something like that, and then I just said, I’d rather stay home.

When Margaret visited her doctor she was always excited to learn her laboratory values. The medical assessment appeared to represent a benchmark of successful abstention. While talking in the interview about her doctor’s praise, she presented herself as hard-working and abstinent (box 2, quote 4). Because of her good laboratory values, she felt rewarded and morally bolstered by her general practitioners’ comments. In contrast, the next example shows how stressful a consultation may be when the results are poor, culminating in a ‘death sentence’ (box 2, quote 5).

Another narrative mirrors the enormous strain of internal and externally perceived moral pressure: Anna reported about the injustice of not losing weight in spite of her substantial effort while other people seem

to manage it easily. She feared that others might draw false conclusions about her eating behaviour. By contrasting the gluttony of others and her own restraint, she defended herself against any potential suspicion of misconduct. She demonstrated her own efforts to restrict her diet and was not the least frustrated because there were no visible results (box 2, quote 2). The moral pressure is also evident in Peter's account (box 2, quote 6). He felt caught by his general practitioner in a supermarket because he had a crate of beer and anticipated his doctor's possible comment although he did not know what his doctor really thought. The mere presence of his doctor in the market put pressure on him.

### How to abstain

All interviewees knew and accepted the medical advice that they needed to change their lifestyle but many did not know how to go about doing so. While health professionals may consider laboratory values and weight as clear indicators of adoption of an improved lifestyle and abstention from culinary treats, many of our interviewees often desperately looked for practical guidance. Doctors were often perceived as demanding strict abstinence or, as Klaus (box 3, quote 1) recounted, seemed to require weight reduction as a prerequisite for treatment. Anna (box 3, quote 2) felt that her doctors believed she was not trying hard enough as her blood sugar level remained too high.

When forced to develop personal rules of how to abstain, some interviewees considered the blood sugar measurement an essential indicator. It could be used to adapt the call for change and abstinence by 'trial and error'. Some interviewees reported how they learned what and how much they had to give up. In turn, they also learned what things are 'allowed'—for instance, if the test results remained within a tolerated range—or how to compensate for a 'lapse'. Then abstinence did lose some of its rigorousness (box 3, quotes 3 and 4).

Good blood sugar readings motivated patients to continue their efforts. In contrast, those patients whose readings did not mirror their efforts and contradicted the paradigm of abstinence, were confused. If they constantly experienced not being able to change their laboratory values or their weight, they began to look for other criteria for a successful lifestyle change. Anna (box 3, quotes 5 and 6), for example, appreciated the advice from a support group, which emphasised well-being as opposed to laboratory values.

The assessment and classification of food was a recurrent theme. Similar to the classification into abstinent and excessive people, food was divided into healthy and unhealthy. Unhealthy dishes were classified—or perceived—as 'forbidden'. If they were, nevertheless, consumed, the interviewees tried to justify their behaviour. Iris gave a detailed account of her desire to have mayonnaise. First she emphasises her desire to be like everybody else and

### Box 2 Moral pressure to prove abstinence instead of excessiveness

*Luise, 51 years, P1:521*

Only he (the general practitioner) must not compare obese with obese. I am not fat because I eat too much. But there are fat people who are fat because of the food they eat. Understand, that's a difference.

*Anna, 42 years, P30:093*

Why do other people do it like that? No idea. (...) Perhaps to top their, um, their dishes, what they simply (pour into themselves by way of food). (...) Well, I am steadfast, I, well, I tell this to the doctors every time (...) "You, you don't know how difficult that is, sometimes, for me, to stand there and, um, abstain." (...) This really is a fresh fight each and every time.

*Katy, 65 years, P27:110*

... but once I ate a whole block of chocolate, with chillies, I wanted to try this. These bars are just wafer-thin, aren't they? (...) Four, five bars throughout a day. (...) (Then) I told my husband: "You know, I just ate a whole block of chocolate." And he said: "You know, you simply needed this for once."

*Margaret, 67 years, P21:570*

And (the doctor) has all this in her computer and (I) am really incredibly keen to know, is it the same or isn't it higher. (She) encourages me to continue, and sometimes even says "Well, you know, you don't need to live in denial. Okay? You. Spoil yourself a little." (laughs) It always sounds so, so forbidden, the way I treat myself.

*Luise, 51 years, P1:545*

Yup, just a regular check-up. That is due every 3 months, I need to go first-first in the morning on an empty stomach for a blood sample and 2 days later I need to go there to discuss the results. And for the past half year I always went there with the hair on my neck standing up, I thou- because I thought all the time: what now, what next, you know. (...) Because one is aware of it, when one's measured it all oneself, and there are only high values in the measurements, then the (long-term) value cannot be great either, you know. Well, and if that's the case I am under pressure again, and then I go to this appointment and say: "I want my death sentence."

Interviewer: And that means?

Luise: Well, he can run me ragged again, can't he. (laughs)

*Peter, 73 years, P8:0977*

W-w-we (the doctor and I) visit the same beverage and drinks shop, and by chance he came around the corner with a crate full of mineral water and I co-incidentally carried a box full of beer (laughs) and he—we didn't need to really talk about it—he let me know in no uncertain terms that it would have been better by far if I had likewise (laughs) taken a crate of water, but I told him when I next saw him at his office: "The beers were not for me at all. You do know, don't you, that I'm a wine person. Bought that for my boys" (laughs).

sometimes has a craving for something ('ravenous appetite'); it is 'human' and you cannot control it. She adds 'a good dollop of mayonnaise and enjoys living thoroughly decadently'. While confessing a 'sin', she legitimises it by underlining how little she ate and how she now feels well and capable of abstaining again. The argumentative effort is impressive and again demonstrates the enormous pressure in even trivial decisions.

**Box 3** How to abstain

*Klaus, 64 years, P2:055*

But I can only say that this (neck standing) is a typical topic of all medical persons. All insist on it and nag (...) they all have an eye on the success, of course, and, um, it really is easiest to come into the room and say right away: "Loose 10, 15 kg, and, um, then you'll feel better." It's quite clear, it's very nice, it's correct, no problem, tell me how to do it and I'll do it.

*Anna, 42 years, P30:215*

They (the doctors) always say (...): "Well, you are young. Try to do this under your own steam (...)." But over the years the values remain too high, and nothing ever works. When they then think: "See, maybe she isn't following the dietary instructions." (...) They just say: "You know, then we'll not do anything, either."

*Margaret, 67 years, P21:534*

We-ell, and that has proven, up until now, that if and when I go across to the bakery after all of an afternoon, and they have freshly made cream puffs, you know, then (I'll) enjoy a cream puff, okay? And I really relish it. Yes, and the values just show that this isn't all wrong, either.

*Thomas, 57 years, P16:1281*

So I ate, um, something I don't usually eat throughout that whole weekend, and lo and behold, I had gained four pounds on Monday, you know, immediately, you know, and then I returned on Monday to my old way of life. Just ate, um, potatoes and veggies...

*Anna, 42 years, P30:093*

Okay, sometimes I eat a little too much. When I have a second helping, despite everything, then I know that it (the blood sugar level) is high, you know. Sometimes when I eat (the same thing) 2 days in a row, I get two different results

*Anna, 42 years, P30:302*

Well, since I've joined this support group, my sugar level has become worse instead of better, with all these recommendations, and here and there, and so on, you know. But I also see, um, the recommendations are spot on and helpful.

*Iris, 54 years, P20:393*

Mustard instead of butter with cheese on your bread tastes quite good, you know. You've just got to find something for yourself where you can say: "Look, I've done without something—the butter, in this case." This way you do without something and still be satisfied, maybe even a little proud. It's very important to have something that one is satisfied and even proud about. You just can't deprive yourself of everything nice all at the same time.

Sometimes, the interviewees described abstaining as an easy task, again obviously with the aim to draw a line between those who supposedly overindulge themselves or to legitimise emotionally important food. Margaret for example, reported to have never liked milk chocolate but only the 'healthy' dark chocolate. Katy told us to eat 'only' half a chicken. Peter admitted happily to having wine instead of beer, even approved by his doctor.

These examples show that the uncertainty of how to abstain often represented a burden, especially after the initial diagnosis. At the same time, it may give some patients freedom to define food that is emotionally important for them as healthy. Or they can create rules they can adhere to without excessive pain, which

contributed to a feeling of success in the case of Iris (box 3, quote 7).

**Abstaining as freedom**

There were several remarkable exceptions where abstinence was not experienced as an internal or external pressure but acknowledged to have changed life positively. Some people, for example, Thomas (box 4, quote 1), discovered new areas and positive experiences when changing lifestyle, sometimes supported by the spouse.

While fasting during Ramadan, Nadim (box 4, quote 2) discovered a form of abstinence. For him this was a radical behaviour, against all medical advice, but at the same time liberating. That this happened during Ramadan might have strengthened the experience since he did not feel excluded or left alone when having to abstain.

In some cases, social withdrawal from various obligations, typically family obligations, was viewed positively. Iris, for example, had a new ritual. She sometimes had a shower in the evening, lit a candle and did not want to be disturbed by her family. While she commented on the many demands on her as a mother and as a diabetic person, her illness gave her the opportunity to enjoy some daily time for herself, as opposed to indulging in food. Nadim (box 4, quote 3) told us about a similar experience, where physical activity no longer felt like a penalty but, rather, as a type of reward.

**Box 4** Abstaining as freedom

*Thomas, 57 years, P16:1680–1729*

It agreed really well with me, that was kind of, um, the second pillar in addition to losing weight, but there is a need for discipline (...) My wife (...) joins me (...) and we go our rounds, regardless of the weather, at 6:30, 7pm or even later than that (...) So by doing this, it is agreeable (...) One feels actually (...) even though hungry (...), one feels (...) also okay, well (...), capable.

*Nadim, 35 years, P32:348–352*

And the month was really wonderful, full of intense experience. Um, in the evening we were served dinner, not for me. I drank my bags. Um, it is strange, all around you eat, only you have your shake and drink that. But you can believe me, it really was, um, very wonderful. It was, well, it was the best fasting month that I have experienced in a long time. It was, you saw all kinds of things in the mosque. I really was intensely included in all of this. Even in the kitchen I was included. (...) Well, as I said, that's the thing that made me go on this trip: I can change this. I can change this, not some medication, not insulin, not even the doctor. He's not with me. I am.

*Nadim, 35 years, P32:433*

I ride my bike for an hour every day after work. It was a revelation, there is something beyond work, home, being at home and with the family. Just shut down, an hour just for me. This was new for me. That's why I say: "Once you get told the diagnosis, take a break." I should have done that much earlier. Go outside to see that there is something else. Life can be different.

## DISCUSSION

Pressure to give up a previous lifestyle was a core experience for people with type 2 diabetes. Body measurements, especially weight, and laboratory values, were often seen as ‘benchmarks’ of successfully abstaining from forbidden culinary pleasures—not only for health personnel but also for diabetic people. Being afraid of moral discrimination, many of the interviewees invested huge efforts to distance themselves from appearing self-indulgent and excessive. In rare cases, abstaining from former pleasures became a positive experience.

The greatest advantage of this study is the openness of the interview situation, which was not led by predefined questions.

Although ‘theoretical sampling’ seems problematic in secondary analysis because the data are already ‘given’, the usual interplay of coding and sampling is still possible by carefully selecting data, namely, people from the available sample. It should be emphasised that all the interview material was accessible, as recommended by Heaton,<sup>12</sup> and not only those parts published on the internet. Even if analysis was conducted with the original interviews held in German, the translation of parts of the interviews for presentation in this paper may have altered the meaning of the participants’ statements—especially the German term ‘verzichten’, which was the key theme in the interviews, and is difficult to capture in other languages because it refers not only to food consumption but also contains the moral requirement to change a considerable part of one’s life.

Given the normative dimension of abstinence, there is a chance of social desirability in the interviewees’ answers and in their account of presenting themselves as disciplined and moderate. Even if they presented a behaviour in their narratives that they did not show in real life, this does confirm the strong pressure to abstain, as it has become an almost natural way of self-presentation in social interaction.

While a major aim in the treatment of chronic illness is to restore or improve well-being and the quality of life, this does not seem to be an accepted target for people with diabetes. From their initial diagnosis, patients need to fight thereafter against their needs and wishes. Swedish women interviewed by Ahlin and Billhult<sup>13</sup> reported a ‘continuous struggle’ to change their lifestyle and felt victims of pressurising demands, similar to the interviewees in our study. Many of the Swedish women described a feeling of life being meaningless if they were unable to live it in the way they were accustomed. They wanted to enjoy life but the demands for a change in lifestyle created great conflict in their lives. Also, women in a Brazilian study<sup>14</sup> showed strong feelings of rage and hate not the least because of feeling pressurised to perform exercise, take medication every day and abstain from their beloved sweets. The results of our study suggest that this feeling is intensified by the impression that patients with diabetes have a higher obligation than others to follow the universal medical advice to live healthy.

It was Broom and Whittaker’s study<sup>15</sup> that showed patients with diabetes used a moral language positioning them either as disobedient children or foolish adults. We also observed this moral language and saw how it can be traced back to the consultation room and the social environment, where laboratory findings and body measures are interpreted as benchmarks of having lived modestly, at least in the eyes of our interviewees. Even in the area of shared decision-making and patient–physician partnerships, many diabetic people feel dependent on their doctor’s moral judgement, awaiting their ‘death sentence’ when they have lapsed. This is in sharp contrast to most other chronic conditions. Laboratory findings that got worse in a case, for example, of cancer or similar disease, would be followed by an emphatic reaction. Many interviewees in our study found their doctor accusatory or had at least anticipated such a reaction when the test results were poor. They felt the need to distance themselves from overweight people and excessiveness.

Our interviewees’ fear to be stigmatised because of their self-indulgence seems to reflect the public discourse that merges diabetes and obesity, without sufficient evidence, into a new social health problem, coined ‘diabesity’, ‘obesity risk diabetes’, ‘obesity causes diabetes’, or ‘weight or fat causes diabetes’.<sup>16</sup> This fear of moral discrimination is also felt when our interviewees pictured themselves as disciplined, to avoid any suspicion of self-indulgence and leading an unhealthy lifestyle. Browne *et al*<sup>17</sup> cite a woman who calls her diabetes a ‘blame and shame disease’. The negative stereotype against obesity was also observed in health professionals and medical students.<sup>17–20</sup>

The pressure to abstain from all culinary pleasures often resulted in the wish to delegate responsibility to external forces, in the end to bariatric surgeries, or the suggestion that the health professional should stock the refrigerator.<sup>21</sup> In addition to these fantasies, our interviews documented the lifelong fight of how to find tolerable ways to abstain from habits and pleasures of a previous life. One way to do this is to define ‘rules’, including the classification of food as healthy or unhealthy, giving some patients a surprising freedom to orient themselves towards other criteria of a healthy lifestyle such as well-being.

Abstaining from former pleasures and habits could also be perceived as beneficial even if only a few patients reported this experience. Similarly, patients in Japan considered the diagnosis of diabetes as a chance to change their life.<sup>22</sup> This is in line with reports of interviewees in our study with the most particular case of a Muslim who used Ramadan to begin to fast and described this as an enthusiastic experience. It should be emphasised that he, like other interviewees, described this behaviour first of all in terms of abstinence and, much later, as a new positive experience.

## CONCLUSION

Abstaining from former culinary treats was a core experience of nearly all interviewees, expressed as the feeling of giving up a previously enjoyable life forever. Our patients all felt under high internal and external pressure to demonstrate a healthy lifestyle. The main origin of this pressure was not so much the fear of diabetic complications but the moral dimension of the disease. In this regard, laboratory values are interpreted as benchmarks of success that could either strengthen a patient's own efforts or undermine the moral status. Diabetic people have internalised the distinction between self-discipline (thin people) and excessiveness (heavy or overweight and obese) and are eager to avoid any association with excessiveness. Doctors and nurses are often perceived as controlling and pressurising without giving advice with regard to how to put medical recommendations into practice. Interestingly, most of our interview partners had received dietary advice or even visited specialised clinics that provide self-management programmes, including advice for lifestyle change and exercises, specifically, of how to control calories and to lose weight by physical activity. However, several of them were disappointed and reported how far off these exercises were from their real life, and described the advice and exercises as often being irrelevant for everyday use. In some instances, the educational programmes even increased the pressure to live a joyless life.

One of the most striking results is that more or less all participants were aware of the association between lifestyle and their condition. So, informing diabetic people again and again to change their life, to do more exercises, to eat less and to lose weight, might not be necessary, and if it were, it should be carried out very carefully. Most of them are already aware of these recommendations and they often feel discriminated if their efforts to change lifestyle are not sufficiently appreciated by medical practitioners. This is regarded as unfair, especially if the body seems 'unpredictable'; many diabetic people have the feeling they cannot, or can only to a limited degree, influence the test results.

A first step to break the vicious circle of judgment and frustration could be to appreciate the patients' efforts even if body measurements and test results are disappointing, and not to automatically conclude that poor measurements represent poor effort. Both parties should know and accept that measurements do not necessarily mirror behaviour.<sup>21</sup>

Instead of exerting even more pressure on patients with diabetes, doctors and nurses should inform patients about the dangers of moral pressure and that recommendations to change lifestyle should not be understood as an accusation of previously poor behaviour. It could be helpful if doctors and nurses acknowledge many patients struggle with the pressure to change their lifestyle, and set up their own rules.<sup>4</sup> Many seem to be aware of their own responsibility and potential for self-management, but often need room and freedom to shape their life and

putting demands into reality. It would be helpful to listen to diabetic sufferers and their strategies. A new role for doctors in diabetes management may be to give patients room to experiment and to support them, to find out what works and helps them best. Doctors could encourage patients to implement small, sustainable changes in their lifestyle behaviours, and be mindful that, in reviewing each patient's progress, they display unconditional positive regard and empathy.

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