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How diabetes forum-users complain about others' expectations: troubles-telling and troubles-receiving

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Abstract

This article offers a qualitative analysis of two instances of troubles-telling threads on a diabetes forum, with a specific focus on how these instances contribute to constructing a way to manage others' expectations concerning how persons diagnosed with diabetes control their condition. From the perspective of conversation analysis and discursive psychology, this article shows some recurrent features of both troubles-telling (namely announcement, stake inoculation and self-deprecation) and of troubles-receiving (namely appreciation, second stories, escalation). Our analysis furthermore shows how inadequate expectations from family members are judged differently from those of health professionals. The latter are judged more harshly for what seems a lack of professional competence, whereas the former are more easily pardoned but pose a particular challenge in that patients do not wish to remove these persons from their lives. Through this analysis, we contribute to showing a particularly important function of patient fora, namely allowing patients to tell troubles about others' expectations and to receive support and advice for these circumstances that put a heavy emotional burden.

How diabetes forum-users complain about others' expectations: troubles-telling and troubles-receiving

In this article, we offer a qualitative analysis of two instances of troubles-telling threads on a diabetes forum, with a specific focus on how these instances contribute to constructing a way to manage others' expectations concerning the lifestyle of persons diagnosed with diabetes. We first briefly introduce diabetes and the research concerning expectations from outsiders towards persons with diabetes (1), then discuss online support groups as a space for troubles-telling (2) and the data used in this study (3). In (4) we show how users structure their posts to display moral transgressions by others, and how this differs when the other is a health professional. In (5) we present the main conclusions of this study.

1. Diabetes and others' expectations towards persons with diabetes

Diabetes is a chronic disease, except for its gestational variant. According to the WHO (2023), it affects 8.5% of adults aged 18 years and older. The majority of these cases concern type 2, which is typically developed later on in life and is partially related to lifestyle (e.g. diet and physical activity). Hence, it is considered partially preventable. It is this variant that is very much on the rise, both in terms of amount of patients and in terms of its appearing at an increasingly younger age. Type 1, on the other hand, is developed early on and not preventable. There are further subtypes, which we will not discuss in detail.

Treatment of diabetes involves everyday decision-making by patients about their diet as well as, for insulin-dependent patients, about the amount of insulin to be injected. The latter concerns all Type 1 patients and part of the Type 2 patients. This constant everyday decision making implies then a strong and permanent involvement of the patients in their treatment.

Thus, Russell et al. (2005) found that diabetes management takes more than 2h per day for experienced type 2 patients. Given the sense of initiative and knowledge required to attend and organize formal care, á Rogvi et al. argue that “the skilled work of being a type 2 diabetes patient is a part of self-care that is both implicit and invisible” (á Rogvi et al., 2021, p. 2736), making appropriate care less accessible for socially vulnerable patients. The pervasiveness of and high involvement in diabetes management is dealt with in very different ways by patients, also in terms of sense of self and identity construction, as shown by Due Christensen et al. (2018) for Type 1 patients.

The fact that lifestyle factors, especially those related to diet, are part of the prevention (in case of Type 2) and of the treatment (for all types) is regularly commented upon in the media from a prevention perspective. This has as a consequence that many persons who are not patients know that diet plays a role in diabetes treatment, without necessarily having in-depth knowledge of which precise dietary requirements are adequate for persons with diabetes. Walker and Litchmann (2021, p. 914) describe the impact of this partial knowledge as follows:

people with diabetes are subjected to two forms of stigmatization. First, they are adjudicated at the point of diagnosis because diabetes is widely perceived as a disease of gluttony reserved for those who “don’t take care of themselves.” Second, they are adjudicated for every micro-decision around food, exercise, and health behavior (e.g., blood sugar monitoring, injecting insulin, taking oral medication) because diabetes management is understood to be controllable by the individuals inflicted with it. In other words, there is cultural compulsion for outsiders (nondiabetics) to perform authoritative surveillance upon the choices of persons with diabetes, a more rigorous judging than what a nondiabetic would be subjected to.

Also for other conditions, studies have shown the difficulties of managing others' expectations and involvement, e.g. Wright et al. (2021) show that 70% of women with breast cancer experience comment upon the burden and emotional strain related to navigating social support, for instance the work of seeming grateful when not necessarily being so or when not necessarily wanting support at concrete moments.

2. Online communities as a support group and as a space for troubles-telling

Online support forums focused on health and illness have been shown to play a role in overcoming the stigma associated with some pathologies, and in seeking (or offering) social support (Walther & Boyd, 2002). While doctors not always react positively to the use of digital media by patients (Roper & Jorm, 2017) - leading the latter to feel wary about bringing them up during consultations (Cuteanu et al., 2021)-, various studies have underlined the benefits of such groups. Indeed, therapeutic benefits of (online) support groups have been shown in the case of eating disorders (Campbell, 2008; Naslund et al., 2016; Stommel, 2009), as well positive effects on diabetes management through peer interaction in diabetes online communities (Litchman, Edelman, & Donaldson, 2018; Litchman et al., 2019). Online health support groups combine a platform to exchange (experiential) knowledge (McCormack & Coulson, 2009, De Cock, 2019, De Cock & Figueras Bates, in press) with the creation of emotional communities (Petersen et al. 2020), constituting online affinity spaces (Tagg, 2015: 234). This support function also appears in that users comment on using these forums in order to minimise the mismatch between the kind of reaction they are looking for and the kind of reaction that non-patients (friends, family,...) might give them (Robinson & Turner, 2003; Walther & Boyd, 2002).

One pervasive way in which users can seek or offer social support on forums is to narrate their own (or comment on others') negative experiences. The form of these narrations is often in what conversation analysts refer to as "troubles telling" (a term originating in Jefferson and Lee, 1981). It allows the speaker or writer to introduce and describe an experience in a way that casts it as a trouble, in a self-contained narrative with various *dramatis personae* - in the cases we are concerned with here, people with whom the diabetic comes into contact, and who may behave in ways which are in some way inappropriate or troubling (for example, a family member giving unwanted and incorrect dietary advice; or, more consequentially, their doctor being ignorant of current best treatment practice). As Drew (1998) observes, the benefit of troubles-telling is that it allows the teller to formulate someone's behaviour in such a way as to ensure that the listener sees it as a transgression - further allowing the teller to express some kind of moral indignation. Other participants to the interaction can then pick up on this expression of moral indignation, making it "collaborative, with the recipient displaying affiliation" (Drew, 1998, p. 311).

The genre of troubles-telling, then, affords the forum user with a device by which they can complain about others in a recognisable format, with a great deal of descriptive license in how to describe other people's behaviour as morally transgressive. In this study, we will analyse forum threads that start with an instance of troubles-telling. Although Jefferson warns that "the elements in actual troubles-telling can be characterised as [only] vaguely orderly" (Jefferson, 1981, p. 419), and we should not insist on perfect regularity in the data, we shall show how it is that the teller can construct other people's responses to the teller's diabetes as transgressions, and how other forum users rally around the subsequent (collective) moral indignation to support and sustain their identities as responsible individuals.

3. Data

The forum under scrutiny is a publicly accessible, general forum on diabetes, based in the UK but used also by non-UK based users. Forum data are approached from an ethical perspective differently depending on the institution/funding body, and country by country. In our case, the first author's University ethics committee's policy on the collection and analysis of data such as ours is permissible if the forum is one to which anyone has access without registration, participants understand that their posts are public, and the terms and conditions of the website hosting the forum do not prohibit research uses, only commercial uses. Since our use of the data matched all those criteria, then we felt safe in proceeding as we did.

The user's profile description consists of a name (often a pseudonym), a picture (not necessarily of the person itself) and the amount of messages posted by them. It may further contain information concerning the type of diabetes and the treatment. When a user has in the meantime been banned or deleted, this information appears explicitly under the username. The forum is moderated in the sense that moderators remove offensive language. When doing so, they mention explicitly that the post has been moderated, leaving a written trace of their intervention.

The messages analysed in this study have been anonymised for ethical purposes but have otherwise been quoted as published, meaning the examples may include non-standard language use and spelling errors.

The forum is structured in various main sections, such as *Greetings and introductions*, *Newly diagnosed*, but also subsections per subtype of diabetes. The posters choose in which section they post a message and choose the heading of the subject thread they start. The poster's choice as to forum affordances then influences the way troubles-telling and advice-seeking evolve or are interpreted. The forum structure allows for very long turns, which in their turn allow for stories with defusing at the end. Although the posts often elicit responses, they do

not necessarily require responses and may remain unanswered. Finally, when answering a post, the next contributor can choose to edit or select parts from the previous post, thus highlighting or clarifying on which aspect(s) he/she wishes to react. The forum also offers the possibility to react via an emoticon, such as a ‘like’, ‘agree’, ‘informative’, ‘humour’, ‘hug’.¹

The two threads analysed in this study were chosen because they had troubles-telling concerning the emotional burden of lack of knowledge as main topic and because they elicited numerous replies, allowing us to look into the development of affiliation.

We have organised the reporting into two sections: telling troubles about family and friends, and telling troubles about health professionals. While the two kinds of narrative share certain features, the requirement on health professionals to be more aware of diabetes as a medical condition means that troubles telling here focuses on professional neglect with the risks for inadequate treatment this may imply. On the other hand, while family members can be pardoned more easily their ignorance, they are a much more central and long-term part of the patients’ lives, making the problem more difficult at the personal and emotional level.

4. Troubles-telling concerning a lack of knowledge

4.1. Interactions with friends and relatives

The first excerpt (1) concerns a post in which the forum user describes the emotional burden of dealing with a family member's ignorance and her unwelcome surveillance (cf. Walker and Litchmann, 2021). The post elicited 34 replies over a 4-day timespan. The poster of this first excerpt gave it the title *Educating Family & Friends*. In doing so, she already frames the topic as a more general concern of the education efforts that persons with diabetes feel they have to accomplish towards family and friends.

¹ The forum currently has reduced the range of possible reactions to ‘likes’ only.

(1) So having been recently diagnosed as T2 diabetic & avoiding carbs like the plague I am seriously frustrated with friends & family - or more specifically my MIL

She's a normally kind & lovely woman who seems to have turned into the evil devil on my shoulder. Going to the supermarket with her is like running a carb gauntlet where I have to constantly remind her that I don't eat certain foods whilst she literally shoves crumpets & bread in my face.

My particular favourite comments so far include 'I don't understand why you can't eat pineapple - its so lovely & sweet' (like REALLY????) & "can't you take the weekend off' (because everyone know you're only diabetic Monday to Friday right??) Swiftly followed by ' you can't eat butter when you're dieting' (because fat = bad to her indoctrinated brain)

And just when i thought I could cope with her I get accused of being 'high maintenance' cos i won't eat bread anymore. If she thinks this is high maintenance what does she think i'll be without my feet or eyesight

All not helped by the fact my father in law continued to eat lardy cake & pasties after T2 diagnosis so she doesn't understand why I take it so seriously.

Rant over! But if anyone has any ideas on how to deal with this level of noddy please share!

There are a number of points to note about her narrative, which will be recurring features throughout the data:

- (a) *Announcement* The user signals the troubles-telling in the very first sentence of the post – *I am seriously frustrated with family and friends*. This - which Jefferson (1988, p. 424) calls the "announcement" - is a common practice in conversational troubles-telling, as it prefaces the coming narrative with a strong steer to the audience as to how to understand it.
- (b) *stake inoculation*. This is a term from Potter (2003) which refers to an effort on the teller's part to show that they are not biased or have any ill will, which would give them a prejudiced "stake" in the description. Here we see that, when first introducing the mother-in-law, who will be the person about who there is a grievance, the poster describes her as *a normally kind & lovely woman*. This inoculates the teller against any accusation that she is already prejudiced against this person. *Normally* describes the general characteristic, as opposed to the episodic transgression of being *evil devil* in a very specific context.
- (c) *self-deprecation*. The tone is at times ironic ("she literally shoves crumpets ... in my face"; "my particular favourite comments so far...", etc.) and the poster self-identifies it as a "rant", showing a willingness to put themselves in an ironic bad light. Indeed, posting to a forum implies the challenge of coming across appropriately (Lamerichs & te Molder, 2003), and this comment on their own rant anticipates possible critiques in this respect.
- (d) *projection of preferred uptake*. The post is ended with an explicit request for advice: *Rant over! But if anyone has any ideas on how to deal with this level of noddy please share!*. This direct invitation is very strongly "close-implicative", as Jefferson (1981) terms it, showing that the story is at an end and soliciting response.

The forum user, then, has set out a narrative to be understood as a trouble about a family member failing to understand the requirements of diabetes, but has done so in a way that both

gets the transgression on record, and encourages, or at least allows, others to respond to it, while at the same time presenting themselves as fair-minded and self aware. Now that the trouble has been laid out, how does the forum react?

Affiliating responses

Troubles-telling consistently projects affiliative responses. In what follows we shall see three ways in which fellow forum users express their affiliation with the original poster – just as, in everyday conversation, listeners find ways to display their understanding for, and sympathy with, the trouble described by their interlocutor.

(a) Appreciation

The reactions to this troubles-telling are overall very supportive towards the initial poster and display affiliation (cfr. Drew, 1998). One replier even quotes only *Rant over* and elaborates on this (2), showing acceptance by saying it made him smile. Moreover, by encouraging to *keep ranting as required* (3), another replier suggests that ranting can sometimes be needed to manage the burden that such comments of relatives may imply.

(2) [QUOTE *Rant over!*]

It was a good rant, though, made me smile. ☺ (...)

(3) *Good luck and keep ranting ☺ as required.*

(b) Second story

Another affiliation strategy that reacts more directly to the content of the troubles-telling itself is this second story through which the replier tells a similar experience, thus proving her understanding of, and affiliation with, the poster's situation (Sacks, 1992, pp. 764-771). Her parallel assessment (Heritage, 2011) starts off with an “entry device” (Jefferson, 1978) that

highlights the parallel experience *I have the same issue* (4). The parallelisms established by this poster concern the shared experience of "lovely" persons (particularly elderly women) who exercise authoritative surveillance and who can give the person with diabetes a hard time by not understanding or dealing well with the specific dietary requirements.

(4) *I have the same issue with all my female elderly relatives - lovely women, but just can't cope with the LCHF [Low Carb High Fat diet] thing, and give me a hard time to varying degrees, always, about it.*

(c) *Escalation*

In some reactions, moreover, we see members not just appreciating the original posters stance, but actively upgrading or escalating it (cf. Drew & Walker, 2009). They can do this by suggesting reducing contact with the offending party (by no longer taking the mother-in-law shopping) (5), seeking a direct confrontation (6) or stopping the conversation (7). Some of these include an explicit moral judgement, e.g. describing her as *offensive* (6).

(5) *Maybe simply don't go to the supermarket with her?*

(6) *If she can be offensive, then so can you!*

(7) *I've long since given up explaining. I now have a two word solution for stuff like this. Stops the conversation in its tracks.*

Moreover, various moderator interventions as to language are indicated, suggesting that offensive language or swearwords were used by some posters, pointing again towards a harshening or escalation of the content of the messages (8).

(8) ***** ***, *I would guess?*

(edited by mod for creatively disguised profanity)

One day and 22 messages later, the initial poster intervenes again, reorienting the tone and content of the thread (9). After an initial thanks for the affiliation (*Thank you all! I glad I am not alone*), which underlines the importance of the community's shared experience to deal with the burden, she reiterates her positive appreciation of her mother-in-law from the initial post and elaborates on it (9). Indeed, by calling her a 2nd mum, which is a highly positive emotional appreciation, and by highlighting the long-standing relationship and good intentions (*I don't think she is trying to be difficult*), she repairs the mother in law's image and underlines that she does not consider this behaviour to be deliberate, thus reducing the complainable nature of the behaviour (cf. Drew, 1998). In addition to redressing the description of the mother-in-law, the poster adds the more episodic feature of the recent bereavement her mother-in-law suffered, another reason why she does not wish to seek a confrontation.

(9) *Thank you all! I glad I am not alone.*

*Its a bit complicated to tell her to be quiet. My FIL [father-in-law] passed away a few months ago (...). She comes to stay with us for weeks & often I take her to the supermarket to give my hubs a break - **i've known her since I was 12 & she's my 2nd mum so I feel like I have to look after her. She's obviously lonely & neither me or my hubs want to make her upset by telling her bluntly to shut up. Tempting though it is!!!***

***I don't think she is trying to be difficult** or annoying, she's just not thinking & has been indoctrinated by years of diet advice which says carbs are good & fat is*

bad. I get it - its just I wish I could get her to understand that doesn't work for me!

Short term, I think I will just start online shopping deliveries so i have no need to go to the supermarket when she's here.

In doing so, this redress redefines the problem of the initial poster, namely as a difficult interaction with a person she overall likes and with whom she wishes to maintain close contact, as opposed to some suggestions of other posters to keep a distance and reduce contact, which do not help her to solve the problem in a way that is satisfying for her from an emotional perspective. This is a very different setting from other instances of troubles-telling related to less close personal contacts or to professionals, where the person with diabetes may wish to cease the contact, as in the following section.

As pointed out by Vayreda and Antaki (2009, p. 933): “One post shapes a space (makes a context for) the next, and the next occupies that space in its own way, and makes another space in its turn.” Indeed, the initial poster’s redress seems to create a new space of context, with a clear effect on the overall tone in the discussion thread. From this point onwards, interventions are less antagonistic about the mother-in-law and more in line with the thread title *Educating family and friends*. Posters either offer very concrete constructive suggestions, such as educational reading material, which may help the mother-in-law to better understand dietary requirements of diabetics and, thus, reduce her inadequate comments. These suggestions moreover build on the (redressed) image of the mother-in-law as an essentially caring person with good intentions, who displays only occasionally and non-deliberately transgressive behaviour.

Others take up the widespread societal misrepresentation of diabetes and diet-related lifestyle advice (as already pointed out by Walker and Litchmann, 2021), referred to in the redress post (*has been indoctrinated by years of diet advice*). Placing the mother-in-law’s behaviour

in a broader context and reducing her individual responsibility opens up the way for a more positive and loving relationship. Thus, these messages posted after the redress probably suggest more effective solutions that allow the poster to deal with the particular emotional burden of conciliating the lack of knowledge of her mother-in-law with a loving and respectful relationship.

4.2. Interactions with professionals

A very different situation is at hand when the person with diabetes is let down not by family or friends, but by professionals. Practitioners ought to be knowledgeable and competent. The following exemplary thread elicited a total of 51 messages, out of which 18 in the first month, and 33 almost three years later, following a relaunch by the initial poster.

In the origin post, (Extract 10 below), poster narrates the case of an eye doctor who did not know the difference between type 1 and 2, nor the adequate treatment, which is considered very basic information by persons with diabetes. Since one of the consequences of diabetes may be retinal damage, knowledge about diabetes is a relevant aspect of a visit to an eye doctor.

(10) [title]: "Incompetent medical professional"

*I went to a new eye doctor and **was/am furious with the lack of knowledge** about diabetes care. **I made sure to specifically state** that I am a type 1 diabetic and ask to see a doctor who has **significant experience** with diabetic patients. The **quack** didn't **even** know the difference between type 1 and type 2 and insisted that I was a type 2 based on my age and that taking or not taking insulin had nothing to do with type 1 or type 2.*

We already see two of the signal characteristics of troubles-telling: the announcement, with a clear prefatory announcement that this is a negative experience (*I... was/am furious*), the stake inoculation (*I made sure to specially state that I am a type one diabetic*) and the hint of moral transgression (*the quack...*). The trouble here focuses heavily on the professional incompetence in that his lack of knowledge is deemed unacceptable (as opposed to lack of knowledge by friends and relatives). As we will see, the threat to health this may imply, although not explicitly present in the initial post, is taken up by some other forum members. Moreover, the user does not solicit advice: that underlines the trouble as a matter of grievance about professionals, rather than remediable trouble about peers.

Affiliating responses

Nevertheless, the trouble is on the table, and is there for others react to - and they do, in a way similar to the familial trouble above: affiliative appreciation, second stories and escalation. We see all these in this follow-up post (11).

(11) *It is really **frightening**, isn't it? When I was first diagnosed as T1 by a nurse at the GP Practise, upon seeing the doctor, I was told that I would have to go to hospital, because she wasn't sure if I needed insulin or not, she couldn't remember. This, unfortunately, is **only the tip of the iceberg**. Hope you manage to **find a doctor who is a bit more knowledgable and conscientious!***

(a) *appreciation* Many responses affiliate by taking up the emotions felt and expressed by the initial poster with replies such as *Pretty shocking!*, *Dear Lord, that's awful*. These suggest

that the repliers understand why the poster is upset about the lack of knowledge and share her position. They thus realize the indignation in a collaborative way (Drew, 1998, p. 311).

(b) second story This poster moreover supports this with a second story of a similar experience, thus making clear why the implicit formulation of the initial post is easily understood by her. By adding that this is *only the tip of the iceberg*, the replier shows that the original poster is not alone and refers to this being a wider problem, which is reflected in a number of similar other second stories in other replies. As also shown by Arminen (2004, p. 338) on second stories in Alcoholics Anonymous groups, the replier not only provides support but also amplifies the initial idea and contributes to forming the group identity.

(c) escalation Some replies also elaborate further, e.g. (11) also takes up the emotions (*it is really frightening, isn't it?*) but defines the emotion not only as anger or shock, but also as fear. This renders explicit why this particular conduct is a problem for persons with diabetes, namely that it causes fear that the doctor is not capable of adequately treating persons with diabetes.

The replier ends her post expressing the hope that the poster will find a more knowledgeable and conscientious doctor, thus deducing that she will definitely not stay with this professional. Here is then a crucial difference with the lack of knowledge by family: one can leave more easily an incompetent professional but it is much more difficult (and often not desirable) to leave one's family and friends. This suggestion for a solution moreover underlines and constructs the groups' identity as offering help or as seeking to engage in collaborative problem-solving. The wish for *a more knowledgeable and conscientious* doctor moreover elaborates upon the lack of knowledge and adds a rather moral judgement, namely of the doctor not being conscientious. This is in line with Drew's (1998) findings of troubles-telling involving a moral evaluation.

Reply (12) also acknowledges the emotions of the original poster but formulates a humorous advice. The fact that this message is reacted to twice with a ‘humour’ emoji and once with a like, shows that the humorous nature is picked up by fellow forum members. The need for more education, which was also part of the advice in the previously discussed example, then pops up here as well.

(12) *In this position, get angry, lock them in the room, then Educate them with a capital E....*

And indeed, while (12) is humorous, many of the following posts contain comments on medical training, continuous education and evaluation of medical staff, thus broadening the initial highly personal troubles-telling to a more societal problem, as we also saw in section 4.1. This places the troubles beyond the personal level of the troubles teller at the level of the community. It furthermore shows that the community seems to agree on the fact that there is (also) a systemic issue in this particular situation of trouble and that it is not an anecdotal isolated matter.

While most repliers then very explicitly support the poster in her indignation and her negative judgment of the eye doctor’s conduct, some repliers do not adhere entirely to the criticism of the doctor. They propose alternative accounts or possible explanations for this lack of knowledge, such as the specific function of opticians (13) or the fact that there are many other conditions to keep up with (14). Note that those repliers formulate these alternative views in a very mitigated way, e.g. using modal *may* or *would*, using modal adverb *probably*, using a generic *you*, acknowledging that practices may differ depending on the location in (15). In doing so, their contribution refrains from contradicting or criticizing the initial poster in a direct way.

- (13) *It may work differently where you live here in the UK most go to an optician just for an eye test for spectacles and **I do not know how much they have to know about diabetes.** (...)*
- (14) *(...)You would think with the increase of diabetes in this world health professionals would be more aware but then again there are **so many other conditions out there it's probably difficult to be fully knowledgeable on everything***
- (15) *There are some people who work in various medical spheres who, **I agree,** need retraining or involved in some kind of continuing professional development. I would however like to **applaud** every one who has contributed to helping me understand and deal with my T1. I am **indebted.***

The narration of similar negative experiences dominates in the replies, yet some repliers focus on positive experiences and gratitude to knowledgeable healthcare professionals, e.g. *applaud, indebted* (15). Even so, this message again starts with an explicit (partial) agreement (*I agree*) with the initial point about incompetent professionals. Thus, while not entirely adhering to the poster's judgment, the repliers do respect the poster's face and maintain as such the functioning of a solidary patient community.

4.3. Discussion

Both forum threads concern the emotional burden of dealing with a lack of knowledge by persons without diabetes. However, there are also considerable differences between lack of knowledge on behalf of relatives vs. lack of knowledge on behalf of professionals. The lack

of knowledge on behalf of professionals is judged more severely as a lack of competence, using terms that also clearly express this (e.g. *quack*). Although the discussion remains fairly implicit on the possible consequences for the treatment and/or well-being of the person with diabetes, the community clearly shares this concern and some repliers explicitly mention fear as the emotion that arises from such lack of knowledge by professionals.

The situation is more complex when relatives or friends display a lack of knowledge. In their case, a lack of knowledge is deemed more understandable in that they have no professional obligation to have this knowledge and in that their lack of knowledge is sometimes explained as linked to a more general societal problem of lack of (correct) information on diabetes.

While the lack of knowledge by healthcare professionals is then judged more harshly, the proposed solution is often more straightforward, namely to change healthcare professionals. In times of increasing strain on healthcare services, this is not necessarily easy to achieve in practice, but it is often suggested. When friends or relatives display a lack of knowledge, however, posters are much less willing to distance themselves. Indeed, the problem is precisely the emotional burden of seeking a balance between reacting to authoritative surveillance with (wrongly informed) judgements on the one hand and maintaining an otherwise valued personal relationship on the other hand. This leads posters to consider various options, ranging from (patient) education over confrontation to ignoring. However, while the emotional burden of lack of knowledge by professionals weighs particularly on the confidence one hopes to be able to have in how professionals treat a certain condition, the emotional burden related to a lack of knowledge by relatives resides mainly in navigating the tension between the weight this lack of knowledge implies for the person with diabetes on the one hand and the value of the personal relationship on the other hand.

As shown in the introduction, the literature has amply documented how online patient communities can function as support groups. Such descriptions may – without necessarily

wanting to do so – create the idea that only moral support work is going on in online patient communities. However, they are also loci for knowledge transmission among peer experts who rely on their experiential knowledge as patients (see e.g. De Cock & Figueras Bates, in press on eating disorder and diabetes forum). The forum under scrutiny in this analysis likewise contains a plethora of threads where knowledge transmission is being done on various aspects of diabetes treatment, such as diet, different tools to administer insulin or monitor glucose levels, as well as on more organizational issues related to the structure and administration of healthcare systems. Knowledge transmission appears in a more implicit way in the advice given to the poster whose mother-in-law lacks knowledge on the dietary requirements of a person with diabetes, in that some suggestions concern accessible educational literature on the topic.

In the forum threads discussed above, there are two main features that underline the community solidarity. On the one hand, a lot of information remains implicit, e.g. why an ophthalmologist ignoring the difference between Type 1 and Type 2 is a problem. Yet, this does not cause any interpretation problems within the community, revealing that the information that is left implicit is shared by the community. This community understanding contributes to building solidarity.

On the other hand, posters who do troubles-telling receive a positive and benevolent reaction, offering the posters a kind of reaction that probably matches their expectations (cf. Robinson & Turner, 2003; Walther & Boyd, 2002). Many repliers simply agree and even those who do not fully agree with the poster's point of view, tend to express their criticism in a mitigated way. The community is then very supportive of each other and maintains itself as a space of common understanding and solidarity, as also evidenced in some of the forum message thanking for support.

5. Conclusions

The qualitative analysis of two discussion threads concerning the burden of dealing with lack of knowledge on diabetes has brought to the fore various features of this particular aspect of troubles-telling.

In both cases, the posters highlight complainable conduct, which is considered a transgression, namely the lack of knowledge of their interlocutor, respectively a mother-in-law and an ophthalmologist, through an announcement, a stake inoculation and, in the former case, self-deprecation. In the former case, not merely the lack of knowledge but more specifically the criticism of the poster's dietary choices by others is the complainable conduct.

However, there are also notable differences between both threads. The lack of knowledge is considered less acceptable on behalf of the ophthalmologist, since he is a healthcare professional, whereas the mother-in-law's lack of knowledge is presented as partly due to societal information and as potentially solvable through education and reading. The solution in the case of the healthcare professional is nevertheless presented as easier, namely changing healthcare professional, whereas the positive personal relationship with the mother-in-law makes it particularly difficult and counter to the poster's own wishes to keep a distance. In both cases the deliberateness of the complainable conduct is discussed. While a redress message exonerates the family member from deliberateness, the troubles-telling about a healthcare professional (and subsequent second stories) underlines the persistence in transgression, hinting at deliberateness.

Both posts are followed by a wide variety of affiliating responses through expressions of appreciation, second stories, and possibly escalation, but sometimes also simply through 'likes'. The other forum members overwhelmingly show support and understanding for the

poster's situation, and share the moral indignation concerning the transgressive behaviour. This, in addition to their understanding information that was left implicit, at times making it explicit, contributes to the group's community-building and solidarity. Such affiliation can escalate in a way that the initial poster may not have wished, as is the case for one message. A redress message to reemphasize the non-deliberateness of the mother-in-law's behaviour leads the rest of the thread to being in line with how the poster initially framed her message, namely as *Educating family and friends*.

The burden placed upon patients by the lack of knowledge of family and friends may at first sight seem secondary to the burden of the disease itself. However, as evidenced by this analysis, patients clearly experience this as a heavy emotional burden. The fact that it is a burden caused by non-patients may be another factor that leads them to discuss it in the relatively safe space of an online patient community, where the other members affiliate with this experience, share advice and, perhaps most importantly, show support for the poster.

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References

Arminen, I. (2004). Second stories: the salience of interpersonal communication for mutual help in Alcoholics Anonymous. *Journal of Pragmatics*, 36(2), 319-347.

- á Rogvi, S., Guassora, A.D., Tvistholm, N., Wind, G., & Christensen, U. (2021). “It’s a full-time job to be ill”: Patient work involved in attending formal diabetes care among socially vulnerable Danish Type 2 diabetes patients. *Qualitative Health Research, 31*(14), 2629-2640. DOI:10.1177/104973232110415
- Campbell, K. (2008). Soliciting and providing social support over the Internet: An investigation of online eating disorder support groups. *Journal of Computer-Mediated Communication, 14*, 67-78.
- Cuteanu, A., Seguin, M., Ziebland, S., Pope, C., Leydon, G., Barnes, R., Murray, E., Atherton, H., & Stevenson, F. (2021). Qualitative study: patients’ enduring concerns about discussing internet use in general practice consultations. *BMJ Open, 11*, e047508.
- De Cock, B. (2019). To be or not to be ... a patient: identity construction of healthcare professionals and patients in public online diabetes-related interaction. In U., Lutzky, & M. Nevala (eds.), *Reference and Identity in Public Discourses* (pp. 205-225). John Benjamins.
- De Cock, B., & Figueras, C. (In press). Peer experts as actors for shared understanding in Spanish online health fora. In S. Bigi, M.G.Rossi (eds.), *A Pragmatic Agenda for Healthcare: Fostering Inclusion and Active Participation through Shared Understanding*. John Benjamins.
- Drew, P. (1998). Complaints about transgressions and misconduct. *Research on Language and Social Interaction, 31*(3), 295-325. DOI:10.1080/08351813.1998.9683595
- Drew, P., & Walker, T. (2009). *Going too far*: Complaining, escalating and disaffiliation. *Journal of Pragmatics, 41*, 2400-2414.
- Due-Christensen, M., Zoffmann, V., Willaing, I., Hopkins, D., & Forbes, A. (2018). The process of adaptation following a new diagnosis of Type 1 diabetes in

adulthood: A meta-synthesis. *Qualitative Health Research*, 28(2), 245-258.

DOI:10.1177/104973231774510

Heritage, J. (2011). Territories of knowledge, territories of experience: Empathic moments in interaction. In T. Stivers, L. Mondada, & J. Steensig (Eds.), *The Morality of Knowledge in Conversation* (pp.159–183). Cambridge University Press.

Jefferson, G. (1988). On the sequential organization of troubles-talk in ordinary conversation. *Social Problems*, 35(4), 418-441.

Jefferson, G., & Lee, J. R. (1981). The rejection of advice: Managing the problematic convergence of a ‘troubles-telling’ and a ‘service encounter’. *Journal of Pragmatics*, 5(5), 399-422.

Litchman, M.L., Edelman, L.S., & Donaldson, G.W. (2018). Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study. *Journal of Medical Internet Research Diabetes*, 3(2), e8 doi:10.2196/diabetes.8603

Litchman, M.L., Walker, H.R., Ng, A.H., Wawrzynski, S.E., Oser, S.M., Greenwood, D.A., Gee, P.M., Lackey, M., & Oser, T.K. (2019). State of the Science: A scoping review and gap analysis of diabetes online communities. *Journal of Diabetes Science and Technology*, 13(3), 466-492.

McCormack, A., & Coulson, N.S. (2009). Individuals with eating disorders and the use of online support groups as a form of social support. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 3(2): Article 5.

Naslund, J.A., Aschbrenner, K.A., Marsch, L.A., & Bartels, S.J. (2016). The future of mental health care: peer-to-peer support and social media. *Epidemiology and Psychiatric Sciences*, 25(2), 113-122.

Potter, J. (2003). Practical scepticism. *Discourse & Society*, 14(6), 799-801.

- Robinson, J.D., & Turner, J. (2003). Impersonal, interpersonal, and hyperpersonal social support: Cancer and older adults. *Health Communication, 15*(2), 227–234.
- Roper, L., & Jorm, C. (2017). Please leave your phone outside: policymakers and medical app providers are encouraging patient participation, but doctors in the consult room are not. *BMJ Innovations, 2017*(3), 65-70.
- Russell, L.B., Suh, D.-C., & Safford, M.M. (2005). Time requirements for diabetes self-management: Too much for many? *The Journal of Family Practice, 54*(1), 52-56.
- Sacks, H. (1992). *Lectures on conversation*. Oxford: Basil Blackwell.
- Stommel, W. (2009). *Entering an online support group on eating disorders: A discourse analysis*. Rodopi.
- Tagg, C. (2015). *Exploring digital communication*. Routledge.
- Vayreda, A. and Antaki, C. (2009). Social Support and Unsolicited Advice in an Bipolar Disorder Online Forum. *Qualitative Health Research, 19*(7), 931-942.
- Walker, H.R., & Litchmann, M.L. (2021). Diabetes identity: A mechanism of social change. *Qualitative Health Research, 31*(5), 913-925. DOI: 10.1177/1049732320984740
- Walther, J. B., & Boyd, S. (2002). Attraction to computer-mediated social support. In C. A. Lin & D. Atkin (Eds.), *Communication technology and society: Audience adoption and uses* (pp 153-188). Hampton Press.
- World Health Organisation. (2023, April, 5). *Diabetes* <https://www.who.int/news-room/factsheets/detail/diabetes>
- Wright, J.D., Kroenke, C.H., Kwan, M.L., & Kushi, L.H. (2021). “I had to make them feel at ease”: Narrative accounts of how women with breast cancer navigate social

support. *Qualitative Health Research*, 31(6), 1056-1068. DOI:
10.1177/1049732321989999