

Making expertise fit: On the use of certified versus experiential knowledge in becoming an informed patient

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Abstract

This article reports a discursive psychological study of online conversations among patients with ADHD, diabetes, or ALS on what constitutes an “informed patient.” Being informed means different things for different patient groups. Whether patients prioritize experiential or certified expert knowledge is not indicative of patients’ preferences per se but depends on how they give meaning to the responsibilities particular to their disease. ADHD patients hold each other accountable for demonstrating the seriousness of their disease. ALS patients use expert information to orient to a norm of thinking positive. Diabetes patients challenge experts to carve out independence from the diabetes regimen.

Keywords

chronic illness, communication, coping, epistemology, experience, information, norms, self-presentation, social interaction, social media

Introduction

Now that the Internet has made health information widely available, patients are increasingly expected to take responsibility for their own health. As a European policy document (European Commission, 2004: 7) puts it:

A growing number of people are looking proactively for information on their medical conditions. They want to be involved actively in decisions related to their own health, rather than simply accepting the considerable discrepancy (“asymmetry”) in knowledge between themselves and health professionals.

Various authors have pointed out that this notion of the “informed patient” or, in the words

of the EU document, “empowered health consumer” (European Commission, 2004: 7) is a problematic one. For instance, Pitts (2004: 45) observes that the wealth of online information can lead patients to think that life-saving information is out there, and that it is their obligation to find it. Friis et al. (2003: 169) point out that (cancer) patients orient to a societal expectation that they should inform themselves even when they

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do not necessarily want to have more information about the disease or their prognosis. Focusing on how Austrian citizens use the Internet as a health information source, Felt (2015: 188) describes how respondents regularly equated “taking one’s health seriously” with “getting informed”. Seeking information has become a moral obligation, although “many patients do not want to take responsibility or seek out information for themselves—they are more than happy to trust their GPs and leave decisions to them” (Henwood et al., 2003: 604; cf. Valentine, 2010). But *not* to choose is often not an option; patients and their loved ones frequently find themselves in dense, complex, and often contradictory webs of information about their disease and the available treatment options. Making informed choices requires them to gather, understand, and assess the available evidence. Or, as Edwards and Howlett (2013: 40) put it: “one cannot choose without recourse to evidence. The significant question, however, is *which evidence?*”

This study focuses on the way in which various patient groups take responsibility for their own health in real-life online interactions; in particular, how they navigate between certified expert advice and individual patient experiences (cf. Rabeharisoa et al., 2014). Previous studies have already pointed to the complexities of patient choice and the accompanying processes of information seeking (e.g. Barker, 2008; Edwards and Howlett, 2013; Kivits, 2011). We add to the existing literature by focusing not on a single disease or patient group but by comparing how different patient groups give meaning to patient responsibility and informed patienthood. For this qualitative comparison, we have selected three chronic illnesses, which strongly differ from each other: (1) attention deficit hyperactivity disorder (ADHD), (2) diabetes, and (3) amyotrophic lateral sclerosis, better known as ALS or Lou Gehrig’s disease. How do patients from these different groups navigate between expert advice and individual experience, what do they treat as appropriate knowledge, and how do they use these knowledge resources in order to take responsibility for their health? We argue that the meaning of taking

responsibility and “being informed” strongly depends on the different identity concerns that are at stake for each particular patient group.

In our analysis, we employ a discursive psychological perspective, which allows for an analysis of utterances within their interactional context. Similar to conversation analysis, a discursive psychological analysis is guided by the question “why that now?” (Schegloff and Sacks, 1973: 299): what does the speaker achieve (consciously or not) by choosing this wording at this particular moment in the interaction? Discursive psychology builds on conversation analysis in treating discourse as action-oriented (see, e.g. Edwards, 1997; Potter, 1996). Closely studying what is and what is not made accountable on a micro-level provides insight into the community norms that participants orient to, without necessarily being aware of this.

It is important to note here that, from a discursive psychological perspective, norms are not considered as a more or less static framework of expectations governing actions. Instead, the discursive psychological understanding of the relationship between actions, norms, and descriptions is described in terms of *accountability*. Speakers attend to accountability by choosing to make relevant certain norms and not others (Edwards, 1997). Rules or norms are thus conceptualized as participants’ resources that constitute a situation as understandable in a particular way, so that “actions are done and described in ways that display their status with regard to some rule or expectation” (Edwards, 1997: 7). We will show in our analysis that each patient group in their utterances orients to a particular norm of taking responsibility for the disease, of which being informed is a key element. But exactly what it means to be or get informed is different for each case and this also affects patients’ relationship with certified experts and care givers.

Data and method

We selected three diseases to be included in our comparison: (1) ADHD is a controversial disease: both the nature of the disorder and the

desirability of the associated treatment are socially contested; (2) diabetes is a chronic disease: patients have extensive and a sometimes lifelong experience with their illness, which may create a tension with certified knowledge about diabetes; and (3) ALS (or Lou Gehrig's disease) is a terminal motor neuron disease for which no cure has been found yet: this means that the quest for new therapies is of crucial importance for this patient group. We chose these three diseases because of their different positions in the spectrum of chronic diseases. We expected that the possibility to choose and the accompanying search for information would be relevant to all three patient groups, but in different ways.

The corpus consists of data from four Dutch online forums. Two of these forums were patient support forums devoted to diabetes and ALS, respectively. The two other forums were general forums ("VIVA" and "FOK"), with subsections devoted to diabetes and ADHD. We included 77 threads in the analysis: 32 about ADHD, 25 about diabetes, and 20 about ALS. The length of the threads varied from less than 10 to more than 300 posts.

We selected these data from a larger existing corpus (Van Berkel et al., 2015: 93) by first scanning the various threads on the basis of title and content. Threads that were not related to the disease (e.g. in the case of ADHD, when Ritalin was mentioned only in the context of another disorder such as autism) were excluded from the study. We purposively sampled the interactions by searching for threads in which either taking responsibility or being informed was at stake. We focused on instances of overt conflict and on threads characterized by a large number of reactions in response to one particular post, as an indication that there was something important at stake for the participants. We compared conversations both between threads and between various forums to identify commonalities and refined the analysis on the basis of deviant cases. We used a "sampling to redundancy" strategy, in which the analyst keeps sampling new interactions until the addition of

new interactions to the analyzed data does no longer yield novel analyses (Cresswell et al., 2014: 2). The extracts shown here provide the most illustrative examples of the practices we identified.

A discursive psychological analysis identifies patterns by looking at how recipients *treat* a particular utterance in sequential interaction, rather than considering the speaker's intentions or the truth value of the utterance (Potter, 2012). The first analytic tool is sequential analysis: what does the speaker achieve (consciously or not) by choosing this particular wording at this particular moment in the interaction? The second analytic tool is rhetorical analysis: descriptions are studied for their capacity to counter (actual or potential) alternative versions of reality. An important question is how participants build their descriptions in a way that heads off attempts to disqualify them as false or interested, for example, using extreme case formulations (Pomerantz, 1986) or adding particular details to pre-empt accusations of stake (Edwards, 1997).

The interactional rules that are relevant to face-to-face conversation do not necessarily exist in any online environment. For instance, whereas a failure to provide an answer is an accountable matter in face-to-face interaction, this is often not the case in asynchronous contexts such as an online forum, or even in a (synchronous) chat session. However, various other features relevant to a discursive psychological analysis demonstrably occur in online interaction (see, e.g. Lamerichs and Te Molder, 2003; Stommel, 2008). As in face-to-face interaction, online participants can engage in identity work, in this case by orienting to or re-establishing the (epistemic and other) norms of the online community in which they participate (e.g. Cranwell and Seymour-Smith, 2012; Giles and Newbold, 2011; Stommel and Koole, 2010).

Online forums typically provide a public space in which participants offer sensitive information that would be considered "private" in other, non-anonymous social contexts. The

threads presented in this analysis stem from “open” forums, which are available in the public domain without registration or passwords. Nicknames provide participants with anonymity. We adhered to the rules of each particular forum in our usage of the data and removed any identifying information in the excerpts presented here. Dutch excerpts have been translated for the purpose of this article: the original excerpts in Dutch can be obtained from the authors.

Analysis

ADHD: protecting certified expertise to maintain doctorability

ADHD is a frequently diagnosed but highly controversial mental disorder (see, for example, Edwards and Howlett, 2013; Horton-Salway, 2013; Singh, 2004). Various authors have observed how patients frequently treat a psychiatric diagnosis as empowering, because the

The diagnosis ADD was therefore a relief for me. I am not crazy or weird, I'm just different with a reason, (R&P _ P&P _ ADD _ ADHD—deel 12—forum.fok.nl.pdf, p. 93.)

diagnosis provides an account for problems that are otherwise difficult to explain (Giles and Newbold, 2011: 421; cf. Klasen, 2000). This type of reasoning often occurs in the analyzed threads, as illustrated by the next excerpt:

The explanatory value of this particular account depends on the exclusivity of the diagnosis of ADHD. It is only by maintaining the exclusivity of ADHD that interactants can protect the status of ADHD as a “doctorable” problem, that is, a problem “worthy of medical attention, worthy of evaluation as a potentially significant medical condition, and worthy of advice and, where necessary, medical treatment” (Heritage and Robinson, 2006: 58).

Forum users protect the exclusivity of ADHD by making a distinction between those who have been officially diagnosed with ADHD and those who merely have ADHD (like) symptoms. Interactants on ADHD forums therefore tend to protect, rather than challenge the knowledge of certified experts, emphasizing the importance of acquiring an ADHD diagnosis from a certified health professional, such as a psychiatrist. However, whereas forum users do not claim the knowledge to positively diagnose a case of ADHD, they *do* claim the right to determine that a particular list of symptoms—frequently offered by neophytes on the subject—is *not* sufficient to be diagnosed with ADHD. Participants are seen to collectively engage in boundary work to distinguish between those who genuinely suffer from ADHD and those who are perceived to be merely jumping on the bandwagon of a fashionable label (cf. Horton-Salway, 2007).

This becomes visible in the frequently impatient or outright negative reactions to “newbies” who are asking whether their complaints could be symptoms of ADHD, as shown in the excerpt below:

R&P _ P&P _ ADHD & ADD #27 Where we look at the dosages—forum.fok.nl

Tiny Post #35

1. When I look at the list below: [...]
2. only what has been bolded applies to me ...
[6 of 33 bullet points, authors]
3. Still, sometimes I think I have a form of ADHD..
4. It takes the most effort to concentrate on something
5. that doesn't interest me sufficiently.
6. (for instance on my job which I like,
7. I don't have problems staying focused),
8. Find it difficult to start studying or doing things for school.

9. Often many thoughts go through my head.
10. I still have to do this, and do that ...
11. and then I go do that ... etc ...
12. I would like to to focus on the things that matter,
13. such as school ...
- 14.
15. What do you think?

Tuck

Post #36

16. That you don't have ADHD.

Toggle

Post #38

That you don't have ADHD. [*quotation Tuck #36*]

17. that ... I believe there are 5 at the most
18. that I don't have ...

1

Tiny presents his complaints to the AD(H)D community in post #35, cautiously identifying himself as a potential ADHD patient. His proposal fails: other forum users deem his complaints insufficiently severe to be indicative of ADHD. The interaction shown here is followed by several other posts, in which users highlight the extensive listings of symptoms they themselves suffer from. In the absence of other certifiable information, having been diagnosed is an important credential in this particular online environment (Giles and Newbold, 2011: 420). Tiny's failed attempt to become part of the diagnosed in-group leads to a discursive strengthening of the boundaries of this in-group. By drawing on their own, allegedly far worse experience, participants protect the severity of the disorder, and with that its exclusivity. Kaufman and Whitehead (2018; cf. Hargreaves et al., 2018) observed that self-display and the display of commonly shared experiences is a key way in which empathy is collaboratively produced in online forums. The example shown here

suggests that the opposite is true as well: when one's offered experience fails to hit the mark, this might well lead to a demonstration of in-group antipathy.

The second way for forum users to assert the exclusivity of the disorder is by stressing the disadvantages of having to take ADHD medication. Outsiders often criticize ADHD medication as a secondary gain or unfair enhancement technology (see for this kind of use, for example, Cadwalladr, 2015). In a mirror image of these criticisms, forum users emphasize the *difficulties* of having to take ADHD medication, implicitly underlining the severity of the disorder which requires them to take this medication. Because users connect the use of medication to the legitimacy of the disorder, they collectively treat *not* taking medication as an accountable matter, even if this is presented as an individual decision. This becomes clear in the following thread, in which topic starter Ann announces her decision to abstain from medication despite being diagnosed with ADHD:

VIVA Forum—Psyche—AD(H)D without medication, who has good advice?

Ann

Post #1 [7 lines omitted]

1. I “swallow” now for over a week, but I have decided
2. that medication just doesn’t fit me.
3. Add to that that I find adhd a (sometimes difficult)
4. character trait, or perhaps better phrased;
5. a list with difficult symptoms
6. and not an illness for which I have to swallow medication
7. (this applies just to me personally,
8. I don’t want anyone to feel insulted because of this!)

[6 lines omitted]

2

Note how Ann presents the choice not to take medication in line 2 as a lifestyle change rather than a medical decision, yet carefully accounts for it. While asking for advice from others, she also explicitly stresses (lines 7–8) that her reasoning is relevant only to her personally and should not be treated as a statement about what others should do, suggesting that she expects it to be read in this way.

As the discussion continues, it becomes clear that various forum users do not heed this reading warning. The next excerpt is preceded by four paragraphs, in which the author describes the efforts and discipline necessary to structure her life. She then emphasizes that medication does not absolve patients from their responsibility:

VIVA Forum—Psyche—AD(H)D without medication, who has good advice?

Post #3 [15 lines omitted]

1. besides: you shouldn’t see medication as a kind of magic
2. that solves your problems.
3. I do use medication, because it makes some things just easier.
4. The medication does not give me structure and overview,
5. does not make my planning, I have to do that myself.

3

Other forum users treat Ann’s decision not to take medication as a choice with collective significance, as in the following response:

VIVA Forum—Psyche—AD(H)D without medication, who has good advice?

Abby

Post #12

Actually I’m not a proponent of medication for a psychological condition, because I think it does not remove the cause. [quotation Ann #1, line not shown in excerpt]

1. Have you been properly informed by your psychiatrist?
2. AD(H)D is a neurobiological disorder.
3. Neurotransmitters such as dopamine and noradrenaline

4. are not properly communicated to the nerve cells.
5. These substances are important for the concentration
6. and the selection of incentives.
7. This causes your behavior.

4

Abby starts by asserting her superior knowledge position, positioning herself as a spokesperson for the absent certified experts (line 1). The decision not to take medication, proposed by Ann as a lifestyle change, is treated by Abby as a knowledge deficit. Rather than using a subjective format, she provides an unmarked declarative statement ("ADHD is a neurobiological disorder," line 2), thereby claiming immediate access to the real, objective nature of ADHD (cf. Raymond and Heritage, 2006). In the next lines, she further elaborates her expert position in defining AD(H)D as a neurobiological disorder. Abby thus acts as a gatekeeper in establishing what counts as legitimate knowledge about ADHD while simultaneously upholding the authority of certified experts.

ADHD patients thus carefully distinguish between (those suffering from) real ADHD—diagnosed by certified experts—and symptoms that could mimic the disorder. Patients hold each other accountable for the realness and out-there-ness of ADHD, which makes it important to produce hard evidence for the disorder. Patients treat the seemingly individual decision (not) to take medication as a collective concern, because the seriousness of the disorder is at stake. Being informed here means adhering to the authority of certified experts; health professionals are the gatekeepers who protect the exclusivity of a disorder that is controversial, yet central to many patients' sense of self.

Diabetes: challenging certified expertise to maintain independence

Diabetes is a disease in which the body's inability to produce (enough) insulin causes elevated levels of glucose in the blood. The monitoring of these glucose levels, necessary to prevent or mitigate complications caused by diabetes, comprises an important aspect of the way in which diabetes patients experience a disease that otherwise can remain largely invisible. A key concern in the conversations between diabetes patients is to demonstrate that although patients have to adhere to the diabetes regimen, they can still lead a life independent of the disease. Challenging certified expertise and prioritizing their lived experience is one way for diabetes patients to acquire this independence. This is in sharp contrast with the previously discussed case of ADHD patients, who adhered to certified expertise in order to prove the serious nature of their disorder.

Given the importance of monitoring, it is not surprising that the exchange of blood glucose readings is a frequently recurring topic in all three diabetes forums of our sample. Patients treat successful management of blood glucose levels as a personal achievement, an example of taking responsibility for the disease. An example thereof is shown below:

Diabetesforum—Blood sugars [sic] not too low now

Tony
Post #1

1. I'm diabetic type 2
2. and have now been taking januvia for a week
3. Until my medication is well regulated
4. I have to test my blood glucose 6 times a day.
5. Since yesterday my blood glucose levels are
6. between 4, 5 and 6.
7. I wonder, is this not too low?

Tom**Post #2**

8. Wow, what good values! 🌟
9. The values are definitely not too low
10. they are beautiful
11. If you can keep it this way,
12. your blood glucose is like that of every person
13. without diabetes, so neat.
14. [...] Keep it this way, [name author post 1] 🌟

Thomas**Post #3**

15. Cool! 🌟

Tim**Post #4**

- (...)
16. Well done!
 17. I also test myself 6 times per day
 18. but I really don't manage to test 4, 5 in the morning
 19. rather between 7 and 8
 20. those values can really be called very good!

Tina**Post #5**

- (...)
1. Unbelievable, really very very neat!
 2. I hope that I may have such values in the future.

5

The low blood glucose readings, presented by topic starter Tony as a potential problem, are treated by the other members of the forum as a reason for congratulations and even admiration. Notice how the language used by the recipients suggests on one hand that good blood glucose readings are a matter of sheer effort (*good, well done, really very neat*), while allowing on the other hand for an element of unpredictability or even fate (*I hope that I may have such values*). Good blood glucose readings are a reason for congratulations, but the other side of the coin is that participants treat a failure to control one's blood glucose levels, or to take responsibility for

the disease, as a reason to feel guilty or ashamed.

It is perhaps because of this that patients regularly construct their blood glucose readings in an alternative way (cf. Peel et al., 2005): not as a result that can be understood if only one acquires sufficient knowledge and follows the rules in a disciplined way, but as a phenomenon that is ultimately a riddle and will always remain so. By emphasizing how blood glucose regulation in everyday life is complicated and its logic difficult to comprehend, patients carve out a space in which they cannot be held accountable for not achieving the readings they strive for, as the following excerpt shows:

Diabetesforum—Much too high, am I such an exception

1. Well I can't do more than my best
2. and even if I do exactly the same for 3 days
3. and eat exactly the same
4. my values will differ anyway!
5. So my motto is: I cannot do more than my best
6. and look critically at myself at regular intervals
7. but don't forget to enjoy the life
8. and sometimes just to accept higher blood glucose levels
9. Tomorrow new day new chances new rounds!!!
10. Keep it up everyone 🌞

6

Note how the author positions herself as a disciplined patient, a good diabetic who is *doing her best*. Despite her best efforts, her blood glucose readings vary in an unpredictable way. By stressing the difficulties in controlling

or even understanding their blood glucose levels, patients assert the epistemic authority of their lived experience relative to the theoretical knowledge of health professionals, as the next two excerpts illustrate:

*Viva- Diabetes country, p 126***Beth
Post 1**

Will really have to find out how that works exactly, with the metformine and then being unable to have hypos (as the medics always assert). *[quotation from previous post not shown here]*

1. Well yes, the medics who always assert everything ...
2. we know that by now, don't we?
3. As if everybody's body is the same and reacts the same.
4. Sure. Hmhm.

7

Viva- Diabetes country, p 97

1. Years ago I had the idea to start jumping rope
2. when my values were high.
3. Effect: before the rope skipping 11, afterwards 17.
4. Just like with walking in the forest with the dogs:
5. before 14, afterwards 20.
6. The diabetes nurse shakes her head in disbelief
7. and does not have any idea how that could be possible. 🤔

8

Beth reacts to a quotation, in which the patient's lived experience is contrasted with "the medics who always assert everything" (line 1). In her own post, Beth positions herself as a spokesperson of the patient community (*we know that*)

familiar with this tendency of M.D.'s to claim more than they know (the Dutch verb, *beweren*, has a decidedly negative connotation), arguing in line 3 that this theoretical medical knowledge fails to describe the more complicated reality of

their individual bodies. Similarly, in excerpt 8, a patient describes how her values reacted in a way that would seem counterintuitive (physical activity should result in lower values). In lines 6 and 7, she makes explicit that her experience baffled the diabetes nurse, employing an emoticon as sign of her exasperation.

Thus, whereas ADHD patients emphasized the authority of certified experts, diabetes patients stress the limits of the theoretical knowledge of medical professionals. It is precisely by emphasizing the unpredictability of their blood glucose levels that patients can reassert their epistemic authority and carve out a space in which not following the diabetes regimen does not make them a bad or irresponsible patient. While patients hold each other accountable for good blood glucose levels, they manage to claim a measure of independence from the diabetes regimen by treating their awareness of the unpredictability of blood glucose levels as a sign of knowing more, not less than the health professionals. Being informed means trusting embodied, experiential knowledge

rather than the theoretical knowledge of certified experts.

ALS: searching certified expertise to maintain hope

Patients with ALS suffer from a progressive degeneration of the motor neurons of the central nervous system, leading to a wasting of the muscles, paralysis, and ultimately death (Oxford American Dictionary). Paradoxically, patients with this terminal disease treat “thinking positive” as an accountable matter, even when health professionals are no longer able to help (cf. Gilbert et al., 2018). This influences their relationship with health knowledge and certified experts. Patients treat it as a moral duty both to be well informed about promising new therapies and to trust the experts developing these.

The following interaction has been initiated by the daughter of an ALS patient, a man whose condition deteriorated in 1.5 years from “hard working, vital” to “severely handicapped”. Post #1 provides an update of his condition:

stopals.nu/voorstellen ... p2

Greta
Post 1

[5 lines omitted]

1. We have tried everything but nothing stops this foul disease.
2.Update follows.....

Gemma
Post 2

3. Frustrating isn't it to see them deteriorating like that..
4. Enjoy the things that he is still able to do
5. and particularly the being together.

Gary
Post 3

We have tried everything but nothing stops this foul disease.
.....Update follows..... [quotation post #1]

6. hello [name], Unfortunately you are (still) right
7. The only thing that helps you through is a positive character
8. and a good temper, and luckily most people develop that
9. after a while—to the extent that they don't have it already
10. It is a fight that each of us has to overcome alone 😞

Greta finishes her message with a formulation of despair: despite their best efforts, ALS cannot be stopped. The first recipient, Gemma, reacts with a token of empathy. Doing this, she also refers to her own experience, thus building the epistemic authority to urge Greta to enjoy what is still possible (lines 4–5). Given the speed with which ALS often progresses, most patients are unlikely to profit from current medical developments, which typically progress at a much slower pace. The addition

(still) in post #3 (line 6) is therefore an example of optimism against better knowledge. Gary proceeds by making explicit the importance of developing (or having) a positive attitude as “the only thing that helps you through” (line 7) and constructing the illness as a fight that has to be won.

The next example, like the previous one derived from an introductory thread, also treats “thinking positive” as an act of will. The author of post #2 is the new member:

stopals.nu/hoi

Larry
Post 1

[5 lines omitted]

1. Aren't you afraid that you find it harder to cope
2. because you live alone?
3. (You're not the only one)

Leah
Post 2

1. It is not that easy to live on one's own,
2. I have a lot of help of friends and family.
3. I have a positive outlook in life,
4. I try lots of things to make me strong again.

10

The question in post #1 is formulated subjectively (“Aren’t you afraid”), but topic starter Leah answers it in an objectivist phrasing: “It is not that easy” rather than, for example, “I don’t find it easy”. She avoids the more personal terms provided by the question in post #1; grammatically, her response stands on its own and could easily

have been produced without the previous prompt. In her response, she avoids any display of negative emotions: her words are understated and almost standardized. It seems likely that this is a stock phrasing of positive attitude that has been produced repeatedly before, in the world outside this forum. We show a third example:

stopals.nu/Evenvoorstellen_DickS

Leanne
Post 1

Hello [name] Welcome to the site. Your story is another wretched one. I hope you will find lots of support on this site.

Don
Post 2

Yes, it isn't nice but one doesn't change it. I take the days the way they come and make the best of it. Together with my girl friend, who takes responsibility for almost all my daily care, we laugh a lot away each day.

11

As in the previous example, the expression of support is, as it were, shrugged off. The speaker in post 2 underlines his positive attitude, emphasizing the laughter instead of the wretchedness of this story. Rather than talking about feelings, participants limit themselves to idiomatic, standardized phrasings, irony and understatements, particularly in relation to complaints about the disease. In everyday life, such phrasings help speakers to avoid placing the recipient of the complaint in the potentially awkward position of working out how to respond (Edwards, 2005: 24). It is an interactional strategy that makes sense for sufferers from a disease that is both grave and rare and therefore somewhat of a taboo in the outside world. Antaki (2007: 536) described how mental health practitioners employed idioms to impose "'ordinariness' on sometimes extraordinary events and

feelings" and to normalize particularly negative experiences. The cases studied by Antaki took place in an asymmetrical and institutionalized therapeutic environment. That patients adhere to this strategy while among fellow-sufferers suggests that the possibility to share extremely negative experiences is even more limited than might have been expected.

Since there is no effective treatment for ALS, many late-stage ALS patients depend on trial participation or experimental treatment to acquire potentially promising medication. Patients treat it as a duty to be informed about new research regarding the disease. When they are unable to keep up with the developments or are no longer optimistic, they provide an account for this. The following excerpt is derived from an interaction in which patients discuss a promising trial that has now been shut down:

StopALS.nu/dexpramipexolefaaltinfaseI

Phil
Post 5

1. I know almost for sure that the majority of the readers
2. of this forum agrees with you, but there comes a moment
3. when you're a bit down from all the disappointments,
4. I have been here now for almost a year and
5. these kinds of things have been discussed so often,
6. both about legal trials and home-cooked concoctions
7. that turned out not to work. you become sick to death
8. of all those disappointments and this was presented
9. really very promising 🤔
10. the way it is, Just carry on 😊

Paul
Post 6

1. I prefer to be able to follow the developments
2. although it is indeed very frustrating

3. that they keep presenting “breakthroughs”
4. where you never hear from again.
5. And when something finally seems to happen,
6. like with “dex,” then it’s extra annoying
7. when it turns out to be nothing after all.
8. For me it was an important straw to grasp 🙄
9. Despite everything, fast forward, that’s what it’s about!

Patrick
Post 7

1. I, as well, understand the frustration
2. but was able to let it go so as not to lose focus
3. because of negative thoughts.
4. Of course I could get agitated too and be frustrated
5. but I don’t think that the research for a medicine
6. will be accelerated because of that and I rather keep my
7. scarce energy for something positive.
8. I hope and presume that the medics of the ALS centre make a
9. thoughtful choice regarding the purchase of a next trial.

12

Phil (post 5) does not complain about the lack of results as such, but rather about the contradiction between the high expectations and the disappointing results. Instead of complaining about what would seem the obvious complainable matter (in this case, the lack of medication able to stop ALS), the complaint focuses on a phenomenon that might seem marginal or incidental to this main complainable (the raising of high expectations). This is an example of displacement, a way of distracting others from the complaint’s seriousness or sensitivity and of showing the speaker’s “above-it-all coping attitude” (Edwards, 2005:17). Phil finishes his post with an idiomatic, upbeat phrasing, orienting to the forum norms of fighting ALS and thinking positive.

In post 6, Paul also orients to the duty of informing oneself. His post contains another example of displacement; he accuses “them”—the scientific experts—of presenting breakthroughs that then turn out to be disappointments. He also admits that, for him personally, the dex-pramipexole trial was an important source of hope, which would give him all the more reason to complain. Having given this personal statement, Paul concludes with another positive idiom in line 9 (“Despite everything, fast

forward, that’s what’s it about!”). By emphasizing that the important thing is an acceleration of research, he displaces his own complaint even further.

The subsequent post 7 presents perhaps the clearest example of orientation to the forum norms. Whereas Patrick expresses understanding for the frustration of his fellow forum members, he presents himself as a person for whom thinking positive is simply the rational option. His assertion that the professionals of the ALS centre can presumably be trusted to make the right choices (lines 8–9) is a further elaboration of his urge not to lose focus: the choices of these experts are, after all, utterly beyond his control.

The thread shows how ALS patients hold each other accountable for thinking positive, of which being informed is a crucial aspect. Whereas ADHD patients protected the authority of certified experts to uphold the exclusivity of their disease, ALS patients do so in order to be able to keep thinking positive (Table 1).

Conclusion and discussion

We employed a discursive psychological methodology to conduct a qualitative comparison of

Table 1. Different patient groups give different meanings to patient responsibility and to the accompanying duty of acquiring and assessing knowledge about the disease.

Patient community	Patients hold each other accountable for...	Patients treat as appropriate knowledge...	Patients' stance toward certified expertise
ADHD	The realness of the disorder	Official evidence of the disorder, such as provided by a diagnosis	Positive: experts are gatekeepers protecting the exclusivity of the disorder
Diabetes	Attaining good blood glucose levels <i>and</i> living a life not dominated by diabetes	Experiential knowledge of the disease, provided by living with it and knowing your body	Negative/critical: experts' theoretical knowledge is insufficient to understand the daily reality of the disease
ALS	Thinking positive	Self-acquired knowledge about experimental, possibly life-saving treatments	Positive: experts are responsible for possibly life-saving treatments

ADHD: attention deficit hyperactivity disorder; ALS: amyotrophic lateral sclerosis.

online conversations between Dutch patients with ADHD, diabetes, and ALS, respectively. Whereas each patient group orients to a norm of taking responsibility for the disease, of which getting informed is a key aspect, exactly what this means is different for each disease. Patients' stance toward expert advice as compared to individual experience varies depending on the norms for which patient groups hold each other accountable.

The ADHD patients in our study hold each other accountable for the realness of the disorder, stressing its severity and the extent to which they suffer from it. To protect the exclusivity of the disorder, patients emphasize the epistemic authority of certified experts as the only ones able to diagnose genuine ADHD. In contrast, participants in the analyzed interactions about diabetes routinely downplay their disease, in an effort to demonstrate their independence from the accompanying regimen. By emphasizing the unpredictability of blood glucose readings, patients carve out a space for not adhering to the diabetes regimen without being a bad diabetic. Patients treat their awareness of the unpredictability of blood glucose levels as a sign of knowing more, not less than certified experts. Being informed means trusting embodied, experiential knowledge rather than the theoretical knowledge and advice of health professionals. Finally,

the ALS patients in our study orient to a norm of thinking positive; what constitutes a complainable matter regarding the efforts of experts who conduct possibly life-saving research is a matter for negotiation. Patients hold each other accountable for thinking positive and being informed about experimental treatments is an important element thereof.

Online forums provide a space where patients can foreground their frequently complicated, lived experience, but these forums are not sheltered spaces; they reflect and mirror concerns as they are voiced in the world outside. In the previously analyzed interactions, ADHD patients emphasize that their medication does not bring joy or unfair advantage; diabetes patients struggle with the notion of diabetes (type 2) as self-inflicted and patients with ALS are careful not to show despair. Paradoxically, where demonstrations of hopelessness would seem to be expected, they are the least accepted and vice versa. ALS patients orient to a norm of hoping against hope, whereas patients with ADHD assert the irreversibility of their disease.

This comparative study adds to the existing literature by unraveling the complicated notion of "the" informed patient: being informed means different things for different patient groups. For ADHD patients, being informed

means adhering to the authority of certified experts, who have the ability to distinguish between real ADHD and bandwagon cases and thus to act as gatekeepers in protecting the disorder's exclusivity. Diabetes patients show much less reverence for the health professionals, who are treated as representatives of the limiting diabetes regimen. Diabetes patients treat being informed as a requirement to acknowledge that they themselves possess a more thorough awareness of their bodies than the theoretical knowledge of health professionals can provide. For ALS patients, being informed is a key element of positive thinking. Certified experts might provide them with a glimmer of hope. Even if there are reasons to be disappointed with certified expertise, this is not a complainable matter to ALS patients in the way it is for diabetes patients.

Our study sheds new light on the notion of informed patienthood (Dedding et al., 2011; Edwards and Howlett, 2013; Felt, 2015; Kivits, 2011), by showing that the relationship between certified and experiential knowledge, and their respective functions, may significantly differ between patient communities. The "evidence agenda" is important in all three environments, but what exactly is accepted as evidence, or credentialed as trustable expertise, radically differs between the three patient groups studied here.

The way in which patients accept or resist certified expertise is part of a broader interactional effort by which speakers position themselves as responsible patients, albeit in sometimes unexpected ways. ADHD patients' repeated emphasis on the disabling nature of their disorder—and their use of official diagnoses as further evidence thereof—is vulnerable to being heard as complaining. Yet, it is also one of the few ways to account for often severe problems, which would otherwise be constructed as failure or laziness. Diabetes patients contest certified expertise, but in doing so legitimize the messy experience of their bodies in everyday life—a knowledge type that is not necessarily regarded as legitimate by health professionals. Finally, ALS patients' search for

treatments is vulnerable to being seen by health professionals as 'patient pressure': an inability to accept what sadly cannot be avoided. However, in their ongoing search for experimental treatment, patients also fulfill the moral duty toward others and themselves to show that they keep thinking positive. The tailoring of knowledge claims thus helps patients to establish an informed and rational identity in taking responsibility for their own health.

The findings described above should not be seen as absolute: ADHD patients may undermine expert authority, diabetes patients can hold each other accountable for thinking positive, and ALS patients might sometimes voice highly emotional complaints. However, our analysis of the norms for which patients hold each other accountable in interaction, does point to different overriding identity concerns for each group. Awareness of these different concerns can explain why particular patient groups accept or reject particular types of expert knowledge (Versteeg, 2018; Versteeg et al., 2018). This, in turn, can lead to better understanding and thus help to improve the relationship between patients and health professionals. Patients may cherish or challenge expert authority, not for the sake of expertise itself but to achieve particular, interactional purposes within a socially, morally, and/or scientifically contested environment, as shown in the cases above. These interactional dynamics become visible only when we study the way in which norms are established and re-established in real-time conversations. A thorough study of the way in which patients make expertise—certified or experiential—relevant to their conversations, helps to gain insight in patients' concerns. Vice versa, a better understanding of the way in which particular patient groups give meaning to responsible patienthood can be an important step toward clarifying seemingly contradictory attitudes toward expertise.

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