“How do you know?”

Everyday negotiations of
expert authority

Wytske Versteeg

Propositions

These propositions are a part of the thesis: “*How do you know*”, *everyday negotiations of expert authority*.

1. It is impossible to have or analyse a conversation with ‘the public’.
2. Scientists need to study the facts of actual interactions before claiming that facts have become merely an opinion. *This thesis*
3. We lack a language with which to discuss what matters, other than by disputing offered facts, research, evidence and other claims to truth. *This thesis*
4. “What we actually want is an independent study with which all of us can agree.” *Subject in this thesis*
5. Rather than lamenting the death of truth, we should (re)consider the consequences of our necessarily incomplete grasp of it. *This thesis*
6. One of the characteristics of opinion is that it’s something lay people are entitled to have when they’re not entitled to have knowledge. *Harvey Sacks*
7. The dream of reason didn’t take power into account. *Kenneth Starr*
8. Within any given system, there are claims which are true but which cannot be proven to be true. *Gödel’s incompleteness theorem*
9. Warum so viel Erkenntniss, die meistens in der Welt ist, meistens unfruchtbar bleibt: vielleicht weil sie sich selber genügt und selten auch noch die Kraft hat, sich auf den andern zu beziehen. *Max Frisch*.
10. Contemporary science would benefit from being considered, as Barthelme described writing, an art of not-knowing.

Wytse Versteeg
Delft, November 2018

“HOW DO YOU KNOW?”
EVERYDAY NEGOTIATIONS OF
EXPERT AUTHORITY

DISSERTATION

to obtain
the degree of doctor at the University of Twente,
on the authority of the rector magnificus,
prof. dr. T.T.M. Palstra,
on account of the decision of the graduation committee,
to be publicly defended
on Wednesday the 19th of December 2018 at 12.45 hours

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Cover design and lay-out: Casper van Tilburg

Printed by: Ipskamp printing

ISBN: 978-90-365-4692-8

DOI: 10.3990/1.9789036546928

The WTMC Netherlands graduate research school of Science, Technology and Modern Culture partially funded the printing of this thesis.

Cover-image and chapter-images by the author.

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Wytske Versteeg

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1

F: You don't know what you're talking about

M: I don't know what I'm talking about? I give you the facts

F: don't give me your fa:::::cts! what facts?

Still from The Master

Chapter 1

**Between talk and the real discussion:
scientific expertise and everyday morality**

Chapter 1

Between talk and the real discussion: scientific expertise and everyday morality

1.1. Introduction: the real discussion

I recently attended an expert meeting that had been organised to present research into online utterances regarding various Dutch environmental policies. When the results were shown on a large screen, the experts described the online utterances approvingly as a probe or sounding line that would enable them to learn more about citizens' sentiments. This view changed, however, as soon as the utterances became more critical. Rather than focusing on the environmental issues, the anonymous online authors used their comments on these issues as a way to voice vehement complaints about greedy, corrupt politicians. "It would be so nice", sighed one of the experts, "if we were able to distinguish between all this talk and the *real* discussion."

Since the Enlightenment, science plays a crucial role in the collective sense making of western societies, that is: in the societal attempt to distinguish between talk and the real discussion, between the subjective and the objective, between lies and the truth. In recent years, however, there seems to be a growing concern that science is no longer taken seriously, but has become one opinion among others, and carries less truth value than personal experience (e.g. Gabriel, 2004; van Zoonen, 2012; van Zoonen et al., 2007; but see Kerr et al., 2007; Felt et al., 2009; Pomerantz, 2002). Oxford Dictionaries chose 'post-truth' as word of the year 2016, and defined post-truth as an adjective "relating to or denoting circumstances in which objective facts are less influential in shaping public opinion than appeals to emotion and personal belief."¹ Kakutani (2018) speaks about "a disregard for facts, the displacement of reason by emotion", and Nichols (2017: xi) complains that: "what I find so striking today is not that people dismiss expertise, but that they do so with such frequency, on so many issues, and with such *anger*." If Nichols' claim is true (but see, for instance,

¹ <https://en.oxforddictionaries.com/word-of-the-year/word-of-the-year-2016>, accessed August 14, 2018

Institute for Government, 2016), the question is where this anger comes from. Why becomes the seemingly innocent question ‘how do you know’ often so contentious?

The public debate about a ‘post-truth society’ shows a nostalgic longing for a past (an implicit ‘truth society’) that probably never existed. It is also rife with often dichotomous images of lay publics and experts. For instance, Nichols (2017: xii; see also Frankfurt, 2006) describes the people dismissing expertise as self-righteous and narcissistic, whereas an editorial in the *New Scientist* after Brexit described experts as ‘those on the side of rationality’ who needed to ‘take back control’.² Experts should should ‘know how to speak truth not just to power, but to ordinary people’. According to the editorial, this could be done by ‘speaking the emotional language’ that was used by the Leave-campaign—a suggestion fully in line with the Oxford Dictionaries’ definition of post-truth.

It has famously been argued that science cannot tell us ‘how to live’, but should present us with the facts and remain disinterested (Weber, 2009; Merton, 1942). In practice, scientific expertise often does have a bearing on our ideas as to what constitutes a good life, or what is the proper way to behave. To borrow a phrasing from Jasanoff and Simmett (2017: 756), “questions of what and how we should know go hand in hand with questions of how we should govern”. Because this is true not only on a political level, but also on a personal level (e.g. Shapin, 2007), negotiations about expertise are not the prerogative of scientists, but occur ubiquitously in processes of mundane reasoning (Pollner, 1987). They are, in other words, the subject of those everyday conversations that would be typically regarded as talk, rather than qualify as real discussions.

In this thesis, I ask what interactants themselves treat as authoritative expertise in those everyday conversations. How are claims to expertise built, challenged and negotiated? What is at stake when speakers claim a specific type of knowledge, such as certified science or personal experience? Statements such as those from Nichols quoted above already indicate that the design and contestation of knowledge claims have moral consequences, yet attempts to redraw a boundary between allegedly rational experts and emotional ordinary people seem short-sighted and potentially undemocratic. An analysis of how

² <https://www.newscientist.com/article/mg23130803-500-post-brexite-experts-need-to-reassert-their-value-to-society/>

expertise is employed in interaction may help to move beyond such dichotomous images of emotion and rationality. Here, I use conversation analysis and discursive psychology to find out what we actually *do* when we struggle about expertise, and how we negotiate the relation between what we (claim to) know and who we are. In short, this thesis focuses on what we achieve by asking that seemingly innocent question: *how do you know?*

In this introductory chapter, I will first elaborate on the dichotomous, but interrelated images of science (1.2.1) and lay publics (1.2.2). From these relatively static images, I will move on to a discussion of expertise in action, and of the moralities associated with the notion of expertise as an ‘entitlement to speak’ (Meyers, 2004) (1.3.1). The negotiation of expertise cannot be studied in the abstract. Therefore, I have selected a main case study for the empirical research in this thesis: Attention Deficit Hyperactivity Disorder (ADHD). My interest lies in the negotiation of expertise rather than in ADHD as such, and in the empirical chapters I will compare the negotiations about expertise regarding ADHD with expertise negotiations regarding vaccination, aspartame, diabetes and ALS. The emphasis throughout the thesis lies, however, on conversations about ADHD. In 1.3.2, I will therefore briefly sketch the context of this field, to which both experiential and scientific knowledge claims are highly relevant. I conclude with a problem statement, before describing my approach and research questions (1.4.1), and the data with which I worked (1.4.2). I conclude with an outline of the rest of the thesis (1.4.3).

1.2. Solving societal reality disjunctures: science, lay publics and the truth

Melvin Pollner (1987) coined the term reality disjunctures for contradictory experiences of the world, where it is not yet clear which of these competing versions will prevail as definitive. In order to solve such a reality disjuncture, one of the contradictory experiences needs to be ironised and treated, for instance, as the consequence of a mistake, impaired sight, rationalisation or denial. In other words, a decision needs to be made which of the competing experiences is seen as true and consequential. The same holds true for debates about public facts: a choice needs to be made which of the competing societal realities is regarded as truthful, and treated as consequential for political behaviour

(Jasanoff & Simmet, 2017: 752). Dichotomous images of lay publics and scientists frequently figure in discussions about such societal choices. These characterisations convey various ideas about what the role of science in society should be, and how the lay public should relate to scientific expertise. I will therefore discuss these characterisations first, before moving on to the notion of expertise itself.

1.2.1. Science and morality: between basement and ivory tower

When Chambers (1983; cf. Finson, 2002 for a later overview of comparable studies) asked school children to draw a scientist, seven elements appeared consistently in the resulting images. Scientists would be wearing a lab coat and eye glasses, and typically sport facial hair growth, such as a beard, moustache or long sideburns – as this list already suggests, children imagined scientists to be male rather than female (and white rather than black). The depicted scientists would carry symbols of knowledge and research, such as books and laboratory instruments, respectively. Drawings might furthermore show the technological products of science, and captions such as formulas or the ‘Eureka’ exclamation. Another striking feature was that almost all scientists would be working indoors, sometimes in basements and at least according to some children accompanied by signs such as ‘Secret!’, ‘Keep out!’ and ‘Private!’.

These drawings of the ideal typical scientist refer both to the identity of the scientist himself – signified by lab coats, books and laboratory instruments – and to the knowledge he can claim as a consequence of that identity. Depictions of scientists as male Caucasians are suggestive of the way in which societal inequality is reflected in universities, whereas signs to keep out point to the fact that knowledge might be produced for some and not for others. The figure of the basement scientist working on secret projects is not unique to children’s drawings: it commonly occurs in blockbuster movies. For instance, *The Amazing Spiderman* (2012) neatly shows some typical anxieties about science spiralling of control; as the movie proceeds, the scientist – who started his project from noble intentions – grows increasingly mad, megalomaniac and dangerous and ends up working underground, gradually transforming into a lizard. Faust and Frankenstein provide the literary example for this narrative scheme, in which the scientist acts as a sorcerer’s apprentice by tinkering with the kind of knowledge of which he fails to grasp the potential danger. Likewise,

when in February, 1997 the newspapers reported about the cloning of sheep Dolly, they feared not only for science *out of* control as in the Frankenstein-story, but at least as much for science *in* control, a depersonalising rationality symbolised by Brave New World (Huxford, 2000). In this imagery, it is not the individual scientist who is feared. Rather, the horror lies in the image of a society fashioned after a scientific, de-individualising and de-humanising way of thinking. Here, the innocent scientist's enthusiasm for pure knowledge has become either uncontrollable, or it is actively abused by the corporate and governmental powers that be.

The imagery of the innocent, enthusiastic scientist frequently implies that abstract, scientific knowledge can only be acquired to the expense of down-to-earth knowledge, and the associated estimation of risks. An example can be found in this excerpt from a story by Alice Munro (2011: 209):

They had lost touch with reality. Educated people, literary people, some rich people like Grant's socialist in-laws had lost touch with reality. (...) That was how Marian would see him, certainly. A silly person, full of boring knowledge and protected by some fluke from the truth about life. A person who didn't have to worry about holding on to his house and could go around dreaming up the fine generous schemes that he believed would make another person happy.

This is the ivory tower-scientist with his head in the clouds, protected from the realities of everyday life. As Shapin (2012) describes, the notion of ivory tower was originally invoked to speak about artistic retreat, and not necessarily in a negative way. Yet in the first decades of the twentieth century, the ivory tower was transferred to other domains in order to describe those who did not fully partake in life, those who were out of touch. When the Second World War broke out in 1939, the trope became positively derisive; whoever at that point still tried to hide in the ivory tower were in need of correction. As many scientific disciplines became enfolded in military, commercial and civic life, the ivory tower became something to get out of, to go beyond or to demolish altogether. (Interestingly, an early study of science fiction found that the percentage of heroic characters that were scientists was 44% in the prosperous period of 1926–1929, but only 24% in the period after the Second World War (Hirsch, 1958: 508).

The ivory tower-scientist works from a position that is elevated from the rest of society and is because of that very reason unaware of the struggles and questions of the ‘plain, reasonable, working man’, as Tolstoy (1898) put it in an early criticism of science. This reasonable working man would suppose, “*in the old way which is also the common-sense way*”, that scientists, who are, after all, paid for and kept by these reasonable working men, would be studying precisely those topics that these men need to know. That is, he:

expects science to tell him how he ought to live; how to treat his family, his neighbours and the men of other tribes, how to restrain his passions, what to believe in and what not to believe in, and much else. But what does our science say to him on these matters? It triumphantly tells him how many million miles it is from the earth to the sun. “But I don’t want any of those things”, says a plain and reasonable man – “I want to know how to live.”

Science, one might paraphrase Tolstoy’s critique, provides knowledge that is simply irrelevant to members of the public, because its triumphs do nothing to help them with their lives—an imagery that is the exact opposite of the previously mentioned fear that science would overtake everyday life.

The ivory tower scientist has his head in the clouds; the basement scientist invents things that might seem promising to him, but will creep up to you dangerously and unexpectedly from some dark corner. If these two images are two sides of the coin that constitutes a highly negative image of science, the scientific amateur might be described as their positive counterpart.

It is now almost a century ago that Weber tried to nuance the idea of science as a vocation, pointing to the bureaucratisation of science that was already common in the US at that time. He compared this development to ‘what happened to the artisan of the past’ (2009: 131), and was sure that this Americanisation would also ‘engulf those disciplines in which the craftsman personally owns the tools, essentially the library’ (ibid.). Now that this bureaucratisation has indeed taken place, the scientist-amateur with his own library seems to have become an ideal to be craved for—a development that is perhaps not unlike the way in which artisan bakers figure prominently in commercials for supermarket bread. The scientific amateur is a scientist because he loves science and has devoted his life to its cause. Unhindered by any

expectations concerning societal or financial status, this scientist stays with his books and instruments in an effort to uncover the truth of whichever phenomenon has captured his interest. A striking example of this image can be found in the following quotation, from the Dutch newspaper *De Telegraaf*:

*Everything about Rörsch breathes science. The Walloon library, where he shares an apartment with his wife, is according to research into the wooden roof, the oldest stone building in Leiden. "From around 1300." Professors from the flourishing Leiden university used to host students here. Nowadays, Rörsch lives there between a daunting pile of books and regularly invites people to the long wooden table for discussions. About climate, for instance. "Primarily the sceptics are willing to join. The adherents of the greenhouse hypothesis do not visit me yet."*³

At the time of this article, *De Telegraaf* actively criticised the scientifically widely supported thesis of anthropogenic climate change. Yet the newspaper presents Rörsch, a microbiologist and fraud specialist and therefore far from an expert in this particular field, as a typical 'amateur' scientist; in a library, amongst a daunting pile of books. Interestingly, *De Telegraaf* here draws on an early modern image of the gentleman scientist, for whom there was no separation between house and workplace, and who would be trusted as an individual or as member of a social class, rather than as a representative of an abstract system (Shapin, 1994).

The images of science as described above are a far cry from any actually existing scientific practice, but they are important because they tend to frame debates, both in the media and in the science communication literature. We can roughly discern the two faces of the dichotomy that Hedwig te Molder (2011: 12) described as grim technology and happy science. Happy science shows us the scientific discovery but not the often messy process that precedes it, whereas grim technology focuses only on the potential dangers of new scientific developments. Happy science, one might argue, is happy precisely *because* it does not concern itself with everyday life; it consists of the discoveries that we read about in the science-section of the newspaper and it remains safely contained within that space. Likewise, the scientific amateur can be trusted because he is not embedded in the bureaucracy of a potentially powerful and corruptible

³ 'Klimatologie zieke wetenschap', *Telegraaf*, 13-12-2009

organisation. And whereas the ivory tower scientist might not be useful to society, he is also unlikely to harm it. The basement scientist, however, tinkers with knowledge that may trespass on other domains. Here, we see a foreshadowing of the expert, rather than the scientist as such. As long as scientists remain in the ivory tower, lay people will typically not bother them with protests. Whereas “particle physics is hard to understand and often counter-commonsensual, this is not a problem for the laity”, argues Steven Shapin (2007: 174), because it “is not an expert practice that they care much about”, and they simply let the experts “get on with it”. As soon, however, as scientific knowledge touches on Tolstoy’s question – ‘I want to know how to live’ – it becomes vulnerable to vehement contestation by ‘the public’.

1.2.2. Publics and morality: between common sense and catharsis

If narratives about science tend to follow particular symbolic schemes, these schemes imply particular definitions of the lay public, too. In the case of the basement scientist, the public seems passive and vulnerable; a victim of inventions thrust upon them by scientists. The public counterpart to the ivory tower scientist as described by Tolstoy and Munro, on the contrary, is plain, reasonable and full of common sense. If someone seems vulnerable in this description, it is the scientist himself. These images are normative, rather than just descriptive; the notion of the ivory tower scientist implies that science should be useful for society, whereas the idea of the basement scientist suggests that science has to be kept in check (cf. Weingart et al., 2003).

Images of the public have this same normative quality. In his study of nanotechnologists, Rip (2006: 357) asserts that:

members of the public are seen as empty vessels, to be filled with understanding of science to avoid emotional reactions running riot (...) The rational-emotional divide continues to be a natural way (and a resource) for scientists and technologists to position the public.

At the start of this introduction, we already encountered this idea of a primarily emotional public in some of the statements about the ‘post-truth society’. Marris (2015), working in the field of synthetic biology, describes the public as both omnipresent and disembodied. Whereas lay people are never physically present, their imagined counterparts hover around. These imagined publics are

either indifferent, passive and easily swayed by information; or terrifyingly overactive, entrenched in their views and intent on shutting down the field. In general, the public is seen as a possible obstruction to public benefit. Likewise, Welsh and Wynne (2013) describe three ways in which publics have been imagined post World War II: as passive non-entities (1950s–1990s, and continuing), as incipient threats due to a presumed knowledge deficit (1990s–2000s, and continuing), and, since circa 2000, as politicised threats to ‘our way of life’ (Aho et al., 2006: 9), even requiring state control.

Braun & Schulz (2009) discern three different meanings of ‘the public’, with each meaning assigning a different task and role to the public. The ‘authentic public’ or ‘affected public’ would be able to emotionally educate the experts because of its own intimate, first-hand experience. Personal interaction with this carefully selected public would presumably have a “cathartic effect on the traditional experts” (2009: 412). For example, the UK based Food Standards Authority, an institution established in the aftermath of the BSE crisis, invited consumer representatives to sit on its expert advisory committees. These public representatives were assigned a highly specific task:

And there would be this high-level discussion, highly technical quite often, about what the risks might be. And she [the consumer representative, WV] would sit there, and in the end she couldn't contain herself any longer and she would say "I want to know whether it's safe for me to give lamb to my children." And she would bring them down – this is really what we need to know. We don't need to know whether a prion is in a particular way in this part of the body or that part of the body. And although there may not be an answer to the question, "Is it safe to give lamb to my children?", it was forever bringing them back to what they were really there for, where they might sometimes just get very excited about highly technical issues which may or may not be relevant to you or me. (Hajer, Laws, Versteeg, 2009)

Note how this perspective, while attributing an important role to the affected public, essentially follows the rational-emotional divide described by Rip. Apart from the affected public, Braun & Schulz (2009) discern three other ways in which the notion of ‘the public’ is discursively employed: the general public, the pure public and the partisan public. The voice of the general public can be heard only via surveys and opinion polls; it is a public that has to be elicited and interpreted by experts. The pure public consists of citizens without a strong

opinion on the subject at hand; citizens who are willing to be educated by the experience of deliberation. The partisan public, finally, is the ‘bad public’, consisting of organised, politicised individuals, ‘opiniated troublemakers’ (2009: 413). The public thus seems to be tasked with a highly specific and limited role. In its authentic task, it is expected to add emotion, or genuine experience to the debate. To the extent that it is asked for an opinion, this shouldn’t be a settled one; if that happens, public emotion is seen as frightening and as an impediment of progress.

More nuanced views argue that publics cannot be seen apart from the methods and settings that create them (e.g. Irwin, 2001). For instance, Michael (1998: 322) warn that various social scientific methods – whether these are questionnaires or ethnographic studies – (re)produce various versions of the ‘lay public’, thus feeding ‘back to ‘the public’ versions of itself’. Hess (2011: 627) describes a common scientific notion of the public as follows:

the public is composed of individuals (rather than organizations or even networks of organizations) who form opinions about science and technology; and the individuals are holders of lay knowledge in the sense that they lack the expertise of the particular science and technology in question, even if they hold occupational and local knowledge that may be relevant to assessing or interacting with scientific and technological expertise.

Whereas such a social scientific perspective describes lay people as reflexive rather than dangerously emotional, it also attributes a very particular and slightly romantic type of knowledge to them: localised, practical and situated in a coherent community—Wynne’s (1996) case study of the Cumbrian sheep farmers is the most famous example. Various authors have criticised this romantic image (Hess, 2011; Michael, 1998; Durant, 2008; but see Wynne, 2008), and even argued that this is the public deficit model turned upside down (Hess, 2011: 628). Whereas a public deficit model (Simis et al., 2016; but see Nerlich, 2017) traditionally assumes that the public needs more information (facts) to be persuaded of the value of science, here, the powers that be – including science – are seen to be in need of public reflexivity. Here, too, the image of the public and that of the scientist are interrelated. The romantic image of the lay local strongly resembles that of the plain, reasonable man who, by asking ‘how to live’, helps to keep science in check. Like the previously mentioned, simplified images of lay publics, it fails to take into account that

these publics in contemporary western societies intimately and continuously interact with scientific expertise.

Static images and folk theories of scientists and laity tell us something about the role of knowledge in the normative order of society. Building an authoritative knowledge claim depends, after all, on the ability to ensure that this claim to expertise (whether in the shape of common sense or scientific facts), rather than its competitors, is taken as truthful and consequential.⁴ But knowing *that* simplified and often exaggerated images of scientists and publics are used to negotiate societal reality disjunctures, does not help us to understand *how* expertise is claimed and challenged in the granularity of everyday life. It is to this everyday interaction with expertise that we will turn now.

1.3. The morality of expertise

1.3.1. *Expertise as an entitlement to speak*

The term expert is originally derived from the Latin *expertus*, past participle of *experiri*, and thus literally means someone who has tried. Yet we typically regard the expert not as a person with hands-on experience, but rather as someone who is able to interpret and explain the characteristics of a particular topic or area. An expert is someone with authoritative knowledge on the subject. This means, according to the Oxford Dictionary, that his or her knowledge can be trusted as accurate or true and reliable. Being an authority, the expert is – still according to the dictionary – commanding and self-confident, unlikely to be improved upon yet likely to be respected or obeyed; his knowledge flows from an official source and therefore requires compliance. Whereas Tolstoy criticised the inability of science to engage with the meaning of life, Max Weber warned against the impossibility and undesirability of such authoritative, ‘scientifically pleading’ for practical and interested stands. In contemporary society, however, scientific knowledge is frequently employed to do just that: to build or challenge an argument, to support a case or, more in general, to claim an entitlement to speak (Meyers, 2004). An expert, Giddens (1994) explains:

⁴ For instance, as Pollner (1987: 8) puts this: “*when the virtuosity of science’s systematical nature is displayed, it is displayed in contrast to the more or less chaotic character of common sense knowledge.*”

is any individual who can successfully lay claim to either specific skills or types of knowledge which the layperson does not possess. 'Expert' and 'layperson' have to be understood as contextually relative terms. There are many layers of expertise and what counts in any given situation where expert and layperson confront one another is an imbalance in skills or information which – for a given field of action – makes one an 'authority' in relation to the other.

In contemporary western society, no one can be an all-round expert, which makes everyone a layperson in all fields outside his or her specialisation. We trust the pilot to fly the plane in which we sit; but the pilot trusts the GP for an understanding of her body, and the GP might in turn have to trust the psychiatrist if her child is diagnosed with ADHD (cf. Warren, 1996). All these forms of expertise are situational, defined and claimed in a particular context; but they are also based on “impersonal principles, set out and developed without regard to context” (Giddens, 1994: 85). Weber has argued that one of the underpinning principles of this trust in the expertise of others is the idea that, although we do not understand the workings of the plane, our body or brains as of yet, we would be able to understand it if only we had chosen a different career path (cf. Giddens, 1994: 89; Warren, 1996). Weber (et al., 2009: 139) called this disenchantment: we can count on the predictability of a streetcar, although we are unaware of its technical details, because its workings can, in principle, be calculated. There is no mysterious force that may or may not grant the streetcar the ability to move; there is merely a process that we could understand if only we would take the time to master it. However, whereas we might in principle be able to understand the workings of the streetcar, in practice there are far too many topics such as the workings of the streetcar for us to be able to personally understand all of them. This means that we all depend on experts, and on the abstract systems that they represent (Giddens, 1990).

Science becomes controversial as soon as it touches on the question ‘how to live’. Can we continue living in the way we are used to without causing worldwide catastrophe? Should we vaccinate our children? What constitutes healthy eating? How should we raise our children? Are we our brains? Lay publics may look to experts for answers – see the bestsellers written by scientists about, for instance, dieting or neuroscience – but will likely also contest those answers when given.

One reason for this contestation – and a central theme in this thesis – is that seemingly scientific debates frequently hide political or moral concerns. For instance, Brian Wynne (2003: 409) argues that western societies “have successfully ‘closed’ many questions of issue-definition and meaning under the institutional presumptions that (...) the issues are scientific, where we should first gain the facts (for example, ‘what are the risks?’) and only then allow human values to be voiced.” Expert claims are inherently transgressive, because these claims must a) respond to issues that are never solely technical or scientific and b) address an audience that never consists of scientists alone (Nowotny, 2000: 16). The expert status is not a given, but needs to be re-established—at each stage of a controversy (Limoges, 1993: 418; Hajer, 2009), but also throughout the different turns of a conversation (I will elaborate on this below). Sociologists of science have shown how the identity of the scientific expert needs elaborate staging (e.g. Hilgartner, 2000). Scientists take care to portray themselves and the limits of their knowledge in different ways depending on the audience they address (Mulkay and Gilbert, 1983). Previous studies have shown convincingly that words matter in this struggle about the entitlement to speak. For instance, in the context of aids activism, Steve Epstein (1995: 419) observes that:

Indeed, the remarkable fact is that once they acquired a certain basic familiarity with the language of biomedicine, activists found they could also get in the doors of the institutions of biomedicine. Once they could converse comfortably about viral assays and reverse transcription and cytokine regulation and epitope mapping, activists increasingly discovered that researchers felt compelled, by their own norms of discourse and behavior, to consider activist arguments on their merits.

It was not merely the *knowledge* of words such as cytokine regulation and epitope mapping that helped activists to enter the world of ‘real science’. It was their ability to ‘*converse comfortably*’ with these words that helped them to access the world of biomedical research. Only by becoming experts themselves, the activists acquired the ability and the entitlement to speak in the scientific community on whose accomplishments their fate depended.

This ability to understand and speak the language of experts was proposed as a criterion for evaluating expertise in a controversial article by Collins & Evans (2002; cf. Wynne, 2003; Jasanoff, 2003; Rip, 2003). In *The third wave of science studies*, Collins and Evans took the problem of extension as their starting point;

the assumption that “the lay contribution to technical assessments has sometimes gone too far” (2003: 436; 2002). Their division of expertise in the categories of ‘no expertise’, ‘interactional expertise’ and ‘contributory expertise’ is interesting from a theoretical point of view, and the need for a “reconception of expert knowledge as something special” (2002: 437) seems by now to have been widely recognised. But it is difficult to see how the distinctions that these authors propose can make a practical contribution to science/society interactions. After all, the bone of contention in struggles about expertise is precisely the question which and whose knowledge should be treated as consequential, and where the boundaries of expertise should be drawn. Rather, therefore, than assuming that such boundaries can be drawn from an outsider’s perspective, I focus in this thesis on the question how these boundaries of expertise are negotiated in interaction. When do interactants treat expert knowledge as something special, and when don’t they? This question cannot be answered in the abstract, but only by studying actual conversational practices. Collecting such conversations requires to zoom in from expertise in general, to the expertise negotiations regarding a particular topic. For my analysis of expertise negotiations, I focus on contested health phenomena, such as vaccination, diet, and – in particular – Attention Deficit Hyperactivity Disorder (ADHD). ADHD is a field to which both scientific and experiential claims to knowledge are highly relevant and morally consequential, which makes it a interesting case to study the negotiation of expertise. I will elaborate on this in the next paragraph.

1.3.2. Expertise in everyday life: the conflicting realities of ADHD

“ADHD is just a brain disease”, proclaimed the Dutch newspaper *Trouw* in bold lettering (Waterval, 2017). “Nothing is gained from expensive brain study”, reads the headline of an opinion piece in the same paper only a few days later (Batstra, 2017). The main author of this “expensive brain study” argues, on the contrary, that regarding ADHD as a brain disorder will remove stigma, because ADHD is “more than just a difficult child.” Too often, the first article proceeds, do people ask this researcher whether ADHD does actually exist. ‘Isn’t it just a bad upbringing, one hears. So, no: we see differences in the brain.’ Almost exactly 115 years earlier, physician George Still (1902) had started his Goulstonian lecture to the Royal College of Physicians as follows:

Mr. President and Gentlemen, — The particular psychological conditions with which I propose to deal in these lectures are those which are concerned with an abnormal defect of moral control in children. Interesting as these disorders may be as an abstrused problem for the professed psychologist to puzzle over, they have a very real practical — shall I say social? — importance which I venture to think has been hardly sufficiently recognised.

Although Still was not the first physician to describe symptoms that are currently associated with the disorder known as Attention Deficit Hyperactivity Disorder, both skeptics and advocates of the validity of ADHD consider his lectures as the scientific starting point of the syndrome (Lange et al., 2010; Rafalovich, 2001).⁵ Of particular importance was the connection Still made between the notion of imbecility — at that time a medical term, used for persons who failed to meet the demands of conventional institutions — and the morality of children (Rafalovich, 2001: 98). Still himself did not mention a diagnostic term for this ‘abnormal defect of moral control in children’, but since his lecture, more than 20 different diagnoses have been applied to children who exhibit problematic hyperactivity, restlessness and inattentiveness (Mayes & Rafalovich, 2007: 436), ranging from minimal brain damage (and later minimal brain dysfunction) to hyperkinesis.

The most common form of drug treatment for ADHD, Ritalin, came on the US market in 1955. Singh (2002: 584) describes how this medication was introduced into a context in which mothers were seen as potentially toxic to their sons, and had to rely on expert advice to avoid becoming an impediment to their boys’ development: “The ‘scientific attitude’ according to one columnist” [writing in 1958, WV], “pervades everything we see, think and know —including our functioning as parents and as people”. In 1976, Peter Conrad used hyperactivity as the central case in his seminal study on medicalisation.⁶ He characterised hyperactivity as an expert category, which unwarrantedly couched childhood behaviour in medical terms: “By defining a problem as medical it is removed from the public realm where there can be discussion by

⁵ Claiming a more or less linear history for a contested phenomenon is not a neutral act. Situating the starting point or discovery of a mental disorder in the past often amounts to a claim to ‘realness’, because it implies that the disorder has had a continuous history as a single phenomenon. This is often a simplification: see Hacking (e.g. 1999, in particular chapter 4) for a criticism of this idea.

⁶ Rafalovich (2001) dryly remarks that, for Conrad and others, ADHD served merely as an empirical example of pre-existing sociological ideas.

ordinary people and put on a plane where only medical people can discuss it” (Conrad, 1975:18; cf. Conrad, 2007).

By now, problematic inattentive and hyperactive behaviour has become one of the most commonly diagnosed mental disabilities in the western world, and ADHD has been described as an almost ‘iconic’ disease, the focal point for various worries about the future of children and of society in general (Singh, 2002: 578). These worries range from concerns about the feminisation of education via those about school quality and excessive computer use to concerns about the loss of normal childhood, boyhood in particular, and the increasing medicalisation of society. The heated nature of many public discussions surrounding the disorder – I will show various examples in this thesis – show that these concerns have a relevance that goes far beyond the group of patients and their next of kin.

One of the key questions in this public controversy surrounding ADHD, at least as it is staged in arenas ranging from television talkshows to online fora, is whether or not ADHD is a ‘real’ or genuine disorder: the “discussion of ADHD becomes confined to an allegiance to one of two camps: ADHD is either a bona fide neurological reality, or ADHD is a falsehood” (Rafalovich, 2002: 2; compare Singh, 2008; Horton-Salway, 2011). Here, the neuroscientific framework provides popular discourse with a language of ‘hard facts’ about ADHD, whereas psychodynamic perspectives attribute ADHD to environmental factors that are much more difficult to pinpoint. Rafalovich (2002: 85) describes the political dynamics between these opposing perspectives as a science war, and quotes Fujimura (1998: 348) to describe some characteristics thereof: “science wars then and now are not about science versus anti-science, not about objectivity versus subjectivity, but about authority in science: What kind of science should be practiced, and who gets to define it?”

The practical relevance of such questions goes far beyond mere scientific forums. For instance, Brunton et al. (2014) describe how parents of children diagnosed with ADHD negotiate accountability for their child’s behaviour by drawing both on biological and on social environmental repertoires. Claims to expertise have moral consequences, because they help to navigate the boundary between ‘just a brain disorder’ and normal – and therefore culpable – disobedience. Starting from a participants’ perspective, I would therefore argue

that the negotiation between subjectivity and objectivity is crucial for interactants to position themselves with regard to the disorder.

Since the late nineteenth century, science has been led by an ideal of objectivity in which nature would “speak for itself” (Daston and Galison, 1992). Following this ideal of objectivity, the scientist should work like, be assisted by or preferably even be replaced by a non-interventionist recording machine in order to provide knowledge “true to nature”.

Neuro-imaging technology is a prototype example of such a recording machine: “the most common trope used to legitimize brain scans is to regard them as transparent, mechanically objective snapshots of the real” (De Rijcke, 2010: 9). Brain scans have a persuasive quality: “the brain is [seen as, WV] a reliable informant (...); the brain does not have an opinion (...); it simply provides facts.” (Schirrmann, 2014: 16). When a scientific article is accompanied by fMRI images representing the level of brain activity associated with cognitive processes, this will positively influence readers’ rating of the scientific merit of the article (McCabe & Castel, 2008). More telling, Weisberg et al. (2008) have shown how even irrelevant neuroscientific information interfered with non-experts’ ability to judge the quality of explanations of psychological phenomena; bad explanations in particular were judged more favourably. In this way, the neurosciences acquired relevance to the lives of those outside the field, in areas ranging from forensic science via psychology to child rearing. There is a growing “belief (...) that by acting on our brains, we can improve our mental life and enhance our everyday capacities to meet the ceaseless demands for self-development and self-management that characterize our contemporary form of life” (Schirrmann, 2013: 291). Locating the causes of troublesome behaviour associated with Attention Deficit Hyperactivity Disorder in the brain rather than in the mind or the environment implies a potentially different story of causality, a different distribution of responsibilities and a different understanding of the self (cf. Fein, 2011: 36).

Sociologists have argued that we might be experiencing a “neurochemical reshaping of personhood” (Rose, 2003), describing a process in which “neuroscientific theories, practices, technologies and therapies are influencing the ways we think about ourselves and relate to others, favoring forms of neurological or cerebral subjectivation” (Ortega, 2009: 426). But this

neurobiological identity is not a stable one, nor does a diagnosis carry a fixed meaning. Foster-Galasso (2005) describes how she employs the diagnosis of her son with a developmental disorder in distinct ways to protect his interests, depending on the exact social context that she finds herself in. Her personal story beautifully illustrates that, rather than assuming a fixed and structural “neurochemical self” (Rose, 2003), we should pay attention to the practices surrounding a neurobiological identity, as a number of authors have recently argued. In the context of ADHD, Singh (2012: 13) observes that:

it is not the case that encounters with neuroscience discourse or technologies necessarily lead children to construct neurological subjectivities. Rather, children are seen to be active and creative participants in discursive power negotiations among social, biological and technological forces.

This makes it relevant to move “away from asking, is neuroscience and the neurological of import for contemporary constructions of subjectivity, and towards questions of when, how and why it is accounted for as significant.” (Pickersgill et al., 2011: 362; cf. Bröer & Heerings, 2012: 14).

This latter question – when, how and why is (neuro)science accounted for as significant or, more generally, how do interactants negotiate the authority of various claims to expertise regarding contested health phenomena such as ADHD – is what I will pursue in this thesis. Before elaborating on how I aim to do this, I will briefly summarise the preceding paragraphs.

We have seen that public debates about scientific expertise – including the contemporary discussion about a ‘post-truth society’ – frequently remain caught in stereotypes of scientists and lay people. These dichotomous images are interrelated, in the sense that the type of expertise attributed to scientists will not be attributed to lay people and vice versa: the latter will be credited with common sense, as opposed to the abstract knowledge of scientists; or the scientists will be credited with rationality, as opposed to the emotional gut reactions of the lay public. From these static images of publics and experts, I have proceeded to discuss the notion of expertise. A major difference between expertise and knowledge is that expertise is inherently transgressive (Nowotny, 2000). Knowledge is something that you may or may not possess, but expertise claims an entitlement to speak (Meyers, 2004) and with that, to be listened to.

Claims to expertise need to be staged, established and negotiated, not in the last place because they have often moral consequences. From this general discussion of expertise, I have zoomed in to a particular field in which competing claims to expertise have a bearing on everyday life: Attention Deficit Hyperactivity Disorder.

In this thesis, I aim to learn more about how scientific and other claims to expertise are employed in everyday conversations. In this way, I hope to move beyond static images of scientists, lay people and the types of knowledge typically attributed to them. This use of expertise in interaction cannot be studied in the abstract, and I have selected ADHD as my main case study. ADHD provides an interesting case study when researching the negotiation of expertise, because it is a controversial field to which both experiential and scientific knowledge claims are highly relevant. Neuroscientific images, including knowledge claims pertaining to ADHD, are often treated as the pinnacle of objectivity. In short, ADHD represents a topic where expertise claims have a bearing on notions of the self and of societal order, and are therefore both vehemently contested and strongly adhered to. To research such everyday negotiations surrounding the sensitive question of ‘how do you know’, I will use the methods of discursive psychology and conversation analysis, which I discuss in the next paragraph.

1.4. Method: *Conversation Analysis and Discursive Psychology*

1.4.1. Approach and research questions

In order to study how interactants negotiate the authority of claims to expertise, I will employ conversation analysis (CA) and discursive psychology (Edwards & Potter, 1992; Edwards, 1997; Potter, 1996). Conversation analysis and discursive psychology start from the Wittgensteinian presumption that understanding language is not primarily a ‘matter of understanding sentences but of understanding *actions*’ (Heritage, 2008: 139), that is: of what utterances achieve within a particular context. Even seemingly simple conversations are actually complicated processes of collective sense making. In that process, they build on resources and an awareness of social norms that are typically not made explicit.

Rather than merely hearing what is said, recipients understand the meaning of each utterance by drawing 1) on the local context of the conversation (e.g., ‘what a beautiful day’ can be used to praise the sunshine, or to complain about the rain), 2) their relationship with the speaker (only parent might say ‘you *do* like Brussels sprouts’, after a child has just expressed his dislike), and 3) their awareness of interactional norms (as it is customary to return a greeting, a failure to do so will be treated as interaction-ally significant).

Garfinkel’s famous breaching experiments (1963) showed how much information is taken for granted in ordinary interactions. When he asked his students, by way of experiment, to try and elicit this normally implicit information from other speakers, this solicited irritated and even offended reactions. This is not surprising, because these breaches threatened ‘the very possibility of mutual understanding and, with it, the existence of a shared world’ (Heritage, 2008: 95). This shared world is usually taken for granted, or, as Heritage (2008: 97) puts this:

Given the enormous array of possible contextualisations for a statement and hence of possible interpretations for it, and given also that the producers of the statements can never literally say what they mean, then the producers of statements can only make themselves understandable by assuming that the recipients are accomplishing the relevant contextual determinations for what is being said. Moreover the producers must assume that the recipients are accomplishing this task by ‘trusting’ and relying on the proposed documentary pattern over the course of its emergence. If a socially organised and intersubjective world stands or falls with the maintenance of this interpretative trust, then it is not surprising that it is attended to as a deeply moral matter. We should, indeed, be surprised if it were not.

Recipients will keep adjusting their interpretation of what has been said in order to make sense of the previous conversation, and keep treating the actions of the other speaker as intelligible, describable and assessable (Heritage, 2008: 100. Thus, when Garfinkel’s students deviated from the interactional norm by asking to elaborate on information that would normally remain implicit, this behaviour was not treated as nonsensical, but as a wilful – and therefore probably malignant – deviation from the norm. There is, in Heritage’s words, no ‘time out’ from normative accountability of actions (2008: 100); interactants will retroactively adjust their understanding of the situation so as to fit it into the

most likely interpretive framework. In order to do so – given the myriad possibilities for interpretation – recipients will interpret what they hear by viewing it against a background of “*who* said it, *where* and *when*, *what* was [140] being accomplished by saying it and in the light of what possible *considerations* and in virtue of what *motives*” (Heritage, 2008: 139-140). The exact same questions will guide a discursive psychological or conversation analytical study. Because conversation analysis starts from the assumption that language is not representative, the conversation analyst does not study utterances in order to gain access to the emotions, cognitions or inner states of the speaker. Rather, the analyst is interested in how seemingly self-evident interaction is accomplished. Interactants will demonstrably adjust and update their understanding of the interaction so as to reconcile it with their expectations of normal behaviour. What becomes visible in this process is the way in which interactants maintain their expectations of what constitutes ‘normal conduct’, instantiated in the context of a particular conversation and in relation to a particular other. Because interactants hold each other accountable for their actions (on which I will elaborate below), the micro-context of a conversation can help to provide insights into the societal norms that provide the contextual framework for the interaction. As this framework is typically not made explicit, interactants would not necessarily be able to spontaneously mention such norms during an interview. (And, from a conversation analytical point of view, their answer would in turn be influenced by the particular situation of the interview, their relationship with the interviewer, et cetera). In short: by making seemingly self-evident interaction into a researchable matter, conversation analysis allows us to gain detailed insight into how societal normality is actively constituted. Or, to focus on the topic of this thesis: by making the everyday negotiation of appropriate expertise into a researchable matter, conversation analysis allows for a detailed insight into the largely unarticulated societal norms regarding the authority of, respectively scientific knowledge and personal experience.

To be accountable means, according to the Oxford American Dictionary, to be required or expected to justify actions. From a conversation analytical perspective, the interesting question is not whether someone is accountable. As we have seen above, there is no ‘time out’ from normative accountability, because interactants are continuously engaged in a process of sense-making. In other words:

The big question is not whether actors understand each other or not. The fact is that they do understand each other, that they will understand each other, but the catch is that they will understand each other regardless of how they would be understood.
(Garfinkel, 1952: 367, as quoted in Heritage, 2008: 119).

Rather than asking, therefore, whether interactants provide accounts, a conversation analytical point of view uses the question *how* interactants design accounts and which interactional goal is served by this. Again, the design of a particular account becomes analytically interesting because there is no single compelling way to describe a particular state of affairs. Interactants choose – whereas this choice is not necessarily consciously made, it will be treated as such by recipients (Heritage, 2008)—for a particular phrasing, for instance, to preempt a challenge, as seen in figure 1.2

Figure 1.2 — Preempting a challenge. Images from Klassen (2011).

Figure 1.3 — Managing identity; right-wing politician Nigel Farage starts his sentence with ‘I’m not a racist’.⁷

The design of an account reflects not only the state of affairs that is being described, but also indexes the identity of the speaker. In answering the question, the hat-wearing rabbit in Klassen’s picture book presents himself as someone who ‘would not steal a hat’; and inadvertently, to the reader if not to the bear, as a liar whose account differs from those of the innocent animals. Likewise, the still from an interview with right-wing politician Nigel Farage shows him as starting his sentence with ‘I’m not a racist’. One does not need to be a conversation analyst to predict how the sentence will continue after this stake inoculation. Before providing an account that is likely to be heard as racist, the speaker manages his identity as ‘not a racist’ (see also Whitehead, 2009; Cresswell et al., 2014). Apart from orienting to societal norms which treat making racist remarks differently from explicitly positioning oneself as a racist, Farage here also works to strengthen the credibility of his account. If a speaker is ‘not a racist’, one would not expect him to make racist remarks, and he must therefore have good reason to make these remarks (compare Edwards, 2005). Thus, rather than treating identity as a static matter, it is a key concern for discursive psychology how interactants manage the relationship between mind

⁷ <https://imgur.com/r/politic/KwYU6L2> (Accessed August 3, 2018).

and world, or between the subjective and objective (Edwards, 1997; Edwards, 2006).

Raymond and Heritage (2006) describe how speaking practices can make relative access to knowledge relevant, and help to invoke a specific identity. Their analysis – called *Owning grandchildren* – shows how a grandmother, in conversation with a neighbour, claims superior epistemic access to her grandchildren than the neighbour, who also knows these children. Embodying the identity of a grandmother, with the corresponding epistemic rights, is an interpersonal, rather than an individual achievement: both the neighbour and the grandmother do interactional work to make this particular identity relevant, for instance, when assessing the children. Whereas this might sound rather technical, the analysis elaborates on something that is probably well-known to everyone on a more intuitive level; the need to be cautious when saying something about a topic that ‘belongs’ to someone else, whether this concerns children, grandchildren, pets or any discipline in which the other seems to be expert. Raymond and Heritage (2006: 701) argue convincingly that by looking at how such rights to knowledge are distributed among speakers – how they are respected or challenged, used to establish agreement or to foster conflict – it becomes possible to see how identities are produced and reproduced in interaction. The acknowledgment that the grandmother’s epistemic privileges are sustained by both speakers, rather than merely claimed by her, is a particularly relevant insight for the topic of this thesis. In this research, I want to look beyond the stereotypes of scientists and lay publics in which debates about expertise frequently remain caught, and it therefore makes sense to analyse how claims to expertise are distributed on a moment-by-moment basis. When writing about ‘the public and its problems’, and more specifically about the methodological problem of identifying this public, Dewey (2008: 354) argued that:

A man may be one thing as a church member and another thing as a member of the business community. The difference may be carried as if in water-tight compartments, or it may become such a division as to entail internal conflict. In these facts we have the ground of the common anti-thesis set up between society and the individual. Then “society” becomes an unreal abstraction, and “the individual” an equally unreal one.

By analysing the distribution of knowledge rights as an ongoing interactional achievement, it becomes possible to study how individuals make a particular identity (as a church member, a member of the business community, a grandmother, a patient) relevant to the interaction by claiming corresponding epistemic access. What is more, epistemic claims also have moral consequences, a theme which I already briefly touched upon in the paragraph about ADHD, and will talk more about in the empirical chapters. Managing the relative rights to knowledge and expertise is a central part of “interactional housekeeping” (Heritage & Raymond, 2005: 36) and crucial to distinguish between ‘right’ or normal, and ‘wrong’ or deviant behaviour.

In summary: epistemic, identity and morality concerns are tightly intertwined. Conversation analysis is a promising approach to learn more about how such concerns are made relevant in negotiations about expertise. An interactional and relational approach to epistemic access can help to go beyond stereotypes: rather than looking at the possession of expert knowledge, the focus shifts to how claims to expertise are used to invoke a specific identity, or to orient to moral concerns.

Employing this approach to the analysis of expertise negotiation regarding contested health phenomena results in the following research questions:

How do interactants negotiate the morality of contested health phenomena by drawing on scientific expertise or on the contrary on experiential knowledge, and which interactional goals are served by this?

1. Epistemic concerns: How do participants construct knowledge regarding contested health phenomena in terms of personal experience or on the contrary of formal scientific expertise?
2. Identity concerns: How does the construction of knowledge regarding contested health phenomena in terms of personal experience or on the contrary of formal scientific expertise help participants to construct a particular moral identity?

1.4.2. Data collection

Ideally, a conversation analysis is based on naturally occurring conversations (in contrast with, for instance, surveys or qualitative interviews which would be at least partially designed by the researcher). The interactional data which I analyse in this thesis are derived from three different settings:

1. Open online forum discussions from Dutch and English-language forums. With the exception of the aspartame data (9 threads), these discussions are patient-to-patient interactions (77 threads, in length varying from less than 10 to more than 300 posts);
2. 8 Dutch and British radio phone-ins, typically host–caller interactions;
3. 13 video recorded, publicly conducted coaching sessions in a Dutch ADHD centre, which consist of coach-coachee interactions conducted by 3 different coaches.

Dutch data have been translated into English by keeping as close as possible to the original wordings, but in such a way as to allow readers to follow the analysis performed on the basis of the Dutch text.

Each of the three settings could be regarded as a public or semi-public space, which nevertheless invited the sharing of personal experience and intimate emotions. The online forums were publicly accessible, the radio phone-ins were broadcast and the coaching sessions were conducted in front of a public. These publics are sometimes explicitly referred to—for instance, when the radio phone-in host mentions the overhearing audience, or when the coach asks the people who are present to give their opinion.

Online forums or message boards are collections of online user-generated content. Sequential posts are organised in a thread. Whereas the online forum is a relatively old way to communicate online, it is still an important medium for patient groups and other communities to exchange experiences. The sequential nature of the interaction makes it suitable for a discursive psychological analysis, even if many of the rules for off-line interaction do not apply online.

The radio phone-in is an institutional environment with particular interactional characteristics. Perhaps the most important of these is what Hutchby (1992) has called the 'arguing for arguing's sake' or the 'pursuit of controversy'. Many everyday interactions are characterised by an avoidance of conflict, but radio phone-in hosts strive for argument in order to entertain their audience. This makes the radio phone-in an interesting 'extreme case', for whereas conflict is often more explicit in this settings, interactants will still draw on the interactional repertoire that they would use in everyday settings.

Coaching sessions are an interesting setting to study the negotiation of expertise, because the coach needs to transform the client's complaints into a problem that allows for agency. This is a complicated interactional agenda, because speakers typically claim epistemic primacy about their own experiences and feelings (Heritage and Raymond, 2005; Raymond & Heritage, 2006). Furthering a coaching agenda of change might therefore result in problems of epistemic access and authority.

Together, these settings provide a multi-faceted perspective on expertise negotiations about ADHD, in contexts which have been designed for conflict (radio phone-in), for the exchange of experience and advice (online forum), or for the provision of understanding and help (coaching sessions).

Central to the methodology of conversation analysis is the understanding that interaction occurs sequentially. When asking the previously mentioned 'why that now'-question, the analyst compares the way in which the rhetorical designs of seemingly similar utterances are treated by the recipients in their next turns. The comparison between utterances within their respective sequential contexts leads to a refinement of the analytical focus. Because the conversation analyst is interested in participants' understandings, rather than their intentions, the analysis will be guided by this 'next-turn proof procedure' (Sacks, Schegloff & Jefferson, 1974). With each utterance interactants display their understanding of what has been said before, and this displayed understanding in turn provides the basis for next actions (Sacks, 1992). The analysis should follow these displayed understandings of participants, rather than meanings imposed by the researcher. Because a conversation analysis makes much of the empirical material available to the reader, she can judge for herself whether the researcher's interpretations of the data are convincing. I will elaborate in more

detail on data and methods, as well as on the research ethics, in the various empirical chapters.

1.4.3. Thesis outline

In order to study how interactants employ scientific expertise and experiential knowledge in their negotiations of the meaning of contested health phenomena, I start my research in an environment where one would expect personal experience to be prioritised: the radio phone-in. In chapter 2, I analyse discussions in Dutch and British radio phone-ins about ADHD and vaccination. I will show that, whereas both personal experience and scientific knowledge can both be challenged as claims to expertise, this happens in strikingly different ways. In chapter 3, I analyse discussions on online forums in Dutch and English, in which interactants talk about aspartame and ADHD. I study the way in which interactants employ the expression ‘listen to your body’ and how they contrast this course of action with following scientific advice. I will show that these utterances, that at first sight seem to be rejections of science, in fact point to a dominant norm of providing scientific evidence for online claims. Chapter 4 is based on a corpus of recorded conversations in a Dutch ADHD coaching centre. I analyse how the coaches negotiate the meaning of their clients’ experiences, by drawing upon their own bodily sensations. Whereas the coaches use the language of neuroscience, they also empathically present themselves as non-experts. As such, the chapter is a deviant case study; in each of the other settings, interactants work to claim the authority associated with expertise. Chapter 5 draws on a corpus of Dutch online conversations between patients suffering from different chronic diseases: ADHD, diabetes and ALS. I analyse how patients negotiate what constitutes appropriate expertise in a context of responsible patient-hood, and how this relates to what is at stake for their particular disease. Finally, in chapter 6, I analyse discussions in British radio phone-ins, between hosts and mothers of children with ADHD. I will show how the mothers carefully tailor their knowledge claims in order to position ADHD as a doctorable disorder, which can only be known and described by experts.

2

Chapter 2

All but naive: patrolling epistemic territories in radio phone-ins

This chapter has been submitted to:

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Chapter 2

All but naive: patrolling epistemic territories in radio phone-ins

2.1. Introduction

A perceived lack of respect for science, and even for truth in general, has recently become the centre of public debate (Nurse, 2011; Nichols, 2017; Kakutani, 2018). “Does the truth matter anymore?”, The Guardian asked itself after the Brexit vote, commenting that we live “in an era when everyone has their own facts.” (Viner, 2017). Academic literature points to the relative authority of personal experience as compared with certified expertise. Van Zoonen et al. (2007: 334) analysed online conversations, observing that those “speaking from their personal observations were never reprimanded by their fellow posters for providing only individual truths”. Given this implicit agreement not to contest personal experience, experiential claims could only be countered by introducing “one’s own, different personal truth” (van Zoonen et al., 2007: 334; cf. van Zoonen, 2012). In contrast to these ‘inoculated’ personal experiences, evidence offered in the form of facts was, according to van Zoonen et al., typically highly distrusted. Personal experience is treated as if it possesses a unique authority; certain narratives seem to have an ability “to inoculate themselves against criticism, precisely by emerging as the voice of authentic experience, an experience that cannot be denied, without violating the integrity of the narrator” (Gabriel, 2004: 177). “Lay knowledge represents a challenge to the ‘objectivity’ of expert knowledge (...) and to the authority of professionals”, observe Popay and Williams (2006: 123; cf. Collins & Evans, 2002). Such observations beg the question what it is that we actually do when claiming authoritative knowledge on the basis of either personal experience or certified expertise.

Given the complexity of contemporary society, trust in certified expertise is the norm. It is simply impossible not to take many decisions upon the implicit authority of certified experts, in fields ranging from airplane technology to food safety (Warren, 1996). At the same time, and perhaps because of this

tremendous importance of expertise, struggles about what constitutes credible expertise erupt over and over again. These struggles are not equally divided over scientific fields, but typically concern the question how to live. As Shapin puts this eloquently: whereas “particle physics is hard to understand and often counter-commonsensual, this is not a problem for the laity”, because it “is not an expert practice that they care much about, and they simply let the experts ‘get on with it’”. (Shapin, 2007: 174) Expertise has been described as an entitlement to speak in a particular context (Myers, 2004: 177), a claim which interactants will evaluate moment by moment. Yet, when claims to expertise touch on topics pertinent to everyday life, such as diet, child rearing, climate change or vaccination, the usually implicit struggle regarding this entitlement to speak becomes much more explicit.

Whether one is recognised as an expert – certified or not – and treated as such by others, is never a given. “Such matters as what is known, by whom, and on what basis are not merely the preconditions for talk, but part of talk’s active business”, argues Edwards (1997: 135). Interactants routinely take care to display how much they know relative to other participants in the conversation: they define, delineate and police the boundaries of their own epistemic territory (Raymond and Heritage, 2006: 680; cf. Heritage, 2011, 2012a, 2012b; Bolden, 2013).

Conversation analysts have since long recognised that participants locate personal experience firmly within the epistemic domain of the speaker who owns it (Sacks, 1984; Pomerantz, 1980; Heritage, 2011). Because all interactants can claim the primary rights to their own thoughts and experience, recipients will need to avoid the twin risks of appearing either disengaged from the affairs of the other, or appearing over-involved with, and even appropriating such experience (Raymond & Heritage, 2006: 701). For instance, Heritage (2011) shows that when speakers display empathy, they need to show proof of their understanding of the other’s experience (avoid appearing disengaged), while being careful that this proof does not overshadow the story of the other’s experience (avoid appropriation) (Heritage, 2011). Yet, starting from the field of science communication, the question remains whether experience is indeed impossible to challenge, and whether certified expertise is perhaps easier to dispute, as the above mentioned observations by Gabriel (2004) and van Zoonen (2012) suggest.

We have used a conversation analytical approach to answer that question, and compared conversations from a corpus of radio phone-ins. The radio phone-in is an extreme case: its format is biased towards personal experience, as this is what callers are invited to contribute (Hutchby, 2001). Within this format, the description of expertise as an entitlement to speak (Myers, 2004) holds literally true; participants have to demonstrate the relevance of their contribution in order to be allowed airtime. Claiming personal experience or abstract, formal scientific expertise are two ways to achieve this.

In our analysis, we compare the way in which personal experience and scientific expertise are evaluated by the recipients. We show that, whereas radio phone-in hosts will typically respect the caller's epistemic primacy regarding her own experience, they can resist the *relevance* of this experience by singling out the caller as a naive individual, treating the experience as mere belief. In contrast, when a caller offers a claim based on the language of scientific expertise, this is *not* treated as belief or merely an opinion. Rather than challenging the relevance of scientific expertise, the host questions the speaker's right to act as its spokesperson. Both caller and host thus protect the status of science by carefully policing both the entitlement to speak for it, and the ensuing responsibilities.

2.2. The radio phone-in as extreme case

The radio phone-in is a specific, highly regulated context, which makes it interesting as an extreme case to learn more about how interactants evaluate claims based on either scientific expertise or experience. Most importantly, the format of the phone-in elicits callers' experiences, but the host is typically in pursuit of controversy (Hutchby, 1992). As such, he is obliged to challenge experiences that aren't his, and claims to science claims that he is often unable – and not necessarily willing – to judge.

Callers contribute to a radio phone-in by offering their first-hand knowledge or non-polished opinion (e.g. Thornborrow, 2001b; Hutchby, 2001; Fitzgerald & Housley, 2002). A radio phone-in provides “one of very few regular environments in which ordinary members of the public are given the opportunity to speak on issues and events in their own voices.” (Hutchby, 2001: 481). Radio phone-in hosts frequently position themselves as the representative of the overhearing audience. At the same time, the radio phone-in provides an

environment in which nobody ever changes his mind (Myers, 2004: 195). In this aspect, they present a microcosm of societal controversies, in which people likewise rarely change their initially displayed opinion (see, e.g., Nyhan et al., 2014). An analysis of the way in which experience and expertise are treated at this microlevel, can help to provide insight into the perceived waxing or waning of their authority at a societal level.

The offering of experience constitutes a regular first turn in a radio phone-in. Callers are highly aware of the need to gain air time and will therefore actively work to present themselves as ‘authentic’, ‘relevant’ and ‘in depth’ (Hutchby, 2001; Thornborrow, 2001a; Fitzgerald and Housley, 2002). For instance, in the flu shot radio phone-in analysed in this paper, a caller validates his call by saying that he is not a scientist, but had an ordinary technical education. This introduction contrasts the identity he draws on with those of the invited experts who were speaking earlier. Presenting himself as ‘not a scientist’, this caller strengthens his right to speak as one of the ‘ordinary people’, in other words, as the voice of common sense. Hutchby (2001) has shown that this is not without danger, suggesting that “the *limits* of the caller’s witnessing can be interactionally managed” (Hutchby, 2001: 492; *italics in original*). We want to elaborate on this suggestion, focusing on the interactional positioning and evaluation of personal experience *relative* to that of claims to scientific expertise.

2.3. Data and method

2.3.1. Data selection

In order to pursue these questions in an exploratory way, we have compared one Dutch and two British radio phone-ins (107 minutes) from a developing corpus of radio phone-in interactions (currently 225 minutes) concerning controversial topics on the science-society axis, such as vaccination, aspartame and ADHD. In this analysis, we compare conversations about ADHD and the flu shot. Although these two topics are radically different, they are both the subject of societal controversy (regarding the question whether ADHD ‘is real’, and whether vaccination ‘helps’, respectively), and are characterised by “complex interactions about just what can be offered as an expert opinion and when it can be offered” (Myers, 2004: 160).

The phone-ins presented here are contentious: the host does not take a neutral stance but defends a particular storyline throughout the program and challenges callers who do not agree with him.

2.3.2. *Transcription, translation and analytic procedure*

The radio phone-ins were first transcribed on a verbatim basis. Selected fragments were then further transcribed using Jefferson's (2004) system for Conversation Analysis (see appendix 1 for an explanation of the symbols used). The original audio material can be found online⁸ or requested from the authors. The data presented here were selected on the grounds that they contained an explicit dispute as to what counts as relevant and/or valid knowledge: all fragments involve callers disagreeing with the host, offering claims to either scientific or experiential knowledge.

The analysis was conducted following CA's guiding principle that participants use the turn-by-turn development of a conversation as a resource to make sense of the social activities that are accomplished. These publicly displayed and continuously updated understandings of what is being said and done are an important 'proof procedure' for the analyst. Discursive psychology shares the conversation analytic focus on activity sequences as the main entry for understanding what people do in interaction. Discursive psychologists analyse how direct and indirect appeals to mental states *do* things in the interaction, such as accusing, complaining, and complimenting. Rather than trying to determine the truth value of what people report – by looking at what a person really thinks, knows or feels, or whether claimed facts are actually correct – discursive psychology focuses on the *interactional business* performed with these descriptions (Edwards and Potter, 2005; cf. te Molder and Potter, 2005). The present analysis remains agnostic regarding the truthfulness of what participants claim to know or to have personally experienced, and focuses instead on what participants *achieve* in the interaction by claiming this particular knowledge.

Dutch data have been translated into English by keeping as close as possible to the original wordings, but in such a way as to allow readers to follow the analysis

⁸ LBC fragments about ADHD on http://www.youtube.com/watch?v=qL5-3fhu9_4; Dutch flu vaccine fragments from NPO 1 on <https://www.nporadio1.nl/avondspits/onderwerpen/36553-grieprik-helpt-alleen-de-pillenindustrie> (Avondspits), both accessed July 14, 2018. BBC fragments about ADHD can be requested from the authors.

as it was performed by the authors on the basis of the Dutch text. Original Dutch data can be obtained from the authors upon request.

2.4. Analytic results

In the next section, we will show how interactants negotiate the value of personal experience (2.4.1) and scientific expertise (2.4.2). The three excerpts presented in paragraph 2.4.1 show how the host manages to challenge what has been offered as personal experience, without trespassing on the epistemic domain of the caller. Rather than disputing the experience as such, he treats it as mere belief, hence not relevant for the overhearing audience. The two excerpts presented in paragraph 4.2 show how both callers and host carefully patrol the borders of what constitutes ‘real’ scientific expertise and who is allowed to speak for it.

2.4.1. *Resisting the prescriptive relevance of experience: treating it as belief*

The following excerpt, a fragment from a Dutch radio phone-in about the flu shot, serves as a first and comparatively simple example of a) how callers try to build a strong claim on the basis of personal experience and b) how the relevance thereof can nevertheless be disputed.

Immediately preceding his introduction of this caller, the host has reinforced his own position that the flu shot is ‘real nonsense’. He argued his point by stating that he ‘sticks to’ the ‘extensive study’ of an ‘authoritative journal’ to argue his point, before introducing the caller as follows: *[name, place] does not agree with me*, thus already depicting the caller’s attitude as illogical. The excerpt shown here occurs later in their conversation:

Excerpt 1 – Avondspits – flu shot

11. Caller: ↓ **yes, then I uh would like to pay for it,**
 ↓ *ja, ikuh wil er graag dan voor betalen,*
12. **becauseuh:uh:**
 wantuh: uh:
13. **I have had the whowhooping cough in the past too**
 ik heb vroeger ook nog de kinkhoeshoes gehad

14. **so uh:uh:**
 dus uh:uh:
15. **I only greatly benefit from it (.)**
 ik heb er alleen maar groot voordeel bij (.)
16. Host: **[well] (.)**
 [nou] (.)
17. Caller: -> **[that]'s my uh:: experience?**
 [dat] is mijn uh:: ervaring?
18. Host: -> **you believe in the flu shot**
 u gelooft in de griepprik
19. -> **and that's why you uh:: keep using it=**
 -> en daarom blijft u humeh:: gebruiken=
20. **=mrs (name). (0.4) good evening=**
 =mevrouw (naam). (0.4) goeieenavond=
21. Caller 2: **=ye:::s?**
 =ja:::?
22. Host: **do you believe in the flu shot? (0.5)**
 gelooft u in de griepprik? (0.5)
23. Caller 2: **no not at all**
 nee helemaal niet

The caller underlines his willingness to pay for the flu shot himself if it were not reimbursed, and emphasises how he, personally, has benefited from the flu shot. The host starts for a final formulation in line 16, using the preface ‘well’. This is a known ‘alert that the turn it prefaces will privilege its speaker’s perspectives, interests or project relative to the expectations for action established in the prior turn or sequence’ (Heritage, 2015). Simultaneously, the caller starts to formulate the beneficial workings of the flu shot as his ‘experience’ (line 17). This puts the host in a difficult position. He cannot directly contradict the caller’s experience (e.g. ‘no, you did not benefit from it’), as it belongs to an epistemic domain to which he has no access (Pomerantz, 1980). But neither can he allow the caller’s last turn to remain unchallenged, because this would threaten his own storyline that the flu shot ‘does not work at all’.

One of the host’s category entitlements is to conclusively formulate the topic opinion of the caller before proceeding to the next one (Fitzgerald and Housley, 2002), a right that reflects the asymmetrical organisation of the phone-in (Edwards, 1997: 127). This host cleverly uses his final formulation to dismiss the

caller's experience as *merely a consequence of his belief* in the flu shot (line 18–19). In this way, he does not need to dispute the experience as such, but he does question the caller's credibility as an observer of this experience, singling him out as an irrational individual, a believer. That this is indeed a charge, can be seen in the defensive extreme case formulation 'not at ↑all' (Pomerantz, 1986; Edwards, 2000) employed by the next caller in line 23. Experience is, according to the electronic *New Oxford American Dictionary*, the “practical contact with and observation of facts or events”, whereas belief is merely the “acceptance that a statement is true or that something exists” and thus decidedly weaker in terms of witnessing. Treating the caller as a believer allows the host to resist the prescriptive implications of the caller's positive experience with the flu shot, and thus to remain in control of the overarching narrative of the show.

We show a second excerpt. Again, a claim on the basis of personal experience is treated as a matter of belief, which is strongly resisted by the caller. This time, an expert is invited to the conversation. The interaction shown here between mother and host starts after the mother has outlined her son's problems with ADHD, and the host starts to question her about her own situation:

Excerpt 2 – BBC radio 5 live breakfast – ADHD

1. Host: and you believe you have it? (.2)
2. Mother: uhm, I don't believe
3. I >I know I have it<, yes. (.3) hm.
4. ehm, I I spent most of my life wondering,
5. I mean uhm, why I couldn't do stuff
6. the way >other people would do it<?
7. because that's. what you do, you know,
8. >you compare yourself to others<?
9. Host: what kind of things?
10. Mother: ehm, for instance, .hh, I'd start dusting.
11. and then I'd see a cob web.hu
12. and it sounds >really silly<
13. but (.2) I'd go and >get the cob web<.
14. and then I'd forget that I was dusting,
15. so I could spend all day
16. >going round the house<,

17. doing stuff and and
 18. (.4) never getting finished.
 18. .hh uhm, putting something on the cooker,
 19. >forgetting about it<.
 20. and I'm not talking occasionally,
 21. this is (.1) all the time, (.6)
 22. uhm so i-
 23. (1.0)
 24. you know, when people say
 25. we all forget things occasionally,
 26. we, you know, we all (.3)
 27. do this and that occasionally,
 28. this is not occasionally, it's all the time.
 29. so it's impacting on your life all the time.
 30. Host: (Name expert), is this a medical condition?
 31. Expert: (1.0)
 32. well, I think that the (.2) latest evidence
 33. shows absolutely. clearly. that there is
 34. no genetic(.3)ally cau:sed brain disorder
 35. involved here.

The host tentatively asks whether the mother believes that she herself has ADHD. The mother corrects the host in her reply, preempting an implicit challenge: she *knows* she has it (line 3). The answer implies that she has been officially diagnosed with attention deficit hyperactivity disorder (te Molder & Versteeg, 2018). The mother positions herself as someone who knows, rather than merely believes, thus establishing her authority. Her answer makes relevant a response along the lines of 'how do you know': the host asks the caller to specify her experience, requesting the underlying evidence of her claim. Responding, the caller lists her own behaviour and contrasts this with what is considered to be normal, again preempting an expected challenge by already providing an answer to what 'people say'.

Instead of reacting directly to the experience, the host introduces the – hitherto silently listening – expert to the program (line 30) and asks him whether this is a medical condition.' Given that the mother has built an account designed to distinguish between her own symptoms and ordinary problems (line 24–29), this question is potentially damaging. It is perhaps for that reason that the expert – a

clinical psychologist and author – avoids the terms of the host’s question, issuing a general statement rather than categorising the individual experience of this particular caller directly. Instead of using the lay category ‘medical condition’, he employs the much more exclusive category of the genetically caused brain disorder. As in the previous excerpt, the preface ‘well’ alerts recipients to an answer that is not in line with the caller’s interactional project. Whereas the expert does not dispute the content of the caller’s experience, his answer fails to engage with it, thus undermining its *relevance*. The mother’s experience is not disputed, but treated as irrelevant with respect to proving the genuine nature of the condition.

The third excerpt shows another example of offered experience that is made irrelevant by the host. Again, it is not the experience itself that is being disputed, but, similar to the first fragment, the capabilities of the caller as a credible observer of her own experience—and with that, the relevance of the offered experience for the overhearing audience.

Excerpt 3a – Avondspits – flu shot

1. Caller: **I am seventy eight (.4)**
 ik ben achtenzeventig (.4)
2. **and I have ha:d it for eleven years?**
 en ik heb hem elf jaar geha:d?
3. **.hh >I will knock on wood< (.3)**
 .hh >ik zal het afkloppen< (.3)
4. **but I have never haduh that flu?=
 maar ik heb nog nooit die griep gehadhe?=**
5. Host: --> **= >but we want to know< (.2)**
 = >maar we willen toch weten< (.2)
6. --> **>if you go to the doctor<**
 >of je ergens voor naar de dokter gaat<
7. --> **for something that makes sense**
 wat zin heeft
8. **you would not follow something,**
 je gaat toch niet ergens achteraan lopen,
9. **that does not work, would you?**
 wat geen effect heeft

The caller uses an extreme case formulation (Pomerantz, 1986; Edwards, 2000) in her opening turn (line 4, never had that flu). By mentioning her age and the eleven years of experience with the flu shot, she provides further experiential evidence to strengthen her argument.

It would be hard for the host to dispute matters that are so clearly within the epistemic domain of the caller. But in his next turn he subtly shifts the topic from the effectiveness of the flu shot to the naivety of the caller. Note how he invokes the overhearing audience as a generalised ‘we’ (line 5), suggesting a common sense found amongst rational citizens/consumers, while singling out this caller as someone who goes the doctor for something that does not make sense. As in the first fragment, the caller is positioned as a naive individual, and this becomes even more clear in the next part of the excerpt, continuing from line 9:

Excerpt 3b – Avondspits – flu shot (continued)

10. Caller: (.2) **but I do not at all follow something,**
(.2) maar ik loop helemaal niet ergens achteraan,
11. **I take care to be educated**
ik laat me goed voorlichten
12. **and you hea- listen to people**
en je hoo- luistert naar mensen
[3 lines omitted]
16. **.hh I have three grandchildren**
.hh ik heb drie kleinkinderen
17. **they have all been inoculated and I hope=**
die zijn allemaal ingeënt, en ik hoop=
18. Host: **=yes**
=ja
19. Caller: **that they will**
dat ze daar
20. Host: **[>for you<]**
[>voor u<]
21. Caller: **[b e n e] fit?**
[b a a t] bij hebben?
22. Host:--> **well (.3) that is in any case**
nou (.3) dat is in ieder geval

23. --> **a reassurance for you**
 een geruststelling voor u
24. **but I think that we should know a bit more than that**
 maar ik denk dat we wat meer moeten weten dan dat

The host's statement that 'you would not follow something that does not work' employs a generalised personal pronoun that does not necessarily address the caller (in Dutch: *je*, rather than *jij* or *u*). Nevertheless, the caller treats this as a personal challenge ('but I do not at all follow something', line 10). Her defence implicitly contradicts the assertion that she made earlier in the conversation (not shown here for reasons of space), that 'one must have a little trust'. Now that the host has held her accountable for uncritically trusting, she starts line 12 with 'and one hea-' (line 12), but repairs this with the much more active verb 'listens', thus indicating an active selection of advice. This is further supported by her assertion that she takes care to educate herself. She then draws again on her own experience and finishes with a cautious 'I hope' [that they will benefit], which makes relevant an answer along the lines of 'I hope so too'.

This, however, is not how the host reacts. Instead, he offers his final formulation, reinforcing the previous one in lines 5-9 and his category division between *you* (easily reassured) and *I* (searching for genuinely trustable numbers). The offered reassurance has a patronising connotation.

Even more explicitly than in fragment 1, the host particularises the relevance of the caller's experience by singling her out as a naive, trusting individual. The caller is treated as gullible, a faulty observer of her own experience, and in this way, the offered experience is rendered as irrelevant for the overhearing audience.

2.4.2. *Resisting the prescriptive relevance of scientific claims: probing the right to speak for scientific expertise*

The previous section showed how the relevance of personal experience can be disputed by formulating it as mere belief. The excerpts also illustrated that being positioned as 'trusting' is an interactional problem for callers, because it can be easily equated with being irrational, gullible or naive.

In the following part of our analysis, we show that, contrary to what might be expected in light of the concerns mentioned in the previous paragraph, interactants do *not* treat claims cast in the language of scientific expertise as belief or ‘merely an opinion’. Instead, both callers and hosts carefully delineate which kind of scientific expertise can be claimed by whom. Rather than contesting the relevance or the authority of scientific expertise itself, they dispute who is allowed to speak for it.

We present three examples in which scientific or certified expertise is employed as trump card. The host probes the caller’s knowledge claims to a greater or lesser extent, depending on whether the caller positions herself as a lay person (excerpt 4) or as an expert (excerpts 5, 6). In the first excerpt, the caller herself emphasises the epistemic authority of certified excerpts. In the two latter excerpts, the host challenges the caller’s entitlement to claim a type of knowledge that would be the prerogative of certified experts. We have seen before that experience can be particularised and made irrelevant to the overhearing audience. In contrast, the relevance of scientific or certified knowledge is not challenged. Instead, the interaction focuses on who is allowed to speak for ‘true’ science.

The first excerpt starts rather philosophically, with the host musing on how the debate surrounding ADHD seems to be primarily about naming:

Excerpt 4a – James O’Brien – ADHD

1. Host: see a lot of this oddly
2. seems to be a conversation about words=
3. Caller: =ya
4. Host: because you don’t think that your son i:s (.4)
5. and I’m >gonna use this word<?
6. you don’t think he’s ill.
7. Caller: no.
8. Host: but the medical establishment does.
9. Caller: (1.4)
10. uuuuh
11. (.2) >well well yes, I mean<, yeah
12. when when you put it like that
13. then yes

[21 lines omitted]

35. Caller: >you know what<
36. I say that he's got a bad case of boy.
37. Host: hehehe
38. Caller: that that is how I would describe it
39. Host: yes but they're describing it
40. as a PSYCHIATRIC ILLNESS
41. Caller: and if thats what they have to do
42. in order to get (.6) um predominantly
43. and I don't know my facts on this at all
44. [but but]
45. Host: [su:re]
46. Caller: but it seems to me that it's more of a boys' thing
47. than a girls' thing

What the host describes as a conversation about words, is in large part about the question whether ADHD-like behaviour should be described in medical or in layman's language. In not regarding her son as ill, the caller dissents from his diagnosis as suffering from ADHD. The host makes this juxtaposition explicit in sceptical terms: describing certified experts as the 'medical establishment' marks their respected position, but also implies room for criticism of this established position. Yet in the caller's next turn (9-13), we see her struggling to account for her disagreement with the medical establishment, rather than questioning the salience of this established knowledge.

In the second part of the excerpt, the caller describes her son's behaviour in lay terms as a 'bad case of boy.' The host responds with laughter, at which point (line 38) the caller repeats her claim—emphasising in this repetition the personal and tentative nature of her description (I would). The host again juxtaposes the caller's description with the expert opinion. The caller does not respond directly, and she does not voice any disagreement. Instead, her answer allows for the expert opinion and her own description to co-exist: the experts will have their own reasons to describe this behaviour as a psychiatric illness. Before repeating her earlier claim that it is more of a boys' thing – again in tentative, particularised terms: 'it seems to me' – she emphasises that she does not know her facts at all. Thus, even when disagreeing with the experts' opinion, the caller carefully claims only the knowledge appropriate to a lay person. The

host has tried his best to set up for a conflict between this mother's assessment of her son's condition (a bad case of boy), and the way in which certified experts described this (ADHD). However, his efforts to antagonise failed because the caller persistently positioned herself as a lay person, thus protecting the authority of certified experts – and with that, the legitimacy of her son's diagnosis.

In contrast to the previous excerpt, the caller in the next fragment starts by positioning herself as an expert:

Excerpt 5a – James O'Brien – ADHD

1. Caller: hi, ↑[eh]
2. Host: [hello]
3. Caller:-> my son has ADHD and what I'd like to know
4. -> is ho:w (.3) this doctor can dispute
5. -> medical evidence
6. from ehm EEG biofeedback? (.3)
7. .hh my son's had this
8. and basically it (.5) maps the (.3)
9. .hh brainwave >activity<?
10. and in his frontal lo:be
11. he had much slower ↓brainwaves. (.7)
12. a::nd (.6) this (.) is (.)
13. >really common< of a child
14. Host: [but he's not]
15. Caller: [or even adult]
16. Host: he's not saying no one's got ↑it
17. he's just saying
18. quite a lot of people
19. who think they've got it
20. haven't got it
21. so he he doesn't have to (.5)
22. refute your your medical evidence

From line 3 onwards, the caller adopts an expert footing, explaining the workings of EEG biofeedback. In his response, the host upholds the expert status of the 'doctor' (in fact, a psychotherapist), whose allegations provided the

starting point for the program, by particularising the general ‘medical evidence’ mentioned by the caller in line 5 to ‘your your medical evidence’ (22).

At this stage, host and caller cooperate in upholding the truth value of both the ‘medical evidence from ehm EEG biofeedback’ and the expert authority of the psychotherapist disputing the realness of ADHD diagnoses. Probably unsure about the caller’s credentials, the host does not yet challenge her claims to scientific expertise, but this changes during the course of the conversation, as we will see below.

In the utterance following this excerpt, the caller apologises for having misunderstood the expert’s statements. The conversation then focuses on the possibility of easily testing for ADHD, which would be possible according to the caller. The host then proceeds to ask why people do not simply take this test. While ostensibly accepting the truth value of the caller’s claim, the seemingly innocent questions implicitly casts doubt on the plausibility of the statement. The caller answers that the test is not widely available on the NHS, to which the host responds with a continuer. The following interaction ensues:

Excerpt 5b – James O’Brien – ADHD (continued)

40. Caller: ehm and again not all doctors
41. believe that biofeedback
42. or EEG biofeedback (.3) wo:rks?
43. Host: oh I see.
44. Caller: but you can have
45. your a (.3) child’s brain mapped, (.5)
46. or even just see their activity,
[8 lines omitted]
56. .hh and then ↑really,
57. any child that takes Ritalin
58. or a derivative of Ritalin,
59. (.5) it should eh (.3)
60. well, again, (.2)
61. I’m I’m not a me- a medical person,
62. but the Ritalin will ehm
63. stimulate their slow frontal brain waves?
64. Host: ah see the problem is,
65. tha- you you just nailed it yourself.

66. everything you say sounds convincing
 67. and then you say two things that
 68. ↑just slightly undermine it ↓all=
 69. Caller: =heh heh
 70. Host: you say some doctors don't agree with it
 71. and then you said I'm not a medical person
 72. so the people who don't agree with it
 73. are medical people.
 74. Caller: but if they did the research? I mean
 75. Host: oh come ↓o:::n
 76. you say the doctors haven't done
 77. enough research into it,

In her first utterances (40–42), the caller treats the effectiveness of biofeedback no longer as a matter of medical evidence but as the subject of belief. She thus positions the alleged minority of doctors who do not subscribe to the effectiveness of neurofeedback as (non-)believers, rather than dissenting experts. Rather than inquiring why some doctors do not believe in neurofeedback or otherwise reacting to the content of the claim, the host merely acknowledges the caller's claim as received information. This token response conveys disinterestedness or scepticism; with her own statement, the caller has further undermined the plausibility of her previous claim. She tries to regain her epistemic authority with a prescriptive claim in lines 44–58, before faltering in line 59 and providing the disclaimer that 'I'm not a medical person' in line 61. In response, the host merely has to point out the discrepancy between the caller's 'convincing' argument and her lack of category entitlements to make this argument, being 'not a medical person' (later on in the conversation, the caller will point out that she has a science background, and is 'just not now medically trained'). In her response to the host's rather damaging statement, the caller refers to another scientific symbol, suggesting that the doctors didn't do the necessary research. The host reacts by treating her no longer as a serious conversation partner (line 75). Rephrasing the caller's statement, he needs no further comment to underline once again the doctors' category entitlement to science. The caller's claim to epistemic authority has by now been thoroughly discredited and she herself is no longer treated as a rational spokesperson. Throughout the interaction, both host and caller have protected the authority

of ‘medical evidence’ and ‘the doctors’—even when trying to defend a standpoint with which ‘some doctors’ don’t agree.

The caller in the next fragment also positions herself as an expert, when recommending the use of elderberry extract instead of taking the flu shot. In this case, however, there is a certified expert – a general practitioner – present in the studio. The host starts to address him in line 8:

Excerpt 6 – Avondspits Flu-shot

1. Caller: **.hh I can tell you**
 .hh ik kan u vertellen
2. **that if you take ↑elderberry: (.1) y- extract**
 dat als je ↑vlierbessen (.1) extract neemt
3. **three times a day, then (.3)**
 drie keer per dag, dan (.3)
4. Host: **fheh heh**
 fheh heh
5. Caller: **[then it does help]**
 [dan helpt het wel]
6. Host: **[.hhh f↓well]**
 [.hhh f↓nou]
7. Caller: **[a lot better]**
 [stukken beter]
8. Host: **this is right? thisf**
 dit klopt ditf,
9. Caller: **[than the whole flu]**
 [dan de hele griep]
10. Host: **[hehe I now look to]**
 [hehe ik kijk even naar]
11. Caller: **vaccination**
 vaccinatie
12. Host: **that helps, elderberry, [i s]**
 dat helpt, vlierbes, [i s]
13. Caller: **[>and that is<]**
 [>en dat is<]
14. **a DOUBLE BLIND study is there is proven that,**
 een dUBBELBLIND onderzoek is daar is dat bij bewezen
15. **has been proven with a double-blind study [thatuh]**
 is door een dubbelblind onderzoek bewezen [datuh]
16. Host: **[well]**
 [nou]

17. Caller: **elderberryextract does [help]**
vlierbessenextract wel [helpt]
18. Host: **[hm]**
[hm]
19. Caller: **but the flu shot does not.**
griepvaccinatie dus niet.
20. Host: **well, tha- thank you very much,**
nou dah- dank u zeer
21. **uhh it it has been noted,**
euh dat dat nemen we mee,

This caller employs an expert footing by referring to a conditional if...then possibility, a recipe-type formulation (cf. Matoesian, 1999; te Molder & Snejder, 2005). The host starts to laugh, doubting either the caller's remedy or her right to provide people with this advice. In the lines 5–11, host and caller struggle for the floor, with the host attempting to interrupt the caller at the transition relevant points, and the caller extending her turn. The host explicitly questions the caller's right to provide this advice by starting a question to the general practitioner who is his studio guest (lines 8, 10 and 12), granting the GP the epistemic right to either confirm or conclusively deny the value of the caller's suggestion. But the GP stays silent and the caller refuses to be overruled, referring instead to the scientific basis of her claim and repeatedly pointing out that this has been 'proven' in a 'double blind study'.

Now that the privileged epistemic status of the expert has been made relevant by the host, the caller claims objective access to a scientific study that has proven her argument. By drawing on a superior kind of scientific knowledge (a double blind study, rather than a single expert's voice) the caller ups the ante. When the GP stays silent, the host retreats and confines himself to a doubtful interjection in line 18 (hm). Only when the caller offers 'so the flu shot does not', responds the host with 'it has been noted'. This response allows him to proceed to a next conversation without evaluating the truth value of this caller's prescriptive claim. It acknowledges the caller's prescription in a tokenistic way rather than engaging with its content. Because the GP – the host's certified expert – did not intervene, the truth value of the double blind study is neither confirmed, nor undermined in a decisive way.

2.5. Conclusion and discussion

In this paper, we discussed the evaluation and treatment of different knowledge sources offered by callers in the context of the radio phone-in. We were specifically interested in whether there would be a difference in the way hosts resist the relevance of offered personal experience as compared to the relevance of scientific knowledge claims.

We found that that personal experience and scientific knowledge are treated by the speakers as incontrovertible sources in themselves, but that their relevance to the overhearing audience can nevertheless be disputed. This, however, happens in strikingly different ways. The host cannot challenge the caller's experience as such, but he can particularise its relevance by treating the caller as naive for blindly trusting his or her own experience. The host acts as the spokesperson of the more rational overhearing audience, singling out the caller as a gullible individual. This practice restricts the pertinence of the caller's experience to the caller himself, resisting its relevance for the overhearing audience.

In contrast, when the host disputes evidence that is presented as scientific, he does not challenge the relevance of science. Instead, he challenges the right of the caller to act as science's spokesperson. Both host and caller treat science as a superior knowledge source to be employed as a trump card in the interaction. Whereas callers may claim knowledge by using a scientific vocabulary ('proven by a double-blind study'), they are also careful to admit their own, non-expert status ('I'm not a medical person') – sometimes, as in excerpt 5, during the same conversation. Paradoxically, while disputing each other's claims, host and caller thus cooperate in upholding the authority of science.

The radio phone-in is a specific, highly regulated environment, in which the host enjoys far-reaching privileges. Whereas one should be careful in generalising the findings of this study to other contexts, we argue that the way in which experience and science are treated in radio phone-ins does provide information about broader societal norms.

First, our results suggest a possible explanation for the frequent contestation of factual sources in semi-public exchanges (van Zoonen et al., 2007). Speakers provide knowledge sources not merely to support or to limit a claim (Pomerantz, 1984), but also to prove their 'epistemic vigilance' (Sperber et al., 2010). Being

treated as a gullible person or believer is an interactional problem, as illustrated by excerpts 1-3 in this article. Referring to scientific knowledge helps speakers to demonstrate that they are not inclined to easy beliefs or vulnerable to being duped. This results in the somewhat paradoxical situation that science is employed as a way to show one's own critical attitude. Providing sources of knowledge becomes part of interactants' ongoing attempt to index the relationship between them—even in a context where this relationship is highly regulated and predefined as asymmetrical.

Second, our results shed a different light on the allegedly diminished authority of scientific knowledge. Given the way in which interactants employ scientific knowledge sources as a trump card and collaboratively police who should be allowed to speak for science, we argue that science constitutes a highly authoritative source of knowledge. Showing how this authority is built in turn by turn interaction adds to the findings of Felt et al. (2009: 18), who observed that all participants – expert *and* lay – at the Round Tables they studied “shared or at least accepted the implicit assumption that argumentations using the authority of scientific facts are to be considered superior to ‘mere values’” (cf. Kerr et al., 2007; Bolden, 2013).

When interactants try to prove a point, they will often do this by emphasising the merits of one particular knowledge source as compared to others. For instance, as Melvin Pollner (1987: 8) argues in his book on ‘mundane reason’ – an early study of how the constitution of a coherent social reality requires the exclusion of contradictory truths in favour of others – “when the virtuosity of science’s systematical nature is displayed, it is displayed in contrast to the more or less chaotic character of common sense knowledge.” In the cases we discussed, experience often provided the entry ticket for callers, whereas science was clearly employed as a trump card to win the argument. This finding reflects the set-up of the radio phone-in, and does not mean that one knowledge source always outranks the other. However, when we combine this finding with the reluctance shown by interactants to challenge the relevance of certified expertise, it does suggest that science carries considerable authority.

We started by quoting the Guardian’s question: does the truth not matter anymore? Our results suggest that it does. If facts didn’t matter, people wouldn’t contest them so vehemently, whether within interactional environments designed to elicit controversy, as shown in this article, or outside thereof

(Versteeg & te Molder, 2018; van Zoonen, 2007). Further research should not limit itself to the question as to *whether* either personal experience or certified expertise is the more authoritative knowledge source. Rather, we should ask how interactants selectively employ knowledge sources to not merely win an argument, but to establish their own credibility as critical, and for that reason trustworthy, observers.

3

Chapter 3

“Listen to your body”: Participants’ alternative to science in online health discussions

This chapter has been published as:

Versteeg, W., te Molder, H. & Sneijder, P. (2018) “Listen to your body”: Participants’ alternative to science in online health discussions. *Health*, 22 (5), 432–450. doi: 10.1177/1363459317695632

Chapter 3

“Listen to your body”: Participants’ alternative to science in online health discussions

3.1. Introduction

The friction between scientific and experiential knowledge has been a matter of concern since antiquity, when Plato contrasted the *doxa* of the opinion-lover with the much more respectable *episteme* of the philosopher. Now that the Internet has become a major source of health information (see, for example, Felt, 2015; Seckin, 2010), the online environment is a prime arena in which this friction between scientific and experiential knowledge becomes visible. Some authors have pointed to the dangers of unreliable and even damaging health information that can be found online (e.g. Kata, 2010) or are concerned that online environments value stories about personal experience higher than evidence-based knowledge (e.g. van Zoonen, 2012). Others emphasise that the use of Internet sources does not necessarily ensue in a challenge to certified medical expertise, not even when users have become dissatisfied with medical advice (Giles and Newbold, 2011; Kivits, 2004). Relatively little attention, however, has been paid to the ways in which online participants *themselves* assess the various kinds of knowledge available (see, for example, Hall et al., 2015; te Molder, 2012) and to what purposes they are actually put to use.

In this article, we study the use of the idiomatic expression “Listen to Your Body” (LTYB) to explore how participants establish and negotiate the value of private, bodily knowledge as compared to factual or scientific knowledge. We collected two data sets in which the mutual relation between scientific and experiential knowledge appeared highly relevant for the interlocutors: one containing online forum discussions about medication in relation to attention deficit hyperactivity disorder (ADHD) and the other about the artificial sweetener aspartame. The LTYB expression attracted our attention because we noticed that participants in both data sets systematically employed the idiom to

position themselves vis-a-vis scientific or factual knowledge. It seemed to play a crucial role in negotiating what should count as trustworthy knowledge.

We used a discursive psychological perspective (Edwards, 1997; Edwards & Potter, 1992; Potter, 1996) to explore the interactional features of the LTYB idiom. Discursive psychology is strongly rooted in conversation analysis (Sacks, 1992) but focuses in particular on how participants practically manage psychological issues such as motive, intent, and identity (see, for example, de Kok & Widdicombe, 2010; Horton-Salway, 2001; Peel et al., 2005; te Molder, 2015). A discursive psychological analysis studies what participants achieve using a particular utterance – in this case, the idiomatic expression LTYB – at a specific moment in the conversation. The analyst is not interested in the truth of or the intentions behind an utterance (te Molder & Potter, 2005) but in how an utterance is understood by next speakers. This allows for an emic perspective (Pike, 1954). Because the analyst studies utterances within the natural dynamics of the interaction and in an environment not orchestrated or influenced by the analyst, the interaction can be shown as approached by participants themselves.

3.2. LTYB as idiomatic expression

In a seminal article on idiomatic expressions, Drew and Holt (1988) identified two distinct usage clusters in which idioms – broadly defined as clichéd phrases, including proverbial expressions – occurred: praise and complaint. They found that complaints are typically formulated idiomatically when there is a lack of alignment between complainant and recipient. The robustness of idioms allows complainants to enhance the legitimacy of their complaint while also bringing it to a close.

Kitzinger (2000) studied how women with breast cancer used the phrase “Think Positive” in group talk on their experiences. Despite it not being a typical proverb, she found a similar robustness for the device. As Kitzinger (2000: 127–128) points out, this is because (1) idiomatic formulations are general and vague; it is never specified exactly what it means to, in our case, LTYB, and (2) idiomatic formulations do not belong to any individual but instead “present themselves as ‘anyone’s knowledge’, part of the stock of ordinary taken-for-granted common sense we all share.” The idiom is a basic object, well characterised by Sacks (1992) as “members are so committed to their

correctness—that if you undercut one, exactly what you’ve undercut is not clear. And one doesn’t exactly know how we can continue talking” (p. 25).

While idiomatic expressions are robust and not easily challenged, this is not to say that they cannot be resisted at all. Rather than overtly questioning or explicitly challenging the idiom, the women in Kitzinger’s (2000) study used pauses and token agreements, produced competing idioms, or particularized the idiom’s relevance. According to Kitzinger, the complexity of these resistance strategies is a further indication of the robustness of idiomatic formulations.

Previous publications have referred in passing to the idiom LTYB and the moral connotations thereof. Hart and Grace (2000) describe how women suffering from chronic fatigue syndrome express the need to “listen to their body” (p. 194), naming their failure to do this as the reason for prolonged illness. The women describe listening to the body as a prerequisite for coming to peace with their symptoms, but as Hart and Grace (2000) point out drily, “[N]owhere [...] is there a sense that their bodies listen to them” (p. 194). Fredriksen et al. (2008) studied online discussions on pelvic girdle pain during pregnancy. They describe how “listening to the body” contributes to constructing this condition as “unpredictable.” The idiom stresses the importance of taking care of oneself, placing health responsibility with the pregnant women rather than medical professionals. Watson et al. (1996) note how “listening to the body” became more imperative to participants once their bodies started to age or were impaired by disability. In the context of food, Niva (2007) argues that participants’ mention of the need to listen to one’s body fitted in a conceptualization of health as “comprehensive wellbeing [...] rather than something that can be measured quantitatively” (p. 390). In summary, the idiom clearly conveys an obligation to care for oneself, or as Niva (2007) puts this, “what is ‘good for you’ becomes an individual issue that demands constant vigilance in observing one’s bodily needs” (p. 386).

In this article, we focus on the way in which participants employ the idiom LTYB to demonstrate a specific type of vigilance, namely, vigilance with regard to factual or scientific sources of health information. We show how the LTYB idiom is used not only to position oneself relative to science and make an alternative knowledge claim but also to build a particular identity. By contrasting the “untainted” information provided by their body with the

potentially “corrupted” information derived from scientific sources, speakers identify themselves as rational rather than gullible individuals.

A discursive psychological approach looks at how identities are made relevant in talk by participants themselves (Antaki & Widdicombe, 1998). They become visible as a demonstration of, or an ascription to, membership of a whole range of possible categories, such as “woman” or “ordinary human being,” which are inference-rich and therefore associated with so-called category-bound activities (Sacks, 1992). Success, however, is not guaranteed: membership needs to be worked up and people can fail to be treated as being a member of a certain category. In the analysis that follows, the participants’ issue is whether “being a rational person” is exclusively bound up with drawing upon scientific expertise or should rather be achieved by “listening to one’s (own) body.”

3.3. Data and method

We selected two health contexts – online conversations about ADHD medication and about the artificial sweetener aspartame – in which the relevance of “lay” knowledge versus that of scientific expertise was expected to be at the heart of participants’ negotiations. Discussions about both ADHD medication and aspartame evolve around the question what choices need to be made in order to take good care of oneself or one’s children. In both contexts, there is substantial public deliberation about the role of scientific knowledge in making good care possible and the trustworthiness of such knowledge. For example, interlocutors voice concerns that the available scientific information is biased because of the financial interests of pharmaceutical and food companies, respectively. The two domains also show diversity in the sense that ADHD is a contested disease category with corresponding discussions about its treatment (Horton-Salway, 2011), while aspartame is a contested sugar substitute in food and beverages used by, in principle, healthy people. We expected that this could result in a different dealing with the status of experiential versus scientific knowledge, for example, because patient experiences carry more weight and are harder to dispute than those of healthy people.

A first exploratory study of online discussions on ADHD medication and aspartame brought the use of the LTYB expression to the surface. We noted that despite the potential influence of differences in topical domain and ways of

being contested, participants positioned themselves vis-a-vis scientific knowledge in a strikingly similar manner, namely, by employing the LTYB idiom. In both data sets, this positioning of the idiom as an alternative for scientific expertise received little or no resistance from recipients.

To gain more insight into the interactional dynamics surrounding this particular use of the LTYB idiom, we performed a broader search in nine Dutch and US-based forums that contained threads about ADHD medication or aspartame or a combination of both (see Appendix 2). We used the search terms “listen to your body,” “ADHD,” “ADHD treatment,” and “aspartame” to identify relevant threads. Within those threads, we collected all 13 instances where LTYB or a variant thereof (such as “you just need to listen to your body,” “just listen to your body,” and “I’d rather listen to my body”) was used.

The threads that are presented in the analysis stem from “open” forums, which are available in the public domain and do not ask for registration or passwords. Nicknames provide participants with anonymity. We acquired university ethical approval, 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.

Discursive psychology treats discourse as action-oriented: language is understood as a tool for achieving particular interactional goals, such as attributing responsibility, claiming a particular identity, or discounting expertise. Discursive psychologists focus on how recipients *treat* a particular utterance in sequential interaction, rather than on the speaker’s intentions. The guiding question in any analysis is what does the speaker achieve (consciously or not) by choosing this particular wording at this particular moment in the interaction. A 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, by using extreme case formulations or adding particular details to preempt accusations of stake.

The analysis of online interaction is complicated in the sense that many rules relevant to face-to-face interaction cannot be simply transferred to the online

environment. A discursive psychological analysis takes those features of interaction into account that are (in)directly oriented to by participants themselves. What they make relevant, and how, may differ between online and offline contexts. For instance, a failure to respond would be an accountable matter in face-to-face interaction but not necessarily in online conversation (cf. Lamerichs & te Molder, 2003; te Molder 2015). Other aspects may be oriented to by participants in similar demonstrable ways as in offline interaction, such as when participants (re-)formulate community norms and hold each other accountable for these rules (e.g. Cranwell & Seymour-Smith, 2012; Giles & Newbold, 2011; Stommel & Koole, 2010). The discursive psychological perspective can therefore be used for a qualitative analysis of online utterances and to learn more about the way in which participants treat these utterances in naturally occurring interaction.

3.4. Analysis

We first show how participants employ LTYB to transform a personal health choice into generally valid advice while avoiding the need to refer to scientific or factual evidence. We will then demonstrate how participants employ LTYB in contrast to blind trust in science, allowing the speaker to position herself as a rational actor *because* she is actively listening to her body rather than relying on scientific or factual sources. Building on that, we show how speakers struggle to claim ownership of the idiom and the rationality associated with it and, finally, how the idiom is employed to achieve closure in discussions about what constitutes a trustworthy knowledge source.

LTYB used to formulate advice that is not underpinned by scientific sources

In this paragraph, we show how participants employ LTYB to transform personal health choices into advice that does not need to be supported by factual or scientific sources. The latter is important because even online communities typically seen as anti-scientific orient to what Hobson-West (2007: 212) has called a “moral imperative to become informed” (see also Felt, 2015). The science as it is discussed in these forums will not necessarily satisfy any scientific standard; however, a failure to provide the kind of evidence that other participants find convincing is frequently a reason for scorn.

The interaction shown below is part of a discussion on a Dutch consumer forum about what constitutes a trustworthy knowledge source when assessing the potentially detrimental health effects of aspartame. The sequence opens when speaker ‘Natural’ ends her post with a cautiously formulated advice, arguing that she personally would use as little sweeteners as possible:

Consumer forum “Radar”—thread: “Aspartame harmful?”⁹

Excerpt 1a: Natural

1 [45 lines omitted]
2 Personally I would use as little
3 sweeteners etc as possible
4 because all of these substances are
5 already in natural products.

Consumer forum “Radar”—thread: “Aspartame harmful?”

Excerpt 1b: Candle

6 A human being can live very well
7 without sugar and sweeteners!
8 Whether this is aspartame or
9 something else!
10 (4 lines omitted)
11 So why ask questions? Just listen to
12 your own body!
13 What is wrong with making everything
14 fresh and making lemonade yourself
15 and cooking without sugar?
16 I don’t need to provide medical
17 grounds to be able to tell that
18 it is rubbish!
19 [3 lines omitted]

⁹<https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

The closing sentences of post 1a can be read as an advice or recipe, but they have been formulated as if they were only relevant to Natural herself (“personally I would”). The relevance of this statement is expanded by Candle in post 1b, who is the first one to use the idiomatic expression “Just listen to your own body!” in lines 11 and 12. The imperative form of the sentence would make this utterance an authoritative command had the idiom not been presented as merely common sense: what could be wrong with listening to your own body?

Candle presents LTYB as if it were on a par with “everything fresh and making lemonade yourself and cooking without sugar”—other actions belonging to the repertoire of motherhood and apple pie. The use of “just” in line 11, combined with “why asking questions?”, suggests that the messages of the body are easily discernible and, as it were, unmediated. Candle contrasts this with medical reasoning (lines 16–18). The phrasing of her sentence – she doesn’t “need to provide medical grounds to be able to tell that it is rubbish” – suggests that providing such medical grounds would normally be expected or required. Listening to the body relieves the speaker from the obligation to offer the scientific evidence that would otherwise be required to make this claim about aspartame. Indeed, Candle’s post suggests that asking questions or demanding medical grounds is superfluous; “listening to the body” is presented here as the rational and sensible alternative.

3.4.1. LTYB as a contrast with blind trust in scientific knowledge

Participants frequently employ the LTYB idiom to contrast the body as a source of knowledge with the more complicated and possibly corrupted information as provided by factual sources, science in particular.

Excerpt 2 is derived from a discussion about alternative treatments for ADHD. It resembles the previously analysed excerpt on aspartame; the speaker asserts that she did “not need a scientific study to know that this [an alternative treatment] worked for MY child” (lines 5 and 6):

ADD forum—thread: “Controversial Treatments for Children With Attention-Deficit/ Hyperactivity Disorder”¹⁰

Excerpt 2: Miller 234

1 [8 lines omitted]
2 You just need to figure out what
3 YOUR body needs.
4 [6 lines omitted]
5 I did not need a scientific study to
6 know that this worked for MY child.

Again, the speaker provides listening to your body (figuring out what your body needs) as a rational alternative for making health decisions independent of scientific knowledge. Lines 2 and 3 and 5 and 6 are linked to one another by means of a juxtaposition which is further emphasised by the use of capitals: “you just need/I did not need” and “what YOUR body needs/that this worked for MY child.” Because of this juxtaposition, the utterance is indicative not merely of what the speaker herself does and does not need but also conveys a judgment about those who do need a scientific study to know whether or not a treatment works. The capitals help the speaker to contrast the generalised type of knowledge that a scientific study can provide, with the specific knowledge necessary to care for her child in particular (compare excerpts 7a, line 9–14 and 7b, line 18–20 for a similar contrast between particular and generalised knowledge).

When employing the idiom, speakers frequently stress the unmediated character of the body’s messages, either directly using the adverb “just” as in excerpts 1 and 2 (“just listen,” line 11; “you just need to figure out,” line 2) or indirectly as in excerpt 3 (“Is it okay to eat or drink then I will, otherwise the body will indicate if it is not good for me,” lines 3–5). Speakers thus portray body messages as transparent, unmediated, and easy to understand:

¹⁰ <http://www.addforums.com/forums/showthread.php?t=26974&page=3>, accessed 14 January 2016.

Youth forum “Fok”—thread: “Child sick after sip of Pepsi Cola”¹¹

Excerpt 3: Oblivion

1 Is a very tiring discussion
2 I'd rather listen to my own body
3 Is it okay to eat or drink then I
4 will, otherwise the body will
5 indicate if it is not good for me
6 But to blindly trust scientific studies
7 that they have performed
8 correctly according to their
9 saying? No ...

Participants also contrast the allegedly legible and clear messages of the body with the messy and possibly corrupted nature of factual sources: excerpt 3 contrasts LTYB with “to blindly trust studies that they have performed correctly according to their saying” (lines 6–9), excerpt 4 refers to the invested claims of food producers (lines 1 and 2), and excerpt 5 contrasts LTYB with studies financed by companies “who make big money out of it” (lines 5 and 6):

Public forum “Joop”—thread: “Aspartame is really not dangerous”¹²

Excerpt 4: Anja

1 Why listen to advertisement and
2 information from food producers
3 I take my body and health too
4 seriously to be dependent on what
5 others who I don't know may or may
6 not think of it.
7 I carefully listen to my body and to
8 the people I take seriously

¹¹ <http://forum.fok.nl/topic/1187178/3/100>, accessed 14 January 2016.

¹² http://www.joop.nl/opinies/detail/artikel/12314_aspartaam_is_echt_niet_gevaarlijk/, accessed 16 January 2014, forum page no longer available.

Excerpt 5: Five Star

1 If a research is needed at all to
2 prove whether something is or isn't
3 good or poisonous I have my doubts
4 about it anyway.
5 There are always companies who make
6 big money out of it
7 and then finance such a research.
8 well.
9 I'd rather listen to my body then.

Speakers offer “listening to the body” as proof of their own critical attitude and contrast this attitude with the reliance on factual sources. It is precisely because these speakers take their health seriously that they listen to their body rather than rely on information provided by others. The speakers in excerpts 3 and 5 present listening to the body as a subjective preference (I'd rather; lines 2 and 9, respectively), thereby stressing their independence in this matter. Excerpt 4 contrasts LTYB with “to be dependent on what others who I don't know may or may not think of it” (lines 4–6), specifying these others as the food companies. Excerpt 5 suggests that the need for research is in itself suspicious (lines 1–4). While participants treat the messages from the body as easy to grasp, they also present listening to these messages as more effortful than the alternative: “blindly” following information provided by others. By asserting that they prefer to listen to their own body rather than “just” following scientific research, speakers position themselves as not gullible, naive, or easily duped, but on the contrary as people who take responsibility for their own health in a rational manner.

The content of the statements extracted above might suggest a suspicion toward science because participants describe scientific sources as corrupted and untrustworthy. However, even when casting doubt on science's trustworthiness, participants orient to the relevance of science each time they claim their epistemic independence. An account for not providing scientific sources would

¹³ <http://www.valtaf.nl/artikel/5441/aspartaam-opnieuw-veilig-bevonden/>, accessed 14 January 2016.

be redundant if science had not been the dominant knowledge source to legitimate one's claims. Participants employ the idiom LTYB to assert rationality on their own terms, that is, make their own choices when it comes to the nature of their information, but each assertion also underlines that referring to science would be the default course of action.

3.4.2. Claiming ownership over LTYB to confirm one's rational identity

Idioms are typically presented as common sense or anyone's knowledge; it is precisely this characteristic that lends them their robustness. Despite this, we found several examples where speakers seemed to compete for the ownership of LTYB. We argue that when a speaker in first position presents "listening to the body" as the rational attitude, this is consequential for the projected rationality of the recipients. It is for this reason that a struggle about the primary rights to the use of the LTYB expression may develop.

Speakers typically index their relative knowledge rights when assessing or discussing a particular state of affairs (Heritage & Raymond, 2005; Raymond & Heritage, 2006). This indexing of relative epistemic rights is partly dependent on the sequential position in which an assessment is made. When a speaker provides an assessment while in first position, (s)he automatically claims primary moral and/or epistemic rights to make this assessment relative to a second speaker (Heritage & Raymond, 2005: 34). When this sequential distribution of epistemic rights is not in accordance with the amount of epistemic authority a speaker "wants" to claim, she can downgrade or upgrade a claim. In third position, a speaker can use a success marker such as "exactly" or "indeed," which "retrospectively transforms what is delivered [by the second speaker, WV] as an initiating action into a supportive response that in fact appreciates the stance independently held and conveyed by the exactly-speaker" (Li, 2008: 22).

To illustrate how the participants use success markers to claim ownership of LTYB, we start by reshowing excerpt 1:

Consumer forum “Radar”—thread: “Aspartame harmful?”¹⁴

Excerpt 1a: Natural

1 [45 lines omitted]
2 Personally I would use as little
3 sweeteners etc as possible
4 because all of these substances are
5 already in natural products.

Consumer forum “Radar”—thread: “Aspartame harmful?”¹⁵

Excerpt 1b: Candle

6 A human being can live very well
7 without sugar and sweeteners!
8 Whether this is aspartame or
9 something else!
10 (...)
11 So why ask questions? Just listen to
12 your own body!
13 What is wrong with making everything
14 fresh and making lemonade yourself
15 and cooking without sugar?
16 I don't need to provide medical
17 grounds to be able to tell that
18 it is rubbish!
19 [3 lines omitted]

Consumer forum “Radar”—thread: “Aspartame harmful?”¹⁶

Excerpt 1c: Natural

20 Exactly! Just listen to your body! A
21 human being can perfectly

¹⁴ <https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

¹⁵ <https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

¹⁶ <https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

22 do without ADDED sugar and
23 sweeteners.

In excerpt 1b, Candle transforms the personal knowledge of first speaker Natural into a generally applicable advice; she is the first to employ the expression LTYB in lines 11 and 12. As noted earlier, Candle's post turns asking questions about the advice or demanding medical grounds for it into superfluous actions; "listening to the body" is presented as the more rational option.

In response, Natural initiates her turn in excerpt 1c with "Exactly!" (line 20) before repeating the idiom. The success marker "exactly" constructs a position of independent epistemic access to the object being assessed and retrospectively transforms Candle's turn into support for Natural's position (Li, 2008; Snejder & te Molder, 2006). Natural implicates that she already held access to the idiom, even though Candle was the first speaker to mention LTYB. In response to Candle's guidelines, Natural thus reclaims the primary epistemic rights over the idiom and the rationality associated with it.

In the next excerpt, we show an example of participants explicitly negotiating what constitutes responsible health information-seeking behavior regarding aspartame. They claim ownership rights over the idiom while also establishing who among them is the expert on aspartame:

Weightwatchers forum—thread: "Light Drinks?"¹⁷

Excerpt 6a: Nadya

1 Personally I am very much opposed
2 against the use of aspartame
3 They write so much about it that it
4 is sometimes difficult to believe
5 what is true and what isn't
6 [5 lines omitted]
7 A quick search on google already
8 provides the following [info]:

¹⁷ http://www.weightwatchers.nl/community/mbd/post.aspx?page_size=25&rownum=1&threadpage_no=1&mod_no=&daterange=2days&viewchange=OPENDATEDESC&since date=26-1-2012&thread_id=8062578&thread_name=light+dranken%3F&board_id=620&forum_id=1, accessed 14 January 2016.

9 By a cruel and ironic twist of fate,
10 aspartame causes an increase of
11 weight rather than weight loss

Weightwatchers forum—thread: “Light Drinks?”

Excerpt 6b: Cencia

12 Yes, because when something is found
13 on the internet it has to be true!
14 I just like [the taste] of cola
15 light, and the optimal products etc

Similar to excerpt 1, Nadya initiates the sequence with a subjectively framed assessment (note the use of “personally” in line 1) that she very much opposes the use of aspartame—an assessment that is further on changed into a more general “trust your own body” advice (excerpt 6c; see also below: *TTYB as closure of a controversy*). She topicalises the knowledge discussion by commenting that so much is written about it that it is difficult to find out what is or is not true and proceeds to quote Internet information suggesting that the use of aspartame is counter-effective. This elicits an ironic comment from Cencia (lines 12 and 13), an example of the way in which online speakers can be scorned for trusting untrustworthy sources. Cencia proceeds to foreground taste as her own main reason for products containing aspartame. She constructs losing weight as a side effect, providing as the main reason for taking aspartame products that she “just like[s]” them (line 14). Given the subjective nature of taste assessments, this argument can hardly be argued with (Sneijder & te Molder, 2006; Wiggins & Potter, 2003).

Cencia’s post was designed as a challenge to Nadya, but in her next response Nadya treats Cencia’s description as an example of “trusting your own body” (lines 30 and 31). She uses the success marker “indeed” (line 30) to present Cencia’s descriptions as a confirmation of her own point of view, rather than a challenge of her first message (6a):

Weightwatchers forum—thread: “Light Drinks?”

Excerpt 6c: Nadya

[1 post omitted between 6b and 6c]

30 Indeed, you need to trust your own
31 body and everybody reacts
32 differently to it
33 But like I said: much is written
34 about it and in most cases it is
35 difficult to see whether the
36 information on internet is
37 indeed evidence based.

Weightwatchers forum—thread: “Light Drinks?”

Excerpt 6d: Cencia

38 Here on the forum everyone has his
39 own opinion too, of course.
40 The same holds true for internet and
41 everybody posting things there.
42 That’s why I only meant to say
43 that there are indeed many different
44 opinions about this topic and that
45 indeed you just need to listen to
46 your own body.

In post 6c, Nadya employs the LTYB idiom to conclude the discussion. She adopts an expert footing by suggesting that she is in principle able to assess the quality of the information and by formulating this statement in objective terms (“it *is* difficult to see whether the information on internet is indeed evidence-based”). By prefacing it with “like I said” (line 33), she also suggests a position held independently of what Cencia has said. Rather than accepting the expert footing adopted by Nadya, Cencia treats Nadya’s post as just one opinion among many others. And instead of “simply” agreeing with Nadya, she, in turn, claims independent access to the LTYB idiom, by using “indeed” (lines 43 and 45) and by underscoring the obviousness of the advice with “just” (line 45).

While Nadya first offered the LTYB idiom from an expert footing, Cencia now achieves closure by suggesting that there are no experts, only opinions, and that it is, therefore, important to listen to your own body. She has reasserted her own rationality, presenting herself as a critical rather than naive person, that is, someone who does not blindly follow any advice or opinion.

3.4.3. *LTYB as closure of a controversy*

While speakers frequently employ idioms to achieve closure, this particular idiom has a characteristic that makes it even more effective; messages from the body belong indisputably to the epistemic domain of the body's owner and are therefore hard to argue with. The idiom allows the speaker to provide advice without seeming to do so—after all, (s)he only urges the recipients to listen to their own bodies.

The next excerpt is derived from the same Dutch forum discussion as excerpt 1. This excerpt follows excerpt 1; in between, six posts have been omitted. We have shown above how speakers employed the LTYB idiom to transform personal knowledge into general advice. It is precisely this transformation that Kuklos now takes issue with in lines 9–14, responding to the words from Natural:

Consumer forum “Radar”—thread: “Aspartame harmful?”¹⁸

Excerpt 7a: Kuklos

“When people have literally experienced that the substance aspartame has had negative consequences for their health then you cannot say that it is not true because it has not been scientifically proven, can you?”

8 That’s why that does not happen, as
9 you could have seen. But as soon as
10 these people generalize their own
11 experience as relevant for every
12 human being, that’s where they go
13 wrong. Because of that, there is no
14 evidence at all.

¹⁸ <https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

Consumer forum “Radar”—thread: “Aspartame harmful?”¹⁹

Excerpt 7b: Natural

15 no, just like I said, listen to your
16 body. I much more value people who
17 have experienced themselves how a
18 substance affects their body (so
19 their own body, not the entire
20 humanity). And who are willing to
21 share their opinions and experiences
22 with us here.

Kuklos problematises the epistemic claims of the previous speakers, Natural and Candle in particular. In her reaction, Natural again employs the idiom LTYB, now to force closure of the knowledge discussion. Her assertion that this is “just like I said” (line 15) conveys that her mind has not been changed by Kuklos but that she has been thinking along these lines all this time, independently of what others may have said (Heritage & Raymond, 2005; Snejder & te Molder, 2006). Now that the indirect advice has been made controversial, Natural particularises the idiomatic expression to its circumscribed domain: “their own body, not on the entire humanity” (lines 19 and 20).

The interaction shown in excerpt 7 (compare also excerpt 6) illustrates how online participants negotiate about who has the right to give advice to others and which relevance can or should be assigned to a particular type of knowledge. In these negotiations, the ambiguous nature of the LTYB device helps participants to provide advice without making themselves vulnerable to criticism. Speakers may compete with each other over the ownership of the LTYB idiom, yet as soon as the associated advice is treated as controversial, speakers assert that they are merely repeating a truth that is already well known by everyone, does not belong to anyone in particular, and can therefore hardly be argued with.

¹⁹ <https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

3.5. Discussion

In the existing literature, the LTYB idiom has mostly been referred to in the context of how people relate to their own body (e.g. Hart & Grace, 2000; Watson et al., 1996). We examined the idiom from an interest in how speakers employ LTYB to position themselves in relation to scientific knowledge. We have added to the literature by showing how speakers employ LTYB to demonstrate that they take their health seriously and *for that reason* avoid scientific knowledge. Speakers contrast the pure, unmediated knowledge provided by the body with the mediated and easily corruptible information provided by scientists, the government, or companies. They portray the body's messages as clear and easily legible, yet difficult to obtain. Speakers position listening to the body as the more effortful rational alternative compared to possibly tainted factual sources of information.

The results of our analysis corroborate previous research into idiomatic expressions (Drew and Holt, 1988; Kitzinger, 2000), to the extent that usage of LTYB is typically successful and difficult to resist. We add to these previous studies by showing that interactants actively compete for the ownership rights of this particular idiomatic expression. The idiom is not treated as “anyone's knowledge,” but becomes an identity marker. Participants struggle for its ownership, for example, by using success markers such as “indeed” in third position, because their rationality is at stake. Interestingly, it is not so much *a lack of* trust in scientific evidence—as experts often state—but *blind* trust that is (treated as) the problem here, and it is this kind of naivety that forum participants equate with a lack of rationality.

These results could be interpreted as an example of lay people choosing to rely on “common sense” and disregarding science. We argue that such an interpretation would be incorrect, as illustrated by the words of forum participant Natural:

What I sense from a number of people here is that everything has to be scientifically proven, otherwise it is not true. [...] When one provides an opinion or shares an experience here, one is treated as a scaremonger and alarmist.²⁰

²⁰ <https://forum.www.radartv.nl/viewtopic.php?f=44&t=26546&start=200>, accessed 14 January 2016.

Felt (2015: 188) observes how patients equate taking one's health seriously with getting informed: they treat acquiring health knowledge as a moral duty, now that this information is available online. Providing or asking for scientific studies, websites or raw data are a way for participants in online health discussions to show that they are not naive or dupable, but have fulfilled the "moral imperative to become informed" (Hobson-West, 2007: 212). This imperative seems a consequence of the neoliberal environment in which health decisions must be made. Edwards and Howlett (2013) argue that scientific evidence is increasingly bound up with patient choice because "one cannot choose without recourse to evidence. The significant question, however, is *which evidence?*" (p. 40).

In this context, the idiom LTYB provides speakers such as Natural with an alternative knowledge source. This is important in forum discussions, where speakers frequently treat seemingly individual health choices (such as the decision to eat aspartame or not to use ADHD medication) as a communal responsibility (Cranwell & Seymour-Smith, 2012). By systematically employing LTYB as an account for not providing the scientific sources underlying their claims, participants implicitly acknowledge that it would be the expected routine to do so. LTYB helps speakers to counter this challenge before it has even been uttered, by suggesting that placing one's blind faith in science is naive and the easiest option.

An awareness of what is at stake in online health discussions might help experts to better understand these frequently contentious interactions. Rather than simply challenging the facts, let alone science in general, forum participants demonstrably orient toward a norm of being critical and are held accountable for this by other forum users. If being critical is perceived as a good in itself, merely providing forum users with more facts is unlikely to promote a more informed health discussion. It seems more fruitful to take into account the identities that people build for themselves rather than to simply deny them. These identities refer to how governments educate citizens nowadays: as critical and self-responsible human beings that do not take things for granted. A first requirement for a good dialogue is to take this inquiring attitude of citizens seriously. If there is a limit to it – as may well be the case – then this limit could and should also be discussed. But it seems odd to make citizens accountable for an overly critical attitude if they have first been educated that way (te Molder, 2012). Experts could start asking questions instead of presenting the facts on a

plate and convincing others of their truth. The motto is to look beyond the facts and to take into account to what use they are put, consciously or not, such as the need to be recognised in one's rationality.

It requires further research to establish how participants employ the LTYB idiom in other contexts. We found various instances of LTYB on body builder forums where speakers discuss whether or not listening to the body has any value as guidance when trying to get fit, topicalising the complicated nature of the body's communication: "my body and I didn't speak the same language. And to some extent, we still speak a different dialect."²¹ Speakers present listening to your body as an excuse not to exercise; the body will provide you with false information, telling you to eat fat and sugar or not to engage in physical exercise (cf. Hall et al., 2015). An interesting avenue for further research on the LTYB idiom is, therefore, to explore when speakers present LTYB as the more difficult or active alternative, and when as the simple or passive option. The assessment of the value and meaning of the information provided by the body clearly depend on the interactional context in and by which speakers collectively negotiate what constitutes trustworthy knowledge.

²¹ forum.bodybuilding.com/showthread.php?t=127366583, accessed 1 October 2015.

4

Chapter 4

What my body tells me about your experience: 'My side' empathy formulations in ADHD coaching sessions

This chapter has been published as:

Versteeg, W. & te Molder, H. (2016). What my body tells me about your experience:
'My side' empathy formulations in ADHD coaching sessions. *Journal of
Pragmatics*, 105, 74–86. doi: <http://dx.doi.org/10.1016/j.pragma.2016.08.005>

Chapter 4

What my body tells me about your experience: ‘My side’ empathy formulations in ADHD coaching sessions

4.1. Introduction

Therapeutic formulations have been the subject of conversation analytical study since Kathy Davis first explored the subject in 1986. Davis explored how the therapist employed formulations to transform a housewife’s ‘problems of fit’ into an individual, psychological problem, rather than a mismatch between her own expectations and the norms governing her social environment. Writing from a feminist perspective, Davis took a normative, critical stance in her account of the interactional work involved in the process of finding a problem that is suitable for therapy. She contrasted this interactional work with the way in which the therapeutic process of establishing a diagnosis was usually portrayed in professional literature, namely, as an objective process of an essentially factual nature (Davis, 1986: 44–45). Other conversation-analytic studies also emphasised how problem identification in psychotherapy “is a product of interaction between client and therapist in which the meaning and significance of the client’s experiences are negotiated” (Madill et al., 2001: 415; Antaki et al., 2005; Morris, 2005). The result of this negotiation will be significant not only for the nature of the problem, but also for the identity of the client; for instance, if a problem is not treated as a legitimate complain-able (Pomerantz, 1986), the problem narrator might be treated as irrational or as a moaner (Edwards, 2005; Heritage and Robinson, 2006). The presentation of a particular problem is therefore always simultaneously a presentation of the self (Heritage and Robinson, 2006: 48).

In this article, we focus on the way in which Dutch ADHD coaches employ formulations about their own body to negotiate the meaning of their clients’ experience. Rather than trying to diagnose their clients with an individual

problem, the coaches in this ADHD centre aim to achieve almost the opposite from what Davis described in her seminal article. Whereas clients in the coaching centre typically attribute their ‘problems of fit’ to the neurobiological disorder ADHD, the institutional outlook of this coaching centre is to resist such causal attributions in order to create room for agency on the part of the client.

Attention Deficit Hyperactivity Disorder is one of the most commonly diagnosed mental disabilities in the western world. It is also one of the most controversial psychiatric disorders, in part because of the frequency with which the disorder is diagnosed and the associated use of medication (e.g. Singh, 2002, 2005; Rafalovich, 2004). Various authors have described how a psychiatric diagnosis is not necessarily stigmatising, but on the contrary provides meaning and legitimacy to complaints that would otherwise be treated as problematic (e.g. Charland, 2004; Giles and Newbold, 2011; Dehue, 2014). Most psychiatric diagnoses are expert categories for a cluster of complaints experienced by the patient or his environment. Thus, if a patient experiences a severe inability to concentrate, fidgetiness, et cetera, this can be a reason to be diagnosed with ADHD or ADD (Attention Deficit Disorder). The diagnostician considers the nature and the severity of the patient’s suffering as indicative of a particular disorder and formulates lay complaints into an expert diagnosis. In both expert and everyday language use, this diagnosis is then frequently understood and treated as if it provided the cause of the complaints (‘I am fidgety because I have ADHD’) instead of the other way around (‘because I am fidgety I was diagnosed with ADHD’) (cf. Dehue, 2014; Hacking, 1999; Visser & Jehan, 2009).

In the Dutch ADHD coaching centre where we conducted this study, clients frequently provide this causal explanation, situating the cause of their problems in a neurobiological condition. The privately owned coaching centre asserts that a focus on solving problems will make those problems all the more dominant, emphasising clients’ strengths instead. We provide an example of these conflicting conceptualisations below. This is an excerpt from a conversation between a coach and a thirteen year old girl, who has presented herself with the question that she wanted to learn how to better cope with her ADHD:

Excerpt 1 (16.43) (coach 2, client R)

- 1 Cli: **yes when I'm con-**
 ja als ik me con
- 2 **>unable to concentrate<?**
 >niet kan concentreren<?
- 3 Cou: **hm↑hm**
 hm↑hm
- 4 Cli: **that's a ↓form of ADHD: too?**
 das ook een ↓vorm van ADHD:?
(1.3)
- 5 Cou: **>of what<?**
 >van wat<?
- 6 Cli: **°of ADHD°.**
 °van ADHD°.
- 7 Cou: **>↑ do you have this ↓then<**
 >↑ heb jij dat ↓dan<
- 8 Cli: **↑ ye::s**
 ↑ ja::
- 9 Cou: **£ never mind.**
 £ laat maar.
- 10 **£ just kidding.**
 £ is flauw.
- 11 **uhh (.4)**
 uhh (.4)
- 12 **yes >you know< if you say it like this**
 ja >weet je< als je het zo zegt
- 13 **it's like you're saying.**
 is het net alsof je zegt.
- 14 **THAT ALWAYS BELONGS TO ME**
 DAT HOORT ALTIJD BIJ ME
- 15 --> **so I'll never. be able. to**
 --> ik kan me dus nooit. meer.
- 16 --> **learn to concentrate well.**
 --> goed. leren concentreren
- 17 --> **because that is just what I have=**
 --> want dat heb ik nu eenmaal=
- 18 Cli: ->[=yes for that is what I] think

--> [=ja dat denk ik ook] gewoon
 19 Cou: ->[and I do not believe that]
 --> [en dat geloof ik niet]

In lines 1 and 4, the client presents her inability to concentrate as evidence of her ADHD. The coach reacts to this statement with a joke, which is not understood by the girl. The joke has a serious undertone to the extent that it does not treat ADHD as a crucial part of the client's identity. The coach implies in lines 12–17 that the client's conceptualisation of her own inability to concentrate as a consequence of ADHD might be counterproductive to change. The client reasserts that it is indeed her point of view that this cannot be changed (line 18); the coach simultaneously says that she does not believe this. In the remainder of her turn (not shown here), the coach explains how believing in the possibility of change might be the first step in achieving this change, a perspective that is only grudgingly accepted by the girl.

The theory behind the coaching centre's approach to change is explained to clients in terms of its neurobiological underpinnings or in the simple version, 'what you water, will grow.' Rather than trying to control the symptoms of the disorder, the coaching centre treats the diagnosis as irrelevant. Instead, coaches help their clients to search for a balance between cognitive thinking (or in the lay variant employed by the centre as well, the thinking brain (*denkbrein*)) and the basic emotions and drives as controlled by the limbic system (the feeling brain (*voelbrein*)), working from the supposition that many problems originate in the fact that clients have learned to trust one of these systems while ignoring the other. Thus, whereas both coach and client refer to neurobiology to make sense of behavior, their explanations point in opposite directions. As illustrated by the example shown above, clients frequently conceptualise their complaints as a result of ADHD or ADD, disorders that can be controlled, but not cured. Coaches, on the other hand, conceptualise their client's complaints as the result of unproductive strategies or thought processes; they emphasize the plasticity of the brain, its ability to learn and change these unproductive routines.

Given this institutional outlook, an important task for the coach is to transform the client's complaints into a problem that allows for agency. This is a complicated interactional agenda, because speakers typically claim epistemic primacy about their own experiences and feelings (Raymond & Heritage, 2006; Heritage & Raymond, 2005). Furthering a coaching agenda of change might

therefore result in problems of epistemic access and authority, for instance, when the coach asserts that a client feels, needs or wants something, but the client herself argues differently. Formulations are a key interactional instrument employed by coaches to solve such epistemic problems.

Formulations, the rephrasing of what has been said, include various descriptive activities, such as summarising, explaining, translating or giving the gist or upshot of the talk (Heritage & Watson, 1979; Garfinkel & Sacks, 1970). Such descriptive activities are not neutral and are rarely undertaken for their own sake. As Antaki (2008: 31) puts it: “formulations became not so much one speaker announcing *where-we-both-are*, but rather observing to the other: *so-you’re-saying-that-x*.” Doing describing helps members to establish, preserve or subtly shift the relevancies in the conversation (Heritage & Watson, 1980: 246–247). This latter characteristic makes formulations into an important interactional resource for psychotherapists and coaches, whose interactional success depends on their ability to transform the trouble presentations offered by clients in such a way that the client’s problem can – and should – be therapeutically addressed. Because such transformations entail a negotiation about the significance of the client’s experience, and by implication, an assessment of the client as narrator of these experiences, it is not surprising that clients frequently resist therapeutic formulations (e.g. Morris, 2005).

In the present article, we focus on a specific type of formulation employed by coaches to address the meaning and significance of what a client has said. The ADHD coaches in our study engage in ‘my side’ tellings (Pomerantz, 1980), describing their *own* bodily state to infer knowledge about their clients’ feelings. Coaches employ these ‘my side’ tellings in order to occasion “a reflexive consultation of the ‘rest’ of the conversation by the co-conversationalists, eventuating in a response which contains a ‘decision “contingent on such consultation” (Heritage & Watson, 1980: 252). Given the institutional goals of this ADHD centre, the ‘my side’ tellings are a helpful instrument for coaches in challenging their clients’ notion that problems result from a failure to control or adapt to ADHD or ADD, and in treating the diagnosis as irrelevant to the client’s complaints. By employing formulations of their *own* bodily sensations to claim knowledge about their client’s inner state, coaches manage the epistemic difficulties associated with assessing another person’s feelings. Our data show that these ‘my side’ empathy formulations are robust and seldom resisted by the

client. Once the client confirms the coach's inference, the coach can set an alternative coaching agenda aiming for change.

4.2. Data and method

For this analysis, we video-recorded 13 coaching sessions. The recorded sessions are conducted by 3 different coaches; 13 clients participated. Before starting the recordings, researcher 1 conducted a short ethnographic study to become familiar with the institutional practices of the coaching centre. We identified 37 instances of 'my side' empathy formulations in our data, the most illustrative of which are presented in this article.

The material discussed during coaching sessions is highly personal and confidential, which made it difficult to make recordings during individual sessions. However, the coaching centre agreed to organise public coaching sessions for the purposes of this study. Whereas these data are not 'natural' in the sense that the sessions have been organised for the purpose of this research, the sessions are typical for the practices of the ADHD coaching centre. The centre offers both individual coaching and group courses including coaching sessions; the presence of an audience during coaching sessions is therefore not unique to these recordings. We have included the presence of the audience in our analysis when the interactants themselves made this relevant, e.g. by referring to the audience or even directly addressing it, as the coaches sometimes did to explain their coaching methods.

All participants were provided with information about the study. The clients – and where applicable, their parents – gave written consent to their session being recorded, and were given the opportunity to withdraw their participation at any point, which one of them did. The university's ethical review board has approved the study.

We transcribed the recordings first on a verbatim basis, looking for instances of formulations. We then transcribed these formulations and their interactional environment in a detailed way, following Jefferson's system of transcription (Jefferson, 2004, see Appendix 1).

The data have been analysed using a discursive psychological perspective (Edwards & Potter, 1992; Potter, 1996; Edwards, 1997). Discursive psychology

conceptualises language in terms of the actions it performs. Like conversation analysts (Sacks, 1992), discursive psychologists do not analyse these actions on the basis of single sentences but as embedded in a series of turns. They are particularly interested in how members *themselves* distinguish between the (subjective) mind and the (objective) world and how they put these categories to use (Edwards, 1997; te Molder, 2015).

Discursive psychology treats actions as situated in three senses (Potter, 2012): sequentially, institutionally and rhetorically. Action is sequentially situated in an unfolding context of utterances: speakers orient to what has just been said and build an environment for what comes next. Action is institutionally situated: the interactional rules in coaching settings (e.g., an asymmetrical distribution of rights between client and coach) are particular to that institutional environment. Action is also rhetorically situated: both client and coach design their utterances to counter actual or potential alternative explanations (Potter, 1996).

The excerpts shown in the analysis are derived from three different clients' coaching sessions conducted by two different coaches.

4.3. Analysis

In the institutional setting of a therapeutic conversation, a psychotherapist or coach can claim to know more about the client than the client herself does. For instance, the therapist described by Davis (1986: 58; cf. Muntigl & Horvath, 2014: 105) alerts his client that: “the way she is talking about these matters would seem to belie her ‘real’ feelings (238–242; 397–405). She is putting up a ‘facade’ and the therapist ‘hears’ her doing it.” In a therapeutic setting, the therapist or coach can employ practices of questioning and formulating – typically distributed in an asymmetrical way – to position the client as knowable if only the right procedure is followed (Bartesaghi, 2009: 171), but interactional work is still required in order to negotiate what can be known by whom and how. The conversation analytical conceptualisation of therapeutic problem negotiation as a process of asymmetrical negotiation brings to the fore that clients can, and occasionally will, refuse the therapist's problem (re)formulation (e.g. Morris, 2005).

Rather than claiming direct knowledge, therapists frequently claim indirect access to their clients' feelings. For instance, Bergmann (1992) describes how

psychiatrists employ ‘my side’ tellings in intake interviews, using their own limited access as a fishing device to invite their clients to provide a more authoritative version (cf. Pomerantz, 1980). Muntigl and Horvath (2014) examine how therapists employ noticings of their clients’ affectual stance display (e.g. “I can see some sadness in your eyes”/“you say you’re scared, but you’re smiling”) to focus the talk on the clients’ here-and-now experience. They find that noticings are designed with varying degrees of empathy, and assert that more empathically designed noticings cede epistemic authority to the client, whereas less empathetic noticings challenge the client’s superior epistemic status regarding her own experience.

In our analysis, we focus on a different interactional strategy: claiming independent access. In what we will define as a ‘my side’ empathy formulation, the coach voices *her own* bodily sensations in order to claim knowledge about the *client’s* inner state. Heritage (2011; cf. Hepburn & Potter, 2007) has pointed to the interactional problems associated with empathy, suggesting that both speakers and recipients face a distance-involvement dilemma in acts of affiliation (Raymond & Heritage, 2006). When ‘sharing’ an experience, interactants have to determine to which extent a told experience can and should be shared, an interactional effort in which the imperative to respect personal experiential preserves grinds into one another moral rule mandating affiliation with other members of the community (Heritage, 2011: 183).

A ‘my side’ empathy formulation may help the coach to solve this distance-involvement dilemma, and the associated epistemic problems. Whereas this formulation is designed to achieve perhaps the highest possible level of empathy (which literally means feeling into), it also claims independent epistemic access to the client’s inner state. At the same time, the formulation remains a ‘my side’ telling, inviting the client to confirm the correctness of the asserted knowledge. Coaches employ ‘my side’ empathy formulations to provide independent evidence for their assessments of what constitutes the client’s authentic self. We argue that ‘my side’ empathy formulations help coaches to negotiate the epistemic problems associated with claiming knowledge about the meaning and significance of someone else’s inner state.

We start by showing an excerpt in which coach 1 explains some of the theory behind her claimed ability to sense her client’s feelings in her own body. The interaction shown here takes place relatively early in the coaching session, at

minute 4.40 of a 50 min session; the client is telling the coach about her reasons to have come to this coaching session. Until now, the interaction has been exploratory; the coach has encouraged the client to tell about her problems without asking directive questions. The client has told that she has had a range of jobs but currently does not work. Now, just as the client starts to elaborate on a recent disappointment, the coach stops her:

Excerpt 2 [4.40] (coach 1, client A)

1 Cou **yes skip for a moment**
 ja skip even

2 **I'm going to stop you very briefly**
 ik ga je heel even stoppen

3 **>you may continue shortly<? (.8)**
 >maar je mag zo verder<? (.8)

4 **I- I- always notice very much.**
 da- ik- ik merk altijd heel erg.

5 **>I just did that didn't I, with [name previous client]**
 >dat deed ik net ook he, bij [name previous client]

6 **and then (.) she asked why?**
 en die vroeg toen (.) waarom?

7 **but that I don't know why**
 maar dat weet ik niet waarom

8 **but I always notice I'm always going to**
 maar ik merk altijd ik ga altijd

9 **feel with someone a bit in my body?(.)<**
 een beetje zo mee zitten voelen in mijn lijf?(.)<

10 **.hh we're just able to do that with each other.**
 .hh dat kunnen wij gewoon van elkaar.

11 **°people are able to do that with each other°.**
 °mensen kunnen dat van elkaar°.

12 **we have special brain cells.**
 we hebben speciale hersencellen.

13 **°mirror neurons they are called (.) that enable us to.°**
 °spiegelneuronen heten die (.) waardoor het kan.°

14 **°that we can feel each other.°**
 °dat we elkaar kunnen voelen.°

15 **.hh and u::h (.) what I what I**

.hh en u::h (.) wat ik wat ik

16 **so I just give it back to you. (.3)**
dus ik geef het je even terug. (.3)
((client nods in approval))

17 **>and perhaps it is not right at all**
>en misschien dat het helemaal niet klopt

18 **that you don't recognise anything?**
dat je niks herkent?

19 **and perhaps >you do<**
en misschien >ook wel<

20 **and both are absolutely fine<.**
uh en beide is helemaal prima<.

21 --> **u::hm (.5) I noticed**
--> u::hm (.5) ik merkte

22 --> **when you were telling like that about school and such,**
--> toen je zo over dat school aan het vertellen was,

23 --> **and all those different jobs and stuff**
--> en al die verschillende banen en dingen

24 --> **then my head almost exploded?**
--> toen ontplofte mijn hoofd bijna?

25 Cli ↓hm↓hm
 ↓hm↓hm

26 Cou -> **f wuhuhuhu a big lot of energy**
--> f woehoehoe hoe heel veel soort van energie

27 --> **or something?**
--> of zo?

 --> ((coach gestures that her head bursts)) ((client nods))

28 --> **and when you: just told me (.)**
--> en toen je vertelt nu net over(.)

29 --> **you:'d quit that. (.2)**
--> dat je: daaruit bent gestapt. (.2)

30 --> **°around your twentysixth.°**
--> °zo op je zesentwintigste.°

31 --> **whoos (.3) my head could immediately empty itself.=**
--> whoos (.3) kon mijn hoofd meteen leeg.=
((coach makes descending movement with her hands))

32 Cli =**yes, that's about right, yes.**
 =ja, dat klopt ook wel, ja.

The coach announces that she is going to stop her client and then proceeds to do an elaborate noticing, starting in line 4 and continuing for the rest of her turn. She starts by claiming insufficient knowledge about the reasons why (line 7), before employing a scripted formulation suggestive of routine. Rather than portraying her ability to feel with her client as an expert's prerogative, the coach describes this in lines 10–11 as something that 'we are just able to do', referring to 'people' in general. She then switches to a more expert like repertoire, explaining that this ability should be attributed to mirror neurons (lines 12–14). The coach starts to embark on a 'my side' telling (Pomerantz, 1980), but first creates space for disagreement (lines 17–20), explaining to the client that what she will tell her next might or might not be correct. Bergmann (1992: 142) has described how doctors employ 'my side' tellings in exploratory interviews, describing the source of their restricted knowledge in order to invite the patient to provide an authoritative version of her personal state of affairs. This coach uses a similar device in describing her own bodily state to the client. She suggests that her own feelings are an indication of her client's feelings, yet her rising intonation in line 24 invites the client to confirm or disconfirm this; she thus respects the client's epistemic authority regarding her own inner state.

The coach describes only her own feelings, which are type 1-knowables about which she would be expected to possess epistemic authority (Pomerantz, 1980). From these personal feelings she infers information about her client's inner state, to which she can claim no direct access. It would be hard for the client to reject the resulting package deal, especially because the coach reduces the distance between what she feels and her client's state of mind with the use of metaphoric language (her head almost *exploded*) (cf. Edwards, 1997: 188–192). This client, however, initially reacts with a mere continuer in line 25. The coach elaborates in lines 28–31, focusing now on a more positive bodily reaction to her client's story, and in response receives the expected confirmation from her client. By describing her own feelings as indicative of the client's inner state, the coach treats the distance between herself and the client as virtually non-existent. What is more, the coach has attributed a positive bodily sensation to exactly that point in the narrative that the client herself assesses positively, but that might receive a less favourable assessment from outsiders, namely the client's decision to quit her job. The 'my side' empathy formulation thus helps the coach balancing between the thinking and the feeling brain, one of the key-points in the centre's institutional outlook.

The following excerpt is derived from the same coaching session. After the session has been completed, the client poses a question. Her current counsellor is based not in this privately owned ADHD centre but in one of the major mental health care institutions of the Netherlands; health insurance reimburses clients for its treatments. This counsellor has urged this client to take ADHD medication to control her symptoms, but the client does not want this. In a previous part of the interaction (not shown here), the client has provided an account as to why she would refuse medication, and why she finds it difficult to discuss this choice with the counsellor in question:

Excerpt 3 [40.50] (coach 1, client A)

- 1 Cli **so how can I make sure that I**
 dus hoe kan ik zorgen dat ik
- 2 **because >she does possess a lot of knowledge<?**
 want >zij heeft wel heel veel kennis<?
- 3 **that I don't have.**
 die ik niet heb.
- 4 Cou **°yes°=**
 °ja°=
- 5 Cli **=that I get the best from it=?**
 =dat ik daar het beste uithaal=?
- 6 Cou **=yes**
 =ja
- 7 Cli **from her. free. coaching.**
 uit haar. gratis. coaching.
 ((makes a gesture of bracketing her words))
- 8 Cou **fyes.**
 fja.
- 9 Cli **because (.2)**
 want (.2)
- 10 Cou **wo:w.**
 wo:w.
- 11 Cli **hhh yes without medication. (.4)**
 hhh ja zonder medicatie. (.4)
- 12 Cou **yes**
 ja
- 13 Cli **>I dont' want< I don't want medication.**

>ik wil geen< ik wil geen medicatie.
 14 Cou **no**
 nee
 15 >**what it really**<
 >wat er helemaal<
 16 **you know**
 weet je
 16 --> **it (.2) it is beautiful**
 --> het (.2) het is prachtig
 17 --> **how your bo:dy**
 --> hoe jouw lij:f
 18 --> **signals to you what is**
 --> je daar aangeeft wat er wel
 19 --> **what is and what is not good for you.**
 --> wat wel en niet goed voor je is.
 20 --> **I can just feel it with you?**
 --> dat kan ik zo meeevoelen?
 21 --> **the moment you talk about (.) medication**
 --> op het moment dat je over (.) medicatie praat
 22 --> **my (.) belly immediately does**
 --> doet m'n (.) buik meteen
 ((makes contracting gesture))
 23 --> **qsh this.**
 --> qsh dit.
 24 Cli **yes, °okay°.**
 ja, °okay°.

25 **I wished she would feel it too.**
 ik wou dat zij dat dan ook voelde.
 26 **instead of just giving me the standard uh stuff.**
 en niet meteen met de standaard uh dingen aankomt.

The client, a soft-spoken woman, has positioned herself as insecure in her interactions with this counselor, whose methods she does not like but stays with nevertheless, because it is a treatment reimbursed by her health insurance. Since this counselor possesses knowledge to which the client has no other access, refusing the medication that the counselor wants her to take is a complicated interactional endeavour. The client repeats to the coach that she does not want

medication, seeking her out as an ally. In her response, the coach starts to produce a sentence in line 15, but self-repairs and delivers an assessment phrased in objective terms, topicalising the clarity of the message provided by the client's body. This particular message, however, has just made explicit by the client herself and this makes the coach's assessment somewhat unconvincing as empathic response (Heritage, 2011; cf. Wooffit, 2001). The coach therefore proceeds to deliver independent evidence, referring to her own bodily sensations. By asserting that she feels the immediate resonance of her client's talk in her own body (line 20), the coach claims independent access to her client's inner state and to what is or is not good for her. The use of medication for ADHD is a controversial and highly sensitive topic (e.g. Singh, 2005). By referring to her belly as an independent subject-actor (lines 22–23), the coach manages to strengthen her client's expressed will without having to express a personal opinion on the subject (i.e. the rhetorical counter-version of independence and objectivity). As in the previous excerpt, the coach employs her bodily sensation to support the client's decision and to strengthen it against potential negative opinions. The client's final response acknowledges the coach's assessment and expresses her displeasure with the other, less sensitive counselor (line 25). Whereas the client first treated her decision not to take medication as an individual choice, it has now become an imperative of her body that, as such, can be experienced by sensitive others.

The next excerpt is derived from a different coaching session. The fragment shows the interaction between a different coach and another client than in the two previous fragments, and demonstrates how the 'my side' empathy formulation is employed to propose an interactionally complicated agenda of change. The coach has started by asking exploratory questions, but she now requests her client's permission to pose a very different kind of question, shifting the topical agenda:

Excerpt 4 [4.34] (coach 2, client B)

- 1 Cou **okay**
 okay
- 2 **I'm going to ask you a very different question.**
 ik ga een hele andere vraag stellen.
- 3 **>may I<=**
 >mag dat<=

4 Cli =yes.
 =ja.

5 Cou **imagine that we would now decide that you**
 stel dat we nu zouden beslissen dat jij

6 **definitively say goodbye to all this junk.**
 definitief afscheid neemt van alle zooi.

7 (1.3)

8 >would that< hehe=
 >zou dat< hehe=

9 Cli =yes.
 =ja.

10 Cou >would that be something,< (.6)
 >zou dat wat zijn,< (.6)

11 Cli uh >yes and no<.
 uh >ja en nee<.

12 Cou °yes°
 °ja°

13 Cli >because that< uh a sort of (.3) still scary empty (.3)
 >omdat dat< uh een soort van (.3) nog enge lege (.3)

14 Cou **okay,**
 okay,

15 --> **because that is what I FEEL.**
 want dat is wat ik VOEL.

16 --> **that it is just like**
 dat het net is alsof

17 --> **that there still so much sadness.**
 dat er nog zoveel verdriet.

18 --> **and fear. and and (.3) heavy emotions? (.3)**
 en angst. en en (.3) zware emoties? (.3)

19 --> **of which I'm uh if I if I sense in my body**
 waarvan ik me uh als ik als ik in mijn lijf voel

20 --> **then I can now almost start >crying on the spot< (.7)**
 dan kan ik nu bijna >ter plekke gaan< huilen? (.7)

21 Cli **yes.**
 ja.

22 Cou **that you recognise?**
 dat herken je?

23 Cli **yes >yesyes<,**

ja >jaja<,
24 Cou **and that I think**
en dat ik denk
25 **and at the same time there is this voice of**
en tegelijkertijd zit er ook zo'n stem in van
26 **god FUCK it for once?**
god FUCK het nou eens een keer?
27 Cli **yes.**
ja.
28 Cou **yes**
ja
29 (1.6)
30 Cli **yes exactly >I have< a bit those two ↑ways**
ja precies een beetje die twee↑sprong >heb ik<
31 Cou **yes.**
ja.
32 (2.0)
33 **so >and and< uhm?**
dus >en en< uhm?
34 (2.0)
35 **and it is just as if that heavy side a bit**
en het is net alsof die zware kant een beetje
36 **uh a bit as if that does not belong >to you at all<.**
uh een beetje alsof dat >helemaal niet bij jou< hoort.
37 (3.0)
38 Cli **mmm it has indeed started to belong. to. me.**
mmm het is inderdaad bij. me. gaan horen.

The coach proposes to her client to think about a situation in which she would 'say goodbye to all this junk' (line 6), phrasing this proposal in voluntaristic terms of deciding. This interactional strategy is not without risks. The client in question has been suffering for years from the problems here presented by the coach as something that she could just decide to take her leave of. Note the choice of personal pronouns; coach and client can decide together, but it is the client who would say goodbye and therefore also the client who is asked to confirm whether or not this prospect sounds appealing to her. The client

responds in a hesitating way (line 11). She provides the start of an account for this ambiguous answer in line 13, but does not finish her sentence.

Instead of focusing directly on the scary emptiness mentioned by her client, the coach first treats her client's answer as a confirmation of what she herself already felt (line 15). She offers independent evidence for her empathic response by describing these negative feelings (cf. Edwards and Fasulo, 2006 on participants' ways of asserting independence and genuineness as the basis of what they are saying on occasions in which something functional or invested is expectable). As in the previous excerpt, the coach refers to her own bodily sensations to claim knowledge about the client's inner state, suggesting that she can feel her client's fear and sorrow to such an extent that she could cry (line 20). The client confirms the coach's claim at the transition relevance place; the coach then asks her explicitly whether she recognises this (line 22). Whereas the coach thus grants the client epistemic authority, the question is designed to elicit a confirmation, which it indeed receives from the client.

Now the coach points to a 'voice' that contradicts the negative feelings she described previously (lines 25–26), and which are now 'shared' between client and coach. When the client confirms this contradicting voice, the coach tentatively defines the negative feelings as not actually being part of the client (lines 35–36), implying that it is possible to disregard these feelings in order to make change possible. This is another 'my side telling': the coach does not explicitly claim that the negative feelings do not belong to the client, but that it *is as if* the feelings do not belong to the client. Employing a 'my side' empathy formulation has allowed the coach to claim knowledge about what does, and what does not belong to her client's authentic self, while still granting the client epistemic authority. Note that, although the client after a long pause agrees with the coach, her response is rhetorically designed in such a way that it also contains an element of resistance. Whereas the coach asserted that this heavy

side does not belong to the client at all, the client responds that it has *started* to belong to her, implying that it although it was not there before, it is there now.

In the next and last excerpt we will show how the coach employs a ‘my side’ empathy formulation to assert a message of change that is initially resisted by the client. This is the same coach as in excerpt 3, here shown in interaction with a different client. The coach starts with a question comparable to the one in excerpt 3, asking her client to imagine a better and easier situation:

Excerpt 5 13.39 (coach 2, client C)

1 Cou **yes**
 ja

2 **so just imagine**
 dus stel je nou eens voor

3 **that things would become easy (.5)**
 dat dingen makkelijk zouden worden (.5)

4 [°]>would that be<[°] nice?
 [°]>zou dat fijn<[°] zijn?

5 Cli **eu:hhh. ↑yes**
 eu:hhh. ↑ja

6 **course.**
 tuurlijk.

7 Cou --> **do you already notice that it changes in your body.**
 merk je al dat het in je lijf verandert.

8 **when you**
 als je

9 **when I ask that question?**
 als ik die vraag stel?

10 (1.3)

11 Cli **uh ((shakes head)) tiny little bit-**
 uh ((shakes head)) heel klein beetje-

12 **>not that much<.**
 >niet zoveel<.

13 (1.6)

14 Cou **to change a tiny little bit**
 'n heel klein beetje veranderen

15 **>is to< change too.=**
 >is ook< veranderen.=

16 Cli **=yes=**
 =ja=

17 Cou **=↑yes**
 =↑ja

18 **>I find that sufficient already<.=**
 >dat vind ik al genoeg<.=

19 Cli **=slowly. ↑yes**
 =langzaam. ↑ja

20 Cou **well not slow↑ly.**
 nou niet lang↑zaam.

21 **but uh if you just (.) wait very much**
 maar uh als je gewoon heel veel (.) wacht

22 **for that one magic wand**
 op die ene magische toverssstaf

23 **which causes everything to change in one blow**
 waardoor het in één klap anders is

24 **then you can wait for a very long time.**
 dan kun je heel lang wachten.

25 --> **whereas I already sense**
 terwijl ik nu al voel

26 --> **that your belly is already a bit cleaner**
 dat jouw buik al iets schoner is

27 --> **>do you notice that as well<?**
 >merk je dat ook<?

28 (1.8) ((clients nods hesitatingly))

29 Cli **>more than before<.**
 >meer als daarnet<.

30 **[yes.]**
 [ja.]

31 Cou **[↑yes] right?**
 [↑ja] he?

The client initially responds positive, albeit first somewhat hesitatingly, when asked by the coach to imagine a better and easier situation (lines 5–6). In her next turn, the coach produces her first claim of epistemic access to the client's inner state. The coach asks the client whether she notices that it starts to change

in her body, describing this change in the client's body as an objective fact that the client herself is perhaps not yet aware of (7-9). The long pause that follows and the client's tentative response in line 11 suggest that she is, indeed, not aware of the change asserted by the coach. This is indicated as well by her self-repair in line 12, replacing her first response with an even less positive assessment.

After another long pause, an exchange follows between coach and client regarding the sensitive question as to what constitutes relevant change (lines 14–18) and, implicitly, a successful coaching session. The coach contrasts a conceptualisation of change as an abrupt transformation with the less spectacular, but more realistic change that she asserts has already been achieved in the course of their interaction. Employing a 'my side' empathy formulation, the coach describes in lines 25–26 how she senses that her client's belly has already become a bit cleaner. As in excerpt 2, the coach uses metaphoric language to provide almost tangible evidence for her description of the client's alleged state (cf. Edwards, 1997: 188–192).

Having produced this 'my side' telling, she asks her client for a confirmation (line 28). Indirectly, however, the coach has claimed not only independent but even superior epistemic access to this client's feelings; the coach described the change in her client's belly in objective terms ('it changes'), asking her client only whether she has noticed this change, as if she were a bystander of her own feelings. This claim of superior access to the feelings of the other is made possible by the particular institutional setting in which this interaction is situated. As we mentioned above, a coach can position her client as knowable to her in a way that would not be possible in the more symmetrical context of everyday interaction. The extended pause that follows here, however, is a sign of trouble. Whereas the client nods in agreement, this is done in a hesitant way. The client finally produces a partial confirmation in line 29, conceding that it is 'better than before', then confirming this with a yes. The coach treats this as a full confirmation of her own assertion, which has now become a collaborative achievement.

4.4. Conclusions and discussion

In this article, we have described how coaches in a Dutch ADHD coaching centre employ what we defined as ‘my side’ empathy formulations in order to negotiate the nature of their client’s ‘problems of fit’. Drawing on the concept of mirror neurons, coaches employ formulations of their own bodily state to claim independent knowledge about their client’s inner state. Once the client acknowledges the coach’s knowledge claim, the coach can successfully set an alternative coaching agenda. The excerpts shown in our analysis indicate that the ‘my side’ empathy formulation is a robust interactional device. Although the clients’ responses range from enthusiastic confirmation to noticeable hesitation, we have found no instances in our data in which the formulation is met with outright disconfirmation.

‘My side’ empathy formulations help the coach to negotiate the epistemic problems associated with telling another person about feelings that would typically be hers to know and more in particular, to successfully solve some of the “knotty dilemmas of empathic moments” (Heritage, 2011: 181).

As we have seen above, coaching sessions in the ADHD centre deal with sensitive issues such as the use of medication or the client’s inability to work. What is more, the institutional outlook of the coaching centre – its explicit focus on the client’s strengths and agency, rather than the diagnosis ADHD – causes coaches to advocate an approach that could easily be misread by clients who conceptualise their problems as a result of this neurobiological disorder. In this potentially hostile environment (cf. Edwards & Fasulo, 2006), the ‘my side’ empathy formulation helps the coach to provide *independent* evidence of her qualities as an empathic listener in the most literal sense of the word, feeling into her client’s story and accompanying inner state. In achieving this aim, the ‘my side’ empathy formulation is a much stronger device than the empathic noticings described by Muntigl and Horvath (2014). Whereas the therapist employing empathic noticings remains an outside observer of the client, the ‘my side’ empathy formulation suggests that the feelings of client and coach collapse into each other, giving the latter an insider’s view of the otherwise well-protected interior of the client.

Bergmann (1992: 158) argues in the context of psychiatric interviews that discreetly exploratory utterances, such as information-eliciting tellings,

reproduced the ambiguous nature of psychiatry as a profession that is both medical (dealing with mental illness) and moral (dealing with improper behavior). The coaching sessions described here navigate a similarly complicated terrain, to the extent that the diagnosis AD(H)D provides medical legitimacy to problems that might otherwise be cast in moral terms. This makes the centre's agenda of agency and change interactionally complicated, vulnerable to being heard as accusation.

Coaches typically employ the 'my side' empathy formulation at sensitive moments in the conversation, e.g. in response to a client's narrative about a decision that might be frowned upon by the outside world (such as quitting a job (excerpt 1) or not taking medication (excerpt 2)), or as part of a coaching agenda aiming for change (as in excerpts 3 and 4). In the former cases, the 'my side' empathy formulation helps the coach to support decisions originating in the client's limbic system or 'feeling brain' (*voelbrein*). In the latter cases, the 'my side' empathy formulation helps the coach to propose a change that the client might otherwise treat as problematic. Whereas coaches sometimes do explain the neuroscientific theory underpinning their notion of bodily empathy, they do not construct their claimed ability to feel the client's inner state as an expert's prerogative. On the contrary, by drawing on their own emotions, the coaches claim independent but mediated access to the client's inner state, inviting the client to produce a more authoritative version of her feelings in relation to the proposed change. In this way, the coach avoids the risk of becoming too involved and supplanting the client's experience with her own (Heritage, 2011). The invitations, however, are designed asymmetrically and typically aim for confirmation of the version as proposed by the coach.

'My side' empathy formulations thus allow the coach to deal with the knotty dilemma of claiming assessments as both independently and jointly held (cf. Edwards & Fasulo, 2006). The coach employs 'my side' empathy formulations, on the one hand, to provide independent evidence for her assessments and thus to strengthen her endorsement of the client's position and emotions (Heritage, 2011: 181); on the other hand, it helps her to present a coaching agenda of change as a collaborative achievement between herself and the client.

5

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Chapter 5

Making Expertise Fit. On the Use of Certified versus Experiential Knowledge in Establishing Responsible Patienthood

This chapter has been submitted to:

Journal of Health Psychology. Co-author Hedwig te Molder.

This chapter is a concise version of the results of research conducted for the RIVM.

The research report *Being (not a) patient: a qualitative comparison of online conversations about medication can be found in RIVM (2015) Luisteren naar de digitale patiënt; Verkennende analyse van gesprekken op social media over medicatie en ziekte*. Available from <https://www.opgmk.nl/dsresource?type=pdf&disposition=inline&objectid=rivmp:314113&versionid=&subobjectname=> (accessed September 16, 2018).

Chapter 5

Making Expertise Fit. On the Use of Certified versus Experiential Knowledge in Establishing Responsible Patienthood

5.1. Introduction

Now that online health information is 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' (ibid.), 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 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 et al. (2015: 188) describe 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?*”

The present 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. Previous studies have already pointed to the complexities of patient choice, and the accompanying processes of information seeking (e.g. Barker, 2008, Kivits, 2004, Edwards & Howlett, 2013). 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 patient-hood. 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. A discursive psychological analysis is guided by the question ‘*why that now?*’: 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. Potter, 1996; Edwards, 1997). Closely studying what is, and what is not made accountable on a micro-level provides insight in 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

conceptualised 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.

5.2. Data and method

We selected three diseases to be included in our comparison: (1) Attention Deficit Hyperactivity Disorder (ADHD) is a controversial disease; both the nature of the disorder and the desirability of the associated treatment are societally 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, (3) Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's disease) is a terminal motorneuron 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 4 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 characterised 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 analysed data does no longer yield novel analyses (Cresswell et al., 2014: 2). The excerpts 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). A 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? A 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, e.g. by using extreme case formulations 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 (te Molder, 2015). However, various other features relevant to a discursive psychological analysis demonstrably occur in online interaction (see, e.g. te Molder & Lamerichs, 2003, te Molder 2015; 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. Giles & Newbold, 2011; Stommel & Koole, 2010; Cranwell & Seymour-Smith, 2012).

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.

5.3. Analysis

5.3.1. ADHD: protecting certified expertise to maintain doctorability

ADHD is a frequently diagnosed but highly controversial mental disorder (see, e.g. Singh, 2004; Edwards & Howlett, 2013; Horton-Salway, 2013). Various authors have observed how patients frequently treat a psychiatric diagnosis as empowering, because the diagnosis provides an account for problems that are otherwise difficult to explain (Giles & Newbold, 2011: 421; cf. Klasen, 2000). This type of reasoning often occurs in the analysed threads, as illustrated by the next excerpt:

R&P _ P&P _ ADD_ADHD
deel 12 — forum.fok.nl

The diagnosis ADD was therefore a relief for me. I am not crazy or weird, I'm just different with a reason.

The explanatory value of this particular account depends on the exclusivity of the diagnosis 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 & 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, emphasising 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:

Excerpt 1

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: [*list, authors*]
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
9. or doing things for school.
10. Often many thoughts go through my head.
11. I still have to do this, and do that...
12. and then I go do that...etc...
13. I would like to to focus on the things that matter,
14. such as school...

15.

16. What do you think?

Tuck — Post #36

17. That you don't have ADHD.

Toggle — Post #38

"That you don't have ADHD"

18. that... I believe there are 5 at the most

19. that I don't have...

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 & 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.

A 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 criticise ADHD medication as a secondary gain or unfair enhancement technology (see for this kind of use e.g. Cadwalladr, 2015). In a mirror image of these criticisms, forum users emphasise the *difficulties* of having to take ADHD medication. In doing this, they indirectly underline the severity of the disorder which requires them to take this medication. Patients emphasise that medication does not absolve them from their responsibility, as the next excerpt illustrates:

Excerpt 2

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

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.

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. We show an example thereof in the next interaction, in which topic starter Ann announces her decision to abstain from medication despite being diagnosed ADHD. Note how she presents this 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:

Excerpt 3

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

Ann — Post #1

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!)

In their reactions to Ann's post, the other forum users treat the decision not to take medication as a choice with collective significance, as in the following response:

Excerpt 4

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."

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.

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 & 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.

5.3.2. 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 prioritising 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:

Excerpt 5

Diabetes-forum – Blood sugars 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

"(...)"

21. Unbelievable, really very very neat!

22. I hope that I may have such values in the future.

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 the one hand that good blood glucose readings are a matter of sheer effort (*good, well done, really very 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 emphasising 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:

Excerpt 6

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

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.

Excerpt 7

Viva – Diabetes country

"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)."

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.

Excerpt 8

Viva – Diabetes country,

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. 🤔

Post 8 reacts to a quotation, in which the the patient's lived experience is contrasted with 'the medics who always assert everything' (line 1). In post 8, the author 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. Likewise, in excerpt 8, a patient describes how her values reacted in 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 emphasised the authority of certified experts, diabetes patients stress the limits of the theoretical knowledge of medical professionals. It is precisely by emphasising 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.

5.3.3. *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:

Excerpt 9

stopals.nu/voorstellen...

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....."

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:

Excerpt 10

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

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

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 standardised. 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:

Excerpt 11

stopals.nu/Evenvoorstellen_DickS

Leanne — Post 1

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

Don — Post 2

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

As in the previous example, the expression of support is, as it were, shrugged off. The speaker in post 2 underlines his positive attitude, emphasising the laughter instead of the wretchedness of this story. Rather than talking about feelings, participants limit themselves to idiomatic, standardised phrasings, irony and understatements, particularly in relation to complaints about the disease. These 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. The fact, however, that patients adhere to this strategy even while among fellow-sufferers, suggests that the possibility to 'share experiences' is limited.

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:

Excerpt 12

StopALS.nu/dexpramipexolefaultinfasel

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

11. I prefer to be able to follow the developments
12. although it is indeed very frustrating
13. that they keep presenting 'breakthroughs'
14. where you never hear from again.
15. And when something finally seems to happen,

16. like with 'dex', then it's extra annoying
17. when it turns out to be nothing after all.
18. For me it was an important straw to grasp 🙄
19. Despite everything, fast forward, that's what it's about!

Patrick — Post 7

20. I, as well, understand the frustration
21. but was able to let it go so as not to lose focus
22. because of negative thoughts.
23. Of course I could get agitated too and be frustrated
24. but I don't think that the research for a medicine
25. will be accelerated because of that and I rather keep my
26. scarce energy for something positive.
27. I hope and presume that the medics of the ALS centre make a
28. thoughtful choice regarding the purchase of a next trial.

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 dexpramipexole 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 19 ('Despite everything, fast forward, that's what's it about!'). By emphasising 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 27–28), 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 5.1

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 towards 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

5.4. Conclusion and discussion

We employed a discursive psychological methodology to conduct a qualitative comparison of 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 towards 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 emphasise the epistemic authority of certified experts as the only ones able to diagnose genuine ADHD. In contrast, participants in the analysed interactions about diabetes routinely downplay their disease, in an effort to demonstrate their independence from the accompanying regimen. By emphasising 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 lifesaving 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 analysed interactions, ADHD patients emphasise 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; Kivits, 2004; Edwards & Howlett, 2013; Felt et al., 2015), 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 treated as trustworthy 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 legitimise 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 fulfil the moral duty towards 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.

Awareness of the diverse nature of these identity concerns can explain why particular patient groups accept or reject particular types of expert knowledge (Versteeg & te Molder, 2017). 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 towards clarifying seemingly contradictory attitudes towards expertise.

6

FOR HERSELF—SHE'LL DARE ANYTHING —BUT SHE'S DIFFERENT ABOUT HER CHILD

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Chapter 6

‘You must know what you mean when you say that’: the morality of knowledge claims about ADHD in radio phone-ins

This chapter has been published as:

Versteeg, W., te Molder, H. (2018) ‘You must know what you mean when you say that’: the morality of knowledge claims about ADHD in radio phone-ins. *Sociology of Health & Illness* 40 (4), 718–734. doi: 10.1111/1467-9566.12720

Chapter 6

‘You must know what you mean when you say that’: the morality of knowledge claims about ADHD in radio phone-ins

6.1. Introduction

Attention Deficit Hyperactivity Disorder is the most commonly diagnosed childhood mental disability in the western world. It is also highly controversial, in part because of its associated use of medication (e.g. Rafalovich, 2004; Singh, 2002). As with many psychological disorders, it is impossible to diagnose ADHD by means of physical or biochemical tests. This apparent lack of objective criteria renders the ‘realness’ of the disorder permanently moot, even after medical diagnosis. To establish the condition as real, neuroscientific explanations are sought after (Conrad, 2007), while public discourses seem to circle around parental neglect and parenting styles (Brunton et al. 2014). This either/or construction, or, as Singh (2004) calls it, the brain-blame versus mother-blame device, seems difficult to overcome, despite the fact that people diagnosed with ADHD tend to blend different accounts of ADHD (Bröer & Heerings, 2013).

One of the reasons for this persistency may be the relative invisibility of the way in which this binary explanatory model is maintained. In this paper, we show how the navigating between the two accounts does not necessarily take place in explicit terms, but may be conducted via the hidden moralities of the knowledge claims made by parents and others regarding the ‘ADHD-ness’ of the children’s problematic behaviours. We explore a number of interactions in which parents point to their child’s behaviour as symptomatic of ADHD. These conversations take place in an interactional environment designed to elicit controversy: the radio phone-in. During radio phone-ins, listeners are invited to call in and participate, frequently in reaction to a statement, question or problem provided by the host. The accounts we will analyse are given by parents describing the behaviour of their children with ADHD, while responding to often critical statements about the disorder.

For our analysis, we use discursive psychology. This perspective argues that psychological phenomena can only be constructed and accessed through interaction (Edwards & Potter, 1992; Edwards, 1997; Potter, 1996). A discursive psychological (DP) perspective treats language as action-oriented: utterances are employed to achieve particular interactional goals, such as the positioning of a particular identity. In the context of medical visits, Heritage and Robinson (2006; Heritage, 2009) have pointed to the issue of doctorability as an important interactional concern for patients. A “doctorable” problem is “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). The need to present one’s problem as “doctorable” is relevant to all patients, but it becomes especially salient for those claiming to suffer from a controversial condition (Horton-Salway, 2004). More than other patients, they are vulnerable to accusations of undeservedly claiming a sick-role and the benefits that are associated with it (Foster-Galasso, 2005). When a speaker claims to suffer from a controversial condition, (s)he needs to discursively establish such a condition as real and therefore deserving of expert treatment. To counter or pre-empt accusations of investment in the disease, they need to actively manage the distinction between what is treated as in the mind (subjective side) or in the world (objective reality) (Edwards, 2005). The same holds true when a speaker describes *someone else* with an ambiguous or controversial condition. Smith (1978: 35) famously described the interactional work necessary for a layperson to build a factual account of the mental illness of a friend. One of the defining characteristics of such an account is that “proper procedures have been used to establish it [the illness] as objectively known”.

Parents are typically treated as having epistemic authority regarding their own child (cf. Raymond and Heritage, 2006). We will show how the parents in our corpus carefully tailor their knowledge claims to the interactional business at hand. We argue that they claim the amount and type of knowledge appropriate for a (concerned) parent, while denying knowledge of the ‘ADHD-ness’ of their children’s behaviour. The ability to locate the ambiguous and highly controversial border between normal and ‘ADHD’ is treated as an expert’s prerogative. What is more, as soon as the parent makes her child’s behaviour available to the host by providing the kind of information that could be provided by any other (lay) person, it becomes vulnerable to being treated as

normal disobedience, that is, the kind of behaviour that does not deserve expert treatment.

6.2. Knowledge and morality in radio phone-ins

The corpus on which we base our analysis is comprised of radio phone-ins. This is an institutional environment with particular interactional characteristics. Perhaps the most important of these is what Hutchby (1992) has called the “arguing for arguing’s sake” or the “pursuit of controversy”. Many everyday interactions are characterised by an avoidance of conflict; radio phone-in hosts, on the contrary, strive for argument in order to entertain their audience. They might commit to a controversial point of view or consistently adopt a position countering what a caller has just said, for example, by using the contrasting device “you say Y, but what about X” (Hutchby, 1992). The radio phone-in is an extreme case: hosts frequently disrespect boundaries that would be observed in everyday conversations, including the distribution of epistemic rights. For instance, hosts can challenge the callers’ right to act as an expert on the subject or question the relevance of the offered experience to the topic at hand (Hutchby, 2001; cf. Thornborrow, 2001).

The interactional indexing of epistemic rights is a dominant concern in contemporary conversation analysis (e.g. Drew, 1991; Heritage & Raymond, 2005; Raymond & Heritage, 2006; Stivers et al., 2011; Heritage, 2012a). Some authors have specifically explored those instances in which interactants claimed non-knowledge (e.g. Beach & Metzger, 1997; Hutchby, 2002; Weatherall, 2011). An overarching concern in this literature is the way in which the tailoring of knowledge claims corresponds with the acceptance of moral accountability. Keevallik (2011: 201) has shown how epistemic disclaimers indicate a problem with the answerability of the question. These disclaimers can be more or less cooperative, depending on the extent to which they are accounted for. By escaping the terms of the prior turn while technically providing an answer, epistemic disclaimers help to manage speaker alignment and social relationships. Iversen (2013) demonstrates how children may employ claims of no epistemic access to create moral distance between themselves and their abusive fathers. A similar pursuit of moral distance can be found in a study by de Kok and Widdicombe (2010). It shows how Malawians

with fertility problems deny having knowledge of possible causes, thereby orienting to the fact that knowing these causes – including abortions or STDs – might suggest that the speaker had personal experience with them.

The aforementioned studies demonstrate that what a speaker claims not to know refers not only to the factual knowledge of the object under scrutiny, but is also consequential for the moral relationship between interactants. The present study adds to these insights by showing that knowledge claims also help shape the (moral) character of the object of assessment itself. By denying access to a particular kind of knowledge, the parents in our corpus present their child's behaviour as symptomatic of ADHD, that is, as 'abnormal' behaviour that deserves expert treatment. When parents do claim access to this knowledge, the object under assessment – how the child gets distracted, for example – changes accordingly, into a phenomenon that anyone can see and understand, in other words, to 'normal' disobedience. In this way, the nature and range of knowledge claims both reflect and shape the moral qualities of the object of assessment.

6.3. Data and method

Data for this analysis are derived from a developing corpus of seven UK radio phone-ins. The corpus consists of 41 conversations between hosts and callers in 217 minutes. The phone-ins in the corpus were broadcast by the BBC and by LBC 97.3, a London-based local radio station. Almost all the callers in this corpus were mothers talking about sons; this reflects the role of gender in discussions surrounding ADHD (see Singh, 2002).

All phone-ins are presented by different hosts; the LBC phone-ins are generally more contentious than the BBC phone-ins. The character of the phone-ins ranges from very contentious, where the host holds on to a sceptical storyline regarding ADHD, to not contentious at all, where callers phone in their questions to an expert in the studio. The phone-ins have been broadcast and the audio is publicly accessible. We have protected the callers' anonymity by removing any names or identifying characteristics.

Radio phone-ins typically orient towards disputation or everyday scepticism (Hutchby, 1992); in the majority of the phone-ins presented in this paper, the radio hosts take an explicitly sceptical stance towards ADHD. As described above, the radio phone-in is a so-called extreme case; the host exercises rights

that are absent in everyday interaction, for example, in formulating the caller's point of view, or in deciding when to end the conversation. However, within this environment, the host presents himself as the voice of common sense and mothers may be expected to draw on the same repertoire of responses that is available to them in everyday life, albeit, perhaps, in a more 'extreme' way.

The data presented here have been analysed using a discursive psychological perspective (Edwards, 1997; Edwards & Potter, 1992; Potter, 1996). Inspired by conversation analysis (Sacks, 1992), a discursive psychological analysis is guided by the question 'why that now?', or in other words: what does the speaker consciously or not achieve by choosing this wording at this particular moment in the interaction? Discursive psychology analyses talk of psychological phenomena in terms of the actions it performs, rather than in terms of the thoughts it might reflect (te Molder, 2015). Action is sequentially situated in an unfolding context of utterances: speakers orient to what has just been said and build an environment for what comes next (Potter, 2012). Action is also rhetorically situated: the mothers design the descriptions of their children to counter actual or potential alternative explanations (Edwards, 1997). Analysts can use the latter quality of talk to understand what action the current version performs, by comparing it to other potential versions.

For our analysis, we first transcribed the data verbatim. We searched this rough transcript for any instances in which claims to insufficient knowledge were made either explicitly ('I don't know') or implicitly ('I kept saying there's something wrong, there's something wrong'). We then transcribed all these instances and their interactional context on a detailed level, using the Jeffersonian system of transcription (Jefferson, 2004). We compared the seemingly similar instances in this corpus using a next-turn proof procedure. Because interactions develop sequentially and turn-by-turn, speakers display their understanding of the previous turn in the design of their own utterance (Sacks et al., 1974). When asking the previously mentioned 'why that now' – question, the analyst compares the way in which the rhetorical designs of seemingly similar utterances (the claims to insufficient knowledge) are treated by the recipient in his or her next turn. The comparison between utterances within their respective sequential contexts leads to a refinement of the analytical focus. Whereas we were initially puzzled by the question what interactants achieved by claiming insufficient knowledge, a comparison between excerpts led us to focus on what

interactants achieved by claiming this particular knowledge at this particular point in the conversation (see Wiggins, 2017, for a more elaborate description of DP methodology).

Given the controversies surrounding the legitimacy of ADHD, we want to clarify how a discursive psychological analysis conceptualises language and the world it represents. We treat language as oriented towards the performance of specific actions; whereas this can be understood as strategic (e.g. in focusing on how speakers employ one particular description, rather than another), this does not mean that a specific phrasing is necessarily a conscious decision. Important for the analyst is how participants understand and treat each other's utterances (e.g. as blame, compliment, empathy) rather than what the speaker 'intended' to achieve. Our analysis should therefore not be read as implicating a judgment about the reality of the disorder. Rather than trying to determine whether something is real, the discursive psychological perspective is interested in the claims interactants make, challenge and accept as to what is or is not real, thus collectively bringing a social reality into being (te Molder, 2015).

6.4. Analysis

The following analysis is divided into three sections, which show different, not necessarily successful attempts to establish doctorability. In the first part, we show the typical interactional pattern: mothers claim specific knowledge about their own child, but not about the 'ADHD-ness' of his behaviour. In the second section, we present a slightly deviant case, which shows an underlying rationale for the typical interactional pattern: when a mother does describe the specific behaviour that is claimed to be symptomatic of ADHD, the behaviour becomes available to other non-experts and vulnerable to being redefined as 'just disobedience'. In the final section, we show a mother claiming neurological expert knowledge of ADHD. This is another deviation from the typical interaction pattern, and it is equally risky: when evidence of a child's ADHD rests on a specific type of expert knowledge, any claims to doctorability depend upon the credibility of the expert in case.

6.4.1. *Claiming ‘not to know precisely’ to establish doctorability*

In the following subsection, we show how mothers refrain from detailed descriptions regarding the ‘ADHD-ness’ of the child’s behaviour, which are an expert’s prerogative. Instead, they position themselves as cautious and trustworthy observers, describing their children’s conduct in such a way that it becomes perceivable as ‘doctorable’, rather than ‘mere naughtiness’.

When a speaker presents a problem as doctorable, but the problem is not treated as such by the recipient, the speaker becomes vulnerable to judgments of being over-concerned or unreasonable (Heritage, 2009). This is certainly the case for controversial disorders such as ADHD; mothers are frequently accused of wanting the diagnosis (cf. Foster-Galasso, 2005).

We start by showing an excerpt to illustrate this particular interactional hazard:

Excerpt 1

LBC 97.3. Host: Petrie Hosken

- 01 Host: >[I find any] excuse not to do something,<
02 Caller: [>it’s not that he<]
03 Host: >I won’t sit still for more than five minutes
04 I’m up and about?< (.4)
05 .hh does that make me have ADHD?
06 Caller: it’s not that he doesn’t like doing it,
07 he can’t do it.
08 he cannot concentrate long enough
09 to achieve something (.6)
10 and that is the difference. (.6) I can=
11 Host: =that could just be him though.
12 why does it have to be a disorder?
13->Caller: >well that, I go, I’m not an expert on this<
14 Host: it’s convenient, >isn’t it,< really [that he]
15 Caller: [uh]

16 Host: that he fits into this disorder?
 17 Caller: well. (.7)
 18 >I have never seen this with any other child
 19 apart from other children that I have seen
 20 that have a diagnosis of ADHD<

The host lists a number of behavioural characteristics that could be symptomatic of ADHD (lines 1,3 and 4). By arguing that she herself displays these behaviours, she implies that the traits are normal, rather than doctorable (5). The mother then claims epistemic authority about the intentions of her child: the host does not like to do tasks, but her child is unable to do them (lines 6–9). The host attributes a stake to the mother by suggesting that she wants her son to be labelled with a disorder (lines 11–12). What is more, she questions the existence of a clearly demarcated disorder (‘that could just be him though’, line 11).

At this point, the mother offers a claim of insufficient knowledge (line 13). By using a well-preface in response to a why-question, she alerts the listeners to the fact that her response will not be straightforward, and that attentive listening is required to understand it fully (Schegloff & Lerner, 2009). The host, however, does not allow the elaboration: she interrupts, and again accuses the mother of wanting her son to be labelled for reasons of convenience (14, 16).

In response, the mother argues – after another well-preface (line 17) – that she has only seen ‘this’ with children who have been diagnosed with ADHD (lines 18–20). Hidden in this rather awkward phrasing is a carefully tailored knowledge claim designed to address the host’s challenge. Whereas the mother needs to establish the legitimate nature of her son’s ADHD, she cannot do this outright; determining whether the behaviour is a disorder or ‘just him’ is an expert’s prerogative, as indicated in line 13. The host has already accused her of having a stake in her son’s diagnosis; any further emphasis on her child’s symptoms will probably only make her more vulnerable to accusations of wanting the label for reasons of convenience. Zooming out, the mother therefore compares his behaviour with that of other children who have been legitimately diagnosed with ADHD—and the mother cannot possibly be accused of having a stake in the diagnoses of these other children. Ostensibly

claiming only the knowledge appropriate to a lay person – the similarity in behaviour that she has seen with her own eyes – she nevertheless manages to categorise her son's behaviour as symptomatic of ADHD. Note how, throughout this conversation, the two speakers characterise the boundary between the normal and the pathological in radically different ways. The host treats the distinction between normal and pathological behaviour as easily observable to laypersons. The mother, on the contrary, makes an interactional effort not only to establish her own son's ADHD, but also to uphold the experts' prerogative to determine this controversial border between disorder and 'just him' (line 13, 20).

A second carefully managed knowledge claim is shown in the excerpt below:

Excerpt 2

LBC 97.3. Host: Jeremy Vine

01 Host: what is the situation with your son.
02 miss [name]?
03 Caller: (.4)_.hh uh well my son's twenty one (.) ↓now.
04 ↑uhm he was diagnosed when he was ↓six.
05 uhm he was a very classic case of of ADHD
06 and still is↑ t'day,
07 .hh uhm it was uhm a very traumatic (.2) time
08 for >all of us in the family< and
09 [((inaudible))]
10 Host: [how how] did it show itself,
11 how did you know
12 your six year old boy had ADHD?
13 ->Caller: I didn't know until
14 he was actually diagnosed but I knew=
15 Host: =right=
16 Caller: =something was wrong=
17 Host: =yes

Having been asked about ‘the situation’ with her son, the caller starts by situating her story in the past, indicating the current age of her child (line 3). She mentions that the boy was six when he was diagnosed; this makes it likely that he was in his first year of primary school at the time of the diagnosis. Describing the child as a classic case of ADHD (lines 5–6), suggests that his symptoms were – and still are – unambiguous.

The host asks her how she knew her six-year-old had ADHD: a way to make the symptoms of the child observable to the overhearing audience (lines 10–12). In her answer, the caller carefully discerns between what she does and does not know; she knew ‘something’ was wrong, but she did not know it was ADHD ‘until he was actually diagnosed’ (line 14). She thus presents herself as someone who does not jump to conclusions: the diagnosis is a privilege of medical professionals. Her knowledge that ‘something was wrong’ simultaneously demonstrates that she *did not* possess expert knowledge, and that she *did* possess the type of non-expert knowledge appropriate to a parent who watches over her child. As in excerpt 1, the caller’s ‘no knowledge’ response (line 13) disaligns with the question’s action agenda and its presuppositions regarding her knowledge (Keevallik, 2011): the caller does not describe how the ADHD ‘showed itself’.

The following excerpt shows a similar claim to a lack of knowledge. In a first turn that is remarkably similar to the previous example, the caller interrupts herself to interject that her son is now twenty-four and doing well, positioning his problems safely in the past. The current, unproblematic situation is contrasted with his troubling behaviour when he was young:

Excerpt 3

LBC 97.3. Host: Andrew Castle.

01 Host: we’re gonna talk to uh [name]
02 further north in uh
03 in [name]
04 hi [name]
05 Caller: oh hi?
06 uhm I >just wanted to say< uhm

07 my son was (.4)
 08 >my son's ↑twenty ↑four now<
 09 and uhhuh >and he's fine<.
 10 uhm when he (.) was young
 11 he was a complete nightmare. (.3)
 12 -> uhm and I knew >there was something< wrong with him
 13 -> but I >didn't know what it was<, (.4)
 14 and I kept thinking oh he >you know< (.4)
 15 he's high range au:tism,
 16 -> or something like tha::t
 17 -> .hh I didn't know what it was.
 18 the school >you know< they were comp complaining
 19 about him all the time
[53 lines omitted, in which caller and host discuss the problems
of the caller's son and the interaction with the son's school]
 20 Caller: and >you know I kept< saying that
 21 there's something wrong
 22 there's something wrong
 23 finally:
 24 we had uh
 25 we were sent to see uh a psychologist? (.6)
 26 .hh uhm he'd had difficult birth?
 27 and they thought that may have uhm
 28 impacted on him as we:ll?
 29 and he was diagnosed that
 30 you know >the school has to do<
 31 uhm (.2) a cha:rt?=
 32 Host: =I know it's a

33 Caller: and >you have to do a chart< at home?
 34 and uh ↑it ↑just ↑came ↑up
 35 he had ↑ADHD?

The caller employs an extreme case formulation: ‘he was a complete nightmare’ (line 11). This formulation, which contrasts the severity of the problems of his youth with his current fine state, is probably designed to pre-empt a challenge, indicating that the caller treats the environment as potentially hostile (Pomerantz, 1986). In the lines that follow, the caller carefully demarcates the knowledge she claims (lines 12–17): ‘I knew there was something wrong with him, but I didn’t know what it was’. She proceeds by detailing this claim, offering a suggestion for what she thought was wrong with him: high-range autism (line 15). Initially employing an expert term (high-range autism), she then adds ‘something like that’, displaying the uncertainty that is appropriate to a layperson and inoculates the speaker against accusations of demonstrating an unjust expert footing (cf. Potter, 1996). She repeats that she did not know what was wrong with her child, before asserting that the school had been complaining ‘all the time’ (line 19) about her son. She thus corroborates her own (uncertain) claim with the (certain) observations of an institution that can be assumed to possess expertise as to what constitutes normal or abnormal behaviour.

Notice the self-repair from the more active ‘we had’ (line 24) to the more passive ‘we were sent’ to see a psychologist (line 25) – emphasising that, although the mother knew that there was something wrong, she did not actively seek the diagnosis. Interestingly, the mother presents the final diagnosis as an almost unexpected result, ‘out there’ and separate from all the efforts she described before: ‘↑it ↑just ↑came ↑up’ (line 34). This is another example of stake inoculation, because any diagnosis of ADHD is based to a large extent on charts filled out by the school and at home (lines 30–31, 33).

To summarise: callers carefully manage their knowledge claims to pre-empt accusations of stake, i.e. seeking the label of ADHD for their child rather than ‘just’ deserving it. Mothers position themselves as non-experts and tailor their knowledge claims accordingly, refraining from providing detailed descriptions of their children’s problematic behaviour. They firmly situate diagnostic knowledge

in the expert domain, but reserve the right to the ‘gut’ knowledge that something was wrong for their own lay-parental territory.

6.4.2. *Claiming ‘not being able to know’ to establish doctorability*

In the previous subsection, we demonstrated how mothers claim ‘not to know precisely’ to present problematic behaviour as evidence of a doctorable condition. In this subsection, we demonstrate how a mother claims she is not being able to know (i.e. describe) her child’s behaviour. We argue that this is inextricably linked with her conceptualisation of the child’s problematic behaviour as ADHD, rather than mere disobedience.

The following excerpt is derived from a LBC 97.3 radio phone-in, in which the host has already shown himself to be sceptical with regard to behaviour claimed to be symptomatic of ADHD. In reaction to this scepticism, the mother quoted in this excerpt has called to assert that ‘not all children with ADHD are naughty children’. As evidence of her children’s ADHD, the caller offers that they are unable to complete the tasks they have been given; not just boring or complicated tasks like homework but also simple tasks like getting dressed. It is within this context that the following interaction takes place:

Excerpt 4

LBC 97.3. Host: James O’Brien.

01 Caller: but they are attempting to
02 do >what you’ve asked them< to do? (.6)
03 they just get distracted (.2) ehm and=
04 Host: =well des describe to me how you get distracted
05 from getting dressed (.4)
06 ->Caller: ehm .hh I don’t get distracted
07 -> so I don’t know how they do get distracted.
08 -> it’s a very good ques
09 -> [tion for which I got no ans]wer?
10 Host: [but you told me they did.]

- 11 Caller: no they get distracted
12 Host: [yes]
13 Caller: [I don't]

The mother starts by claiming knowledge about her children's good intentions in lines 1–3: her children attempt to get dressed. As in excerpt 1, having good intentions – a knowledge type that is firmly within the parental domain – seems to serve as a lay criterion to discern normal disobedience from doctorable behaviour. Bad intentions are treated as evidence of normal disobedience (a 'bad' child); good, but unsuccessful intentions are dealt with as evidence of doctorable behaviour in a 'good' child.

At stake in this interaction is the question as to what it means to get distracted. The host's question in lines 4–5 is phrased in general terms; 'how you get distracted' has probably been designed to be heard as a variant of how *one* gets distracted. The question treats the children's distractedness as something that can be observed and understood by the mother. The mother, on the other hand, is wary of providing an answer: she treats her children's behaviour as something that cannot be understood by others and that is for that very reason significant as a symptom of ADHD.

In the host's framing, the caller would be in a position to answer his question, because she has just mentioned that her children get distracted while getting dressed. The mother has observed this distractedness and should therefore be able to describe it. The caller treats distractedness as a symptom of ADHD: she situates the problem inside her children's heads, instead of in their behaviour. When distractedness is conceptualised in this way as symptomatic of a brain disorder, it cannot be observed from the outside by a layperson who has not personally experienced this type of distraction from the inside of her own head. She therefore treats the question as if the host were asking how she personally gets distracted (line 6), and responds with a claim of insufficient knowledge (lines 6–7). By describing the question as 'a very good question' (lines 8–9), the mother signals that there is a problem with its answerability. At the same time, she positions herself as cooperative by providing an account for her epistemic disclaimer (Keevallik, 2011). She is unable to answer, because she possesses no insider's knowledge of the disorder *and* because she is not an expert who could

claim authoritative outsider's knowledge. By treating a seemingly normal occurrence – getting distracted – as puzzling behaviour, the mother heightens the contrast between those who, like her children, suffer from ADHD and are therefore unable to complete an ordinary activity like getting dressed; and those who – like herself and the host – do not suffer from this condition and are therefore unable to understand how one could get distracted from an ordinary activity like getting dressed (cf. Smith, 1978).

In line 10, the host prompts the caller to answer his question by implying that her response is inconsistent with what she said before ('but you told me they did'). This challenge makes the caller accountable for providing an answer; she is liable to being treated as an inconsistent or even irrational speaker if she fails to do so. In her response, the caller repeats that they – her children – get distracted, re-asserting her inability to provide an answer, thus reconfirming her previous conceptualisation (line 11). The host merely reacts with a recipient token, indicating that this answer does not contain new information and does not resolve the caller from the obligation to answer. Even when the caller repeats that she herself does not get distracted in line 13, the host is not prepared to let her off the hook:

Excerpt 5

LBC 97.3. Host: James O'Brien (continued).

- 13 Caller: [I don't]
14 Host: [yes so]
15 -> you must. know. what. you mean. when you say that.
16 Caller: (.4) well, you you ask them
17 to go >put their shoes and socks ↑on<
18 and ten minutes later they're still putting one sock on
19 Host: yes.
20 -> that >just means< they're disobedient,
21 (.7)

The caller is urged again to provide an answer to the host's initial question as formulated in lines 4–5: describe to me how you get distracted from getting dressed. The host explicitly holds the caller accountable for the knowledge that she claimed to have (You must know what you mean when you say that, line 15). With a continued denial, the caller risks being treated as someone who does not know what she means when she says something, in other words, as an incompetent interactant. This would retrospectively devalue the experience that she contributed earlier in the conversation, and it might be for that reason that the mother finally responds to the host's prompts and starts to describe her children's behaviour.

The delay and well-prefaced response in line 16 is already a sign of trouble (Heritage, 2013; Schegloff & Lerner, 2009), suggesting a dispreferred answer or one that in some way departs from the preceding talk. In trying to describe how her children get distracted, the mother follows the host's conceptualisation. This is a departure from her previous answers, in which she treated the distraction as a symptom of ADHD that she was unable to understand or to describe.

The host's seemingly innocent question in lines 4–5 has been designed to bring the caller in a difficult position (Gruber, 2001; Reynolds, 2011). By suggesting that the process of getting distracted can be observed from the outside, the terms of the question already implied an answer that can be rephrased as normal disobedience. Now, as soon as the mother offers a more detailed description of her children's behaviour, the host responds with a formulation, reconfirming his own conceptualisation: 'that >just means< they're disobedient,' (line 20). Once the claimed symptoms have been described as phenomena that can be observed from the outside and thus understood by anyone, read: people without expert knowledge, the host can formulate the behaviour as indicative of normal disobedience, rather than of the doctorable disorder ADHD.

This case illustrates the interactional dangers of providing a more precise description than the knowledge that 'something' is wrong. Where the mother treats 'getting distracted' as a symptom of a brain disorder that can only be understood from the inside, the host defines it as behaviour that laypeople can observe from the outside. This difference is crucial for the 'ADHD-ness' of the child's behaviour: as soon as the mother makes her child's behaviour available to

any non-expert observer, the host treats it as normal disobedience, rather than evidence of a doctorable condition.

6.4.3. *Claiming an expert's way of knowing to establish doctorability*

In the final subsection of this analysis, we discuss a deviant case in which a mother does position herself as a formal expert to claim doctorability for her son's condition. This strategy carries a considerable interactional risk, which further underlines the normative complexities of claiming appropriate knowledge. We show three excerpts, all of which are fragments of a single conversation between the host and one mother in a LBC 97.3 phone-in. The first excerpt is exceptional to the extent that the caller in her first turn presents herself as a mother, but also positions herself as an expert:

Excerpt 6

LBC 97.3. Host: James O'Brien

01 Caller: my son has ADHD,
02 and what I'd like to ↑know is (.2)
03 ho:w (.3) this doctor can dispute >medical< evidence,
04 from ehm (.) EEG biofeedback?
05 (.3)
06 .hh my son's had this
07 and basically it (.5) maps. the(.3)
08 .hh brainwave >activity<?
09 and in his frontal lo:be
10 he had much slower ↓brainwaves. (.7) a::nd (.6)
11 this (.) is (.) >really common< (.2) of a child
12 Host: [but he's not]
13 Caller: [or even adult]
14 Host: he's not saying no one's got ↑it.
15 he's just saying >quite a lot of people<

16 >who think they've got it haven't got it<
 17 so he he doesn't have to (.5)
 18 refute. your your medical evidence
 19 he he can say no there's one
 20 there's one of the (.4)
 21 true ones.

The caller first claims her right to speak as a mother, before positioning herself as an expert concerning the medical evidence of ADHD. She explains her son's ADHD in technical terms, pointing to the neurological underpinnings of the disorder (lines 3–11). Initially unable to refute this claim to expert knowledge, the host concedes that the caller's son might be one of the 'true ones'. He thus allows for the possibility that the caller is indeed an expert, squaring her argument with that of the doctor who provided the show's controversial starting point (lines 14–21). Note, however, that the host describes the caller's knowledge claim as 'your' rather than 'the' medical evidence (line 18), implying that her claimed knowledge might contradict the body of accepted medical evidence. Shortly thereafter, the caller has to admit that she herself is 'not a medical person' and therefore not a certified expert. In the next bit of the conversation, which cannot be shown here for reasons of space, the host treats the caller's claims in an overtly sceptical way.

In response to his scepticism, the caller positions herself as a mother and limits her knowledge claims accordingly. What follows, is an interaction similar to the examples shown above:

Excerpt 7

LBC 97.3. Host: James O'Brien

22 Host: fair enough.
 23 what what is it (.4)
 24 that made you think your son did have
 25 something. (.2) like this.
 26 what was the behavioural (.3) manifestation

27 Caller: from a very young age I could see
 28 something (.) >wasn't right<=
 29 Host: =what.
 30 Caller: and I (.3) eh I still >to this day<
 31 can't put >my finger on it<,
 32 >I mean he could< he
 33 at nursery he was (.3) different.

The host's relatively open question 'resets' the conversation after the scepticism he expressed earlier. He does, however, leave room for doubt regarding the child's condition: he asks 'what (...) made you think' (lines 23–24) rather than, for example, when did you know or what made you realise, and he phrases the condition as 'something like this' rather than ADHD. The caller responds with a variant of the familiar phrasing I knew something was wrong: 'I could see something wasn't right' (lines 27–28).

When the host asks her rather brusquely to specify this claim, the mother characterises her child's behaviour with the general description that he was 'different' (line 33). In contrast with her first turn, the caller now positions herself as a layperson: as a parent, she has a gut feeling that something isn't right, but as a layperson she is unable to describe the problem more precisely.

The mother's claims become even more vulnerable when she admits that the school regarded her son's problems as an example of non-doctorable immaturity:

Excerpt 8

LBC 97.3. Host: James O'Brien

34 Caller: .hh some schools, >you know<,
 35 I mean (.6) where my son's at school
 36 they didn't (.4) pick up on it
 37 because they worked things down
 38 to immaturity. =

39 Host: =yes.

40 Caller: but then >as I say<, (.2)

41 .hh I wasn't, you know we had to,

42 >I had to have<

43 his brain (.5) actively looked at

44 Host: okay.

45 Caller: cause I needed to be really sure to know there

46 Host: [okay.]

47 Caller: [was so]mething

48 Host: and where do you go for that. (.4) incidentally.

49 Caller: uh pri- we went privately=

50 Host: =but where to,=

51 Caller: =uhm=

52 Host: =a private hospital

53 or is it like a sort of (.) clinic eh

54 (1.2)

55 Caller: eh there are I think

56 >there are< clinics >around<

57 >we went to a lady< that >actually ehm< (.2)

58 she's in Templeford and she's ehm

59 Host: well a sort of self-appointed

60 (1.0)

61 [expert.]

62 Caller: [she uh qua]lified in but

63 yeah EEG and neurofeedback. (.4)

64 Host: tshai. (.2) okay.

The mother asserts that there are signs of ADHD, before conceding that in her son's case, these signs were put down to immaturity. Note the pause in line 36,

prior to the choice of verb; ‘pick up on it’ implies that the ADHD was there, but the school didn’t see it. Schools frequently play a crucial role in bringing about a diagnosis of ADHD, and the fact that this school ascribed her son’s problems to immaturity, is highly damaging to the claim to doctorability. With the self-repairs in line 41, the caller – monitoring and editing her own speech – struggles to establish a new footing for her now damaged claim, which she finds in line 42. Here, she reverts to her previous conceptualisation of ADHD as a neurological condition that can only be diagnosed by ‘actively’ looking at the brain (line 43), thus invoking certified expertise that would clearly trump the observations of the school.

In response, the host asks where she found this expertise. Given the preceding conversation, his question is not as ‘incidental’ as he claims (48), and the caller’s hesitations and first, vague answers (49, 51) are already signals of potential trouble. When prompted, she chooses perhaps the worst possible phrasing to describe the relevant expert: a lady in Templeford (lines 57–58).

The host’s rephrasing (59–61) – his long pause discredits the expert even more than calling her ‘self-appointed’ – and subsequent sigh (64) end the conversation. The caller has proven herself unable to back up her assertions with credible expert knowledge, and is no longer treated as a rational interactant.

6.5. Conclusion and discussion

We have drawn on a corpus of UK radio phone-ins about Attention Deficit Hyperactivity Disorder (ADHD) to show how interactants manage epistemic claims in order to negotiate the doctorability of children’s behaviour. Mothers carefully tailor their epistemic claims in response to – or as a way to pre-empt – the accusation that their claim to the ADHD-ness of their child is ‘motivated’. They claim the type of knowledge appropriate to a mother who watches over her child (knowing that there is something wrong; knowing that the child has good intentions), but disclaim knowledge about the borderline between a disorder and normal behaviour, the determination of which is an expert’s prerogative. Mothers thus portray themselves as cautious observers, unlikely to jump to unwarranted conclusions. They position the disorder as ‘out there’,

worthy of medical attention and advice and not sought after by them. The almost scripted character of the mothers' knowledge claims suggests that these descriptions pre-empt an objection that is not unique to the interactional environment of the radio phone-in, but encountered just as often – albeit probably less explicit – in their everyday lives.

The seemingly innocent act of description implicitly claims access to knowledge, for which a speaker can be subsequently held accountable. As a parent, the mother is entitled to describe her child as naughty, but as a non-expert she cannot credibly describe the child as an ADHD patient. It is precisely because she treats the behaviour as indicative of ADHD that it becomes puzzling to the extent that it cannot be observed or described from the outside, by laypeople. As soon as the mother does provide a detailed description of her child's behaviour, the recipient – in this case the host – can treat this behaviour as (also) understandable for other people without certified expertise. When this happens, and the behaviour becomes knowable to laypeople, it is treated as normal disobedience and therefore not doctorable behaviour. In this way, the nature and range of knowledge claims co-shape the understanding of the children's behaviour, and the other way around.

Existing literature has shown that speakers employ claims of insufficient knowledge to escape the terms set by a prior turn, while technically providing an answer (e.g. de Kok & Widdicombe, 2010; Iversen, 2013; Keevallik, 2011). We argue that declining to provide a description – in this case, of the child's problematic behaviour – can in itself be regarded as a claim to insufficient knowledge, and that it has similar consequences for the speaker's alignment.

Attributions of blame and accountability are typically performed through apparently straightforward descriptions of the 'world-as-it-is'. As Edwards and Potter (1992: 103) point out, 'people *do* descriptions and *thereby do* attributions'. Whereas the knowledge claims have a descriptive character, they are treated by both host and callers as blame-implicative. Even indirect claims to knowledge as to what constitutes genuine ADHD are susceptible to being treated as moral arguments. Mothers are caught between a rock and hard place: they are vulnerable both to accusations of being a bad mother (with a disobedient child), and of being overprotective and wanting the label (cf. Brunton et al., 2014; Singh, 2002). A good mother is expected to show a certain amount of

knowledge about her child (enough knowledge to know that something is wrong). However, in order to claim that troubling behaviour is symptomatic of the doctorable condition ADHD, and to avoid accusations of wanting the label, she has to abstain from claiming the kind of knowledge about her child that would be an expert's prerogative. That is: the detailed knowledge about what is wrong, exactly; whether this is evidence of a disorder; and, more in general, the exact boundary between 'normal' naughtiness and a doctorable disease.

Considering the way in which interactants tailor their knowledge claims helps to understand the everyday moral complexities regarding a contentious subject such as ADHD (cf. Rafalovich, 2005; Singh, 2013). In making and evaluating knowledge claims, interactants orient to societal and moral norms that they are not necessarily aware of (even when, as in the contentious environment discussed in this paper, they choose their words strategically), but that they do reinforce in the process. As various authors have pointed out, patients may treat a psychiatric diagnosis as empowering, because it provides an account for problems that are otherwise difficult to explain (Giles & Newbold, 2011; cf. Klasen, 2000). Whereas children (Singh, 2013) and adults (Bröer & Heerings, 2013) with the diagnosis ADHD have some leeway in interpreting their diagnosis, and the boundaries between brain and self, the space for parents to negotiate this ambiguous territory seems highly restricted (Brunton et al., 2014). For them, making a credible claim to 'a real disorder' (brain-blame) is often the only way to account for a child's problematic behaviour, to access (special) care and to elicit even basic sympathy from recipients. This requires parents to fit complex individual situations into a highly simplified and necessarily vulnerable construction of neurobiological pathology, because the only alternative to brain-blame, is mother-blame ('normal disobedience').

Our analysis provides an empirical illustration of Conrad's claim that processes of medicalisation do not occur because of 'medical imperialism', but via the 'interaction of lay and professional claim-makers' (Conrad, 2007: 67). At stake in all the interactions shown here is the border line between the normal and the pathological. This border line cannot be drawn clearly (Jacobs & Cohen, 2010; Rose, 2009), but it becomes increasingly important as interactants – following the trend in mental health and educational systems, in which acquiring a

diagnosis is a prerequisite for an entitlement to (extra) care – keep trying to categorise children’s behaviour as either normal disobedience or a doctorable disorder. In this way, lay interactions do not only reflect, but can also reinforce the unproductive opposition between brain-blame and mother-blame (Singh, 2004; cf. Rafalovich, 2004), between the normal and the pathological, and between deserving and undeserving children.

Implicitly present in what seems to be a struggle about the nature of these children’s behaviour, are moral questions as to how the good mother should know her child, and to what care she and her child are entitled. These hidden moralities of knowledge should be articulated and made part of a broader public dialogue on ADHD, in order to move beyond the unproductive dichotomies in which participants so frequently find themselves caught.

7

Chapter 7

Conclusions

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Conclusions

7.1. Introduction

This study has explored the ramifications of a seemingly innocent question: ‘how do you know?’ Requesting, providing and considering evidence is a key part of societal repertoires, both in official settings, such as courts of law, and in informal, everyday conversations (Pomerantz, 1984). Current western societies have been described as “infected by epistemic uncertainty” (Levinovitz, 2017), which makes it all the more important to better understand these everyday negotiations of what constitutes authoritative expertise. In this thesis, I have tried to learn more about what we actually *do* when asking or telling how one knows. Such negotiations of claims to expertise cannot be studied in the abstract. I have chosen to focus on discussions about contested health phenomena, in particular ADHD: a field to which both scientific and experiential knowledge claims are highly relevant. Or, as I phrased it in the main research question:

How do expert, practitioner and patient interactants negotiate the morality of contested health phenomena by drawing on standardised, scientific expertise or on the contrary on experiential knowledge, and which interactional goals are served by this?

Here, I will first answer this question by presenting the conclusions of the empirical case studies. Secondly, I will discuss both the limitations of this study and its theoretical implications, including suggestions for further research. Thirdly, I will consider the practical implications of these findings within the context of an alleged ‘post-truth’ society.

7.2. Conclusions: scientific expertise – merely an opinion?

The starting point for this thesis was the question whether science had become ‘merely an(other) opinion’, as one might infer from the news media headlines.

To quote just one recent example, from a Guardian headline: ‘The death of truth; how we gave up on facts’.²² Did ‘we’ give up on facts? On the basis of this research, the short answer to that question would be: no, to the contrary—at least not when negotiating about expertise in everyday interactions about contested health phenomena.

Before revisiting the empirical research of the preceding chapters to elaborate on that very short answer, it is useful to reconsider the subquestions mentioned in the introduction. In the initial research proposal, I distinguished between epistemic concerns and identity concerns:

1. *Epistemic concerns*: How do participants construct knowledge regarding contested health phenomena in terms of personal experience or on the contrary of formal scientific expertise?
2. *Identity concerns*: How does the construction of knowledge regarding contested health phenomena in terms of personal experience or on the contrary of formal scientific expertise help participants to construct a particular moral identity?

In order to answer these questions, I have conducted empirical research in different settings. I have selected Attention Hyperactivity Disorder (ADHD) as the main case study in this thesis. Because I am interested in negotiations about expertise, rather than in ADHD as such, I have compared conversations about ADHD with discussions in similar settings about other controversial health topics. ADHD is a knowledge field to which both experiential and scientific claims are highly relevant. What is more, the heated nature of the controversies surrounding this disorder shows that there is far more at stake than ‘merely’ the symptoms suffered by a defined group of patients (see, for instance, Bolt, 2009; Dehue, 2008). ADHD touches on topics with broad societal relevance, such as what is or should be the quality of schooling and parenting, and even on the nature of childhood and normality itself.

To learn more about the negotiations of what constitutes authoritative expertise regarding ADHD and the controversies associated with it, *chapter 2* focused on the interaction between interactants and hosts in Dutch and British radio phone-ins. The two topics under discussion were ADHD and vaccination.

²² <https://www.theguardian.com/books/2018/jul/14/the-death-of-truth-how-we-gave-up-on-facts-and-ended-up-with-trump>. Accessed July 18, 2018.

Chapter 3 showed online interactions between ‘lay’ interactants on forums in Dutch and English, discussing aspartame and ADHD. The analysis in *chapter 4* is based on conversations conducted in an ADHD coaching centre between coach and coachee, with an audience present. *Chapter 5* draws on a corpus of Dutch online conversations between patients suffering from different chronic diseases: ADHD, diabetes and ALS. Finally, *chapter 6* analyses discussions about ADHD in British radio phone-ins, between hosts and mothers of children with ADHD.

7.2.1. The morality of expertise: the moral importance of not being duped

In order to analyse how, exactly, interactants dispute claims to expertise, I conducted a study of Dutch and British radio phone-ins focusing on ADHD and vaccination (*chapter 2*). The radio phone-in is an interesting environment for this type of research questions, because it presents an extreme case in which one would expect experience to be prioritised (Hutchby, 2001).

I found that, **whereas interactants can dispute the authority of both scientific and experiential claims to expertise, this interactional challenge is built in different ways**. When disputing expertise offered in the form of personal experience, recipients can challenge its relevance, by treating the experience as mere belief. When disputing expertise offered in the form of scientific knowledge, recipients do not challenge its relevance, but on the contrary carefully patrol the borders of ‘real’ science and who is allowed to speak for it. Lay interactants thus collectively protect the symbols of science, even if their interpretation of what constitutes a scientific method is not necessarily correct.

The thesis contains a second example of a seemingly anti-scientific environment: an analysis of online conversations in which interactants use the idiomatic expression of ‘listening to the body’ (*chapter 3*). Speakers in online discussions about ADHD and aspartame contrast the allegedly untainted information as provided by the body with ‘blindly following’ certified science. They employ the idiomatic expression of ‘listening to the body’ to demonstrate their vigilance with regard to health information. The device helps interactants to transform their personal health choices into an advice for others, that does not need to be supported by factual or scientific sources. Speakers provide an

account for not basing their choice on a scientific study, suggesting that this would be the normal procedure. By treating information provided by their body as trustworthy but difficult to obtain, and by contrasting this with the allegedly corrupted information derived from factual sources, speakers position themselves as rational, rather than naive individuals, and as prepared to make an effort for their health. Likewise, in the comparative study between ADHD, ALS and diabetes patients (*chapter 5*), ALS patients make excuses if they do not do enough research into their disease, which suggests that it would be ‘normal’ or expected to do this. And in the negotiations of claims to expertise in radio phone-ins (*chapter 2*), speakers treat it as an interactional challenge when they are said to ‘believe’ in something, and claim knowledge instead. Throughout the case studies, interactants work to follow what Hobson-West (2007) has aptly termed the ‘moral imperative to become informed’. In general, then, **speakers take care so as not to be treated as gullible. Both claiming scientific or factual expertise and disputing its authority when offered by others are an essential part of building a critical identity.**

The findings from the research conducted in a Dutch ADHD coaching centre form an interesting contrast with this almost ubiquitous disputation of expertise. Coaches employ ‘my side empathy formulations’ to further a conceptualisation which is often at odds with their clients’ view. In order to pursue this potentially controversial, agency-oriented coaching agenda, they present their own bodily sensations as indicative of their client’s inner state. While these coaches do draw on neurological knowledge, they carefully avoid to claim exceptional expertise. Instead, the ‘my side empathy formulation’ allows them to keep their knowledge claims literally close to themselves. Because of this, they can challenge the meaning of their clients’ personal experience – an epistemic domain to which they would otherwise have no access – and promote an agency-oriented coaching agenda.

7.2.2. *Expertise in everyday life: the conflicting realities of responsible patients*

A key conclusion of my research – by no means a new finding, but one that still bears repeating – is the importance of being careful with general statements about the waxing or waning authority of expertise. **The way in which**

interactants treat claims to expertise – whether scientific or experiential – depends not merely on their assessment of the knowledge itself, but also on the interactional goals at stake. These are often very particular. What is required, for instance, in order to position oneself as a good mother, or a responsible patient? Here, epistemic and identity concerns are closely intertwined, because skilful navigation of the mind/world distinction is crucial to position oneself in a particular moral order.

The best empirical illustration of this close and varying connection between epistemic and identity concerns is found in *chapter 5*. This case study draws on a corpus of Dutch online conversations between patients suffering from different chronic diseases: ADHD, diabetes and ALS, to unravel the notion of the ‘informed’ or responsible patient. I have shown that the way in which a particular patient group treats certified health expertise depends strongly on the social responsibilities associated with their disease. Thus, in the online interactions between patients with ADHD analysed here, patients typically adhere to the authority of certified experts. Certified experts have an important role as gatekeepers, protecting the legitimacy of the contested disease by controlling access to diagnosis and medication. The interactions between diabetes patients, on the other hand, are much more critical towards certified expert knowledge. These patients show themselves to be committed to achieving ‘good’ blood glucose levels, but contest the experts’ ability to grasp the lived reality of the disease. Treating the achievement of good glucose levels as a largely unpredictable endeavour allows patients to carve out some space from the diabetes regimen, while still remaining a good patient. Although the necessity for ADHD patients to take medication is often compared with the diabetic’s need of insulin (see Singh, 2005), the concerns of these two patient groups are clearly very different. Finally, patients suffering from ALS or Lou Gehrig’s disease generally protect the authority of certified experts. In their case, this adherence to expertise is obviously not required to underline the serious nature of their disease, as it is for ADHD patients. On the contrary, in the online interactions I have studied, ALS patients hold each other accountable for thinking positive. Certified expertise, as the only possible source for experimental treatments, here becomes a symbol of hope—as is doing your research. In short: all patient groups orient towards a norm of being a good, responsible patient (*identity concern*), but the exact shape of this norm – the type of behaviour that patients hold themselves and each other accountable for –

differs depending on what is at stake for this particular disease. This influences what patients treat as appropriate knowledge or authoritative expertise (*epistemic concern*). Thus, **patients' treatment of scientific expertise cannot be understood without taking into account the identity concerns specific to their disease, even if the utterances in all three cases adhere to a more general norm of responsible and informed patienthood.**

For patients with ADHD, a diagnosis often provides an account for behavioural patterns that are otherwise difficult to explain (the most obvious illustration thereof are statements like: 'I used to think I was lazy/stupid, but now I know I have ADHD'). Yet this account remains precarious, given the controversies surrounding the disorder and its associated use of medication. I have found several ways in which patients try to stabilise the account of their (child's) disease in interaction.

First, in the interactions analysed here, **ADHD patients typically adhere to the authority of certified experts** (*chapter 5; chapter 6*). These health professionals act as gatekeepers to the disease. The legitimacy of a controversial disorder depends partly on the ability of experts to exclude people from the diagnosis, and to thus make the distinction between 'normal' and 'doctorable' behaviour (cf. Horton-Salway, 2007). Whereas the ADHD patients in my analysis did not hesitate to assess lists of problems offered by newbies as insufficiently problematic to be diagnosed as ADHD, they oriented to certified experts for a positive diagnosis of ADHD. Likewise, in mothers' accounts of the process of acquiring an ADHD diagnosis of their child (*chapter 6*), they oriented to the right of certified experts to diagnose problematic behaviour. Previous to this diagnosis, they only knew that there was 'something wrong', but did not know what. The almost formulaic nature of this phrasing suggests that it is part of a stock repertoire, with which the mother positions herself as a careful parent (she knows that there is *something* wrong), who is unlikely to jump to conclusions or to want a diagnosis (she does not know *what* is wrong).

Second, in the interactions I have studied, **ADHD patients treat individual decisions regarding the disease as having collective consequences.** When, as shown in the comparative case study (*chapter 5*), a patient decides to stop using medication and tells about this on an online forum, the recipients treat this as a form of irresponsible patienthood. Probably because of the

controversial nature of the disorder, this individual decision is treated as if it undermines the seriousness of the disease. Ironically, a diagnosis which provides an account for an individual's trouble to fit into a collective system (school, work), thus becomes a collective responsibility to uphold.

Third, and this is related to the first point, **interactants carefully tailor the knowledge they claim**. In my analysis of a corpus of British radio phone-ins, I found that mothers of children with ADHD typically claim knowledge about their children's good intentions, but not about the 'ADHD-ness' of their conduct (*chapter 6*). For ADHD to be treated as a brain disorder, the problematic behaviour needs to be situated inside the brain, and can therefore not be available to lay descriptions. As soon as the child's problematic behaviour is treated as something that can be observed from the outside and that can therefore be described by the mother, it becomes available to other lay people as well, and vulnerable to being formulated as 'normal disobedience'. Claiming no or insufficient knowledge about the manifestations of the disorder upholds the authority of certified experts, and helps to build an identity as a 'good mother'.

7.3. Discussion

7.3.1. *Limitations of the study*

Before discussing the implications of this study, a number of its limitations should be mentioned. First, due to the time-consuming nature of conversation analysis, only a limited number of interactions can be studied. I have chosen to focus on ADHD as an example of a field in which expertise is contested, and I have focused within that field on semi-public conversations. I have then compared the negotiation of expertise about ADHD with expertise negotiations about other contested health phenomena. I would argue that this method provides a kaleidoscopic view of practical negotiations of the abstract notion of expertise. However, it is worth repeating the conclusion of *chapter 5*; the way in which expertise is built or resisted, depends on what other concerns are at stake. One should therefore be cautious when generalising the findings of this study to other fields of expertise.

Second, conversation analysis studies solely what is made relevant by interactants themselves. This means that the history, context and background of

interactants only becomes a topic of analysis when this is referred to in the interaction. One drawback of this method – and, more in general, of studying already existing semi-public conversations – is the lack of information regarding the personal context of interactants. As the interactants are largely self-selected, it is likely that they consist of a narrow segment of the general population; namely, of those people who feel comfortable to contribute to an online forum or radio phone-in. The latter, in particular, probably comprises a predominantly white public (Glennie, 2015; Karpf, 2018). Whereas a conversation analytical study by definition does not strive for statistical representativeness, it is important to be aware that the way in which societal norms are made relevant in conversations may differ between groups.

Third, the interaction in two of the three settings – the radio phone-ins and the coaching sessions – is organised in an asymmetrical way, to the advantage of the host, respectively the coach. Whereas these settings are, in this sense, atypical, I would argue that this does not diminish their relevance for understanding the everyday negotiation of expertise. On the contrary; these are extreme cases, in which people draw – perhaps more explicitly – on the same interactional resources and repertoires that are available to them in ‘ordinary’, more symmetrical conversations.

7.3.2. Theoretical implications

I started this thesis with an anecdote in which an expert made a distinction between ‘talk’ and ‘the real discussion’. It is questionable whether that expert, had he read this thesis, would consider it to be part of the real discussion. My analysis of expertise negotiations focuses on expertise as invoked, challenged and defined by participants themselves; and thus on their own claims to expertise, rather than the accuracy of these claims. What is the relevance, one might ask, of online communities referring to science, if these same communities tend to ignore the scientific consensus? A different, but related question might be posed by sociologists of science: what does micro-level analysis as conducted in this thesis add to already existing theoretical accounts of expertise? The argument that negotiations of knowledge are tightly intertwined with the establishment of collective moralities is, after all, hardly new.

In the introduction to this thesis, I briefly discussed the diametrically opposed images of publics and experts. I sketched the ‘communicating vessels’ of the basement scientist and the vulnerable public; of the ivory tower scientist and the plain, reasonable man full of common sense. We have also seen how images of the rational scientist were contrasted with those of a public governed by emotions (most often, dangerously controlled by it, but sometimes able to provide for a cathartic experience). Finally, I noted how each scientific method creates its own public. This holds true for the general and disembodied public whose opinions are gleaned from surveys, but also for romantic notions of the public as they are sometimes encountered in science- and technology studies (Lapadat & Lindsay, 1999; Billig, 1999), full of situated, local knowledge. Such a discussion begs the question which kind of public is created in this thesis by using the methodology of conversation analysis and discursive psychology, and how this particular notion of the public adds to or improves upon the previously mentioned images.

By studying the organisation of actual talk, conversation analysis and discursive psychology claim to take an emic, rather than etic perspective (Pike, 1954). That is, the methodologies starts with the perspective of the speakers, rather than from an externally imposed scheme, and analyses which rules speakers themselves orient to (see Potter & te Molder, 2005: 19–21). It is doubtful whether conversation analysis provides such a transparent window to this actual discursive reality as some of its practitioners claim it does (Lapadat & Lindsay, 1999; Billig, 1999). But CA’s attention to sequentiality and interactional detail – as compared to the more impressionist treatment of interaction in mainstream science- and technology studies (STS) – does allow the analyst to study language in action. By looking at language ‘as we speak’, CA can help to provide insight into norms which interactants themselves are not necessarily aware of, and which will therefore not necessarily emerge from other qualitative, let alone from quantitative research methods. An interest in the workings of our collectively constituted normality has been a crucial part of CA since its very beginnings, but the findings resulting from such studies have not necessarily been connected with existing societal concerns. For instance, Stivers et al. (2011)’s *The Morality of Knowledge in Interaction* collects several highly interesting essays about the interactional management of epistemic rights and access, but it does not reflect upon what these findings might imply for contemporary debates about knowledge and morality outside the field of CA. Whereas this is a

perfectly defensible choice, I would argue that a highly interesting and relevant avenue for research opens up where the methods and underlying ontology of CA meet with societal concerns as expressed in STS. I hope to have shown that the added value of CA as a method for studying the negotiation of expertise results precisely from the fact that it *refuses* to distinguish between talk and the real discussion. As te Molder (2012: 106) puts this: “The ordering of our life is a task that is always with us (...) Apparently negligible details make the conventional framework that we call ‘society’ not only visible and relevant, but also keep it in existence”. As a consequence, the analysis of these apparently negligible details can help to observe that what is so seemingly self-evident that it is difficult to perceive in the first place; the day to day workings of normality, the water in which we swim.

CA’s general disinterest in the prioritisation of utterances in terms of importance is particularly helpful to study negotiations of expertise. Such negotiations, after all, typically evolve around the very question which claims to expertise and which concerns should or should not be taken into account (te Molder, 2012; Swierstra & te Molder, 2012). Because of its refusal to distinguish between talk and the real discussion, a CA approach regards it as meaningful when, for instance, participants on an anti-vaccination forum refer to science, regardless of the truth value of such statements. Focusing on the truth value of such utterances typically results in glossing them as ‘pseudo-science’ (e.g. Kata, 2010). When using CA, the question becomes why interactants orient to scientific expertise in this way and at this point of the conversation. This has practical benefits with respect to improving the dialogue regarding contested expertise, on which I will elaborate in the next paragraph.

CA’s understanding of authority as a contingent achievement is by no means unique (see, e.g., Hajer, 2009), but the method is distinctive in its dogged pursuit of the detailed interactional practices that underly, constitute and at times also challenge this collaborative achievement. This attention for details that might seem inconsequential to other methods makes conversation analysis a valuable approach for further research into expertise. CA’s approach to expertise as a profoundly interactional and relational achievement (see, e.g. Raymond, 2000; Heritage & Raymond, 2005; Raymond & Heritage, 2006) helps to transcend the dichotomous images of publics and experts I summarised above. It allows for an understanding as to how members of the public, rather than forming a

unified bloc against scientific expertise, hold *each other* accountable for following largely implicit moral rules (what constitutes good motherhood, good patienthood, responsible behaviour). The treatment of expertise is a crucial aspect of this ongoing management of social order. CA thus helps to gain insight into how claims and challenges to expertise figure in processes of collective sense making on the level of everyday life. These dynamics would otherwise go unnoticed, and cannot be understood without taking the sequentiality of interaction into account. Thus, whereas the argument that negotiations of knowledge are tightly intertwined with the establishment of collective moralities is hardly new, CA is uniquely capable of fleshing out exactly *how* this intertwinement works, and how normality is instantiated at an interpersonal level. Its focus on *why that now* – why this utterance at this point of the conversation – helps to understand what else may be at stake than knowledge as such, and can thus contribute to more insight as to why claims to expertise are sometimes resisted, at other times unquestioningly accepted and at still other times wholeheartedly embraced.

Approaching expertise as an interactional achievement has, however, important drawbacks too. As well suited as CA is to understand the asymmetries within interactions, it is by itself not capable of observing the socio-political aspect that might shape those interactions in asymmetrical ways. With respect to the research conducted here, this means that a CA approach can help to understand how interactants question claims to expertise to position themselves as not-gullible, but is unable to see the wider context in which, for instance, interested actors can actively promote epistemic uncertainty (see, e.g., Oreskes & Conway, 2010; Glenza, 2018). Furthermore, because the focus of CA is mostly linguistic, it is ill suited to observe the material and corporeal aspects that are relevant to expertise negotiations (e.g. Boyer, 2005). In short, like any other method, CA will provide only a partial and incomplete image of the public. However, because of its unique perspective on language in (inter)action and its refusal to distinguish between talk and the real discussion, it can nevertheless contribute tremendously to our understanding of how expertise is negotiated, contested and established in those everyday dialogues where we collectively and accountably talk normality into being (Heritage, 2008: 290). In the next paragraph, I will elaborate on the practical implications of such a CA understanding of expertise negotiation, and of the findings of this thesis in particular.

7.3.3. Practical implications

It is an ongoing debate how to respond to a society that is allegedly ‘post-fact’; a society in which expertise (Nichols, 2017) – or even truth in general (Kakutani, 2018) – has been declared dead. Kakutani (2018) speaks about ‘a disregard for facts, the displacement of reason by emotion’, whereas Nichols (2017: x) argues that:

To reject the advice of experts is to assert autonomy, a way for Americans to insulate their increasingly fragile egos from ever being told they’re wrong about anything. It is a new Declaration of Independence: No longer do we hold these truths to be self-evident, we hold all truths to be self-evident, even the ones that aren’t true. All things are knowable and every opinion on any subject is as good as any other.

Harry Collins (2014) asked provocatively: ‘are we all scientific experts now?’, and in *On truth* (Frankfurt, 2006: 33) argues that:

societies cannot afford to tolerate anyone or anything that fosters a slovenly indifference to the distinction between true and false. Much less can they indulge the shabby, narcissistic pretense that being true to the facts is less important than being “true to oneself.”

In descriptions as shabby, narcissistic and with a fragile ego a new, stereotypical and rather monstrous image of the public emerges. And just as with all the other notions of the public, an expert counterpart is implied: careful, selfless and self-assured.

This image of the public-expert divide is ironic, because one could well make the case that lay publics contesting certified expertise follow one of the basic dictums of the Enlightenment, even if they have an insufficient understanding of the science involved. *Sapere aude*, dare to know, or dare to use your own understanding, exhorted Kant (2015), and proceeded:

it is all too easy for others to set themselves up as their guardians. It is so convenient to be immature! If I have a book to have understanding in place of me, a spiritual adviser to have a conscience for me, a doctor to judge my diet for me, and so on, I need not make any efforts at all.

The public that emerges from the research in this thesis is, perhaps above all, a public that makes an effort—or at least orients to the importance of being seen

as making an effort. An effort to be a responsible patient, whether suffering from ADHD, diabetes, or ALS. An effort to do one's own research, to listen rather than hear, to know rather than believe. An effort to be a good mother in difficult circumstances, or to keep thinking positive even when dying from ALS. Ulrich Beck (1995: 121) argued that:

If it had been assumed, with naive faith in science, that epistemic progress was a cumulative approach to truth and security, that increased scientific research leads to the greater unavailability of its pronouncement, then this inadequate image of scientific work is turned upside down as the scientific society is established. The heightened version of scientificity is: truth, doubt, self-limitation.

Following Beck, one could well argue that public contestations of expertise are a result of a scientific society, particularly if such a society is governed by neo-liberal principles. Such principles encourage individuals to behave as consumers and make their own, rational choices on all kinds of terrains, including health. Because health is increasingly seen as an individual responsibility, it is important for these individuals to inform themselves and choose well - they will, after all, be held accountable for these choices by health professionals, fellow patients (and even by strangers. The research in this thesis thus provides further empirical support for what Dehue (2008; cf. Rose, 2006) called "the duty to take fate in hand" ("de plicht het lot in eigen hand te nemen"), and shows how people orient to this duty in everyday interaction. Rather than in a society in which being true to the facts has become less important than being true to oneself, we seem to have arrived in a society in which being true to 'the facts' (which includes caring enough about said facts to contest, defend, negotiate and challenge them) has become perhaps the most important way to be true to oneself. As a consequence, experts and publics have become locked in a language game, in which neither party can ever be fully successful. If claims to expertise are not publicly disputed, they are typically less relevant to Tolstoy's famous question to science; 'I want to know how to live'. But as soon as experts do try to provide (part of) an answer to this question, their expertise is likely to be challenged by publics with less knowledge of their field. The other side of the coin is that, if publics do not contest expertise, they are vulnerable to being treated as naive, or to being accused of failing to care (sufficiently). To further complicate this already complex situation, the spreading of misinformation and the active encouragement of doubt has become a strategy for corporate and

political actors with an interest in discrediting science (Oreskes & Conway, 2010).

Communicating about science in situations of contestation is notoriously difficult. To name just one example: research by Nyhan et al. (2014) into the consequences of vaccination information suggests that whereas pro-vaccine information reduced misperceptions about the link between MMR (measles, mumps and rubella vaccine) and autism, it also *decreased* vaccination intent among parents with the least favourable vaccination attitudes. In fact, none of the interventions with which Nyhan and his group experimented, including a dramatic narrative about measles and images of sick children, managed to increase vaccination intent among this group. This selective uptake of information causes Nyhan et al. (2014) to suggest that ‘respondents brought to mind other concerns about vaccines to defend their anti-vaccine attitudes’. Reflecting on Nyhan’s research, Konnikova (2014) suggests that:

Facts and evidence, for one, may not be the answer everyone thinks they are: they simply aren’t that effective, given how selectively they are processed and interpreted. Instead, why not focus on presenting issues in a way [that] keeps broader notions out of it—messages that are not political, not ideological, not in any way a reflection of who you are?

Providing more facts and evidence is indeed not the answer to improve science-society relations, but I would argue that it is simply not possible to present issues in such a way that they do not reflect any personal concerns – at least, not for any topic that people care about. We have seen in *chapter 2* how challenging a knowledge claim may imply challenging either the capability to judge one’s own experience or one’s right to speak for science, and in *chapter 6* that even providing a seemingly simple description can already be a morally loaded act. Whereas these interactions took place in the heated environment of a radio phone-in, everyday conversations outside of this context are not necessarily much friendlier—especially not with regard to contested health phenomena such as ADHD (Foster-Galasso, 2005; Jamison, 2014). The analyses in this thesis suggest that it is important to people to position themselves as not gullible. If this is true, then the way in which information is received and understood will be a reflection of who you are on a *personal*, if not necessarily political or ideological level.

The verb to contest, which we now understand primarily as to dispute, is derived from Latin *contestari*, which meant to call upon to witness. Conversation analytical research as conducted in this thesis can help to shed light on speakers' concerns: on what exactly they want us to be a witness of when they are claiming or contesting expertise.

If, as the current research suggests, it is important to interactants to demonstrate their critical attitude so as to show themselves not gullible or naive, this is likely to have consequences for the way in which they receive and respond to information. Whereas science communicators typically see distrust in science as the problem, interactants themselves treat being (seen as) trusting as the main interactional problem. An increased awareness that it is often an important identity concern for interactants to position themselves as epistemologically vigilant might contribute to the quality of science-society interactions.

To make such concerns visible to interactants and thus to improve the dialogue in situations where expertise is contested, the findings of conversation analytic research can be used in intervention methods such as CARM or DAM. CARM (Conversation Analytic Roleplay Method, Stokoe, 2014) and DAM (Discursive Actiemethode, Sneijder et al., 2007) take conversation analytical findings as a basis for a learning session with participants. Usually, fragments of the transcript – if possible in combination with audio or video material – are shown to and discussed with participants, with the intention to improve skills related to listening, self-reflection or participation (Sneijder et al., 2007). The research in this thesis could serve, for instance, as input for discussion in groups with health professionals or health policy makers (to improve the understanding of patients' concerns), ADHD patients or their relatives (to try and open a dialogue about the everyday meaning of the disorder), or with those wanting to communicate about science (to correct or at least nuance the image that facts do not matter anymore. Both CARM and DAM benefit from CA's interactional approach, because the emphasis on the sequentiality of the interaction and on how an utterance is treated rather than on how it had been intended, helps to shift the focus from 'who is to blame' to 'what actually happens here?' Participants take part in a collaborative analysis of conversations that are relevant to them, and are in this process guided by the analyst. Ideally, such an intervention would take place in an experimental setting where its effect can be measured—but any effect would have to be thought of in terms of improving the dialogue, rather

than in getting an experts message across. At its best, a CA based intervention shows interactants the concerns that prevents them from hearing each other.

7.3.4. *The art of not knowing: science and societal reality disjunctures*

While writing this conclusion, I wander through my living room, and pick up a random book from one of the stacks. (I know that this description seems to reiterate that of the amateur scientist in the introduction of this thesis, but so be it.). The book is called Common Ground, and the page that falls open starts like this (Cowen, 2015: 283):

Seeking a voice in the dark, I flick on the radio and walk straight into an argument. An impassioned affair, already well underway, echoes of the walls, forcing me to dash back and turn it down. That is not what our research suggests... growls an irate government minister before the interviewer cuts in: But it is what the evidence says and isn't that the problem?

Isn't that the problem, indeed. In the Dutch context, the argument that science is now seen as merely an opinion is repeated time and time again—but most often by scientists themselves (e.g. van Dijk & Saarloos, 2017; Keppel Hesselink & Bouter, 2016; Kolkman, 2017). That might not seem surprising; scientists can be expected to care about science, and, as a consequence, to closely monitor its status. The statement that science is now seen as merely an opinion runs, however, counter not only to the findings of the current thesis (in particular *chapter 2*) and previous qualitative research (Kerr et al., 2007; Hobson-West, 2007), but also and perhaps more telling to rather consistent survey results comparing the trust in science to that in other sources (European Commission, 2010; European Commission, 2014). Starting from a CA perspective the question would again be: *why that now?* What do scientists and others achieve, not necessarily consciously, by treating science as a singular, vulnerable unit in the claim that science has by now become merely an opinion? This question can obviously not be answered on the basis of the research in this thesis. Instead, I will conclude by offering some more speculative reflections and questions as directions for further research into the use of expertise to negotiate societal reality disjunctures.

The word *truth* finds its etymological origins in old-English *triewð*, which did not merely mean true, but also trustworthy, loyal and honest (compare, for instance,

the Dutch word *trouw*). Truth refers, in other words, not just to correctness or accurateness; it is, or is supposed to be, reliable in the way that one might trust a friend. However, in order to fulfil that role, it needs to be kept constant and this, in turn, requires interactional work, as Pollner (1987) and others have shown. What is the truest truth? And what is the language in which we may speak of it?

In their history of the development of the scientific ideal of objectivity, Daston & Galison (2007) discern three epistemic virtues, chronologically arising in reaction to the other, but not overcoming or nullifying the previous form: truth-to-nature, objectivity and trained judgment. Truth-to-nature started from an interest in the ideal type, requiring scientists to actively use their judgment to find this perfect form in the chaos of nature. Objectivity, in contrast, aimed to nullify the subjectivity of the scientist in order to let nature speak for itself through the mechanical eye of machines. Finally, when it turned out that mechanically generated, natural images could be just as enigmatic as the phenomena they represented, trained judgment became the chief epistemic virtue. The expert was expected to have a trained eye, with which he could produce and interpret authoritative images of the world, which in turn could be used to instruct others. The accuracy of this grand periodisation can be disputed; it is, for instance, questionable whether objectivity as ideal experienced its heyday in the nineteenth or rather in the twentieth century (see e.g. Porter, 1995; 2008). But the distinction between these three epistemic virtues is instructive because it shows the various selves on which experts may draw (and also, the various selves which publics may expect from them). A strict orientation to objectivity as a regulative ideal requires that the scientific expert absences or even nullifies himself as a person, leaving emotion, imagination and personal will at the door of his lab or study. One can expect that disenchantment will follow, especially if the incentives in the scientific infrastructure are almost exclusively geared towards publishing in peer-reviewed journals, while failing to value the societal – rather than merely financial – valorisation of science.

If we zoom in to the cases of this thesis, it is clear that patient groups – whether these patients suffer from ADHD or any other condition that finds itself in the middle of a controversy – crave for biomedical recognition. Without such expert recognition, their pain is not ‘real’ – at least, it will not be treated as such – and little support will be available. The difficulties experienced by such groups do

thus not count in any way that is societally meaningful, unless these difficulties have been recognised by certified professionals, on the basis of scientific expertise. (Likewise, on a meso-level, social protests are easily treated as based on mere emotions, therefore as irrational and to be ignored in policy making.) This leads to the paradoxical situation that a regulative ideal which strives for the elimination of subjectivity, and for the annihilation of scientists as persons (rather than passive observers), deeply influences the subjectivity of those affected by the field. One could imagine why it might be safer for non-experts, in reaction to this, to also hide their vulnerabilities behind a contestation of the facts. (Or to hanker after the image of the amateur scientist, the one whose library one can actually enter, because it is next to or even part of his own home (cf. Shapin, 1994).

In short, knowing the scientific facts has become a powerful tool for moral negotiation and financial distribution, to the exclusion of almost all other types of knowledge, such as experience, emotion and belief. Everyone unable or unwilling to build his claims on scientific grounds – that is, in terms of the epistemic virtues to which the current scientific language orients – risks losing any entitlement to speak. We simply lack a language with which to discuss what matters, other than by disputing offered facts, research, evidence and other claims to expertise. This results in a race focused on appearing ‘more scientific than thou’ in which it often seems impossible to find a common ground.

I would suggest that rather than to keep deploring science’s demotion to merely an opinion, the more interesting question is how can we solve – or even just discuss – the pressing societal reality disjunctures of our time in a way that leaves room for other languages than science as we know it. This does not mean that ‘anything goes’, as some experts might object. But it does imply that scientific experts might need to pay more attention to the history of their own discipline. Some of these – as in the case of ADHD – have contributed significantly to the same processes of doubt and contestation for which publics are now faulted (see Singh, 2002). What does it mean to take experience seriously? Are there other discourses or disciplines, such as the arts, which might help to acknowledge both the value of scientific expertise and of other types of knowing, the combination of which might be a step towards a new epistemic virtue, and a new idea of the scientific self? After all, emotion and experience were crucial for the everyday practice of some of those who built the very

foundations for modern day science, such as Humboldt (Wulf, 2015) and Santiago Ramón y Cajal, who pioneered in neuroscience, not least by conceiving of the brain in terms of fiction (Ehrlich, 2017). Searching for such a common ground requires – I recognise the utopian nature of this assumption, but utopian thinking has been described as a method on its own (Levitas 2013) – that experts, politicians and publics acknowledge more often that there are questions that science cannot answer, at least not authoritatively and at least not on its own. Rather than lamenting the death of truth, we should (re)consider the consequences of our necessarily incomplete grasp of it.

Appendix 1

Transcription symbols according to the Jefferson (2004) transcription system

[]	indicates the start and end of overlapping speech
<u>underlining</u>	indicates emphasis
><	indicates fastened speech
<>	indicates drawn out speech
CAPITAL	indicates a section of speech noticeably louder than that surrounding it
he he	indicates voiced laughter
.hh	indicates in-breath
(1.1)	indicates pauses in seconds
(.)	indicates micro-pause, too short to measure
:	colons indicate (degree of) elongation of the prior sound
£	indicates smiley voice
↑	indicates marked rising intonational shift
↓	indicates marked falling intonational shift
?	indicates questioning intonation, regardless of grammar
.	indicates a downward intonation
=	indicates the immediate 'latching' of successive talk
° °	indicates markedly soft voice

Appendix 2

Instances of LTYB

Forum	Thread	LTYB occurrence
Dutch opinion forum (FOK)—2008	Aspartame and ADHD	2
Dutch consumer forum (Tros Radar)—2009	Aspartame damageable?	3
US forum ADHD	Controversial treatments diagnosed children	1
US ADD forums—2009	Aspartame deadly poison (ADHD)	1
Dutch weight loss forum (valtaf)—2010	Aspartame	1
Dutch weight watchers forum—2012	Light drinks	2
Dutch opinion forum (Joop)—2012	Aspartame really is not dangerous	1
Dutch consumer forum (kassa)—2013	How harmful is cola light?	1
Dutch news forum—2013	Psychiatrist admits ADHD is a made-up disease	1

LTYB: Listen to Your Body; ADHD: attention deficit hyperactivity disorder.

Appendix 3

Het beste willen, het beste weten

Gepubliceerd in:

Podium voor Bio-Ethiek jaargang 20 | nr 1 | maart 2013. Themanummer Ethische aspecten van vaccinatie.

Appendix 3

Het beste willen, het beste weten

Inleiding

Ouders die negatief of kritisch staan tegenover vaccinatie worden dikwijls beschouwd als goedgelovige individuen. In dit artikel laat ik zien dat juist deze ouders in hun uitingen veel moeite doen zowel hun keuze als de onderliggende informatiebronnen te verantwoorden, en zichzelf te presenteren als kritisch denkende individuen. Kennisrechten en identiteit lopen hier nauw in elkaar over.

Vaccinatie als keuzeplicht

De website van de Nederlandse Vereniging voor Kritisch Prikken (NVKP) biedt uitgebreide informatie over het Rijksvaccinatieprogramma.²³ Bij elk van de veelgestelde vragen, en dat zijn er meer dan negenenveertig, geeft de NVKP netjes het antwoord van het RIVM, met daarnaast het antwoord dat de NVKP op deze vraag zou geven – meestal lijnrecht tegengesteld aan dat van het RIVM. Boven die twee doorgaans tegengestelde antwoorden benadrukt de NVKP nog eens: “Vaccineren is een keuze. **Uw keuze.** Geen plicht. Laat u informeren over vaccineren.”

Inderdaad. Vaccinatie is een keuze geworden – één van de vele keuzes die ouders moeten maken in de opvoeding van hun kind. Net als het kiezen van de juiste school is de keuze om al dan niet, of vertraagd of selectief, te vaccineren, er één geworden waarvoor tenminste een aantal ouders een grote verantwoordelijkheid voelt. Het gaat immers om een besluit dat, althans volgens sommige informatiebronnen, de gezondheid en daarmee de toekomst van het kind sterk kan beïnvloeden. De ouder moet kiezen voor dat ene kind, niet voor een grote groep. De kans dat het mis gaat mag dan klein zijn, maar dat geldt

²³ <http://nvkp.nl/veelgestelde-vragen/>

daarmee nog niet voor het risico en zo bezien is het geen wonder dat ouders kritisch staan ten aanzien van de beschikbare informatie.

Maar die kritische houding is, vanuit het oogpunt van beleidsmakers, niet per se een goede ontwikkeling (zie ook de bijdrage van Van Rijswoud in dit nummer). Ouders die wél vaccineren doen dit immers dikwijls mede omdat ze vertrouwen op de medische wetenschap en de verantwoordelijke instanties. De inenting ‘hoort er nu eenmaal bij’: “Cos I’m a sheep and that’s what you do. You know, I just... it’s just another thing that you do, you know.” (Tickner et al., 2007: 7404) Wanneer vaccinatie echter een bewust besluit wordt en een ouder actief op zoek gaat naar informatie om dat besluit op een weloverwogen manier te nemen, is de kans groot dat hij of zij stuit op websites als de bovenstaande, aan het twijfelen slaat en er misschien zelfs voor kiest om de vaccinatie te weigeren. Wie eenmaal begint met twijfelen kan daar dikwijls niet meer mee stoppen, en het internet speelt daarbij een belangrijke rol.

Pseudo-wetenschap?

Wie tegenwoordig naar informatie zoekt wendt zich bijna automatisch tot internet. Maar wie als zoekterm ‘vaccinatie’ gebruikt krijgt andere, dikwijls kritischer resultaten dan wie ‘inenting’ intypt (zie Wolfe et al., 2005). En terwijl alle websites feiten aanbieden, zijn die feiten het maar zelden met elkaar eens. Zoals het voorbeeld waarmee ik begon al aantoonde, is het dikwijls moeilijk te zien welke informatie nu betrouwbaar is.

Internetfora vormen een relatief beschermde plek waar ouders, vooral moeders, onder andere over dit soort kwesties discussiëren. Waar het gaat om vaccinatie hebben dergelijke fora een slechte naam; ze worden afgeschilderd als broedplaatsen van pseudo-wetenschap, bastions van kwakzalverij.

Maar juist hier kunnen we meer te weten komen over de manier waarop moeders hun besluit nemen. Discursieve psychologie (Sacks, 1992; Edwards, 1997) biedt een theoretisch perspectief dat ons maant te letten op wat de spreker met zijn uitingen bij anderen bereikt. Waarom doet de spreker op dit moment in de conversatie juist deze uitspraak, en hoe wordt daarop gereageerd? Een uitspraak als “cos I’m a sheep” kunnen we aannemen op zijn letterlijke betekenis, dat wil zeggen: de moeder vindt zelf dat ze handelt als een schaap of meeloper, en haar uitspraak is simpel de verwoording daarvan. Maar we

kunnen ons ook afvragen waarop de moeder precies reageert, waarom ze de noodzaak voelt om zich te verantwoorden en wel met juist deze woorden. In haar formulering legt ze, bijna verontschuldigend, de nadruk op het niet-uitzonderlijke karakter van haar keuze: “that’s what you do.”

Bekijken we de (anti-)vaccinatiefora door deze discursief psychologische lens, dan moeten we de vraag stellen wat er nu precies gebeurt wanneer moeders daar hun ervaringen en inzichten delen. Wat onmiddellijk opvalt is de grote rol die wetenschap in deze uitwisselingen speelt. Zo wordt er frequent verwezen naar al dan niet op PubMed gepubliceerde wetenschappelijke studies en bezigen de *posters* ook een wetenschappelijk taalgebruik. In discussies wordt gehamerd op de noodzaak van harde feiten en ruwe data, er wordt gevraagd naar bewijs voor claims en steeds opnieuw wordt betwist of aangehaalde bronnen wel betrouwbaar zijn.

Het voortdurende betwisten van wetenschappelijke bronnen wordt dikwijls geduid als een teken van het wankelende gezag van diezelfde wetenschap. Liesbeth van Zoonen wijst er bijvoorbeeld op dat op fora wel aan feitelijke bronnen wordt getwijfeld, maar dat dit niet gebeurt bij claims die berusten op persoonlijke ervaring (van Zoonen, 2012). Maar als geloofwaardigheid inderdaad steeds meer zou afhangen van persoonlijke betrokkenheid blijft onduidelijk waarom er zoveel moeite wordt gedaan om de waarde van wetenschappelijke studies te betwisten of juist te verdedigen. Er lijkt nog een andere factor mee te spelen dan de uitwisseling van kennis op zichzelf: identiteit. Wat je al dan niet voor waar aanneemt, zegt namelijk ook iets over wie je bent.

Je bent wat je kent

Wanneer de moeders beschrijven hoe ze besloten om niet te vaccineren, benadrukken ze dikwijls hoe sceptisch ze eerder stonden tegenover vaccinatie en/of alternatieve geneeswijzen:

I used to think that I would want an elective c/sec whenever I got pregnant. I thought gluten free was a silly trend. I thought non-vaxers were paranoid and I used to wish drs. would give out antibiotics quicker. Hahaha.²⁴ Of: I knew some people who didn't

²⁴ Alle uitspraken zijn afkomstig van het Amerikaanse, maar wereldwijd invloedrijke forum *mothering.com*

vaccinate their children. At first I thought they were crazy, but it made me look into the topic.

Volgens de eigen verklaring van deze vrouwen is het dikwijls een factor van buitenaf die voor een omslag zorgt. Heel letterlijk zien we dat in het volgende voorbeeld:

My cousin, who was an ER nurse in Boulder, CO. She talked to me during a family reunion when I was only 3 months preggo for ds#3 [dear son, WV], I will never forget... She walked up to me and said 'you're not planning on vaccinating that baby are you?' As she pointed at my belly. That started an insane research ride.

De nicht wordt hier aangehaald als een betrouwbare bron die vanwege haar beroep gezaghebbend is—van de vele mogelijke manieren om haar te beschrijven wordt alleen genoemd dat ze verpleegkundige is op de spoedeisende hulp. Interessant is ook de manier waarop ze aan ons gepresenteerd wordt: actief sprekend, en daarmee des te dwingender. Door de manier waarop de nicht haar vraag formuleert wordt het bijna onmogelijk om bevestigend te antwoorden; als lezers kunnen wij alleen tot de conclusie komen dat de moeder haast wel op onderzoek uit moest gaan.

Of dat in werkelijkheid het geval was, doet hier niet terzake. Wel belangrijk is dat er een patroon valt waar te nemen in de manier waarop moeders hun keuze om niet te vaccineren presenteren. Dat gebeurt namelijk opvallend vaak op de manier waarvan ik hierboven enkele voorbeelden gaf: eerst was er mainstream-gedrag, dan volgde een gebeurtenis of gezaghebbende bron van buiten die hen op het kritische spoor zette, daarna kwam het eigen onderzoek en dan pas het besluit om niet of selectief te vaccineren. Al deze moeders benadrukken kortom juist hoe uitzonderlijk hun besluit om niet te vaccineren was: de keuze kwam niet voort uit al bestaande overtuigingen of hun karakter, maar was écht een keuze. Blijkbaar voelen ze de noodzaak om dit te expliciteren, en zo het rationele karakter van hun keuze te benadrukken.

Conclusie

De keuze om je kind al dan niet te laten vaccineren is niet alleen iets wat je doet; het zegt iets over wie je bent. Dat is niet nieuw. Zo legden in Nederland de commerciële reclames rond de invoering van de HPV-vaccinatie een verband

tussen vaccinatie en goed moederschap. In de huidige samenleving hangt ‘het beste willen’ sterk samen met ‘het beste weten’. Denk bijvoorbeeld aan de uitgebreide publicaties over resultaten van scholen, maar ook aan de simpele slogan van reisrecensie-website Zoover: ‘je had er kunnen zitten’. Ook de overheid moedigt burgers op allerlei terreinen aan om kritisch te zijn en bewust te kiezen, denk bijvoorbeeld aan de zorgkosten. Wie zich niet goed informeert loopt het risico verkeerd te kiezen en zichzelf te benadelen, een sukkel te zijn – of in dit geval, een slechte moeder. Zo beschouwd gedragen twijfelende ouders zich als de volmaakte burger van deze tijd.

Het voortdurende bevragen van informatiebronnen wijst op de zoektocht van burgers naar betrouwbare en onpartijdige kennis, een zoektocht die mede voortkomt uit zorg over de verstrengeling tussen wetenschap, overheid en bedrijfsleven. Tegelijkertijd lijkt een dergelijke kritische houding in veel contexten juist bedoeld om een bewijs van rationaliteit te leveren; zo maken pro- en anti-vaccinatiewebsites elkaar op bijna spiegelbeeldige wijze uit voor gelovigen. Gegeven deze dubbele dynamiek is het geen wonder dat juist binnen de vermeende broedplaatsen van pseudo-wetenschap een roep ontstaat om steeds ‘echtere’ wetenschap, waarbij eisen worden gesteld waaraan de wetenschap nooit kan voldoen. Of zoals het werd geformuleerd in een inbelprogramma over de griepvaccinatie: wat we eigenlijk willen is een onafhankelijk onderzoek dat we met z’n allen kunnen steunen.²⁵

²⁵ <http://www.radio1.nl/items/40571-griepvaccinatie-helpt-alleen-de-pillenindustrie>

Appendix 4

Dutch online excerpts

Chapter 3

Excerpt 1a: Natural

2. Persoonlijk zou ik zo weinig mogelijk
3. zoetstoffen etc gebruiken
4. aangezien al deze stoffen
5. reeds in natuurlijke producten zitten.

Excerpt 1b: Candle

6. Een mens kan heel goed leven
7. zonder suiker en zoetstoffen!
8. Of deze nou aspartaam is
9. of een andere!
- 10.
11. Dus waarom vragen stellen? Luister gewoon naar
12. je eigen lichaam!
13. Wat is er mis met alles
14. vers en zelf limo maken
15. en koken zonder suiker?
16. Ik hoef geen medische onderbouwing te geven
17. om te kunnen vertellen dat
18. het troep is!
19. [3 lines omitted]

Excerpt 3: Oblivion

1. Is verder een zeer vermoeiende discussie,
2. ik luister liever naar mijn eigen lichaam.
3. Is het okay om te eten of te drinken dan doe ik dat,
4. anders geeft het lichaam wel aan
5. of het slecht voor me is.
6. Maar om blind te gaan op onderzoeken
7. die ze naar zeggen
8. goed hebben uitgevoerd? Nee...

Excerpt 4: Anja

1. Waarom luisteren naar de reclames en
2. informatie van voedselabrikanten?
3. Ik neem mijn lichaam en gezondheid te
4. serieus om afhankelijk te zijn
5. van wat anderen die ik niet ken
6. er wel of niet van vinden.
7. Ik luister goed naar mijn lichaam
8. en de mensen die ik serieus neem.

Excerpt 5: Five star

1. Als er al een onderzoek nodig is om
2. aan te tonen of iets wel of niet
3. goed of giftig is, dan heb ik daar
4. toch wel mijn twijfels over.
5. Er zijn altijd bedrijven die er
6. gigantisch aan verdienen
7. en dan zo'n onderzoek financieren.
8. tsja.
9. Laat ik dan maar naar mijn lichaam luisteren.

Excerpt 1a

See above

Excerpt 6a: Nadya

Unfortunately, the original Dutch version of this post cannot be retrieved due to a computer crash

Excerpt 6b: Cencia

12. Ja, want als het op internet staat,
13. dan moet het wel waar zijn!
14. Ik vind cola light, en de
15. optimel producten, etc gewoon lekker.

(1 post omitted)

Excerpt 6c: Nadya

30. Je moet inderdaad op je eigen
31. lichaam afgaan, en iedereen reageert
32. er anders op.
33. Maar ik gaf al aan: er wordt veel

34. over geschreven en het is in de meeste gevallen
35. moeilijk te zien of
36. informatie op internet
37. daadwerkelijk evidence based is.

Excerpt 6d: Cencia

38. Hier op het forum heeft natuurlijk ook iedereen
39. een eigen mening.
40. Datzelfde geldt voor internet en
41. iedereen die daar dingen opzet.
42. Ik bedoelde daarom ook alleen maar te zeggen
43. dat er inderdaad veel verschillende
44. opvattingen over dit onderwerp zijn en dat
45. je inderdaad gewoon naar je eigen lichaam
46. moet luisteren.

Excerpt 7a: Kuklos

"Als mensen letterlijk hebben ervaren dat de stof aspartaam negatieve gevolgen heeft gehad op hun gezondheid dan kun je toch niet zeggen dat het niet waar is omdat het niet wetenschappelijk onderbouwd is?"

8. Dat gebeurt dan ook niet, zoals
9. je had kunnen zien. Maar zodra
10. deze mensen hun eigen ervaring
11. doortrekken naar geldend voor ieder
12. mens dan slaan ze dus de plank
13. mis. Want daarvoor
14. ontbreekt nu elk bewijs.

Excerpt 7b: Natural

15. nee precies wat ik aangaf, luister naar je
16. lichaam. Ik hecht veel meer waarde aan mensen
17. die zelf ervaren hoe een
18. stof uitwerking heeft op hun lichaam (dus
19. op hun eigen lichaam, niet op de gehele
20. mensheid). En hier hun meningen en ervaringen
21. met ons willen delen.

Chapter 5

Excerpt 1

R&P_P&P_ADHD & ADD

#27 Waar we de doseringen bekijken — forum.fok.nl

Tiny - post #35

1. Als ik onderstaande lijst bekijk: [list]
2. Dan is alleen het dik gedrukte bij mij van toepassing...
[6 of 33 bullet points]
3. Toch denk ik wel eens dat ik een vorm van ADD heb..
4. De meeste moeite heb ik met concentreren
5. als iets mij niet genoeg boeit.
6. (bijvoorbeeld op mijn werk wat ik leuk vindt
7. heb ik geen moeite om de focus te houden),
8. Kan mezelf moeilijk aan zetten tot leren
9. of dingen voor school doen.
10. Gaan vaak vele gedachtes door mijn hoofd.
11. Ik moet nog dit doen, en dat doen...
12. en daarna ga ik dat doen...etc...
13. Ik zou me wat graag willen focussen op de dingen die er toe
doen,
14. zoals school...
- 15.
16. Wat denken jullie?

Tuck - Post #36

17. Dat je geen ADD hebt.

Toggle - Post #38

"Dat je geen ADD hebt."

18. dat...
19. ik heb er geloof ik hooguit 5 niet...

Excerpt 2

VIVA Forum – Psyche – AD(H)D zonder medicatie, wie heeft nuttige tips?

1. daarnaast: je moet de medicatie ook niet zien als een sort
tovermiddel
2. dat je problemen oplost.

3. Ik gebruik wel medicatie, omdat het sommige dingen gewoon makkelijker maakt.
4. De medicatie geeft me geen structuur en overzicht,
5. maakt niet mijn planning, dat moet ik zelf doen.

Excerpt 3

VIVA Forum – Psyche – AD(H)D zonder medicatie, wie heeft nuttige tips?

Ann - Post #1

1. Ik 'slik' nu ruim een week, maar ik heb besloten
2. dat medicatie gewoon niet bij mij past.
3. Daarbij komt dat ik adhd een (soms lastige)
4. karaktereigenschap vind, of misschien beter gezegd;
5. een lijst met lastige symptomen,
6. en geen ziekte waarvoor ik medicatie moet slikken
7. (dit geldt voor mij persoonlijk,
8. hiermee wil ik niemand tegen de haren instrijken!)

Excerpt 4

VIVA Forum – Psyche – AD(H)D zonder medicatie, wie heeft nuttige tips?

Abby - Post #12

"Nou ben ik geen voorstander van medicatie voor een psychische aandoening, omdat ik denk dat het de oorzaak niet wegneemt."

1. Ben jij wel goed voorgelicht door je psychiater?
2. AD(H)D is een neurobiologische stoornis.
3. Neurotransmitters zoals dopamine en noradrenaline
4. worden niet goed doorgegeven aan de zenuwcellen.
5. Deze stoffen zijn belangrijk voor de concentratie
6. en de filtering van prikkels.
7. Dit veroorzaakt jouw gedrag.

Excerpt 5

Diabetes-forum – Blood sugars not too low now

Tony - Post #1

1. Ik ben diabetes type 2
2. en sinds een week slik ik nu januvia.
3. Ik moet me tot ik goed ingesteld ben op medicijnen

4. 6x per dag prikken.
5. Sinds gister zijn mijn bloedsuikerwaardes
6. tussen de 4,5 en de 6.
7. Ik vroeg me af, is dit niet te laag?

Tom - Post #2

8. Wow, wat een goede waardes!
9. De waardes zijn zeker niet te laag,
10. ze zijn prachtig.
11. Als je het zo kunt houden, heb je bloedsuikers
12. zoals ieder persoon
13. zonder diabetes, dus keurig.
14. Houden zo, [naam]

Thomas - Post #3

15. Gaaf!

Tim - Post #4

(...)

16. Goed hoor!
17. ik prik ook 6 keer per dag,
18. maar het lukt mij echt niet om smorgen's 4,5 te prikken
19. meer tussen de 7 en 8,
20. die waarden zijn echt goed te noemen hoor!

Tina - Post #5

(...)

21. Ongelooflijk, echt heel erg netjes!
22. Ik hoop dat ik ook in de toekomst zulke waarden mag hebben.

Excerpt 6

Diabetesforum – Veel te hoog, ben ik nou zo'n uitzondering_

1. Tja ik kan niet meer dan mijn best doen
2. en al doe ik 3 dagen precies hetzelfde
3. en eet ik precies hetzelfde

4. mijn waarden verschillen toch!
5. Dus mijn motto is: Meer dan mijn best kan ik niet doen
6. en regelmatig kritisch naar mezelf kijken
7. maar vergeet niet te genieten van het leven
8. en hogere bls waarden soms gewoon te accepteren.
9. Morgen nieuwe dag nieuwe kansen nieuwe rondes!!!
10. Zet m op iedereen

Excerpt 7

Viva – Diabetesland

"Moet toch eens goed uitzoeken hoe dat nou precies zit, met dat metformine en dan geen hypo's kunnen krijgen (wat de medici altijd beweren)."

1. Ach ja, de medici die altijd van alles beweren.....
2. dat kennen we zo onderhand wel toch?
3. Alsof ieders lichaam hetzelfde is en hetzelfde reageert.
4. Tuurlijk. Hmhm.

Excerpt 8

Viva – Diabetesland

1. Jaren geleden had ik bedacht dat ik wel kon gaan touwtjespringen
2. als ik hoog zat.
3. Gevolg: vóór het touwtjespringen op 11, erna op 17.
4. Net als met wandelen in het bos met de honden:
5. ervoor op 14, erna op 20.
6. De dvk schudt haar hoofd in ongeloof
7. en heeft géén idéé hoe dat nou zo kan komen.

Excerpt 9

stopals.nu/voorstellen

Greta - Post #1

1. We hebben van alles geprobeerd maar niets stopt deze rotziekte.
2. Update wordt vervolgd

Gemma - Post #2

3. Frutrerend he om ze zo achteruit te zien gaan..
4. Geniet van de dingen die hij nog wel kan
5. en vooral van het samen zijn.

Gary - Post #3

"Hand en armfunctie gaan sterk terug. We hebben van alles geprobeerd maar niets stopt deze rotziekte. Update wordt vervolgd"

6. hallo [naam], Helaas heb je (nog) gelijk
7. Het enige dat je er doorheen helpt is een positief karakter
8. en een goed humeur, en gelukkig ontwikkelen de meesten
9. dat wel na verloop van tijd - voor zover ze dat nog niet hebben
10. Het is een gevecht dat ieder van ons afzonderlijk moet overwinnen 😊!

Excerpt 10

stopals.nu/hoi.pdf

Larry - Post #1

1. Ben je niet bang dat je jezelf moeilijker kunt redden
2. omdat je alleen woont?
3. (Je bent niet de enige hoor)

Leah - Post #2

4. Op je zelf wonen is niet zo gemakkelijk,
5. ik heb veel hulp van vrienden en familie.
6. Ik sta positief in mijn leven,
7. ik probeer veel dingen om mij weer sterk te maken.

Excerpt 11

stopals.nu/Evenvoorstellen_DickS

Leanne - Post #1

1. Hallo [naam]
2. Welkom op de site.
3. Ook bij jou weer zo,n ellendig verhaal.
4. Ik hoop dat je veel steun zult vinden op deze site.

Don - Post #2

5. Ja, leuk is anders maar je verandert er niets aan.
6. Ik neem de dagen zoals ze komen en maak er het beste van.
7. Samen met mijn vriendin, die bijna mijn gehele dagelijkse verzorging op zich neemt,
8. lachen we een hoop weg elke dag.

Excerpt 12

StopALS.nu/dexpramipexolefaaltinfasel

Phil - Post #5

1. ik weet haast wel zeker dat het gros van de lezers
2. van dit forum het met je eens is, maar er komt een moment
3. dat je een beetje down ben van alle teleurstellingen,
4. ik draai nu bijna een jaar mee en
5. dit soort dingen zijn al zoveel besproken,
6. zowel over legalen trails als zelf brouwsels
7. die niet bleken te werken. je word doodziek
8. van al die teleurstellingen en dit werd
9. wel erg hoopgevend gepresenteerd 🤔
10. is niet anders, Gewoon Doorgaan 😊

Paul - Post #6

11. Ik wil liever wel de ontwikkelingen kunnen volgen,
12. al is het inderdaad erg frustrerend
13. dat ze steeds 'doorbraken' presenteren
14. waar je vervolgens niks meer van hoort.
15. En als er dan eindelijk wel wat lijkt te gebeuren,
16. zoals met 'dex', dan is het extra balen
17. als het toch weer niks wordt.
18. Voor mij was het een belangrijke strohalm 🤔
19. Ondanks alles, gas erop, daar gaat het om!

Patrick - Post #7

20. Ook ik snap de frustratie wel
21. maar heb het van me kunnen laten afglijden om niet m'n focus te laten vertroebelen
22. door negatieve gedachten.
23. Natuurlijk zou ik me er ook over kunnen opwinden en me ergeren
24. maar volgens mij gaat het onderzoek naar een medicijn hier
25. niet sneller door en behoud ik liever
26. deze kostbare energie voor iets positiefs.
27. Ik hoop en ga er van uit dat de medici van het ALS centrum

28. een weloverwogen keuze maakt als het gaat om de aankoop van een volgende trial.

Summary

How do you know? Everyday negotiations of expert authority

News headlines often argue that science has become just another opinion, that truth has died or that we have given up on facts. In order to investigate this claim within the field of health, I employed Discursive Psychology and Conversation Analysis. Using this interactional approach to expertise, I analysed a corpus of health-related radio phone-in conversations, online conversations and coaching sessions. I focused on semi-public interactions about ADHD (Attention Deficit Hyperactivity Disorder) as an example of a controversial field to which both experiential and scientific knowledge claims are highly relevant. As my interest lies in the negotiation of expertise, rather than in ADHD as such, I compared the negotiations of expertise in the interactions about ADHD with those in conversations focusing on vaccination, aspartame, diabetes and ALS. The main research question was *How do interactants negotiate the morality of contested health phenomena by drawing on scientific expertise or on the contrary on experiential knowledge, and which interactional goals are served by this?*

In order to analyse how interactants dispute claims to expertise, I conducted a study of *Dutch and British radio phone-ins focusing on ADHD and vaccination (chapter 2)*. The radio phone-in is an interesting environment for this type of research questions, because it presents an extreme case in which one would expect experience to be prioritised. I found that, whereas interactants can dispute the authority of both scientific and experiential claims to expertise, this interactional challenge is built in different ways. When disputing expertise offered in the form of personal experience, recipients can challenge its relevance, by treating the experience as mere belief. When disputing expertise offered in the form of scientific knowledge, recipients do not challenge the relevance of scientific knowledge, but on the contrary carefully patrol the borders of ‘real’ science and who is allowed to speak for it. Lay interactants collectively protect the symbols of science, even if their interpretation of what constitutes a scientific method is not necessarily correct.

The thesis contains a second example of a seemingly anti-scientific environment: an analysis of instances in which interactants use the idiomatic expression of ‘listening to the body’. Speakers in *online discussions about ADHD and aspartame* (chapter 3) contrast the allegedly untainted information as provided by the body with ‘blindly following’ certified science. They employ the idiomatic expression of ‘listening to the body’ to demonstrate their vigilance with regard to health information. By treating information provided by their body as trustworthy but difficult to obtain, and by contrasting this with the allegedly corrupted information derived from factual sources, speakers position themselves as rational individuals who make an effort for their health. What, at first sight, seems to indicate pure disregard for science turns out to be an attempt to take a *more* scientific attitude. As in the case mentioned above, this attempt to following a scientific method is not necessarily successful. But that does not change the importance of what is at stake for interactants; the recognition of their efforts to take active care of their health and ultimately their identity as a rational individual.

I conducted a comparative study of *online interactions between patients suffering from, respectively, ADHD, diabetes and ALS* (chapter 5). This comparison showed that the various patient groups each took a different stance towards expertise, depending on what was at stake for their particular disease. In the analysed interactions, patients with ADHD treat the expertise of certified health professionals with respect. Certified professionals have the right to diagnose, and thus to act as gatekeepers for the disease and protect its legitimacy. Diabetes patients – who are held and hold each other accountable for following a strict regimen – are much more critical about the ability of certified experts to grasp their lived reality. Patients suffering from ALS – who are held and hold each other accountable for thinking positive, an aspect of which consists of ‘doing one’s own research’ – uphold the status of certified experts as the last ones to offer them hope in the form of trials and experimental treatment. Paradoxically, the ADHD patients in this corpus tend to underline the serious nature of their disease – pointing, for instance, to the need for medication – whereas the interaction between ALS patients hardly allows for complaints. I conclude that speakers’ treatment of expertise cannot be understood without taking the identity and accountability concerns into account that are relevant to the knowledge field in question. Because of this, one should therefore be careful when speaking about the waxing or waning authority of expertise in general.

This thesis focuses on interactions about ADHD as example of a knowledge field where the negotiation of claims to expertise has important consequences for the understanding of the self. For patients, a diagnosis of ADHD typically provides an account for behavioural patterns that are otherwise difficult to explain (the most obvious illustration thereof are statements like: “I used to think I was lazy/stupid, but now I know I have ADHD”). Yet this account remains precarious, given the controversies surrounding the disorder and its associated use of medication. In the interactions I have studied, I found several ways in which patients with ADHD, or their parents, try to stabilise the account of their (child’s) disease in interaction.

First, as indicated above, the interaction between ADHD patients typically adheres to the authority of certified experts, because these health professionals act as gatekeepers to the disease, classifying their problems as doctorable by diagnosing it as ADHD. Patients orient to health professionals to make a positive diagnosis of ADHD, but are confident in making statements regarding what is *not* ADHD.

Second, ADHD patients treat individual decisions regarding the disease as having collective consequences. When, as shown in the comparative case study (*chapter 5*), a patient decides to stop using medication and tells about this on an online forum, the recipients treat this as a form of irresponsible patienthood, which has relevance for their own life with this disorder. Ironically, a diagnosis which provides an account for an individual’s trouble to fit into a collective system (school, work), thus becomes a collective responsibility to uphold.

Third, and this is related to the first point, interactants carefully tailor the knowledge they claim. Building on a *corpus of British radio phone-ins*, I found that mothers of children with ADHD typically claim knowledge about their children’s good intentions, but *not* about the ‘ADHD-ness’ of their conduct (*chapter 6*). As soon as the child’s problematic behaviour is treated as something that can be observed from the outside and sufficiently understood to be described by their mother, it becomes vulnerable to being formulated as ‘normal disobedience’. In this way, claiming no or insufficient knowledge – thus upholding the expertise of someone else – can be just as important to build an account or an identity as the claim to expertise is.

Throughout the various case studies, speakers take care so as not to be seen as gullible or naive and to build a critical identity. Both claiming scientific or factual expertise *and* disputing its authority when offered by others are an essential part of this. In the comparative study between ADHD, ALS and diabetes patients (*chapter 5*), ALS patients provide an account if they do not do enough research into their disease, which suggests that it would be ‘normal’ or expected to do this. In the analysis of the idiomatic expression ‘listening to the body’ (*chapter 3*), interactants use the device to transform their personal health choices into advice that does not need to be supported by factual or scientific sources. Here, too, speakers provide an account for not basing their choice on a scientific study, suggesting that that would be the normal procedure. In the negotiations of claims to expertise in radio phone-ins (*chapter 2*), speakers treat it as an interactional challenge when they are said to ‘believe’ in something, and claim knowledge instead. In short, throughout the empirical cases, interactants work to follow what Hobson-West (2007: 212) has aptly termed the ‘moral imperative to become informed’.

The findings from *chapter 4*, based on video recordings conducted in a Dutch ADHD coaching centre, are an interesting contrast with this almost ubiquitous disputation of expertise. Coaches employ ‘my side empathy formulations’ to further a conceptualisation which is often at odds with their clients’ view. In order to pursue this potentially controversial, agency-oriented coaching agenda, they present their own bodily sensations as indicative of their client’s inner state, literally keeping their knowledge claims close to themselves. While they do draw on neurological knowledge, their careful avoidance to claim exceptional expertise helps them to achieve their interactional goals.

The conversation analytical findings of this thesis have theoretical and practical implications for the understandings of expertise negotiations in present day society. Conversation analysis (CA) makes visible how members of the public, rather than forming a unified bloc against scientific expertise, hold *each other* accountable for following largely implicit moral rules (what constitutes good motherhood, good patienthood, responsible behaviour). The argument that negotiations of knowledge are tightly intertwined with the establishment of collective moralities is hardly new, but CA is uniquely capable of fleshing out exactly *how* this intertwining works in interaction. Its focus on the sequentiality of everyday interactions helps to understand what else may be at

stake than knowledge as such, and can thus contribute to more insight as to why claims to expertise are sometimes resisted, at other times unquestioningly accepted and at still other times wholeheartedly embraced.

If, as the current research suggests, it is important to interactants to demonstrate their critical attitude so as to show themselves not gullible or naive, this is likely to have consequences for the way in which they receive and respond to information. Whereas science communicators typically see distrust in science as the problem, interactants themselves treat being (seen as) trusting as the main interactional problem. An increased awareness that it is often an important identity concern for interactants to position themselves as epistemologically vigilant might contribute to the quality of science-society interactions.

Based on the research conducted in this thesis, I would argue – contrary to what is often stated in the media, and frequently by scientists (see *chapter 7*) – that science has not become just another opinion and that ‘we’ have not given up on facts. That claim is, in any case, not true with regard to the topics and themes I have researched in this thesis. On the contrary; *it often seems as if we are lacking a language to discuss what matters, other than by disputing offered facts and claims to expertise, which frequently results in a race focused on appearing ‘more scientific than thou’.* I suggest that we stop deploring science’s alleged demotion to merely an opinion, and start wondering how can we solve – or even just discuss – the pressing problems of our time in a way that leaves room for other languages than science as we know it. Rather than lamenting the death of truth, we should (re)consider the consequences of our necessarily incomplete grasp of it.

Samenvatting

Hoe weet je dat? Alledaagse onderhandelingen over het gezag van experts

In de krantenkoppen lees je vaak dat wetenschap tegenwoordig ook maar een mening is, dat de waarheid is gestorven of dat we niet meer geven om de feiten. Om deze claim nader te onderzoeken op het gebied van gezondheid, maakte ik in dit proefschrift gebruik van discursieve psychologie en conversatie analyse. Met behulp van deze interactionele benadering van expertise analyseerde ik een corpus van gezondheidsgerelateerde inbelprogramma's, online gesprekken en coaching sessies. In het bijzonder richtte ik me op semi-publieke interacties over ADHD (Attention Deficit Hyperactivity Disorder). ADHD is een voorbeeld van een controversieel veld waarin zowel kennisclaims gebaseerd op ervaring (hierna: ervaringsclaims), als kennisclaims gebaseerd op wetenschappelijke kennis een belangrijke rol spelen. Voor een breder beeld van expertise-onderhandelingen, vergeleek ik de gesprekken over ADHD met gesprekken over vaccinatie, aspartaam, diabetes en ALS. De leidende vraag in het onderzoek was hoe gespreksdeelnemers onderhandelen over de moraliteit van controversiële gezondheidsfenomenen door een beroep te doen op wetenschappelijke dan wel gecertificeerde expertise, of juist op ervaringskennis, en welke interactionele doelen hiermee werden gediend.

Om te onderzoeken hoe gespreksdeelnemers kennisclaims betwisten, deed ik onderzoek naar *Nederlandse en Britse radio inbelprogramma's over respectievelijk de griepvrijheid en ADHD (hoofdstuk 2)*. Het inbelprogramma is een interessante omgeving voor onderzoek naar de onderhandeling over kennisclaims, omdat het een zogeheten *extreme case* is: het ligt in de lijn der verwachting dat kennisclaims gebaseerd op ervaring in deze omgeving voorrang krijgen. Ik vergeleek de manieren waarop gespreksdeelnemers het gezag en de relevantie van wetenschappelijke kennisclaims en ervaringsclaims betwisten. Dit gebeurt op verschillende manieren. Wanneer de recipiënt een ervaringsclaim betwist, gebeurt dit door de ervaring te behandelen als iets dat de spreker ten onrechte gelooft, en dat daarom niet relevant is. Wanneer de recipiënt echter een claim

op basis van wetenschappelijke kennis wil aanvechten, betwist hij of zij niet de relevantie van die wetenschappelijke kennis. Integendeel; gespreksdeelnemers onderhandelen zorgvuldig over wat de grenzen van ‘echte’ wetenschap zijn, en wie daarvoor als woordvoerder kan optreden. Zo bewaken leken gezamenlijk de symbolen van wetenschap, ook wanneer hun interpretatie van de wetenschappelijke methode niet per se correct is.

Het proefschrift bevat een tweede voorbeeld van een schijnbaar anti-wetenschappelijke omgeving: gesprekken die draaien om de idiomatische uitdrukking ‘luister naar je lichaam’. Deelnemers aan *online gesprekken over ADHD en aspartaam (hoofdstuk 3)* contrasteren de ‘zuivere’ informatie die wordt verkregen door naar het lichaam te luisteren, met het ‘blind volgen’ van wetenschap. Ze gebruiken de idiomatische uitdrukking ‘luister naar je lichaam’ om hun waakzaamheid ten aanzien van gezondheidsinformatie te demonstreren. Door de informatie van het lichaam te behandelen als betrouwbaar maar moeilijk te verkrijgen en door dit te contrasteren met eenvoudiger te verkrijgen, maar ‘corrupte’, feitelijke kennis, positioneren gespreksdeelnemers zichzelf als rationele individuen, die kritisch zijn en moeite doen voor hun gezondheid. Wat op het eerste gezicht een minachting voor wetenschap lijkt, blijkt bij nadere analyse een poging om juist een meer wetenschappelijke houding aan te nemen. Dat die kritische houding wederom niet per se voldoet aan wetenschappelijke eisen, doet niets af aan wat er voor de sprekers op het spel staat; de erkenning van hun inspanning om verantwoordelijkheid te nemen voor hun gezondheid, en uiteindelijk hun identiteit als een rationeel individu.

In een derde case study vergeleek ik *online gesprekken tussen patiënten met respectievelijk ADHD, diabetes en ALS (hoofdstuk 5)*. De vergelijking toonde dat de manier waarop patiënten gecertificeerde expertise behandelen, sterk afhangt van wat er voor hun ziekte op het spel staat. In de geanalyseerde gesprekken behandelen ADHD patiënten de gecertificeerde kennis van gezondheidsprofessionals met veel respect; deze zijn immers de poortwachters van hun aandoening, en daarmee belangrijk voor de legitimiteit ervan. Diabetespatiënten – wier ziekte vaak vooral zichtbaar wordt in het management van bloedsuikerwaarden, iets waarvoor patiënten elkaar ook verantwoordelijk houden—zijn juist kritisch ten aanzien van de kennis van gezondheidsprofessionals. Deze zouden vaak onvoldoende inzicht hebben in de geleefde werkelijkheid van hun ziekte, en daarmee niet begrijpen hoe moeilijk het is om bloedsuikerwaarden op peil te

houden. ALS patiënten – die elkaar verantwoordelijk houden voor positief denken, waarvan zelf onderzoek doen naar behandelingen deel uitmaakt – behandelen gecertificeerde experts als de laatsten die nog hoop kunnen bieden, in de vorm van experimentele behandelingen. Paradoxaal genoeg onderstrepen de ADHD patiënten in dit corpus vaak de ernst van hun aandoening, bijvoorbeeld door te wijzen op de noodzaak van medicatie, terwijl er in de interactie tussen ALS patiënten amper ruimte is om te klagen. Ik concludeer dat de manier waarop gespreksdeelnemers gecertificeerde expertise behandelen moeilijk te begrijpen valt zonder aandacht voor de identiteits- en verantwoordelijkheidsconcerns die relevant zijn voor het specifieke veld van expertise. Om deze reden is het belangrijk om voorzichtig te zijn met claims over het afnemende (of groeiende) gezag van expertise in het algemeen.

Dit proefschrift richt zich op gesprekken over ADHD als voorbeeld van een kennisveld waar de onderhandeling over expertise claims belangrijke gevolgen heeft voor het begrip van het zelf (zie *hoofdstuk 4*). Voor patiënten voorziet de diagnose van ADHD dikwijls in een verklaring voor gedragspatronen die anders moeilijk te verklaren zijn (het duidelijkste voorbeeld zijn uitspraken als: “Ik dacht dat ik lui/dom was, maar nu weet ik dat ik ADHD heb”). Maar deze verklaring blijft kwetsbaar, gezien de controverses rond de aandoening en het gebruik van medicatie dat daar dikwijls mee geassocieerd wordt. In de gesprekken die ik heb bestudeerd, vond ik verschillende manieren waarop ADHD patiënten en hun ouders de verklaring stabiel trachtten te houden.

Ten eerste, zoals hierboven aangegeven, tonen de gesprekken tussen ADHD patiënten doorgaans respect voor het gezag van de gecertificeerd expert of gezondheidsprofessional. Deze expert is immers een poortwachter voor de aandoening; hij of zij beschikt over de mogelijkheid om problemen te classificeren als ‘*doctorable*’ met de diagnose ADHD. Patiënten leggen de macht om positief te diagnosticeren consequent bij de professional, terwijl ze wel uitspraken doen over wat *geen* ADHD is (*hoofdstuk 5*).

Ten tweede behandelen ADHD patiënten individuele beslissingen over de ziekte alsof deze collectieve consequenties hebben. Wanneer, zoals getoond in de vergelijkende studie (*hoofdstuk 5*), een patiënt op een forum vertelt over haar besluit om te stoppen met medicatie, reageren de overige gespreksdeelnemers op dit besluit als een voorbeeld van onverantwoordelijkheid. De beslissing wordt behandeld alsof die afbreuk doet aan de serieuze aard van de aandoening, en

daarmee ook het leven van de andere patiënten beïnvloedt. Ironisch genoeg wordt een diagnose die een verklaring biedt voor de moeilijkheden van een individu om te functioneren in een collectief systeem (school, werk), zo een collectieve verantwoordelijkheid om in stand te houden.

Ten derde, en dit bouwt voort op het eerste punt, meten gespreksdeelnemers de kennis die ze claimen over ADHD zorgvuldig af. Uit een *analyse van Britse inbelprogramma's* (hoofdstuk 6) bleek dat moeders van kinderen met ADHD kennis claimen over de goede bedoelingen van hun kinderen, maar niet of slechts in zeer algemene termen over de ADHD-aspecten van hun gedrag. Zodra het problematische gedrag behandeld wordt als iets dat van buitenaf zichtbaar is, en voldoende wordt begrepen om door de moeder beschreven te kunnen worden, komt het ook binnen het epistemische bereik van andere leken. Deze kunnen het vervolgens simpel afdoen als 'gewone ongehoorzaamheid'. Om dergelijke reacties te voorkomen en een identiteit als goede moeder neer te zetten, kan het claimen van *geen of onvoldoende* kennis – en daarmee het ondersteunen van de expertise van beter gecertificeerde anderen – even belangrijk zijn als het *wel* claimen van kennis.

De diverse case studies laten zien dat sprekers moeite doen om niet over te komen als goedgelovig of naïef. *Zowel het claimen van wetenschappelijke of feitelijke expertise en het betwisten van het gezag ervan wanneer deze expertise door anderen wordt aangeboden zijn belangrijk om een kritische identiteit neer te zetten.* In de vergelijkende studie tussen ADHD, ALS en diabetes patiënten (hoofdstuk 5) geven ALS patiënten een verklaring wanneer ze onvoldoende onderzoek doen naar hun ziekte, wat suggereert dat het als normaal beschouwd wordt om dit wel te doen. In de analyse van de idiomatiche uitdrukking 'luister naar je lichaam' (hoofdstuk 3) zetten gespreksdeelnemers de uitdrukking in om hun persoonlijke gezondheidskeuzes te verbreden tot een algemener advies, zonder dit te hoeven onderbouwen met feitelijke bronnen. Ook hier geven sprekers een verklaring wanneer ze hun keus niet baseren op wetenschappelijke studies, wat suggereert dat dit de verwachte gang van zaken zou zijn. In de onderhandelingen over kennisclaims in inbelprogramma's (hoofdstuk 2) reageren sprekers beledigd wanneer er wordt gezegd dat ze ergens in geloven, en haasten zich om kennis in plaats van geloof te claimen. Samengevat; door de empirische cases heen

werken gespreksdeelnemers hard om te voldoen aan wat Hobson-West (2007: 212) “het morele imperatief om zich te informeren” noemde.

De bevindingen uit *hoofdstuk 4*, gebaseerd op *video opnames uit een Nederlands ADHD coachings centrum* vormen een interessant contrast met de twistgesprekken over kennis, die in de overige empirische hoofdstukken bijna alomtegenwoordig zijn. Hier maken coaches gebruik van ‘my side empathy formulations’, om een perspectief naar voren te brengen dat niet per se gekoppeld is aan de diagnose ADHD maar gericht op het vergroten van de handelingsvrijheid, en dat daarom vaak afwijkt van dat van hun cliënt. Om deze potentieel controversiële coachingsagenda naar voren te brengen presenteren coaches hun eigen fysieke gewaarwordingen als aanwijzing voor de innerlijke toestand van hun cliënt, en houden hun kennisclaims hiermee letterlijk dichtbij zichzelf. Terwijl de coaches vaak een beroep doen op neurowetenschappelijke kennis vermijden ze zorgvuldig om uitzonderlijke expertise te claimen, en deze combinatie helpt hen om hun doelen in het gesprek te bereiken.

De bevindingen in dit proefschrift hebben theoretische en praktische gevolgen voor het begrip van onderhandelingen over kennis en expertise. Conversatie analyse (CA) maakt zichtbaar hoe ‘het publiek’ geen uniform blok vormt tegen wetenschap of gecertificeerde expertise, maar *dat kennisclaims van belang zijn voor de manier waarop publieken elkaar onderling verantwoordelijk houden voor het volgen van grotendeels impliciete morele regels* (wat betekent het om een goede moeder of een goede patiënt te zijn, wat is verantwoordelijk gedrag). Het argument *dat* onderhandelingen over kennis sterk verweven zijn met de onderhandeling over morele regels is niet nieuw, maar CA is bijzonder geschikt om uit te vinden *hoe* deze onderhandelingen plaatsvinden in interactie. De aandacht voor volgtijdelijkheid in interactie geeft de methode unieke mogelijkheden om te helpen begrijpen wat er op het spel staat, anders dan kennis als zodanig. Dit kan bijdragen aan het inzicht waarom kennisclaims en het gezag van gecertificeerde expertise het ene moment tot verzet leiden, maar op andere momenten zonder vragen geaccepteerd worden of zelfs met enthousiasme omarmd.

Als het, zoals dit onderzoek suggereert, belangrijk is voor gespreksdeelnemers om hun kritische houding te demonstreren, heeft dit waarschijnlijk gevolgen voor de wijze waarop ze informatie ontvangen en behandelen. Terwijl

wetenschapscommunicatoren eraan gewend zijn om wantrouwen jegens wetenschap als het probleem te beschouwen, lijken gespreksdeelnemers het zelf juist als een interactioneel probleem te zien wanneer ze worden behandeld als goed van vertrouwen. *Het besef dat het belangrijk kan zijn voor de identiteit van interactanten om zichzelf te positioneren als epistemologisch waakzaam kan bijdragen aan de kwaliteit van wetenschap-samenleving interacties.*

Op basis van het voor dit proefschrift verrichte onderzoek stel ik dat, anders dan in de media vaak – en met name door wetenschappers (zie *hoofdstuk 7*) – wordt beweerd, wetenschap tegenwoordig *niet* ook maar een mening is. Die claim geldt in ieder geval niet voor de hier onderzochte onderwerpen en interacties. Integendeel; *dikwijls lijkt het alsof er gebrek is aan een taal waarin we kunnen praten over dat wat er toe doet, anders dan door het betwisten van feiten en kennisclaims.* In plaats van te blijven treuren over de vermeende degradatie van wetenschap tot ‘ook maar een mening’, lijkt het productiever te verkennen hoe we maatschappelijke problemen kunnen bespreken op een manier die ruimte overlaat voor andere waarden en kennisclaims, dan slechts via de symbolen van de wetenschap. In plaats van te rouwen om de dood van de waarheid, wordt het tijd om opnieuw na te denken over de gevolgen van ons noodzakelijkerwijs incomplete begrip van die waarheid.

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Acknowledgements

I thank the ADHD centre and all participants in the study, including those with who I have spoken for case studies which could not be pursued.

I would like to thank Hedwig for introducing me to a new perspective on the world; everyday talk will never sound the same again. I will fondly remember the conversations in which we discussed not merely the topics of this PhD-research, but literature and humanity in general. I thank Geoff not only for your always inspiring feedback, but also for the tremendously warm welcome I received in California. Whatever I expected from a PhD-research, I never dreamt it would involve climbing over fences to receive trampoline lessons.

Bas, Jonne, Melis, Olya, Sophie, David, Ching, May-Li; it was very nice to have you as fellow PhD-students, even if only for a short period of time. I thank Marianne for your help with procedures for ethical approval, and Erwin for being a wonderful colleague during the first year of my research. The WTMC graduate research school of Science, Technology and Modern Culture provided intellectual input and inspiration, for which I thank Teun Zuiderent-Jerak and Willem Halfman in particular, as well as my fellow graduate school students.

Maarten: it is great to work with you again. Thanks to you and the rest of the UFS team, in particular Peter and Jesse, for 're-enchanting science' and providing the sparks needed to finish this thesis. I thank Wim and Merel for being the most welcoming chief whips one could hope for, Dick for making the space in which questioning takes place and Peter-Ben for acting as chief advisory auntie. Casper: I'm afraid you endured the most stress from this thesis. Thank you for being there from California all the way to Sweden, and for the wonderful design of this booklet.

Jean-Léon Gérôme, 1896. La Vérité sortant du puits (Truth coming out of her well).