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“I just know”: exploring self-knowledge in chronic obstructive pulmonary disease

Veronika Williams¹ and Sara Ryan¹

ABSTRACT The importance of lay knowledge in health care settings, particularly in relation to long-term conditions, has received increasing attention over the past few decades. However, there remains some way to go before patients' experiential or self-knowledge forms part of current clinical decision making and care provision. Chronic obstructive pulmonary disease (COPD) is a chronic respiratory condition which affects people on a daily basis. People living with this condition develop experiential knowledge about their symptoms and are, arguably, best placed to assess these and treat any acute worsening of their condition accordingly. Here we explore how people with COPD articulate their knowledge and make sense of it within the context of their everyday lives. We re-analysed data from a qualitative interview-based study with 44 participants living with moderate to severe COPD using a grounded theory approach. We found that participants focused their attention on symptoms and sensations of the chest while developing an embodied self-awareness that allowed them to assess whether they were experiencing an acute worsening of their condition. Participants appeared confident in using this self-knowledge to distinguish such acute flare ups from the daily variability of their condition, described as good days and bad days. We suggest that people with COPD are very attuned to their bodies despite the vagueness and sometimes seemingly unrelated nature of their symptoms and signs. We argue that self-knowledge should be acknowledged as valid and meaningful by both patients and clinicians. This is particularly important because of the clinical uncertainty about the precise onset and presentation of acute exacerbations in COPD.

¹ University of Oxford, Nuffield Department of Primary Care Health Sciences, Radcliffe Observatory Quarter, Oxford, UK Correspondence: (e-mail: veronika.williams@phc.ox.ac.uk)

Introduction

The importance of “experiential” as opposed to “expert” knowledge has gained increasing attention within the UK National Health Service over the past few decades, particularly in the care of people living with long-term conditions (Popay and Williams, 1996; Williams and Calnan, 1996; Greenhalgh, 2009; Pickard and Rogers, 2012; Garthwaite and Bambra, 2017). This is reflected in current policy initiatives such as the Department of Health’s “expert patient” programme (Tattersall, 2002) and state sponsored self-management programmes, such as Expert Patients Programme (EPP), which actively encourage health care professionals to take patients’ experience into account (DoH, 2001).

These programmes are not without challenge. For example, Greenhalgh (2009) argued that “it is time to move beyond expert patient programmes and embrace richer, more holistic models which consider a person’s family, social and political context” (631). Pickard and Rogers (2012) turn a critical lens on the EPP and highlight how it valorises cognitive practices and rationality as well as the limitations it offers for patients with co-morbidities. These authors discuss the everyday practices of chronic illness work emphasising interactions between patients, their bodies, symptoms and the context of their everyday lives. One outcome of this everyday day work is the development and production of experiential knowledge.

There is a large body of research within medical sociology exploring the concept of lay knowledge of health and illness (Blaxter, 1983; Popay and Williams, 1996; Prior, 2003) and how this fits within the epidemiological model of disease. Caron-Flinterman and colleagues (2005) found evidence of the concrete use of patients’ experiential knowledge but conclude that a more structural and interactive approach to patient participation is needed. This is further supported by Greenhalgh (2009) who argues that the evidence base for efficacy of the expert patient model remains weak. Britten and Maguire (2016) recently discussed how lay knowledge is taken more seriously now but argue that this is an outcome of social movements and social action rather than advocacy by clinicians. They conclude that we still have a way to go to promote the validity of lay knowledge in medical decision-making.

One of the difficulties in positioning self-knowledge as “valid” knowledge in health care is that the concept of validity sits within a positivist paradigm while embodied knowledge sits within an interpretivist paradigm. The “rules” of validity are not applicable to knowledge derived from the subjective knowing of one’s body (Mol and Law, 2004; Conrad and Barker, 2010). Yet, as Mol and Law (2004) argue, we all *have* and *are* a body (45) and therefore it is important to consider both the body that is objectively assessed by clinicians, and the body that we know ourselves by being self-aware.

In addition, it has been argued that experiential knowledge gained through “personal or bodily experience” can play a significant role in biomedical research where knowledge acquisition tends to focus on propositional or procedural knowledge acquired through communication and practice of skill (Caron-Flinterman *et al.*, 2005). However, to effectively integrate patients’ self-knowledge to provide both patient centered care and contribute to research it is pertinent for us to understand how such experiential knowledge is acquired, understood and applied over the chronic illness trajectory (Pickard and Rogers, 2012).

Chronic obstructive pulmonary disease (COPD) is a chronic, incurable respiratory condition which affects approximately 8% of the UK adult population (over 3 million people) and can have a serious impact on people’s lives (Mannino *et al.*, 2014). Symptoms include breathlessness, particularly on exertion, chronic cough and fatigue. COPD cannot be cured, deteriorates

over time and is marked by acute exacerbations, often linked to chest infections, which increase mortality risk and further reduce quality of life (Celli *et al.*, 2004). Clinical management aims at maintaining people’s independence and reducing the impact of symptoms. It is therefore crucial that any acute deterioration such as exacerbations are identified and treated promptly in order to minimise mortality risk and further functional decline (NICE, 2010).

Among clinicians there is no consensus on how such exacerbations are identified, however most agree that these are related to a significant deterioration of at least two major respiratory symptoms, a change in medication and/or contact with health care services (Aaron, 2014; Pauwels *et al.*, 2004) compared with people’s normal health status. Since people living with COPD are arguably most knowledgeable about their symptoms and any variation of these, both during stable and acute phases of their condition, it seems imperative that we seek to understand both their experience and knowledge of their symptoms, and how they articulate these.

We previously reported the clinical impact of such self-knowledge in relation to identifying, managing and treating exacerbations in COPD (Williams *et al.*, 2014). Based on these previously published findings we undertook further analyses on how people with COPD articulate such self-knowledge and this forms the focus of this article.

Methods

The study from which the data was produced took place over 18 months during 2012–14. Ethical approval was obtained from South Central Berkshire Research Ethics Committee (ref 12/SC/0437) and Research Governance was granted by Oxford Health NHS Foundation Trust and Oxford University Hospitals NHS Trust. All names were changed to ensure anonymity of participants.

Participants were recruited as part of a clinical trial (including pilot trial) (Farmer *et al.*, 2017) evaluating the effectiveness of a digital health intervention supporting self-management in COPD. A qualitative, interview based study was conducted to explore participants’ understanding and experience of living with and managing their condition at home, and how such an intervention might influence their self-management. Participants were interviewed twice. The first interview focused on the experience of everyday symptoms of COPD and how acute flare-ups were recognised and treated (please see appendix 1 for the topic guide). The second interview, conducted 12 months later, focused on the impact of using the digital health intervention (appendix 2). Our focus here is on the data generated during the first set of interviews as we explored how patients communicate self-knowledge within a space where medical language dominates.

All participants gave written consent when initially entering the trial and this was confirmed immediately before the interview.

Participant recruitment. Participants were identified and recruited from hospital admission records, pulmonary rehabilitation programmes and general practice by a respiratory research nurse. Participants in the interview study were recruited from the trial sample using purposeful sampling strategies, whereby initially patients with different backgrounds (such as age, gender, COPD severity, length of diagnosis, frequency and number of exacerbations) were invited to represent the variety of characteristics found within the sampled population. Theoretical sampling strategies were subsequently used to recruit participants with particular characteristics to further explore emerging findings. Sampling continued until data saturation was achieved.

Data collection. Data were generated through two in-depth interviews over one year for each participant conducted at participants’ homes by the first author. A semi-structured topic guide was used and questions focused on how patients experienced living with COPD and their understanding of symptoms, both during stable and acute phases of their condition. Interviews lasted between 20 and 55 min. Field notes were recorded immediately after the interview to provide context and aid the analytical process.

Data analysis. Interviews were audio-recorded, transcribed verbatim and anonymised transcripts were imported into NVIVO 10 (qualitative software data programme) to facilitate storage, organisation and analysis of data. Our initial methods of analysis using grounded theory (including constant comparative method, open, axial and focused coding and memo-writing) have been published elsewhere (Williams *et al.*, 2014). Our re-analysis focused specifically on how participants

articulated their self-knowledge in relation to their bodily experience and its context within their everyday lives. We used open, axial and focused coding and memo-writing to identify theoretical links and concepts from the data (Charmaz, 2006).

To ensure rigour two interviews were independently coded by (second author) and part of the analysis was conducted together to further refine theoretical concepts. Both of these processes increased the transparency and credibility of our findings.

Findings

In total, 44 participants were recruited to the interview study and the characteristics of patients are provided in Table 1.

Here we focus on how people living with COPD use their experiential self-knowledge to understand and make sense of their symptoms, both on “good” and “bad” days and during acute exacerbations. Participants described their experience of their symptoms and how they knew their condition was getting worse.

Understanding of bodily symptoms: the chest is telling. Bodily symptoms discussed mainly related to how participants’ chest and breathing were felt. Participants described these sensations referring to pain, soreness, tightness and heavy pressure in their chest affecting their breathing.

Peter, who has been living with severe COPD for over 7 years, explained how he experienced his breathlessness and how he has developed his own understanding of his changing symptoms:

When it starts hurting, when I start breathing even shallowly like that, I can feel it twinge-ing. Yes...I would say it hurting, when I start breathing even shallowly like that, I can feel pain as such but it starts feeling, see just across there, it starts feeling a bit sore there [points at chest with hand]

Similarly, other participants, who lived with severe or very severe COPD for a number of years, also referred to sensations of their chest when talking about how they knew their condition was getting worse:

[I know] straight away... my chest starts burning
Your chest gets tight
I start to feel, feel unwell and I can feel the weight on my chest

Here, the chest takes on a central feature in participants’ self-knowledge whereby their chest is “telling them” how their condition is progressing. Interestingly participants referred to their respiratory system as their chest focusing on the outer part of the body that contains the respiratory system. Yet clinicians

and medical science would focus on the lungs as the organ that facilitates the gas exchange that permits breathing. The chest not only represents a larger and visual representation of the respiratory system but also encompasses other sensations such as pain across the upper torso. Philip, who was diagnosed with moderate COPD 5 years ago explained “I get a pain in the back of my neck” when experiencing exacerbations, pointing towards his upper chest and back.

Participants also referred to sensations relating to audio-receptive and taste senses which helped them understand any changes in their condition. Descriptions such as “rattling” sounds of the chest were common. Alison explained “I can get all this rattling on my chest”. Others, such as Peter talked about foul tasting sputum that developed when he would have to “start coughing up a bit of phlegm and that and it tastes vile and then I know I’m getting an infection”.

Embodied self-awareness: Just knowing. Although participants presented their chest as the main part of their body which generates important signs about their respiratory condition, they also referred to a general embodied feeling that their condition was acutely deteriorating into an acute flare up, rather than what they would describe as a “bad” day. This was articulated as “just knowing”; participants knew they were deteriorating without relating to this knowing to a specific symptom. Mark, for example, who has been living with COPD for nearly two decades explained “you always know” when experiencing an exacerbation.

This knowing is more akin to instinct or intuition, two concepts that rarely feature within biomedicine and yet participants appear to be comfortable with this individualised, embodied knowing and do not try to articulate it in more medically relevant terms. As Maria, who was using long-term oxygen therapy at home and had been living with severe COPD for over 8 years, said “You know, in your own body what’s right or wrong”. Participants were aware that no objective signs or markers for their deterioration were present but nonetheless *knew* that they were experiencing an exacerbation:

I knew I was deteriorating but didn’t have a cold. And didn’t really have [um] too much of a, very pale yellow phlegm. But I knew I was going down (Betty, 77 years old and living with moderate COPD for over 4 years)

It’s just that I’m feeling, feeling really bad in myself, and I know I’m not right then (John, 67 years old, living with very severe COPD for over 5 years)

A few participants linked certain bodily signs to deterioration although these were, at least at first sight, unrelated to their respiratory condition. For example, Vishaka, talked about how she would often have a fever when she had an acute flare up of her COPD. She did not refer to any worsening of her breathing or other respiratory symptoms but focused on the bodily sensations of having an increased body temperature:

I know it sounds silly but when Ier respiratory symptoms but focused on the bodily sensations of having an increased body tempe I know

Vishaka uses metaphor to describe the feeling she has along her spine. She brings her lay knowledge and understanding to illustrate and explain how she feels. Philip uses “bit funny” to explain the unusual sensation he experiences in his neck and the “trapped wind” in his lungs when his COPD worsened: “... my neck started to feel a bit funny and I, oh I know I tend to burp a lot. There a lot, there seems to be a lot of wind trapped in my

Table 1 | Patient characteristics

	<i>Number of patients</i>
Sex (male/female)	27/17
Age (years, mean; range)	71; 55-85
<i>Severity of COPD (GOLD)</i>	
GOLD stage II	14
GOLD stage III	21
GOLD stage IV	9
Duration of symptoms (years; range)	1->25
Home oxygen use	11
Previous attendance of pulmonary rehabilitation programme	33
Living set up	
Living with spouse/ family	29
Living alone	15

lungs. [um] Those are the two things that always seem to happen just beforehand”

Participants also described how changes in their everyday practices could alert them, or those close to them, to an acute episode. These include changes in appetite for food and drink and could involve interventions from other people. Sue explained that she “really [doesn’t] want to eat anything.” Edward goes off drinking beer. He described how his friends notice this and remarked: “What’s up with you? What up with you? You’ve been on about an hour and a half on that pint” Edward explained he “just couldn’t drink it”.

Understanding “good” and “bad days”: self-knowledge of variability. Participants were able to identify acute worsening of their condition, as we illustrated in the previous section, and were also aware of the day to day variability of their symptoms which would not necessarily require additional medical treatment or contact with health services. These “bad” days were distinguished from “good” days as participants explained that these often improved within a matter of hours or from one day to the next, rather than presenting an acute deterioration leading to an exacerbation which would last for a week or more. Dorothy, Martha, Sue and Raymond all of whom were living with moderate to severe COPD for a number of years, described this variability of their symptoms or overall well-being in terms of good and bad days:

one day I [would] be not be so good and then another day I could be a bit better.

I’m not very good in the afternoon. I get worse in the afternoon. I’m better in the mornings definitely, and I can do a lot more in the mornings. When it gets to the afternoons I’m not quite as good.

Some days I’m a lot, a lot better.... some days I don’t do hardly anything

You know, it comes and goes, you know, you can have your good days and you can have your bad days.

These descriptions capture the everyday practices, or work, of chronic disease management as people relate them to times of the day and being able to “do” things. Again, there is no attempt to medicalise these experiences, instead they are talked about in lay terms.

Participants perceived “bad” days as interruptions to everyday life and functional ability, as Lisa, Lily and Violet described:

And some days I’m worse than others and I say, “Oh go and take the cover off the scooter for me”, because I just feel I can’t do it you know?

Some days I do things without thinking that another day I might have to think, “Well, have I really go to go all the way up the stairs to fetch my book?” You know...And sometimes I just go and do it without thinking.. So, yes, it’s, some ...some days I’m better than others

Some days I have good days, some days I have not so good days...I tend to give in to the bad days and stay in bed and the good days they, they, then I’m a maniac because I go round doing things

These examples illustrate how participants relate the variable and varying limitations they experience to everyday practices; getting the scooter, fetching a book and, again, “doing things”. Within their lives, their chronic condition relates less to biomedicine and more to the everyday and the fluctuating ability of their bodies to do every day activities.

Discussion

We previously highlighted (Williams *et al.*, 2014) how people with COPD use both objective “visible” symptoms and subjective “invisible” symptoms to understand and identify when they are experience an acute worsening of their condition. Here we further develop the importance of self-knowledge in COPD by identifying how participants possess both knowledge of their respiratory symptoms, particularly in relation to their chest and develop an embodied understanding of their overall well-being over time. Most importantly we found that participants felt confident in identifying acute worsening of their condition by focusing on non-clinical signs, using lay language, and trusting their own instinct by simply “knowing”.

A survey of patients with COPD (Barr *et al.*, 2009) found that despite participants living with COPD symptoms and 41% of the sample reporting previous hospitalisation for COPD exacerbation, patients’ “self-knowledge” of COPD was poor. Yet the authors focused on biomedical knowledge such as spirometry test results rather than participants’ experiential knowledge of the variability of symptoms and related outcomes. The value of knowing biomedical values and diagnostic test results are important since we know that there is a lack of knowledge amongst people with COPD with regard to their diagnosis and cause of COPD (although we could argue that this relates to issues around clinical communication and information giving rather than a lack of understanding). However, the self-knowledge people with COPD need to manage everyday life, gained through interaction with their own bodies, others, spaces and objects, such as mobility aids, is more meaningful to people who are required to use such knowledge in identifying early signs of worsening symptoms, distinguish these from everyday variabilities, such as good and bad days, and treat them accordingly.

People living with COPD experience disruption on an ongoing basis as they move through good days (with minimal disruption) and bad days (intensive intrusion of illness) to acute crises, such as exacerbations (Charmaz, 1991). Our findings show that participants position their illness within their everyday day lives and use their self-knowledge to judge the severity of their symptoms. Immersion in their condition (Charmaz, 1991) means that people with COPD are reminded daily of their condition and its impact on their lives, independence and relationships, however, it also enables participants to gain experiential knowledge of the trajectory of their illness, recognise subtle changes in their otherwise ever present symptoms such as breathlessness and thus allow them to use this self-knowledge of their bodies to identify acute worsening of their condition. “Knowing as practice” as described by Pickard and Rogers (2012), where patients integrate different types of knowledge, including biomedical and self-knowledge, is essential to effective self-management of long-term conditions in primary care. Furthermore, our analysis highlights how patients with COPD feel at ease using their own language to describe in detail what it happening to their bodies, both in terms of symptoms linked to their respiratory system such as chest sensations, and a sense of “just knowing”. Simon *et al.* (2016) explored patients’ self-management strategies for episodic breathlessness and concluded that patients need individualised support tailored by their own experiences. We argue that people are very attuned to their bodies despite the vagueness and sometimes seemingly unrelated symptoms and signs they experience, and this is further supported by research into people’s experience of hypoglycaemia in diabetes (Mol and Law, 2004).

Given the uncertainty both clinicians and patients can feel in diagnosing exacerbations (Burge and Wedzicha, 2003; Bailey *et al.*, 2004; Pauwels *et al.*, 2004) and the importance of prompt

treatment with antibiotics to avoid hospitalisation (NICE, 2010), both biomedical and lay knowledge should be used in clinical decision making processes. Patients' self-knowledge needs to form an integral part of the democratic relationship between health care professionals and patients whereby the *validity* of such knowledge is not judged by positivist assumptions of scientific assessment but self-awareness and knowledge is viewed as what it is: the subjective assessment of one's own body. We need to focus less on reliability and validity and, instead, explore how patients *gain* such knowledge as this may reveal the path by which patients make decisions about identifying acute exacerbations in COPD and thus add to effective self-management.

Conclusion

Self-knowledge frames how people with COPD experience and articulate exacerbations of their condition and these are positioned within the context of their everyday life. People living with a long-term condition such as COPD develop an embodied understanding of their symptoms which allows them to "just know" when their condition deteriorates. In the absence of definitive markers identifying exacerbations of COPD and given the differences in patient experiences of such acute and recurrent flare ups, it is crucial that both health care professionals and patients feel enabled and empowered to use patients' self-knowledge alongside biomedical knowledge to identify and understand deterioration in COPD. Thus both patients and health care professionals need to feel assured that patients' self-knowledge in COPD is important, meaningful and valuable in identifying exacerbations and distinguishing these from the variability of good and bad days.

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Data availability

All data analysed or generated in this study are cited and included in the paper.

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