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**Opening up dialogues and airways: using vignettes to enrich** 

# asthma understandings in sport and exercise

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# Opening up dialogues and airways: using vignettes to enrich asthma understandings in exercise participants

This article explores the lived experience of asthma in a specific population of sport and exercise participants, drawing on an approach currently under-utilised in studies of asthma: vignettes. These were used as an elicitation technique in research with19 frequent exercisers and sports participants with asthma, eight of whom responded to vignettes. We describe and evaluate this approach as deployed in relation to a phenomenological study of the lived experience of asthma, and consider how employing vignette-based research can encourage people with asthma to reflect critically on their experiences and ways of being-in-the-world. This was found to be a powerful way of challenging taken-for-granted assumptions, and stimulating consideration of behaviour change. The findings we report here cohere around two principal themes that emerged as salient: 1) somatic empathy; and 2) the power of sharing stories and opening up dialogues. Understanding the complexity of asthma experiences can, we argue, be of great practical value both to those with asthma and also to healthcare and exercise professionals in tailoring more effective treatments.

Keywords: asthma; exercise participants; phenomenology; vignettes

#### Introduction

The World Health Organization (WHO 2014) identifies asthma as a global health concern, affecting around 334 million people in the world. Exact numbers and prevalence are difficult to determine, given the lack of an agreed diagnostic test, differing classification methods and symptom interpretation (Monaghan and Gabe 2015). Asthma is generally characterised by a myriad of different symptoms that include cough, wheeze, chest tightness and breathlessness, primarily caused by the

inflammation of the airways (McArdle et al. 2007), but symptoms vary greatly between individuals. Symptoms are typically classified by clinicians as ranging from mild and intermittent through to severe and life-threatening (e.g. British Thoracic Society and Scottish Intercollegiate Guidelines Network 2012). Research indicates that poor asthma self-care and self-management are responsible for exacerbating symptoms, and contributing to asthma attacks, asthmadeaths (Royal College of Physicians 2014), and asthma-related conditions (Denford et al. 2013). In the UK, the Royal College of Physicians (RCP 2014) published the results of a confidential enquiry, the largest undertaken worldwideThe aim of the review was to understand the circumstances surrounding asthma deaths in the UK, to identify avoidable factors and make recommendations to improve care and reduce the number of deaths. The report suggests that many asthma deaths could be prevented by better self-care. Other global research similarly indicates that with better treatment asthma attacks are preventable (Global Initiative for Asthma 2009). The Foreword to the NRAD (2014: 4) raises an important question for medical practitioners: 'If our patients do not always take medication as we advise, is that their fault or our failure to involve them in a process of shared decision making?' This article explores a means by which people with asthma might (if they so wish) have a greater input into shared decision-making about their own treatment, by encouraging the communication of the lived experience of asthma. We focus here specifically upon a research project with frequent exercisers suffering from asthma; those who had participated in sport or moderate to vigorous exercise at least twice per week for a minimum of 12 months prior to participation in the study.

Participating in exercise - and physical activity generally - can constitute a double-edged sword for people with asthma; whilst it is often prescribed as a way of strengthening the cardiovascular system and improving lung function (Ram *et al.* 2005),

exercise can be problematic (Owton and Allen-Collinson 2014, Owton *et al.* 2015). Around 80%-90% of asthma sufferers experience exercise-induced asthma (EIA) (McArcle *et al.* 2007) also termed exercise-induced bronchoconstriction (EIB). EIA/EIB is a condition in which moderate to vigorous physical activity triggers acute airway narrowing in people with heightened airway reactivity (McFadden Jr. and Gilbert 1994), often producing coughing, wheezing, tightness of the chest and breathlessness. To date, there has been relatively little qualitative research on asthma experiences in exercise participants (Allen-Collinson and Owton 2014; Owton and Allen-Collinson 2014), and it is important to understand this group's experiences of their condition, particularly for the purpose of healthcare and exercise consultations, decision-making and the tailoring of effective treatment options.

In recent years, there have been increasing calls for a phenomenology of the embodied subject in the age of evidence-based medicine (EBM), and a new phenomenology of medicine (Goldenberg 2010) that brings together the best of EBM and of patient-centred care (Lacy and Backer 2008). This work develops Husserl's (1989) phenomenological quest (see below) to synthesize science with the life-world (the everyday world of immediate experience). Despite offering much promise, as Goldenberg (2010) argues, the early forms of medical phenomenology were somewhat weak on the issue of embodiment, and consequently a problematic 'absent body' (Leder 1990) often tacitly operated. As we argue below, combining sociological insights and those of existential phenomenology, with its strong focus on embodiment, can provide us with a potent theoretical and methodological framework (Allen-Collinson 2009, 2011, 2012) for investigating the lived experience of asthma (Allen-Collinson and Owton 2014, Owton and Allen-Collinson 2014) and other chronic illnesses (Allen-Collinson and Pavey 2014). Taking account of a person's embodied experience and

somatic ways of knowing - often developed over a considerable period of time – and integrating this experiential knowledge with the professional knowledge of health and exercise specialists, offers a powerful synthesis. This combination can be used to develop better treatment modalities for those with asthma, which are individually tailored, relevant and workable within people's own life-worlds.

As background to our study, we note that although asthma healthcare provision has generally improved in advanced industrial societies, morbidity remains high (WHO 2014). Differences between medical and patient understandings of asthma can make asthma patients sceptical about the efficacy of treatments, and reluctant to take medication when asymptomatic (Choi *et al.* 2008), thus influencing adherence/nonadherence to prescribed treatments. Efforts are being made to enhance the management and clinical care of patients with asthma. The UK's national guidelines (NICE 2013), for example, encourage the provision to patients of written Personal Asthma Action Plans (PAAPs), inhaler technique training and structured annual reviews. Further to improve treatment options and health outcomes for people with asthma, including those committed to exercise and sport participation, there is also a need to understand asthma from the perspective of those who live it (Owton *et al.* 2015). A narrative-based approach has been suggested as one way forward.

#### Narrative and vignette approaches in healthcare

Advocates of the narrative approach in healthcare (for example, Frank 1995, Bochner 2001, Charon 2006, Carless and Douglas, 2008, Lewis 2011, Sparkes and Smith 2011) argue that investigating people's lived illness experience can bridge what may be very different understandings of asthma held by patients and clinicians. Debates about what constitutes a narrative approach, narrative methods or illness narratives (e.g. Smith and

Sparkes 2012), continue, as do debates about the methodological merits and limitations of research on/with patient narratives (e.g., Atkinson and Delamont 2006). It falls outside the remit of this particular article to discuss the merits and demerits of narrative research and narratology per se; here we are specifically interested in critically examining a form of narrative, the vignette. This, we argue, is one means of allowing 'stories to breathe' and exploring how they can inform our lives (Frank 2010; Owton 2012, 2013). Amongst other things, we were interested in developing ways to encourage greater patient involvement and voice in the doctor-patient decision-making process, encouraging a co-production of PAAPs between General Practitioners (GPs) and/or respiratory nurse specialists and sport/exercise participants. One such way of encouraging individuals to give voice to their own experiences of asthma involves using the narratives of other asthma sufferers recounting their lived experience via vignettebased research. A vignette (French for 'a little vine') is a hypothetical scenario with fictional characters, which may be based on data derived from actual participants' accounts. The vignette usually provides sufficient context and information for participants to have an understanding of the scenario being depicted, but needs to be vague in ways that encourage participants to fill in the detail (Braun and Clarke 2013, Sparkes and Smith 2014). Vignettes have been used in a range of health research, including the investigation of attitudes toward complex public health issues (Jackson et al. 2015), as well as understandings of illness symptoms (Oberoi et al. 2015), and the impact of sociological variables such as age and ethnicity upon lived experiences of illness (Higginbottom 2006). They have also been found to assist health professionals in identifying and understanding how people's asthma narratives may be helping or hindering positive healthcare behaviours and self-management (Owton et al. 2015).

The remainder of this article is structured as follows. We first describe our theoretical framework of sociological phenomenology, followed by the research project itself, before presenting the findings of the project, cohering around two key themes that emerged as highly salient: 1) somatic empathy; and 2) the power of sharing stories.

#### Sociological phenomenology and lived illness experience

Developed from the work of the philosopher, Edmund Husserl, modern phenomenology is a philosophical movement centred on the scholarly study of phenomena, things as they present themselves to our consciousness. Phenomenology nowadays comprises a complex array of different traditions (see Allen-Collinson 2009). In general, however, it examines lived experience (Erlebnis), to identify structures or patterns of experience via the phenomenological method, which employs the techniques of epochē and reduction. The phenomenological epochē requires researchers temporarily to bracket, or stand aside from the 'natural attitude', our everyday, common-sense ways of being and thinking. Thus, researchers seek to identify existing beliefs and presuppositions enveloping a particular phenomenon, in order to reduce it to its essence, or core element(s).. Phenomenology and sociology both share a commitment to challenging the 'natural attitude' of everyday life and to uncovering taken-for-granted assumptions, including those of science and medicine. Of direct relevance to research in sport, exercise and health, existential phenomenology focuses attention upon the lived body, der Leib; the sentient, sensible, directly lived and experienced body. This stands in contrast to das Körper, the object body, the objectified and reified body evident in many bio-medical and sport science accounts (e.g. Chimenti et al. 2009, Mickleborough et al. 2001)

Adapting Husserl's ideas, existential phenomenologists such as de Beauvoir (1972) and Merleau-Ponty (2001) highlighted the centrality of the body in our being-inthe-world (*Dasein*). Departing from its original philosophical base, a form of empirical phenomenology has been utilised within social science research, including in health studies (e.g. Allen-Collinson and Pavey 2014, Svenaeus 2015) as well as in exercise contexts (Allen-Collinson 2012, Crust *et al.* 2014). In North America, the development of sociological phenomenology can be argued to originate with the pragmatist work of Dewey (1980 [1934]). Subsequently, Schütz (1967) synthesised aspects of Husserl's thinking with Weberian interpretive sociology, to create what has been termed phenomenological sociology (Wagner 1973, Allen-Collinson 2009). Phenomenological sociologists acknowledge the social-structural and historically-located specificity of embodiment and corporeal ways of knowing, thus departing from philosophical phenomenology's quest for universal *essences* of experience.

Phenomenology promotes the recognition and analysis of differences between the immediate lived experience of illness, and the putatively objective scientific and medical conceptualisation of illness as a disease state or set of symptoms. It focuses attention and reflection on the epistemological space in between these two perspectives. The lived body of a sportsperson or exerciser with asthma may thus be analytically contrasted with the asthma body-as-object (*Körper*) of scientific and biomedical inquiry, particularly as this latter construction is often accorded pre-eminence due to the dominance of biomedical and scientific discourses. Understanding the phenomena of health and illness in all their richness and complexity can be of enormous practical value to healthcare professionals in improving doctor-patient interactional processes (see for example, Denford *et al.* 2013). Furthermore, combining 'objective' health parameters, such as spirometry results, with patients' accounts of their lived experience of wellbeing,

provides healthcare professionals with important information (Carel 2011), particularly as empirical evidence shows that 'objective' assessments of health and wellbeing are poor predictors of subjective wellbeing (Angner 2009, 508). Eliciting accounts of the direct experience of asthma as lived in the body can help health professionals understand, for example, why people may not always undertake prescribed exercise and/or other treatment in the ways (or indeed at all) they are advised. Exploring and developing different understandings can help health professionals and patients work together to co-construct PAAPs that are meaningful and achievable within the patient's own specific circumstances and life-world. Eliciting the reflections of asthma patients on their lived experiences and thus developing new understandings of how they live with asthma lay at the core of the research project we now describe.

# The research project

The project reported here constitutes part of a wider programme of research on the lived experience of asthma and sporting/exercise embodiment, undertaken by a multidisciplinary team, based at two UK universities, and led by Jacquelyn. The current project was supported by a small grant from the University of Lincoln, from which ethical approval was granted by the appropriate University Ethics Committee. Informed written consent was obtained from all participants by Helen, who undertook the majority of the data collection. The research team comprised academic staff, including an academic GP, and was undertaken in the East Midlands region of England. The overarching theoretical and methodological framework for the project was sociological phenomenology (Allen-Collinson 2009, 2011).

#### Sampling and recruitment

Purposive, criteria-based sampling (Sparkes and Smith 2014) was utilised in order to select 19 individuals with asthma for the main, overarching study. Criteria for selection were: 1) self-definition as someone with asthma; 2) having been clinically diagnosed as having asthma; 3) participating in moderate to vigorous exercise/sport at least twice per week for at least 12 months prior to participation in the study. Via these criteria, we sought participants who were familiar with the lived experience of both asthma and sporting/exercise embodiment, commensurate with our phenomenological perspective. Participants were then recruited by Helen via a process of convenience and snowballing sampling through her social networks, including a University-community engagement network and via social media channels. Participants were interviewed in a location of their choice (including cafés, a library, hotel lobbies); a place that was convenient, comfortable, and helped put interviewees at ease whilst affording some privacy, as we wanted to ensure confidentiality of discussions. Participant information sheets and informed consent forms were approved by Jacquelyn's University Department's Ethics Committee. These were circulated in advance to all interviewees in order to explain, inter alia, the rationale and purpose of the research, the nature of participation involved, procedures relating to confidentiality of data and anonymity of participants, the ways in which data would be recorded, stored and utilised, and their right to withdraw from the study at any point prior to publication of the findings...

#### In-depth interviews

Following the recruitment process, a total of 19 semi-structured, in-depth interviews was undertaken by Helen between July 2014 and March 2015, with each digitally-recorded interview lasting between 30 and 100 minutes. The interviewer adopted an open, conversational approach, allowing the interviews to become more interviewee

orientated, commensurate with the phenomenological approach (Allen-Collinson 2009, Crust *et al.* 2014). Questions were open-ended, asking for example: 'Can you tell me about the history of your asthma?'; Can you tell me a little bit about the first time you started running (or whatever the sporting/exercise activity), what that was like for your asthma? During the interviews, respondents were asked whether they would be interested in participating in a further stage of the research: reading and responding to vignettes. Out of 19 participants, eight participants responded positively that they wished to engaged in this second phase. It is upon this vignette stage of the research that we focus the remainder of the article, and from which the data are drawn. Details of these eight participants are provided in Table 1 below.

#### Table 1 here

#### Vignette-based research

As noted above, vignettes usually provide sufficient context and information for participants to have an understanding of the scenario being depicted, but remain vague in ways that encourage participants to imagine further detail (Braun and Clarke 2013). Participants are usually asked to respond to questions about the vignette(s), for example, how they themselves would react to the scenario depicted, and in the case of our own research, whether the situations and characters portrayed resonated with respondents' own lived experience, their attitudes, perceptions, beliefs and behaviours. Vignettes are often used as elicitation tools in individual and group interviews (Sparkes and Smith 2014), to generate 'talk data' (Barter and Renold 1999; Braun and Clarke 2013). As Frank (2012) notes, vignettes can provide a powerful form of representation in health and illness studies, and may help people acknowledge needing to employ different narratives in coping with their illness.

In the earlier interview-based asthma research (Owton and Allen-Collinson 2014), we sought to show how transforming interview data into vignettes can be used as a way of resonating with others' experiences – both those with and without asthma – to give a feel for how asthma is lived in everday life. This type of approach, as Smith et al. (2013) argue, can provide an evidence-based resource, to generate a better understanding of the embodied psycho-social worlds of other people (see also Smith 2013, Smith et al. 2015). In the current research project, vignettes were created from a typology grounded in a detailed, thematic analysis of the interview data from the initial asthma study. The tripartite typology that emerged from the latter comprised the following types: contesters, conformers and creators (described below). Commensurate with our phenomenological perspective, we strongly emphasize the fluidity and contextdependency of these three types. The purpose of the typology was to be useful as a heuristic framework to assist healthcare professionals and others in understanding asthma experiences, and thus potentially developing more appropriate and effective care regimes. More detailed accounts of the typology and the original vignettes generated can be found in Owton and Allen-Collinson (2014), but in brief the typology comprised the following 'types' of asthma patient.

**Conformers** seek control and predictability of asthma symptoms via reliance upon a medical regime, particularly through the use of steroid inhalers that allow them to continue with their everyday sporting/exercising lives. This mode of being-in-the-world has analogies with Frank's (1995) concept of the 'disciplined body'. Conformers generally 'manage' their asthma and its corporeal and biographical consequences by adopting a narrative along the lines of: 'A moment ago I could breathe, now I'm having difficulty, but in a moment I'll be able to breathe again.'

**Contesters** tend to demonstrate a fighter attitude, contructing narrative accounts that portray 'beating asthma', 'overcoming asthma', drawing on language that connotes fighting, attacking, battling, and struggling. Asthma is perceived as an attack on these participants' sense of self, often leading to anger and frustration. Contesters may engage in risk-taking behaviour that at times jeopardizes or compromises their health.

**Creators** generally adopt a long-term approach towards managing their asthma, and are noted for taking responsibility for their asthma (see also Monaghan and Gabe 2015). Creators may perceive asthma as a learning experience involving a process of listening to their bodies as a source of valuable information, which develops 'somatic knowledge' (Allen-Collinson and Hockey 2016) in an attempt actively to manage their asthma, sometimes via alternative and complementary remedies and therapies. Commensurate with Frank's (1995) 'comunicative body-self', creators appear highly associated with their bodies. They undertake various forms of 'somatic work' (Vannini *et al.* 2012, Allen-Collinson and Owton 2014) in relation to body and environment, and actively seek out support and advice when needed. Somatic work has been defined by Vannini *et al.* (2012: 19) as the range of linguistic and alinguistic reflexive experiences and activities by which we interpret, create, extinguish, maintain, interrupt, and/or communicate somatic sensations that are congruent with personal, interpersonal, and/or cultural notions of moral, aesthetic, and/or logical desirability. This involves 'tuning in' to, and making sense of, sensory input (Allen-Collinson and Owton 2014).

This was our heuristic asthma typology, but it should be stressed that our original study participants did not always fit neatly and squarely within any particular type, with some changing from one dominant aspect to another. Similarly, we did not expect interviewees in the current study to identify a single asthma type or way of being, when relating to the vignettes they were shown. Rather, we encouraged participants to allow their thoughts and feelings free rein. The aim was to elicit their reflections on other people's experiences of asthma and exercise embodiment, and to gauge empathetic resonance with aspects of these vignettes and the embodied ways of knowing they portrayed. We fully acknowledge the limits to intersubjectivity, or interpersonal understanding (Zahavi 2010), and empathetic understanding of another person's experience (see Allen-Collinson 2013; Smith et al. 2009). We can never actually feel what another is feeling, as phenomenology acutely highlights. We can, however, make and encourage best efforts at understanding another person's feeling, drawing on our own lived experience of similar or related instances, to make an imaginative leap. The use of vignettes can encourage participants to try and make that leap and to empathise with what it is to be a person with asthma. We are not suggesting that this is the only way to seek to convey the lived reality of those with asthma, but such an approach can be conducive to opening up dialogues, eliciting somatic ways of knowing that encourage participants to think and experience 'from the body' as well as about the body (Williams and Bendelow 1998). In our project, these 'bodyful' accounts of sport/exercise as lived by people with asthma were employed both to generate the vignettes, and to elicit the responses (see also Sparkes and Smith 2014) of our interviewees, as described below.

#### Vignette-focused interviews

Each individual was interviewed once on topics that were broad and open-ended, and included modes of asthma management, challenges to managing asthma, sensorial and bodily responses, and the impact of asthma on exercise/sports participation. Out of 19 participants, eight subsequently chose to be involved in the vignette-focused interviewes, and were provided with three vignettes to read and reflect upon. These interviewees

were not involved in the development of the vignettes, but rather responded to direct and open-ended questions relating to them, to encourage further reflection on their own experiences. Some examples of the questions posed are: have people told you their asthma stories previously? How much have you reflected on other people's stories about asthma in the past? How did you find engaging in the process of reflecting on others' stories?

# Data analysis

Transcription was undertaken by a professional audio transcriber, and transcriptions were thematically analysed by all members of the research team. A phenomenologically-inspired approach to data analysis (Allen-Collinson 2011) was utilised, drawing on Giorgi's (1997) guidelines. These include: i) the collection of concrete descriptions of phenomena; ii) the adoption of the phenomenological attitude (including suspending as far as possible our own preconceptions and assumptions surrounding asthma and exercise); iii) initial impressionistic readings of the descriptions; iv) in-depth re-reading of these descriptions as part of a data-immersion process to identify themes and sub-themes. In the next section, to provide readers with a feel for the kind of data that can be generated by utilising vignettes, we portray some of our key findings.

# Findings

The findings presented here cohere around two principal themes: 1) somatic empathy; and 2) the power of sharing stories and opening up dialogues. In the data extracts that follow, pseudonym and age are given for each participant quote.

# Empathy and somatic empathy

A theme that emerged strongly from the data was the element of empathy, a form of intentional experience directed upon the experiential life of others (see Santo and Moran 2015, following Stein 1917/1989), or a feeling of being able to 'step into the shoes' of another, imaginatively inhabiting another's body (Merleau-Ponty 2001), to try and understand her/his lived experience. For us, empathy involves seeking temporarily to enter into another's life-world, to experience it as much as possible as the other experiences it. Empathy connotes the ability to *feel* with, rather than *about* a person or a story, and to be sensitive toward their reality. As Carl Rogers (1975) argues, empathy means entering the private world of the other and becoming thoroughly at home in it. It involves being sensitive, moment to moment, to the changing felt meanings which flow in this other person.

As noted earlier, commensurate with our phenomenological perspective, we are acutely aware that there are limits to empathy, and that no one can actually experience the lived reality of another (Smith *et al.* 2009, Zahavi 2010). Indeed, it can be experienced as highly patronising and finalising (Smith *et al.* 2009) when someone claims to 'know exactly' how another person feels, without allowing the other due dialogue space to express her/his experience and alterity. That being said, it was clear from participants' responses that they expressed empathy with the people portrayed in the vignettes, particularly when it seemed the latter were encountering more difficulties with asthma than was the reader her/himself, or when it was clear that asthma was deleteriously affecting exercise or sporting participation: I feel very sorry for the people it affects where it stops them doing things (Will, Runner/Swimmer, 38 yrs)

Their experience is more significant than mine. That they were having to work against it in the present whereas I have much more choice over that; I feel guilty almost (Ian, Serious Cyclist, 51 yrs)

For interviewees, specific instances recounted in the vignettes engendered a feeling of shared experience with the subject(s) of the narrative. Having to use an inhaler in public, for instance, generated empathic feelings of embarrassment for many:

I kind of empathise with her [Jennifer], she is talking about taking her inhaler in public and she says she feels stupid and I can empathise with the reservations she might have (Ian, Serious Cyclist, 51yrs)

Asthma flare-ups similarly generated arecognition of shared experience and intersubjective understanding, particularly when contrasted with 'normal', non-serious, ongoing asthma (see also Monaghan and Gabe 2015 on normalisation of 'basic' asthma), which participants felt was not of great concern:

When it flares up it's rubbish, but if it doesn't then it doesn't really worry me; that's really accurate (Kate, Serious Exerciser, 26yrs)

Particularly notable was the strong corporeal or *somatic* element to participants' empathy, with many expressing the benefits of reading about shared bodily experience and understandings amongst other exercise/sport participants with asthma:

I think if people are asthmatic it's good that they know that other people are *feeling* similar things (Adam, Marathon Runner, 22 yrs)

This included the co-recognition of asthma as being unpredictable and 'fickle' in nature, leading to a feeling of existential 'thrownness' (Heidegger 1962):

The fickle nature of the condition comes across [in the vignettes]. One of the things that is very difficult to manage is the symptoms can arise when you are not expecting it (Ian, Serious Cyclist, 51 yrs)

The importance of the shared sport/exercise embodiment dimension also emerged clearly in interviewees' responses, when they expressed empathic resonance with the physical-cultural experiences portrayed in the vignettes. This highlights how sportspeople and exercisers often become finely attuned to not only their own, but also other people's corporeality, including the importance of respiratory patterns (Allen-Collinson and Owton 2014, Allen-Collinson and Hockey 2016):

The breathing, it's interesting quite a few of them [vignettes] emphasize breathing slow and breathing deep and certainly that's something I think of when I am running (Sally, Marathon Runner, 58 yrs) As Sally went on to explain further:

You are kind of familiar and open about physical things, you are aware of being sweaty and breathing heavily and the other things that happen when you are doing a sport alongside people. So you get to recognize other people's bodies and their behaviour in a way that you don't in normal life. So you can tell, I find it quite interesting that, I am sure with other sportspeople, you can see someone a mile away or quite a long way in the distance running and you know who it is just because you recognise the gait... So people come up behind you in a race or a run and you know who it is because of the footfall or the *breathing* and so on. (Sally, Marathon Runner, 58 yrs; our emphasis)

Thus, the way in which participants read and experienced the vignettes incorporated a strong corporeal dimension, with the resonance of the vignettes heightened by participants' own personal somatic experiences of sporting/exercise domains.

Interviewees reported that not only did the vignettes resonate with and confirm their experiences, but they also challenged their taken-for-granted assumptions and behaviours, and encouraged the consideration of new ways of thinking about and approaching their asthma. Ian, for example, explained:

My overall impression was there were things in their [stories], [...] that resonated with me [...] there were things that I had not thought about at all that applied potentially to me, there were things that I hadn't thought about that wouldn't apply to me I suspect. So there were things that were confirmatory in that sense. (Ian, Serious Cyclist, 51 yrs)

As participants imagined themselves in another person's body-world, some recounted developing a greater understanding of their own asthma. This type of somatic understanding and empathy is described by Finlay (2006) as 'embodied intersubjectivity' where, for example, a researcher may experience embodied feelings that seem to mirror those of her/his interviewee. Furthermore, Frank *et al.* (2015) found that the more directly relevant a narrative was felt to be to a person's own life, the more effective the narrative in stimulating reflection and behaviour change.

Conversely, we also found that a lack of empathy for those portrayed in the vignettes was reported as promoting self-reflection, as participants contrasted themselves with the vignette subjects. Gavin, for example, was initially highly critical of those with asthma who were not physically fit and/or who appeared unwilling to change their behaviour to adopt a healthier, more active lifestyle:

It does wind me up sometimes when people are complaining about having asthma and they are so out of condition that it is no surprise they are struggling to breathe. Also if they are unwilling to change their habits and improve their lifestyles (Gavin, Serious Runner and Triathlete, 41 yrs)

Having criticised these people, however, this particular interviewee went on to admit that perhaps his view could be judged as somewhat 'harsh'; reading the vignettes had subsequently made him consider how he himself managed his asthma: It's made me realise that I may sound harsh against others with asthma. Even a bit blasé about mine. I do think people should be made more aware of the health benefits of staying cardiovascular fit [...] You need to work at it [...] For me it's just about getting on with it and managing it in a way that you enjoy. Try and try again until you find something that you a) enjoy and b) can benefit from (Gavin, Serious Runner and Triathlete, 41 yrs)

In addition to eliciting empathic resonance and understanding, interviewees also described how the vignettes made them reflect on the relative dearth of asthma narratives in circulation generally, and their felt need to hear and share more accounts of asthma; a finding we now discuss in more depth.

# The power of sharing stories and opening up dialogues

Following exposure to the vignettes, most participants expressed some surprise that they had not previously reflected in any depth on their own asthma experiences or been privy to other people's asthma narratives. When asked about this latter, Will for example, responded:

Not really ever, people I know don't seem to share stories about it or maybe I don't tend to ask (Will, Marathon Runner/Recreational Swimmer, 38 yrs)

In a similar vein, Gavin admitted:

If I'm honest, I haven't reflected much about others' asthma stories in the past (Gavin, Serious Runner/Triathlete, 41 yrs)

Despite having reflected on other people's stories about various aspects of their lives, Sally reported that she had done little to date by way of seeking out information on, or accounts of asthma experiences specifically:

I have reflected on other people's stories about other things as I have gone through stages in my life [...] It's true to say I have done very little looking up on the internet or talking with other people. (Sally, Marathon Runner, 58 yrs)

Given the prevalence of asthma in the UK generally, and in the participants' own families in particular, the lack of shared asthma narratives seemed surprising to interviewees when they were encouraged to reflect on this. Andy represented the views of many interviewees in noting a certain lack of disclosure amongst the asthma sufferers he knew, primarily due to embarrassment, he suspected:

It's still quite new to read stories about people who have asthma even though my family, we all have it. I guess we don't really talk about how it feels because we know, so it's unique [...] Apart from my family, I haven't met many people who, people aren't openly asthmatic, it's not like something you wear with pride – 'look at my inhaler'. People are quite embarrassed about these kinds of things [...] We don't talk about it that much (Adam, Marathon Runner, 22 yrs) Another interviewee, Kate, similarly indicated her normalisation of asthma, that she had never really discussed asthma with anyone, and noted that when asthma stories actually *are* heard, it tends to be only in severe cases of serious asthma attack, or death:

I've had it for so long I don't think about other people having it. The only time you hear about it is when someone unfortunately dies from it. So things like this I have never really had a discussion with anyone (Kate, Serious Exerciser, 26 yrs)

On engaging with the vignettes, all participants without exception expressed the benefits of being exposed to other people's narratives of asthma, and highlighted the usefulness of learning from others' experiences, both negative and positive:

I think it's a really good approach [using vignettes] (Sally, Marathon Runner, 58 yrs)

Maybe it would have been helpful from the point of view of thinking: I don't want to be like that, now how do I get away from that? (Ian, Serious Cyclist, 51 yrs)

Yes, of course. It would be good if other younger asthma sufferers could also access this type of information so that they can learn from other people's experiences and get their own symptoms under control (Will, Marathon Runner/Recreational Swimmer, 38 yrs) I think that other people will be able to relate to these stories, not just those with asthma but anyone with a condition that impacts their ability to exercise (Diane, Recreational Runner, 49 yrs)

Further, as Adam noted, having the encouragement and opportunity to talk freely about asthma and to reflect upon one's own experiences, was in itself beneficial:

It's been quite enjoyable talking about my asthma, take some time to think about it [...] I am not used to doing all the talking [...] just talking about it helps you to get your thought processes in order (Adam, Marathon Runner, 22 yrs)

The benefits of sharing narratives of lived experience with medical practitioners were strongly endorsed by all, with Diane exemplifying these sentiments:

I absolutely feel that these stories should be shared with medical professionals... as they can benefit from hearing about the individual's experiences and feelings, which in turn should be used to inform their practice and assist them in reflecting as practitioners (Diane, Recreational Runner, 49 yrs)

In earlier work (Owton and Allen-Collinson 2014), we examined the heuristic benefits of using a typology of asthma identities and ways of being-in-the-world as a useful framework to assist in identifying and understanding different ways of beingwith-asthma in the sporting/exercising world. Participants in the current study similarly acknowledged that these ways of being are complex, shifting, mutable and context-dependent. They were emphatic in highlighting how beneficial they considered being exposed to both the stories of others (see also Frank, 2010), and thetypology of asthma ways-of-being, in stimulating reflection upon their own lives. The vignettes provided interviewees with insight into, and empathic resonance with, others' lived experience of asthma, and the various somatic ways of knowing they developed and employed in order to live with asthma (see also Owton and Allen-Collinson 2014). Narrative approaches generally are of interest because research has demonstrated that audiences can be 'transported into' narratives (Green and Brock 2000) and identify with characters in a way that leads to changes in health-related knowledge, attitudes, beliefs, and behaviours (Frank 2010, Murphy *et al.* 2011).

#### Conclusion

In this article, drawing on a sociological-phenomenological theoretical framework, we have considered the use of vignette-based research in eliciting the narratives of people with asthma, in relation to the ways in which asthma is lived in their everyday sporting and exercise life-worlds. Many participants expressed how the vignettes resonated strongly with their experiences and signalled clearly the benefits of reading the accounts of others with asthma, in encouraging critical reflection on their own ways of being-with and coping with asthma in exercise environments and beyond. This finding coheres with socio-narratological research that argues for the power of stories in helping generate new stories and ways of understanding lived experience, which then feed back into wider societal narrative resources (see for example, Frank 2010). The question remains, however: why should healthcare professionals who work under pressure of

time and resources, be interested in opening up the dialogue space to elicit these narratives, and understanding the experiential and somatic ways of knowing of their asthma patients? One might think it sufficient for medical practitioners, such as GPs and respiratory nurse specialists, to base their treatment decisions on the published research evidence, without seeking patients' lay accounts.

A persuasive rationale for eliciting such accounts is posited by Guyatt et al. (2004: 991), who argue that: 'Because clinicians' values often differ from those of patients, even those who are aware of the evidence risk making the wrong recommendations if they do not involve patients in the decision making process.' As these authors (2004: 990-991) warned a decade ago, although evidence-based medicine has come a long way, nevertheless, the incorporation of evidence as well as the inclusion of patient values into all clinical decision-making remains a distant goal. It is therefore important to open up the dialogue space, and listen to patients' voices, in order to improve the informational basis on which key decisions, including treatment decisions, are made. A form of Experience-Based Co-Design (Larkin et al. 2015) of treatment plans can empower patients to feed into the patient-doctor dialogue their own, often hard-learnt lessons regarding ways of living with, exercising with, and managing asthma within their own everyday life-worlds. More tailored and effective planning, treatment and self-care regimes can subsequently be developed that are specific to the needs of individual asthma patients, many of whom are highly committed to maintaining an active lifestyle that involves sports and exercise participation. Individuals are then much more likely to adhere to health regimes agreed and coproduced by themselves and their healthcare professionals (Corsico et al. 2007) and exercise professionals.

# **Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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#### References

- Allen-Collinson, J., 2009. Sporting embodiment: Sports studies and the (continuing) promise of phenomenology. *Qualitative Research in Sport and Exercise*, 1, 3, 279-296.
- Allen-Collinson, J., 2011. Intention and epochē in tension: Autophenomenography, bracketing and a novel approach to researching sporting embodiment. *Qualitative Research in Sport, Exercise & Health*, 3, 1, 48-62.
- Allen-Collinson, J., 2012. Feminist phenomenology and the woman in the running body. In I. Martínková and J. Parry, eds, Phenomenological Approaches to Sport. London: Routledge, 113-129.
- Allen-Collinson, J., 2013. Autoethnography as the engagement of self/other, self/culture, self/politics, selves/futures. *In* S. Holman Jones, T.E. Adams and C. Ellis, eds, *Handbook of Autoethnography*. Walnut Creek, CA: Left Coast Press, 281-299.
- Allen-Collinson, J. and Owton, H., 2014. Take a deep breath: Asthma, sporting embodiment, the senses, and 'auditory work'. *International Review for the Sociology of Sport*, 49, 5, 592-608.
- Allen-Collinson, J. and Pavey, A., 2014. Touching moments: Phenomenological sociology and the haptic dimension in the lived experience of Motor Neurone Disease. *Sociology of Health & Illness*, 36, 6, 793-806.
- Allen-Collinson, J. and Hockey, J., 2016 in press. Intercorporeal enaction and synchrony: The case of distance-running together. *In C. Meyer and U. van Wedelstaedt, eds, Intercorporeal and Interkinesthetic Enaction in Sports.*Amsterdam: John Benjamins Publishing.

- Angner, E., Ray, M. Saag, K. and Allison, J., 2009. Health and happiness among older adults: A community-based study. *Journal of Health Psychology*, 14, 4, 503-512.
- Atkinson, P. and Delamont, S., eds, 2006. Narrative Methods. 4 Volumes. London: Sage.
- Barter, C. and Renold, E., 1999. The use of vignettes in qualitative research. *Social Research Update*, 25, 9, 1-6.
- de Beauvoir, S., 1972. *The Second Sex* (trans. H. Parshley). Harmondsworth: Penguin Books.
- Bochner, A.P., 2001. Narrative's virtues. Qualitative Inquiry, 7, 2, 131-57.
- Braun, V. and Clarke, V., 2013. Successful Qualitative Research: A Practical Guide for Beginners. London: Sage UK.
- British Thoracic Society and Scottish Intercollegiate Guidelines Network, 2012. British Guideline on the Management of Asthma: A national clinical guideline. May 2008, rev. January 2012. Cited October 23, 2015. Available at:
- https://www.brit-thoracic.org.uk/document-library/clinical-information/asthma/btssignguideline-on-the-management-of-asthma/
- Carel, H., 2011. Phenomenology and its application in medicine. *Theoretical Medicine and Bioethics*, 32, 1, 33-46.
- Carless, D. and Douglas K., 2008. Narrative, identity and mental health: how men with serious mental illness re-story their lives through sport and exercise. *Psychology of Sport and Exercise*, 9, 5, 576-594.
- Charon, R., 2007. What to do with stories: the sciences of narrative medicine. *Canadian Family Physician*, 53, 8, 1265-1267.

- Chimenti, L., Morici, G., Paterno, A. Bonanno, A. Vultaggio, M., Bellia, V. and Bonsignore, M.R., 2009. Environmental conditions, air pollutants, and airway cells in runners: A longitudinal field study. *Journal of Sports Science*, 27, 9, 925-935.
- Corsico, A.G. *et al.*, 2007. Factors affecting adherence to asthma treatment in an international cohort of young and middle-aged adults. *Respiratory Medicine*, 101, 6, 1363-1367.
- Crust, L., Swann, C., Allen-Collinson, J., Breckon, J., and Weinberg, R. 2014. A phenomenological exploration of exercise mental toughness: Perceptions of exercise leaders and regular exercisers. *Qualitative Research in Sport, Exercise* & *Health*, 6, 4, 441-461.
- Denford, S., Campbell, J.L., Frost, J. and Greaves, C.J., 2013. Processes of change in an asthma self-care intervention. *Qualitative Health Research*, 23, 10, 1419-1429.
- Dewey, J., 1980; originally published 1934. Art as Experience. London: Perigee.
- Finlay, L., 2008. The body's disclosure in phenomenological research. *Qualitative Research in Psychology*, 3, 1, 19-30.
- Frank, A.W., 1995. *The Wounded Storyteller. Body, Illness and Ethics*. (First edn.). Chicago: University of Chicago Press.

Frank, A.W., 2010. *Letting Stories Breathe: A Socio-Narratology*. London: University of Chicago Press.

- Frank, A.W., 2012. Practicing dialogical narrative analysis. *In*: J. Holstein and J. Gubrium, eds, *Varieties of Narrative Analysis*. London: Sage, 33-52.
- Frank, L. B., Murphy, S. T., Chatterjee, J. S., Moran, M. B. and Baezconde-Garbanati, L., 2015. Telling stories, saving lives: creating narrative health messages. *Health Communication* 30, 2, 154-163.

- Giorgi, A.P., 1997. The theory, practice and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28, 2, 235-260.
- Global Initiative for Asthma, 2009. Asthma Management and Prevention: A practical guide for public health officials and health care professionals. Cited 9 October, 2015. Available at www.ginasthma.org/guidelines-gina-report-global-strategy-for-asthma.html.
- Goldenberg, M.J., 2010. Clinical evidence and the absent body in medical phenomenology. *The International Journal of Feminist Approaches to Bioethics*, 3, 1, 43-71.
- Guyatt, G., Cook, D. and Haynes, B., 2004. Evidence based medicine has come a long way: the second decade will be as exciting as the first. *British Medical Journal*, 329, 7473, 990–991.
- Heidegger, M., 1962. *Being and Time*, (trans. J. Macquarrie and E. Robinson). New York: Harper & Row.
- Higginbottom, G.M.A., 2006. 'Pressure of life': ethnicity as a mediating factor in midlife and older peoples' experience of high blood pressure. *Sociology of Health and Illness*, 28, 5, 583-610.
- Husserl, E., 1989. Ideas Pertaining to a Pure Phenomenology and to Phenomenological Philosophy: Second Book: Studies in the Phenomenology of Constitution (trans. R. Rojcewicz and A. Schuwer. Dordrecht: Klewer.
- Jackson, M., Harrison, P., Swinburn, B., and Lawrence, M., 2015. Using a qualitative vignette to explore a complex public health issue. *Qualitative Health Research*, 25, 10, 1395-1409.

- Lacy, N.L. and Backer, E.L., 2008. Evidence-based and patient-centered care: results from an STFM group project. *Family Medicine Journal*, 40, 6, 417–422.
- Larkin, M., Boden, Z.V.R. and Newton, E., 2015. On the brink of genuinely collaborative care: experience-based co-design in mental health. *Qualitative Health Research*, 25, 11, 1463-1476.
- Leder, D., 1990. The Absent Body. Chicago: Chicago University Press.
- Lewis, B., 2011. *Narrative Psychiatry: How Stories Can Shape Clinical Practice*. Baltimore: The John Hopkins University Press.
- McArdle W., Katch F. and Katch V., 2007. *Exercise Physiology: Energy, Nutrition, and Human Performance*. Philadelphia: Lippincott, Williams and Williams.
- McFadden Jr., E.R. and Gilbert, I.A., 1994. Exercise-induced asthma. *The New England Journal of Medicine*, 330, 1362-1367.
- Merleau-Ponty, M., 2001. *Phenomenology of Perception* (trans. C. Smith). London: Routledge and Kegan Paul.
- Mickleborough, T.D., Gotshall, R.W., Cordain, L. and Lindlsey, M., 2001. Dietary salt alters pulmonary function during exercise in exercise-inducted asthmatics. *Journal of Sports Science*, 19, 11, 865-873.
- Monaghan, L.F. and Gabe, J., 2015. Chronic illness as biographical contingency?
  Young people's experiences of asthma. *Sociology of Health and Illness*, 37, 8, 1236-1253.
- Murphy, S. T., Frank, L. B., Moran, M. B. and Patnoe-Woodley, P., 2011. Involved, transported, or emotional? Exploring the determinants of change in knowledge, attitudes, and behavior in entertainment-education. *Journal of Communication*, 61, 3, 407-431.

- National Institute for Health and Clinical Excellence (NICE), 2013. *Asthma QS25*. Cited 15 July, 2015. Available at: <u>http://guidance.nice.org.uk/QS25</u>.
- Oberoi, D.V., Jiwa, M., McManus, A. and Parsons, R., 2015. Do men know which lower bowel symptoms warrant medical attention? A web-based video vignette survey of men in Western Australia. *American Journal of Men's Health*. Online early.
- Owton, H., 2012. A breath of fresh air: Breathing stories of the lived experiences of asthma and sporting embodiment. Unpublished PhD thesis. Exeter: University of Exeter.
- Owton, H., 2013. Integrating multiple forms of representation. *Qualitative Inquiry*, 19, 601-604.
- Owton, H. and Allen-Collinson, J., 2014. Conformers, contesters, and creators: Vignettes of asthma identities and sporting embodiment. *International Review for the Sociology of Sport*. Online early.
- Owton, H., Allen-Collinson, J. and Siriwardena, A.N. 2015. Using a narrative approach in clinical practice to facilitate change in asthma patients. *Chest*, 148, 1, 288-293.
- Ram, F.S., Robinson, S.M., Black, P.N., and Picot, J., 2005. *Physical Training for Asthma. Cochrane Database Systematic Review*, 4.
- Rogers, C.R., 1975. Empathic: an unappreciated way of being. *The Counseling Psychologist*, 5, 2, 2-10.
- Royal College of Physicians (RCP), 2014. Why Asthma Still Kills. The National Review of Asthma Deaths (NRAD). London: Royal College of Physicians.
- Santo, T. and Moran, D., 2015. Introduction: empathy and collective intentionality the social philosophy of Edith Stein. *Human Studies*, 38, 4, 445-461.

- Smith, B., 2013. Sporting spinal cord injuries, social relations, and rehabilitation narratives: an ethnographic creative non-fiction of becoming disabled through sport. *Sociology of Sport Journal*, 30, 132-152.
- Smith, B. and Sparkes, A., 2012. Narrative analysis in sport and physical culture. *In*: K.Young and M. Atkinson, eds, *Qualitative research in sport and physical culture*.Rotterdam: Emerald Press, 81–101.
- Smith, B., Allen-Collinson, J., Phoenix, C., Brown, D. and Sparkes, A., 2009. Dialogue, monologue, and boundary crossing within research encounters: a performative narrative analysis. *International Journal of Sport and Exercise Psychology*, 7, 3, 342-359.
- Smith, B., Papathomas, A., Martin Ginis, K. and Latimer-Cheung, A., 2013. Understanding physical activity in spinal cord injury rehabilitation: translating and communicating research through stories. *Disability and Rehabilitation*, 35, 24, 2046-2055.
- Smith, B., Tomasone. J., Latimer-Cheung, A., and Martin Gins, K., 2015. Narrative as a knowledge translation tool for facilitating impact: translating physical activity knowledge to disabled people and health professionals. *Health Psychology*, 34, 4, 303-313.
- Sparkes, A. and Smith, B., 2011. Inhabiting different bodies over time: narrative and pedagogical challenges. *Sport, Education & Society*, 16, 357–370.
- Sparkes, A.C. and Smith, B., 2014. *Qualitative Research Methods in Sport, Exercise and Health: From Process to Product*. London: Routledge.
- Stein, E., 1989 (originally published 1917 in German). On the Problem of Empathy. The Collected Works of Edith Stein (3<sup>rd</sup> Volume) (trans. W. Stein). Washington, DC: ICS Publications.

- Svenaeus, F., 2015. The phenomenology of chronic pain: embodiment and alienation. *Continental Philosophy Review*, 48, 107-122.
- Wagner, H.R., 1973. The scope of phenomenological sociology: considerations and suggestions. In G. Psathas, ed., Phenomenological Sociology: Issues and Applications. London: John Wiley, 61-87.
- Williams, S. and Bendelow, G., 1998. The 'Lived' Body: Sociological Themes, Embodied Issues. London: Routledge.
- World Health Organisation (WHO), 2014. *Chronic Respiratory Diseases: Asthma*. Cited 5 August, 2015. Available at: <u>http://www.who.int/respiratory/asthma/en/</u>.
- Zahavi, D., 2010. Empathy, embodiment and interpersonal understanding: from Lipps to Schütz. *Inquiry*, 53, 3, 285-306.

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