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Health and illness interactions

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Health and illness interactions

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Table of contents

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Editorial: Health and illness interactions

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Editorial on the Research Topic
Health and illness interactions

A focus on *Health and illness interactions* is an invaluable starting point for exploring everyday, taken for granted, processes and experiences with reference to health, illness, healthcare, and public understandings of all of these (e.g., Scambler, 2018). Sociological research and theorization on such interactions has focused on lay and medical meanings/definitions and experiences and has fed directly into healthcare policy and the education of healthcare professionals. Attention has been given to, and remains on, the relationships between patients, the public and healthcare professionals (e.g., Davis, 1984; Barry et al., 2001; Scambler, 2019; McLaughlin et al., 2023), and relationships between individuals and institutions (e.g., Stacey et al., 1976/2018; Strauss et al., 1982; Abraham and Balendran, 2025). Sustained focus on health interactions has influenced public health initiatives (e.g., Goodrich and Cornwell, 2008; Silverman and Kurtz, 2017; Coulter et al., 2022) and continues to challenge the practice of healthcare. Specific concerns within the broad field of health and illness interactions include interacting with healthcare environments, diagnosis and the treatment journey, popular perceptions and misunderstandings of conditions and experiences, public health messages and political changes, and life choices and chances. Contemporary interest in health and illness interactions is generating new understandings of experiences of acute and chronic illness and disability, COVID-19 and other pandemics, antibiotic resistance, conspiracy theories, technologies, changing models of healthcare, migration and austerity.

This Research Topic contains eight articles and follows a tradition of work which acknowledges and highlights that health and illness interactions are more than just those between patients and health professionals. Three papers refer specifically to encounters between patients and experts. Scambler in *Combining experiential knowledge with scholarship in charting the decline of the national health service in England* provides a critical auto/biographical account of his own recent experiences as a patient with type 2 diabetes and subsequent polymyalgia in both primary and secondary care and deploys analytic induction to consider, and explain, his experience, against the background of the shifting nature of doctor-patient interaction occasioned by governmental politics in relation to the NHS. Scambler insists that the present impoverishment of management and care must be understood with reference to wider aspects of macro-social change. In "*Whatever I said didn't register with her*": *medical fatphobia, and interactional and relational disconnect in healthcare encounters,* Kost et al. argue that medical fatphobia creates an "interactional and relational disconnect" between "fat" patients and healthcare practitioners. This leads to fatness being seen as the underlying cause of medical problems and entrenches patient and practitioner ambivalence and joint decision-making. A more positive picture is provided of patient and healthcare encounters and relationships in *Insights, beliefs, and myths surrounding tuberculosis among pulmonary patients with delayed healthcare access in a high-burden TB state in Nigeria - a qualitative inquiry,* written by Adeoye et al.. Here the authors argue that Tuberculosis (TB), as a persistent health challenge in Nigeria, necessitates more than medical intervention. TB requires a profound understanding of the diverse insights, beliefs, and myths held by patients. In this instance data from both patients and healthcare providers emphasizes a need for nuanced and culturally sensitive interventions.

The importance of relationships amongst care-givers (both formal and informal) is explored further by Stjerna and Brady and Corrigan et al.. In *Inter-embodied parental vigilance; the case of child food allergy,* Stjerna and Brady highlight the embodied aspects of parental vigilance in parenting children who have a food allergy. They argue that the lens of inter-embodiment, with a focus on bodies in relation, captures how parents' lived experience of managing food allergy intertwines with that of their children in the parent-child-health/illness triad. This embodied knowledge is often not verbalized, but Stjerna and Brady's approach offers the potential for new understandings of parent-child relations that center on chronic child health conditions. Corrigan et al.'s concern in *Integrated care systems in England: the significance of collaborative community assets in promoting and sustaining health and wellbeing* is with health policy aimed at improving health and wellbeing and reducing inequalities through local collaborative partnerships with public sector organizations, community groups, social enterprise organizations and other local agencies. The authors highlight how community groups (also known as community assets) play an important role in empowering citizens and providing much needed support to vulnerable and disadvantaged communities. However, community assets are not a substitute for functioning funded public sector services that are currently being undermined by ongoing cuts in government funding.

All authors in this special edition are concerned with the knowledge that healthcare professionals, patients, and the public hold and the impact this has on health and illness encounters. Gilbert's *Learning journeys - student learning development in the first years of a medical degree: an analysis of student conversations* explicitly focuses on undergraduate medical education and the need for the curriculum to both recognize individual learner differences and promote self-motivated, flexible, open minded, empathic lifelong learners through problem/enquiry-based curricula. The importance of experiential learning is further explored by Marks in *Invalidated and 'Salty': an auto/biographical and theoretical review of the lived experiences of individuals with PoTS.* Drawing on her own experiences and available literature, Marks reflects on interactions between patients and healthcare providers as well as interactions between PoTSies (persons with Postural Orthostatic Tachycardia Syndrome) and those around them. Marks further examines the consequences for individuals who remain undiagnosed.

Patterson's conceptual analysis article *INTO THE WILD: Uncertain frontiers and sustainable human-nature interactions,* considers health and illness interactions between humans and the natural environment. Patterson argues that in the anthropocentric Global North political economies have historically cultivated a separation of people from nature and suggests that this separation is an eco-anomie, a damaging relational autoimmune disorder.

This special edition celebrates methodological pluralism within the field of sociology and the rich interpretations that this generates. Although a wide range of substantive topics is explored, key recurring themes include cultural perceptions of health and illness in various contexts, such as medical settings, communities, homes, and natural environments. The focus extends to both emotional and physical wellbeing, issues of inclusion and exclusion, and concepts related to the body, self, difference, and diversity in status and identity. Additionally, attention is given to the emotional management of risk. Crucially these articles demonstrate that at every level health and illness interactions do not occur in a vacuum. Rather they are bound up within personal and professional power relations although all too often this is ignored.

Author contributions

TC: Writing – original draft, Writing – review & editing. GL: Writing – original draft, Writing – review & editing. LO-K: Writing – original draft, Writing – review & editing. TS: Writing – original draft, Writing – review & editing.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Inter-embodied parental vigilance; the case of child food allergy

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There is developing interest in issues of embodiment in studies of children, health and illness. We take our point of departure in the parent-child-health/illness triad to explore the embodied aspects of parental vigilance in parenting children who have a food allergy, utilizing the concept of inter-embodiment. Drawing on a focus group study with parents in Sweden the analysis reveals that this vigilance can be seen as the embodied manifestation of concern for children's bodies in perpetual liminality, when constantly exposed to allergens and the risk of becoming ill. We argue that the lens of inter-embodiment, with a focus on bodies in relation, captures how parents lived experience of managing food allergy intertwines with that of their children in the parent-child-health/illness triad. The analysis uncovers a form of embodied knowledge that is often not verbalized, offering potential for new understandings of parent-child relations that center on chronic child health conditions.

KEYWORDS

inter-embodiment, child health, food allergy, parental perspective, parental vigilance

Introduction

In contemporary society, parents' understandings and ways of addressing child health are influenced by "warnings and anxieties about risks and dangers to which children may be susceptible" (Lupton, 2012, p. 45), and parents are found to be highly aware of their responsibility for managing their children's health (Lee et al., 2010; Lupton, 2011). As parents are primarily the mediators of children's health and well-being, the parent-child relationship can be depicted as a triad: parent-child-health/illness. Characteristic of this triad is that any imperative to observe and monitor the child's body and behavior becomes intensified in cases of child illness. Studies indicate that in addition to a "normal" watchfulness, parents develop a "parallel vigilance" looking for signs of illness, as is indicated in cases of child Type 1 diabetes (Niedel et al., 2013). Parents seem to base their understandings of their children's health on detailed observations of the child's body. They explore threats to the child's health, act upon those threats and evaluate how their actions influence their children's health (Olin Lauritzen, 1997; Lupton, 2011). Also, parents separate what they regard as "natural" and "cultural" in infants' bodies, such as childrens' diseases contra medical interventions. These understandings of the body as a dynamic system, where the inner body is connected to the outside world in complex ways, further enhance the parental responsibility. As it is difficult to comprehend and predict bodily consequences of actions related to children, today parents seem to be "responsible for everything" but at the same time "powerless" (Brownlie and Leith, 2011, p. 206). Parenting a child who is experiencing illness can amount to "living" the child's illness, as the lives of parents and children are intertwined in various ways in terms of caring, responsibility and, not least, bodily intimacy. Earlier, the first author and colleagues analyzed social aspects of the phenomena of parental vigilance in studies with parents of children with food allergy in a range of everyday contexts as well as cross-culturally (Stjerna et al., 2014, 2017). In this paper we are pursuing further understandings of the lived experience of parenting children who have a food allergy, through an exploration of the more embodied aspects of this parental vigilance, by utilizing the concept of inter-embodiment.

The case of child food allergy

The food allergy condition offers a productive case to explore parental vigilance and bodily aspects within the parent-child relationship as food allergy is characterized by a constant parental responsibility to prevent allergic reactions, together with uncertainties involved in the diagnosis and management of the condition. Also, since reactions toward food allergens produce visible bodily manifestations such as rashes, swollen lips, shortness of breath and cough, food allergy is advantageous to study from an embodiment perspective. Further, the concept of inter-embodiment is useful to explore parental vigilance in cases of child illness since this concept focuses on bodies in relation (see e.g., Lupton, 2012). Food allergy is of increasing public health concern and affects up to 12 percent of the child population in the Western world (Burks et al., 2012), and is likely to increase globally in the coming decade (Prescott et al., 2013). It is well known that parents of food allergic children experience anxiety and fear due to the constant vigilance needed to prevent allergic reactions (Gillespie et al., 2007). The only treatment is avoidance of certain foods, as well as management of symptoms. The most common food allergies are to milk-protein, egg and nuts, but almost any food can cause allergic reactions (Arias et al., 2009). Allergic reactions to food typically occur shortly after exposure, with symptoms varying from mild oral itch to life-threatening anaphylaxis (a potentially fatal reaction involving multi-organ systems). Children with risk of severe allergic reactions are therefore given adrenaline auto-injectors to be carried all of the time (Simons, 2010). Even when given a food allergy diagnosis, the condition involves uncertainties. It is possible to determine if an individual reacts to an allergen with a blood- or skinprick test or an oral food challenge, but none of these tests can predict how severe a reaction could be (Hu et al., 2008).

The lived body and the concept of inter-embodiment

The lived body, although individuated and autonomous, in contrast to an "abstract" medical body (see e.g., Armstrong, 1983) actually experiences the intertwining with other bodies. Here we draw on Merleau-Ponty's ((2002[1962])) understanding of perception and the lived body. According to Merleau-Ponty we experience ourselves, others and the world *through* our bodies. The intentional body not only responds to the world but creates meaning about different phenomena and the world through its sensations. Following the intercorporeality of Merleau-Ponty ((2002[1962])) the body is at once both subject and object; entangled and interconnected to other bodies. Springgay (2005) states that by taking the point of departure in Merleau-Ponty's ontology "a re-conceptualization of body knowledge must consider the possibilities of interactions *between* bodies—knowledge as intercorporeality" (page 37). Lupton, drawing from the work of Merleau-Ponty, uses the term inter-embodiment as a "concept of relation" that highlights the ways bodies "live alongside and in response to others" bodies' (Lupton, 2012, p. 39). During infancy, and also later in the child's life, this inter-embodiment is experienced through embodied caring practices such as feeding- or hygiene practices carried out as part of everyday parenting (Lupton, 2012). However, as has been pointed out within the sociology of childhood (James et al., 1998), children are not just recipients of care or passive bodies that parents "act upon", but active social agents who also shape their bodies and social lives (Mayall, 2002; Christensen and James, 2008; Brady et al., 2015). Thus, the parent-child-health/illness triad can be seen as characterized by a dynamic relation between active parents *and* children. It is also depending on the health issues at stake as well as changing relationships over time as the child grows older and their ability to exercise agency increases in the context of intra-generational dependencies (Brady et al., 2015; Mayall, 2015; Holloway et al., 2019). Children's bodies need to be understood through the practices, materials and processes that produce and maintain them. Indeed, bodily relations, which emerge within power-inequalities, are central to the understanding of inter-generational relations (Mayall, 2015; Holloway et al., 2019). Today there is growing interest in children and embodiment within the field of childhood studies and children's geographies (Prout, 2000; Colls and Hörschelmann, 2009; Lupton, 2012) and studies have shown that aspects of embodiment and inter-embodiment within the parent child relation can surface in fruitful ways in interviews with parents about their children's health (Olin Lauritzen, 1997; Lupton, 2011; Henderson et al., 2020).

Aim

It is against this backdrop that in this paper we will address issues of inter-embodiment in the parent-child-health/illness triad, drawing on the case of child food allergy. More specifically the aim is to explore the character of the inter-embodied parental vigilance in parenting children with food allergy; how this is reflected in parents accounts about their lived experience of managing their child's illness within the parent-child-health/illness triad.

A focus group study of parents of children with food allergy

This paper draws on a study that was carried out in 2009–2010 in Sweden and included ten focus group interviews with 31 parents (25 mothers and six fathers) of children with food allergy, aged 1–17 years (Stjerna et al., 2014). The study was approved by the Ethics Committee at the Karolinska Institutet (Nr: 2008/569-31, 2012/1051/32)[1]. All children had been diagnosed with a food allergy, either single food or multiple, varying from mild allergy to potentially life-threatening allergy, and most were prescribed an adrenaline auto-injector to be administered in case of severe reactions. Focus group interviews are particularly suited to explore shared knowledge, opinions and underlying attitudes with a group of people who share similar experiences and/or characteristics. The interactions which take place in focus groups are in many ways similar to everyday interaction in more informal settings. For example, speech acts are mostly spontaneous, overlapping speech occurs and a good story is often used as an example of something. One of the advantages of the focus group method is that the group dynamics in the interview situation can stimulate reflection as participants are allowed to build on each other's experiences and thoughts as they are expressed in the on-going conversations (Marková et al., 2007). The focus group interviews took place at the two hospitals where the children were patients and were moderated by the first author. A physician participated as a silent observer and answered medical questions at the end of each session, important for ethical reasons. The sessions lasted for 1.5–2 h and were digitally recorded with the parents' permission. The parents were asked to share their experiences of their lives with a food allergic child and a topic guide was used, covering everyday management of the allergy at home, nursery, school and other arenas. The parents expressed that they appreciated the opportunity to share experiences in a group with other parents of children with food allergy and that they largely lacked such opportunities in their daily lives. They presented detailed accounts of their experiences, often as a course of events resulting in sequences with a narrative character where the individual parent "takes the floor", sometimes in an alliance with another parent/s who fills in or asks a question. There are also sequences when several participants, in a collective way, jointly contribute to a topic. All parents took part in the conversation, albeit a few contributed less to the conversation than others. This can be seen as typical of focus group interviews, but here, these parents referred to differences in the severity of their child's food allergy; stating that the child's food allergy was not such a big problem in the family and that other parents have more to contribute. Throughout the focus group sessions though, parents positioned themselves as "we" in contrast to "others", who did not share their experiences of managing child food allergy.

Analysis

Since this study was conducted in 2009–2010 there is evidence that food allergy is increasing in Western countries; the "second wave" started in the in the early 2000s and is also likely to spread globally in the coming decade. This development will have a major influence on healthcare provision of specialist allergy services worldwide (Prescott and Allen, 2011; Prescott et al., 2013). There is also concern that allergies that tended to outgrow in earlier generations of children, such as egg and milk allergies, are less likely to outgrow among children of this second wave (Prescott and Allen, 2011). Thus, food allergy continues to be of increasing public health concern. Since there is no cure those who have the allergy have to manage it on a daily basis in a number of situations, and there is no reason to suspect that parents of children with food allergy or children's experiences of living with food allergy have changed in fundamental ways since this study was conducted. To our knowledge there are a dearth of studies that shed light on inter-embodiment aspects from a parental perspective in cases of chronic child illness and this study offers empirical material to explore such experiences. A first analysis of this material showed that bodily aspects were salient in parents' talk. This urged for a deeper analysis of the meaning of these bodily aspects as a part of the parental vigilance.

This re-analysis is based on the already transcribed and anonymised material, and no other information about the individual participants was used by the researchers. The analysis was carried out by the first author, who had collected the data and thus had a first-hand inside perspective on the material, in collaboration with the second author. Although, the interaction in the focus groups was not the specific focus of this analysis, attention was also paid to how the interaction in the groups produced the data (Morgan, 2010). The analysis entailed that topical episodes were identified in the material; sequences that were held together internally by the content during a sequence of time (Marková et al., 2007). These episodes are chosen as they revolve around bodily aspects of the parental vigilance when parenting children with food allergy. In a second step these episodes were brought together into more overarching themes. From the point of departure of an embodiment perspective and utilizing the concept inter-embodiment the authors continuously discussed the emergent themes. Finally, three major themes that were of relevance to the issue of inter-embodied parental vigilance were identified. These are;

1. How parents identify and understand signs of food allergy by observing the child's body and how inter-embodiment aspects are part of those identification processes
2. How parents understand allergy risk as localized to the child's body, as something internal, and how they make sense of these inner, invisible aspects
3. How parents support their children to identify and interpret food allergy signs and respond to bodily reactions.

Results

Generally speaking, the infant's body is characterized by its' vulnerability and being "at risk" and inter-embodiment is part of parents' care-taking practices (Olin Lauritzen, 1997; Lupton, 2012). However, with the case of illness in children, parental surveillance entails responses which are related to the ways the particular illness manifests in everyday life. The food

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[1] The project *'Dangerous food' and child health: Living with food and eating risks of everyday life. A qualitative study of parents of food allergic children'*, was headed by professor Sonja Olin Lauritzen, Department of Education, Stockholm University and carried out by the first author (M-LS), and Med Dr. Mirja Vetander, as part of a larger research program headed by Professor Magnus Wickman and associate Professor Gunnar Lilja *'Severe child food allergy: from diagnostic to practice'* at the Sachs Children's and Youth Hospital in Stockholm. For full details of the study see Stjerna et al. (2014).

allergy case demonstrates how the parents pay attention to deviances from the child's normal functioning and behavior; the body exterior.

To read the body of the child

The parents use their own senses to identify signs of illness. They describe how they *look* at the child's skin, face, body movements as well as behavior—*listen* to the child's breathing or wheezing or coughing. There is the awareness that allergic reactions potentially are life-threatening:

> it has affected her breathing, you can hear how it "gurgles", it sounds difficult and it is difficult for her to breath, but she has always had enough oxygen in her blood so luckily she has never experienced this as very uncomfortable (6 years old, allergic to egg, hazelnuts, cashew, pistachio)

This mother points out that when it comes to a reaction that affects breathing, the oxygen level in the blood is crucial. This indicates there is a moment when the reaction might get worse, pointing to the unpredictability of a reaction. Further examples also demonstrate how the child's experiences of having severe reactions might influence the child's embodied agency; both during the course of events and afterwards. Some of the parents describe that their children express stress, fear and bodily resist when entering the ambulance or being treated in emergency care. One father said that when his daughter had difficulties breathing he gave her adrenaline and called for the ambulance. His daughter, 4 years old, who had experienced a number of medical examinations, first refused to go into the ambulance: "she was holding so tight to me that I could hardly breath, so much strength in this little body". Some of the parents also describe how they witness dramatic changes in their children in cases of severe reactions. This mother depicts severe reactions in her daughter: she can *see* how the rashes grow all over her body, she can *hear* a "strange cough", she can *observe* how her behavior changes:

> she gets so aggressive, she can hardly breath, because her chest gets tight, she still manages to wrestle her way out, even though there are fifteen people in the emergency room, but after a while she comes around. Molly[2] "turns up" and one of the nurses says, hello, there you are, they are so used to this, but I just wonder where she went (9 years old, allergic to cereals, shellfish and nuts)

The above excerpt shows that a severe reaction can be compared to a sudden metamorphosis of the child. This mother says that it is "so difficult" to see her daughter in these life-threatening situations; she can "just hope that it goes well". Adopting the concept of inter-embodiment to episodes of emergency care could be understood such as parents experience limited control over their child's body and life during those episodes. Parents can indeed give their children adrenaline and call for help but then they have to put their trust in others. The mother in the above example says that after such difficult incidents she has noticed that her daughter is worried and reluctant to eat. Another example of the way that the allergy can influence the child's relation to food is from another mother who explains that her daughter had a reaction when she had a lasagne and now links this dish with her experiences of emergency care:

> she usually loves lasagne, but when she says I am not hungry, I know immediately we will have something else, she becomes very scared because she has had two bad experiences at the emergency department (10 years old, allergic to milk-protein and egg)

Some parents describe that their children develop a more general aversion to food and in some situations refuse to eat, which could be understood as a strong bodily response to difficult illness experiences. This mother says that her son has had so many bad experiences that he has developed an aversion against eating: "he weighs fifteen kilos, he is really small and he cannot eat and he does not want to eat because food is associated with something that hurts him". He will soon be 5 years old and only recently have the family been remitted to a dietician, she adds. Further, to learn to recognize how their child's condition presents and to recognize these signs of illness is knowledge that the parents develop over time:

> it was actually at nursery (first allergic reaction) when he was given the wrong type of pasta, with wheat, but did not react until an hour later, and I thought he would react at once, but now I have learned (8 years old, allergic to milk-protein, wheat, barley rye, oatmeal, egg, hazelnut, peanut)

But even if the typical pattern is learnt, there is always uncertainty regarding how severe the reaction will be at this particular time, something completely "new" can happen. In spite of a diagnosis, parents express an uncertainty regarding their child's condition; stating "this is what we know right now". This implies that it is possible to discover new allergens and receive a revised diagnosis. Furthermore, the allergy could affect closeness between the child and others since it requires such a small amount of an allergen to have a reaction and some children may react on skin contact. In this way the boundaries between the child and others bodies in some situations need to be maintained and observed. Here is an example of a mother's recollection of when she first discovered her son's allergy. A touch from a sibling during family cooking is enough to trigger a reaction:

> the first time was when we made pancakes, and his older brother participated in mixing all ingredients, and then went up to Martin who was sitting in his baby chair and patted him, Martin didn't eat anything himself, he was just patted, but that was enough to trigger a reaction, and then we went to the emergency department (2 years old, allergic to egg)

Parents also have to consider the social risks that their children encounter due to their allergy, foremost in settings outside home. One mother says that her son (9 years old, allergic to milk-protein, wheat, barley rye, oatmeal, egg, hazelnut, peanut) is "hyper allergic"

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[2] All namnes are fictious.

and explains that the home has to be "clinically clean"; even a bread crumb may trigger a reaction. He has his separate plates, cutlery and pans and knows that the other family members cannot sit "too close to him". At school he has a buffet made just for him. Similarly, to other parents, this mother comments on how difficult it might be to be singled out because of the allergy. She tries to "turn it around a bit, well you get your food served, I mean that it can be a bit fun if everyone is envious because he gets his tray with food". Another example is a father who realized his daughter was sad when the staff separated her from the other children during meal time, since she (2 years old, allergic to egg, milk-protein) had had a severe allergic reaction at nursery and had to go to hospital in an ambulance. He explains that the staff noticed that she was sad and therefore "moved her to sit close to the door, so she would sit closer to the others". In line with his reasoning other parents argue that certain routines and allergy policies at school might influence the child's social life.

The allergy condition as constantly present in the child's body

The analysis reveals that the allergy is understood as embodied; it is constantly present, "silent" and disguised in the child's body. It becomes visible as an allergic reaction when the child comes into contact with the allergen/s or via medical assessment. Food allergy risk is thus localized to the child's body, as something internal, existing all the time, depicted by some parents as a "ticking bomb". For example, this mother describes the dramatic course of events when they discovered her daughter's allergy. The first time her daughter tasted a cashew nut her lips swelled and she began to cough. At the emergency department, her reactions suddenly became worse:

> they started to treat her and then there were more and more spots, rashes all over, and I asked several times if this is ok, when will it stop, and she is suffering. And they say this is how it can be, no reason to worry, but then everything goes wrong because she starts to vomit, and excrete, and blood pressure goes down and red phones and people everywhere and we had to stay in the hospital (6 years old, allergic to cashew, hazelnut)

The mother explains that this experience was a "very traumatic 24 hours". She felt that her daughter's allergy was a "matter of life and death". Afterwards her allergy toward cashew was confirmed and they were prescribed an Anapen. The mother comments; "I felt I was bringing a ticking bomb with me when we left the clinic, later on it has become much better". She uses a strong metaphor when she talks about her daughter as a "ticking bomb". It implies that something could happen at any time and that the reaction may be powerful. Her account is a typical example that allergic reactions often emerge suddenly and unexpectedly, and that parents often seek hospital emergency care when the child has their first reaction.

Some parents discuss the idea that the food stuff could trigger a latent allergy and that an avoidance of the allergen is necessary in order for the child to outgrow the allergy. This mother whose 4-year-old son is allergic to peanut says that she "regrets that she gave him those nuts". Another mother responds that she has also thought about that, but at some point in time her daughter, 4 years old, would have tasted nuts, and so they would have found out she is allergic. Her reasoning indicates that it is not possible to avoid the allergy by not exposing the child to the allergen. However, there is also an idea that by avoiding contact with the allergen, the allergic condition will not be "added to" and "expanded":

> I think this is difficult when they say you can eat a small amount of something, to provoke the body, this is what many people think, but many people also say that it will be like a ticking bomb, that the body will eventually explode. I have a friend who has a son who has always had tomatoes, until one day he had some ketchup, at the same time as hard physical exercise, and then it said "boom" and he had to go quickly to the emergency department. The doctor said you cannot be allergic to tomatoes, but obviously he was

This mother uses the metaphor "ticking bomb" to depict the ways food allergy can be added to if you expose the body to the allergen. At some point in time the body will "explode" in a powerful allergic reaction. This reasoning also implies that there are at least some possibilities to control the development of an allergy, as a parent of a food allergic child by not exposing the child to the allergen(s). A father refers to the "allergy doctors" he has met and argues that a prerequisite for an egg allergy to be outgrown is that the child does not consume eggs:

> as the doctor said, if you manage to stay away from the eggs for some time, there is a good chance of the child outgrowing the allergy, so it is a matter of not adding to the allergy, try to keep him away from eggs, and when he reaches school age it will perhaps have disappeared

Parent's accounts further demonstrate how food and eating practices might become problematic for their children, but also impact on their own wellbeing, due to the stressful situation of not being able to feed their children properly or of the risk of transmitting allergens, for example, via breastfeeding. The mother recollects that her baby, now 6 years old, literally incorporated potential allergens through her own body via breastfeeding, an example of inter-embodiment, as the threat of illness comes from the body of the mother "into" the child:

> the child health clinic advised me to test different things, to not have milk or eggs. But whatever I did, nothing became better, I lost weight because I didn't dare to eat anything, and finally, when I avoided everything, I demanded an allergy test even though she was only 5 months, and it turned out to be several things such as eggs and milk and I actually stopped breastfeeding because it was easier to know what she had when having formula

This mother's own body is affected as she has to avoid the potential allergens in her own diet, which has consequences when she loses weight during this period of "trial and error", before the child's allergy was confirmed. Similarly, Brownlie and Leith (2011) in their UK study of MMR immunization, argue that parents' "sense of self is shaped through embodied interaction", such as the piercing of the infant's surface and the anxieties related to that. They take their point of departure in an understanding of the infant's skin as a "site of *relationality*"(page 202); a place where self, others and societal imperatives intermingle. They emphasize that we need to understand the parental responsibility in this context of inter-corporeality. Here, empirical examples demonstrate that food consumption involves inter-embodiment aspects. Together with imperatives to eat healthy food and ideas about "good" parenting (Lee et al., 2010; Lupton, 2011) it is reasonable to assume that their difficulties of feeding their children shape parents' sense of self.

In the above examples, the risk of exposing the child to allergens is presented as two-fold; there is the more immediate risk of an allergic reaction, and the longer-term risk of building on or adding to the child's allergy. In line with Lupton (2011) and Brownlie and Leith's (2011) studies parents' give explanations and account for how they understand that the child's body may react to threats from outside. Lupton (2011) demonstrates how mothers discussed the importance of building up the infant's immune system by not exposing the baby to the risk of too much infection in this early lifestage. Here, drawing on their own experiences, together with medical information, alongside references to a "general" knowledge about causes of allergies, parents discuss how the allergy could be avoided or built on if the child is exposed to allergens. Parents do not explicitly mention the immune system but their suggestions are in line with biomedical knowledge; their accounts imply that the immune system does get sensitized to an allergen when exposed to it and then continues to react if triggered by that allergen[3].

Helping the child to identify, interpret and respond to bodily reactions

There are many variations in allergic reactions. Also, the seriousness of reactions might be difficult to judge. Crucially, in an allergic episode, it is the child's life that is at stake. It is against this backdrop that some parents emphasize that it is important that their children learn to recognize their own bodily reactions: "she recognizes her own symptoms, so she can say that now I feel this tickling on my tongue or now I will start to cough" (6 years old, allergic to egg, hazelnuts, cashew, pistachio). Some children have learnt to recognize when something is wrong:

> he had the coconut soup, and felt it was perhaps not right and asked the staff, was there coconut in the soup, and yes, then he felt in his body that there was something, and then they started to act (went to see the school nurse) and this sort of recognizing in his body, I think that is so important, to recognize the symptoms because then you can stop things (14 years old, allergic to nuts, peanut, coconut, almond)

This mother focuses on her son's ability to "know through the body" and thus to recognize an allergic reaction. This also means, she underlines, that he can get help in case of a reaction. Another example is a mother who explains that her 15 year old son is able to discriminate between a mild and a severe reaction. "He knows the difference"; in his case a mild reaction means an itchy throat in contrast to a tingling effect in the body and paleness, which indicates it is a more severe reaction. This knowledge is so important since a reaction can evolve rapidly and might be life-threatening. She says that it "happens so quickly for her son", who is allergic to almond, nuts and seeds. Within 10 minutes he has a reaction, and she has "the fear that he should die", that you don't have enough time to do anything". Another mother comments that in their case it is "the opposite". It can take 3 hours before her daughter reacts, but then it can be "dramatic". She says that now, at 10 years of age, her daughter has "learned to feel this (symptoms of allergy)". This mother says that she hopes that in the future her daughter, allergic to milk-protein and nuts, will "dare to trust herself and not just others". Parents express that with growing age children should be given opportunities to be more independent and learn from their experiences. But that they also experience conflicts in "letting their children go" and at the same time having to remind them of being constantly vigilant. A mother, whose daughter is 9 years old, addresses this contradiction, reflects about the future and says that she wants her daughter to be allowed to be "free and young", but at the same time has to make her attentive to the risks associated with the allergy. Another mother says it is difficult for her when her son, 15 years old, goes away on his own, but that she really tries to not show her fears to avoid passing on her own anxiety. She feels he probably is a "bit worried about having the condition". In line with Bruno de Sousa et al. (2022) study, with parents of children with chronic kidney disase, the results here demonstrate that the parenting of children with chronic conditions or lifelong diseases in many ways is challenging. It involves the parental responsibility to support children to be autonomous and at the same time give children "prolonged, constant and intensive—but unobtrusive—attention and support" (Bruno de Sousa et al., 2022, page 18). We argue that this imperative to consider somewhat contradictory approaches regarding the child's autonomy can be understood as the complexity to striving to *balance* the support within the parent-child-health/illness triad.

Throughout the material there are examples of how parents, regardless of the child's age, talk with their children about the food allergy, to help them understand and manage the risks. As has been demonstrated; children show resistance in different ways. Parents do not describe outright rebellion from their teenage children, but give examples of how their children on occasions "forget" to bring their adrenaline injector or do not "stand up for themselves" in every situation. One mother describes that her son, 15 years old, was "thin as a rake" after the summer camp, she believes that he didn't dare to eat the food served. These examples could be understood as a form of resistance toward parental control and/or that children are in the midst of a learning process to manage their food allergy. The above examples further demonstrate that some symptoms of allergy, such a tingling effect in the body, are invisible to others. The child can feel them and in order to get help, needs to make others aware of them. Other symptoms, such as a cough or paleness, can be observed by others, but still need to be identified

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[3] Food allergic reactions occur when the body's immune system erroneously targets a non-harmful food as dangerous. This sets in motion an immune response that in most cases causes a reaction mediated through the antibody immunoglobulin E (IgE). IgE attach to mast cells and basophils, which leads to an immediate release of histamine and cytokines causing the symptoms of the reaction.

as symptoms of food allergy to be responded to as such. This shows children's competence to recognize the feeling of becoming unwell is based on experience rather than age. Following Merleau-Ponty ((2002[1962])) this knowledge is entrenched in their embodied existence. These children are able to interpret their own body; they are *living* the experience of allergic reactions, feeling and naming the sensations. Thus, it is clear that children with food allergy take responsibility for their own health from a young age and act more independently with growing age. As highlighted by Bluebond-Langner (1978), Alderson (2007) and Brady (2014) lived experience provides children with relevant knowledge, leading them to competent decision-making, particularly regarding issues important to them. Yet, their parents also play an active role in the inter-embodied experience as they narrate their experiences. The results also demonstrate that with growing age the children will face new challenges when they are acting more independently in different arenas. Drawing on the sociology of childhood perspective this demonstrates the context-bound aspects of children as social actors (Holloway et al., 2019). To summarize, by utilizing the concept of inter-embodiment the results demonstrate, from the parental viewpoint, how their experiences of managing food allergy within the family intertwine with that of their children in a parent-child-health/illness triad.

Discussion

Taking an inter-embodiment perspective on parental meaning-making of this case of child illness, food allergy, demonstrates that the character of the parental vigilance is not just a heightened awareness, but an active, constantly on-going process of closely observing and interpreting the child's body and behavior, and of helping the child to recognize bodily reactions of allergy. As we have seen through the deployment of qualitative methods which allow for in-depth exploration, the parents acquire an embodied, practical knowledge of how to manage the allergy. One advantage with focus group interviews as we have seen in this study is that the interaction between the participants and the dynamics in the focus group trigger reflections on the topics discussed and more elaborate accounts to make individual experiences understandable to other participants. Further, whilst we recognize that children themselves did not participate in this study the findings demonstrate important issues about children with food allergy as health actors. Adopting a childhood studies perspective enables an analysis of children's actions and voices within inter-generational relations; in this case, within the parent-child-health/illness triad. At the same time a limitation of the analysis is that we explore this triad from the parental perspective. Thus, aspects of the intersubjective relationships between children with food allergy and their parents might be overlooked, which data from children could have shed light on. There are also limitations in drawing on verbal accounts in exploring bodily issues. Thus, to further advance knowledge of the lived experience of child food allergy or other chronic conditions additional studies, preferably ethnographic approaches, are needed that explore the experiences of *both* parents and their children.

Parental anxiety and vigilance are not unique to parents of children with food allergy, but involve the management of other chronic conditions, such as Type 1 diabetes (Sullivan-Bolyai et al., 2003; Niedel et al., 2013; Rifshana et al., 2017), and hypoplastic left heart syndrome (Meakins et al., 2015). Here, Type 1 diabetes is especially relevant since there are similaries between the management of food allergy and Type 1 diabetes. Both food allergy and Type 1 diabetes are potentially life-threatening conditions that profoundly affect daily life. The individual has to control her eating to avoid allergic reactions or to maintain an even blood sugar level. Food allergy management also involes the administration of adrenaline in cases of severe reactions (Simons, 2010). In addition to diet management and to monitor the childs activity level, diabetes management also requires the need to regularly perform glucose control and to administer insulin (Doyle and Grey, 2010). Sullivan-Bolyai et al. (2003) and Rifshana et al. (2017) use the term "constant vigilance" to capture the circumstance that parental vigilance is a constantly ongoing process to manage the childs diabetes. This care-giving experience, the constantness and the never-ending endeavor to manage the child's condition has been explored by the first author and colleagues in an earlier study of parents of children with food allergy (Stjerna et al., 2014).

What seems to be an important characteristic of the parental vigilance in both cases is the threat of what *could* happen if not paying enough attention or not taking the right measures. Parents of children with food allergy depict food allergy as life threatening, a "death risk" lurking in the background, more or less constantly present in different everyday situations, amounting to an existential condition in parenting (Stjerna et al., 2017). Here, as we have seen, the empirical examples demonstrate parents experiences of their children having severe allergic reactions and being in need of intensive care, as well as less dramatic situations when they "read" their children's bodies to dectect potential signs of illness. Ultimately the child's life is at stake. This entails that *if* the child comes into contact with an allergen/s an ordinary situation might suddenly change and become dangerous. In a similar vein constant vigilance is strongly connected with the parents fear of hypoglycemia and the worry of not being vigilant enough to prevent the the long-term complications associated with Type 1 diabetes (Sullivan-Bolyai et al., 2003). Niedel et al. (2013) who have coined the term "parallel vigilance" to capture the process of how parents learn to discern symtomps of diabetes from other types of symptoms and reactions in the child, demonstrate how parents learn to manage the child's diabetes with more accuracy and confidence over time. The parental vigilance needed to manage children's chronic conditions is therefore to be understood as a certain form of lay expertice. Focusing on the more embodied aspects of this parental vigilance, we can detect similaries to the the care-giving experience of parents of children with Type 1 diabetes. Rifshana et al. (2017, p. 3231) found that parents of children with diabetes "spoke about the embodied experience of caregiving in terms of control and surveillance" but that their attempts to control were undermined by the unpredictable body of the child. Similar to the food allergy case, this unpredictability urged parents of children with diabetes to pay on-going attention to the childs body and actions, and to individualize their care-giving responses. But even with careful planning outcomes were not guaranteed (Rifshana et al., 2017).

Here, the inter-embodiment lens on the parental perspective on the *relations* between children and parents adds to this understanding and reveals how *bodily* interconnected and intertwined parents' and children's lives are. We argue that inter-embodiment is a concept that bridges relations between parents and children as social actors, (...) "children and adults negotiate the status of the child's body and emotions, in the daily give-and-take of relational processes" (Mayall, 2015 p. 313). As Lupton (2012, p. 40) puts it "each body's 'being-in-the-world' is shaped by the other's". What comes through in this study is that children with food allergies could be characterized as being in a state of liminality; a position *in between* different categorizations, such as *neither* healthy or ill (see also Stjerna, 2018). This means that mostly the child is symptom free but at the same time constantly exposed to allergens and the *risk* of becoming ill. The notion of liminality has been used to explore how adults with chronic conditions experience liminal spaces in between health and illness in their everyday life (see eg. Jackson, 2005). But here the analysis demonstrates that parental vigilance is the embodied manifestation of concern for children's bodies which is in perpetual liminality. As children can go from being "healthy" (asymptomatic) to very sick in a moment, parents need to be constantly vigilant. Parents use all of their senses to identify signs of illness in their children and are attentive to their children's bodily expressions as part of their vigilance.

This study further demonstrates that the agency of children with food allergy and parents is intertwined in a complex web of *social* relations, including a range of actors, such as health care personnel, dietitians, and pedagogues at day care and school. This is line with a study of Swedish and Scottish parents' that depicted that different places where the child with food allergy spent time not only demanded different types of risk management but also could vary within the same space from day to day and was depending on several actors (Stjerna et al., 2017). Here, the interactive perspective on inter-embodiment adds to this complexity. It demonstrates how *material* circumstances, such as allergens hidden in food, how the body reacts to an allergen/s and medical treatment to stop an on-going reaction, influence allergy management. Throughout, the analysis of this material clearly demonstrates parental conceptualizations of the child's allergic body as both external and internal. Ideas about the the "external body" are manifested in the ways the parents "read" the child's body to identify potential illness, using their own senses, across minor to serious cases of food allergy. The empirical examples demonstrate that the ubiquity of allergens in many situations, together with the potential severity of allergic reactions, are material circumstances that shape the agency of the child and their surroundings. The health precautionary measures even affect closeness between the child and others, which entails that children may face social risks in situations involving food. Ideas about the "internal body" surface in the parents' understandings of the condition as constantly present in the child's body, depicted by some parents as a "ticking bomb". The metaphor "ticking bomb" implies that allergic reactions might be severe and even life-threatening, arise unexpectedly and, despite precautions, are difficult to avoid altogether. So, despite that parents and children learn to recognize symptoms of allergy over time and thus can exercise some control over the allergy, parents' accounts also demonstrate that the allergy entails this threatening aspect of sudden and severe reaction. In addition, the unpredictability of reactions requires constant vigilance and individualized responses. In addition to parents' understandings of their children's immediate reactions they also discuss the more long-term implications of food allergy avoidance or exposure, in the context of medical advice. The uncertainty of competing discourses of food allergy (different hypotheses of what causes food allergy) and what is the right thing to do, adds to complexity and parental responsibility, which has also been demonstrated in the case of MMR immunization (Brownlie and Leith, 2011).

We argue that parental vigilance has to be understood in the context of inter-corporeality where societal imperatives intermingle with the parental embodied interaction and experience of managing child food allergy. To eat properly is key to maintain health; in Olin Lauritzen's (1997) study the quality of the baby's feeding was used by mothers' as a basic indicator of the child's health, and if perceived as not sufficiently good, subject to mothers' actions. However, this very fundamental imperative to properly feed the child, is actually challenged in cases of food allergy. Here, parents accounts address these issues when they for example narrate about their children's reluctance to eat after having severe reactions. In the context of moral parenthood it is reasonable to assume that such difficulties not just are challenging in the everday practical management of the child's allergy, but also have the potentiality to affect parents sense of themselves as "good parents"(see eg. Lee et al., 2010). The intertwinedness of parents and childrens lives further entails that parents bodies and wellbeing are affected and that bodily boundaries sometimes get blurred, such as in times of breastfeeding. In those cases it is not just the child's food allergic body that is at risk. Also, the mother's own body might get affected by a restricted diet. Parents also express that the constant vigilance means that they experience the emotions of anxiety and worries and try not to pass their own anxiety to their children. This also highlights how the more emotional boundaries between parents and children might get blurred when managing the child's allergy.

In this context of inter-corporeality the results of Henderson et al. (2020) are relevant. They adopted the analytical lens of inter-embodiment in a a study with families who were members of the Choctaw Nation of Oklahoma in the United States who had a child with Type 1 diabetes. These parents who, due to tribal membership had relatively good access to medical care, still experienced anxiety because of the daily glycemic control of their child's diabetes. The results demonstrate how potentially fatal outcomes required parental hypervigilance. This constant vigilance and lived experiences of their children's disease resulted in parents experiencing a stress-induced toxic condition, a kind of embodiment Henderson and colleagues term "diabetes-by-proxy". This psychological embodiment of their childrens disease reveals 'the parent as such a close disease-partner with the child that they experience everything about the condition minus only the physical sensations concurrent with it' (page 35). Thus, this kind of embodiment is virtual as parents have no symptoms of Type 1 diabetes, but cognitively engulfe their children's metabolic physiology, behaviors and mood.

Henderson et al. argue that the parents' absorption of the child's Type 1 diabetes is more than an intellectual endeavor to mangage their childrens condition. It is a way to take virtual control of the death threat that is ever present in the child's body. In a similar vein our analysis reveals that parents of food allergic children are heavily influenced by the uncertainty of the condition and the potentially life-threatening outcome of allergic reactions, which urge parents to be constantly vigilant. The results also demonstrate how the embodiment aspect of this vigilance entails the interconnected food allergy experience of parents and children.

Further, dependency on others is an underlying theme throughout the material presented here and what comes through is the *relational embodied agency* of parents and children. Importantly, childrens' agency is inflicted by power relations. Adopting the inter-embodiment lens these childrens' resistance is associated to the lived experience of allergic reactions and medical treatment and the stress and fear such experiences arouse. Children show reluctance to eat after having a severe reaction or try to resist intensive medical care. Thus, children are far from passive bodies; they recognize symptoms, they make others aware of their sensations and in some instances try to avoid food or medical treatment, evidence of powerful bodily responses to their lived experience. Parents accounts also show how the interaction with service providers, such as health care personnel and dietitians, may be of special importance in some situations in supporting parents to manage those situations. In developing our thinking about children/parents/health and illness it is evident from the above illness narratives that the identification and response to risk (of allergic reaction) is shared, taking place in social interaction between the child, their parents and sometimes health care professionals. Whilst it may be difficult to articulate what takes place in this interaction we contend that the concept of inter-embodiment comes close to explaining the complexity of children's competency in managing their own bodies as they develop experiential knowledge intertwined in embodied relation to parents.

The role of parents is to prevent danger and mitigate risk whilst not being over-protective, which is regarded as a risk in itself. "Wrapping children in cotton-wool" is seen as highly undesirable (Jenkins, 2006). But here we have demonstrated how parents are learning to trust that their child knows their own body and encourage their children to give voice to their experiences and help them to interpret their sensations and feelings. Parents accounts also demonstrate the complexity of this endeavor since children with food allergy in many ways are more "at risk" than other children. They describe tensions in "letting their children go" and at the same time making their children aware of the risks, which have also been demonstrated in the case of chronic kidney disease (Bruno de Sousa et al., 2022). Adding to this, earlier research demonstrates that risk and trust can be seen as closely related in the management of food allergy and that parents "on the one hand have to encourage their children to be constantly aware of food allergy risk and on the other hand develop trust in their children as risk managers and let them live as normal lives as possible" (Stjerna et al., 2017, p. 364). Taken together, these results challenge the simplistic view and dominant discourse which characterizes parents as being over-protective. Thus, our analysis supports McLaughlin and Goodley (2008, p. 323) argument that there is a need to inform social theory by exploring "the day-to-day contingent and situated agency that people enact" when living with disabled, and we argue, chronically ill children. Children with complex health issues or long term health conditions, alongside children with disabilities, are often regarded as being more vulnerable and at risk of various forms of abuse. Parental actions can be misinterpreted or misunderstood by health and social care professionals, perceiving vigilance to be over-protection or intensive behavior that denies children any autonomy. Such perceptions, including carer anxiety, are often a focus of child in need or child protection concerns and assessments. Yet most often parents and carers of children with long term conditions, such as food allergy, are following medically recommended regimes and trying to comply, however they also know their own child and when recommended routes may not be appropriate. Increasing the capacity of parents and carers to care and safeguard their children involves professionals recognizing that parents are a source of support and information and can be relied upon to interpret and to explain signs, symptoms, behaviors of children, their knowledge should be valued by professionals who interact with the child and their family. Ultimately, the needs of the child should remain at the forefront and children should be consulted in matters affecting them, to gradually decrease their dependence on parental carers and to increase their independence. According to Mayall (2015) parents can contribute to children's health and wellbeing in ways other than health, welfare and education service providers often recognize, stemming from their lived experience with their children. Without this recognition parental views and lay-perspectives more generally risk being undervalued. To accomplish successful management of the child's chronic condition, valuing the parental perspective within healthcare interactions is pivotal. The adoption of this perspective of inter-embodiment uncovers a form of embodied knowledge that is often not verbalized and can serve to enhance understandings of the parental perspective of managing child food allergy. These findings offer a new perspective to health and social care professionals who aim to enhance health care and social support for families who experience the complexity of managing food allergy or other chronic conditions, in the daily life of their child.

Conclusion

Taking our point of departure in the parent-child-health/illness triad to explore the embodied aspects of parental vigilance in parenting children who have a food allergy, utilizing the concept of inter-embodiment, has proved to be useful. Acknowledging the limitation of focusing solely upon the parent perspective, this conceptual lens recognizes the interconnected food allergy experience of parents and children. The parents acquire an embodied, practical knowledge of how to manage the allergy. This inter-embodied parental vigilance is constantly carried out trying to exercise some control over the allergy, but the unpredictability of sudden and severe reactions remains. The allergy management also entails that parents are learning to trust that their child knows their own body. They help their children to recognize and interpret symtoms of allergy and encourage them to voice their experiences. However, the character of the potential food allergy risk, the life and death aspect, makes this endeavor especially challenging and accentuates the existential dimension of this care-giving experience. Further, parents experience the constant vigilance as an inter-embodied experience in terms of their own wellbeing and bodies might be affected by managing their children's food allergy. Thus, adopting an inter-embodied lens focusing on the parental experience of managing chronic child illness demonstrates how the illness experiences, in different ways, transcend individual bodies.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The study was approved by the Ethics Committee at the Karolinska Institutet (Nr: 2008/569-31, 2012/1051/32). The patients/participants provided their written informed consent to participate in this study.

Author contributions

M-LS has initiated and formulated the conception and design of the article, collected the data, and together with GB carried out the analysis of the material. All authors contributed to the development of the theoretical perspectives, concepts utilized in the qualitative analysis, manuscript revision, read, and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Combining experiential knowledge with scholarship in charting the decline of the National Health Service in England

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The sustained governmental assault on the National Health Service (NHS) in England during post-1970s financialised or rentier capitalism has received considerable attention by the research community. There is some evidence, however, that many of those members of the public who have not had occasion to use the NHS remain largely ill-informed about the extent of, and reasons for, its present troubles. In this paper I offer an auto/biographic account of my own recent experiences as a patient with type 2 diabetes and subsequent polymyalgia in both primary and secondary care. I then deploy analytic induction to consider, and explain, my personal travails against the background of the shifting nature of doctor-patient interaction occasioned by governmental politics in relation to the NHS. The result is an illustrated story of the decline of health care at a political juncture when the ever-expanding capital assets of a tiny minority of the population trumps the health care needs of the population as a whole. The present impoverishment of management and care must be understood with reference to wider aspects of macro-social change. The paper concludes with some ideas about how to (re)fund a severely ailing NHS.

KEYWORDS
auto/biography, NHS, neoliberal politics, funding, auto-biography, biography

Introduction

This contribution seeks to combine a research-based account of changes in the English National Health Service (NHS) with my recent and ongoing personal experience of long-term illness and resultant contact with local medical practitioners in primary and secondary care. In the first section the scene is set via an abbreviated account of the quite rapid evolution of health care policy in England. The central theme here is the privilege being accorded to the concept of the market and to what might be termed the incremental privatisation or "Americanisation" of health care facilities and services. In the second section I introduce and address my own experiences and the methods adopted in this paper, drawing on a mix of auto/biography and analytic induction. I attempt to both illustrate the changes to the NHS as I experienced or "came up against" them, and to suggest that my series of encounters allows for a degree of extrapolation to, and a two-way or dialectical relation to, the national picture. In the third section I reflect on the social and sociological ramifications of this narrative. In the fourth and final section the analysis is more explicitly sociological. I advance research-based explanations for the policy changes detailed in section one and define these changes as regressive and rooted in policy-based evidence rather than evidence-based policy. I then go on to establish the explanatory salience of macro-social transformations linked to post-1970s financialised or rentier capitalism.

The evolution of policy: the NHS under threat

As I write this the English National Health Service (NHS) is beset by any number of emergency incidents, which is reflective of a long-term decline in its funding which the advent of the COVID-19 pandemic served to expose. In this contribution to understanding and explaining what is now widely perceived to be a crisis in both the health and social care systems, a crisis with long tap roots, I combine an account based on scholarly research with what I classify as "experiential knowledge". The latter draws on my personal and ongoing experience of primary and secondary care following the onset of polymyalgia in March of 2022, compounding the continuing accommodation and management of type 2 diabetes. By way of context, it should be noted that plans to radically "reform" the NHS were planted and began to germinate during Thatcher's period of office in the 1980s, for all that they were largely arrested by alert and antagonistic public opinion: the strength of the public's commitment to the NHS had yet to be effectively undermined (Pollock and Leys, 2004). The introduction of a makeshift "internal market" via the NHS and Community Care Act of 1990, which encouraged private providers, was as far as she could go. This half-way house or pseudo-market sat somewhere on a spectrum between a bureaucratic command and control economy and a private free market, but it was a sign of things to come. Of the reforms introduced by Thatcher's successor, John Major, the introduction of Private Finance Initiatives (PFIs), which were enthusiastically endorsed by the Blair/Brown New Labour regimes between 1997 and 2010, is of special salience. PFIs allowed for the private sector to build, and own, new hospitals and other health care facilities, which they then leased back to the NHS, often at higher rates than would have been the case with government funding and on the basis of 20–30 year deals. They appealed to successive governments because PFI building and refurbishment did not appear on governments' books: they represented an investment of private not public monies. Predictably enough, PFIs subsequently became major contributors to the indebtedness of many NHS Trusts. Thomas (2019) notes that PFIs have become a postcode lottery, and he estimated that 20 years after they were introduced only around £25 billion of the £80 billion expected total cost had been paid; that is, less than a third of the final price, with £55 billion still to pay. This indebtedness was exacerbated by the cuts and austerity measures following the financial crash of 2008–9.

If the future of the NHS as a universalistic and inclusive health care system was rarely openly challenged prior to 2010, a lot was happening behind the scenes. There is evidence of protracted and persistent private sector lobbying prior to the 2010 election (Leys and Player, 2011). Despite David Cameron's pre-election promise that there would be no top-down reorganisation of the NHS by a Conservative government, Health Minister Andrew Lansley, well primed by for-profit health care providers, was in fact already well advanced in his preparations for what was to become the Health and Social Care Act of 2012. This complex and far-reaching piece of legislation further opened the door to for-profit providers of health care. It should be noted in this connection that firm evidence already existed that privatised health care: (i) augments costs because it requires an expanded bureaucracy that comes with contracts, billing and litigation; (ii) encourages "cherry-picking", with the private sector focusing on the most lucrative work, like hip and knee replacements; (iii) opens the way for fees to be introduced as services are cut and hospitals pushed into – often PFI-induced – debt, with for-profit companies "coming to the rescue": (iv) prioritises cost of care over quality of care; (v) leads to rationing, another trigger for patients to "go private"; (vi) under cover of commercial confidentiality makes it impossible to properly scrutinise public spending via contracts with private providers that are primarily oriented to their shareholders; and (vii) promotes a fragmentation of health care services as these are refashioned according to market principles (see Scambler, 2019).

But if the Health and Social Care Act opened the door for the promotion of for-profit health care, a tranche of further intricate, extra-legal "devices" were put in place by stealth and under the public radar. Lansley's successor as Health Minister, Jeremy Hunt, who was already on record as personally favouring NHS privatisation (see Stone, 2016), championed a series of initiatives which, whatever merits might be claimed for them, were also designed to accelerate the privatisation of health care in England. For example, a new model of care via Accountable Care Organisations (ACOs) was introduced, and on Hunt's watch a plan devised to "bundle up" services into "giant contracts" awarded by Clinical Commissioning Groups (CCGs) – and local authorities – to ACOs. ACOs comprised Multi-Speciality Community Providers (MCPs) and Primary Acute Services (PASs), which could involve private and/or public providers. ACOs could subcontract and sub-subcontract for services. And MCP and PAS providers could form Special Service Vehicles, a device to clandestinely engage the likes of private health insurers, property companies and investment bankers. A local service operating under the NHS brand could subsequently be owned by an American private equity company. Following up on this last point, a good deal of attention had been paid recently to the involvement of Centene/Operose in health care in England.

Operose was formed early in 2020 when the American company Centene Corporation brought together its UK subsidiaries, The Practice Group (TPG) and Simply Health. TPG had been acquired by Centene in 2016. In January 2020 Centene increased its stake in UK-based health care by investing in Circle Care (a 40% stake according to Company House). In February 2021 Operose acquired AT Medics and its considerable number of GP surgery contracts in London. Previously owned by six GPs directors, AT Medics had been operating 49 practices across 19 London boroughs, providing services to around 370,000 people, with 900 employees. On being acquired by Operose, its directors resigned and were replaced by Samantha Jones (CEO of Operose, ex-head of NHS England's new care models programme, previously chief executive of Epsom and St Hellier University Hospitals and West Hertfordshire Hospital Trusts, and later PM Boris Johnson's health adviser). A case brought by a patient at an AT Medics surgery protesting the award of dozens of contracts to Operose was dismissed by a High Court Judge in February 2022.

Two observations are in order at this point. The first is that it was under the rubrics of "modernisation", "partnership working", and "patient/consumer choice" sponsored by Blair and Brown's New Labour governments that initiatives like the formation of AT Medics were positively welcomed and encouraged. AT Medics was set up in 2004. The six founding "doctorpreneurs" won several contracts under conditions allowing GP companies to run publicly funded GP surgeries and to employ doctors; patients did not pay fees but 'GP consortia' companies could profit from public NHS funds to run GP surgeries. So it was New Labour who pioneered new business models that the Conservatives went on to develop post-2010 and to refine post-2020. At present (June 2022) the Operose website lists contracts for 20 GP surgeries, plus one treatment centre in Birmingham (plus nine ophthalmology services). This website also now lists the contract for AT Medics to provide services for all of Croydon and some of the South-West London Clinical Assessments Service. With the addition of the AT Medics contracts, the company will have 69 GP surgeries and become the largest GP surgery network in the UK. Second, a well-advertised BBC Panorama programme shown on 13 June 2022 drew on the research of an undercover reporter, who found that Operose employs less qualified US-style Physician Assistants (PAs) to see patients without adequate supervision. Reports from administrative staff confirmed that some correspondence had not been processed and seen by a GP or pharmacist for up to six months. The undercover journalist working as a receptionist at one of the company's London surgeries quoted a GP as saying that they were short of eight doctors and that the practice manager said they hired less qualified PAs because they were "cheaper" than GPs. This new model represents as abandonment of the principles on which the NHS was founded. No longer is the NHS insulated from the profit motive. Centene/Operose are in it to make money and they and their like are permeating England's health care with the blessing of a succession of governments (Mann, 2022).

The most recent top-down reorganisation of the NHS came via the Health and Social Care Act of 2022. This Act established Integrated Care Systems (ICSs) as commissioners of local NHS services, whilst also granting the Minister ultimate authority over the health service. Specifically, the two component parts of the ICS – the Integrated Care Board (ICB) and the Integrated Care Partnership (ICP) – are to have statutory status and will collectively hold the ICS's legal powers and responsibilities. ICBs will be responsible for the NHS functions of the ICSs, while the ICPs will oversee their wider public and population health work. What this means in effect is that Clinical Commissioning Groups will be absorbed into their local ICSs; and their commissioning powers and most of their staff will become part of the ICS body. The British Medical Association had expressed concerns at these projected changes at the Bill stage, seeking assurances that there would be: appropriate clinical and patient involvement at every level of ICSs; a default option for establishing the NHS as provider of NHS contracts to protect the NHS from costly procurement and fragmentation of services; guarantees that private providers would not exercise undue influence by sitting as members of NHS decision-making bodies; and safeguards and limitations over the Minister's powers to avoid unnecessary political influence in NHS decision-making. It is already hard not to see this intervention as too little too late, but then the BMJ was primarily focused on its members' interests.

Other critics have been more forthright. One such critique runs as follows: now the old system of Clinical Commissioning Groups has been replaced by ICBs, it is up to NHS England, not parliament, to decide who each ICB will be responsible to. It could be, for example, that ICBs might be able to challenge allocations and thereby, in effect, to select patients. New groups of people could be excluded from NHS care, as certain migrant people currently are. Another compelling criticism is that after many years of NHS under-funding, and then COVID, the inevitable result will be more rationing and care will become a postcode lottery. It will, it was presciently claimed, become harder to see a GP and the NHS could well become a kitemark for providers. For-profit companies will receive taxpayer money to deliver procedures, and shareholders will be prioritised over reinvestment in the NHS. These may be early days, but there is no doubt that a door deliberately left ajar in 2012 to welcome and incentivise private providers has been opened further by the 2022 legislation (see Scambler, n.d.). These are issues I return to in the final section of this paper, but it is now time to address my personal experiences.

Knowledge via experience: methods and the unfolding of events

Auto/Biographic data can put compelling, including emotional, flesh on otherwise bald skeletal accounts of social phenomena by appending experiential to scholastic knowledge (see Twinley and Letherby, 2022). It offers a return route from the personal to social structural and cultural relations (Ellis et al., 2011). In their discussion of auto/biographical approaches to researching death and bereavement, Brennan and Letherby (2017) extend this argument by contending that auto/biographical studies can constitute a challenge to "traditional" claims to objectivity both by recognising and factoring in the personhood of researchers and respondents and by providing a more intimate access to and way of analysing the complexity of the relations between self and other. My personal narrative in this contribution contains a fair amount of detail and covers a period of nearly a year between March of 2022 and February 2023. I had for a number of years been experiencing type 2 diabetes, for which I was taking routine medication when, out of the blue, I began to experience severe pain in my joints. The discomfort was omnipresent, accompanying all movements, and was particularly inhibiting when lifting or carrying. It was even painful to change position in bed. Adopting a not uncommon – and characteristically British – policy of "wait and see", I tolerated this for some weeks before seeking help. As "encouraged" by my local GP surgery, I went online to request a face-to-face appointment, incorporating a suggestion that I might be suffering from polymyalgia (which had afflicted my mother and which had also been confidentially raised as a possibility by a professorial clinical colleague via DM on Twitter). I was granted a phone call, a mode of contact that I was instinctively reluctant to regard as "a consultation". Despite being registered with the practice for nearly 20 years, "GP A" who rang me was not known to me. On being told that I had experienced a bout of COVID two months previously, she diagnosed long COVID and was reluctant to consider alternative diagnoses. She prescribed strong painkillers to be taken for six to eight weeks. These painkillers had absolutely no effect and I stopped taking them after a month. At this point an insistent phone call to the practice secured a face-to-face GP appointment, once again with a hitherto unknown practitioner, "GP B". "GP B" was very receptive and helpful, made a provisional diagnosis of polymyalgia and arranged for both a blood test and a consultation with the local consultant rheumatologist. In the meantime, he started me on a low dose of steroids and, at my prompting, we discussed the likely disruptive effect of the steroids on my glucose levels. So around two months after the onset of symptoms, and a month after my initial contact with the surgery, some progress was being made.

I was not to see "GP B" again, though he did later phone me with the blood test results to confirm that the diagnosis of polymyalgia was the front runner and to see if I had yet seen the consultant rheumatologist. I replied that I had not at that point but that an appointment had been arranged. I was never to hear from him again. When I saw consultant rheumatologist, "Consultant 1", at my "local" – it was a half-hour drive – hospital, she advised upping the dose of steroids and prescribed a selection of other drugs to mitigate any negative effects of the steroids. She asked me what I had done prior to retirement and, on discovering that I had been Professor of Medical Sociology at UCL Medical School, initiated a relaxed conversation about shared experiences. She gave me a personal mobile number and told me to let her know if any problems arose. This consultation led to a series of blood tests and follow-up encounters at the same hospital, which was her base. I was also referred to have a scan – incidentally from a privatised facility – to check that I was not suffering from temporal arteritis, a potentially serious condition that can lead to irreversible sight loss (I wasn't). Over time, the steroids alleviated the symptoms of pain and discomfort without eliminating them. The principal residual pain was, and has remained up to the present, in the fingers and hands. But a lot of water has passed under the bridge between then and now.

Somewhat to my surprise there was no attempt on the part of my general practice to either monitor the effect of the steroids on my glucose levels, which did indeed become predictably unpredictable, or to assume general responsibility for my continuing treatment and care. In fact I had to return for a second visit to have the scan to check for temporal arteritis because my unmonitored glucose level was too high on the first visit to proceed. I wrote to the senior GP partner at this point articulating my concerns in what I hoped was a sensitive fashion, but she did not reply. I subsequently redacted all personal and local details and made this letter available as an 'open letter', the final two paragraphs reading as follows:

> 'I am sure this is all stressful for everyone working in the NHS, the more so if they are aware of the politics. It is of course stressful for their patients too. Patients, as you will know only too well, are now angry when they cannot see 'their' GP, or indeed any GP. Receptionists too are in the front line. What I would say is that we patients are right to be angry at the effective termination of continuity of primary care and at what is without question a deterioration in the service, with worse to come. The problem is that few patients either realise the constraints within which you work or that this is all a predictable consequence of the political strategy deployed by central government.
>
> I would like to see blame apportioned appropriately. In particular I would personally like to see pithy posters in every NHS surgery and clinic explaining that staff are doing all they can to meet growing patient demand, but that services have been impacted by central government underfunding, which has long affected staffing levels, hospital beds etc., but which has been made worse by restraints on doctors and nurses trained overseas, COVID, practitioner burn out, exhaustion, and so on. Might something like this be desirable/possible? I think health workers and patients should be united in standing up for the NHS.'

It was in fact only courtesy of "Consultant 1" that the diabetes issue was addressed. She referred me across to "Consultant 2", who duly fortified my existing diabetes medication with another top-up drug. Over the following months I had repeated blood tests and saw "Consultant 1" quite regularly, after a while at a more convenient out-patients clinic, and I was at the same time monitored also by "Consultant 2". Whereas initially my now-multiple repeat prescriptions were available from my local community pharmacy, this was discontinued due, I was informed, to a shortage of delivery drivers. From that point on I switched to another community pharmacy and attempted to arrange for the relevant prescriptions to be requested in timely fashion from my general practice: these would normally take two or three working days to be processed and made ready for my collection.

I negotiated another face-to-face appointment, this time with "GP 3", yet another stranger to me, to ensure that all the drugs I required were recorded in my file. He told me that he was not "allowed" to add any drugs to the list and that I would have to see the practice pharmacist. "But your'e a doctor! Are you telling me that you cannot check and update my file yourself?" "Sorry." An appointment with the pharmacist was not possible for two or three weeks. When I did see her, I went through each of the nine drugs I was taking at that point. During this period I became increasingly dependent on "Consultant 1" to compensate for the tardiness of the general practice: I would text her, with profuse apologies, to ask her to send through prescriptions for whatever drug I was running out of to the local community pharmacy for me to collect. This unhappy routine was eventually to reach a climax when I was thwarted in acquiring more steroids (which as the card in my wallet affirms, it is not advisable to run out of). I visited the practice personally on four occasions over two or three days to sort out any apparent confusion. On each occasion the receptionists were concerned and helpful, and on each occasion the prescriptions were in the event not signed off by the duty GP, this despite me showing the receptionists my copies of letters from "Consultant 1" to the practice that explicitly confirmed that she had prescribed the relevant drugs and new copies of these letters being taken (they should of course have been in my practice file anyway). In the end, in despair, I filed a complaint online, this time making my personal experience and knowledge of healthcare and of the pressures GPs and other health workers were under clear. Within hours I was rung by the practice manager, offered an apology, and reassured that it would not happen again. I expressed my scepticism.

Knowledge via experience: reflections

Familiarity with the research literature on long-term illness is of limited help in coming to terms with its day-to-day intrusion. In my favour was the fact that I was retired and therefore not obligated to fulfil routine work-related tasks. Coming to terms with type 2 diabetes, a common enough issue, had not troubled me. I was aware that severe and unrelenting weight loss through dieting could remove it, but I was no less aware that people who take this option tend to relapse sooner rather than later. Polymyalgia occasioned different problems. These fell into several categories. First, it was and remains painful, even when mitigated by strong medications. Give the concentration of this pain in the fingers, hands and wrists, the left marginally more than the right, the price paid in loss in functional engagement has been considerable: my hands and arms have lost their powers of leverage. This is an impairment that exacts a continuing cost. Second, there is continuing uncertainty about both the prognosis, though polymyalgia might typically be expected to loosen then relinquish its grip between 18 and 24 months, and the likely medium-to-long-term effectiveness of quasi-experimental cocktails of drugs. Third, and perhaps of most salience, there is a lingering uncertainty about the precision or "completeness" of the diagnosis of polymyalgia. "Consultant 1" has been refreshingly open-minded here. Is it possible that long COVID triggered, or is even mimicking, polymyalgia? And is it possible that the unremitting pain in the fingers is mostly or partly a symptom of rheumatoid arthritis? Furthermore, how might the undoubted iatrogenic effects of the drug regimens be factored in? It is something of a cliché in medical sociology that patients abhor uncertainty, sometimes even preferring, at least in the short term, negative surety over continuing doubt. I confess to seeking answers to constrain and retract uncertainty's boundaries; but I am only too aware that experts like "Consultant 1" are necessarily extemporising, especially given the lack of data around COVID in general and long COVID in particular. In my case, as I awake in the morning and ritualistically clench my fists and flex my fingers to appraise the day's likely level of discomfort, I am confronted not only by "rational clinical uncertainty" but by other potentially intrusive causal factors like the typical impediments of ageing and the relatively unstructured, even anomic, day that lies ahead. Just what is doing what to me, and how will it pan out over what time scale?

What of my views of my encounters with the medical profession? I have been very impressed by "Consultants 1 and 2", though I may well have had a degree of preferential access, especially to "Consultant 1", by virtue of my professorial past in UCL Medical School. This was not a privilege I sought by mentioning/trading on my university position – I was asked in passing about my career by "Consultant 1" – but I suspect I was subsequently and remain a beneficiary. But between them, "Consultants 1 and 2" have simultaneously applied their specialist expertise *and* substituted for the lack of engagement or continuity in GP care. I would put it more strongly: my experience of GP care throughout this lengthy episode has been close to abysmal. Like many others I have found it exceptionally difficult to arrange face-to-face consultations, this despite being personally informed by one GP – in the midst of my period of illness – that the practice partners had met and decided that face-to-face consultations were to be the default option. Every time I attended the local surgery, usually for simple procedures like blood tests, the waiting room was virtually empty, even in peak mid-morning shifts. When I asked where the twelve GPs associated with the practice were, I was told they were either in their rooms, at one of the other two surgeries covered by the practice or working from home.

These observations, or impressions, coalesce into a series of propositions that I will seek to contextualise and examine in more depth and more sociologically in the concluding section of this paper.

1. From my experience, which routine reports on the mainstream and social media confirm are not unusual, GP care has suffered a marked deterioration. The differences between the GP care available when I was a child in the 1950s and now are almost beyond characterisation. In the 1950s I could turn up and queue for an appointment with my GP and get one in either daily morning or evening surgeries. If I needed a home visit, I could have one on the same day. It will be objected that 70 years on we now inhabit a more complex, highly differentiated world; rapid population growth has taken place, especially of third and fourth agers; concepts of illness and disease have expanded; medical interventions and technologies have become more sophisticated; and the provision of clinical treatment and care has become much more expensive in real terms. All this is true. But we should note and not downplay the vivid contrast between GP access during my childhood and GP access now.
2. The degree and rate of deterioration in GP services has accelerated since the Thatcherite 1980s. The notion of 'deterioration' is pivotal here. Back in the 1980s I was asked by a group of consultant neurologists to specify the criteria for good quality care in relation to epilepsy. When I did so, one consultant responded by politely protesting: "That's all very well Graham, but we simply do not have time to do this." My response is germane: "Then do not claim to offer good quality care. The best you can do in unfavourable circumstances does not necessarily equate to good quality care."
3. It is important that GPs acknowledge that the service they currently offer *has in fact deteriorated*.
4. It does not follow from this deterioration in primary care that GPs and their colleagues in allied professions are culpable. They might be on occasion, but they are more often not.
5. The oft-heralded rapid displacement of face-to-face consultations by phone calls is not *primarily* a rational innovation but rather a GP practice coping device. This is not to deny any future role for phone calls, emails, telemedicine and so on (far from it); but it is to insist that the current shift in modes of contact is GP-led not patient-led. I have found phone calls with "Consultant 1" and "Consultant 2" convenient and helpful, but with GPs nominally responsible for continuing care much less so. The point to emphasise is that it is simply disingenuous to suggest that this switch from actual to virtual consultations is the result of patient choice. It is not! It's a mechanism that helps GPs and their colleagues get through their day-to-day workloads.
6. What can easily go missing in virtual dialogue are those aspects of human relations that find their expression in gestures like nods, smiles and "bodily concern". As a prospective patient I have happily had very little contact with doctors over the years, but perhaps it is not unsurprising that now, in my mid-70s, and drawing on what little experience I have had as a patient, I want, I almost wrote "demand", to sit down and speak to someone face-to-face who manifestly cares about my pain and discomfort and the stresses they occasion. I have had this with "Consultants 1 and 2", but it has been missing from general practice.
7. I have argued that GPs might put up posters in their surgeries apologising for *what now really is a poor service* and stating that the medical and allied staff are doing the best they can in new and challenging circumstances that have their origins in the underfunding of both primary and secondary care plus the sequelae of COVID etc. Patients are (often) right to be angry when they cannot see their GPs, but they are (equally often) wrong when they take this anger out on GPs and their colleagues.

Why this impasse? How might sociology help explain it?

In this section an attempt is made to place both the moves of successive governments to 'reform' the NHS and to promote private health care and my own experiences seeking help with long-term illness in context. Here scholarship informs experience. What the data show is that the top-down reorganisations of the NHS have been accompanied by constraints placed on funding, most conspicuously during the decade of austerity introduced by the Cameron government from 2010. Drawing on resources from the King's Fund (2022) and the British Medical Association (BMA) (2022a,b,c), a summary of pertinent statistics on annual expenditures on the NHS in England and on changes affecting primary and secondary care reads as follows:

- Funding for health services in England comes from the Department for Health and Social Care's budget. Planned spending for 2022/23 is £180.2 billion, the majority of which will go to NHS England (£152.6 billion), with the remainder allocated to other national bodies for spending on other health-related functions such as public health. After several years showing modest increases, the Department's spending in 2020/21 and 2021/22 included funding to respond to COVID, with the result that the Department's budget grew rapidly between 2019/20 and 2021/22 before falling in 2022/23. It is projected to increase by 1.2% in real terms over the next two years. To provide further context it should be noted that the NHS continues to face severe financial pressures, with Trusts across the country spending more than they are bringing in. NHS England in 2013 said it faced a funding gap of £30 billion by the end of the decade. Despite this, the NHS was asked to find £22 billion in savings by 2020. The Nuffield Trust and King's Fund have shown that tight spending and increasing demand for services have already led to some treatments being rationed and the quality of care in some areas being diluted.
- Referring to the hospital sector, COVID laid bare the fact that England does not have enough critical care beds. Bed shortages alongside high occupancy are unsafe for patients and staff. Data for the second quarter of 2022/23 indicate that bed occupancy levels in England have risen substantially and have passed the recommended Sage threshold again. In fact, since 2010 average bed occupancy has consistently surpassed 85%, the point at which safety and efficiency are at risk. Coming into the pandemic, England had an average bed occupancy of 90.2% in 2019/20, though local variation in supply and demand have seen many Trusts regularly exceeding 95% capacity in the winter months. Prior to COVID, the total English NHS hospital bed stock reduced by 8.3% between 2010/2011 and 2019/20 as the average daily total of available beds fell from 153,725 to 140,978 (in 1987/88 there were 299,000 beds). Issues around bed occupancy are compounded by discharge delays caused by pressures in social care. Social care has been neglected by successive political regimes and remains on the backburner despite multiple political promises to the contrary. The UK in general continues to have a very low total number of hospital beds relative to its population: the average number of beds per 1,000 people in both OECD and EU countries is 5, while the UK has just 2.4 (Germany has 7.8).
- These general data on NHS expenditure and hospital capacity and care accessibility have clear implications for general practice, the core topic here. GP appointment bookings peaked over the winter of 2021. In terms of access, 48.1% of appointments in December 2022 were booked to take place on the same day (85% were booked to take place within two weeks); in terms of 'appointment mode', 68.3% of appointments were booked to take place face-to-face. At the same time, a number of practices have closed and more than two in five (42%) GPs are planning to work more flexibly and from home more. A long-term decline in GPs coincides with a rise in patient numbers. While there are 1,990 fewer fully qualified "full-time-equivalent" (FTE) GPs now than there were in September 2015, each practice has on average 2,224 more patients than in 2015. The average number of patients each GP is responsible for has increased by 335–17% – since 2015, and now stands at 2,273. Since 2017 the number of GPs working full-time hours or more in GP practice-based settings has been steadily decreasing. At the same time the number of GPs choosing to work less than full-time has been climbing, probably because doctors are moving to working patterns that allow them better to control their hours and workloads to reduce stress, ill-health and burnout. In reality, however, many part-time GPs often work additional unpaid hours just to get through the number of appointments, essential patient follow-ups and administrative work. In December 2022 there were 36,622 fully qualified GPs working in the NHS in England; in FTE terms, this equates to 27,375 fully qualified GPs. The overall number of GPs has seen little growth since 2015 while the number of GP partners has declined significantly. In a BMA survey, one in 10 GPs said they planned to leave the NHS altogether after the pandemic. Government plans to reverse this problem have so far failed.

What this assemblage of data confirms is that while patient dissatisfaction with primary care is understandably high, this problem cannot simply be laid at the door of GPs behaviour. It is obviously linked, for example, to growing deficits in secondary care options and, especially, in the long-term collapse of social care. But we need to delve deeper yet. In what follows I draw on a previous detailed study of the sociology of health and health care (Scambler, 2018). I shall argue that the top-down NHS reorganisations post-2010 were indeed aimed at facilitating the involvement of the private sector, and that *the strategy adopted to accomplish this was to deliberately underfund the NHS to create sufficient public dissatisfaction to allow the government to call in for-profit providers to "come to the rescue of the NHS" without having to face a crisis of state legitimation* (Habermas, 1975). It is revealing in this connection that several Conservative MPs and donors hold paid positions and/or shares in private health care companies (see Scambler et al., 2021).

The decade of political austerity from 2010 to 2020 was the product of a pre-planned Conservative government strategy to push back on post-WW2 "welfare statist capitalism"; and the underfunding of the NHS was at the core of this strategy. It was a plan awaiting a propitious moment. Thatcherite Conservative MPs had come to see the NHS both as "socialism in practice" and as ripe for plunder by business. As welfare statist gave way to financialised or rentier capitalism, an emergent and ultimately ubiquitous neoliberal ideology afforded cover for this act of political sabotage. But political action typically has tap roots in social structure and culture. I have long argued that social class qua social structure remains a vital causal force in contemporary English society. I have referred elsewhere to a new, or revised, "class/command dynamic" in post-1970s rentier capitalism. "Big business" has always exerted its influence on government and on policy. But in rentier capitalism this influence has grown exponentially, giving a new bite to the formula: *capital buys power to make policy in* *its interests*. Stated more precisely, a tiny hard core of owners of capital (well under the 1% exposed by the Occupy Movement), comprising a global mix of financiers, major shareholders and CEOs, many of them transnational 'nomads' with no loyalty or commitment to the nation states in which they reside and operate, can now buy far more political power to influence policy in their interests than could their predecessors in welfare state capitalism. Arguably, they now have representatives in the Conservative cabinet, not least in the form of multimillionaire Prime Minister Rishi Sunak. In terms of the class/command dynamic, class relations have come to exercise more control over the command relations of the state. It is the reinvigorated class power that the less than 1% of 'capital monopolists' have come to enjoy in rentier capitalism that has enabled the Conservatives to set about undermining the NHS and opening it up for international profiteering. All the evidence from comparative studies tells us that introducing markets into the provision of health care is a regressive move, and as mentioned earlier it is a process already well underway.

My deliberately provocative "greedy bastards hypothesis" (GBH) was advanced to address not primarily the assault on the NHS but the reconfiguration of what have come to be called "social determinants of health". *If you want to understand and explain poverty, study the wealthy*. The GBH asserts that the growing health inequalities documented in England since the 1980s, actually accentuated during the COVID pandemic (Marmot and Allen, 2020), also have their genesis in the strategic behaviours of the capital monopolists. It is their telling influence on policy via their attacks on the welfare state, the NHS, benefits, employment security, disability, pension entitlements, trade union rights, protests and so on that have amplified health threats to the poorest and most impoverished in society; and the evidence is entirely consonant with this thesis. Poorer lives have been disfigured and cut short during rentier capitalism in general and particularly during the years of austerity and since (Scambler, 2018, 2020).

The impact of the COVID pandemic had several sequelae of relevance to the analysis in this paper. First, it showed the deep and deepening fissures in our fractured society in even sharper relief; and it did so in the domain of people's health via COVID-enhanced morbidity and mortality rates for those disadvantaged by structural relations of class and race in long-deprived regions, communities and neighbourhoods. Second, it shone a harsh spotlight on a decade of NHS underfunding and the resultant worsening of public access to over-stretched and under-staffed NHS services (see above). Third, it placed intolerable burdens on already overworked doctors, nurses, and allied health and community and residential care workers, resulting ultimately in high rates of job-stress, burnout and people leaving their jobs. Fourth, it illustrated just how readily a government can find a "magic money tree", not only when it needs to bail out banks but when a crisis of state legitimacy is in the offing. Fifth, it provided efficient cover for a stealthy pursuit of the government's longstanding agenda of involving for-profit companies in the provision of health care services in the name of "meeting the COVID challenge". As COVID began to fade as an alarming threat, so too did the welfare-statist default option of the in-house provision of clinical services. And sixth, it exposed afresh the levels of political corruption in awarding contracts for ameliorating the effects of COVID to Conservative Party donors, network allies and friends (Scambler et al., 2021; Maugham, 2023). At the time of writing this, a post-COVID "cost of living crisis", consequent on new Conservative Prime Minister Sunak's political resurrection of economic austerity following the implosion of the short-lived, flailing Truss premiership, has not only led to widespread strikes, including but by no means confined to health workers in the guise of junior doctors, nurses and ambulance staff, but once again holds out the promise of an imminent crisis of legitimation.

What is to be done?

I have elsewhere discussed the structural and cultural obstacles to the kind of social transformation that might allow for a lasting reinvigoration of institutions like the NHS, distinguishing in the process between "attainable" and "aspirational" reforms (Scambler, 2022). The objective here is more modest. It is to suggest ways in which the NHS might be "saved" in the absence of some sort of social revolution. It draws on the work of Murphy and Hines on behalf of Tax Research UK (2023). Their underlying premiss is that the NHS is currently underfunded by approximately £30 billion *per annum*, the culmination of 'austerity in NHS funding since 2010'. In sum, there is a shortfall of more than £400 per person per year in NHS funding. The authors address various imaginative but orthodox options for addressing this shortfall:

- £10 billion of the funding could be raised by the additional taxes paid by those employed by the NHS to deliver the requisite services, were they to be "lured back to the service by better working conditions and higher pay" (many of them now work in lower-paid jobs in the private sector). The impact of the extra NHS spending on growth elsewhere in the economy is taken into account in this estimate.
- At least £5 billion could be raised from taxes paid by those able to return to the workforce, either because their own conditions will be sufficiently well managed to allow this or because those that they care for will enjoy better health, letting them return to work.

If half the funding required to return the NHS to a healthy functioning state could be generated from the benefits created by this additional spending, what about the other £15 billion?

- The government could simply opt to run a bigger deficit to satisfy the remaining £15 billion. The impact on national debt would be insignificant, at less than 0.6% of national debt (according to the criteria that "the government likes to state it *per annum*").
- Alternatively, the Bank of England currently has in place "a quantitative tightening programme of selling the government debt that it owns that it bought under the quantitative easing programmes that paid for the banking crises of 2008/9, the Brexit crisis of 2016 and the Covid crisis of 2020/21". If £15 billion of this programme was cancelled each year and bonds to fund the NHS were sold instead, this step would deliver the necessary NHS funding. In such a case there would be no net impact on the amount of national debt owned by third parties.

Monies might also be raised via changes to the tax system that would have no effect on the vast majority of taxpayers:

- The tax reliefs on savings available to the wealthiest 10% of citizens each year might be halved. Presently this group enjoys at least £30 billion of pension and ISA tax reliefs each year. That subsidy per wealthy person might exceed average Universal Credit payments to each person in receipt of that benefit. Halving this relief would still provide the wealthy with very generous subsidies for their savings but would underwrite the NHS "we all need".

- Or, given that the Public Accounts Committee of the House of Commons has found that for every £1 spent on tax investigations £18 of additional tax is raised, investing £1 billion in additional funding with HM Revenue and Customs might be sufficient to recover the funds required for the NHS each year.
- Another option might be to set the rate of capital gains tax, currently set at half the rate of income tax in most cases, and very largely paid by the wealthiest groups in society, at the same rate as the income tax rate. The revenue from this tax might then double, raising £15 billion per year.
- Other options might include: (i) raising £6 billion a year by charging an additional 15% income tax on the investment income of those below pensionable age who have more than £5,000 of investment income *per annum* (since they do not pay national insurance but enjoy the benefits of the NHS); or (ii) the so-called "non-dom" rule that lets wealthy people with an origin outside the UK live here but not pay tax on their overseas income could be abolished, raising in the region of £3 billion per year.

I am not economist, but it is clear from this "attainable" menu of options that there exist several routes out of the NHS underfunding that do not require the overthrow of rentier capitalism. That there is no prospect of any of them being followed at the time of writing bears testimony to the Conservative's commitment to destroying rather than saving the NHS and, at a deeper or more sociological level, to the salience of the class/command dynamic.

Concluding comments

In this brief contribution a personal narrative has been outlined as a way of introducing, preparing the ground for, and illustrating an analysis of the current state of play in the ailing NHS in England. It is not of course being claimed that this narrative is a substitute for a representative survey of the experiences of people-*cum*-patients, but we know enough from regular items on the mainstream and social media to suggest that it might well strike a chord. We also know that while patients are becoming increasingly dissatisfied with the health care on offer, they remain committed to the core principals of the NHS, namely, that it's free at the point of use, available to everyone and funded by tax (Health Foundation poll, reported in an editorial in the Guardian, 2023). At the same time, the difficulty of accessing health care is prompting more people to jump NHS queues by "going private". According to Dorling (2023), while in 1980 about 0.5% of Gross Domestic Product was spent on private health insurance, in 2021 it was more than 2%. In other words, *just as planned*, the involvement of the private sector in the provision of health care is growing apace. This brief paper has sought to place the day-to-day experiences of people-*cum*-patients like myself into a broader social and political context, and to link this to deeper structures like the changing relations between class and state. It is often GPs and GP receptionists who bear the brunt of people's disillusionment.

My general assessment of a changing medical and health care environment might be summarised as follows. First, the medical and allied health professions should not only focus on extant problems with health care delivery but recognise and be upfront about the government's agenda and direct responsibility for this deterioration. Second, the switch to phone calls and telemedicine as default options should be recognised for what it is, a coping device, and not presented as an innovation motivated by patient choice. This is *not* to reject a role for virtual expedients, far from it. But many third and fourth agers (like me) value *actual* contacts with *our* doctors, people who are familiar with us and our medical histories and have time enough to demonstrate through their attention and action that they *care* about our wellbeing. Finally, health care, just like population health, is intrinsically political. To pretend otherwise, or to remain institutionally or personally aloof, is effectively to genuflect to the status quo, a status quo which in contemporary England is irrational, exploitative and unacceptable. The "cost of living crisis", and its articulation via the related "health care crisis", might in the first half of 2023 yet issue in a crisis of state legitimacy and a more progressive than regressive package of reforms. We shall see.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

The author confirms being the sole contributor of this work and has approved it for publication.

Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Learning journeys – student learning development in the first years of a medical degree: an analysis of student conversations

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Introduction: Students starting medical school generally come from a learning background that expects them to learn content, which is reproduced to pass an exam. As a part of their learning development, they must adapt and become self-motivated learners who can determine the underlying principles or concepts and use these to problem solve in the uncertainty of real-life clinical practice. Whilst much has been written about designing curricula to promote learning development, there is no one-size fits all approach to facilitating this type of learning, thus an analysis of what helps and hinders learning development is indicated.

Methods: Student pairs in Y2 and Y3 of an undergraduate Bachelor of Medicine, Bachelor of Surgery (BMBS) programme of a South-West UK medical school, were asked to audio record a conversation about their learning through a facilitated problem-based learning approach during the BMBS course so far. They were provided with a brief to aid them in their discussion in the style of the outside broadcast method of BBC Radio 4s listening project. Using this method, the conversation was unfacilitated and allowed to take its natural course. Conversations were transcribed and coded to determine emerging themes with respect to the developing understanding of the students about what and how they were learning.

Results: Four student pairs volunteered for the project one from Y2 and three from Y3. Five key themes were identified including: from 'learning it all, to structured learning'; 'developing understanding and the spiral curriculum'; 'working alone versus working with others'; 'integrated learning and understanding context' and 'assessment and resources.' Narrative analysis within these themes suggested that over the course of the first two to three years of study, participants developed a better understanding of how best to learn, although there were differences in both time and order that participants reached a point where learning felt more natural to them.

Discussion: Analysis of the data suggested that students develop independently towards being self-motivated lifelong learners. There were several key aspects of curriculum design that could be used to facilitate this development, which could easily be incorporated into developing or creating problem- / enquiry-based curricula.

KEYWORDS

learning journey, problem-based learning, medical education, narrative analysis, thematic analysis (TA), listening project, conversations about learning, understanding learning

Introduction

Students arriving on day one of the Bachelor of Medicine, Bachelor of Surgery (BMBS) undergraduate medical programme are predominantly school-leavers or school-leavers returning from a gap year. Secondary education in the UK still focusses on factual knowledge reproduced under exam conditions as a measure of success, rather than learning skills required to succeed in independent learning (Beers, 2006; Jones, 2011). Accordingly, to access the course, entrants must have been diligent in learning the syllabus of their A-levels. As a medical student and by inference a trainee doctor, it is not possible to know everything there is to know. Therefore, it is no longer enough to regurgitate knowledge and students must learn to remember useful key concepts that can be used to process and evaluate information in different situations. Students entering a medical (and many other university) programme(s) need to adapt quickly to a very different learning approach. This BMBS programme, presents an integrated curriculum across, multiple themes. Students in year 1 and 2 spend much of their time in the classroom learning theory and content through a range of learning activities including enquiry-based learning, lectures, interactive and practical classroom learning and small-group discussion. This is complemented by early clinical exposure through placements in a wide variety of healthcare settings, where they can see the value of their learning through working with patients. In year 3 and beyond, students spend more of their time in hospital placements, integrating and stimulating their academic learning through clinical exposure to a broad variety of patients on longer clinical pathways. Thus, it is necessary for students to adapt to a new learning environment early in the course. The curriculum design requires them to consider complexity and the broader perspective of medicine from the outset. Furthermore, assessment via a progress test that measures applied medical knowledge at the level of a newly qualified doctor demotes their attainment to single-figure percentages rather than the A/A* grades to which they have been used. This presents a dilemma for many students. Although they are marked against the rest of the cohort, in terms of their overall grade percentage, they are faced with a score that would previously, have represented failure, or at least, significantly below-average attainment (Rodway-Dyer, 2010). In addition, students are marked by their tutors in terms of their professionalism and ability to learn both individually and as a member of a team, as well as via more traditional means, such as essay writing and knowledge tests. Unsurprisingly, this presents a challenge to their learning approach, which for many includes a complete re-evaluation of learning from a syllabus to attain top scores, to development of understanding to progress. Within this, they must learn to weave in the knowledge that they learn from both traditional structured learning and personal experiences. Current thinking in terms of learning in any social setting, which by extension includes medicine, particularly where an holistic approach following the biopsychosocial model is employed (Engel, 1977), requires more than an accumulation of knowledge (McInery, 2018). Indeed, professional development requires a lifelong learning approach where students must start to transfer and use their knowledge to new or unfamiliar contexts. This in turn helps them to improve their understanding of each topic and develop their overall knowledge (Maton, 2009).

During the design and development of curricula, all stakeholders must be considered in deciding which concepts are necessary and relevant to overall understanding (Davenport et al., 2004). In an integrated medical education, this is complex. Multiple stakeholders with a broad-range of subject expertise, understanding of the complexity of human health and an appreciation of the bigger picture of healthcare delivery are needed. A particular difficulty arises from differing opinions between discipline experts from academic and clinical arenas as well as from the student cohort (Kobus, 2013; Quinlan et al., 2013). This is not exclusive to medicine, dissonance has also been highlighted between stakeholders in other disciplines, e.g., engineering education (Knight et al., 2014). Morcke et al. (2006) report the completely different perspectives of stakeholders, regarding what learning is required and the way in which it should be delivered. Thus, it is proposed that the cognitive aspects of learning and the ability to develop understanding alongside the socio-cultural construction within the learning environment play a key role. Whilst much has been written about curriculum design to promote useful learning skills, little has been reported on how students view the changing landscape of their learning. Specifically, there is little written about what students perceive as getting in the way of learning (barriers) or what helps them to take steps towards success in acquiring effective and lifelong learning skills (enablers). Therefore, the approach to optimise learning context, should be exploratory and reflective, as there is no single, one-size fits all formula to 'crack' learning in all contexts (Kobus, 2013; Barradell and Kennedy-Jones, 2015). This would suggest the need for a thorough analysis of what causes difficulty for students in the context of the learning environment and how various approaches can help or hinder the learning process as well as considering the opinions and approaches of discipline experts and educationalists (Noonan, 2013).

Methods and methodology

Using student-generated narrative

Narrative and stories are increasingly used in the health and the social sciences to better understand the lived experiences of people's lives. There is no specific or predefined way to analyse the stories told, so interpretation relies on the individual perspective of the listener to make sense of the 'message' that comes from the (re)-telling of the participants lived experience (Lai, 2010). Stories can be told in different ways and the method of storytelling affects the ensuing narrative. Thus, narrative can be impacted by a number of factors, e.g., time of telling; audience; whether it is told as an individual monologue or unfolds as part of a conversation etc. (Charon, 2006). From this viewpoint, it can be surmised that narratives will also change over time, with re-telling and with the developing experience of the teller or, because of the influence of the listener, particularly if it is part of a conversation or discussion. Storytelling is a natural part of human behaviour, we all tell stories to justify our actions, reflect upon and learn from experiences, to continue our personal journey of development. The relationship between the storyteller and audience, is crucial to the telling of the story (Squire et al., 2008). If the storyteller feels that they will be judged by the listener, they are more likely to tell their story in a self-affirming and uncritical way, or even altered to protect the teller. To a varying extent, storytelling leads to self-reflection and helps the teller to search for advice, support or affirmation for their position (Bolton, 2006). Thus, storytelling can be adopted in qualitative research to unpick and seek to understand the issues being researched. In so doing there is a co-construction of understanding to make sense of the relevance of the lived experience. Narrative enquiry is a powerful tool in the development of meaning from experience to underpin improved understanding of a community or group (Berry, 2016). In terms of learning in a specific setting, this provides a useful tool to shape the environment to enhance the experience of individuals in a learning community. As the analysis of narrative is subjective by its nature, care must be taken to consider the form in which the data is collected and to limit the influence of the researcher in the telling of the story (Lai, 2010). The Listening Project encourages participants to discuss shared experience privately, in a radio booth, recorded for sharing on national radio ("Radio 4: The Listening Project", 2016). Resultant conversations are influenced only by the pair having the discussion, as there is no set process or questions to lead their discussion. As a method for collecting data, this provides an opportunity to explore narrative away from the influence of the researcher responsible for, and thus influencing, the interpretation. This means that the influence of the researcher is confined to the interpretation of the already recounted story (to some extent), rather than during the data collection process (Maynes et al., 2008).

Data collection

Students were recruited from Year 2 and 3 of the Bachelor of Medicine, Bachelor of Surgery (BMBS) Course via email, asking if they would like to take part. Participants volunteered as a pair and in this respect were self-selected, rather than being randomly assigned to a pair. This was intentional as it was felt that the students would have a pre-existing rapport, rather than needing to develop a relationship during the development of a conversation. This is in-keeping with the Listening Project from which this methodology was derived ("Radio 4: The Listening Project", 2016). All participants were given pseudonyms to preserve anonymity (Table 1).

Each pair of students were given a brief explanation of the aims of the project in terms of understanding how students use group learning to develop their learning skills to cope with the volume of knowledge and understanding required to succeed on the course. Student participant pairs were then asked to record a conversation at a place and time of their choosing and given a conversation brief, outlining areas of interest of the project and some prompt questions to use if they got stuck (See below).

Conversation brief:

I am interested in hearing your learning stories (experiences), with this in mind, please consider the following questions:

Were your learning experiences what you expected? – How and in what ways were they similar or different?

What do you like about them? What do you dislike?

What has helped you to learn? What has hindered your learning?

Is there anything that could have been done to make your learning experience better?

If you were going to give some advice about learning, to your younger self starting this course, what would it be?

TABLE 1 **Student pair labelling key: (f) = female participant; (m) = male participant.**

Year group	Name 1	Name 2	Pair code
2	Annie (f)	Belinda (f)	A
3	Clare (f)	Dan (m)	B
3	Eashi (f)	Freddie (m)	C
3	Hannah (f)	Gafoor (m)	D

Recruitment

Eight student participants were recruited as four pairs, two (one pair) from the second year and six (three pairs) from the third year of the BMBS course (Table 1). From this a total of 90.11 min of conversation were recorded comprising: 40.04 min, 8.55 min, 22.05 min, and 19.47 min for each conversation. Students used language indicating different stages of understanding in relation to being a competent learner. Interestingly, one of the Year 2 students and four of the Year 3 students appeared to have a deeper understanding of how their learning was taking shape as an organic and iterative process in which, understanding developed over time, whereas the other students seemed to struggle with how to build on what they had learnt and found learning much more a process of learning topics separately.

Transcribed conversations were read thoroughly several times and analysed according to similar narratives / themes arising *viz*: 'from learning it all, to structured learning'; 'developing understanding and the spiral curriculum'; 'working alone vs. working with others'; 'integrated learning and understanding context' and 'assessment and resources'. Quotations were selected to reflect these 5 main / key themes (see Table 2 for example).

Analysis

Data was analysed using a mixture of thematic analysis (TA) to identify patterns and themes within the dataset in relation to the research question (Braun and Clarke, 2006) and narrative enquiry to consider the socio-cultural perspective of learning, rather than taking a cognitivist psychological viewpoint (Maynes et al., 2008). This approach facilitated the interpretation of practical barriers and enablers borne out of the student's approach and beliefs about learning, rather than the cognitive process of assimilation of information and development of understanding (Case et al., 2010; Lai, 2010). The language used in the narratives obtained through listening project conversations were analysed to determine the course of participant journeys through struggle to understand how time, topic, sequence, student and facilitator interaction and context of learning empower or inhibit learning within the context of learning through the early years of this BMBS programme. Thus, as experience affects comprehension, language changes to reflect a deeper appreciation of the complexity and linkage of ideas that explain a more rounded understanding of a topic in the context of other issues or learning. In this context, this type of analysis focuses more attention on the process and development of learning, rather than the specific issues that students face at a particular moment in time (David and Sutton, 2011b).

Participant use of the conversation brief

It was evident that some of the participants stuck more closely to the conversation brief (the brief) than others. Where conversation was

TABLE 2 An example of theming of conversations.

No	Theme	Description
1	From learning it all, to structured learning	Participants discuss how at first, they felt that they needed to learn everything about medicine to succeed on the programme but came to understand that this was not the case and that learning was an individual experience.
2	Developing understanding and the spiral curriculum	Participants in all conversations mentioned the spiral curriculum. Whilst this was not a theme that dominated conversations it is key to understanding the learning process
3	Working alone versus working with others	Participants discussed their experiences of working in groups – particularly in terms of opportunities and missed opportunities
4	Integrated learning and understanding context	Participants discuss how they begin to understand the integrated nature of learning as they progress through the programme and have to apply their learning in a clinical context.
5	Assessment and resources	Assessment is discussed as a driver of learning early in the programme, as participants develop their learning skills it appears to become less of a driver.

freer, i.e., seemingly unhindered by the brief, there seems to have been a more iterative and developmental aspect to the discussion, with participants seemingly learning from their discussions, exploring ideas, and shaping their understanding as the conversation progressed. Interestingly, these conversations gave the impression that the researcher was ‘forgotten’ for some of the time. Whereas, participants who stuck more closely to the brief, appeared to have a less dynamic interaction, only answering the questions set by the brief. The conversations where the brief was more closely followed were in contrast to the freer conversations in that they showed much more evidence of researcher presence. Thus, it could be speculated that the methodology outlined above did, at least in part, ameliorate the effects of my influence collecting participant stories and led to a more personal recounting of the learning journey. It is also worthy of note that participants story-sharing led to changes in perception of their own understanding of learning. When this happened, the conversation veered into new areas of exploration, perhaps demonstrating a transformative effect of participants on one another, which could be ascribed to peer-to-peer learning.

Analysis of themes to the data

From learning it all, to structured learning

Students come to medical school with the feeling that they are more than capable of learning, having spent many years getting the top grades at school and achieving A/A* grades at GCSE and A-level. Over the same time period, they have narrowed their learning topics and focused their study on individual subjects. A key aspect of success in this setting, is learning to a syllabus, taught directly by their subject teachers. This approach, whilst offering success in knowledge-based exams, stifles natural, spontaneous ability to learn organically through enquiry, discovery and thinking (Bonawitz et al., 2011).

Students are introduced to the PBL approach early in this BMBS programme and this was acknowledged by participants, as an issue for them as they made their transition to learning in the medical school environment, for example:

> *I think this is quite a big jump [from 6th form, where] …there's a syllabus, there's a beginning and an end.* (Gafoor C: Y3)

Medicine covers a broad range of topics, which crossing several disciplines and themes, not only biomedical science disciplines, but also arts, humanities and social sciences. Therefore, far from specialising, students diversify considerably to become individuals with a broad knowledge across a number of areas. This can be daunting and was reflected in participant conversations. There was a consensus early in the course that they need to learn everything they are taught:

> *…there was so much information …such a short space of time and you really thought you had to know everything.* (Belinda A: Y2)
>
> *I carried round a pack of about 100 maybe 200 …little questions with …if I knew all of these …I'd know I'd learnt everything.* (Annie A: Y2)
>
> *…Year 1 was a lot of notetaking and …going over lectures …it was quite productive …I knew my stuff for end of year but …a long time was spent making notes.* (Clare B: Y3)

Flexner in the early 20th Century, suggested that pre-clinical learning should include a firm grounding in the biomedical sciences that underpin diagnostic medicine, before moving on to clinical training (Flexner, 1910). However, medical understanding has improved over the past 100-years and it is no longer necessary, appropriate or possible to learn everything, although this may not be appreciated by a student new to learning in higher education (Irby et al., 2010; Miller et al., 2010; Jones, 2011). Thus, the keystone of medical curriculum development is deciding the key concepts required to develop understanding and thinking pertinent to progression through the medical graduate foundation training programme, where new graduates are expected to determine their own learning development, whilst undertaking specific training to demonstrate capability as a practitioner in medicine (Norman, 2002; Mann, 2011). The medical curriculum adopted at this medical school attempts to equip students with the learning skills requisite for good clinical decision making, based on a firm grounding of the biomedical, psychological and social sciences (including current literature and evidence), alongside an appreciation of the holistic view of the patient (Bleakley and Brennan, 2011). Clinical reasoning sessions begin in Y3, when students have greater exposure to the clinical environment, but students in earlier years are introduced to the skills required to develop clinical reasoning thinking from the outset, through problem-based learning and other small-group sessions (Schmidt, 1983;

Mattick and Knight, 2007; Artino, 2008), which draw on their learning throughout the course. This approach aims to ease the transition, which is often seen as problematic, from largely non-clinical learning in Year 1–2 to the experiential, self-directed experience encountered in the clinical pathway framework from Year 3 (Rodway-Dyer, 2010; Teunissen and Westerman, 2011).

As the participants began to discuss how their learning progressed, there was disagreement as some started to explain that their learning had become targeted, or 'smarter', instead of learning topics in detail, they were beginning to understand that some of the key underpinning concepts would facilitate their work with new material. This was juxtaposed with the apparent reluctance to let go of the feeling that if they did not know everything, they might miss out. In the early part of the conversation between Belinda and Annie (pair A). Annie expressed her frustration that at school she knew where she was, there was a syllabus, you were taught, you were tested on what you were taught, and you passed the exams. It was clear cut, there was a pre-determined and definite path to success. Annie also commented about not being tested on Year 2 learning, there is no end of year test as there was in Year 1, which made learning even more difficult. She felt that it was no longer necessary to attend any teaching sessions, because there would be no test. Whereas Belinda found that she enjoyed the new freedom to follow her curiosity and was not encumbered by a syllabus, having scope to learn as she saw fit:

> *I liked the way we were taught in secondary school was sit down, shut up, this what you need to learn… …get tested on the stuff that you've actually learnt.* (Annie A: Y2)
>
> *…it's all chill …I understand it, whereas you …you're actually …this is way too much and stressing out.* (Belinda A: Y2)

Annie and Belinda's discussion also highlights the feeling of some participants, that everything needs to be taught and that their lecturers are experts who can impart their wisdom, for their absorption, so they too can become 'wise' (Wingate, 2007). This is commonly experienced across higher education, presumably because of the syllabus-led school system (Teunissen and Westerman, 2011), rather than an expectation that higher level learning requires a more active participation and curiosity to develop understanding (Magolda, 2001; Bassendowski and Petrucka, 2013).

Interestingly, there seems to be a hint that Belinda (pair A) experienced a different approach in school, which has potentially, allowed her to adapt more quickly, affirming the notion that transition is influenced by expectation and prior experience (Byrne and Flood, 2005; Teunissen and Westerman, 2011):

> *… they'd explain it and you'd understand it… …you'd talk about it and talk to the teacher and it was so much more open relationship.* (Belinda A: Y2, discussing how her 6th form teachers approached learning)

As conversations developed it was interesting that some students started to change their perception of how they might learn. For instance, as one of the pairs was talking, it became clear that one participant was struck by the difference in their approach compared to their research partner's and even appeared to have a change of perception on how learning might be made more effective. Considering the developing notion that learning does not need to be structured in terms of specific learning outcomes, but rather in development of understanding of the broader topic, with an emphasis on the concepts that underpin current medical knowledge, Annie and Belinda (pair A) exchanged ideas that provoke thinking about what is holding Annie back. Annie is clearly worried that by opening the box, she will quickly be drowned by too much content, whereas Belinda seems to be confident that by following her curiosity she can learn enough to develop critical thinking, which she can use to work with ideas to synthesise new understanding:

> Annie: *I just don't get on with the whole, like go away, go free … there's nothing that I'd particularly go 'that's really interesting' …and research more into …I don't like the freedom of it basically.*
>
> Belinda: *I feel like the opposite …I'm not very good at structured learning …I like to follow my curiosity.*
>
> *…last year I thought I knew what I was doing [but] …I figured out a new way of learning and I think I've learnt the mentality of work smart not hard …I think that it's definitely a journey.*

Belinda's vociferation that it is about working smart; considering what she is learning and how it fits in, echoes a development of understanding of the learning process and fits with developing evidence that deep learning is underpinned by individual goal-setting, rather than by following pre-determined learning outcomes (Mattick and Knight, 2007; Wijnen et al., 2017). This is a common theme in year three participant conversations, as they appeared to be more in-tune with the notion that their learning needed to be more holistic, rather than focussed on the knowing of facts. This is epitomised in Freddie's (pair C) comment below:

> *…I feel like if you did it in the didactic compartmentalized way that they're doing in a lot of other medical schools you don't have the ability to form those connections* (Freddie C: Y3)

By Year 3 Eashi is beginning to gain an appreciation of what is expected and seems able to reflect on the issues that faced her as a first-year student. As someone who had spent time on an undergraduate biomedical degree course, before joining the medical programme she discusses her confusion at trying to learn holistically, rather than in the discipline-led style she had encountered previously:

> *…having come from the biomed route …looking at things …in separate courses …in real life you like you have a patient it's not a separate thing …all of that stuff is happening in one person, …from an undergraduate perspective it's really kind of a bit confusing* (Eashi C: Y3)

In considering the transition from a largely didactic approach to teaching, to the more experiential, guided approach, it is interesting to note that by Year 3, students are largely more accepting of the process and appreciate the benefits. This raises the question of whether earlier intervention to develop this way of learning could or should be included. Eashi sums up this progression:

> *…first years and second years …are like criticizing it and complaining …when I hear about 3rd, 4th and 5th years, most of them are singing the praises of their learning and learning style of Peninsula and the spiral curriculum …but it takes that hindsight to actually see the worth.* (Eashi C: Y3)

The experiential nature of this transition, is perhaps, a first step to adaptability in the professional clinical environment and may begin to explain the feeling by students that they are prepared for practice on day one of their first Foundation Year job (Goldacre et al., 2010; Bleakley and Brennan, 2011; Illing et al., 2013). The comments above reflect that Freddie and Eashi realise that their developing understanding of whole issues, which alongside their comments below further supports the idea that they feel as if they are developing the required skills for clinical practice:

> *I actually feel like I'm becoming a doctor rather than – I know about physiology or I know about the kidneys like I know about being a doctor of the kidneys.* (Freddie C: Y3)
>
> *…it's made me feel more confident with my clinical reasoning because I talk about things I've looked up rather than just reading it off a piece of paper.* (Eashi C: Y3)

The development of a professional identity is paramount to the success of students on an undergraduate medical programme. It is common in traditional undergraduate medical programmes, for students to start to grapple with this as they enter the clinical years. From this study, it would appear that our participants have already begun to develop their personal identity prior to Year 3 when, traditionally the clinical years, and 'learning' professional behaviour begins (Arnold et al., 2005; Clandinin and Cave, 2008; Hatem and Halpin, 2019). This is in-keeping with this school's approach, where students are exposed to clinical experiences early and are provided with learning spaces, such as small-group learning and problem / enquiry-based learning to practice their professionalism from early in the programme. Indeed professionalism is judged as part of the assessment process by their academic and clinical facilitators throughout the course. The literature on transition would seem to support this notion, particularly easing the transition by encouraging earlier introduction of experiential and curiosity-based learning (Fallows and Steven, 2013).

Participants coming from school, where all they need to learn is taught by a teacher, expect higher education to offer the same. Thus, the anticipation that they will be taught enough to pass the course is implicit in their understanding (Wingate, 2007).

Interestingly, Annie suggests that a GP would not need to know the details of Kreb's cycle:

> *There's no way a single GP knows the Kreb's cycle…* (Annie A, Y2)

Annie expresses a view that learning is there to be done, but then forgotten, and so 'what is the point?' This echoes how I felt as an undergraduate in biochemistry. What was the point of learning the whole thing just to write it down in an exam? This would appear logical, but by understanding the mechanism of the pathway, the knowledge can be applied. Knowing what it does and how, helps when seeing patients, so, in a sense, Annie is right, GPs are unlikely to remember the detail of Kreb's cycle 'in the moment', but they will understand the underlying principle that it is a generator and producer of energy and that if it is not functioning effectively, it will cause particular issues for a patient. Furthermore, they will be able to apply their understanding of the biochemistry, to other disorders of metabolism.

Thus, although the detail is 'forgotten' understanding of the system has, to some extent, become implicit. Should the GP need to know more detail, they will find it [relatively] easily and apply it to their case. Annie's next comment hints that she is starting to get the point, an oscillation between thinking it is not necessary to learn only to forget, but then beginning to realise that the learning and forgetting aspect of understanding is fundamental to development of understanding required as an experienced practitioner:

> *I understand we have to know all the nitty gritty detail now, …so that we can forget it later, but we have the basis for it.* (Annie A: Y2)

But then…

> *…PBL catches the extra things, which you maybe should have learnt that week, but you just haven't, they haven't been taught to you properly* (Annie A: Y2)

Annie then flips back to her original position that the details need to be taught 'properly', although acknowledging the role of PBL in development of understanding in context, she sees it as a safety net, rather than a means to develop her comprehension. This oscillation between knowing what needs to be done and how to do it in terms of learning, measured against the feeling of wanting to be taught is interesting. Later in the course, there is still an acknowledgement of the difficulties faced earlier on, but an acceptance that learning is a journey, requiring personal development. This reflects the oscillation described by threshold concept literature, where there is a period of understanding and not understanding before a permanent transformation to the irreversible state of 'getting it' (Meyer and Land, 2003; Perkins, 2006).

Developing understanding and the spiral curriculum

During induction when the students arrive in Year 1, the BMBS course is presented as operating a spiral curriculum (Harden and Stamper, 1999; Rodway-Dyer, 2010), meaning that each area of learning will be presented at various times as the course progresses. Thus, by learning the basic concepts in the first year, students will lay a foundation, which provides a basis for future learning. This does not mean that each topic is taught to a greater depth each year, but that general concepts embedded in the core curriculum are used in new contexts and situations to develop a thorough understanding, allowing transfer of knowledge and engendering the skill to work with new and unfamiliar issues in clinical practice, using prior learning (Mattick and Knight, 2007; Rodway-Dyer, 2010). This approach is key to developing understanding and although it represents a small proportion of participant conversations, it is a key aspect of learning development and the timescale and process by which it happens is worthy of note.

Although the spiral curriculum and its underpinning theory, is introduced at the start of Year 1, there appears to be an urgency amongst Year 1 students to learn everything in as much detail as possible, as demonstrated by Belinda's (pair A) reflection:

> *Last year I felt very much like a lot of stress because there was so much information and such a short space of time …you really thought you had to know everything* (Belinda A: Y2)

However, by the middle of Year 2, there appears to have been a shift in these participants' perception of how the curriculum works, which aids in organising workload and trusting that learning is iterative in its development over the undergraduate years. Indeed, by mid-Year 3, the participants in this project were convinced by the value of the spiral curriculum and really appreciated what it had to offer. Reflection on the value of the spiral curriculum is echoed in comments by three of the participant pairs, two explicitly and one by implication, for example:

> *…repetition is really so important, …the spiral curriculum …you know it's gonna come up again and every time it comes up you get sort of like a new piece of the jigsaw* (Belinda A: Y2)
>
> *…thinking about other medical schools …they do …one case unit on the heart in the entire two years. You're never gonna look at the heart again, I'd dread that* (Annie A: Y2)
>
> *…that spiral learning, which when you start seems a bit like …so we're just going to revisit things again and again it's a bit frustrating …but actually you …just build on that knowledge and put another layer* (Eashi C: Y3)
>
> *Don't get too hung up on …the minute details of an ECG for example. …you're not going to learn it unless you see it and you have at least three years …What you need to do for first and second year is to learn basic science* (Hannah D: Y3)

The comments participants make about the spiral curriculum and how their appreciation of it as a concept develops over the first few years, would suggest that in this case, learning for themselves is an important aspect of learning development, which is in-keeping with the findings of an earlier review of this curriculum (Mattick and Knight, 2007). This work emphasises that although the evidence is presented early, it is not until students experience it in practice and understand the advantage it imparts, that they begin to accept it as a useful learning tool in curriculum design (Mattick and Knight, 2007), which would seem to be borne out by the conversations recorded as part of this study.

Working alone vs. working with others

A key element of working as a healthcare professional, is working collaboratively in teams. Patient care is regularly discussed in multi-disciplinary teams (MDT), thus learning to communicate and work together is key to becoming a doctor (General Medical Council, 2009). Educational research also presents a plethora of evidence to support learning as a team is effective (Levin, 2005; Madrid et al., 2007; Stankov et al., 2012; Thondhlana and Belluigi, 2014). Interestingly, participants described learning as a group as an alien concept and often struggled to understand how it might benefit them:

> *I personally like working in my room by myself doing my own thing at my own pace…* (Annie A: Y2)
>
> *I never liked group learning and never got it, cos I just thought like being with other people was such a distraction* (Clare B: Y3)
>
> *I was just like reading through the power points …going over and over them again, I did actually make quite a lot of notes …I had a folder full of notes* (Dan B: Y3)

On the other hand, others recognised group learning as an advantage from the start:

> *…one of the things that attracted me to Plymouth …the whole group-based aspect of it, being allowed to discuss stuff. I always found it really helpful.* (Hannah D: Y3)
>
> *I know for me that I'm a discussion-based learner, I learn by chatting to people …thinking of it out loud and talking myself to an answer …it will click in my head* (Freddie C: Y3)
>
> *…I will talk through it and I might say a bunch of things that might be totally irrelevant …I'm making links to all the previous learning …which actually you do a lot and you don't even realise* (Eashi C: Y3)

An important consideration for people working as a group is how much each person gains as an individual. It is commonly expressed that the group's overall learning can be detrimentally affected by students' who do not 'pull their weight' (Thondhlana and Belluigi, 2014). If a student has experienced this previously, or within group work in PBL, it is likely that their opinion of group work as a means for learning will be negatively impacted. However, if they have good, or improving experiences, their opinion of how working with others benefits them develops over time. By incorporating group work through PBL and small-group sessions from the outset, students are strongly encouraged to develop their group-working skills. Indeed, as group-working is included as part of their professional assessment, it is incumbent on them to work effectively together. For students who have been encouraged to discuss and learn together previously, e.g., Belinda and Hannah – they can see how their learning has developed using this approach, whereas those who have started from a more traditional learn and regurgitate, e.g., Annie and Dan (pair A and B respectively) – seem to take longer to appreciate the advantage of group learning.

Freddie reflects that some groups were better than others and that the success of the group is based on who is involved:

> *…when you put 10 people together, you're going to have different personalities and also different learning styles* (Freddie C: Y3)

Listening to participant conversations, I heard a lack of motivation to work with other students, within their friendship groups. Thus, whilst they were beginning to appreciate the relative benefits of working as a team, there was not a concurrent development of understanding that made them think beyond their course-imposed groups:

> *My housemates obviously all do medicine and there's seven of us in total, …that's a resource we don't really tap into that much…* (Belinda A: Y2)

Belinda goes on, as she starts to realise the missed opportunity, to consider why this might be the case:

> *… [we're] all really good friends, all relate to each other and yet so many times people I know, friends …don't feel that they can share weaknesses with each other …we very rarely come together, actually study together.* (Belinda A: Y2)

Interestingly, Belinda seems to suggest that it is an element of competition that causes students to shy away from being collaborative with their friends. This is interesting, as it has been reported that students in a competitive environment are less likely to be collaborative (Butler and Kedar, 1990). However, as students are encouraged to collaborate from Year 1 it might reasonably be assumed to be sending a message that collaboration is a key skill for learning. From this it could be postulated that the perceived competitive nature of assessment has a negative impact on student learning development early in the course, where it could be advantageous for students to collaborate to develop self-direction of their learning. As the course progresses, this seems to become less of an issue. In Year 3, participants have moved into a clinical setting where team-working is an expectation. At this stage of the course, participants have less formal group time with their peers and more ward-based learning. Thus, it would seem their appreciation of peer-learning heightens as the structured opportunities for it diminish.

Freddie (pair C) voices the dissonance raised in some participant conversations. Explaining that he can now see why groups are changed, although at the time it felt uncomfortable. This suggests that it is only by experiencing group change in the clinical environment and how it alters dynamic, that they become aware of the educational value of group changes earlier in the course:

> *…you have to adjust your learning style, which I can see why they mix it up because obviously in real life …we have MDTs …and you have to learn to work with other people …[but] it can throw you off kilter a little bit* (Freddie C: Y3)

Eashi reinforces this in response, explaining that she now finds it easier to adjust when she moves from one team to another:

> *…you can adjust to that style of then being thrown around because you know that you're more confident in your own abilities, …for a while you just feel a bit lost* (Eashi C: Y3)

Gafoor displays confidence that his learning has effectively prepared him for learning within the clinical environment:

> *…now being in my clinical years I can really see sort of the impact of studying in a PBL way. I feel quite prepared to enter the clinical environment.* (Gafoor D: Y3)

Whilst it is difficult to tell whether by this point in the course, students have learnt to share ideas and develop learning, or whether inculcation in a clinical environment, where team-working is necessary for the provision of effective patient care, is difficult to tease apart, given that there is no control group on which to test the hypothesis. However, evidence gathered on preparedness to practice drawn from students (Monrouxe et al., 2009; Brennan et al., 2010) and from their supervising clinicians (Morrow et al., 2012), would suggest that early group work plays a role for the high scores achieved by this school.

Integrated learning and understanding context

As discussed earlier, participants described how they tried to learn everything that they came across in the formal 'taught' part of the course. This was particularly evident when participants discussed their learning during the first year:

> *…anatomy wise, I used to just print out diagrams and try and remember. I don't think that was the best at all to learn anatomy.* (Clare B: Y3)

Clare qualifies this by explaining the lack of context as they started learning. So, although there is an acknowledgement that trying to learn by rote may not be the most effective means to learning, without experience of other content / context, it is difficult to apply a different technique. Mattick and Knight (2007) and Finn et al. (2010) suggested that adding a context stimulus to learning can affect information recall, and Clare's comments seem to reflect a feeling that this is the case in the context of learning early in the BMBS programme, where clinical experience and thus context on which to pin learning is limited (Mattick and Knight, 2007; Finn et al., 2010):

> *…but then what else were we supposed to do because we've not like got much patient contact or anything* (Clare B: Y3)

Dan (also suggests that lack of context made learning, particularly anatomy, quite difficult):

> *That was always a great problem with anatomy, it was just like we were remembering stuff with no context* (Dan B: Y3).

For most participants, it becomes evident that their learning approach shifted as they progressed, so instead of only learning topics they had 'covered', they began to cross-reference to the work they had done before, e.g.:

> *…I get all the questions that I've had from last year and I'll make notes …by the end of it I'll have had one set of notes …I've kind of paired them up with the case units from last year,* (Annie A: Y2)

There was a general impression that the participants who had progressed into the clinical environment appreciated the approach to teaching and their learning development, in terms of how it helped them to adapt to the clinical environment. Freddie sums this up, explaining that the PBL approach, in terms of setting his own learning goals, means he is more ready to learn from clinical experience and more confident of uncertainty as an acceptable part of clinical competence (Simpkin and Schwartzstein, 2016):

> *…if someone just told me a bunch of learning points …I wouldn't have developed the skill that we need in clinical practice which is: what don't I know, what uncertainties are there and what's the information I'm lacking* (Freddie C: Y3)

Freddie's comments suggest that he is becoming adept at lifelong learning skills. He can assess a situation he has not previously encountered and work out what he knows in order to manage the situation and what he does not know and will need to learn or ask someone for help, depending on the urgency and context of the situation. This is a key professional skill for doctors – knowing what you know and can deal with and what you do not know and need further knowledge or help with is crucial for patient safety (Passi et al., 2010; Monrouxe et al., 2011). As a Year 3 student, that Freddie is, at least, beginning to be able to assess his own strengths and weaknesses, is a big step towards developing his professionalism and ability to operate in the clinical environment (Goldacre et al., 2010; Illing et al., 2013).

When working with students in Year 1 and 2, Hannah recognises the change in her approach, in that she was now looking for clinical context, rather than learning for the sake of learning. This would suggest that the context of learning is an important factor and that it is difficult to understand what is expected in terms of learning without an authentic framework (Teunissen and Westerman, 2011; Teunissen et al., 2018):

> *I think one of the difficulties with first and second [year] though was you never see the bigger picture because you're not in hospitals or placement enough.*
>
> *…I was mentoring …year two students on how to do ISCEs …it was really interesting how my perspective was very different to theirs. …for them it's very much like I've got to say this this… …[whereas] I'm thinking 'well what does this mean?', 'and how could I apply …biosciences that I've learned and all the pathology' …it's very different now. …you put everything together don't you* (Hannah D: Y3)

It would seem from these observations, that student learning in Years 1 and 2, whilst abstract in terms of authentic clinical context, the methods of learning instilled in them are effective in aiding transition from non-clinical environment to the pathways of clinical learning introduced in Year 3. Working in small groups seems to be a factor in preparing students for the clinical world, where they are regularly moving between teams and forced to direct their own learning through understanding where the 'holes' or weaknesses in learning lie. This fits well with the observations of Teunissen and Westerman (2011), who suggest that medical education should be designed to help students cope with the challenges faced when entering new environments. Participants went further, articulating that as the course progressed, they felt like they were learning to think. This is a key reflection, as it highlights a complete transition in learning. So, learning is not about knowing, but being able to work with information. Eashi (pair C) makes an explicit comment about a sea-change in her learning:

> *…you actually had to actually learn to think… …to look at different sources and find different information and apply knowledge to answer your questions* (Eashi C: Y3)

This seems something of a revelation to Eashi, which is perhaps surprising in the sense that, as a lifelong learner, it seems obvious that thinking is a key skill in development. It is interesting to note that children in nursery and primary schools are more skilled at enquiry-based learning than students starting medical school (Rogoff and Matusov, 1996; Cook et al., 2011). This is widely reported in the literature, although medical schools that use small-group or discussion-based learning such as PBL, report that their students are better problem solvers (Albanese and Mitchell, 1993; Norman and Schmidt, 2000; Koh et al., 2008). Thus, it is reasonable to assume that the 'correct' answer approach to examinations may slow the development to lifelong learning through the secondary school years. Indeed, this transition may be prolonged by continuing with a didactic approach in lecture-based courses, which does not appear to be lost on Eashi:

> *…if you did it in the didactic compartmentalized way that they're do in a lot of other medical schools you don't have the ability to form those connections …everything sits in its box* (Eashi C: Y3)

A key component in developing critical thinking is identified by Eashi and by Freddie (pair C) as they discuss how using questions to stimulate learning helped them not only to find information, but also how it helped with long-term memory and contextual understanding:

> *…so questioning side of things …it helps you understand where to where to find things* (Eashi C: Y3)
>
> *…it was surprisingly effective at making me remember stuff …and apply learning …in a more integrated way …I suppose it reminded me how to work with groups as well* (Freddie C: Y3)

Freddie goes on to discuss the development of a more holistic view of patients, suggesting the integrated approach to learning has helped him to consider patients as people, rather than just a presenting complaint or condition:

> *…PBL teaches us to integrate the kind of psychosocial elements as well. I know we all think at the start what a load of rubbish, but then really when you talk to a patient all things are so important, …when you talk systematically and compartmentalised you don't really apply that stuff* (Freddie C: Y3)

This is also reflected in Eashi's comments, where she explains how the early small group learning she has done has made her more attentive to the broader issues in patient care. Particularly, she discusses the detail that she is likely to consider, alongside the patient's main issues:

> *… it's made me …more attentive to detail when patients talk, … rather than just thinking right here's the presenting complaint …the past medical history, done it's taught me to kind of think more holistically* (Eashi C: Y3)

Freddie appears to recognise that the integrated approach to learning, using a biopsychosocial framework, is crucial to consideration of the patient in terms of working towards wellbeing. He goes on to reflect on how this approach has helped him to make sense of discussions during multi-disciplinary team meetings (MDTs), on clinical placements:

> *…I feel like even if I don't know everything that's going on I can pick up on bits and …notice things and I'm able to listen to a conversation that an MDT might be having and just make those links …it takes time though, it doesn't happen after your first PBL session* (Freddie C: Y3)

Freddie continues to discuss a PBL case he remembers that provided him with a framework for asking pertinent questions and considering the available services to help the patient:

> *…there was one [PBL case] about carers and it was …how can we make sure that the carers are doing ok, support groups for carers …all that psychosocial stuff, it's not …just like a tick box thing it really has a lot of implication on someone's recovery and health* (Freddie C: Y3)

He goes on to relate this directly to a clinical experience, where the issues considered in the PBL case can be used to help understand a patient's needs. This example clearly demonstrates his ability to use the learning from PBL, in a real clinical scenario; not as a learnt behaviour, but as a cognitive process, where what has been learned is being actively and deliberately applied to a real-life clinical case. Thus, the premise that PBL is a valuable learning tool for the development of critical thinking and clinical reasoning is demonstrated in Freddie's lived experience (Prince et al., 2005):

> *…if someone's a bit down… a bit worried about the fact that they're not going to be able to …walk after their knee or hip replacement.*
>
> *…[if you] link that into their [mindset] and then they might be more positive… …not just like this is how you do the surgery, it's understanding …about their recovery, the post op care …all that stuff …I wouldn't necessarily always think about but having …PBL …helps you think, look at the bigger picture.* (Freddie C: Y3)

Freddie's thoughts provoke Eashi to reinforce his comments, as she also recognises how her learning in PBL has helped her to consider the whole patient, rather than just dealing with their immediate medical concerns:

> *That's just exactly what I was just thinking …makes you remember that patients have a life outside of the hospital …you're dealing with an individual case but there's so much surrounding this case, …all their home environment …family, …children, …friends, …work and you remember …this isn't just an illness this is a person* (Eashi C: Y3).

This is a powerful affirmation that learning that has taken place over the first 2 years has allowed participants to enter the clinical world with a firm educational background, not just in the application of facts about medical conditions, but in considering all the patients' needs to promote overall well-being. This would suggest that the journey towards lifelong learning has a firm basis in the early part of this programme. Furthermore, Eashi's insight with respect to this understanding is cemented by the conversation she is sharing with Freddie, as she recognises their shared experience.

Assessment and resources

It is widely acknowledged that assessment is a key driver of learning (Epstein, 2007; Wormald et al., 2009). The progress test, an Applied Medical Knowledge test (AMK), is designed as a tool to monitor and assess progress frequently over the duration of the course (Ricketts et al., 2010). The test is set at the expected cognitive ability and understanding of F1 doctors, i.e., at a point where the candidates will have completed five-years of undergraduate training in medicine. Thus, students with very little or no training in medicine are bound to struggle with the content presented and their scores will be low. However, students will see a steady climb in score, which will show them how they are progressing in terms of their development as a doctor. The initial intention in designing this as a means of assessment was to provide a snapshot of how each student was progressing as they moved through the course, using their earlier scores as a reference point (McHarg et al., 2005). For adult / lifelong learners, this is a logical way to ensure appropriate development, so that any issues in learning development can be picked up early and remediated for to avoid short-term problems, becoming long-term issues. The original premise was that the test could be imposed at a moment's notice, as it was not intended to test knowledge *per se*, but to visualise the development of students to apply their understanding and knowledge to clinical situations, using critical thinking and clinical reasoning skills (Van der Vleuten et al., 1996; Norman, 2002). This works well as students gain clinical experiences and opportunities to apply their learning to real-life cases, using their knowledge and understanding. However, it is often noticed that students in the early years of the course, who have little clinical exposure, lack the skills to apply clinical reasoning to complex scenarios and thus try to learn facts to attain higher scores. This is not surprising, given that as school-leavers they have come from a setting where attainment is measured by examination of factual knowledge. To ameliorate for this, Year 1 students have an end of year test that examines the learning they should have done during the first year. However, students in Year 1 and Year 2 often attempt to improve their AMK scores by learning clinical facts, e.g., disease frameworks and drug profiles. This may divert them from core learning, which in turn may be counter-productive in terms of longer-term progression on the AMK (Mattick and Knight, 2007). The effect of learning for AMK and the later realisation (or not) that this may be counter-productive was discussed in all the participant conversations. For example, Gafoor (pair D) points out that learning for tests is done without clinical understanding, because students are 'intimidated' by AMK. He does not say whether he did this in Years 1 and 2, but he does recognise as a third year that younger students over-emphasise learning for AMK:

> *I think a particular reason …especially first and second years … seem quite hung up on the clinical context is, …AMK is quite an intimidating exam …a lot of students tend to be using all of these question-generating websites …learning buzzwords …looking at guidelines …managements for conditions that they don't really … know…* (Gafoor D: Y3)

Hannah (pair D) also suggests that this approach is counter-productive:

> *…get rid of this culture …of learning for the AMK …it's a huge culture, particularly as you go into second year when you haven't got any other exams …The danger is you learn the basics, but you don't know the detail. So, you still get things wrong…* (Hannah D: Y3)

The issue is raised by Belinda, who seems to intonate that students somehow 'cheat the system' and improve their grades by learning for AMK. It appears that she recognises that students are not clinically competent, but by learning key facts and words, which lead them to the correct answers, they improve their scores, at least in the short-term:

> *…I think actually, I find you can pass the exams and do quite well without necessarily having that clinically applicable stuff sometimes.* (Belinda A: Y2)

Furthermore, it is suggested that student re-runs of exams, explaining answers, without really understanding their clinical relevance or application is an issue in terms of learning in Years 1 and 2:

> *…you've got some people to re-run exams who perhaps have no idea clinically… their actual knowledge of applying themselves to a medical scenario is really awful.* (Belinda A: Y2)

Annie seems to have a moment of realisation in response to Belinda's comment, explaining that she had not seen the AMK in that way. She understands that it is clinical but had not thought that by learning and applying knowledge, she might achieve a better outcome in the exam over time:

> *I've never thought of AMK like that, that has completely changed my thoughts …yeah AMK is very, very clinical.* (Annie A: Y2)

This is particularly interesting in terms of Annie learning from the discussion, as earlier in the conversation she had expressed her frustration that the teaching in Year 2 was not being tested, as there was no end of year exam.

A conversation between Clare and Dan (pair B), suggests that AMK became their sole focus in Year 2, to the detriment of engagement in learning in other parts of the course. This is put down to there being nothing else to learn for as there is no end of Year 2 test:

> *…I think for Year 2 …the focus was just AMK, I didn't do as many notes in Year 2* (Clare B: Y3)

> *…even with PBL it fell off a bit towards like halfway through Year 2, I suppose. Most of it was not relevant …to the AMK, so I would just do AMK separately* (Dan B: Y3)

Gafoor and Hannah's (pair D) conversation also makes this conclusion. The stage of learning in Year 2, is not enough for students to understand that their learning contributes to their progression in AMK and that, in their opinion, further testing would be an advantage in terms of encouraging learning for the content presented in Year 2:

> *I think the reason perhaps people's attention to PBL in second year kind of changes, …it didn't really aid assessment. …we didn't have an exam to …consolidate our anatomy …physiology and pharmacology …apart from the AMK.* (Gafoor D: Y3)

He goes on to suggest that further assessment of the learning in Year 2 might lead to better engagement with learning content rather than superficial learning for the AMK:

> *…different people would be more engaged with the content and be more likely to revise it and retain the knowledge. …that's just my view, …there should be more assessments.* (Gafoor D: Y3)

This is interesting, and fully reinforces that in the early development towards lifelong learning, students are driven to learn for assessments, rather than to work with the issues they face as part of their clinical experience. There are several ways of looking at this; it could be assumed that by increasing the number of assessments in Year 2, students would indeed pay more attention to the topics explored. From appreciation of the participant conversations discussed, it is likely that this would lead to a greater focus on taught aspects of the course, as there would be an immediate reward (i.e., a high grade) for learning the content in depth. This might seem at first appealing, but it could be argued that this would stifle learning development, as students would focus their attention on a narrow field of content, rather than being driven by the outward focus of clinical experience. In the early years of the medical school, students sat an end of Year 2 exam, which provided an alternative means to passing the Medical Knowledge module (*via*the AMK). Analysis of second year results, over a number of years, suggested there was no advantage to learning and the test was dropped.

In general, by Year 3 most students are taking AMK in their stride and seem to understand the testing of learning progress. In contrast, it is striking that if this is not the case – i.e., a student is still putting store in learning specifically for AMK that it is easy to negatively affect confidence in student learning. Dan's (pair B) comment suggests he has not yet developed a learning to understand approach:

> [About AMK] *…it only like takes small changes to make a huge difference and knock you out of your comfort zone so much.* (Dan B: Y3)

From this, it seems that the point at which assessment is no longer seen as a driver of learning, but merely a means of testing progress is not clear cut. However, Dan does appear to be alone amongst participants in this study, given Clare's response:

> *I feel like I've learned loads in third year, like tons and tons and tons of stuff. Lots of new things.* (Clare B: Y3)

Whilst she does not explicitly acknowledge her transition, her comment suggests that learning is more experiential, and curiosity driven than it was in Year 2.

Discussion

Using the themes emerging from the student discussions as described above I will take each in turn and discuss how these fit with the curriculum at this medical school and with the more general topic of learning development with respect to progressing towards becoming a lifelong learner.

Individual learning development from Year 1 to 3

The evidence presented here suggests that the transition from school leaver to medical student entering the clinical environment in Year 3 is helped and / or hindered in a number of ways. I look at each in turn and address the subordinate aims in each section, i.e., what factors:

- Affect whether students learn or not in a small-group setting?
- Enable students to learn effectively?
- Hinder students from effective learning?
- Is it possible to better manage the learning environment to promote learning?

Learning 'smart', rather than learning it all

A key factor in coming from an outcomes-based approach where passing exams with top grades, is mastering how to pace learning for the development of understanding. This is tricky to overcome, as everything that students have done to gain a place at medical school has been based on attaining high grades. Within this, assessment plays a part and although Peninsula assessment has been set-up to ensure a frequent look at progress (Ricketts et al., 2010; Rodway-Dyer, 2010), students start with the notion that the AMK is there to be 'passed'. It may be that this is not something that can be overcome and that life-long learning, in the academic sense, is something that each individual student comes to at their own pace. Clinical experience does appear to impact on understanding the concept and perhaps the programme already engenders an optimal approach to guiding students to this conclusion.

Understanding the spiral curriculum

This theme ties in with learning smart. Students have been used to learning for an endpoint, not learning for life. Thus, learning outcomes have been short-term goals, rather than lifelong approaches. The PBL approach does appear to facilitate learning development in this respect, in that students are encouraged to link their learning. Three of the participant groups suggested that whilst they found the concept of the spiral curriculum frustrating at first – by Year 3 there was an acceptance that it worked, and they could see its value.

Learning together

One of the most prominent factors in helping students to adapt their learning, seemed to be focused on educational background. Participants from schools that used a discussion-based and cooperative learning approach had a distinct advantage [e.g., Belinda (pair A) and Hannah (pair D)]. This is perhaps not surprising, particularly, as a school where this is not the case is likely to raise students for whom competition is a key driver, which appears to impinge on learning development. Freddie (pair C) did not express whether he came from a background of cooperative learning, but he seems to wholeheartedly accept it as a good way of learning. The small study group size meant that it is not possible to determine whether he is an exception or one of a larger sub-group, for whom, for whatever reason, collaborative learning is attractive from its first introduction. For the other participants in this study, collaboration appears to be a learned skill and thus, early exposure to a collaborative learning approach is more likely to prepare students for a programme where this is an expectation. Clearly, it is not possible or desirable to select students based on their school's learning approach (particularly as it would appear this is a learnable skill). However, in terms of small group learning, the use of team activities for small groups early in the course might help students to see the advantage of learning more collaboratively. This is likely to work in conjunction with other issues that appear to hinder learning, such as understanding assessment, particularly in terms of progress rather than as a finite determinant of knowledge.

Integrated learning

Students in Year 1, as school leavers, used to learning facts for exams, at first struggle with learning across disciplines and topics. This seems most clearly apparent in the learning of anatomy, where several of the participants comment that it is only possible to learn anatomy by rote, rather than in the context of other learning. Comments made by Annie (pair A) and Clare (pair B) suggest that they acknowledge that the lack of context is a factor, presumably this is a position that comes from reflection of their earlier learning methods, and it is when they start to consider their more effective learning in terms of their clinical exposure.

A key point of transition for the participants in the study appears to occur when they start to meet and have more in-depth conversations with patients when they progress to Year 3. This is highlighted by Freddie and Eashi (pair C), as they talk about how they have both considered the effects of psychosocial factors on their patients' wellbeing. Again, this suggests that learning in context is tightly associated with experiential learning in practice. This is interesting from the point of view that students have early clinical exposure in Year 1 of their studies at Peninsula, yet in most cases, they do not appear to make the connection that weaving their learning into clinical context is advantageous until Year 3 of the programme. It seems that this transition is reliant on the development of skills in parallel before they can be combined and used simultaneously. It would be interesting to pursue this line of query to determine whether this is a rite of passage, or if experiential learning from the outset might lead to earlier integration of academic and experiential learning.

Assessment and resources

The data presented here seems to suggest that the progress testing of Year 1 and 2 students distracts them from deep learning. Indeed, it is recognised by participants that student learning specifically for AMK has developed as a culture amongst Year 1 and 2 students, whereas by Year 3, there is an acceptance of its nature as a test of developing progress in clinical understanding. Thus, it might be surmised that the AMK is counterproductive in terms of learning development, in the first 2 years of the programme. However, another way of considering this could be that to understand how the AMK works, it is necessary to try to pass it in the first instance, this is particularly likely to be the case in students who have been top scorers in their exams to this point. It is difficult to envisage how the development of an earlier understanding of the test can be instilled. However, changing the stakes in terms of results may alter the way AMK is viewed, which may promote a better understanding of its aim. There have been numerous discussions around whether to make AMK formative in the first year, given the observations from this study, there is a chance that this would reduce the anxiety for students who would be able to see how they are progressing, without the threat of failure and might lead them to take a more relaxed view towards the test. On the other hand, for students who fail to take a formative test seriously, it could have the effect of causing the anxieties currently experienced in Year 1 to be pushed into Year 2, where the stakes would be higher. Another suggestion would be to allow collaboration between students in their first progress tests, which would generate an opportunity for developing group learning, alongside a development of understanding how the progress test works.

Methodological review

The method used for this study demonstrated the value of conversation in eliciting student views on their developing learning. The BBC listening project has long since provided interesting insights into the shared, lived experiences of ordinary people and this is what prompted the approach used here ("Radio 4: The Listening Project", 2016). The use of this method in collecting data from student participants does appear, at least to some extent, to ameliorate the relationship between students as participant and facilitator / tutor as researcher. The narratives collected provided a rich seam of data, which could be further analysed to study the relationships of students with learning in different ways, beyond the scope of this project, such as, how discussion about learning impacts on the understanding of learning and how separating learning into disciplines, e.g., anatomy in some aspects of an integrated curriculum.

A further observation, regarding this approach, points towards the value of conversation / talking together, thus introducing opportunities for students to discuss and reflect on their learning may lead to a better understanding of the overall process of development of learning skills over the first 2 years of the course, as was in evidence, particularly in the conversations of Alice and Belinda (pair A), where several instances of apparent change in their comprehension of how the learning activities facilitated their understanding of learning were apparent. Such an intervention would be innovative in curriculum development by facilitating a powerful tool in the armoury of personal and professional development in the early years of medicine.

In the analysis of the data, the use of the auto/biographical reflection to assert my position, proved helpful, as it enabled me to look at the conversational narrative from my own- alongside the participant- perspective. By acknowledging my own experience, it was possible to evaluate the participant experience in terms of both similarity and difference. In some cases, the conversational analysis cemented my own understanding, such as in terms of the spiral curriculum, where the concept struck me early on and helped me to understand how learning developed. At other times, the conversations, alongside my own position, helped my understanding to develop further, e.g., I became aware that the PBL process had for me been a key to understanding the iterative process of learning. However, I realised that this came from the experience of being able to look at PBL from a curriculum development point of view, rather than from that of the learner; and that from within the process, where the learning seems overwhelming, students may find it difficult to stand back and appreciate it in the same way.

Limitations and further work

There are several limitations to this qualitative study. One of the major limitations was the number of students who volunteered to be participants. To develop a more detailed understanding of the commonalities between factors that help or hinder students in their early learning development in HE would require analysis of a greater number and variety of conversations between student pairs. However, it should be noted that there was a degree of convergence in terms of the narratives collected, which would suggest that the number required to achieve this may not be prohibitive (David and Sutton, 2011a). Additionally, I was not able to get the participants together as a focus group to discuss the findings from the conversations collected. This would have added a further dimension to the study in terms of discussing common enablers and barriers to learning development in the first years of study on the medical programme. The transferability of the results reported is limited as this Medical School is different from others in the UK (indeed all are to an extent, individual in their approaches). Furthermore, because of the study group size the results do not provide a complete generalisable set of data, although the individual issues raised are still valuable in the context of the participant group as a representative of the overall cohort.

Further work with similar programmes would be valuable. There are two ways that I would like to broaden the study, *viz* to look at whether the learning journeys of students at this medical school are comparable with students in similar and different (more traditional) schools and within this environment, how students from a widening participation background compare in terms of their adaptation to the programme. There is also scope to build on the data presented here regarding assessment in a study to determine whether the approach to the progress test in the first year could be developed to promote an earlier understanding of its purpose.

Summary conclusion

The project on which this paper reports considers how student learning develops from Year 1 to Year 3 of a specific BMBS programme. My interest was sparked from an observation that some students found the transition from school to learning within a university setting on a programme where students must be self-guided, professional and learn through an integrated approach. From this work, I have developed an understanding of some of the drivers and developments that help students to make this transition *viz* learning what to learn, rather than trying to learn everything; which is generated from developing an understanding of the iterative nature of learning and facilitated by the spiral nature of this particular curriculum; understanding the nature of learning development through working as a group; learning that holistic learning in context makes understanding easier to achieve and that assessment drives learning in students in the earlier years, but as time progresses assessment is more a monitor of progress than an exam to be passed. My aims were to find out what:

- Affects whether students learn or not in a small-group setting?
- Enables students to learn effectively?
- Hinders students from effective learning?
- and
- Is it possible to better manage the learning environment to promote learning?

From the results presented here there are a number of issues: if students have been used to discussion in their school setting, they are more likely to adapt to this way of learning; group make-up in the earlier years may be a barrier to effective learning, but as time progresses and there is more exposure to clinical experiences, students begin to understand that it is up to them to work with the group and that it is important that they do this as a matter of good clinical working and practice. Learning skills must be developed to gain an understanding of how to maximise learning. It is no longer sufficient to pass exams as the overall assessment is of a wholesale approach to medicine, which in part includes some knowledge, but much more than that in terms of professionalism, team working and clinical capability. This is something that develops over time, but that could be improved by developing modes of assessment to better reflect the skills required – e.g., adapting progress testing in the earlier years to encourage group learning and integrated development of understanding. The evidence here suggests that learning is hindered when students do not adapt to the learning environment – earlier understanding of this may be facilitated by developing some of the areas described, but there may be to some extent a natural progression, which cannot be accelerated.

Whilst this represents a relatively small study group, and it is recognised that the number of participants in the project is not large enough to form any firm generalisations about the overall issues in development in learning here (David and Sutton, 2011a). It is also recognised that this study was an initial exploration of the factors that influence learning, where thick description was the aim, so a small number of participants was appropriate to achieve this. Furthermore, the transcribed conversations presented a rich seam of exploration and synthesis of aspects of learning, where the main themes coming through in each conversation were similar. Thus, the data can be assumed to reflect some of the key themes that help or hinder learning in the context of transition to study at this medical school. In considering the themes raised here against some of those raised incidentally in a previous audio diary project, some issues might reasonably be used to inform further research in this area.

The understanding of development of learning of the participants discussed here is of immense value in terms of the further development of medical curricula in this context. The findings from this project have been applied to the development of the curriculum to a broader remit of enquiry-based learning (formerly PBL). This has promoted a broader scope of cases to allow for a greater diversity of learning stimuli to promote critical thinking and development of learning approaches over the first 2 years of this BMBS programme.

Data availability statement

Anonymised raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Plymouth University Faculty of Health and Human Sciences and Peninsula Schools of Medicine and Dentistry Student Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

KG was the sole author of this work contributing conception, design, collection of data, analysis, and authorship of the manuscript.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Into the wild: uncertain frontiers and sustainable human–nature interactions

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Humans seldom consider themselves as animals, and that humans are animals is a truth frequently turned into an insulting metaphor indicating “uncivilized” behavior in many cultures. Interestingly, the “civilizing” aspects of Western Culture in the Global North are historically derived from traditions of democracy based on living in cities from which the wild has been banished. This is embedded in the English language since civilizing and civilization come from the Latin for city, *civitas*, the place where citizens hold voting rights. Beyond the gates of civilization is the wild. How the wild and nature have been constructed and demarcated is an enormously complex and enduring challenge in western philosophy as it relates to knowledge-making, existence, truth, and reality. Indeed, whilst people generally believe they know what nature means, they rarely realize that little in nature is wild. Furthermore, the concept of uncertainty, central to the pandemic, is compounded by climate instability and a potentially disastrous future. This is breaking down what is known, requiring porous and flexible conceptual frontiers and a transdisciplinary approach. This article traces the linguistic separation of humans from their animal origins and wilder environments for political and increasingly greedy economic purposes. It explores the acknowledged complexity of healthy human–nature interactions, juxtaposing information mainly from the humanities and social sciences. Demonstrating how unhealthy the current paradigm has proven to be for humans and the natural world, it brings together conflicting information to disrupt traditional certainties using an innovative bricolage methodology. It weaves and combines different ways of knowing as it considers forms of knowledge-making, rewilding, foraging, the place of magical thinking, and vital force. It concludes that a new paradigm is needed to enable a way of working toward any vision of healthy human–nature interaction.

KEYWORDS

Earth ethics, deep ecology, paradigm change, eco-anomie, rewilding, sustainability, sustainable health

Introduction

The French feminist philosopher, Irigaray (1999), has pointed out that we share breath with the Earth. Her lifetime of theoretical work engaging with the philosophical and psycho-critical implications of experience has moved focus from visual to inner, sensory experiences. She indicates the breath we share is an often-forgotten part of our lived experience, something that makes us one with nature (Irigaray, 1983). Yet, despite this lived experience, we pollute the air we exchange. The Earth’s temperature is rising. We know this is exacerbated by gases caused by increasing human consumerism and that people living in more polluted areas are also becoming ill (European Environment Agency, 2023). Yet, while awareness of a pollution health crisis is increasing, air is rarely the subject of social research and theory and is almost always disassociated from the human bodies that breathe it (Allen, 2020). Such perspectives conflict with one another, and whilst being in nature, whether urban or rural, is enjoyed and considered good for people, not everyone considers a relationship to nature necessary for physical or spiritual health.

This conceptual article for the health and illness interactions special issue of *Frontiers* investigates the health of human–nature relations, using a bricolage methodology to review the situated knowledge of the Global North and consider how a language, research, and concepts of health have been constructed. It reviews counter-current theories and new directions before considering how to move forward. Crucially, global warming is a dire situation involving loss of the whole planet, a material reality that confronts different theories and positions on what is known, the linear past. Arguably, this requires new ways of thinking, recently described in the USA by Haraway (2016) as tentacular, forms of sympoiesis that move away from the Anthropocene (with people at the center of the universe). We are now in the Chthulucene, a "sort of time-place for learning to stay with the trouble of living and dying in response-ability on a damaged planet" with a networked, evolving universe of chattering critters or oddkin, creating stories on a warming dystopian compost heap (Haraway, 2016, p. 2). This article deploys standpoint theory (Hartsock, 1983; Haraway, 1988), poring over some frequently conflictual and often clumpy material in the heterogenic anthropocentric compost heap, where a plethora of historical and philosophical matter offers food for thought and indicates enduring beliefs. With its premise that all knowledge is socially situated and stems from a social position, this standpoint places emphasis on marginalized experiences, especially those of women. The premise of marginalization permits me to align my thinking as well as to consider the Earth as an exploited and marginalized entity in anthropocentric politics. Placing political and social power relations at the center, standpoint theory further supports my consideration of philosophical power relations embedded within disciplines (Haraway, 1988).

As a feminist critical thinker, I am particularly interested in the disruption of mainstream knowledge-making ideologies and the power they hold over other ways of thinking. I am influenced by the subversive and transgressive aspects of Harraway's work, where the compost heap forms a perfect analogy for the plethora of material. It is easy to get trapped in continually reviewing this dead material. It is incredibly hard to formulate a new position from which to speak, as Harraway does.

A linguist and critical theorist in French and Art History, I am an Irish white feminist academic working in education and an interdisciplinary researcher working across the humanities and social sciences. My interests include health, sustainability, and research methods. I draw upon the various methods that inform my academic background, including my professional practice as an integrated health practitioner and medical herbalist and my life experience as a person relating to the natural world. I make no claims to absolutes because the theories I engage with involve human and social worlds. Working with language and images across several disciplines with sustainability in mind, "thinking-through" (Ahmed et al., 2000) as much as "thinking-with-care" (De la Bellacasa, 2012) is part of the practice of transparency. For me, this is an activist political feminist engagement, a *practique* in Bourdieu's sense that it brings together theory and practice, behaviors and activism. Theorizing and conceptualizing what I see, feel, and believe are part of my passionate engagement with the natural world and my ongoing phenomenological engagement with a changing reality.

In my view, Western material worldviews are firmly embedded in economic and political ideologies of civilizing, rooted in Classical Greco-Roman culture, and fertilized by Enlightenment notions of truth. Language contains references to this anthropocentric politics of land ownership that positioned the natural world as a resource to be controlled, cultivated, and plundered. I believe this historic agenda, which includes patriarchal power dynamics and toxic masculine ideals, still influences contemporary capitalist human–nature relations. Furthermore, these environmental, political, socio-economic, and gendered implications persist and are embedded in academic research on the natural world. Indeed, as Haraway (1988, p. 205) states, "science as heroic quest and as erotic technique applied to the body of nature are utterly conventional figures." Acknowledging that definitions of proof and truth entail conceptual complexity, I therefore examine how historically, mainstream culture placed the wild in opposition to it, a divisive practice unhealthy for maximal human flourishing that negatively influences human actions toward climate change.

For me, the recognition that the reality of living well in the Global North involves poisoning the Earth on which human life depends forms the starting point. To explore existing conflicts in this symbiotic relationship, I therefore question what "health" and "living well" mean. This requires reflection on how migration from the country into cities at key political and economic points historically underpins Western civilization and governance. I suggest that where a land-based belonging forms part of many peoples' construction of identity, place forms an anchor for existence, and being-in-the-world is an existential crisis that sits behind discourses of "dis-placement" faced by many people forced to migrate. Yet, outsider identities demonstrate that whilst citizenship identity is mainly state- or place-based, these are entangled political and social topics (Yuval-Davis, 2004; Nordberg, 2006). I have also been influenced by a recent video for the Association of Medical and Healthcare Humanities (AMHH), in which Columbia's first indigenous Ambassador to the United Nations, Leonor Zalabata, discussed how place is central to identity and conveys healing for the Arhuaco people (Patterson, 2022). I had not considered place as having a healing role other than in relation to plant species and phytochemical constituents, and yet for me, this is a critical part of my Irish identity. I am indebted to Zalabata for this insight. In this article and thinking of place and displacement, I particularly consider how mainstream culture has not only separated people from their animal identity but also from a sustainable, ethical care for the Earth. This implies a relationship with nature is necessary for improving physical, mental, and spiritual wellbeing and for lived experience, a phenomenology that gives life particular meaning. Yet, whilst I consider existential, spiritual, and physical identity, I also recognize that climate change is a material reality and not something that can be controlled by humans. Physical events bring death, injury, starvation, and trauma, and climate anxiety is an increasing mental health issue

(Hickman et al., 2021). Faced with unknown science, it is my contention that all knowledge becomes theoretical and requires imagination to "perceive" any future.

To get to this space, I review and deconstruct existing culture and knowledge in the form of language, research and mainstream, philosophical counter-currents, and contemporary actions, uncovering a diagnosis of eco-anomie. Bearing in mind again that the matter in the compost heap is text (from the Latin *texere*, to weave), what I do here is to unravel materials, texture, and threads. I contend that the process of dissecting and reframing presents a systematic and rigorous rationale that identifies the pathological damage of the Anthropocene as societal eco-anomie, a profound un-knowing that results in stagnation or stasis. I aim to demonstrate how the current paradigm devalues the relational systems necessary for human health and healthy human–nature interactions. Metaphorically raking over her compost pile to generate heat, Haraway (2016) argues that stories in the Anthropocene end badly, and she generates new ones, refiguring new myths for possible futures that storytelling brings into being. For me, reconnecting with the earth is essential for human wellbeing, for working with uncertainty, and for envisaging any possible future, with or without humans. In this article, I use bricolage as a method that repurposes and changes the materials.

Proposing that it is necessary to step "into the wild" I am calling for a paradigm shift (Kuhn, 1962). By "staying with the trouble" alongside Haraway (2016) and reviewing counter-current human–nature ideologies, my arguments clarify the need for this metacontextual shift. Thus, my call to improve healthy interactions from within the humanities and social sciences echoes calls for reframing the field of ecological theory to support eco-criticism (Glotfelty and Fromm, 1996) and those from environmental observational research by scientists such as Will Steffen (Boonstra et al., 2023). Through sustained arguments, I conclude that an Earth-centered paradigm with inputs from many disciplines (Rigolot, 2020) and transgressive practices, premising the Arts is needed to bring healthy human interactions together with those of an unpredictable, dynamic, and changing planet. Imagining creates hope. Located at the crossing places or boundaries of disciplinary mainstreams, I occupy a hedgerow-space where wild things flourish outside of cultivated and well-plowed fields. From this space, I sketch out the new paradigm.

I acknowledge their fractious perspectives, methodological challenges, and limitations of the disciplines I draw on, as well as the impossible size and complexity of the topic. The selection and use of materials necessarily present my partial views, a perspective supported by using standpoint to clarify the politics of place-based situated knowledge in the Global North (Haraway, 1988). Used flexibly here, this standpoint further supports my researcher's insider expertise and outsider engagement with various disciplines, and my readings and juxtapositions of common philosophical episteme together with intersectional differences in lived experience (Wylie, 2003).

Methodology and concepts

In this article, I build a theory located within a transformative social constructivist paradigm. Drawing on different disciplines, it includes real-life practicalities aiming to produce something that is innovative and fundamentally transdisciplinary (Rigolot, 2020). It is a makery that involves "bricolage," a DIY methodology of taking things apart, examining them, and reassembling them. It deploys this creative and philosophical method for diagnosing cultural production. In social sciences, bricolage was conceptualized in 1999 and elaborated by Denzin and Lincoln (2011) as an epistemological research methodology, extensively explored in 2001 in the work of Kincheloe et al. (2011), and discussed in Rogers (2012). It is associated with qualitative methods that combine to represent whatever is being researched from different perspectives. Bricolage supports methodological transgression, is useful for pushing boundaries and for a politics of including unusual material. It suits the selection and deconstruction of materials used here. The process of recycling, upcycling, and repurposing for future use correlates with the aims of the research. Important for reframing its methodological use, bricolage has different origins, not only in social anthropology but also in art.

For the French anthropologist Lévi-Strauss (1966), bricolage is not imaginative since what is built is pre-conceived. He named skilled craft work using bits of leftovers, "bricolage," differentiating intuitive knowledge and wild or uncivilized knowledge in place-based and plant knowledge as magical thinking (Lévi-Strauss, 1966). This signifies making do with what is to hand; the French verb *bricoler* means fiddling about with leftover materials. Bricolage is an analogy for mythical thought (Johnson, 2012). Levi-Strauss contrasts the bricoleur (maker of myths) with the engineer (modern science). In complex arguments, Derrida (1967a) counters that the bricoleur has created the engineer since the materials (signs and structures) pre-exist and become decentered because meaning and knowledge-making shift.

The innovative and transgressive bricolage methodology I use here explicitly incorporates both social science and humanities aspects. Bricolage references the found art of Dada and Surrealism, whose conceptual dislocations have origins in Modern Art as a visual metaphor for viewing dislocated or distorted planes of color dating back to the nineteenth-Century French Impressionist painter Paul Cézanne (1839–1906). When he becomes interested in or moves around something, it is enlarged out of proportion to the rest, as, for example, the statue's foot in his painting *Still Life with Plaster Cupid,* c.1894 (Courtauld Gallery London). Cubism's distortions exaggerated this process and were followed by dislocations of time and space in de Chirico's art. These processes influenced the Surrealists, the theories of Lefebvre and the Situationalists and later urban films (Patterson, 2014). Surrealist poems also use grammatical structures to bind together words and images (signs) that do not logically belong together. The anti-art premises of Dada's found objects led to the surrealist incongruity of placing things together that did not usually appear together (famously a sewing machine and an umbrella), creating a different sense of reality and challenging what "art" means in terms of content. From the 1960s onwards, drawing on these origins, the *arte povera* movement actively reinforced the creative sense of the bricolage technique. More recently, Fortais (n.d.) described the bricolage technique used in her Ph.D. (2013–2018) at the Slade School of Art as "disassembling and repurposing." In art, the creative aspect of bricolage generates something new and innovative. Making new ways of putting things together possible, bricolage can present an original and creative way of talking about something, generating a postmodern form transcending Levi-Strauss' structuralist anthropology (Hester, 2005). Furthermore, a contemporary reading includes the current everyday sense of DIY doing home repairs associated with commercial outlets such as "Monsieur Bricolage."

I embrace this transgressive aspect of bricolage that is allied to innovation. The methodology incorporates its multidisciplinary ontological premise to emphasize the need for disrupting unilateral perspectives by a purposive selection of materials from a wide range of sources on human–nature relations. Examining and deconstructing these materials, it aims to disrupt by moving beyond traditional perspectives, changing and upcycling information aligned to a different, more sustainable purpose as it considers how to place the new material. The process focuses on bits and pieces of information that serve intention and arguments rather than aiming to be comprehensive. As I aim for fluidity in a creation that may necessarily sketch ideas and thoughts, I acknowledge its limitations as problematic barriers I step over, for now.

Deconstruction, and particularly Foucault, form a secondary methodological consideration. Foucault (1969) engaged in radical social critique by tracing power and control in Western Culture and institutions. Philosophically, (Foucault, 1988) late work moves beyond poststructuralist ontological containment associated with Derrida's (1967b) deconstruction techniques, by pointing to two possible types of truth: the truth of life and that of lived life, or life experience. These final lectures at the College de France examine cultural technologies for developing knowledge, classified as production, sign systems, power, and the self, the latter critical for transformation. Foucault's few references to nature emphasize its role in the spiritual dimension of human identity. He considers how self-examination (reflection on experience) historically supported ways of dealing with future misfortune and uncertainty, arguing that since the Enlightenment, material and spiritual culture sit in opposition to one another, placing people in a dilemma and confusing what it means to be human, to know oneself, and to live well.

Although the bricolage used in this article did not intentionally follow a Foucauldian pattern, I certainly sampled mainstream language (signs), research (knowledge-making process), and counter-current theories in consideration of knowledge. I use reflection and occasionally discourse, and there are other parallels. Living well, elements of standpoint, positioning, and Haraway's work align with my main arguments. Returning to Foucault, care of the self requires revaluation of a human spiritual dimension that includes the natural world, a conclusion echoed here. Aiming for transdisciplinary transformation, I am adapting critical and social theory tools, including aspects of feminist theory, to inform my deconstruction and reasoning as I walk firmly into the agentic wild. Here, a sensory aspect forms part of experiential and relational connections between people and nature. This permits reference to other ways of knowing, intuitive practices, and shamanic aspects of different cultures and traditions. What follows then is an analysis of material that I have gathered with respect to human–nature interactions. It references first "mainstream culture", and second "counter-currents and new directions." In my discussion of mainstream culture, I consider ideas embedded in language, looking at words such as "nature," "wild," "soil," and "Earth." Consideration of mainstream knowledge production through research in relation to health and nature interactions follows. A proposition about the health of mainstream human–nature relations concludes the first section. In the second section, counter-currents and new directions, I consider ideas about vitalism, biophilia, deep ecology, and rewilding. This is followed by a second set of propositions. My call for a paradigm change brings together the main strands of the work.

Mainstream culture

Language, diagnosis, and human–nature relationships

Human–nature interaction is worthy of critical social investigation since at its heart sits a discussion on cultural reproduction. Civilizing practices created a damaging dualism, including the extensive "nature" vs. "nurture" debates whose origins go back to Classical writers with their underpinning ontology of "truth." Mythological and lived examples include feral or wild children: Romulus and Remus in Ancient Rome; Truffaut - Truffaut and Berbert's (1970) film *L'Enfant Sauvage*; and the abusive 1960s case of Genie (b. 1957) in the USA. This binary between civilized and wild shifted humans from mammal identity.

Language: nature

Trying to define "nature" demonstrates that something seemingly familiar is incredibly complicated. The first session on my outdoor learning course involved students being in "nature," in the park by the campus (without phones), observing their surroundings, clouds, and trees. Only one student ever commented that this was "managed nature" or discussed what they believed "nature" to be. Taking a step back, it is important to question from the outset what "nature" is and to clarify its socio-linguistic construction.

Consider what this often-used word means in a concrete sense. Whilst most would agree that nature is part of being human and humans are part of nature, being "an animal" has a long derogatory linguistic tradition. Calling someone "an animal" is an insult. Historically, this animal aspect has been negatively associated with showing emotions, with women, with female sexuality, and with a shameful animalistic feminine (Nussbaum, 2006). This may partly account for a substantive feminist disengagement with nature (Alaimo and Hekman, 2008). Moreover, as early Earth worship in female form (Gimbutas, 2001) and subsequent patriarchal subjugation (Lerner, 1987) presented a binary sexual politics in second-wave feminist culture, navigation is complex. Yet, as Alaimo and Hekman (2008) comment, the separation of people from nature has not only harmed women but also indigenous peoples and other marked groups.

Ducarme and Couvet (2020) demonstrate how the concept of "nature" appears as a later translation of Classical Western texts. Etymologically formed from the root of the Indo-Germanic "be" or "being" in the sense of "grow" and "born," nature is an ambiguous concept. Aristotle struggles to define whether it is form or matter, substance or vital property, concrete or abstract principle. In Roman translations of his writings, "nature" involves the complex essence of things, as, for example, in the phrase, "the nature of plants and of humans" or it was "her nature." So, in its early sense, the nature of a thing is its essence, whether it is plant, human, animal, or natural environment. Later, Cicero introduces the nature/culture opposition. This complex, enduring philosophical debate is critical for thinking about humans and existence. In the global North, "nature" carries these patriarchal western cultural origins.

Ducarme and Couvet (2020) describe how "nature" has been further subjected to religious appropriation and material realism. The nature/culture opposition frames the "nature" vs. "nurture" debate running through educational theory and extending today into genetic science. Art and literature romanticized the natural world during the eighteenth and nineteenth Centuries. Rousseau's political work *Du contrat sociale* (1762) underpins modern rights discourses and the constitutions of republics such as France, the USA, and Australia. Meanwhile, his work *L'Émile ou de l'Éducation* (also 1762) locates the ideal education for a (male) moral citizen as being brought up in nature to avoid social corruption. These wide trends of real and ideal representations of nature informed the work of artists, writers, and even gardeners such as Capability Brown (1716–1783). Simultaneously, the enormous classification projects of the eighteenth-Century Enlightenment presented new systematized ways of categorizing (and dominating) the natural world, eventually placing the word "science" in opposition to nature and observational study. Formerly a core scientific concept, nature is clearly a concept changing over time that is entirely socio-culturally created and embodies the knowledge-making ontologies that it intersects.

Moreover, as knowledge (*scio*) became more closely associated with education, other ways of knowing, such as intuitive, kinaesthetic, and sensory understandings, became devalued in mainstream culture. The social anthropologist Lévi-Strauss (1966) privileges science over indigenous knowledge of nature, which he calls "*sauvage*" or "wild," rationalizing it as magical thinking. I grasp this term with gratitude. There is something linguistically magical about an intangible, familiar, and unaccountable idea of nature that comforts me. Its existential aspect has been abstracted and refracted. Its meaning is discontinuous and fractured (Larrière and Larrière, 2015).

In mainstream culture, nature has become a phenomenon that is known to exist but hard to define. Yet it is an attribute that humans share with the wild. Even as a cultural creation, nature is still essentially understood to be alive and to involve a living force. Today, it is neither a scientific term nor a philosophical concept. Its conflicting meanings only sometimes include people. Importantly, whilst widely understood, the word "nature" is used in entirely different ways in different academic disciplines, from philosophy and literature to ecology, conservation initiatives, and climate change policies. So, there is a political necessity behind the call for linguistic socio-critical consideration of words such as "nature," which includes recognizing variability if they are to be used from an eco-centric perspective.

Language: polite, civilizing, and urbane…

Stepping further back, the words for politics (*polis* in Greek), civilization, civilized, civilian (*civitas* in Latin), and urban, urbane (*urbs* in Latin) refer to the origins of democracy in Classical city-states. These were individually organized defensive structures and units of government, with aristocratic hierarchies and slavery. Rural nature was farmed to provide for citizens. Indeed, the word "economy" from the Greek (*oikos* meaning household and *nemein* meaning management) originally referred to natural abundance. It incorporated ethics and the frugal management of a wider estate, in the sense of managing agriculture (land) and slavery (people) for ethical purposes or a good life (Leshem, 2016). During the first 400 years of the Roman Republic, lines were drawn at the gates of the city, and only citizens could vote. Domination over the wilderness demonstrated power, particularly imperial power. Citizens were protected from the wild, which was presented as spectacularly fearful and unpredictable. Wild animals were brought to Rome and killed in the Colosseum for propaganda and entertainment. Elsewhere, I have written about contemporary regulatory practices that grew out of identifying "risk" in Medieval times. This new word describes nature's unpredictability and a fear of it interfering with commerce and the delivery of goods (Patterson, 2017). Material culture is built on changing ideas of the economy for growth or profit. The insurance business was created to avoid unpredictability. The English colloquial phrase "beyond the pale" means being unpredictable beyond civilization, in reference to the area beyond the ditches surrounding the city limits of Dublin, Ireland. It is still used to signify impolite behavior. Underlying these examples is a message of wilderness subjugated in both animal and human form.

Language: wild

Associated with words such as *weald*, *wold*, and *welt*, the word "wild" comes from Saxon, Norse, and proto-Germanic origins, signifying early historical invasions marked in language. Much like the word "nature," "wild" has been negatively associated with something that is not under control, with uncontrollable sexuality and emotions, primarily with women but also young men. The etymology of "weed" from Anglo-Saxon is allied with words such as *weald*, which may reflect similar meanings of wilderness or plants taking over the landscape. Today, many plants considered weeds, such as dandelions or nettles, are valuable herbal medicines, whilst phytochemical constituents in others have been used to create an estimated over 50% of mainstream medicines (Gurib-Fakim, 2006). In English, there is a broad division between words from Old French, encompassing those associated with courtly (cultivated) behaviors from the incoming French-speaking William the Conqueror in 1066 and over 500 years of ruling nobility. Hence words such as baron, manor, royal, court, dance, chivalry, and the words for meat such as mutton, pork, and beef come from French. Meanwhile, the farmer, being local, spoke Old English (Anglo-Saxon and Germanic origins), using the names of the animals, for example, sheep, pig, and cow. It is not surprising that etymologically, "wild" sits outside of civilizing premises. Another

Old English word useful for the arguments in this article is "heal," which literally means whole.

Language: soil, dirt, and Earth

In the USA, the material that covers the planet is called "dirt." I have observed children at Forest School terrified of becoming "dirty." UK English uses the word "soil" rather than Earth. Whilst they are synonyms, soil also means dirty, where Earth and Earthy have life-supporting, healthy associations. Earth is now more commonly used to describe the planet, yet Earth-writing is writing of the soil, comprising a politics of laboring and a visceral sensory engagement linking past and future (Griffin, 2023). Human manure was the Victorian "night soil" collected and taken to fields where it was spread as fertilizer. This is still the case. Today, Britain is known for the adept re-use of sludge cake (Sustainable Food Trust, 2015). Yet a large study (Wilkinson et al., 2022) across the globe found high levels of active pharmaceutical ingredients, specifically carbamazepine, metformin, and caffeine, polluting rivers across the globe, highest in lower to middle-income countries, and posing threats to human health. Carbamazepine is associated with epilepsy and diabetes, and metformin is a well-known antidiabetic pharmaceutical that disrupts the endocrine system. UK rivers showed higher pollution levels than other European rivers. People ignore how the increasing use of processed food and fertilizers is affecting agrobiodiversity (Leite et al., 2022). Dietary issues are linked with current health issues, especially for those on lower incomes globally (World Health Organisation, 2023). Even without pharmaceutical pollution, food can make us ill (excessive sugar), provide nutrition for health, or act as medicine, one example being beetroot for blood pressure (Bonilla Ocampo et al., 2018). Meanwhile, soil feels tangible, and the Greek root of the word gives the chthonic origins for Haraway's ecological shift to the Chthulucene compost heap.

Research: benefits and behaviors in human–nature interactions

Research in health is driven by illness and treatment or medicines. Only recently has research around human–nature connections begun to evidence wellbeing and health benefits. Chawla (2020) reviews methods and measures deployed for children and Beery et al. (2023) for adults. Meanwhile research evidences a positive correlation between adults' active care for the environment and significant time spend in nature during their childhood, something needed for the future of caring for the earth (Chawla, 2007).

Research: children

In the UK, Margaret and Rachel McMillan (Moriarty, 1998) created outdoor nursery camps over 100 years ago to address children's illnesses from pollution and poverty, harms that persist today. Currently, outdoor freedom includes stranger danger and a cultivated fear of nature in literature. Louv (2005) pathologized "nature deficit disorder" with symptoms of rising anxiety and decreasing knowledge and understanding, like thinking food comes from supermarkets and eggs from cows. The United Nations Convention on the Rights of the Child (United Nations, 1989) gives children a right to natural behavior (play) but no right of access to nature. Yet, in the Global South, time can be an unaffordable luxury, and nature is physically dangerous. Many children must spend time growing food in fields rather than going to school. However, four indigenous Huitoto children survived a plane crash in the jungle for a month thanks to their knowledge of fruits (Youkee et al., 2023). In the Global North, it is increasingly clear that children experience benefits from time in nature, developing risk-mediated behaviors, fine motor and social skills, as well as knowledge (Murray and O'Brien, 2006, 2007; Chawla, 2020). Dillon et al. (2006), like Louv, found significant barriers. Children are afraid of outdoor settings. Such findings underpin changes in early childhood education in the UK (Forest School Association, 2023). Meanwhile, multicultural identities need consideration; the existential challenges of UK nature for different ethnicities are rarely considered.

Research: adults

In Japan, research found that *Shinrin-yoku*, or forest bathing, has beneficial physiological and psychological effects, especially for people with depressive tendencies (Furuyashiki et al., 2019). Shanahan et al. (2016) used a nature-dose framework (intensity, frequency, and duration), finding that long visits to greenspaces correlate with lower rates of depression and high blood pressure and more frequent visits with better social cohesion. In a randomized control trial (RCT) with 30 allotment gardeners, Van Den Berg and Custers (2011) demonstrated that gardening reduced biomarkers of stress (cortisol) more strongly than reading. Research like this now informs social prescribing, such as gardening, by qualified UK GPs for mild depression and other illnesses.

Ulrich's (1984) frequently cited research compared a window view of nature vs. one of a brick wall for gall bladder surgery patients. Obtaining 23 matched pairs of patients from 9 years of records, we found statistical differences in recovery rates, pain medication, and longer-lasting positive mood changes vs. negative feelings. The research is interesting yet problematic; the data are retrospective, with different nursing staff reports on mood, unconscious allocations, and other variables.

The UK Office for National Statistics (Office National Statistics, 2021) reported the impact of lockdown on peoples' relationship to nature, visiting parks or playgrounds, outdoor attractions, or beauty spots. However, the focus was on exercise rather than the type of environment. Natural England's (2021) "People and Nature Survey" (PANS) aimed to establish the impact of COVID-19 on people's engagement with green spaces. Building on 10 years of data, it used a panel method for continuous sampling of up to 25,000 adults. The study combines a survey with segmentation of questions and social media analyses. PANS found that visits remained consistent. Confirming earlier studies, affluence (household annual income > £50,000) was a factor. Disadvantaged households visited green spaces less frequently. People from minority ethnic groups and those on low incomes were less likely to access nature, especially blue spaces, and young peoples' wellbeing was more likely to be impacted by lockdown. Higher wellbeing and happiness scores indicated a greater likelihood of visiting green spaces for physical health and exercise than those with lower scores, for mental health. Interestingly, different ethnicities visit different spaces, and particular environments demonstrate gender affiliations. The detail in the study demonstrates that human–nature interaction is socially and culturally construed.

Vespestad and Lindberg (2011) consider nature experiences within the tourist industry using an ontological framework. They identified four categories where nature is central: a setting, a state of being, or a means of framing identity. Their marketing slant focuses on consumer desires. It highlights something I call "nature-tainment" from "nature" and "entertainment" that requires unpacking elsewhere but ranges from managed nature "bubbles" that exclude animals but where people can stay, through conservation-type experiences, to attractions that are far from natural and where nature simply provides a backdrop. Finally, a growing body of research, considering whether stimulated nature can positively affect human health, demonstrates positive results (Depledge et al., 2011; Browning et al., 2020).

Digging deeper: health, health culture, and healthcare

Concepts of health, wellbeing, and illness are framed and challenged by what health means in biomedical terms. Engel proposed his inclusive systems-based biopsychosocial model over 40 years ago, yet un-ease between different world views about the body of a person continues in tangible and intangible entanglements (Patterson and Kinchington, 2019). The current and evolving bio-psycho-social UK medical model emphasizes the interplay of different factors (Alonso, 2004; Gifford, 2016; Gask, 2018). However, the transition from the traditional science-based medical model (driven by STEM, science, technology, engineering, and medicine disciplines) to the biopsychosocial model (influenced by the social sciences, humanities, and the arts for people and the economy, or SHAPE) has been slow and uncomfortable (Imafidon and Black, 2023).

Medicine, or biomedicine, is described by Sontag (1978) as a country with its own language, culture, and inhabitants. Financially, it is the dominant form of healthcare globally, rooted in western knowledge-making and market-driven practices and dominating indigenous and other medicines. Historically, numerous treatments have been wrong, including thalidomide drugs and the various re-categorizations of trauma, previously seen as genetic weakness. Meanwhile, specialization into different body systems has created distinctly siloed fields. In humanities and social sciences research, reading data out of context is a serious ethical issue, yet this is how biomedical research into human bodies and biomedicines has functioned until recently.

The National Health Service (NHS) works with illness, not health. Patient waiting lists are long. High staff attrition rates (Finlayson et al., 2002; Lock and Carrieri, 2022) portray an institution at breaking point. Burnout is common, race discrimination continues (NHS, 2023), and leadership is problematic (Messenger, 2022). Iatrogenic causes (doctor-related) are the third leading cause of death in the USA (Greger, 2015). For O'Mahoney (2016), kindness has become sclerotised. If illness is the "night side of life" (Sontag, 1978, p. 3), death is even more problematic. Medicine has become "a service industry" with death, something people and society hide from (O'Mahoney, 2016, p. 270). Yet death is as important as life; it is part of being an animal and of spirituality.

Advancing technology has brought earlier diagnoses, and it confirms how illness is connected to the patient's body as much as their experience. The application of systems theory from land ecologies signifies an exciting shift in viewing bodies as interconnected living systems allied to the natural world. The gut, tongue, colon, and intestines are now called microbiomes, each with individual communities of bacteria. In previous centuries, medicine was underpinned by a holistic view of the body, treating the whole person to achieve "healing," meaning "whole." Mind–body connections in specializations like psychneuroimmunobiology demonstrate how psychological and behavioral modalities affect physiological health (Irwin, 2008). Recognition includes personalized medicine, environmental medicine, and social prescribing. Crucially, happiness and wellbeing influence physical health.

The best prevention of illness is health and wellbeing, yet "health" research funding is geared toward restoring, not sustaining, health. This goes some way toward explaining the paucity and methodological challenges in researching healthy human–nature relations. Currently, living "a good life" in the Global North involves over-consumption that contributes to illness throughout the globe. Moreover, the disconnect between notions of health and illness arguably affects personal agency and healthy practices. Rethinking medicine as a whole system for sustainable health requires a transdisciplinary dynamic. It's important to consider whether biomedicine has moved too far away from the human animal and from the plants and foods from which much of our health originates.

The health of mainstream human–nature relations: eco-anomie

Most eco-critical human health research comes from a perspective where nature is benign and therapeutic. Large predators are long extinct, and danger is predictable. Yet, every year, people die from being in nature. For some, this is a lack of real-world knowledge; others underestimate individual fitness levels or enjoy dangerous challenges (Gatterer et al., 2019). It is as much about not-knowing as existential values, since there is evidence linking addiction to extreme environmental challenges and psychiatric disorders (Habelt et al., 2023). Micro-level stressors in the immediate environment negatively influence mental health, and evidence is growing for macro-level stressors, such as climate anxiety. Health, illness, and wellbeing in human–nature relations are worthy of further exploration.

There is less recognition in the temperate Global North of different perceptions in the Global South, which experiences extreme climates and life-threatening conditions such as poverty, war, famine, and flooding. Glaring economic and societal imbalances demand reflective critical race theory. Meanwhile, politicians enact an unhealthy mix of blame and shame around pollution, child labor, and consumer culture. Literature on topics such as climate change, fashion, and conservation by writers and journalists such as Naomi Klein, Lucy Siegle, and Jo Mooalem, evidence and question the global environmental and social consequences of real-life consumer production processes and behaviors. If environmental problems are a known by-product of the Western civilizing culture of the Global North (Glotfelty and Fromm, 1996), the existential human–nature identity dilemma that separates people's existence from ethical and spiritual understandings, polarizes arguments. Seeing people as human animals places them closer to nature and uncertainty within an unstable, terrifying (alien) environment.

Drawing on social theory and particularly on Durkheim (1858–1917), I use the term "eco-anomie" to describe the separation leading to this breakdown in the human ethics of Earth management (the Ancient Greek *eco-nomie* discussed earlier). For Durkheim, "anomie" (relating to labor relations and disconnection between those who work with the soil and professional bureaucratic classes) exists in balance with understanding of cultural norms or "nomie" (Marks, 1974). Today, capitalist material consumer culture is upheld by wealthy people who demonstrate cultural and societal nomie and mostly profound eco-anomie.

The French social theorist Pierre Bourdieu (1930–2002) talks about habitus, capital, the field, and practice or *practique* (behaviors). Capital is usually added through education and carries cultural value, whilst habitus is more about personal and informal traits. Human behavior (*practique*) comprising a powerful consumer politics of greed has propelled human–nature relations out of balance. Contributions to climate change initiated in the Global North also constitute a profound political eco-anomie (un-knowing or ignoring) because what poisons the Earth also poisons the animals that live on it, including people. Indeed, this *practique* increasingly suggests other forms of disconnection negatively affecting health: poor diet, processed foods, lifestyle, and stress. Eco-anomie is a loss of habitus that can only be partly addressed through education.

Eco-anomie has caused an increasing mental and physical disease, a new sort of autoimmunity, and the alienation of self. A 2023 study shows that clinically diagnosed autoimmune disorders now affect 1 in 10 people in the UK. The authors have concluded that some people are more susceptible (or less immune) to environmental and social risk factors (Conrad et al., 2023). Modern diet and lifestyle are important contributors (Greger, 2015). Indeed, the structures involving intracellular immune receptors that recognize pathogens, causing immune system cascades and ultimately cell death, are similar in plants and mammals (Mermigka et al., 2020). The autoimmune split between people and nature is a disease resulting in disorder, withdrawal, and stasis in actions to address climate change. Fear and anger generate extreme positions. In this, I understand alienation as a form of "othering" and autoimmunity as a metaphor comparable with Derrida's poststructuralist concept based on rational identity (Rae, 2022).

Eco-anomie, the un-knowing of healthy human–nature relations, is a result of culture-generated divisions between humans, nature, illness, and health. Loss of connection to nature frames disruption of identity and dislocation of reality. Eco-anomie further creates loss and separation in human intersubjective space and body and place-based disconnection in the sense of Lefebvre's Situationalist urban journeys and dystopias (Patterson, 2014). Healing, or the wholeness of human–nature relations, is required for a healthy balance. In this sketch, I acknowledge the need for further elaboration on the social and environmental complexity of eco-anomie.

The state of relations

Diagnosis of eco-anomie in mainstream culture means people are relationally disconnected, and lack agency and knowledge for connecting themselves to nature, the Earth, and uncertainty. Societal "norms" have wiped out agency. This is a disease in life, an autoimmunity, with increasing mental and physical effects. Current anthropocentric frameworks and terminology for knowledge-making are academically and culturally protective. Eco-anomie is profoundly harmful to human flourishing, yet it is a disease inimical with any form of biomedical "treatment." A new paradigm is necessary to begin to improve homeostasis and restore balance. Innovation in the field of ecological theory within an Earth-centered paradigm may support a degree of healing but cannot undo the damage. The next section searches for hope as it considers alternative theories for human–nature relations.

Counter-currents and new directions

An intermittent parallel discourse of positive human–nature relations is entwined with mainstream culture (Glotfelty and Fromm, 1996). Important historical ontological premises around spiritual and mental health include pagan nature spirits and the importance of gardens (and wilderness) in all major religions, as well as philosophical inquiry around what it means to be human. Environmental markers include vitalism, deep ecology, and the psychological concept of biophilia, briefly outlined below and followed by a critique of rewilding, a currently popular practical solution.

Counter-currents: vitalism, deep ecology, and biophilia

Originating in Ancient Greek philosophy, vitalism is a metaphysical paradigm that holds that there is a hidden vital spirit, energy force, or soul in every living thing. Vitalism was accepted thinking in observational science until Cartesian dualism placed it in opposition to material science in the seventeeth century. Its main concepts, including homeostasis, or a healthy system being in balance, underpin integrated medicine and Gaia theory today. Coulter et al. (2019) discuss vitalism's history and philosophical debates in healthcare, calling for a rethinking of its application. As a principle of life processes, it may offer ways of thinking about treating imbalance in patients as much as human–nature relations.

Deep ecology is a term coined by Arne Næss in 1973 that has been called a revolutionary ecology movement (Devall, 1980). Predicated on twentieth-century authors including Rachel Cason and James Lovelock, deep ecology bears a clear relationship to the approach in this article. It incorporates environmental ethics, refutes an anthropocentric approach, and involves self-examination of behaviors and beliefs. Critical of nature being viewed as a collection of resources, deep ecology is a gestalt person-in-nature philosophy, viewing people and nature as one and looking to reform values and social organization (Devall, 1980). Today, an increasing amount of literature demonstrates its counter-current vitality. The literature is sensuous, poetic, and reflective, evidencing rich animal-in-nature experiences. In Monbiot's (2013, p. 230) *Feral*, taste sensations of cockchafer larva breaking on his tongue recall memories, and he "porpoises" whilst diving for dinner during spider crab migrations, in a world that he "could give [himself] up to." Abram (2010, p. 230) feels the "enfleshed body" as a "sensitive threshold through which the world experiences itself." Tree's (2018) intimate experience of rewilded land belongs here too. Deep ecology identifies the creative joy of human beings as nature, evidencing possibilities and hope.

Proposed by Fromm in 1964 as a human personality trait or psychological orientation toward life, biophilia was further developed by Wilson in 1984, meaning people form a mental link with living organisms. Wilson stated that this was something evolutionary, involving emotional dependence. Reprising the origins of biophilia, Barbiero and Berto (2021) argue it can refer both to a love of life between living creatures and to a love of nature, including animals and the environment. Perhaps because it reads almost as a diagnosis, the authors evidence how Fromm and Wilson understood this as a basic human force for developing balanced relations between people and the biosphere. They suggest it may be a fundamental evolutionary adaptation, with wilderness remaining deeply imprinted on the human psyche. Indeed, as Mooalem (2014) points out motivation drives some people to rescue animals in danger of extinction to extraordinary lengths, dressing as giant birds to support migratory patterns, for example. Barbiero and Berto cite an excellent range of research on positive emotional and psychological benefits such as happiness, relaxation, and wellbeing for adults and children in support of human biophilic nature relations as a rationale for biophilic design in human environments. The marketisation of the emotional value of human–nature interactions, including corporate use of "greenwash" (Gatti et al., 2019), would benefit from the further critical multidisciplinary study. Biophilia is in part a psychological spin on deep ecology and evidences the academic need to rationalize (and separate) some peoples' need to connect with nature.

New directions: rewilding

More recently, Rewilding has emerged as a practical response to rural estates generating a new form of economy that recognizes that "nature" should be in charge (Tree, 2018). Initiated in Europe, Global Rewilding (2023) has formed partnerships focused on animal and land conservation. Rewilding functions differently in agriculture and conservation. Conservation usually involves the preservation of "wild spaces," something that is frequently accompanied in the UK and the USA, more than in Europe, by a fear of "letting go" (Monbiot, 2013, p. 226).

Writing about the rewilding project at Knepp, in Sussex, Tree (2018, p. 61) concluded that scrubby pasture populated by large grazing herbivores is nearer the mark than previous understandings of "closed-canopy woodland," correcting longstanding conservation mythologies of a tree-covered Earth before human intervention. Tree (2018, p. 153–154) argues that the term originates in the USA (citing Forman for its first use in the 1980s), comprises "a Pandora's box" full of idealist traps, and warns about "playing loose" with it. Academic descriptions of rewilding reference "cores, corridors and carnivores" (Soulé and Noss, 1998) and "a type of large-scale biological and ecological restoration, emphasizing the recovery of native wide-ranging species, top carnivores and other keystone animals in natural patterns of abundance to regain functional and resilient ecosystems" (Johns, 2019). Examining the literature, Carver et al. (2021) found 10 rewilding principles, including native species, the need for iterative feedback, and a transformative form of co-existence that he suggests establishes a shift in established relations.

Rewilding is a large-scale cultivated response, driven by landowners or those working with land (Rewilding Britain, 2023a). Informed by discourses of hope in mitigation of the climate crisis and by crises in agriculture, it is an emotive topic (Tree, 2018). Consumers and supermarkets in the Global North demanding cheaper production, perfect produce, and year-round availability drive agricultural production, especially in poorer countries with warmer growing conditions. Production requiring water and fertilizers results in over-production of food waste, animal waste (slurry), an increased carbon footprint from transport, poor working conditions, desertification of land, water shortages, and pollution of rivers, reservoirs, and oceans from fertilizers and plastics. Responses include local sourcing, box schemes, and organic and regenerative agriculture, but there are cost implications.

Where rewilding takes agricultural land out of production, it both reduces the carbon footprint and stores carbon. A huge expansion is needed for a substantive impact on carbon emissions (Monbiot, 2019). Rewilding supports greater and much-needed biodiversity. Technically, the essence of nature is a wildness that transgresses managed spaces. Recently, on a well-known gardening programme, the panel was asked if they would pay to see weeds. Disparaging responses included words like "untidy," "anarchic," and "native weeds." Nobody pointed out the irony of getting in a petrol-driven car to visit an attraction that aims to reduce carbon emissions. Crucially, in their animal form, despite large predators, people are noticeably absent from rewilded landscapes, whether they are apex predators or prey. At Knepp, people walk on paths, occasionally crossing public rights of way. They are found in the café or the shop. Wider behavioral change is needed in the face of climate change. It neglects social considerations, places where people work with land for their survival, and the politics of global social diversity and critical race theory.

The question is whether rewilding can be more than an anthropocentric, affluent, and mainly Eurocentric fashion, encouraging nature to take over un-managed spaces like my hedgerow. Rewilding is clearly a force for good. It is an enormous educational opportunity to reconnect people with nature's "vital force" and learn about flourishing and unpredictability. It communicates life principles, offers space for actions, and evidences people's need to act. It accesses people's love of nature, their emotional need to reconnect, and drives agentic, small-scale individual and community actions. It has both reach and popularity. It is fast becoming a business, spawning books, educational work, and marketing that proposes to rewild everything from window boxes to the self (Barnes, 2018). Rewilding Britain (2023b) has a comprehensive glossary. Yet, however beneficial, rewilding is an anthropocentric response that maintains the status quo and is dependent on landowners and the government. As the Earth is critical to human survival, relational change necessitates an eco-centric, Earth-centered paradigm.

Paradigm change

Earth-centered arguments: relational aspects

The relational aspect of human–nature interactions informs my call for replacing an anthropocentric view with an eco-centric one. For Aline Lapierre, replacing therapeutic neutrality with a relational-centric therapy paved the way for embodied clinical understandings and active participation. She (LaPierre, 2015, p. 18) states that we exist in "a relational matrix within ourselves, with each other, and within our planet." Arguing that humans are hardwired to connect, communicate, and make relationships, she uses body–mind theory to understand this complex relational matrix, outlining how humans reconcile inner and outer worlds through somatic (sensory), linguistic (narrative), and relational (attachment, identities, dyads) organizations. Disorganization in any of these forms is a rupture that limits development and results in withdrawal, an incapacity to heal therapeutically, to connect deeply, and to function relationally. This is precisely what eco-anomie looks like. Agency is compromised. The concerns of those who care deeply go unaddressed. Thus, individual and collective environmental actions that are suppressed by self-protective mainstream political and institutional culture become extreme, a polarization seen in protests by groups such as the Extinction Rebellion (2023) and democratic crises in the UK where political actions threaten human rights (Liberty, 2023).

Earth-centered arguments: an ethics of balance

Planetary and health-based ecosystem concepts share similar goals around balance, achieving homeostasis, building functionality, and resilience. In addition to the need to theorize the concept that nature is in charge and not humans, it is important to consider the colonializing of peoples, taking care not to prioritize an anthropocentric mode. The Global North's mainstream political and economic culture informs and influences international policies, operating institutional power politics over the Global South and the planet. Its disproportionate contributions to climate change are, in no doubt. The Global South requires resources to implement appropriate science-based research that is not simply imposed from the Global North (Rodrigues, 2021). Anthropocentric processes require critique, and UK actions proceed more slowly than those of other countries (Monbiot, 2023). Protectionism in the North must not mean the South loses out again.

Designed as a collaborative and collective global community agreement with Earth in mind, the 17 United Nations Sustainable Development Goals (UNSDGs) called for change by 2030. Although collectively designed, they involve compromises between nations that operate within the dysfunctional power system and a "development" agenda (Sultana, 2018). From an earth-centered perspective they are not sustainable. They do not respect the fragile integrity of the Earth as a global system. Indeed, Kotzé and Adelman (2023) precisely argues that the SDGs are mainly human-focused rather than earth-centered and simply constitute the most recent anthropocentric agenda.

Tensions between positivist notions of absolute truth and human perceptions and experiences of the same have led to post-positivist framing and the development of systems-based approaches. However, like the SDGs, such improvements (and research funding) involve the agenda of an overarching anthropocentric paradigm driven by over-consumption and over-production. The earth's resources have been depleted by an economics of mismanagement, blocking future visions of more sustainable, healthy human–nature interaction. For some time, research and the United Nations have both acknowledged that burning fossil fuels is the biggest contributor to climate change (Karl and Trenberth, 2003). The second is agriculture and land use. Clearly, human management of earth resources cannot be trusted.

From the hedgerow, I observe the fundamental disconnect between humans and their knowledge/education (loss of capital + habitus) of the changing space that they/we inhabit (eco-anomie) and how to function within it (practice). This knowing-doing gap disrupts collective consciousness and actions, making it a problematic place from which to call for change. Yet for decades, individuals and communities of people have been calling. Governments need to act faster. Time is running out. A radical change of paradigm is urgently needed, where human interests no longer come first. The politics of human ownership over the earth do not serve our animal dependency on it. This requires that Earth law and rights come first (Cullinan, 2011).

The new paradigm: Earth laws and wild law

Clearly, Earth laws are needed now to protect the planet and prevent further damage. Reframing Earthrights involves limiting human power and shifting perspective. Using combinations of natural law, ancient wisdom, and human and ecological laws, Cullinan (2011) advocates that the wellbeing of the planet is paramount. Human wellbeing cannot take precedence. He argues that Earth jurisprudence would bring animals back into the frame, meaning all animals would be equal. Land ownership and the purposes for which it is used would require revision. Time and natural cyclical rhythms need reprising to think differently about our short-term focus. Drawing inspiration from the practices of indigenous peoples, he compares human duty to the contributory role and allegiance of a cell to the health of a body, in an analogy that describes the Earth as a "vast network of interrelationships" (Cullinan, 2011, p. 101). Earth laws premise that all aspects of the Earth, air, and waters have rights relating to their nature, which is essentially wild. For example, it is the nature of rivers to flood. The flow of rivers would have rights requiring precedence over housing on flood plains. Wild laws such as these could inform Earth laws bringing balance back to the planet.

With the Earth laws foremost, information from Earth scientists and geographers who have identified climate change and ways of working with the Earth within the Anthropocene is needed. Observational science and other ways of knowing that Levi-Strauss called magical thinking are crucial, as are models from nature.

Listening to the Earth

The Global North needs to learn from the Global South. In the Global North, Christianity has incorporated and transformed pagan knowledge, and science has eschewed indigenous practices in favor of epistemological knowledge (Glotfelty and Fromm, 1996). Many indigenous communities retain the ecological principles of working with and communicating with the Earth. These intuitive and magical practices are valuable for rethinking Earth laws, but they are fragmented or lost in the Global North. Bricolage can help create new narratives, and deep ecology and biophilia offer hope for relational functioning—that what has been lost may grow and resonate intuitively.

Scientists working with the Earth have learned useful forms of listening. Identifying human influences shaping the Earth and their potential to enable sustainable resources, Crutzen (2006) theorized the Anthropocene. Steffen's et al. (2005) contributions include initial empirical data analysis that informed current understanding of the Earth as a global integrated system and extrapolation of the Anthropocene. These cumulated in his understanding that environmental law had failed to limit or address damage and the need for Earth laws to challenge continuing political agendas (Steffen et al., 2005; Boonstra et al., 2023).

Hope for creativity

Earth laws premise *returning to the bricolage*: Its creative process goes to the heart of ontological and existential questions about the purpose, meaning, and survival of human and planetary existence. Threads emerge in shreds and tatters as overarching politics maintains eco-anomie and climate change accelerates. Bricolage engages ontologically with this process to reconstitute a network of calls for action. Threads in vitalism and deep ecology sparkle with hope for change and food for future thought. Haraway's insects, fragments of tree worship, and early alphabets combine bits of myth and storying in this bricolage. Textures in philosophy, language, and research softly demonstrate that human–nature relations are integral to human flourishing. Integration requires altered perception and new thinking that involves experiencing, listening, and learning.

Individuals can enact care of the self:

- Spend more time in nature to come into being, to sustain health and nourish the soul;
- Actively seek creative interaction with the natural world;
- Become informed, recognize stasis, and develop Earth-centered actions;
- Eat well, exercise, develop community, and reduce over-consumption;
- Drive change by voting and making governments more accountable.

Staying with the trouble: conclusion

Haraway has pointed out that all stories end badly in the Anthropocene. I have considered language, research, practices, and concepts in human–nature relationships. There are inevitable gaps, yet clear patterns of dis-ease have exposed the roots of a cultivated split identified as eco-anomie. The disconnected and unethical economy is the result of human mismanagement of the Earth, abusing resources to feed expansion, production, development, and ownership of land and peoples, with unhealthy results across all living systems and species. And as Haraway argues, we need to stay with the problem, perhaps drawing on old paradigm research, perhaps to generate and measure feedback systems as temporary Earth communications. There is no solution to climate change. All that is certain is that a new paradigm based on Earth laws is needed to regulate the political and economic mismanagement of our planet.

There is some hope that, as people have created the current problems, some mitigation may lie in healing people–nature relationships. Chawla's (2020) research on children caring for nature found their distress and sadness in coping with environmental loss and degradation may be helped by connecting with nature. Foucault's appraisal of Classical Stoicism also considers time in nature as a form of self-care and healing, especially for the human spiritual dimension.

Arguably, human–nature interactions form an intimate relationship like no other. Sensing or knowing when a plant is ready and how to gather sustainably, how to touch, taste, cut, and prepare, what and when to take and what to leave—all of this gives a rich and tangible practice of different and magical ways of knowing living assemblages that nurture. If the psyche is the breath of life and one that people share with the Earth, it may be emotions and senses that come to the rescue, but change needs to come quickly to enable people to embrace uncertainty.

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"Whatever I said didn't register with her": medical fatphobia and interactional and relational disconnect in healthcare encounters

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Introduction: This article focuses on medical fatphobia as a specific phenomenon structuring interactions between patients and healthcare practitioners. Throughout the article, we use 'fat' and 'fatphobia' as the preferred terms in the body positivity and fat acceptance communities. It is well documented that 'fat' people frequently experience negative and highly stigmatising healthcare encounters where weight is disproportionately centred and over-attributed as a cause of ill-health. This can compound and worsen disordered eating, trigger mental health problems, and lead to healthcare avoidance. Although the regularity and risks of these weight-focused encounters are well established, there does not yet exist a coherent theoretical framework for understanding such discriminatory practises.

Methods: In this article, we draw on the experiences of 15 fat women who are members of the Health at Every Size (HAES) online community to explore how they perceive their fatness impacting medical encounters.

Results and discussion: Through these data and specifically drawing on the framework of 'cultural health capital,' we suggest that given the deep purchase of cultural tropes surrounding it, fatness is perceived to embody and therefore confer on patients' assumptions of low cultural health capital. We argue that ubiquitously characteristic of medical fatphobia is what we call an 'interactional and relational disconnect' between fat patients and healthcare practitioners. We suggest that this disconnect structures fatphobic interactions by over-attributing fatness as the underlying cause of medical problems, which entrenches patient and practitioner ambivalence because of a lack of joint decision-making. We argue that interactional and relational disconnect is produced by, sustained by, and reproduces asymmetric power relations between patients and practitioners. While we demonstrate that patients develop tactics to mitigate and manage fatphobia in healthcare encounters, the persistent interactional asymmetry between doctors and patients means these attempts often fail. We conclude with a plea for sociology to take medical fatphobia seriously as a form of intersectional systemic discrimination. While movements like HAES, fat positivity, and body acceptance create kinship and support fat patients with self-advocacy in healthcare interactions, we suggest that systemic rather than individual change is necessary for effective healthcare inclusion and interaction.

KEYWORDS

fat, fatphobia, medical fatphobia, interaction, cultural health capital

1 Introduction

Ellen Maud Bennett died on 11 May 2018, because she was fat. Ms. Benett had been feeling unwell for several years and had repeatedly sought medical intervention. Each time, her symptoms were attributed entirely to her size, she was sent home with advice to return only once she had lost a significant amount of weight. She was offered no support or suggestions about her ill-health beyond weight loss. When the root of her malaise was eventually identified as an inoperable cancer, Ms. Bennett was given just days to live.

While Ms. Bennett's story became very public—particularly because she used her obituary to call for 'women of size' to reject fatness as the primary determinant of their health—it is not a particularly exceptional case (see Kassam, 2018; Ulrey, 2023). Rather, it encapsulates well the persistent and disproportionate focus on weight in healthcare interactions and the potentially devastating implications of such myopism (Brown and Ellis-Ordway, 2021). Indeed, it is well documented by fat studies scholars and activists that fat patients experience poorer interactional exchanges with healthcare practitioners. Fat patients generally have shorter appointment times (Flint et al., 2021), are more likely to be treated discourteously (Aldrick, 2010), and, like Ms. Bennett, are likely to receive generic, banal weight-focused advice rather than robust, tailored medical support (Ananthakumar et al., 2020). Given that fat patients are seen by healthcare practitioners as partially, if not fully, responsible for their own health troubles, they are seen as 'unworthy of medical time' and experience delays to specialist referrals and investigative procedures (Ananthakumar et al., 2020, p. 1). Research repeatedly demonstrates that such negative treatment leads to trauma, poorer long-term outcomes (Phelan et al., 2015), internalisation of weight bias (Williams and Annandale, 2019; Davidsen et al., 2023), and in some cases, total avoidance of healthcare encounters (Kost and Jamie, 2022).

Although such endemically poor treatment has been widely documented, there does not yet exist a coherent theoretical framework for understanding such systemic discriminatory healthcare practises. Using the notion of 'cultural health capital' (Shim, 2010), we identify the assumptions about fat patients that underpin medical fatphobic practise and describe how it manifests and unfolds in healthcare encounters, sustained by a wider system of healthcare inequality linked with entrenched medical power. As such, we demonstrate that medical fatphobia operates at both expansive and contracted scales, in individual one-on-one healthcare interactions as well as in wider systemic healthcare structures.

2 Literature and theoretical context

In this section, we discuss the empirical and theoretical drivers of our article and argument. We provide an overview of empirical research about the extent and nature of fatphobia in healthcare encounters. We then move on to outline the notion of 'cultural health capital' (hereafter CHC), which provides a lens through which to understand the disrupting nature of fatness in healthcare interactions. First, we offer some brief reflections on terminology, particularly our use of the term 'fat' throughout the article.

2.1 A note about terminology

There is a lack of consensus on how to refer to and describe 'fat' people in medicine, policy, the media, and society more generally (Bednarek et al., 2023; Jepsen et al., 2023). Descriptors that incorporate terms like 'overweight' or 'obese' have been widely critiqued by fat scholars and activists because they are based on flawed and simplistic body mass index (BMI) measures. While BMI has some value as a population-level public health tool, it has been widely critiqued for its use to classify individuals as healthy or unhealthy based solely on weight without reference to other factors like exercise or general health (Gutin, 2018). The BMI has also been criticised as rooted in white supremacy and for its disregard of the potential need for different cutoffs for different ethnicities (Maffetone et al., 2017). Indeed, considerable attention has focused on the racist and eugenicist roots of BMI measurements and their contemporary hangovers. In a post for her Your Fat Friend (Gordon, 2019) blog, body positive advocate Aubrey Gordon outlines the 'bizarre' history of the BMI, which is wrapped up in mid-century European academic attempts to map and measure 'the average man' using research subjects disproportionately recruited from white nations. In this white supremacist model, 'the average man' actually means 'the average *white* man.' Therefore, Black and minoritised bodies whose composition differs in terms of muscle-to-fat ratio are inaccurately recorded and inappropriately treated when stacked against the white norm of the BMI (Strings, 2019). For Strings (2019), this racist history, coupled with contemporary and historical sexism, feeds into the disproportionate fatphobia faced by people, particularly women of colour. For Redpath (2022), then, BMI 'must be abolished completely and with immediacy.' In addition to this over-reliance on BMI measures, terms like 'overweight' and 'obese' medicalise and problematise particular body types, leading to and compounding anti-fat attitudes. In an effort to temper such overly stigmatising terminology, person-first language has been suggested by various practitioners, groups, and policymakers. Armstrong et al. (2018), for example, argue that using 'person with obesity' places the individual before the condition and reduces bias, while Palad and Stanford (2018) argue that such person-first language brings obesity in line with wider medical conventions such as 'person with diabetes' or 'person with autism.' But such efforts at diplomacy have been wholly rejected by fat individuals, scholars, and activists for continuing to use terminology based on BMI, equating fatness or high weight with ill-health, and locating fatness as a biological dysfunction (Meadows and Daníelsdóttir, 2016).

Avoiding such medicalised and stigmatising language like 'overweight' and 'obese,' though, risks ushering in well-meaning but largely meaningless euphemisms such as 'big-boned,' 'full-figured,' or 'plus-sized' (Bednarek et al., 2023). Such phrasing others fat people by introducing a degree of implicit comparison to a normative, yet undefined, baseline—'full-figured,' for example, implies a deviation from some kind of 'standard-figured.' Even if such a standard figure, bone size, or body size exists, it is likely again to be based on simplistic measures like BMI, and it is telling that there are very few polite euphemisms to describe those deviating from it in the other direction who might be described as 'underweight.'

Despite these debates about phrasing in medicine, media, and policy rumbling on, fat activists are clear in their approach to terminology—just say 'fat' (Gordon, 2020), 'say it loud, say it proud:

Fat! Fat!' (Wann, 1998, p. 18). As a neutral descriptor of body size which avoids socially constructed disease categories of 'overweight' or 'obese,' using the term 'fat' is common practise in the body positivity and fat acceptance communities (Tovar, 2018; Williams and Annandale, 2019). For Meadows and Daníelsdóttir (2016, p. 1), in sanitised and euphemistic phrasing, 'the apparent need to separate a person from the characteristic in question (i.e., their fatness) implies an inherent adverse judgement.' Therefore, using 'fat' is a way to describe and 'say my body's name' in a way that avoids medicalising and moralising that body (Gordon, 2020). In this way, using the notion 'fat' is a political endeavour, enabling fat people to (re)gain control over their own stories and experiences and taking a stance against the negative connotations the term bears in wider society (Saguy and Ward, 2011).

Given this linguistic context, we use the term 'fat' throughout the article to describe individuals of higher weights who experience discrimination based on their body size. Moreover, we use the term 'fatphobia' as a way to encapsulate the 'fear, hatred, and loathing of fat bodies' (Stoll et al., 2022, p. 37), which, like other 'phobias' and 'isms'—sexism, racism, and homophobia—exists at the intersection of and stretches across both individual psychopathologies and cultural and structural perspectives.

2.2 Fat patients and healthcare interactions

Despite research demonstrating the medical, social, and cultural complexity of 'obesity,' the (mis)conception persists that fatness is a result of poor individual lifestyle choices, apathy, and a lack of willpower (Lupton, 2013). Within this individualised approach, wider structural factors that serve as health determinants become deprioritised, and fatness is located solely as 'a failure of individual control' (Brandt and Rozin, 1997, p. 64) and an inability or unwillingness to heed basic public health advice. As a result, fat people are often subject to weight-based stereotyping, stigma, and discrimination in a variety of everyday spaces such as work (Flint et al., 2016), education (Sykes and McPhail, 2008), public transport (Evans et al., 2021), and health-related settings like gyms (Harjunen, 2019), obesity policy (Flint, 2021), and public health campaigns (Department of Health and Social Care Committee, 2022). In short, fatphobia is a broad and deeply embedded societal issue which 'circulates' around diverse spaces, rendering them and their social interactions 'uncomfortable, unwelcoming, unsafe and inaccessible' (Rinaldi et al., 2020, p. 38). Those who attempt to challenge such fatphobia (e.g., with body positivity) are often met with abuse both online (Kristensen, 2023) and in-person (Johanssen, 2021). Our concern in this article is medical contexts—doctors' offices, hospitals, nurses' rooms, and the like. In their narrative review of weight discrimination and its effects, Phelan et al. (2015) demonstrate that fat patients in these settings are subject to discriminatory, stigmatising, and unequal treatment. This biased medical treatment can be seen as partly rooted in the complex and often contradictory story of the medicalisation of 'obesity.' On the one hand, Sobal (1995) argues that during the twentieth century, the understanding of fatness as a moral failing decreased in prominence to be replaced by a conception of fatness as a disease. In other words, fatness moved into the medical gaze as a 'problem' to be addressed through medical intervention. While such an ontological move might be reasonably expected to garner support or sympathy for fat individuals, the question of agency complicates the picture. Hence, on the other hand, the march of neo-liberal public health models in the latter years of the century placed the focus on individual decision-making and personal responsibility for health. Within this new public health context, the enduring and simplistic 'calorie intake over expenditure' model of fatness (Chang and Christakis, 2002) became an issue of individual failure to monitor and control eating habits, contributing to individual ill-health (in the form of 'obesity') and a collective 'obesity crisis.' Against this backdrop, Lupton notes that practitioners often uncritically adopt wider anti-fat cultural tropes and view fat patients as 'lazy, stupid, non-compliant and worthless' (Lupton, 2013, p. 68), embedding and normalising poor treatment of fat patients (Tomiyama et al., 2018). Healthcare practitioners frequently spend less time with overweight patients (Phelan et al., 2015) and are often reported to be rude and disrespectful or even verbally abusive (Ananthakumar et al., 2020). In these shorter consultations, practitioners are also likely to disproportionately focus on weight at the expense of the actual reason for the patients' visit (Roy et al., 2023) and may 'weaponize' weight shame and stigma, albeit ineffectively, to encourage weight loss (Williams and Annandale, 2020).

As well as impacting immediate healthcare interactions, the assumption that health problems result from excess weight also results in practitioners' reluctance to proceed with investigative procedures (Phelan et al., 2015). A recent review of breast, cervical, and colorectal cancer screening, for instance, demonstrates that practitioners' unconscious bias against overweight patients places considerable barriers to uptake of screening opportunities (Graham et al., 2022). Aldrick (2010) also reports that one-fifth of obstetrics and gynaecology practitioners express a reluctance to perform pelvic and breast examinations on fat women.

These biases, unsurprisingly, have significant consequences for fat patients. Healthcare interactions are often experienced as stressful, dehumanising, and traumatic (Phelan et al., 2015), which can lead to the internalisation of fatphobia (Davidsen et al., 2023) and, in turn, result in fat patients delaying seeking support or healthcare avoidance altogether. For example, Aramburu and Louis (2002) found that amongst 'obese' women, 34% had delayed seeking out medical advice out of fear of being criticised for their weight. Moreover, Ms. Bennett's story above demonstrates potential iatrogenesis and an increased risk of premature and unnecessary death resulting from fatphobia.

2.3 Cultural health capital

Concepts such as 'weight bias,' 'weight discrimination,' and 'weight stigma' have been variously mobilised by scholars and activists to explain this 'rife' fatphobia in healthcare practise (Brown and Ellis-Ordway, 2021). These concepts offer useful starting points for understanding the ways that practitioners adopt, internalise, and then play out wider cultural tropes about fatness as a failure of individual control (Nutter et al., 2016). Yet, as Nutter et al. (2016) outline, these notions have been somewhat disparately developed across academic and medical disciplines with divergent priorities, theoretical sensibilities, and end goals. Inasmuch, while these frameworks share some common foci, there does not yet exist a cohesive theoretical core to understand what lies behind endemic discrimination against fat patients and how it is sustained through power relations.

To remedy this, we apply the notion of cultural health capital to understand how healthcare interactions are structured by fatphobia. Following Bourdieu (1986) concept of cultural capital, cultural *health* capital captures 'how broad social inequalities operate in patient-provider interactions and shape the content and tone of health care encounters' (Shim, 2010, p. 1). Firmly rooted in the Bourdieusien view that society is deeply hierarchical, Shim (2010) proposes CHC as a particular form of cultural capital that can be leveraged by patients in healthcare interactions to more effectively engage with practitioners. She suggests that particular components of CHC include: medical knowledge based on normative scientific rationale, communication and interaction competency, a proactive and instrumental stance towards health and body, self-discipline, a future-oriented perspective, and an ability to communicate social privilege and resources (Shim, 2010, p. 3). Together, these skills cohere as a 'toolkit' for self-presentation, which, depending on providers' reactions, can positively influence the quality and responsiveness of healthcare interactions, resulting in more attentive care, more equal decision-making, and better outcomes (Dubbin et al., 2013). Like cultural capital more generally, CHC is embedded within social structures and processes of stratification, meaning that patients' available skills and resources, as well as their ability to acquire and deploy CHC, are impacted by broader inequalities in social structures, institutions, and social life. As such, the acquisition and deployment of CHC is most commonly tacit, accumulated through habitual healthcare practises and experiences that are themselves shaped by wider inequalities of social, cultural, and financial capital. In short, those at the sharp end of health inequalities are likely to possess limited cultural health capital, which constrains the effectiveness of their healthcare interactions and relationships, in turn compounding pre-existing inequality and health determinants.

Broadly speaking, Madden (2015) argues that CHC includes a good knowledge of medical vocabulary, effective communication skills, subscription to neo-liberals of self-discipline, and prioritisation of future health outcomes. A previous study highlights how healthcare practitioners use visual and audio clues to inform their *readings* of patients as dispossessed of these characteristics and, therefore, lacking CHC. Weerasinghe (2012), for example, highlights how immigrant women in Canada experience disrespect, verbal ill-treatment, and exclusion in healthcare interactions based on their audible and visible minority identities. Similarly, the healthcare practitioners in Chang et al. (2015) study describe assuming low CHC in patients with histories of substance misuse. Both examples highlight how macro-level social relations and norms manifest in micro-level healthcare encounters and legitimate power within patient–practitioner interactions (Shim, 2010). Indeed, Shim (2010, p. 4) argues that practitioners 'do not simply respond to the CHC that patients mobilise' but are, given their relative power in healthcare encounters, active agents in evaluating and shaping CHC. In this way, patients' *perceived* CHC is dependent on practitioners' attitudes towards their individual attributes stemming from wider cultural stereotypes. As such, even when patients *do* have high levels of CHC, practitioners may not recognise or acknowledge this and therefore may fail to give adequate space for patients to deploy their CHC, instead adopting a paternalistic interactional and relational style.

Given the cultural tropes about fat people as lazy, apathetic, and non-compliant with medical advice (Gailey, 2014), we suggest that fatness is often interpreted by practitioners as a visual clue of a lack of CHC. If CHC is rooted in understandings of medical vocabulary, belief in ideals of self-discipline, and investment in the future health outcomes, then deeply engrained anti-fat stereotypes locate fatness as antithetical to possession of CHC (Vartanian et al., 2013; Strings, 2015). As a result, fat patients are understood and treated by practitioners as apathetic, health-illiterate, in need of medical paternalism, and unable to actively participate in their own care decisions (Blackburn and Stathi, 2019). We suggest that this leads to what we call an 'interactional and relational disconnect' between fat patients and healthcare practitioners, which is rooted in and reproduces medical fatphobia and is sustained by 'persistent' medical power (Pilnick and Dingwall, 2011).

CHC is further compromised in fat *women* due to their deviation from both health and beauty standards (Fikkan and Rothblum, 2012). While fat men comparatively escape or offset aesthetic scrutiny around their body size, women are expected to fulfil the expectation of slimness/thinness, which is perceived as both healthy and attractive (Kwan, 2010). Women who do not comply with this health and beauty ideal are understood as somewhat pathological, failing to fulfil the expectations of self-discipline and adherence to normative biomedical constructions of health and unhealthy bodies. As such, their bodies are positioned as 'extreme' (Hockin-Boyers et al., 2020). Fatphobia resulting from the double deviance of being fat *and* a woman permeates healthcare encounters where practitioners meet fat women with bias, dismissiveness, weight focus, and assumptions of fat women having more negative personal qualities (Fikkan and Rothblum, 2012).

Before reporting our findings, we offer an outline of our methodological approach.

3 Methods

3.1 Study site: HAES groups

This article draws on qualitative data collected in interviews with 15 fat women who were recruited from a private Health at Every Size (HAES) Facebook group. HAES is an 'alternative public health model' focused on healthy day-to-day food, exercise, and other practises that aim to achieve good health and wellbeing regardless of weight, body status, or changes (Burgard, 2009, p. 41). Unlike traditional weight-based health models, HAES dispenses with standardised measures—such as weight, BMI, or body fat percentages—which determine categories of 'healthy' and 'unhealthy,' and instead advocates for a 'holistic' approach to health based on intuitive food and exercise practises appropriate to a *personal* sense of health, happiness, and wellbeing (Bacon, 2010). For Robinson (2005), such holism goes hand-in-hand with challenging normative medical ideas of health and weight, whereby HAES (i) embraces natural diversity in body type, shape, and size rather than aiming for a universalised ideal; (ii) acknowledges the long-term ineffectiveness of dieting and weight loss projects; (iii) emphasises the importance of intuitive and relaxed approaches to eating in response to bodily cues rather than external, quantitative targets; and (iv) recognises the contribution of social and emotional wellbeing to overall physical health.

Against this backdrop, HAES online groups are hubs of health-focused information, support, and kinship, offering a space to share advice and experiences of being a fat person, including navigation and negotiation of discriminatory healthcare interactions (Kost and Jamie, 2022). The HAES group from which we recruited our participants is one of the busiest and most diverse in the 'fatosphere.' At the time of recruitment, this group had approximately 6,500 members from a range of countries and a variety of socioeconomic, ethnic, and age backgrounds. While participants were sampled from this specific HAES Facebook group, many of them were part of other similar networks, meaning our analysis is not limited to one HAES case study.

3.2 Sampling and recruitment

We recruited participants by publishing a post on the group page in October 2019. The post outlined the focus of our research—to understand fat women's experiences of healthcare interactions and how online groups support them to navigate these encounters—and invited potential participants who met our inclusion criteria to contact CK if they wished to be interviewed. This recruitment post specified that we were seeking women residing in Australia, Canada, the UK, or the USA; aged 25–45 years old; self-defined as middle or upper socioeconomic class; and who described themselves as 'fat.'

We restricted our recruitment to these countries in contexts where fatness is understood as deviant and where English is the first language. This latter point was important given our focus on participants' experiences of spoken interactions with healthcare practitioners. We opted for English-speaking countries to ensure alignment between the language of participants' healthcare encounters and the language of our interviews so that participants could accurately recount stories and avoid the loss of any linguistic nuance. There are, of course, notable differences between the healthcare systems of our participants' countries which impact interactions and relationships between healthcare practitioners and patients. While Canada and the UK operate universal health coverage models, the USA has a privatised insurance-based system, and Australia adopts a hybrid approach where the government actively encourages private health insurance for higher earners despite universal coverage being in place. As such, care obligations, long-term patient–practitioner relationships, and consumer choice operate differently across these systems. While models of universal coverage traditionally offer less choice to patients about their care (policy shifts towards expanded patient choice notwithstanding), these systems commonly use general practitioners as gatekeepers to provide more specialist services, meaning that patients build sustained relationships over a great many years. Private healthcare systems, in contrast, are often built on fragmented engagements with specialist services accessed directly by patients. In the latter case, where patients are positioned as consumers of services, patients' dissatisfaction with practitioners can be voiced through withdrawal of custom.

Notwithstanding the differences between these healthcare systems, we recruited participants based on shared experiences of medical fatphobia, which is ubiquitous in Western countries and their medical systems (Lee and Pausé, 2016). We decided on the latter inclusion criteria to control for factors that may compound or complicate participants' experiences of healthcare interactions, such as racism, classism, or ageism (Crenshaw, 1991; O'Campo and Burke, 2004). Through an analysis of Canadian fiction, for example, Bruusgaard (2021) argues that ageing fat women of middle- and later years are socially positioned as shameful, unfeminine, desexualised and even cautionary tales of unhealthy futures. We take seriously such intersectional prejudices that inevitably come to bear on healthcare encounters and recognise that Black and ethnically minoritised women are disproportionately stigmatised by fatphobia. However, our research to fully understand the basis of medical fatphobia and how it manifests in interactions required a degree of participant homogeneity. We focused only on women because research consistently demonstrates that they are more likely to be stigmatised for being fat (Bordo, 1990) and are more likely to experience medical fatphobia (Anderson et al., 2001).

Upon contacting CK, potential participants received a participant information sheet and a consent form, and a mutually convenient time for the interview was arranged. Our final sample size was 15, comprising two Canadian, 10 US, and 3 British participants. Participants were aged 27–44 years, with a mean age of 35. Although we did not seek an ethnically homogenous sample, all of our participants were white. All participants described themselves as upper- or middle-class and 'well-educated,' though we did not specify any particular educational level as a criterion for inclusion.

3.3 Data collection and analysis

All interviews were conducted online by CK between October 2019 and January 2020. They lasted 30–60 min and were audio-recorded to be later transcribed verbatim. Interviews were structured by a topic guide, which explored how participants perceived their fatness to impact healthcare interactions and how they used fat positive online communities to navigate these encounters. We have detailed our findings on the latter focus elsewhere, where we argue that online platforms and groups act as spaces of 'kinship' based on shared knowledge and experience of medical discrimination (Kost and Jamie, 2022).

We opted for semi-structured interviews to allow participants to freely share their experiences while also enabling us to embed a degree of consistency and comparability between interviews. Given that experiences of medical fatphobia are both deeply personal to a particular individual and relatively consistent in their nature, identifying the 'data saturation point' was challenging. While we noticed significant thematic similarities in participants' accounts after around nine interviews, there was sufficient diversity in participants' reflections to warrant further data collection. We conducted six further interviews until we were certain we had reached a sufficient saturation threshold, and no new participant inquiries were forthcoming.

Following transcription, the data were analysed thematically using constant case comparison and deviant case analysis. We took an abductive approach to data analysis, whereby we were guided by existing frameworks but also ensured space for novel theoretical understandings to be identified in the data (Tavory and Timmermans, 2014). In particular, we were guided by pre-existing ideas of weight discrimination and bias and more specific conceptualisations of medical fatphobia (Hardy, 2023). At the same time, we retained flexibility to develop and draw in other theoretical ideas to conceptualise the interactional and relational manifestations of such prejudices. While we took a fat positive approach to research, we were careful not to stray into activism in our analysis. We did this by ensuring that our participants' narratives took centre stage and drove our analysis, keeping all literature (both academic and activist) at arms-length during analysis.

We undertook data analysis in three stages and as both an individual and group endeavour. First, CK conducted open coding to label data with descriptors of its content. This phase allowed participants' key reflections and experiences to emerge and ensured that CK had a deep familiarity with the data. In the second phase of the analysis, CK organised these descriptive codes into broader themes based on points of confluence in participants' accounts. To ensure trustworthiness of findings, this phase of analysis utilised constant case comparison, wherein data segments were compared with each other both within individual transcripts and across the whole dataset (Jamie and Pattison Rathbone, 2022). Deviant cases where codes and emerging themes sat in contrast to identified patterns were singled out for specific analysis and to test unfolding findings. The final set of themes and codes emerging from this second stage of research was agreed upon by both CK and KJ in collaboration to ensure robustness. At this stage of analysis, we noticed recurring patterns around assumptions that participants felt practitioners made about their engagement with health and the interactional and relational disruptions that this caused. These patterns in participants' reflections were reminiscent of other work on cultural health capital, its impacts on healthcare encounters, and the influence of medical power (Shim, 2010). As such, in the third stage of analysis, we proceeded with using this framework to further interrogate the data and more robustly situate our emerging themes within theoretical frameworks for understanding unequal and disrupted healthcare interactions.

3.4 Research ethics

The research was given ethical approval from Durham University in September 2019. As per the British Sociological Association (2017), all participants gave fully informed consent prior to beginning their interviews and were informed that they could withdraw without reason. In line with these principles too, during the transcription process, CK fully anonymised participants' responses by giving participants pseudonyms and removing any details that could be traced back to individuals. Although we closely followed standard sociological procedures for anonymity (i.e., by anonymising the data), there is debate about the anonymisation process in research, which overlaps with activist and political concerns. Allan (2017), for example, describes the desire of her participants in occupied African territories to have their names linked with the personal testimonies they had shared with her. Given that fat studies academic research is often informed by, overlaps with, and is mobilised in fat activism, research such as ours straddles both worlds and, therefore, complicates the question of anonymity. While we adopted a blanket approach to anonymise all our participants' data, we echo Allan (2017) and others in recognising the need for nuance in approaching the issue of anonymity.

Beyond these universal ethical concerns, interviewing fat participants raised some additional considerations. Given the endemic stigmatisation of fat individuals, traumatic experiences associated with living in a fat body resurfaced several times during interviews, potentially causing psychological distress (Muennig, 2008). We mitigated this risk in several ways. First, the project was carried out within a fat positive framework, which involved not inquiring about participants' weight and deliberately avoiding any framing of fatness that could seem pathologising. Second, participants were given contact details of mental health support associations in instances where this was deemed appropriate. Third, CK sent a follow-up email to participants after their interviews to ensure they did not suffer negative consequences because of trauma from the interview encounter. This email also served to check participants' on-going consent. Finally, participants were reminded of CK's researcher status and encouraged to visit a trained healthcare practitioner for mental or physical health support. Despite the risk of trauma, several participants reported experiencing interviews as something of a therapeutic space for mental healing (see Rossetto, 2014).

4 Findings

Below, we report our participants' experiences of interactional and relational disconnect within healthcare encounters, which is rooted in and stems from fatphobia, the core of which is the assumption that fat patients lack cultural health capital. The relationship between this disconnect, its anti-fat biases, and the role of CHC is circular and interwoven. But we begin our analysis with healthcare practitioners' assumptions of low CHC as the scaffold structuring fatphobic interactions through sustained medical power.

4.1 Embodying low cultural health capital

Participants reported feeling that their fatness was hyper-visible in medical settings and used as a reference point by practitioners to make assumptions about their health behaviours and attitudes (Gailey, 2014). As such, participants felt that their bodies took on a more active and central role in healthcare encounters than would be experienced by other patients. While slim/thin bodies become central to healthcare encounters in particular ways (through their acute dysfunctions) and at particular moments (describing symptoms), participants talked about feeling that their bodies were permanently visible throughout interactions with practitioners. Participants talked about their bodies being visually read as 'extreme' (Hockin-Boyers et al., 2020) the moment they entered the medical setting and the rest of the encounter unfolding from this reading. Charlotte, for example, talked about feeling that her body was hyper-visible, while Penelope described her sense that practitioners used her body to make assumptions about her exercise habits and sedentary lifestyle:

> *Charlotte: I felt like [my weight] was all anybody saw. […] And so it almost felt like people were just looking at the biggest piece of the puzzle, and that's all they saw.*
>
> *Penelope: When I walk in, I feel like doctors look at me and immediately make an assumption that this is someone who sits on the couch all day long, [and] does not take care of their health.*

In another example, Dilara talked about significant delays to her eating disorder diagnosis stemming from the hyper-visibility of her fatness and normative assumptions about fat bodies, health, and lifestyles:

> *Dilara: My eating disorder went undiagnosed for a really long time. If people had the knowledge of what eating disorders […] look like in children who aren't thin, I think I would have gotten intervention much earlier. But I did not! And that added years of living with an eating disorder that were really distressing…. Nobody saw the eating disorder because all they saw was that I was overweight.*

Such assumptions about health behaviours were manifested in, carried by, and communicated through participants' fat bodies, which they felt were dismissed as transgressive, antithetical to good health, and in need of management. This is despite the lived realities in which participants *did* take an active interest in their health and wellbeing. Ilya, for example, described feeling that her exercise routine and interest in health were superseded in healthcare interactions by the visuality of her fatness and the assumptions it produced:

> *Ilya: [When entering a doctor's office], I feel dismissed immediately. There's a story about my body the minute they meet me. I have had doctors in the past tell me flat-out that they do not believe me that I exercise as much as I do or watch what I eat at all. They […] say you cannot possibly be this size if you work out that much.*

Participants felt that the assumptions made through their bodies rested not solely on surface-level tropes about fat patients' laziness and apathy but also on suppositions about fat patients' more fundamental skills and competencies. In other words, participants described feeling that their assumed apathy was not just rooted in assumptions about their *unwillingness* to engage in health but their *inability* to do so owing to a fundamental lack of health-related skills and literacy:

> *Charlotte: I said to her, I do not want weight to be part of this consultation. And her response was, I will not bring it up if you do not, just keep your cheat meals to the minimum. I thought that was the most inappropriate and tone-deaf statement, given what I had written and said. I just felt that she did not take me seriously and did not think I was capable of making decisions about my own health.*
>
> *Mary: I have had doctors that kind of ignore my actual question and talk about other things. Usually it's weight-related—they tell me, your weight can lead to this, this and this. And I'm like, I know, but I'm trying to deal with another acute health issue now! It feels like they think I've never heard of the idea that losing weight may be good for my health. It's ridiculous, really.*

These assumptions about participants' inability to engage can be understood as an assumption about participants' lack of CHC, embodied in their fatness. In particular, Shim (2010) and Madden (2015) draw attention to the futurity of CHC, where positive long-term health outcomes are understood, given primacy, and accomplished through adherence to specific routines and ideals. In this way, CHC is not just a set of skills to be mobilised in healthcare encounters for the benefit of better care but, rather, an outlook on health, bodies, and wellbeing that is understood as antithetical to fatness. As such, several participants reported feeling that practitioners had limited faith in their long-term health planning abilities:

> *Sarah: I was […] looking for fertility treatment. [Doctor] said, I do not recommend you get pregnant because it is dangerous. […] The whole appointment, he kept hinting at the fact that I had not fully thought this [wish to be pregnant] through and that getting pregnant was an irresponsible, almost reckless decision.*

In being read *from* their bodies, participants felt that low CHC was simultaneously conferred *upon* them too. Given their relative power (Pilnick and Dingwall, 2011), practitioners' interpretations of participants' lack of CHC were perceived to become a 'truth' at the centre of healthcare encounters. This offered little space for participants to exercise their actual CHC, wherein their autonomous and well-informed choices about their bodies were not given space, and practitioners occupied a paternalistic expert role in unfolding interactions. Mary encapsulated well the relationship between medical power and participants' CHC:

> *Mary: They're in a position of authority, so you kind of take them up on what they are saying.*

Participants perceived that their compromised CHC created what we call an 'interactional and relational disconnect' between themselves and healthcare practitioners, which we explore in the next section.

4.2 Interactional and relational disconnect in fatphobic interactions

The interactional and relational disconnect perceived by participants was rooted in a misalignment between participants' actual health competencies and their desire for egalitarian healthcare interactions where fatness was deprioritised in favour of immediate health concerns, and practitioners' paternalistic approach, which compromised participants' CHC and centred fatness as the primary health consideration. This disconnect led to fatphobic interactions, which unfolded in a similar way across participants' experiences. Participants consistently reported that healthcare encounters disproportionately focused on fatness, which created a sense of ambivalence and rested on and reproduced existing power imbalances.

All participants strongly felt that their fatness was perceived by practitioners as the root cause of many, if not all, of their medical woes. They repeatedly recounted instances when their body size was centred in healthcare interactions, despite them presenting for issues disconnected from their weight. Charlotte demonstrated this well where she described how her struggles with anxiety and depression, which at times lead to suicidal ideations, went undiagnosed for years despite the significant impact they had on her quality of life:

> *Charlotte: I felt like [my weight] was all anybody saw. […] Nobody ever asked me about my relationship with food, my body, my depression or anxiety and how that impacted food […]. And so it almost felt like people were just looking at the biggest piece of the puzzle, and that's all they saw.*

This centring of fatness as the key problem meant that medical encounters were disproportionately focused on weight loss advice. In some instances, participants felt that practitioners positioned weight loss as a kind of panacea, and, as such, they described feeling pressured into reducing their body size, or at least discussing the possibility of doing so:

> *Ilya: It seems like he thinks losing weight will magically solve all my issues. This is even though I have repeatedly told him I have no desire to discuss my body size.*

This over-attribution of fatness as a cause of ill-health and the subsequent focus on weight loss advice were perceived to stem from deeply engrained anti-fat biases upheld by policy, media, and medical education. As such, the over-focus on weight in healthcare interactions was understood to be sanctioned even in instances where participants had expressly stated they did not want to discuss weight-related matters. Mary, for example, described an encounter where she had requested not to discuss weight, but the practitioner did so anyway:

> *Mary: I straight up told that doctor, I do not want to discuss my weight. I'm in recovery from an eating disorder. And his parting words were that it would really help if I lost weight. It just feels like they cannot help themselves.*

As well as being legitimised through normative tropes of fatness and health, such disregard of participants' wishes was also perceived to be authorised by fat patients' compromised CHC and practitioners' relative power. In other words, the presumption that fat patients lack skills, knowledge, and competencies around health means that practitioners feel more freely able to steer conversations. Lucy summed this up by contrasting her experiences of patient–practitioner communication as a fat patient with her previous experiences before she gained weight:

> *Lucy: I gained a lot of weight over the last few years—I have not always been fat. And now, suddenly, I get asked different questions and things are assumed about me that were not […] before. There seems to be a lot less open-mindedness. Gaining weight really has been a turning point in the communication with my healthcare providers.*

Participants reported that keeping the interactional focus on weight left them feeling ambivalent about healthcare interactions. While participants sought help for a specific medical issue and wanted to be treated like 'thin people,' they reported feeling disrespected and unheard. This created a tension where participants were often enthusiastic about the principles of patient-centred care and joint decision-making and *wanted* to actively participate in their medical care but were prevented from doing so by practitioners' directing conversations towards weight. This meant interactions offered limited space for participants to exert their CHC, which in turn compounded their compromised CHC. Indira, for instance, recalled an encounter where the interactional disconnect rooted in fatphobia and the ambivalence it created were particularly notable:

> *Indira: I went to my GP because I was experiencing a lot of fatigue and headaches […]. And […] told me that I'd have to go on a diet. And I told her that I've tried that before, and if I restrict, I start bingeing. And she just—she did not listen. She just told me that, yeah, well, I can refer you to the local weight loss program. And again, I said, that's not something I'm interested in. […] And then she said, well, you have to try intermittent fasting and only eat twice a day. […] So it just did not go anywhere. Whatever I said did not register with her.*

In this encounter, despite Indira's repeated attempts to assert her CHC, steer the conversation to more weight-neutral terrain, and become more actively involved in her care, her practitioner remained disproportionately focused on weight. In some instances, this hyper-focus on weight led to significant long-term healthcare anxiety. In Charlotte's case, for example, she attributed her current anxiety about healthcare encounters to a lengthy history of medical fatphobia experiences:

> *Charlotte: [My doctor] used to be very not compassionate at all. […] She used to say you are going to get diabetes, you are going to have a heart attack because of your weight […] I still have white coat anxiety. Anytime I see a doctor I have elevated blood pressure […]. My GP in Vancouver has learned that they have to put me in the room by myself and do an automatic blood pressure reading because my nervous system is already so heightened just by being in a doctor's office.*

Others described a sense of frustration that this kind of interaction created, particularly over time as participants became increasingly involved with fat positive online communities and reflected on their history of healthcare interactions as matters of injustice and inequality:

> *Ilya: I had surgery to remove this very large cyst from my ovary, and they thought it might be cancer. And my doctor said, all that fat in there is just a skinny woman dying to get out when she was looking at my MRI. And years later, I was, like, are you kidding me?! This is not the time! You should be telling me about the surgery and what to expect.*

While Ilya described her anger about instances of interactional and relational disconnect, other participants described a feeling of resignation and acceptance. Given that attempts to create more equitable interactions often '*did not register*' with practitioners, they commonly failed to create an equitable atmosphere in which fat patients could voice their struggles and find adequate treatment for them. In these instances, like Sarah, participants described reluctantly acquiescing to compromised CHC, exclusion from joint decision-making, and disproportionate focus on fatness:

> *Sarah: Over the last year, I've kind of just given up. I had this horrible appointment with a gastroenterologist who was very dismissive, violating and not respectful.*

4.3 Managing and mitigating fatphobic interactions

Given this context of disrupted fatphobic interactions, participants described developing several tactics to manage and navigate healthcare encounters. For Sarah, managing medical fatphobia meant avoiding healthcare encounters altogether. After a particularly fatphobic previous interaction related to her medications, she described her decision to take matters into her own hands and withdraw from some of her medications despite potential risks:

> *Sarah: [My doctor] added a beta blocker to my medication to help with my anxiety […]. That interacts with my antidepressant in a way that I'm, after two minutes of walking, drenched in sweat. It's really uncomfortable. He of course did not attribute that to the medication though, but to my weight. So I now have, without his advice, withdrawn the medication step by step.*

While Sarah's decision to forgo medical intervention altogether was an anomaly, all participants reported significantly delaying seeing practitioners. After an earlier '*horrible appointment with a gastroenterologist*,' Sarah reported waiting 6 months until she found the psychological strength to visit another practitioner. Courtney similarly talked about how the constant judgement and hyper-focus on fatness in fatphobic medical encounters left her feeling hesitant to visit practitioners:

> *Courtney: I do not even want to engage with [healthcare] because I'm already being scolded from the get-go.*

In their interviews, Carmen and Claudia described having current and worsening health conditions that they were delaying seeking support for because of their anticipation of problematic interactions:

> *Carmen: I actually think I am developing arthritis in my right hip, and it's been going on for a couple of months, and it's becoming more of a problem. And I know I should go see somebody, but I'm not. I know that one of the first things they'll tell me is to lose weight. And I do not want to have to have that conversation, so I put off dealing with that.*
>
> *Claudia: If it's serious enough then […] I think I would raise anything with a doctor. But at the moment I have this issue that I have not seen my doctor for because I know they might blame my size for it. And I know if I was in a smaller body, I probably would not have waited, I would have gone already.*

In both cases, Carmen and Claudia described delaying engaging with healthcare until a problem becomes '*serious enough*,' rather than eschewing medical support altogether. Given that none of our participants had formal medical education, this threshold of '*serious enough*' was somewhat nebulous and idiosyncratic. It was also changeable for different conditions—as Claudia suggested, participants tended to delay seeing practitioners even further for conditions that they thought would be attributed to their weight.

Given their concerns about interactional and relational disconnect, where possible, participants sought out practitioners with whom they were less likely to have fatphobic encounters. For most participants, this process entailed extensively researching local practitioners, collecting recommendations from fat kinship networks (Kost and Jamie, 2022), and trying out a series of different practitioners. Liz explained how initial appointments with potential new practitioners acted as opportunities to assess the likelihood of future medical fatphobia:

> *Liz: My first appointment with my primary care was intended to be, kind of, like an interview appointment and not necessarily a full exam because I just wanted to see if I would like to continue seeing her.*

In instances where these initial appointments foreshadowed problematic interactions, participants would move on to try another practitioner. Monica and Lucy described the significant investment of time, effort, emotion, and money that this trial-and-error process involved:

> *Lucy: I'd definitely drive out of my way [to find the a non-fatphobic practitioner].*
>
> *Monica: I moved to this area in 2018, and just now [autumn 2019], I have found most of the care team that I needed. And that is with me not working, with me going to appointments at the last minute, whenever, wherever, and unfortunately subjecting myself to abuse to find the right practitioner.*

As such, finding practitioners who were not fatphobic required a level of economic privilege and time commitment that not all participants had. Moreover, given the deep purchase of medical fatphobia and the troublesome interactions it spawns, even participants who had successfully found a supportive healthcare practitioner had to concede to some level of comprised CHC and interactional disconnect. For example, following traumatic experiences with previous practitioners and a lengthy search process, Lorena described finding an obstetrics and gynaecology doctor with whom interactions were only slightly disconnected and who demonstrated some willingness to address medical fatphobia:

> *Lorena: I had to find another OBGYN who pushes the idea of weight loss in a subtle way and uses words that I'm okay with and focuses more on behaviours than on weight and will throw out little hints of oh, your weight is down. That's so good! But at least she is working with me, and she is adjusting her language somewhat to not be an awful healthcare provider.*

These data from Lucy, Monica, and Lorena show that finding non-fatphobic healthcare practitioners is most often unfeasible, both from an individual and systemic perspective. As such, most participants described being left with few options but to visit fatphobic practitioners and to try to develop communication strategies for managing potential interactional and relational disconnect with them. The most common starting point of these strategies was a refusal to discuss weight or weight loss in encounters where these topics were irrelevant:

> *Ilya: I have a discussion letting practitioners know that I am not going to discuss weight loss, and that I just want to discuss my medical situation the way they would discuss it with a lower-weight person.*
>
> *Charlotte: If someone talked to me about my weight as a potential contributor to the fact that I have a cold, I'd just be, like, no! And I would just say, I'm not willing to discuss that.*

Participants felt that these kinds of assertions about what they were un/willing to discuss should be enough to ensure effective rather than disconnected interactions. Yet, participants pointed to the need for continual boundary-setting within interactions to ensure that conversations did not take a fatphobic turn. Courtney, for example, talked about the need to be '*insistent*' that practitioners focus on the reason for her visit rather than her fatness:

> *Courtney: Sometimes I've had doctors dismiss things unless I'm really insistent about it. And so I have to be really insistent that no, this is a problem, and I want you to look at it before you go, and if you do not look at it, I'm gonna make another appointment.*

To keep conversations on a non-fatphobic track and minimise the extent of interactional disconnect, Courtney went on to describe her practise of taking along a pre-prepared 'script.' Monica described a similar approach:

> *Courtney: And so I also feel like I have in my mind already, if they were [discuss weight] I already know what I would say. And that's calming.*
>
> *Monica: In some cases I have come up with a list of bullet points. Almost a plan of attack if I am addressed with the weight loss thing, I have to have a plan to counter and advocate for myself.*

Given that participants were aware that practitioners are often not trained to work with fat patients, this preparatory work sometimes went as far as educating themselves on how practitioners could accommodate their bodies during medical procedures:

> *Courtney: I had to go to the gynaecologist because I had all these issues going on. And before I went in, I researched what fat people should know at the gynaecologist's office. I so had things in my mind that I could suggest to my doctor if they were having a problem.*

These attempts by participants to mitigate and manage fatphobic interactions entailed exercising their CHC through demonstrating high levels of health literacy, honed communications, self-advocacy, and endeavours to co-shape healthcare encounters. However, engrained medical fatphobia and the relative power of practitioners to dictate the direction of the conversation (Pilnick and Dingwall, 2011) meant there were limits to the extent that participants could actually challenge and mitigate fatphobia. In particular, the power asymmetry in healthcare encounters meant that participants' communication and self-advocacy tactics would sometimes crumble in practise. Most commonly, participants described 'freezing' when interactions took a fatphobic turn. Although freezing in medical encounters is relatively common for *all* patients, our participants described fatphobia as a particular trigger for their seizing up. In other words, while participants were able to deploy their high CHC to generally navigate and even out healthcare power imbalances, they became powerless when interactions became structured by fatphobia, as Hannah and Mary described:

> *Hannah: I just always feel so powerless in medical spaces. Like, I feel like I know what my body needs and is capable of doing pretty well, but when it comes to challenging a doctor's assumptions or disrespect, I often just feel frozen.*
>
> *Mary: kind of, like, shut down. I just stop talking. It's like I'm—I've gotten good at that first step, this is not weight related, I would prefer not to discuss weight. But once it comes up, I tend to freeze.*

In these instances, despite careful preparation and well-practised scripts, participants freezing in the face of medical power further compromised their CHC by stripping them of their abilities to demonstrate their agency, care, literacy, and investment in health. Lorena demonstrated clearly how an encounter becoming particularly fatphobic led to her freezing and abandoning her communication strategies in a bid to end the encounter as soon as possible:

> *Lorena: I was completely shocked. And I immediately almost felt like I was getting beat up on. So I retreated into a defensive posture. And equivocated to get the visit over with as quickly as possible.*

Lorena went on to describe her equivocation as a source of personal frustration, particularly because of the potential for her quietness to be read by the practitioner as acceptance of biomedical models of fatness. Yet, in this instance, Lorena had not given up her shaping the direction of conversation easily. Rather, she had done so to protect her emotional wellbeing. Her story of this encounter demonstrates how tenuous participants' management and mitigation strategies are in the context of persistent medical power.

5 Discussion

Despite repeated appointments with healthcare practitioners over several years, Ellen Maud Bennett died on 11 May 2018, because she was fat. Her obituary drew attention to the 'fat shaming' she had experienced in healthcare encounters, which resulted in her tumour going undiagnosed until it became inoperable. In this article, we have used qualitative data from interviews with 15 fat women to illuminate the ways that healthcare encounters involving fat people—particularly fat women—like Ms. Bennett are structured by fatphobia and lead to adverse experiences and outcomes for fat patients. We have argued that ubiquitously characteristic of medical fatphobia is what we call an 'interactional and relational disconnect' between fat patients and their practitioners, which over-attributes fatness as the cause of ill-health, leading to ambivalence within health interactions and driving fat patients to potentially risky tactics of management and mitigation.

While this disconnect manifests in one-on-one health encounters, we have demonstrated throughout the article that it is not an issue of individual communication failure. Rather, we have argued that medical fatphobia and interactional and relational disconnect are systemic issues linked with, sustained through, and reproduced by persistent medical power (Pilnick and Dingwall, 2011). In particular, healthcare practitioners' power enables their readings and assumptions about fat patients' embodiment of low CHC to become embedded within, and dictate the direction of, medical interactions. We have shown that despite their best efforts at managing and mitigating this embedded fatphobia, fat patients' tactics of resistance are often stymied by their relative powerlessness.

While scholars have previously drawn attention to the unequal treatment of fat patients in medical encounters, we have mobilised, Shim (2010) notion of cultural health capital as a lens to better locate such treatment as a structural and systemic matter of inequality. We have demonstrated how wider cultural tropes about fat people's health capital are manifested in individual health interactions and, together with engrained medical power, shape the abilities of fat patients to exercise their health agency, literacy, and engagement in those interactions. By taking this systemic approach and anchoring it in a robust theoretical bedrock, we are moving towards coalescing disparate disciplinary understandings of medical fatphobia. For Nutter et al. (2016), such a coalescence rests on the positioning of medical fatphobia as a social justice issue wherein maltreatment of fat patients can be understood, taken seriously, and addressed in the same way as inadequate healthcare experienced by other marginalised groups.

This social justice approach also requires an intersectional sensibility to illuminate and untangle the ways that fat patients' other characteristics come to bear on their CHC. In this article, we have concentrated on fat women's experiences because gender and fatness intersect to produce a double transgression of both health *and* beauty standards, where fat women are read to lack both health and aesthetic capital. But our participants were all able-bodied, white, and described themselves as middle-class, all of which confer a high level of CHC. As such, our argument necessarily misses the intersections between CHC and gender and other characteristics shaping healthcare encounters, such as race. This is not simply a methodological issue but rather one that potentially constructs the ways that interactional and relational disconnect plays out and is managed. In other words, diverse voices in our sample may well have altered our arguments about how bodies are 'read' and how these readings are then managed by fat patients. For example, our finding of participants' refusal to discuss weight and their uses of scripts to shape healthcare encounters may be more complicated for Black women, who are also juggling society's prejudices and tropes about Black women attempting to engage in self-advocacy. An intersectional approach, coupled with a focus on marginalised groups, would benefit future research by interrogating how different incarnations of systemic discrimination—sexism, racism, ableism, etc.—work together and compound medical fatphobia.

As well as advancing fatphobia and its interactional and relational disconnect as an academic and theoretical interest, closer attention to the role of fatness in health encounters also presents the possibility of a framework for improved patient care. While weight-based ill-treatment of patients has been creeping up the policy and practise agenda in recent years (e.g., Department of Health and Social Care Committee, 2022), calls for better care of fat patients have tended to be couched within a weight loss framework. This approach, in short, rests on the idea that better care that is more attuned to and avoids weight-based discrimination will create environments in which fat patients can be more effectively counselled into weight loss. The focus on more equitable care for fat patients is laudable in these policy and practise drives and clearly echoes our participants' desires to be fully involved in their care decisions. Yet, the end goal of weight loss in these calls still belies their fatphobic foundations, where fatness is disproportionately constructed as a key medical 'problem' to be solved. Moreover, these calls do little to challenge the systemic power asymmetry on which medical fatphobia rests and thrives. A move towards understanding medical fatphobia as a systemic issue connected to health capital and power may present a fruitful scaffold for a more fundamental (re) organisation of these policy drives.

In addition to our fairly homogenous and relatively privileged sample, there are some other limitations to our research. First, we recruited participants from a Health at Every Size social media group, meaning that our participants already had a fairly high level of engagement with issues of medical fatphobia. Moreover, the high number of participants from insurance model healthcare systems wherein patients have more capacity as consumers might have accounted for the particular patterns of resistance and management reported by our participants. Given our ambitions to understand medical fatphobia, how it unfolds, and how fat women find comradeship in online communities (findings reported in Kost and Jamie, 2022), this somewhat partisan sample did not represent too much of a problem. However, future research would benefit from recruiting participants whose views of medical fatphobia are not as shaped by activism or their connections in the fatosphere to obtain 'naïve' accounts of fatness in health interactions.

Second, and relatedly, using retrospective interviews always presents the risk that participants misremember or recast particular events. In our case, given participants' engagement with HAES as a form of fat activism means, it is likely that participants (re)interpreted their health encounters through this specific lens. That is not to say that participants deliberately misrepresented their health encounters or experiences to us during interviews or that their (re)interpretations in collaboration with other HAES members are in any way problematic. However, using retrospective interviews alongside 'live' methods like observations or audio-recordings of appointments would enable a more holistic analysis of health encounters where unfolding interactions can be analysed alongside participants' interpretations of them.

Finally, our analysis is based only on the recollections and narratives of the fat women and makes several inferences about practitioners' assumptions and motivations without having collected data from practitioners themselves. Given our fat positive stance, we aimed to centre the voices of fat people, which are seldom heard even amongst policy and practise discussions of weight-based discrimination. Notwithstanding this, future research would benefit from gathering data from practitioners to understand medical fatphobia and the role of their own relative power in sustaining it.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Durham University Department of Sociology Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

CK: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. KJ: Formal analysis, Supervision, Validation, Writing – original draft,

Writing – review & editing. EM: Formal analysis, Writing – original draft, Writing – review & editing.

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Publisher's note

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Insights, beliefs, and myths surrounding tuberculosis among pulmonary patients with delayed healthcare access in a high-burden TB state in Nigeria – a qualitative inquiry

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Introduction: Nigeria grapples with a substantial burden of tuberculosis (TB), particularly in Oyo State, designated as a high-burden State for TB. Effectively addressing this persistent health challenge necessitates more than just medical interventions; it requires a profound understanding of the diverse insights, beliefs, and myths held by TB patients.

Methods: This qualitative study explores the perspectives of pulmonary TB patients with delayed healthcare access in Oyo State, Nigeria, focusing on their beliefs, and conceptions. In-depth interviews were conducted with 25 TB patients and 20 healthcare providers.

Results: Thematic analysis of patients' responses revealed a complex interplay between cultural, spiritual, and biomedical insights. These challenges questioned the germ theory, associating TB with witchcraft and spiritual attacks. Beliefs in hereditary transmission, links between tobacco use and health outcomes, and uncertainties about infection nature underscored disparities influenced by socio-economic factors. Insights into transmission ideas, preventive measures, and treatment beliefs highlighted a blend of culturally influenced and scientifically supported strategies. Healthcare providers' insights emphasized the necessity for targeted health education.

Discussion: These findings contribute to a nuanced understanding of TB perceptions, emphasizing the importance of culturally sensitive interventions to enhance awareness and promote timely and accurate health-seeking behaviors.

KEYWORDS

tuberculosis, insights, beliefs, myths, pulmonary patients, delayed healthcare access

1 Introduction

Tuberculosis (TB) remains a persistent and complicated global health challenge, demanding attention and understanding on multiple fronts (Kidanemariam et al., 2023; Madebo et al., 2023). Caused by the bacterium *Mycobacterium tuberculosis*, this infectious disease primarily targets the lungs but can extend its reach to other organs (Pele et al., 2021;

Amare et al., 2022). TB is transmitted through the air, primarily when an infected individual coughs or sneezes, making it a challenging social and public health concern (Datiko et al., 2019; Gopalaswamy et al., 2021). The symptoms of TB range from a persistent cough and chest pain to weight loss, fatigue, and fever (Peirse and Houston, 2017; Field et al., 2018; Long et al., 2020). Despite being treatable with antibiotics, challenges such as drug-resistant strains and societal stigmas surrounding the disease continue to complicate efforts to control its spread (Bashorun et al., 2020; Craciun et al., 2023).

Globally, TB stands as the second most prevalent infectious cause of death, trailing behind COVID-19 (Pan American Health Organization, 2023). In the year 2022, an estimated 10.6 million individuals were afflicted with TB worldwide, encompassing 5.8 million men, 3.5 million women, and 1.3 million children (Pan American Health Organization, 2023; World Health Organization, 2023). TB is pervasive across all nations, with more than 80% of cases and fatalities concentrated in low- and middle-income countries (World Health Organization, 2023). Notably, in 2022, the largest proportion of new TB cases emerged in the South-East Asian Region (46%), followed by the African Region (23%) (Africa Renewal, 2022; World Health Organization, 2023). Nigeria holds the sixth position among the 30 countries with the highest TB burden globally, having the highest burden in Africa and contributing to 4.6% of the global TB load (World Health Organization, 2021).

Tragically, approximately 245,000 Nigerians die from TB annually, with around 590,000 new cases reported. TB alone is responsible for over 10% of all deaths in Nigeria, claiming nearly 30 lives per hour despite the existence of effective treatments (Copenhagen Consensus Center, 2023). The United Nations Sustainable Development Goals (SDGs) include the ambitious health target of eradicating the TB epidemic by 2030, aiming for a 90% reduction in TB-related deaths and an 80% reduction in new cases by the specified year (United Nations, 2015).

Within Nigeria, Oyo State has been identified as a very high-burden region for TB (Akinyemi, 2022; Oguntola, 2023). In the year 2022, the state documented 11,934 confirmed TB cases out of a total presumptive count of 136,222 cases (Oguntola, 2023). Successful TB control initiatives are contingent not only on medical interventions but also on a comprehensive understanding of the diverse factors shaping the lived experiences of those directly affected (Adepoju et al., 2022; Sharma and Khokhar, 2022). Factors contributing to the persistence of TB include socioeconomic disparities, limited access to healthcare, and sociocultural influences that shape community perceptions and behaviors (Du et al., 2022; Olarewaju et al., 2022; Kaaffah et al., 2023).In social psychology, the health belief model posits that individual choices to see health practitioners (registered doctors and nurses) are influenced by perceptions of susceptibility, severity, benefits of action, and barriers to action (Rosenstock, 1974; Limbu et al., 2022). Similarly, the cultural competency theory emphasizes the importance of healthcare professionals acknowledging the ideas and assumptions about health divergent from their own, as well as understanding and respecting cultural beliefs and practices in healthcare delivery (Britni, 2017). In Nigeria, cultural factors such as traditional healing practices and beliefs about the causes of illness influence TB patients' healthcare-seeking (Asuke et al., 2022; Olarewaju et al., 2022). Policy makers and healthcare providers need to be culturally competent to address these beliefs effectively and provide culturally sensitive care. Oyo State, situated in the southwestern region of Nigeria, mirrors these challenges and serves as a microcosm for understanding the complexities of TB within the broader Nigerian context.

Previous studies have focused on the determinants of TB knowledge, perceptions and treatment adherence, utilizing mainly quantitative approaches (Ojiezeh et al., 2015; Min et al., 2019; Asuke et al., 2022; Chebet et al., 2022; Vericat-Ferrer et al., 2022). The few past studies utilizing qualitative approaches had focused mainly on opinion about TB associated stigma and health seeking behavior (Khan et al., 2020; Huq et al., 2022; Chaychoowong et al., 2023). This study aims to bridge the gap in knowledge by delving into the lived experiences, myths and beliefs among TB patients with delayed access to healthcare in Oyo State. By adopting a qualitative research design, this study seeks to unravel the multifaceted dimensions of insights among patients in Oyo State, exploring the depth of awareness about the causes, symptoms, transmission, and treatment of TB. Attention is also given to examining the sociocultural factors that influence how TB patients interpret and respond to their diagnosis. This is important because ideas about illness can impede effective TB control by fostering fear, stigma, and delayed healthcare-seeking behavior (Ayalew et al., 2020; Onyango et al., 2021). By identifying and understanding these notions, the study aims to contribute insights that can inform targeted awareness campaigns, policies and educational interventions tailored to the specific needs of the study population.

2 Materials and methods

2.1 Research design

This study adopts a qualitative research design to explore the dimensions of TB-related insights, beliefs, and conceptions among patients in Oyo State. Qualitative methods allowed for an in-depth understanding of patients' experiences within the sociocultural context. The Standards for Reporting Qualitative Research (SRQR) guided the writing of this manuscript (O'Brien et al., 2014).

2.2 Study setting

The research was conducted in various healthcare facilities across Oyo State, encompassing both urban and rural areas, with the aim of capturing diverse perspectives. The selection of these facilities was based on their substantial patient load, ensuring representativeness of the TB patient population. The study area, Oyo State, is situated in the South-West geopolitical zone of Nigeria and was carved out of the former Western Region in 1976. Oyo State is geographically divided into five zones: Ibadan Areas (11 Local Government Areas - LGAs), Oke-Ogun Areas (10 LGAs), Ogbomoso Areas (5 LGAs), Oyo Areas (4 LGAs), and Ibarapa Areas (3 LGAs), totaling 33 local government areas. With a population of 7,512,855 people and covering a landmass of 28,245.26 square kilometers (National Bureau of Statistics, 2020), Oyo State is marked by rich traditions and cultural beliefs. The profound influence of religious and traditional beliefs within the population is evident through the prevalence of various religious and traditional healing establishments offering healthcare services. The majority of residents in the State adhere to either Christianity or Islam. It is noteworthy that Oyo State is among the three states in Nigeria with the highest TB prevalence rate, underscoring the significance of understanding TB-related knowledge, perceptions, beliefs, and conceptions in this particular region. The diverse geographic and cultural landscape of Oyo State provides a unique context for exploring the complexities of TB experiences among its residents (Ojiezeh et al., 2015).

2.3 Sampling

Purposive sampling was utilized to select pulmonary TB patients undergoing treatment in the designated health facilities with evidence of delayed healthcare access. The participants were deliberately chosen to ensure a diverse representation across various factors, including age, gender, socioeconomic status, and geographic location within Oyo State. In-depth interviews were conducted with two distinct categories of respondents: healthcare providers and TB patients, using a purposive sampling method. The first category comprised 20 healthcare providers, predominantly nurses and doctors (15 nurses and 5 doctors), directly involved in the treatment of TB patients. These practitioners provided accurate and valuable information essential for this research. Specifically, 5 healthcare providers were selected from directly observed treatment (DOT) centers, 5 from state hospitals, and 10 from the University College Hospital (UCH), a prominent federal teaching hospital.

The second category of interview respondents consisted of pulmonary TB patients with records of delayed healthcare access to facility for TB treatment. In general, guidelines recommend that individuals seek medical evaluation promptly if they experience symptoms suggestive of TB, such as persistent cough, fever, night sweats, weight loss, and fatigue. Delays in seeking care beyond a few weeks to a month after the onset of symptoms is an indicative of delayed healthcare seeking (Centers for Disease Control and Prevention, 2005, 2023b). However, this timeframe may vary depending on the severity and nature of the symptoms, hence we relied on health facility records (Centers for Disease Control and Prevention, 2005), A total of 25 TB patients were interviewed, drawn from the University College Hospital (UCH-Ibadan) and Oyo State government hospitals (Adeoyo and Oluyoro Hospital). Among these, 15 patients were selected from UCH federal teaching hospital, and 10 patients, comprising 5 from Oyo State government hospitals, Adeoyo and Oluyoro Hospital, respectively. The decision to focus on federal and state hospitals was driven by the belief that these institutions would yield a sufficient number of patients capable of providing comprehensive information. In total, 45 respondents (20 healthcare providers directly involved in TB treatment and 25 TB patients) participated in the in-depth interviews using structured guides. While patients provided information about their perspectives on TB, the healthcare providers shared insights about accurate information and appropriate medical interventions, diagnoses, treatments, and symptoms of TB. Additionally, they conveyed general information, including ethical considerations, about TB patients' reasons for delaying visits to healthcare facilities for diagnosis and treatment. Their responses aided in assessing the alignment of patients' beliefs, myths, and information regarding TB with medical perspectives. The determination of the sample size was guided by the principle of data saturation, ensuring that the inclusion of additional interviews did not yield new themes or insights.

2.4 Data collection

In-depth Interviews were conducted with both pulmonary TB patients and healthcare providers to explore their knowledge, perceptions, beliefs, and experiences related to TB. Semi-structured interview guides were employed to cover essential topics while providing flexibility for participants to express their unique perspectives. Participants granted consent for the interviews, which were audio-recorded. The interviews were facilitated by the researchers with the support of a trained research assistant at each study location to ensure the collection of accurate and comprehensive information. For the in-depth interviews with TB patients, precautions were taken to prevent the potential transmission of TB infections. Health professionals guided researchers to position themselves not directly in front of TB patients but by their side, preferably in well-ventilated areas. Additionally, nose masks were provided to the researchers in certain instances. Interview questions included "What do you think are the causes of TB? What are TB modes of transmission? How can TB be prevented? Where do you think TB can be best treated and why?" Conducting interviews with TB patients posed challenges as a significant number were apprehensive about potential stigmatization and expressed anger about their situation. Some initially hesitated to participate in the interviews. To address these concerns, researchers actively encouraged and assured participants of the confidentiality of their responses, fostering a cooperative and trusting environment for meaningful engagement in the research process.

2.5 Data analysis

The audio-recorded interviews were transcribed verbatim, and anonymized for analysis Thematic analysis was employed to identify patterns, codes, and themes within the qualitative data (Castleberry and Nolen, 2018). Transcripts were independently coded by two researchers, and regular meetings were held to discuss emerging themes and resolve discrepancies. Themes were organized to capture the complexity of TB-related knowledge, perceptions, beliefs, and notions. The study utilized ATLAS.ti, a computer-aided software for qualitative data analysis. The process included a multi-step approach to gain insights into TB beliefs and myths. Initially, researchers composed memos and reflections. Subsequent readings of transcripts unveiled significant patterns, coded and organized into themes and subthemes. This iterative process allowed for the extraction of meaningful insights and exploration of connections between variables of interest. Beginning with the generation of initial codes, essential concepts within the data were succinctly summarized. Open coding segmented data into meaningful units, assigning codes to each segment. Relationships between codes were scrutinized, leading to the grouping of similar codes into categories and the derivation of primary themes through the exploration of their connections. Utilizing these categories, themes emerged, reflecting central ideas. Sub-themes within these larger themes provided in-depth insights. Themes underwent review, complemented by detailed descriptions and narratives to enhance understanding. A comprehensive thematic analysis report was compiled, encompassing primary themes, sub-themes, descriptive narratives, and interpretive insights. Direct participant quotes were included to add authenticity. Additionally, peer review feedback from colleagues and subject matter experts reinforced the analysis's rigor. Following expert feedback, the themes were revised and finalized, as presented in the manuscript's results section, shedding light on the complex landscape of TB beliefs and myths among pulmonary patients in Nigeria (Michael, 2024).

2.6 Ethical considerations

This research adhered to the ethical principles outlined in the Declaration of Helsinki for research involving human subjects. Prior to data collection, the study was thoroughly explained to recruited respondents, and written consent was obtained from each participant. Informed consent underscored the voluntary nature of participation and ensured the confidentiality of their information. Ethical approval was secured from the Ethics and Research Review Board of Federal University, Oye-Ekiti, Nigeria (Reference Number: FUOYE/SOC/ETHICS/002). To protect participants' identities, pseudonyms and unique codes were employed during data analysis and reporting.

2.7 Reflexivity

Researchers maintained reflexivity throughout the study, acknowledging their own biases and preconceptions (Wilson et al., 2022). Reflexivity was documented to enhance transparency and rigor. In the context of the study, researchers openly acknowledged and reflected upon their biases, assumptions, and beliefs regarding TB. This involved recognizing any preconceived notions about TB patients, their communities, or the effectiveness of existing TB control programs that might impact the research process. Reflexivity was crucial in this study because the first and second authors, both sociologists, collaborated with the third author, a medical doctor whose expertise lies in the biomedical domain, hence having insights rooted in the medical scientific understanding of TB, including methods of prevention and treatment. Reflexivity further informed the interactions between researchers and participants during data collection, ensuring that the researchers' presence did not unduly influence participants' responses. Researchers strived to maintain an open and non-judgmental attitude during interviews. Reflexivity extends to the data analysis phase, where researchers critically examined their role in shaping the interpretation of findings. The researchers actively engaged in discussions to challenge and validate their interpretations, reducing the risk of biased conclusions. Researchers maintained a reflexive record, documenting insights, challenges, and personal reflections throughout the research process. This documentation served as a reference point for understanding how the researchers' perspectives may have influenced decisions and interpretations. By openly addressing their own subjectivities and presenting findings without biases, researchers contributed to the overall trustworthiness and credibility of the study (Yip, 2023).

3 Results

3.1 Socio-demographic characteristics of the participants

The socio-demographic characteristics of the participants are illustrated in Table 1. In relation to gender, the patient group comprises 14 males, while the healthcare provider group consists of 13 females. Educational backgrounds display variations, with 12 patients having a secondary education. Concerning residence, 15 patients reside in rural areas. Healthcare providers are evenly distributed between rural and urban residences, with 10 in each category. Regarding professional categories, nurses constitute 15 of the healthcare providers.

TABLE 1 Socio-demographic characteristics of the participants.

Variables	Patients (P)	Healthcare providers (HCP)
Sex		
Male	14	7
Female	11	13
Education		
Primary	6	–
Secondary	12	–
Tertiary	7	20
Residence		
Rural	15	10
Urban	10	10
Category		
Doctors	–	5
Nurses	–	15
Total	25	20

P, Patient; HCP, Healthcare provider.

3.2 Theme 1: insights and beliefs about the causal factors for TB

The interview transcripts reveal a diverse array of beliefs regarding the cause of TB among the respondents, encompassing spiritual attacks, hereditary influences, punishment for wrongdoing, bacterial or viral infections, tobacco use, and environmental factors (Figure 1).

3.2.1 Local names, germs versus witchcraft

The interviews with TB patients also highlight the diverse local names attributed to TB within the community. More than half of the respondents (52%) in the study commonly identify TB as Ikofe, translating to "Dry Cough." Additionally, 28% refer to TB as Iko Jedojedo, meaning "Cough that eats up the liver," 12% recognize it as Iko Awule, describing "Cough that causes people to emaciate," and 8% associate TB with Iko Eleje, signifying "Bloody Cough." This indicates that participants characterize TB based on their understanding of the effects or damages it may cause in the body.

Notably, some participants challenge the widely accepted germ theory by attributing TB to witchcraft, positing that germs are not the cause, but rather the disease emanates from spiritual sources. This is exemplified by the assertions, "*Germs do not cause TB… Witchcraft is the source of TB*" *(P5)*. The participants link the onset of their TB to spiritual attacks, correlating coughing episodes with recent deliverance ceremonies and suggesting the possibility of TB being cast as a spell by malevolent individuals.

> *"In my TB case, I knew it was a spirit world attack since the cough did not start until 3 days after we performed a deliverance for someone." (P2). "I know TB has something to do with coughing, and it may be cast as a spell on someone by those who are evil." (P3).*

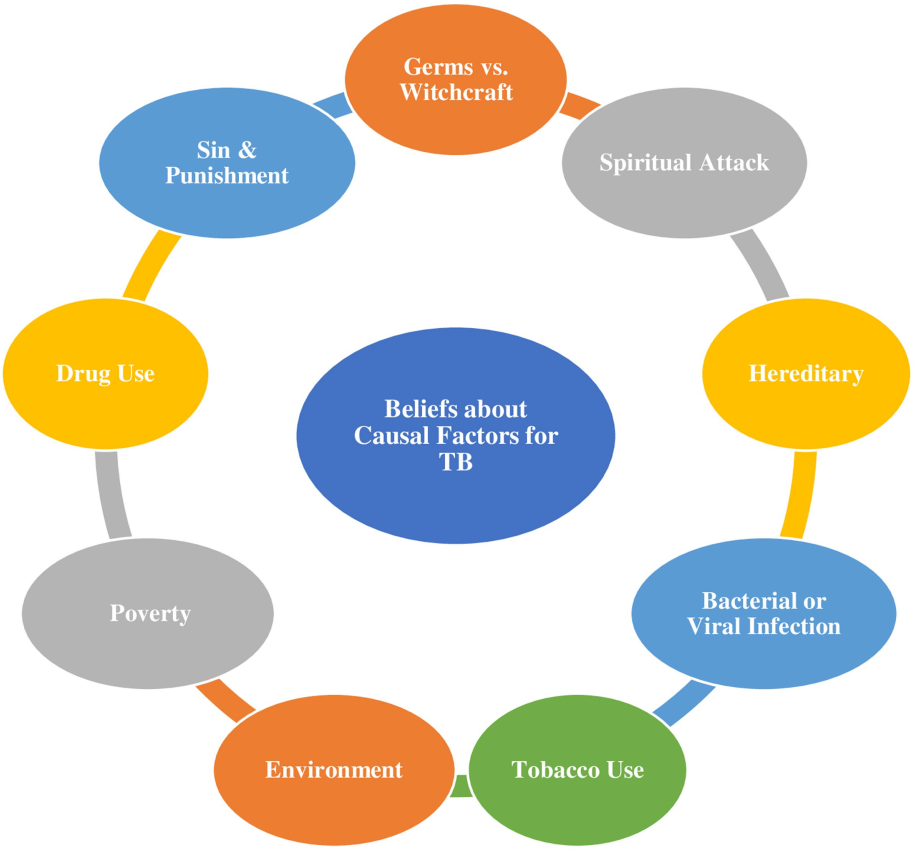

FIGURE 1
Schematic illustration of participants' beliefs about the casual factors for TB.

3.2.2 Hereditary, drug/tobacco use, and infections

Furthermore, the belief in hereditary transmission of TB is emphasized, with participants drawing connections between their own cases and family histories of the disease. Statements such as "*TB is inherited, meaning that it runs in families… I am not surprised by the cause of my TB because it runs in my family" (P14)* underscore the perception that if one family member has TB, others within the family may also be susceptible. According to participants, this belief aligns with the practice of doctors inquiring about family history during medical consultations, emphasizing the significance placed on familial connections in understanding TB susceptibility.

> *"Because TB is a hereditary disease, if one person in a family gets it, another person in the family may also have it; which is why hospitals usually ask about your family history and whether anyone in your family has ever had TB." (P21).*

Tobacco use is intricately linked to the participants' conceptualization of TB, with an emphasis on smoking history as a diagnostic factor for TB. Additionally, a distinctive perspective emerges, associating TB with the hereditary transmission of punishment for violating traditional rules, indicating a complex intertwining of cultural and health-related beliefs. *"TB is hereditary, meaning it is passed down from one person in a family line who has committed a crime. The main cause of TB can be traced back to punishment for violating traditional rules and regulations." (P8).* The statements, "*Tobacco use causes TB, which is where the name tuberculosis comes from*" *(P17)*, highlight the intricate connections drawn between cultural practices, substance use, and health outcomes.

While some participants accurately attribute TB to infection, the specific nature of the infection (bacterial or viral) remains uncertain in their understanding. *"An infection causes TB. I just do not know if it's caused by a bacterial or viral infection. But I know it is caused by an infection that is breathed through the air." (P9).* Additionally, the interviews reveal a prevailing perception of TB as a disease of the impoverished, linked to an unclean environment and poverty. This belief suggests that maintaining a healthy lifestyle through cleanliness and proper nutrition is seen as a preventive measure against TB. *"TB is a disease of the poor since it is caused by an unclean environment and poverty. You will not get TB if you eat healthy and live in a clean environment." (P20).*

Personal experiences with substance use contribute to the participants' association of TB primarily with drug use. "…*I know my tuberculosis is caused by the harsh drugs I use." (P11).*

3.2.3 Sin, punishment, and spiritual attack

The interviews further unveil a belief in sin as the root cause of TB, aligning it with a form of divine punishment analogous to HIV/AIDS. This spiritual perspective is captured in the statements, *"Sin is the root cause of TB. It is punishment for wrongdoing. God sends diseases like tuberculosis and HIV/AIDS to punish sinners." (P22),* underlining the influence of cultural and religious beliefs in shaping perceptions of health and illness.

Interestingly, despite the prevalence of spiritual explanations, some participants acknowledge bacterial or germ infections as the cause of TB, demonstrating a divergence in beliefs within the community. *TB is caused by bacteria or germs that have infected us and have remained in our bodies for an extended period of time without being treated." (P16)*. Healthcare professionals, particularly a doctor and a nurse, shed light on the community's inclination to perceive TB more as a spiritual than a physical ailment.

This perception, as mentioned by a doctor, contributes to delayed hospital visits among residents who frequently attribute the disease to spiritual causes. A nurse notes that patients often believe TB is an intentional attack from adversaries. Another nurse highlights the common assumption by patients that TB has genetic roots, prompting individuals to trace it back to their parents or family members.

> *"People in this area believed that TB was more spiritual than physical, which is why they frequently delayed seeking treatment at the hospital." (HCP, Doctor 3). "…they believe that tuberculosis is an attack from their enemies." (HCP, Nurse 1). People assume that tuberculosis is genetic and frequently want to trace it back to their parents or family members." (HCP, Nurse 9).*

3.3 Theme 2: transmission and myths surrounding TB

The interview transcriptions provide insights into a spectrum of beliefs and conceptions surrounding the transmission of TB, reflecting the impact of cultural perspectives and individual experiences, as shown in Figure 2.

3.3.1 Contact with a coughing friend, kissing and intercourse

A participant attributes their TB infection to close interaction with a coughing friend, aligning with the recognized mode of transmission through respiratory droplets. The statement, "*My tuberculosis was caught through interaction with a coughing friend. I later discovered he had tuberculosis" (P14),* illustrates a common scenario where individuals unknowingly expose themselves to the bacteria during close contact.

Also, the introduction of the belief that "*kissing or having intercourse with someone with tuberculosis can lead to TB infection (P5)* oversimplifies the primary mode of transmission, which is through inhaling respiratory droplets. This notion may contribute to stigma surrounding the disease, highlighting the need for accurate information dissemination and education.

3.3.2 Sharing plate, public restroom, and airborne saliva

The interviewees express a belief that sharing a plate with someone who has TB may result in contracting the disease. The statement, *"If you share a plate with someone who has tuberculosis, you may contract the disease. That is why individuals isolate themselves from people who have tuberculosis. I no longer advise my children to come near me" (P16),* reveals a misunderstanding of the primary mode of TB spread.

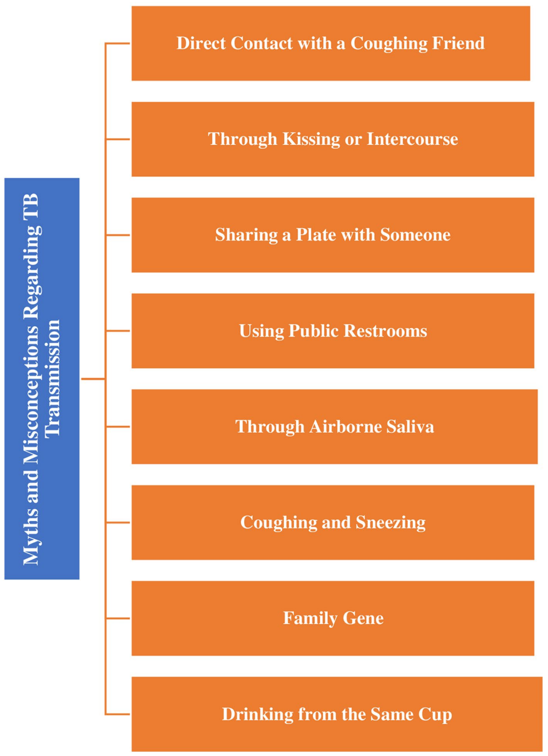

FIGURE 2
Schematic illustration of myths and misconceptions regarding transmission of TB.

The decision to isolate oneself and advise children to stay away underscores the fear and stigma associated with TB, emphasizing the importance of addressing misconceptions to reduce social isolation.

Another notion introduced by participants is the belief that sharing a public restroom or toilet can expose individuals to TB. This idea is medically unfounded, as the primary mode of transmission is through airborne respiratory droplets, not casual contact in shared spaces. The statement, "*Sharing a public restroom or toilet with others can expose you to tuberculosis" (P1),* emphasizes the need for public health education to dispel misconceptions and foster an accurate understanding of TB transmission dynamics.

Participants also introduce the belief that airborne saliva in a room where someone has TB can lead to infection. While TB is an airborne disease, the likelihood of transmission through airborne saliva is minimal. The statement, "*By spitting forth saliva. If you enter into a room where someone has TB and you do not know who it is, and the saliva is still in the air, you can contact TB" (P3),* may contribute to heightened anxiety and precautions, emphasizing the importance of clear communication to address fears grounded in the belief about TB.

3.3.3 Family gene and drinking from the same cup

Additionally, participants express the belief that TB can be contracted through a family gene, suggesting hereditary transmission. While there is a genetic component influencing susceptibility, TB is primarily an infectious disease. This belief may contribute to fears about familial transmission and underscores the importance of addressing genetic conceptions surrounding TB. The statement: "*TB can be contacted through a family gene. It's in the blood. Because I inherited it from my parents, one or two of my children may develop tuberculosis in the future." (P22).*

The introduction of the belief that sharing a cup with a TB-infected person can lead to infection is not supported by medical evidence, as TB is primarily transmitted through respiratory droplets. The statement, "*If a TB-infected person drinks water from a cup and you drink water from the same cup, you can catch TB. As a result, it is not advisable to share a cup with someone you do not trust. I'd like to think that's how I got TB" (P3),* reflects a perception of potential contagion, highlighting the need for clear communication to dispel unfounded fears.

Amidst these ideas, some participants' statements align with accurate information, recognizing that TB is spread by infected individuals coughing or sneezing. The cultural practice of keeping one's mouth closed during coughing or sneezing reflects an understanding of preventive measures to reduce the risk of transmission. *TB is spread by another infected individual coughing or sneezing. As a result, in our culture, everyone is instructed to keep their mouth closed when coughing or sneezing." (P19).* This statement exemplifies the potential for cultural practices to align with evidence-based public health recommendations, emphasizing the importance of incorporating cultural sensitivity in health education initiatives.

3.4 Theme 3: TB prevention strategies: insights from interviews

The interviews conducted reveal a range of beliefs and practices related to TB (TB) prevention among participants (see Figure 3).

3.4.1 Avoiding coughing individuals and handwashing in public spaces

Patients with TB suggest avoiding proximity to someone who is coughing as a preventive measure: "*To avoid TB, avoid being around somebody who is coughing because you do not know how long the individual has been coughing or if the person has TB" (P2).* This advice aligns with scientifically supported preventive measures, given that TB is primarily transmitted through respiratory droplets. However, it's crucial to note that individuals with latent TB infection may not display symptoms, and solely avoiding those who cough may not entirely eliminate the risk. Nevertheless, the recommendation demonstrates an awareness of the respiratory route of transmission.

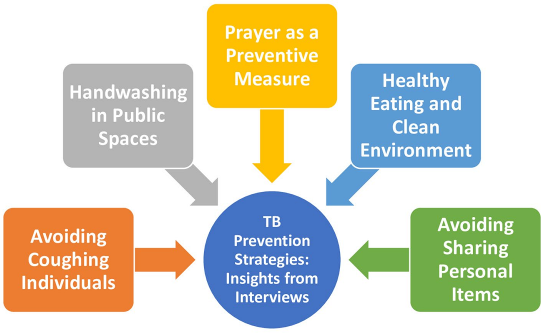

FIGURE 3
Schematic of participants' beliefs about TB prevention.

Participants emphasize the importance of hand hygiene, suggesting that hands should be washed after touching items in public due to concerns about potential contact with surfaces touched by a TB patient: *"Always wash your hands after touching items in public since it could have been touched by a TB patient" (P23).* While TB is not typically transmitted through surface contact, promoting good hand hygiene is a positive measure to prevent the spread of various infections, including respiratory ones.

3.4.2 Prayer, healthy eating and clean environment

Spiritual beliefs are introduced as a preventive measure, with participants expressing faith in the power of prayer to avoid TB: *"There is nothing that prayer cannot achieve. Always pray to avoid tuberculosis. Pray before leaving your house, while outside, and when you return home to keep diseases away" (P4).* While prayer can provide emotional support, it is not scientifically proven to prevent TB. The recommendation underscores the importance of combining spiritual beliefs with evidence-based practices, such as vaccination, hygiene, and avoiding close contact with infected individuals.

The connection between healthy eating, a clean environment, and TB prevention is highlighted, with participants attributing the disease to poverty: *"To prevent tuberculosis, eat healthily and live in a clean and sanitary environment because TB is a poor people's illness, which is why it is common in poor nations" (P25).* While malnutrition and poor living conditions can weaken the immune system, making individuals more susceptible to infections, TB is not exclusive to poor nations. The advice to eat healthily and maintain a clean environment is generally sound for overall well-being but should be supplemented with other evidence-based preventive measures.

3.4.3 Avoiding sharing personal items

Participants also stress the importance of not sharing personal items, such as drinking cups and eating plates, to avoid TB:

> *"To avoid tuberculosis, avoid sharing personal items with strangers. Drinking cups and eating plates should not be shared. Eat from different plates" (P1).*

This recommendation aligns with good hygiene practices and may help reduce the risk of various infectious diseases, including TB. While TB is not typically transmitted through shared utensils, the emphasis on avoiding sharing personal items reflects a cautious approach to minimize potential exposure.

3.5 Theme 4: TB treatment perspectives: insights from interviews

Interviews with TB patients shed light on diverse beliefs and treatment approaches related to TB, reflecting a complex interplay of traditional, spiritual, and medical practices (Figure 4).

3.5.1 Combining spiritual and medical approaches

The participants stated that there is no single approach to treating TB because the root cause of the condition may be either spiritual or physical, or perhaps a combination of both. The interviewees mention a multifaceted approach to seeking treatment. In addition to going to the hospital for medical care, they also incorporate spiritual practices by visiting a prayer house. Additionally, they mentioned using holy water and olive oil, indicating the inclusion of religious or spiritual rituals as part of their approach to managing TB. This reflects a belief in the interconnectedness of physical and spiritual aspects in dealing with the illness: *"There is no one approach to treat tuberculosis because you may not know the specific root of the condition, whether spiritual or physical. When I go to the hospital, I also go to the prayer house. I also make use of holy water and olive oil" (P2).* This amalgamation of traditional, spiritual, and medical elements in their treatment plan illustrates the multifaceted nature of their approach.

Advocates for combining traditional and medical treatments are prevalent among participants, emphasizing the incorporation of local herbal remedies such as ginger, garlic, and alligator pepper: *"To cure tuberculosis, both traditional and medical treatments are required. You must drink local medications manufactured from herbs while receiving hospital care. Ginger, garlic, and alligator pepper are also useful in the treatment of tuberculosis. I do the same" (P8).* While the cultural significance of traditional practices is evident, the effectiveness of such treatments warrants scientific validation to ensure safe and evidence-based care.

3.5.2 Bitter kola and body incisions as treatment aids

Bitter kola is perceived as aiding in TB treatment, with participants consuming it alongside prescribed medications*: "Bitter cola aids in the treatment of tuberculosis. Eat extra of it while taking the medications prescribed by your doctor, that is what I do" (P24).* This belief in the medicinal properties of bitter kola is rooted in traditional practices, highlighting the need for scientific scrutiny to evaluate its overall efficacy.

The use of body incisions for treating TB, particularly when perceived as genetic or a result of a spiritual attack, is mentioned. The recognition that spiritual attacks require different treatment approaches, coupled with the pragmatic shift to hospital care, demonstrates an evolving understanding of evidence-based interventions: *"We use body incisions to treat tuberculosis, especially when it is genetic or the result of a spiritual attack. Spiritual attacks are not treated with hospital medicine. I'm in the hospital because I discovered that the incision does not work, indicating that my TB is not a spiritual attack" (P6).*

While some participants believe herbs and concoctions treat TB faster than hospital drugs, they acknowledge the challenge of finding trustworthy herbalists. Seeking hospital treatment reflects a pragmatic response to concerns about fraudulent practices: "*Herbs and concoctions treat tuberculosis faster than hospital drugs. Finding a good herbalist is now difficult. We now have a lot of fake herbalists, which is why I'm in the hospital for treatment" (P17).*

3.5.3 Belief in over-the-counter cough medicine and religious centers

The interviews also uncover a common notion among TB patients who initially believed that any antibiotic cough medicine could cure TB. The subsequent realization of the necessity of hospital drugs highlights the critical role of evidence-based medical interventions:

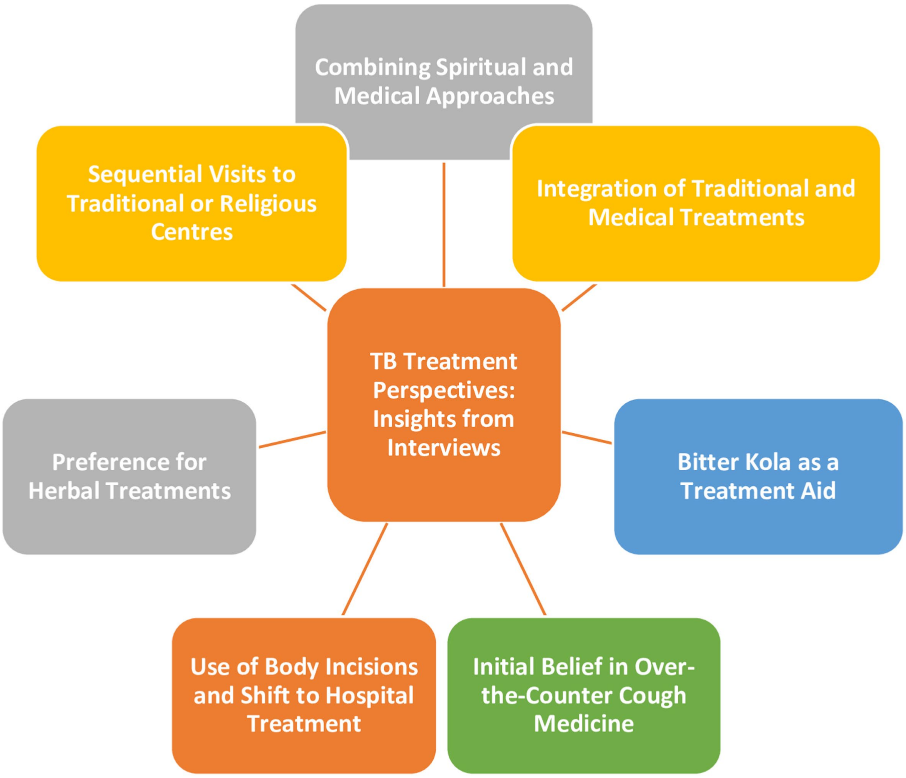

FIGURE 4
Schematic of participants' perspectives about TB treatment.

> *"I used to believe that any antibiotic cough medicine might heal tuberculosis. I was taking cough medicine that I had purchased from a pharmacy. When that did not work, I went to the hospital. To cure tuberculosis, you must use hospital drugs" (P5).*

Healthcare providers acknowledge that many TB patients initially visit traditional or religious centers, potentially delaying hospital treatment. This delay underscores the need for improved health education and community outreach to promote timely medical intervention: *"When other forms of treatment failed to cure the ailments, the majority of TB patients who visited the hospital first visited traditional or religious centers before coming to the hospital for treatment" (HCP, Doctor 5).*

Additionally, healthcare providers note that most TB patients arrive at the hospital late due to beliefs in self-medication. This observation emphasizes the urgent need to address conceptions and promote early medical intervention through effective public health campaigns: *"Most TB patients arrive at the hospital late because they believe they can cure the disease with remedies or self-medication" (HCP, Nurse 14).*

4 Discussion

Participants challenging the germ theory and attributing TB to witchcraft highlight the imperative for culturally sensitive health communication, aiming to reconcile traditional beliefs with biomedical knowledge (Brooks et al., 2019). Spiritual explanations for TB, intertwined with cultural practices like correlating coughing episodes with deliverance ceremonies, echo findings from other regions, like Eritrea, where a significant percentage of respondents (79.8%) did not associate TB with bacteria/germs (Kidanemariam et al., 2023). The influence of education on TB knowledge aligns with studies in China and Indonesia (Du et al., 2022; Kaaffah et al., 2023).

The belief in hereditary transmission resonates with familial connections, emphasizing the importance of addressing concerns and promoting accurate understanding of genetic components in TB. Associations between tobacco use, cultural practices, and health outcomes mirror previous findings linking tobacco smoking to TB (Wang et al., 2018). The uncertainty about the specific nature of infection (bacterial or viral) highlights a crucial knowledge gap that necessitates targeted education. The perception of TB as a disease linked to poverty emphasizes socio-economic influences on health beliefs, contrasting findings from South Africa (Onyango et al., 2021). Associations between substance use and sin as TB causes underscore the complex interplay of cultural and religious beliefs, deviating from the results of a study conducted in Limpopo Province (Matakanye et al., 2021). In support of the social determinant of health theory, this perspective highlights how social factors such as poverty, education, beliefs, and access to healthcare services influence health outcomes (Dean et al., 2013). In Nigeria, socio-economic disparities contribute to delayed healthcare access for TB patients (Onyango et al., 2021). For instance, impoverished individuals may lack resources to seek timely medical care, while limited healthcare infrastructure in rural areas exacerbates accessibility issues.

Participants acknowledging bacterial or germ infections demonstrate a divergence in beliefs within the community, emphasizing the need for nuanced health communication and intervention. Insights from healthcare professionals about the community's inclination to perceive TB as more spiritual than physical underscore potential barriers to timely medical intervention. Addressing these notions through targeted health education, cultural and behavioral improvements are critical (Adepoju et al., 2022; Amare et al., 2022). This is essential because according to health belief model, individual health behaviors are influenced by perceptions of susceptibility, severity, benefits of action, and barriers to action (Limbu et al., 2022). Similarly, in the study, cultural beliefs and myths surrounding TB influence individuals' perceptions of susceptibility and severity, leading to delays in seeking healthcare. Stigma associated with TB and conceptions about its transmission also act as barriers to seeking timely diagnosis and treatment.

Conceptions and ideas about TB transmission through kissing, sharing plates, using public restrooms, and exposure to airborne saliva highlight the importance of accurate information dissemination to reduce stigma. Our findings align with studies in Indonesia, emphasizing cultural practices' role in TB transmission (Pele et al., 2021). Participants' beliefs about genetic transmission and the need for isolation reflect underlying fears and misconceptions. Harmonizing cultural practices with evidence-based public health recommendations is vital (Centers for Disease Control and Prevention, 2023a). TB prevention beliefs and practices showcase a blend of culturally influenced measures and scientifically supported strategies. Advocacy for avoiding proximity to coughing individuals aligns with recognized preventive measures. While emphasizing hand hygiene may not directly relate to TB, it promotes general infection control practices (Centers for Disease Control and Prevention, 2022).

The inclusion of prayer as a preventive measure highlights the intersection of spiritual and health beliefs. Combining spiritual beliefs with evidence-based practices offers a holistic approach to address physical and emotional well-being. The connection between healthy eating, a clean environment, and TB prevention underscores the importance of comprehensive well-being (Centers for Disease Control and Prevention, 2023a). Emphasizing not sharing personal items aligns with good hygiene practices but dispelling conceptions about TB transmission through shared utensils is crucial (Madebo et al., 2023). Our interviews with TB patients uncover a diverse range of treatment beliefs and approaches, emphasizing the complex interplay of traditional, spiritual, and medical practices. The amalgamation of these elements underscores the need for culturally sensitive healthcare. Advocacy for combining traditional and medical treatments, incorporating local herbal remedies, and the perceived benefits of bitter kola warrant scientific scrutiny for safe and evidence-based care. Acknowledgment of the ineffectiveness of body incisions for spiritual attacks indicates a pragmatic shift toward evidence-based treatment (Audet et al., 2023).

Challenges in finding trustworthy herbalists and the recognition of the necessity for hospital drugs underscore a critical need for accurate health information dissemination. The conception about over-the-counter cough medicine and the subsequent realization of the necessity for hospital drugs highlight the importance of promoting accurate health-seeking behaviors (Khan et al., 2020). The delay in hospital visits due to initial visits to traditional or religious centers emphasizes the need for improved health education and community outreach. Addressing misconceptions and promoting early medical intervention is crucial for reducing disease severity and transmission risk (Onyango et al., 2021). Our findings align with studies in Nigeria, emphasizing patient-related diagnostic delays associated with education, religion, and healthcare workers' attitudes (Olarewaju et al., 2022; Michael et al., 2023).

5 Research and policy implications

Given the diverse array of beliefs and perceptions uncovered, future research should focus on developing and implementing culturally sensitive health interventions. Tailoring education and awareness programs to local beliefs and practices could bridge the gap between traditional perspectives and biomedical knowledge, facilitating more effective TB prevention and control strategies. The identified knowledge gaps, such as uncertainties about the nature of TB infection, underscore the need for targeted educational campaigns. Research should explore innovative ways to enhance community understanding of TB, particularly focusing on the realities about the disease and dispelling misconceptions.

Policymakers should consider incorporating cultural competence into TB control policies. Recognizing and respecting local beliefs can enhance the acceptability and effectiveness of health interventions. Collaborations between health authorities and community leaders can facilitate the development of culturally sensitive policies. Policies should prioritize the integration of robust health education programs that target both urban and rural communities. These programs should emphasize accurate information dissemination about TB transmission, prevention, and treatment, aligning with the diverse cultural and educational backgrounds of the population. Implementing community-based TB screening programs can enhance early detection and intervention. Policy efforts should focus on decentralizing testing services and ensuring accessibility, especially in remote areas, to reduce diagnostic delays and improve patient outcomes. Given the prevalent use of traditional and herbal remedies, policies should explore the integration of traditional healers into the broader healthcare system. Collaborative efforts between traditional healers and medical professionals could lead to a more comprehensive and culturally aligned approach to TB care.

6 Conclusion

Our study provides valuable insights into the complex dynamics of TB perceptions, transmission beliefs, and treatment approaches within the community. Bridging the gap between cultural beliefs and biomedical knowledge, dispelling misconceptions, and promoting evidence-based practices are crucial for effective sociological and public health interventions. Culturally sensitive health education initiatives are necessary to foster accurate understanding, reduce stigma, and encourage timely medical intervention for TB prevention and treatment. This includes training healthcare providers in cultural competency to understand and respect local beliefs, engaging community leaders and traditional healers to dispel myths, creating educational materials in local languages, organizing interactive workshops and discussions, establishing peer support networks, and integrating TB services into existing healthcare facilities. For instance, healthcare providers could undergo training to understand and address cultural beliefs about TB, such as involving traditional healers in TB education campaigns or creating community-led support groups for TB patients. These efforts would help to bridge the gap between medical knowledge and community beliefs, ultimately improving TB prevention, diagnosis, and treatment outcomes in culturally sensitive ways.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Ethics and Research Review Board of Federal University, Oye-Ekiti, Nigeria. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

BA: Conceptualization, Data curation, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Writing – original draft, Writing – review & editing. TM: Conceptualization, Data curation, Formal analysis, Methodology, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. RA: Investigation, Methodology, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Invalidated and 'salty': an auto/biographical and theoretical review of the lived experiences of individuals with PoTS

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Postural orthostatic Tachycardia Syndrome (PoTS), sometimes also written as 'POTS', is a form of dysautonomia (dysfunction of the autonomic nervous system) and orthostatic intolerance (which causes symptoms to be worsened when standing). This paper explores the extant literature on the lived experiences of those living with PoTS in relation to interactions between patients and healthcare providers as well as interactions at the level of the individual between PoTSies and those around them. My title contains the word 'salty' because it can be used to describe the feeling of being frustrated, while also reflecting a specific dietary change recommended to many (but not all) PoTS patients when they are told to consume additional sodium to minimise symptoms. COVID-19 is thought to have led to an increased prevalence of PoTS so this topic is particularly relevant to contemporary discussions and debates. In this sociological article, I refer not only to existing research on the lived experiences of having PoTS but also that of other chronic illnesses when relevant. The following themes are explored through auto/biographical and theoretical analysis: Undiagnosed and Invalidated; (In)Visible; Impacts of Diagnosis; Recovery and Expectations; Community. Reflecting auto/biographically, I have included analysis of interactions related to my lived experiences of presyncope, COVID-19 and dysautonomia, as I have been diagnosed with PoTS myself, which is thought to have been significantly exacerbated by the COVID-19 virus. This research is sociological, rather than medical or psychological, and conclusions are drawn about what is known so far about the lived experiences of living with PoTS, as well as discussion about what remains unknown, as there is currently a paucity of research on the lived experiences of individuals with PoTS and its comorbidities.

KEYWORDS

invisible illness, health interactions, PoTS, dysautonomia, lived experience, COVID-19, disability, auto/biography

Introduction

In this paper, I thematically, auto/biographically analysed the lived experiences of those with PoTS in relation to interactions between patients and healthcare providers as well as interactions at the level of the individual between PoTSies and those around them. I conducted the theoretical aspect of the review by exploring extant literature and secondary data on the ways in which interactions are experienced and perceived by individuals with PoTS and similar or related chronic (long-term) illnesses. 'Understanding health, illness, disability, and medical interactions through a sociological framework is the basis of the sub-discipline of medical sociology' (Frane, 2023: 10) and as Frye et al. (2022: 623) asserted, 'the lack of qualitative methodology [in research on patients' experiences of PoTS] is concerning, given qualitative data can improve our understanding of patient impairments, needs, and experiences, which may facilitate patient recommendations or services'. As Morgan (1998: 655) explained, auto/biography is 'not simply a shorthand representation of autobiography and/or biography but also [a] recognition of the inter-dependence of the two own lives' (in Letherby, 2022: 14). Sharing patient voices, including through auto/biographical research, may be vital in addressing, and working towards preventing, the social challenges of having disabilities/chronic illnesses such as PoTS so that in future, there can be more understanding from others. This introductory section of my paper summarises the findings of key texts in the field and the rationale behind my themes, as well as how and why I incorporated auto/biographical analysis.

Initially, my research aims were to understand the impacts of social interaction, condition invisibility and misdiagnosis/ delayed diagnosis on individuals with PoTS. While a small number of texts qualitatively explored the lived experiences of those with PoTS (such as Waterman et al., 2021; Frye et al., 2022; Knoop and Dunwoody, 2022), and Frane's (2023) recent thesis explored the lived experiences of those with PoTS and Ehlers-Danlos Syndrome (EDS), I soon realised that there was/is a paucity of research in my chosen area. In these key texts, the authors analysed themes such as reduced functionality, invisibility, (in)validation, advocacy, condition management, adapting to cope, loss of control and agency, identity changes, mixed feelings, being expensive in many ways, gendered issues and the journey to diagnosis (Waterman et al., 2021; Frye et al., 2022; Knoop and Dunwoody, 2022; Frane, 2023). My paper's final themes emerged through a combination of manually reviewing the interaction-related experiences of myself, other PoTSies in previous research and non-academic sources of patient stories such as some of those on the PoTS UK (a) website. I decided to structure my review somewhat chronologically, focusing on the lived experiences within different stages of a PoTS journey from being undiagnosed, to the impacts of diagnosis, to post-diagnosis life with PoTS and expectations for the future. In addition, I explored the varied visibility of PoTS (including examples of the illness being visible, partially visible and/ or invisible) and (un)helpful experiences of community support groups. In my paper, I referred to wider sociological texts and theories such as Goffman's work (Goffman, 1959, 1963) and Parson's sick role paradigm (in Kelly and Millward, 2004: 6–7; Cheshire et al., 2021: 299) to contextualise discussions.

As Moore (2013: 201) explained, articles on illness stories have tended to be 'constructed by a third party, the researcher, an individual looking at the story from the outside, understanding the story from their (perhaps removed) perspective and interpretative lens'. However, she used autoethnography to 'try to offer a "true" picture' of living with ulcerative colitis (Moore, 2013). I was inspired by her paper and the ways in which she analysed her experiences, endeavouring to write an article like this of my own. As Frane (2023: 11) explained in her autoethnographic thesis, 'my own identity and lived experiences have contributed to the framing of the research aims I sought to explore, as well as influencing the lens through which I conducted my research'. While these two papers used autoethnography, my article utilises auto/biography. Despite some scholars criticising auto/biography, Letherby (2022: 14) posited that 'all research and (scholarly) writing is in some ways auto/biographical, involving intersections of the lives of those who write and those who are written about' and 'all texts bear traces of the author'. I incorporated my lived experiences through various stages of my journey with dysautonomia, presyncope and COVID-19 as well as the social, medical and emotional impacts of receiving a diagnosis of PoTS. I chose to share my story because I wanted to help others and aid healthcare professionals (HCPs) and able-bodied members of the public in gaining understanding, in depth, of what it is like to be chronically ill and how interactions can be experienced by someone with a diagnosis of PoTS. I wrote two poems about my lived experiences shortly after my PoTS diagnosis, which I have included to help convey my emotions (Figures 1, 2). Although using 'I' can still present challenges to more traditional academic writing, like Davies (2012: 7), I hope that 'by writing in the first person, I have produced a more effective piece of research and writing', which can help others.

The remainder of my paper is split into three sections: 'Background and Context', 'Theoretical and Auto/Biographical Review' and

Thank you Covid,
My life has exploded.
Never ached so much,
Legs tender to touch.
Drowsy from exhaustion,
I approach stairs with caution.
Two red lines,
Affecting all this time.
It's been a year already,
I can only move steadily.
But thank you Covid,
For I have noticed.
Being tired brings clarity,
Of who I am and want to be.
I realise things I've been hiding,
On the hamster wheel, abiding.
I'm bi, introverted,
Neurodivergent.
The friendships worth keeping,
Hold rewards I am reaping.
For our connections are stronger,
Now I am no longer a fawner.
No longer feel obliged,
To keep it all inside.
When socialising for hours,
Tiredness overpowered.
Faking a smile,
In case people ran a mile.
I no longer subscribe,
To masking all the time.
Covid, you made me start fresh,
Stop, think and reassess.
What I wish to spend time on,
Now I can't stand for as long.

FIGURE 1
Thanks a lot, COVID.

'Too loud, too hot, too bright,
Not a chair or bench in sight.
Where was I headed again?
I needed to be there, when?
My eyes start to feel heavy,
Heartbeat far from steady.
When did I last drink water?
Shit, the lift's out of order.
I sink to the floor,
Can't stand anymore.
Dizzy and confused,
Coat now removed.
My head sways,
As strangers look my way.
I try to shout out loud,
My voice, a murmur in the crowd.
Can no longer feel my legs,
I fear my arms are next.
Hands shaking towards my phone,
Wishing I just stayed home.
A medic takes my call,
I don't feel well at all.
He asks my name and age,
My mouth too dry to engage.
I whisper where I am,
'No, I need your details first ma'am.'
I don't know the answers,
So, I take my chances.
I repeat where I'm sat,
Passing out after that.
I begin to come around,
Confused why I'm on the ground.
Medics ask what I have,
Gesturing at my swollen calves.
I explain I have no idea,
Told nothing's wrong, tests are clear.
Six months on,
I now know what's wrong.
Why I hate stairs, queues and showers,
When dizziness overpowers.
I have PoTS which I can manage,
With each new Amazon package.
I wish I could tell my old self,
That soon, she will get help.'

FIGURE 2
Dizzy and confused.

'Discussion and Conclusion'. In the former, I began by introducing my story, before giving an overview of what PoTS is and how it can present. In the next section, I explored the following themes subsequent to conducting an auto/biographical and theoretical analysis, combining the lived experiences of myself and PoTSies in previous research: Undiagnosed and Invalidated; (In)Visible; Impacts of Diagnosis; Recovery and Expectations; Community. Lastly, in the 'Discussion and Conclusion', I summarised this review's findings, limitations and proposed areas for future research.

Background and context

When I first caught COVID-19 in January 2022, I felt particularly dizzy, fatigued, confused and sensitive to heat. I struggled to stand up for long or to stay awake. Before the virus, I used music when I felt tired and needed to feel more alert so a couple of weeks after my positive PCR test, I tried putting on a song and dancing to it. Usually, I would dance for 10–15 min and then feel ready for the day or task ahead of me but I swiftly realised I felt too weak and unbalanced to stay on my feet. I realised I had been dancing for less than a minute and assured myself that although I was in a lot of pain and felt upset by the disruption to my plans and my life, it was a temporary bug, I was young and it would pass. As the months went on, things were improving at a shockingly slow pace. Before, I loved cooking curry, stir-fries and pasta dishes but the heat from the kitchen made me feel like I was going to faint so I mostly stuck to microwaving soup. I could go to work but I had to stop and sit several times on my way there, as the short distance I could previously walk with ease was still challenging for me to navigate 5 months after infection. In Moore's (2013: 204) paper, she described her chronic illness as 'The Beast', stating, 'I feel The Beast within me beginning to tighten its grip. […] I want to just rip it out of me. I want to be able to run around, train with [her football] team. I want my body back, back to normality'. This resonated with me as I saw my post-Covid symptoms as a destructive and disruptive force and wanted to feel how I did before.

Almost 7 months after my first bout of Covid, I found out that I had caught it again. This was distressing news, as I felt emotional and scared about how it would impact my health. My friend texted me to ask if I felt better this time and I replied, 'No.' before explaining, 'I'm so achy, dizzy and fatigued. I've defo [meaning definitely] felt I've had [L]ong Covid anyway and […] I'm completely out of breath from going up the stairs like I was last time'. This time, my symptoms became more severe, which was not helped by it now being the summer because 'heat exposure' (Bryarly et al., 2019: 1222) and 'environmental heat' (Bryarly et al., 2019: 1223) can exacerbate symptoms of orthostatic intolerance (OI). This time also held more social offers from friends, which I was almost entirely declining. This included saying goodbye to a friend who was moving away, going to the beach, the cinema, shopping, for meals, a trip to another city and anything that involved alcohol, as alcohol caused me to flare-up and I now know that it can exacerbate OI symptoms (Bryarly et al., 2019: 1222). Moore (2013: 204) reflected on being asked to play in a football match, stating, '"YEEEEESSS" screams my heart' but that she knows her body's answer would be different; 'Which one should I listen to?' (Moore, 2013). This encapsulated how conflicted I felt, as I longed to do everything that my body was unable to do. I felt deflated when declining opportunities but when I accepted things I should not have done, my mind was writing a cheque that my body could not cash. The summer heat made me feel confused and dizzy and being put on medical waiting lists made me feel impatient. I just wanted to be able to live my life again and to be 'able', full stop.

While large questionnaire-based studies 'have detailed the symptoms people with PoTS experience, very little has been described about the intricacies and ongoing impact of these on daily life' (Waterman et al., 2021: 185). It took approximately 17 months from my first infection of COVID-19 to my diagnosis of PoTS and much of that time was rife with frustrating interactions with HCPs, leading to invalidation and fear. It is believed by my HCPs and I that I likely had dysautonomia before catching the virus so COVID-19 exacerbated, rather than caused, my symptoms. Postural orthostatic Tachycardia Syndrome (PoTS), also written as 'POTS', is 'a type of autonomic dysfunction often characterised by orthostatic intolerance, dizziness, fatigue, syncopal events, nausea, dyspnea, and excessive postural tachycardia' (Frye et al., 2022: 1). It mostly affects young women (Ormiston et al., 2022: 1881; Fedorowski, 2019: 352; Dipaola et al., 2020: 2) and is the most prevalent form of OI and dysautonomia (Ormiston et al., 2022: 1881). Symptoms and severity vary and there is a paucity of research on the lived experience of individuals with PoTS, despite this chronic illness having an 'enormous impact on patients' quality of life' (Fedorowski, 2019: 353). I hope that this paper conveys the impacts of health and illness interactions on the lived experiences of individuals with PoTS, who have an often-invisible chronic illness, as well as helping those who have, or will later develop, the condition.

Theoretical and auto/biographical review

Undiagnosed and invalidated

Dipaola et al. (2020: 2) stated that 'patients are often underdiagnosed or misdiagnosed and are evaluated on average by seven doctors before receiving a POTS diagnosis' and 'the median diagnostic delay is 24 months, with peaks reaching 10 years', although in Courtney and Lesley's stories on PoTS UK (a), they described struggling for 17 years and over 20 years before their diagnoses (respectively). In Knoop and Dunwoody's (2022: 1631) study, 'the importance of being heard and believed was a central aspect of living with POTS' and 'this was complicated by misdiagnosis, which led to anger, feelings of being discredited and "fighting" for a diagnosis'. Similarly, Frye et al. (2022: 5) found a common theme in their research was 'medical professionals not believing' adolescents with PoTS with one participant stating, 'I just felt like [my doctor], had his mind set already'. 'Feelings of dismissal and invalidation were reported to negatively impact the family and the adolescent's emotional well-being' (Frye et al., 2022: 6). One parent stated that in the car after specialist doctors' appointments, her daughter would 'break down just in hysterics and […] be crying and sobbing', 'saying what's wrong with me, why do they keep telling me there is nothing wrong with me' (Frye et al., 2022). This resonated with my experience of trying to work out the cause of my symptoms, as the phase in which I was undiagnosed—particularly before I had heard of PoTS/dysautonomia and started suspecting I may have it—was the most stressful in my health journey to date. When I told one doctor how much I was struggling since catching COVID-19 twice and having a severe flare-up from a flu jab, he replied that many people were tired since being infected by the virus, including him, and that he just went to bed earlier. I found this very rude and invalidating because rest did not refresh me as it did him and if an earlier bedtime was all I needed, I would not have been having the appointment with him in the first place.

While there is a paucity of academic research on the lived experiences of the journey from being undiagnosed to receiving a PoTS diagnosis, Spillmann et al. (2017: 1) found that individuals with undiagnosed illnesses expressed frustration at being undiagnosed and adults felt 'they had to provide validation of their symptoms to providers, given the lack of objective findings'. In Dóczy's (2022) article, she reflected on having an undiagnosed illness, stating that 'the hardest part for me is waking up to hopelessness every day, starting each new day with pain – because the pain is all day, every day'. She listed activities that she used to do before, stating 'now everything is lost' and 'without health, everything feels impossible to do'. Lacking and seeking a diagnosis can cause frequent appointments and tests and personal, familial, emotional and financial stresses (Spillmann et al., 2017: 2). BJGP Life (2023) explored experiences of having an undiagnosed illness, stating, 'Susan has been examined by 20 doctors' leading to 'only a long list of rule-outs'. 'The function of a diagnosis is more than to guide treatment planning. It often provides emotional relief for patients, even if the diagnosis is dire', with Susan explaining, 'I keep hoping that some doctor will tell me exactly what this 'skin issue' is, even if there's no cure' (BJGP Life, 2023). When seeking a diagnosis, some HCPs may be more validating than others, for example, one specialist's delivery was particularly understanding and considerate towards me as she phrased the lack of answers or diagnoses as a negative, stating that she was sorry to inform me that she could not be of more help. However, most HCPs that I interacted with presented the news as positive, almost using it to imply that I had nothing wrong with me, which was frustrating as I felt no closer to knowing what I had or what I could do to treat it. I was once told by an HCP, 'you feel dizzy because you are skinny' but since catching COVID-19, I have been told multiple times that my dizziness must be the result of me being overweight. Both felt/feel frustrating, hurtful and invalidating because since puberty, I have struggled with presyncope and fatigue regardless of how much or little I weigh and when HCPs focused on my weight, it made me feel concerned that they were not seriously searching for the cause of my symptoms.

Some of my post-Covid symptoms were new to me but over time, I realised that the vast majority were not. Realising that I may have had a condition that worsened from the virus, rather than just taking a while to recover from infection, was somewhat validating but also nerve-wracking as I worried about whether the time delay between initial symptom onset (believed to be around puberty) and my viral infection (in my early 20s) could mean that I had worse prospects for the future than if whatever was wrong had been identified sooner. I had a pelvic and abdominal ultrasound to find out if there were any signs of endometriosis (or a cyst) and when the HCP performing this asked me what else I had on for the day, I replied, 'I'm having this because my main symptom is fatigue, I'm not very well at the moment so I will need to go to bed after all the walking to get in here'. 'Ooooh lucky you, I'm soooo jealous – I'd love a day off', he replied animatedly. I felt frustrated and wanted to cry but felt that because he was holding the medical wand that was inside of me and my legs were in stirrups, this was probably not an appropriate time to express myself. Although he probably had good intentions, I did not want to have to go back to bed and felt that he would not be jealous of what was happening to me if he truly understood how draining and challenging it was. Spillmann et al. (2017: 1-2) explored three types of illness narratives identified by Frank's past research: 'restitution (expectation of recovery), chaos (suffering and loss), and quest (unexpected positive effect from illness)'. 'Living with an undiagnosed condition prevents the probands from being able to transition out of chaos to quest and the very nature of chaos prevents them from being able to clearly communicate their illness story' (Spillmann et al., 2017: 9). Similarly, in Frane's (2023: 72) thesis, 'the conclusion to which most [participants'] illness narratives built tended to be that of the point of diagnosis'.

A survey found that in the almost 4 years on average from symptom presentation to obtaining a PoTS diagnosis, psychiatric mislabelling was 'common', as 48% of respondents were advised that symptoms were 'due to a psychological or psychiatric disorder, such as anxiety, panic disorder, depression, or hypochondriasis' (Kavi et al., 2016). On PoTS UK (a), Chloe stated that her 'PoTS story' began in 2020 after she tested positive for COVID-19 and became 'very unwell with Long Covid and pleurisy', which caused her heart to beat rapidly 'but this was just put down to anxiety'. In May 2023, she began experiencing dizziness and a fast heart rate when she changed position and 'after endless doctor's appointments and monitoring of my heart I was eventually referred to a PoTS specialist [..] in August 2023' (PoTS UK, a). 'Although anxiety is […] commonly described in POTS, the excessive tachycardia is not simply a physiological manifestation of anxiety' (Bryarly et al., 2019: 1216) and misdiagnoses of panic disorder or other psychiatric conditions (Waterman et al., 2021: 185) can prolong suffering. In one of my pre-diagnostic experiences, I went to my GP surgery to pick up a prescription and while I was there, I had my heart rate tested. During this, the HCP posited, 'umm you have heart problem, yes?', before dropping her pen and paper on the floor and seeming startled. She went to leave the room, leaving me attached to the machine still. 'Is everything okay?' I laughed because I thought it all seemed worse than it was. 'No, very bad, very very very bad, heart is. very bad', she replied, as she left the room hurriedly. When she returned, she informed me that I needed to see the urgent care team so I felt confused and numb.

The team were supportive and kind but it felt embarrassing having to take my T-shirt and bra off for the tests. Then, I sat with a medical professional to hear my results. Everything looked normal structurally with my heart (and my lungs which had also been tested) but my symptoms were apparently concerning. This was a relief but also stressful to hear. He said that I would need a 24-h ECG, a urine test and then his voice trailed off as he saw something else on his screen. I wondered which result he was looking at and started to feel worried by this reaction. 'Oh. You picked up anxiety and depression medication today so nevermind'. I did not know what to reply. I explained that these had been prescribed to me to potentially help with my physical symptoms, particularly as low dose anti-depressants can help with gastrointestinal (GI) issues, and that I had not tried them yet. This was the truth but he looked at me as if it was not. He said that we were finished and I could go home and I felt lost and dazed about how anticlimactically such an unexpectedly stressful trip had ended. 'Overall, the burden of living with an undiagnosed condition is high, with suffering, frustration and uncertainty' (Spillmann et al., 2017: 8). For me, there were periods of anticipatory stress before a test, uncertainty and nerves when awaiting the results, followed by a recurrent and deflating anticlimax. While I was relieved at times not to have worse news and did eventually get the tests done that he had suggested and then un-suggested, I wanted an answer. Frustratingly, I also experienced my results being lost/misplaced before I received them multiple times (causing tests to have to be repeated), as well as referrals that my GP sent off (such as to neurology for my headaches and migraines) being rejected by the specialist departments. In Frane's (2023: 69) thesis, participants with 'a shorter diagnostic period' or those who 'struggled less with obtaining answers regarding their symptoms' were diagnosed by private health professionals rather than the NHS and all but one of my appointments have been through the NHS, which may have affected my experiences.

Ormiston et al. (2022: 1881) stated that recent studies 'have described patients recovering from COVID-19 as presenting with significant and debilitating POTS and POTS-like symptoms, suggesting that COVID-19 is yet another viral infection that can trigger POTS and that POTS is a distinct phenotype of long COVID'. In Au et al.'s (2022: 7) paper on Long Covid and medical gaslighting, one respondent wrote, 'A nightmare. Gaslighting and denial and doubt. Dismissal. Western medicine has absolutely failed us' (Au et al., 2022: 6) and a respondent with medical credentials recalled 'being dismissed by their own colleagues', as they explained, 'I sought treatment at the healthcare system where I worked. I was treated like an anxious child. Nobody listens… Despite concrete evidence that something was wrong with me' such as results of a heart monitor (Au et al., 2022). The paper stated, 'while the majority of our [...] respondents were able to obtain a test, 86 (26%) [...] were unable to confirm their initial infection'. A long hauler explained, 'in the beginning, it was terrifying. No one believed or understood that covid lasted longer than 2 weeks and it wasn't a life-or-death thing. At the most terrifying point of my life I had to fight not just to live but for people to believe that my illness existed let alone to get help' (Au et al., 2022). Interestingly, 'the post-acute sequelae of COVID-19 is being diagnosed not only in those who developed severe acute COVID-19, but also in infected individuals who had mild and even asymptomatic cases' (Plaut, 2023: 1). 'There is a need for widespread education of health professionals about PoTS to avoid misdiagnosis and to facilitate timely diagnosis' (Kavi et al., 2016). In Lesley's story on PoTS UK (a), she reflected that upon receiving her diagnosis, 'initially, I was so relieved that I wasn't going crazy, then I realised that not only does my future look different to what I expected, my past also could have as well; if only I had been listened to, believed, and diagnosed sooner'. Hopefully, the increased prevalence of PoTS and PoTS-like conditions since the pandemic will increase research into, and awareness of, dysautonomia so that the time PoTSies go undiagnosed and invalidated is reduced/avoided.

(In)visible

'One of the challenges with POTS spanning diagnosis, treatment, and QoL [meaning quality of life] is the invisibility of this condition' (Frye et al., 2022: 5). Kessler (2022: 57-59) analysed Cleasby's story of being judged for using a disabled toilet despite having GI conditions and an ostomy, which 'exposes the challenges of both living with an invisible disease and facing stigma', through an 'onlooking woman's visual practices (staring) and verbal practices' (tutting). A PoTSie from Waterman et al.'s (2021, 189) study stated, 'I want people to understand that even though I look well...I really really am not feeling well.' In Sophie's story on PoTS UK (a), she reflected, 'when people look at me, they see a normal, smiling teenager. [...] On the inside, things are very, very different' and Chloe stated, 'lots of people think there's actually nothing wrong with me as I'm just a smiley, bubbly character. The hardest part about PoTS is not being able to do the things I used to do' with walking up the stairs or getting out of bed being 'so hard when your feel like the whole room is spinning constantly'. Kessler (2022, x-xi) stated that illnesses related to the digestive system are 'an ideal case for rhetorically theorising stigma because these conditions sit on the edge' of the boundary between being 'invisible, until they become visible (visually, auditorily, or olfactorily)'. Similarly, my syncope and presyncope can sit on the edge of (in)visibility, as people may not realise that I feel like I am going to faint, cannot concentrate and am experiencing visual and auditory disturbances (due to presyncope) but do notice when I experience conscious blackout episodes, need to lay on the floor or start swaying.

One parent in Frye et al.'s (2022: 5) study on the lived experiences of adolescents with PoTS and their parents felt that children with invisible disabilities such as PoTS 'look normal' on the outside 'but on the inside, they are struggling to get up every day and people do not take seriously what they are really going through'. The parent stated that she feels her children 'go through more than the average adult does by the time they are 90 [years old]' (Frye et al., 2022). In Poku and Pilnick's (2022: 1036) study of the lived experiences of children and young people with sickle cell disease (SCD), one participant stated that saying she is tired after doing 'something small' makes people think 'you do not want to do it, or you are lazy. They make it sound like you have decided to be tired' and 'they do not believe you because how can you be tired when you have almost done nothing and when you are not disabled or an older person who is weak and frail'. Another stated that tiredness makes him 'feel like an old man' and 'it makes me feel bad because they tease me that I'm weak, girly, and there's no fun in playing with me because I'm always complaining that I'm tired' (Poku and Pilnick, 2022). These excerpts indicate that 'reduced functionality and physicality are perceived as synonymous with old age and physical disability' (Poku and Pilnick, 2022). Age may also impact PoTSies interactions with others, as it can be presumed that they look too young to be struggling in the ways that they claim to be. As a woman diagnosed with PoTS in my early 20s, I find it particularly invalidating when people tell me that I will know real muscle aches or tiredness when I am older or that I will know real hot flushes when I hit the menopause, as I already experience these symptoms severely now.

For individuals who develop PoTS, 'the most common demographic is young, previously active women, and frequently, there is an identifiable event (such as illness, pregnancy, or surgery) that precedes symptom onset and precipitates withdrawal of activity or frank bedrest' (Bryarly et al., 2019: 1225). Miles (1991: 88) argued that 'problems of legitimacy and credibility loom larger in the illness experience of women than in that of men', as well as asserting that 'the widely-held stereotyped picture of woman as complaining, weak and inclined to magnify problems leads to general scepticism about the extent and severity of women's symptoms. Much less are the symptoms of men called into question (Nathanson, 1975).' A parent of an adolescent with PoTS in Frye et al.'s (2022: 6) study stated that her daughter's school principal said to her, 'I know you are playing everybody, but you cannot play me, I know there's nothing wrong with you'. Because PoTS predominantly affects those assigned female at birth (AFABs), discussions around invalidation, invisibility and questioned credibility should be contextualised within the wider debate around whether AFABs' health issues are taken as seriously as those assigned male at birth's (AMABs'). As a woman and AFAB, I do not know the extent to which my gender or sex have contributed to my pre- and post-diagnosis experiences, however, I experience increased severity of symptoms preceding my period. 'Women with POTS often report fluctuations in the severity of POTS symptoms throughout their menstrual cycle, with worsening during either the pre-menstrual or early follicular phase' (Bryarly et al., 2019: 1212). However, these worsened symptoms rarely affect the visibility of my suffering, instead adding another invisible, often-invalidated struggle.

In Poku and Pilnick's (2022: 1037) study, participants described the extent to which they felt pressured to meet masculine and feminine ideals. One male stated, 'when I think of a man, what comes to mind is fitness, strength and energy levels' (Poku and Pilnick, 2022), while another pursued 'an unconventional biography informed by his own capabilities [such as drawing] rather than the conventional biographies of adolescence and masculinity' (Poku and Pilnick, 2022: 1041). He said, 'I do not see myself as weak because sometimes I do things my friends cannot do [...] Those who say I'm weak do not know me very well [...] [and] I do not think being strong is all about running or playing for long' (Poku and Pilnick, 2022). Sometimes, I wonder whether I would receive as much help with carrying things in public places if I were not a young woman, for example, if I were a young man who was socially assumed to be strong. On PoTS UK (a), 38-year-old James described catching 'Glandular Fever (EBV)' and 'within a year I could not fight the fatigue, insomnia and daily migraines any longer and had to stop working'. He explained, 'they [HCPs] wrote me off as being depressed and having ME/CFS [myalgic encephalomyelitis/chronic fatigue syndrome]. I never really had the symptoms of depression, and I certainly did not meet the criteria for ME/CFS', as well as stating that it was frustrating that his GP notes had said that he had a high heart rate multiple times, which they 'put [...] down to "anxiety"' despite him having tonsilitis or a headache and never complaining 'about anxiety or anxiety symptoms' (PoTS UK, a). 23-year-old Conor described having PoTS, Inappropriate Sinus Tachycardia (IST), Orthostatic Hypotension (OH), Neurocardiogenic Syncope (NCS) and OI (his 'primary forms' of dysautonomia), along with 'chronic fatigue', 'digestive issues' and mast cell activation syndrome ('MCAS'), all stemming from hypermobile Ehlers-Danlos Syndrome (hEDS; PoTS UK, a). He stated, 'I think it's extremely important to share my story as a man with PoTS as it can be overlooked as a 'woman only illness', as I was once told by an incompetent doctor' (PoTS UK, a). Thus, getting a PoTS diagnosis can also be subject to challenging, invalidating interactions for men/AMABs, not just women/AFABs.

After receiving a flu jab roughly 4 months after my second bout of Covid, I entered into a long, horrible flare-up and subsequent increased experience of syncope and migraine. Due to this, I sent my friend a voicenote saying that I was considering buying a walking stick but was unsure what people might think. I worried that others would ask why I was using it and thought I would have to admit that nothing had been found to be wrong with me that would justify its use. I knew it would help me to feel steadier, which would improve my QoL as I would be able to walk longer distances and have more independence but I doubted whether I was being overdramatic for wanting one. Stacey (a), a wheelchair user with moderate ME/CFS stated that she was 'put off using a wheelchair for a long time', as she 'thought that they were only 'allowed' in certain cases and for certain people, and that [she] wasn't one of them'. However, 'my wheelchair allows me to do more of the things I love, with less detriment to my health' as and when she chooses to use it (Stacey, a). The first time that I used my mobility aid, I felt amazing as it helped me to go into the optician's without needing to hold onto anyone else and enabled me to feel secure and confident in the midst of dizziness and weakness. A theme identified in Waterman et al.'s (2021) study was 'loss of control and lack of agency over body' and when referring to those with rheumatoid arthritis, Nettleton (2013: 65) stated that individuals can become 'dependent upon others' and in 'a culture which emphasizes independence and self-reliance, [this] can be threatening to the sufferer's self-esteem'. It can 'make social interactions, which in our society are for the most part based […] on reciprocity, particularly precarious' (Nettleton, 2013). This resonated with me as it knocked my confidence having to depend on others when lacking agency over my body and I did not want to see my friends until I knew that if a dizzy spell occurred, I would be able to walk without linking arms or holding hands with them.

When I used my walking stick to go to work and occasionally to cafés or supermarkets, I felt thrilled that I had bought it but wished I had gotten it sooner. It would have made a huge difference to me to have bought this before my flu jab-induced flare-up, particularly when I went to my friend's graduation a couple months before and stood for a long period of time feeling dizzy. Friends who I saw or spoke to frequently were unsurprised to see my walking stick and were happy for me that it had made such an improvement but some friends who I do not see often seemed to feel confused and/or perceive this negatively. Miles (1991: 87-88) stated that in cases of 'episodic illness, psychiatric disorder and diseases which develop slowly and are not always apparent, it is the legitimacy of the condition itself' that may need to be re-affirmed sometimes. When I told a friend I had seen at the graduation that I now had some limitations on what I could do when we met up, she kept saying that she was confused, including by my use of the word 'disabled' to describe myself. She remembered my symptoms but did not understand that this may cause me limitations sometimes and said, 'I did not know you would say you were... *disabled?*' The 'invisible nature of the condition' may not match up 'with people's expectations of someone with a disability', with one PoTSie saying that they have been glared at for putting up their blue badge and asked if it is for them (Waterman et al., 2021: 189). For me, having PoTS is disabling due to its impacts such as me needing to sit down more often than able-bodied people. It was disabling before my walking stick and compact stool made it more visible and, in some ways, it was more disabling before I looked disabled.

This term 'disabled' can be viewed through the medical or social paradigms, with the former suggesting that people are disabled by their impairment(s)/difference(s). The latter, however, posits that individuals are disabled by barriers in society, not by their impairment(s) or difference(s; Oliver, 2013: 1024; SCOPE, n.d.; SENSE, n.d.); Societal barriers can be physical (such as a building not having a disabled toilet) or caused by people's attitudes/ignorance (Oliver, 2013; SCOPE, n.d.; SENSE, n.d.). In Frye et al.'s (2022) study, one of the identified themes was 'negative changes in functioning' and Knoop and Dunwoody's (2022: 1633) participants 'not only coped with debilitating symptoms, but also the grief of lost friendships, previously enjoyed activities and to a certain extent, loss of independence'. Rich et al.'s (2020: 6) study identified 'challenges with participation in functional daily activities, such as self-care, showering, cooking, shopping, spiritual activities, and doctor appointments', which encapsulated 'difficulties which were not directly linked to one symptom, but overall lead to additional challenges due to a lack of participation'. 'Socializing with friends or family was interrupted due to routinely cancelling plans, which often led to withdrawal from future plans' and 'others reported a lack of energy to engage, inability to participate in activities, and fears surrounding being out in public due to safety concerns' (Rich et al., 2020). I describe myself through medical terminology, my diagnosis was important to me and I see my impairment/chronic illness as somewhat disabling through the medical lens, however, I also feel that the extent to which I am (un) able to participate in activities/society is partially dependent on factors associated with the social model such as understanding from others and receiving help if I am unable to carry heavy items. Having the right accommodations such as being able to wear sunglasses indoors, refill my drink more often than other people and move my legs around to improve circulation make a huge difference to the extent to which my dysautonomia is disabling and to my confidence that I can retain control over my symptoms/body to participate socially. When I cannot control my environment, for example if all available lifts are out of order (which happens far more often than I realised before I was dependent on them), I am more risk-averse, fearful and less likely to participate in activities.

In Kavi et al.'s (2016) research on the experiences of individuals with PoTS, 23% were wheelchair users, 37% were unable to work, 5% were bedbound and 7% were mobile without restriction. I would describe myself as having 'mobility issues' as I can stand and walk but not for long without taking breaks. It takes me more energy than it would for an able-bodied person, as well as causing me to be more symptomatic and require longer to rest afterwards. Stacey (a) reflected that 'because of the way mobility aids are typically portrayed in the media, I naively assumed they should only ever be a last resort, a worst-case scenario, viewed as an absolute tragedy' but that actually, 'using a wheelchair has given me my life back'. Ambulatory wheelchair users are people who use a wheelchair sometimes, rather than always, as despite possibly having some ability to stand, walk or move their legs, remaining seated may help them to avoid/reduce fainting, seizures, pain and/or over-exertion (Stacey, a). Stacey (b) discussed experiencing post-exertional malaise (PEM) in which symptoms flare-up after mental or physical activity, reflecting, 'at my worst, it would only take accidentally standing for a couple of minutes longer than I should have done or walk[ing] a couple of metres further than my baseline, and I would go through hell for days afterwards [...] I'd be hollow with exhaustion'. However, her wheelchair has helped her to experience PEM much less, as 'I began to feel more…okay. Not necessarily stronger, but much less breakable' (Stacey, b). Despite advantages such as this, ambulatory wheelchair users, such as those with PoTS, may face abuse sometimes, as others see them standing up from their wheelchairs or moving their legs and presume that they do not actually need to be using one.

In Rich et al.'s (2020: 7) study, some participants 'reported apprehension in leaving home without a wheelchair or other adaptive tool, fearing an episode of syncope or pre-syncope'. Individuals with visible illnesses may have less autonomy about disclosure than those with entirely or partially invisible disabilities (Joachim and Acorn, 2001: 245). Middleton (2023) explained that masking autism or other forms of neurodivergence can be exhausting and challenging but is also a privilege as those with high support needs, who are non-verbal/non-speaking and/or have comorbid (co-occurring) learning disabilities may not have the option to hide their traits to help keep themselves safe or prevent ostracisation. While I struggle to decide whether to wear my medical identification cards for PoTS and migraine on my lanyard and deliberate over the extent to which I want to disclose my health differences, it is a privilege that I can often choose whether to make my disabilities visible. For PoTSies who use wheelchairs, their disability's visibility can prove challenging socially. Joachim and Acorn (2001: 244) state that 'those without stigma generalise from a particular disability to a variety of disabilities or imperfections (Strauss et al., 1984)', which may explain 'why some people talk to a person in a wheelchair as if the afflicted cannot comprehend, shout at the blind, or speak to a companion of a disabled person rather than to the person with the disability'.

Cognitive challenges, also known as 'brain fog, mental fog, mental clouding, or mental fatigue' (Raj et al., 2018: 46), can also prove to be an invisible but debilitating aspect of having PoTS. Ross et al. (2013) found that over 95% of PoTS patients self-reported cognitive impairment (cited in Raj et al., 2018: 46; Rich et al., 2020: 2) and previous studies cited by Raj et al. (2018) suggested that depression and anxiety related to having a chronic's illness can negatively impact cognition. In Rich et al.'s (2020: 7) research, 'cognitive limitations identified by participants included issues with concentration, word-finding, focus and memory' and nearly 20% of participants believed 'these limitations impacted participation in daily life including decreased concentration and mental fatigue while driving, working, and during social activities'. I struggle with oscillating mental energy, as I can think clearly sometimes but this is dependent on my postural position, management of hydration (through consuming electrolytes), raising my legs, reducing sensory input and resting appropriately. When experiencing PEM, migraines or standing for too long, I find talking challenging so I am particularly cautious about trying to manage relevant factors including my energy before activities so that I can avoid running out of cognitive energy during them. I think most people would be surprised by the extensive effort I put in to prepare for activities and avoid cognitive issues, only seeing the version of me who can converse and present well, rather than all the work I have done backstage (Goffman, 1959) to achieve this.

However, some people with PoTS experience brain fog constantly or at least more independently of other factors than I do. For example, Raj et al. (2018: 46) stated that with PoTS, 'importantly, this cognitive dysfunction can occur even while lying down or seated, limiting ability to engage in work and educational activities'. An adolescent with PoTS in Frye et al.'s (2022: 626) study described struggling with schoolwork due to brain fog and feeling 'so dumb', while a PoTSie participant in Rich et al.'s (2020: 7) study reflected, 'my memory is horrid which also affects my social life. It's hard to explain to people you have been around for years that you cannot remember their names or children's names, and even complete conversations you have had with them'. The extent to which those around PoTSies are understanding about their cognitive challenges may impact their lived experiences, inclusion in social events, wellbeing and identity. Frye and Greenberg (2024: 3) referred to Frye et al.'s (2022) study, stating, 'one participant reported concerns about independently cooking due to difficulties of brain fog and forgetfulness, that could lead to food or an oven unattended for long periods'. In Au et al.'s (2022: 7) paper, one respondent with Long Covid reflected, 'you do not know frustration until you have had to advocate for your own care against a system that is reticent to adapt while you are debilitated by a novel illness that includes dense brain fog'. Extant literature illustrates the disabling nature of cognitive issues in PoTS and related conditions, both socially and in medical settings.

Impacts of diagnosis

Receiving medical diagnoses such as PoTS may cause different emotions in different people and in Knoop and Dunwoody's (2022: 1632-1633) study, one theme was 'a mixed bag of emotions', as some participants detailed challenges (such as feeling like a burden on others) but also gratitude (such as for the support from other people/partners). Monk (2024) and San Filippo (2020) described grieving their PoTS diagnoses with the latter explaining, 'if I am being honest, I grieved. I grieved the woman I used to be and some days still do' but that her mindset for this and other aspects of life is to 'take it for what it is and learn to make the best of it'. However, in Frane's (2023: 72) thesis, 'out of all 12 participants, none described their final accurate diagnosis of POTS and/or EDS as a negative event', despite 'the conflicting feelings this may produce', with the most cited emotion being 'relief'. Kelly and Millward (2004: 6-7) stated that 'the sick role paradigm established by Parsons (1951) […] is one of the most significant and important pieces of theorising about the social nature of illness of the last century'; This included 'his idea that sickness was a form of social as well as biological deviance' (Parsons, 1951). Cheshire et al. (2021: 299) stated that according to Parsons' theory, the sick role 'was entered into with a physician's diagnosis' and 'entering this role was thought to free a person from some social expectations (e.g., work) and blame for being sick, while they temporarily occupied the role (Parsons, 1951)'. After I received my PoTS diagnosis, I felt somewhat freed from able-bodied expectations and have found it easier to accept myself as I am. I have noticed that, in some cases, my diagnosis has affected the way in which people treat me, as before I was asked sentences beginning, 'are you sure you cannot.?' and was told, 'no, you'll be fine to...' but my limits are generally more socially acceptable now. When I reflect on the sick role and my own experiences, I feel that sometimes people only believe there is an excuse or reason for ill-health and altered functioning when a medical professional has agreed this. A person is still sick before they are diagnosed and I hope that in the future, there will be more societal acceptance towards the undiagnosed but unwell populations.

Cheshire et al. (2021: 300) stated that some theorists, 'including Parsons himself, argue[d] that the theory highlights responsibility of the chronically ill person to minimise the effects of their health condition (rather than recover from it), by engaging with medical advice/treatment, displaying motivation to recover, and not "give in" to the illness (Varul, 2010)'; 'Bury (1982) proposes that a chronically ill individual may only have periods where they occupy the sick role due to, for example, symptom flare-ups or surgery' (Bury, 1982). In my experience, there can be a stigma attached to not being perceived to be displaying enough motivation or effort to recover and I have had time in and out of the sick role since puberty. Early on in my post-viral flare-up, several people who did not know about my situation confidently told me that they thought that people who claimed to have Long Covid were 'faking it', exaggerating or using it as an excuse to work less hard. I found this really awkward initially but have become more vocal over time as my symptoms have become more severe. I find this offensive and rude, as it implies that those suffering after the virus are not deserving of occupying the sick role and are to blame for their reduced or altered functionality. Long Covid is an example of a chronic health issue in which 'feelings of invisibility and stigma due to others not understanding the condition are prevalent' (Waterman et al., 2021: 189).

I feel that one of the main advantages of receiving my PoTS diagnosis was that I was able to begin accessing and taking medication. For the first 4 months after I began taking one of these, I had no episodes of conscious blackouts, fainting or drifting in and out of consciousness, compared to these occurring twice to three times per week on average before (since my flu jab). I had a pre-medication heart rate that jumped up to 150-180 bpm from minimal exertion but medication helps my heart rate to be less excitable now. However, one HCP has been vocal with me about feeling that I should come off the medications prescribed by the dysautonomia specialist (in favour of going on other medications suggested by him). He argued that conditions such as PoTS and ME/CFS are not based on proper science, that I should identify as having 'a post-viral syndrome' instead and that too many people with post-Covid symptoms are being falsely diagnosed as having syndromes such as PoTS and ME/CFS (which he stated that many HCPs do not 'believe in') when they are just deconditioned and need to exercise more. Because I have no medical background, I find the varied perspectives on using medication for PoTS and on the contested validity of these conditions stressful and confusing. I find that interactions with friends or others who have not experienced chronic illnesses themselves illustrate a naivety that receiving a diagnosis means that health challenges will end, almost automatically. In Knoop and Dunwoody's (2022: 1633) study, 'making sense of symptoms was very individualistic and a diagnosis did not always lead to instantly reliable management strategies' for those with PoTS, as much like in ME/CFS and Multiple Sclerosis (MS), 'there was an emphasis on the need to "get to know" their own symptoms, some of which were difficult to control'. I have experienced—and continue to experience—very conflicting advice on managing my dysautonomia. I believe that regardless of an HCP's perspective on diagnostic labels, they should show compassion for the patients experiencing challenging symptoms. In my post-viral experiences, those who reject labels such as PoTS, ME/CFS and Long Covid tend to also invalidate my symptomatic experiences, which I find more hurtful and unhelpful than the questioning of the labels themselves.

PoTS UK (b) explained that there are no approved medicines for treating PoTS, thus medications are prescribed 'off licence'. 'Treatments must be tailored to each patient, taking into account the cause of their PoTS', individual symptoms, co-existing conditions and side effects (PoTS UK, b), as well as any interactions with other medications. Arotin (2019) described taking 'medication to lower my heart rate, antinausea tablets, dizziness tablets, and car sickness medication, all in an attempt to reduce my symptoms' before seeking alternative therapies and Sara, a patient from the PoTS Treatment Center (n.d.), explained that she was 'just covering up [her] symptoms with medications' so she 'needed a true solution'. I find that those who have not experienced chronic illnesses themselves often wrongly assume that doctors always choose which medications their patients take and that this is a quick decision, rather than a more personal process. Some people do not want to take medication, while it may prove ineffective for others and may or may not be worth the side effects or potential long-term risks. On PoTS UK (a), James explained that medication really helped him but Kira stated that the same medication made her symptoms more severe. Conor described having PoTS and other conditions and stated, 'medication unfortunately does not work with my body and has little effect on my symptoms' (PoTS UK, a). While two medications that my dysautonomia specialist prescribed have been brilliant, I could not withstand the side effects of a third and came off it after only a few weeks. I experienced challenging side effects from all three initially, as like San Filippo (2020) explained, 'with POTS, my body is very sensitive to medication'. PoTS UK (c) described four 'causes/subtypes' of PoTS: Neuropathic, Hypovolaemic, Hyperadrenergic and Deconditioning. Different causes and types can affect the suitability of medications and nonpharmacological interventions so it should not be oversimplified that all PoTSies improve with more salt, medication or other changes. Some friends/family have excitedly told me about people with PoTS who have tried something and gotten much better (or recovered entirely), however, their advice has not appeared to work for me so PoTS interventions can have varied success for different individuals.

O'Connor (2024: 2) has Long Covid and 'meets diagnostic criteria' for PoTS, MCAS and ME/CFS, as well as showing 'signs of immune system dysfunction'. She explained that 'Long Covid is a debilitating and devastating chronic illness' causing 'loss of employment, inability to parent your children, breakdown of marriages, and destruction of your identity and life as you previously knew it' (O'Connor, 2024: 9). This links to Bury's (1982) concept of 'biographical disruption', which is 'the influence of a significant, sudden event or events on the course of an individual's life that cardinally changes its direction and plans' (in Pranka, 2018: 1). Illnesses can break 'an individual's social and cultural experience by threatening [their] self-identity' (Pranka, 2018). I have experienced biographical disruption due to my severe COVID-19 symptoms continuing to have debilitating impacts on me over 2 years after my initial infection. Stopping to reassess my life while spending great lengths of time in bed with little ability to tolerate distractions (such as music or TV shows due to exhaustion and noise/light sensitivity, as well as involuntary sobriety due to alcohol-induced flare-ups) helped me to realise things about my life that I wanted to change and ways in which I wanted to better distribute my energy in future. It caused me to come out to my friends and family about being bisexual and believing I may be autistic, as well as encouraging me to live and communicate more authentically in general. This could be conceptualised as fitting into Frank's (1995) quest narrative in which there are unexpected positive effects from illness (Spillmann et al., 2017: 1–2). When I first got unwell from COVID-19, my friend called it 'divine intervention' due to its significant upheaval on my life and her feeling that I needed something like that to happen. My perspective on this fluctuates, as often I think it may be true but when I flare-up, for example having more than 20 migraines in a month, I do not, as I utilise more of a chaos narrative of suffering and loss (Spillmann et al., 2017). My poem in Figure 1 illustrates some of my conflicting emotions about my post-Covid diagnoses' impacts on my life.

Recovery and expectations

PoTS can cause a variety of symptoms and variable outcomes (Pandian et al., 2007: 529). There are divisive academic arguments and public discourses about the extent to which remission and/or recovery are possible for everyone with PoTS, with Knoop and Dunwoody (2022: 1632) stating, 'currently, there is no cure, approved or licenced treatment for POTS' but that individuals create self-management strategies. Kizilbash et al. (2014: 1), who explored adolescents' experiences of PoTS, argued that 'full recovery is possible with multi-faceted treatment' and 'aerobic exercise is a key to successful recovery' (Kizilbash et al., 2014: 29). They asserted, 'patients with POTS should resume regular physical and academic activities. Sometimes, this must be done in an incrementally increasing fashion over several weeks, but recovery from POTS hinges on avoidance of daytime recumbency and inactivity' (Kizilbash et al., 2014: 19). In Knoop and Dunwoody's (2022: 1633) study, no participants expected to be 'cured or symptom-free' but one participant hoped for day-to-day improvements, 'advocating for better management and, ideally a cure being discovered someday'. However, another participant 'felt that a cure was a long way off and of little consequence to her current situation' and her 'resigned outlook' was echoed by another participant who 'despite having been told that POTS may possibly get better over time, [...] held a fatalistic attitude and limited hope of ever fully recovering, coupled with a prevailing sense of uncertainty about how her symptoms may worsen' (Knoop and Dunwoody, 2022). San Filippo (2020) described her PoTS as 'a chronic illness. Chronic meaning it will be around for, well… ever, or at least until some genius finds a cure. At first, it took me a while to swallow that sentence. I will forever have to deal with this illness. My life was and is forever changed by this diagnosis'.

PoTS 'can be mild to disabling' with most PoTSies experiencing fluctuating pain and symptom severity (The Dysautonomia Project, 2015). Some dysautonomia patients become bedridden due to their illness (Dysautonomia International, n.d.) and The Dysautonomia Project (2015) asserted that 'approximately 25% of POTS patients experience symptoms so severe that they are unable to attend school, work, drive, and some are bedridden'. I have met people who have had to quit their jobs/careers due to their Long Covid and subsequent PoTS and fatigue (thus, entering into the sick role) but have also met people who feel their PoTS barely affects them, as it is 'under control' or simply impacts dizziness upon standing and little else. I was surprised (and inspired) to read of some PoTSies who have accomplished exercise-related goals such as being able to run races. Cathi, a PoTSie, 'runs 5 k races while pushing a wheelchair, in case she feels too dizzy' (Lisa, 2014) and Tulley (n.d.) detailed her challenges, accommodations and accomplishments in running ultramarathons with PoTS. Tulley (n.d.) stated, 'It is my dream to complete 100 miles, and it is a bigger dream to beat POTS, be a fast runner again, and win a 100-mile race. [...] I know I can do it, I know there is a formula, and somewhere there is a cure for POTS waiting to be discovered' before later adding, 'I still have POTS, but it is not dictating my life'. In Jade's story on PoTS UK (a), she stated that it is confusing for her and those around her that on some days, she can 'go for a run and be what looks like normal (the truth is I mask my symptoms) but then there are days that I can get up and faint or I'm completely unable to get out of bed at all'. Thus, not only can PoTS vary between different individuals but it can also vary from 1 day to the next for each person.

In a quest to uncover whether she could run a marathon with PoTS, Monk (2024) explained, 'I wasn't searching for a cure. I was just desperate to find out if more was possible in my life'. Detailing taking many walking breaks and running with friends who slowed down for her, she reflected, 'when we stopped to walk, we showed each other that needing a break—needing help—does not have to mean getting left behind. My nervous system still sucks, but that simple solidarity healed something deeper in me. Running a marathon did not take away the grief that came with my POTS diagnosis. But it gave me a way to practise letting others help me through hard things' (Monk, 2024). This shows that interactions at the level of the individual, including conversations with friends, can impact PoTSies' abilities to participate in activities, set and meet personal goals and cultivate a happier QoL. In my post-viral experience, it is difficult to entertain the idea of gradually increasing my exercise to run races as the more I do, the longer I seem to suffer for. My attempts at slightly improving my standing and walking times have not resulted in improvements to my mobility, instead giving me more frequent migraines and worsened fatigue symptoms. While my first draft of this manuscript has been in the review process, I received a diagnosis of ME/CFS so I am in the preliminary stages of understanding what this means to me emotionally and physically, how it impacts my exercise (in)tolerance and how it affects my recovery prospects. While I do not relate to training to run a marathon and currently need to sit down to fry an egg, the idea of adapting a task to make it possible and surrounding myself with people who understand how I might need to do things differently resonates with me, with the extent to which I can participate in activities significantly affecting my wellbeing. I find reading too many stories of particularly mild or severe PoTS, including narratives of immense improvement or deterioration, unproductive for me, as I find it most helpful to focus on my own body, boundaries, goals and dreams (which is easier said than done sometimes).

When Bryarly et al. (2019: 1225) discussed POTSies becoming 'more active and mobile as they embark upon their path to recovery', this made me think about Cheshire et al.'s (2021: 301) research on what 'recovery' means to people with ME/CFS, as they found that 'the meaning of recovery differed between participants'. This is interesting, partially because of the similarities between PoTS and ME/CFS but also because 'chronic fatigue has been cited in up to 48% of POTS patients' and 'patients with CFS often have POTS as well' (Bryarly et al., 2019: 1216). 'In medical terms, this could be considered a return of one's health to that before illness' with some participants appearing to define recovery as being '100%' symptom free or 'able to do everything other healthy people could do' (Cheshire et al., 2021: 301) but others 'appeared to respond by moving their "recovery goal posts"—highlighting the achievement of obtainable goals over a full return to health' (Cheshire et al., 2021: 302). This included one participant saying that she wanted to enjoy 'personally rewarding and meaningful activities, such as creative endeavours and being able to have fun', stating 'even if I do not recover completely but if I got to a stage where I could do some fun things' such as having a social life, not being housebound and travelling home to see her family (Cheshire et al., 2021: 303) as what she hoped for. When reflecting on what recovery means to me, I asked my 14-year-old sibling for help and the response I got was, 'for your PoTS, recovery would be more Bro Sis time [the time we spend together], more work, more going out with friends for nice food and more fun'. I loved this answer and the idea from some of Cheshire et al.'s (2021) participants that it does not have to mean a full return to previous health which I do not feel I have control over but instead offers more focus on joy, which I am able to work towards.

This idea of recovery and adjusting expectations reminds me of two friends who frequently used the phrase 'when you are better' to me and how this can feel. When reflecting on interactions at the level of the individual, I have remembered the kindness, thoughtfulness and empowerment that I have received from my five closest friends and new postgraduate friends during my post-virus journey with Long Covid and PoTS, for which I am very grateful. It has also reminded me, however, of a few comments from my wider circle of friends that I have found to be quite irritating or dismissive. When having to decline social offers due to ill-health, there have been times when I have explained my limitations, offered alternative plans and hoped to still be able to keep in contact with others but there has been a lack of interest in return to go to cafés, call, meet locally, socialise for shorter lengths of time or meet without alcohol (the latter being important to me due to alcohol's exasperation of OI; Bryarly et al., 2019: 1222–1,223). Kelly and Millward (2004: 5) asserted that 'illness states [can] have consequences for self and identity' and 'identity changes' was a key theme in Waterman et al.'s (2021: 191) study, as 'overall participants reported a significant impact to their identity and sense of self since developing PoTS'. The disinterest to scale down or alter plans makes me feel like I am not perceived as being worth seeing or contacting and that I am not enough as I am now; To me, it suggests that only my past self and a potential future version of me (that may or may not ever exist) qualify as deserving of social interaction, company and inclusion and that I am perceived in terms of what I can offer and do, not in terms of who I am.

'A frequently described comorbidity in POTS patients is migraine, as well as other chronic headache types' (Bryarly et al., 2019: 1216); 'Intractable migraines often lead to physical inactivity, which may exacerbate orthostatic intolerance, and conversely, the increased sympathetic activity associated with POTS may contribute to increased frequency of headaches' (Bryarly et al., 2019). After a week of one of my worst post-PoTS-diagnosis migraines, a little boy who looked about 6 years old shouted 'excuse me' and asked me where I was walking so I replied that I was going to the end of the road and smiled before turning to keep going. 'Dats [meaning that's] NOT far', he said as he furrowed his brow. I laughed to myself that he was a physical manifestation of my self-critical inner monologue and replied, 'I'm happy with that for today'. He carried on, 'but dats not far! It's only over there! Dats not far'. I shrugged, smiled and kept going. When I spoke to my uncle about the improvements I have experienced socially, physically and emotionally since beginning to understand OI and dysautonomia, I nonchalantly mentioned that my pre-diagnosis experiences were 'inconvenient'. He replied, 'no, at its worst, it's been terrifying'. Before I had an MRI on my head and ears, my migraines frightened me, as did my syncope before I understood its causes. I may not be 'recovered' in the sense that I have a disability which is still disabling (medically and socially) but I am recovering from being in a period characterised by significant fear and uncertainty. I hope to have conveyed some of these emotions in the poem that I have written (see Figure 2).

Community

In Rich et al.'s (2020: 9) study, 'participants held mixed feelings on the benefit of support groups, with some feeling better understood and others feeling triggered or brought down'. Laird-Gion et al. (2022: 211) 'completed a feasibility study of a virtual, interactive, empowerment-based small-group workshop for patients with POTS', which was 'created and presented by […] physicians and patients'. The session topics were 'Introduction to POTS'; 'Nutrition, Salt, and Compression', 'Exercise' and 'Living with POTS' (which included 'how to talk about illness with friends and family'; Laird-Gion et al., 2022). Although living with PoTS can be challenging, chronic illness communities, workshops and support groups can be helpful for some PoTSies. In Knoop and Dunwoody's (2022: 1632) study, most PoTSie participants had 'made use of online support groups' in an 'attempt gain self-management information', 'however, these tended to reinforce negativity' with one PoTSie saying, 'it does not feel productive for me'. Similarly, in my experience, Facebook groups for PoTS and other chronic illnesses can feel overly negative and unproductive, however, I found Tik Tok to be an accepting, humorous and helpful community for learning about PoTS and feeling empowered to manage it. While content on the platform can be criticised for encouraging self-diagnosis of PoTS, interactions that I had with PoTSie Tik Tokers felt productive and offered me a sense of belonging in contrast to the isolation that can come with being unwell, losing friendships and socialising less. In Frane's (2023: 66) study, a participant with EDS who was awaiting a potential PoTS diagnosis explained, 'because I've gone my whole life without a diagnosis, I've worked out that I need to pace myself with contacting medical professionals in terms of the admin and the emotional trauma of just simply trying to get medical help. It is so hard.' She noticed in PoTS and EDS communities, 'a large prevalence of people with these illnesses who also suffer with poor mental health, perhaps due to the experiences of medical gaslighting that many have to contend with' (Frane, 2023). Seeking advice from support groups, virtual communities and platforms such as Tik Tok may be perceived as a welcome alternative to the risk of being invalidated in medical settings.

One of the main positives of chronic illness communities, for me, is the freedom of discussing chronic illness without concerns of how to present my symptoms and experiences in a way that is comfortable for able-bodied people without the fear of stigma. Tik Tok can form an accessible way to learn about the condition without having to read too much (which can be useful for those with fatigue and brain fog). When reflecting on managing her ulcerative colitis socially, Moore (2013: 204) stated, 'I lean against the wire fence and try to hide my hunch of pain by pretending to undo my shoelaces'. When she was asked 'mate what's up?', she replied, 'my stomach. It's just being really weird at the moment, hurts when I run' (Moore, 2013). Because loud sounds can trigger my PoTS, I often wear noise-reducing earbuds to prevent flare-ups during loud group conversations and when in busy public spaces. This idea of playing down pain or trying to manage it subtly resonated with me as when choosing my earbuds, I chose subtle colours so that they would hopefully not draw much attention and when asked about them, I rarely disclose the sheer pain and discomfort that I may experience from sensory sensitivities, tinnitus and a migraine if I do not wear them. In Rich et al.'s (2020: 5) study, 'sensitivities to smells, temperatures, sounds, and lights impacted socialization, childcare, bathing, attendance at religious gatherings, and grocery shopping'. I find that most people who do not experience sensitive sensitivity or sensory-induced symptoms struggle to comprehend how challenging they can be or how much thought goes into managing them. Moore (2013: 204) reflected, 'my pre planned line, akin to "covering," (Goffman, 1963) offers little to her but in my mind it is enough' and explained that Goffman (1963) argued that people 'who are ready to admit possession of a stigma (in many cases because it is known about or immediately apparent) may nonetheless make a great effort to keep the stigma from looming large'; 'The individual's object is to reduce tension, that is, to make it easier for himself and the others to withdraw covert attention from the stigma' (Goffman, 1963).

Moore (2013: 204) stated, 'that's as much as I give', as she does not say 'every time it hurts, I have to go to the loo and it takes all my energy not to be reduced to tears' or 'I'm struggling to cope with getting things done'. I relate to this disparity between the challenging reality and the version of events presented to others. In Goffman's (1959: 9) 'The Presentation of Self in Everyday Life', he considered 'the way in which the individual in ordinary work situations presents himself and his activity to others, the ways in which he guides and controls the impression they form of him, and the kinds of things he may and may not do while sustaining his performance before them'. I tend to find that when speaking to fellow chronically ill people, whether they have PoTS or very different conditions, I feel less concerned about Goffman's (1959) idea of impression management or spoiled identity (Goffman, 1963) and more comfortable to be honest and vulnerable about my situation. I attend group hypnotherapy for people with Long Covid, ME/CFS and/or PoTS and in these sessions, the sense of belonging and shared understanding negates the need to mask or obscure challenges, pain and limitations. I find this more productive than interactions on Facebook support groups because we all attend due to wanting to feel better, calmer and more empowered through the hypnotherapy so we have a shared focus and desire to improve and/or accept our situations. When talking to fellow chronically ill people, I value being able to be unfiltered and not having to worry about whether my reality would be stressful, depressing, repetitive or boring for them to hear.

Discussion and conclusion

This qualitative, sociological article explored the invalidation that can arise from trying to receive and manage a diagnosis for an often-invisible, understudied health challenge. Difficulties with misdiagnosis, communicating and declining plans were discussed, as well as the varied experiences of medication. Auto/biography 'disputes the conventional genre distinction between biography and autobiography, as well as the divisions between self/other' and 'public/private' (Stanley, 1993: 42). Having struggled with presyncope and symptoms conceivably caused by dysautonomia for over a decade, I reflected auto/biographically on the decision to use a mobility aid and to label myself as 'disabled', as well as my interactions in and out of occupying the sick role. Depending on others, adjusting plans and reconsidering what 'recovery' means to me can help me to cope with the uncertainty of having PoTS and Long Covid, while both nonpharmacological and pharmacological interventions (such as increasing salt and taking medication) have helped me practically with symptom management/predictability. Pre-diagnostic interactions can involve disbelief, uncertainty, fear and frustration for PoTSies, while interactions with chronic illness communities can (with varied perceived success) offer spaces with less pressure to engage in impression management to avoid stigma.

While my initial research aims were to understand the impacts of social interaction, condition invisibility and misdiagnosis/delayed diagnosis on individuals with PoTS, additional themes and sub-themes emerged during conduction of my review such as community, running, wheelchair use, varied experiences with medication and expectations for the future. Partially because of the lack of relevant qualitative research specifically about PoTS lived experiences, I also drew from non-academic sources such as blogs which detail experiences and perspectives on managing PoTS (such as Lisa, 2014), as well as academic evidence from wider qualitative lived experience literature (such as Joachim and Acorn, 2001). This article covers a variety of perspectives, arguments and experiences, including those that differ from my own. For example, I struggle persistently with mobility issues and intermittently with cognitive issues, whereas others diagnosed with PoTS may experience the opposite. Causes/triggers of PoTS can vary, for example, including sepsis for Jade, COVID-19 for Ellie and Chloe, tonsillitis for Sophie and Glandular Fever (EBV) for James in their (PoTS UK, a) health stories. For others such as Conor and Rebecca, symptoms may be present before notable events but then become worse, for example, Rebecca's symptoms came and went until she experienced flare-ups due to having her appendix removed and later being pregnant. Some people with PoTS feel they will or will not recover fully, whereas I feel uncertain. Future research should explore the extent to which varied beliefs about recovery are affected by other factors such as the causes of developing PoTS or length of time spent undiagnosed. Symptoms and severity of PoTS vary, as well as lived experiences and their impacts on identity and wellbeing.

The term 'POTS' was first used in 1993 by Schondorf and Low from Mayo Clinic, 'however, reports about similar conditions can be found earlier in the medical literature' (Fedorowski, 2019: 352). Because the term 'POTS' (which can also be written as 'PoTS') was first used only 30 years ago, research, understanding and awareness of this chronic illness are in their infancy. While the increased experiences of PoTS and PoTS-like symptoms due to the COVID-19 pandemic are very unfortunate and challenging, it is hopeful that the increased awareness of the condition will help to improve understanding from HCPs and wider society. A limitation of this study is that understanding of Long Covid is contentious and the prospects are yet to be fully known or understood. My paper focused on interactions, rather than on other impacts of experiencing PoTS such as financial challenges (Rich et al., 2020: 7) due to what is known as the disability price tag. A theme in Knoop and Dunwoody's (2022: 1633) study was titled, 'I'm expensive in so many ways', which included issues socially, emotionally and financially. Participants discussed the expense of healthcare in the US and issues such as loss of earnings (Knoop and Dunwoody, 2022), which future research should address in more detail. My research can only be based on what is known so far about each of the conditions and experiences discussed without foresight about the future research and understandings that may emerge. PoTS is the most prevalent form of OI and dysautonomia but future research should explore the lived experiences of individuals with other forms of autonomic dysfunction and OI too, for example, the thoughts, feelings and experiences of those with IST, which is 'sometimes confused with POTS, but occurs independent of body position' (Bryarly et al., 2019: 1215). Future studies should also seek to understand the positive and negative impacts of new, emerging virtual chronic illness communities such as those on TikTok and the motivations leading PoTSies to get their information from there.

More research should explore health issues predominantly affecting women/AFABs, as it is argued that these have not received enough research focus thus far. The impacts of expectations of masculinity on men/AMABs with PoTS should also be explored due to the findings about those with SCD (Poku and Pilnick, 2022). A limitation of my paper is the lack of focus on associated conditions so future research is needed to explore the experiences of those with dysautonomia and its potential comorbidities. 'Reported comorbidities in children with POTS mainly include allergic disorders, migraine, psychological disorders, hyperventilation syndrome, chronic fatigue syndrome, hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorder (hEDS/HSD), gastrointestinal dysfunction, and fibromyalgia' (Wang et al., 2021: 8946). Current understandings of comorbidities of PoTS tend to vary with some links seeming likely but not well understood. For example, 'despite well-established clinical associations' between hEDS and PoTS, 'the precise prevalence is unknown' (Miller et al., 2020: 1) and MCAS is 'a relatively unknown condition that may affect some people' with PoTS, however, 'PoTS and MCAS are not very well understood and the overlap between the two conditions is complicated' (Clarke and Nicholson, 2021). 'Observational studies indicate that up to 30–40% of convalescent COVID-19 patients develop chronic widespread pain and fatigue' and fulfil 'the 2016 diagnostic criteria for "fibromyalgia."' (Plaut, 2023: 1) and '"Long COVID-19″ exhibits fibromyalgia-like manifestations and symptomatology including chronic fatigue, cognitive impairment, low mood, functional impairment, and last but not least-myofascial pain (i.e., "fibromyalgia-ness")' (Plaut, 2023: 10). Future research is needed to understand the potential connections between PoTS and conditions such as hEDS, MCAS, and fibromyalgia and the lived experiences of those diagnosed with a combination, including that of individuals who have developed PoTS as a secondary condition (meaning, their PoTS is caused by a different condition).

There are also limitations in terms of my methodology. As I conducted qualitative research, my findings are not as generalisable, reliable or representative as that of quantitative studies such as large-scale surveys on how PoTS presents for a wide variety of people. These issues are also exacerbated by the lack of research on the lived experiences of individuals with PoTS, as there was a paucity of relevant qualitative, academic studies for me to draw from and analyse. Frye et al. (2022: 623) stated, 'the current literature review [meaning their paper's review of past research] did not identify a single study using qualitative methodology to explore the experiences of patients living with POTS'. While, thankfully, there are some papers like this now, there are simply not enough. Although I referred to the first 10 patient stories visible on PoTS UK (a), future research should seek to represent and analyse more, if not all, of these, as their lived experiences are insightful. Knoop and Dunwoody (2022: 1634) stated under their 'limitations' subheading that 'the lead researcher had a diagnosis of POTS, so there was a risk of researcher bias' in their paper, which was countered using a reflexive diary with results audited by a second researcher. While I believe this was a good decision and that avoiding researcher bias when possible is important to ensure academic rigour and robustness, I also feel that sharing researchers' positionality and lived experiences can be valuable particularly in such an under-researched area. However, illustrating the often-dynamic nature of chronic illnesses, I was struck by how much has changed in my health and my conceptualisations of what I have experienced in the relatively short time between submitting my first draft manuscript and updating it according to revisions. For example, I was infected with COVID-19 for a third time (causing a severe, debilitating flare-up) and have been diagnosed with ME/CFS. I am still in the preliminary stages of understanding what these changes mean to me emotionally and physically so my paper primarily remained focused on my lived experiences before these events. It has proved difficult trying to decide the extent to which to adapt my paper in some ways to reflect changes in my positionality versus the desire to ensure it remains representative of how I felt when I first wrote it. Regardless of this methodological difficulty of writing auto/biographically, I ultimately hope that sharing my story will make a difference, even if just to one person.

From a chronically ill patient's perspective, I recommend that HCPs are more validating towards patients with unexplained symptoms and/or PoTS in future, as interactions with HCPs can greatly impact our lived experiences, wellbeing and perceptions of ourselves. It is crucial to avoid and challenge any potential discriminations due to sexism, ageism, disablism and ableism. I hope that my poetry and lived experiences can help to improve future interactions for those with PoTS due to increased public awareness and compassion. I recommend that anyone who wants to learn more about the lived experiences of those with PoTS reads some of the patient stories on PoTS UK (a), as these are accessible and powerful, illustrating the diversity of experiences of those with the condition. When considering my experiences, I am very grateful for the medical tests that I had access to thanks to my primary HCP and the NHS, as well as some of the positive and validating interactions that I have experienced. However, I remain 'salty' about the challenges faced by those who are attempting to uncover the causes of their symptoms including for PoTSies who are dismissed and ignored. I am also 'salty' about the lack of public understanding towards those with invisible illnesses who feel obliged to try to disguise their challenges or are delegitimized when symptom severity varies over time. I encourage researchers in the medical and sociological fields to research PoTS so that understanding of how to treat it, and treat those who have it, can improve.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical approval was not required for the study involving humans in accordance with the local legislation and institutional requirements. Written informed consent to participate in this study was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and the institutional requirements.

Author contributions

HM: Writing – original draft.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Integrated care systems in England: the significance of collaborative community assets in promoting and sustaining health and wellbeing

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Until recently the healthcare system in England was based on a commissioning/provider model. However, this has been replaced with an Integrated Care Systems (ICSs) approach, aimed at improving health and wellbeing and reducing inequalities through local collaborative partnerships with public sector organizations, community groups, social enterprise organizations and other local agencies. Part of this new approach is an emphasis on the role of community assets (i.e., local resources), that are considered integral to promoting positive health and wellbeing outcomes. This paper presents research from a series of three research studies on "community assets" conducted in the East of England within a newly established ICS. Based on analysis of qualitative data highlighting the lived experience of community asset members, this paper shows the positive wellbeing impact on vulnerable community members that assets provide. Further insight on the local impact and the collaborative nature of the research is provided suggesting that new asset-based approaches recognize the social determinants of health. This presents a shift away from positivistic linear approaches to population health and wellbeing to a new non-linear collaborative approach to addressing health inequalities and promoting wellbeing. The authors suggest that exploring this through a complexity theory lens could illuminate this further. Finally, the authors warn that while community assets have an important role to play in empowering citizens and providing much needed support to vulnerable and disadvantaged communities, they are not a substitute for functioning funded public sector services that are currently being undermined by ongoing local governments funding cuts. As such, while community assets can help ameliorate some of the negative effects people experience due to economic, structural and health disadvantages, only a more fair and more equal distribution of resources can address growing health inequalities.

KEYWORDS

integrated care systems, community assets, complexity theory, health inequalities, community

1 Introduction

This paper presents findings from a series of three research studies conducted on "community assets" in the East of England within a newly established regional Integrated Care Systems (ICS). In accordance with the Health and Care Act (2022), ICSs were established across England between 2019 and 2023 as legal entities with statutory powers and responsibilities (Kings Fund, 2022). There are forty-two ICSs in England, and they are reputed to have brought about a fundamental shift in the way that health and care systems are organized and delivered, with an emphasis on collaboration, place-based partnership and bolstering local community assets (Goddard, 2023).

ICSs have been deploying new approaches to tackle growing regional inequalities by supporting community assets and ABCD (Asset Based Community Development). The NHS Ten Year Plan for England (NHS, 2019a) has placed an emphasis on preventing illness and tackling health inequalities. Part of that plan is to "do things differently" and it sets out an ambition to:

> *…increase the focus on NHS organisations working with their local partners, as 'Integrated Care Systems',* [and] *plan and deliver services which meet the needs of their communities* (NHS, 2019b).

Community assets often involve a range of complex relationships, where different factors and people interact with each other in order to be responsive to peoples' needs in specific places (Thirsk and Clark, 2017). The general ABCD approach is seen as a shift away from approaches that previously focused on identifying prevailing social deficits to one where existing community assets are identified and supported; where communities are given a voice and enabled to grow and thrive. While recognizing that health inequalities arise because of structural inequalities in society (the conditions in which people are born, grow and live), in the present absence of a fairer economic redistribution of resources, community assets are seen as playing an important role in ameliorating some of the negative effects of growing inequalities (Marmot et al., 2013). Block (2018) and Russell (2020) have been highly influential protagonists in criticizing more traditional, top down, interventionist approaches to improving public health and argue that these are often ineffective and unsustainable. They contend that social change is not the result of individual behavioral change but emerges as a result of effective grassroot building at the community level and what is needed is a ground-up approach (Russell, 2020, p. 14). Block (2018) too is concerned with social transformation through fostering and building connected communities where citizens have a sense of belonging and social capital is promoted. These ideas have been informing local community government practices in the UK and elsewhere. For example, Nurture Development is a network providing ideas and practical support including training in promoting a shift to more place based, citizen centered approaches throughout the UK and beyond, influencing local government practices here and overseas (see Nurture Development, 2024). This shift represents a change in policy priorities away from a universal, non-context specific and traditional hierarchical expert-led approach, to one that highlights the importance of adopting place-based approaches and an increasing collaborative citizen/community centered approach to improve health and wellbeing outcomes (Charles et al., 2021).

Moreover, there is some evidence suggesting that community assets can have a positive health and wellbeing impact, helping to prevent some long-term conditions, and increase resilience and wellbeing in individuals and communities (Howarth et al., 2020). However, while they are often considered as an important means to tackle social deprivation and growing health inequalities, questions remain as to whether community assets can reduce health inequity in disadvantaged, marginalized or vulnerable communities (Cyril et al., 2015; Mughal et al., 2022).

In this paper we draw on the findings of three waves of research conducted between 2019 and 2022 in the East of England to reveal ways that community assets can and do improve wellbeing in vulnerable communities. Given that ICS and ABCD approaches involve more collaborative less linear hierarchical approaches to health and wellbeing, in this paper, we question whether "complexity theory" might further develop analysis of community assets as part of a wider system of collaborative integrated pluralistic approaches that gives appropriate weight to real-world case studies and embraces non-linear causality (Greenhalgh and Papoutsi, 2018).

1.1 Complexity theory

Complexity theory has been used to describe fluid, non-linear change within organizations and how they can adapt to their environments and manage conditions of uncertainty (Long et al., 2018). This theoretical perspective often emphasizes co-evolving, complex adaptive systems (Kauffman, 1993, 1995; Holland, 1995) and it has been influential in the field of organizational studies (Currie et al., 2012) and is being used to understand the contemporary healthcare landscape.

Conventional theories that seek to explain health and social care systems have traditionally been tethered to a quest for certainty, predictability, and linear causality. In contrast, complexity theory has started to be used to reveal the complexities of contemporary healthcare based on a recognition of the interrelated dynamics of the multiple components, systems and subsystems within wider socio-economic, and political spheres of healthcare (Apker, 2012; Greenhalgh and Papoutsi, 2018). As such, complexity theory may offer some useful insights into understanding the multiple dimensions of healthcare within the dynamics of ICSs. For example, Nason (2023) suggests that traditional knowledge about health has been held by professionals, and in the clinical setting, professional expertise is highly valued. However, knowledge about the determinants of health, and the context of health promotion and health equality, is held in many different domains, by professionals and ordinary citizens. By using the lens of complexity theory, we can see how community assets can be considered as part of the complex systems of healthcare involving communities in actively shaping their own development, through a process of co-production (Stutton, 2018).

When referring to health and or wellbeing we are using the terms broadly alluding to the relationship between the two where health relates to the physical and mental aspects broadly and where wellbeing suggests a positive state shaped by subjective feelings as well as social experiences (Daykin et al., 2021). The concept of wellbeing has multiple elements that transverse broad categories of emotion, behavior, cognition, and relationships. Adopting a complexity theory lens can help illuminate a well-used definition of wellbeing by exploring "how people feel and how they function both on a personal and social level, and how they evaluate their lives" (Michaelson et al., 2012, p. 6).

1.2 This research

The original research was commissioned by the North-East Essex Health and Wellbeing Alliance who are one of three place-based alliances within the Suffolk and North East Essex Integrated Care Partnership. The Alliance consists of a number of different organizations working in partnership to tackle specific community health issues, and to improve population health and wellbeing across the districts of Colchester and Tendring in North-East Essex (NEE-Alliance, 2020).

The commissioners were keen to understand how and to what extent community assets could help alleviate growing health inequalities and support those communities in socially deprived areas serving populations who are disadvantaged and/or vulnerable.

The region concerned can be characterized as complex, having a wide range of economic and social disparities, with some areas experiencing extreme social deprivation leading to increasing poor health and wellbeing outcomes (Essex County Council, 2019; Ministry of Housing, Communities and Local Government, 2019; Colchester Borough Council, 2020). Three waves of research were conducted between 2019 and 2022 (see Corrigan et al., 2020, 2021, 2023a,b). The first wave of research was conducted just prior to the first national COVID lockdown, the second wave immediately after lockdown restrictions were lifted and some community groups were resuming face-to-face activities, and the third when an emerging cost of living crisis was looming across the UK.

For the first wave of research the Alliance wished to improve their understanding of how local people's health and wellbeing was supported (or not), by "*community assets*". Research findings were employed to inform their overall strategies to address inequalities and support ABCD. For subsequent waves, the Alliance wanted to know more about the resilience of the assets and the experiences of members during the and following the COVID pandemic, and in the context of an emerging cost of living crisis (Hill and Webber, 2022).

The research outlined in this paper can be considered as a new approach to community health and development insofar as the Alliance was seeking to work with local government public health officers, local charities and community groups to best understand how these assets work in practice. This was not a linear health intervention study but an example of co-production, as the researchers worked in collaboration with senior local government officers, commissioners, local community leaders, and members of the different community assets.

The aims of this research were 2-fold. (1) To provide a means for "vulnerable" citizens voices to be heard and to better understand people's "lived experiences" of those belonging to a community forum and engaging with a community asset. (2) To understand the impact of community assets and their effectiveness in supporting individuals' sense of wellbeing within the East of England.

2 Materials and methods

2.1 Research design

The research methodology adopted encompassed elements of both phenomenology and ethnography. Phenomenology focuses on the lived experiences of people and the way they construct their experiences and reality and is a useful way to understand social phenomena through interpretation (Kienzler, 1991; Smith, 2018). It facilitates deep and empathetic engagement with individuals, in order to understand how they give meaning to their lives and their "lifeworld" (Schutz et al., 1978). This was combined with ethnographic (observational) methods, which are well-suited to exploring people's actions in a given social context and their own interpretation of such behavior (Hammersly and Atkinson, 1983) and this included observations of activities and meetings and interviews with participants and community assets group leaders. This approach enabled researchers to develop a more contextual understanding of the relationship between wellbeing and community activities (Corrigan et al., 2020) as well as facilitating rapport and gaining the trust of community group leaders and members. Semi-structured interviews were conducted either face to face, or online when pandemic restrictions were in place. One hundred and thirty three interviews were conducted in total across the three waves of research: 42 for wave one, 36 for wave two and 55 for wave three (see Table 1). Where possible the same participants who took part in the initial wave also participated in the two subsequent waves. As is evident from Table 1, two new community assets (Essex Integration, a voluntary sector organization providing practical help and support refugees and Colchester Islamic Community Centre, a group aiming to meet the needs of local Muslims) were added to the first sample list, as we recognized that there was little representation of ethnically diverse participants in our original sample.

2.2 Study setting, sampling, and data collection

A purposive sample of community assets in Tendring and Colchester were chosen in consultation with members of the project Steering Group, and information was also provided by the two local Community Volunteer Service organizations. The sample selection followed the brief to include participants who were availing themselves of a community asset, and to ensure those groups reflected the health and wellbeing vulnerabilities of communities within the geographical areas of Tendring and Colchester. Together with the Local Authority commissioners we developed a "vulnerability matrix" focusing on groups located in areas of social deprivation, and/or vulnerable in terms of health, disability, and age and/or intersectional characteristics that would be considered as potentially excluded or marginalized (see Table 1

TABLE 1 Overview of the three waves of community assets research conducted between 2019 and 2022.

Wave	Community assets	Total number of participants per wave
Wave one: data collected 2019 from eight community assets (Corrigan et al., 2020)	Dementia Café, Clacton Teen Talk, Harwich Clacton and District Indoor Bowls Club Project NOVA (a regional charity supporting veterans) DNA Networks Uniform Exchange, Colchester (providing the exchange of second-hand children's school uniforms for vulnerable families) Friendship Group (self-funded group of members who meet weekly, share lunch and participate in various social activities) Parent/toddler: Colchester. The club provides a weekly meeting space for toddlers (from birth to 3 years) led by a trained volunteer. Multiple Sclerosis Support Group (peer support)	42 participants took part in qualitative interviews
Wave two: data collected 2020 from community ten assets during the pandemic (Corrigan et al., 2021). The wave of the study reveals how the COVID-19 pandemic affected members of the original Community Groups and the study participant cohort was also extended, to include two new Community Assets composed of minority ethnic populations.	Community Assets as above, plus two additional groups Fresh Beginnings (later known as Essex Integration) Colchester (A voluntary sector organization providing practical help and support refugees) Colchester Islamic Community Centre. A group aiming to meet the needs of local Muslims.	36 participants took part in qualitative interviews this included 15 follow-up interviews with previous assets, 8 from Colchester Islamic Community Centre and Fresh Beginnings and 13 organizers or co-organizers of Asset Groups.
Wave three: data collected from nine community assets post-pandemic (Corrigan et al., 2023a,b) Building upon previous waves (one and two), this study provides longitudinal insight to explore effects on the health and wellbeing of members since the lifting of lockdown restrictions brought about by the pandemic and the cost-of-living crisis	As above. However, it was not possible to conduct interviews with the Multiple Sclerosis Support Group as the group had not reassembled during the data collection period	55 participants took part in qualitative interviews

for details of sample based on our vulnerability matrix). A charity supporting veterans was also included, as they make up 2.79% of the population of Colchester Borough Council (2020) and have poor access to mental health support. Given that the definition of a community asset can include a place, three of the groups (the MS Group, the Parent and Toddler Group and the Friendship Group) included were part of a "community halls partnership project" serving vulnerable parts of Colchester. This project enabled several community halls to develop new ways of working collaboratively by centralizing management and administration with the aim of forming a "network" of appropriate and sustainable community buildings.

To identify socially deprived areas we used official statistics (Ministry of Housing, Communities and Local Government, 2019), which measured relative deprivation at small-area levels in England. The organizational structure of the assets varied, and this was intentional in our sampling, as we wanted to find out the wellbeing benefits irrespective of group size, frequency of meetings, purpose, and funding sources.

To help identify assets we also used information previously gathered by the Community Volunteer Services in Colchester and Tendring who had mapped and identified community assets and we carried out online searches to find other community assets. We then approached the asset leaders about their co-operation in the study who then asked members if they would be willing to potentially participate in our research. The initial scope of the recruitment from wave one (Corrigan et al., 2020), was extended in waves two and three (Corrigan et al., 2021, 2023a,b) to increase the representation from minority ethnic participants (see Table 1).

2.3 Data analysis

All data was transcribed verbatim, except for the interviews with some members of Essex Integration, as the interviews were conducted in Farsi, and were translated by the interviewer using a "free translation" approach (Witcher, 2010). The transcriptions were analyzed using a thematic analysis approach, which involved identifying key topics and patterns, regularities, and contrasts in the data to create interpretive meaning (Braun and Clarke, 2006). The analysis was informed by issues and concepts that stemmed from the data, such as the identification of asset group members' resources (Antonovsky, 1987), as well as reading the data for "capabilities" that enabled some citizens to thrive (or not) in challenging situations (Nussbaum and Sen, 1993). To ensure internal validity of the data, the field researchers conducted initial coding and thematic analysis of the transcripts, and another member of the research team also read and analyzed a sample of transcripts. The findings were discussed further by the whole team.

2.4 Ethical considerations

Each wave of the study was granted ethical approved by Anglia Ruskin's University Research Ethics Panel and informed consent was recorded prior to interviewing and the ethnographic observations. Pseudonyms were used to protect the identity of participants.

3 Results

The collective findings from the research highlighted some common themes, and the research also informed a series of recommendations, and many of these were actioned within partnerships across the local ICS.

3.1 Sociality

One of the strongest themes to emerge from the research was the significance of sociality. Sociality is a variously defined term, but we use it here as a concept that captures the inherent nature of people to form social links, interact and engage in group activities while gaining pleasure in doing so. Across the three waves of the research, participants/asset members and leaders, highlighted the benefits of belonging to a community group and provided narrative accounts of the experiences of wellbeing that participants acquired through making social connections and bonds with others. By wellbeing we are referring to a broader concept than health that allude to a positive state shaped by subjective feelings and social experiences (Daykin et al., 2021). While there is no universally agreed measure of wellbeing, our analysis was based on narrative accounts of participants' lived experience and feelings such as feelings of happiness or anxiety, as well as on the perceptions of the extent of meaning and purpose associated with their experiences of the community asset (Daykin et al., 2021).

Participants revealed how social interactions, friendships, acts of kindness, the sharing of activities, food/refreshments and information improved people's feelings of wellbeing. A major benefit that members appreciated across all groups was how much community leaders, volunteers, and members genuinely cared for each other. The members of the different asset groups frequently reported that they felt "heard," "understood," "listened to." and "valued." Participants enjoyed being part of a group and expressed feelings of camaraderie with other members. Many participants regarded the community asset group they belonged to as a second family. During the first wave of research all participants were asked how important the asset was to them and their wellbeing. All described it as extremely important with many describing it as a "lifeline".

3.2 Overcoming challenges

Another strong messages to emerge from the data was that the connections made within the community assets helped facilitate members' ability to cope with challenges they faced, with many members highlighting how their relationships with others helped them build resilience and maintain wellbeing. For some, the sense of belonging and connectedness found within the community assets helped them to recover from illness and manage their disability (Corrigan et al., 2023a,b).

Undoubtedly, pandemic lockdowns and the cost-of-living crisis were experienced as challenging for many participants. Community assets were valued more so during these periods of time. In many ways this finding is not unexpected, as social connectedness is now recognized as an important determinant of both physical and mental wellbeing (WHO, 2003; Cruwys et al., 2014). Furthermore, longitudinal research has found that membership of community groups and other organizations is strongly associated with positive mental health outcomes (Yu et al., 2015). However, what is distinctive about the research findings is the recognition of the role of community assets played in helping to maintain health and wellbeing through social connectedness irrespective of the function, size, funding, activity or frequency of meetings. Participants described how being part of a community asset and meeting up regularly, provided them with strength and resilience in the face of ongoing life challenges. Sharing with others who are facing similar situations and receiving support from group organizers also really helped most participants cope with adversity and build resilience.

3.3 Social isolation

Participants living alone and or experiencing challenges reported that meeting with others made them feel less isolated. Also, those living in places with poor transport infrastructure felt less isolated in communing together with others. Members of Teen Talk for example spoke of how coming together with like-minded peers helped overcome their negative feelings of living somewhere that was neglected and "left behind", and the free transport provided to those attending the Dementia Café was highly valued by members who lived in remote areas and were no longer able to drive. Some members who traveled together in the minibus to the Dementia Café provided said how journey together lifted their moods.

Unsurprisingly, when the COVID-19 pandemic restrictions were implemented and group members were unable to meet, this had an extremely negative impact on participants' wellbeing. It was notable that those people who were isolated, living alone, and living some distance away from family, found the lockdowns extremely challenging (Corrigan et al., 2021). Many spoke of how they experienced feeling socially isolated. Social isolation is defined as a state in which "the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and is deficient in fulfilling and quality relationships" (Nicholson, 2009, p. 1346). Recent research has also identified elevated levels of anxiety and distress in communities during the pandemic, often related to anxiety of the unknown and the disruption of human connections (Xiong et al., 2020). Some participants experienced significant mental distress because of pandemic restrictions and not being able to meet with others. For example, one male member of the bowls club who lived on his own in a mobile home said that he experienced very bad depression and mental distress. Difficult emotions were more often described by those with a history of mental health problems and those who had experienced prior traumatic events (such as former soldiers, and refugees). Those living with difficult home situations, such as those living with a partner with dementia, also experienced very poor mental health while the pandemic restrictions were in place. Indeed, in some cases spouses of those with dementia experienced mental health breakdowns.

Most community assets were able to respond to the pandemic crisis by providing some form of remote support to members during the lockdowns, with some being quick to develop new forms of "remote" interaction when face to face contact was not permitted (e.g., meetings via zoom, telephone support and practical support such as dropping off food and medicine). Furthermore, most participants reported that they had some form of remote social contact from community asset leaders, other members, family, friends, and neighbors.

It was notable that the Colchester Islamic Community Centre excelled in its use of social media to communicate with members, although a few of the community assets were unable to offer a service or support members during lockdowns. Nonetheless, where community leaders reached out, this was greatly valued by participants, although smaller groups such as the friendship group, and the parent and toddler group, paused during lockdowns. However, most group leaders felt that the response that they were able to offer did not fully meet members' needs. This was the particularly the case with the Dementia café whose leaders reported that the welfare telephone calls they undertook were simply not sufficient to meet the distress of those living with dementia caused by lockdown restrictions. Prior to, and following the pandemic restrictions, participants living in less accessible parts of Tendring spoke of feeling isolated because of a lack of convenient and cheap transport. This was a particular problem for some older participants attending the Dementia Café who could no longer drive due to ill health and disability, as well the young adult members of Teen Talk who also spoke of Harwich as depressing and run down. This is not surprising, as Harwich is ranked in the top 10% of the most socially deprived areas of England (Ministry of Housing, Communities and Local Government, 2019).

3.4 Safe places

Listening to the members of the different groups, it was clear that the assets and activities took place in safe supportive environments, enabling participants to "be themselves" and many participants spoke of how "safe" and "welcome" they felt when attending the assets. These places were considered as inclusive, and many people spoke of how belonging to the asset boosted their self-confidence as they felt accepted and not judged. For example, one member of the parent and toddler group who self-identified as deaf, spoke of how she had, for the first time, experienced feeling so welcome and at home and not feeling like an outsider as she would usually experience in such social settings. Also, participants attending the free school uniform forums spoke of having to overcome initial feelings of shame and fear of stigma before first attending but how they soon felt at ease and welcome. Different participants offered numerous examples of ways in which friendships with members and asset leaders provided practical and emotional support and a sense of "belonging" (Corrigan et al., 2020, 2021, 2023a,b).

3.5 Information sharing

Most groups facilitated informal and formal modes of information sharing. People spoke and shared information with members about their experiences. Some groups had invited speakers on issues of common interest. It was interesting to note that some community assets also provided pathways of support enabling members to access public services. This "bridging role" was particularly apparent in community assets that were developed to meet the needs of minority ethnic communities (i.e., the refugee support group and the group for the Islamic community), who were sometimes less familiar with public sector services. It was also notable that during the pandemic lockdowns, many of the community assets were seen as a significant source of "trusted information". For example, within the Colchester Islamic Community Centre many of the members and volunteers were medically trained, and they were able to offer culturally appropriate information and advice to the members during the pandemic (Corrigan et al., 2023a,b).

3.6 Activities

The research also identified a wide range of collective, physical and/or mental activities that groups engaged in Corrigan et al. (2020, 2021, 2023a,b). There is substantive evidence to show that physical activity can help to prevent some serious health conditions (Naci and Loannidis, 2013; Kyu et al., 2016; da Silveira et al., 2021). The indoor bowls club provided an opportunity for physical activity and many members spoke of the physical health benefits of playing bowls, as well as the positive effect that social interactions had on their mental health. Other groups also provided a wide range of opportunities for members, for example, Teen Talk linked members with other local charities and organizations to facilitate the learning of new skills, including gardening and sailing, as well as cookery and painting. The Bowls club and Teen Talk are in socially deprived towns and research indicates that many people from lower socio-economic groups are often unable to participate in physical activity (Sport England, 2018) and have limited access to sports facilities (Alliott et al., 2022) so this exemplifies the importance of such assets in supporting physical activity. Moreover, it has been suggested that when physical activity is located within local community groups, it often offers members an opportunity to collectively influence activities that meet their needs and priorities, rather than simply attending formal sports activities (Spaaij and Jeanes, 2013). Again, this was evident from the data as many participants spoke of how activities were provided at their request, and opportunities to try something new such as the sailing sessions with Teen Talk members or chair yoga for the MS group were greatly appreciated. In groups such as the friendship and MS groups where physical activities such as outings and exercise classes happened less frequently, participants said that just getting out of the house to attend meetings meant that they were more active. Members of the Friendship Group reported feeling physically and mentally better when they attended group meetings.

3.7 Volunteering

All the asset groups who took part in the study promoted volunteering and some assets such as the Bowls club were run entirely by volunteers, while others such as the refugee group, had a blended structure of paid staff and volunteers. It was notable that during the pandemic new volunteers often came forward in response to the changing needs of the asset group. For example, within the Colchester Islamic Community Centre, some people volunteered to help older members use the internet so that they could keep in touch and attend online activities, while other people volunteered to drop off food parcels and medicines to members, and masks for NHS workers and the wider community. Research shows that volunteering has a highly beneficial effect on the wellbeing of volunteers (Nichol et al., 2024). We found that some participants, particularly the volunteers who lead community assets, spoke of the sense of wellbeing they experienced in "giving back" to the community and helping others. However, some community assets experienced new challenges in recruiting volunteers in the post-pandemic setting. For example, a young person's community asset (Teen Talk) had relied heavily on volunteers prior to the pandemic. Many of their volunteers were older people offering to help young people with cookery and other skills but none of the 40 people who volunteered prior to the pandemic were willing or able to commit to volunteering in the aftermath. This experience is not unique to Essex, as other research has also highlighted that volunteering has fallen across the country (Dederichs, 2023). One of the recommendations we made was to provide support and training for volunteers.

3.8 Impact

The testimonies and voices of community assets members were presented to key stakeholders in a variety of forums including presentations given to working groups within the two Local Authority areas of concern. In addition to published written reports, Power Point presentations, other mediums of communication were deployed to promote study findings and recommendations. These included i-poems based on original transcripts that were produced as part of the initial study and a film of Bowls Club members that was produced to accompany the second report following their resumption of activities after lockdown (Corrigan et al., 2021). The dissemination was wide reaching, and coverage of the research was presented on BBC television news and local BBC radio (BBC News, 2021). The talk on BBC Essex radio program in October 2021 was part of a public phone in discussing the wellbeing benefits of belonging to a community group.

The three reports resulting from the different waves of research contained recommendations based on the findings and many of these were actioned within partnerships across the local ICS (Corrigan et al., 2020, 2021, 2023a,b). For example, following publication of wave one research findings, Colchester City Council (formerly Colchester Borough Council) began to develop a new strategy for communities in collaboration with voluntary and community groups, as well as statutory providers of services, under a new unified multi-agency umbrella group (ONE Colchester). They now work in partnership on significant issues affecting local communities, aiming to develop solutions that will lead to more resilient communities and secure lasting improvements to local life for future generations. It was reported at the time by the Chair of the Alliance that the findings would continue shape priorities in the future (Bryson, 2020). Moreover, the research findings from wave two and three (during and after the pandemic), contributed toward the growing understanding of the complexity of the health landscape and the multiplicity of actors who are able to promote health, beyond the traditional structures of public sector organizations in England. Presentations to different departments were given to both local government areas throughout the 3-year period of the research and the value of these assets as entities that support wellbeing was appreciated by those in attendance. Reporting back to the commissioners also led to additional funding allocation to support the on-going activities of some groups by the local government, as well as additional support and funding to Teen Talk by a local mental health charity. A workshop, jointly organized by the research team and members of North East Essex Health & Wellbeing Alliance, was held on completion of all three waves of research. More than 40 delegates from the local government offices, charities, community groups including some of the participating community assets attended to discuss the research findings and actions being taken to support communities. Workshop sessions included discussions on social prescribing activities within the region as well as funding and training support provision for community assets.

4 Discussion

The research undertaken undoubtedly illustrates the important positive role community assets play in supporting the wellbeing of members and those communities that assets support. Given that participants were vulnerable in terms of age, health, disability, ethnicity, or economic demographic circumstances, the support received by some individuals was life changing. Indeed, many described the community asset as a lifeline, and some went as far as to report that without it they would not be alive. Some participants reported that their experience of the support they received from the assets was in stark contrast to support (or lack of support) often experienced when they sought support from statutory services. Nevertheless, our final wave of research found that post-pandemic challenges and a cost-of-living crisis meant that many assets were under considerable strain. Ongoing UK Government spending cuts for public services following the pandemic and high rates of inflation and associated rises in the cost of living have left very many vulnerable populations more exposed. Some of the asset leaders we studied were experiencing a great increase in demand for their support. For example, the leader of the school uniform asset reported that the demand for free school uniforms had risen dramatically and that that there was a new demographic of working parents in non-deprived areas seeking support. Other assets previously mentioned such as the MS group and Teen Talk had been unable to resume full services since the pandemic. Also, the Dementia Café said that they were unable to support as many people as they had previously due to new policies on number of attendees since the pandemic. Some participants living in Tendring reported that public transport was reduced making them feel more isolated than before the pandemic.

4.1 Research and policy implications

Nevertheless, that this research was commissioned by the newly formed ICS organization, and the enthusiastic response by commissioners and local health and wellbeing staff who acted upon the studies' recommendations must be acknowledged. This research was part of these local government areas overall ABCD endeavors to support and listen to community voices and experiences. There is some indication therefore of a shift to a more complex, non-linear, collaborative approach to health and wellbeing indicative of complexity theory. The research reported here and elsewhere by Corrigan et al. (2020, 2021, 2023a,b) has highlighted the value of engaging community assets as partners in the co-production of local resources, and their value in contributing toward a therapeutic landscape that is part of a complex system that seeks to promote health and social inclusion.

This research represents a shift away from more positivistic approaches to population health that focus predominantly on epidemiological data and health interventions targeted at populations based on their behaviors, to one that recognizes social determinants of health and wellbeing and foregrounds narrative accounts based on people's lived experiences. We suggest that it can be considered an example of complexity theory insofar as it is a more complex approach that goes beyond the characteristics of the individual case and focuses on health as something which emerges from social environments (Byrne, 2002). We would recommend that further research be carried out to explore in more depth the relationship between community assets and complexity theory given the limited and tentative nature of this research.

While we welcome this more holistic approach, the current cuts in local government and healthcare systems that have followed a decade of austerity measures in the UK is undermining statutory services including funding to support ABCD. A recent report by the Institute for Government (2023) state cuts in public services are having a devastating impact with a record number of local government authorities going bankrupt and new NHS ICSs struggling to balance their budgets. Moreover, at a time when the public sector is subjected to deep fiscal cuts and reforms (Beatty and Fothergill, 2016; Carroll et al., 2021) community assets are at risk of being considered to be able to "fill the gap" in health and social care, despite often facing challenges in accessing funding and support themselves. Nonetheless, as Turnbull (2023) suggests, in this time of recession, community assets have the potential to be generative spaces that foreground "*everyday acts of care*", where individuals and groups can "*share their experiences of navigating welfare bureaucracies*" and importantly, find friendship, companionship and a co-produced understanding of "living in place" in the wake of austerity.

Data availability statement

The datasets presented in this article are not readily available because while the data is anonymous in its raw form it may be possible to identify individuals based on details revealed from the interview transcripts and we need to ensure anonymity to protect confidentiality as agreed with participants. Requests to access the datasets should be directed to oonagh.corrigan@aru.ac.uk.

Ethics statement

The studies involving humans were approved by Faculty (of Health, Education, Medicine, & Social Care) Research Ethics Panel, Anglia Ruskin University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

OC: Conceptualization, Formal analysis, Funding acquisition, Investigation, Writing – original draft, Writing – review & editing. SDa: Writing – review & editing. SDo: Writing – review & editing. PL: Conceptualization, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Using the knife to build the trust? The role of trust in the decision-making process of aesthetic surgeons and women patients/clients

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Trust is a fundamental element in decision-making processes. In medicine, trust also helps to build relationships between patients/clients and doctors (aesthetic surgeons) and will influence a woman's decision to undergo aesthetic/cosmetic surgery. Patients/clients, as well as aesthetic surgeons, use different ways to build trust. Our analyses are based on fifteen qualitative interviews with aesthetic surgeons, fifteen qualitative interviews with women who have undergone or are planning to undergo aesthetic surgery procedure(s) and non-participatory observations at the clinic of aesthetic surgery in the Czech Republic. Based on our analysis, three levels of trust were identified: macro level: trust in medicine as a social institution; meso level: *a priori* trust to the aesthetic surgeon; and micro level: trust in aesthetic surgeon and/or other medical staff in the process of medical aesthetic encounters. These results call for further studies outside of primary care and a deeper understanding of how these 'voluntary' medical specialties work and influence patients/clients and their 'treatment'.

KEYWORDS

aesthetic surgery, cosmetic surgery, medical encounter, aesthetic encounter, gender, trust, decision-making, Czech Republic

Introduction

Trust is "*confidence in the reliability of a person or system, regarding a given set of outcomes or events, where that confidence expresses a faith in the probity or love of another, or in the correctness of abstract principles*" (Giddens, 1991, p. 34). Trust is a fundamental element in people's decision-making processes. In general, people tend to trust people they know more than abstract systems (Meyer et al., 2008), which have been studied in sociology for several decades (Giddens, 1991; Luhmann, 1979). In contemporary society, a certain level of trust in medicine, technologies, and sciences is necessary for people and populations to access the healthcare they need for their health (Solomon, 2021), even though they are not familiar with these systems and do not know precisely how they work.

Especially in medicine, trust is a source of sustainable relations between patients/clients[1] and doctors (aesthetic surgeons). It influences a woman's decision to undergo treatment that,

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[1] We have used both terms throughout the text because our participants used them interchangeably, which is also reflected in the research literature that we discuss later in the article.

in the context of this article, is an aesthetic/cosmetic surgery procedure(s). Aesthetic (or cosmetic)[1] surgery is "*surgical procedures that alter, change or modify the surface, function, and appearance of the body purely for aesthetic purposes*" (Cook and Dwyer, 2017, p. 893). Existing sociological research on aesthetic/cosmetic surgery primarily focuses on women's motivations that influence them to undergo aesthetic/cosmetic surgery procedures (Derakhshan et al., 2022), litigations (Macgregor, 1984), the reshaping/reconstructing of race/ethnicity, gender, and age (Arian et al., 2023; Menon, 2016), and how social media and other cultural factors can influence why women pursue aesthetic/cosmetic surgery (Arab et al., 2019; Furnham and Levitas, 2012). Collectively, this research has suggested that there exist social norms in which women's bodies need to be altered to become "acceptable," including aligning to what is considered to be "beautiful" and "normal."

Historically, in sociological and feminist research, there have been two perspectives regarding women's uptake of aesthetic/cosmetic surgery, as comprehensively examined by Cook and Dwyer (2017). One perspective suggests that aesthetic/cosmetic surgery is a form of gendered oppression that involves patriarchal control over women and women's bodies. In reflection of Western society's unrealistic and ideal feminine beauty norms, aesthetic/cosmetic surgery is a means to correct physical "defects" that deviate from these ideals of beauty and youth. In this process, women are victims of structural patriarchal control and manipulation. The other perspective, which Cook and Dwyer (2009) label as post-feminist arguments, suggests that women are aware of these beauty standards but are not tricked by them. Rather, aesthetic/cosmetic surgery can allow women to assert agency, control their bodies, and experience liberation. This is not to achieve the dominant feminine ideal but rather to look "normal" (Cook and Dwyer, 2017). As such, by aligning with social norms and expectations, women can achieve improved self-esteem, self-confidence, and self-perception (Al Ghadeer et al., 2021; Kazeminia et al., 2023). Of note for our research, these outcomes or possibilities are not achievable without trust being developed across the different levels including before and during the aesthetic encounter.

Despite the wealth of existing social and feminist research on women and aesthetic/cosmetic surgery, there is a lack of sociological problematization of what happens between women (potential clients/patients) and aesthetic surgeons during the consultation process at the clinic of aesthetic/cosmetic surgery. In this article, we focus on how trust is created between aesthetic surgeons and women patients/clients and the role of trust in decision-making processes that lead to undergoing aesthetic surgery procedure(s). During the medical encounter, women may seek to develop feelings of trust with medical professionals that can influence their decision to proceed—or not—with aesthetic/cosmetic surgery. While trust is commonly acknowledged as necessary in professional interactions, it is nonetheless a complex process that needs to involve two or more parties. This article explores the important individual factors and strategies for trust-building and the role of trust in decision-making between potential patients/clients, aesthetic surgeons, and/or medical system.

Background

Decision-making is about choosing. By repeatedly making choices, social reality is continuously constructed. Sociological research on decision-making focuses mainly on how social structures and institutions construct, constrain, and control individual choices. According to Tallman and Gray (1990), individual decision-making processes or choices are constructed, constrained, and controlled through socialization and other historical, structural, and cultural forces. This includes considering the influential role of ideology, belief systems, wealth distribution, and technological change and progress (Sofo et al., 2013).

Decision-making processes also require developing and maintaining trust (Güroğlu et al., 2009). According to Simmel (1950), trust is conceptualized as enabling social action in decision-making situations where the actor is not entirely sure about the course of future events. Therefore, the primary function of trust is to facilitate negotiation between individuals (Luhmann, 1979). According to Giddens (1991: pp. 38–39), trust is essential to ontological security. It denotes an optimism that things will generally turn out "okay" in the end, as well as to create a sense of confidence in the world or what he refers to as the "existential anchoring of reality." For example, he suggests that positive relationships early in life with caregivers produce basic trust in individuals, developing a sense of dependability in others and one's surroundings. Significantly, trust is not only established between two persons but is also a link between the individual and wider social systems, including social institutions (Giddens, 1991).

In the social sciences, there is often an attempt to distinguish between intrapersonal (or facework) trust, which may characterize a specific doctor-patient relationship, and general (or faceless trust—institutional, social, or systemic trust)—which refers to attitudes toward social organizations (Hall et al., 2002; Luhmann, 1979). In this latter form of trust, which can be seen as nonpersonal, it is possible to further distinguish between a known institution, such as a specific medical clinic, and trust in the broader social or professional system (Hall et al., 2002), which can encompass medical knowledge. Social theorists have long argued that trust diffused within broader social and occupational systems is essential for the functioning of modern societies (Fukuyama, 1995; Luhmann, 1979). The stronger the trust at the systemic level, the easier it is for individuals to form interpersonal relationships without comprehensive knowledge of individual and personal characteristics. This type of trust is significant in modern societies because people must have a certain level of trust in, for example, science and technology, even though they are not entirely familiar with these areas (Solomon, 2021).

The healthcare system is an important social institution where the development of trust is vital for individual and collective acceptance of its dominance over health and well-being. This includes accepting medical specialists as sources of medical authority and knowledge (Williams and Calnan, 1996). As such, trust is a key component of the relationship between physicians and patients.

There is an extensive history of research on doctor-patient relationships and communication in primary care [see, for example, Arber (2008); Flatt et al, 2013; Mattson and Roberts (2001)]. Scholars interested in the healthcare encounter have long recognized that medicine is communication-intensive (Thompson et al., 2003) and that physicians' conversational techniques have consequences that affect patients' satisfaction with care, their adherence to recommended treatments, health outcomes, and litigation risk (Brown et al., 2003; Stewart and Ryan, 2003). The decision to opt-in for services is based on the patient's expectations of interactions with the physician (Roter and Hall, 2006). Trust is crucial in the relationship between the service provider and the receiver (patient/client), serving an important function by creating intrinsic value in the medical relationship (McDonald and Heydenrych, 2022). Building interpersonal trust is considered crucial for achieving better therapeutic results, increasing patient happiness, and ensuring the patient's medical 'compliance' (Van Den Assem and Dulewicz, 2015). Patients place equal value on a clinician's interpersonal abilities, including building a trusting relationship with them, as they do on the clinician's technical expertise and knowledge (Hall et al., 2002). Physicians must be able to gain the trust of new potential patients who, previous to the medical encounter, may know nothing about the physician. This process depends on the patient's general perceptions and beliefs about the physician and the health care system in general (Axelrod and Goold, 2000; Parsons, 1951).

While there has been a sociological examination of the patient-doctor relationship and trust-building process, most studies have been done in primary or acute care systems, where deferral is made to doctors' decisions and their expertise (Chipidza et al., 2015). Some research has also examined specialized settings such as pediatric encounters (Stivers, 2002), oncology (Beach et al., 2005), and general physicians (also called local doctors or primary care doctors) (Boubshait et al., 2022). Patients depend on the doctor's knowledge, abilities, and goodwill in these cases. These cases have an inherent power imbalance between the patient and physician, and trust becomes essential to the treatment process. In this article, our concerns are not about how trust is developed in the medical approach to and treatment of serious or life-threatening illnesses but how trust is developed during aesthetic/cosmetic surgery decision-making, something in which treatment is not necessary or required. This development of trust outside of primary and acute care settings has been overlooked in sociological research. Yet the field of aesthetic/cosmetic surgery is different and unique because it encompasses both the medical field and an elective relationship that makes it possible to perform procedures on healthy (in contrast to unhealthy) individuals (McDonald and Heydenrych, 2022). Furthermore, little sociological attention has been paid to what occurs between clients/patients and aesthetic surgeons during their encounters. This has occurred despite the blurred borders of power and roles (client vs. patient, doctor vs. helper vs. businessperson, etc.) that exist in these encounters (Honelova, Vidovićova; in review). These gaps are addressed in our article.

Despite the aesthetic surgeon's prominent role in the decision to undergo aesthetic/cosmetic surgery, this specialty is more than other medical disciplines marked by commercialization, with the paying client-provider relationship disrupting the decision-making asymmetry between patient and doctor. Potential patients/clients come to the clinic as healthy individuals with specific demands and expectations about the surgery that they are proposing (for example, breast augmentation). On the one hand, some aesthetic surgeons use the legitimacy of sovereign medicine (Novotný and Svobodová, 2014), which supports their expertise and work. On the other hand, women-clients/patients may come to the clinic with knowledge of the body modification or intervention that they desire and expect (or demand) a specific service from the aesthetic surgeon. That is, women have certain expectations from the service (aesthetic procedure) they choose (Mirivel, 2007) and assume that the aesthetic surgeon will meet their expectations both in terms of the "technique" of the procedure and the aesthetic outcome. This is because aesthetic/cosmetic surgery is done purely for aesthetic reasons that are not medically necessary and are based primarily on (individual) aesthetic concerns (Griffiths and Mullock, 2018). This contrasts with the traditional diagnostic approach of medicine when physicians diagnose patients with a disease or illness and subsequently lead and prescribe a treatment for patients who may have life-threatening conditions.

There is limited research on the role of aesthetic surgeons in patient/client decision-making and trust-building processes. Existing studies emphasize that aesthetic surgeons use both a personal, subtly erotic approach (for example, Spitzak, 1988) and technical means, such as before and after photographs or visualization (Blum, 2003), to induce hesitant patients/clients on the expertise of the provider. This advertising of the aesthetic surgeon's work and skills is done to assure the patient/client of their skills and to undergo the procedure. Expertise based on previous work and friendly/erotic communication aims to evoke certainty in women and create trust in the aesthetic surgeon. Patients/clients are asked to present their problems or treatment plans/preferences in consultation with an aesthetic surgeon who then evaluates the individual's requests and whether they are 'reasonable' (Hostiuc et al., 2022). The patient's/client's preferences are a significant determinant of the treatment chosen. Generally, aesthetic surgeons and patients/clients have the same goal, but each side approaches the "problem" from a different angle and perspective. However, how aesthetic surgeons conceptualize, manage, and negotiate their power as medical experts when interacting with their potential patients/clients remains unexamined.

Methods

The data presented in this article represent a subset of a more extensive project titled Anti-ageing aesthetic surgery as a social construction of (non-) ageing and old age of women: The Phenomena of aesthetic surgery in the Czechia. The main aim of the project is perception of beauty and ageing toward cosmetic/aesthetic surgery and the journey leading to the cosmetic/aesthetic surgery.

In the first phase of the project, the entry criteria for participants were middle-aged women (aged 30–55 years) who are Czech nationals and have undergone or are planning to undergo anti-aging aesthetic/cosmetic surgery procedures. Study participants were recruited through posts on social platforms as well as the snowball method, which involved spreading word-of-mouth about the project. In all cases, potential participants were provided with full information about the project before they consented to participate. This process resulted in recruiting fifteen women (Table 1), with whom in-depth semi-structured interviews were conducted by Author 1 between December 2022 to May 2023. All interviews were conducted in locations according to the participant's preferences to ensure a safe and comfortable place, mainly cafes or the participants' homes.

In the second phase, Author 1 conducted eighteen in-depth interviews with individuals working in aesthetic/cosmetic surgery clinics (Table 2). This included aesthetic surgeons, an operating nurse (one interview), and managers of aesthetic/cosmetic surgery clinics (two interviews). These interviews were guided by an interview guide and took place between May to December 2023. The criteria for research participation in the second phase included working in an anti-aging aesthetic/cosmetic surgery and the place of practice, which was

TABLE 1 Information about aesthetic surgeons.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Name	Kate	Lena	Barbara	Victor	Igor	Adam	Marcel	George	Adele	Pavel	Samuel	David	Susan	Michelle	Charles	Marika	Jane	Sylvia
Age	39	59	53	44	46	44	79	46	47	66	57	64	49	64	44	47	32	32
Type of practice	Owner	Employee	Owner	Owner	Head of the clinic	Owner	Owner	Head of the clinic	Owner	Head of the clinic	Owner	Owner	Owner	Head of the clinic	Head of the clinic	Surgery nurse	Manager of clinic	Manager of clinic

TABLE 2 Information about female participants.

Pseudonym	Victoria	Valery	Emily	Michelle	Olivia	Jane	Caroline	Lucy	Rosarie	Casandra	Ariel	Rebeca	Stella	Samantha	Erica
Age	40	43	33	52	39	32	49	42	38	31	35	55	36	42	31
Education	University (Master)	University (Master)	University (PhD)	University (Bachelor)	High school	High school	High school	High school	High school	University (Bachelor)	High school	High school	University (Master)	High school	University (Master)
Marital status	Married	Married	Single	Divorced	Partner	Married	Divorced	Single	Married	Single	Partner	Married	Partner	Married	Engaged
Children	2	0	0	1	1	0	2	1	0	0	0	2	0	1	0
Job	Project manager	CEO	University teacher	Policewoman	Assitant of ceo	Nanny	Director in kindergarten	Real estate	Businesswoman	Accounter	Logistic	Nanny	Administrative poistioon	CEO	People manager

restricted to the three largest cities in the Czech Republic (Brno, Prague, and Ostrava) where most aesthetic/cosmetic surgery clinics are located (McLaren and Kuh, 2004). We identified potential study participants via their practice website, from which we gathered data on location and the procedures offered to ensure the clinic met the study criteria. From this, we sent an informational email to 98 potential participants meeting the study criteria, in which we described the purpose of the research and opportunities for participation.

In both two phases of the project, the interview questions focused on the patient/client encounters, including communication, negotiation, expectation(s), trust, and the decision-making processes. As Author 1 moved through the interviewing process, they frequently adapted the interview guide to reflect new lines of inquiry. As part of this process, Author 1 acknowledged the sensitivity of this topic by modifying the interview structure to reflect the participants' specific contexts and their responses to the interview questions. Interviews lasted between 60 and 90 min. All interviews (except three with aesthetic surgeons) were recorded and transcribed with the participants' informed consent. Three interviews that were not recorded were annotated by Author 1 during the interview, with these notes subsequently clarified and modified by the aesthetic surgeon participants.

In the third phase, interviews were also supplemented by non-participatory observations. This involved Author 1 spending time with women participants (the same as those who were interviewed) during different activities. One of the activities was attending appointments with aesthetic surgeons. In total, six visits between four participants and their aesthetic surgeons were attended by Author 1, with each appointment lasting between 15 and 30 min. Author 1 was introduced to the aesthetic surgeon as an accompaniment and researcher. During these appointments, observation notes were taken on selected elements of the medical (aesthetic) encounter, such as the communication process between the participant and the aesthetic surgeon, communication techniques (words used) by the aesthetic surgeon, the participant's reactions and behavior during the medical (aesthetic) encounter, and Author 1's discussion with participants about the consultation immediately after the encounter. These notes helped to provide a deeper understanding of the medical encounter, how women make decisions and act in different situations, and what meanings the women attach to particular actions and choices.

In the fourth phase, Author 1 also volunteered at one aesthetic surgery clinic. During this time, Author 1 helped at reception and attended six medical aesthetic encounters of between 15 to 30 min with random potential patients/clients. All employees, as well as patients/clients, were informed about the research position of Author 1, and everyone involved gave informed consent about Author 1's presence during the encounter. During these appointments, Author 1 made observation notes on the same topics noted in the previous paragraph.

We acknowledge that Author 1's presence in both cases could influence the natural process of medical aesthetic encounters and the behavior of aesthetic surgeons and patients/clients. We reflect on this potential bias in our analysis. This article draws on interview and (non)participatory observation data. When presenting the data, we clarify whether this is interview or observation data (Fieldnote).

All interviews were recorded and then transcribed verbatim with the participant's consent. All interviews were anonymized, and pseudonyms were based on random calendar names. The interview transcripts and observation notes were uploaded to Atlas.ti for coding, and the transcripts were analyzed by the author team. We followed the principles of thematic analysis (Braun and Clarke, 2006; Ezzy, 2002) to identify key features and rhetorical tools participants employed to describe their decision-making and trust-building. Our analysis mainly focused on the part of the interviews when the participants were asked how they associate and describe trust and the decision-making process. Authors focused on entire narratives/stories contexts to capture and map different personal conceptions of how women and aesthetic surgeons understand and perceive the decision-making process and building trust and what those concepts mean to them. Detailed field notes ensured that the depth of context can persist with the data to allowed us to conduct robust research in line with qualitative approaches (Phillippi and Lauderdale, 2018).

The research received ethics approval from the Committee for Ethical Research of the Charles University.

Findings

Through our study, we found that, in general, women's decision-making and trust-building were developed in, shaped by, and revisited across a series of medical (clinical consultations) and non-medical encounters (friends, family relatives) as well as studying the available information (non-medical expertise). The decision-making of aesthetic surgeons was generally based on consultation with the (potential) patient/client, such as assessing the woman's needs and the subsequent decision on whether and to what extent the cosmetic procedure was needed. The decision-making processes from both sides are based on 'relational autonomy,' where decision-making occurs in a co-production of interested dependence and within encounters with other people.

Based on our analysis, we developed three levels of trust building that influenced women's and aesthetic surgeon's decision-making processes on receiving or providing aesthetic/cosmetic surgery: (1) macro level: trust in medicine as a social institution and the specific aesthetic surgery clinic; (2) meso level: trust in other medical staff and aesthetic surgeon developed prior the medical aesthetic encounter; and (3) micro level: trust in a specific aesthetic surgeon and other medical staff, built while visiting the aesthetic surgery clinic. Categories can be linked, but we use them as an analytical tool.

Macro level: trust in medicine

At the most general level, women had trust in medicine as a social institution. Women believed that the Czechia medical system worked well and that they could trust it. This trust emerged from understanding medical information communicated by their doctor/s and their previous interactions with other physicians. In their interviews, many women stated that they would not have aesthetic/cosmetic surgery anywhere abroad because they have less confidence in that medical system compared to the Czechia one, which they believe has higher quality standards, including the expertise of physicians:

> "[I] *certainly have more confidence in Czech medicine and medical system.*" (Mrs. Rosarie, age 38).

In this case, participants shared their experience living abroad and with other medical systems. They were able to compare two medical systems, believing that the Czech medical system is of higher quality and that Czechia is more trustworthy for her than the other countries. In familiarity, past experiences are condensed, and their continuity is assumed, allowing for future-oriented trust. Their past positive experiences with the Czech medical system allow participants to believe that the Czech medical system is trustworthy, which influences their expectations of future experiences. In other words, individuals tend to trust things they are familiar with.

Some women also articulated this general trust as a trust in a specific aesthetic/cosmetic surgery clinic as a representant of the medical social institution:

> "*So, I went there because I actually had confidence in the institution. And… I've never actually heard anything bad about* [the clinic]." (Mrs. Samantha, age 42).

This general trust was based on the clinic's generally positive feedback, including word-of-mouth, name, brand, and reputation, as shaped by the history, surgical outcomes, and feedback on the clinic in the (online) media. In addition, some women believed that if the prices of the procedures were high, it was a guarantee of quality they could trust:

> *"I'm still of the mindset that higher price equals higher quality, so I would probably look for clinics where the price is maybe, like exorbitant. And I would feel like I could find that quality."* (Miss Casandra, age 31).

Conversely, women with higher socio-economic status tended to opt for smaller "no-name" clinics that offered greater intimacy and privacy. For them, these aspects created a sense of trust because undergoing aesthetic/aesthetic surgery was a personal and intimate experience for them:

> *"I'm not really a believer… I do not believe in marketing. So when it's the most well-known ones* [aesthetic surgery clinic] *that you see everywhere, and it does not seem they know each other here* [aesthetic surgeons], *and you learn a lot* [gossip about other clients/patients and aesthetic surgeons]. *So, I try to stay away from those* [aesthetic surgery clinics]" (Mrs. Victoria, age 40).

Participants noted that gossip about clients/patients is an abuse of trust, and the need to rely on confidentiality with the aesthetic surgeon and/or aesthetic surgery clinic. Participants were convinced that almost everyone knew each other in these medical circles and a visit to a reputable, well-known aesthetic/cosmetic surgery clinic could be akin to a visit to, as noted by Mrs. Rebecca (age 55), "*a live television broadcast where women would publicly admit their body modification*." In other words, gossip is often present in these clinics and among their patients/clients.

Because women such as Mrs. Victoria try to keep their visits to aesthetic/cosmetic surgery clinics secret, avoiding large aesthetic surgery clinics was vital to preserve her privacy. These concerns expanded beyond the clinic itself and included considering the clinic location and car parking availability:

> "*I still choose* [the aesthetic surgery clinic] *based on parking - it's an important thing. Because you do not want to be seen ….*" (Mrs. Victoria, age 40).

In this case, the general trust in medicine or specific aesthetic surgery clinics emerges from the confidentiality they can offer. This confidentiality is not only a perception of the patient/client but a marketing tool of the clinics, where some clinics advertise on their websites discretion in the clinic location and car parking as a guarantee of trust or "why" women should choose them.

Aesthetic surgeons also emphasized the importance of creating trust with potential clients/patients through their medical knowledge and experience, as well as staff professionalism across their entire aesthetic/cosmetic surgery clinic. Aesthetic surgeons believed they should present their expertise and skills through their work (for example, photographs of before and after aesthetic/cosmetic surgery). According to some aesthetic surgeons, examples of their work, including positive post-surgery outcomes, can create a trusting environment for potential patients/clients and can encourage women undergoing aesthetic/cosmetic surgery and support these women in deciding that their clinic is a good decision as well as undergoing cosmetic/aesthetic surgery in general.

Meso level: *a priori* trust in the aesthetic surgeon

This category represents how trust is developed in aesthetic surgeons and other medical staff prior to the medical encounter. In these cases, the decision-making process was based on and influenced by pre-encounter trust. For example, some women trust aesthetic surgeons because they are doctors. Therefore, their medical qualifications, recognition as qualified doctors, and acceptance to practice in the Czech medical system allowed women to develop trust prior to the medical aesthetic encounter.

> "*So, I'm like… I'm probably - maybe naive, but just like the doctor, I a priori trusted him.! ……And so, I went in, I'd already sort of decided, and I chose him with the confidence that he was the best then; everyone says so, so he must be, and also, the clinic had a great reputation.*" (Mrs. Rebecca, age 55).

For Mrs. Rosarie and other participants similar to her, the expert power and knowledge of the aesthetic surgeon were unquestionable. In this way, their qualifications and acceptance as medical professionals translated into trusting their professionalism and the surgical outcomes that they could achieve. Trust in the aesthetic surgeon was therefore reinforced by trust in the institution; for patients/clients such as Mrs. Rosarie, trust is not built through the patient/client's interactions with the individual surgeon or the clinic. Rather, trust in the aesthetic surgeon is built through networks and/or on the general perception of the medical system and is supported by positive feedback gathered through social media and other medical environments or encounters.

Also, even though aesthetic/cosmetic surgery procedures are an elective medical service that women pay for, women may believe aesthetic surgeons to be prestigious people who are very busy and capable and should be afforded respect and esteem. This means that women may question their uncertainty and information-seeking and believe they should defer to medical expertise rather than raise "what if" questions. This perception reinforces and perpetuates the medical expertise and privilege of the aesthetic surgeons over women's choices on their bodies.

Some women noted how the presence and interaction of the aesthetic surgeon with other medical team members (for example, nurses and general staff) and the functioning of the clinic in general also played a role in fostering trust.

> "*So I went to the clinic, and when I was admitted there, one of the nurses and I started talking. She told me that if she had a choice, she would also go to Dr.* [the name of the aesthetic surgeon]. *And I would say that was the clincher for me. I had no argument when the nurse there knew all these doctors and told you this.*" (Mrs. Victoria, age 40).

In this case, participants developed trust in the aesthetic surgeon and the clinic based on a friendly interaction with one of the nursing staff. This allowed her to develop trust in the staff employed in this aesthetic/cosmetic surgery clinic, which also reflects their trust in the medical institution more broadly.

This importance of staff in developing trust in potential clients/patients and in recruiting the right staff who reflect the values of the clinic was noted by aesthetic surgeons:

> "*Anyway, it's all about the staff. If you do not have good people with a heart for the job, thinking about it, you probably cannot do anything with the best laser in the world. So, I would say that the most important thing is the human factor.*" (Dr. Adele, F, aesthetic surgeon, age 47).

Aesthetic surgeons are aware that women go to the clinic to spend money, so the whole experience has to be to the potential client/patient's satisfaction and turn, impact their potential client/patient's trust-building in the clinic and staff. This was described by the manager of the aesthetic surgery clinic, Jane, who noted, as part of the trust-building process *"aesthetic clinics must differentiate themselves in appearance from medical clinics"* (Miss Jane, F, the aesthetic surgery clinic manager, age 33). This perception of aesthetic clinics is based on the participant's belief, that how a space looks and feels must encourage potential patients/clients to spend money and, therefore, must be similar to non-medical consumer spaces such as beauty salons:

> "*Aesthetic surgery clinics try to make the space not look completely medical, but more… like more spa… It's luxurious just* [the space of an aesthetic surgery clinic], *so it's just, it feels like, a place where I understand I'm going to spend money.*" (Miss Jane, F, the aesthetic surgery clinic manager, age 33).

On the other hand, other participants preferred strictly medical visage of the clinics and believed, the trustfulness is based on medical authority which was represented by the space and dress codes of the (non-)medical staff.

Micro level: trust in the aesthetic surgeon and other medical staff

This category represents how trust is built between the potential patient/client and the aesthetic surgeon during the aesthetic encounter. At this level, aesthetic surgeons play an active role through their actions, behavior, and work that (inevitably) influence women's decisions and trust formation. For aesthetic surgery to occur, the aesthetic surgeon must gain the trust of potential patients/clients who know nothing or very little about them (beyond the information on the websites of the clinics, internet or concretely on the social media). In aesthetic surgeons' words, "*trust comes first*" (Dr. Igor, M, aesthetic surgeon, age 46).

For potential patients/clients, the communications from the aesthetic surgeon were described as practical in obtaining information, negotiating the terms of surgery, and establishing whether surgery was necessary. This type of interaction established their expertise and, through this, helped to generate feelings of trust:

> "*Medical perspective. I mean, it seemed to me that, like… I was like, well, this one probably understands it, so maybe she knows what she's doing*" (Miss. Erica, age 31).

The trust in the medical expertise of a specific aesthetic surgeon was strengthened when women had previous aesthetic surgery and were pleased by the results. This is similar to the macro-level of trust building, though here, this is about individual relationships rather than a relationship with an institution. This is represented by Mrs. Valery:

> "*Absolutely, because I am always satisfied with the result and know that he is really an expert in his field… If I could not trust him, I probably would not be able to be with him and put myself in his hands….*" (Mrs. Valery, age 43).

From the observations and interviews, it was prevalent that personal interaction with the aesthetic surgeon was a key component of women's trust-building. Some aesthetic surgeons used a "friendly" and sometimes slightly "erotic" approach to encourage open discussions during the aesthetic encounter:

> "The aesthetic surgeon explained the aesthetic/cosmetic surgery process in a friendly voice, still smiled at the participant, and asked if she understood everything. Also, he used the phrase, "*You are a beautiful woman. Are you sure you need the surgery*?" The participant seemed to be flattered and smiled, too." (Field notes, October 22nd, 2023).

This friendly or erotic approach was often complemented by a technical and expert approach through the use of medical jargon and terminology.

Some aesthetic surgeons also believe that trust-building can involve saying "*No*" to women's requests for specific forms or types of aesthetic/cosmetic surgery. This was explained by aesthetic surgeon Dr. David:

> "*You have to be able to say no. Those women will come back to you* [for another procedure] *when they understand that you meant well by them…of course, I have an economic incentive to get that person to have surgery from me. But…I'm far more economically incentivized to have happy patients. Which sometimes means not operating.*" (Dr. David, M, aesthetic surgeon, age 64).

In this case the aesthetic surgeon's ability to say "no" to surgical requests from women means they can trust that surgery will not be done at any cost and that they can invest their trust in his medical expertise to make the best decision. For Dr. David, refusing to perform specific aesthetic procedures is part of the trust-building process. It can result in women coming back with "other problems," demonstrating to Dr. David that they trust his decisions and points of view as medical experts.

Although trust in medical knowledge/expertise and aesthetic surgeons was an important point in women's decisions to undergo an aesthetic procedure, in some cases, the aesthetic surgeon's enforcement of their medical expertise translated to a perceived paternalistic approach that was „detrimental" to developing trust with their potential patient/client:

> "*I remember one* [aesthetic surgeon]. *Well, he was a very arrogant man. He hardly let me speak at all. He refuted everything I wanted and forced his procedures on me, which I did not want. He almost told me I should be quiet if I did not understand it and that he was the expert, yet he knew best how to do it. Well, I left the clinic quite horrified, wondering if this is how things are supposed to work normally, that I do not like this approach at all.*" (Mrs. Valery, age 43).

In cases such as Mrs. Valerie, women were unable to establish trust in the doctor and chose not to undergo the procedure with them.

Gender influenced this assessment, with the physical appearance of an aesthetic surgeon who was a man being less important than that of an aesthetic surgeon who was a woman. However, for some women, the appearance of aesthetic surgeons who are men were described as Hollywood stars:

> "*He* [aesthetic surgeon] *was so Hollywood. It's a good thing I had freshly washed my hair because otherwise, I would have felt completely… standing there like he was over me. So, it was almost… how do I say …. intimidating.*" (Mrs. Rosarie, age 38).

In this encounter, participants are not only evaluating the appearance of the surgeon, but they are also evaluating their own appearance in relation to him. Therefore, the "intimidating" performance of the aesthetic surgeon helped to reinforce their own feelings that they needed aesthetic surgery. At the same time, the charm of aesthetic surgeons was a factor in developing trust.

The appearance of an aesthetic surgeon who is a woman played a more significant role for some women in their decision-making process and trust-building, as opposed to how aesthetic surgeons who are men were discussed.

> *"My doctor, she actually looks like what I would imagine. So, actually, that's where the trust is. For me now, it's even higher thanks to this… Plus, she has the same personality as me when we talk. "*(Mrs. Stella, age 36).

In this case, the visage of the aesthetic surgeon guided trust-building and was reinforced by the personality of the aesthetic surgeon. Some women preferred it if the aesthetic surgeons had the same sense of humor, interests, and values. Notably, the appearance of women aesthetic surgeons is no guide to their medical knowledge or expertise, nor their skill in surgical procedures, but nevertheless played a role in trust-building.

During their interviews, women extensively explored their feelings and emotions toward aesthetic surgeons and the environment of the clinic in general (layout and modern look). Participants trusted aesthetic surgeons whom they felt they could connect with, including experiencing understanding, sympathy, and empathy from the aesthetic surgeon. Some participants also reported qualities such as kindness, friendliness, commitment to quality, being listened to, not being rushed, concern for the patient/client, and support contributed to trust:

> "*Just that humanity and a very positive attitude. When I came for the consultation, the doctor smiled, asking me what was bothering me and how I would like to solve it. He then informed me what he could do, how he could do it, what it would entail, and how it could specifically work for me*" (Mrs. Valery, age 43).

Women also considered the importance of establishing trust through aesthetic surgeons' understanding of what they require and meeting their demands from the procedure.

> "*… They* [aesthetic surgeons] *should probably take their time with me. I should not feel I'm under pressure. It's just a treadmill, that's for sure. They should be able to answer all my questions and try to come out of the woodwork.*" (Mrs. Lucy, age 43).

Aesthetic surgeons also considered the importance of an emotional 'bond' with a potential patient/client and believed it is essential to trust building:

> *"Um, I guess it's hard to explain in words. It's more of an in-between, more of an in-between on some sort of emotional side, I guess, where some vibes, some really like emotions. And that's like, in the 17 years I've been doing aesthetics, I've already got that like in me. Like somehow cultivated."* (Dr. Susan, F, aesthetic surgeon, age 44).

Although Dr. Susan speaks of the emotional side and feelings, the statement also evokes expertise created through experience and practice in the field. In other words, aesthetic surgeons 'exactly *know what women want/expect/need*' (Dr. Susan, aesthetic surgeon, age 44). Nevertheless, aesthetic surgeons link the emotional or psychological aspects with their medical expertise, and this creates an intimate and comfortable environment for their patients/clients:

> "*The psychological side is very important. It's about trusting the surgeon, knowing whether she/he is an expert or not, what kind of practice she/he has, what the environment of the surgery is like.*" (Dr. Lena, F, aesthetic surgeon, age 59).

Limitations of the study

We are aware that our study also has some limitations. The study is limited by its small sample size and sampling techniques. All our participants were from the three largest cities in the Czech Republic.

An exclusively urban sample of communication partners could produce a specific bias regarding over-representing selected (socio-economic) characteristics. In our sample, most women were from the middle and higher social classes. On the other, the limitations could also be counteracted. The study focuses only on women because it is still an important issue, as women are primary consumers of cosmetic/aesthetic surgery clinics. Also, participants were primarily from middle and higher social classes as most of consumers as cosmetic/aesthetic surgery is not accessible or affordable for all as the procedures are not cheap.

In the future, this raises a question about whether and how the socio-economic status of women influences their trust and questioning of medical authority. In some cases, we found different strategies for choosing aesthetic surgeons, and the trust-building process of women were based on their socio-economic status. Some higher-class women choose smaller clinics offering a more secure and trustful environment. Therefore, it will be important to analyze the data further to determine the impact of socio-economic status on women's trust-building and decision-making process.

Discussion

In general, aesthetic surgeons work with their patients/clients to shape the profile of an 'appropriate,' 'acceptable,' or 'normal' feminine body, defined by socially acceptable ideals of gendered body image (Parker, 2009). While aesthetic surgeons seek to assert their professional status and expertise during the consultation(s), the patient/client expects a service they are willing to pay for (or have paid for). This complex and negotiated process creates a bond between the aesthetic surgeon, the medical staff, and the client/patient.

Most participants trusted in Czech medical system on the general level. This trust can emerge from familiarity and familiarization as the familiarity is a precondition for trust (Luhmann, 1979). This can be connected also with familiar faces, which is from the psychological perspective, powerful tool in creating trust. We instinctively believe a face or voice we are familiar with; therefore, some aesthetic surgery clinics reach celebrities as representativeness of their brand.

Notably, developing trust was not just about the medical expertise of the aesthetic surgeons and their technical skills or the friendliness and communication between staff and potential clients/patients. Some women based their feelings of trust on the aesthetic surgeons' appearance, feelings, and emotions. However, our participants did not include or mention (dis)trust in technology and modern methods in aesthetic/cosmetic surgery. Some research was already interested in how modern technologies influence the client/patient's trust (McDermott et al., 2020). In this study, most female participants voiced worries about the perceived safety and use of modern surgical technology.

Although we have identified three types of trust in this article, these are not the only types of trust that can occur in the patient/client and the aesthetic surgeon relationship. The woman's trust in the cosmetic/aesthetic surgeon (does not) help to build her self-trust to stand up to society and its scrutiny and judgments. This can be seen in the participant's testimonies which talked about choosing a clinic of aesthetic surgery based on parking and/or location. The anonymity is seen as trust in the clinic, through which participants believe that they will not be disappointed in society's acceptance of her as she is trying to "*not be seen*" publicly. This may manifest the fear that women who visit clinics of aesthetic surgery may be judged or stigmatized by society. This claim can be supported by research by Bonell et al. (2021), which noted that women who are seeking cosmetic/aesthetic surgery procedures could be potentially subject to experience adverse psychosocial outcomes and unfavorably by society. Also, other variables can influence trust-building and then decision-making, such as the influence of three parts, especially if the woman's partner is present during the encounter. Sometimes, the partner/husband comes to the aesthetic clinics with the woman and 'dictates' to the aesthetic surgeon what to do with the woman's body and how he/she should do it. According to Morgan (1991), women undergoing cosmetic/aesthetic procedures are victims of beauty dictates manipulated by their partners and aesthetic surgeons. She called that a 'false consciousness' where women believe they are making a voluntary choice (free will) but are merely conforming to prevailing cultural (male) ideas about the female body. Therefore, future researchers can discuss between whose parties the trust is established - partner-cosmetic/aesthetic surgeon, cosmetic/aesthetic surgeon-woman, partner- cosmetic/aesthetic surgeon-woman.

Aesthetic/cosmetic surgery clinics are becoming new kinds of beauty salons, and a gradual domestication of medical procedures can be seen. As Cook and Dwyer (2017) claimed, Botox is already beyond normalization and has become domesticated as a routine in everyday life. Although the procedures our participants underwent are not performed as frequently as Botox injections, the number of invasive procedures is increasing, and the perception of aesthetic surgery clinics as a place of rest is increasingly causing the normalization and standardization of these procedures. According to our results and discussion, further analysis of aesthetic surgery is needed as aesthetic surgery brings both positive and negative changes to societies. This research examined only a group of women and aesthetic surgeons. Future research could thus explore whether trust in cosmetic/aesthetic surgery differs based on gender and whether and how trust-building and decision-making would differ for male cosmetic/aesthetic surgery patients/clients.

Data availability statement

The datasets presented in this article are not readily available because participants did not give consent to share data. Requests to access the datasets should be directed to michaelahonelova@seznam.cz.

Ethics statement

The studies involving humans were approved by the Ethic Committee, Charles University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MH: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Resources, Writing – original draft, Writing – review & editing. PC: Writing – original draft, Writing – review & editing. LV: Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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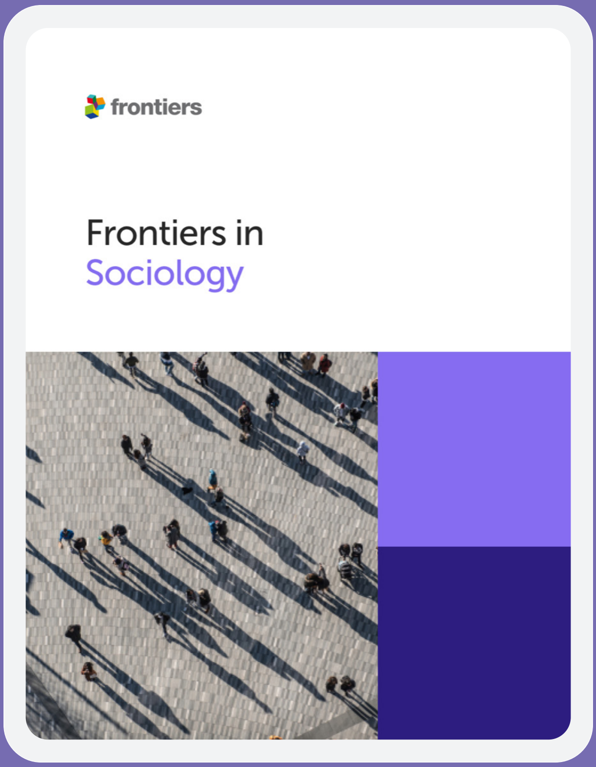

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