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Understanding the disconnect between lifestyle advice and patient engagement: a discourse analysis of how expert knowledge is constructed by patients with CHD

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ABSTRACT

Objective: Adherence to healthy lifestyle advice is effective in prevention of non-communicable diseases like coronary heart disease (CHD). Yet patient disengagement is the norm. We take a novel discursive approach to explore patients' negotiation of lifestyle advice and behaviour change.

Method: A discourse analysis was performed on 35 longitudinal interviews with 22 heterosexual British people in a long-term relationship, where one had a diagnosis of CHD. The analysis examined the relationships between patients' constructions of expert knowledge and the implications of these accounts for patients' dis/engagement with lifestyle advice.

Results: Expert knowledge was constructed in four ways: (1) Expert advice was valued, but adherence created new risks that undermined it; (2) expert knowledge was problematised as multiple, contradictory, and contested and therefore difficult to follow; (3) expert advice was problematised as too generalised to meet patients' specific needs; and (4) expert advice was understood as limited and only one form of valued knowledge.

Conclusion: Patients and partners simultaneously valued and problematised expert knowledge, drawing on elaborate lay epistemologies relating to their illness which produced complex patterns of (dis)engagement with expert lifestyle advice. Recognition of the multiple and fluid forms of knowledge mobilised by CHD patients could inform more effective interventions.

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Preventative medicine and health promotion focus strongly on advising lifestyle change for patients diagnosed with coronary heart disease (CHD), a leading cause of death globally. In response to population-level research indicating that certain lifestyle

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behaviours are associated with improved outcomes in primary and secondary cardiovascular diseases (Mentrup et al., 2020; WHO, 2023), this advice focuses on encouraging individuals to increase consumption of vegetables and fruit, reduce red meat consumption, participate in physical activity, weight management, quitting smoking, and adhere to secondary prevention medication (Ambrosetti et al., 2021)

From a critical perspective, we recognise that healthy lifestyle advice is considered universal, scientifically robust, and behaviour change as a matter of individual choice and agency (O'Hara & Taylor, 2018). Despite recommendations by the WHO in 1986 and 2024 to recognise the role of wider social factors, such as inequality and the lived environment, major policy and infrastructure changes are rarely implemented, leaving individuals' uptake of information and enactment of behaviour change as the main focus of health promotion and advice (Ambrosetti et al., 2021; Baum & Fisher, 2014; Kelly & Barker, 2016; Mentrup et al., 2020).

A major focus of interventions has therefore been upon patients' access to and engagement with expert information as central to making individual behaviour change. Adherence to lifestyle change remains low globally (Aggarwal et al., 2021; Kotseva et al., 2021; Marzà-Florensa et al., 2024) across varied medical systems, and 30 years of policy and interventions aimed at individual behaviour change to improve diet and exercise have not produced significant changes at a population level (Theis & White, 2021). With outcomes for CHD patients worsening in the UK (BHF, 2022), there is an urgent need to better understand the disconnect between health advice and patient engagement and how presentations of healthy behaviour as a series of simple and rational choices contradict lived experience and research evidence that change is difficult to achieve and sustain.

Areas of investigation for how to enhance people's engagement with expert healthy lifestyle advice currently include: (1) healthcare professionals' communication styles, including how to provide information in a way that it can be heard, remembered, and enacted (Soyoon & Ekaterina, 2022; WHO, 2003; Wilhelmsen & Eriksson, 2018); (2) shifting questions of compliance to those of adherence, which advocate collaborations between patients and healthcare professionals to work out how best to enact that knowledge in patients' lives (Kelly & Barker, 2016; Soyoon & Ekaterina, 2022); (3) how to understand and reduce barriers to individuals' engagement with, and acting upon health information such as enhancing self-efficacy by simplifying the information and presenting it as easy, doable and a rational choice (Hagger et al., 2017; Leventhal et al., 2011); and, to a lesser extent, (4) how to shape wider structural and environmental elements shaping consumption.

Combined, these areas of investigation represent questions around the transmission of information and medical knowledge, including how to give patients access to expert information, or how to enhance their ability to put it into practice by providing easy-to-follow guidance, such as eating red meat no more than twice a week. Failure to engage in lifestyle advice is often attributed to a lack of information or health literacy, or an inability to properly evaluate risk or exert appropriate self-control (Kelly & Barker, 2016). But these attributions do not satisfactorily explain the complexity of the disjunction between advice and action (Fitzpatrick et al., 2014; Frakes et al., 2021; WHO, 2003).

In the search for mechanisms to explain the disconnect between expert advice and patient engagement, we argue it is time to focus research attention on the nature

of expert knowledge itself as a factor in the complex ways in which health information may be taken up or resisted.

We draw on Foucauldian poststructuralist concepts of knowledge to provide a framework for understanding these complexities and their implications for health behaviours and identities. For Foucault (1980), knowledge is inseparable from power, because the ability to have one's knowledge accepted as valid, or privileged over another's, involves the enactment of power. For example, scientific and medical knowledge tends to be afforded greater legitimacy, which creates social disparities through more and less privileged knowledge systems such as expert and lay (Angermuller, 2018; Beetz & Schwab, 2018). As Foucault argued, patient perspectives often exemplify knowledge 'located low down on the hierarchy, beneath the required level of scientificity…unqualified, even directly disqualified knowledges' (Foucault, 1980, p.82).

Foucault's insight was that medical or scientific truths are not universal, objective, and stable, but rather historically and socio-culturally situated (Foucault, 1980). The outcome is that people negotiate shifting sets of understandings as they adopt, resist, or transform knowledge in their engagement with expert and lay discourses. Lifestyle advice thus has the potential to create 'diffuse, local, and reversible power relations' (Foucault, 1992, p.98) as well as preferred and dispreferred identities.

Foucault also saw knowledge as a creative, productive force, and this mix of the benign, the affirmative, and the oppressive can be seen in the promise of the benefits of a healthy lifestyle, and positive and negative affects when people achieve, or fail to achieve, health norms (Davies, 2013). This theoretical framework suggest that lifestyle advice inevitably generates complex power relations and that learning and change are non-linear, affective and embodied experiences rather than purely cognitive processes. These concepts afford a focus on expert advice as an object of study and our theoretical framework aligns with the small critical literature that we outline below.

One critique of healthy lifestyle advice is that it applies population-level evidence to individual patients. This can create a mismatch between robust population level research and individual outcomes, given that there is more variation in the latter (Braithwaite, 2018; Frakes et al., 2021). Further, even at the population level, lifestyle science is not uncontested, because like all scientific knowledge, it evolves over time and is 'heterogeneous, contextual, and fragmented' (Hansen & Easthope, 2007, *x*), seen in debates around the relationship between dietary fat and CHD, for example (Kromhout, 2015). Scientists acknowledge this fluid, uncertain, and changeable nature of evidence-based medicine (Timmermans & Angell, 2001), but the lifestyle advice transmitted through health promotion and given by healthcare practitioners usually simplifies this complex scientific knowledge with the aim of reducing perceived barriers to lifestyle change (Kelly & Barker, 2016; Sanabria, 2015).

While lifestyle advice tends to minimise the contested and fluid nature of evolving scientific knowledge (O'Hara & Taylor, 2018), a plethora of often contradictory media reports present a complex field of conflicting messages and/or flawed or compromised science. Such multiplicity creates uncertainty and a context in which expert advice related to scientific and medical knowledge may be questioned or mistrusted (Au & Eyal, 2022; Kromhout, 2015; O'Hara & Taylor, 2018). This problem is further intensified by non-expert online or social media sources that can perpetuate misunderstandings (Stanford et al., 2018).

Healthcare professionals most tasked with giving lifestyle advice may also not have expert knowledge about this branch of medicine. UK trainee doctors report feeling a lack knowledge and skills to provide lifestyle counselling (Aggarwal et al., 2020; Buckley et al., 2020; Frame, 2021). Accordingly, they may draw on a similar combination of 'folk, common-sense, and personal knowledges' as lay people in their understandings of lifestyle medicine (Hansen and Easthope (2007, p. xi).

A further problem is that while the population-level evidence base for lifestyle change is robust, there is also strong evidence that dietary and exercise change is difficult to achieve and sustain (Theis & White, 2021). The simplified expert advice recommended as best practice to facilitate patient engagement (eat healthily, exercise, take your medicine, stop smoking) may fail to address research indicating complex, subtle, and non-linear processes in lifestyle behaviour, which mean that enacting this information in everyday life not simple or easy (e.g. Bauman et al., 2012; Braithwaite, 2018; Frakes et al., 2021; Robson et al., 2023; Rutter et al., 2017). For example, risk is a complex concept and patients may grapple with evaluating competing risks relating to medical treatment and lifestyle behaviours (Brown et al., 2016).

Health advice is also not simply experienced as neutral, objective information, because is given within a wider discursive context of 'healthism'. Defined as the contemporary intense government, medical, scientific, commercial, and social focus upon health (Crawford, 2006), healthism is characterized by a medicalization of everyday life and the locating of responsibility for health problems and solutions with individuals rather than systems. Healthism produces a 'good health citizen' subject position, who is expected to gain and act upon health knowledge and complex understandings of the causation and prevention of disease (Cheek, 2008; Zola, 1977). Health thus becomes a site of identity formation, with positive identities requiring adherence to lifestyle advice, while non-adherence opens individuals up to criticism or judgement (Lupton, 2014). Further complexity can arise in the context of relationships, as couples may also enact 'relational healthism' by working on each other's health and seeing health as a joint endeavour (Robson et al., 2023).

Healthism creates an illusion of mastery over health such that becoming ill elicits a logic of blame as an 'ill person'. Thus, rather than being experienced as empowering, expert health advice holds the potential to position patients as failed subjects, eliciting a range of difficult feelings, emotions, and dis-preferred identities (Davison et al., 1991). Relatedly, the wide dissemination of lifestyle advice with its intense focus on health and ill-health can produce anxiety, cynicism, and fatigue with health information (Crawford, 2006; Rutter et al., 2017), with the implication that expert health advice itself may fuel patient disengagement.

Healthism interacts with current policies relating to patient choice that place responsibility for understanding and managing health upon patients, creating the identity of 'expert patients', who are envisioned as informed, agentic, and responsible for engaging with their medical conditions, choices, and care. This blurs traditional boundaries between expert medical and lay/patient knowledge (Hansen & Easthope, 2007; Mol, 2008; Schulz & Nakamoto, 2013), so that, within healthism, individuals develop and draw on an 'elaborate and intricate … lay epidemiology' which includes knowledge about disease causation, medical advice, preventative and protective measures (Crawford, 2006, p.403). Thus patients, in a form of 'informational

biocitizenship' (Rose & Novas, 2005, p.439), bring their own expertise and expectations of the validity and power of their own decision-making to medical encounters (Soyoon & Ekaterina, 2022). Expectations to enact health citizenship may thus paradoxically be creating lay epistemologies that compete with expert medical knowledge.

Patient lay epistemologies can include forms of knowledge or values that differ from their healthcare professionals' advice. For example, awareness of side effects may dissuade patients from adhering to medication (Brown et al., 2016). Lay epistemologies are also more likely to be situated and relational, in comparison to decontextualized expert scientific knowledge, and neither form of knowledge is neutral, but part of wider systems of power, privilege, and resistance (Foucault, 1980; Gauchat, 2012; Gudowsky & Rosa, 2019). This includes how scientific and medical knowledge is highly valued and given the status of truth, creating differentials in expert and lay understandings that play out in health care interactions (Sanabria, 2015). Thus, despite wide advocacy for centring care on patient knowledge, lay epistemologies are rarely recognised by experts (Wynne, 2008).

Above, we have shown that while the benefits of a healthy lifestyle are uncontested in preventative medicine, there may be a range of reasons why recipients of this advice could problematise it. Building on this argument, we offer a novel approach to considering the disconnect between healthcare professionals' expert advice and patient engagement by examining the taken-for-granted assumption in health promotion research—that this expert knowledge is straightforwardly valued and uncontested. Accordingly, we asked patients with a diagnosis of CHD how expert advice related to eating, exercise, smoking cessation, and medicine adherence is constructed. When is it given value and when it is problematised? Do patients draw on different lay epistemologies? And what are the implications of these for shaping patients' dis/engagement with lifestyle advice?

Method

Design

The study was part of a larger project that used a longitudinal qualitative interview design to enable detailed analysis of sense-making the often-subtle processes that underlie and help explain health behaviours (Braithwaite, 2018; Riley et al., 2021). Participants were recruited through a CHD rehabilitation program designed to support lifestyle change. One arm of the study aimed to interview people in a long-term relationship living with their own and a partner's diagnosis of CHD to explore their experiences of lifestyle advice and change in this relational context. Co-habiting couples were recruited to include participants who had day-to-day experience of managing lifestyle change while living with a partner. If they agreed, couples were interviewed together to capture their lifestyle-related interactions. The research team included critical health researchers with expertise in qualitative methods. The first author is from a working-class family and trained as a nurse which informed a more mainstream scientific perspective, alongside lived experience of a parent's early death from heart disease and caring for a sibling with CHD. The challenges of making purportedly simple lifestyle changes raised her awareness of the complexity and power relations that operate in

processes relating to lifestyle advice, leading to her engagement with critical health theories. Author two is a feminist critical qualitative researcher, who resonated with Foucauldian informed psychology because it helps surface how power shapes meaning making, subjectivity and practice. She has no personal experience of CHD, but her experience of, for example, giving up smoking, sensitised her to both the value in, and difficulties of, engaging with lifestyle advice. Author three is a senior cardiologist who has studied and practiced mainstream medicine, but through his recognition of the intersection of multiple wider determinants of health, has come to value poststructuralist theory for its insights into health behaviours and its implications for clinical practice.

Participants with a diagnosis of CHD were interviewed once a month for three months to gain insights into their sense-making as they applied expert medical lifestyle advice to everyday lives after their diagnosis. The purpose of a longitudinal design was to explore how participants talked about and negotiated lifestyle over a significant period while they sought to implement the lifestyle advice the had received in their rehab. Given the wider study's aim to explore the complexity that existing literature indicated was part of individuals' and couples' negotiations of health, a longitudinal interview design provided possibilities for participants to provide nuanced and multiple accounts over the period of the study.

A total of 35 interviews were conducted. The aspect of the study focusing on couples' management of lifestyle change led to a paper that presented the concept of relational healthism (Robson et al., 2023). This paper focuses on other salient findings in the data that relate to participants' constructions of knowledge and expertise and the implications for engagement with lifestyle advice.

Participants

Participants were recruited through a National Health Service (NHS) cardiac rehabilitation (CR) programme in rural Wales that offered exercise classes, and lifestyle and self-management advice to patients with CHD. Convenience sampling took place through invitations to all patients referred to the programme with a recent new diagnosis of CHD and if they were in a cohabiting relationship of at least 2 years. Given that 61% of people in the UK are in long-term relationships (ONS, 2024), one focus of the study was to understand how patients make sense of lifestyle advice and change within their social and relational context. Recruitment lasted 9 months by which time a substantial data set was achieved for a discourse analysis of participants' talk about lifestyle management and change. Table 1 displays the demographic characteristics of the 22 study participants.

There were 11 men and 2 women with a recent diagnosis of CHD and nine of their partners (seven women and two men; four male participants diagnosed with CHD chose to be interviewed alone). All were in long-term cohabiting relationships of over 15 years, identified as heterosexual, with age range 50-82 years (mean 63.3); 19 of the 22 participants were white British, two were white and from North America, and one was from East Africa. Sixteen were retired, six were working (employment backgrounds include 15 from public service or professional, 7 from skilled or manual work). Most participants were interviewed three times, but two couples did only one due to health reasons, producing a total of 35 interviews, each taking between 30

Table 1. Participant demographic information.

Name	Age	Work	Relationship length
Henry *	mid 60s	Semi-retired skilled	32 years
Catherine	mid 60s	Retired office	
Louise *	late 60s	Self-employed professional	
Dan	late 60s	Working professional	44 years
Eddie *	mid 60s	Retired public service	
Lily	early 60s	Retired public service	30 years
George *	mid 60s	Retired professional	15 years
Susan	early 60s	Retired skilled	
Holly *	early 50s	Retired public service	26 years
Graham	early 50s	Retired public service	
Paul*	early 80s	Retired agricultural	50 years
Ellen	early 80s	Retired agricultural	
Tom*	late 70s	Self-employed professional	43 years
May	Mid 60s	Home maker	
Jack*	Late 60s	Retired skilled	20 years
Deb	Early 60s	Retired skilled	
Carl*	Late 60s	Retired public service	39 years
Elsa	Mid 60s	Retired public service	
Robert*	Late 70s	Retired skilled	45 years
Richard*	Mid 60s	Business professional	29 years
Alun*	Early 50s	Public service	27 years
James*	Early 80s	Retired professional	48 years

Note: * indicates partner who has diagnosis of CHD.

to 90 min (with an average of 60 min). NHS ethics stipulated that invitation letters were sent out by the CR team, not the researchers, so the number of people potentially eligible to participate was not known. One couple withdrew from the study without giving a reason after one interview and were not included in the dataset.

Interviews

The audio-recorded interviews were conducted by the first author, a heterosexual, white woman from Wales in her early 50s with experience as a nurse and counsellor. The first and second authors developed the interview guide in discussion with the CR team lead, and the questions were piloted with a volunteer patient. Questions related to whether and how patients and partners had made and managed lifestyle change (see supplementary file for interview schedule). An open interview structure allowed participants to direct the content and direction of talk. The questions and previous experiences were re-visited at each serial interview.

Ethics and procedure

Ethics approval was granted by the NHS. The researchers undertook NHS Good Clinical Practice training. The counselling service Relate gave guidance on interviewing couples. Project-specific ethical issues included being sensitive to the potentially stigmatising experience of talking about engagement (or not) with lifestyle advice. The relatively unstructured interviews allowed participants to direct the talk. Written and ongoing verbal consent was gained. Both partners' right to withdraw was protected, and the potential to cause or expose tensions between partners was considered.

The interviews were transcribed verbatim. Transcription notation includes short pauses (.), and double square brackets showing additional information, for example, where quotes have been condensed [[data cut]]. Basic punctuation, like commas and question marks, were also added for clarity of reading.

Data analysis

Discourse analysis allows the identification of the taken-for-granted knowledge through which people understand the world, themselves, and others (Foucault 1980). Dominant discourses structure what can be thought, felt, said or done, producing identities and generating affective experiences that impact on people's capacities to act and be in the world (Deleuze, 1988; Riley et al., 2019). Combining Willig's (2013) and Riley et al. (2021) guidelines for a Foucauldian-informed discourse analysis, each transcript was read multiple times, coding direct and indirect references to experts and knowledge in relation to healthy lifestyle. Patterns and extracts relating to scientific knowledge, medical, and lifestyle advice were then analysed in terms of how expert knowledge was constructed. Wider discourses informing or challenging this sense-making were also identified, as was the action orientation of talk evidenced in rhetorical devices such as repetition, extreme case formulations and three-part lists that strengthen an argument (Edwards & Potter, 1993; Pomerantz, 1986). Subject positions within discourses were also identified, including discursive constructions that indicated troubled identities where individuals are excluded from valued social norms (Davies & Harré, 1990; Riley et al., 2021; Wetherell, 1998). The affects (Davies, 2013) and consequences in these accounts for engaging with expert-led lifestyle advice and practices were considered. The complexity of multiple interviews with the same participants was managed through mapping between and across participants' transcripts, using Excel sheets for systematic and comprehensive coding management.

This overall process enabled a theoretically informed, multi-layered Foucauldian-informed discourse analysis that addressed the research questions. Other quality criteria included iterative cycles of separate and collective data analysis by the authors allowing for multiple interpretations and in-depth discussion of any different interpretations; searching for alternative interpretations or patterns in the data; and interrogating our analysis with peer review and reflexivity. The first author kept a journal which was used to reflect on the interview and analytic process. Reflexive insights into the multiple ways in which knowledge constructed, for example, informed iterative cycles of data analysis which were developed through regular meetings between the first and second authors. Peer review of analysis-in-progress occurred through a qualitative research support group at key milestones, where analysis was discussed with colleagues with expertise in methodology and cardiology. Consensus was achieved through a collaborative and iterative process of discussion, reflection, and revision.

The data that support the findings of this study are stored on a repository and available on request from the first author; they are not publicly available due to their sensitivity and the inclusion of information about diagnoses and treatments that could compromise the privacy of research participants and health care providers in this relatively small community.

Analysis

Four discursive patterns were identified in participants' talk that constructed expert lifestyle advice as: (1) valued, but undermined by the dispreferred identities and new risks that adherence brought with it; (2) problematised as multiple, contradictory, contested, and difficult to follow; (3) problematised as too generalised to meet patients' individually specific information needs; and (4) understood as limited and only one form of knowledge among other values, including acceptance and embodied, affective knowledge. Below, we offer a detailed analysis of an exemplar that illustrates each of these re-occurring patterns.

'I listen to my GP'. Accepting expertise but negotiating the new risks that it brings

In this pattern, healthcare professionals were constructed as experts and sources of valid and valued information for their health-behaviour related decisions. However, even within this discourse of acceptance, medical advice and knowledge were problematised in the context of associated dispreferred identities and risks, such as when patients considered that the lifesaving promise of medical technologies simultaneously held costs. For example, Eddie (Eddie and Lily, mid and early 60s, retired public service workers) distinguished between expert medical advice on eating/exercise and expert medical advice on the use of statins. Eddie constructed lifestyle change as valuable, natural, and ideal, but medication as risky, even toxic. As the extract below shows, Eddie expressed a desire to be natural *and* healthy, but he struggles to reconcile both within his understanding of medical advice:

> Eddie: you read the paper one day, and they say everybody should be taking statins and then you read the newspaper the next day and nobody should because they cause so much damage and things, so you don't know what to believe
>
> Int: how do you feel when you hear about things like that do you
>
> Eddie: you have to listen (.) to the advice of people who you know hopefully know more than you do, you know, and I listen to my GP and I've listened to the consultants, at least I've got from 80mgs down to 40 (.) who knows maybe with diet, now that I've got the stent in, eventually maybe I'll be able to kick them in the head completely.

Above, there is ambiguity in the way that Eddie positioned his doctors as sources of reliable information. His use of the imperative 'have to' takes for granted the necessity of listening to medical advice, positioning healthcare professionals as people who '*know more than you do*'. The repetition of '*listening*' implies a one-way transmission of information and emphasises his compliance with the normative practice of patients listening to healthcare professionals. Eddie further consolidates his position as health citizen compliant with medical expertise by enumerating practices consistent with being an 'expert patient', including his knowledge about dosages.

But even when participants oriented to expert knowledge as valued, tensions could develop between lifestyle advice and patients' own knowledge, values, and desires. In the extract above, Eddie's reasonableness in listening to his doctors also establishes a platform for his dissent as his knowledge about his medication was aimed at

reducing and elimination rather than adherence to it. He tempers his assertion of doctors' expertise with the word 'hopefully', suggesting that there is a possibility for ambiguity and that healthcare professionals' knowledge is not absolute. This tension opens possibilities for Eddie's resistance to expert clinical advice. This is seen in Eddie's expression of the hope that he would be able to stop taking the medication his healthcare professional had recommended, which he problematises by drawing on another medical discourses - the language of drug addiction - '*maybe I'll be able to kick them in the head completely*'.

Eddie's construction of a medication-free future as something to be aspired to was common amongst participants who constructed changes to diet and exercise as safe, 'natural', and preferable to medication that they considered potentially toxic and risky, especially in relation to side effects (for similar accounts of concerns over medication, see Davison et al., 1991; Rosenbaum, 2015). In such accounts, medical treatment itself became a risk to be managed.

This dilemma between the risks of adhering or not adhering to medical treatment created potential for conflict between partners that needed to be carefully managed, putting additional pressures on adherence to practitioner-prescribed treatment. For example, when Eddie's partner Lily, explains why she wants him to remain on medication:

> Lily: but if you don't take statins and your cholesterol builds up (.) you could get the the artery could block again
>
> Eddie: yes I realise, I mean you just have to take advice on on that
>
> Lily: sorry that's my concern I think he's he needs to keep taking them (.) you've just got to
>
> Eddie: I know
>
> Lily: not be precious about it you've just got to accept it as part of your routine
>
> Eddie: yeah yeah

Above, Eddie concurred with Lily's argument about the need for medication adherence, though only weakly, given that he responded by deferring to a vague source of *'advice'*. Lily then stated her position more strongly, suggesting that she heard Eddie's agreement as equivocal. Her apology when doing so also signalled that she was transgressing relationship norms in her opposition to Eddie's doubts, but her claim '*that's my concern*' functioned to legitimise her involvement in and anxiety over his health, aligning with the concept of health as a joint endeavour (Robson et al., 2023). When Eddie does not fully agree, she strengthened her stance with the imperative '*you've just got to*' and even moved to an explicit critique positioning him as inappropriately fussy - '*precious*'.

Eddie's response, '*yeah yeah*', worked as both agreement and dismissal, an ambiguity that left unresolved tensions between Eddie and Lily's divergent positions within this long term, relationship. Being compliant with medical advice thus left Eddie in a dispreferred illness identity (someone on medication) that contravened his own lay epistemology of being 'naturally' healthy. These competing accounts was aversive enough to evoke his resistance to his doctor's advice.

In this example, we show how expert advice was understood as multiple (in this case that eating/exercise advice was separate from adherence to medication), so that accepting one element of the advice did not preclude acceptance of all expert advice. And even when an expert's advice was accepted, it was not necessarily constructed as valued enough to override other competing forms of expert information from alternate sources, and other values and identities, even when these caused distress to loved ones. Eddie's story is thus an example of how expert advice was accepted and valued, but in ways that came into tension with other valued ways of being (e.g. being medicine free). In other patterns in our data, expert advice was less accepted, and challenged more directly, as we demonstrate below.

'All these ridiculous things': problematising multiple and contradictory knowledge

Preventative medicine and health promotion aims to offer accessible, consistent, clear, and viable advice. But the pervasiveness and multiplicity of health information that participants received from different sources, including healthcare professionals and media, meant that our participants constructed health information as part of a complex, uncertain, contradictory, and contested nexus of information that was therefore difficult to evaluate, trust, and follow.

Henry and Catherine's (mid 60s, semi-retired skilled and retired office worker) discussions below offer an example of this pattern, where trying to be a good health citizen by keeping up with dietary research was constructed by Henry as an impossible task.

> Henry: if you believe everything that's said on television you'd never do anything would you [[data cut]] there would be different opinions wouldn't there, and some people get different ideas, so yeah, but er I mean they do come out with all these ridiculous things, that you can't eat this it's bad for you, you shouldn't do this, you shouldn't do that (.) you know, as I say, if you took note of all that they say you should or shouldn't do then

In the interview, Henry initially constructed television as an important source of health advice, but his extreme-case formulations '*everything*', '*never*', '*anything*' position this advice as prohibitive, paralysing, and impossible to follow and function to legitimise mistrust and non-engagement in the advice. Henry did not construct health information as universal, objective, and uncontested, but as consisting of '*different opinions*' and '*different ideas*', and thus multiple, subjective, and conflicting. He disparages the content of health advice, '*all these ridiculous things*'; and the prohibitive nature of advice evident in his three-part list, '*can't…shouldn't…shouldn't*', forms constraints and reductions in one's powers of acting which for Henry are unequivocally negative. Henry's talk also constructed health advice as an enumeration of what is '*bad for you*', a message of fear and risk of negative outcomes rather than affirmative or productive of health.

For Henry, expert advice was multiple, conflicting, and potentially 'ridiculous'; a pattern found across the data set, where, in line with the changing nature of knowledge, expert advice was framed as one of many contesting ideas for how to live a healthy life. This opened the possibility for expert advice to be rejected, for when

multiple ideas of health were considered, they were understood as impossible to follow because of their changing, contested, and contradictory requirements.

'I'm an answers person': the need for certainty and specificity

Participants constructed expert knowledge as valued, and turned to experts for tailored knowledge that was specific to them and their illness and recovery. But in so doing, they reached some of the limits of expert, scientific knowledge to account for their illness and inform their risk management. Participants thus problematised expertise because it failed to provide certainty or address their specific case and needs.

Below we offer an example of how our participants talked about the limits of expert knowledge to explain causality and offer the promise of better health. We start with Louise (late 60s, academic and Dan, late 60s, professional) establishing the importance of knowledge in the processes of recovery and regaining control, particularly for her own identity:

> Louise: but my biggest concern and the part that makes me crazy (.) I mean crazy crazy it's crazy making (.) is I don't have answers and I am an answer person … that's part of who I am I want to know why and the biggest emotional factor I have in all of this is, is it because I walked up the hill? Is it because I had a spam sandwich that day? Is it because I wasn't drinking enough water? Is it because something I had no control over? Is it was I doing something wrong? (.) was I doing something that, you know, what caused it? What's the reason? And I think that's the part I have the hardest time, that's the hardest issue I have to deal with, and I also understand I may never, this side of the grave, get an answer for that

Louise claimed that after her diagnosis a lack of answers was her '*biggest concern*', constructing an expectation for knowledge, understanding, and certainty through the desire to have answers. But, as discussed above, lifestyle advice is based on generalised, population-level patterns, and rarely offers the answers that Louise was seeking or expecting. This lack of knowledge troubled her identity as '*an answer person*', a rational, self-governing health citizen, and was productive of an opposite self—'*it's crazy making*'. Her multiple repetitions of '*crazy*' evoke an extreme, incoherent, and irrational self produced by this situation, and her expression of intense frustration at this positioning.

Her extreme-case formulations of '*never*' and '*hardest*' emphasise her frustration at the absence of certainty, which affected her powerfully as she grappled with what could be known and understood. Expert advice that did not meet her needs was thus deeply affective and produced dispreferred identities and emotions. Louise's evocation of death in her reference to '*this side of the grave*' evoked both the risk and precariousness produced by an absence of certainty and control, but also, importantly, the limitations of medical science to give her the answers she wants.

Louise's construction of unfulfilled expectations of medical experts related to specificity and causality, with the implication that knowing the cause of her heart disease would also allow her to apportion blame, and control future risks. She listed a range of possibilities, with the first three linked to dominant elements of lifestyle advice (exercise and diet) that also located responsibility within Louise, such as eating the '*wrong*' food, or over-exerting herself, that may have caused her illness.

We read this talk in relation to healthism, and its construct of health (and by implication illness) as shaped by lifestyle choices and under the control of a rational, health citizen. Her repeated use of questions related to causation produced a sense of an unfulfilled search for answers that she was not able to get from expert advice.

We also note that within her list of questions she briefly considered a random cause, '*something I had no control over*', before returning to a direct attribution of blame and moral judgement in her designation of her actions as '*something wrong*'. This structure, where an alternative position is 'sandwiched' between more conventional positions (Riley, 2002), allowed Louise to air a less acceptable or more radical statement (that lifestyle was not a causal factor and that she wasn't responsible for her illness) whist otherwise still adhering to, and reproducing, healthism. Her talk thus hints at the possibility of being able to articulate a position outside of the healthism narrative, but this is not sustained, creating the ongoing sense of frustration.

The example above shows how healthism (with its dual promise of health and attribution of blame to illness) becomes entangled with the limits of expert knowledge to account for an individual's specific illness. In this pattern of talk, expert knowledge failed to meet the needs of patients, not just to understand the aetiology of their illness, but also to have confidence in enacting specific lifestyle changes as preventatives for further disease progress.

'They're not living in your body': contrasting expert and lay knowledge

Where expert knowledge was constructed as failing to meet their information needs or afford positive identities, our participants turned to alternative values and understandings to manage risk, uncertainty, and identity. Participants drew on other forms of knowledge that combined to create an elaborate lay epistemology within which they frame their illness and thus appropriate responses to it. Within these lay epistemologies, participants balanced their experiential, affective, and embodied knowledge of themselves and their partners against expert medical advice and broader social discourses of healthy living, negotiating the legitimacy of these different knowledges and the various identities associated with them.

Our example comes from Holly and Graham (early 50s, retired public service employees) whose extracts below draw on pattern three (the limits of generalised expert knowledge and its potential to produce negative affective states) and contrasts it with their own embodied knowledge.

> Graham: they do see patients as erm (.) something to stimulate their brains in a way that they don't I don't think they give much thought to the stress on patients [[data cut]] it's a problem doctors have in their training I think that they're not, they're they're trained to solve the problem, but they don't seem to be ever concerned about the state people might get in or

> Holly: well yeah, I think you're right there because, I mean, it's like with the body, it's like with the person, isn't it, everybody is different

Above, Graham problematized medical knowledge for its focus on intellectual problem solving, and consequent lack of attention to people's affective responses or

individuality. He constructed a dichotomy between mind and emotion, an impasse in which doctors' training in how to apply expert knowledge and problem solve reduces their capacities to care, empathise, and understand how diagnosis and treatment might be experienced as psychologically harmful ('the state people might get in'). Holly supported this point, emphasising the uniqueness of individuals, '*like with the body it's like with the person…everybody is different*'.

Later, Holly further identified the limitations of medical knowledge in contrast to her own embodied knowing, describing how, during a diagnostic angiogram, her physician '*went up to my heart and he says oh I wasn't expecting that neither, nor that, and I thought (.) but I was*'. For Holly, valued knowledge included not just medical expertise, but her own embodied experience, which medical experts did not have access to ('*they're not living in your body*'). These different knowledges set up power relations between patients and health care professionals. As an institution, medicine's power emanates from its production of scientific knowledge and expertise, but compared with her own embodied knowledge, Holly understood medical knowledge as uncertain- in her story when the physician said, '*I wasn't expecting that*', she thought, '*I was*'. Despite her affirmation of her own embodied knowledge, Holly orients to the subjugated position of this lay knowledge, as she '*thought*' but did not speak these thoughts to her doctor. Holly's story is thus one of negotiating the limitations and power relations that operate between medical expertise and patient knowledge, silencing herself in conversation with the expert, but, in a research context, sharing her conclusion that her knowledge was more accurate.

The divide between couples' and medical professionals' knowledge could, however, be bridged by empathy for patients' affective, embodied experiences. Below Graham describes a doctor's reaction to Holly's smoking as a form of stress management:

> Graham: I think the doc the doctor's (.) kind of unofficial attitude to (.) smoking and and eating the wrong things is 'okay' and and the doctor's never going to say carrying on smoking, but I think his view has been (.) you've got so much wrong with you and if it does that little bit to de-stress you then (.)
>
> Holly: it does help

Their account of the doctor's response introduced a new form of knowledge, one that was negotiated between patient and doctor, and which found a common ground between 'official' medical advice, which would never condone smoking, and Holly and Graham's construction of diet and smoking as part of an intricate, affective coping strategy. It seemed that the doctor's '*okay*' signalled a recognition of Holly's experience, encompassing an acknowledgement of Holly's suffering, and a concern for her stress and agency to determine what was good for her. This response contrasts with Graham's earlier statement that doctors '*aren't concerned about the state people might get in*'.

In coming closer to the couple's embodied, affective experience, Graham understands the doctor as able to overcome the boundaries of a purely intellectual, rational position, access empathy and concern, and through this, recognise and give value to their lay epistemology. When Holly said, '*it does help*', she may have been referring to her smoking, but also to the affirmation of her experience and knowledge by a medical professional.

Discussion

Our patients with CHD, and their partners, constructed expert knowledge as valued when they understood it as efficacious in reducing their risk of illness and enhancing their wellbeing. But crucially, they often constructed lifestyle advice as failing to meet that criteria because it (1) brought additional risks or created dispreferred identities and affective experiences (including frustration, distress, anxiety, guilt, confusion and irritation); (2) it seemed difficult, if not impossible, to follow within a wider context of competing scientific discourses communicated across multiple media; and (3) it did not meet their informational needs in relation to understanding their own bodies, and (4) expert advice was understood as only one form of valued knowledge. We discuss these below in relation to how participants created their own lay epistemologies in response.

Within the participants' own lay epistemology, medical expertise was constructed as valued but could compete with other needs and desires, for example, to meet cultural ideals of health citizenship or to decide upon the changes that they felt they *could* make, both practically and emotionally. For example, Holly 'knows' her body, Eddie rejects an illness identity related to medication, and Louise expresses guilt over the logic of blame inherent in lifestyle advice. In the context of quotidian but often multiple and contradictory health advice circulated across a range of actors, lifestyle advice became questionable, and problematic to follow.

Lay epistemologies were thus produced through lived experience and their affective responses to, and interpretations of, that experience. Participants drew on multiple and sometimes conflicting knowledges including scientific information as well as experiential, embodied, and affective kinds of knowing in their management of risk. In this sense, participants' behaviour and understandings were always situated and embodied, negotiated in the context of their own needs, desires, constraints, and possibilities, as they worked to both maintain a positive sense of self and make claim to good health citizenship, while managing their CHD diagnosis.

The participants' elaborate lay epidemiology of health and illness developed by participants thus disrupted traditional divisions between lay and expert knowledge (Crawford, 2006; Davison et al., 1991; Hall et al., 2015). Expert knowledge was negotiated dynamically between patients, partners, and their health care providers, in ways that added layers of complexity to current information-transmission understandings of health behaviours (Braithwaite, 2018; Fullagar et al., 2017; Kelly & Barker, 2016). These findings also suggest that lay epidemiologies is a useful concept for considering how patients engage with expert health advice, developing this concept beyond its current use to explain different values in research priorities (Gudowsky & Rosa, 2019**).**

Important for the development of lay epistemologies was that patients constructed expert knowledge as multiple and conflicting, such as when injunctions to achieve health through lifestyle change appeared to conflict with medical advice to take statins, or when the benefit of mediation was balanced against risk of side effects. Our participants therefore did not construct scientific knowledge as singular, rational, objective, and universal. A fruitful direction for future research and clinical practice might therefore be to explore how to give efficacious advice while recognising, rather

than minimising, the complexity and dynamism of scientific knowledge and therefore the process of following expert advice.

Our findings also highlight a tension between patients' construction of a desire for individualised expert information and the generalising tendencies of medical advice from population-level studies. Participants recognised the limits of current scientific knowledge to provide individualised medical knowledge related to causation and prediction of their illness. These uncertainties evidenced the limits of expert, scientific knowledge to account for their illness and inform their risk management. This distinction between population and individual knowledge creates challenges for doctors in determining what constitutes the best care for individuals (Aronson, 2016) and for policymakers who assert the value of patient-centred medicine (NICE, 2015). To this, we show how patients' engagement with lifestyle advice could be limited because it did not provide answers specific enough for them to conduct appropriate health-enacting work on their bodies.

Our findings also support research showing the importance of healthism in shaping patients' experience of lifestyle advice. For those with non-communicable diseases, such as CHD, healthism creates both dis-preferred identities and an understanding of health as a risk to be managed, with the outcome that health advice may become disempowering, creating cynicism and fatigue (Crawford, 2006; Davison et al., 1991; Morden et al., 2012; Rose & Novas, 2005). We develop this literature by demonstrating the complexities and power relations that arise at the intersection of healthism with expert and lay knowledge and how they can work against behaviour change even in patients with CHD who are motivated to engage with lifestyle advice. Our findings also show a normative engagement with that discourse of risk, and a relative absence of framing healthy eating in relation to pleasure. Vogel and Mol (2014) argue that encouraging people to reconnect pleasure with eating can lead to greater satisfaction, recognition of satiety, and a move towards healthier food consumption. In the context of our findings, this suggests that future research might explore how incorporating affirmative affects and pleasure in healthy lifestyle advice might reduce the disparity between clinician's lifestyle advice and patients' engagement with it.

The promise of patient-centred care is predicated on mutual recognition of value in knowledge and decision making (NICE, 2015; WHO, 2003). However, given that expert, scientific knowledge subjugates lay knowledge to expert, it can be difficult for patients to share or assert their own experience, knowledge, and values. Future research might explore if, paradoxically, patients might be better supported to engage with lifestyle advice if healthcare professionals recognised the complexities and limitations of lifestyle advice, including recognising affects that circulate with a diagnosis and lifestyle advice, and considering the multiplicity of scientific knowledge.

Professional advice is incorporated into and filtered through patients' own knowledge, affective and embodied experiences, social relations, and wider social discourses of health. A model of complex, fluid, contested, and de-contexualised information being negotiated rather than transmitted offers possibilities for future research and clinical practice (O'Hara & Taylor, 2018). This would include creating inviting spaces for patients to share, and have valued, their lay epistemology. In our study, for example, health care providers' empathic transactions in relation to distress arising from uncertainty, or a patient's difficulty in quitting smoking, allowed patients to be seen and heard in ways

that might facilitate future conversations about smoking cessation or engagement with other health behaviours. Creating such spaces may also allow clinicians to identify factors in their patients' lives that can facilitate adherence to lifestyle advice beyond individual-level behaviour change. These might include important issues not identified within the context of this UK and NHS-based study, such as those related to wider social determinants of health, access to and type of health care provision, and religious or ethnic-community understandings.

There is an urgent need to better understand the disconnect between health advice and patient engagement (Fitzpatrick et al., 2014; Frakes et al., 2021). Our novel approach to this topic, by focusing on how expert advice is constructed by patients, offers a radical shift in understanding for both clinicians and researchers. Rather than focusing on how to help patients put health advice into practice, we show that there is more than one valued knowledge system operating, with patients drawing on scientific knowledge in interaction with their situated, embodied, affective, and experiential knowledge. Thus, to only recognise expert knowledge underestimates the complexity of these processes and potentially dooms lifestyle advice to failure (Rutter et al., 2017). Further, we show that the scientific expert knowledge system was not understood as simple or unified but experienced by patients (as it is recognised by life science researchers) as multiple and dynamic.

Our findings indicate that patients did not frame themselves as ignorant, irrational, or careless about their health, but rather that lifestyle advice often failed to meet their needs because of layers of complexity that belie the apparently simple and do-able information given relating to exercise, diet, medicine adherence and smoking cessation. Our study connects with research examining diverse constructions of and engagement with 'self-care' among different population groups (e.g. Jones, 2018) which also suggests that the disjuncture between advice and action relates to the paradox identified in this study - that lifestyle advice is both simple and complex, and that by focusing on the simple, preventative medicine and health promotion only offers only a partial solution (Braithwaite, 2018; Rutter et al., 2017).

Our study focused on participants with a diagnosis of a so-called lifestyle disease. In the context of a global rise in non-communicable diseases (WHO, 2023), and widespread health promotion that charges individuals with managing their health through lifestyle change, and of pervasive healthism that requires all of us to engage as health citizens, the implications of the study have wider applications to the general population as well.

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