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"The more you know, the more you realise it is really challenging to do": Tensions and uncertainties in person-centred support for people with long-term conditions

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ABSTRACT

Objective: To identify and examine tensions and uncertainties in person-centred approaches to self-management support – approaches that take patients seriously as moral agents and orient support to enable them to live (and die) well on their own terms.
Methods: Interviews with 26 UK clinicians about working with people with diabetes or Parkinson's disease, conducted within a broader interdisciplinary project on self-management support. The analysis reported here was informed by philosophical reasoning and discussions with stakeholders.
Results: Person-centred approaches require clinicians to balance tensions between the many things that can matter in life, and their own and each patient's perspectives on these. Clinicians must ensure that their supportive efforts do not inadvertently disempower people. When attending to someone's particular circumstances and perspectives, they sometimes face intractable uncertainties, including about what is most important to the person and what, realistically, the person can or could do and achieve. The kinds of professional judgement that person-centred working necessitates are not always acknowledged and supported.
Conclusion: Practical and ethical tensions are inherent in person-centred support and need to be better understood and addressed.
Practice implications: Professional development and service improvement initiatives should recognise these tensions and uncertainties and support clinicians to navigate them well.
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1. Introduction

As the prevalence of long-term conditions rises and pressure on public health care budgets increases, policy leaders internationally promote support for self-management to improve health and the sustainability of health services [1–3]. Such support is often presented, or advocated for, as person-centred [4–6].

The concept of person-centredness (and its close relative patient-centredness) can be variously interpreted [7–9]. Here we consider it as an approach to clinical practice that both respects and enables patients as moral agents and collaborative partners whose own perspectives on their lives and how they live them, matter [9,10].

The respect and enablement we associate with person-centred care are not universally evident in practice. It is increasingly clear that they are constrained when services, clinicians or interventions aim narrowly for biomedical risk reduction [11,12], or focus narrowly on patients' knowledge, skills and confidence while neglecting the constraints that social circumstances and relationships can place on their autonomous agency and health [13–16]. We thus take a position that person-centred self-management support must be oriented to help people to live (and die) well on their own terms with their long-term conditions [12], and that it requires clinicians to work in autonomy-supportive ways that are sensitive to diverse influences on what people value, can do, and achieve [12,17–19]. (By clinicians we mean any healthcare professionals working directly with patients).

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In practice, clinicians sometimes find it hard to shift from biomedically-driven and directive approaches to more biopsychosocial and person-centred approaches [20,21]. It is now well documented that target-oriented performance management can restrict clinicians' scope for responsiveness to people's particular situations and values [e.g. 22,23]. In this paper we explore the more inherent challenges of working collaboratively with patients as moral agents and of enabling them to live (and die) well on their own terms.

2. Methods

2.1. Project design

The overall project – Concept:SSM – was an interdisciplinary endeavour designed to develop an account of self-management support that could reflect and help nurture forms of clinical practice consistent with person-centred ambitions to respect and enable people with long-term conditions. The project included:

a) a review of literature examining clinicians' perspectives on self-management support [11];
b) individual interviews exploring clinicians' experiences and perspectives on success [24];
c) subsequent group discussions with clinicians to help develop the interpretation of the interviews and test alternative descriptions of self-management support [24];
d) a series of knowledge exchange events with broader stakeholders; and
e) applied philosophical analysis (conceptual and ethical reasoning) to examine the implications of different ways of thinking about key aspects of self-management support [12].

The philosophical analysis (e) was woven throughout the project, as we worked iteratively to inform and respond to what we were learning from the empirical elements (a–d). Research Ethics Committee approvals were obtained (14/NS/0011).

This paper presents an analysis of the individual interviews, informed and supported by learning from the other elements of the project.

2.2. Sampling, recruitment and consent

We set out to interview 24 clinicians working in diverse front-line service roles with people with diabetes or Parkinson's disease.

We used publicly available staff listings and contacted most potential participants 'cold', but some participants suggested colleagues who might have different perspectives to their own. Invitations were sent on an opt-in basis. The participant information leaflet said the project aimed "to develop better ways of thinking about helping people to manage and live well with long term conditions". We requested a 45 min audio-recorded interview about experiences of working with people with diabetes or Parkinson's disease. Of 65 clinicians contacted, 26 responded expressing interest. They were interviewed after signing informed consent forms.

2.3. Data generation

Two non-clinical researchers (JO and ZS) conducted semi-structured conversational interviews, supported by a topic guide. They started with a question about the participant's current job, then asked for examples of when their work with people with diabetes or Parkinson's had been more and less successful, and of when things had 'turned around' from better to worse or vice versa. These examples, and comparisons between them, were used as a basis for inviting participants to reflect on how they were defining success, on how they thought patients viewed success, and on what contributed to more consistent success in practice. Towards the end of their interviews, we asked participants to comment on policies promoting 'collaborative' working with patients. We adopted this timing, and intentionally avoided asking directly about 'person centred care' in order to avoid 'leading' what clinicians said about what was good and why in the support they offered patients.

2.4. Data analysis

The interviews were audio-recorded and transcribed. After team discussions of six transcripts, we developed an initial coding framework that was applied to all transcripts by JO and ZS, using NVivo-10 software. Some codes reflected our interview questions and were used to underpin our primary analysis [24]. Other codes reflected other potential themes of interest, including several 'tensions' in clinicians' accounts of what they were trying to achieve in practice. Interview fragments tagged by these latter codes were a starting point for the analysis reported here. The analysis was refined as the project progressed. It has been informed by our philosophical work and supported by our conversations with key stakeholders.

Although the topic guide was not designed specifically to explore the challenges of more person-centred working, such challenges were strikingly evident in the interview data. They featured in the details of some clinicians' practice-based examples, in reflections on 'success' (especially when clinicians considered how patients' perspectives compared to their own), and in comments on 'collaborative working'. We initially focused our attention on four interviews in which clinicians discussed challenges associated with what we interpreted as person-centred practice quite explicitly and extensively. These four interviews were read by all authors and used by VE to develop a provisional version of this analysis. VE then revisited all 26 transcripts, systematically looking for evidence of relevant challenges (e.g. in mentions of tensions, difficult judgement calls, or uncertainties about what course of action was best). Our theorising about these tensions and uncertainties also drew on consideration of how the interviews seemed to reflect varying degrees of person-centred working. The analysis was developed in discussions with all authors.

3. Results

26 clinicians working in varied roles gave individual interviews (Table 1). We present our analysis of the challenges of person-centred working in three sections: 'Striving for balance'; 'Underlying uncertainties'; and 'Practising person-centred care'. Illustrative quotations are presented in Tables 2–5 and referred to in the text by numbers Q1–Q13.

3.1. Striving for balance

As reported in our primary analysis, all 26 clinicians identified multiple aspects of success in their work, and some explicitly mentioned a need to find a balance between these [24]. Some clinicians used phrases such as "walking a tightrope", and some described doing or trying to achieve one thing "but without" doing or causing another, and perhaps "at the same time" trying to do or achieve other things as well. For example, when trying to encourage someone with diabetes to act to lower their blood glucose levels to reduce the risk of major complications, clinicians might also be seeking to address their particular fears about hypoglycaemic episodes, avoid offering false hope, and limit the potential for inappropriate guilt.

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Table 1
Characteristics of the 26 clinicians interviewed individually.

Healthcare profession/specialisation	**N**
General medical practitioner (family doctor)	4
General primary care nurse (practice nurse)	2
Medical specialist (including in care of the elderly, diabetes, neurology and psychiatry)	9
Specialist nurse	7
Allied health and social care professional (clinical psychologist, dietician, physiotherapist, support worker)	4
Condition focus (for the purpose of this study)	
Diabetes	9
Parkinson's Disease	11
Both*	6
Location of current practice	
London	8
North of England	6
Scotland	12
Sex	
Female	15
Male	11

* The general medical practitioners and practice nurses all said they had more experience of working with people with diabetes than Parkinson's disease.

Table 2
On the need for balance in support: the compromises of collaboration.

	Data summary/quotation	Clinician
Q1	*[Talking about success and how it is assessed in work with people with Parkinson's]* "The reason we use [standardised measures of risk] as well as the patient's own goals is because these are the kind of things which help us feel more confident they aren't going to fall over. They may be able to do . . . what they wanted to be able to do, to run around with their children more, but if they're still at risk of failing then we as clinicians haven't really done our job right . . . and that's what we need to balance as clinicians"	Stephanie Physio-therapist
Q2	*[Talking about work with people who have difficulties managing their diabetes].* "You're constantly working with them for them for them to set their goals, really small goals. They come back, they haven't done it. So then you talk about the barriers, why they didn't manage that. And try and encourage them to think about [what they would be] confident to take on next time . . . But actually sometimes . . . the patient just keeps coming back and coming back, and you've got to be careful you don't almost collude with them that something's happening, when all that's happening is they're coming to their appointments. They're not doing anything in the in-between time. So, something's saying you've got to be the person that supports them, and tries to encourage them to do well. And every little bit . . . 'Well, that's good, that's great'. But actually, there has to come a time when you have to *challenge* what they're doing . . . "	Dawn Specialist nurse
Q3	*[Giving an example of when work was not so successful]* "I've got a type 1 diabetic who's got retinopathy, lost the vision in one eye. Was thrown out of the hospital diabetes clinic for non-attendance, very intermittent whether he comes here or not . . . His wife came in and verbally attacked me that it was my fault her husband's lost his sight in his eye: it wasn't good enough; we weren't making enough of an effort to get him in. The fact that he DNAs appointments, cancels them and just fails to respond? I should go round to his house and *make* him come!"	Andrea Specialist nurse

Table 3
On the need for balance: ensuring efforts to enable are not disabling.

	Data summary/quotation	Clinician
Q4	*[Discussing collaborative working with patients and with colleagues]* "We do have [inter-professional] disagreements . . . Quite often if a patient isn't looking after themselves very well, the diabetes physician . . . will . . . sort of step in and say 'Okay we need to help them'. WE need to help them. But what needs to happen is THEY [the patient] need to internally recognise that THEY need to help themselves more. And if that balance isn't there, if the physicians aren't able to step back . . . they get enmeshed in a kind of process where they put them on technology . . . give them more monitoring, . . . lots and lots of input. And the core thing is . . . that the person . . . isn't able to recognise the fact that their lives could be different . . . to think 'I could be doing better with this'"	Daniel Medical specialist
Q5	*[Talking about success]* "Do they find that the input and the support that they get from me and the service . . . has helped them deal with their Parkinson's in as positive a way as possible without becoming over-dependent? One of the things is the risk that they become almost paralysed: they don't want to do anything because they have to refer back to a doctor, and we see a little bit of that . . . There is no doubt there is a balance between leaving people . . . completely unsupported and throwing a huge amount of resource – well-meaning as it may be – which actually they become sort of dependent on . . . There is a balance there . . . So it is something about getting the right balance between patient autonomy and . . . professional support in its broadest sense."	Alistair Medical specialist
Q6	*[Talking about success]* "I suppose what I try to do is . . . to empower them to make decisions about their problems and to support those decisions . . . kind of just trying to back them up and make them feel like they are in charge but they have got some kind of supervision . . . I don't know, that's a difficult line to walk because obviously providing too much supervision is dis-empowering in the same way but also you don't want people to feel totally unsupported and I think you just have to try and judge that on an individual basis and inevitably sometimes that is going to go better than others."	Matthew Medical specialist

The specific considerations that clinicians talked about balancing varied, and there were often more than two considerations to be balanced at once. These could include different aspects of people's current and future health as well as their broader wellbeing, sense of self and (particularly important when we are considering person-centred care) autonomous agency and scope to do particular things that mattered to them.

In this section we examine two inter-linked kinds of balancing that seem to be required by person-centred working: (a) the compromises of collaboration (balancing responsiveness to a patient's agendas with commitment to biomedical-professional goals); and (b) ensuring that support intended to enable people does not become disabling.

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Table 4
Examples of clinicians' uncertainty about what matters to people – and reasons for caution about interpreting someone's expressed preferences as guides to professional action.

	Data summary/quotation	Participant
Q7	"People say, 'I don't mind, I want to enjoy myself now, I'm not caring if it makes me ill later'. And I again wouldn't mind that, except I know that quite a proportion of the patients saying that are feeling insecure and scared and guilty as hell about these bad decisions they are making. So they have developed a rationalisation, a bluster around how they're coping, but they're sometimes hurting badly, and are badly intimidated by the condition they've got. So there's always this dilemma: how far do you interfere with somebody's head when they tell you one story and you worry that the truth is maybe a different story?"	Barbara Medical specialist
Q8	*[Talking about side effects of drugs sometimes prescribed for Parkinson's Disease]* "So we are now seeing things like pathological gambling, sometimes overeating, sometimes excessive sexual activity, occurring or at least being unmasked by some of the medication. [Gives an example of someone who used to like 'putting a fiver on the horses' who suddenly realises they've spent £1000 in a week]. That's a choice, but whether it's a completely free choice I suppose depends on your view of addiction in relation to human nature and human will. Are alcoholics making bad choices or are they ill?"	Craig Medical specialist
Q9	*[Talking about a discussion with a man who "never seemed to engage"]* "And then while I was giving him a leaflet, he, without looking at it, just put it into his pocket. And I sort of challenged him then and said 'Do you want me to go through the leaflet with you now?' I found that actually he had dyslexia. All the information I had been giving him over the years, he hadn't been reading because of his problems . . . "	Kate Specialist nurse
Q10	"In terms of diabetes, failure is definitely when the patient starts to develop complications. And patients . . . are often then keener to control things, but it's too late to prevent what's already happened . . . People don't realise how precious their sight is until they can't see; they don't realise how precious two legs are until they're losing part of one. But it's very difficult to get people to understand, you know, because you're talking about what ifs".	Mark General medical practitioner

Table 5
Clinicians' uncertainty about people's current health status, health behaviours, and what they are capable of.

	Data summary/quotation	Participant
Q11	"If the patient is sitting there saying everything is fine and there is someone in the corner shaking their head violently, then you know there is a problem . . . The patient may not be aware that they are dementing and it will be someone else that will tell you that, and around other psychiatric things that you see quite a lot in Parkinson's, like hallucinations. Often the patient will not volunteer that because – or difficult behaviour like some of these impulsivities: the patient will often be a bit embarrassed, or not sometimes regard it as a problem"	Alistair Medical specialist
Q12	"I can think immediately of one lady, who's also got sort of ongoing mental health problems, which might well explain things, but, you know, she tells you that she follows a diet and does all the right things, but then when you go round to her house she's in a very chaotic situation, you know, there's tins of biscuits, open tins of biscuits, chocolate wrappers, bottles of Lucozade and things like that here, there and everywhere about the place . . . She said 'Oh well yes, I did have those, I did have a little snack, but it's a very rare occasion' [but] you get the impression that it's a regular occurrence"	Mark General medical practitioner
Q13	"I think sometimes it's difficult because patients want to please you as a clinician, so they tell you all the right things . . . And then suddenly you get the results and things are not matching. So people actually lie about their blood sugars. They write all these perfect readings down . . . there are patients that do that, and I see that on a daily basis. And it's really hard because then you have to challenge them, and you know they are lying, but how to kind of solve in their minds without breaking down the relationships? . . . Because at the same time you don't want to break that rapport you have with them, but you want to challenge what they're doing a little bit."	Shania Specialist nurse

(a) The compromises of collaboration

Several clinicians discussed collaborative working in terms of attending to both patients' and their own professional agendas, and engaging in "a bit of give and take" or "compromise" between these. Sometimes this seemed relatively straightforward, other times (when a patient's and their own perspectives were not well aligned) less so. A commitment to collaboration raises questions about what kinds of compromises and which means of achieving them are appropriate.

Particularly in the context of diabetes, clinicians were aware that a strong professional emphasis on standardised biomedical targets could leave insufficient room for individual patients' agendas. But biomedical issues could still be relevant for what mattered to patients, and some clinicians recognised that a strong emphasis on patient choice or patient-led goal-setting could also be problematic if it led to a neglect of these or other legitimate professional concerns (Q1,Q2). Several indicated that a good compromise, while responsive to a patient's personal agendas, would avoid somehow inappropriate "collusion" and might involve challenging the person's beliefs, claims or actions (Q2). However, recognition of a need to challenge a patient could raise further questions about what constitutes an appropriate compromise, not least because of concerns about respecting and supporting people's autonomous agency as well as their substantive agendas (Q3,Q7).

- Ensuring support intended to enable people does not disempower them

Some clinicians clearly appreciated that simplistic approaches to patient choice would not always ensure patients could exercise autonomous agency. They saw a need for more support to bolster or enable such agency, particularly when they were working with people with mental health problems, people with limited socio-economic resources, and/or people whose autonomy had never been well fostered (Q4).

Efforts to enable people, however, can generate several tensions. First there are tensions between respectful support for autonomous agency per se and the promotion of particular goals to which that agency might be oriented (e.g. dietary intakes and blood glucose reduction). If a clinician tries to enable someone to pursue activities or achieve goals that the person does not value so highly, they can in some sense undermine that person's autonomous agency. Clinicians clearly considered it impossible or inappropriate to force people to do things, however much they regretted the consequences (Q3). And even if someone would rather have something done to or for them to secure an outcome that they valued, this could be at some cost to their autonomy and perhaps be seen as a failure to recognise and support the development of their responsibility in their own lives (Q3,Q4, Q5,Q7).

Second, some clinicians also identified potential tensions within efforts to enable people more generally, suggesting that

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too much or the wrong kind of support could become in some respects disempowering (Q4,Q5,Q6). There is something of a paradox about intervening to support someone's autonomous agency and, indeed, about the concept of support for self-management. Not only does the success of such intervention seem to lie in the eradication of its need, but the intervention might in some respects contradict its purpose.

As some clinicians explicitly recognised, opinions can differ about how much support to offer and where it is appropriate to put the emphasis (Q3,Q4). Not surprisingly, some acknowledged that it could be "difficult" or "tricky" to judge how to strike a balance in their efforts to enable people. They admitted, for example, "feeling my way" or being "not sure I'm right".

Various other uncertainties could underlie these and add to the challenges of person-centred working. We turn to these now.

3.2. Underlying uncertainties

We consider uncertainties associated with efforts to work supportively with patient's autonomous agency and agendas in two broad, somewhat overlapping domains as uncertainties about: (1) what matters to and for someone; and (2) their health and realistic scope for improvement in their lives.

3.2.1. Clinicians' uncertainty about what matters to and for someone

Clinicians who seek to be attentive to what matters to patients can sometimes – perhaps often – feel quite confident about what particular people value. Our participants, however, sometimes felt they had insufficient time to listen well. They also had several reasons for being wary of taking what patients said at face value to guide their action. Various examples illustrated that what someone gave the impression of (not) caring about, or what they *said* about what mattered to them or what they wanted to do, might not reflect their authentic, deep and lasting value commitments. It could, for example:

- be influenced by various things including fear (Q7), the side-effects of medication (Q8), and practical difficulties or embarrassment (Q9);
- change as they adjusted psychologically to a diagnosis, and/or;
- lead to harms that they perhaps had not appreciated (Q10).

Uncertainties about what really matters to people and why, and about how to prioritise that, can sometimes be resolved with further discussion or investigation. However, some clinicians also recognised a need to navigate further uncertainty about when and how it was appropriate to query what people said (Q7). This uncertainty is related to the challenge of finding a balance in providing support that aims to enable people. It arises in part because although a clinician's questions to explore someone's values or ambitions might aim to help clarify what matters to them, they might also be interpreted as suggesting the clinician doubts the person's honesty or competence. They risk damaging not only the clinician-patient relationship (see Q13) but also the person's sense of self and confidence. They can also appear to undermine the person-centred ideal of supporting someone on their own terms.

3.2.2. Clinicians' uncertainty about people's health and realistic scope for improvement in their lives

Clinicians also mentioned uncertainties about: what was going on with someone's health condition(s); what health-related behaviours (including medication-taking) they were currently engaging in; what they were realistically able to change; and how clinical or other support would influence their health and other important aspects of their lives.

Sometimes, potentially useful information was unavailable because patients were, for various reasons, unaware of issues or reluctant to disclose things (Q11). And sometimes clinicians saw a need to interpret what someone *did* say with caution, for example because it was possible they were downplaying behaviour or symptoms they were embarrassed about, or more concerned to please the clinician than to describe their behaviour accurately (Q12,Q13).

Clinicians' uncertainty about what, realistically, people *could* do and achieve in terms of condition management reflected their awareness that:

- people sometimes over- or under-estimate their ability;
- the progression of health conditions and responses to medication are variable and somewhat unpredictable; and
- dynamic aspects of people's health and social circumstances can constrain their scope to act.

As one clinician explained it, outcomes are sometimes unpredictably poor because "life throws shit in the works" of people's motivation, actions and achievements.

On the more optimistic side of what life throws at people, some clinicians also noted that patients could always surprise them when unforeseen events in their lives served as "catalyst[s]" or "triggers" for positive changes in their health-related attitudes and behaviours. This hope seemed to underpin a strategy which several clinicians mentioned, of sometimes "parking" the health issues on their professional agendas but "keeping the door open" for patients and "trying again" later. Again, however, there could also be practical and ethical uncertainty about when and how to do this.

And more generally, several clinicians acknowledged in various ways that the impacts of their support were to some extent unpredictable. In part these uncertainties arise because of interactional complexities associated with people's particular histories, characteristics and circumstances.

3.3. Practising person-centred care

Shades of qualitative difference across our interviews suggest that the more deeply clinicians attend to patients' personal situations and perspectives, and the more broadly they consider what matters in life, the more aware they are likely to be of tensions and uncertainties in their work. As the quotation in our title suggests, the practice of person-centred approaches may foster a greater appreciation of the challenges they entail.

Some clinicians seemed more alert than others to the scope for supportively intended healthcare to fall short of the respect and enablement entailed by person-centred care. They mentioned, for example, the potential to cause emotional damage, fail to respect what matters to people, otherwise undermine aspects of people's autonomous agency, and inadvertently foster dependency. Such awareness did not seem to stop clinicians from getting on with supporting people with long-term conditions. It did, however, seem to be associated with careful reflection on their practice and some humility about both what they could achieve and the extent to which they were right. Some clinicians who articulated the tensions and uncertainties of respectful and enabling practice particularly clearly had roles in professional education, clinical supervision and/or service development. The exposure these roles provide to others' perspectives might have facilitated their reflection on a wider range of practice-based examples and different opinions about the balances required in person-centred working.

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4. Discussion and conclusion

4.1. Discussion

Our data and analysis have illuminated some particular kinds of tensions and uncertainties that can arise when clinicians seek to support people in person-centred ways. We suggest that the need for clinicians to strike sometimes tricky balances is inherent to person-centred approaches. There are several reasons for this. First, person-centred approaches pursue a plurality of goals relating to patients' autonomous agency and agendas, as well as professional perspectives on their health. Actions oriented to one or more of these goals can sometimes limit or undermine the achievement of others. Second, efforts to enable people can for various reasons be disempowering or otherwise harmful: there is something of a paradox to be navigated when intervening to support someone's autonomous agency. Third, there can be sometimes intractable and interlinked uncertainties about (i) what matters to and for someone and (ii) their health and realistic scope for improvement in their lives – with or without particular kinds of support.

The tensions and uncertainties of person-centred working that we have illustrated have not received much attention in the literature on support for self-management to date. There is, however, no reason to think they are peculiar to the practice of the diverse clinicians who participated in our study, or an aberrant artefact of our questions or analysis. They *can* be seen to some extent in some other studies in which clinicians have discussed supporting people with long-term conditions [e.g. 25–27], and they have been readily recognised by clinicians who have participated in our knowledge exchange events or otherwise discussed our project with us.

We will briefly speculate why the tensions and uncertainties we have identified have not been widely discussed to date, before considering their implications for the promotion and recognition of person-centred support.

One reason that the tensions and uncertainties we have highlighted may have been neglected in previous research is that person-centred approaches are not used universally. Clinicians vary in the extent to which they attend to patients' autonomous agency and agendas and so bring these tensions and uncertainties to light. In addition, clinicians who do adopt person-centred approaches will not have equal confidence and facility in discussing the tensions and uncertainties they experience, especially while these are not widely spoken of.

However we suggest that the main reason for the neglect of these tensions and uncertainties may be that much discourse about self-management support draws on very narrow frames of reference. For example, it often focuses on individual patients' knowledge, skills, confidence and preference-based choices [28], and sometimes links these simplistically to biomedical health outcomes, neglecting richer realities such as the deeply social nature of autonomous agency and the inherent complexity of interpersonal support and healthcare. These neglected richer realities are key sources of the tensions and uncertainties we have focused on. If the broader aspects of human experience and social life are not included within the frames of reference of clinical practice and research, there is a risk that tensions and uncertainties will be missed even when they are most acute (for example, when patients are struggling with mental health problems alongside other conditions, or are socioeconomically disadvantaged in ways that limit their agency and might mean they have priorities quite different from their clinicians').

Whatever the reasons for the relative lack of discussion to date, these tensions and uncertainties have important implications for the pursuit of person-centred support. This becomes more apparent in the light of calls to move beyond reductive, mechanistic and technicist approaches to person-centred care, evidence-based medicine and shared decision-making. Several authors have highlighted the need to attend more carefully to, for example: patients' experiences and existential concerns; the emotional and relational dimensions of health care; the complexity of both patients' and clinicians' embodied, biographically and socially influenced and reflective thought; and the full range of human values and capabilities as well as the social arrangements that influence these [12,29–32]. Attention to these – which we agree is important – will render tensions and uncertainties more evident, and consideration of how clinicians can best deal with them more urgent.

Clinicians have to navigate the tensions and uncertainties of working with patients' autonomous agency and agendas somehow. If we are concerned about the quality of healthcare, it is important that they are supported to navigate them well. Recognition of the key areas and sources of tension and uncertainty associated with person-centred approaches is one important aspect of what is required. We hope that the work reported here will facilitate this recognition – at the level of health systems as well as of individual clinicians. We anticipate our analysis will be extended by further empirical study and conceptual refinement, perhaps including the extension of typologies of medical uncertainty [33,34] and a linking to work on epistemic (in)justice in healthcare [35].

The question of what constitutes a good handling of the tensions and uncertainties of person-centred working is philosophically as well as empirically challenging [36]. Here we can only offer a few observations. First, our study suggests that a shift to person-centred practice makes it more necessary than ever for ethical analyses of healthcare to take seriously the ambiguities of inter-subjectivity and relationships of care [37]. Second, person-centredness has the characteristics of an essentially contested concept [38], so we cannot expect consensus about exactly which supportively intended practices are 'most person-centred' or how that should be established in any particular situation. This does not mean there is no possibility of any useful consensus, but it does suggest a need for some flexibility combined with constructively critical discussions about good practice. Third, the judgement calls required for respectfully enabling practice seem to demand a kind of phronesis or practical wisdom among clinicians [39]. Work will be needed to develop accounts of how such phronesis can be recognised and fostered, and attention must be paid to basic and continuing professional education and to clinical work environments and the opportunities they offer to exercise it. Some experienced clinicians in our study expressed concerns that current approaches to professional education, performance management and the pursuit of systemic efficiencies would make it harder for less experienced colleagues to provide responsive and enabling support and to learn to make good judgement calls in doing so.

4.2. Conclusion

Approaches to support for self-management that take patients seriously as moral agents and orient professional support to enable them to live (and die) well on their own terms require clinicians to work with value tensions and uncertainties. These value tensions and uncertainties are arguably inherent to person-centred practice and relevant beyond work with people with long-term conditions.

4.3. Implications for practice

The value tensions and uncertainties that clinicians can experience when they seek to work responsively with patients'

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autonomous agency and agendas are not obviously reflected in the somewhat simplistic ideas that underpin much policy advocacy of self-management support and many service or practice development tools and evaluation strategies. If these tensions and uncertainties are not acknowledged and discussed, progress in person-centred support for self-management is likely to be limited. Future research should investigate how clinicians can be supported to understand and work well through the tensions and uncertainties of person-centred practice. The findings should inform professional education, service development, performance assessment and quality improvement work.

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Author contributions

The study was originally conceived in discussions between VE, AC and IW. VE was principal investigator. VE, AC, IW, ZS, JO, HM and SC all contributed (in team meetings and via email) to the development of the study design and approaches to data generation (including interview topic guides). ZS and JO conducted the individual interviews. VE, AC, IW, ZS, JO, HM and SC all read and discussed a sample of transcripts and contributed to the development of an initial coding frame, which was led by VE, JO and ZS, and applied by ZS and JO. All authors contributed to discussions about the interpretation of data and development of a conceptual account of support for self-management. The development of the analysis of tensions and uncertainties reported here, and the drafting of this manuscript, were led by VE and AC. All authors have read and approved the final version.

Data statement

The interview and group discussion transcript data that support this analysis may be available on reasonable request from the principal investigator [VE]. They are not publicly available in their entirety as they contain information that could compromise research participant privacy and consent agreements.

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