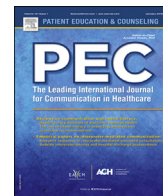




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“The more you know, the more you realise it is really challenging to do”: Tensions and uncertainties in person-centred support for people with long-term conditions

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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 review of literature examining clinicians' perspectives on self-management support [11];
- individual interviews exploring clinicians' experiences and perspectives on success [24];
- subsequent group discussions with clinicians to help develop the interpretation of the interviews and test alternative descriptions of self-management support [24];
- a series of knowledge exchange events with broader stakeholders; and
- 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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