PROs for personalized care: patient perspectives on potential use of the Long-Term Conditions Questionnaire (LTCQ) in clinical practice

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Background

- High burden and increasing complexity of long-term health conditions (LTCs)
- The UK Government and England’s National Health Service are committed to outcomes-focused service delivery for LTCs (Domain 2, NHS Outcomes Framework)
- The ‘House of Care’ model encourages person-centred collaboration within the health system, but it is not clear how the model will be applied to clinical practice.

Methods

1. Patients were randomly selected by eight primary care practices in southern England, on the basis of having one of ten specified LTCs
2. Eligibility for the study was checked by the research team when patients made contact to arrange an interview
3. Audio-recorded semi-structured interviews were conducted, usually at the participant’s home, with 42 people living with diverse LTCs
4. Interviews were transcribed and analysed using an iterative coding framework (described in Peters et al. 2016)
5. Data coded under the theme ‘value of a long-term conditions questionnaire’ were further analysed for sub-themes

Results

Participants indicated that a PRO for LTCs would be most useful to them as a tool for informing individual-level care. They signalled the PRO’s value as a ‘conversation starter’ with health and social care professionals, as a means of prompting and structuring discussion on issues that concerned them. Some participants also indicated its value for capturing changes in their health status over time, potentially opening dialogue with health professionals across multiple services about unmet need.

Conclusions

Patients’ perceived value of the LTCQ aligns with aims to extend the use of patient-reported outcome measures beyond population-level monitoring, i.e. for informing individual-level care. As a PRO that taps into broad domains of living well with LTCs, the LTCQ could be used by individual patients to facilitate routine health reviews and communication across multiple services. The LTCQ could thus play a role in operationalizing current policy goals, such as enhancing personalized care planning and encouraging coordination across health and social care.

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