

Item Generation for the Long-Term Conditions Questionnaire (LTCQ): Qualitative Interviews with Patients

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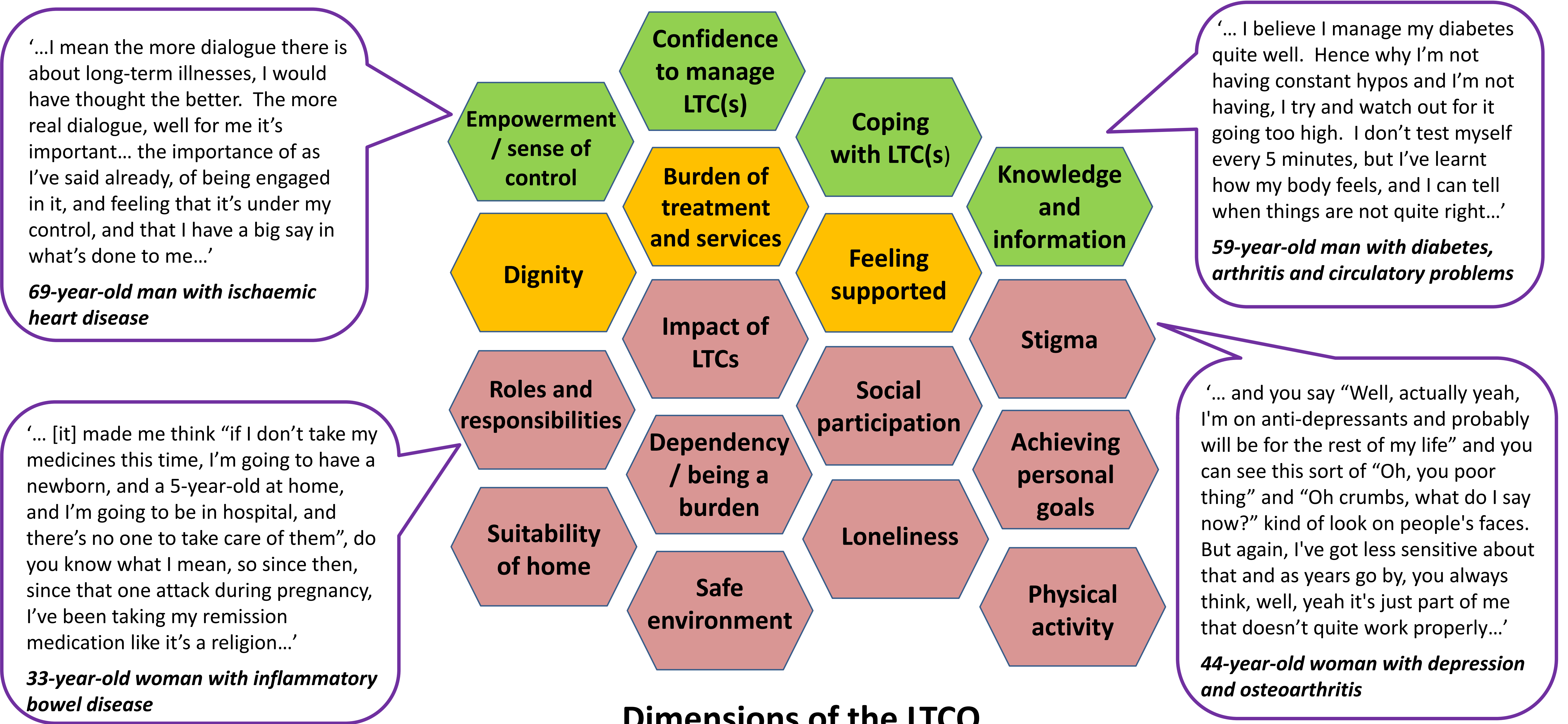
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Introduction

- Long-term chronic conditions are the main challenge of health and social care services today due to their increasing prevalence and complexity (including multi-morbidity).
- Monitoring PROMs scores is a key focus of UK health care policy, with the EQ-5D the current measure of choice.
- The EQ-5D does not capture all issues of importance for people living with long-term conditions (LTCs). Professional and lay stakeholders support the idea of a new measure for LTCs.
- The aim of this work was to develop items for the Long-Term Conditions Questionnaire (LTCQ),** a short self-report measure for people living with a broad range of LTCs.
- The LTCQ is intended to be used across both health and social care services, on its own or as a complement to the EQ-5D.

Methods

- 1 • Random selection of patients with at least one of ten selected LTCs, identified by eight primary care practices in southern England
- 2 • Verbal eligibility check by the research team when patients made contact to arrange an interview
- 3 • Audio-recorded semi-structured interview, usually at patient’s home
- 4 • Interviews transcribed, analysed using an iterative coding framework
- 5 • Data were supplemented by six interviews from a previous study with schizophrenia patients, as none were recruited through primary care



Participants (N=48)

- 42 recruited through primary care, 6 from a previous study
- 26 men, 22 women. Age range 29-97 years (average 60 years)
- 40 white British or Irish, 4 South Asian, 2 white European, 1 black British, 1 Middle Eastern
- 23 single morbidity, 25 multi-morbidity
- Representation from selected LTCs:** cancer (5 participants), chronic obstructive pulmonary disease (3), depression (3), diabetes (14), inflammatory bowel disease (4), ischaemic heart disease (6), multiple sclerosis (7), osteoarthritis (10), schizophrenia (6), stroke/TIA (5)
- Participants experienced **23 co-morbidities** in addition to the ten LTCs for which they were recruited into the study.

Summary

- The LTCQ is a new measure for assessing outcomes in people living with long-term conditions.
- Participants in qualitative interviews experienced a wide range of LTCs, including physical and mental health and multi-morbidity.
- 17 dimensions underpinned the first 23-item draft of the LTCQ. These dimensions reflect three overarching themes: **impact of LTC(s), experience of services and support**, and **self-care** (pink, yellow, and green in figure above).
- The LTCQ will undergo further refinement through cognitive testing and validation through a large-scale survey.

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