Experiences of long-term life-limiting conditions among patients and carers: what can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease?

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ABSTRACT

Objectives: To summarise and synthesise published qualitative studies to characterise factors that shape patient and caregiver experiences of chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD) and chronic kidney disease (CKD).

Design: Meta-review of qualitative systematic reviews and metasyntheses. Papers analysed using content analysis.

Data sources: CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus and Web of Science were searched from January 2000 to April 2015.

Eligibility criteria for selecting studies: Systematic reviews and qualitative metasyntheses where the participants were patients, caregivers and which described experiences of care for CHF, COPD and CKD in primary and secondary care who were aged ≥18 years.

Results: Searches identified 5420 articles, 53 of which met inclusion criteria. Reviews showed that patients’ and caregivers’ help seeking and decision-making were shaped by their degree of structural advantage (socioeconomic status, spatial location, health service quality); their degree of interactional advantage (cognitive advantage, affective state and interaction quality) and their degree of structural resilience (adaptation to adversity, competence in managing care and caregiver response to demands).

Conclusions: To the best of our knowledge, this is the first synthesis of qualitative systematic reviews in the field. An important outcome of this overview is an emphasis on what patients and caregivers value and on attributes of healthcare systems, relationships and practices that affect the distressing effects and consequences of pathophysiological deterioration in CHF, COPD and CKD. Interventions that seek to empower individual patients may have limited effectiveness for those who are most affected by the combined weight of structural, relational and practical disadvantage identified in this overview. We identify potential targets for interventions that could address these disadvantages.

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Strengths and limitations of this study

- This is the first synthesis of qualitative systematic reviews focusing on patient and carer experience of life-limiting chronic conditions that consider them against pathophysiological deterioration towards the terminal phase of illness.
- The review builds on systematic review and analysis to develop a robust conceptual model of the factors that shape patient and caregiver expectations and choices about help seeking and self-care, and which shows how these are the products of rational decisions and experiential processes.
- The review demonstrates the value of qualitative research that identifies and characterises important aspects of patient experience and health and healthcare-related behaviours.
- The review provides proposed domains of patient and caregiver experience that may represent potential targets for new interventions to support patients and caregivers to improve capacity and better manage workload to promote improved experience of illness.
- This is an overview of a heterogeneous set of papers and as such there was considerable variability in research aims, methods and perspectives which is a limitation of the study.
INTRODUCTION

Globally, health services are responding to an increasingly older population characterised by complexities of multimorbidity that include long-term life-limiting conditions. As the burden of disease grows, so too does another kind of problem—burden of treatment—which occurs as the work of disease management has been shifted from formal healthcare provision to self-management at home. This shift has been a major focus of policy effort in health services that deliver care for people with long-term conditions. However, for a significant proportion of people with chronic and often life-limiting conditions, illness trajectories are characterised by major disruptions. They include increasingly frequent cycles of hospital admission and discharge, supported self-management at home and readmission as exacerbation events occur. Here, there is a complex balancing act to be performed around the work of being a patient. This involves managing the limiting effects of symptoms while also managing complex therapeutic regimens, self-monitoring technologies and assessment regimes, and interactions with healthcare providers and organisations. These admission–discharge–readmission cycles may lead to increasing experiences of complex workload for patients and their carers which can sometimes be overwhelming and may have important effects of quality of life.

Understanding the parameters of patient workload and the experiences of complexity that stem from it has recently become an important focus of research on long-term conditions, and has led to modelling work that has focused on the relationships between treatment burden, symptom burden and healthcare systems. This has taken place against the background of a programme of policy and practice development that, internationally, focuses on reworking the sick-role and rethinking the relationship between the sick person and healthcare system, and understanding the dynamic role of social networks in supporting them. Yet problems remain in the way that researchers, clinicians and policymakers understand patients with long-term conditions. In policy terms, this group is sometimes seen as the source of inappropriate and excess demand on primary care services and emergency departments. These factors are becoming increasingly important as healthcare systems find themselves under significant pressure to control costs and reduce spending.

Much clinical and health services research on long-term conditions focuses on controlling symptoms or delaying their onset—achieving equilibrium, even when this may be punctuated by acute exacerbation events—but in this paper, we are concerned with the experiences of people with chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD) and chronic kidney disease (CKD) as they approach the terminal phase of their illness. Here, factors leading to pathological deterioration limit their capacity to participate independently in self-management and healthcare processes. As this happens, they experience new dependencies on health services and new demands on informal networks that provide care and social support. All of these factors must be balanced against the wider demands of everyday life, and we need to better understand how these problems are framed and experienced by people with long-term conditions, and this review aims to ‘identify, characterise and explain the common factors that shape patient journeys through care in CHF, COPD and CKD in order to inform future intervention development.

METHODS AND ANALYSIS

Eligibility criteria

This is a systematic review including data from qualitative reviews and the eligibility criteria for study inclusion have been developed using the PICO (participants, interventions, comparators and outcomes) framework (box 1).

Inclusion and exclusion criteria

We included papers that met the PICO criteria (box 1) and were published in English reporting qualitative reviews of patients’ or caregivers’ experiences of healthcare provision. Some of these studies also included the views of health professionals. Mixed methods reviews were included if analysis of primary qualitative studies could be clearly differentiated from analysis of other kinds of primary studies in the text. Papers were excluded if they were: reports of treatment; reports of healthcare organisation or delivery which were not concerned with patients’ or caregivers’ experience; summaries or discussions of the literature or editorials, notes, letters and case reports.

Searches and information sources

Searches were conducted in the following bibliographic databases: MEDLINE(R) In-Process and Other

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**Box 1** PICO criteria for including studies

- **Population:** Patients (aged >18 years and diagnosed with chronic heart failure, chronic kidney disease or chronic obstructive pulmonary disease), and formal or informal caregivers and health professionals in healthcare settings (including triage services, emergency departments, in-patient hospital care, outpatient/ambulatory care departments, primary care service/family practice doctor’s offices, community nursing services or at home).
- **Intervention:** Experiences of healthcare provision.
- **Comparator:** This review not limited to comparator studies. Where comparators are present these may include: usual care or control groups.
- **Outcomes:** Qualitative data on patients and caregivers experiences of care for those with chronic heart failure, chronic obstructive pulmonary disease or chronic kidney disease.
- **Study type:** Secondary studies (qualitative or mixed method systematic reviews, qualitative meta-syntheses and meta-ethnographies).
Non-Indexed Citations and MEDLINE(R); Embase; CINAHL Plus; Science Citation Index Expanded; Social Sciences Citation Index; Arts and Humanities Citation Index; PsycINFO; and Scopus. Searches were completed by April 2015 and identified papers published between 1 January 2000 and 31 December 2014. Full details of the search strategy are provided in figure 1.

Study selection and data extraction
All titles and abstracts were screened independently by AC and CRM or AC and MM. Screening of full-text articles was undertaken independently by AC and CRM with assistance from JH. Disagreements about eligibility for inclusion at title and abstract screening stage were resolved by discussion and majority vote; disagreements about inclusion at full-paper screening were resolved by discussion, or by referral (n=3) to colleagues not involved in this review.

Quality assessment
Although there are now several quality assurance frameworks for assessing primary qualitative studies,29–31 there are none that are generally accepted for meta-reviews of such studies. Quality appraisal of included papers was conducted retrospectively at the request of the journal, and was undertaken using a tool that combined elements of the AMSTAR32 and CASP33 34 instruments. The tool is shown in online supplementary appendix 1. Each paper was appraised independently by two researchers. Overall scores were expressed as a percentage. Papers scoring over 80% were awarded a high (H) quality rating, those between 60% and 80% a medium (M) rating and papers scoring below 60% were attributed a low (L) rating. No papers were excluded on grounds of quality, and agreement statistics were not calculated. Results of this exercise (presented in tables 1–3) should be treated with considerable caution because this meta-review includes studies using integrative (mixed methods) reviews, thematic analyses and qualitative metasyntheses applied in very different ways by their authors.

Data analysis and synthesis
Formal data for analysis consisted of the discussion and conclusions sections of each included paper, and a qualitative content analysis35 36 of attributions within these was undertaken. An attribution is a statement that characterises a state and that relies on a causal inference or explanation about the supposed antecedents of that state.37 Attributions were identified on (1) patient and caregivers’ experiences of illness and journeys through care, (2) experiences of healthcare practices and (3) evaluations of illness and healthcare practices. Each identified attribution was matched to any causal inferences and explanations for it that were made by authors. Where such explanations could not be directly linked to an attribution about patient or caregiver experience, they were

Figure 1 Search strategy.

May CR, et al. BMJ Open 2016;6:e011694. doi:10.1136/bmjopen-2016-011694
| Review                  | Year | Type of review                        | Phenomena of interest                           | Number of qualitative studies included | Key aim(s)                                                                 | Quality score |
|-------------------------|------|--------------------------------------|-------------------------------------------------|----------------------------------------|-----------------------------------------------------------------------------|---------------|
| Molloy et al<sup>38</sup> (UK) | 2005 | Mixed methods (integrative) review    | Role of family caregivers                         | 3/16                                   | Evaluate effect of CHF on caregivers’ well-being; evaluate role of caregivers in management of CHF; outline policy and practice implications of current studies | 77% M         |
| Yu<sup>39</sup>          | 2007 | Qualitative systematic review with thematic analysis of qualitative studies | Older people’s experiences                       | 14                                     | Synthesising qualitative studies of people with CHF to advance understanding of lived experience and inform intervention and service development                                                                 | 94% H         |
| McEntee et al<sup>40</sup> (USA) | 2009 | Mixed methods (integrative) review    | Barriers to CHF care                             | 15                                     | To synthesise research on barriers to CHF care at patient, provider and system levels                                                                                       | 61% M         |
| Westland et al<sup>41</sup> (UK) | 2009 | Qualitative integrative review of living with heart failure | Experiences and perceptions of people living with CHF | 18                                     | To explore the experiences and perceptions of patients who have heart failure                                                                                                                                                   | 77% M         |
| Hopp et al<sup>42</sup> (USA) | 2010 | Systematic review with thematic analysis of qualitative studies | Older people’s experiences                       | 15                                     | Understand the ‘lived experience’ of CHF among older people to inform social work practice with this group                                                                                                                      | 72% M         |
| Jeon et al<sup>43</sup> (Australia) | 2010 | Narrative review                      | Experience of living with CHF                    | 30                                     | Conduct a narrative review of qualitative studies of people’s experiences of living with CHF to develop a wide-ranging understanding of the patient experience of CHF                                                                 | 77% M         |
| Barclay et al<sup>44</sup> (UK) | 2011 | Systematic review with narrative synthesis of qualitative studies | End-of-life care in CHF                          | 17/23                                  | Identify patient and professional preferences around end-of-life conversations in CHF, and to identify barriers and facilitators of these conversations                                                                 | 77% M         |
| Dev et al<sup>45</sup> (USA) | 2011 | Qualitative metasynthesis             | Self-care CHF with comorbid conditions           | 3                                      | Identify and characterise factors that affect integration of CHF self-care with other comorbid conditions                                                                                                                             | 38% L         |
| Dickson et al<sup>46</sup> (USA) | 2011 | Systematic review with thematic analysis of qualitative studies | Self-care in CHF with comorbidities              | 3                                      | Identify and characterise aspects of self-care for CHF that are complicated by comorbidities                                                                                                                                         | 55% L         |
| Kang et al<sup>47</sup> (China) | 2011 | Qualitative metasynthesis             | Role of family caregivers                         | 10                                     | Synthesise qualitative studies of caregivers’ experiences of CHF to inform nurses as they support families affected by CHF                                                                                                              | 94% H         |
| Low et al<sup>48</sup> (UK) | 2011 | Systematic review with thematic analysis of qualitative studies | End-of-life care                                 | 28/48                                  | Explore studies on patient and professional understandings of disease processes and perceived needs and experiences of care provision in palliative care for CHF                                                                 | 77% M         |
| Tierney et al<sup>49</sup> (UK) | 2011 | Qualitative systematic review with framework analysis | Physical activity                                | 20                                     | Identify barriers and facilitators of physical activity in CHF and identify beliefs and behaviours that could be targeted by interventions to promote activity                                                                 | 88% H         |
| Thomas and Clark<sup>50</sup> (Canada) | 2011 | Qualitative metasynthesis             | Sex and gender                                   | 5/6                                    | Identify and understand sex-related and gender-related factors that shape women’s self-care beliefs and behaviours in CHF                                                                                                               | 83% H         |
| Review          | Year  | Type of review                                      | Phenomena of interest                                      | Number of qualitative studies included | Key aim(s)                                                                                                                                  | Quality score |
|-----------------|-------|----------------------------------------------------|------------------------------------------------------------|----------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| Clark et al⁵¹   | 2012  | Qualitative metasynthesis                          | Help-seeking decisions and behaviours                      | 58                                     | Identify and characterise elements of help seeking in CHF and model the main factors and processes associated with help-seeking decisions     | 94% H        |
| Jani et al⁶²     | 2012  | Qualitative systematic review with framework analysis | Treatment burden in heart failure at end of life           | 16                                     | Identify, characterise and explain workload associated with treatment burden in CHF                                                      | 83% H        |
| Procter⁵³       | 2012  | Qualitative systematic review with thematic analysis of qualitative studies | Contribution of palliative care specialists to end of life care | 5                                      | Identify barriers to collaborative working in palliative care, and characterise CHF patient and carer expectations and needs                | 83% H        |
| Rolls and Young⁵⁴ | 2012  | Discourse analysis                                 | CHF from the perspective of older women                    | 4                                      | From a feminist standpoint, to critically apprehend women’s lived experiences of CHF from the perspective of women themselves              | 77% M        |
| Buck et al⁶⁵     | 2013  | Systematic review with content analysis of qualitative studies | Caregivers’ contributions to self-care                     | 13/30                                  | Identify and characterise specific activities by which caregivers contribute to self-care beliefs and behaviours in CHF                  | 88% H        |
| Falk et al⁶⁶     | 2013  | Mixed methods (integrative) review                 | Lived experience of CHF among older patients               | 5/23                                   | Synthesise knowledge about self-reported symptoms, illness experience and self-care management by older patients with CHF                  | 77% M        |
| Siabani et al⁶⁷  | 2013  | Qualitative metasynthesis                          | Factors that promote or inhibit self-care                  | 23                                     | Identify the factors that prevent optimal engagement with self-care regimens to inform future intervention development                   | 77% M        |
| Sookhoo et al⁶⁸  | 2013  | Qualitative metasynthesis                          | Participation in CHF self-management education programmes   | 8                                      | Synthesise studies about experiences of educational interventions to support people with CHF in self-care                               | 83% H        |
| Clark et al⁶⁹    | 2014  | Qualitative metasynthesis                          | Patients and caregivers’ perceptions of effective self-care | 49                                     | Synthesise studies about the determinants of effective self-care in CHF, identify and characterising experiences                         | 83% H        |
| Dekker⁷⁰         | 2014  | Qualitative systematic review with thematic analysis of qualitative studies | Experiences of depressive symptoms                          | 13                                     | Identify and characterise the contributing factors, role and effects of depressive symptoms in shaping experiences of CHF                 | 44% L        |
| Harkness et al⁷¹ | 2014  | Qualitative metasynthesis                          | Strategies for self-care                                   | 47                                     | Identify strategies used by people with CHF to accommodate self-care techniques in daily life and characterise elements of social context that affect self-care in CHF | 83% H        |
| Strachan et al⁷² | 2014  | Qualitative metasynthesis                          | Contextual factors that influence self-care                | 45                                     | Identify and characterise elements of social context that affect self-care in CHF                                                        | 83% H        |
| Wingham et al⁷³  | 2014  | Meta-ethnography                                   | Attitudes, beliefs, expectations and experiences of self-management | 19                                     | Develop an explanatory model of patients’ attitudes, beliefs, expectations and experiences of self-management in CHF that could inform the development of future self-management strategies | 88% H        |

CHF, chronic heart failure.
Table 2  Summary of overview of qualitative systematic reviews and metasyntheses of experiences of COPD

| Review                  | Year | Type of review                        | Phenomena of interest                             | Number of qualitative studies included | Key aim(s)                                                                 | Quality score |
|-------------------------|------|---------------------------------------|---------------------------------------------------|----------------------------------------|----------------------------------------------------------------------------|---------------|
| Gysels et al<sup>64</sup> (UK) | 2007 | Qualitative systematic review with thematic analysis of qualitative studies | Experiences of breathlessness                      | 22                                     | Synthesise qualitative evidence about breathlessness as a common symptom of multiple conditions, including COPD (and CHF) | 83% H         |
| Cullen and Stiffler<sup>65</sup> (USA) | 2009 | Qualitative metasynthesis              | Experiences of oxygen therapy                      | 4                                      | Identify and characterise new evidence about patients’ perspectives on oxygen therapy in COPD and other conditions to guide intervention development | 83% H         |
| Disler et al<sup>66</sup> (Australia) | 2011 | Mixed methods (integrative) review     | Factors that promote or inhibit self-care          | 13/44                                  | Identify and characterise factors that influence self-care in COPD          | 88% H         |
| Keating et al<sup>67</sup> (Australia) | 2011 | Mixed methods (integrative) review     | Barriers to participation in rehabilitation        | 5/11                                   | Identify and characterise factors that affect attendance and participation in pulmonary rehabilitation for COPD | 88% H         |
| Kirkpatrick et al<sup>68</sup> (UK) | 2012 | Qualitative metasynthesis              | Patients and caregivers’ perceptions of support    | 39                                     | Identify and characterise forms and experiences of support for people with COPD from informal and formal caregivers, and identify and characterise those forms of support believed to be beneficial | 77% M         |
| Giacomini et al<sup>69</sup> (Canada) | 2012 | Qualitative metasynthesis              | Experiences of living and dying with COPD          | 101                                    | Synthesise studies of people with COPD and their informal caregivers, identify and characterise insights into their experiences and inform future interventions | 88% H         |
| Thorpe et al<sup>70</sup> (Australia) | 2012 | Mixed methods (integrative) review     | Participation in physical activity                 | 8/11                                   | Identify and characterise barriers and enablers of participation in physical activity, including pulmonary rehabilitation, among people with COPD | 94% H         |
| Langer et al<sup>71</sup> (UK) | 2012 | Qualitative metasynthesis              | Use of unscheduled/emergency care in long-term conditions | 5/42                                  | Identify and characterise the range of psychosocial and other influences on use of unscheduled care by people with long-term conditions, including COPD and CHF | 83% H         |
| Momen et al<sup>72</sup> (UK) | 2012 | Qualitative systematic literature review and narrative synthesis | End-of-life conversations                          | 12/30                                  | Identify factors that promote or inhibit discussions of management of end of life in COPD | 66% M         |
| De Souza Pinto et al<sup>73</sup> (Spain) | 2013 | Meta-ethnography                      | Impact of pulmonary rehabilitation                 | 8                                      | Explore the lived experience of COPD and identifying positive and negative aspects of pulmonary rehabilitation from the perspective of people with COPD | 94% H         |
| Harrison et al<sup>74</sup> (UK) | 2013 | Qualitative metasynthesis              | Impact of acute exacerbation events in COPD        | 8                                      | Identify and characterise people’s experiences of exacerbation events that inhibit engagement with pulmonary rehabilitation in COPD | 100% H        |
| Disler et al<sup>75</sup> (Australia) | 2014 | Qualitative metasynthesis              | Lived experience of COPD                           | 22                                     | Identify and characterise the lived experience of COPD and inform the development of healthcare services | 83% H         |
| Oishi et al<sup>76</sup> (UK) | 2014 | Mixed methods (integrative) review     | Provision of palliative care for patients with non-cancer | 17/30                                  | Identify and characterise aspects of professional role, performance and barriers and facilitators to primary palliative care | 77% M         |

CHF, chronic heart failure; COPD, chronic obstructive pulmonary disease.
| Review                        | Year | Type of review                  | Phenomena of interest                                      | Number of qualitative studies included | Key aim(s)                                                                                                           | Quality score |
|------------------------------|------|---------------------------------|------------------------------------------------------------|----------------------------------------|---------------------------------------------------------------------------------------------------------------------|---------------|
| Low et al<sup>77</sup> (UK)   | 2008 | Mixed methods (integrative) review | Impact of end-stage CKD on caregivers                       | 11/36                                  | Identify all studies exploring the impact of CKD on ‘close persons’ during and after withdrawal from dialysis, and during end-of-life care | 77% M         |
| Morton et al<sup>78</sup> (Australia) | 2010 | Qualitative systematic review with thematic analysis of studies | Views of people and carers on treatment decision-making in CKD | 18                                     | Identify patient and carer perspectives on treatment decisions, and characterise factors that shape these decisions   | 77% M         |
| Wadd et al<sup>79</sup> (Australia) | 2011 | Qualitative systematic review with thematic analysis of studies | Parents’ experiences of dialysis for CKD                   | 17                                     | Identify and characterise experiences of parenting while undergoing dialysis for CKD, to inform family-centred holistic care | 72% M         |
| Bayhakki and Hattaki<sup>80</sup> (Indonesia) | 2012 | Qualitative metasynthesis        | Experience of haemodialysis for CKD                        | 10                                     | Characterise and understand aspects of lived experience of haemodialysis                                              | 83% H         |
| Harwood and Clark<sup>81</sup> (Canada) | 2012 | Qualitative metasynthesis        | Decision-making about treatment modalities in CKD          | 16                                     | Understand how people with CKD decide on treatment modalities and to explain underuse of home dialysis                  | 83% H         |
| Makaroff<sup>82</sup> (Canada) | 2012 | Qualitative metasynthesis        | Lived experience of end-stage CKD                          | 13                                     | Understand experiences of people with end-stage CKD aiming to inform future interventions                               | 77% M         |
| Moustakas<sup>83</sup> et al (Australia) | 2012 | Mixed methods (integrative) review | Supportive care needs of older people with advanced CKD    | 4/12                                   | Identify and characterise supportive care needs of older people with advanced CKD, to inform future research and intervention design | 66% M         |
| Tong et al<sup>84</sup> (Australia) | 2013 | Qualitative systematic review with thematic analysis of studies | Perspectives of adults living with peritoneal dialysis      | 39                                     | Identify and characterise experiences, attitudes and beliefs relating to peritoneal dialysis                            | 83% H         |
| Casey et al<sup>85</sup> (Australia) | 2014 | Qualitative systematic review with thematic analysis of studies | Perspectives on haemodialysis vascular access               | 46                                     | Identify and characterise the psychosocial impact of vascular access for haemodialysis, and the concerns, beliefs and attitudes of patients during treatment. Informing strategies to maximise quality of life and quality of care | 88% H         |
| Luckett et al<sup>86</sup> (Australia) | 2014 | Mixed methods (integrative) review | Advance care planning for adults                           | 6/54                                   | Identification of advance care planning interventions and evaluations and inform understanding of barriers and facilitators to implementation | 100% H        |
| Palmer et al<sup>87</sup> (New Zealand) | 2014 | Qualitative systematic review with thematic analysis of studies | Patients view of dietary and fluid restrictions in CKD     | 46                                     | How people with CKD meet the challenge of managing complex fluid and dietary requirements, to inform clinical practice | 83% H         |
| Tong et al<sup>88</sup> (Australia) | 2014 | Qualitative systematic review with thematic analysis of studies | Women’s experiences of pregnancy and CKD                   | 15                                     | Identify and characterise factors that affect how women with CKD experience pregnancy, to inform shared decision-making processes and to optimise quality of care and quality of life | 83% H         |

Continued
traced back through the analysis presented in the results section of each review or metasynthesis. This tracing work was especially important where integrative reviews were concerned since these drew on quantitative and qualitative primary studies and we wished to exclude the former from our analysis. Related attributions and explanations were grouped together in sets and then simple explanatory propositions were formulated to characterise them. Formal analysis of textual data was undertaken by CRM and then reviewed in detail by other authors.

RESULTS
Results of searches
The review process is shown in figure 2: 10,866 possible articles were identified, and after the removal of duplicates, 5,420 were left. Of these, 847 were reviews or metasyntheses. Further screening identified 132 potentially eligible papers and full-paper reading led to 53 reviews that fully met the criteria for inclusion. These reviews consisted of 26 articles concerned with CHF38–63 (see table 1); 13 articles concerned with COPD64–76 (see table 2) and 14 studies of CKD77–90 (see table 3). Of these, most reviews focused on aspects of everyday experiences of long-term conditions with an emphasis on understanding patient and caregiver behaviours related to self-management regimens, and a subset of 10 papers explored elements of experiences of care towards end of life.44 48 52 53 69 76 77 82 86 89 These 53 reviews synthesised the results of 559 reports of primary qualitative studies.

Three types of review method are represented in this sample of papers: integrative reviews that synthesised qualitative studies alongside other studies (often cross-sectional surveys, reviews of routinely collected clinical data and case notes),38 40 56 66 70 76 77 83 86 systematic reviews of qualitative studies that employed some kind of thematic analysis,39 41–44 46 48 49 52 55 56 60 64 72 78 79 84 85 87 88 89 and reviews that were identified by their authors as qualitative meta-syntheses or meta-ethnographies.45 47 50 51 57–59 61–63 65 68 69 71 73–75 80–82 89 In addition, one paper was explicitly characterised as a discourse analysis by its authors.54 Irrespective of the method that authors stated that they had employed, the body of reviews and metasyntheses included in this synthesis were largely descriptive in their approach to data analysis.

Social structure
Socioeconomic disadvantages that play a role in structuring the unequal distribution of health problems and inequalities in access to health services were often treated as ‘contextual’ factors,49 62 70 71 73 76 and reviews emphasised the importance of social inequalities, employing broad and inclusive definitions of disadvantage that include access to transport and other socioeconomic resources, and environmental factors such as poor air quality and exposure to other sources of environmental pollution. Other structural variables, such as

| Number of qualitative studies included | Key aim(s) | Phenomena of interest | Type of review | Year | Review |
|---------------------------------------|-----------|----------------------|---------------|------|--------|
| 26                                    | Patient and caregiver perspectives on end-of-life care | Patient and caregiver perspectives on end-of-life care, informed by qualitative systematic review | Qualitative systematic review | 2014 | Tong et al (Australia) |
| 24                                    | Patient and caregiver perspectives on home dialysis | Patient and caregiver perspectives on home dialysis, informed by qualitative systematic review of studies | Qualitative systematic review of studies | 2014 | Walker et al (Australia) |

Table 3 Continued
gender and ethnicity, were not well represented at all.42 50 54 88 One demographic variable that was given consideration was age: many reviews explicitly dealt with CHF, COPD and, to a lesser extent, CKD as diseases of old age. The views of patients and caregivers were often that such diseases were a ‘natural’ consequence of ageing.

**System behaviour**

Experiences of poorly coordinated and organised care,43 45 48 52 poor communications between professionals40 45 47 48 52 and between patients and professionals42 47 were common. Even so, patients and caregivers had high expectations of clinicians, especially when they needed urgent assistance,76 even though clinicians were sometimes seen as lacking important expertise around coordinating care in multimorbidities.46 Treatment decisions were restricted not only by the quality and timing of information but also by dealing with the prospect of death.78 81 Conversations about treatment decisions were often focused on day-to-day problems of disease management,44 53 78 83 and seemed to be rarely oriented towards decisions about the future—especially about palliative and supportive care, and discontinuation of treatment (eg, implantable cardiac devices or dialysis).45 81–83 86 Reviews suggested that conversations about end-of-life issues rarely took place, either because of patients’ poor understanding of their conditions or because professionals recognise high levels of prognostic uncertainty and the risk of sudden death. When patients were aware of disease progression and potential prognosis, they were able to discuss end-of-life issues openly,53 although the key decision-maker was the clinician.44 48 83 This may mean that the life-limiting nature of disease was not apparent to patients.41 75 When it was, some patients saw living wills, and advance care plans as useful decision-making tools,77 even though these could lead to conflict and discomfort.59 Experiences of poor communications seemed to be endemic in the patient groups included in all of the reviews included in this synthesis, and common to all healthcare systems.

**Understanding disease progression and symptoms**

Reviews emphasised the importance of patients’ and caregivers’ poor understanding of disease, disease progression and the significance of symptoms.40 41 43 45 50 52 58 59 69 75 76 88 Women and older people were presented as being particularly
vulnerable to a lack of correct knowledge, and most patients were seen as ill-prepared to face their disease and symptoms. Symptom recognition was particularly challenging, in the context of comorbidity, for patients, caregivers and clinicians. Poor understanding of disease mechanisms and progression was characterised as a key source of distress for patients and caregivers. It was sometimes attributed to low levels of health literacy and to fragmented, limited and ineffective educational resources. It led to negative consequences that included failure to understand the life-limiting nature of disease; wrong beliefs about the causes of acute exacerbations of symptoms; incorrect assumptions and actions that follow from these; feelings of powerlessness over disease progression and low expectations of clinical interventions. These factors were seen to interfere with symptom management and help seeking, and adherence to self-management regimens. They were especially important where patients needed to understand how comorbidities ‘fitted’ with each other and needed to manage complex polypharmacy. Unpredictable disease progression made planning daily and longer term activities difficult and either meant that threat to life was not explicitly acknowledged, or that if it was, uncertainty interfered with planning for end of life and the initiation of palliative care.

Self-management regimes

Self-management regimes include participating in pulmonary and cardiac rehabilitation programmes; adhering to instructions about exercise and diet; adhering to often complex therapeutic regimens; operating and monitoring medical devices (such as implantable cardiac devices, or home oxygen equipment) along with other technologies and assessment regimes. Self-management also includes significant administrative and organisational work, as people with long-term conditions interact with healthcare providers and organisations. Reviews suggested that the performance of self-management tasks was valued by patients, who actively invested in them and displayed considerable resilience as they did so. They sought to overcome the disruptive effect of illness on their lives and to assimilate self-management strategies into everyday life. However, negative changes in self-identity, self-esteem, social functioning, physical capacity and experiences of social loss were common. Fear, anxiety, isolation and discomfort were consistently characterised as consequences of disease that interfered with participation in self-management. Experienced symptoms and physical limitations led to attempts to avoid physical activities in case they precipitated (potentially fatal) acute episodes. Adherence to self-management programmes was adversely affected by disruption to everyday activities and routines and by conflicts with competing self-management regimes or treatment regimens for comorbidities.

Reviews also offered evidence of adaptive processes in the face of disease progression and the disruptions that stem from this. Such adaptations included the accumulation of expertise and associated self-management strategies developed over time. Patients sought to develop strategies that would ensure better symptom control, and that increased the duration of periods between acute episodes and reduced the impact of acute episodes. Poor quality self-management instruction or interactions with health professionals could have adverse effects, especially because patients were sensitive to evidence of clinicians’ doubts about the value of different self-management strategies.

Burdens for patients and caregivers

Inequalities of access to informal support and material assistance from family and social network members, and health professionals, and problems of continuity of care, figured prominently across all three conditions. Experiences of symptom burdens (eg, breathlessness, fatigue and anxiety) were characterised as leading to affective responses. These included psychological responses to limitations on everyday activities and relationships that led to social isolation, loss of hope and fear of death. Feelings of worthlessness and burdensomeness were commonly experienced. Some reviews suggested that they were experienced more acutely by women. Against this background, social support was characterised as important, especially when it was connected with practical contributions to self-management that might include symptom monitoring and management, information gathering and interaction with health professionals and help seeking at moments of crisis. Although social support was often marked by shared experiences of solidarity and collective engagement, patients appreciated the disruptive and demanding effects of their illness on caregivers and their wider social networks. These included increased workload, and economic consequences—as well as stress, anxiety and isolation—as disease progressed. Reviews also pointed to the importance of life-sustaining interventions (eg, dialysis and implantable devices) and patient and caregiver preferences for those interventions that promoted self-efficacy and delayed disease progression. They provided opportunities to gain some control and establish a limited degree of normality. However, some patients reported heightened vulnerability, feelings of dependence and unpreparedness, along with anxiety about their capacity to perform procedures and the risks of treatment failure or complications. Using health technologies of different kinds brought only ‘temporary mastery’ over disease, and required continuous attention. This led to a constant tension between managing disease and technological supports, and the other demands of everyday life. Technologies could be intrusive because of the demands that they made on patient and caregiver time and...
assumptions about the presence and importance of two kinds of deficits. First, there is a patient deficit rooted in poor understanding and non-adherence to treatment regimens, and that is expressed through lack of motivation to participate. Second, there is a professional deficit rooted in poor communications and coordination and that is expressed in reluctance to engage in end-of-life planning. An important finding of our synthesis, however, is that these individual behaviours are linked to structural factors (eg, socioeconomic status, spatial location) and system qualities that are much more than mere ‘context’. They may act as causal mechanisms that have important determining effects on the experiences of patients and caregivers. Their role, however, is underinvestigated. Against the background of these effects, patients and caregivers value resilience, functional performance and social support that make practical contributions to self-management, and they develop cumulative expertise in negotiating self-management tasks and in navigating healthcare systems. They also carry significant burdens. The burden of symptoms—the inevitable consequences of pathophysiological deterioration—may include frightening and potentially lethal acute episodes of disease. The burden of treatment includes additional moral responsibilities, affective and cognitive demands, increased workload and economic consequences of participation in self-management and formal healthcare. Once again, these factors are underinvestigated but may also include mechanisms that likely shape patient and caregiver behaviours.

The effects of pathophysiological deterioration mean that patients and caregivers experience cognitive, affective and interactional disadvantages derived from diagnostic uncertainty. They also experience poor communications among health professionals and uncoordinated services, and they have an increasingly limited capacity to make sense of their illness and its effects. Although self-management practices, technological investments and clinical interventions are valued, they may bring only temporary gains. Their benefits are ultimately overwhelmed by disease progression and do not change its final outcome.

**Process tracing model**

An important secondary aim of this synthesis was to identify potential targets for interventions. In table 4, we identify and characterise a set of constructs that form a framework for the development of coordinated interventions that could act together to relieve the weight of structural, systemic, relational and individual disadvantages that are conferred on patients and caregivers experiencing these diseases and their comorbidities. Reducing these burdens is likely to improve patient outcomes and thus reduce system costs. However, it makes no sense to isolate them from each other. The constructs that are defined in table 4 represent phenomena that already are, or are in principle, measurable. In figure 3, we offer a logic model of the processes that link them: proposing that patient expectations and choices in the face of pathophysiological deterioration are mediated by their personal attributes (eg, socioeconomic status) as well as their experiences of healthcare, and moderated by the extent of resilience that they together with their caregivers and wider social support networks possess which may be influenced by a myriad of circumstantial factors. We need to better understand the design and implementation of interventions that might mitigate some of the key system and behavioural factors that negatively affect patient and caregiver experiences and outcomes, and that modify the chains of causation that are implicated in them.

**Limitations**

Like all evidence syntheses, ours is subject to a number of important limitations. This is an overview of a heterogeneous set of reports. There was considerable variability in research aims, perspectives and methods. There were also very significant differences in authors’ underlying assumptions about patient and professional motivation and behaviour. A limitation of syntheses of qualitative work is that these variations in assumptions and perspectives, and methodological heterogeneity, are often difficult to tease out. It is therefore not clear to what extent reviews continuously reproduce a particular set of ideas.
Table 4  Factors affecting patient and caregiver experience of long-term life-limiting conditions

| Finding                                                                 | Measurable construct | Summary results of included papers: factors that shape patient experience of long-term life-limiting conditions |
|-------------------------------------------------------------------------|----------------------|--------------------------------------------------------------------------------------------------------------|
| 1. Structural, spatial and systemic disadvantages are important factors that inhibit active engagement with formal healthcare and self-management | Socioeconomic status  | Patient experience is negatively affected by inequalities related to income,62 age and gender,39 56 54 80 and ethnicity42. Patients and caregiver experience is negatively affected by unequal access to services and transport,40 70 73 76 and unequal distribution of environmental pollution70. System quality Patients and caregiver experience is negatively affected by poor professional support and material assistance,40 70 73 76, coordination of services43 46 48 52 and intraprofessional communications,40 45 47 48 52. Limited professional expertise in multimorbidities,46 and slow professional responses to anxieties and emergencies76 are also markers of poor system quality. |
| 2. Patients and caregivers experience multiple affective, cognitive and interactional disadvantages as they seek to participate in encounters with clinicians, decisions about their formal healthcare and self-management processes | Cognitive advantage   | Patients and caregivers are cognitively disadvantaged by lack of educational resources57 83 and information.78 81. Disadvantage is exacerbated by poor understanding of disease and disease progression.40 41 43 45 46 50 52 56 58 59 64 69 75 76 88. These may lead to hypervigilance about symptoms, poor or confused symptom recognition43 45 57 64 88 and ill-preparedness for crises45. Affective state Patients and caregivers may experience changes in self-identity, along with reduced self-esteem and self-worth, and loss of social functioning.41 43 50 54 60 79 84 89. They may experience increased fear, anxiety, isolation and discomfort,49 51 57 60 70 82 and this may lead to inappropriate responses to acute episodes.42 47 57 67 71 74. Interaction quality Good professional–patient relations42 47 76 and individualised timing and type of information delivery44 53 78 83 can have a positive effect on patient and caregiver experience. Fear of death43 50 60 68 87 negatively affects patient–professional interaction. |
| 3. Patients and caregivers value resilience, functional performance and social support that make a practical contribution to formal healthcare and self-management | Adaptation to disruption | Patient and caregiver experience is positively affected by adaptive processes,43 61 63 the normalisation of experienced symptoms and physical limitations39 71 80 and normalisation of self-management strategies.63. Patient and caregiver resilience,58 61 73 84 capacity to manage uncertainty,39 42 76 82 tolerance of disruption of everyday activities and competing clinical priorities43 45 46 55 58 87 also positively affect patients experience of technology as life sustaining;45 73 as mastery;84 85 90 as burden;58 65 79 as intrusion;31 90 risks of treatment failure/complications85 90. Caregiver support Caregiver support is defined by material assistance,38 55 71 84 symptom management and self-management,57 61 65 66 and emotional and relational solidarity.47. It is negatively affected by perceived burdens and workload that interfere with normal life.38 39 76 77 81 89 90. Competence Patients and caregivers demonstrate competence when they are able to exert control over disease progression,74 effectively participate in self-management,77 understand multimorbidities69 70 and manage polypharmacy.64. Help seeking Patient and caregiver help seeking is governed by interactions between expectations of clinical interventions,76 isolation and help seeking.51 64 67 79. Help seeking is framed mainly through rational responses to emergency situations,73 and patients and caregivers valued the security and safety of hospital care.67 73. Technological support Technological interventions as life sustaining,45 73 as mastery,84 85 90 as burden,58 65 79 as intrusion,31 90 risks of treatment failure/complications85 90. Situated decision-making Patient and caregiver decision-making about help seeking and use of services was framed by the degree of awareness and uncertainty about prognosis.41 44 48 75 83. Difficulty and conflict over decisions35 86 could be ameliorated using tools and techniques to increase patient control.77 81 83. |
about why and how patient experiences and behaviours are a problem. Using an analytic approach that focuses on identifying, characterising and explaining sets of attributions brings these factors into the foreground and helps us to detect underlying conventional assumptions. We also identified all of the underlying qualitative studies covered by these reviews. It was clear that some reviews had interrogated very similar sets of primary research papers. This may also introduce problems of publication bias.

**Results in context**

To the best of our knowledge, this is the first synthesis of qualitative systematic reviews focusing on patient experience of life-limiting chronic illness. Previous primary qualitative systematic reviews about the experiences of treatment burden in those with stroke and CHF excluded carer accounts and focused on developing taxonomies of treatment burden, excluding illness burden issues and did not seek to explain factors that shape patient journeys through care. We have explored long-term life-limiting conditions from the perspective of pathophysiological deterioration. Its point of departure was a consideration of patients’ experiences of healthcare and burden of treatment in three long-term life-limiting conditions. This was situated against a background in which good decision-making about treatment, engagement with self-management and other treatment regimens, as well as conversations about end of life, are often regarded as problems of individual motivation and adherence. Many of the reviews included in this synthesis were aimed at informing professional practice and the development of interventions to support patients and caregivers with these illnesses. However, very few made concrete proposals in this regard. An analysis of this kind may be better placed to inform such work. A key finding of this synthesis is in its emphasis on what patients and caregivers value. This is not simply a matter of preferences. It also suggests that there are attributes of healthcare systems, relationships and practices that make experiences of pathophysiological deterioration worse.

**CONCLUSION**

An important implication of this review is that patient and caregiver expectations and choices are not random or arbitrary but are the outcome of an experiential process. A paradigm shift is called for in service development and research in this area. Interventions that seek to empower individual patients may have limited effectiveness for those who are most affected by the combined weight of structural, interactional and resilience factors identified in this synthesis. There are likely causal interactions between these different factors that need to be better characterised and understood, but linking service and intervention development with robust theoretical models and rigorous practically oriented research ought to be the strategic direction for this. As a start in this direction, we have proposed domains of patient and caregiver experience that may represent good targets for new interventions that respond to the combined disadvantages that they may face.

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**Figure 3** Factors that shape patient and caregiver expectations and choice.
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Experiences of long-term life-limiting conditions among patients and carers: what can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease?

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