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Qualitative Review on Domains of Quality of Life Important for Patients, Social Care Users, and Informal Carers to Inform the Development of the EQ-HWB



Clara Mukuria, PhD, Janice Connell, BSc, Jill Carlton, PhD, Tessa Peasgood, PhD, Alison Scope, PhD, Mark Clowes, MSc, Stacey Rand, PhD, Karen Jones, PhD, John Brazier, PhD

ABSTRACT

Objectives: To identify the themes to inform the content of a new generic measure, the EQ-HWB (EQ Health and Wellbeing), that can be used in economic evaluation across health, social care, and public health, based on the views of users and beneficiaries of these services including informal carers.

Methods: A qualitative review was undertaken. Systematic and citation searches were undertaken focusing on qualitative evidence of the impact on quality of life from reviews for selected health conditions, informal carers, social care users, and primary qualitative work used in the development of selected measures. A subset of studies was included in the review. Framework analysis and synthesis were undertaken based on a conceptual model.

Results: A total of 42 reviews and 24 primary studies were selected for inclusion in the review. Extraction and synthesis resulted in 7 high-level themes (with subthemes): (1) feelings and emotions (sadness, anxiety, hope, frustration, safety, guilt/shame); (2) cognition (concentration, memory, confusion, thinking clearly); (3) self-identity (dignity/respect, self-esteem); (4) “coping, autonomy, and control” relationships; (5) social connections (loneliness, social engagement, stigma, support, friendship, belonging, burden); (6) physical sensations (pain, discomfort, sleep, fatigue); and (7) activity (self-care, meaningful activities, mobility, communication, hearing, vision). Apart from physical sensations, most of the other themes and subthemes were relevant across both health and social care, including for informal carers.

Conclusions: The findings from this broad review identified themes that go beyond health and that are relevant to patients, informal carers, and social care users. The themes and subthemes informed the domains for the EQ-HWB.

Keywords: economic evaluation, EQ-HWB, informal carers, patients, preference-based measures, quality of life, social care users, QALYs, qualitative.

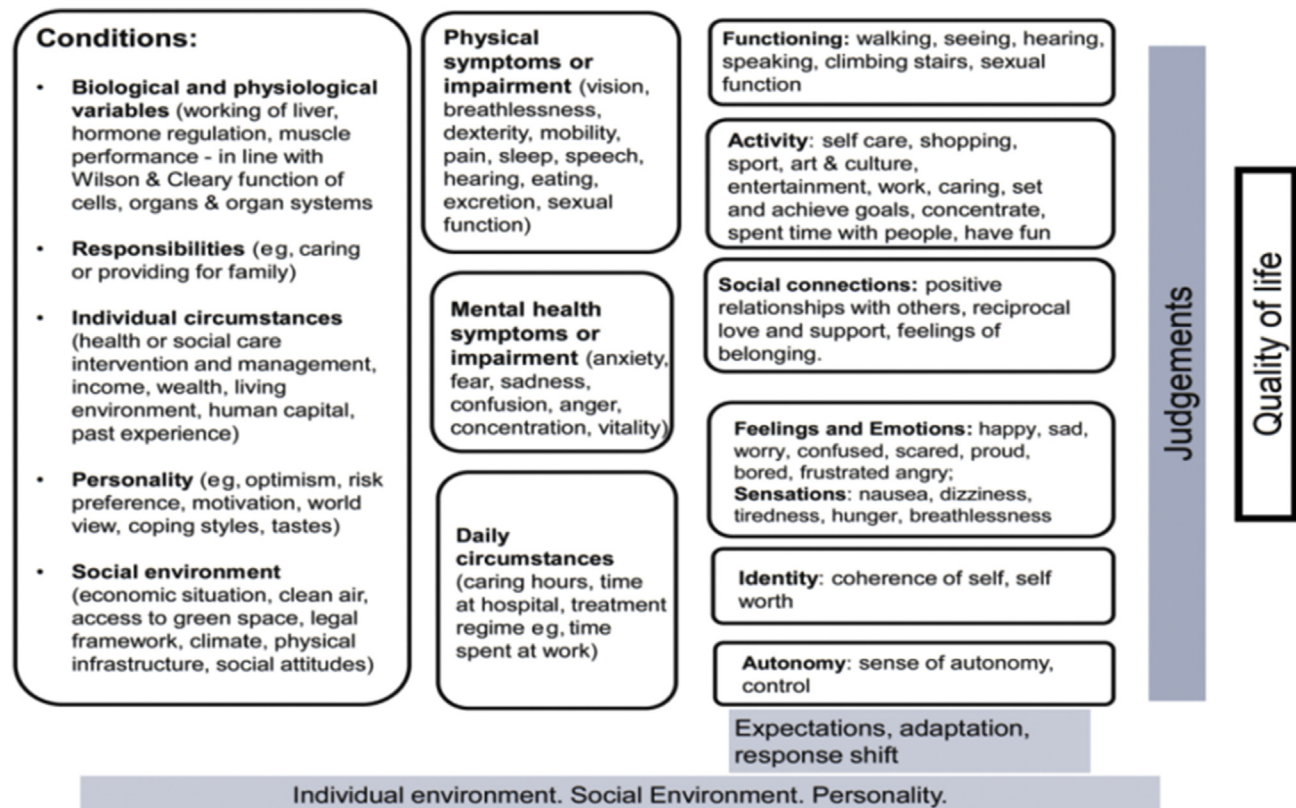
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Background

Utility values to inform the “Q” in quality-adjusted life-years (QALYs) can be generated using preference-based measures. Nevertheless, the coverage in preference-based measures may be too narrow for some areas of healthcare¹ and in contexts in which other aspects of quality of life (QoL) are important, such as supporting independence through social care.² The Extending the QALY project aimed to address this problem by developing a broader multidimensional measure of benefit within an extrawelfarist theoretical tradition.³ This article presents stage 1 of the project (see Brazier et al⁴ for further details), which aimed to identify the aspects of QoL that were considered for potential inclusion in the EQ-HWB.

Methods

The study research question was “Based on the voice of adult (aged 18 years and over) patients, social care users, and informal carers, what is the impact on QoL of health conditions and interventions (health, social care, and public health interventions)?” The aim was to produce a qualitative review to inform the content of the new measure and provide rich data from a broad range of different groups of individuals.⁵ Due to resource constraints, this review adopted a pragmatic, targeted approach focusing on a sample of qualitative reviews with supplementary information from primary studies on the development or validation of selected measures.

Figure 1. Working conceptual model.

Identification of Studies

Search strategy

QoL and related terms were used in the search. The Wilson and Cleary's⁶ model, which links biological impairments to sensations/symptoms and QoL, was extended (eg, daily circumstances were added to include carer impacts) to form the conceptual model^{3,4} (Fig. 1).

Qualitative reviews search strategy. A sample of conditions was selected to represent the spectrum of the impact of health conditions (different types of symptoms, functioning limitation, and impact; acute vs chronic, etc). Conditions were selected based on the burden of disease (years lived with a disability) in the United Kingdom using the World Health Organization Burden of Illness data from 2015.⁷ In each International Classification of Disease–10 classification system⁸ chapter 1 or more top burden conditions were selected to ensure representativeness of the chapter, for example, lower back pain and rheumatoid arthritis for musculoskeletal conditions. Each condition was also assessed against International Classification of Functioning, Disability, and Health core sets (in which these were available) to minimize redundancy across the selected conditions, for example, if 2 conditions were very similar in their impact, then only 1 was included (see Appendix 1 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.11.1371>). Eighteen conditions were identified (lower back pain, rheumatoid arthritis, depressive disorder, autistic spectrum disorder, migraine, Alzheimer's disease and other dementias, hearing loss, cataract, diabetes, asthma, dermatitis, ischemic heart disease [IHD], stroke, edentulism and severe

tooth loss, iron-deficiency anemia, breast cancer, and prostate cancer). IHD and stroke had a similar impact based on the International Classification of Functioning, Disability, and Health core sets, therefore, IHD was dropped. Search terms including the selected health conditions, informal care, and social care were used in the systematic search (Table 1 and Appendix 2 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.11.1371>). The search identified studies up to October 2017.

Primary qualitative studies search strategy. The project team and the steering group identified a list of commonly used generic health and social care measures. Two reviews were used to identify informal care measures: the reviews of Van Durme et al⁹ and Chow et al.¹⁰ Citation searches were undertaken to identify primary qualitative work from the development or testing of identified measures.

Inclusion and exclusion criteria

Reviews were included for consideration if they were qualitative including mixed methods, focused on QoL (impact of condition or interventions), and were directly elicited from adult patients, social care users, or informal carers (or a proxy when it was not possible for individuals to report their own QoL). Studies were excluded if they were only quantitative, not in English, focused only on side effects (considered too narrow), or focused only on posttraumatic growth, given that the interest is on deficits in QoL.

Primary studies were included if they were qualitative or mixed methods and were related to the development or testing of the identified measures. Studies that were only quantitative or not

Table 1. Search term definitions

Outcomes	QoL and Wellbeing and related terms - those aspects of a person's QoL or Wellbeing that are impacted by their health condition(s), health care, public health interventions, social care, and informal caring role.
Populations and measures	Patients – conditions selected on the basis of data on the burden of disease. Informal carers - anyone caring "... for a friend or family member who cannot cope on their own without support because of illness, disability, a mental health problem or drug and alcohol dependency" (source: https://carers.org/what-carer) including parents caring for children with long-term health conditions. Social care users were identified based on public or privately-funded activities that they used to support everyday living either in their own homes or in supported-living facilities. The primary focus in the review was on "social care," not social services because the latter includes other interventions related to employment and housing, among others, and groups such as children and families. Generic measures used in the populations of interest in evaluations of interventions and to assess QoL.
Methods	Qualitative reviews focused on outcomes and populations. Primary qualitative studies focused on the development of generic measures used in the populations of interest.
Language	English
Countries	A primary focus on studies from Europe, the United States, Canada, Australia, and New Zealand as these were considered the most similar to the United Kingdom.

QoL indicates quality of life.

in English were excluded. Informal care measures that focused only on the caring process, rather than QoL, were also excluded.

Screening and selection

All qualitative review titles and abstracts were screened by 1 reviewer following agreement of the process across 3 reviewers based on piloting using 1 randomly chosen condition. Two or more reviews were selected within each health condition, social care, and informal care group to ensure broad representativeness. No formal quality assessment was undertaken but the selection was based on qualitative reviews that reported clear methods, including search strategy, inclusion/exclusion criteria, synthesis methods, and original quotes.

Extraction was undertaken independently by the 4 reviewers for all the primary qualitative studies on generic and social care measures. A selection of informal care measures was selected to represent the experience of caring based on different groups, for example, caring for the elderly versus unwell adults or children.

Data Extraction and Synthesis

The framework analysis method,¹¹ which uses a thematic indexing approach to analysis was used because it is suited to analysis where a conceptual model exists. A framework based on the conceptual model (Fig. 1) was developed in Microsoft Excel (Microsoft Corporation, Redmond, Washington) and quotes or summaries were extracted into it after it was independently piloted by 3 reviewers and refined on 1 condition. Study details (see Table 2¹²⁻⁵³ and 3^{2,54-75}) were also extracted. Emerging themes and subthemes were added to the existing framework.

Thematic synthesis was undertaken to identify key themes and subthemes, associations, and key terminology. Subsequent discussions with the wider team and the stakeholder groups resulted in changes in themes/subthemes.

Theme Selection

A set of criteria for domain selection were drawn up that was related to good questionnaire design^{76,77} and the overall aims of the project to support the selection of themes and subthemes.⁷⁸ This included whether they were: (1) applicable to QoL for most of the groups; (2) not strongly related to other themes/subthemes; or (3) nonjudgmental to avoid social desirability problems and

considering what participants would be willing to disclose (eg, sexual intimacy); and not included if they were considered to be instrumental to a higher-level theme (eg, dexterity was considered to be instrumental to doing activities).

Stakeholder Involvement

Different stakeholder groups (National Institute of Health and Care Excellence staff, members of the EuroQol Descriptive Working Group, the Project Steering Group) were asked to comment on the protocol and the synthesized findings. The EuroQol Descriptive Working Group and the Steering and Advisory groups had members drawn from the United Kingdom and other countries. Members of the UK public with a health condition (not specified) or formal/informal carers of adults were recruited to a public involvement group (n = 7). The public involvement group was asked to consider which themes and subthemes they would include or exclude, and this information was considered alongside the synthesis of the results from the review.

Results

Study Selection

A total of 33 qualitative reviews were included for health conditions (Fig. 2 and Table 2^{12,22-53}). Reviews for chronic headache, vision loss and age-related macular degeneration, and systemic sclerosis were included for migraine, cataract, and dermatitis; none was included for anemia. A qualitative review of QoL in all mental health conditions that was identified separately, Connell et al,¹² was also included. Four informal qualitative reviews were selected based on the individuals being cared for (general¹³ and those caring for individuals with dementia,¹⁴ multiple sclerosis,¹⁵ and depression¹⁶) (Fig. 3 and Table 2¹²⁻⁵³). Five social care reviews focused on support for those with intellectual disabilities,¹⁷ palliative care,¹⁸ and care for the elderly (daily care in their own home,¹⁹ respite care,²⁰ and nursing homes²¹) (Fig. 2 and Table 2¹²⁻⁵³) were included.

The citation search identified 18 studies that were related to generic measure development or validation (Table 3^{2,54-75}). Eleven carer measure studies were identified and 3 of these were selected based on the target populations (carer of adults or children)

Table 2. List of included reviews and studies by International Classification of Disease Chapter and Condition

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Lawrence et al ²³	Cardiovascular diseases: Stroke	To describe the experience of stroke from the perspective of young adults.	Y	QL	NR	N	4	Not stated	69	English	NR
Salter et al ²⁴	Cardiovascular diseases: Stroke	To examine the contribution of the published qualitative literature to our understanding of the experience of living with stroke.	Y	QL	1980-2007	Y	9	United States, Sweden, Canada, United Kingdom	250	English	Descriptive meta- synthesis
Gater et al ²⁵	Chronic respiratory diseases: Asthma	To summarize the qualitative research conducted to inform the initial development of the Asthma Daily Symptom Diary.	Y	QL	1997-2012	N	18	United States, China, United Kingdom, Denmark, Canada, France, Germany, Norway, The Netherlands, Australia	11-60	English	NR
Disler et al ²⁶	Chronic respiratory diseases: COPD	To increase understanding of the experience and ongoing needs of individuals living with COPD.	Y	QL, Mixed	1990-2013	Y	22	NR	4 - 63	English	Thematic synthesis
Foss et al ²⁷	Diabetes, urogenital, blood, and endocrine diseases: Diabetes	To provide insights NR based on a bottom-up approach that has the potential to develop innovations in policy/practice that are patient-led in the self- management of diabetes.	NR	QL	2004-2014	Y	29	The United Kingdom, Denmark, The Netherlands, Sweden, Norway, Switzerland, Germany, Belgium	553	English	Staged coding
Vanstone, M et al ²⁸	Diabetes, urogenital, blood, and endocrine diseases: Diabetes	To examine the perceptions of patients with uncontrolled type 1 diabetes on how it affects their lived experience and quality of life.	Y	QL	2005- 2015	Y and N	31	Canada, United States, Europe, Australia, New Zealand	Patients 752 caregiver or family member 103 clinicians 10	English	Staged coding similar to grounded theory
Garcia- Sanjuan et al ²²	Digestive diseases: Inflammatory bowel disease/ Crohn's disease	To identify and describe the evidence on life experiences and perceived social support of people affected by Crohn's disease.	Y	QL +QT	2002 to 2012	N	23	United Kingdom, United States, Canada, Sweden, Chile, Brazil, Switzerland, New Zealand, Austria	2-5960	Spanish, Portuguese, German, and English	Nr

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Table 2. Continued

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Hakanson ²⁹	Digestive diseases: IBS	To review current knowledge about illness-related experiences of IBS from the perspective of everyday life, healthcare and self-care management.	Y	QL	Start of database to 2012	N	23	European, North America, and, North East Asian	144	English	Stepwise integrative review
Depape and Lindsay ³⁰	Mental health and substance abuse disorders: Autistic spectrum conditions	To identify the experiences of individuals with ASC across major areas of life, including successes and challenges, and how these experiences affected by their developmental stage, such as childhood, adolescence, and adulthood?	Y	QL	1980-2014	Y	32	NR	318	NR	Narrative synthesis
Toor et al ³¹	Mental health and substance abuse disorders: ASC	To identify what factors facilitate or act as obstacles for individuals with ASC transitioning to “and” or “or” in further and higher education and the support needs of individuals with ASC in this context.	Y	QL	NR (studies cover 2005-2015)	Y	12	Belgium, United Kingdom, United States, Sweden	3-23	English	Thematic synthesis
Corcoran et al ³²	Mental health and substance abuse disorders: depression old age	To synthesize the qualitative studies that have been conducted on elders’ to better understand older people’s perceptions and experiences.	Y	QL	Any year up to 2010	N	13	Mostly the United States, also Sweden, and Australia	356	Not stated but assume English	Framework
Connell et al ¹²	Mental health and substance abuse disorders: Mood, neurosis, and stress-related, personality and schizophrenia, schizotypal and delusional disorders	To identify the domains of quality of life important to people with mental health problems.	Y	QL	Start of database to 2010	Y	16	Canada, United Kingdom, Sweden, United States, Australia, and New Zealand	Nr	English	Framework

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Table 2. Continued

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Mollard ³³	Mental health and substance abuse disorders: PPD	To synthesize existing qualitative literature on the first-hand experiences of women suffering from PPD, to uncover potential common themes.	Y	QL	2003-13	N	12	United States, Australia, Norway, United Kingdom, India, Sweden, Canada, France, Ireland, Italy, Portugal, Austria, Switzerland, Japan, And Uganda	485	English	Meta- ethnography
Bunzli et al ³⁴	Musculoskeletal disorders: Low Back Pain	To provide clinicians with a richer understanding of their patients' lower back pain experience to highlight the importance of moving away from biomedical paradigms in clinical management.	Y	QL	1991-2011	N	24	United Kingdom, United States, Sweden, The Netherlands, Australia, Canada, New Zealand	713	English, French, and Spanish	Meta aggregate review
Froud et al ³⁵	Musculoskeletal disorders: Low back pain	To inform the debate about the coverage of back pain outcome measure core sets, and to suggest areas worthy of exploration within healthcare consultations.	Y	QL	1991-2010	Y	49	United States, Sweden, Israel, New Zealand, Australia, Canada, The Netherlands, Iran, South Africa	Nr	English	Meta- ethnography and a meta- narrative approach
Daker-White et al ³⁶	Musculoskeletal disorders: Rheumatoid Arthritis	To synthesize published qualitative studies concerning the lived experience of rheumatoid arthritis.	Y	QL	1975-2001 & updated 2002-2009	Y	1975- 2001: 25 2002- 2009: 14	1975-2001: Canada, Denmark, New Zealand the United Kingdom, United States	1975- 2001: 4- 54	1975-2001 no restrictions on language 2002-2009 English only	Meta- ethnography
Poh et al ³⁷	Musculoskeletal disorders: Rheumatoid Arthritis	To provide an overview of the evidence on the experiences and needs of adults living with rheumatoid arthritis.	Y	QL+QT	2003 - March 2014	N	19 ql+ 19 qt	Canada, Denmark, England, Lithuania, Morocco, The Netherlands, Portugal, Singapore, Sweden, South Korea, Taiwan, United States	Ql 5-39 Qt 45-750	English	Integrative
Adams et al ³⁸	Neoplasms: Breast Cancer	To identify their specific experiences, needs, and concerns if young women with breast cancer.	Y	QL	1989-2009	Y	17	United States, Canada, Sweden, Australia, Japan	Not indicated	English	Meta- ethnography

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Table 2. Continued

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Campbell- Enns and Woodgate ³⁹	Neoplasms: Breast Cancer	To summarize the psychosocial experience of women with breast cancer from a lifespan perspective.	Y	QL	1990-2014	Y	24	United States, Australia, United Kingdom, Canada, Sweden, Korea	427	English	Meta-aggregate review
Paterson et al ⁴⁰	Neoplasms: Prostate Cancer	To identify the different domains of unmet supportive care needs in men living with prostate cancer?	Y	QL (9)+QT(8)	1990-2014 (studies cover 1997-2014)	Y	17	Canada, United Kingdom, United States, Australia, Sweden, Europe	2914		Narrative synthesis
Rivas et al ⁴¹	Neoplasms: Prostate Cancer	To summarize black and minority ethnic patients and partners' experiences of prostate cancer by examining the findings of existing qualitative studies.	Y	QL	2000-2015	Y	21 articles covering 13 studies		NR	English	Meta-ethnography
Nichols et al ⁴²	Neurological disorders: Chronic headache	To systematically review the qualitative literature of the lived experience of people with a chronic headache disorder.	Y	QL, QL+QT	1988-2016	Y	4	United States, Sweden, Italy, Finland, United Kingdom	73	English, Spanish, German, and French	Thematic synthesis approach and meta-ethnographic approach
de Boer et al ⁴³	Neurological disorders: Dementia	To gain a better understanding of how people with dementia experience and value their situation.	Y	NR	Start of database to 2006	N	50	Western Countries	NR	Dutch, English, German, and French	Thematic
O'Rourke et al ⁴⁴	Neurological disorders: Dementia	To identify the factors that affect the quality of life from the perspective of people with dementia (PWD).	Y	QL	1975-2012	Y	12 articles (11 studies)	United Kingdom, The United States, Canada, The Netherlands, Ireland, Australia, And Japan	345	English	Meta-synthesis
Greenwood and Smith ⁴⁵	Neurological disorders: YOD	To synthesize the qualitative literature on the experiences of people diagnosed of YOD.	Y	QL	1937-2016	Y	8	4 United Kingdom, 4 Western Countries	87	English	Meta-ethnography
Kashbour et al ⁴⁶	Oral disorders: Edentulism	To identify patients' experience of dental implant treatment at various stages of their implant treatment.	Y	QL	Up to July 2014	Y	10	Sweden, United Kingdom, Canada, Nz	206	English	Thematic

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Table 2. Continued

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Nordenram et al ⁴⁷	Oral disorders: Edentulism	To identify patients' perceptions of loss of teeth, edentulism, and oral rehabilitation.	Y	QL	Not indicated	Y	7	Sweden, Brazil, United Kingdom,	168	English	Thematic
Bennion et al ⁴⁸	Sense organ diseases: AMD	To explore people's experiences of living with AMD to ensure recommendations for practice fit with patients' demands.	Y	QL	1996-2012	Y	9	Nr	165	English	Interpretative analysis following the principles of meta- synthesis
Nyman et al ⁴⁹	Sense organ diseases: Vision loss in later life	To review perceived emotional Wellbeing in older people with visual impairment and perceived factors that inhibit/ facilitate psychosocial adjustment to vision loss.	Y	QL	1st Jan 1980 - 31st Dec 2010	Y	17	United States, The Netherlands, Sweden, United Kingdom, Australia	538	English	Inductive thematic-style
Barker et al ⁵⁰	Sense organ diseases: Hearing loss	To examine the psychosocial experiences of hearing loss from the perspectives of both the person with hearing loss and their communication partner.	Y	QL + Mixed	start of database to 2016	Y	12	NR	NR	NR	Meta- synthesis
Lehane et al ⁵¹	Sense organ diseases: Hearing loss	To identify the effect of sensory loss, and associated communication difficulties, on couples' relational and psychosocial adjustment.	Y	QL+QT	start of database to 2014	Y	24	Australia, Norway, South Africa, United Kingdom, United States, Sweden, Canada	7-19	English	NR
Hong et al ⁵²	Skin and subcutaneous diseases: Dermatitis	To review the psychological, social, and occupational impact of psoriasis and atopic dermatitis.	N	NR	Not indicated	N	32	NR	NR	NR	Narrative
Nakayama et al ⁵³	Skin and subcutaneous diseases: Systemic Sclerosis in place of dermatitis	To describe the patients' perspectives and experiences of living with systemic sclerosis.	Y	QL	Start of database to 2014	Y	26	United Kingdom, Canada, United States, Belgium, France, Austria, Turkey, Germany, Switzerland, Sweden, Romania, The Netherlands	463	NR	Thematic

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Table 2. Continued

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Pozzebon et al ¹⁴	Informal Care - Dementia	To synthesize the findings of published qualitative research that has focused on the spousal caregiver's experience of living with a partner diagnosed of dementia.	Y	QL	1980-2014	Y	16	NR	234	English	Thematic
Priestley and McPherson ¹⁶	Informal carer - Depression	To explore the experiences of family members caring for a partner or relative with depression, to consider the findings in light of the impact on family relationships and how policy and practice might seek to best support caregivers in their role.	Y	QL	NR	Y	15	Australia, Canada, Chile, Denmark, Iran, Norway, Sweden, United Kingdom, United States	263	NR	Meta-ethnography
Topcu et al ¹⁵	Informal carers - MS	To identify factors that may affect the QoL of MS carers positively "and" or "or" negatively, and derive a new conceptual understanding of the views and experiences of carers of patients with MS-related to caregiving to help inform future research and practice.	Y	QL	NR - search conducted 2014	Y	17	NR	1023	English	Meta-ethnography
Rand and Fox ¹³	Informal carers - not condition- specific	To identify the common factors that affect carers' quality of life across different care settings.	Y	QL+QT - QL only extracted	2002-2012	N	7	The Netherlands, India, United States, United Kingdom, Australia, Hong Kong, Denmark, Sweden	NR	English	Review of reviews
Shaw et al ²⁰	Social care - Frail elderly	To assess barriers to respite care and to identify needs for service provision.	Y	QL	Up to Oct 2005; update 2008	Y	70 articles (69 studies)	United Kingdom, United States, Canada, Australia/New Zealand, Other	1-597 (content analysis for large n)	English	Meta-synthesis

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Table 2. Continued

Reference (Author, year)	Group	Research question/aims and objectives	Methods				Results				
			Systematic search (Y/ N/NR)	Review method included (QL, QL+QT, NR)	Review period	Quality check (Y/N)	Number of articles	Countries	Overall sample size/ range	Language	Analysis method
Griffith et al ¹⁷	Social care - Intellectual disabilities	To examine and bring together qualitative research that reports the experiences of individuals with ID who engage in challenging behavior when in receipt of support services and how individuals feel that support services they receive affect their challenging behavior.	NR	QL	Up to Jan 2013	Y	17	United Kingdom, United States, Canada	184	English	Thematic analysis
Vaismoradi et al ²¹	Social care - Nursing homes	Aims to integrate current qualitative findings and enhance the experiences of and perspectives on pain and pain management in the context of nursing homes.	Y	QL	Not stated	Y	6	United States, Norway, Iceland, United Kingdom, Australia	109+	English	Interpretative thematic approach
Fjordside & Morville ¹⁹	Social care - Older people	To review the literature on how older people perceive opportunities and limitations with regard to participation in autonomous decisions concerning their daily care in their own homes.	Y	QL	Up to May 2014	Y	12	Sweden, Denmark, Canada, Australia, Norway, United Kingdom,	250	English	Thematic
Bradley et al ¹⁸	Social Care - SPDC	To systematically evaluate the literature on patient-perceived psychosocial experiences of attendance at SPDC.	Y	QL+QT	Up to Jan 2009	Y	12	NR	4-102	English	Thematic

AMD indicates age-related macular degeneration; ASC, autistic spectrum conditions; COPD, chronic obstructive pulmonary disorder; IBS, inflammatory bowel symptoms; MS, multiple sclerosis; N, No; NR, not reported; PPD, postpartum depression; QL, qualitative; QT, quantitative; SPDC, Specialist Palliative Day Care; Y, Yes; YOD, young-onset dementia.

(Table 3^{2,54-75}), whereas 4 social care measures were identified, and 3 were included as 2 referenced² the same information.

Study Characteristics

Most reviews were systematic (n = 39/42), only qualitative studies (n = 32/42), and undertook quality checks (n = 30/42) (Table 2¹²⁻⁵³). The most common countries were the United

Kingdom, United States, Canada, and other European countries primarily focusing on English language studies (Table 2¹²⁻⁵³), although some included other languages, for instance, the article of Garcia-Sanjuan et al²² included Spanish, Portuguese, and German studies. Most of the studies on measures were undertaken in a single country (n = 17) and most of those were in the United Kingdom (n = 11) (Table 3^{2,54-75}).

Table 3. List of included studies for generic, informal care, and social care measures

Reference (Author, year)	Measure	Research question/aims and objectives	Language	Methods included (QL, QL+QT, NR)	Methods	Inclusion criteria	Overall sample size/ range	Country
Richardson et al 2012 ⁵⁴ ; Peacock et al 2010 ⁵⁵	Generic measure: AQL 6D	To create a descriptive system - a set of questions whose answers describe a person's health state. To create additional items for the item bank.	English	QL + QT	Focus groups	Health professionals and members of the public	22	Australia
Paterson 2004 ⁵⁶	Generic measure: Dartmouth Primary care Cooperative Information Project (COOP)	To explore patients' experience of completing 3 outcome questionnaires - EQ-5D, COOP-WONCA charts, and MYMOP.	English	QL	In-depth and cognitive interviews. Grounded theory and content analysis.	Patients with a health problem of at least 6 months duration, receiving acupuncture and available within 5 weeks of treatment	23	United Kingdom
Fox-Rushby and Selai 2003 ⁵⁷	Generic measure: EQ-5D	To summarize the work on how EQ-5D is interpreted from a number of studies with EQ members, patients, and members of the general population in different contexts.	English, Dutch and Danish	QL+QT	Content analysis and narrative summary.	NA (Studies on the interpretation of EQ-5D using official translations were relevant)	23-270	United Kingdom, The Netherlands, Denmark
Shah et al 2017 ⁵⁸	Generic measure: EQ-5D	To analyze the views of the United Kingdom general public about important aspects of health considered to be missing from the EQ-5D.	English	QL	Interview with an open-ended question on what is important for health content analysis.	A representative sample of the UK general public	179	United Kingdom
van Dalen et al 1994 ⁵⁹	Generic measure: EQ-5D	To elicit lay concepts of health and to see whether these are related to various sociodemographic factors.	English	QL	Interview with open-ended and structured questions. Thematic coding.	Adult (18 and over) general representative population	196	United Kingdom
Paterson 2004 ⁵⁶	Generic measure: EQ-5D	To explore patients' experience of completing 3 outcome questionnaires - EQ-5D, COOP-WONCA charts and Measure Yourself Medical Outcome Profile (MYMOP).	English	QL	In-depth and cognitive interviews. Grounded theory and content analysis.	Patients with a health problem of at least 6 months duration, receiving acupuncture and available within 5 weeks of treatment	23	United Kingdom
Herdman et al 2011 ⁶⁰	Generic measure: EQ-5D-5L	To select severity labels for the EQ-5D-5L and to test the face and content validity of the resulting instrument.	English and Spanish	QL	Focus groups and interviews.	General population and patients	80 interviews 16 focus groups	United Kingdom, Spain

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Table 3. Continued

Reference (Author, year)	Measure	Research question/aims and objectives	Language	Methods included (QL, QL+QT, NR)	Methods	Inclusion criteria	Overall sample size/ range	Country
Al-Janabi et al 2012 ⁶¹	Generic measure: ICECAP-A	To elicit concepts and develop items for a capability Wellbeing measure for the general adult population for use in economic evaluation.	English	QL	Interviews. Thematic analysis.	Informants were selected for interview from 4 electoral wards in England chosen to maximize the socio-economic diversity of the sample and to ensure ethnic diversity and representation from both urban and rural areas	36 phase I, 18 phases II	United Kingdom
Al-Janabi et al 2013 ⁶²	Generic measure: ICECAP-A	To investigate whether individuals could provide information on their capabilities.	English	QL	Think aloud and semistructured interviews. Framework analysis	Informants were selected from 4 geographical wards in the UK with wards chosen for maximum socio-economic diversity	34	United Kingdom
Castel et al 2008 ⁶³	Generic measure: PROMIS	To assess the content validity of the PROMIS social health item banks.	English	QL	Focus groups. Thematic coding	Participants who had reported social health limitations	25	United States
Kaplan et al 1976 ⁶⁴	Generic measure: Quality of Wellbeing scale	To clarify the meaning of the term "validity" as it applies to health status measures in general, and, second, to present a preliminary assessment of the validity of the IWB.	English	QL+QT	Open-ended follow-up question	Probability sample of San Diego area households	867	United States
Hill et al 1996 ⁶⁵	Generic measure: Short Form 36 (SF-36)	To examine the short form 36 (SF-36) health status measure when used to assess older people's views of the outcome of community-based health care.	English	QL +QT	Interviews with a subsample of the interviewees who completed a questionnaire	Patients are referred to mental health or incontinence services with a new episode of treatment. Mental health patients had to have a score of 20 or above in the mini-mental state score	47	United Kingdom
Jenkinson et al 1996 ⁶⁶	Generic measure: SF-36	To determine the face validity and internal reliability of the short form 36 (SF 36) health survey questionnaire in women presenting with menorrhagia.	English	QL	Interviews. Content analysis	Women with excessive menstrual bleeding	49	United Kingdom

continued on next page

Table 3. Continued

Reference (Author, year)	Measure	Research question/aims and objectives	Language	Methods included (QL, QL+QT, NR)	Methods	Inclusion criteria	Overall sample size/ range	Country
Mallinson 2002 ⁶⁷	Generic measure: SF-36	To explore the various interpretations which arose during the administration of the SF-36 health status questionnaire.	English	QL	Interviews. Framework analysis	People aged 65 yrs. or more who were newly referred to 2 teams of community physiotherapists and one team of rehabilitation occupational therapists	56	United Kingdom
Üstün 2001 ⁶⁸	Generic measure: WHODAS	To identify the cultural consistency of the disability construct found in the WHODAS to identify appropriate assessment domains and facets and eventually appropriate questions for instrument development.	Different languages	QL+QT	Key informant interviews and focus groups	Prototypical representation to identify the best possible informants within each culture. The UK included health professionals, other professionals, consumers, health service users, individuals with a physical disability, and caregivers	45 + 2 focus groups for the United Kingdom	Cambodia, Canada, Greece, India, Japan, Luxemburg, The Netherlands, Nigeria, Romania, Spain, Tunisia, Turkey, United Kingdom
WHO 1992 ⁶⁹	Generic measure: WHOQoL	To check the validity and comprehensiveness of the provisional WHOQoL domains and facets. Secondary aims included providing preliminary indications of the perceived importance of facets, establishing if any facets are difficult to discuss in any of the field centers.	Different languages	QL+QT	Discussion groups.	Individuals demographically typical of the population	6-8 in each field center	Thailand, United Kingdom, India, Australia, Russia, Croatia, The Netherlands, Panama, United States
World Health Organization 1993 ⁷⁰	Generic measure: WHOQoL	(1) To check further on the existing facet structure; (2) to generate items/questions for the pilot WHOQoL and; (3) To obtain preliminary importance ratings of facets from participants.	Different languages	QL+QT	Focus groups. Structured analysis.	Inpatient and outpatient users, the general population including informal carers, health personnel	6-8 in each focus group; minimum of 2 focus groups for each target group	Thailand, United Kingdom, India, Australia, Russia, Croatia, The Netherlands, Panama, United States
Al-Janabi et al 2008 ⁷¹	Informal Carer Measure: Carer Experience Scale	To develop a concise measure of the caring experience for use in economic evaluation.	English	QL	Meta-ethnography followed by semistructured interviews. Framework analysis.	Purposive sampling across qualitative studies on older people and informal care experience	6/44 studies in meta-ethnography 16 semistructured interviews	United Kingdom, United States, Australia

continued on next page

Table 3. Continued

Reference (Author, year)	Measure	Research question/aims and objectives	Language	Methods included (QL, QL+QT, NR)	Methods	Inclusion criteria	Overall sample size/ range	Country
Szmukler et al 1996 ⁷²	Informal Carer Measure: Experience of Caregiving Inventory	To develop a practical, comprehensive, and a valid self-report measure of the experience of caring for a relative with a serious mental illness.	English	QL	Focus groups and interviews. Content analysis	Two major self-help organizations focused on mental health	120	Australia
Farnik et al 2010 ⁷³	Informal Carer Measure: QLCCDQ	To describe the development of the QLCCDQ and report on the assessment of its validity and reliability.	NR	QL+QT	Semistructured interviews and rating importance of items.	Health professionals (pediatricians, nurses) and parents of children with diabetes, asthma or eczema	28 health professionals 22 parents 65 parents rated the importance	Poland
Netten et al 2012 ²	Social Care Measure: ASCOT	To develop an equivalent measure to the QALY in health that would reflect the particular characteristics of social care and could be used in a range of circumstances to reflect the impact and value of social care interventions.	English	QL+QT	Cognitive debriefing interviews	Decision-makers used to identify important outcomes in social care	30	United Kingdom
Sutton and Coast 2013 ⁷⁴	Social Care Measure: End of life care	To develop a descriptive system for a measure for use in an economic evaluation of end-of-life care.	English	QL	Interviews. Constant comparison analysis.	People aged 65 were recruited from the general population, residential care, and receiving palliative care	23	United Kingdom
Grewal et al 2006 ⁷⁵	Social Care Measure: ICECAP-O	To determine the important attributes of quality of life for older people.	English	QL	Interviews. Framework analysis	Purposive sampling to include the range of personal characteristics (sex, age, health, household composition, occupation)	40	United Kingdom

AQoL indicates assessment of quality of life; ASCOT, adult social care outcomes toolkit; COOP-WONCA, Cooperative World Organization of National Colleges, Academies and academic associations of general practitioners/family physicians; ICECAP-A, ICEpop CAPability measure for Adults; ICECAP-O, ICEpop CAPability measure for older people; IWB, index of Wellbeing; MYMOP, measure yourself medical outcome profile; N, No; NA, not applicable; PROMIS, patient-reported outcomes measurement information system; QALY, quality-adjusted life-years; QL, qualitative; QLCCDQ, quality of life in the child's chronic disease questionnaire; QT, quantitative; WHO, World Health Organization; WHODAS, WHO disability assessment schedule; WHOQoL, WHO quality of life assessment; Y, Yes; YOD, young-onset dementia.

Synthesis of Results

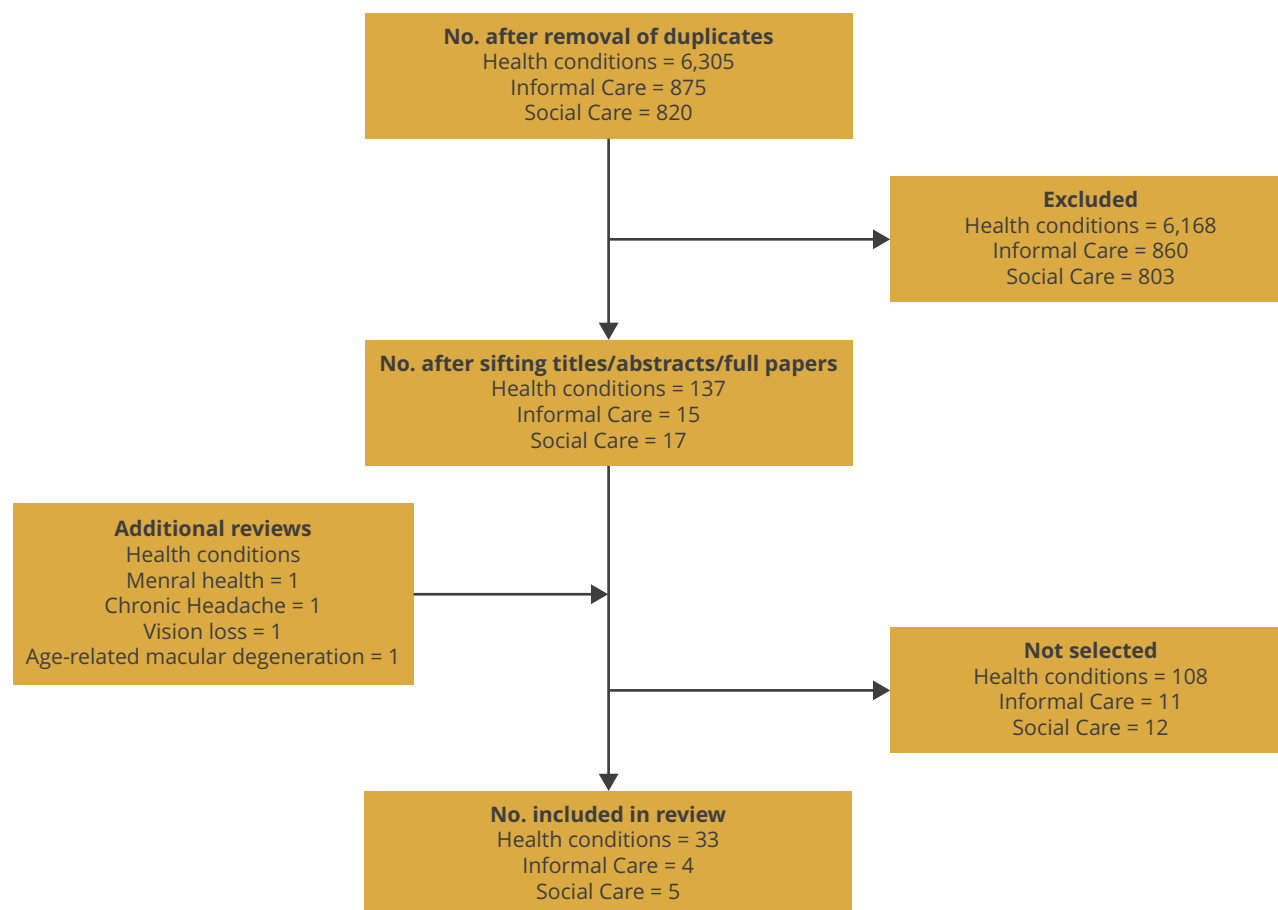
Seven broad themes were identified: feelings and emotions; activity; self-identity; relationships and social connections; "coping, autonomy, and control;" physical sensations; and cognition (Fig. 3).

Feelings and emotions

Feelings and emotions were an important theme (Fig. 3). Fear or feeling scared was merged with anxiety. Cognition-related

subthemes were initially extracted within this theme as they were considered to be related to mental health, but these were separated into a separate theme following discussions with stakeholders who considered it conceptually different to feelings and emotions.

Sadness, depression, and related concepts such as emotional pain and grief were common in mental health^{12,32,72,79} and other conditions. These feelings were associated with physical symptoms such as pain in rheumatoid arthritis,^{36,37} poor vision,⁴⁸ intellectual disabilities,¹⁷ providing care including feeling sad

Figure 2. Qualitative reviews search results.

because of the experience of those cared for,^{15,16,73} and lack of physical capability.²⁶ Impact on the ability to take part in “normal life” was a common reason for feeling low.^{14,28,30,44,75} Acceptance of what was happening was associated with avoiding negative feelings “I am not depressed about it, I just accept it.”⁴⁸ The use of the term “depressed” was sometimes considered to be related to a diagnosis of depression rather than feelings of sadness.^{56,57,70} Feelings of joy or happiness were considered in studies that assessed the meaning of QoL for respondents with dementia,⁴⁴ who identified functioning and social activity as related to these concepts, and more generally.^{59,61,69} There was also enjoyment in receiving⁴³ and giving support.^{13,72}

Anxiety or worry along with related concepts of fear was associated with how physical symptoms could be managed^{46,49} including their progression and impact on the future.^{24,34,37,57,73,79} It also occurred because of limitations imposed by conditions or situations, for example, on leisure.^{12,28,30} For carers, there was anxiety in how to manage their caring and also the impact of symptoms in those they cared for.^{15,16} In potentially life-limiting conditions such as cancer,⁴⁰ systemic sclerosis,⁵³ and chronic obstructive pulmonary disease,²⁶ there was fear of death. Few studies considered the positive end of the scale, such as feelings of calm or feeling relaxed.⁵⁹ Some studies related spirituality as a way to remain worry-free in the context of change.^{41,49,75}

Feelings of vulnerability or lack of safety were experienced^{2,12,28,33} because of health conditions, for example, in mental

health^{12,33} or because of caregiving.¹⁵ Some informal carers feared that those they cared for could cause them harm.²⁸ Receipt of supportive care was associated with reductions of these feelings.²²

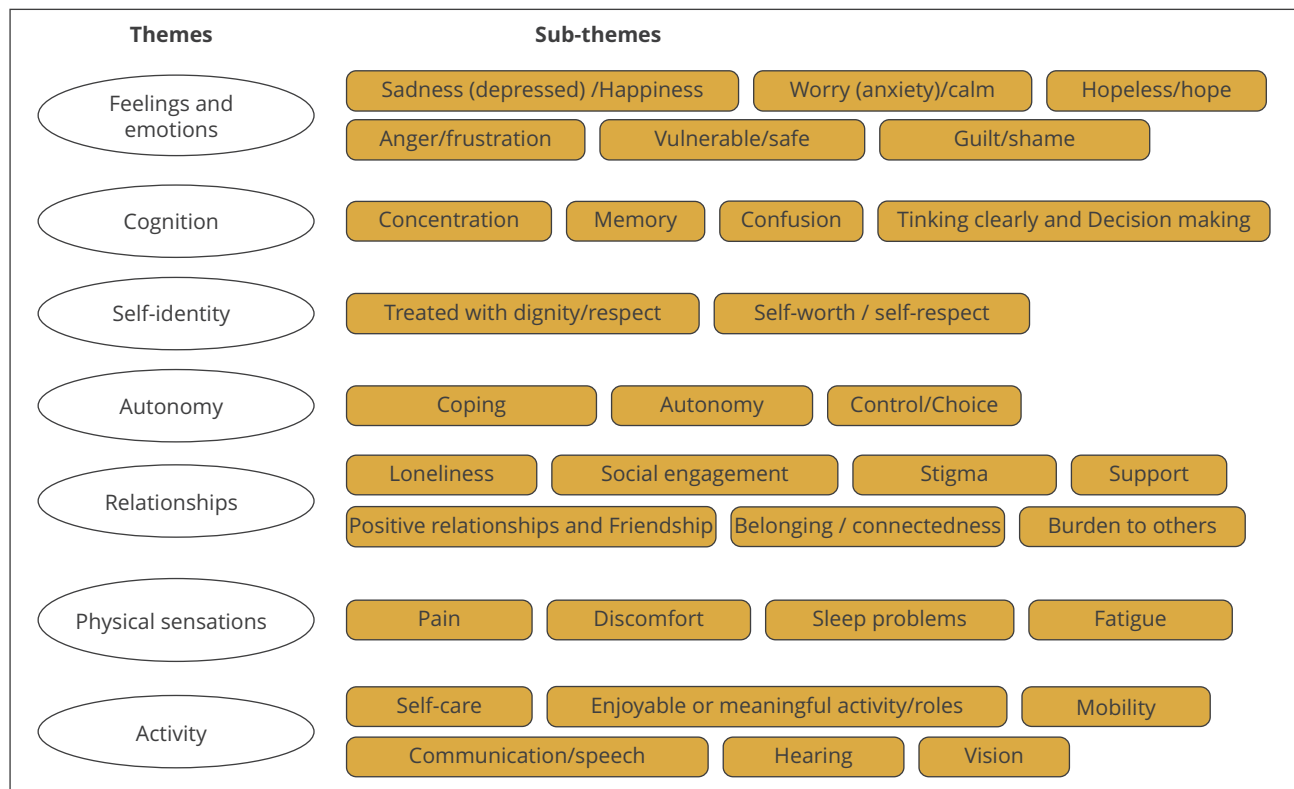
Hopelessness was framed around uncertainty and frustration with diagnosis or situations,^{26,34,35,43,45} and helplessness with lifelong conditions.^{30,32,48} Hope was associated with regarding what individuals had rather than what they had lost, which was often the case in life-limiting conditions,^{39,49} whereas some remained optimistic by considering potential improvements through treatment.^{22,50} Hope was also associated with returning to normal daily activities (“I’m looking forward to being able to go back to work again ...that is very important”).²⁴

Anger and frustration were associated with hopelessness. Experience of symptoms or situations,^{35,42,79} experiences of poor interactions with family^{15,53} or health and social care workers,¹⁹ and uncertainty with regard to diagnosis and future prognosis^{17,20} were all associated with anger and frustration.

Individuals experiencing changes such as the inability to undertake their usual activities because of limitations felt guilt and shame.³⁶ These feelings were also associated with diagnosis (eg, in dementia),⁴⁴ symptoms (eg, IBS),^{22,29} or failure to meet particular treatment goals (eg, blood sugar levels in diabetes²⁸). Carers felt guilt and shame in relation to those they looked after.^{20,72,73}

Cognition

The cognition theme covered aspects related to brain function (Fig. 3), which were considered important for health.^{58,59,65}

Figure 3. Themes and subthemes.

Concentration and forgetfulness or memory problems were related to specific conditions such as stroke,^{23,24} dementia,^{44,45} and mental health conditions.¹² Poor concentration was also because of conditions such as diabetes²⁸ and chronic headaches.⁴² Confusion or disorientation was associated with dementia in which it was a primary symptom, but it was also associated with a change in care (eg, respite care)²⁰ and poor information.⁵³ Poor concentration, memory problems, and confusion had an impact on overall cognitive function including making decisions^{12,15} and learning,⁶⁴ which impacted autonomy and undertaking of daily activities.³¹

Self-identity

The self-identity theme had self-esteem/confidence and self-perception as subthemes. Self-perception referred to “loss of normality” that participants experienced as a result of changes in what they could do or were expected to do because of their conditions^{22,24,28–30,34–39,43–45,49,50,61} or circumstances.^{14–16,61,72} These losses were considered to be predominantly transitional states and were, therefore, not included as potential aspects of QoL. Nevertheless, these feelings of loss of normality were also associated with how individuals felt in terms of maintaining “respect and dignity.” This was related to how individuals felt they were perceived or treated because of their conditions or situations.^{2,16,22,36,43,46,49,69,74,80}

Low self-esteem was a result of their own judgments and feelings of disappointment (eg, carers who gave up jobs had decreased self-esteem)¹⁵ or inability to perform certain roles (eg, being a “competent mother”),⁴⁹ whereas interventions increased feelings of confidence.⁶⁵ For those with mental health problems,

low self-esteem was also because of impairments in how individuals viewed themselves (“Mostly just that—feeling like you are not good for anything...”).³² The negative attitudes of others about mental health had an impact on self-esteem¹² with reference to terms such as feelings of inadequacy, uselessness, helplessness, and lack of worth or value.

Coping, autonomy, and control

Conditions and situations resulted in change, often accompanied by uncertainty.^{14,15,22,24,34,35,39,40,43,53,61} Individuals considered being able to cope with these changes while retaining independence as having an impact on QoL. Having information and knowledge and associated levels of certainty, and acceptance or adjusting were considered instrumental to coping. “Control of illness” was merged with “control of life,” whereas “dependence” was merged with being a “burden to others” (relationships theme).

The subthemes coping, autonomy, and control were retained, although with substantial overlap between these concepts. Acceptance of changes in health or circumstances along with treatment or adaptations that were necessary were seen as key to coping.^{19,26,30,35,36,39,45,48,50,51,69} Nevertheless, there were other ways to cope including relying on formal and informal support,^{15,22,48} relying on spiritual help,^{15,41} self-management techniques,^{14,42} and medication.⁷⁹

Autonomy was about being able to make decisions about one's life even when those receiving interventions relied on others such as doctors or carers to undertake activities resulting from decisions. A change in ability was linked with the need to maintain autonomy as a means to maintain identity.^{33,36,38,39,44,61}

Independence and the ability to live without limitations were considered important for QoL.^{55,69,74,75} There was also a lack of autonomy for carers as their decision-making centered on those they cared for.¹⁶ When individuals relied on others, there was a balance between remaining autonomous and being dependent.^{12,19} Those who received help from people who “cared too much” were more likely to experience a lack of autonomy.^{36,45}

Control was associated with choices that individuals had on how to manage their lives given their conditions, situations, or their immediate environment. Experiencing conditions was associated with uncertainty about progression, treatment, and even day-to-day experience of symptoms and related uncertainty, which led to feelings of lack of control.^{22–25,29,34–39,42,44,49,53} Choice was an important aspect for those being cared for.^{17,74} and had a negative impact if choices were ignored^{19,81} reflecting the need for good engagement with those providing support.² Control was also important for informal carers⁷¹ who felt that they lacked control because of uncertainty¹⁵ and lack of information.^{13,15,16}

Relationships

Social interactions and relationships (Fig. 3) were an important theme with regards to QoL.⁶⁹ Reciprocity, which referred to the ability of individuals to reciprocate when they had help/support was not included as this was seen as instrumental to feelings and emotions and positive relationships. Subthemes of “understanding,” “being believed,” “disclosure” and “reactions of others” were captured in the “stigma” subtheme. “Being over-cared for” was captured in autonomy, “strain/stress of relationships” in feelings, and “helping others” in meaningful activity.

Individuals experienced loneliness because of isolation because they withdrew from social situations,^{13,16,30–32,34–36,45} they no longer engaged in certain activities because of restrictions,^{13–15,22,24,25,29–31,40,45,44,48–50} or those who were close to them lacked understanding or withdrew from them.^{49,50,53} Although social withdrawal was sometimes used as a coping mechanism, the loss of relationships that accompanied it meant that overall the impact on QoL was more likely to be negative.⁴⁰ In some cases, feelings of alienation were a result of what individuals needed to do to manage their situations, for example, food restriction in diabetes.²⁸

Negative aspects emerged for those in relationships. Individuals felt that they were a burden to others, especially family.^{23,26,28,39,43,49} There were also negative impacts of navigating other social spaces such as work but also within the context of close relationships in which they felt that they had to legitimize their conditions.^{34,35,48} One consequence of not being believed was the perceived stigma because of lack of legitimacy and perceptions of fraud (eg, conditions seen as fraudulent ways to get time off work). This was the case for hidden conditions or conditions that were not obvious such as lower back pain,³⁵ chronic headaches,⁴² gradual vision loss,^{48,49} and some aspects of systemic sclerosis.⁵⁷ In contrast, visible conditions/situations or disclosed conditions that made individuals look or act differently to expectations attracted unwanted attention, which led to stigma and discrimination.^{36,50,55,68}

This was contrasted with the support that was received when individuals had supportive or good relationships.^{14,23,38,51,61,70,74,75} Support was not limited to close family but also peers^{18,22,27,41,49,71} and professional support.^{16,17,65,71} Engaging in social activities and maintaining friendships were also seen as important for QoL.^{26,30,35,55,61,63} Social interactions were important for a sense of belonging and acceptance or attachment.^{14,31,75,82}

Physical sensations

This theme was originally referred to as “physical symptoms and functioning” and was used to extract information on symptoms/sensations and also functioning limitations such as vision, communication, and mobility. Weight loss or gain,^{28,40,59} dexterity,^{36,53} disfigurement,⁵³ menopause symptoms,³⁸ sensory sensitivity,^{30,31} and fertility³⁹ were excluded as they were considered instrumental or not relevant to all. Following the consultation process, this theme was reduced to physical sensations, which focused on pain, discomfort, sleep, and fatigue, whereas all the other subthemes were moved to the activity theme.

Physical pain was a dominant issue for conditions in which it occurred^{21,22,25,26,29,34–37,42,46,47,53,59} and was linked to other themes such as feelings of depression, poor sleep, and limitations in daily activities. Its pervasive nature meant it had an impact on all of life and was a concern at the end of life.⁷⁴

Lack of sleep^{15,25,33–36,42} or sleeping too much¹² was highlighted as problems that impact health.^{58,59} The physical sensations associated with poor sleep were, therefore, considered in this subtheme. Fatigue was a problem across different conditions^{12,22,23,25,26,29,32,33,36,37,40,42,53} and was associated with symptoms and poor sleep. It was also a problem for carers¹⁵ and energy or vitality was considered important for health.^{57–59,64}

Other symptoms were associated with specific conditions such as breathlessness, coughing, and tightness in the chest for asthma/chronic obstructive pulmonary disease,^{25,26} nausea/vomiting because of treatment or chronic headaches,^{40,42} and diarrhea.²⁹ These were grouped into a single subtheme referring to discomfort. Fox-Rushby et al⁵⁷ noted that individuals included these and other symptoms such as dizziness and pins and needles when considering discomfort but also included pain.⁶⁴ Symptoms were more likely to be associated with specific time frames that did not always match up with the time frames in questionnaires.^{56,66}

Activity

The “activity” theme reflected functioning, such as walking, vision, and communication, among others. Some initial constructs were excluded as they were not relevant to all or were instrumental to other activities (eg, sexual function, dexterity). “Activity avoidance” was also added to the framework. This was both positive (individuals avoided activity as a way to manage their symptoms) and negative (individuals avoided activity that they needed to do but were unwilling or felt unable to undertake). This dichotomy would raise ambiguity in the context of measurement and valuation, therefore, this subtheme was not explored further.

Limitations in everyday activities such as washing and dressing, work, and leisure activity featured as important aspects.^{13,14,34–40,42,43,48,15,49,53,55,57,59–61,48,70,71,22,72,73,75,79,24–26,28,30,31} Individuals modified activities that had an impact on feelings and relationships.⁶³ Job insecurity and associated financial implications were also considered but reference to work was not considered appropriate as not everyone undertakes paid work. Leisure was also considered to be something that may not be relevant in some contexts by members of the public involvement group. Therefore, work and leisure were referred to as meaningful, valued, or enjoyable activities with separate subthemes for everyday activities such as washing and dressing and other daily activities.

Mobility was important in some conditions because of physical limitations^{36,37} or other physical limitations such as breathing or dizziness that made mobility difficult.^{25,26,57} and it was a common concern in health measures.^{55,59,68–70,83} The context mattered, for example, the distinction between walking up a hill, on their street, or around shops.^{56,67} Communication was a problem for those

with hearing problems,⁵⁰ vision loss⁴⁹ because of loss of visual communication, and autism,³⁰ because of limitations in the ability to understand social cues. Loss of speech or lack of clarity also had an impact on communication.^{24,43,47} Sensory and communication impairments were considered important.^{54,55,57–59,64,84} These problems with physical functioning were associated with limitations in activities and social interactions and, in some cases, resulted in negative feelings.

Adaptation to limitations (eg, changing “usual activities” to match their abilities)^{56,57} or changing their assessment of severity⁶⁷ affected activity. Interventions designed to improve activity engagement such as hearing aids were not always used because of failure to accept the limitation or feeling that the intervention did not work as anticipated.⁵⁰ This is also related to distinctions between what people say they can do (capability) and what they actually do (functioning).⁶²

Discussion

Summary of Evidence

Seven broad thematic areas (feelings and emotions; cognition; self-identity; coping, autonomy and control; relationships and social connections; physical sensations; and activity) were identified covering 32 interrelated subthemes on how conditions, interventions, or being an informal carer affected QoL and well-being. Aspects related to feelings and emotions; relationships and social connections; autonomy, coping, and control; and activity were recurring themes across the different populations—that is, patients, social care users, and informal carers.

A set of predefined criteria informed the process of theme selection, where strongly related themes or subthemes were merged. Nevertheless, some themes retained strongly related subthemes such as belonging, stigma, and loneliness in the relationships theme as they were considered important in their own right. Conversely, although analysis aimed to group closely related subthemes into themes, the activity and physical sensations themes had subthemes that were varied. The activity theme reflects different aspects of functioning (eg, walking and sensory functioning) whereas the physical sensations included different physical symptoms. The discomfort subtheme covered many unrelated physical symptoms, which were challenging in the context of item development to ensure that questions capture the different physical symptoms. Nevertheless, this approach allowed for the focus to remain on the generic—that is, broadly applicable to patients, social care users, and informal carers, rather than on specific physical symptoms.

Themes that were considered instrumental to other themes were not included, although this was done alongside considering whether a theme was important, for example, mobility (instrumental to activities) was included as it appears as an important theme in measures. Other themes were excluded on the basis that they were not relevant for all (eg, fertility). Included themes were framed in a way that ensured that they would be applicable across different groups, for example, reference to working was removed to avoid potential value judgments. Whether a theme is judgmental may reflect cultural norms rather than universally held concerns, which have implications for applicability in other contexts.

The identified themes were broader than those covered by commonly used measures specific to health, social care, or informal care. The themes cover aspects that are included in measures such as the EQ-5D (mobility, self-care, usual activities,

pain, depression/anxiety) in health, the Adult Social Care Outcomes Toolkit² (social participation and involvement, occupation, control, dignity, comfort, and cleanliness) in social care and Carer Experience Scale⁷¹ (control, activities, support) in informal care.

Strengths and Limitations

This broad qualitative review provides evidence for including aspects of QoL beyond the core construct of health when considering evaluating health and social care interventions. The study benefited from a multidisciplinary team and stakeholder consultation, including public involvement. The methods used aimed to address the research question in a pragmatic and timely way with a key focus on consideration of questionnaire development in the context of economic evaluation. Health conditions were selected using an objective process. The review benefited from the rich qualitative evidence drawn from a wide range of patient, social care, and informal carer groups. The analysis was informed by a clear conceptual framework and several reviewers devised and piloted the extraction framework.

There are several limitations. Selecting conditions based on burden may have given priority to conditions with larger populations at the expense of smaller populations. Measures were not identified or searched for systematically. Not all the identified studies were included and double extraction was not undertaken because of resource limitations. The review only includes studies up to October 2017. No formal assessment of quality was undertaken. Recurring themes across the targeted groups provides some support for this pragmatic approach but we may have missed important themes. The tradeoff between broad versus condition-specific representation is one that generic measures need to make and is often missing in reports of the development of generic measures. The review also primarily focused on a European or Northern American context, which may have missed important themes or included themes that are not relevant in other contexts. For example, perceptions of self-identity that were centered on individualistic concerns may not fit in more collective cultures.⁷⁰ Wider stakeholder involvement involved individuals from other countries but there was a larger United Kingdom presence and focus. Future work will need to assess cross-cultural issues. Finally, the final themes were not subjected to further primary qualitative work to confirm them.

Conclusion

This qualitative review identified 7 broad themes of QoL that are relevant to patients, social care users, and informal carers. The next step was to identify and develop relevant items⁸⁵ for the new measure that would be amenable to valuation.

Supplemental Material

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.jval.2021.11.1371>.

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Author Affiliations: School of Health and Related Research (SchARR), University of Sheffield, Sheffield, England, UK (Mukuria, Connell, Carlton, Peasgood, Scope, Clowes, Brazier); Personal Social Services Research Unit (PSSRU), University of Kent, Canterbury, England, UK (Rand, Jones)

Correspondence: Clara Mukuria, School of Health and Related Research (SchARR), University of Sheffield, Regent Court, 30 Regent St, Sheffield, England, UK S1 4DA. Email: c.mukuria@sheffield.acu.uk

Author Contributions: *Concept and design:* Mukuria, Connell, Carlton, Peasgood, Brazier

Acquisition of data: Clowes, Connell, Mukuria, Carlton, Scope

Analysis and interpretations of data: Mukuria, Connell, Carlton, Peasgood, Rand, Jones, Brazier *Drafting of the manuscript:* Mukuria, Peasgood, Carlton *Critical revision of the paper for important intellectual content:* Carlton, Peasgood, Brazier, Rand, Scope, Clowes, Connell

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