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Extended Research Article

How lived experiences of illness trajectories, burdens of treatment, and social inequalities shape service user and caregiver participation in health and social care: a theory-informed qualitative evidence synthesis

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This article

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Abstract

Background: The workload service users and caregivers take on, and their capacity to do this work, when they engage with and participate in different kinds of care is important. It is reflected in policy and practice interventions that identify service users and caregivers as part of a team that consists of informal networks beyond provider organisations and the professionals within them in health and social care.

Aims and objectives: To synthesise qualitative studies of the lived experience of the work of service user and caregiver engagement in three kinds of conditions: long-term conditions associated with significant disability (Parkinson's disease, schizophrenia); serious relapsing–remitting disease (inflammatory bowel disease, bipolar disorder); and rapidly progressing acute disease (brain cancer, early-onset dementia).

Design: Theory-informed qualitative evidence synthesis of primary qualitative studies, qualitative systematic reviews and meta-syntheses. Papers analysed using qualitative attribution analysis, and Event-State Modelling.

Data sources: Cumulative Index to Nursing and Allied Health Literature, EMBASE, MEDLINE, PsycInfo, Scopus and Social Care Online were searched from January 2010 to April 2021.

Eligibility criteria for selecting studies: Qualitative primary studies, systematic reviews and meta-syntheses where the participants were service users, or caregivers, aged ≥ 18, with one of six index conditions, and which described their lived experiences of care.

Methods: Qualitative evidence synthesis to model core components of service user and caregiver work, and to identify common factors across index conditions, disease trajectories and service contexts.

Results: Searches identified 34,787 records. Following deduplication, 13,234 records were assessed for relevance, and after first-stage screening, 7782 records were excluded at this stage, leaving 5452 for further screening, and 279 of these met inclusion criteria and were included in the evidence synthesis. These showed that patients' and caregivers' lived experiences of illness trajectories were shaped by mechanisms of enabling agency (personal capacity, social capital, affective contributions of others), and their degree of existential threat, competence in managing processes of care, and caregiver responses to new responsibilities. Their degree of structural disadvantage was framed in terms of loss of income, employment and housing, and by the presence of stigma, rather than by intersectional position and socioeconomic status.

Conclusions: This evidence synthesis maps intervention points to support service users and caregivers, and the trajectories of work that frame their effective participation in their care. We identify potential targets for interventions that could support their outward-facing work as they seek to mobilise agency, sustain personal capacity, maintain their social capital and draw on the affective contributions of others.

Limitations: Our pragmatic search strategies led to a maximum variation sample of studies of lived experiences of index conditions but may have missed relevant studies. No papers with an explicit social care focus were discovered for brain cancer, bipolar disorder and inflammatory bowel disease. Most studies were descriptive, and samples and methods were often poorly described.

Future work: Future research should explore interactions between personal capacity, social capital and affective contributions, in lived experiences of service users and caregivers.

Study registration: This study is registered as PROSPERO CRD42020224787.

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List of abbreviations

CASP	Critical Appraisal Skills Programme
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
GDPR	General Data Protection Regulation
GRADE-CERQual	Confidence in the Evidence from Reviews of Qualitative Research
LSHTM	London School of Hygiene and Tropical Medicine
NIHR	National Institute for Health and Care Research
PPI	patient and public involvement
RCT	randomised controlledtrial
SARS-COVID-19	severe acute respiratory syndrome coronavirus 2

Plain language summary

When we become ill or need to look after others, we may have to do a lot of work. We may need to check, manage and record our symptoms: do different diets or physical activities; obtain and use different drugs, dressings and medical devices. We may also need to learn new skills to look after ourselves and others. Sometimes, we have to work out how we are going to pay for care. Doing this work may be affected by the inequalities and differences that we start out with when we are ill, for example, our incomes, ethnicity, housing, education, gender and age. The kinds of illnesses we have, and how these change over time as symptoms progress, can make this work harder, and we may find it difficult to look after ourselves or others.

To understand these challenges, and how they affect people's experiences of health and illness, we looked at 279 studies by other researchers. They told us about people's everyday experiences of living with six health problems. These were long-term conditions (Parkinson's disease and schizophrenia); diseases that change over time (bipolar disorder and inflammatory bowel disease); and rapidly progressing diseases (brain cancer and young-onset dementia). These studies explored the ways in which people – and their caregivers – described their experiences of illness in their own words.

The 279 studies we looked at did not say much about the advantages and disadvantages that people start out with, but they did tell us about what is lost when people become sick. They lose 'social capital': this is their income, access to transport, and access to employment and networks of friends. They lose their 'personal capacity'; this happens when people find it difficult to access care, find their diagnosis shocking and become fearful about the future. Symptoms can make it difficult to manage and may also make people think differently about them. Finally, they may need to take responsibility for their care, as diagnoses and symptoms become more difficult over time. This study has identified key 'pressure points' that are opportunities for supporting people as they travel through pathways of illness and care. Interventions that fit these pressure points are likely to effectively solve problems around their ability to influence the organisation and delivery of their care.

Scientific summary

Background

Globally, there is a shift to encouraging people with a variety of health problems to engage in programmes of self-care. This makes sense in an economic and social environment in which health and social care services are perceived to be subject to unsustainable levels of demand and expectations of expenditure. What comes with this shift, however, is a complex rearrangement of responsibilities, skills and expectations of service users and their caregivers. This study is concerned with the ways in which lived experiences of service users' and caregivers' work of participation are shaped by interactions with experienced social inequalities (socioeconomic disparities in health and health care) and illness trajectories (disease progression over time, and their reflection in status passages). This work is central to understanding the ways in which illness, medical knowledge and practice, and healthcare professions and institutions are experienced.

Aim

The aim of this qualitative evidence synthesis was (a) to review, compare and synthesise studies of the lived experience of physical and mental health problems characterised by (1) long-term, (2) relapsing–remitting and (3) rapidly progressing trajectories; and (b) to conceptualise the predictable and generalisable mechanisms that motivate and shape lived experiences of these interactions among service users and caregivers.

Research question

From this aim, we derived a primary research question. What do these bodies of literature tell us about the ways in which treatment burdens, illness trajectories and social inequalities interact with each other to shape the lived experiences of service users and caregivers over time?

Methods of investigation

Identification of studies

We systematically searched for qualitative studies of the lived experience of three kinds of conditions: long-term conditions associated with significant disability (Parkinson's disease and schizophrenia); serious relapsing–remitting disease (inflammatory bowel disease and bipolar disorder); and rapidly progressing acute disease (two common types of brain cancer – astrocytoma and glioblastoma – along with young-onset dementia).

Inclusion criteria

We included peer-reviewed qualitative studies that met the following criteria.

Participants

People aged > 18 years; diagnosed with brain cancers (glioblastoma and astrocytoma), young-onset dementia, inflammatory bowel disease, bipolar disorder, schizophrenia, Parkinson's disease, and their caregivers.

Reports

Results of qualitative studies of service users' or caregivers' accounts of the lived experiences of eligible conditions; their interactions with health professionals, healthcare provider organisations, treatment settings, technologies and regimens of care and self-care; and the social and economic contexts in which experiences of illness and care are set.

Study designs

(1) Primary qualitative studies using semistructured and unstructured interviews; primary qualitative studies using participant or non-participant observation studies; (2) systematic reviews of qualitative studies, qualitative meta-syntheses and meta-ethnographies.

Settings

Studies of illness experiences within self-care programmes, healthcare systems and social care systems.

Date of publication

Because there have been important changes in the organisation of care (and especially self-care) in the UK since 2010, we restricted eligible studies to those published between 1 January 2010 and 31 March 2022.

Language

English.

Search strategy and searches

Searches were conducted in March and April 2021. They identified 34,787 records. Following deduplication, 13,234 records were assessed for relevance, and 7782 records were excluded at this stage. Following from this, 5452 records remained for further assessment and were sent on to reviewers. We then sought 907 articles for full text review and excluded 380 on the grounds of ineligibility. We were unable to obtain three articles. This left 524 papers that were quality assessed, which led to the exclusion of a further 238 articles. We included 244 primary studies and 35 reviews in this evidence synthesis.

Quality assessment of eligible articles

We used the Critical Appraisal Skills Programme (CASP) checklist to inform assessment of the quality of qualitative research proposals and papers. It provides clear criteria for identifying high-quality reports. CASP can only guide decision-making on eligibility for inclusion. For review papers, we used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative Research) approach to assess our confidence in findings.

Methods of analysis

We used a structured extraction instrument. We recorded country of origin, topic, sample size and data collection, sample composition (gender, age range and ethnicity), study design, mode of analysis and presentation of results. Within each paper for each index condition, clusters of service user and caregiver activity were identified and mapped in relation to inequalities, trajectories, and burdens using attribution analysis, and they were coded using a theory-informed framework to develop an iterative taxonomy of activities. The next phase of analysis was to perform an Event-State Analysis. Event-State Analyses are intended as precursors to causal network analysis. In this context, we mapped clusters of service user and caregiver activities against contexts of action, experienced trajectories, lifeworld resources and mechanisms that shape participation in care. We traced interactions between burdens, trajectories and inequalities, and presented these through Event-State Matrices for both data from primary studies and authors' proposals for supportive interventions for service users and caregivers in secondary studies.

Results: mapping the work of service users and caregivers

Searches identified 279 articles that could be included in this evidence synthesis. Of these, 26 primary studies and 4 reviews focused on brain cancers; 23 primary studies and 9 reviews on young-onset dementia; 25 primary studies and 4 reviews on inflammatory bowel disease; 36 primary studies and 1 review on bipolar disorder; 78 primary studies and 10 reviews on schizophrenia; and 56 primary studies and 7 reviews on Parkinson's disease. In analysing these, we sought the common features of a maximum variation sample of illnesses and their trajectories.

Qualitative analysis of primary studies revealed a common set of service user and caregiver activities across all six index conditions. Their degree of structural advantage and disadvantage was framed in terms of micro-structural consequences of illness rather than societal-level social determinants. These included loss of income, employment and housing, and by the presence of stigma, rather than by intersectional position and socioeconomic status. We mapped the work of participating in care using biographical disruption theory, identifying stages in illness trajectories as pressure points at which interventions could be delivered.

1. *Candidacy and help-seeking*: In all index conditions, service users and caregivers pointed to the limitations of diagnostic services and difficulties for professionals, service users and caregivers in interpreting symptoms that were often diffuse and vague at the beginning of illness trajectories.
2. *Diagnostic shock*: All conditions were described as leading to activities that responded to perceived or actual threat from their illness. The most common of these was seeking information and extending understanding. Some conditions led to perceived existential threat and fear of the future, activities responding to this were much less well-characterised.
3. *Biographical and relational disruption*: This is best characterised as departure from perceived normal health and called for service users and caregivers to develop symptom recognition and medication management skills. The mobilisation of caregiver contributions was central to this; and they were implicated in struggles over care and access to services, dealing with difficult interactions with health professionals and services, and supporting service users through difficult decisions and decisional conflicts.
4. *Biographical and relational erosion*: Throughout illness trajectories, service users and caregivers experienced cumulative effects of stigma, role strain, and restrictions on mobility, employment and income. These led to the diminution of social networks and other relations over time. As symptom severity and disability increased, it also led to transfers of responsibilities to caregivers, and complex negotiations about the distribution of supportive work within families.
5. *Biographical and relational fracture*: Increasing disease severity and deterioration called for greater investment in managing symptoms and mitigating social dislocation, but this work broke down in the terminal phases of brain cancers, dementia and Parkinson’s disease, and in very acute episodes of inflammatory bowel disease, bipolar disorder and schizophrenia.
6. *Biographical and relational repair*: Throughout illness trajectories, service users and caregivers performed activities that were outward-facing. They sought to acquire skills in self-management and attempted to build productive relations with health professionals who were sometimes described as hostile or indifferent to them. Importantly, they sought to enhance their social capital, seeking to rebuild social networks, and to manage stigma and protect their identities as competent social actors through controlled disclosure of information about their condition.

Qualitative analysis of primary studies revealed the parallel structures of service users and caregivers’ systemic trajectories. Here, service users’ and caregivers’ lived experiences of illness trajectories were shaped by mechanisms of enabling agency which form a bridge between them: personal capacity, social capital, affective contributions of others. We used the following constructs to map supportive interventions proposed by review authors. These set out a range of supportive interventions that are needed by caregiver and service users as they pass through illness trajectories. These set out a range of supportive interventions that are needed by caregiver and service users as they pass through illness trajectories. Once again, these describe domains of service user and caregiver experience that merit both further research and the development of policy and practice interventions.

1. *Systemic trajectories*: These consist of modifiable aspects of their experiences of health professionals and services. Policy and practice interventions are needed to improve access to diagnostic and specialist services, improve the quality of interactions with clinicians and supportive gatekeepers, and to better understand and target information needs of service users and caregivers.
2. *Personal capacity*: Service users and caregivers possess varying degrees of personal psychological, social and economic resources. Policy and practice interventions are needed to reinforce their capacity to assert control over illness identities and trajectories. Access to psychological therapies would improve coping strategies. Interventions that improve access to continued employment and financial resources will reduce dependence and reinforce self-efficacy and self-esteem.

3. *Social capital*: Service users and caregivers may be members of networks of social relations through which informational, material and symbolic resources flow. Policy and practice interventions that reinforce and restore social networks and improve mechanisms for communications add to relational solidarity between service users, caregivers and health professionals. Social networks can foster shared caregiving strategies through which caregivers can find respite support.
4. *Affective contributions*: Service users' and caregivers' social relations with others are characterised by varying bonds of affection and moral obligation. Policy and practice interventions are needed to build practical skills to improve collaborative problem-solving and build and reinforce emotional resources. Interventions that support family and other informal networks increase their potential for sustaining wider practical and emotional support. Exhaustion and devitalisation of service users and caregivers is common, and access to respite care uncommon, and this is an important area where support is needed.
5. *Relational trajectories*: Consisting of modifiable aspects of their subjective experiences of illness and care. Psychological interventions that support service users and caregivers in coping and adapting to loss, distress and existential threat are vital. Policy and practice interventions that mitigate decisional conflict about treatment pathways, and mitigate loss of control in the face of disease progression, loss of treatment effectiveness, and symptom exacerbation.

Patient and public involvement

Throughout the period leading up to the study, and during its conduct, we worked with patient and public representatives to define the focus of the work, and identify the illnesses and trajectories that we would investigate.

Strengths and limitations

Our search strategies deliberately prioritised variation over specificity, and led to a maximum variation sample of studies of lived experiences of index conditions. We acknowledge that our approach to searches was pragmatic and had limitations which increased the risk of missing relevant studies. No papers with an explicit social care focus were discovered for brain cancer, bipolar disorder and inflammatory bowel disease. They were more than sufficient for identifying key features of the six index conditions and thus for building theory. An important problem that resulted from this was the sheer number of primary studies for inclusion ($n = 244$). Most studies were descriptive, and samples and methods were often poorly described. However, our methods of qualitative analysis enabled us to produce a rigorous account of lived experience of illness trajectories and their consequences.

Discussion and conclusion

This evidence synthesis provides the foundation for a theory of lifeworld resources in serious illness. Personal capacity, social capital and affective contributions are fundamental features of social identity and relations. When serious illness occurs, they are mobilised to achieve individual or collective goals, and they form a set of combined, or entangled, lifeworld resources that enable agency among service users and caregivers. Here, events or processes that disrupt, interrupt or terminate the equilibrium of lifeworld resources (e.g. onset of illness or disability, existential threat, anticipated bereavement, loss of employment and income, and stigmatisation) may lead to the structural failure of lifeworld resources and diminish capacity for care and self-care. The disruption of lifeworld resources, and the depletion of enabling agency, call for collaborative work that creates co-operative and solidaristic relationships within families and informal networks, and links them to the available resources of health and social care providers and other agencies. The resources that flow through these social relations can be devoted to repair and adaptation. This enables either (1) the recombination of lifeworld resources in the face of continuously disruptive processes (where the effects of disruption are irreversible), or (2) the recovery of lifeworld resources that existed before disruption (where the effects of disruption are reversible).

Study registration

This study is registered as PROSPERO CRD42020224787.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR130407) and is published in full in *Health and Social Care Delivery Research*; Vol. 13, No. 24. See the NIHR Funding and Awards website for further award information.

Chapter 1 Introduction

Background

Globally, there is a shift to encouraging people with a variety of health problems to engage in programmes of self-care. This makes sense in an economic and social environment in which health and social care services are perceived to be subject to unsustainable levels of demand and expectations of expenditure. What comes with this shift, however, is a complex rearrangement of responsibilities, skills and expectations of service users and their caregivers. It inspires a question: what do service users and their caregivers need to do to participate effectively in their care? This is an increasingly important question. In earlier work,[1] we have pointed to the ways in which this shift is often realised through the delegation of care – and sometimes clinical work – from health and social care professionals to service users and caregivers. This may involve service users and their caregivers taking on a significant workload. Treatment burdens, which are the material and relational activities that service users and caregivers have to perform to effectively participate in their care, and to meet the normative expectations of health professionals and health services,[1–6] are at the centre of the qualitative evidence synthesis presented in this report. We are also concerned with the ways in which lived experiences of service users' and caregivers' work of participation are shaped by interactions with experienced social inequalities (socioeconomic disparities in health and health care), and illness trajectories (biogenic and sociogenic aspects of disease progression over time, and their reflection in status passages). Our point of departure in considering the relationship between treatment burdens, social inequalities and illness trajectories was that they would be reciprocal but also represented at different levels of analysis. They are the products of causal mechanisms that are generative of (1) social determinants of health;[7–9] (2) interactions between biogenic and psychogenic aspects of disease progression in individuals, and the status passages that stem from these;[10] and (3) the work that stems from these and that is represented in their biographical and relational effects.[11] These reciprocal relations are shown in *Figure 1*.

Trajectories, inequalities and burdens

In the social sciences applied to health, there are long traditions of research that have emphasised different aspects of the work of being a service used and caregiver. This work is central to understanding the ways in which illness, medical knowledge and practice and healthcare professions and institutions are experienced. It can be seen to take four important and intimately connected forms:

- Illness and its progression require service users and caregivers to negotiate and renegotiate experience and identities,[5,11] as they take on and perform new – and often unexpected and unwelcome – social roles that are assigned to them within their social networks and by health professionals.[12–14]
- Acquiring and living with illness identities and their related social roles mean that service users and caregivers are called upon to negotiate and manage temporal experiences of status passage and biographical and relational disruption as they are drawn into processes of care and structures of healthcare provision.[10,11]
- Engagement with processes of care and structures of healthcare provision means that service users and caregivers must negotiate and manage sets of interactions and relationships with professionals and service providers,[15] as well as reshaping relations within their informal social networks.[16]
- Socially patterned interactions with health professionals and relationships with service provider organisations incorporate expectations about the skilled performance of health behaviours and healthcare and self-care practices.[17–19]

The work that service users and caregivers do has always been seen as important in the sociology of health and illness, and it is impossible to overestimate the impact of the work of Anselm Strauss and his co-researchers[5,17,20,21] in shaping the research terrain around these relational and interactional topic areas, and in developing highly nuanced concepts of illness identity and status passage through to the end of the 20th century. However, over the past 25 years, service users and caregivers have taken on an additional layer of work, as healthcare provider organisations have increasingly promoted models of care in which service users and caregivers are seen to be integral to the healthcare team and are

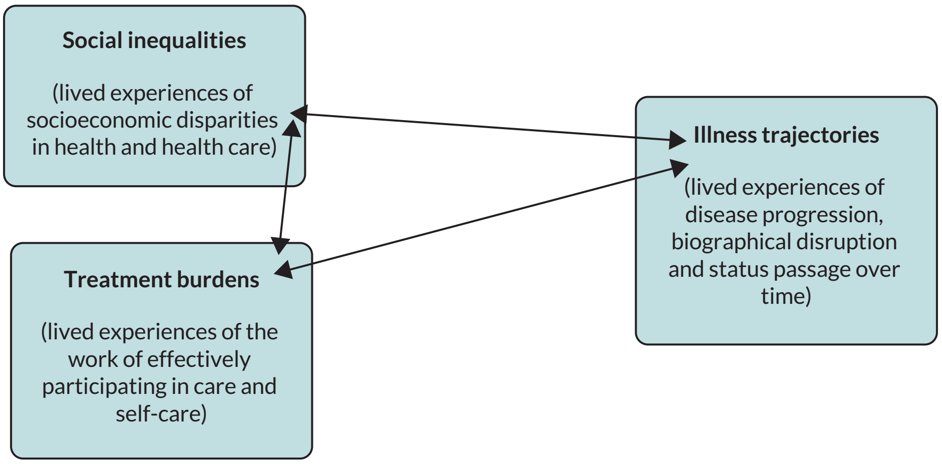

FIGURE 1 Interactions between inequalities, burdens and trajectories.

thus incorporated into the healthcare workforce. This leads to a fundamental proposition upon which this study is founded: that service users and caregivers are expected to contribute and to do work when they engage with self-care, health care and social care. In the UK, the NHS has been explicit about the value of such engagement.

> *Evidence tells us that supporting patients to be actively involved in their own care, treatment and support can improve outcomes and experience for patients, and potentially yield efficiency savings for the system through more personalised commissioning and supporting people to stay well and manage their own conditions better.*[22]

Health Education England's workforce strategy to 2029 is also clear that engagement and incorporation of patients and caregivers is central to the development of effective and economical models of care.

> *When we talk about 'the workforce' we are usually referring to the formal, paid workforce. But in addition to people employed by the NHS and other organisations, there is an army of individuals caring for themselves and each other.*[23]

The workload that this 'army' of service users and caregivers take on, and their capacity to do this work, when they engage with and participate in different kinds of care is important. It may play a key part in shaping the adoption and implementation of innovations in service delivery and organisation, utilisation and satisfaction with services, and the outcomes of care.[1] This is reflected in policy and practice interventions that identify service users and caregivers as part of a team that consists of informal networks beyond provider organisations in health and social care, as well as professionals within them.[23]

The policy of incorporating service users and their caregivers in the organisation and delivery of care has been particularly important in the case of long-term conditions. Our earlier work, and that of our collaborators, has to date focused on the ways in which service user and caregiver activities are shaped by the transfer of work from the clinic to the home and the delegation of clinical and organisational tasks to service users and caregivers. Importantly, these practices of transfer and delegation seem to presage a very different set of normative expectations of service users and caregivers to those embedded in 20th-century depictions of the sick role like those developed by Talcott Parsons at the end of the 1940s and which is still widely taught to student health professionals. He set out the sick role as one[24] in which the patient possesses certain rights:

- They are exempt from normal social roles.
- They are not responsible for their condition and have a right to be taken care of.

The patient also has certain obligations.

- They should try to get well.

- They should seek and co-operate with technically competent help.

This perspective has been widely criticised because it generalises patient behaviour from a very particular setting. Parsons developed the theory of the sick role by making unstructured observations of patients of an obliging single doctor – a physician at the Massachusetts General Hospital in Boston – as he accompanied him on occasional ward rounds.[25] Parsons himself acknowledged the limits of his sick role theory when applied to chronic illness[12] and to mental health problems.[26] Not surprisingly, then, we have subsequently seen a very different set of policy and practice perspectives about people with complex and long-term conditions. These are not framed as rights and obligations but rather as normative expectations of effective participation,[27] in which service users should:

- minimise the load that they place on formal healthcare systems
- work to overcome obstacles to accessing service provision
- actively engage with decision-making and treatment processes
- work to become knowledgeable about symptoms, treatments and disease processes.

Our earlier work[28,29] has built on the notion of the service user and caregiver as workers and has explored the problems of transfer of workload from formal care provision to the domestic sphere of the service user and caregiver.[30–36] We have pointed to the complexity of the workload that service users and caregivers take on when they have to manage their health and health care,[37] and when they have to understand and organise their interactions with healthcare agencies and other entities.[2] We have explored how self-care and healthcare workload can burden service users and their families, and how capacity to handle this workload varies between individuals.

In this qualitative evidence synthesis, we are concerned with the ways in which social inequalities shape changing experiences of illness, and burdens of treatment, over time. There is now a tremendous body of literature that identifies the ways in which health and healthcare advantages are distributed across the population of the UK[38,39] and across the populations of other countries too. These can be defined and mapped against many different practices of categorisation and stratification, including socioeconomic status, race and ethnicity, disability and health status, sex and gender, age and religion.[40,41] Importantly, structural determinants of health – operating at a societal level – have fundamental causal effects on lived experiences of health and illness,[7] because they shape the capacity to mobilise enabling agency around delegated clinical tasks, and because the wider pattern of resource allocation places a significant proportion at a disadvantage in accessing and utilising health services. Structural theories of inequalities,[9] networks[42] and social capital[43] were also important here. In collaboration with an international group of researchers, we have provided a synopsis of these elsewhere and have shown how they can be linked to a social justice model of care.[44] These theories provided a set of fundamental conceptual building blocks for modelling the social context of burden of treatment for service users and caregivers. We drew together key concepts from these theoretical frameworks, and from earlier reviews that had developed and deployed them,[31,33–36,45–48] in a set of hierarchical models.

Disparities, inequities and inequalities can be defined and mapped against many different practices of categorisation and stratification, including socioeconomic status, race and ethnicity, disability and health status, sex and gender, age and religion. However, these forms of categorisation can be blunt instruments, since the lived experiences and identities they represent intersect with, and may amplify, each other in complex ways.[49,50] Ideas about intersectionality have therefore increasingly been drawn into analyses of lived experiences of health and illness. These approaches point to the ways in which organisational policies and practices in health care translate higher-order social determinants into every day practice, as they produce and reproduce inequalities at the meso and micro level through the design and delivery of services, and through the behaviours that these services call for.[49,51,52] This perspective has important implications for understanding what service users and caregivers can do as they interact with health services.[53]

Against this background, we propose that a synthesis of qualitative studies will tell us important things about these lived experiences – of inequalities, trajectories and treatment burdens – because apprehending and understanding the meanings attributed to lived experience by people are at the very centre of qualitative investigation. These methods reflect the fluidity of everyday life. But they also reflect how this fluidity often coalesces around organised and predictable interactions and relations. In the synthesis that follows, of course, we are not able to access these first-order accounts of meanings and actions. Instead, we are concerned with the ways in which already published qualitative analyses translate them into descriptions and explanations of experience. In the EXPERTS I qualitative evidence synthesis,[28,29] some of us – with colleagues – developed a set of procedures for theory-informed analysis of the interactions between treatment burdens and other features of lived experiences, especially of the ways in which inequalities are revealed in interactions between disease progression trajectories and structural and interactional inequalities. What we were not able to do in EXPERTS I was to develop an empirically robust conceptual model of the predictable and generalisable mechanisms that motivate and shape lived experiences of these interactions. Following Vaughan's method of analytical ethnography, we now focus on a mode of analysis that 'extracts form from content to find common processes and structures in similar activities across different settings' (p. 697).[54]

The aim of this qualitative synthesis

Much is now known about service user and caregiver experiences of treatment burden in a group of long-term conditions, especially diabetes,[30] heart failure,[34] chronic obstructive pulmonary disease,[35] chronic kidney disease[36] and stroke,[33] because they are common diseases that generate high levels of demand for health services, consequent workload and expenditure, and are targets for self-care interventions intended to promote service user activation and slow down disease progression. This had made them important foci for research. It is clear, however, that experiences of symptoms and care, workload and capacity, are very different in disease of long duration (e.g. chronic obstructive pulmonary disease) and relatively rapid progression (e.g. lung cancer), although these diseases have similar effects and are equally lethal.[35] Much less is known about the ways in which workload and capacity are constituted and experienced by people living with complex neurological conditions such as Parkinson's disease, or significant and disabling mental health problems such as schizophrenia. Understanding the dynamics of interactions between inequalities, illness trajectories and treatment burden by using a comparative qualitative analysis – while methodologically challenging – is therefore likely to help us find common features of the experience of service users and caregivers, as well as foregrounding disease-specific aspects of these experiences.

The aim of this study was therefore to review, compare and synthesise qualitative studies of the lived experience of physical and mental health problems characterised by long-term, relapsing–remitting and rapidly progressing trajectories and to conceptualise the predictable and generalisable mechanisms that motivate and shape lived experiences of these interactions among service users and caregivers.

From this aim, we derived a primary research question: what do these bodies of literature tell us about the ways in which treatment burdens, illness trajectories and social inequalities interact with each other to shape the lived experiences of service users and caregivers over time?

Objectives

Identification of studies

We systematically searched for qualitative studies of the lived experience of three kinds of conditions: long-term conditions associated with significant disability (Parkinson's disease and schizophrenia); serious relapsing–remitting disease (inflammatory bowel disease, bipolar disorder) and rapidly progressing acute disease (two common types of brain cancer – astrocytoma and glioblastoma – along with young-onset dementia).[55]

Qualitative analysis

In this evidence synthesis, we used attribution analyses and qualitative content analysis to identify the work of service user and caregiver engagement and participation in self-care, health and social care. We used Event-State Analyses to characterise how these are shaped by interactions between burden of treatment and social inequalities, and to identify and understand the elements of these that could contribute to responsive service design.[55]

Theoretical development

Comparative qualitative analyses led to (1) a taxonomy of service user and caregiver work associated with lived experiences of different condition types and trajectories; (2) a taxonomy of theoretical constructs that explain interactions between condition types and trajectories, service contexts and social inequalities; and (3) a 'translational framework to support the development and implementation of new, person-centred models of care for service users and caregivers'.[55]

The value of comparative qualitative analysis

This is a theory-informed qualitative comparative synthesis. It has focused on lived experiences of inequalities, trajectories and burdens across multiple conditions, rather than single index conditions. We have been interested in the ways in which work and capacity are played out differently across a space characterised by different service providers and different patterns of social inequality, rather than by a specific clinical problem. Four foundational features of the synthesis make this possible. First of all, the conditions of interest are physical and mental health problems that are defined by their trajectories. These are as follows: long-term conditions associated with significant disability (Parkinson's disease and schizophrenia), relapsing–remitting disease (bipolar disorder and inflammatory bowel disease), and rapidly progressive acute disease (brain cancer and young-onset dementia). These conditions were selected because they gave us a wide range of opportunities to identify and characterise common features of very different conditions. An important tendency in studies of lived experiences of health and illness is that physical and mental health problems are seen as profoundly ontologically different. We recognise that these are experienced in very different ways. For example, experienced workload and capacity are likely to be very different in schizophrenia and astrocytoma, in part because of differences in service organisation and delivery and social context. However, there are also important commonalities in the ways in which service users and caregivers interact with services and professionals, and as we shall show, there are also some important commonalities in the structures of illness trajectories and the ways in which participants invest enabling agency in these. Finally, much work on service user work, workload and capacity has focused on conditions of relatively long duration, in which behaviour modification and self-care are important components of management. Much less is known about relapsing–remitting conditions and the different workload and capacity problems that stem from them, or about diseases that progress rapidly to conclusion, in which workload and capacity may be transferred from service users to caregivers quite early in their trajectory.

Methodological approaches to synthesising qualitative studies like qualitative meta-synthesis[56–60] and meta-ethnography[61–65] have led to important conceptual contributions to understanding the phenomena of interest encompassed by this evidence synthesis. However, the results of many of the primary studies of interest in our review were largely descriptive and thematic. Our methodological approach to the synthesis therefore drew together several different modes of qualitative analysis: abductive analysis and taxonomy building; attribution analysis and process mapping; biographical analysis and Event-State Tracing; and theory-building on a propositional scheme. These enabled us to effectively frame, identify, characterise and interpret different aspects of qualitative data and bring these analyses together to build a robust conceptual model of lived experiences of service users and caregivers and explore the implications of this model for NHS services.

Theoretical foundations of the evidence synthesis

Our interests in the topic of this evidence synthesis have been focused through theoretical development as well as empirical research. Over the past 20 years, the application of normalisation process theory[66] has helped us to understand the ways in which experiences of service user-hood involve implementing material and relational work that moves back and forth between the clinic and home, a process that is driven by sociotechnical developments.[4] The Cumulative Complexity Model[3] helped us to understand service user workload and capacity over linear time and proposed that it is associated with poor healthcare utilisation and outcomes. Burden of Treatment Theory[1] has helped us to understand the distribution of service user and caregiver workload and capacity over relational space, and the Cognitive Authority Model[6] helped us to understand how service users negotiate the normative expectations of healthcare providers. These theoretical developments enabled us to model burden of treatment as a result of micro-level phenomena in which material and interactional practices are allocated and negotiated in complex interactions between people, disease processes and healthcare environments.[29,30,32,33,47] Understanding service user capacity, balancing preferences, and workload allocation and capacity call on us to consider the ways in which service users and caregivers must always take note of, and often actively manage, the expectations of others.[6] In this evidence synthesis, we use a wider range of theories. It is helpful to summarise these, and we do so below.

Candidacy theory: negotiating access

Candidacy theory[67] provides a framework for understanding how individuals navigate access to healthcare services. It emphasises the dynamic and negotiated nature of healthcare access, focusing on how people perceive and present their eligibility for medical attention and how healthcare systems respond to these presentations. When applied to experiences of illness, candidacy theory highlights the complex interplay between patients and healthcare providers in determining who receives care, how quickly, and with what outcomes.

- The first step in candidacy involves recognising and articulating a health need. This recognition is not always straightforward, as it depends on individuals' health literacy, cultural understandings of illness and prior experiences with health care. For example, people from marginalised communities may have different thresholds for identifying health needs due to previous encounters with discrimination or mistrust of medical institutions. Consequently, they might delay seeking care, affecting their health outcomes.
- Once a health need is recognised, individuals must see themselves as legitimate candidates for care. This perception is shaped by personal beliefs about health and illness, as well as societal norms about who deserves medical attention. Patients with stigmatised conditions, such as mental health issues or substance abuse, may struggle to view themselves as worthy of care, affecting their willingness to seek help. Similarly, gender, race and class can influence perceptions of candidacy, with certain groups feeling less entitled to healthcare services.
- The next stage involves presenting one's candidacy to healthcare providers. This presentation is a negotiated process, where patients must effectively communicate their health needs and convince providers of their legitimacy. Factors such as communication skills, assertiveness and cultural competency play crucial roles in this interaction. Patients who can articulate their needs clearly and confidently are more likely to receive timely and appropriate care. Conversely, those who face language barriers or lack confidence may encounter challenges in presenting their candidacy, leading to suboptimal care.
- The final stage of candidacy involves navigating the healthcare system's response. This response is mediated by institutional practices, resource availability and healthcare providers' perceptions. Patients from disadvantaged backgrounds often encounter systemic barriers, such as long wait times, complex referral processes and implicit biases from providers. These barriers can diminish their chances of receiving adequate care. Additionally, healthcare providers' judgments about patients' candidacy are influenced by their own biases and institutional constraints, further complicating access to care.

Candidacy theory underscores the importance of context in shaping healthcare access. Socioeconomic conditions, cultural contexts and local healthcare infrastructure all affect how candidacy is constructed and negotiated. For instance, in resource-limited settings, the criteria for candidacy may be more stringent, with healthcare providers prioritising patients based on severity of illness and perceived ability to benefit from treatment. This prioritisation can marginalise patients with less acute but chronic conditions, exacerbating health inequities. Moreover, candidacy theory highlights the role of power dynamics in healthcare interactions. Patients with greater social capital, greater health literacy and greater access to material resources are better positioned to navigate the candidacy process effectively. They can leverage their knowledge and networks to advocate for their health needs, while those with fewer resources may struggle to do so. In this report, candidacy theory provides a framework for thinking about the way in which people negotiate access to care, not just at the point of diagnosis but around.

Biographical disruption theory

The theory of biographical disruption[11] addresses how chronic illness fundamentally alters an individual's life trajectory and self-perception. Bury argues that the onset of chronic illness can shatter the continuity of one's life narrative, creating a sense of disorientation and requiring individuals to re-evaluate their life plans, roles and identity. This disruption is marked by three key processes: the disruption of taken-for-granted assumptions and behaviours, the need to respond to the loss of certain functions and abilities, and the necessity to mobilise resources to manage the new reality.

The theory posits that chronic illness forces individuals to question previously stable aspects of their lives, including their body, relationship and future aspirations. The biographical disruption experienced can lead to a period of biographical work, where individuals engage in reconstructing their life story to incorporate their illness. This involves negotiating new meanings, roles and relationships, often leading to a redefined sense of self and social identity. It highlights the profound personal and social impacts of illness, beyond the physical symptoms, and underscores the importance of considering patients' narratives in health care. In this report, the concept of biographical disruption provides a framework for examining how people make sense of and adapt to their chronic illnesses, offering insights into the broader implications of health and illness on personal identity and life course.

Status passage theory

Status passage theory[10] explains the transitions individuals undergo as they move through different social statuses over their life course. It highlights how these passages are socially constructed and managed, emphasising the role of societal norms, institutions and interactions in shaping these transitions. Status passages refer to the changes in an individual's social position or identity, which can be either voluntary or involuntary, planned or unplanned. Examples include transitioning from student to employee, single to married, or healthy to ill. The theory identifies key dimensions of status passages, including timing, duration, reversibility, desirability and the level of ceremony or formality associated with the transition. These dimensions help to understand the complexities and variations in how different status passages are experienced and managed. The theory posits that status passages involve both individual and collective processes, requiring the negotiation of new roles, identities and relationships. Individuals must adapt to new expectations and often engage in identity work to align their self-concept with their new status. Simultaneously, institutions and social groups play a crucial role in defining, legitimising and facilitating these transitions through rituals, support systems and regulatory frameworks. In this report, status passage theory contributes a framework for understanding the social and psychological consequences of illness trajectories.

Burden of Treatment Theory

Burden of Treatment Theory[1] addresses the challenges patients face when managing chronic illnesses and the complex treatment regimens that often accompany them. It focuses on the workload that chronic illness management imposes on patients and their families, and the resultant impact on their daily lives. Burden of Treatment Theory shows that the burden of treatment encompasses not only the medical tasks, such as taking medications or attending appointments, but also the organisational, relational and emotional work required to manage a chronic condition. This includes co-ordinating care across multiple providers, negotiating healthcare systems, and maintaining social roles and relationships despite the limitations imposed by illness. The theory highlights how these activities can be time-consuming, physically demanding and emotionally draining, significantly affecting patients' quality of life. A key aspect of the Burden of Treatment Theory is the recognition of the disparities in patients' capacities to bear these burdens. Factors such as socioeconomic status, social support networks and health literacy can influence how well individuals can manage their treatment workloads. Those with fewer resources or less support may experience greater difficulties and stress, leading to poorer health outcomes. Burden of Treatment Theory emphasises the need for healthcare systems to recognise and mitigate these burdens. This involves designing interventions and care practices that are patient-centred, taking into account the practical and emotional challenges that patients face. By addressing the burden of treatment, healthcare providers can help improve adherence to treatment regimens and overall health outcomes, ultimately supporting better management of chronic illnesses and enhancing patients' quality of life. In this report, it provides insights into the ways that service users and caregivers must attempt to balance the workload of participation in care with their capacity to do so.

Social capital theory

Social capital theory[43] emphasises the importance of resources embedded in social networks and how these resources are accessed and mobilised for individual benefits. Lin conceptualises social capital as resources available to individuals through their social connections, which can be leveraged for various purposes, including health-related needs. In the context of illness, this perspective provides a nuanced understanding of how patients utilise their social networks to manage their health and navigate the healthcare system. In this study, we explore how social capital plays a significant role in shaping the illness experience of patients.

- *Structure of social networks*: The configuration of a patient's social network – comprising family, friends, colleagues and community members – determines the potential resources available. Networks characterised by diversity and extensive reach offer greater opportunities for accessing varied resources. For instance, a patient with a broad

and diverse network can tap into a wide range of expertise, advice and support, enhancing their ability to manage complex health conditions. Conversely, a patient with a limited or homogeneous network may struggle to find the necessary resources, impacting their health outcomes negatively.
- *Resources in social networks*: The value of social capital is closely tied to the resources that network members possess. These resources can include medical knowledge, emotional support, financial assistance and access to healthcare services. For example, having a friend who is a healthcare professional can provide critical insights into treatment options and medical procedures. Similarly, support from family members can alleviate stress and aid in recovery by providing practical help and emotional comfort. The availability and quality of these resources directly influence a patient's ability to cope with illness and navigate healthcare systems effectively.
- *Accessibility and mobilisation of resources*: Lin emphasises that having access to resources within a network is not sufficient; the ability to mobilise these resources is equally important. This mobilisation depends on the strength of relationships, trust and the willingness of network members to assist. For patients, effectively mobilising social capital can lead to better health outcomes. For instance, a patient who can effectively communicate their needs and garner support from their network is more likely to receive timely help, whether it is arranging transportation to medical appointments or obtaining reliable health information.

Applying a social capital framework to service user and caregiver experiences shows that service users and caregivers with robust social capital often experience smoother care co-ordination, better information flow and increased emotional resilience. These advantages can translate into improved adherence to treatment plans, quicker recovery times and overall better health outcomes. However, disparities in social capital can exacerbate health inequities. People from disadvantaged backgrounds may lack access to valuable social networks or the ability to mobilise necessary resources, resulting in poorer health outcomes. Addressing these disparities requires targeted interventions to strengthen social networks and enhance resource accessibility for marginalised groups. In this report, social capital theory offers a comprehensive framework for understanding how social networks influence patient experiences of illness. By examining the structure of networks, the resources they contain and the ability to mobilise these resources, we gain insights into the diverse ways social capital impacts health.

Theorising inequalities in health care

Theories of structural inequalities in health examine how socioeconomic, racial and other hierarchical social structures create and perpetuate disparities in health outcomes among different population groups. This theory posits that health inequalities are not merely a consequence of individual behaviours or genetic differences but are deeply embedded in the societal framework, influenced by historical, political, economic and cultural factors. Reynolds' Health Power Resources Theory[8] and Link and Phelan's Fundamental Causes Theory[7] provide valuable insights into these structural inequalities. Reynolds' theory focuses on the distribution of health power resources – such as money, knowledge, prestige, social connections and access to health services – arguing that these resources are critical determinants of health. Those with greater access to these resources can better navigate the health system, adopt healthier behaviours and utilise preventive measures, thereby enjoying better health outcomes. Conversely, those with fewer resources face significant barriers to maintaining and improving their health. At the same time, other social characteristics – race, ethnicity, age, gender, sex, age, (dis)ability and faith – frame intersectional inequalities.[51]

At the core of structural inequalities in health are politically modifiable determinants of health, which include factors such as income, education, employment, housing and access to health care. Healthcare access and quality are also crucial components of structural inequalities. Marginalised groups often face barriers to accessing healthcare services, including lack of insurance, transportation issues and discriminatory practices within healthcare settings. Even when access is available, the quality of care can differ significantly. For example, research indicates that racial and ethnic minorities often receive lower-quality care compared to their white counterparts, even after controlling for insurance status and other factors. Integrating Reynolds' Health Power Resources Theory and Link and Phelan's Fundamental Causes Theory with intersectionality theory enriches our understanding of structural inequalities in health by highlighting the critical role of social identities and the persistent influence of socioeconomic status on health disparities. In this report, we draw on theories of structural inequality and intersectionality to frame the consequences of complex and serious illness.

Chapter 2 Methods of investigation

Introduction

Following on from the procedures developed for our earlier qualitative synthesis of studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease,[28,29] we undertook a theory-informed synthesis of qualitative studies of brain cancer, young-onset dementia, bipolar disorder, inflammatory bowel disease, Parkinson's disease and schizophrenia. The synthesis was conducted between 2021 and 2023, and we reviewed primary studies and qualitative reviews published between 2010 and 2022. The general structure of the review is shown in *Figure 2*.

We employed structured manual approaches to framing, classifying, characterising and interpreting qualitative data. In addition, we used the 'auto-code' facility in NVivo® (QSR International, Warrington, UK) to undertake 'unsupervised' textual analysis across the data set to identify elements of missed in 'manual' analysis.

Changes to the protocol during the life of the study are described in *Table 1*.

Linking healthcare constructs with social care literature

An important theoretical and methodological problem in this review was synthesising research literature from different fields in which different technical vocabularies and theoretical constructs are employed. We expected to find differences in the ways in which health and social care researchers identified, characterised and explained key elements of lived experience of illness. This was also important in the production of a coding manual for use in the review. To support this, we sought advice from public and patient involvement (PPI) representatives, an ad hoc group of health and social care professionals, and members of the EXPERTS II oversight/steering group.

During the development of EXPERTS II, the National Institute for Health and Care Research (NIHR) asked us to explore views from social care practitioners about the way in which review topics were described in our protocol. Because of the pandemic, this part of the work was initially suspended. Over time, it was transformed into a set of conversations with people who were actually doing work at (and across) the social care/healthcare boundary [two care home managers, two paid (private sector) domiciliary caregivers, one social worker, two social care liaison workers and an 'integrated care worker']. These were not formal research interviews, but rather they were conversations about how we should frame our analysis of the literature. They were very useful because they produced a very different picture of the work of being a service user and caregiver. They drew attention to three things that were missing from the conceptual model and coding frame that informed our evidence synthesis.

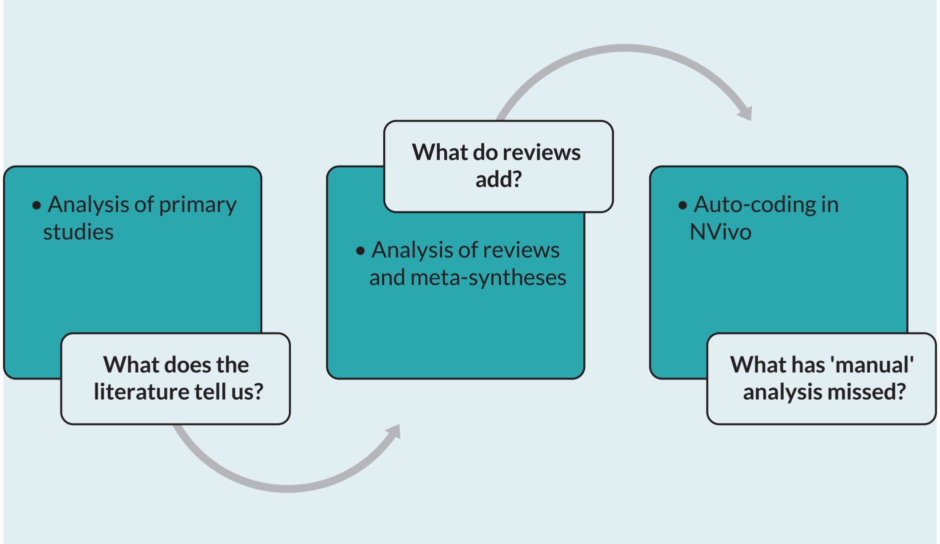

FIGURE 2 Structure of the review.

TABLE 1 Changes to the protocol

Date of approval by the NIHR	Change to the protocol
17 November 2020	Our original protocol called for two task groups with social care professionals to support the development of a taxonomy of service user and caregiver activities and to discuss the ways in which these are shaped by social inequalities and illness trajectories. The onset of the SARS-COVID-19 pandemic made this impossible, since most social care professionals had other, more urgent, priorities. Later, in 2021, we were able to have detailed conversations with social care professionals 'on the ground'. These are reported in *Chapter 6*.
12 October 2021	As our search strategies developed, we saw that we needed to refocus them. We had originally focused on rapid-onset dementia but replaced this with young-onset dementia as it became clear that rapid-onset dementia was marked by a clinical, rather than qualitative literature. We saw that most qualitative studies that included people with ulcerative colitis combined them with people with Crohn's disease under the ambit of inflammatory bowel disease. It was therefore agreed to incorporate these papers into the review where we were sure that papers included people with ulcerative colitis.
5 March 2022	It was agreed that bibliographic searches could be updated to 31 March 2022, to identify patient and caregiver activities related to SARS-COVID-19, and that COREQ Quality Assessment Tool would be that replaced by CASP Quality Assessment Tool.
15 March 2023	The original protocol proposed that we would use LEXIMANCER® (Leximancer Pty Ltd, Brisbane, Queensland) software to perform auto-coding of included papers. For technical reasons, this was not possible. It was therefore agreed that a similar facility within NVivo qualitative analysis software would be used.

CASP, Critical Appraisal Skills Programme; COREQ, consolidated criteria for reporting qualitative research; SARS-COVID-19, severe acute respiratory syndrome coronavirus 2.

- Difficulty in identifying sources of help.
- The exhausting struggle to identify health and social care professionals who are able to actually deliver support.
- Difficulty of communicating with people whose help is needed.

These kinds of accounts were not reflected in the literature, which tends to smooth out the incivilities that shape the personal experiences suggested above. These are forms of service user and caregiver work that reflect huge pressures in health and social care in the UK, and also demoralisation and exhaustion of many practitioners.

The role of representatives of patients and the public in EXPERTS II

Public representatives played a prominent part in the development of EXPERTS II. In fact, the history of this involvement is significant. Initial development of key ideas that led to this study began with a conference (led by CRM, FSM and AR) under the auspices of NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) Wessex in 2015, in which patient representatives and the public, social scientists, and clinicians met to develop an agenda for investigating the experiences of service users and caregivers and the boundaries of their work to drive effective participation in care. An important part of that cocreated agenda was understanding the contributions to a much wider range of conditions and refinement of the concepts used to characterise and understand the work that service users and caregivers do. This involved moving away from participants in that meeting called the 'big four' self-care problems (diabetes, chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease, the last three of which were covered by the EXPERTS I review[29]). The late Mark Stafford-Watson (patient advisor to NIHR CLAHRC Wessex) played an invaluable part in these discussions.

As we moved away from the EXPERTS I model towards the present study, Andrew Cooper joined the team as PPI co-applicant. He commented in detail on the focus and design of the EXPERTS II study as it was being developed and written. Unfortunately, he had to leave the study shortly after funding had been agreed. Thereafter, and throughout the duration of EXPERTS II, we were fortunate to be able to call on the very considerable experience and expertise of Antony Chuter. He has been our main PPI representative, serving both as a member of our oversight and steering committee and as a committed advisor to the research team. His advice and willingness to share his own experiences were invaluable to us.

During the preparation of the grant, we also had the benefit of advice from Peter Johnson on important aspects of service user work associated with care in mental health problems. His very astute remarks about the distinction between individualised self-care work and the complex set of hard-to-manage relationships that people living with serious mental health problems need to build with mental health services were extremely helpful. The late Margaret Colle told us about her experiences as a person living with Parkinson's disease who had also cared for a partner living with early-onset Alzheimer's disease. Her account emphasised the importance of felt and enacted stigma. Members of an informal inflammatory b?owel d?isease Support Group in West London helped us by discussing their experiences of patient work and illness trajectories, and also talked about the ways in which NHS professionals' judgements about their diet and family relations were shaped by views about ethnicity and religion. These views were not always well founded, and sometimes were experienced as frankly racist attributions.

All of our PPI contributors made important contributions not just to our thinking but more concretely to the ways in which we approached key research tasks, such as the construction of our analytic framework. Much more, they questioned the ways in which we characterised service user and caregiver contributions to care as work. They experienced high levels of demand for them to undertake specific tasks, and they often saw these as part of a mutual or reciprocal exchange relationship with health and social care providers. They also saw some of these activities as duties that were shaped by bonds of moral obligation and personal affection. This posed a question later about how to characterise service user and caregiver participation in care, and about what effective participation might mean, and for whom. Indeed, Mrs Colle described her relationship with what she described as very indifferent local authority care services as one in which her role was that of a concerned citizen.

Development of a coding manual for the review

The aim of the EXPERTS II qualitative synthesis is to understand the role of interactions between service user and caregiver work and social inequalities in shaping lived experiences of physical and mental health problems characterised by different illness trajectories. Because we were using 'manual' and 'unsupervised' qualitative analysis in tandem, it was important to develop a clear coding framework that represented the theoretical framework that informed the study. NVivo software performs semantic and relational searches within and across a corpus of texts when the auto-code function is used, but this still requires human interpretation.

Systematic literature searches

Inclusion criteria

We included peer-reviewed qualitative studies that met the following criteria.

Participants

People aged > 18 years; diagnosed with Parkinson's disease, inflammatory bowel disease, brain cancers (glioblastoma and astrocytoma), young-onset dementia, bipolar disorder, schizophrenia and their caregivers.

Reports

Results of qualitative studies of service users' or caregivers' accounts of the lived experiences of eligible conditions; their interactions with health professionals, healthcare provider organisations, treatment settings, technologies and regimens of care and self-care; and the social and economic contexts in which experiences of illness and care are set.

Study designs

(1) Primary qualitative studies using semistructured and unstructured interviews; primary qualitative studies using participant or non-participant observation studies; (2) systematic reviews of qualitative studies, qualitative meta-syntheses and meta-ethnographies.

Settings

Studies of illness experiences within self-care programmes, healthcare systems and social care systems.

Date of publication

Because there have been important changes in the organisation of care (and especially self-care) in the UK since 2010, we restricted eligible studies to those published between 1 January 2010 and 31 March 2022.

Language

English.

Exclusion criteria

We excluded reports which did not report the results of qualitative research with service users or caregivers; reports of treatment effectiveness, for example, randomised controlled trials (RCTs), where the focus was on the treatment effect rather than the service user's or caregiver's experience; reports of healthcare organisation or delivery which were not focused on service user's or carer's experience; and editorials, notes, letters and case reports.

Search strategy and searches

Searches were designed and undertaken at the York Health Economics Consortium by MA in close collaboration with CRM and KCG. The literature search methods were informed by those used for the EXPERTS I qualitative synthesis.[28,29] The strategy was developed in MEDLINE ALL (OvidSP). The strategy was pragmatic; it was not designed to be exhaustive but to achieve a balance of sensitivity and precision appropriate to the review context and aims.

The main conceptual structure of the MEDLINE search strategy was index conditions AND qualitative research AND patient/caregiver experience AND social inequalities OR patient/caregiver participation. This structure was supplemented by a number of additional highly pragmatic search approaches.

Search terms for the qualitative research and patient/caregiver experience concepts were largely informed by the terms used in the EXPERTS I study for the same concepts. Search terms for the social inequalities concept were focused on socioeconomic status, gender, ethnicity, migration and age, and drew heavily on terms included in the search filter developed by Prady *et al.*[68] to identify equity-focused studies.

Performance of the draft strategy was assessed by checking retrieval of records for a set of known, relevant studies. The final MEDLINE strategy was peer-reviewed by a second information specialist to check for errors in spelling, syntax and line combinations. The final MEDLINE search strategy as run in April 2022 is shown in *Appendix 1*.

The final MEDLINE strategy was translated appropriately for EMBASE (OvidSP), APA PsycInfo (OvidSP), Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete (EBSCO*host*), Scopus (www.scopus.com/), Social Care Online (www.scie-socialcareonline.org.uk/), Science Citation Index Expanded (Web of Science), Social Sciences Citation Index (Web of Science) and Arts and Humanities Citation Index (Web of Science). The searches were initially conducted in March–April 2021. Results were imported into an EndNote [Clarivate Analytics (formerly Thomson Reuters), Philadelphia, PA, USA] library and deduplicated. The searches were updated in April 2022; all searches were re-run in full, and results were deduplicated against the 2021 results.

Screening

Searches generated a large number of records and so first-stage screening aimed to eliminate those that were obviously irrelevant, such as notes, comments, editorials, non-systematic reviews, RCTs and studies in diseases that are not eligible. Second-stage screening began with an assessment of relevance of citations and abstracts by two reviewers independently. Any studies which were eligible, or which may be eligible, were obtained in full text. If agreement about inclusion could not be reached, we could call on an independent assessor to act as final arbiter. Full-text papers were screened by two reviewers (KCG and CRM) independently. Papers selected for inclusion were then stored as portable document format (pdf) files in secure EndNote libraries that were automatically backed up.

Quality assessment of eligible articles

There are many proposed sets or reporting criteria for qualitative studies. We used the Critical Appraisal Skills Programme (CASP)[69] checklist to inform assessment of the quality of qualitative research proposals and papers. It provides clear criteria for identifying high-quality reports. However, since there is no universally accepted reporting

TABLE 2 Elements of analytic work in the EXPERTS II review

The work of qualitative analysis	Practical analytic tasks	Contribution to interpretation of textual data	Contribution to development of the theoretical framework	Value-added outcomes of the EXPERTS II review
Theorisation – framing work	Familiarisation with a priori theories and the application of their relevant constructs informed an initial reading of qualitative data, and led to the identification of strategic narratives and other key features of included articles	Iterations of a theory-informed coding frame provided the foundation for identification and classification of elements of the data	Development of a taxonomy of service user and caregiver activities	Creation of a workable generic model of components of interactions between social inequalities, illness trajectories and treatment burden
Identification – classification work	Development, refinement and application of the coding frame-enabled systematic identification of service user and caregiver activities, illness trajectories and social inequalities	Attribution analysis developed a set of hierarchical models of relevant phenomena using attribution analysis	Participation in care was mapped against a model of biographical and relational disruption	Identification of potential intervention points to support service users' and caregivers' effective participation in care
Characterisation – analytic work	Modelling the relative position and significance of clusters of service user and caregiver activities. Search for potential causal relations	Analytic descriptions of key elements of textual data	Event-State Matrix that links contexts of action, system and relational trajectories, with unequal lifeworld resources	Creation of an Event-State Matrix links contexts of action to lifeworld resources to potential supportive interventions
Explanation – interpretive work	Generate interpretive constructs that explain the patterns and themes in the data. These constructs draw together the results of analytic work, existing theories and concepts, and new theoretical constructs generated within interpretive work	Explanation of key results from the review	Theoretical model of lifeworld resources	Creation of a Lifeworld Resources Model that shows how illness trajectories, social inequalities and treatment burdens interact to shape enabling agency

standard for qualitative studies, CASP can only guide decision-making on eligibility for inclusion. This was especially important because we drew on bodies of literature (e.g. social work and social care) that may have different disciplinary criteria for reporting. Reports that provided insufficient information about sample, question, method and setting were excluded from the review.

For review papers, we used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative Research)[70] approach to assess our confidence in findings. GRADE-CERQual assesses confidence in the evidence, based on the following four key components: methodological limitation of included studies, coherence of the review finding, adequacy of the data contributing to a review finding, and relevance of the included studies to the review question. After assessing each of the four components, we made a judgement about the overall confidence in the evidence supporting the review finding.

Methods of analysis

The elements of analytic work involved in this evidence synthesis are described in *Table 2*. Analysis was accomplished in four stages, in which practical analytic tasks (framing, identification, characterisation and interpretation) developed novel analytic outcomes, and led to value-added outcomes of the study.

Theorisation – framing work

The first phase of qualitative analysis of the materials collected for this evidence synthesis was theoretically informed. This means that we drew on already existing theories relevant to illness trajectories, treatment burden and social inequalities. We have described these theories in *Chapter 1*. In turn, this meant that we did not perform an inductive approach to the analysis of textual data, assuming that a substantive grounded theory[71] could be directly derived from it. Through these theories and their use in our earlier work, we developed a coding framework that defined what we were looking for in the content analysis of papers included in the review. We tested it on a set of qualitative systematic review and meta-synthesis papers collected for this evidence synthesis[72–113] to show that it was workable and generated usable results.

Identification – classification work

The second phase of analysis was descriptive, and it encompassed the classification work of qualitative research. In *Chapter 4*, we have shown how we combined two approaches to this work. First, we used attribution analysis,[114] to map the ways in which specific patterns of ascribed causes and reasons for service user and caregiver work of participation in care[115] appear in qualitative data sets. We presented these as a set of hierarchy diagrams. These were within-case analyses,[116] each of which described clusters of activities associated with mechanisms that motivate and shape the lived experience of service users and caregivers with a specific index condition. These hierarchy diagrams are presented as *Figures 3–8*. In using the term 'mechanism', we mean that the hierarchy diagrams show sequences of qualitatively associated processes 'that brings about, or prevents, some change in a concrete [social] system' (p. 182).[117] In this case, the term 'social system' has been used to denote a set of structured social relationships organised through the negotiation of norms and roles.[43] Our analytic approach focused on the presentation of results by authors of included papers, and the inferences that these suggest. Second, we used the coding frame to guide classification of (1) the work of service users and caregivers in participating and engaging with the expectations of self-care, health and social care providers; (2) the work of negotiating and interacting with health and social care providers and professionals; (3) the shaping effects of social inequalities and structural disadvantages. This work led to hierarchical diagrams, content analysis, and to the taxonomy of service user and caregiver activities presented in *Appendix 2*. We then mapped these onto a framework derived from biographical theory.

Characterisation – analytic work

The analytic work of qualitative analysis links descriptions of phenomena of interest represented in the data with proposals about their meaning and significance. In this evidence synthesis, we have done this in three ways. First, we mapped service user and caregiver activities against a biographical theoretical framework developed by Bury.[11] We then developed this model to provide a general biographical and relational model of trajectory that progresses from candidacy through diagnostic shock, biographical disruption, erosion, fracture and repair. This model of trajectory provided a way of describing the contexts of action of service users and caregivers as they negotiated institutional and personal trajectories of care. The combination of theory-informed attribution analysis and qualitative content analysis also revealed patterns of lifeworld resources (personal capacity, social capital and affective contributions).

Explanation – interpretive work

The final stage of analysis was to sift and sort constructs, writing them as context-independent propositions. Following Vaughan's[54] account of analytical ethnography, we aimed to identify mechanisms that 'connect actors, action, and outcomes' and that 'bridge micro, meso and macro levels of analysis in [their] explanations' (p. 689).[54] To do this, we compared elements of data and emergent theoretical constructs for six index conditions. We assessed the role, relative significance and degree of universality of constructs that represented aspects of social inequalities, burdens of treatment and illness trajectories. We also assessed their position and role in relation to each other. We brought these together in the form of a series of the simplest possible process-tracing diagrams.[118,119] These describe the core features of an action-oriented theory of lifeworld resources that can be used to identify and explain the mechanisms implicated in shaping service users' and caregivers' effective participation in care.

Auto-coding with NVivo

An additional analytic strategy was to use the auto-coding function in NVivo software to identify and explore missed opportunities for data extraction and analysis. In fact, this was unhelpful and added little to the analysis presented in this report. In part, this was because working across the whole data set composed, as it was, of very different conditions led to very general and descriptive lexical associations. Much more successful was the use of key word searches based on the taxonomy of constructs presented in *Appendix 2*, in which we focused specifically on searches for references to structural inequalities. Using this strategy emphasised how far we are from successful and informative techniques of computational analysis using software that searches for lexical associations. In the future, approaches using large language models such as Chat-GPT may be more successful in developing analytic frameworks, but genuinely interpretive advances in this area may be some way off.

Chapter 3 Results: summary of results of searches

Introduction

We undertook two rounds of searches. The first round of searches was conducted at York Health Economics Consortium in March and April 2021. This identified 34,787 records. Following deduplication, 13,234 records were assessed for relevance. These were screened by a single reviewer in York to remove those records that were obviously irrelevant, such as notes, comments, editorials, non-systematic reviews, RCTs and studies in diseases that are not eligible, and 7782 records were excluded at this stage. Following this first-stage screening, 5452 records remained for further assessment and were sent on to reviewers.

Although it was clear that we had achieved analytic saturation in the papers included in the first round of searches, a second round of searches was undertaken in April 2022. Our aim here was to identify any evidence of the impact of the severe acute respiratory syndrome coronavirus 2 (SARS-COVID-19) pandemic on the lived experiences of people living with any of the six index conditions. These searches identified a total of 41,439 records. After deduplication, 2582 results were screened to remove those records that were obviously irrelevant, and after excluding a further 1879 records, 703 records remained for further assessment. This showed that there was insufficient evidence of the impact of the SARS-COVID-19 pandemic on the literature exploring the lived experiences of people in our six index conditions. We therefore did not incorporate them into the evidence synthesis.

Article selection

As the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart in *Figure 3* shows, after deduplication and the elimination of irrelevant and obviously ineligible articles, we screened title and abstracts of 5452 articles and excluded a further 4545 of these. We then sought 907 articles for full text review. Despite our best efforts (including multiple web searches and attempting to contact authors), we were unable to obtain three articles. After this, we obtained 904 full texts for review, excluding 380 on the grounds of ineligibility. This left 524 papers to go through quality assessment, which led to the exclusion of a further 238 articles.

Data extraction

The process of article selection described above led to the inclusion of 279 articles in the synthesis. These are described in *Tables 3–9*. Data were extracted as described below, and a complete index of results of coding is given in *Table 10*.

Data mapping and taxonomy building

In this study, we employed a structured extraction instrument to systematically collect and organise data.[55] This instrument was crucial in ensuring consistency and comprehensiveness in the recording of various study parameters. For each included paper, we documented the country of origin, topic, sample size and methods of data collection. We also described the sample composition, including gender, age range and ethnicity, alongside the study design, mode of analysis and the presentation of results. These comprehensive details allowed understanding of the studies reviewed. The data sets are described in *Tables 3–9*. These data were subjected to attribution analysis.

Attribution analysis[114] is a qualitative method used to identify and understand causal relationships and patterns in qualitative data.[115,388] This method involves examining how different factors contribute to outcomes and behaviours in broader social, economic and cultural contexts. This method enabled us to identify and characterise clusters of patient and caregiver activities. Each paper was scrutinised to identify clusters of service user and caregiver activity specific to each index condition. The taxonomy of service user and caregiver activities derived from this is presented in *Appendix 2*. These clusters were then mapped in relation to inequalities, trajectories and burdens experienced by the service users

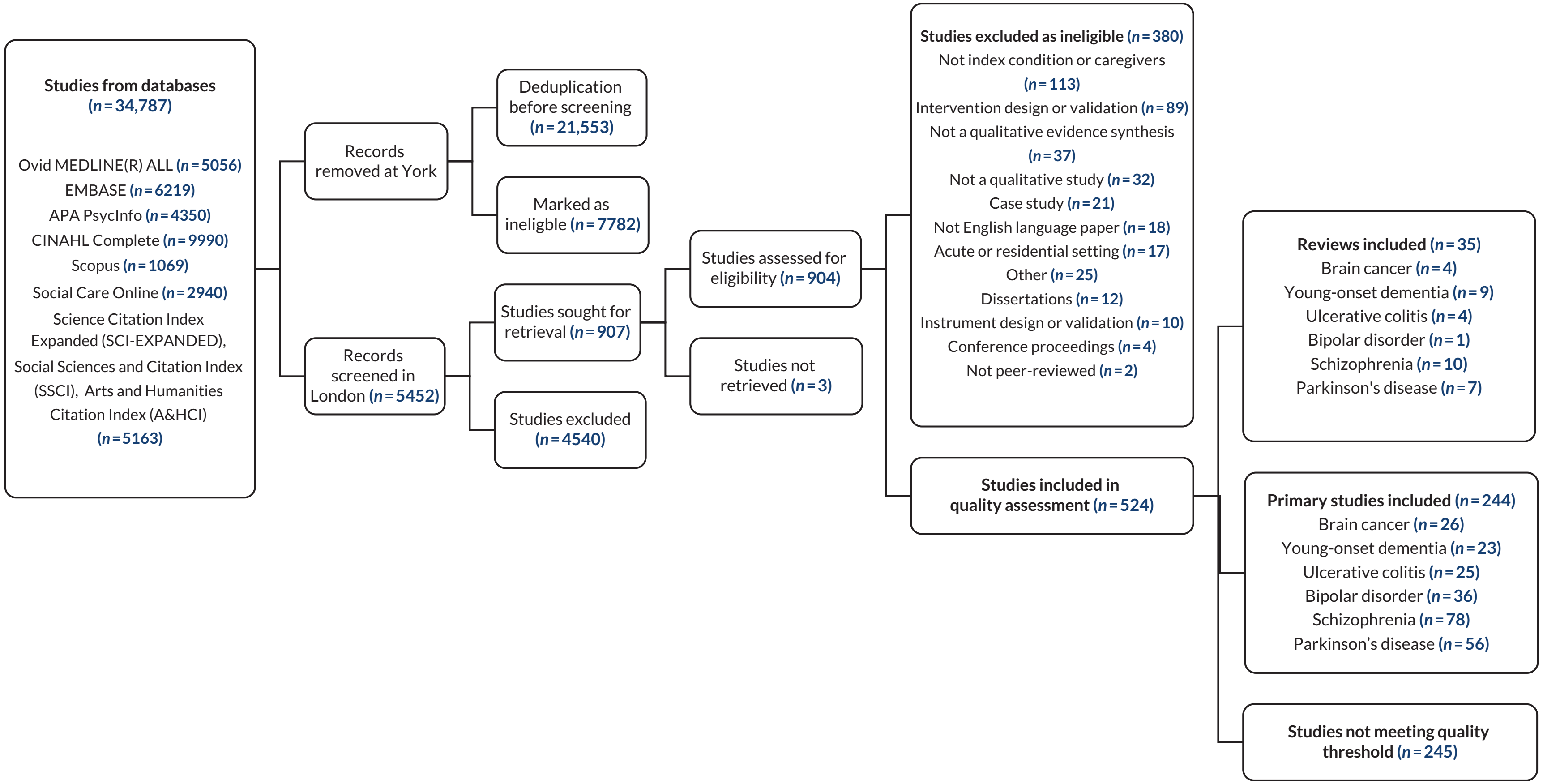

FIGURE 3 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart.

TABLE 3 Included papers: brain cancer

First author, year of publication	Country	Topic	Sample size (no. of caregivers) and data collection	Stated gender of service users (stated gender of caregivers)	Stated age range	Stated ethnicity	Stated study design or approach	Stated mode of analysis	Presentation of results
Amano, 2019[120]	Japan	Life adjustment in service users at onset of glioma	10 10× semistructured interviews	4M/6F	Range 30–63	–	Qualitative descriptive study	Modified grounded theory approach	Themes
Arber, 2013[121]	UK	Support needs of caregivers	22 caregivers 22× semistructured interviews	7M/15F	17 under 60 years	–	Constructivist grounded theory	Constant comparative approach	Themes
Baba, 2020[122]	Canada	Unmet needs of service users with intracranial meningioma	42 (12) 50× interviews	15M/27F (4M/8F)	Service users range 31–90 (caregivers range 31–80)	27 Caucasian, 4 black, 5 Asian, 3 Middle Eastern, 2 Central/South American, 1 European	–	Thematic analysis	Themes
Cavers, 2012[123]	UK	Social, psychological and existential well-being in people with glioma and their caregivers	49 (23) 134× longitudinal interviews	14M/12F	Range 21–76	–	Grounded theory	Constant comparative approach	Themes
Collins, 2014[124]	Australia	Challenges and suffering when caring for people with primary malignant glioma	23 caregivers 23× interviews	9M/14F	Range 27–77	–	–	Thematic analysis and cross-case analysis	Themes
Francis, 2020[125]	Denmark	Ethical dilemmas for spouse caregivers	10 caregivers 20 semistructured interviews	3M/7F	Range 36–76	–	Longitudinal qualitative descriptive design	Hermeneutic approach	Themes
Francis, 2021[126]	Denmark	Suffering among caregivers	10 caregivers 20× interviews	3M/7F	Range 36–76	–	Hermeneutic approach (longitudinal)	Hermeneutic analysis	Themes
Fletcher, 2012[127]	UK	Patient experience of awake craniotomy	7 caregivers 7× structured interviews	3M/4F	Range 26–41	–	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Gately, 2020[128]	Australia	Surviving glioblastoma and disconnection	10 10× interviews	4M/6F	Range 35–78	–	Qualitative approach	Thematic analysis	Themes

TABLE 3 Included papers: brain cancer (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers) and data collection	Stated gender of service users (stated gender of caregivers)	Stated age range	Stated ethnicity	Stated study design or approach	Stated mode of analysis	Presentation of results
Hackman 2011[129]	UK	Rehabilitation for people with brain cancer	10 5× interviews, 7× written narratives and 7× field notes	6M/4F	Range 26–63	All Caucasian	–	Thematic analysis	Themes
Hammill, 2019[130]	Australia	Participation and the impact of brain cancer	16 16× interviews	13M/3F	Range 44–75	–	–	Thematic analysis	Themes
Heckel, 2018[131]	Germany	Experiences and needs of informal caregivers	28 caregivers 28× interviews	7M		–	–	Thematic analysis	Themes
Howie, 2016[132]	UK	Experiences of awake craniotomy	6 6× interviews	–	Range 30–60	All white	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Hricik, 2011[133]	USA	Changes in caregiver perceptions over time	10 caregivers 10× phone interviews	8F/2M	–	All Caucasian	Longitudinal descriptive design	Content analysis	Themes
Lovely, 2013[134]	USA	Long-term survivorship with a malignant brain tumour	70 (35) 35× interviews	35M/35 (13M/22F)	Service users range 30–65 (caregivers range 43–77)	64 Caucasian, 6 other	Qualitative biographical	Thematic description	Themes
Mallya, 2020[135]	Canada	Benefits and barriers of support groups	16 (8) 4× focus groups	5M/11F	Support group attenders, range 35–57; support never attenders, range 25–54	–	Qualitative	Content analysis	Themes
McConigley, 2010[136]	Australia	Experience of caring	21 caregivers 21× interviews	4M/17F	Range 30–70	–	Grounded theory	Constant comparison	Themes
Molassiotis, 2010[137]	UK	Symptom experience in service users with brain tumours	9 21× interviews	7M/2F	Range 33–73	All white Caucasian	–	Content/framework analysis	Themes
Numata, 2020[138]	Japan	Decision-making among service users with early-stage malignant brain tumour	16 (2) 26× interviews	6M/8F (1M/1F)	Service users range 38–79 (caregivers range 40–69)	–	Grounded theory	Grounded theory	Categorical ‘pattern’

continued

TABLE 3 Included papers: brain cancer (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers) and data collection	Stated gender of service users (stated gender of caregivers)	Stated age range	Stated ethnicity	Stated study design or approach	Stated mode of analysis	Presentation of results
Ownsworth, 2015[139]	Australia	Support needs of caregivers	11 caregivers 11× interviews	6M/5F	Range 33–79	–	Phenomenology	Thematic analysis	Themes
Philip, 2014[140]	Australia	Experience of living and dying with brain cancer	10 10× interviews	6M/4F	Range 40–70	–	Qualitative	Grounded theory	Themes
Piil, 2015[141]	Denmark	Support needs of service users with brain cancer	30 (33) 63× semistructured interviews	19M/11F (10M/23F)	Service users range 29–82 (caregivers range 29–72)	–	Prospective longitudinal exploratory study	Thematic analysis	Themes
Piil, 2018[142]	As above								
Scott, 2019[143]	UK	Help-seeking preceding brain cancer diagnosis	39 39× interviews	21M/18F	–	–	–	Inductive thematic analysis	Themes
Sterckx, 2015[144]	Belgium	Care needs of service users with brain cancer	17 17× interviews	10M/7F	Range 28–73	–	Grounded theory approach	Qualitative analysis guide of Leuven	Themes
Walter, 2019[145]	UK	Experiences of missed opportunities for diagnosis of brain cancer	39 39× interviews	21M/18F	–	–	Qualitative	Inductive thematic analysis	Themes

F, female; M, male.

TABLE 4 Included papers: young-onset dementia

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Presentation of results
Barca, 2014[146]	Norway	Experiences of adult children of persons with young-onset dementia	14 caregivers 12× semi-structured interviews	2M/12F	Range 20–37	–	Grounded theory	Thematic analysis	Themes
Bergman, 2016[147]	Sweden	Meaning of living close to a person with young-onset dementia	10 caregivers 10× semi-structured interviews	5M/5F	Range 40–64	–	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Busted, 2020[148]	Denmark	Experience of losing sense of self young-onset dementia	9 9× interviews	5M/4F	Range 47–65	–	Qualitative	Reflexive thematic analysis	Themes
Cations, 2017[149]	Australia	Lack of uptake of formal services among people with young-onset dementia and their caregivers	50 (40) 7× focus groups	–	–	–		Thematic analysis	Themes
Clemerson, 2014[150]	UK	Coping among people with early-onset dementia (EOD)	8 8× interviews	7M/1F	Range 35–63	–	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Ducharme, 2013[151]	Canada	Experience of spouses	12 caregivers 12× interviews	4M/8F	–	–	Phenomenology	Miles and Huberman method	Themes
Ducharme, 2014[152]	Canada	Unmet support needs among family caregivers	32 caregivers 32× interviews	8M/24F	–	–	Mixed methods	Thematic content analysis	Themes
Evans, 2019[153]	Australia	Impact of young-onset dementia on employment	15 (7) 10× interviews plus life grids	5M/3F (2M/5F)	Service users: range 49–63 (caregivers: age not given)	–	Retrospective biographical approach	'Within' and 'between' cross-case analysis	Case studies and themes
Holthe, 2018[154]	Norway	Caregiver experiences of assistive technology	25 (13) 78× interviews	11M/14F (7M/6F)	Services users: range 55–65 (caregivers: range 19–89)	–	Qualitative interview study	Kvale and Brinkman's analysis	Themes

continued

TABLE 4 Included papers: young-onset dementia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Presentation of results
Hutchinson, 2016[155]	Australia	Empowering young people with parent living with young-onset dementia	12 caregivers 12× interviews	1M/11F	Range 10–33	–	Social model of disability	Thematic analysis	Themes
Hutchinson, 2016[156]	Australia	Emotional well-being of young people with parent with young-onset dementia	As above						
Johannessen, 2016[157]	Norway	Coping and resilience among adult children with parent with young-onset dementia	14 caregivers 27× interviews	5M/9F	Range 18–30	–	Grounded theory	Grounded theory	Themes
Johannessen, 2019[158]	Norway	Coping with transitions of single people with young-onset dementia	10 60× interviews	3M/7F	Range 49–67	–	Grounded theory	Narrative inquiry	Themes
Johannessen, 2018[159]	Norway	Experiencing deterioration among people with young-onset dementia living alone	10 42× interviews	3M/7F	Range 49–67	–	Grounded theory explorative descriptive		Themes
Millenaar, 2014[160]	The Netherlands	Experiences and needs of children living with parent with young-onset dementia	14 caregivers 14× interviews	6M/8F	Range 15–27	–	–	Inductive content analysis	Themes
Pang, 2019[161]	Hong Kong	Positives in caregiving among Chinese spousal caregivers	6 caregivers 6× interviews	3M/3F	Range 61–73	All Chinese	Qualitative descriptive study	Qualitative content analysis	Themes
Roach, 2014[162]	UK	Identifying family storylines in young-onset dementia	13 (8) 126× interviews	7M/6F (5M/3F)	Service users: range 49–64 (family members: range 32–76)	–	–	Narrative analysis	Family biographies and storylines presented as themes
Thorsen, 2021[163]	Norway	The meaning of caring or a spouse with young-onset dementia	16 caregivers 16× interviews	6M/10F	Range 51–68	–	Hermeneutic	Narrative qualitative using Steger's three-step analysis	Themes
Thorsen, 2020[164]	Norway	Awareness and coping to preserve quality of life	10 68× interviews	3M/7F	Range 49–67	–	Narrative method	Grounded theory	Themes

TABLE 4 Included papers: young-onset dementia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Presentation of results
van Vliet, 2017[165]	The Netherlands	Feeling useful and engaged in daily life among people with young-onset dementia	39 (21) 8× focus groups	18M/21F (7M/14F)	–	–	–	Inductive content analysis	Themes and model
Wawrziczny, 2016[166]	France	Couples' experiences with young-onset dementia	32 (16) 16× interviews	–	–	–	–	Interpretive phenomenological analysis	Themes
Werner, 2020[167]	Israel	Caregivers' stigmatic experiences with persons with young-onset dementia	6 caregivers* 1× focus group	2M/4F	Range 51–69	–	–	Thematic analysis	Themes
Withers, 2021[168]	USA	Experiences of Latino family caregivers	27 caregivers 5× focus groups	7M/20F	Range 18–76	All Latino	–	Thematic analysis	Themes

F, female; M, male.

TABLE 5 Included papers: inflammatory bowel disease

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Presentation of results
Alexakis, 2015[169]	UK	Challenges faced by young people with inflammatory bowel disease from black and minority ethnic communities	20	13M/7F	Range 16–24	17 Asian/Asian British, 2 black/Black British, 1 mixed Asian/white	–		Themes
Allison, 2013[170]	UK	Surgery in young adults with inflammatory bowel disease	24 24× interviews	11M/13F	Range 18–25	11 white, 8 Asian British, 5 Black British	Narrative	Story-mapping and re-storying	Themes
Baker, 2017[171]	UK	Informational needs and preferences of service users considering surgery for inflammatory bowel disease	16 16× interviews	7M/9F	Range 22–74	–	Qualitative methodology	Thematic analysis	Themes
Cooper, 2010[172]	UK	Beliefs about control and self-management when living with inflammatory bowel disease	24 24× interviews	–	Range 30–40	–	Qualitative	Systematic framework analysis	Themes
Czuber-Dochan, 2020[173]	UK	Perceptions and psychosocial impact of food, nutrition, eating and drinking in people with inflammatory bowel disease	28 28 semi-structured interviews	13M/15F	–	–	Qualitative	Thematic analysis using Colaizzi's framework	Themes
Dibley, 2018[174]	UK	Decision-making about emergency and planned stoma surgery for inflammatory bowel disease	48 4× focus groups, 29× interviews	17M/31F	Range 20–73	45 White British, 2 Indian, 1 other white background	Qualitative	Thematic analysis	Themes
Flanagan, 2021[175]	Australia	Pregnancy-related concerns in women with inflammatory bowel disease	15 15× interviews	15F	–	–	Qualitative study	Thematic analysis	Themes
Garcia-Sanjuan, 2019[176]	Spain	Experiencing the care of a family member with Crohn's disease	11 caregivers 11× interviews	2M/9F	Range 20–60	–	Qualitative study	Thematic analysis	Themes
Horgan, 2020[177]	Ireland	Perceptions of life with inflammatory bowel disease and a Stoma among young males	5 5× interviews	5M	Range 20–30	All Caucasian	Qualitative	Interpretive phenomenological analysis	Themes
Kemp, 2013[178]	UK	Follow-up needs of people with inflammatory bowel disease	24 24× interviews	9M/15F	Range 27–72	–	Qualitative study	Framework analysis	Themes

TABLE 5 Included papers: inflammatory bowel disease (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Presentation of results
Larsson, 2017[179]	Sweden	Stress, coping and support needs of people with inflammatory bowel disease	15 15× interviews	6M/9F	Range 29–63	–	Qualitative descriptive	Content analysis	Themes
Lesnovska, 2017[180]	Sweden	Perceptions of health care by people with inflammatory bowel disease	26 5× focus groups	14M/12F	Range 19–76	–	Qualitative explorative	Krueger and Casey Method	Themes
Lindberg, 2014[181]	Sweden	Experiences of complementary and alternative medicine in people with inflammatory bowel disease	15 15× interviews	6M/9F	Range 20–80	–	Qualitative	Content analysis	Themes
Lopez-Cortes, 2018[182]	Spain	Factors influencing life experiences of people with inflammatory bowel disease	14 14× interviews	6M/8F	Range 19–61	–	Grounded theory	Constant comparison	Themes
Matini, 2016[183]	UK	Adaptation in the experience of living with inflammatory bowel disease	22 22× interviews	8M/14F	Female: range 19–60, male: range 36–48	–	Qualitative	Thematic analysis	Themes
McMullan, 2017[184]	UK	Adapting to inflammatory bowel disease to live a ‘normal’ life	28 28× interviews and fieldnotes	12M/16F	Range 18–57	24 white, 4 Asian	Qualitative	Framework analysis	Typologies
Palant, 2015[185]	Germany	The significance of food for people with inflammatory bowel disease	42 42× interviews	19M/23F	Range 17–79	–	Grounded theory	Grounded theory	Themes
Restall, 2017[186]	Canada	Information and health-related decision-making in daily life	45 45× interviews	22M/23F	Range 21–73	–	Phenomenological approach	Phenomenological approaches	Themes
Restall, 2016[187]	Canada	Work experiences of people with inflammatory bowel disease	As above						
Ruan, 2020[188]	China	Body image changes among people living with inflammatory bowel disease	16 16× interviews	8M/8F	Range 21–58	–	Descriptive qualitative	Content analysis	Themes
Ryhlander, 2019[189]	Sweden	Experiences of repeated colonoscopies	33 33× interviews	15M/18F	Range 20–77	–	Gadamer’s interpretation analysis	Hermeneutic interpretation	Themes

continued

TABLE 5 Included papers: inflammatory bowel disease (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Presentation of results
Sammut, 2015[190]	–	Experiences of adults with inflammatory bowel disease	10 10× interviews	4M/6F	Range 29–60	–	Explorative qualitative design	Interpretive phenomenological analysis	Themes
Skrautvol, 2015[191]	Norway	Experiences of nutrition as long-term care in inflammatory bowel disease	13 13× interviews	3M/10F	Range 18–45	–	Hermeneutic approach	Thematic analysis	Themes
Skrautvol, 2017[192]	Norway	Tolerance limits, self-understanding and stress resilience in integrative recovery of inflammatory bowel disease	As above						
Whiteley, 2018[193]	Australia	Embodied experiences of pregnancy with an ileostomy	8 8× interviews	8F	Range 26–37	–	Qualitative	Hermeneutic phenomenology	Themes

F, female; M, male.

TABLE 6 Included papers: bipolar disorder

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Analytic presentation
Baruch, 2018[194]	UK	Caring for a relative with bipolar disorder	18 caregivers 18× interviews	4M/14F	Range 31–67	8 White British, 4 other white, 4 Asian/Asian British, 2 mixed backgrounds	Qualitative	Framework analysis	Themes
Billsborough, 2014[195]	UK	Support needs in bipolar disorder when 'going up' and 'going down'	27 (11) 27× interviews	9M/18F (2M/9F)	Service users range: 18–64 (caregivers range: 18–75)	21 White British, 3 no data, 1 Afro-Caribbean, 1 mixed other, 1 white other	Reflexive collaborative approach	Thematic analysis	Themes
Bonnington, 2014[196]	UK	Stigmatisation among people with bipolar disorder or borderline personality disorder	24 3× focus groups, 14× interviews and 'lifeworld network' diagrams	8M/16F	Range 18–51	18 white, 6 Black African or Black Caribbean	Critical realist inquiry	Constant comparative analysis	Themes
Cappleman, 2015[197]	UK	Managing bipolar moods without medication	10 10× interviews	5M/5F	Range 29–50	–	Grounded theory	Grounded theory	Themes
Chatzidamianos, 2015[198]	UK	Involvement of relatives in care for bipolar disorder	23 (12) 35× interviews	10M/13F (5M/7F)	–	22 White British, 1 white other	Qualitative	Framework analysis	Themes
Clements, 2019[199]	UK	Experience of mental health care for suicidal behaviour	11 (11) 22× interviews	4M/18F	Range 18–66	–	Qualitative	Thematic analysis	Themes
Crowe, 2012[200]	New Zealand	Feeling out of control and the impact of bipolar disorder	21 21× interviews	5M/16F	Range 22–71	All New Zealand European	Inductive qualitative approach	Thematic analysis	Themes
Daggenvoorde, 2013[201]	The Netherlands	Use of a relapse prevention plans by service users with bipolar disorder	15 15× interviews	7M/8F	Range 32–62	–	Phenomenology	Colaizzi's method of data analysis	Themes
Demissie, 2021[202]	Ethiopia	Experiences of living with bipolar disorder	27 27× depth interviews	15M/12F	–	–	Phenomenology	Thematic analysis	Themes

continued

TABLE 6 Included papers: bipolar disorder (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Analytic presentation
Doherty, 2013[203]	USA	Perceptions of supportive behaviour by young adults with bipolar disorder	30 30× interviews	6M/24F	Range 18–30	–	–	Grounded theory	Themes
Echezarraga, 2019[204]	Spain	Resilience process	15* 9× interviews, 1× focus group	4M/11F	–	–	Phenomenology	Thematic analysis	Themes
Fernandez, 2014[205]	Australia	Experiences of loss and recovery for women with bipolar disorder	10 10× interviews	10F	Range 29–68	–	–	Constant comparative method	Themes
Fisher, 2018[206]	Australia	Treatment decision-making	41 (13) 41× semistructured interviews	12M/29F (3M/10F)	–	–	Qualitative	Thematic analysis	Themes
Johansson, 2020[207]	Sweden	The experience of being diagnosed with bipolar disorder	7 7× interviews	1M/6F	Range 23–50	5 Swedish, 1 Nordic, 1 European	Qualitative	Inductive, experiential thematic analysis	Themes
Lan, 2018[208]	Taiwan	Explanatory models of bipolar disorder among service users and family caregivers	20 (22) 42× interviews	9M/11F (–)	Range 19–63	–	Descriptive qualitative	Thematic analysis	Themes
Lekoadi, 2019[209]	South Africa	The experiences of family members caring for individuals living with bipolar disorder	9 caregivers 9× interviews, plus observations	5M/4F	Range 30–65	–	Qualitative	Thematic analysis	Themes
Maassen, 2018[210]	The Netherlands	Challenges of living with bipolar disorder	56 7× focus groups	18M/38F	Range 24–75	–	Qualitative	Thematic analysis	Themes
Madden, 2021[211]	USA	Healthcare costs among people with employer-sponsored insurance and bipolar disorder	40 (12) 40× interviews	8M/32F	Range 18–64	29 white, non-Hispanic, 5 Asian American, 2 African American, 4 Others	Qualitative	Iterative immersion-crystallisation process	Themes
Mansell, 2010[212]	UK	Recovery from bipolar disorder	13 13× interviews	4M/9F	Range 32–61	–	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes

TABLE 6 Included papers: bipolar disorder (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Analytic presentation
McNamara, 2015[213]	Ireland	Driving with bipolar disorder	18	–	–	–	Qualitative phenomenology	Thematic analysis 2 focus groups	Themes
Pallesen, 2020[214]	UK	The experience of being diagnosed with bipolar disorder	9 9× interviews	7M/2F	Range 26–45	7 White British, 1 Black British, 1 African	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Perich, 2017[215]	Australia	The experience of menopause for women with bipolar disorder	15 15× interviews	15F	Range 46–60	–	Social constructionist framework	Thematic analysis	Themes
Peters, 2011[216]	UK	Involving relatives in relapse prevention for bipolar disorder	31 (10) 52× interviews	12M/19F (4M/6F)	Service users: range 24–63 (caregivers range: 29–57)	–	Qualitative	Grounded theory	Themes
Ralat, 2018[217]	Puerto Rico	Reasons for non-adherence to psychiatric medication and cardiovascular risk factors treatment	22 3× focus groups	3M/19F	Range 23–60	18 white (21 Puerto Rican, 1 Dominican Republic)	Qualitative (health belief model)	Content analysis	Themes
Rusner, 2012[218]	Sweden	The existential meaning of being closely related to a person with bipolar disorder	12 caregivers 12× interviews	6M/6F	Range 21–71	11 Swedish, 1 Asian	–	Phenomenological analysis	Themes
Rusner, 2010[219]	Sweden	Conditions that enable a good life with bipolar disorder	10	4M/6F	Range 30–61	–	Reflected life-world approach (phenomenology)	Dahlberg's 'whole-parts-whole' analysis 10 interviews	Themes
Rusner, 2013[220]	Sweden	Coping among family caregivers	12 12× interviews	6M/6F	Range 21–71	11 Swedish, 1 South American, 1 Asian	Phenomenology	Phenomenology	Themes
Suto, 2010[221]	Canada	What works for people with bipolar disorder	32 23× interviews 3× focus groups	12M/20F	–	–	–	Thematic analysis	Themes

continued

TABLE 6 Included papers: bipolar disorder (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis Data breakdown Longitudinal	Analytic presentation
Tjoflåt, 2013[222]	Norway	Experiencing parenting of people living with bipolar disorder	6 6× interviews	1M/5F	Range 31–50	'Ethnically Norwegian'	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Tse, 2019[223]	Hong Kong	Recovery from bipolar disorder	32 32× interviews	9M/23F	Range 26–66	All Chinese	–	Thematic analysis	Themes
van den Heuvel, 2018[224]	The Netherlands	Caregivers' experiences of self-management support of individuals living with bipolar disorder	10 caregivers 10× interviews	3M/7F	Range 33–65	–	Descriptive phenomenology	Phenomenological analysis	Themes
van den Heuvel, 2015[225]	The Netherlands	Service user experiences of self-management of bipolar disorder	16 16× interviews	8M/8F	Range 23–66	–	Descriptive phenomenology	Phenomenological content analysis	Themes
Veseth, 2012[226]	Norway	Self-care in recovery for bipolar disorder	13 13× interviews	6M/7F	Range 27–65	–	–	Hermeneutic phenomenology	Themes
Ward, 2011[227]	USA	Lived experience of bipolar disorder and substance use disorder	12 12× interviews	1M/11F	Range 33–52	7 African American, 4 Caucasian, 1 Asian	Descriptive phenomenology	Colaizzi's method of data analysis	Themes
Warwick, 2019[228]	Multiple countries	Living well following diagnosis of bipolar disorder	12 12× interviews	6M/6F	Range 32–63	–	Grounded theory	Grounded theory	Themes and model
Yuen, 2019[229]	China	Perceptions of recovery and peer support services for people with bipolar disorder	14 caregivers 14× interviews	3M/11F	Range 30–75	All Chinese	–	Thematic analysis	Themes

F, female; M, male.

TABLE 7 Included papers: schizophrenia

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Alasmee, 2020[230]	Jordan	Primary caregivers experience of anti-psychotic medication	21 caregivers 21× interviews	8M/13F	Range 21–51	–	–	Thematic analysis	Themes
Alshowkan, 2015[231]	Saudi Arabia	Quality of life of people with schizophrenia	159 159× interviews	97M/62F	–	–	Descriptive qualitative	Thematic analysis	Themes
Amsalem, 2018[232]	Israel	The experience of stigmatisation among professionals	31 (15) 16× semistructured interviews	20M/12F (8M/8F)	–	–	Retrospective case study	Grounded theory	Themes
Asher, 2017[233]	Ethiopia	Physical restraint	4 (17) 6× interviews 5× community focus groups	3M/1F (9M/8F)	Service users: range 25–59 (caregivers: range 25 to > 60)	–	Qualitative	Thematic analysis	Themes
Avieli, 2016[234]	Israel	Aging with schizophrenia	18 18× interviews	11M/7F	Range 60–69	–	Existential phenomenological tradition	Phenomenological content analysis	Themes
Blomgren Mannerheim, 2016[235]	Sweden	Caring for adult child with schizophrenia	8 caregivers 8× interviews	3M/5F	Range 58–63	–	Qualitative		Themes
Butcher, 2020[236]	UK	Experiences of negative symptoms of schizophrenia	20 20× interviews	17M/3F	Range 35–62	12 White British, 8 Black African	Qualitative	Thematic analysis	Themes
Buzukashvili, 2019[237]	Israel	Motivation for medical treatment among people with schizophrenia	10 10× interviews	5M/5F	Range 31–55	–	Self-determination theory	Theory-driven approach	Themes
Cheng, 2019[238]	Taiwan	Psychosis risk syndrome	25 40× interviews	13M/12F	Range 20–40	–	Grounded theory	Constant comparison analysis	Themes
Chidarikire, 2021[239]	Zimbabwe	Quality of life of people with schizophrenia	18 18× interviews	12M/6F	–	–	–	Thematic analysis	Themes
Coblentz, 2015[240]	USA	Schizophrenia and metabolic syndrome in rural communities	7 21× interviews	4M/3F	Range 30–49	All white	–	Inductive content analysis	Themes

continued

TABLE 7 Included papers: schizophrenia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Cohen, 2017[241]	USA	Managing schizophrenia symptoms among high-achieving individuals	20 53× interviews	10M/10F	–	7 Caucasian, 6 African American, 4 Hispanic or Latino, 2 Asian, 1 Persian	Qualitative	–	Themes
Darban, 2021[242]	Islamic Republic of Iran	Family achievements in struggling with schizophrenia	15 caregivers 15× interviews	4M/11F	Range 24–65	8 Baloch, 7 Sistani	Qualitative	Content analysis	Themes
Faulkner, 2017[243]	UK	Experience of sleep disturbance in schizophrenia	15 15× semistructured interviews	10M/5F	Range 23–69	–	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Gater, 2014[244]	USA	Caregiver burden in schizophrenia	19 caregivers 19× interviews	4M/15F	Range 28–67	11 black, 2 Hispanic, 6 white	Qualitative	Grounded theory	Themes
Gill, 2016[245]	UK	Atypical medication in schizophrenia	19 38× semistructured interviews and diaries	13M/6F	Range 28–56	–	Phenomenology	Thematic content analysis	Themes
Gloria, 2018[246]	Ghana	Caring for people with schizophrenia	60 caregivers 60× interviews	29M/31F	Range 25–81	–	–	Interpretive phenomenological analysis	Themes
Gooding, 2019[247]	UK	Resilience in people experiencing schizophrenia and suicidal thoughts and behaviours	23 23× interviews	14M/7F	Range 20–67	19 Caucasian	Qualitative	Thematic analysis	Themes
Guner, 2014[248]	Türkiye	Perceptions of people living with schizophrenia	9 9× interviews	8M/1F	Range 27–45	–	Qualitative explorative study	Content analysis	Themes
Gunnmo, 2011[249]	Sweden	Living well with schizophrenia	7 7× interviews	1M/6F	Range 33–66	–	Qualitative study	Grounded theory	Themes
Harris, 2019[250]	UK	Resilience in people experiencing schizophrenia and suicidal thoughts and behaviours	20 20× interviews	10M/10F	Range 23–75	16 White British, 3 mixed ethnicity, 1 Black British	Qualitative	Inductive thematic analysis	Themes

TABLE 7 Included papers: schizophrenia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Hsu, 2014[251]	Taiwan	Violence towards parents in adults with schizophrenia	28 (14) 28× dyad adult child–parent interviews	16M/12F (16M/8F)	Service users: range 28–49	–	Qualitative phenomenology	Content analysis	Themes
Huang, 2020[252]	China	The experience of shared decision-making among caregivers of people diagnosed with schizophrenia	15 caregiver 15× interviews	6M/9F	Range 27–59	–	Qualitative	Inductive thematic analysis	Themes
Huang, 2020[253]	China	Perceptions of shared decision-making among hospitalised people diagnosed with schizophrenia	12 12× interviews	7M/5F	Range 19–49	–	–	Inductive thematic analysis	Themes
Imkome, 2018[254]	Thailand	Caring for people with schizophrenia	30 caregivers 30× interviews	4M/26F	Range 19–87	–	–	Qualitative inductive analysis	Themes
Irarrazaval, 2015[255]	Chile	The lived body in schizophrenia	15 15× interviews	15M	Range 18–25	–	Explorative descriptive	Phenomenology	Themes
Iyer, 2013[256]	Canada	Experiences and perceptions of long-acting injectable antipsychotics	34 4× focus groups	27M/7F	Range 18–40	31 Caucasian, 3 Asian	–	Deductive and Inductive Analysis	Themes
Jacques, 2019[257]	Canada	Coping among people with schizophrenia	30 30× interviews	24M/6F	Range 19–44	–	Constructivist grounded theory	Constructivist grounded theory	Themes
Joy, 2019[258]	USA	Caring for people with schizophrenia	10 caregivers 10× interviews	3M/7F	Range 32–62	All African American	–	–	Themes
Kageyama, 2018[259]	Japan	Coping with violence from adult children with schizophrenia	26 caregivers 8× focus groups 2× interviews	8M/18F	Range 50–83	–	Grounded theory	Constant comparative analysis	Themes
Kageyama, 2019[260]	Japan	Family violence and perceived solutions in persons with schizophrenia	10 (5) 2× focus groups	10M (5F)	Service users: range 30–59 (caregivers: range 60–79)	–	Descriptive qualitative	Thematic analysis	Themes
Karanci, 2019[261]	Türkiye	Experience of living with schizophrenia	23 23× interviews	19M/4F	–	–	–	Thematic analysis	Themes

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TABLE 7 Included papers: schizophrenia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Kertchok, 2014[262]	Thailand	Collaboration in caring for people with schizophrenia	17 caregivers 34× interviews	–	–	–	Grounded theory	Constant comparison	Themes
Klages, 2020[263]	Multiple countries	Health professional mothers of adult children with schizophrenia	13 caregivers 13× interviews	13F	–	–	Qualitative narrative	Thematic analysis	Themes
Klages, 2020[264]	Multiple countries	Health professional mothers of adult children with schizophrenia	As above						
Ko, 2014[265]	Taiwan	Reintegration of people with schizophrenia	15 15× interviews + diaries and observations	7M/8F	Range 30–64	–		Interpretive phenomenological analysis	Themes
Koschorke, 2014[266]	India	Stigma and discrimination	36 (36) 36× dyad interviews	18M/18F (12M/24F)	Range 16–65	–	–	Reflexive thematic analysis	Themes
Krupchanka, 2018[267]	Czech Republic	Stigma and discrimination in families	25 caregivers 25× interviews	7M/18F	Range 42–63	–	Qualitative	Thematic analysis	Themes
Krupchanka, 2016[268]	Belarus	Experience of stigma among family caregivers	20 caregivers 20× interviews	9M/11F	Range 40–62	–	Qualitative	Thematic analysis	Themes
Landon, 2016[269]	New Zealand	Parents providing support to adult children with schizophrenia	6 caregivers 6× interviews	1M/5F	Range 58–73	All European	–	Framework analysis	Themes
Le Lievre, 2011[270]	Australia	Schizophrenia and the progression of emotional expression	7 28× interviews	4M/3F	Range 30–55	–	Descriptive phenomenology	Descriptive phenomenology	Themes
Leutwyler, 2010[385]	USA	Belonging in older adults with schizophrenia	28 28× interviews	22M/6F	Range 55–76	17 European American, 5 African American, 3 Asian/Pacific Islander, 2 Native American, 1 Hispanic	–	Grounded theory	Themes
Liersch-Sumskis, 2015[271]	Australia	Meaning of medication for people living with schizophrenia	14 14× interviews	–	–	–	–	Psycho-phenomenological method	Themes

TABLE 7 Included papers: schizophrenia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Liu, 2020[272]	China	Caring experience of family caregivers	16 caregivers 16× interviews	3M/13F	Range 25–58	–	Descriptive phenomenological	Inductive content analysis	Themes
Liu, 2012[273]	China	Meaning of psychotic experiences to people with schizophrenia	16 16× interviews	5M/11F	Range 21–52	–	Qualitative approach	Constant comparative analysis	Themes
Loganathan, 2011[274]	India	Gender perspectives of living with schizophrenia	200 200× free text entries on a survey form	118M/82F	–	–	–	Thematic content analysis	Themes
Loughland, 2015[275]	Australia	Communication of a schizophrenia diagnosis	14 14× interviews	9M/5F	Range 33–65	–	–	Qualitative approach	Themes
Marquez, 2011[276]	USA	Monitoring medication usage among caregivers	12 (12) 12× interviews	6M/6F (2M/10F)	Service users: range 45–70 (caregivers: range 45–70)	Service users: 8 Mexican-born, caregivers: 9 Mexican-born	Qualitative	Consensual qualitative research	Themes
McAuliffe, 2014[277]	Ireland	Caring experience of family caregivers	6 caregivers 6× interviews	1M/5F	Range 66–77	–	Descriptive qualitative	'Eclectic' thematic analysis	Themes
Meshach, 2014[278]	Nigeria	Adherence to antipsychotics	11 11× interviews	7M/4F	Range 22–49	–	Qualitative, phenomenological approach	Thematic analysis	Themes
Mizuno, 2013[279]	Japan	Caring experience of female family caregivers	11 caregivers 2× focus groups	11F	Range 37–76	–	Descriptive exploratory	Content analysis	Themes
Molefi, 2011[280]	South Africa	Caring experience of family caregivers	11 caregivers 10× interviews	1M/10F	Range 20 to >50	4 Xhosa-speaking black families, 6 black families	–	Thematic analysis	Themes
Mora-Rios, 2016[281]	Mexico	Coping with stigma	23 23× interviews	11M/12F	Range 22–63	–	Qualitative study	Inductive thematic analysis	Themes
Mushkin, 2018[282]	Israel	Aging with schizophrenia	20 20× interviews	12M/8F	Range 60–81	All Caucasian	Phenomenological reflective lifeworld approach	Thematic analysis	Themes
Niimura, 2016[283]	Japan	Challenges following discharge from inpatient care	18 18× interviews	8M/10F	Range 17–68	–	Qualitative descriptive study	Inductive qualitative content analysis	Themes

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TABLE 7 Included papers: schizophrenia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Nordick, 2014[284]	Canada	Insight development and risk of relapse	19 19× interviews	10M/9F	Range 29–65	–	Qualitative	–	Themes
Nxumalo Ngubane, 2019[285]	Swaziland	Meaning of recovery for women living with schizophrenia	15 15× interviews	All female	Range 21–70	–	Interpretive phenomenological analysis	Interpretive phenomenological analysis	Themes
Ogden, 2014[286]	USA	Living well with schizophrenia in later years	6 Longitudinal: 31 interviews and 38 observation points	4M/2F	Range 56–73	3 white, 2 black, 1 Caribbean	Narrative inquiry	Thematic narrative analysis	Narratives
Ogden, 2018[287]	USA	Importance of work in narratives of older adults with schizophrenia	8 Longitudinal: 35 interviews and 43 observation points	4M/3F	Range 56–73	4 black, 3 white	Developmental life course perspective	Thematic narrative analysis	Themes
Outram, 2015[288]	Australia	Communication of schizophrenia diagnosis	13 caregivers 10 semistructured interviews (including 3 dyads)	4M/9F	–	–	Qualitative (Caelli's generic principles)	Thematic analysis	Themes
Paul, 2016[289]	India	Responses to stigma	20 20× interviews	10M/10F	Male range 32–52, female range 22–59	–	–	Thematic analysis	Themes
Paul, 2017[290]	India	Stigma and discrimination	34 (14) Longitudinal: ~60× interviews 5× focus groups	10M/10F (7M/7F)	–	–	Grounded theory	Grounded theory	Themes
Ponting, 2020[291]	Mexico	Gendered experiences of schizophrenia	19 19× interviews	11M/8F	Range 27–60	–	–	Content analysis	Themes
Poremski, 2016[292]	Singapore	Adherence to schizophrenia treatments	20 (25) 54× interviews	–	–	–	Grounded theory	Grounded theory	Themes
Qin, 2020[293]	China	Medication self-management	17 17× interviews	7M/10F	Range 17–65	All Mandarin-speaking	Grounded theory	Constant comparison	Themes
Rezayat, 2020[294]	Islamic Republic of Iran	Responses to stigma	16 (9) 17 interviews	5M/2F (2M/7F)	Service users: range 40–55 (caregivers: range 22–58)	–	Grounded theory	Constant comparison	Themes

TABLE 7 Included papers: schizophrenia (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Rujkorakarn, 2018[295]	Thailand	Experiences of living with schizophrenia	10 10× interviews	5M/5F	Range 33–69	–	Qualitative descriptive	Content analysis	Themes
Salyers, 2013[296]	USA	Activation in schizophrenia	46 46× interviews	35M/11F	–	29 African American	Triangulation	Iterative, emergent thematic analysis	Themes
Sariah, 2014[297]	Tanzania	Risk and protective factors for relapse	7 (7) 14× interviews	4M/3F (3M/4 F)	Service users: range 25–56 (caregivers: range 31–79)	–	Descriptive qualitative	Content analysis	Themes
Saunders, 2013[298]	USA	Caregiving burden in family caregivers	10 caregivers 60× interviews	10F	Range 48–59	Hispanic	Qualitative explorative	Content analysis	Themes
Shepherd, 2012[299]	USA	Schizophrenia over the lifespan	32 32× interviews	19M/13F	Range 50–72	22 Caucasian, 4 African American, 3 Hispanic/Latino, 3 others	Qualitative	Grounded theory	Themes
Souraya, 2018[300]	Ethiopia	Involvement of people with schizophrenia in decision-making	6 6× interviews	4M/2F	Range 18–70	–	Qualitative	Thematic analysis	Themes
Stein, 2015[301]	USA	Changes in community mental health care over time	14 14× interviews	7M/7F	–	85.7% Caucasian, 7.1% African American, 7.1% Hispanic	–	Content analysis	Themes
Sweers, 2013[302]	USA	End-of-life perspectives of people with schizophrenia	20 20× interviews	12M/8F	Range 38–61	–	Grounded theory	Thematic analysis	Themes
Teferra, 2013[303]	Ethiopia	Reasons for non-adherence to psychiatric medication	43 (19) 6× focus groups 9× interviews	–	–	–	Qualitative	Thematic analysis	Themes
Urlic, 2010[304]	Australia	Occupations of people with schizophrenia	6 18× interviews	4M/2F	Range 33–51	–	Naturalistic inquiry	Thematic analysis	Themes
Williams, 2015[305]	Canada	Recovery in mental illness	20 20× interviews	14M/6F	–	11 racial minority, 9 white	Mixed methods	Deductive analysis	Themes
Young, 2019[306]	Canada	Caring experience of family caregivers	12 caregivers 12× interviews	4M/8F	Range 52–77	–	Interpretive description	Conventional content analysis	Themes

F, female; M, male.

TABLE 8 Included papers: Parkinson's disease

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Abendroth, 2012[307]	USA	Caregiver decision-making about institutionalisation	20 caregivers 20× interviews	3M/17F	–	All white	Grounded theory	Dimensional analysis and constant comparison method	Themes
Anderson, 2013[308]	USA	Perioperative experience of service users with Parkinson's disease	13 14× interviews	10M/3F	Range 44–80	All white	Qualitative descriptive	–	Themes
Armstrong, 2019[309]	USA	Communication about off-periods in Parkinson's disease	40 (20) 60× interviews	18M/22F (9M/11F)	–	–	Exploratory	Qualitative descriptive	Themes
Barken, 2014[310]	Canada	Caring for a spouse with Parkinson's disease	8 caregivers 8× interviews 8× months participant observation	4M/4F	> 65	All white	Symbolic interactionist approach/narrative inquiry	Grounded theory	Themes
Berger, 2019[311]	USA	Caring for a spouse with Parkinson's disease	20 caregivers 58× interviews	8M/12F	Range 61–78	All Caucasian	Grounded theory	Grounded theory	Themes
Boersma, 2016[312]	UK	Palliative care needs of people with Parkinson's disease	41 (11) 30× interviews 4× focus groups	21M/20F (2M/9F)	–	–	–	Inductive qualitative data analysis	Themes
Dauwerse, 2014[313]	The Netherlands	Quality of life of people with Parkinson's disease	57 27× interviews 4 focus groups	35M/22F	Range 19–56	–	Transformative qualitative	Content analysis	Themes
Drey, 2012[314]	UK	Medication adherence in Parkinson's disease	15 15× interviews	9M/6F	Range 44–74	–	Explorative qualitative	Thematic analysis	Themes
Fox, 2017[315]	Ireland	Palliative care needs of people with Parkinson's disease	31 (12) 25× interviews	14M/17F (1M/11F)	Service users: range 51–79 (caregivers: range 58–78)	–	Qualitative	Thematic analysis	Themes
Gibson, 2016[316]	UK	Medication adherence and the lived body in men with Parkinson's disease	15 30× interviews	15M	Range 62–85	–	Qualitative phenomenology	Narrative analysis	Themes
Habermann, 2017[317]	USA	Care needs in advanced Parkinson's disease	14 (14) 42× interviews	14M/14F	–	All Caucasian	Descriptive qualitative	Thematic analysis	Themes
Hurt, 2017	UK	Illness uncertainty in Parkinson's disease	18 caregivers 18× interview	8M/10F	Range 56–73	All White British	–	Thematic analysis	Themes

TABLE 8 Included papers: Parkinson's disease (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Hurt, 2012[318]	UK	The relationship of depression and disease stage to patient perceptions of Parkinson's disease	37 37× interviews	19M/18F		–	Qualitative	Framework analysis	Themes
Johansson, 2019[319]	Sweden	Perceptions of balance	18 9× interviews	9M/9F	Range 46–83	–	Qualitative inductive	Content analysis	Themes
Jonasson, 2018[320]	Sweden	Fear of falling	12 12× interviews	6M/6F	Range 58–90	–	Qualitative	Content analysis	Themes
Kang, 2015[321]	UK	Living well with Parkinson's disease	8 8× interviews	3M/5F	Range 57–78	–	–	Thematic analysis	Themes
Kennedy-Behr, 2017[322]	Australia	Well-being and occupation for people with Parkinson's disease	11 11× interviews and 11 diaries	7M/4F	Range 55–81	–	Descriptive qualitative	Thematic analysis	Themes
Kudlicka, 2018[323]	UK	Everyday functioning in Parkinson's disease	17 (6) 17× interviews	7M/4F (–)	Range 65–72	–	Qualitative exploratory	Thematic analysis	Themes
LaGrone, 2020[324]	Sweden	Choreographing life experiences of balance control	18 18× interviews	9M/9F	Range 46–83	–	Qualitative description	Qualitative content analysis	Themes
Lee, 2018[325]	Republic of Korea	Health care for people with Parkinson's disease	12 2× focus groups	3M/9F	Range 51–74	–	Qualitative	Thematic analysis	Themes
Leiknes, 2012[326]	Norway	Family caregivers' experience of professional home care services	9 caregivers 9× interviews	3M/6F	Range 44–83	–	Phenomenological lifeworld research	Interpretive analysis	Themes
Lennaerts-Kats, 2020[327]	The Netherlands	Palliative care needs of people with Parkinson's disease	10 caregivers 10× interviews	2M/8F	Range 44–81	–	Phenomenology	Interpretive phenomenological analysis	Themes
Liddle, 2018[328]	Australia	Lived experiences of Parkinson's disease and deep brain stimulation	24 (10) 24× interviews	14M/10F (4M/6F)	Range 47–75	–	Phenomenology	–	Themes
Mach, 2021[329]	USA	Family caregiver involvement in treatment	9 caregivers 9× interviews	1M/8F	Range 61–81	All white	Mixed methods	Qualitative analysis	Themes

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TABLE 8 Included papers: Parkinson's disease (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Martin, 2016[330]	USA	The experience of identity threats	47 47× interviews	29M/18F	Range 41–89	45 white, 1 African American	Constructivist grounded theory	Constant comparison	Themes
Martin, 2016[331]	USA	Relational issues of coping with Parkinson's disease in couples	44 (23) 44× interviews	21M/23F (8M/15F)	Service users: range 41–89 (partners: range 38–84)	42 white, 2 African American	Grounded theory	Constant comparison	Themes
Moriarty, 2016[332]	USA	The experience of lower urinary tract symptoms in men with Parkinson's disease	11 11× interviews	11M	Range 60–80	9 white, 2 black	Theory of Unpleasant Symptoms	Qualitative analysis	Themes
Mshana, 2011[333]	Tanzania	Perceptions and experiences of Parkinson's disease	28 (28) 56 interviews 6× focus groups	Interviews: not stated Focus groups: 24M/26F	Range 45–94	–	Qualitative	Inductive approach	Themes
Mullin, 2018[334]	UK	The experience of working for people with Parkinson's disease	17 17× interviews	9M/8F	Range 39–77	–	Grounded theory	Grounded theory	Themes
Murdock, 2015[335]	UK	The experience of occupation for people with advanced Parkinson's disease	10 10× interviews	6M/4F	Range 58–86	–	Phenomenology	Thematic analysis	Themes
Nazzal, 2017[336]	Jordan	The experience of Parkinson's disease	8 8× interviews	4M/4F	Range 32–76	–	Qualitative phenomenology	Content thematic analysis	Themes
Nilsson, 2015[337]	Sweden	Participation in people with Parkinson's disease	29 9× focus groups	16M/13F	Range 53–81	–	–	Constant comparison	Themes
Nunes, 2015[338]	Portugal	Self-care technologies and collaboration in Parkinson's disease	17 (8) 17× interviews 12× observations	–	–	–	Qualitative	Grounded theory	Themes
Olsson, 2013[339]	Sweden	Meanings of fatigue for women with Parkinson's disease	11 11× interviews	11F	Range 45–64	–	Phenomenological–hermeneutic interpretation	Phenomenological–hermeneutic interpretation	Themes
Padovani, 2018[340]	Brazil	Caring for people with Parkinson's disease	10 caregivers 10× interviews	2M/8F	Range 30–60	–	Qualitative	Thematic analysis	Themes
Plouvier, 2018[341]	The Netherlands	Coping with changes in care	16 21× interviews	11M/5F	Range 58–79	–	Exploratory qualitative	Comparative content analysis	Themes

TABLE 8 Included papers: Parkinson's disease (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Prizer, 2020[342]	USA	Palliative care needs of people with Parkinson's disease	23 23× interviews	13M/10F	–	22 white, 1 African American	–	Thematic analysis	Themes
Ravenek, 2017[343]	Canada	Uncertainty in young-onset Parkinson disease	39 7 focus groups 47× interviews	26M/13F	Range 27–60	–	Constructionist grounded theory	Constructionist grounded theory	Themes
Read, 2019[344]	UK	Care needs of people with late-stage Parkinson's disease	10 10× interviews	7M/3F	Range 70–80	–	Qualitative	Thematic analysis	Themes
Rosengren, 2021[345]	Sweden	Life satisfaction and adaptation in persons with Parkinson's disease	13 13× interviews	3M/9F/1 non-binary	Range 47–62	–	Phenomenological–hermeneutic approach	Phenomenological–hermeneutic approach	Themes
Rosqvist, 2021[346]	Sweden	Caring in late-stage Parkinson's disease	20 (9) 20 interviews	10M/10F (2M/7F)	Range 64–89	–	–	Content analysis	Themes
Shaw, 2017[347]	UK	Challenges to ethically managing Parkinson's disease	12 12× interviews	7M/5F	Male: range 60–86, female: range 51–70	–	–	Thematic analysis	Themes
Shin, 2016[348]	USA	Initiation of Parkinson's disease medications	21 (5) 16× interviews	13M/8F (2M/3F)	Service users: range 53–82 (caregivers: range 64–80)	All Caucasian	Exploratory descriptive qualitative	Content analysis	Themes
Simpson, 2015[349]	UK	Experiences of apathy in people with Parkinson's disease	7 7× interviews	7M	Range 45–75	–	–	Interpretive phenomenological analysis	Themes
Sjödahl Hammarlund, 2018[350]	Sweden	The impact of living with Parkinson's disease	19 19× interviews	8M/11F	Range 55–84	–	–	Qualitative content analysis	Themes
Smith, 2017[351]	UK	Living well with Parkinson's disease	9 9× interviews	4M/5F	Range 67–85	–	–	Interpretive phenomenological analysis	Themes
Soleimani, 2014[352]	Islamic Republic of Iran	Disruption of social connectedness	10 10× interviews	7M/3F	Range 60–90	–	–	Content analysis	Themes

continued

TABLE 8 Included papers: Parkinson's disease (*continued*)

First author, year of publication	Country	Topic	Sample size (no. of caregivers)	Gender of service users (gender of caregivers)	Mean age (range)	Ethnicity	Stated study design or approach	Mode of analysis	Data presentation
Soleimani, 2016[353]	Islamic Republic of Iran	Perceptions of people living with Parkinson's disease	17 17× interviews	10M/7F	Range 60–90	–	Exploratory qualitative study	Content analysis	Themes
Spurgeon, 2015[354]	UK	Experiences of speech and language therapy in patients with Parkinson's disease	9 9× interviews	7M/2F	Range 54–78	–	–	Thematic network analysis	Simplified illustrative networks and themes
Tan, 2012[355]	Singapore	Caring for people with Parkinson's disease	21 caregivers 21× interviews	4M/17F	Range 31–71	18 Chinese, 2 Indian, 1 other	Qualitative explorative	Framework analysis	Themes
Thomson, 2020[356]	Australia	The impact of deep brain stimulation on personality, self and relationships in Parkinson's disease	22 (11) 22× interviews	9M/13F (2M/9F)	Service users: range 45–73 (caregivers: range 51–69)	–	Prospective qualitative	Thematic analysis	Themes
Thordardottir, 2014[357]	Sweden	Participation among people with different levels of severity of Parkinson's disease	29 6× focus groups	16M/13F	Range 53–81	–	–	Krueger's analysis	Themes
Todd, 2010[358]	UK	Delusions in people with Parkinson's disease	8 8× interviews	7M/1F	Range 63–79	All White British	–	Interpretive phenomenological analysis	Themes
Vann-Ward, 2017[359]	USA	Preserving the self in Parkinson's disease	25 62x interviews and observations	15M/10F	Range 40–95	–	Constructivist grounded theory	Constant comparison	Themes
Whitehead, 2010[360]	UK	The psychosocial impact of communication changes in people with Parkinson's disease	8 (4) 8× interviews	4M/4F (1M/3F)	–	All white	–	Phenomenology and thematic analysis	Themes
Zizzo, 2017[361]	Canada	Preferences for involvement in healthcare decision-making	20 20× interviews	10M/10F	Range 50–77	–	Mixed methods	Thematic qualitative content analysis	Themes

F, female; M, male.

TABLE 9 Included papers: evidence syntheses

First author, year of publication	Country of origin	Index condition	Topic	Type of qualitative synthesis	Number of papers included	Method of analysis	Presentation of data
Warwick, 2019[77]	UK	Bipolar disorder	Sources of distress for people diagnosed with bipolar disorder	Meta-synthesis	52	Thematic synthesis	Themes
Applebaum, 2016[79]	USA	Brain cancers	Existential distress among caregivers of patients with brain tumours	Framework	35	Thematic	Existential themes
Cubis, 2018[362]	Australia	Brain cancers	The social trajectory of brain cancers	Meta-synthesis	21	Thematic analysis	Themes
Li, 2020[363]	USA	Brain cancers	Experiences and Needs of Patients with Gliomas	Systematic review	13	Meta-aggregation	Themes
Sterckx, 2013[80]	Belgium	Brain cancers	The impact of a high-grade glioblastoma on everyday life	Systematic review	16	Thematic analysis	Themes
Maffoni, 2017[107]	Italy	Parkinson's disease	Stigma experienced by people with Parkinson's disease	Descriptive review	14	Thematic analysis	Themes
Perepezko, 2019[108]	USA	Parkinson's disease	Social role functioning in Parkinson's disease	Mixed-methods systematic review	23 qualitative studies	Thematic analysis	Themes
Tomagová, 2019[364]	Slovak Republic	Parkinson's disease	Lived experiences of people with Parkinson's disease	Systematic review	16	Thematic synthesis	Themes
Rutten, 2021[98]	The Netherlands	Parkinson's disease	The subjective experience of living with Parkinson's disease	Meta-ethnography	20	Thematic analysis	Themes
Soundy, 2014[99]	UK	Parkinson's disease	Lived experiences of Parkinson's disease	Systematic review and meta-ethnography	37	Thematic analysis	Themes
Theed, 2017[88]	UK	Parkinson's disease	Experiences of caring for a family member with Parkinson's disease	Meta-synthesis	11	Thematic analysis	Themes
Tuijt, 2020[93]	UK	Parkinson's disease	Experiences of self-management for people with Parkinson's disease and their caregivers	Systematic review	6	Thematic synthesis	Themes
Carmona, 2019[365]	Spain	Schizophrenia	Employment support needs of people with schizophrenia	Scoping	12	Thematic analysis	Themes
Cleary, 2020[366]	Australia	Schizophrenia	Caregivers' experiences of caring for family diagnosed with schizophrenia	Scoping	43	Thematic analysis	Themes
Klages, 2017[367]	Australia	Schizophrenia	Experiences of parents of adult children with schizophrenia	Integrative review	14	Thematic analysis	Themes
Lewis, 2017[368]	USA	Schizophrenia	Experience of being a partner to an individual with schizophrenia spectrum disorder	Meta-ethnography	13	Thematic analysis	Themes

continued

TABLE 9 Included papers: evidence syntheses (*continued*)

First author, year of publication	Country of origin	Index condition	Topic	Type of qualitative synthesis	Number of papers included	Method of analysis	Presentation of data
Mestdagh, 2014[110]	Belgium	Schizophrenia	Stigma in patients with schizophrenia receiving community mental health care	Systematic review	18	Thematic analysis	Themes
Ning, 2011[369]	Singapore	Schizophrenia	Perception and experience of stigma among people with schizophrenia	Meta-synthesis	6	Aggregation	Attributions
Shiraishi, 2019[90]	Japan	Schizophrenia	Positive and negative impacts of schizophrenia on family caregivers	Systematic review and qualitative meta-summary	23	Narrative summaries	Themes
Soundy, 2015[104]	UK	Schizophrenia	Facilitators and processes which influence recovery in individuals with schizophrenia	Systematic review and thematic synthesis	20	Thematic analysis	Themes
Wals, 2016[105]	UK	Schizophrenia	The lived experience of schizophrenia	Meta-synthesis	27	Thematic synthesis	Themes
Young, 2019[113]	Canada	Schizophrenia	Experiences of parent caregivers of adult children with schizophrenia	Qualitative evidence synthesis	5	Content analysis	
Byron, 2020[72]	Ireland	Inflammatory bowel disease	Challenges of living with and managing bowel disease	Meta-synthesis	11	Thematic	Themes
Fourie, 2018[73]	UK	Inflammatory bowel disease	Living with inflammatory bowel disease	Systematic review	23	Thematic synthesis	Themes
Kamp, 2018[74]	UK	Inflammatory bowel disease	Factors that influence treatment and non-treatment decision-making among individuals with inflammatory bowel disease	Integrative review	28	Thematic analysis	Themes
Kemp, 2012[264]	UK	Inflammatory bowel disease	Health and social care needs of people living with inflammatory bowel disease	Meta-synthesis	7	Lines of argument	Themes and second-order constructs
Andrew, 2019[81]	Australia	Young-onset dementia	Impact of dementia on occupational competence, occupational participation and occupational identity in paid employment	Scoping	6	Thematic	Themes
Bannon, 2020[82]	USA	Young-onset dementia	Psychosocial stressors and adaptive coping strategies of persons with young-onset dementia and their caregivers	Meta-synthesis	60	Thematic	Themes
Cabote, 2015[92]	Australia	Young-onset dementia	Family caregivers’ experiences of caring for a relative with younger-onset dementia	Systematic review	5	Thematic	Themes
Greenwood, 2016[96]	UK	Young-onset dementia	Experiences of people with young-onset dementia	Meta-ethnography	8	Line of argument synthesis	Themes

TABLE 9 Included papers: evidence syntheses (*continued*)

First author, year of publication	Country of origin	Index condition	Topic	Type of qualitative synthesis	Number of papers included	Method of analysis	Presentation of data
Holdsworth, 2018[106]	Australia	Young-onset dementia	Impact of younger-onset dementia on relationships, intimacy and sexuality in midlife couples	Systematic review	11	Thematic analysis	Themes
Mayrhofer, 2018[84]	UK	Young-onset dementia	Age-appropriate services for people diagnosed with young-onset dementia	Thematic synthesis	20	Thematic analysis	Themes
Millenaar, 2016[85]	The Netherlands	Young-onset dementia	Care needs and experiences with the use of services of people with young-onset dementia and their caregivers	Systematic review	17	Thematic analysis	Themes
O'Malley, 2021[97]	UK	Young-onset dementia	Receiving a diagnosis of young-onset dementia	Scoping review	8	Thematic analysis	Themes
Svanberg, 2011[86]	UK	Young-onset dementia	The impact of young-onset dementia on the family	Mixed-methods systematic review	6 qualitative studies	Summaries	Topics

TABLE 10 Coding frame and results

Phenomena of interest	Topic	Brain cancer	Young-onset dementia	Inflammatory bowel disease	Bipolar disorder	Schizophrenia	Parkinson's disease
Structural inequalities. Are structural and intersectional disadvantages identified in the paper and are aspects of their role in shaping patient and caregiver burdens and trajectories of illness characterised and explained?	Intersectional disadvantage (age, ethnicity, sex/gender, sexual orientation)					274,276,291,298	
	Material disadvantage (social class, housing class, educational attainment, employment, income, pensions, social security/health insurance, access to internet)	122,124,128,130,134,186, 187,370	149,152,153	144,172,176,178–180, 182,186,187,189, 190,297	196,202,208,209,211,224,225	233,234,236,242,248,249,256, 266–268,278,281,285,289, 291,303,304,371	307,308,330,331,337
Access inequalities. Are access inequalities identified in the paper, and are aspects of their role in shaping patient and caregiver burdens and trajectories of illness characterised and explained?	Spatial relations (spatial distribution of services, transport links, proximity to formal and informal support)	122,124,131,137,370			213	240,256,306	330,331,337,344
	System co-ordination (access to care, co-ordination of services, organisation of services, professional divisions of labour, hierarchies of care/caregiving)	121,122,125,131,134,136, 144,370	149,151,152,154–156, 160,161,167,372	172,176,178–180, 182,190	196,198,199,216,218,227	230,232,233,237,240,247,248, 256,258,262–264,371,373	312,313,315,329,337,338, 344–347,350,352–354,374
	Candidacy, warrantability, access to service providers, investigations, hospitalisation (voluntary/involuntary), conflict with providers	124,131	146	170–172,174,176, 178–180,182	195,199,203	240,257,264,275,283	308,356
	Care pathways, professional/service boundaries	136–138,370	146,153	170–172,174–178, 180,182	196,198,201,203,206,207, 216,218–220,223	237,254,256,371	307–312,315,329,337, 338,344,345,350,352,353, 356–361
Changes in affect. Are aspects of effect identified in the paper, and how are these related to enacting, negotiating and navigating experiences of illness and care?	Loss (of self-esteem, self-worth, loss of intimacy, feelings of dependence and loss of independence, loss of sense of time and place); of confidence anxiety, fear, guilt, shame, denial, isolation	123,125,134,136,139–142, 144,375,376	146–148,150,151,157, 163,165,166,372, 377–379	170,172,174–177, 182,186,188,191,192	195,196,202,205,207,208, 212,221,226	233,242,245,248,251,255, 259–261,263–265,270,279, 281,294,296,301,371,373,380	207,307,308,313,317,319,323, 328,333,339,340,345,350,352, 353,357,358
	Distress (fear-avoidance, changing self-identity, implications of diagnosis and prognosis)	121,123,128,133,134, 136–142,144,375,376	146,148,149,166,372	170,171,174–176	200,203,208,209	230–232,234,237,247,248,255, 259,260,263,264,272,279,284, 293,294,301,371,373	310,312,314,315,325,335,336, 346,351,358,360,361

TABLE 10 Coding frame and results (*continued*)

Phenomena of interest	Topic	Brain cancer	Young-onset dementia	Inflammatory bowel disease	Bipolar disorder	Schizophrenia	Parkinson's disease
Self-identity. Are aspects of self-identity discussed in the paper, and how are these related to enacting, negotiating and navigating experiences of illness and care?	Decisional conflict, negotiation, resolution	124,125,127,128,138,140–142,144,376	151,153,165	144,170–172,174–177,181,186–188,190,193	195,197,206,208,216,218,222	230,232,233,237,245,251,254,256,262–265,275,373	307,309,310,312,317,330,331,333,335,336,346,356,361,381
	Illness identity and personal meanings	120,123,127,130,134,137–139,141,142,375,376	148,150,167,379	144,171,174,175,177,178,180,185,189,190,297	195,196,198,199,201,203,206,207,210,212,214,216,223–225,227,229,382	230,231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,383	310,312,313,315,318,325,328,330–337,341,345,347,350,351,359,361,384
Disruption, disclosure and their consequences. Are aspects of biographical disruption discussed in the paper, and how are these related to managing personal disclosures and tolerance of disruption?	Disclosure of information about self and illness, tolerance of disruption	120	147,151,153,155–157,164,166,372,377,379	170,172,174,176,177,179,182,186,188,189	196,200,202,207,212,214,216,229	231,232,234,259,260,262,266–268,274,284,294,385	312,336,341,345,352–354
	Biographical disruption and erosion	123–125,127,128,130,131,133,134,136–142,144,370,375,376	147,149,151,153,155–157,160,161,163,164,372,377,378	170,172,174–180,182,186–188,191,192	195,196,198,199,201–203,205–210,212,218–220,222,224,225,227	230,231,233,237,247,248,255,257–260,263,264,270,272,275–277,279,281,284,285,289,298,302,371,373,383	307,310–312,314,315,317,318,325,330–332,334–337,339,340,342,344,345,350–353,358,360,384
Making sense of the self. Are aspects of personal sense-making identified in the paper, and how are these related to enacting, negotiating and navigating experiences of illness and care, and how do these experiences reflect the (negative) evaluations of others?	Stigma [internalised (felt) stigma, externalised (enacted) stigma]		146–153,155,156,164,372	170,174,176,179,182,186–188,190–192	195,196,198,200,205,206,208,210,213,214,218–220,222,226	230–232,237,245,247,248,259–264,266,272,279,283,285,289,291,292,298,300,303,305,371,373,385,386	312,325,328,330,331,334,336,337,339,345,347,351,360
	Tolerance of distress and disruption Problem-solving, loss of social competence and functioning	125,131,133,134,136	147,153,157,161	178,179,182,186,190,192	196,200,201	237,247,254,257,296,371,386	207,310,319,322,323,326,330,331,333,334,336,337,339,341,344,347,350,351,358–361,381
Making sense of symptoms. Are aspects of embodied experiences of illness and identified in the paper, and how are these related to enacting, negotiating and navigating illness trajectories?	Symptoms (recognition and awareness, knowledge of disease processes and outcomes, self-monitoring, self-management strategies)	123–125,127,128,133–135,138,140,375	146,150,152–154,160,168,372	170–172,174–179,182,185,188–190	195–197,201–203,205–208,210,215,216,221–226,228,382	230,232,236,237,242,247,248,254–258,262,272,275–280,282,283,285,291,292,296,298,301,302,371,383,387	307,308,311–314,316,317,322–325,327,328,334,335,337–339,341,342,344,345,350,352,353,356–358,374,381
	Restrictions (physical and psychological pain and discomfort; restrictions on diet, movement and social interaction, others' disbeliefs, and misperceptions of symptoms and disease processes)	120,122,125,130,131,135,136,140–142,144,376	147,149,151,160	170,174,176,177,185,190	202,212	233,234,242,245,282	307,310,311,324,325,328,336,339,341,344,350,354,359

continued

TABLE 10 Coding frame and results (*continued*)

Phenomena of interest	Topic	Brain cancer	Young-onset dementia	Inflammatory bowel disease	Bipolar disorder	Schizophrenia	Parkinson's disease
Living with the consequences of disease. Are consequences of disease identified in the paper, and how do these relate to the ways in which service users and caregivers enact, negotiate, disease progression and outcomes	Disease progression (unpredictable relapse–remission cycles, uncertainty about capacity to manage disease)	123–125,133,134,136, 138–140,375	146–153,155–157,160, 161,163,166,168, 372,377–379	170,172,174–176, 178,182,186–189	195,196,201–203,205,209,210, 215,216,218–221,223–225,228,382	230,232,234,240,242,254–258, 262–264,270,275–277,279,280, 282,283,285,291–293,302,373,383	307–318,323,325–328, 332–337,339,341,342, 346,347,350,351,356–358, 360,374,384
	Processing existential threat	120,123–125,128,130,131, 134–142,144,375,376				302	310,342,344,347,359
	Pathophysiological deterioration, status passage	121,131,133,134,136–138, 141,142,144,376	149–156,160,161,163, 165–167	171,174,178		232,236,245,248,257,262,270, 271,275,280,284,291,293	307–315,318,326–328, 336,337,339,345–347, 351,354,358,374,384
Reconfiguring social roles and identities. How are effective contributions to personal capacity configured, and how do these change over the course of illness trajectories?	Roles (domestic contributions, personal and shared decisions, emotional and relational solidarity, others monitoring self and health, competing priorities of others, crises readiness for crises)	124,125,131,133–136, 138–140	146–149,151,152,160, 162,167,372	170,176,177,187, 190–192	195,198,202,203, 206–209,216,222,229	230,232,234,242,248,251,258, 263,264,272,276,279,281,282, 289,291,300,305,371,373	307,309–315,318,322,325, 327,328,332,333,335,336,338, 342,345,347,350,352,353,356, 360,374,381,384
	Transfer of responsibility to caregivers, caregiver role and obligations	121,124,125,133–142,376	146–152,155–157, 160–163,165–168, 372,377,378	176,180	195,199,202,203,206,208,209, 216,218,220,222,224,229	230,248,254,262–264,270,276, 277,281,288,305,373	307,310–312,317,325–328, 330–333,336–338,345–347, 356,361,374
Social networks and social capital. Are aspects of distributed sense-making and practical support identified in the paper, and how are these related to enacting, negotiating and navigating experiences of illness and care?	Others (lack of knowledge, domestic routines, disorganisation, dependency, interpersonal conflict, integration of illness identity into family relations, relations with significant others)	121,125,131,133,135,375	147–149,151,372	170,176,177,179, 186,297	198,202,203,206,216	233,242,254,257,258,262,300	307,310,311,326,336,342,360
	Social networks (informal social networks and network formation, restoration of social capital, collaborations around care and self-care, other sources of social support, sources of resilience)	121,125,128,131,133–135, 138–140,375	146,147,149,155–157, 161,162,165,372,377	170,179,191,192	196,198,200,203,209,216	245,247,254,257,258,262–265, 281,373	307,310,313,322,333,335, 347,356,360

TABLE 10 Coding frame and results (*continued*)

Phenomena of interest	Topic	Brain cancer	Young-onset dementia	Inflammatory bowel disease	Bipolar disorder	Schizophrenia	Parkinson's disease
Delegated care work. Are aspects of delegated care work identified in the paper, and how do these relate to the ways in which service users and caregivers enact, negotiate and navigate health/care knowledge and practice at home?	Information-seeking and processing	120–122,139,141,142,144,317,370,376	146–153,155,156,161,166,372	170–172,174–178,180,192	197,210,216	232,245,248,256,257,275–277,281,285,288	309,341
	Responsibility, prudence supportive equipment, mobility aids	127,133,134,138,140	146,154,372	170–172,176			207,307,310,319,324,338,344,360
	Workload: medical terminology and meanings, temporal and cognitive	121,124,135,136,140	146,147,149,152,372				
	Demands of care, supply of medication/equipment	124,131,138	154	172,174,180,189			307,309,311,317,338,344,346,356
	Medication management, medication decisions, requesting/refusing treatment multiple medications, testing and monitoring equipment, pain control	124,130,133,135–138,140–142,376	146	170,171,175–178,180–182,185	196,197,202,203,206,207,209,210,213–216,218–220,222,226,228,382	230,232–234,237,243,245,247,248,254,256,257,261,262,271,275–278,285,293,296,387	207,308–310,312,314–316,318,319,326–328,330,331,334,336,337,344,347,359,374,381,384
	Medication side effects	136,138		175,180	196,210,214,216,223,382	230,242,256,271,275,276,284,303,371	309,313,381
	Provider role and obligations, self-care/care skills, knowledge and practice, lifestyle changes, dietary changes	124,133,136	146,151,154	174,178,182,185–187,191,192	199		207,307,311,319,327,334,336,337,341,347,358
Interactional inequalities. Are interactional inequalities identified in the paper, and are aspects of their role in shaping patient and caregiver burdens and trajectories of illness characterised and explained	Provider behaviour (acknowledgement of expertise)	124,140,370	154	170	198	231,232,237,240,263,264,270,279,284,288,296,373	309,326,329,337,338,344
	Interaction quality, communication skills	121,124,125,127,133,140–142,376	148	170,172,175,176,178–180	195,196,198,199,201–203,205–207,214,216,218,220,222,223,228	230,232,237,240,242,248,275,279,283,285,288,383	307–309,313,314,317,325–327,329,334–337,346,354
	Responsiveness to crisis, relational quality, interaction opportunities	124,125,127,133		172,176,178	195,196,198,199,201–203,205–207,214,218–220,222,223		309
	Continuity of care	124,137		172		230	310,344
	Loss of control over care processes	120,138,144	146,148,150–152,165	170,174,177,179,189	195–197,200,202,207,222	233,237,245,247,284,298,301,305,383	307,309,310,315,323,324,326,334,336,342,345,356,358,361

and caregivers.[116] Hierarchy diagrams[116] were employed to visually represent the relationships and hierarchies within the data. Coding these activities involved using the framework outlined in *Table 10*, which provided a structured framework from which to categorise and interpret the data. This framework facilitated within-case analyses. Within-case analyses were pivotal in understanding the unique contexts and dynamics at play in each scenario.

We contextualised these clusters of activities against biographical disruption theory[11] and Burden of Treatment Theory.[1] These provided a lens through which we could interpret the data, grounding our findings in established theoretical frameworks. This integration helped to elucidate the contexts of action that motivate and shape the lived experiences of patients and caregivers. By situating our findings within this theoretical context, we were able to offer deeper insights into how inequalities, trajectories and burdens are experienced. In summary, our qualitative attribution analysis was a process involving structured data extraction, activity identification, taxonomy-building, hierarchical mapping and theoretical analysis. By combining the methodological steps of attribution analysis with biographical disruption and burden of treatment theories, we provided a comprehensive picture of the complex interplay of factors influencing patient and caregiver experiences.

Event-State Analysis

Having subjected the data set to attribution analysis and mapped the causes and reasons for patterns of activities performed by service users and caregivers, the next phase of our analysis involved performing an Event-State Analysis as described by Miles *et al*.[116] Event-State Analysis serves as a precursor to causal network analysis and involves mapping clusters of service user and caregiver activities against contexts of action, experienced trajectories, lifeworld resources, and mechanisms that shape participation in care. The primary aim of our Event-State Analysis is to trace and understand the interactions between lifeworld resources, experienced trajectories and the complex inequalities that influence participation in care. In this study, we utilised Event-State Matrices to systematically present these interactions. Specifically, we mapped data from primary studies, which are detailed in *Table 11*, and incorporated authors' proposals for supportive interventions for service users and caregivers, as presented in secondary studies given in *Table 12*.

By using Event-State Matrices, we were able to visually represent the dynamic states and transitions that service users and caregivers experience over time. We used biographical disruption theory[11,13,389,390] to provide a staged process model of the contexts of action that define service user and caregiver trajectories through care. This allowed us to capture the temporal sequence of events and states that define the caregiving experience, including critical junctures where changes in lifeworld resources or trajectories occur. A key aspect of this Event-State Analysis was tracing the interactions between lifeworld resources and illness contexts. Lifeworld resources refer to the personal, social and material assets that individuals draw upon to manage their health and caregiving responsibilities. By mapping these resources against the illness contexts, we were able to identify how different resources are mobilised in response to various health challenges and caregiving demands. This analysis provided insights into the mechanisms that either facilitate or hinder effective participation in care.

Event-State Analysis allowed us to hypothesise a set of relations between lifeworld resources and their corresponding illness contexts. By examining these relations, we aimed to uncover the underlying factors that drive participation in care and to identify potential points of intervention. We proposed that access to social support networks, healthcare services and financial resources plays a critical role in shaping the trajectories of service users and caregivers. These propositions were grounded in the empirical data collected from primary and secondary studies and were further explored through the Event-State Matrices. In summary, the Event-State Analysis provided a comprehensive framework for understanding the dynamic and contextual nature of caregiving activities, and mapping these against proposed interventions. By mapping clusters of activities against contexts of action, trajectories, and lifeworld resources, we were able to trace the interactions and causal relations that shape participation in care. This methodological approach not only enhanced our understanding of the caregiving process but also offered valuable insights for designing supportive interventions that address the complex needs of service users and caregivers.

Chapter 4 Results: mapping the work of service users and caregivers

Chapter summary

In this chapter, attribution analysis of included articles focuses on the work service users and caregivers must do to effectively participate in their care. The chapter highlights the importance of incorporating service users and caregivers in care delivery, a longstanding policy in the NHS. However, participation work itself is often ill-defined, prompting our detailed mapping of its lived experience.

The chapter categorises illnesses into three groups based on their trajectories: rapid progression (brain cancers, young-onset dementia); relapsing and remitting (bipolar disorder, inflammatory bowel disease); and long-term duration (schizophrenia, Parkinson's disease). It explores ways in which biographical disruption and existential threat lead (1) to the erosion of personal capacity, social capital and social networks; (2) that expectations of service users and caregivers are framed through delegated obligations (impersonal expectations from the healthcare system), and assumed obligations (those voluntarily taken on by service users and caregivers); while (3) service users and caregivers divide their energies between goal-oriented work that involves engaging health and social care providers, and compensation-oriented work that involves caregivers compensating for the patient's diminished capacity. These processes are exhausting.

Our analysis identifies inequalities as a significant context for the work of service users and caregivers. Macro-structural disadvantages are rarely mentioned, but micro-structural consequences of illness generate inequalities. The mobilisation of caregiver and family members' affective resources is central to the lived experience, with biographical disruption and erosion shaping the work of care. Negotiating delegated and assumed obligations involves extensive organisational and emotional work. The chapter maps service user and caregiver work across different illness trajectories, emphasising the relational and biographical aspects of participation in care. This understanding has implications for designing interventions that support self-management and relational care. The analysis highlights the importance of family caregivers and the shared nature of care work, which must be considered in policy and practice to effectively support service users and caregivers.

Introduction

The starting point for our analysis of the literature included in this review is the idea that to be a service user or caregiver is to be involved in the work of effective participation in care.[391] The incorporation of service users and caregivers in the organisation and delivery of care is a longstanding policy imperative in the NHS.[23] What the work of participation involves, however, is often understood in very general terms because policy itself takes a population perspective rather than focusing on the experiences of individual service users and caregivers. In this chapter, we map the work that qualitative studies have revealed to be part of the lived experience of care. The chapter contributes to the review in three ways:

1. It maps the dynamics of service users' and caregivers' participation in care. It draws on results from the best-quality empirical reports of service user and caregiver experiences collected in the review.
2. It contributes to the development of qualitative methods that facilitate better understanding of the dynamics of lived experiences of service users and caregivers. We employed within-case[116] analyses of attributions[114] made by the authors of included papers about causes and reasons for service user and caregiver experiences in each condition.
3. It contributes to policy and practice by identifying pressure points in service user and caregiver experiences of specific index conditions, and also those pressure points that are common to all included conditions.

Index conditions, hierarchies and intersections

This chapter is concerned with mapping the factors that shape the dynamics of service users' and caregivers' participation in their care. We are concerned with how participation in care is enacted as people navigate illness trajectories and negotiate social inequalities. We deal with index conditions in turn: looking first at illness trajectories in which the disease progression is experienced relatively rapidly and that pose a predictable and immediate existential threat (brain cancers and young-onset dementia); diseases that have trajectories characterised by remission and recurrence that may not be easily predicted (bipolar disorder and inflammatory bowel disease); and diseases that have trajectories of long duration (schizophrenia and Parkinson's disease). In the course of this descriptive analysis, we draw on four important sets of concepts.

1. *Biographical disruption and its consequences*. Diagnosis of serious illness disrupts the service users' self-concept and structures of everyday life.[11] As illness proceeds, service users' and caregivers' capacity, social capital and social networks may be eroded over time.[391]
2. *Delegated and assumed obligations*. The descriptor-delegated obligations refers to expectations of service users and caregivers that are allocated to them, impersonally, by the healthcare system. Assumed obligations are expectations that are defined and taken on, voluntarily, by service users and caregivers.[6]
3. *Collaborative work*. Collaborative work is goal-oriented or compensation-oriented. Goal-oriented work refers to tasks that are undertaken by service users as they engage with health and social care providers. Compensation-oriented work refers to tasks that are taken on by caregivers as disease progression depletes service users' capacity to contribute to their own care.[37]

Brain cancer

In this section, we draw on 26 primary studies and 4 reviews reporting on lived experiences of primary brain cancers. These are described in *Tables 4* and *10*. The trajectory of malignant brain cancers tends to be a short one. At the outset, however, what is wrong may not be clear. Initially, diffuse symptoms of uncertain causation are described, meaning that multiple doctors' visits may be required before referral to specialists and investigations takes place.[124,131]

> *Primary malignant brain tumours are associated with poor prognosis and an average life expectancy of 12–15 months. The treatment regime is usually a combination of surgery followed by outpatient radiotherapy and chemotherapy taking 9–10 months … patients may suffer from both oncology-related side effects – impaired appetite, nausea, vomiting, and fatigue – and various neurological and cognitive deficits – concentration, attention, memory, intellect and functional impairments, seizures, and changed behaviour and personality (p. 588).*[124]

Diagnosis, when it arrives, signals a massive existential threat or diagnostic shock.[120,123–125,128,130,131,134–142,144,375,376] Included papers suggested that this shock is followed by a shared process of experiencing and trying to repair the emotional and practical consequences of diagnostic shock,[123–125,127,128,130,131,133,134,136–142,144,370,375,376] and taking on an illness identity.[120,123,127,130,134,137–139,141,142,375,376] The nature of pathophysiological deterioration in brain cancers mean that in most cases these repair attempts fail. As *Figure 3* shows, what follows from diagnostic shock is the bifurcation of illness-related work that is framed by sets of assumed obligations. First, there is specific illness-related goal-oriented work that is shaped by, and shapes, the succession of biographical disruptions that follow from diagnosis and the patient's incorporation into programmes of treatment. The first of these is organised through a cluster of attempts to conceptualise risk and understand pathophysiological deterioration, in interaction with the neurosurgeon with whom patients and caregivers may come to have a dependent relationship.[124,140,370] This is work that is directed at trying to understand what is happening and what it means for the future. It is associated with three clusters of activities:

1. Activities that seek to extend understanding by finding complementary or alternative sources of information,[120–122,139,141,142,144,317,370,376] searching for ways to manage experienced disease progression, and palliating existential distress,[121,123,128,133,134,136–142,144,375,376] and loss of self.[123,125,134,136,139–142,144,375,376]
2. Activities that frame decisions and decisional processes around medication management,[124,130,133,135–138,140–142,376] and decisional conflicts over radical treatment, decisional regret, and its consequences.[124,125,127,128,138,140–142,144,376]
3. Activities around enacting relations in the clinic,[121,124,125,127,133,140–142,376] and managing complex and sometimes negative relations with health professionals.[124,125,127,133]

Second, there is compensation work that stems from the transfer of clinical work into the home. This is work that is about compensating for the ways in which pathophysiological deterioration means that the patient ceases to be a socially competent actor quickly. It brings about a further biographical disruption in which a family member undergoes significant adjustment of role – and experiences role strain – as they become identified as a, or more likely the caregiver. These changes can be characterised as a source of biographical erosion which are also associated with three clusters of activities.

1. Activities that stem directly from the transfer of responsibility. This includes taking on delegated obligations for organising and enacting medical care – and sometimes much more than this – from the patient to caregiver(s),[121,124,125,133–142,376] and the expectations of health professionals that stem from this,[127,133,134,138,140] for symptom and medication management at home.[124,130,133,135–138,140–142,376]
2. Activities that mobilise caregiver contributions to maintaining relationships and services with health and social care professionals,[124,125,127,133] and wider social networks,[121,125,128,131,133–135,138–140,375] as the caregiver negotiates access to care,[121,122,125,131,134,136,144,370] and navigates care pathways,[136–138,370] on behalf of the person with brain cancer.
3. Activities that manage the diminishing horizons of patient and caregiver as the disease progresses. These include restrictions on participating in employment and access to the workplace,[122,124,128,130,134,186,187,370] restrictions on mobility and access to transport,[122,124,131,137,370] and reduced access to friendship networks and social interaction.[120,122,125,130,131,135,136,140–142,144,376]

The structure of service user and caregiver work reported in these studies is shown in a hierarchy diagram in *Figure 4*. We have focused attention on concrete activities that can be identified across a range of different kinds of brain cancers and across different health system contexts. It is important to acknowledge that qualitative studies on these topics often focus on existential, emotional and psychosocial aspects of confronting life-ending disease, and there is no doubt that these aspects matter to people with brain cancers and their caregivers. Three review papers[79,80,362] emphasised these aspects of experience of illness. However, serious consideration of structural inequalities is largely absent and mainly focuses on the 'financial impact' of disease. For example, Sterckx *et al.*[80] observe that 'patients mention how cost of their cancer care causes worry and contributes to fear and uncertainty' and that 'this concern can be caused by loss of income, increased medical costs, and the cost of disability. Whether to get financial benefits or reimbursements can cause appreciation or frustration' (p. 112).[80] Such problems seem overwhelmed by relational aspects of the lived experiences of illness and care across the literature.

Young-onset dementia

Aslett *et al.*[372] assert that there are more than 42,000 people living with young-onset dementia in the UK. It is well represented in our evidence synthesis. We have reviewed 23 primary studies and 9 reviews. These are described in *Tables 4* and *10*.

> *[Young onset dementia (YOD)] is defined as dementia diagnosed before age 65. YOD has greater heterogeneity than dementia in individuals over 65, where the Alzheimer's type predominates … The needs of people with YOD also differ both because of faster disease progression and socially as a result of being at a different life stage … Individuals may still be in employment, raising families and have financial commitments (e.g., mortgages). As dementia is perceived as a disease of old age, the impact on young-onset families may also be greater as it is 'out of sync' with the normal life course (p. 1090).*[372]

As *Figure 5* shows, the attributional structure of young-onset dementia seems to involve a bifurcation between goal-oriented work stemming from biographical disruption (in young-onset dementia, formal diagnosis may be the cumulative effect of multiple episodes of cognitive impairment), and compensation work that stems from biographical erosion (characterised as transfers of responsibility to caregiver(s) and their continuing contributions).[147–151,153,155–157,160,161,163,164,167,372,377–379] What follows from this are three main clusters of activities.

1. Activities that manage diminishing horizons over time. Dementia impairs cognitive and social competence and leads to restrictions on employment,[149,152,153] and loss of quality in informal social interactions with others.[147–149,151,372] They have consequences for the ways in which the extent of loss of social competence – and

the gain of illness identity – is disclosed to others,[147,151,153,155–157,164,166,372,377,379] leading to episodes of enacted stigma[146–153,155,156,164,372] and feelings of loss.[146–148,150,151,157,163,165,166,372,377–379]

2. Activities that organise enacted relations with health professionals and services. These develop over time through interactions with specific health and social care professionals.[146,148,150–152,165] People with young-onset dementia and their caregivers actively seek to understand disease progression,[146–153,155–157,160,161,163,166,168,372,377–379] and seek information about its consequences and the range of services available to them,[146–153,155,156,161,166,372] against the background of awareness of an existential threat.[149–156,160,161,163,165–167]
3. Activities that stem directly from transfers of responsibilities to caregivers, in which they accept both delegated and assumed obligations for care responsibility[146–152,155–157,160–163,165–168,372,377,378] – who may also be adult children of people with young-onset dementia.[146,157,160,377] Delegated obligations include negotiations around access to services,[149,151,152,154–156,160,161,167,372] and managing symptoms at home.[146,147,149,152,372] But they also involve caregivers in the work of navigating professional expectations and judgments about their capacity and skill.[146,151,154] Assumed obligations mean that caregivers need to work to adopt and sustain practically and emotionally supportive roles,[146–149,151,152,160,162,167,372] and to work to capture social capital and relational solidarity from members of their family and broader social networks.[146–149,155–157,161,162,165,166,372,377] Decisional conflicts that arise when waypoints in care are reached – in particular, when the time comes to relocate the person with young-onset dementia to a residential care facility – can deplete both the social and emotional capital available to the caregiver.[151,153,165]

In this section, we have reviewed studies reporting on lived experiences of young-onset dementia. We have mainly focused attention on the work that caregivers need to do as the person with young-onset dementia describes the arc of disease from mild to severe cognitive impairment. Accounts of the psychosocial consequences of this work are paramount in this literature and are emphasised in reviews.[82,83,85–87,92,96,97,106,146,148,154,156,160,372,377] There is good reason for this: experiences of young-onset dementia are marked by chronic feelings of loss and anxiety; varying degrees of social isolation and the breakdown of solidaristic social networks; sometimes unhelpful interactions with, and feelings of abandonment by, health and social care professionals; and emotionally charged and difficult decisions about residential care.

Inflammatory bowel disease

As we have noted earlier in this report (see *Table 1*), one of our original index conditions was ulcerative colitis. Our coverage of this disease was hampered by the way in which similarity of symptoms and the course of disease meant that the qualitative literature did not differentiate between ulcerative colitis and Crohn's disease. We have therefore included 25 primary studies and 4 reviews that focus on inflammatory bowel disease. These are described in *Tables 5* and *10*.

Illnesses with varying degrees of relapse and remission tend to be experienced as episodes ('flares' or 'exacerbation events', and periods of inactivity of disease), rather than as having a continuous-arc or trajectory-like young-onset dementia. For this reason, inflammatory bowel disease has a completely different attributional structure to irreversible degenerative diseases like young-onset dementia and Parkinson's disease.

> *Inflammatory bowel disease (IBD), which mainly comprises Crohn's disease and ulcerative colitis, is a common chronic disease often diagnosed early in life (peak age 15–35 years) … It is estimated that more than 4 million people in Europe and North America alone live with inflammatory bowel disease – around one in every 240 individuals … Because of the early age at onset and the absence of curative treatment, the vast majority of patients require lifelong medical care, which periodically leads to outpatient contact and hospitalisations (p. 3677).*[180]

Here, the hierarchy diagram of inflammatory bowel disease (see *Figure 6*) seems to show a bifurcation between the clinical dynamics of unpredictable disease progression[170,172,174–176,178,182,186–189] and the complex dynamics of family life.[170,176,177,187,190–192] Diagnosis in inflammatory bowel disease is by no means clear cut at the outset, and papers included in this synthesis[170–172,174,176,178–180,182] acknowledge the difficulties that stem from this. The cumulative effect of multiple episodes of disease over time – some of which may be very severe and potentially life-threatening – involves not so much biographical erosion as biographical constraint. Rather than psychosocial resources being depleted by the lived experience of the disease, the symptoms of the disease impose limits on normal activities that call for different kinds of workarounds.

1. Sustaining perceived social competence through activities that manage boundaries of disclosure and the management of stigma. Important symptoms of inflammatory bowel disease include chronic abdominal pain, chronic urgent diarrhoea accompanied by significant blood loss and a risk of faecal incontinence, and fatigue. In its severest forms, inflammatory bowel disease can be life-threatening. Voluntary control over the time and place of bowel movements is a fundamental feature of social competence in all human societies, but this cannot be guaranteed in flares of inflammatory bowel disease. Loss of status as a socially competent adult runs through accounts of lived experience of inflammatory bowel disease.[170,172,174–177,182,186,188,191,192] Intimately linked to that experience of loss is the acknowledgement of felt and enacted stigma linked to illness identity and the need to find workarounds to manage the effects of stigma.[170,174,176,179,182,186–188,190–192] An important workaround is controlling the extent to which personal information about illness identity is disclosed to others.[170,172,174,176,177,179,182,186,188,189] The combination of experienced pathophysiology, threats to social competence, stigmatisation and fear of disclosure can lead to restrictions on mobility and on interactions across wider social networks,[170,174,176,177,185,190] and on access to and utilisation of workplaces, with consequences for stable employment.[144,172,176,178–180,182,186,187,189,190,297] Indeed, managing social relationships within families, intimate relationships, friendship networks and places of employment is centrally important in accounts of the lived experience of inflammatory bowel disease.[170,176,177,179,186,191,192,297]
2. Activities that stem directly from negotiations within families. Illness identities are complex in inflammatory bowel disease because the search for symptom control[170–172,174–178,180,182] intrudes into important aspects of the affective or relational resources – the family contribution[170,176,177,187,190–192] – available to the person with inflammatory bowel disease.[144,171,174,175,177,178,180,185,189,190,297] Integrating illness identity[170,176,177,179,186,297] into family life frequently involves work around diet and dietary change. This involves trial and error work – since there is no evidence about the effectiveness of different diets in mitigating symptoms – and sometimes also involves navigating professional expectations of ethnic difference, especially in South Asian families.[174,178,182,185–187,191,192]
3. Activities associated with enacted relations with health professionals and services. The search for symptom relief is central to inflammatory bowel disease. Access to well-co-ordinated specialist care is centrally important to achieving this but is not always available.[172,176,178–180,182,190] People with inflammatory bowel disease need to invest in building relationships with clinicians (often specialist nurses) around sifting and sustaining options for symptom relief,[170–172,174–179,182,185,188–190] medication management,[170,171,175–178,180–182,185] and responding to anxiety about disease progression.[170,171,174–176] Continuous and severe symptoms may call for surgical intervention. Surgery precipitates work to negotiate informational inadequacy and so be better informed about surgery, its alternatives and its effects.[170–172,174–178,180,192] Managing decisional conflict about consenting to surgery is also a common problem, and one that appears to be difficult to resolve.[144,170–172,174–177,181,186–188,190,193] Building resilience[178,179,182,186,190,192] is one outcome of successful negotiation of inflammatory bowel disease as people work through formal care pathways.[171,174,178]

In this section, we have reviewed primary studies of the lived experience of inflammatory bowel disease. The sources of work that we have mapped are mainly around managing relationships, and they are also reflected in review papers: people with inflammatory bowel disease invest effort in managing the ways in which they are perceived to be (or not to be) competent social actors by others,[72] in managing restrictions on relationships and employment arising out of pathophysiological processes,[74] and in managing the complex relational effects of disease within families.[72] They invest in relationships with health professionals to solve problems about symptom management,[74] and to work through decisional conflicts about consenting to surgery.[74] There is no clear distinction between goal-oriented and compensation work in inflammatory bowel disease, in part because the division of labour between people with inflammatory bowel disease and their caregivers is not so clear as in many other conditions.

Bipolar disorder

We have already noted that illnesses characterised by relapse and remission tend to be experienced as episodes rather than as having a progressive downward trajectory. Whereas inflammatory bowel disease is an invisible disorder, bipolar disorder is made evident in behaviour in public. In this section, we review 36 primary studies and 1 review that explores the lived experience of bipolar disorder. These are described in *Tables 6* and *10*. In *Figure 7*, we set out a hierarchy diagram that maps the clusters of activities of people living with bipolar disorder and their caregivers.

> *People with bipolar disorder endure extreme changes in mood related to such fluctuations, and some also experience distorted or confused thinking that can lead to actions that are dangerous to self and others. The fluctuations make it difficult to provide the appropriate and effective support and treatment (p. 9).*[195]

The person living with bipolar disorder has to negotiate their public identity according to their sense of their own interior or ‘true’ identity: while they may experience deeply distressing depressive episodes, they may also experience episodes of tremendous activity that they characterise as creative and productive.[195,196,198,199,201,203,206,207,210,212,214,216,223–225,227,229,382] The cumulative effect of multiple episodes of symptoms over time that stems from this involves not so much biographical constraint as the need for biographical repair in the face of constant risk of recurrence of symptoms. In bipolar disorder, mapping sources of work that are associated with the illness also shows bifurcation between unpredictable disease progression[195,196,201–203,205,209,210,215,216,218–221,223–225,228,382] and the complex dynamics of family life.[195,198,202,203,206–209,216,222,229] What follows from this are four main clusters of activities.

1. Activities associated with struggles over care and access to services. Access to services cannot be assured in bipolar disorder.[196,198,199,216,218,227] Candidacy and help-seeking are organised through negotiations with gatekeepers,[195,199,203] and descriptions of depressive symptoms and their significance may be contested by health professionals.[195–197,201–203,205–208,210,215,216,221–226,228,382] Indeed, help-seeking may need to be made in the context of health professionals’ assumptions about the culpability of service users for their condition.[195,196,198,199,201–203,205–207,214,218–220,222,223] An additional significant problem for people with bipolar disorder in some healthcare systems was payment for pharmacological treatment.[196,202,208,209,224,225]
2. Activities associated with experiences of distress and personal risk. Living with bipolar disorder involves multiple episodes of distress,[200,203,208,209] in the face of experienced biographical disruption and the need for biographical repair.[195,196,198,199,201–203,205–210,212,218–220,222,224,225,227] Feelings of loss[195,196,202,205,207,208,212,221,226] and loss of control over the self[195–197,200,202,207,222] that are experienced during these episodes may also be associated with experiences of the effects of stigmatisation and marginalisation.[195,196,198,200,205,206,208,210,213,214,218–220,222,226] These may be amplified by poor-quality interactions with, and sometimes hostile responses from, health professionals.[195,196,198,199,201–203,205–207,214,216,218,220,222,223,228] They may also be related to thoughts of suicide.[199,203,207,219,223]
3. Activities associated with the acquisition of skills in self-management. Recognition, acknowledgement and management of negative symptoms are central to living with bipolar disorder.[195–197,201–203,205–208,210,215,216,221–226,228,382] The corollary of these are efforts invested in therapy and related activities,[221,392,393] and managing medications[196,197,202,203,206,207,209,210,213–216,218–220,222,226,228,382] and their side effects.[196,210,214,216,223,382] Attempts by people with bipolar disorder to gain control over disease progression and relapse included working within formal relapse prevention plans,[201,216] relaxation techniques,[205,226] avoiding stressful situations,[202,212] focusing on structured activities – especially paid work[394] – and for some, self-medication with drugs and alcohol.[195,197,382] An important defensive strategy was restricting disclosure of information about self and illness to others.[196,200,202,207,212,214,216,229]
4. Activities associated with the mobilisation of caregivers. Family caregivers needed to work in complex relationships with both the person with bipolar disorder and the professionals that they interacted with. They had episodic transfers of responsibility[195,199,202,203,206,208,209,216,218,220,222,224,229] that involved significant stress and role strain.[195,198,202,203,206–209,216,222,229] These included interactions in which they had to negotiate the legitimacy of their involvement in the care of the service users with professional gatekeepers,[149,199] and which could be met with indifference or outright hostility in situations where exchanges of information were often constrained by policies on disclosure and confidentiality.[195,196,198,199,201–203,205–207,214,216,218,220,222,223,228] Wider patterns of social relations could also be sources of complexity and work,[198,202,203,206,216] while they could also be unsupportive in the face of symptom exacerbation.[196,198,200,203,209,216]

The sources of work that we have mapped are around complex negotiations between people with bipolar disorder, their family caregivers, and mental health professionals. The illness identity of the person with bipolar disorder is directly connected to their mood and is thus never stable. This means that the role and workload of family caregivers are also unstable over time, adding to complexity and role strain. The review of experiences of distress in bipolar disorder by Warwick *et al.*[77] confirms this. Triadic relationships – in this case between the person, familiar caregiver and healthcare providers – are consistently revealed to be inherently unstable across a wide range of contexts,[395] and the course of the disease itself adds a complicating factor to self-care and to the work of caregivers. Perceived hostility[195,196,198,199,201–203,205–207,214,216,218,220,222,223,228] from professionals and disagreement about the significance of symptoms mean that the set of triadic ‘strong ties’ relationships through which social capital and affective resources flow are constantly at risk of renegotiation.

Schizophrenia

Unlike illnesses that involve relapsing and remitting processes, schizophrenia is commonly seen as a disabling condition that is characterised by 'chronic progression with clinical, cognitive, [and] social deterioration' along a progressively downward trajectory of long duration (p. 520).[230] However, some qualitative studies of lived experience suggest that there is variation in trajectory.[282]

In this section, we have reviewed 75 primary studies and 10 reviews exploring the lived experience of schizophrenia. These are described in *Tables 7* and *10*. A hierarchy diagram describing the clusters of activities for people living with schizophrenia and their caregivers is shown in *Figure 8*.

> *Schizophrenia is a severely disabling condition, potentially of long duration (World Health Organization 2015), which may also have a significant impact on the affected person's family … Its prevalence varies greatly across the world, with national estimates ranging from 0.5% to 1%, depending on diagnostic criteria.*
>
> *The prevalence in the UK and US is about 1%. In the UK people who are diagnosed with schizophrenia continue to live in an environment in which both the public and health professionals tend to have low expectations of them (p. 12).*[245]

Almost every aspect of schizophrenia as a diagnostic category – and as a lived experience – is contested in some way,[396,397] so we use this term cautiously. Like bipolar disorder, schizophrenia is made evident by behaviour in public. But it is also made evident in flatness of affect, disordered thoughts and beliefs, and sometimes auditory or visual hallucinations, of the person with schizophrenia.[245] These symptoms can cause great suffering. In this context, illness identity itself can be unstable.[230,231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,383] While biographical disruption is an important element of the diagnostic process, biographical stabilisation also seems to be a major source of work, not just for people with schizophrenia but also for their caregivers (see *Figure 8*). We can identify three main clusters of activities.

1. Activities associated with managing symptoms and disease progression. Help-seeking, and establishing eligibility for care,[240,256] was an important source of work for both people with schizophrenia and their caregivers. In the face of troubling symptoms, it was often caregivers who sounded the alarm and sought to contact healthcare providers.[240,257,264,275,283] Even so, access to, and the co-ordination of care, often seemed to present obstacles to effective intervention.[230,232,233,237,240,247,248,256,258,262–264,371,373] These difficulties formed the frame for complex problems around experienced distress in the face of biographical disruption during the diagnostic process,[230,231,233,237,247,248,255,257–260,263,264,270,272,275–277,279,281,284,285,289,298,302,371,373,383] and as the implications of diagnosis were worked through,[230–232,234,237,247,248,255,259,260,263,264,272,279,284,293,294,301,371,373] including the risk of suicide.[302] In this context, both people with schizophrenia and their caregivers were often confronted with negotiating inadequate information about the illness, not just at the beginning of the illness journey but almost at every episode of serious symptoms.[232,245,248,256,257,275–277,281,285,288] Work was devoted to understanding disease progression,[230,232,234,240,242,254–258,262–264,270,275–277,279,280,282,283,285,291–293,302,373,383] to understanding, recognising and monitoring symptoms,[230,232,236,237,242,247,248,254–258,262,272,275–280,282,283,285,291,292,296,298,301,302,371,383,387] to managing medications and complying with therapeutic regimens,[230,232–234,237,243,245,247,248,254,256,257,261,262,271,275–278,285,293,296,387] and to participating in treatment decisions.[237,254,256,371] These are the core elements of this cluster of activities. However, many studies pointed to poor-quality interactions between people with schizophrenia and their caregivers and indifferent or hostile health professionals.[230,232,237,240,242,248,275,279,283,285,288,383]
2. Activities associated with mitigating social dislocation. People with schizophrenia and their caregivers both experience feelings of profound loss – along with anxiety, fear, guilt, shame, denial, isolation – in the face of the complex life circumstances brought about by illness.[233,242,245,248,251,255,259–261,263–265,270,279,281,294,296,301,371,373,380] Feelings of felt and enacted stigma, and consequent isolation were central to this,[230–232,237,245,247,248,259–264,266,272,279,283,285,289,291,292,298,300,303,305,371,373,385,386] as family relationships are placed under strain, and support from social networks may break down in the face of behavioural differences and disturbances.[245,247,254,257,258,262–265,281,373]
3. Activities associated with seeking social (re)integration. The dynamics of relationships between people with schizophrenia and their – mainly family – caregivers is made complex by different understandings of disease,[230,231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,383] and patterns of disease progression that may involve relational challenges and interpersonal conflict.[232,236,245,248,257,262,270,271,275,280,284,291,293] Effectively managing symptoms at home[230,232,234,242,248,251,258,263,264,272,276,279,281,282,289,291,300,305,371,373] supports the person with schizophrenia's

presentation of self as a socially competent actor[233,242,254,257,258,262,300] and provides a foundation for different coping strategies.[230,232,236,237,242,247,248,254–258,262,272,275–280,282,283,285,291,292,296,298,301,302,371,383,387] These strategies include confidence-building practices, sometimes involving faith-based activities,[237,247,254,257,296,371,386] and attempt to find meaning in everyday activities.[233,234,242,245,282] Material disparities also call for investment: they include finding solutions for housing and financial problems.[233,234,236,242,248,249,256,266–268,278,281,285,289,291,303,304,371]

The sources of work that we have mapped are like those we saw in bipolar disorder. They involve complex and contested relationships between people with schizophrenia, their family caregivers, members of their wider social networks, and health professionals who are sometimes categorised as indifferent or hostile. At the centre of this is work that is directed at attempting to sustain the integration of the person with schizophrenia in a matrix of meaningful and supportive relations. These are not patterns of relationships that the person with schizophrenia necessarily wants, and they may involve entirely transactional encounters. This is undoubtedly a source of stress for caregivers, as the review by Cleary *et al.*[366] makes clear. Here, stress can derive from role strain. The caregiver is expected to act on behalf of the person with schizophrenia but may not have their support in doing so (their assumed obligations can be contested),[367] has no rights to intervene in the formal provision of care and may not have support from professionals in doing so (their delegated obligations are absent).[104]

Parkinson's disease

Like schizophrenia, Parkinson's disease is a disabling condition characterised by chronic progression along a downward trajectory of long duration. In this section, we review 56 primary studies and 7 reviews of lived experiences of Parkinson's disease. These are described in *Tables 6* and *10*. A hierarchy diagram showing the clusters of activities related to this disease is shown in *Figure 9*.

The combination of acknowledgement of existential threat, unpredictable episodes of disabling symptoms, and disease progression of long duration means that both people with Parkinson's disease and caregivers live through combined or entangled experiences of biographical erosion.

> *Parkinson's disease (PD) is a progressive, neurological disease involving motor (e.g. bradykinesia, tremor, rigidity, and postural impairment) and nonmotor (e.g. depression, anxiety, sleep disorders, fatigue, dysautonomia and pain) symptoms …. Its symptom profile and progression differ between individuals. Symptomatic dopaminergic therapy is initially successful, but a fluctuating drug response and dyskinesias often develop after some years. With the occurrence and progression of both motor and nonmotor symptoms, often in complex and fluctuating patterns, the disease is typically perceived as unpredictable and difficult to control (p. 2).*[350]

These experiences are dominated by fear of the future,[310,312,314,315,325,335,336,346,351,358,360,361] in which the person with Parkinson's disease progressively loses personal autonomy and control over important aspects of their life,[207,307,311,319,327,334,336,337,341,347,358] and in which caregivers' experience very significantly increased workload and responsibility over time.[307,310–312,317,325–328,330–333,336–338,345–347,356,361,374] Attribution mapping and intersecting coding revealed four clusters of activities that dominated qualitative studies of the lived experience of Parkinson's disease (see *Figure 9*).

1. Activities associated with enacting relations in the clinic. Candidacy in Parkinson's disease seems to be organised around pre-diagnostic symptoms that are often difficult to interpret.[308,356] Once a diagnosis is established, access to care and availability of specialist clinical investigations may be constrained by fragmentation of care and consequent waiting times.[312,313,315,329,337,338,344–347,350,352–354,374] Within clinical services, both people with Parkinson's disease and their caregivers take up delegated obligations that include participating in treatment decisions, medication management, and management of medication side effects,[309,313,381] often trial and error experiments in medication use and adherence.[207,308–310,312,314–316,318,319,326–328,330,331,334,336,337,344,347,359,374,381,384] People with Parkinson's disease also draw on supportive equipment and mobility aids,[207,307,310,319,324,338,344,360] and other equipment.[307,309,311,317,338,344,346,356] Maintaining autonomy and control remains important throughout the illness trajectory.[207,307,311,319,327,334,336,337,341,347,358] However, people with Parkinson's disease and their caregivers reported poor interaction quality with health professionals, and perceived abandonment by specialists at the end of effective treatment.[307–309,313,314,317,325–327,329,334–337,346,354] Caregivers and family members often felt excluded from clinical

interactions,[309,326,329,337,338,344] and they pointed to perceived inadequate care in community[307–312,315,329,337,338,344,345,350,352,353,356–361] as a key problem, especially after the end of active treatment and towards end of life.

2. Activities associated with responding to existential threat. Biographical disruption and erosion are amplified in Parkinson's disease because of its unclear trajectory, uncertain timescales and clear existential threat.[307,310–312,314,315,317,318,325,330–332,334–337,339,340,342,344,345,350–353,358,360,384] What follows from this is evident distress and fearfulness about the future.[310,312,314,315,325,335,336,346,351,358,360,361] These shape illness identity and the personal meanings of symptoms.[310,312,313,315,318,325,328,330–337,341,345,347,350,351,359,361,384] Knowledge about symptoms and disease processes is challenged by difficulties in controlling important symptoms. These include motor symptoms, psychological problems, incontinence and sexual dysfunction.[307,308,311–314,316,317,322–325,327,328,334,335,337–339,341,342,344,345,350,352,353,356–358,374,381] These are symptoms that grow worse over time,[307–318,323,325–328,332–337,339,341,342,346,347,350,351,356–358,360,374,384] and both people with Parkinson's disease and their caregivers acknowledge that a there will be a point at which treatment ceases to be effective.[310,342,344,347,359] The combination of trajectories of pathophysiological deterioration and treatment degradation over time emphasise the existential threat posed by Parkinson's disease.[307–315,318,326–328,336,337,339,345–347,351,354,358,374,384]
3. Activities associated with managing biographical erosion. People with Parkinson's disease and their caregivers experience anxiety, fear, guilt, shame, denial and isolation.[207,307,310,313,317,319,323,328,333,339,340,345,350,352,353,357,358] They also experience different kinds of loss of control[307,309,310,315,323,324,326,334,336,342,345,356,358,361] as disease progression overwhelms the possibilities of managing symptoms at home.[309,310,326,344,354] These lead to the inevitable transfer of responsibility for organising and delivering care to family caregivers, especially to women,[307,310–312,317,325–328,330–333,336–338,345–347,356,361,374] and which are evident in decisional conflict about transferring the person with Parkinson's disease to residential care at the point when this becomes necessary.[307,309,310,312,317,330,331,333,335,336,346,356,361,381] As symptoms become more visible, felt and enacted stigma are consistently experienced,[312,325,328,330,331,334,336,337,339,345,347,351,360] and people with Parkinson's disease and their caregivers seek to control disclosure of information as a way of damping down discriminatory stigma.[312,336,341,345,352–354]
4. Activities associated with responding to role strain and restrictions. The roles of people participating in the shared trajectory of people with Parkinson's disease and their caregivers reflect social expectations of relational solidarity and readiness to respond to crises.[307,309–315,318,322,325,327,328,332,333,335,336,338,342,345,347,350,352,353,356,360,374,381,384] Through the arc of illness trajectories, illness identities are integrated into family relationships and domestic routines.[307,310,311,326,336,342,360] Similarly, caregivers seek to restore informal social networks of family and friends and the social capital that supports resilience.[307,310,313,322,333,335,347,356,360] Restrictions that were consequent on structural inequalities were emphasised in studies included in this evidence synthesis. These were connected to experiences of loss. This included dependence on the support of others after the surrender of driving licenses,[330,331,337,344] with consequent restrictions on freedom of movement.[307,310,311,324,325,328,336,339,341,344,350,354,359] Material disadvantages followed from loss of employment income, or from dependence on social security benefits or health insurance.[307,308,330,331,337]

In this section, we have reviewed 57 primary studies of the lived experience of Parkinson's disease. The sources of work that we have mapped involve complex relationships between people with Parkinson's disease, their family caregivers, members of their wider social networks and health professionals. Studies of lived experiences of people with Parkinson's disease focus attention on the ways in which progressive disability results in the transfer of responsibility from the person with Parkinson's to their caregiver(s), and the patterns of isolation that follow from this as their social horizons diminish. Reviews bear this out, focusing on important elements of social functioning, including responses to stigma.[93,98,99,108] They also show that social roles, often established over many years, come under strain as the disease progresses – for both the person with Parkinson's disease and their caregiver. This strain exercises a powerful influence on the conduct of care. In this context, relational solidarity within family relations is revealed as an important feature of lived experience but is called into question as the burden of care shifts to the (family) caregiver.

Inequalities and obligations

Living with intersectional inequalities

The role of structural inequalities in forming a context for sometimes hard and heavy work for service users and caregivers is well established.[398,399] References to macro-structural disadvantages associated with socioeconomic status, older age, ethnicity, sex/gender and sexual orientation were rare in the qualitative papers reviewed in this study.

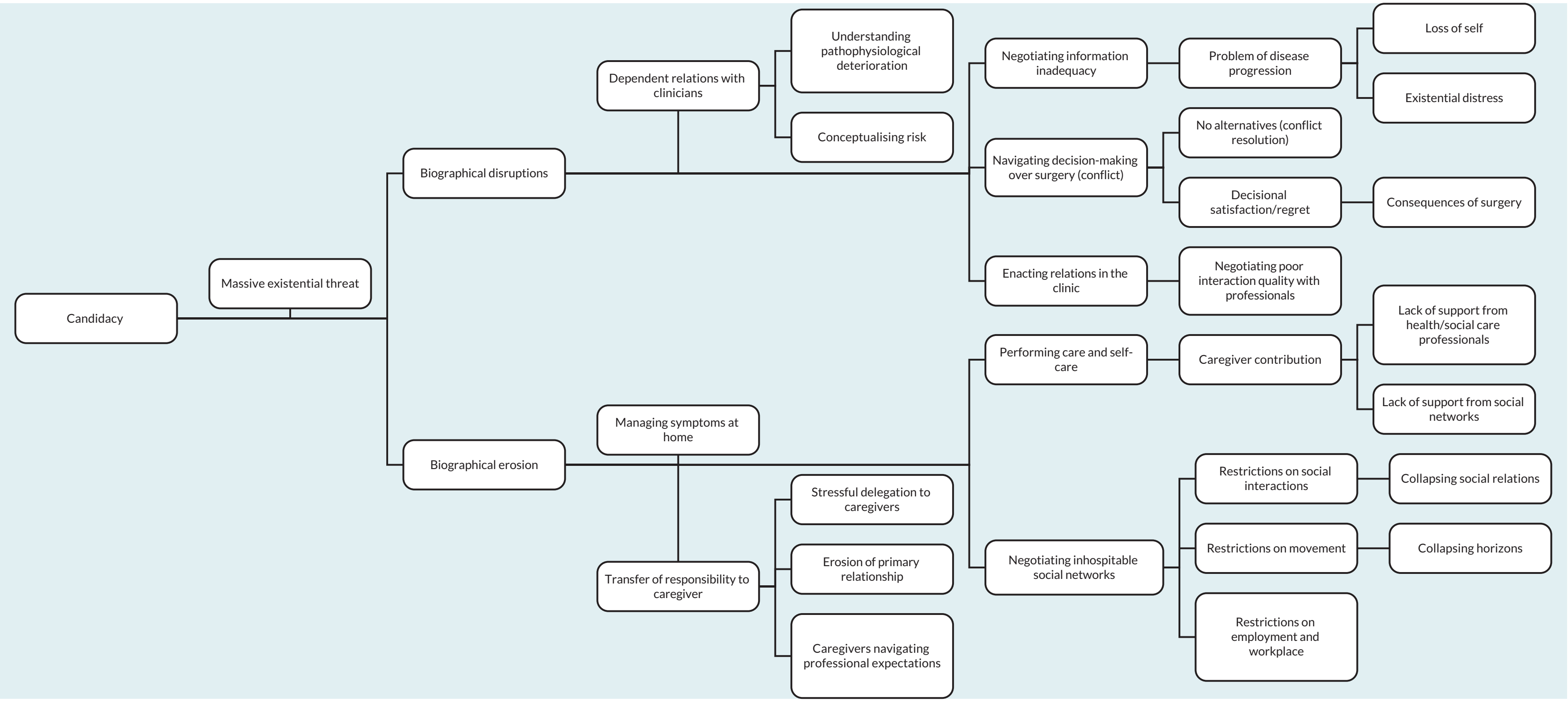

FIGURE 4 Mapping the work of brain cancer.

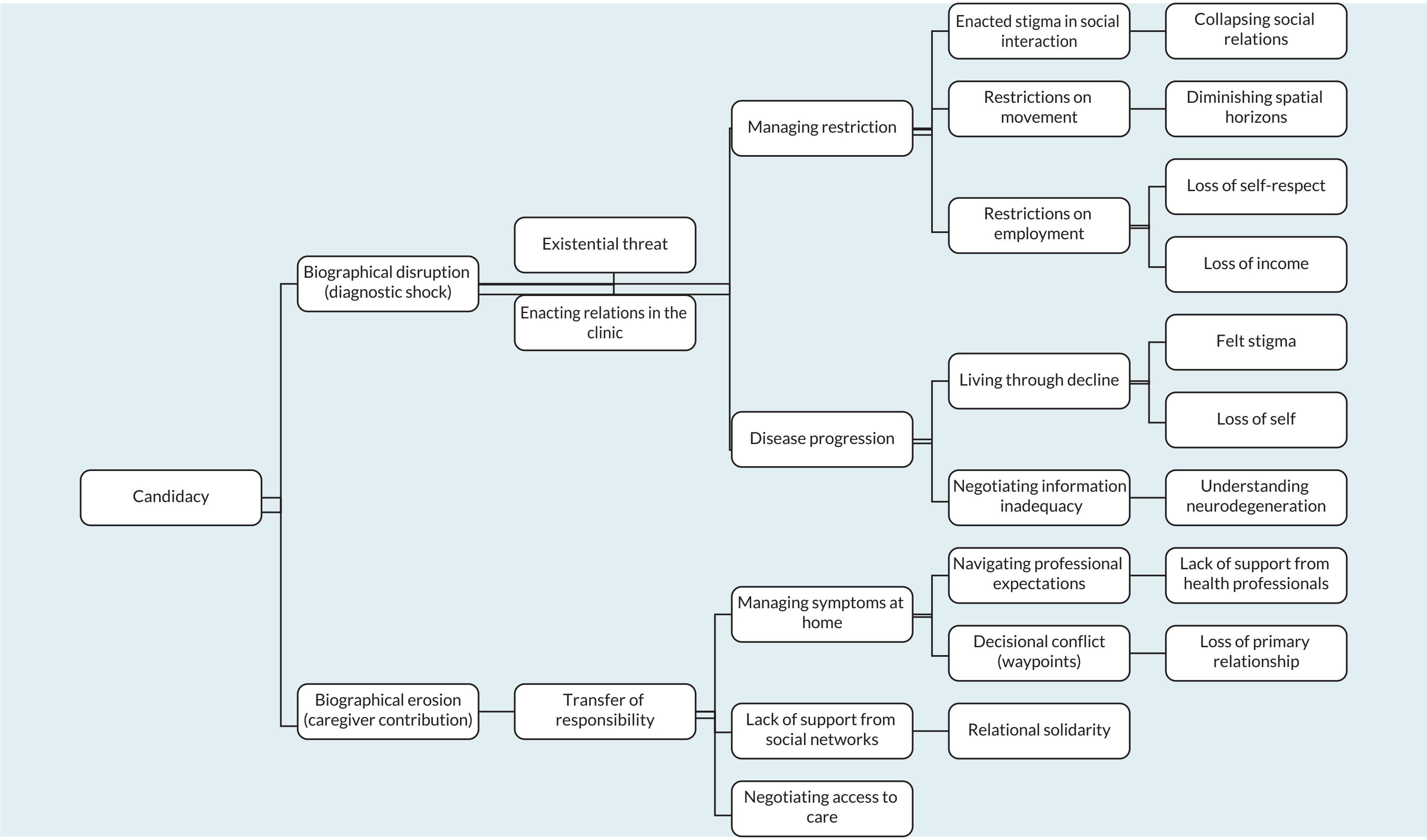

FIGURE 5 Mapping the work of young-onset dementia.

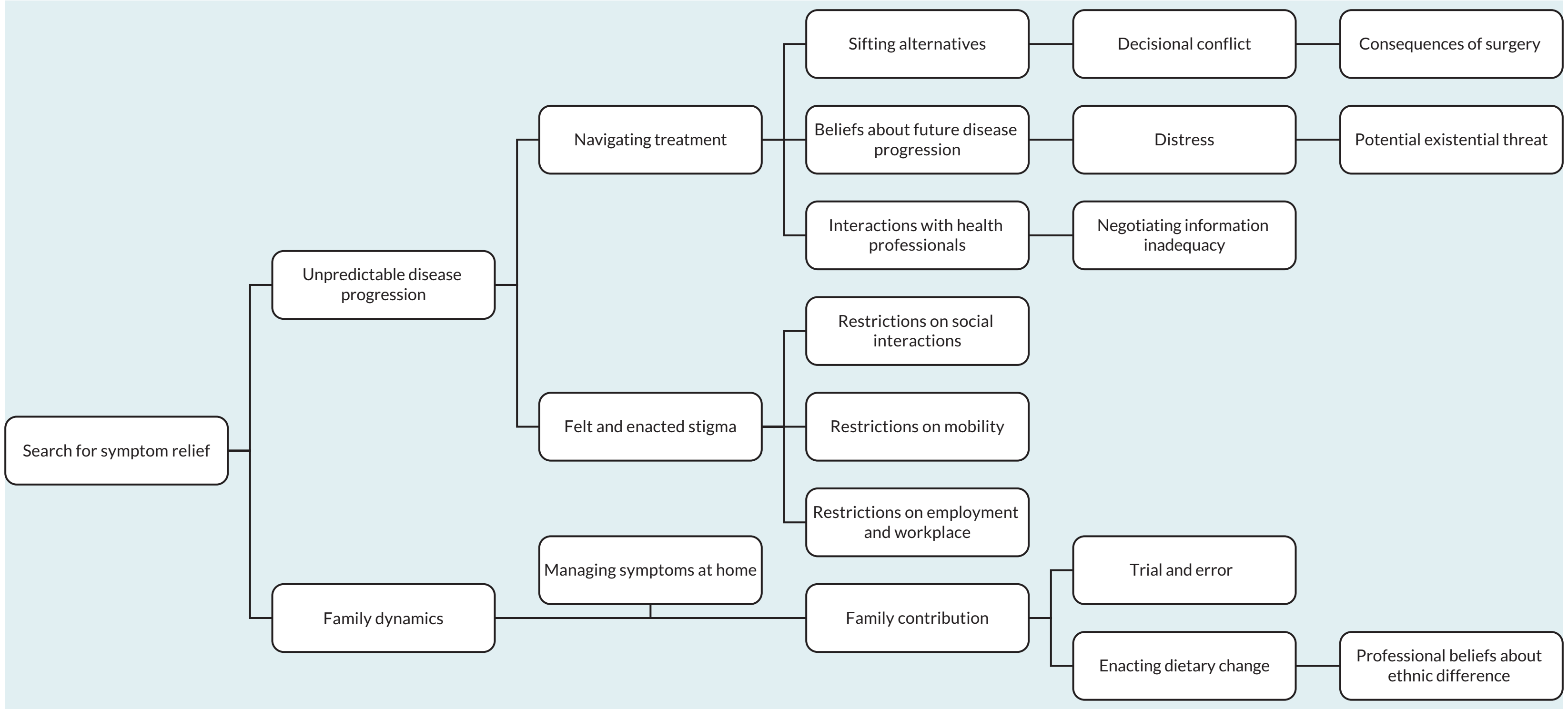

FIGURE 6 Mapping the work of inflammatory bowel disease.

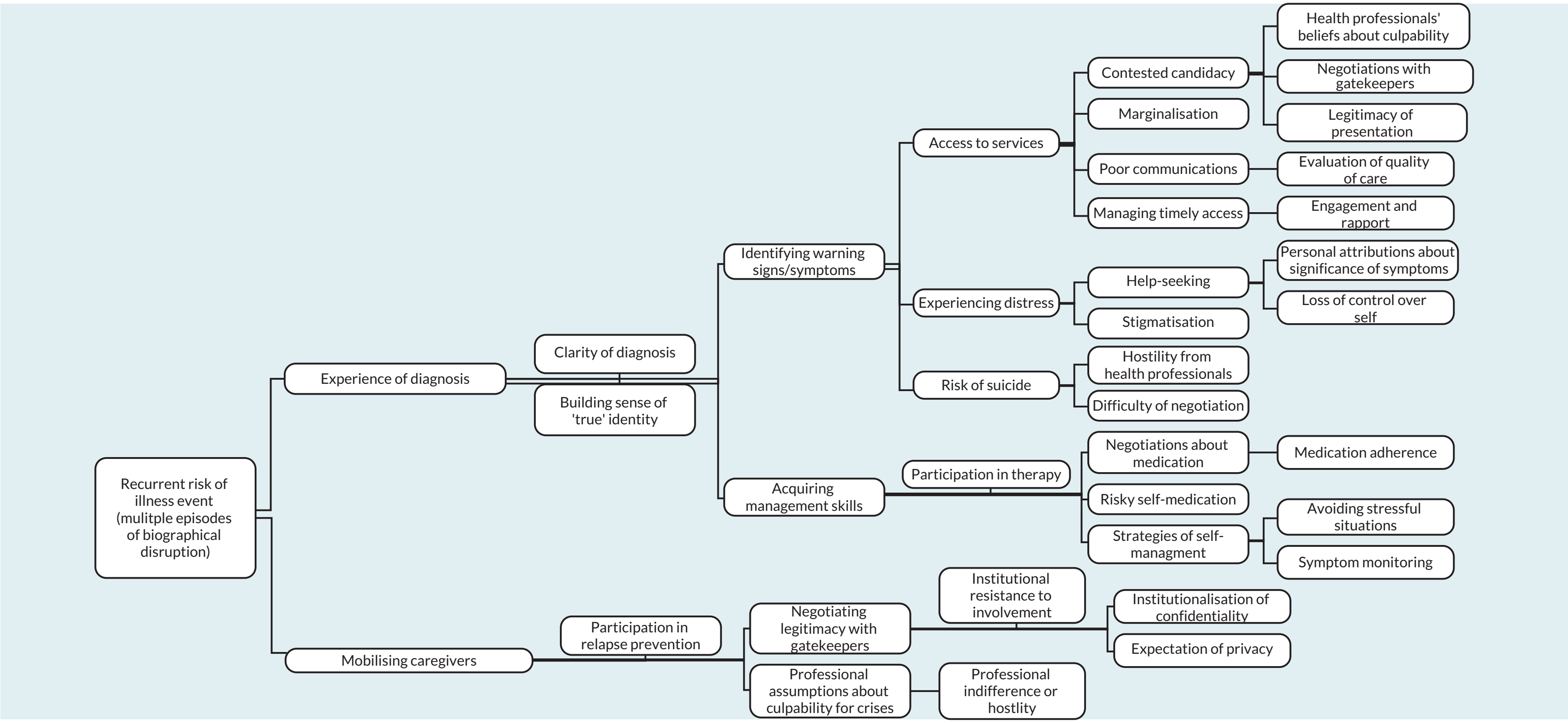

FIGURE 7 Mapping the work of bipolar disorder.

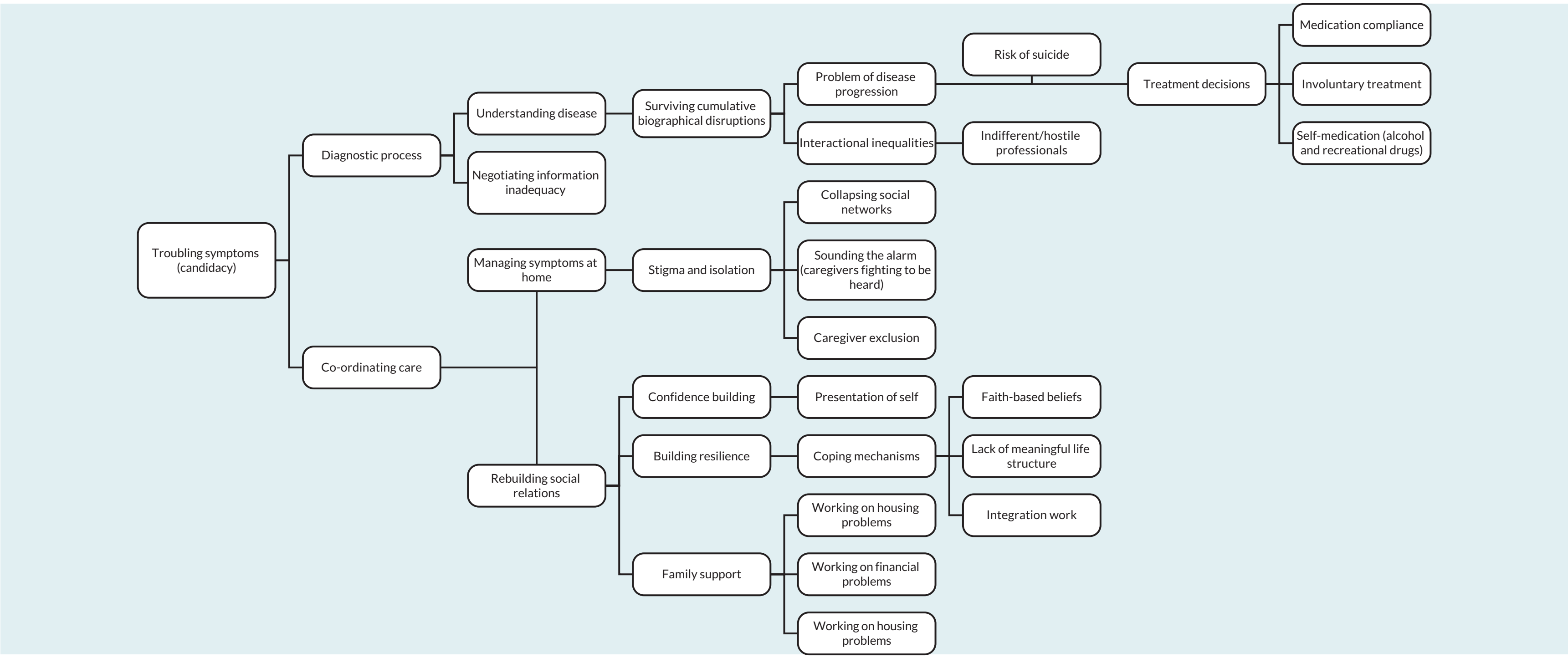

FIGURE 8 Mapping the work of schizophrenia.

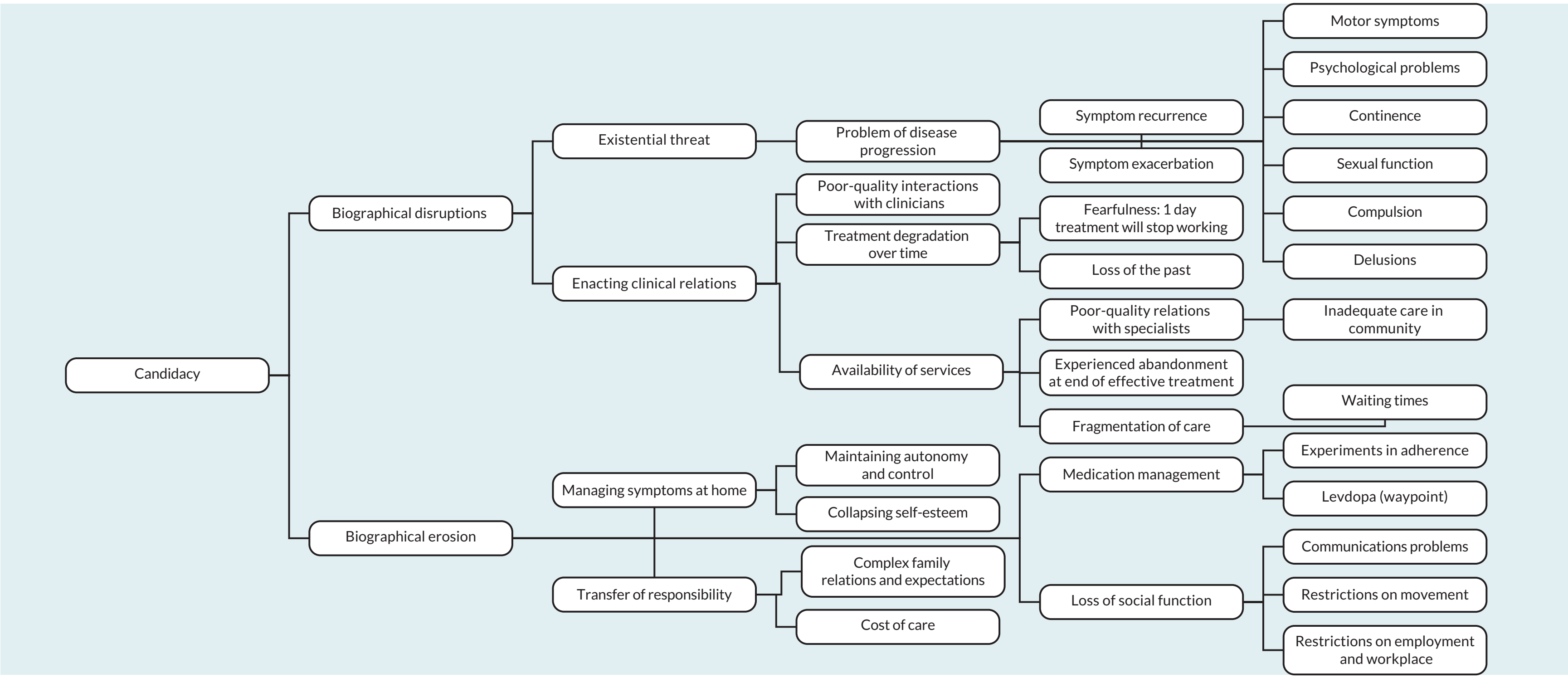

FIGURE 9 Mapping the work of Parkinson's disease.

While macro-structural mechanisms that shape lived experience of illness were rarely mentioned, the micro-structural consequences of illness were raised in almost every paper. These are factors that are consequences of illness and that are generative of inequalities. Service users and caregivers may experience significant disadvantage as a result of these.[400] They are organised around things that are made absent in illness (adequate health insurance, high-quality accommodation); resources that have been taken away because of illness (income from employment, driving licenses); or are elements that impose organisational difficulty (difficult to access, or poorly co-ordinated, care).[401]

Affective resources are central to the lived experience of illness

We have identified and characterised patterns of effective work that result from biographical disruption and erosion, stigma and distress, and decisional conflict. These data told us about the work of enacting, negotiating and navigating experiences of illness and care over the course of illness trajectories. Central to these were the assumed obligations that arise when service users and caregivers must take on the organisational work that they need to do to engage, and stay engaged, with health and social care providers. This includes tasks relating to participation, accessing, navigating, co-ordinating and managing processes of care with (often unco-ordinated) multiple service providers and their complex administrative systems and care pathways.[6,32,402]

Negotiating delegated and assumed obligations

We have identified and characterised ways in which candidacy, administrative burden and treatment burden are described in included papers. These papers tell us about the ways in which service users and caregivers enact, negotiate and navigate their formal relations with health and social care providers over the course of illness trajectories. They also show patterns of delegated obligations around the performance of a range of tasks. These include conforming to expectations of behaviour modification and change; symptom monitoring and management; adhering to complex treatment regimens and managing multiple drugs, dressings, medical devices, web-enabled tools and information sources, and assistive technologies.[6,32,402]

Biographical and relational change

In this chapter, we have reported on the results of within-case attribution analysis and cross-case intersecting coding of all primary studies (n = 244), and reviews (n = 35), included in the EXPERTS II review. We have systematically identified and described service user and caregiver work associated with lived experiences of three kinds of conditions: long-term conditions associated with significant disability (Parkinson's disease and schizophrenia); serious relapsing–remitting disease (inflammatory bowel disease, bipolar disorder); and rapidly progressing acute disease (brain cancer, young-onset dementia). These have been presented through detailed taxonomies relating to each index condition (see *Figures 4–9*).

We now turn to developing a theory-informed generic taxonomy of service user and caregiver work. This is framed by biographical theory.[11] All of the index conditions investigated in this review follow from a profound experience of diagnostic shock,[403] when help-seeking and candidacy work by service users and family caregivers lead to a clear statement of illness identity and its actual or possible consequences. *Figure 10* places elements of the generic taxonomy of service user and caregiver work in the context of ideas that stem from Bury's[11] classic paper on biographical disruption, which focused attention on the ways in which the onset of serious illness 'requires a fundamental rethinking of the person's biographic and self-concept' (p. 169)[11] and thus 'disrupts personal expectations and plans and the structures of everyday life' (p. 1044).[389]

Other authors have added to 'biographical theory',[390] further developing it by exploring the ways in which people who experience significant disruptions find that they 'fracture' narrative constructions of the self.[390] Lippiett *et al.*[391] have added the concept of biographical erosion to this to characterise the ways in which the practical and emotional work associated with serious illness grinds away at the taken-for-granted world, replacing it with a new set of constraints on independent agency. Locock *et al.*[389] have added the important concept of biographical repair, in which people seek to 'make sense of their remaining life, restore normality and control, and find new meaning and identity' (p. 1043).[389]

We need to be cautious about the claims that we make about the 'biographical' content of the material that we have analysed in this chapter. Much of what we see here is evidence not of individual cognitive work about biography and

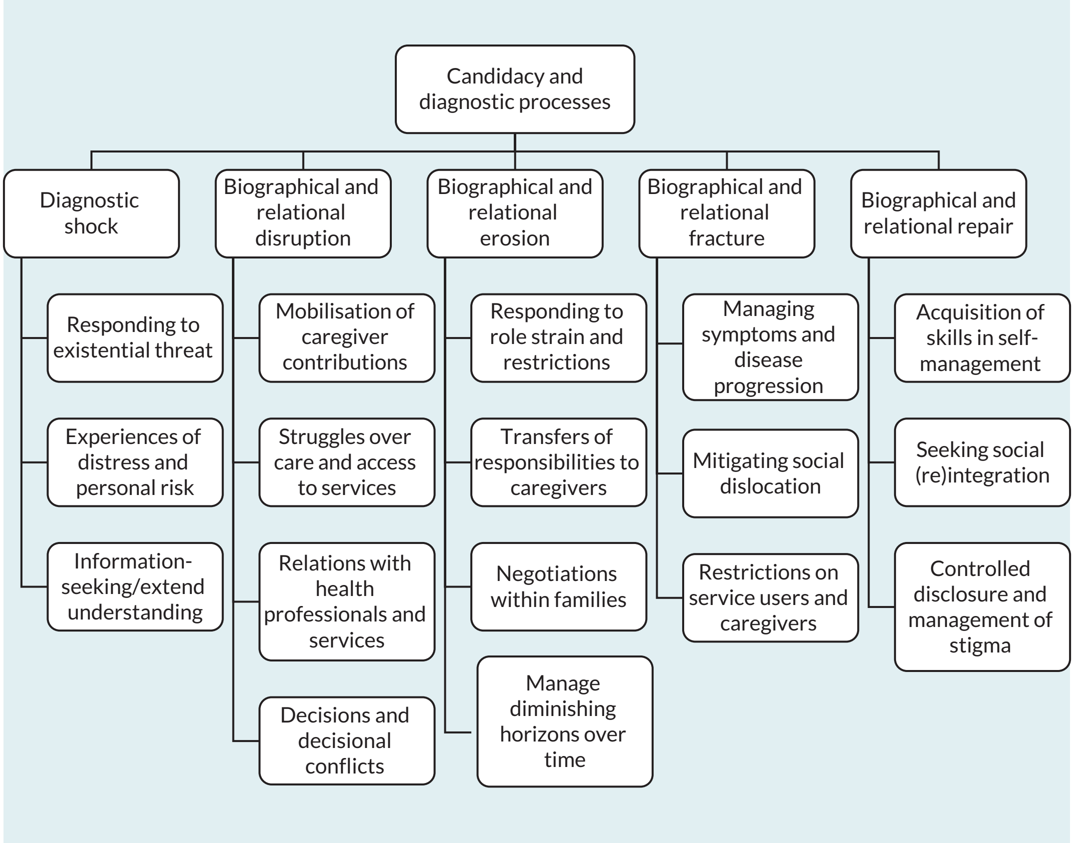

FIGURE 10 Relational disruptions and lifeworld pressure points.

personal meaning, but relational or distributed work that is unequally delegated or assumed among service users and caregivers, health and social care professionals, family members and their wider social networks, and employers and institutions. It therefore makes more sense to think of these events, states and processes not so much as biographical as relational. In all the studies that we have reviewed, the role of family caregivers is centrally important. Indeed, family caregivers often appear to portray themselves not only as the primary source of care but also as nests of resistance to the effects of index conditions, the incivilities of impersonal healthcare systems and sometimes unhelpful clinicians. We find little discussion of other kinds of caregivers.

What is evident in this chapter is that the work of participation in these index conditions is rarely individualised and is most often shared work undertaken within families. Our headline taxonomy of service user and caregiver activities associated with participation in care across illness trajectories (see *Appendix 2*) acknowledges this by showing that biographical (i.e. individuated lived experience) and relational (i.e. supportive and solidaristic contributions) elements are always intimately connected. Biographical and relational participation are therefore at the centre of our analysis. This has important implications for the design of interventions intended to encourage self-management and supported self-care. In *Chapter 5*, we will develop this relational taxonomy and identify ways in which these ‘pressure points’ offer opportunities for interventions at health system and individual levels.

Chapter 5 Results: mechanisms that shape illness intervention points, trajectories and treatment burdens

Chapter summary

This chapter performs three main tasks: (1) it analyses the interactions between components of lived experiences over time, identifying activities and supportive interventions; (2) it employs Event-State Analysis to understand the temporal dynamics of these experiences; and (3) it contributes to policy and practice by identifying key intervention points and contextualising them within a theoretical model of patient-centred care.

Event-State Analysis brings into the foreground the significant effort invested in managing illness trajectories. Service users and caregivers engage in various activities, from help-seeking and establishing eligibility for care to managing symptoms and maintaining relationships with healthcare providers. These activities are often disrupted by diagnostic shock, biographical and relational disruptions, and the chronic workload associated with advancing disease and increased symptom severity. The document emphasises the need for interventions that address both the psychological and practical aspects of living with chronic illness. Psychological interventions, such as counselling and psychotherapy, are essential for managing distress and existential threats. Additionally, improved information and educational interventions are crucial for helping service users and caregivers cope with their conditions. These interventions should be carefully targeted and delivered.

Caregivers play a critical role in managing the practical aspects of care, often experiencing increased workloads and stress. Our analysis emphasises the importance of better co-ordination of services, access to respite care, and support for caregivers to mitigate their workload. It also highlights the importance of reinforcing both social capital through interventions that support social networks, and reinforcing affective contributions through interventions that support relational solidarity within families and friendship groups.

Introduction

The starting point for our analysis of the literature included in this review was the idea that to be a service user or caregiver is to be involved in the work of effective participation in care.[391] In *Chapter 4*, we mapped key elements of patient and caregiver work that contributes to participation. In this chapter, we are concerned with the ways in which elements of effective participation interact with each other in relationships in which different kinds of mechanisms may be in play. Centrally important to understanding these is an analysis that reveals and characterises the ways in which these interactions and mechanisms may shape the trajectories of lived experiences of care. The taxonomy of activity that we developed in *Chapter 4* to underpin our descriptive analysis of service user and caregiver work suggests that great effort is invested in trajectory management, a process that requires their constant attention. In this chapter, we are concerned with the lived experience of trajectories. The chapter performs three tasks:

1. The chapter analyses interactions between key components of service users' and caregivers' lived experiences of participation in their care over time. We identify key service user and caregiver activities and proposed supportive interventions described in the literature and locate them in their experiential trajectories.
2. Using Event-State Analyses of service user and caregiver activities, and of proposed supportive interventions, we contribute to the development of qualitative methods that facilitate better understanding of the temporal dynamics of the lived experiences of service users and caregivers.
3. The chapter contributes to policy and practice by identifying intervention points in service user and caregiver experiences of complex illnesses, and contextualising these in relation to ideas about patient-centredness. We

place these within a theoretical model that identifies, characterises and explains the mechanisms that motivate and shape service user and caregiver experiences of illness, in its social context, over time.

Dynamic illness trajectories

In *Chapter 2*, we pointed to the value of Event-State Analysis[116] in considering service user and caregiver lived experience. Their accounts of illness in papers included in this evidence synthesis tended to represent narratives that combined temporal schemas. The first of these was structured around interactions with health services, and we have called this the systemic trajectory. The storylines around systemic trajectories emphasise events – modifiable features of the operation of health services and the ways in which service users and caregivers interact with them. The second temporal narrative was structured around states – service users' and caregivers' subjective modifiable responses to lived experiences of illnesses. We have called this a relational trajectory. The bridge between systemic and relational narratives is built up by service users and caregivers as they mobilise a constellation of lifeworld resources.

Systemic trajectories

These are medical storylines that point to organic or psychogenic processes that are generative of experienced symptoms over time, and that occur as a disease advances or symptoms worsen.[404] This may involve the initial onset of symptoms, the spread or worsening of the disease within the body, the involvement of different organs or systems, potential complications or adverse effects, or temporary or permanent recovery. These accounts describe the institutional impact of disease upon the person over time.[121,131,133,134,136–138,141,142,144,149–156,160,161,163,165–167,171,174,178,232,236,245,248,257,262,270,271,275,280,284,291,293,307–315,318,326–328,336,337,339,345–347,351,354,358,374,376,384] Accounts of systemic trajectories rest upon organisational storylines about the ways in which clinical pathways are used as system-level tools for organising service users according to diagnosis, treatment modality, professional contact and disease progression.[136–138,146,153,170–172,174–178,180,182,196,198,201,203,206,207,216,218–220,223,237,254,256,307–312,315,329,337,338,344,345,350,352,353,356–361,370,371] Pathways differ between different specialisms and healthcare provider organisations.[405] For service users and caregivers, the situation may be more complex.[20]

Relational trajectories

Qualitative studies and reviews tell us about temporal processes[406] through which symptoms are subjectively experienced,[123–125,133,134,136,138–140,146–153,155–157,160,161,163,166,168,170,172,174–176,178,182,186–189,195,196,201–203,205,209,210,215,216,218–221,223–225,228,230,232,234,240,242,254–258,262–264,270,275–277,279,280,282,283,285,291–293,302,307–318,323,325–328,332–337,339,341,342,346,347,350,351,356–358,360,372–375,377–379,382–384] as episodes of biographical and relational disruption over time.[11] They lead to interactions with informal social networks, formal healthcare providers and social services. They are 'characterised by interdependent patterns and pathways of decisions, social interactions, and experiences' (p. 139).[407] Relational trajectories are more than changes that take place over time, and they are often more than the sum of pathophysiological processes. Instead, they may take the form of subjective experiences of status passages,[10] in which service users' and caregivers' personal identities and roles[120,123,127,130,134,137–139,141,142,144,148,150,167,171,174,175,177,178,180,185,189,190,195,196,198,199,201,203,206,207,210,212,214,216,223–225,227,229–231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,297,310,312,313,315,318,325,328,330–337,341,345,347,350,351,359,361,375,376,379,382–384] are formed and changed according to the ways in which others relate to the character and effects of their illness,[124,125,131,133–136,138–140,146–149,151,152,160,162,167,170,176,177,187,190–192,195,198,202,203,206–209,216,222,229,230,232,234,242,248,251,258,263,264,272,276,279,281,282,289,291,300,305,307,309–315,318,322,325,327,328,332,333,335,336,338,342,345,347,350,352,353,356,360,371–374,381,384] the degree of disruption to relationships and socioeconomic status that follow from it, and anticipated outcomes of disease progression.[11]

Lifeworld resources

We have divided one of our basic phenomena of interest – illness trajectories – into two. First, systemic trajectories that are richly contextualised products of the provision of health care, and of the activities of clinicians, and second, micro-level relational trajectories that are subjectively experienced and worked within by service users and caregivers over biographical and relational time. An important feature of service users' and caregivers' investment in effort and work as they seek to manage and shape illness trajectories is that these are oriented towards action and to controlling

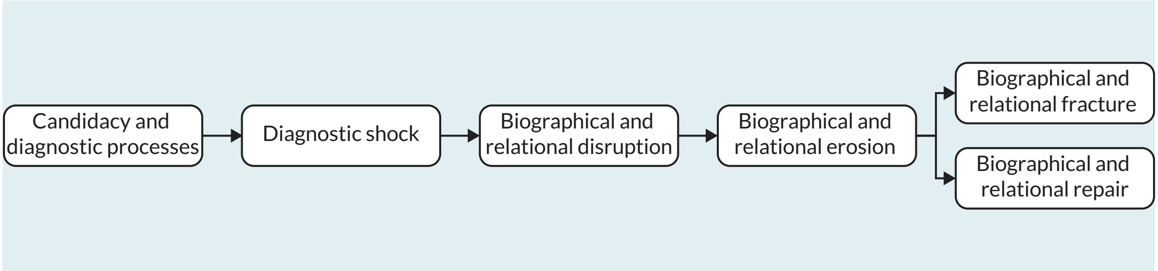

FIGURE 11 Biographical and relational trajectories over time.

complex and dynamic disease processes as much as they are to adjustment to the disruption and loss that illness can bring in its wake. Burden of Treatment Theory[1] suggests that this work is formed through a set of resources that form a bridge between systemic and relational trajectories and their consequences. We call these lifeworld resources, and they are composed of four elements.

1. *Personal capacity*. People possess varying degrees of personal psychological, social and economic resources. These make possible the exercise of agency under conditions of constraint.[1,3,14,30]
2. *Social capital*. People are embedded in networks of social relations through which social capital (informational, material and symbolic resources) flows between their members, and through which social skills are exercised to secure the co-operation of others.[42,408,409]
3. *Affective contributions*. People are implicated in a set of social relations with others characterised by varying bonds of affection and moral obligation. They make possible mutually supportive action and allocation of affective contributions between persons.[1,42,408]
4. *Enabling agency*. Personal capacity, social capital and affective contributions are fundamental features of social identity and relations. When they are mobilised to achieve individual or collective goals, they form a set of combined, or entangled, lifeworld resources that enable expressions of applied agency among individuals and groups.

In *Figure 10*, we set out a simple action-oriented model of lifeworld resources. Lifeworld resources form a bridge between Events (systemic features of trajectories) and States (relational features of trajectories). In *Figure 11*, we set out a temporal model of the contexts of action that are specified by contributors to biographical theory.[11,389,390,391,403] Taken together, these provide a structure for analysis of the implications for service improvement and their associated intervention points that are proposed by authors whose papers are included in the review.

Lifeworld resources and supportive interventions

In what follows, we show how both service user and caregiver activities (see *Table 11*) map on to lifeworld resources, and how these lifeworld resources build a bridge between systemic and relational illness trajectories (see *Table 12*). In this section, we characterise the ways in which social capital, personal capacity, affective contributions and collaborative work mediate between events and states to shape contexts for service user and caregiver action. We also show how these contexts for intervention define opportunities for practical and supportive interventions proposed by authors of review papers included in this evidence synthesis.

Diagnosis and diagnostic shock

Across all six index conditions, there was strong support for improvement in diagnostic services, processes and pathways. This accords with results from analysis of primary studies, where diagnostic pathways and processes were the focus of criticism from both service users and caregivers. This is not surprising: service users and caregivers must both demonstrate that their call on health services is warrantable, and they are eligible for those services. Across the evidence synthesis, there were accounts of the ways in which service users experience candidacy – often presenting pre-diagnostic symptoms that were difficult to interpret and entering into explicit negotiations around help-seeking as they participated in diagnostic processes. In this context, and throughout illness trajectories, caregivers were often described as 'sounding the alarm' as they saw emergent symptoms of new illnesses and exacerbations of existing ones.

TABLE 11 Event-State Matrix: service user and caregiver activities and their contexts of action

Contexts of action	EVENT (modifiable components of systemic trajectories)	Lifeworld resources				STATE (modifiable components of relational trajectories)
		Social capital	Personal capacity	Affective contribution	Enabling agency for collaborative work	
Candidacy and diagnostic processes	Service users experience candidacy, perform help-seeking as they participate in diagnostic processes[124,131,146,170–172,174,176,178–180,182,195,199,203,240,257,264,275,283,308,356]				Service users and caregivers work to establish eligibility for care and seek access to services[135,140,240,256,370]	Service users and caregivers may gain illness identity[120,123,127,130,134,137–139,141,142,144,148,150,167,171,174,175,177,178,180,185,189,190,195,196,198,199,201,203,206,207,210,212,214,216,223–225,227,229–231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,297,310,312,313,315,318,325,328,330–337,341,345,347,350,351,359,361,375,376,379,382–384]
Diagnostic shock	Service users and caregivers interact with clinicians, and negotiate diagnostic process[121,122,125,131,134,136,144,149,151,152,154–156,160,161,167,172,176,178–180,182,190,196,198,199,216,218,227,230,232,233,237,240,247,248,256,258,262–264,312,313,315,329,337,338,344–347,350,352–354,370–374]		Service users may seek to exert and maintain control over important aspects of their life[120,123,127,130,134,137–139,141,142,144,148,150,167,171,174,175,177,178,180,185,189,190,195,196,198,199,201,203,206,207,210,212,214,216,223–225,227,229–231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,297,310,312,313,315,318,325,328,330–337,341,345,347,350,351,359,361,375,376,379,382–384]	Caregivers may seek to demonstrate readiness to respond to crises[124,125,127,133,172,176,178,195,196,198,199,201–203,205–207,214,218–220,222,223,309]	Service users and caregivers may seek information about condition[120–122,139,141,142,144,146–153,155,156,161,166,170–172,174–178,180,192,197,210,216,232,245,248,256,257,275–277,281,285,288,309,317,341,370,372,376]	Service users and caregivers can experience profound sense of loss and distress, and awareness of existential threat[121,123,125,128,133,134,136–142,144,146–151,157,163,165,166,170–172,174–177,182,186,188,191,192,195,196,200,202,203,205,207–209,212,221,226,230–234,237,242,245,247,248,251,255,259–261,263–265,270,272,279,281,284,293,294,296,301,307,310,312–315,317,319,323,325,328,333,335,336,339,340,341,346,350–353,357,358,360,361,371–373,375–380] Service users and caregivers may feel that they have lost control[120,138,144,146,148,150–152,165,170,174,177,179,189,195–197,200,202,207,222,233,237,245,247,284,298,301,305,307,309,310,315,323,324,326,334,336,342,345,356,358,361,383]

continued

TABLE 11 Event-State Matrix: service user and caregiver activities and their contexts of action (*continued*)

Contexts of action	EVENT (modifiable components of systemic trajectories)	Lifeworld resources				STATE (modifiable components of relational trajectories)
		Social capital	Personal capacity	Affective contribution	Enabling agency for collaborative work	
Biographical and relational disruption	Service users and caregivers search for effective symptom control and negotiate pathways to care[121,122,125,131,134,136,144,149,151,152,154–156,160,161,167,172,176,178–180,182,190,196,198,199,216,218,227,230,232,233,237,240,247,248,256,258,262–264,312,313,315,329,337,338,344–347,350,352–354,370–374] Service users and caregivers experience felt and enacted stigma[146–153,155,156,164,170,174,176,179,182,186–188,190–192,195,196,198,200,205,206,208,210,213,214,218–220,222,226,230–232,237,245,247,248,259–264,266,272,279,283,285,289,291,292,298,300,303,305,312,325,328,330,331,334,336,337,339,345,347,351,360,371–373,385,386] Caregivers encounter new and unstable workloads[127,133,134,138,140,146,154,170–172,176,207,307,310,319,324,338,344,360,372]	Service users may seek to build relationships with clinicians[121,122,125,131,134,136,144,149,151,152,154–156,160,161,167,172,176,178–180,182,190,196,198,199,216,218,227,230,232,233,237,240,247,248,256,258,262–264,312,313,315,329,337,338,344–347,350,352–354,370–374] Caregivers may seek to maintain and reinforce wider and supportive social networks[121,125,131,133,135,147–149,151,170,176,177,179,186,198,202,203,206,216,233,242,254,257,258,262,297,300,307,310,311,326,336,342,360,372,375]	Service users may lose stable employment, income and housing[122,124,128,130,134,144,149,152,153,172,176,178–180,182,186,187,189,190,196,202,208,209,224,225,233,234,236,242,248,249,256,266–268,274,276,278,281,285,289,291,297,298,303,304,307,308,330,331,337,370,371] Service users may lose personal autonomy, independence of action and freedom of movement[120,122,125,130,131,135,136,140–142,144,147,149,151,160,170,174,176,177,185,190,202,212,233,234,242,245,282,307,310,311,324,325,328,336,339,341,344,350,354,359,376] Service users can become dependent on social security benefits and limited health insurance[122,124,131,137,213,240,256,306,330,331,337,344,370]	Service users seek to integrate illness identity into everyday life[120,123,127,130,134,137–139,141,142,144,148,150,167,171,174,175,177,178,180,185,189,190,195,196,198,199,201,203,206,207,210,212,214,216,223–225,227,229–231,234,236,242,245,249,254,255,257,258,261,265,272,275,279,281,283,284,289,291,294,297,310,312,313,315,318,325,328,330–337,341,345,347,350,351,359,361,375,376,379,382–384] Caregivers seek to sustain family, friendship and wider networks[121,125,131,133,135,147–149,151,170,176,177,179,186,198,202,203,206,216,233,242,254,257,258,262,297,300,307,310,311,326,336,342,360,372,375]	Service users and caregivers seek to manage stigma by controlling disclosure about illness[120,147,151,153,155–157,164,166,170,172,174,176,177,179,182,186,188,189,196,200,202,207,212,214,216,229,231,232,234,259,260,262,266–268,274,284,294,312,336,341,345,352–354,372,377,379,385] Service users and caregivers work to build knowledge about symptoms and disease progression[120–122,139,141,142,144,146–153,155,156,161,166,170–172,174–178,180,192,197,210,216,232,245,248,256,257,275–277,281,285,288,309,317,341,370,372,376] Service users and caregivers manage symptoms, medications, side effects, and contributions to treatment adherence at home[123–125,127,128,130,133–138,140–142,146,150,152–154,160,168,170–172,174–182,185,188–190,195–197,201–203,205–210,213–216,218–226,228,230,232–234,236,237,242,243,245,247,248,254–258,261,262,271,272,275–280,282–285,291–293,296,298,301–303,307–319,322–328,330,331,334–339,341,342,344,345,347,350,352,353,356–359,371,372,374–376,381–384,387] Service users work through, and attempt to resolve, decisional conflict[124,125,127,128,138,140–142,144,151,153,165,170–172,174–177,181,186–188,190,193,195,197,206,208,216,218,222,230,232,233,237,245,251,254,256,262–265,275,307,309,310,312,317,330,331,333,335,336,346,356,361,373,376,381] Caregivers may attempt to navigate professional expectations about caregiving capacity and skill[121,131,133,134,138,140–142,146,148,151,152,154,168,172,233,288,309,310,326,344,354,370,376]	Service users can experience uncertainty, and growing existential threat[121,123,125,128,133,134,136–142,144,146–151,157,163,165,166,170–172,174–177,182,186,188,191,192,195,196,200,202,203,205,207–209,212,221,226,230–234,237,242,245,247,248,251,255,259–261,263–265,270,272,279,281,284,293,294,296,301,307,310,312–315,317,319,323,325,328,333,335,336,339,340,345,346,350–353,357,358,360,361,371–373,375–380] Caregivers may respond to anxiety about disease progression[121,131,133,134,136–138,141,142,144,149–156,160,161,163,165–167,171,174,178,232,236,245,248,257,262,270,271,275,280,284,291,293,307–315,318,326–328,336,337,339,345–347,351,354,358,374,376,384]

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TABLE 11 Event-State Matrix: service user and caregiver activities and their contexts of action (*continued*)

Contexts of action	EVENT (modifiable components of systemic trajectories)	Lifeworld resources				STATE (modifiable components of relational trajectories)
		Social capital	Personal capacity	Affective contribution	Enabling agency for collaborative work	
Biographical and relational erosion	Caregivers seek to negotiate with gatekeepers, to participate in treatment decisions, but may experience exclusion from clinical decisions[124,140,154,170,198,231,232,237,240,263,264,270,279,284,288,296,309,326,329,337,338,344,370,373] Caregivers may experience care that they regard as inadequate[121,124,125,127,133,140–142,148,170,172,175,176,178–180,195,196,198,199,201–203,205–207,214,216,218,220,222,223,228,230,232,237,240,242,248,275,279,283,285,288,307–309,313,314,317,325–327,329,334–337,346,354,376,383] Service users negotiate challenging interactions with health and social care professionals[124,125,127,133,146,148,150–152,165,195–199,201–203,205–208,210,214–216,218,220–226,228,230,232,237,240,242,248,275,279,283,285,288,307–309,313,314,317,325–327,329,334–337,346,354,382,383]	Service users and caregivers can seek to capture relational solidarity and social capital in the face of loss of support from social networks[121,125,128,131,133–135,138–140,146,147,149,155–157,161,162,165,170,179,191,192,196,198,200,203,209,216,245,247,254,257,258,262–265,281,307,310,313,322,333,335,347,356,360,372,373,375,377] Service users may seek to maintain relationships with health and social care professionals[124,137,172,230,310,344]	Service users may lose qualities that define social competence[120,122,125,130,131,135,136,140–142,144,147,149,151,160,170,174,176,177,185,190,202,212,233,234,242,245,282,307,310,311,324,325,328,336,339,341,344,350,354,359,376]	Caregivers may seek to mobilise family contributions to care[124,125,131,133–136,138–140,146–149,151,152,160,162,167,170,176,177,187,190–192,195,198,202,203,206–209,216,222,229,230,232,234,242,248,251,258,263,264,272,276,279,281,282,289,291,300,305,307,309–315,318,322,325,327,328,332,333,335,336,338,342,345,347,350,352,353,356,360,371–374,381,384] Service users seek to sustain intimate relationships[123,125,134,136,139–142,144,146–148,150,151,157,163,165,166,170,172,174–177,182,186,188,191,192,195,196,202,205,207,208,212,221,226,233,242,245,248,251,255,259–261,263–265,270,279,281,294,296,301,307,310,313,317,319,323,328,333,339,340,345,350,352,353,357,358,371–373,375–380]	Caregivers can be expected to accept transfers of responsibility[121,124,125,133–142,146–152,155–157,160–163,165–168,176,180,195,199,202,203,206,208,209,216,218,220,222,224,229,230,248,254,262–264,270,276,277,281,288,305,307,310–312,317,325–328,330–333,336–338,345–347,356,361,372–374,376–378]	Caregivers may experience stress and role strain as they are overwhelmed by burden of managing at home[124,125,131,133–136,138–140,146–149,151,152,160,162,167,170,176,177,187,190–192,195,198,202,203,206–209,216,222,229,230,232,234,242,248,251,258,263,264,272,276,279,281,282,289,291,300,305,307,309–315,318,322,325,327,328,332,333,335,336,338,342,345,347,350,352,353,356,360,371–374,381,384]
Biographical and relational fracture	Caregivers sound the alarm and contact healthcare providers[240,257,264,275,283]		Service users may attempt to gain control over disease progression and relapse[122–124,132,133,135,137–139,145–152,154–156,159,160,162,165,167,169,171,173–175,177,181,185–188,194,195,200–202,204,208,209,214,215,217–220,222–224,227,229,231,233,239,241,253–257,261–263,269,274–276,278,279,281,282,284,290–292,301,306–317,322,324–327,331–336,338,340,341,345,346,349,350,355–357,359,371–374,376–378,381–383]		Caregivers may perform increased workload[121,124,135,136,140,146,147,149,152,372] Service users may attempt to perform coping strategies[124,131,138,154,172,174,180,189,307,309,311,317,338,344,346,356]	Service users may be fearful of the end of active treatment[310,312,314,315,325,335,336,342,344,346,347,351,358–361] Service users may feel that they have no control over disease progression[123–125,133,134,136,138–140,146–153,155–157,160,161,163,166,168,170,172,174–176,178,182,186–189,195,196,201–203,205,209,210,215,216,218–221,223–225,228,230,232,234,240,242,254–258,262–264,270,275–277,279,280,282,283,285,291–293,302,307–318,323,325–328,332–337,339,341,342,346,347,350,351,356–358,360,372–375,377–379,382–384] Service users seek palliation of existential distress[6,8–10,21,24,33,54,58,60,61,92,97–103,138,149,175,191,197,199]

continued

TABLE 11 Event-State Matrix: service user and caregiver activities and their contexts of action (*continued*)

Contexts of action	EVENT (modifiable components of systemic trajectories)	Lifeworld resources				STATE (modifiable components of relational trajectories)
		Social capital	Personal capacity	Affective contribution	Enabling agency for collaborative work	
Biographical and relational repair	Service users and caregivers invest in participation in formal care pathways[136–138,146,153,170–172,174–178,180,182,196,198,201,203,206,207,216,218–220,223,237,254,256,307–312,315,329,337,338,344,345,350,352,353,356–361,370,371]	Service users and caregivers seek to restore informal social networks[120,122,125,130,131,135,136,140–142,144,146–149,155–157,161,162,165,166,372,376,377]	Service users attempt to retain access to work and workplaces[122,124,128,130,134,144,149,152,153,172,176,178–180,182,186,187,189,190,297,370] Caregivers work to solve service users' financial and housing problems[233,234,236,242,248,249,256,266–268,278,281,285,289,291,303,304,307,308,330,331,337,371]		Caregivers work to adopt and sustain supportive roles[123,133,136,146,151,154,174,178,182,185–187,191,192,199,207,307,311,319,327,334,336,337,341,347,358] Service users attempt to build resilience[125,131,133,134,136,147,153,157,161,178,179,182,186,190,192,196,200,201,207,237,247,254,257,296,310,319,322,323,326,330,331,333,334,336,337,339,341,344,347,350,351,358–361,371,381,386]	Service users seek to maintain identity as socially competent actor[120,122,125,130,131,135,136,140–142,144,147,149,151,160,170,174,176,177,185,190,202,212,233,234,242,245,282,307,310,311,324,325,328,336,339,341,344,350,354,359,376]

TABLE 12 Event-State Matrix: proposed supportive interventions

		Lifeworld resources				
Contexts of action	**EVENT (modifiable components of systemic trajectories)**	**Social capital**	**Personal capacity**	**Affective contribution**	**Collaborative work**	**STATE (modifiable components of relational trajectories)**
Candidacy and diagnostic processes	Improved pre-diagnostic support,[83,86] diagnostic pathways and disclosure[77,78,80,83–87,90,97,104]					
Diagnostic shock	Improved understanding of information needs among health professionals[99]		Psychological therapies to support coping with progressive disease[93]	Skills to reduce family distress after diagnosis[82,87,96]	Targeted information delivered at pace to suit both service users and caregiver[75,77,80,82,84,85,90,97,363,366,367,369]	Psychotherapy services that mitigate existential threat[79,80,362,363] Supportive interventions to mitigate distress and loss[77,78,88,104,364,367,369] and anxiety about risk and symptoms[73,75]
Biographical and relational disruption	Improved access to care and specialist referrals,[73,88,98] continuity of care[78] Need for better access to specialist referrals Improved co-ordination of services[84,97] Improved access to respite care	Improved mechanisms for communication between health professionals and families[78,366,367]	Support for access to welfare benefits[365]		Tools for mitigating conflict between service users, caregivers and health professionals[90] Shared decision-making tools to support treatment choices[74,98]	Support for adaptive coping strategies[82,85,86,98,104,108] Improved training for health professionals in emotional support[73] Mitigation of caregiver stress[88]
Biographical and relational erosion	Web-based psychological support for caregivers[79,80] Mitigating service user and caregiver fatigue[77,80] Improving access to respite care[85,88,92]	Support for identification of shared caregiving strategies[86,92,97,106] Social support interventions[80,363]	Intervention to improve personal coping strategies[75] Individualised support for employment[81,96,106,365,369]	Tools for collaborative problem-solving for caregivers[82,85,86] Interventions to preserve or improve family contribution[93,108,113] Support and advice for families around diet and symptom management[72,74]	Reduction of caregiver burden[368,369] Interventions to promote collaboration between caregivers and health professionals[367]	Skill-based training for family members[113] Couples therapy[368] Family therapy[90]

continued

TABLE 12 Event-State Matrix: proposed supportive interventions (*continued*)

Contexts of action	EVENT (modifiable components of systemic trajectories)	Lifeworld resources				STATE (modifiable components of relational trajectories)
		Social capital	Personal capacity	Affective contribution	Collaborative work	
Biographical and relational fracture	Educational interventions for symptom recognition and management[362] Interdisciplinary rehabilitation interventions[362] Improved management of physical symptoms[80,363] Improve symptom management[97] Peer improve management of non-motor symptoms[107,108] Effectively manage disease severity[88,98,104,108,364] Improve self-monitoring[93] Improved interventions for managing fatigue[73,75] Reframing inflammatory bowel disease as chronic not acute[75] Professional support for service users and caregivers[79]			Interventions to promote self-determination, autonomy and independence[78]	Improve self-monitoring[105] Early interventions to relieve symptoms[367] Self-care interventions for inflammatory bowel disease as a chronic disease[72,74]	Develop support groups to maintain autonomy, confidence and independence[99,104,108]
Biographical and relational repair		Community advocacy around building new networks[362] Stigma-reduction interventions[83,85,92,96,106] Enhancing interpersonal resources[90] Support groups to develop practical coping and self-care skills[90,110,365,366,368]	Interventions to support service users to find meaningful occupations[81,96] Individualised support for independence[84]	Interventions to mitigate and overcome stigma[77] Interventions to compensate for loss of autonomy[93,98,107,364]	Interventions to mitigate stigma[110] Strengthen capability for self-care[364]	Promote physical activity[93] Interventions to mitigate stigma[99,104,107]

Diagnosis often seemed to lead to an experience of diagnostic shock. Here, service users and caregivers gained illness identities as they confronted the implications of diagnoses of life-altering and sometimes life-limiting diseases. In response to diagnostic shock, service users – and caregivers – seemed to seek ways to exert control over important aspects of their life. For example, they actively sought information about their condition. In parallel, caregivers often sought to demonstrate readiness to respond to crises. In the face of diagnostic shock, service users and caregivers may undergo profound experiences of loss and distress, and awareness of existential threat.[121,123,125,128,133,134,136–142,144,146–151,157,163,165,166,170–172,174–177,182,186,188,191,192,195,196,200,202,203,205,207–209,212,221,226,230–234,237,242,245,247,248,251,255,259–261,263–265,270,272,279,281,284,293,294,296,301,307,310,312–315,317,319,323,325,328,333,335,336,339,340,345,346,350–353,357,358,360,361,371–373,375–380] Against this background of shocking disclosure of diagnosis – and of its implications – they may feel that they have lost control of the taken-for-granted trajectory of their own lives.

Interventions to support people and families going through diagnostic shock and its consequences reflected concern with the psychological and emotional consequences of unwelcome news and the ways in which this disrupts their taken-for-granted world. Counselling and other psychological interventions (including phone and web-based tools) were called for as ways of ameliorating distress in the face of existential threat to the service user and consequent relational threats to caregivers.[77–80,82,87,88,96,104,362–364,367,369] However, it was also clear that experienced distress was a result of uncertainty and anxiety about symptoms and risks,[73,75] and about the extent to which service users and caregivers believed that they were able to cope with them.[93]

Beyond psychological or counselling interventions, improved information about conditions and services was called for.[77,80,88,363] Condition-specific information and educational interventions needed to be carefully targeted,[90,366,367,369] and related to improving personal adjustment to a new illness trajectory.[75] They also needed to be delivered at the right pace, so that service users and caregivers were not overwhelmed by the scale of the challenge that they faced.[82,84,85,97] Finally, improved understanding of health professionals' information needs was brought into the foreground in a review of qualitative studies in Parkinson's disease.[99] This accorded with our descriptive analysis, which identified information-seeking as a major part of the work of effective participation in care, across all index conditions.

Asserting the self in processes of biographical and relational disruption

Disruption brings with it a multitude of complex and difficult to manage events. Service users and caregivers participate in the search for effective symptom control and negotiate pathways to care. They negotiate challenging interactions with health and social care professionals, and experience felt and enacted stigma. Caregivers may encounter new and unstable workloads, and realise that the burdens of caregiving will grow along with disease progression and changes in symptom severity.

Service users and caregivers may seek to assert themselves and build social capital. First, they may work to develop friendly and supportive relationships with clinicians as these may present opportunities to be better informed and obtain advantages in care. Second, as the effects of felt and enacted stigma begin to bite, service users and caregivers may also seek to maintain and reinforce wider supportive social networks. Caregivers may also seek to sustain family, friendship and wider networks, and thus to build up the potential affective contribution available to them. At the same time, service users' personal capacity to participate in everyday life may be depleted as they lose stable employment opportunities and income, and also face housing problems. Here, service users can become dependent on social security benefits and limited health insurance. As symptoms take hold and grow more severe, service users may also lose personal autonomy, independence of action and freedom of movement, as their illness identity is integrated into everyday life.

In the face of the complex effects of biographical and relational disruption, service users and caregivers consistently demonstrate high levels of collaborative work, as they meet delegated obligations to participate in their care. They manage symptoms, medications, side effects, and contributions to treatment adherence at home;[123–125,127,128,130,133–138,140–142,146,150,152–154,160,168,170–172,174–182,185,188–190,195–197,201–203,205–210,213–216,218–226,228,230,232–234,236,237,242,243,245,247,248,254–258,261,262,271,272,275–280,282–285,291–293,296,298,301–303,307–319,322–328,330,331,334–339,341,342,344,345,347,350,352,353,356–359,371,372,374–376,381–384,387] they work to build knowledge about symptoms and disease progression; and they work through, and attempt to resolve, decisional conflicts about treatment and care choices. Service users and caregivers actively work to manage stigma by controlling disclosure about illness. In parallel, they may have to navigate professionals' expectations about caregiving capacity and skill. Service users and caregivers also experience uncertainty, anxiety and growing existential threat in the face of disease progression.

Illness careers are profoundly disruptive to normal life. They introduce a new set of relationships and dependencies between people who are becoming, and learning to be, service users, their caregivers, and health professionals. Qualitative reviews called for better access to specialist referrals, to ensure rapid assistance for service users and caregivers,[73] for improved training for health professionals in emotional support techniques,[73] for improvements in communications and interaction quality between families and health professionals,[78,366,367] and for greater continuity of care.[78] This accorded with our descriptive analysis of primary studies, which revealed that poor-quality interactions between service users, caregivers and health professionals are reported across all six index conditions. Studies of the lived experience of schizophrenia called for tools to support mitigation of conflict between service users and health professionals.[90] Reviews called for shared decision-making tools for surgery in inflammatory bowel disease,[74] and for treatment choices in Parkinson's disease.[98] Beyond the quality of interactions between service users, caregivers and health professionals, their structural context was also important. Reviews called for improved co-ordination of services,[84,97] access to care,[88,98] access to respite care,[85,92] and support for identifying and receiving welfare benefits.[365] Finally, review papers called for support for coping strategies that would facilitate family adjustment to complex conditions.[82,85,86,98,108]

Holding on in the face of biographical and relational erosion

Over time, service users and caregivers may be exposed to chronic workload as they seek to effectively participate in their care, and as illness trajectories become defined by advancing disease progression and increased severity of symptoms. As some service users become less able, their caregivers may seek to negotiate with gatekeepers, and to participate in treatment decisions, but may experience exclusion from clinical decision-making processes. They may also experience care that they regard as inadequate. As disease progression continues, and chronic workload becomes increasingly evident, service users and caregivers must work to capture relational solidarity and social capital in the face of loss of support from social networks. For the same reason, they may invest effort in continuing to maintain relationships with health and social care professionals involved in their care. While caregivers and service users may be working hard to maintain and grow their social capital, service users themselves may be losing the qualities that define them as competent social actors, even as they seek to sustain intimate relationships with others.

Affective contributions are central to experiences of biographical and relational erosion. These require continuous investments in mobilising and maintaining family contributions to care. Disease progression, increasing symptom severity, and disability mean that many caregivers must accept transfers of responsibility for care and relations with health and social care providers to themselves. These transfers are pivotal, and caregivers may experience significant stress and role strain as they are overwhelmed by burdens of managing care at home. An important feature of primary studies is the shift of responsibility for the conduct of care from service user to caregiver that follows from an increase in symptom severity. These shifts may be quickly completed, as in brain cancer, or they may be episodic, as in inflammatory bowel disease, bipolar disorder and schizophrenia, or they may be gradual and of much longer duration, in both young-onset dementia and Parkinson's disease.

Transfers of responsibility bring with them significantly increased emotional and practical workload, role strain and fatigue. Interventions proposed in review articles included generic social support interventions,[77,80,363] consisting of identification of shared caregiving strategies,[86,92,93,97,106,108,113] tools for collaborative problem-solving and skill-based training for family members.[82,85,86,113] Two reviews called for a general reduction of caregiver burden.[368,369] Others called for general interventions to promote collaboration between caregivers and health professionals,[367] for example, support and advice for families around diet and symptom management in inflammatory bowel disease.[72,74] It was also proposed that people with schizophrenia and their caregivers would benefit from couples therapy,[368] or family therapy.[90] Like people with young-onset dementia,[81] it was proposed that people with schizophrenia could benefit from individualised support for employment.[365,369]

Mitigating biographical and relational fracture

We use the term 'fracture', following Reeve *et al.*,[390] to denote Events and States that form around episodes of severe disruption or transitions to impairment that lead to the collapse of service user participation in their care, and the complete transfer of decision-making capacity to the caregiver. These are especially relevant to understanding illness trajectories in brain cancer, young-onset dementia and Parkinson's disease, where impairments are likely to be irreversible. These also occur in bipolar disorder and schizophrenia, where episodes of illness are not irreversible. No accounts of such transitions were found in included papers on inflammatory bowel disease, although acute disease in that condition may lead to very severe symptoms and in a small proportion of cases, death.

Although service users may continue to seek control over disease progression and relapse, and to mobilise coping strategies, they may also be fearful of the end of active treatment, and they may seek palliation of existential distress. In the same frame, caregivers often experience significantly increased workload, and interactions with health professionals that they find very challenging.

Descriptive analysis of primary studies showed that symptom management, disease progression, and experiences of episodes of exacerbation and processes of deterioration are central to descriptions of the lived experiences of service users and caregivers. Review authors called for educational and supportive interventions for symptom recognition and management,[362] self-care interventions for inflammatory bowel disease as a chronic disease,[72,74] and improved techniques for self-monitoring.[105] Importantly, they also focused directly on proposing interventions that would improve service provision. These included interdisciplinary rehabilitation interventions and improved management of physical symptoms in brain cancers,[80,362,363] improved symptom management in young-onset dementia,[97] the development of self-care interventions and effective methods for managing fatigue for inflammatory bowel disease as a chronic disease,[72,74] development of early interventions for schizophrenia,[367] improved management of non-motor symptoms,[107,108] effective responses to disease severity,[88,98,104,108,364] and improved self-monitoring in Parkinson's disease.[93]

Promoting biographical and relational repair

Throughout illness trajectories, service users and caregivers invest in biographical and relational repair. They invest in participation in formal care pathways and seek to restore informal social networks. They also seek to repair material lifeworld resources, by retaining access to work and workplaces, solving service users' financial and housing problems, and building resilience. An important element of repair work is role-taking: caregivers work to adopt and sustain supportive roles, and service users seek to rebuild and maintain their identities as socially competent participants in their lifeworlds.

Review authors offered partial solutions to two significant sources of biographical and relational fracture, managing illness-related stigma, and working towards social integration. Review authors emphasised the importance of educational interventions to reduce stigma in young-onset dementia,[83,85,92,96,106] bipolar disorder,[77] schizophrenia[110] and Parkinson's disease.[99,104,107] The precise form that these interventions should take remains unclear, however. Similarly, it was proposed to enhance social integration by developing community advocacy around building new informal social networks in brain cancer,[362] enhancing interpersonal resources,[90] and developing interventions to compensate for loss of autonomy in Parkinson's disease.[93,98,107,364] Once again, how these interventions might be accomplished was unclear.

So far, we have described the supportive interventions proposed in included papers, and mapped them onto lived experiences of systemic trajectories (events) and relational trajectories (states), and the lifeworld resources that form a bridge between them. Qualitative studies reviewed in this chapter help us to identify the work that service users and caregivers need to do to demonstrate their engagement with processes of care, and to enact, negotiate and navigate illness trajectories as they are interwoven with care pathways. These trajectories may take the form of status passages,[10] in which service users' and caregivers' personal identities are formed and changed according to the ways in which others relate to the character and effects of their illness, the degree of disruption to relationships that follow from it, and anticipated outcomes of disease progression.[11] Integrating illness identity with control over disclosure of illness; competence in decision-making and resolving decisional conflict; effective help-seeking, symptom recognition, medication management and understanding disease progression; and building relationships with health and social care providers are all centrally important features of the work of service users and caregivers revealed by attribution analysis of papers in this review. They may form a special category of work around trajectory management.

Chapter 6 Discussion

Chapter summary

This evidence synthesis has drawn on qualitative studies of work that service users and caregivers need to do to effectively participate in care. It examines how social inequalities, illness trajectories and treatment burdens interact to shape lived experiences of biographical disruption and its consequences. Key findings of the synthesis show common activities across conditions that are influenced by micro-structural consequences of illness, such as income loss, employment issues and stigma. We have mapped these using sociological theories, identifying critical pressure points where interventions could be most effective. Interventions needed to support people at these pressure points include improved diagnostic and specialist services, psychological therapies, and tools for shared decision-making. Three policy and practice approaches are centrally important.

- Improving personal capacity through psychological, social and economic support.
- Enhancing social capital by improving social networks and relational solidarity.
- Supporting affective contributions through offering respite, adding to emotional resources and improving problem-solving skills.

The chapter offers a conceptual model of lifeworld resources which are essential for enabling agency and collaborative work in care. It proposes that the mobilisation and adaptation of these resources shapes illness trajectories and adds to the effectiveness of care participation, emphasising the need for interventions to support the dynamic interplay of these resources.

Key results of the evidence synthesis

In this evidence synthesis, we have sought to review, compare and synthesise qualitative studies of the lived experience of physical and mental health problems characterised by long-term, relapsing–remitting and rapidly progressing trajectories. As we have done so, we have worked to identify, characterise and explain generalisable mechanisms that motivate and shape lived experiences of interactions between social inequalities, illness trajectories and treatment burdens. We have asked: What do the bodies of literature that we have reviewed tell us about the ways in which service users and caregivers experience interactions between treatment burdens, illness trajectories and social inequalities, and their role in motivating and shaping effective participation in care?

A maximum variation sample of included articles

The EXPERTS II qualitative evidence synthesis has ranged across six index conditions: three illness trajectories; and three kinds of policy and practice problem. Our analysis of the literature – 244 primary studies and 35 reviews were included in this synthesis – has effectively been one of a maximum variation sample of studies. Our analysis was theoretically informed, and our research aim, research questions and research methods have primed this study to focus on the work that service users and caregivers do to participate in their care. We have been interested in what is common across index conditions, trajectories, and policy and practice problems.

Attribution analysis of primary studies revealed a common set of service user and caregiver activities across all six index conditions. Their degree of structural advantage and disadvantage was framed in terms of micro-structural consequences of illness rather than societal-level social determinants. These included loss of income, employment and housing, and by the presence of stigma, rather than by intersectional position and socioeconomic status. We mapped the work of participating in care using biographical disruption theory, identifying stages in illness trajectories as pressure points at which interventions could be delivered. We have shown that service user and caregiver activities around participation in care can be placed in a conceptual framework that defines a set of contexts of action (biographical and relational candidacy, shock, disruption, erosion, fracture and repair), and systemic and relational trajectories that define modifiable features of health and social care services at work and modifiable features of service user and caregiver responses to illness, respectively. We have identified six domains of service user and caregiver work that are shaped by illness trajectories and the micro-consequences of social inequalities. These are areas that both merit further research and additional intervention development.

- *Candidacy and help-seeking*: In all index conditions, service users and caregivers pointed to the limitations of diagnostic services and difficulties for professionals, service users and caregivers in interpreting symptoms that were often diffuse and vague at the beginning of illness trajectories.
- *Diagnostic shock*: All conditions were described as leading to activities that responded to perceived or actual threat from their illness. The most common of these was seeking information and extending understanding. Some conditions led to perceived existential threat and fear of the future, activities responding to this were much less well characterised.
- *Biographical and relational disruption*: This is best characterised as departure from perceived normal health and called for service users and caregivers to develop symptom recognition and medication management skills. The mobilisation of caregiver contributions was central to this, and they were implicated in struggles over care and access to services; dealing with difficult interactions with health professionals and services; and supporting service users through difficult decisions and decisional conflicts.
- *Biographical and relational erosion*: Throughout illness trajectories, service users and caregivers experienced cumulative effects of stigma, role strain, and restrictions on mobility, employment and income. These led to the diminution of social networks and other relations over time. As symptom severity and disability increased, it also led to transfers of responsibilities to caregivers, and complex negotiations about the distribution of supportive work within families.
- *Biographical and relational fracture*: Increasing disease severity and deterioration called for greater investment in managing symptoms and mitigating social dislocation, but this work broke down in the terminal phases of brain cancers, dementia and Parkinson's disease, and in very acute episodes of inflammatory bowel disease, bipolar disorder and schizophrenia.
- *Biographical and relational repair*: Throughout illness trajectories, service users and caregivers performed activities that were outward-facing. They sought to acquire skills in self-management, and attempted to build productive relations with health professionals who were sometimes described as hostile or indifferent to them. Importantly, they sought to enhance their social capital, seeking to rebuild social networks, and to manage stigma and protect their identities as competent social actors through controlled disclosure of information about their condition.

Event-State Analysis of primary studies revealed the parallel structures of service users' and caregivers' systemic trajectories. Here, service users' and caregivers' lived experiences of illness trajectories were shaped by mechanisms of enabling agency which form a bridge between them: personal capacity, social capital and affective contributions of others. We used the following constructs to map supportive interventions proposed by review authors. These set out a range of supportive interventions that are needed by caregiver and service users as they pass through illness trajectories. Once again, these describe domains of service user and caregiver experience that merit both further research and the development of policy and practice interventions.

- *Systemic trajectories*: These consist of modifiable aspects of their experiences of health professionals and services. Policy and practice interventions are needed to improve access to diagnostic and specialist services, improve the quality of interactions with clinicians and supportive gatekeepers, and to better understand and target information needs of service users and caregivers.
- *Personal capacity*: Service users and caregivers possess varying degrees of personal psychological, social and economic resources. Policy and practice interventions are needed to reinforce their capacity to assert control over illness identities and trajectories. Access to psychological therapies would improve coping strategies. Interventions that improve access to continued employment and financial resources will reduce dependence and reinforce self-efficacy and self-esteem.
- *Social capital*: Service users and caregivers may be members of networks of social relations through which informational, material and symbolic resources flow. Policy and practice interventions that reinforce and restore social networks and improve mechanisms for communications add to relational solidarity between service users, caregivers and health professionals. Social networks can foster shared caregiving strategies through which caregivers can find respite support.

- *Affective contributions*: Service users' and caregivers' social relations with others are characterised by varying bonds of affection and moral obligation. Policy and practice interventions are needed to build practical skills to improve collaborative problem-solving, and build and reinforce emotional resources. Interventions that support family and other informal networks increase their potential for sustaining wider practical and emotional support. Exhaustion and devitalisation of service users and caregivers is common, and access to respite care uncommon, and this is an important area where support is needed.
- *Relational trajectories*: These consist of modifiable aspects of their subjective experiences of illness and care. Psychological interventions that support service users and caregivers in coping and adapting to loss, distress and existential threat are vital. Policy and practice interventions that mitigate decisional conflict about treatment pathways, and mitigate loss of control in the face of disease progression, loss of treatment effectiveness, and symptom exacerbation.

To make sense of the factors that motivate and shape service user and caregiver participation in care, we have proposed a robust conceptual model of the ways in which mobilising lifeworld resources makes possible enabling agency. Service users and caregivers bring this to bear on the collaborative work of participation in care. We develop this model in the next section.

A conceptual model of lifeworld resources

Having presented an empirical account of data from primary and secondary qualitative analyses – drawing together analyses of service user and caregiver activities relational and systemic trajectories, and lifeworld resources – our next task is to develop a robust theoretical model of illness careers as they are shaped by social inequalities and patterns of patient and caregiver workload. This takes the form of the scaffolding for a substantive theoretical model[410] of the structure of lifeworld resources and their mobilisation and adaptation across the illness trajectories. The aim of this model-building component of our work is to better understand how illness trajectories are shaped by different configurations of lifeworld resources (personal capacity, social capital, and affective contribution, as well as collaborative work), which are mobilised as service users and their caregivers experience and respond to the disruptive effects of illness and treatment. The relationships between constructs of the theoretical model are developed through propositions, since we are concerned with the ways in which lifeworld resources are played out in ways that appear to operate at micro-level activities of individual service users and caregivers, but which in practice seem to represent generalisable social processes.

Across the literature examined in this qualitative synthesis, the time before the transition to an illness identity was clearly demarcated. Because the papers we reviewed focused on investigating people who already had established diagnoses, it was these lived experiences that framed the data that were collected and the analysis that was offered. We must therefore make inferences about the life before diagnosis and the adoption of illness identity, based on often very brief and fragmentary descriptions of what has been lost. These key features form the focus of our starting assumption. This is that people may possess varying degrees of lifeworld resources (personal capacity, social capital and affective contribution). These interact with each other in dynamic ways that are generative of co-operative and collaborative action that is central to the experience of both service users and caregivers. Throughout the description of their activities in studies that have contributed to this evidence synthesis, we have seen the primacy of attempts to build co-operative and collaborative work around the events and states of illness careers. Service users and caregivers attempt to engage with others, and to build and reinforce social relations through which social capital and affective contributions will flow. These attempts have varying degrees of success, but they are nonetheless evidence of the social life of illness and its consequences. This leads to our first proposition:

1. People may possess varying degrees of lifeworld resources (personal capacity for action, social capital and affective contributions). These cohere with each other in complex and dynamic ways and are generative of applied agency that enables collaborative work.

How are lifeworld resources arranged before the onset of illness? They are unevenly distributed among individuals, family groups, and more complex social networks. As people respond, emotionally and practically, to diagnostic shock and biographical and relational disruption, their lifeworld resources may undergo a rapid and traumatic structural failure. This depends on the severity, density and proximity of disruptive events and processes. As these events proceed, lifeworld resources may begin to fail. In brain cancer,[362] this is a process in which symptom severity impacts on personal capacity (the service user quickly begins to lose potential agency), and social capital (they begin to lose contact with – and are sometimes excluded from – their wider social networks). This process, which appears to be common across all six index conditions, is mobilised around transitions to illness identities[75,79,96,242,330] that transform them into service users. As the disruption and potential failure of their lifeworld resources continues, others may seek, or be expected, to compensate for their depletion, by realising bonds of affection and norms of moral obligation. As they do so, they are transformed into caregivers. This process is profound and is evident not just in brain cancer but also in young-onset dementia[92] and Parkinson's disease.[98]

It is equally evident, but also complicated by the dynamics of family relationships, in bipolar disorder[216] and schizophrenia.[105] In those index conditions, collaboration took on different meanings when the experiences of service users and caregivers were framed by contested perspectives and interpersonal conflict. The extent to which service users and caregivers can repair or rebuild lifeworld resources after their structural failure depends on the extent to which they are able to call upon, co-ordinate and mobilise the collaborative work of others. Our second proposition is derived from this.

2. Events or processes that disrupt, interrupt or terminate the equilibrium of lifeworld resources (e.g. onset of illness or disability, existential threat, anticipated bereavement, loss of employment and income, and stigmatisation) may lead to the structural failure of lifeworld resources. This may reduce the possibility for collaborative work around the service user.

Service user experiences of relational trajectories are about managing the interruption or depletion of lifeworld resources as symptoms become more serious and disease progression continues. Service users attempt to sustain lifeworld resources but must increasingly rely on the mobilisation of caregiver contributions. As we have seen, those contributions may be shaped not just by increasing workload but may also be shaped by poor-quality interactions with health professionals and transferred burdens of work from health services.

The extent to which caregivers have to work on the processes through which lifeworld resources are shaped is important. They need to work in ways that compensate for the service user's loss of social capital and personal capacity – connecting the service user with both clinicians and with other members of their informal networks. They also have to demonstrate commitment to both delegated and assumed obligations, expressing those commitments through performing participation in care, and also maintaining that participation as their responsibilities become more onerous.

The lived experience of illness trajectories, for both service users and caregivers, is marked by complex processes of biographical and relational shock, disruption, erosion, fracture and repair. As we have shown, these lead to the breakdown and sometime structural failure of their entanglements of available lifeworld resources. This leads to our third proposition.

3. The disruption of lifeworld resources, and the depletion of collaborative work, call for repair, adaptation and re-combination of lifeworld resources. This enables either (a) the recombination of lifeworld resources in the face of continuously disruptive processes (where the effects of disruption are irreversible), or (b) the recovery of lifeworld resources that existed before disruption (where the effects of disruption are reversible).

In this context, service users may be involved in a set of relations with caregivers and characterised by differences in the strength of social ties, by varying bonds of affective and moral obligation, and by unequal normative expectations of socially supportive action and allocation of resources. The extent of these available affective contributions determines the degree to which caregivers are able – or willing – to perform compensating activities. Illness identities are also an important currency for service users, and are formed against the background of external attributions of social identity and role, legitimacy of condition, of culpability or susceptibility to disruption, and successful mobilisation of collaborative work. In the index conditions included in this evidence synthesis, illness identity was also profoundly associated with existential threat and distress, successful symptom management, and interactions with healthcare providers and health professionals.

A key resource, here, is the value of illness identities as diagnostic capital, a symbolic resource that service users and caregivers can deploy to give currency to their interactions with health professionals, caregivers, other family members and members of wider social networks. For service users, adaptive capacity is centrally important because it denotes the extent to which they can respond to experiences of disruption, erosion and fracture, of their psychological, social and economic resources. They must invest in repair, and individually or collaboratively make adaptive investments in redirecting existing lifeworld resources or capturing new ones. Thus, the life trajectories of service users and caregivers after disruption are determined by the extent to which they are able to repair and recombine their lifeworld resources and translate these into renewed collaborative work.

Future research

Interactions between personal capacity (including self-efficacy), social capital and affective contributions are under-explored in investigations of lived experiences of service users and caregivers and their engagement with care and self-care. This is fertile ground for intervention development. Comparative research across a range of conditions will open up the way to more economical, generic approaches to supportive interventions and care. These can be pursued through these 10 potential research questions.

1. Do individuals with higher levels of personal capacity (including psychological, social and economic resources) prior to experiencing serious illness demonstrate greater adaptive capacity in response to disruptions in lifeworld resources caused by their illness? Research that looks at experiences of minoritised and marginalised people is an important component of this.
2. Is there a relationship between the extent of disruptions in lifeworld resources and reported levels of distress and quality of life among individuals facing serious illness?
3. To what extent is the disruption of lifeworld resources associated with the initiation of collaborative work by service users and caregivers aimed at repairing and adapting these resources?
4. Can supportive interventions aimed at enhancing personal capacity (e.g. coping strategies, financial resources) lead to improved overall well-being and increased satisfaction with care for service users and caregivers?
5. How does the presence of stigma as a disruption in lifeworld resources relate to the levels of social capital and affective contributions within the social networks of service users and caregivers?
6. Does collaborative work initiated by service users and caregivers moderate the relationship between disruptions in lifeworld resources and their overall quality of life?
7. Can supportive interventions that focus on enhancing social capital (e.g. improved communication with healthcare professionals, building caregiving networks) lead to improved psychological well-being and reduced caregiver burden?
8. To what extent does the ability of service users and caregivers to repair and adapt lifeworld resources vary depending on the nature and severity of the illness, especially in cases where disruptions are irreversible?
9. Is there a positive association between collaborative work initiated by caregivers to support service users and the service users' overall quality of life and their ability to effectively manage their illness.
10. Do service users and caregivers who successfully repair and recombine lifeworld resources report a heightened sense of control over their illness trajectories and a more positive perception of their illness identity?

Strengths and limitations of the evidence synthesis

Search strategies

Our search strategies deliberately prioritised variation over specificity. Indeed, the final selection of papers included in the synthesis could be characterised as a qualitative maximum variation sample of studies that presented information about lived experiences of inequalities, burdens and trajectories. This meant that we drew on a wide variety of studies of lived experiences of index conditions. We acknowledge that our approach to searches was pragmatic and thus had limitations which increased the risk of missing relevant studies. A search with a greater emphasis on sensitivity would not take the same approaches as were used in this strategy. As in our earlier work,[28,29] our search strategies found a selection of – but by no means all – relevant studies. Even so, this approach meant that no papers with an explicit social care focus were discovered for brain cancer, bipolar disorder and inflammatory bowel disease. They were more than sufficient for identifying key features of the six index conditions and thus for building theory. An important problem that resulted from this was the sheer number of primary studies for inclusion (*n* = 244).

Methodological quality and value of included papers

We observed earlier that 241/244 primary studies included in this synthesis presented their results in the form of themes. Qualitative analyses were often descriptive, and themes appeared to be presented as proxies for interpretation. Discussion sections in such papers often simply re-described the thematic results of the work. This is evidence of thematic reductionism, in which themes were presented as facts, rather than as the product of subjective and reflexive interpretation of textual accounts. Similarly, the included literature often included examples of philosophical overclaiming. Here, there was often little difference in the analytic products of studies whether they claimed epistemological antecedence in phenomenological–hermeneutic perspectives,[411,412] grounded theory,[71,413] reflexive thematic analysis[414] or interpretive phenomenological analysis.[415] Papers included in this synthesis tended to be descriptive and thematic. Explanatory studies were rare.

An important deficiency of many papers was under-description of both the composition of samples of service users and caregivers, and of the actual process of analysis, thus erasing or mystifying rather than foregrounding connections between the contexts of care, and subjective identity and experiences of participants. Variations in disease severity, medication management work and medication side effects were often poorly described. The role of primary care was rarely discussed, even in health systems where there was a strong primary care component. Innovations in care such as social prescribing were absent from the literature.

The literature included focuses on white populations in high-income countries

White women and men were well-represented in included studies. One study reported a single non-binary participant,[345] and minority and vulnerable populations experience the heaviest disease and treatment burdens. Only 66/244 primary studies presented data on race and ethnicity of participants. Studies based in the USA (*n* = 27), the UK (*n* = 17) and Canada (*n* = 4) were most likely to report data on minority, with other countries only sporadically identifying demographic diversity. A small number of papers focused on specific non-white populations. These included Chinese people in the People's Republic of China or Taiwan;[161,223,229,293] Latinx people in the USA[168,298] and Mexico;[291] African Americans in the USA;[258,296] Baloch and Sistani ethnic groups in Islamic Republic of Iran;[242] Xhosa-speaking people in South Africa[280] and people with mental health problems in Ethiopia.[202,233,300,303]

Delay between last searches and completion of the study

The last search of bibliographic databases took place in March 2022. The first draft of the final report was completed and submitted in October 2023, and reviewers' comments were received for action in April 2024.

Equality, diversity and inclusion

The EXPERTS II study was a qualitative evidence synthesis and therefore did not seek to recruit research participants from the general population. PPI participants were White British *n* = 5, South Asians *n* = 6 and Afro-Caribbean *n* = 1; male *n* = 7, female *n* = 5. Social care practitioners 'on the ground' (*n* = 7) were all female (White British *n* = 5, South Asian *n* = 2). The research team were White British (*n* = 9), female (*n* = 7) and male (*n* = 2).

Summary of patient and public involvement

Section and topic	Item	Where reported
1: Aim	Report the aim of PPI in the study	*Chapter 6*, *Strengths and limitations of the evidence synthesis* and *Equality, diversity and inclusion*: The aim of PPI in EXPERTS II was to support the design and development of the study, and interpretation of data.
2: Methods	Provide a clear description of the methods used for PPI in the study	PPI representatives were recruited formally to the study oversight committee. In addition, during the SARS-COVID-19 pandemic some PPI advisors were recruited through informal social networks.
3: Study results	Outcomes – Report the results of PPI in the study, including both positive and negative outcomes	PPI advisors positively informed the interpretation of results, but some questioned the idea that service users and caregivers were involved in *work*. Others pointed to the disadvantage stemming from fragmented services and to sometimes racist assumptions made by NHS staff about service users and caregivers. Social care practitioners on the ground described complex problems of access and service quality in their interactions with health and social care services.
4: Discussion and conclusions	Outcomes – Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Developing strong PPI in this qualitative evidence synthesis was complicated by the social effects of SARS-COVID-19 pandemic.
5: Reflections/ critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this experience	Some PPI advisors were seriously ill, and one died during the course of the study. Not all PPI advisors were comfortable with videoconferencing.

Additional information

CRediT contribution statement

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Patient data statement

No patient data were collected in this study.

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

This study was a qualitative evidence synthesis that did not involve research on human subjects, human tissue or animal models. No research ethics committee approval was required.

Information governance statement

The first author is a member of staff at the London School of Hygiene and Tropical Medicine (LSHTM). LSHTM is Data Controller and Data Processor as defined in the General Data Protection Regulation (GDPR). LSHTM has an information security policy which is compliant with ISO/IEC 27001. This is updated from time to time as needed to keep up with legal, procedural and technological developments. All data are held securely by LSHTM and are treated confidentially, stored on secured servers, with access restricted to authorised personnel only, and in accordance with UK Data Protection Law and GDPR. The Data Protection Officer at the LSHTM can be contacted via e-mail at dpo@lshtm.ac.uk or by phone at + 44 (0)20 7958 8396. However, as the EXPERTS II study is a qualitative evidence synthesis, no personal data were collected, stored, retained or distributed.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/HGTQ8159.

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Katja C Gravenhorst declares no conflicts of interest related to this study.

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Publications, conference papers and seminars

May C. *The Patient as Worker: Relational Inequalities and Social Capital in Complex Long-Term Conditions.* Departmental Seminar, School of Psychology, King's College London, UK. March 2022.

May C, Gravenhorst, K. *Practising Translational Social Science Through Qualitative Research: What Do Studies of the Lived Experience of Patients, Caregivers, and Practitioners Really Tell Us*? Seminar, Faculty of Medicine and Life Sciences, University of Nottingham, UK. March 2022.

May C. *We Need Darwinian Simplicity: Is It Possible to Create Care That Fits People, Rather Than People Who Fit Care.* Mayo Clinic Symposium on 'Care that Fits', Mayo Clinic, April 2022, Rochester, MN, USA.

May C, for the EXPERTS II Investigators. *How Are Service-User and Caregiver Participation in Health and Social Care Shaped by Experienced Burden of Treatment and Social Inequalities*? Monash University, Melbourne, May 2024.

May CR, Hillis A, Bradley CD, Geng E, Gallacher KI, Chew-Graham CA, *et al. Complex Interventions and Service Innovations: Development and Application of the COMPLETE Framework for Patient-Centered and Justice-Oriented Design*. Research Square (Preprint Server) 2023. https://doi.org/10.21203/rs.3.rs-3059427/v1

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Appendix 1 Search strategies

Source: Ovid MEDLINE(R) ALL

Interface/ URL: OvidSP

Database coverage dates: 1946 to 29 March 2021, Search date: 30 March 2021

Retrieved records: 5056

Search strategy:

1. Parkinson Disease/ (69,010)
2. Parkinsonian Disorders/ (8215)
3. parkinson$. ti,ab,kf. (124,476)
4. paralysis agitan$. ti,ab,kf. (1176)
5. (hemiparkinson$ or antiparkinson$). ti,ab,kf. (4029)
6. (shaking palsy or shaking palsies). ti,ab,kf. (80)
7. or/1-6 (133,694)
8. exp Schizophrenia/ (106,532)
9. "Schizophrenia spectrum and other psychotic disorders"/ (0)
10. Schizotypal Personality Disorder/ (2752)
11. (schizophren$ or schizoaffect$ or schizotyp$ or schizoid$). ti,ab,kf. (133,699)
12. (schizo-phren$ or schizo-affect$ or schizo-typ$). ti,ab,kf. (378)
13. (dementia praecox or dementia precox). ti,ab,kf. (553)
14. (hebephren$ or oligophren$). ti,ab,kf. (1414)
15. or/8-14 (154,992)
16. Colitis, Ulcerative/ (35,373)
17. (ulcer$ adj3 colitis). ti,ab,kf. (43,253)
18. (ulcer$ adj3 (colorectitis or proctocolitis or procto-colitis or colon$)). ti,ab,kf. (2319)
19. (colitis gravis or idiopathic proctocolitis or idiopathic procto-colitis or mucosal colitis). ti,ab,kf. (49)
20. or/16-19 (52,495)
21. "Bipolar and Related Disorders"/ (15)
22. Bipolar Disorder/ (41,258)
23. bipolar. ti,ab,kf. (65,758)
24. (manic adj (depress$ or disorder$ or state or states)). ti,ab,kf. (4759)
25. (mania or manias or maniodepress$). ti,ab,kf. (10,999)
26. (cyclothym$ or cyclophren$). ti,ab,kf. (1001)
27. rapid cycling mood. ti,ab,kf. (12)
28. or/21-27 (85,236)
29. Brain Neoplasms/ (113,984)
30. ((brain or brains) adj6 (adenocarcin$ or cancer$ or carcin$ or malignan$ or metasta$ or neoplas$ or oncol$ or tumor$ or tumour$)). ti,ab,kf. (81,577)
31. ((cerebral or cerebri or cerebrum or intracerebral or intra-cerebral or intracranial or intra- cranial or midline or mid-line or subtentorial or sub-tentorial or supratentorial or supra-tentorial) adj6 (adenocarcin$ or cancer$ or carcin$ or malignan$ or metasta$ or neoplas$ or oncol$ or tumor$ or tumour$)).ti,ab,kf. (27,673)
32. (cerebroma$ or encephalophyma$). ti,ab,kf. (56)
33. Glioma/ or exp Astrocytoma/ (74,192)
34. Gliosarcoma/ (685)
35. astrocytoma$. ti,ab,kf. (16,623)
36. (astroglioma$ or oligoastrocytoma$ or xanthoastrocytoma$). ti,ab,kf. (1695)

37. glioblastoma$. ti,ab,kf. (40,523)
38. (glyoblastoma$ or glioma$). ti,ab,kf. (60,932)
39. spongioblastom$. ti,ab,kf. (160)
40. (gliosarcom$ or glyosarcom$). ti,ab,kf. (1172)
41. or/29-40 (204,159)
42. Dementia/ (53,101)
43. dementia$.ti,ab,kf. (118,939)
44. (predementia$ or pseudodementia$ or demention or amentia$).ti,ab,kf. (717)
45. Alzheimer Disease/ (97,770)
46. (alzheimer$ or alzeimer$).ti,ab,kf. (157,288)
47. ((senile adj3 (confusion or psychos$)) or senilit$).ti,ab,kf. (1518)
48. (cortical adj3 scleros$).ti,ab,kf. (337)
49. or/42-48 (250,383)
50. 7 or 15 or 20 or 28 or 41 or 49 (825,967)
51. exp qualitative research/ (61,319)
52. qualitativ$.ti,ab,kf,jw. (299,942)
53. interviews as topic/ (64,669)
54. Interview/ (29,609)
55. interview$.ti,ab,kf. (378,226)
56. focus groups/ (31,570)
57. focus group$1.ti,ab,kf. (50,494)
58. grounded theory/ (1905)
59. (grounded theor$ or grounded study or grounded studies or grounded research or grounded analys$).ti,ab,kf. (12,566)
60. phenomenol$. ti,ab,kf. (28,194)
61. (ethnograph$ or ethnonurs$ or ethno-graph$ or ethno-nurs$).ti,ab,kf. (11,752)
62. ((story or stories or storytelling or narrative$1 or narration$1) and (analys$ or approach$)).ti,ab,kf. (30,139)
63. (open-ended or open question$).ti,ab,kf. (25,939)
64. (text$ adj6 analys$).ti,ab,kf. (12,278)
65. Narration/ or exp personal narrative/ or personal narratives as topic/ (18,281)
66. (discourse$ analys$ or discurs$ analys$).ti,ab,kf. (2140)
67. content$ analys$.ti,ab,kf. (32,785)
68. ethnological.ti,ab,kf. (229)
69. purposive sampl$. ti,ab,kf. (8656)
70. (constant comparative or constant comparison$1).ti,ab,kf. (5039)
71. theoretical sampl$.ti,ab,kf. (742)
72. (theme$ or thematic$).ti,ab,kf. (125,782)
73. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).ti,ab,kf. (18,223)
74. data saturat$.ti,ab,kf. (1120)
75. (participant observ$ or nonparticipant observ$).ti,ab,kf. (4944)
76. (observation study or observation studies).ti,ab,kf. (1604)
77. experiential$.ti,ab,kf. (9850)
78. Postmodernism/ (375)
79. (social construct$ or postmodern$ or post-modern$ or poststructural$ or post-structural$ or feminis$ or constructivis$).ti,ab,kf. (10,184)
80. (action research or cooperative inquir$ or co-operative inquir$).ti,ab,kf. (4585)
81. human science.ti,ab,kf. (257)
82. biographical method$.ti,ab,kf. (27)
83. theoretical saturation.ti,ab,kf. (228)
84. group discussion$1.ti,ab,kf. (15,994)
85. direct observation$.ti,ab,kf. (12,737)
86. mixed method$.ti,ab,kf. (25,916)
87. (observational method$ or observational approach$).ti,ab,kf. (1071)

88. key informant$1.ti,ab,kf. (8279)
89. (field study or field studies or field research$ or field work$ or fieldwork$).ti,ab,kf. (23,992)
90. "face-to-face".ti,ab,kf. (30,666)
91. ((guide or structured) adj5 (discussion$1 or questionnaire$1)).ti,ab,kf. (26,607)
92. (heidegger$ or colaizzi$ or speigelberg$ or van manen$ or van kaam$ or merleau ponty$ or husserl$ or giorgi$ or foucault$ or corbin$ or glaser$).ti,ab,kf. (5386)
93. (audio record$ or audiorecord$).ti,ab,kf. (7719)
94. or/51-93 (872,581)
95. Consumer Behavior/ (22,188)
96. attitude/ or exp attitude to health/ or Attitude to Death/ (491,746)
97. "Activities of Daily Living"/ (66,187)
98. personal satisfaction/ (19,879)
99. exp Emotions/ (255,540)
100. Stress, psychological/ (124,317)
101. Adaptation, Psychological/ (96,716)
102. exp Patients/px (17,769)
103. Caregivers/px (23,846)
104. professional-patient relations/ or nurse-patient relations/ or physician-patient relations/ or Hospital-Patient Relations/ (136,865)
105. professional-family relations/ (15,091)
106. Empathy/ (19,756)
107. Feedback/ (30,250)
108. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) and (experienc$ or perspective$1 or perception$1 or perceiv$ or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1 or satisf$ or unsatisf$ or dissatisf$ or disatisf$ or belief$1 or believ$)).ti. (147,872) ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver $1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) adj3 (experienc$ or perspective$1 or perception$1 or perceiv$ or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1 or satisf$ or unsatisf$ or dissatisf$ or disatisf$ or belief$1 or believ$)).ab,kf. (406,493)
109. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) and (emotion$ or feeling$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet$ or anxious$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat$ or stress$ or distress$ or embarrass$ or empath$ or accept$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother$ or unbother$ or pleased or displeased$ or concern$ or burden$ or hassl$ or convenien$ or inconvenien$ or confus$ or hope or hopeless or hopeful or trust or trusts or mistrust$ or distrust$ or entrust$ or trusting or trusted or confiden$ or unconfiden$)).ti. (92,554)
110. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) adj3 (emotion$ or feeling$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet$ or anxious$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat$ or stress$ or distress$ or embarrass$ or empath$ or accept$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother$ or unbother$ or pleased or displeased$ or concern$ or burden$ or hassl$ or convenien$ or inconvenien$ or confus$ or hope or hopeless or hopeful or trust or trusts or mistrust$ or distrust$ or entrust$ or trusting or trusted or confiden$ or unconfiden$)).ab,kf. (247,406)
111. (actual experience$1 or real experience$1).ti,ab,kf. (896)
112. or/95-112 (1,635,215)
113. 50 and 94 and 113 (12,214)
114. health status disparities/ (16,973)
115. Health Services Accessibility/ (77,923)
116. Health Equity/ (1693)
117. Social determinants of Health/ (3992)

118. Psychosocial Deprivation/ (2026)
119. Sociological Factors/ (640)
120. Working Poor/ (16)
121. Hierarchy, Social/ (2242)
122. disparit$.mp. (95,058)
123. inequalit$.mp. (38,113)
124. inequit$.mp. (12,019)
125. equity.mp. (19,004)
126. deprivation.mp. (89,631)
127. gini.mp. (1471)
128. concentration index.mp. (1605)
129. Socioeconomic Factors/ (161,663)
130. Social Welfare/ (9376)
131. exp Social Class/ (42,216)
132. exp Poverty/ (45,076)
133. Income/ (30,359)
134. social class$.mp. (47,513)
135. social determinants.mp. (11,300)
136. social status.mp. (6196)
137. social position.mp. (1064)
138. social background.mp. (1193)
139. social circumstance$.mp. (1266)
140. socio-economic.mp. (33,312)
141. socioeconomic.mp. (228,161)
142. sociodemographic.mp. (5,1821)
143. socio-demographic.mp. (26,307)
144. SES.mp. (22,030)
145. disadvantaged.mp. (14,218)
146. impoverished.mp. (3693)
147. poverty.mp. (62,647)
148. economic level.mp. (1112)
149. assets index.mp. (24)
150. income$.mp. (153,608)
151. medically underserved.mp. (8152)
152. or/115-152 (731,171)
153. Cultural Deprivation/ (1166)
154. Acculturation/ (6526)
155. Culture/ (33,442)
156. Cross-Cultural Comparison/ (26,085)
157. Cultural Characteristics/ (16,604)
158. Cultural Diversity/ (11,826)
159. Language/ (42,460)
160. “Transients and Migrants”/ or Human Migration/ (13,414)
161. exp “Emigrants and Immigrants”/ or “Emigration and Immigration”/ (37,597)
162. Minority groups/ (14,586)
163. Minority health/ (813)
164. Prejudice/ (24,909)
165. Racism/ (3208)
166. Xenophobia/ (72)
167. Social Discrimination/ (1355)
168. exp Race Relations/ (5619)
169. exp Ethnic Groups/ (158,541)
170. exp Continental Population Groups/ (226,980)

171. Refugees/ (10,813)
172. minorit$.mp. (83,555)
173. (migrat$ or immigrat$ or emigrat$).mp. (379,242)
174. (migrant$ or immigrant$ or emigrant$).mp. (52,937)
175. (refugee$ or asylum seeker$ or displaced person$ or displaced people$).mp. (15,798)
176. racial.mp. (44,862)
177. racism.mp. (6589)
178. ethnology.mp. (168,469)
179. race.mp. (115,882)
180. ethnic$.mp. (188,710)
181. (non-English or nonEnglish).mp. (3124)
182. language other than.mp. (460)
183. latino$.mp. (13,866)
184. latina$.mp. (4551)
185. hispanic$.mp. (62,868)
186. whites.mp. (27,676)
187. caucasian$.mp. (64,055)
188. (non-white$ or nonwhite$).mp. (7996)
189. Torres Strait Islander$.mp. (1797)
190. aboriginal$.mp. (9331)
191. native american$.mp. (5416)
192. inuit$.mp. (4713)
193. eskimo$.mp. (1558)
194. first nation$.mp. (4999)
195. indigenous.mp. (36,351)
196. english as a second language.mp. (443)
197. foreign language.mp. (1101)
198. or/154-198 (1,157,264)
199. exp Gender Identity/ (20,293)
200. Women's Health/ (28,071)
201. gender differences.mp. (28,924)
202. sex difference?.mp. (38,022)
203. gender identity.mp. (20,966)
204. sex role.mp. (1662)
205. wom#n$ role?.mp. (632)
206. m#n$ role?.mp. (10,607)
207. gender$ role?.mp. (3300)
208. servicewomen.mp. (106)
209. Sex factors/ (270,048)
210. or/200-210 (368,242)
211. Age Factors/ (460,087)
212. (ageism or agism or ageist or agist).ti,ab,kf. (1362)
213. disadvantag$.ti,ab,kf. (80,636)
214. discriminat$.ti,ab,kf. (248,627)
215. or/212-215 (782,640)
216. 153 or 199 or 211 or 216 (2,581,069)
217. 114 and 217 (2576)
218. Patient Participation/ (26,843)
219. Social Participation/ (2688)
220. Sick Role/ (11,324)
221. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) adj6 interact$).ti,ab,kf. (60,882)

222. (experienc$ adj6 interact$).ti,ab,kf. (5728)
223. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) adj3 (access$ or coordinat$ or co-ordinat$ or engag$ or involv$ or navigat$ or negotiat$ or participat$)).ti,ab,kf. (234,865)
224. (experienc$ adj6 (access$ or coordinat$ or co-ordinat$ or engag$ or involv$ or navigat$ or negotiat$ or participat$)).ti,ab,kf. (25,731)
225. "Cost of Illness"/ or Caregiver Burden/ (28,517)
226. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) adj3 burden$).ti,ab,kf. (23,477)
227. (experienc$ adj6 burden$).ti,ab,kf. (4094)
228. (burden$ adj6 (care or healthcare or treatment$ or therap$ or medicine$ or medication$ or medicament$ or illness$ or condition$ or disease$ or disorder$)).ti,ab,kf. (77,774)
229. (unmet need or unmet needs).ti,ab,kf. (15,264)
230. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) adj3 needs).ti,ab,kf. (52,090)
231. ((experienc$ or perspective$1 or perception$1 or perceiv$ or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1) and "living with").ti,ab,kf. (17,902)
232. or/219-232 (521,756)
233. 114 and 233 (4228)
234. 218 or 234 (5896)
235. 50 and lived experience$.ti,ab,kf. (373)
236. 50 and (lifeworld$ or life-world$).ti,ab,kf. (63)
237. 50 and 94 and (experienc$ and lived). ti,ab,kf. (388)
238. 50 and 94 and (experienc$ adj3 living).ti,ab,kf. (185)
239. 50 and 94 and (experienc$ adj3 (life or lives)).ti,ab,kf. (242)
240. 50 and 94 and ((every day or every-day or normal) adj (life or lives or living)).ti,ab,kf. (293)
241. 50 and 94 and ((everyday or every-day or normal) adj experience$).ti,ab,kf. (28)
242. 50 and 94 and ((barrier$ or facilitat$) adj6 (interact$ or access$ or coordinat$ or co- ordinat$ or engag$ or involv$ or navigat$ or negotiat$ or participat$)).ti,ab,kf. (393)
243. or/236-243 (1492)
244. (parkinson$ or paralysis agitan$ or hemiparkinson$ or antiparkinson$ or shaking palsy or shaking palsies or schizophren$ or schizoaffect$ or schizotyp$ or schizoid$ or schizo- phren$ or schizo-affect$ or schizo-typ$ or dementia praecox or dementia precox or hebephren$ or oligophren$ or (ulcer$ adj3 colitis) or (ulcer$ adj3 (colorectitis or proctocolitis or procto-colitis or colon$)) or colitis gravis or idiopathic proctocolitis or idiopathic procto-colitis or mucosal colitis or bipolar or (manic adj (depress$ or disorder$ or state or states)) or mania or manias or maniodepress$ or cyclothym$ or cyclophren$ or rapid cycling mood or ((brain or brains) adj6 (adenocarcin$ or cancer$ or carcin$ or malignan$ or metasta$ or neoplas$ or oncol$ or tumor$ or tumour$)) or ((cerebral or cerebri or cerebrum or intracerebral or intra- cerebral or intracranial or intra-cranial or midline or mid-line or subtentorial or sub-tentorial or supratentorial or supra-tentorial) adj6 (adenocarcin$ or cancer$ or carcin$ or malignan$ or metasta$ or neoplas$ or oncol$ or tumor$ or tumour$)) or cerebroma$ or encephalophyma$ or astrocytoma$ or astroglioma$ or oligoastrocytoma$ or xanthoastrocytoma$ or glioblastoma$ or glyoblastoma$ or glioma$ or spongioblastom$ or gliosarcom$ or glyosarcom$ or dementia$ or predementia$ or pseudodementia$ or demention or amentia$ or alzheimer$ or alzeimer$ or (senile adj3 (confusion or psychos$)) or senilit$ or (cortical adj3 scleros$)).ti. (421,997)
245. qualitativ$.ti,kf,jw. or qualitative research/ (104,442)
246. 245 and 246 and 113 (1597)
247. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) and experiences).ti. (18,264)
248. 245 and 248 (610)

249. ((patient$1 or client$1 or user$1 or consumer$1 or personal or people$1 or person or persons or carer$1 or caregiver$1 or care-giver$1 or family$1 or families or adult$ or women$ or men or mens) and (experienc$ or perspective$)).ti. and 94 (25,110)
250. 245 and 250 (1022)
251. 246 and (*Parkinson Disease/ or *Parkinsonian Disorders/ or exp *Schizophrenia/ or
252. *"schizophrenia spectrum and other psychotic disorders"/ or *Schizotypal Personality Disorder/ or *Colitis, Ulcerative/ or *"Bipolar and Related Disorders"/ or *Bipolar Disorder/ or
253. *Brain Neoplasms/ or *Glioma/ or exp *Astrocytoma/ or *Gliosarcoma/ or *Dementia/ or
254. *Alzheimer Disease/) and 113 (1527)
255. 246 and (Parkinson Disease/px or Parkinsonian Disorders/px or exp Schizophrenia/px or "schizophrenia spectrum and other psychotic disorders"/px or Schizotypal Personality Disorder/px or Colitis, Ulcerative/px or "Bipolar and Related Disorders"/px or Bipolar Disorder/px or Brain Neoplasms/px or Glioma/px or exp Astrocytoma/px or Gliosarcoma/px or Dementia/px or Alzheimer Disease/px) (934)
256. 50 and (meta-synthes$ or metasynthes$ or meta-ethnograph$ or metaethnograph$).ti,ab,kf. (103)
257. 235 or 244 or 247 or 249 or 251 or 252 or 253 or 254 (7907)
258. exp animals/ not humans/ (4,805,701)
259. (news or comment or editorial or letter or case reports or randomized controlled trial).pt. (4,599,124)
260. case report.ti. (253,813)
261. 255 not (256 or 257 or 258) (7452)
262. limit 259 to (english language and yr="2010-Current") (5056)

Appendix 2 Taxonomies of service user and caregiver activities

Relational activities

Caregiver seeks to sustain friendship networks.
Caregiver seeks to capture relational solidarity.
Caregiver seeks to capture social capital.
Caregiver mobilises family contribution to affective or relational resources.
Caregiver encounters indifferent or hostile health professionals.
Caregiver experiences loss of support from social networks.
Caregiver manages social relationships.
Caregiver manages symptoms at home.
Caregiver shows readiness to respond to crises.
Caregiver seeks to restore informal social networks.
Caregiver attempts to solve service users' financial problems.
Caregiver attempts to solve service users' housing problems.
Caregiver navigates complex relationships.
Service user performs confidence-building practices.
Service user performs controls on disclosure.
Service user experiences enacted stigma.
Service user performs faith-based activities.
Service user integrates illness identity into family life.
Service user works through decisional conflict.
Service user seeks to sustain friendship networks.
Service user seeks to sustain intimate relationships.
Service user works to manage symptoms at home.
Service user seeks information about condition.
Service user seeks to demonstrate social integration.
Service user attempts to retain access to work and workplaces.

Social roles

Service user experiences loss of status as a socially competent adult.
Caregiver performs episodic transfers of responsibility.
Caregiver experiences exclusion from clinical interactions.
Caregiver performs increased workload.
Caregiver experiences increased responsibility over time.
Caregiver works to manage symptoms at home.
Caregiver seeks to participate in treatment decisions.
Caregiver experiences stress and role strain.
Caregiver works through sustained transfer of responsibility.
Caregiver understands, recognises and monitors symptoms.
Caregiver experiences unstable workload.
Caregiver works to adopt and sustain supportive roles.

Service utilisation

Caregiver contacts healthcare providers.
Caregiver attempts to reconcile different understandings of disease.
Caregiver engages in interactions with health and social care professionals.

Caregiver manages medications.
Caregiver navigates professional expectations about caregiving capacity and skill.
Caregiver experiences negative relations with health professionals.
Caregiver negotiates the legitimacy of their involvement with professional gatekeepers.
Caregiver negotiates health providers' policy on disclosure and confidentiality.
Caregiver negotiates inadequate information.
Caregiver organises and delivers care.
Caregiver is overwhelmed by burden of managing at home.
Caregiver experiences inadequate care in community.
Caregiver experiences hostile responses from health professionals.
Caregiver transfers the service user to residential care.
Service user seeks access to services.
Service user seeks access to well-co-ordinated specialist care.
Service user seeks access to co-ordinated care.
Service user seeks specialist clinical investigations.
Service user builds relationships with clinicians.
Service user experiences health professionals contesting their view.
Service user experiences diagnostic process.
Service user fears the end of active treatment.
Service user works to establish eligibility for care.
Service user participates in formal relapse prevention plans.
Service user negotiates with unsupportive health professionals over mental health symptom exacerbation.
Service user negotiates health professionals' assumptions about culpability.
Service user builds knowledge about symptoms and disease processes.
Service user maintains relationships with health and social care professionals.
Service user performs management of medication side effects.
Service user performs management of medications.
Service user negotiates informational inadequacy.
Service user negotiates obstacles to effective intervention.
Service user seeks palliation of existential distress.
Service user searches for symptom control.
Service user experiences indifference or hostility from health professionals.
Service user searches for symptom relief.
Service user performs treatment adherence.
Service user experiences treatment workload.

Social inequalities

Service user loses stable employment.
Service user loses employment income.
Service user is dependent on social security benefits.
Service user is dependent on health insurance.
Service user negotiates payment for pharmacological treatment.
Service user experiences restrictions on employment.
Service user experiences restrictions on freedom of movement.

States

Caregiver experiences feelings of loss.
Service user seeks to find meaning in everyday activities.
Service user is aware of an existential threat.
Service user lives through biographical disruption.
Service user lives through biographical erosion.

Service user attempts to build resilience.
Service user seeks to maintain control over important aspects of their life.
Service user performs coping strategies.
Service user experiences decisional regret.
Service user experiences evident distress.
Service user lives with an existential threat.
Service user experiences pathophysiological deterioration.
Service user focuses on structured activities.
Service user gains illness identity.
Service user loses personal autonomy.
Service user has no control over disease progression.
Service user experiences loss of control over the self.
Service user experiences loss of social competence.
Service user attempts to maintain autonomy and control.
Service user seeks to maintain identity as socially competent actor.
Service user works to achieve biographical repair.
Service user has personal meanings of symptoms.
Service user performs self-medication with drugs and alcohol.
Service user experiences threats to social competence.

Trajectory

Caregiver navigates care pathways.
Caregiver negotiates with gatekeepers.
Caregiver responds to anxiety about disease progression.
Caregiver sounds the alarm.
Caregiver seeks to understand disease progression.
Service user attempts to gain control over disease progression and relapse.
Service user seeks biographical stabilisation.
Service user experiences candidacy and performs help-seeking.
Service user experiences trajectory, uncertainty and existential threat.
Service user lives with fear for the future.
Service user experiences fragmentation of care.
Service user experiences waiting times.
Service user help-seeking.
Service user illness journey.
Service user implications of diagnosis.
Service user manages experienced disease progression.
Service user negotiates access to care.
Service user lives with pathophysiological deterioration.
Service user lives through patterns of disease progression and status passage.
Service user perceives abandonment by specialists at the end of effective treatment.
Service user is concerned by pre-diagnostic symptoms.
Service user experiences symptoms that become more visible.
Service user experiences symptoms that grow worse over time.
Service user experiences treatment that ceases to be effective.
Service user experiences treatment degradation over time.
Service user must work through formal care pathways.

EME
HSDR
HTA
PGfAR
PHR

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