Health and Social Care Delivery Research

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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Scientific summary

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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

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