

Treatment burden and capacity in older people with chronic kidney disease: a qualitative study

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Background

Older individuals (aged 60+) with chronic kidney disease (CKD) frequently have multiple comorbidities that together represent 'disease burden'. Demands on patients arise not only from symptoms, but from the workload incurred in managing these conditions (including arranging and attending appointments, having tests, taking medications) and their impact. These have been described as the 'treatment burden' and are often driven by individual disease guidelines/pathways. An individual's ability to manage them has been described as 'capacity'. While early CKD may not entail much treatment burden, progression to stage G3b-G5 may lead to new disease management requirements, including lifestyle change, greater clinician involvement and more frequent monitoring. The nature and extent of treatment burden and factors that support capacity for older individuals with CKD are not well understood.

Methods

Semi-structured interviews were conducted with 29 individuals aged over 60 with varying degrees of CKD severity (stage 3b-5, not requiring renal replacement therapy) to explore treatment burden and capacity in the context of CKD stage and comorbid conditions. One primary care and one secondary care focus group with multiprofessional healthcare teams working with CKD patients were conducted to explore their perceptions of patients' treatment burden and capacity. Interviews and focus group discussions were recorded and transcribed verbatim. Inductive thematic analysis was used to analyse the data.

Results

Eighteen participants were recruited in secondary care and 11 in primary care. Mean age of participants with CKD was 75 years. Sixteen participants were male and 13 female. Eleven, 12 and 6 were CKD stage 3a/3b, 4 and 5, respectively. Treatment burden was categorised into 4 themes: (a) understanding CKD, its treatment and consequences, (b) adhering to treatments and management (such as lifestyle changes), (c) interacting with others including health professionals and family in the management of their CKD and (d) monitoring treatments and their effects. Experienced burden and capacity were compounded by care deficiencies, existing co-morbidities and other life responsibilities such as caring for relatives. Capacity was categorised into 5 themes: (a) personal attributes (such as optimism, pragmatism), (b) social network (including family, friends, carers, service providers), (c) financial resources, (d) life responsibilities, and (e) environment (geographical distance to unit, adaptations to home).

The secondary care group included consultant nephrologists, nephrology specialist nurses, research nurse, renal dieticians, renal pharmacist, and the multidisciplinary team (MDT) coordinator (n=10). The primary care focus group consisted of general practitioners from a single practice. Health professionals noted patient characteristics (anxiety, sociodemographic factors), appointment attendance (travel, parking, waiting time), multiple medication, and system factors (poor communication with patients, fragmented care, multiple care providers) contributed to treatment burden. Continuity of care (nephrology) and taking ownership of a treatment plan were considered to enhance capacity.

Conclusion

Patients with CKD experience considerable treatment burden, which is influenced by individual-level and system-level factors. Better infrastructure (for example more effective transport services), more holistic

care, and provision of medication aids may help reduce patient workload and enhance patient capacity which in turn will improve patient experience, adherence and health-related outcomes.