

## POSTER ABSTRACT

### **Systemic work of carers of community dwelling older people with complex care needs: A qualitative study of carers' experiences**

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**Introduction:** Informal carers provide the majority of care to Australians living in their own homes and are essential in assisting older people with complex care needs. This means carers are navigating and co-ordinating complex service systems in the wake of widespread reforms to manage a growing burden of disease. The aim of this study was to explore carer experiences about the nature of this systemic work.

**Theory/methods:** Drawing on Burden of Treatment theory, this study used a descriptive phenomenology approach and semi-structured interview methods. Participants included 16 carers of older community-dwelling adults with complex care needs. An inductive thematic analysis was used to derive the themes.

**Results:** Two themes were identified. First, 'Taking on the caring work', explores the notion of burden for carers taking on the work, by way of a sense of obligation and duty and how they perceive the challenge of this work. Participants described piecing together disjointed pathways in systems that were driven for, and by, organisations and their procedural needs rather than for the client and their carer. In the second theme, 'Mastering the caring system' participants described the challenge of systemic work which included managing multiple and complex organisational and administrative processes across different systems while locating, accessing and co-ordinating services for the older person. Participants also described the work involved in ensuring the systems were responsive to their needs to secure successful outcomes for both themselves and the older person. Varied skills were required to master the systems including organisational, administrative, communication, advocacy, problem-solving and negotiation abilities.

**Discussion:** Informal carers are taking on more responsibility for managing the complex support needs of older people. The findings of this study suggest that the systemic work is arduous and places significant demands on carers who have varying capabilities to negotiate multiple systems to access needed supports. Without appropriate and targeted investment to integrate systems, the risk is widening disparities and potentially poor outcomes for both the older person and carer.

**Conclusion:** Carers of older people need specific skills and knowledge to navigate increasingly complex and multiple systems of care. Integrated systems of care which support better exchange of information and more efficient assessment, administrative and access processes will aid and equip carers for this systemic work.

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**Lessons Learned:** Although useful, system navigation skills do not solve the problem of fragmented health and aged care systems. Models of integrated care could bring together systems for the provision of quality care that support the carer and keep the older person living at home.

**Limitations:** Study participants were those from a regional centre and were those that had had recent contact with health professionals, however carers who were potentially more vulnerable, either isolated geographically or those navigating the system without health professional contact may have been under-represented.

**Suggestions for future research:**

- Models of integrated care that include carers in their design, to better align health care and aged care systems.
- Longitudinal research to examine if carers develop their own capabilities to master the specific work required.