

Caring for those with Parkinson's Disease: The Effect of Social Networks on the Family Carer's Role

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Background

An increasing ageing population in the UK means that demand for informal care is growing. Family carers are therefore providing greater amounts of care against a backdrop of social change with smaller, more diverse family structures and diminishing public sector resources.

Aims of the study

This study explored the social networks of informal carers for those with Parkinson's Disease and how these impacted on their caring role.

Methods

A case study design was used with 20 carers recruited through Parkinson's UK. Social network data, carer diaries and interviews acted as complementary data collection methods. The diary-interview method with visualisation of the network sociograms at interview offered a valuable means of developing and exploring the data with the carer.

Data Analysis

Case analyses were undertaken using the Framework Method. An in-depth view of the carers' networks was possible, that uncovered the structural features and the detailed and intricate practices and interactions that occurred in relation to the caring role.



Findings

Network approaches and a Bourdieusian lens, found that the carers were uniquely positioned in relation to their Personal Community (the informal sector), the state and the market as the providers of formal health and social care. Third Sector Organisations were a 'Lifeline', with the support offered by these groups acting synergistically with the formal care sector. Over time, carers increasingly acted as network bridges, brokers, and coordinators through navigation and negotiation across the networks of care.

Conclusion

New insights into the networks of those caring for a family member with Parkinson's Disease have been uncovered. Carers engaged in a complex series of transactional processes to access assistance and support through bonding, bridging, and linking social capital whilst also drawing on other personal resources of economic and cultural health capital. Their role in co-ordinating these networks is complex and forms part of the 'work' of care.

Relevance in practice

The findings can inform the practice of health and social care professionals to aid carer recognition, assessment, and partnership working.

References

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