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'Self' and 'Dyadic' Managing in the Last Year of Life

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Background and aim: People in the last year of life receive support to live with their illness from a range of health and care professionals. Research has highlighted the role that professionals undertake with these populations and the challenges of collaborative working between the various professionals, but less is known about the patient and carer experience. The broad aim of this study was to explore the lived experience of patients and their carers who receive care from a range of organisations. In this paper, we report on one key finding from the larger dataset in relation to how patients and carers undertake self and dyadic (both the patient and carer) managing of their situation.

Design and methods: An interpretive phenomenological methodology was used. People with a diagnosis of advanced disease and an anticipated prognosis of less than twelve months (N=12), and their spousal carers (N=8) were included. Patients and carers participated in research interviews in their own homes. Data were analysed using phenomenological methods, supported by Template Analysis to facilitate transparency in the analytic process.

Findings and interpretation: Patient and carer experiences are interconnected as they attempt to manage their lives to achieve a sense of balance between a continually changing embodied experience and the desire to maintain normality. Previous roles and relationships are negotiated in light of the multi-faceted losses that characterise advanced disease. Health and care professionals are involved in varying degrees with supporting people to maintain this balance. Patients and carers utilise a variety of strategies that help them to manage their contacts with these professionals. They make choices about when, how and who to utilise for their self-assessed needs. Where self/dyadic managing fails and the sense of balance is not achieved, there can be a breakdown in people's sense of safety and confidence living in the home environment.