DOES RESPITE CARE ADDRESS THE NEEDS OF PALLIATIVE CARE SERVICE USERS AND CARERS?
AN EXPLORATION OF THEIR PERSPECTIVES AND EXPERIENCE OF RESPITE CARE
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10.1136/bmjspcare-2011-000105.34

Introduction There are clear indications that over the coming years, an increasing amount of support for carers of patients with palliative care needs will be required. In recent UK policy and guidance respite care is frequently mentioned as a key factor in supporting carers. However, little is known about respite care services for people with palliative care needs and their carers and services appear to have developed on the assumption that they are a “good thing”. This study addresses this gap in knowledge. It is located in a professional doctorate study where parallel application in practice is encouraged.

Aims To explore the perspectives and experience of palliative care service users and carers of respite care.

Method The participants were hospice service users and carers who had experienced respite care in that hospice and other settings. The approach was qualitative and data collection was carried out by unstructured informal interview and analysed in accordance with Grounded Theory strategies.

Results Analysis of the data showed that there is nothing straightforward about respite care and the concepts of need and acceptance, vulnerability and resilience, risk and enablement, loss and gain all emerged.

Discussion This study confirmed that respite care suffers from a problem with definition and is often talked about in a trite way which doesn’t reflect the complexity of the caring relationship it is supposed to be sustaining.

Conclusion Respite care is valued by palliative care service users and carers. The articulation of respite care needs and the insights gained in this study have the potential to influence practice and provide a platform for service development and improvement.