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SUPPORTING PEOPLE WITH LEARNING DISABILITIES WHO ARE AFFECTED BY A RELATIVE OR FRIEND WITH CANCER

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10.1136/bmjspcare-2011-000105.123

Introduction Around 2.5% of the population have LD. 55% of people with LD live with parents; significant numbers have become carers of elderly parents. Around 15% of people with LD live in residential care homes, often with an ageing population of peers. Most people with LD will therefore be affected by cancer of family or friends at some point in their lives. Their support needs are insufficiently understood.

Aims

- ▶ To explore the experiences and support needs of adults with LD who have a relative or friend with cancer
- ▶ To make recommendations for practice.

Methods

22 people with LD took part in focus groups and face-to-face interviews. All participants had experience of having a close relative/friend with cancer. The groups were co-facilitated by two co-researchers with LD; each group met four times, using a range of methodologies (including story-telling, role play and Nominal Group Technique) to extract participants' experiences and views. Data were analysed using content analysis.

Results

- ▶ Being protected from information (as many participants were) negatively affected their coping.
- ▶ Participants worried about their relative/friend's illness and the impact on both the patient and on themselves; but had not shared their worries or questions with others.
- ▶ The greatest need was for "someone to talk to"; this need was not met by either families or professionals.
- ▶ There was a lack of understanding about cancer itself, and a lack of access to cancer information; participants wanted such information.

Discussion The needs of people with LD who are a relative/friend of someone with cancer are often overlooked. This group does not ask for support, and therefore pro-active support is needed from cancer- and palliative care professionals as well as from LD professionals. This includes emotional support and the provision of accessible information about cancer.