European Journal of Oncology Nursing 16 (2012) 512–519

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

People with intellectual disabilities who are affected by a relative or friend with cancer: A qualitative study exploring experiences and support needs

Irene Tuffrey-Wijne*, Nikoletta Giatras, Gary Butler, Amanda Cresswell

St George's University of London, Division of Population Health Sciences and Education, Cranmer Terrace, London SW17 0RE, UK

Keywords:
Intellectual disabilities/learning disabilities
Cancer
Death and dying
Bereavement
Care givers
Health information
Focus groups
Qualitative research
Nursing

ABSTRACT

Purpose: To explore the experiences of people with intellectual disabilities (ID) who have a relative or friend with cancer, and to identify their support needs.
Methods and sample: Participants were 21 adults with ID who had a relative/friend with cancer, now or in the past. Data were collected using focus groups and face-to-face interviews. Focus groups met four times, using a range of data collection techniques. Sessions were audio recorded and transcribed verbatim. Data were analysed using thematic content analysis. Data were collected between March 2010 and March 2011.
Results: Four themes emerged: (1) Protection and inclusion: participants who had not been told about their loved one's illness felt excluded; (2) Coping with cancer: participants had vivid memories of events and feelings. They worried about their families. Many had become carers themselves; (3) Understanding cancer: participants lacked knowledge about cancer and wanted to know more. (4) Someone to talk to: participants would have liked to share their feelings and questions with family, friends or professionals, but had not voiced their questions or concerns. 'Someone to talk to about my feelings and worries' and 'Someone to support the rest of my family' were voted the most helpful support strategies.
Conclusions: Cancer nurses should ensure that people with ID in their patients' social circle are included in the family unit and receive adequate emotional support. They should be proactive in giving them information that is easy to understand. Using fictional stories can be particularly helpful in eliciting questions and concerns.

Introduction

Good communication and support for carers and families during patients' illness and after death are important aspects of high quality care, recognized in UK cancer and palliative care strategies (Department of Health, 2008, 2011). The impact of cancer on life, including the impact on family and others, was identified as a top research priority by cancer patients themselves (Corner et al., 2007). In response to this, Macmillan Cancer Relief (a UK charity for improving the lives of people affected by cancer) instigated a programme of user-led research around the impact of cancer. The study reported in this paper was set up as part of this programme, focussing on the impact of cancer on carers, relatives and friends who have intellectual disabilities (ID).

Background

People with ID make up 1–3% of the world population (Mash and Wolfe, 2004). The definition of ID (or 'learning disability' as it is known in the UK) includes significant limitations in intellectual functioning (intelligence quotient [IQ] below 70), together with significant limitations in adaptive behaviour as expressed in conceptual, social and practical skills, which originates before the age of 18 (Schalock et al., 2010). In the UK, most people with ID (55%) live with parents, and a further 12% with other relatives. Significant numbers have themselves become carers of elderly parents. Around 15% of people with ID live in residential care homes, often with an ageing population of peers. It is estimated that the number of people with ID in England within the 50+ age range will increase by 53% between 2001 and 2021 (Emerson and Hatton, 2008).

Around one in four people in the general population die of cancer (Office for National Statistics, 2010). Cancer incidence is lower among people with ID, but rising, particularly in the older ID population (Hogg and Tuffrey-Wijne, 2008). It is likely that most

---

* Corresponding author. Tel.: +44 (0)20 87255497; fax: +44 (0)20 87253538.
E-mail addresses: ituffrey@sgul.ac.uk (I. Tuffrey-Wijne), ngiatras@sgul.ac.uk (N. Giatras), gbutler@sgul.ac.uk (G. Butler).

1462-3889/$ – see front matter © 2012 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejon.2012.01.002

people with ID will be affected by cancer of family or close friends at some point in their lives.

There has been no published research to date where the central focus was on the experiences and support needs of people with ID who have a relative or friend with cancer. A few studies have explored the experiences of people with ID themselves around cancer, death and dying. The limited available evidence suggests that people with ID are often excluded from knowledge about cancer by both families and professionals, and that this lack of involvement and information can cause distress (Tuffrey-Wijne et al., 2006; Tuffrey-Wijne, 2010; Forbat and McCann 2010). The death of a parent can therefore come as a surprise, when other relatives without ID may well have been able to anticipate it (McCann and Forbat, 2007; Todd, 2005). Bad news of cancer is often not given to people with ID, or is given in a confusing way (McEnhill, 2008; Tuffrey-Wijne et al., 2010). The need for more accessible cancer information materials is increasingly recognized (O'Regan and Drummond, 2008; Gilbert et al., 2008).

A study of the challenges faced by palliative care staff who support patients with ID showed that these challenges include the support of relatives who have ID (Tuffrey-Wijne et al., 2008a).

Significant ethical and methodological challenges may have prohibited meaningful involvement of this vulnerable group in research around sensitive issues (Tuffrey-Wijne et al., 2008b). However, there is evidence to suggest that people with ID can and want to be involved in such research (Tuffrey-Wijne et al., 2007). The study reported in this paper used inclusive research methods. Best practice in research concerning people with ID in the UK requires their participation (Department of Health, 2001). It is crucial for the development of future resources and best practice recommendations that consumers' own views and experiences are taken into account.

Aims

The aims of the study were to explore the experiences of people with ID who have a relative or friend with cancer, and to identify their support needs.

Methods

Study design

Focus groups were used to explore participants' experiences and ideas (Kitzinger, 1995). Focus groups involving people with ID have been successfully used in research (Abbott and McConkey, 2006; Brown and Gill, 2009; Llewellyn, 2009; McConkey et al., 2004). They can help people with ID gain confidence in a group environment, and encourage contributions by providing opportunities for peer support and validation of common experiences (Cambridge and McCarthy, 2001).

Focus groups met four times for an hour at intervals between a week and a month, depending on group logistics and preferences. The meetings were conducted in a large room at day- and community centres. They were co-facilitated by the principal researcher (IT) and two researchers with ID (GB and AC), with a fourth researcher (NG) taking notes. Between one and five support staff who knew the participants were also present at the meetings. A range of data collection methods was used (Table 1).

Single semi-structured face-to-face interviews were conducted with participants who were unable to take part in the focus groups for practical reasons but were keen to contribute to the study (Table 1).

Each meeting was audio recorded, transcribed verbatim and verified by the researchers. Notes and reflections of the researchers formed part of the data set. Data collection took place between March 2010 and March 2011.

Participants

Inclusion criteria were: adults (aged 18 or over) with ID who had some verbal communication skills (able to understand and speak in short sentences); who had lived with, or been close to, someone with cancer in the past ten years and during their adult life; and who were able to give informed consent. Those with a recent bereavement (six months ago or less) of a close relative or friend were excluded. For people with ID, time needs to be

Table 1
Schedules for focus group meetings and interviews.

Focus groups

Meeting 1: Introduction to the study and explanation of what will happen in the different meetings. Watching the DVD again that explained the study. Participants had the opportunity to explain why they joined the group and who it was they knew that had cancer. Participants began to talk about their experiences.

Meeting 2: A short slide show with drawings of a fictional story of 'Jim'. Jim's father is taken ill and goes into hospital. His mother is crying because she is told that the father has cancer. Jim looks sad and worried. The group is asked 'What is Jim worried about?' and 'What would help Jim?' (Pictures taken from (Hollins and Sireling, 1994)

Meeting 3: Flexible, as each group had different needs and wishes. One group wanted the researchers to explain facts about cancer, which was given with the aid of a specially prepared slide show. One group wanted to look at more pictures and stories to discuss. One group wanted more time to talk about their experiences. Some role-play was included, where participants had an opportunity to act as 'Jim' and ask the 'doctor' (acted by a co-researcher with ID) questions.

Meeting 4: Based on earlier meetings, nine cards with pictures were prepared, representing the various strategies that participants had said would help them (pictures taken from Books Beyond Words Series). Each participant was asked to rank the five "top ideas" in order of preference, using adapted Nominal Group Technique (Tuffrey-Wijne et al., 2007). Celebratory refreshments served as a way of closing the group.

Face-to-face interviews

Tell me about the person who had cancer

The interviewee is invited to share their experiences, including:

- What was wrong with him/her?
- How did you find out?
- What happened (eg experiences of hospitalisation, symptoms, death of the person)?

How did you feel?
- What was it like for you when X had cancer?
- What was difficult?
- Was there anything good about it?
- How did it make you feel?
- How do you feel about it now?

What helped?
- What helped you to cope?
- What did (or didn't) other people do to help you?
- What advice can you give to doctors, nurses and carers, about how to support someone with ID whose family/friend has cancer?

OPTIONAL: If the person has difficulty answering the above questions:

The researcher will bring pictures, as in Meeting 2 of the focus groups.