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Contents lists available at SciVerse ScienceDirect

## European Journal of Oncology Nursing

journal homepage: [www.elsevier.com/locate/ejon](http://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

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## A B S T R A C T

**Keywords:**

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

**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.

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### 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

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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.

**Table 1**

Schedules for focus group meetings and interviews.

Focus groups
<p><b>Meeting 1:</b> 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.</p> <p><b>Meeting 2:</b> 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))</p> <p><b>Meeting 3:</b> 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.</p> <p><b>Meeting 4:</b> Based on earlier meetings, nine cards with pictures were prepared, representing the various strategies that participants had said would help them (pictures taken from <i>Books Beyond Words</i> 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.</p>
Face-to-face interviews
<p>Tell me about the person who had cancer</p> <p>The interviewee is invited to share their experiences, including:</p> <ul style="list-style-type: none"> <li>• What was wrong with him/her?</li> <li>• How did you find out?</li> <li>• What happened (eg experiences of hospitalisation, symptoms, death of the person)?</li> </ul> <p>How did you feel? • What was it like for you when X had cancer?</p> <ul style="list-style-type: none"> <li>• What was difficult?</li> <li>• Was there anything good about it?</li> <li>• How did it make you feel?</li> <li>• How do you feel about it now?</li> </ul> <p>What helped? • What helped you to cope?</p> <ul style="list-style-type: none"> <li>• What did (or didn't) other people do to help you?</li> <li>• What advice can you give to doctors, nurses and carers, about how to support someone with ID whose family/friend has cancer?</li> </ul> <p>OPTIONAL: If the person has difficulty answering the above questions: The researcher will bring pictures, as in Meeting 2 of the focus groups.</p>

## 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

considered flexibly; a bereavement that has happened years earlier may be experienced as recent (Blackman, 2003). The provision that the cancer experience should be within the last ten years proved to be somewhat haphazard. This criterion was added following funding reviewers' concerns about retrospective bias and memory distortion. However, several participants did have such experience in the past decade, but had also lost a parent to cancer much earlier; these early experiences were very much 'alive' for them and are included in the data. Exact details of length of time since the cancer experience were not available, as support staff did not always know this and many participants were unable to give precise information.

Participants were recruited through approaching the managers of day centres, self-advocacy groups and community ID professionals. They were asked to distribute study information materials written in easy-read and pictorial format and invite those interested to attend an information meeting. At this meeting, two researchers (including one researcher with ID) showed a DVD in which the four research team members explained the study, using the explicit words 'cancer' and 'die'.

Three groups were convened as follows. A day centre manager selected six clients because she knew they fitted the inclusion criteria. A team of community ID nurses put forward nine of their clients who had been bereaved through cancer. An advocacy group leader invited 20 clients to the information session and was surprised to find that more than half of the group volunteered enthusiastically ('I really want to be in that cancer study'); five were purposively selected.

Participants were encouraged to take the information sheet home and discuss it with partners, friends, families and/or support staff. Three people decided not to participate after attending the information session, despite initial interest; they indicated that the topic would be too upsetting for them after all. Those agreeing to participate signed informed consent. Ongoing consent was ensured by emphasising after each session that participants could withdraw; none did so, although some participants missed some of the sessions for other reasons. Participants received financial remuneration for taking part.

Setting up the focus groups was more difficult than anticipated. At several potential advocacy/day centre groups, the staff member who would be responsible for passing on information about the study did not know who of their clients had been affected by cancer and were reluctant to ask, or felt that the issue might be too difficult for their clients. This corresponds with previous studies around ID and cancer, where researchers found that gate-keepers often blocked participation, making it difficult to find a large enough sample from which to select participants purposively (Forbat and McCann, 2010; Tuffrey-Wijne et al., 2006).

#### *Data analysis*

Data were analysed using thematic content analysis. Throughout the study, the research team held discussions about emerging themes. The data were initially analysed by two researchers (IT and NG) who developed a coding framework. After data collection ended, the full research team (including the two researchers with ID) looked at data extracts and held repeated discussions about coding, labelling and interpretation of the data. Qualitative data analysis involving researchers with ID has been successfully done before (Department of Health, 2006; Tuffrey-Wijne and Butler, 2010). Initial findings were presented to the Research Advisory Group, which consisted of people with ID, family carers, cancer/palliative care/ID professionals and academics, who provided feedback. Data management was supported by Nvivo 8 for qualitative analysis (Bazeley, 2007).

#### *Validity and reliability*

Many people with ID have receptive and expressive language difficulties, and this remains the most prohibitive aspect of their participation in research, particularly research that involves answering questions. There are obvious challenges if participants have difficulties in understanding or correctly interpreting the questions and coping with the research requirements. Threats to the reliability and validity include long-recognised difficulties people with ID have in question-and-answer sessions, such as the inclination to answer with a single word or short sentence rather than a free-flowing conversation, requiring a higher level of input from the researcher (Booth and Booth, 1994); the tendency to answer 'yes' regardless of the question, and the tendency to select the last option (Sigelman et al., 1981); and problems with questions about time and frequency (Flynn 1986). This study confirmed that unless the participant has a reasonably high level of verbal skill, simply asking questions is not enough: additional research techniques are needed in order to elicit the necessary data, which presents analytical challenges.

Triangulating the data from the various focus group sessions went some way in addressing validity. For example, the results from session 4 (voting) confirmed the themes that had emerged in previous sessions. The results from the single interviews, where participants' experiences could be explored in more depth, further confirmed this.

The presence of support staff or carers during interviews or focus groups with people with ID has mostly been highlighted in the literature as a positive one, as they can interpret participants' communication (Fraser and Fraser, 2001), enable participants to understand what is required of them (Abbott and McConkey, 2006) and provide general support (Gibbs et al., 2008). However, there is a threat to validity, as support staff may not simply facilitate discussion but also have a clear opinion of the 'right' responses to the questions raised by the facilitator, and encourage participant to express 'desirable' responses (Kaehne and O'Connell, 2010; Llewellyn, 2009). We had to be alert to this and direct staff to provide support, not opinion.

#### *Ethical issues*

Ethical approval for the study was obtained from the national NHS Research Ethics Committee (reference 09/H0716/37). Careful thought was given to the support needs of participants, as the research topic was potentially distressing. In all three groups, the managers felt that they themselves would be able to monitor the emotional well-being of the participants and inform us if they thought anyone needed additional support. The principal researcher checked with the managers before and after each group that all participants were coping well with the study. In addition, all participants were given the principal researcher's contact details and told that they should speak to either her or anyone in their own support system if they felt they needed extra help. At each meeting, staff members who knew the participants were present and able to take participants outside the meeting for a short break if they wanted to (several did, but they always chose to return to the meeting). The research team kept in contact with these staff after the meetings, to check whether participants needed any further follow-up support. In the case of face-to-face interviews, the interviewer made a follow-up phone call with the participants and/or their carer.

Work of this nature can be emotionally demanding for the researchers. A number of support measures were in place, including team debriefing sessions after each focus group and supervision for all team members. The ethical aspects of the study

were reported to and supported by the Research Advisory Board, which included a psychiatrist with many years experience on Research Ethics Committees.

**Results**

*Participants*

There were 21 participants aged from 19 to 63 (mean age 42). The participants mentioned 40 cancer patients between them. Almost all of these had died; only five of the cancer patients had survived. One participant's husband (who also had ID, and whom she cared for) was terminally ill (see Table 2). Seventeen participants took part in three focus groups (two groups of six and one group of five). Four participants were interviewed face-to-face, one of which was in the presence of a husband with ID who had survived cancer.

*Main themes*

Four main themes emerged from the data: protection and inclusion; coping with cancer; understanding cancer; someone to talk to. Participants had clear ideas about what would have helped them.

*Protection and inclusion*

When presented with the story of 'Jim', which left it open whether or not he had been told about his father's cancer (Table 1), participants answered to the question what was worrying Jim: 'Nobody's told him' (see Tables 3 and 4 for an example of such a group discussion). They talked repeatedly about whether or not they themselves had received timely information from their families about the ill or dying person, and how they had felt (and still felt) about this. Several families seemed to not have shared information with participants as a way of protecting them from the bad news. This had the effect of participants feeling excluded as a family member, causing distress or anger that, in some cases, persisted years later. Participants agreed that they had the right to know like the rest of their family members.

**Table 2**  
Participant characteristics.

Participant number	Sex	Age	Focus group/ interview	Who had cancer
1	F	42	Interview	Father, mother, aunt, uncle
2	F	58	Interview	Husband <sup>a</sup>
3	F	28	FG1	Grandfather
4	F	25	FG1	Grandfather
5	F	28	FG1	Mother, father, aunt
6	F	19	FG1	Aunt <sup>a</sup> , friend
7	F	29	FG1	Friend
8	F	51	FG2	Mother
9	M	60	FG2	Mother, father, partner, sister <sup>a</sup> , niece <sup>a</sup>
10	M	51	FG2	Sister
11	F	31	FG2	Father, mother <sup>a</sup> , grandmother
12	F	51	FG2	Mother, sister
13	F	62	FG2	Husband <sup>b</sup> , two friends
14	F	35	Interview	Uncle
15	F	48	Interview	Partner, friend, grandmother
16	F	34	FG3	Friend, brother
17	M	48	FG3	Mother
18	F	44	FG3	Mother
19	F	52	FG3	Partner
20	F	37	FG3	Mother, partner
21	M	63	FG3	Friend

<sup>a</sup> Survived cancer; expected to live.  
<sup>b</sup> Living but prognosis short.

**Table 3**  
Example of focus group discussion.

**Researcher:** I don't know whether Jim knows [that his father has been diagnosed with cancer][Referring to a fictional, pictorial story of a young men and his ill father]  
**Participant 17:** No, he doesn't know, does he.  
**Several participants speaking at once:** No, he doesn't know.  
**Researcher:** Why do you think he doesn't know?  
**Participant 21:** Because he hasn't been told.  
**Participant 17 (speaking with passion):** He hasn't been told, has he!  
**Researcher:** Has he not?  
**Participant 19:** I don't think so.  
**Researcher:** Why not?  
**Several participants speaking at once:** The nurses haven't told him, mum hasn't told him.  
**Researcher:** Mum hasn't told him you said?  
**Participant 17:** Don't think so. I don't know.  
**Participant 18:** I can agree.  
**Researcher:** You think mum hasn't told him?  
**Participant 18:** Yeah.  
**Researcher:** And the nurses haven't told him either?  
**Several participants speaking at once:** No.  
**Participant 17:** It's against – they can't tell him.  
**Participant 21:** And he'd probably be upset as well, wouldn't he?  
**Researcher:** So the nurses and the doctor have told mum, but they haven't told Jim yet?  
**Participant 17:** It's up to the mother.  
**Researcher:** It's down to mum to tell Jim?  
**Participant 17:** Yes.  
**Researcher:** What do you think, should mum tell Jim?  
**Participants 17, 18 and 21:** Yes.  
**Researcher:** Why?  
**Participant 19:** So he knows and so he's prepared.  
**Participant 18:** So he knows what's going to happen and how he's going to cope. I'm not blaming anyone.  
**Researcher:** We're not blaming anyone either, we're just wondering what's happened here.  
**Participant 18:** Oh, that's good. (...)  
**Participant 17:** He must think something is going on but nobody is telling him properly (...) He can sense something's not right.

'I didn't know anything about it at all, with my mum or my sisters. It's like talking about it and I didn't know anything. They put me in a room and I didn't hear about it, I didn't know about it. It's not nice. I didn't know people get locked in a room you know. It's frightening.' (Participant 11)

**Table 4**  
Helpful support strategies, suggested and voted for by the participants (n = 16).

	Total points	Mean rating (min: 0.00; max: 5.00)	Total no. of participants who selected this in their top 5
Someone to talk to about my feelings and worries	40	2.50	12
Someone to support the rest of the family	35	2.19	13
My family, carers and doctor should tell me everything	34	2.13	9
Someone I can ask questions about cancer	32	2.00	9
A support worker to be with me	31	1.94	10
Other people with LD to talk together about our experiences	29	1.81	9
Easy words and pictures to explain cancer	18	1.13	6
Photos of the ill person to help me think and talk about them	10	0.63	6
Someone to help look after the ill person	9	0.56	5

Participants selected 5 out of these 9 statements and ranked them in order of preference. Participants' first preference was given 5 points; second preference was given 4 points etc. The maximum total points per item was therefore 80 (if all 16 participants ranked it first).



Some participants' families did not hide the cancer diagnosis from them.

'I got a phone call from my dad saying "Hurry up and come home, cause I don't think your mum has got long" and she died on Sunday night (Participant 20)

Most participants seemed to have been aware of the diagnosis, but being told someone has cancer does not necessarily mean that all the implications are understood. Participants who had been helped to understand what was happening remembered the situation with feeling. Memories of the ill person dying were still painful to discuss, but the focus was on missing that person and on trying to continue living without them.

#### *Coping with cancer*

Many participants had vivid memories of their loved one being ill and dying, recalling the details even years later. The experience of coping with someone who was ill and watching them die involved feelings of worry and general distress. Reflecting on the question 'What is difficult for Jim?' the participants described an overwhelming worry that the father would die.

'Me and my family witnessed my mum dying and that was *shock-ing!* She had a tumour, cancer in her brain. And she went to hospital thinking they could help her but... she came back home and that was sad. It was hard. I still cry sometimes cause it hurts. I do miss her. It was six years ago and it's still taking time to get used to.' (Participant 18)

In many cases, as the cancer progressed and the cancer patient needed more assistance in daily tasks, the role of participants changed. Seven participants indicated that they had gone from being cared for or being an equal partner to being the carer of their relative, partner or friend. Participants viewed themselves as able to understand, help and to be responsible, but they seemed to have received no credit or support for this. Many participants 'got on' with it and took on their new roles as carers, even though this was distressing for them. They were acutely aware of the distress and needs of their families.

I looked after my mum at home (...) Difficult, it was. I was looking after her 24 hours a day. On the commode and that. She used to sleep upstairs, she used to call me. (Participant 9)

The thing is, you've got to be responsible in the family. (Participant 11)

As many of the participants had experienced bereavement of someone close to them, their descriptions of how they coped were strongly coloured by their coping with grief. Much time was taken up with simply remembering what had happened. Many participants had not had an opportunity before to talk about their bereavement; their sense of loss was raw, even many years later.

#### *Understanding cancer*

There was a significant need for information about cancer from all participants. They had many questions highlighting the lack of information available to them. This was associated with anxiety as some participants had seen their relative die and wondered when they themselves would get cancer and also die. As one participant said:

'I wake up every day thinking is it today that I get cancer? Is it tomorrow? Is it the next day? And you think 'don't be silly you're not going to get it!' (Participant 10)

There was general ignorance about cancer, with several participants asking whether you can catch cancer, to which other group members did not know the answer.

'Is it like a living, a living organism or a little, a little – like a little flea or something? (...) You see I don't know what sort of symptoms to look for if I had it. I've got nobody here to tell me, to explain it to me. So how am I meant to know?' (Participant 1)

Participants particularly wanted to know why someone gets cancer. They believed that doctors should have the answer to everything. Participants expressed the need for more information about cancer and proposed that this could include pictures to make it easier for both doctors and nurses to explain, and for people with ID to understand.

#### *Someone to talk to*

The majority of participants found it helpful to talk with someone, whether it was a friend, relative or professional. Only two participants mentioned receiving counseling after their parent had died. Both participants found this to be a very positive experience.

'The hospice was very good because they were very supportive. They have counseling which I thought was really great. And I think it really helps. I think I would never have got over all of it completely if I didn't have counseling. (Participant 15)

Most participants said that they would look to their families for support in the first instance. However, they also seemed to be protecting their families from their own distress, and found that they could not actually ask their families for support. They also did not know how to approach professionals, and sometimes feared that they would be dismissed as they had been from their families.

Participant 18: 'My family don't talk about it. I find it easier to talk to someone else. (...) It's not always easy to find someone. It's a good thing to talk about worries but if there is no one around it's difficult.'

Researcher: So it's good to talk to someone, but it can be very difficult to find someone to talk to? [group makes sounds and gestures of agreement] (...) How easy is it for you to go up to a nurse and ask them?

Participant 18: Ooohhh, I would have to be very brave. It would take a lot of courage.

Participant 20: I would do it because I'd have to.

Participant 17: They would understand...

Researcher: What if a doctor or a nurse came to you and asked you "Is there anything you want to ask?"

Participant 18: I would like to, but without crying. And I'd be crying my eyes out.

Researcher: Did any of you talk to a nurse? [None of the six participants had done so]

#### *Support strategies*

The participants suggested a wide range of strategies that they would have found helpful. During the last session, the focus group participants were presented with the nine most frequently mentioned strategies, using picture cards. They each selected the five strategies that they would have found most useful and ranked them in order of preference. The results are given in Table 3.

#### *Taking part in the study*

At the end of the final focus group session, when asked what it had been like to take part in the study, participants' responses were

overwhelmingly positive. Although it had been difficult and sometimes painful to talk about the issues raised, they were glad they had done so. For many, it was the first time they had an opportunity to talk about cancer and how it had affected them. The participants said that they found the presence of researchers with ID particularly helpful in enabling them to share their thoughts. They especially liked the fictional stories, the voting, and the opportunity to share with others and find out that 'you're not the only one'.

*Theoretical framework*

The findings led to the development of a theoretical framework for supporting people with ID who have a relative or friend with cancer, which is presented in Fig. 1.

**Discussion**

*Accessible cancer information*

The lack of knowledge and understanding of many people with ID was unsurprising, and has been noted before (Tuffrey-Wijne et al., 2006). There is a clear need for easily accessible cancer

information. This need is increasingly recognised, with a welcome trickle of new resources available (Donaghey et al., 2002; Hollins Tuffrey-Wijne, 2009; FAIR Multimedia, 2011; CHANGE, 2011). Our study found that showing people with ID just a few relevant pictures of situations that bore similarities to their own, and inviting them to voice their comments and questions, was a very effective way of eliciting concerns. Existing pictorial resources could therefore be used flexibly in a clinical setting to support not only people with ID who have cancer, but also cancer patients' family and friends with ID.

However, accessible cancer information is of limited use unless people with ID have access to someone who recognises their information need, wishes to meet this need, and knows how to meet it (including finding the accessible materials). Most people with ID are unable to access information on their own. Pictures and easy-read resources can be an invaluable tool, but they are only as good as the people using them.

*The need for support*

The extent to which participants felt isolated and in need of emotional support was striking. This was not primarily a desire for straightforward cancer information, but for someone to share

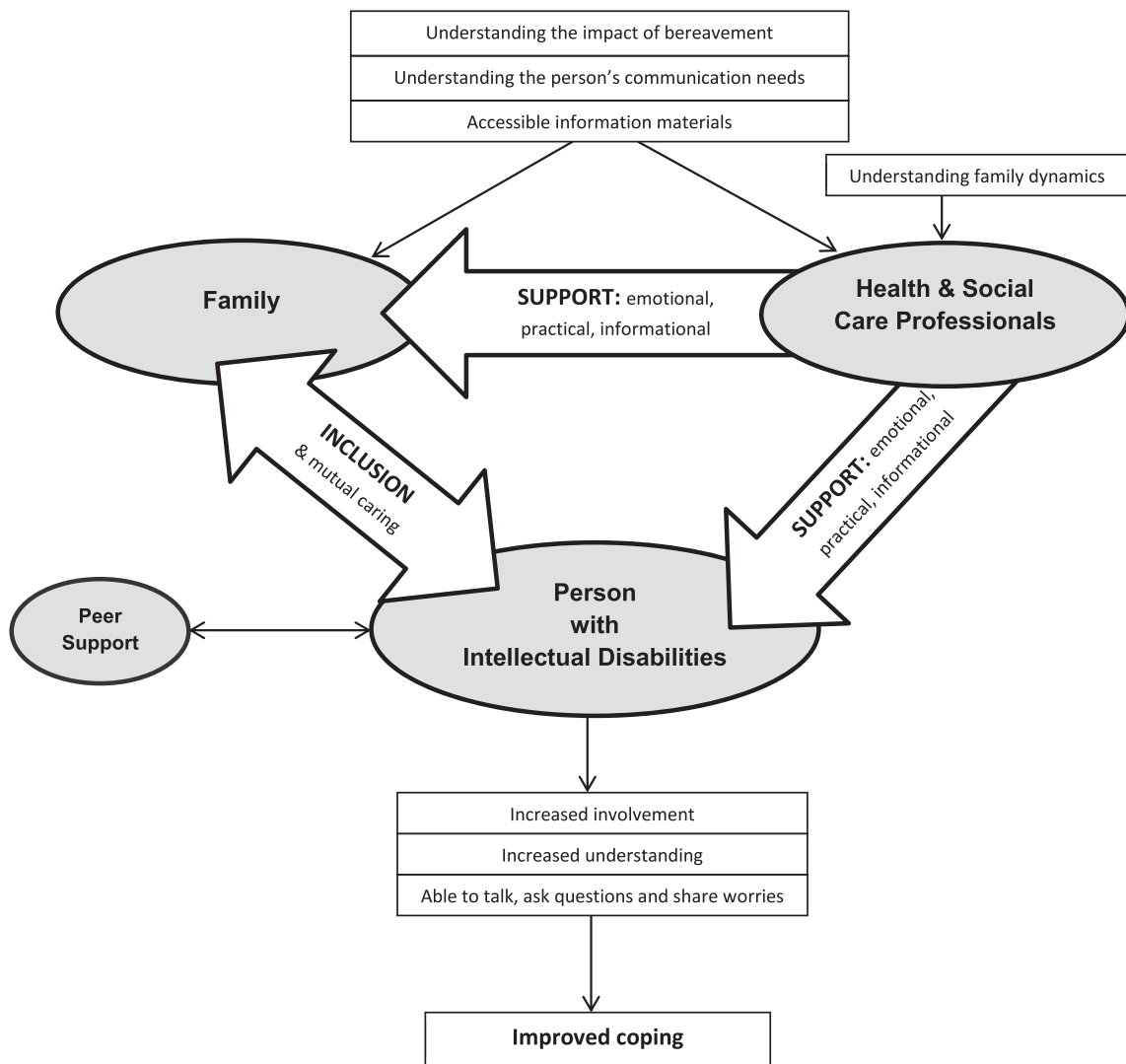


Fig. 1. Theoretical framework for supporting people with intellectual disabilities who are affected by a relative or friend with cancer.

worries and concerns with. Many people with ID have limited opportunities to build and maintain social networks and friendships (Lippold and Burns, 2009; Snell, 2007), and therefore their support system consists primarily of their immediate family or care givers. For some people with ID, families and care staff are crucial in understanding and helping with communication. The participants did not know who to go to for support and information beyond their families and carers. At a time of crisis caused by cancer, when they most needed support, they were acutely aware of their families' distress. They appeared to have hid how they really felt, partly because they did not want to burden their families. One member of the research team, who had ID himself, concluded that people protected their families by not asking 'a thousand and one questions because the family was too busy grieving'.

Families may be protective of the person with ID, not realising that this protectiveness can have a negative effect on the person's coping. Health care professionals should be aware of these complexities and offer support to families and carers. This includes encouragement to talk about the situation and involve the person with ID; reassurance that it is normal for the person to show strong emotions; and factual information about the cancer and treatment, so that this can be passed on or reinforced to the person with ID in a way he or she can understand.

A significant proportion of participants reported that they took on a caring role. Relationships within the family home can be highly interdependent, but people with ID who are carers are often invisible to services because of lack of recognition of mutual caring of parents or partners (Department of Health, 2009). Without information about and access to a range of mainstream services, and help at points of crisis, the needs of people with ID may escalate to the point where their support networks break down (Department of Health, 2009).

We found that the participants had not been given sufficient recognition of their emotional capacities; in some cases, even their long term support workers present at the meetings were surprised by this. The distress around situations where a loved one has cancer and may be dying is inevitable, but it certainly seems that some of the suffering of people with ID could have been avoided if they had been given an opportunity to share their worries with someone they did not feel the need to protect, such as a nurse or other professional.

The impact of bereavement, particular parental bereavement, on people with ID can be considerable. Blackman (2003) explains that people with ID are at higher risk of grief becoming complex because of a range of factors, including their understanding of the concept of death; being shielded from the reality of death; lack of recognition for their grief; difficulties in keeping the memories of the deceased alive; and complications in forming early attachments with a parent. A study comparing different bereavement interventions found that whilst family members and direct care givers considered the provision of emotional support as part of their role, they were in fact unable to provide such support for a variety of reasons, including a fear of the emotional repercussions and coping with the loss themselves (Dowling et al., 2006). This echoes our finding that family members did not provide sufficient support during and after the illness.

#### *Study limitations*

It is worth noting that people with ID are a highly heterogeneous group with wide variations not only in their intellectual ability but also in their ability to think in abstract concepts and in their life experience. Our study sample could not be representative of the entire population of people with ID. The greatest limitation of this study was the fact that only people with mild and moderate ID

who had some verbal skills could take part. Accessing the viewpoints and experiences of people with severe and profound ID would require a different methodology such as ethnography (Agrosino, 2004), which is time consuming and expensive. The study sample was further limited by logistical constraints and issues of gate keeping, as described in the *Study Design* section.

A further limitation is the fact this study was retrospective, relying on participants' memories of events that, for some, had happened a number of years earlier. A longitudinal design, or one that includes participant observation, may reflect more accurately participants' experiences during a loved one's illness.

Given the limited sample size, the findings need to be treated with caution and are not easily generalisable. The aim of studies of this kind is to generalise to theory, highlighting potential issues and perspectives that may not have come to light previously.

#### **Conclusion**

This is one of the first studies looking at the needs of people with ID who have a relative or friend with cancer. Despite the study limitations, the findings of the study are striking and significant. There is a clear need for proactive support on a number of levels: emotional (eliciting worries and concerns), practical (ensuring people with ID receive support in helping their families) and informational. Cancer nurses are in a unique position to provide such support. It will be hugely beneficial if they give time and attention to people with ID who have a relative or friend with cancer. It is also important to note that people with ID are unlikely to ask for such support, or to know that it might be available to them. In order to provide adequate support, nurses will need to familiarise themselves with the accessible cancer information materials available (as described above), but may be more importantly, with any additional communication issues and needs (Tuffrey-Wijne and McEnhill, 2008) and with specific family dynamics. Families and carers need help and support to include and involve the person with ID.

In most situations, using simple, clear sentences without jargon, and being kind and open, is enough; when communication needs are more complex, the help from an ID professional may be beneficial. It would be useful for all nurses to know where to find such professionals, and to collaborate with them. In the future, more accessible materials are needed to help people with ID make sense of a range of difficult situations and experiences. Research into the needs of a wider group of people with ID who have a relative or friend with cancer, including those with severe and profound ID, would also be highly beneficial. Finally, this study has strongly demonstrated the benefits of including people with ID in researching areas that affect their lives, both as participants and as co-researchers.

#### **Funding source**

This study was funded by a grant from Macmillan Cancer Support.

#### **Conflict of interest statement**

None declared.

#### **Acknowledgements**

With thanks to Baroness Prof Sheila Hollins for supervisory support, and to the Research Advisory Group for overall support and advice.



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