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## **Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities**

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### **Key Words**

Learning disability, family carers, palliative care, education

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## **Abstract**

**Background and Objectives:** Evidence from European and American studies indicates limited referrals of people with learning (intellectual) disabilities to palliative care services. Although professionals' perceptions of their training needs in this area have been studied, the perceptions of people with learning disabilities and family carers are not known. This study aimed to elicit the views of people with learning disabilities and their family carers concerning palliative care, to inform health care professional education and training. **Methods:** A qualitative, exploratory design was used. A total of 17 people with learning disabilities were recruited to two focus groups which took place within an advocacy network. In addition three family carers of someone with a learning disability, requiring palliative care, and two family carers who had been bereaved recently were also interviewed. **Results:** Combined data identified the perceived learning needs for health care professionals. Three sub themes emerged: 'information and preparation', 'provision of care' and 'time with family and friends'. **Conclusions:** This study shows that people with learning disabilities can have conversations about death and dying, and their preferred end-of-life care, but require information that they can understand. They also need to have people around familiar to them and with them. Health care professionals require skills and knowledge to effectively provide palliative care for people with learning disabilities and should also work in partnership with their family carers who have expertise from their long term caring role. These findings have implications for educators and clinicians.

**Word Count: 242**

## **Background**

Disability is recognised as a global human rights issue yet many people who are disabled lack equitable access to healthcare.[1-3] Likewise the international palliative care community asserts that palliative care is ‘an international human right’ with many people lacking adequate provision.[4] Given this context it is not surprising that world wide concerns exist regarding the quality of palliative care available to people with disabilities and those with a learning (intellectual) disability. Diversity in service development and delivery in different countries along with varying definitions of palliative care and learning disability present additional global challenges.[5,6] An international priority is to make palliative care more accessible to this population and family carers.[2,3]

However, internationally there is a consensus that learning disability exists when three criterion are present: ‘learning impairment (reduced IQ), social or adaptive impairment and early onset, before 18 years of age’.[7] People with these disabilities are disadvantaged by others shielding them from death and bereavement.[8] They are also less likely to be referred to hospice services as evidenced in studies across Europe, America and United Kingdom.[9-11]

As people with learning disabilities are living longer internationally [12] their risk of advanced, progressive disease will increase leading to an increased demand for palliative care services. Thus palliative care services need to be tailored to individual needs with a workforce educated and competent to provide care. It is recognised that service users have expertise to inform professional training as they are ‘people with direct experience of using health services’.[13] In the

general population this has included family carers where a family member has received palliative care.[14] Likewise examples have been reported where the involvement of people with learning disabilities provided richness and real life insights into professional education.[15] Studies have obtained professionals' perceptions of their training needs in providing palliative care to someone with a learning disability [16-18,11] and the views of people with learning disabilities on end-of-life care.[19,20] Yet no studies have specifically sought the views of people with learning disabilities, or their family carers, about the palliative care training needs of professionals. The risk then is that services are not adapted to the particular needs of this group and their carers.[21-23] Furthermore training resources that enable professionals to provide care should centre around a service user perspective.

## **Aim**

This study aimed to inform the education and training of health care professionals by eliciting the views of people with learning disabilities, and family carers, concerning palliative and end-of-life care.[24]

## **Methods**

Ethical approval was obtained from the University Ethics Committee and ORECNI(09/NIR/03/38).

### *Research design*

In order to capture the views of people with learning disabilities and family carers a qualitative, exploratory design was used with a transformative

paradigm as the theoretical underpinning, which has an emphasis on addressing inequalities.[25, 26] Focus group discussions and interviews were the qualitative methods employed.

### *Participants*

Two focus groups (n=17) and individual interviews (n=5) took place with two distinct groups of individuals who volunteered to participate in the study. These included a purposive sample of adults with learning disabilities recruited via an advocacy network and family carers recruited from health and social care trusts and hospice care across Northern Ireland. (See Tables 1 & 2).

**Table 1: Demographic details of people with learning disabilities (Focus Groups)**

<b>Gender</b>	<b>Number</b>
Female	12
Male	5
<b>AgeRange</b>	
19-34yrs	6
35-59yrs	9
60yrs plus	2

**Table 2: Demographic details of family carers (Semi-structured Interviews)**

<b>Family Carer</b>	<b>Gender</b>	<b>AgeRange</b>	<b>Relationship to Person</b>	<b>Length of time in caring role</b>
Active	Female	50-59yrs	Sister	4 yrs
Bereaved	Female	50-59yrs	Mother	20yrs (Bereaved 4yrs)
Bereaved	Female	40-49yrs	Mother	23yrs (Bereaved 1yr)
Active	Female	50-59yrs	Mother	20yrs
Active	Male	50-59yrs	Father	20yrs

Focus groups have been shown to be a viable data collection method with people with learning disabilities.[27-31]The inclusion criteria for the focus group participants were: they were considered able to contribute to a group discussion

on palliative care, had given valid consent and had not experienced bereavement in the previous six months. The inclusion criteria for family carers were that they had been involved with a family member with a learning disability who had required palliative and end-of-life care within the past five years, had given informed consent and had not experienced a bereavement within the past six months. Face to face interviews were used with family carers as this method was considered more sensitive when dealing with the loss or imminent loss of a loved one with a learning disability. In total there were 22 participants and data collection took place November 2009- May 2010.

#### *Data collection with people with learning disabilities*

The proposed study was described, in an accessible leaflet and discussed, at the User Council of an advocacy network for people with learning disabilities, who then circulated it to their wider membership. At a second meeting all members of the two focus groups were able to give written consent by signing an accessible consent form. Each focus group took place in a private room within the advocacy network offices and lasted around 30 minutes. The discussion was recorded with participants' permission. Field notes were also made.

Illustrations have been found to be valuable in enabling people with learning disabilities to take part in focus groups.[29] A pictorial approach similar to that taken in previous research [20]was used with the author's permission. Participants were told that the meeting was to find out what they felt doctors, nurses and other professionals needed to know when caring for someone with

a learning disability at the end of life. They were shown a drawing [20] of a lady called Susan who had learning disability, sitting with her dog, and were told that this lady, was very ill and was going to die and were asked what people could do to help her. A number of focused open questions were used around how Susan might be feeling and how she could be best supported and made comfortable. The open questions were asked verbally, using straightforward language, and were also shown to the group in clear, written format. At the end a debriefing session took place. An accessible support pack was also distributed giving details of support services and a named person to contact, if anyone had further questions or concerns. The researcher and advocacy group staff were also available.

#### *Data collection with family carers*

Family carers were informed about the study through information circulated by advocacy groups, Hospices and services within the Health and Social Care Trusts. They were told that it was to develop education for doctors, nurses and other professionals. Despite repeated efforts to boost recruitment only five family carers requested an information pack, all of whom returned the signed consent form indicating that they understood the information about the study and would be willing to take part in an interview.

The interview guide used was contextualised to this study from a previous one [32] with additional questions on the family's views on professional training in end-of-life care for someone with a learning disability. The interviews with family carers took place in their home, lasted 40-60 minutes, were conducted in a



sensitive manner and recorded with their permission. Field notes were made. All were provided with written details on counselling, support services and a named person to contact after the interview if needed.

### ***Analysis of data***

The focus groups and semi-structured interviews were transcribed verbatim and content analysed by the first author using a recognised framework.[33] Transcripts were also independently analysed by two other members of the team and agreement on themes reached through discussion.

### **Results**

The combined data highlighted holistic end-of-life care that participants felt someone with a learning disability and family carers would require and which education for doctors, nurses and other professionals should contain. But, the data also had a varying focus relating to both the needs of the person with learning disability and family carers.

Three sub themes emerged under an overall theme 'Learning needs of professionals in end-of-life care provision to people with learning disabilities' - (Fig 1-Web only file). These are presented below with participants' quotations..

### **Information and preparation**

This was related to knowing and understanding about the illness, treatment and prognosis.

### ***Issues at diagnosis***

People with learning disability highlighted the importance of professionals explaining about the illness, treatment and prognosis to the person in away that they could understand, using 'signs' or 'hearing aids' if needed.

*'She'd want to know what her illness really is.....Try to explain it someway to her' (FG4)*

Another issue was the family carer's experience of being told the diagnosis.. This sometimes occurred shortly after the birth of a child with learning disability and life-limiting disease.

*'I was told he had it and that was it...it's a shock somebody telling you your child has got something wrong with them and there's no cure. I had no support' (BC2)*

### ***Meeting information needs***

People in the focus groups were asked if the person with a learning disability should be told that they had not long to live. Responses suggested a role for both professionals and the family:

*'Yes they (professionals) should tell her how long she's going to live...t' (FG6)*

*'I think it's up to a member of the family to tell them .... if she can't understand the doctor' (FG4)*

Family carers thought that it would have been helpful to receive information rather than this having to be self sought.

*'I went to every course, or information day .....but if I wasn't that type of person, I don't feel I would have anybody coming to me' (AC1)*

### ***Being prepared for the death***

There was a sense among people with learning disability that the person may be concerned about who would take care of practical arrangements around the death:

*'She'd be wondering who's her next of kin to arrange her funeral....She might have worries about that' (FG16)*

Being prepared for the death was about how well informed family carers had been. One felt angry in not being told that her son was dying as she could not prepare his siblings. For another there were difficulties in prognostication:

*'The nurse thought that I knew he was dying, but if I had of knew I wouldn't have left the hospital.....Because I could have got my other kids prepared' (BC3)*

*'We use to go every six months well ... what's the long term prognosis?.....after a while we gave up' (AC5)*

### **Provision of care**

This theme reflected where the person with learning disability should have end-of-life care, their need for equitable, timely care focusing on the whole person and the need for family members to have support..

### **Place of care**

The importance of the person's preference for place of care was recognised in the focus group discussions. Interestingly a hospice was not highlighted:

*'She might want to stay in her own home' (FG4)*

*'In hospital...she'd get better care- nurses and doctors' (FG13)*

*'Maybe in a nursing home where they can be looking after her' (FG12)*

Some family carers had experienced difficulties in obtaining an appropriate place of respite care for a young adult with a learning disability.

*'We went to three different places and it took me about a month to recover- ... they were basically old people's homes...'* (AC4)

### **Equitable holistic palliative care**

There were support services, identified by people with learning disabilities, which the person should be able to access. Insightfully this was related to

physical, social, emotional and spiritual support. 'Social workers', 'the minister', 'a psychiatrist' the 'community nurse' and 'physiotherapist' were highlighted.

Other practical help included:

*'Bring some help in to do cooking, washing, dishes, cleaning her house' (FG2)*

*'It's a pity a nurse wouldn't come in at night and say a prayer for her' (FG3)*

Some of the family carers felt that professionals needed more awareness of the right of people with learning disability to access equitable palliative care:

*'A young adult who has a disability...they can't say I am dying...what is going to happen...will it be sore, - they don't have those thought processes, but they are due exactly as much as the adult who does know the journey they are about to take...'* (AC4)

### ***Supporting family members***

The focus groups demonstrated the need for family members to have bereavement support as participants talked about past and imminent losses of significant people:

*'If someone in your family dies...you would be entitled to go for grief counselling...my other Granny is the only one that's left-so if she dies going to miss her'* (FG13)

The individuality of bereavement support needs was discussed by family carers including 'a counsellor' who understood about people with learning disabilities and someone who was sensitive. Other thoughts were:

*'I had my family supporting me and that was enough... People may want somebody there after...you have to do what's right for yourself' (BC2)*

Family carers felt that professionals had a responsibility to provide more timely coordinated care at end of life and in transitional care for young adults:

*'From he left the children's to go to the big hospital, it was a big change. The doctors and nurses in the children's knew all about him and his treatment...if there had been something in between...it's a big gap' (BC3)*

*'They provided an educational package for him...the package included stimulation and development- that's stopped...so I would respectfully suggest that they continue that education package...stopping at eighteen is crazy...go on until the end' (AC5)*

### **Family centred care**

Participants in the focus groups believed that doctors, nurses and other professionals needed to know the importance of having family around familiar to and with the person, at the end of their life.

***Being with family*** reflected the connection between the person with learning disability and family members:

*'Time with her own family'(FG5)*

*'Her brother...grandmother...daughters also inside her in own heart' (FG8)*

Family carers stressed the importance of their prior knowledge of the person, and for professionals to work in partnership with them and acknowledge this.

Recognising that the person was unwell, in pain or needed to use the toilet were skills from their long term caring role that they could educate professionals about:

*'We just read him by facial expression and the expression in his eyes...he would have moaned- that was the only way we could tell that he was in pain '* (AC4)

**Having friends and familiarity around** was associated with other important relationships in the person's life such as the 'the dog': that they may wish to have around.

*'She might just want the ones that she's used with, but she might not want strangers'* (FG4)

*'And her dog...company-pet'* (FG7 and FG8)

With family carers maintaining familiarity was seen as being about the personhood of someone with a learning disability which professionals should be mindful of.

*'If he's happy with somebody sitting reading him a story or holding his hand I think that they (professionals) need to see that even though it's a child going into adulthood with a very severe physical and learning disability...they have to see them as a whole person and the parents are part of that'* (AC4)

It was also evident that maintaining that familiarity required family members to cope, adapt and be resilient in a long term caring role:

## **Discussion**

This study showed that people with learning disabilities are able to talk about death and dying and their insight is much greater than acknowledged.[19,20,34] The natural and comfortable manner with which they took part in focus groups corresponds with previous studies.[19,20] There are lessons to be learned from people with learning disabilities who are willing to take part in conversations about taboo subjects like dying.[35]

Similar to previous research [20] people with learning disability preferred holistic, end-of-life care support.. They articulated how those needs should be met within a multi-disciplinary team approach [36,37] and identified educational priorities for doctors, nurses and other professionals. There were three core messages from people with learning disabilities and family carers:

### **Information and preparation**

They wanted to be able to access support and information around the illness, treatment and prognosis. For people with learning disabilities this information needed to be provided in a format that they could understand. This underscores the need nationally and internationally for information to be tailored to their needs [5,2,1] such as that signposted within the international Palliative Care for People with Learning Disability Network ([www.pcpld.org](http://www.pcpld.org)). The openness about the person dying, and the role of the family in disclosure, is relevant to the evidence based Breaking Bad News Model for this population and associated guidelines for professionals to assist people with learning disabilities to indicate, where possible, how much information they want -



see [www.breakingbadnews.org/](http://www.breakingbadnews.org/).<sup>[38]</sup> Professional training needs to raise awareness of these resources, and promote their adaptation to local and national contexts, given that global competencies in palliative care emphasise the importance of choosing methods of communication appropriate for people with learning disabilities.<sup>[39]</sup>

This study evidences the unmet information and support needs for family carers of people with learning disabilities from diagnosis and throughout the disease trajectory. This is similar to previous research in the United Kingdom with people with advanced disease and informal carers.<sup>[40]</sup> However, this study builds on research findings in care-giving internationally <sup>[41,32]</sup> through putting the spotlight on a specific family carer population in end of life care who have previously had little focus. What can be seen is the long term caring role which begins at the birth of a child with learning disability and life limited disease, but this does not negate their need for more adequate information, emotional support and preparation for the death.

### **Provision of care**

This study emphasises equity of access to palliative care services, for people with learning disability, but for them also to have those around who are familiar to them and with them. This highlights a dilemma as in accessing specialist palliative care services, they would then be dealing with unfamiliar professionals. One possible solution is for increased joint working and learning between palliative care personnel and professional staff in learning disability services who currently support the person and family carers. Collaborative

working between palliative care services and other specialist services is promoted in national and international policy to widen access for people with non-malignant disease.[42, 22, 6] This study supports the case for similar policy on collaboration to widen access to palliative care for people with learning disabilities. This emphasis around service collaboration builds on other studies [16, 11] and internationally can inform the standards for palliative care of people with learning disabilities being developed across fifteen European countries.[43]

Two other issues are noted. First, a hospice, as a preference for place of care, was not identified by people with learning disabilities. This links with studies globally which show lack of referral to hospice care for this group of people [9-11] and indicates hospice as one setting where professional education should be targeted. Second, the gaps in transitional care and respite and the need for adequate continuity from children's to adult care were highlighted by family carers and link with a recent systematic review of transitional care [44] and European standards for paediatric palliative care.[45]

### **Family centred care**

The personhood and humanity of the person with a learning disability was highlighted. First, in the focus groups through the value placed on relationships with people and their pets and how they like to have them around. Second, in the family carer interviews when being familiar with a person with a learning disability meant knowing what they liked and being familiar with them as a person. Joint working and learning is needed between family carers, people with learning disability and services.[2]

The long term caring role of these family carers is different to that of other carers in end-of-life care. These differences have yet to be more fully researched and have been recognised as a research gap internationally.[46] This study suggests that family carers of people with learning disabilities have the potential to work in partnership with services and have particular expertise to share, as well as receiving support from professionals to meet their needs as carers.

### *Limitations*

Those who took part in the focus groups were a self- selected sample of well volunteers, with learning disabilities, who may have had limited experience of chronic illness, death and dying. Also greater insights may have been obtained with a larger number of family carers.

### **Conclusions**

This study provides key messages from people with learning disability and family carers. First, people with learning disabilities can have conversations about death and their preferred end-of-life care, but need information that they can understand. Professionals need skills and knowledge to facilitate such conversations. Second, people with learning disabilities need people familiar to them and with them around. Services should work in partnership with their family carers in end-of-life care as they have expertise from a long-term caring role. Access to hospice and palliative care needs to be widened for people with learning disabilities who have the same holistic, end-of-life care needs as the general population, but have other additional needs in accessing support and

information, as this study has demonstrated. Findings have implications for educators and clinicians. The specific needs of family carers of people with learning disability in end-of-life care should be further explored.

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### **Contributors**

DMcL undertook this work as part of a larger PhD study with OB, SMcI and RMcC as the Research Supervisory Team. All authors contributed to the study conception, design and development of data collection tools. DMcL and OB facilitated the data collection in focus groups with people with learning disability. DMcL facilitated the family carer interviews. Data were analysed by DMcL and for also independently analysed by OB and SMcI.

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