Exploring the lived experiences of people with learning disabilities who are dying of cancer

Little is known about the additional needs of people with learning disabilities who have cancer. This observational study aimed to address this knowledge gap.

**Method**
The study used participant observation with 13 people with learning disabilities who have cancer. The study aimed to explore the experiences of people with learning disabilities who are dying of cancer, and dying of age related illnesses such as cancer.

**Results**
The main themes were: dependent living; communication difficulties; however, none had looked directly at the experiences of people with learning disabilities who have cancer. There have been only a few case reports from nurses in inpatient settings (Millioud et al, 2005; Black and Hyde, 2004). Some studies have examined the end of life care needs of people with learning disabilities from the perspectives of social care staff and palliative care staff (Tuffrey-Wijne et al, 2008; Todd, 2004), and highlighted communication difficulties; however, none have looked directly at the experiences of people with learning disabilities who have cancer from their own perspective.

**Conclusion**
To understand the experiences of people with learning disabilities who are dying of cancer, it is important to understand their previous life experiences and key relationships. Healthcare professionals who treat people with respect, dignity and openness can make a positive difference to their care.

**Participants**
The participants were 13 people with mild to severe learning disabilities, aged between 36 and 66 years (mean age 53 years). Seven were able to reach a degree of independence and had adequate verbal communication skills; six needed continuous support and had severely limited communication skills.

**Analysis**
Data collection and analysis took place at the same time. All five authors (one of whom has learning disabilities) were members of the research team, and were involved in data analysis.

**Design**
To gain in depth insights, and to accommodate the wide range of abilities, needs and living circumstances of the study population, we used the qualitative research method of ethnography, which typically involves “participant observation”.

Put simply, to understand the world from another person’s perspective, the researcher tries to become part of that world. To that end, the first author (Irene Tuffrey-Wijne) spent over 250 hours in participants’ company, visiting them regularly (often weekly) during time frames ranging from one day to over two years (median seven months). They were visited at home, in day centres and inpatient settings, including hospitals, nursing homes and hospices, and accompanied on outpatient appointments.

The researcher also spoke to relatives, social care staff and healthcare staff (including many nurses), attended case reviews, studied case notes and attended funerals. She wrote detailed notes straight after each visit or telephone call.

**Background**
Some 1.2 million people in England – around 2.5% of the population – have learning disabilities (Department of Health, 2001a). Growing numbers of people with learning disabilities are now living into old age and, by 2021, the number over the age of 50 is expected to have increased by 53% (Emerson and Hatton, 2008). They are therefore at increased risk of developing illnesses whose incidence tends to increase with older age, such as cancer.

Although no firm figures are available about the overall risk of developing cancer for people with learning disabilities, there is evidence that incidence in this group is rising (Hogg and Tuffrey-Wijne, 2008). Nurses on hospital wards, in hospices and in learning disability services will see growing numbers of people with learning disabilities who have cancer. It is therefore important to understand the needs of this group, and how they can best be supported.

Little is known about the additional needs of people with learning disabilities who have cancer. There have been only a few case reports from nurses in inpatient settings (Millioud et al, 2005; Black and Hyde, 2004). Some studies have examined the end of life care needs of people with learning disabilities from the perspectives of social care staff and palliative care staff (Tuffrey-Wijne et al, 2008; Todd, 2004), and highlighted communication difficulties; however, none have looked directly at the experiences of people with learning disabilities who have cancer from their own perspective.

**AIM AND METHOD**
This study aimed to explore the experiences of people with learning disabilities who had cancer, from their own perspective.

**Design**
To gain in depth insights, and to accommodate the wide range of abilities, needs and living circumstances of the study population, we used the qualitative research method of ethnography, which typically involves “participant observation”.

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**Participants**
The participants were 13 people with mild to severe learning disabilities, aged between 36 and 66 years (mean age 53 years). Seven were able to reach a degree of independence and had adequate verbal communication skills; six needed continuous support and had severely limited communication skills.

All had a cancer diagnosis and 10 were terminally ill. Eight died during the study period (including one person whose cancer was in remission and who died of other causes). After the study, the researcher kept in contact with the surviving participants, two of whom have since died.

At the time of cancer diagnosis, seven participants lived in staffed residential care homes, four in their own flats, one in the parental home and one with foster carers.

**Analysis**
Data collection and analysis took place at the same time. All five authors (one of whom has learning disabilities) were members of the research team, and were involved in data analysis.

At the start of the study, there were no preconceived ideas about the research problem; all themes emerged from the data. The notes were constantly reviewed, and emerging themes were compared with earlier data. As the study progressed, it became increasingly focused on the emerging theories. No new themes were found with the final three participants. This
Nurses can make a positive difference to the experiences of people with learning disabilities who are ill and dying:  

- Assess capacity to consent, then follow the Mental Capacity Act’s legal framework;  
- Always listen to the person, and act if they say that the care or treatment is not right;  
- Find out as much as you can about their life story and try to find out their likes and dislikes;  
- Listen carefully to whatever the person communicates to you. Talk to family, carers and close friends;  
- Introduce yourself each time you meet and always address the person directly. Be prepared to allow some extra time;  
- Think about pain control as the person may not complain of pain openly;  
- Make reasonable adjustments to ensure that health, where decisions were mostly made for them, rather than with them. Almost all treatment decisions were made or influenced by family or paid carers (Box 1). Participants were highly dependent on others to access the healthcare system. The cancer diagnosis itself depended on someone noticing that something was wrong and acting upon that observation. Sometimes, participants had not complained, they were not believed or their symptoms were misinterpreted.

Deprived lives  
Participants’ experiences of cancer and dying could only be understood in the context of their life experiences. For all 13, this included lifelong experiences of being bullied and abused, not only by peers but also by people in authority, including teachers and care staff. Many had a history of being abandoned, starting in early childhood; six had been removed from their families at an early age. Participants’ loneliness was sometimes hard to witness. Even those living in group homes could have isolated lives, without much interaction with peers. Vincent Sweeney (47, mild learning disabilities) lived on his own. He said:

“I get really lonely here. I worry or I panic. Sometimes I sit here and there is something on TV that makes me panic, like when they talk about cancer. Then I ring people up, and they ask me ‘What’s wrong?’, so I tell them that I am having pain. I am not in pain really, I am just lonely and worried. But I can’t keep ringing people up, can I? I can’t

One effect of participants’ life experiences was that they were not accustomed to being important, and had very low expectations of life. Although the researcher was sometimes shocked when doctors or nurses failed to communicate directly with participants in hospital, the person concerned seemed to take this for granted. Conversely, if nurses make an effort to understand people’s needs and to communicate with them, the positive impact was great. For example, Lily Lamb was very happy to be in a hospice during her final weeks, and her sister-in-law commented on the many staff members popping into her room to visit. Participants had learnt to hide their pain and distress. One man had deformed feet, causing him to suffer terrible physical pain in childhood; now, in the final stages of cancer, he rarely complained. “I am all right,” he kept saying, even when he was very weak. Several participants were acutely aware of the burden they placed on others, and somehow carried on without asking for extra help when their support needs increased. Even Vincent Sweeney, who did complain quite regularly to those around him, said about his sister-in-law:

“I can see in her face that it is really too much for her. . . . It shouldn’t really be her job to help me.”

Truth telling and understanding  
The questions “Should we tell him? What should we tell, how, and by whom?” were an issue for almost all families and carers.
Several participants themselves wondered what was happening to them. Although 11 out of 13 had been told they had cancer, this did not mean they understood what it meant. Only two asked their doctor further questions and were helped to understand the implications of their diagnosis.

In most cases, relatives and paid carers made the decision about how much to tell the person. This was sometimes based on their own attitudes towards truth telling, rather than on an assessment of the person’s needs.

Participants’ dependence on their carers was a defining influence on how much they were told. A staff member in the residential care home of Marion Prentice (61, severe learning disabilities, breast cancer) said:

“What is the point of putting people through worry, and adding stress? Why would she need more tests? They are talking about a scan, but why? Because it is what we want to know. There is no point for her in knowing.”

Most carers thought it was in the person’s best interest not to upset them with bad news, that is, most appeared to abide by the philosophy that “ignorance is bliss”. This seemed to be mostly true for those who genuinely lacked the capacity to understand the implications of their illness. Those who could be helped to understand, however, were clearly distressed when they were not given enough information.

Vincent Sweeney kept turning his doctors’ words over in his head, greatly worried:

“My doctor says that I should go and have a holiday whilst I still can. What is that supposed to mean? Whilst I still can?”

There was a forced jollity around people with learning disabilities, who were often urged to “give us a smile”. One man who had every reason to be sad and who, for once, was not smiling, was told by his carer: “We don’t want all this grumpiness!”

The importance of families
It was important to understand the key relationships in participants’ lives. Families had a significant place; this was true even for those who had not been in regular contact. For most participants, “family” meant siblings or, in some cases, a parent.

It was striking that no participants had children, and only one had an openly acknowledged partner. In addition, most had very few friends; they often could not maintain friendships independently. As a result of this, they lacked the support systems that many middle aged and older people have.

Having a son, daughter or sibling with learning disabilities had a huge impact on relatives’ lives. It was extremely important that they were included in the person’s care and support at the end of life. Many relatives had feelings of guilt and regret about not having been more involved in the person’s life, and were distressed at the unfairness of cancer at the end of an already difficult life. Paid carers did not always appreciate the crucial and irreplaceable bond participants had with their families.

Inexperienced carers, unprepared services
The majority of participants were supported by social care staff who had received no medical training.

Staff in learning disability services could be extremely dedicated to participants’ welfare – sometimes well beyond the call of duty – but they needed much practical and emotional support, which was mostly lacking. Staff had little knowledge of the physical and emotional processes of cancer, and panicked when the person was in pain or when they found someone on a bedroom floor. Staff in residential care homes did not recognise the signs of advanced illness or impending death.

Residential care staff were extremely concerned that hospital staff would lack an understanding of people with learning disabilities and felt their own role was misunderstood. One home manager complained that hospital nurses expected her to stay in hospital with the person with learning disabilities, unaware that she had to support other residents in her care home.

Hospital staff, including nurses, were often inexperienced in coping with the needs of patients with learning disabilities. Many did not communicate directly with them, but addressed carers instead. They found communication issues particularly difficult (Tuffrey-Wijne and McEnhill, 2008). One hospital nurse explained, shortly after the death of Ursula Smith (65, severe learning disabilities) who had been on her ward for two days:

“It was difficult to understand her. We couldn’t understand what she wanted. But then she shouted ‘Water, water, water’ and we could understand that... I think she was anxious. She was shouting a lot. I don’t think she liked being here. She wanted to be at home.”

Learning disability services were largely unprepared and sometimes unable to support residents who were terminally ill. Facilities in residential care homes were inadequate and staffing levels were too low to cope with the increased care demands, leaving staff exhausted and frustrated about their inability to care for both the person who was ill and other residents. Only two participants died in their residential care home. Questions were raised about where a person could go, as there was a lack of services that could cope with the dual needs of learning disability and end of life care.

Resilience
Despite all the difficulties, participants were remarkably resilient. A number of aspects helped them to cope with their illness:

- They were “experienced sufferers” with lifelong training in coping with adversity;
- They were skilled at living in the present moment and “taking each day as it comes”;
- They were used to being caring for, making the loss of power and control that often accompanies terminal cancer less shocking for them;
- The presence of one or two trusted carers (usually a relative or a dedicated paid carer), who knew them intimately and was present throughout the illness, made a huge difference to their ability to cope;
- Many participants simply “kept going” with what they enjoyed. They were helped by keeping up their routines as much as possible, for example, by going to their day centre even when they were no longer well enough to take part in activities.
a careful assessment of what is in the person's best interest, there also needs to be an assessment of whether the person does, in fact, lack capacity to decide.

In some cases in our study, learning disability staff made a huge effort to help participants understand what was happening. However, we found a general lack of willingness or skill among doctors and nurses when it came to helping these participants to understand their diagnosis, prognosis and treatment.

It was clear that people with learning disabilities needed special attention within healthcare services. The sometimes worrying lack of adequate support for this group in hospitals has made headlines several times in recent years, including reports of avoidable deaths (Parliamentary and Health Service Ombudsman, 2009; Michael, 2008; Mencap, 2007). Our study confirmed their findings that primary and acute healthcare staff lacked insight into the needs of people with learning disabilities.

Communication issues and a lack of experience or confidence among healthcare staff could also be detrimental to the support of people with learning disabilities in hospitals. On the other hand, when healthcare staff focused their attention on the person with learning disabilities and made an effort to understand them, they could contribute to the safe environment most participants needed.

Collaboration with other services has often been highlighted in the literature as a key factor in effective end-of-life care (Read, 2006; Todd, 2004; Brown et al, 2003), and this study confirms it. Where families, health and social care staff worked together, it benefited the care of people with learning disabilities.

It is important that nurses have a clear understanding of what “reasonable adjustments” healthcare services can make to ensure equal access for people with learning disabilities (Disability Rights Commission, 2006). Examples include offering longer appointments, different waiting arrangements and information material that is easy to understand. Box 1 outlines some useful resources for nurses.

The sample size in qualitative research of this kind is necessarily small, and therefore it is not possible to generalise the findings. The aim of qualitative research is not to argue that “this is how it is” for everyone, but to open our eyes to possible feelings, problems and strengths that may not have considered. This study has provided unique and valuable insights into the lived experiences of an often forgotten and marginalised group of patients who are vulnerable.

CONCLUSION

People with learning disabilities who have cancer have a unique and important story to tell. To provide them with sensitive and appropriate care, it is essential that we listen to their stories.

Participants in this study, and their families and carers, needed an enormous amount of support. It is essential that all those involved work together and communicate openly.

If healthcare professionals treat people with learning disabilities with respect and openness, they can make a real difference to their experience of illness and dying.

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REFERENCES


