

'AM I A GOOD GIRL?' DYING PEOPLE WHO HAVE A LEARNING DISABILITY

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This article describes the challenges of 'being with' suffering people who have learning disabilities. People who have learning disabilities often hide their pain and distress, exhibiting a tendency to comply. This stems partly from life-long powerlessness and partly from the inability of others to bear that distress. This article reflects on the author's involvement with two women who had learning disabilities and who were dying of cancer. The author describes how, because there was little that could be done to relieve the women's distress, 'being with' the two women was almost unbearable. The manner in which hospice nurses related to the women is examined. The author also reflects on her own interactions with the women using her contemporaneous field notes, concluding that listening, without the notion of helping, is an important skill. Recommendations include focusing fully on such patients with the desire to understand, and avoiding the urge to 'help'. *Conflicts of interest: none*

KEY WORDS

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This article describes some of the suffering of Lily Lamb and Sally Burnett (pseudonyms), two women who had learning disabilities and were dying of cancer. It is an account of my personal experience as I attempted to 'be with' the women, even though I was unable to relieve their suffering. Lily and Sally took part in a qualitative study of the experiences of people with cancer, who also have learning disabilities (Tuffrey-Wijne and Davies, 2007; Tuffrey-Wijne et al, 2009). The aim of the study was to gain insight into the perspective of such people.

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The technique that was used was mainly participant observation. This is a qualitative, observational technique which involves the researcher in the activities of the individuals or group being observed. It is the best method for understanding the experiences of people, and the meanings they attach to them (Bowling, 2002). To achieve that end, it was necessary for me to spend many hours taking part in the lives of the subjects. The study lasted 3 years and involved 13 participants.

I visited Lily and Sally, until they died, for 10 weeks and 25 weeks respectively. After each session, I wrote down everything I remembered, e.g. what had occurred, what people had said, how they behaved, as well as my own reactions and feelings.

Most of the participants were terminally ill and nine died during the course of the study. My regular contact with the subjects inevitably resulted in the formation of close relationships. Throughout the study, I reflected deeply on the lives of the participants. I also reflected on the mutual effects of our interactions. The details and results of the study are to be published elsewhere, and some of

the participants' stories have already appeared in print (Tuffrey-Wijne and Davies, 2007; Cresswell and Tuffrey-Wijne, 2008).

The purpose of *this* work, however, is to describe some of my experiences as a participant observer and listener. My experience with the participants in these roles was different from any other I had previously.

I trained as a nurse over two decades ago. Since then I have worked as a support worker and manager in homes for people who have learning disabilities and as a palliative care nurse in a hospice, before taking up a research post, focusing on the end-of-life care needs of people with learning disabilities. The crucial difference between my research role and my nursing role is that, as a researcher, it is not my task to help. Of course, if I notice that any participant of a study is suffering because of inappropriate care, I have a duty to intervene. I make sure that the care team members are aware if a participant is experiencing unrelieved pain. When staff or families look to me for help, I must guide them to the appropriate agencies. However, as a researcher, my primary role is to

listen, to ask questions and to try to understand what is happening (Tuffrey-Wijne et al, 2008).

What followed in my encounters with the research participants (Lily and Sally in particular) was a humbling realisation that I was not as good at listening as I had previously thought. To learn *truly* to listen required me to relinquish my role as 'the nurse who will help you'. It was a distressing experience, one that has transformed my practice. I was also forced to face the fact that many people with learning disabilities lead painfully difficult and marginalised lives, and that practitioners find their distress impossible to face.

When working with research participants such as Lily and Sally, my experience of being a palliative care nurse can be useful. It often helps patients to know that I am not afraid to broach difficult subjects such as suffering, dying and death. However, I have also found that my professional knowledge can be a barrier to truly listening to a person's suffering.

Truly listening to Lily and Sally required me to disregard the list of nursing assessments at the back of my mind. I had to cease my constant, silent, intrusive wondering how I could help.

Am I allowed to cry?

People with learning disabilities are highly dependent on others. They are rarely in a position of power (Goodley and Ramcharan, 2005). Nurses need to become aware of *their* power and the lifelong experience of people with learning disabilities that their opinion does not matter. Many people with learning disabilities cannot easily say 'no'. They are conditioned to please and not be a burden. Booth and Booth (1994), who carried out in-depth research with parents who have learning disabilities, point out that the tendency to 'acquiescence' (responding affirmatively, regardless of the question) results not just from cognitive limitations, but as a result of being under someone else's control. They note that such acquiescence

is part of the way people who have learning disabilities relate to health and social care professionals who exercise power over their lives. During my study, I observed several participants who would quickly decide what staff wanted from them and give it, anxious to comply.

The tendency to comply was most painful to watch when it concerned regular encouragement from staff and relatives to 'smile' and 'be happy'. Even people who were very ill and had good reason to look sad or miserable, even people who were dying, were often told to 'cheer up'. 'We don't want all this grumpiness', was a typical comment to someone who was, for once, not smiling. It was as if the participants were not allowed to be unhappy: as if people could not bear to witness the participants' distress. I was shocked to find that most of the 13 participants were, in some way, hiding their distress. One participant said: 'I make out that I'm all right when inside I'm not. I'm just fed up!'

I find it poignant that the first researcher to pay serious attention to the ability of people with learning disabilities to grieve, titled her book *Am I Allowed to Cry?* (Oswin, 1991). Sinason (1992) introduced the concept of what she called 'the handicapped smile', the smile that many people with learning disabilities have learned to wear, because those around them expect it:

'People who are close to grief and cannot bear it, encourage "happiness" and "smiling"...Guilt that people exist who have to bear unfair and appalling emotional, physical or mental burdens can be so unbearable that a state of denial is brought about where those in greatest pain are asked to be the happiest' (p. 141).

My colleague Gary Butler (a research adviser who has learning disabilities and who was a member of the project's research steering group) helped me to analyse my field notes. He also noted that many of the participants were expected to be cheerful, and said: 'It's a mask. That's all

it is, a mask...It's because they don't know how to cope with people with learning disabilities being upset...this is so...fake!'

The pain of many people with learning disabilities is a pain of loneliness, of not being listened to, of never being in control, never having a voice. I wanted to learn to listen to such people and not walk away. This was not easy and there were times when I failed.

Lily

Lily had moderate learning disabilities and limited capacity for speech. She was suffering advanced stomach cancer. From the first time I visited her, she appeared desperate to draw me in, to make me stay with her and listen to her. She often held my hand. Lily had been experiencing agonising physical pain, which prompted a transfer from her residential care home to a hospice. However, despite frequent assessment and increases in analgesia, Lily's pain was never fully controlled. Learning about Lily's life, I came to realise that her pain was probably part of her emotional suffering, stemming from a life-long feeling of inferiority and fear of abandonment. She often sought reassurance from nurses, 'Am I a good girl? Are you cross with me?' Like many other people with learning disabilities, she had been separated from her family in childhood and sent to a remote, special needs boarding school. Her brother, who visited her often, said, 'She allowed me to go home, as long as I promised to come back the next day. She was always worried that she would be abandoned.'

I felt that Lily was experiencing 'total pain' as described by Dame Cicely Saunders, who founded the modern hospice movement (Clark, 1999). Knowing this, it was hard for me not to focus solely on my inability to relieve her pain and to try to understand her communication. It was very hard to stay with her and face the truth of her painful life. My field notes describe one of our last meetings. Lily was half awake and was drifting in and out of consciousness:

'The following hour is extremely difficult for me. Lily keeps repeating single words...apparently related to her discomfort and how she wants it reduced...I am struggling to understand...Throughout the first half hour, she says "up"... often gesturing weakly with her hand, making "up" movements...I try moving pillows, moving the headrest up. Nothing helps. Lily looks in real distress, undisguised by the midazolam. She is frowning and struggling desperately to make herself understood, too weak to explain properly...she changes her words and I make out that what she is saying is "get a nurse".

'I go in search of a nurse, relieved that I can leave her for a while and do something constructive, get someone else to unburden me from having to help Lily. The nurses are all busy...I wait in the corridor for the nurse allocated to Lily today to finish giving another dying patient some medication...She comes to see Lily when I ask her. She takes Lily's hand, puts her own face very near Lily's and asks her "what is it?". "Up", gestures Lily. The nurse explains to Lily (as she had already explained to me) that she has just been given some extra painkillers (about 20 minutes ago) and needs to give it some time to work. The nurse is patient and kind, and we spend the next couple of minutes trying to adjust Lily's pillows in various ways. Nothing is completely right...

'Lily remains unsettled. She is beginning to indicate her leg...I can't make out whether or not she wants it raised on a pillow. She says "it hurts" and "pain in leg". She keeps appealing to me for help that I cannot give. I feel helpless. I keep looking at her face. I read the distress in it: the frown, the unhappiness. I am a nurse with many years' experience of supporting dying patients and here I am, sitting next to a woman in her final days and I cannot bear her distress. I

cannot bear sitting here. I want to be the nurse who just came in to help her, who adjusted some pillows, spoke to her gently and warmly, but then left the room again with the promise of more medication if things didn't settle. I want to leave the room too...to do some supporting of other dying people in other rooms. I do not want to stay here and witness Lily's distress...

'Lily is beginning to ask me again to get a nurse, to ring the bell. What can I do? I know the nurses are busy, I know there is probably not much more they can do than I have already tried, yet I also know why Lily wants a nurse. I can feel it. I want a nurse, I want someone to come again and sort us out. She keeps asking me to ring the bell. I press it. I watch...nurses walk past the door and I realise more than ever how important it is to be acknowledged as a patient, as a relative. I can hear one of the nurses (whom I know is very busy) say: "Yes I've heard it" ...(i.e. the bell). After a minute or two...a nurse enters...I turn off the bell. I am hugely apologetic, saying what Lily wanted. The nurse does not come into the room completely. She explains to me...that the other nurse has given Lily a painkiller and that she will give her another one soon. Then she leaves the room, leaving me with a feeling of having done something "naughty". I don't mind, but I do feel a fraction of the dependency that Lily must be feeling...

'Lily keeps complaining of pain, keeps frowning in distress...I cannot stay. She asks me again to get a nurse. I tell her I am going to get a cup of coffee and then come back...I tell myself that this is a way of helping her to get off to sleep; maybe she will be able to drop off when there is nobody around to ask for help. I know the real reason for my trip to the canteen is simply escape.'

In retrospect, what difference would it have made had I stayed? As the minutes

ticked by, my defences shattered. I began to *feel* Lily's pain. It was unbearable. I ran away, yet what she needed was someone to stay. Of course, sometimes we need to take action: painkillers must be prescribed and administered. A person in distress might be referred for counselling or for complementary therapies. However, that does not absolve us from the responsibility to stay with a person in distress. I now believe that, if I had stayed with Lily, I might have made a deeper connection with her.

Dame Cecily Saunders recognised the importance of listening decades ago:

'Our most important foundation for St Christopher's is the hope that in watching we should learn...how to free patients from pain and distress, how to understand them and never let them down...how to be silent, how to listen and how...to be there' (Saunders, 1965).

It can be difficult to listen to people with learning disabilities. Such people often lack the capacity to communicate their needs. Difficulty in communicating can make nurses feel disabled. When words are useless, sometimes the silence becomes unbearable. However, silence is hardly ever silent. Sometimes it is comfortable, but often unspoken questions hang in the air, unspoken questions of suffering and pain.

After Lily's death, other research participants demonstrated to me that *listening itself* can transform people's lives, rather than the notion of helping. I am grateful for the lesson. It enabled me, one year later, to 'be with' Sally and stay with her distress.

Sally

Sally had mild learning disabilities and autism. She was dying of widely metastasised bowel cancer. She was in a hospice. She had lost the ability to walk, but no one had told her that she would not get better. Her family encouraged her to think that she might go home if her legs became stronger. The medical staff colluded with the relatives, stating that they did not know enough about learning disabilities and the family probably knew best. Sally was confused

and distressed by the reassurance that everything was progressing well, desperately trying to exercise her legs, but realising that she was only getting weaker. Here is an extract of my field notes, describing what happened during one of my visits:

“I need the physio,” she cries. She wants to get stronger... We sit, we talk... she sometimes looks at me and smiles... most of the time she looks distraught and she cries... I sit with her, in turmoil... It is so very... hard to sit with someone in such deep distress... I feel her distress. In the same way as... Lily a year ago, it is almost too agonising to bear. At first, my instinct is to run away, to say “I’ll go and get some coffee” as I usually do; but I cannot actually bring myself to do that this time, because now I understand that what Sally really needs is someone to stay with her... Something quite powerful happens. The longer I sit with her, the more I want to stay. The longer I sit with her raw distress, the less I am able to leave her. This is the opposite from... my past experiences... It is as if I have learnt not to do anything, but simply to be present. It is the most wonderful thing, but also heart-breaking. I am aware that if I allowed myself, I could quite easily feel Sally’s pain within myself and I could quite easily cry. Now, sitting at home and typing this, I am crying...

‘Sally rings the buzzer... a nurse walks in. ‘I can’t move my legs,’ Sally says... ‘I know that,’ says the nurse. ‘We know you can’t move your legs.’ And she sets about raising Sally’s pillows, making her sit up a bit higher... ‘We don’t know when [the physiotherapist] is coming,’ says the nurse. ‘The doctors haven’t been yet either.’ And she leaves. Nurses leave! This is a revelation... As a nurse I always thought I had been present with my patients. This nurse certainly wasn’t. And I would probably have done exactly what she did; cheerful, breezy, competent.

‘What would I do now, if I walked in and my patient was distressed, crying “I can’t move my legs?” I hope I would sit down, take the patient’s hand, and quietly try to understand exactly what she was saying, exactly what is so distressing. What she wants. Why is she crying? Is her leg painful? Does the lack of movement indicate, with frightening clarity, that she is not getting better? Does she need painkillers, physiotherapy, or emotional and spiritual support?’

It is only when we truly connect with another person that we can be real catalysts for healing. A mother does not turn away from her distressed child. A mother *feels* her child’s pain. The more she feels it, the more she wants to stay. She gives the child a place of total safety, where it is possible to be in pain and to be supported in pain. It is through such love and compassionate support that pain becomes bearable. Without such love and compassion, it is impossible to stay with a person in pain. I think that sometimes nurses are in danger of focusing too closely on tasks and responsibilities, that love and compassion are forgotten. Nurses then become unable to share patients’ pain. If nothing can be done, it is sometimes easier to be busy elsewhere. I longed to be busy elsewhere when I was with Lily.

Becoming damaged

Palliative care has sometimes been defined as ‘a safe place to suffer’ (Stedeford, 1987). The issue for nurses is how far they should be led along the path of suffering with the patient. Becoming skilled in being with vulnerable and suffering clients without becoming damaged is a huge challenge. It requires nurses to examine their own needs, motivations and barriers. It requires high-quality supervision. However, if support and supervision are in place, it becomes possible. Some nurses, caring for the participants in my study (including many of Lily’s and some of Sally’s nurses), made a huge effort to understand their patients. They were touched by their lives, deaths and vulnerability. Some attended their funerals. ‘I just had to come’, one hospice nurse explained, ‘I was really fond of her.’ A year later, this nurse still remembered her learning-disabled patient vividly and said she now used the listening and communication skills she had learned.

Many nurses are affected deeply by certain patients, patients who remain with them for years, even decades. The emotional cost of such connections can be high, particularly if the nurse is poorly supported or supervised. However, it is often such encounters that inspire nurses to improve their clinical practice. I have often heard nurses say that patients with learning disabilities have this inspirational effect on them.

Table 1

Examples of communication techniques when conversing with people with a learning disability

- Try asking open questions or change the question round to check if you still get the same response. Many people with learning disabilities will simply say ‘yes’ to closed questions such as ‘Do you understand?’ or ‘Do you have pain?’
- When presented with a choice, some people with learning disabilities tend to repeat the final option (‘Tea or coffee?’ ‘Coffee’)
- Concrete examples are better understood than abstract concepts, such as concepts of time: ‘Take one tablet with your breakfast and one tablet when you go to bed’ is better than ‘Take it twice a day’

Source: Tuffrey-Wijne and McEnhill (2008)

Discussion and recommendations

Nurses regularly tell me that they are at a loss to know how to communicate with people who have learning disabilities. There are certain communication skills that may be helpful and can be learned easily (Tuffrey-Wijne and McEnhill, 2008) (Table 1). However, I have found that it is not 'tricks of the trade', but 'quality of time' and 'focus' that are most important in my role as a researcher. I believe this is also relevant to nursing.

Busy nurses may think that listening and simply 'being with' someone is too time consuming and impossible to achieve when someone has learning and communication disabilities. Of course the amount of time is important, but it is my experience that the quality of time is what matters. What is most important is an ability to reveal that whatever the other person says or does or thinks or feels is acceptable; that you will not try to change them or tell them that you know best. You will enable them to feel safe. I have found that sometimes spending just 10 minutes in complete openness and willingness to listen has transformed interactions and relationships.

It can be difficult to banish 'being busy elsewhere' and the multitude of responsibilities from the nursing mind. However, I have found that the ability to focus completely on the person I am with is key to making a real and life-transforming connection.

During my interactions with people, I try to give my absolute and undivided attention. I constantly ask myself the question: 'What is it like to be you?' It is extraordinary to see how people start to reveal themselves, simply because I am genuinely interested.

If you are able, try to spend 5 or 10 minutes with a patient you find difficult, perhaps someone whose distress you feel you cannot relieve. See what happens if you just listen and acknowledge their complaints or distress. I have used sentences such as: 'You really want me to know how hard this is for you. I can see that it is hard.' This has been effective, even with people whose verbal understanding is limited.

Try to sit in silence with the patient. Somehow, you will communicate that you do not expect anything. You do not expect them to be okay. You certainly do not expect them to smile. You simply want to be with them and support them. The benefit of such focus and of the ability to 'be with' someone has been described beautifully by Dorothy Judd who is a psychotherapist working with dying children:

'To sit with him, quietly, but thinking about him and his situation, seemed to give him the opportunity to "be". There is an irony in a situation which, by allowing the child to be dying, actually seems to validate him and in that sense allows him to be alive' (Judd, 1995, p. 166).

People with learning disabilities, like anyone else, deserve to be heard. They have much to teach us. My involvement with Lily, Sally and the other project participants has showed me that people who have been disadvantaged can bestow on us the most extraordinary gifts. Our challenge is to be able to receive those gifts. **EOLC**

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Key Points

- » People who have learning disabilities are dependent on others. They often learn to comply and hide their distress.
- » It can be unbearable for others to witness the distress of people who have learning disabilities.
- » People who have learning disabilities are often expected and encouraged to 'be happy'.
- » When listening to the pain of people who have learning disabilities, nurses must spend quality time focusing fully on that person, trying to understand their world, without necessarily trying to help.