CHAPTER 6

Choice and priorities

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OVERVIEW OF THE CHAPTER

A recurrent theme that has emerged throughout our consideration of each aspect of compassionate care, so far, is the importance of meeting patient or client needs by adopting a person-centred approach. If we are serious in wanting to meet these needs, this will involve working in partnership with those for whom we care. As nurses we need to support people to actively participate in trying to make choices about their care a reality. We need to ensure that we prioritise what they would prioritise in relation to their care, wherever possible. This process may well pose dilemmas for nurses as prioritising patient needs could conflict with resources available and practitioner priorities. Therefore, this chapter will look at these issues in more depth in order to ensure that there is a humane and caring approach to practice.

KEY THEME ONE – CHOICE

CASE STUDY 6.1

Sally had been visiting Bob and Betty at home for some time in her role as nurse coordinator of Bob's care. She felt that she knew them quite well and she knew when something was worrying them. Bob was very close to death from lung cancer. He had never smoked, but had worked for many years in an environment that would have been considered unsafe nowadays because of the high levels of asbestos. Neither of them dwelt on the unfairness of his disease. He was only 70 and should have had many more years to live. As a couple they were exceptionally close and Sally felt very sad for them, especially when she saw how strong Betty was trying to be for Bob.

When she went in today she could see that something was on their minds. Bob was looking frailer every day, but as usual they both greeted her with a smile. Their home was full of Christmas cards; they had a large loving family and a lot of friends and were very much loved and appreciated by a lot of people. Sally admired the cards and asked how things were today. Bob was struggling to breathe and looking very cyanosed, and he looked to Betty to say what he obviously wanted to say.

Betty started very tentatively by saying how much they appreciated the care that had been available to them at home. They felt very much cared for and appreciated everything that Sally and the team were doing to help ease Bob's final days. However, they knew how little time he had

left; this would be his last Christmas and they wanted it to be as special as possible. Their family would be popping in throughout the Christmas period, but Bob was easily tired and needed to have time to rest between visits from them. They wanted to spend as much of the precious time they had together just on their own and being with each other. Their families understood this and a plan had been worked out for who would visit when, and for how long. This left the majority of the time free for Bob and Betty to just be together.

Sally could see that there was something more they wanted to say and asked how they wanted the nursing side of Bob's care to fit in with their plans over the holidays, because there were plans for various people to visit over that time. Betty said that they really did not want any visits over the next few days. They felt that they understood enough about Bob's analgesia to keep his pain under control. His oxygen supplies were already there and they felt that his other care needs could be managed by them or left for a while.

Sally's immediate feelings were of concern for Bob's welfare. He was a seriously ill man whose needs could become very acute and distressing very fast and she did not want either of them to suffer any more than they already were. However, she could see how important their last days together were to them both. It must be very intrusive and disruptive to have visits from care agencies all the time. Sally smiled reassuringly, made these points and said that as long as they were happy with the situation at any given point then nobody would visit. However, if that changed, and they were worried, then she would be available on her mobile and would make sure that problems were solved or alleviated as they arose. She also asked if she could phone a couple of times a day, and they arranged mutually convenient times for the calls. She could see their anxiety starting to ease when they realised that she was not offended and, indeed, understood their point of view, while still feeling that the care that might be needed could still be available.

Discussion

This situation created a dilemma for Sally. She was trying to balance the nursing needs that she knew Bob had with trying to honour their personal choice about what they felt they wanted at this time. She was concerned that his care might be compromised and wanted to reach some negotiated agreement about how contact could be maintained from both sides. It is always difficult

to ensure that patients and clients actually make an **informed decision** based on real knowledge about the problems they might face. Bob and Betty just wanted to have time on their own, but they might have failed to appreciate emergencies that can develop when someone is as ill as Bob. This would have needed a full and frank discussion, which is not fully represented in the case study discussion. Sally was using all her interpersonal skills and clinical decision making, including:

- assessment skills;
- tact and diplomacy;
- advanced decision making;
- advanced problem solving;
- empathy and understanding of their needs and priorities;
- working in partnership;
- verbal and non-verbal skills about what was said and not said;
- negotiation and real-choice options;
- anticipation of needs based on real knowledge of their situation;
- use of her therapeutic long-standing relationship;
- coordination skills with other agencies.

In their Norwegian based study, Hauge and Heggen (2008) make the point that by moving into a care environment, choices can be more limited and many compromises have to be made. They say that relationships can be enforced and privacy and control can be lost. This could have been the case with Bob and Betty, who were still in their own home. Choices could have been limited by Bob's health needs and the services that were available. It is important that nurses work within the boundaries of what is reasonable and realistic in a resource constrained health service and patient choices cannot always be honoured. However, it would also be easy for Sally to have made decisions purely from her own professional perspective, without trying to make compromises, based on Bob and Betty's choices. Their privacy and sense of control could have been severely compromised by Sally providing the service that she normally would have given, rather than providing a service that met their individual needs. It is important for nurses to realise that people who have been in long-term partnerships probably have an intimate relationship that could be compromised if only one partner needs care. At this point, partners can be separated as their care needs become too difficult to manage within one environment, be it at home or in more formal care settings. This can be an impossible problem to solve. However, if nurses have used all their problem-solving skills to try not to separate partners, and if they are aware

and sensitive about how this separation might be affecting both parties, they can be sure that they are providing care that is as good as possible within the services constraints that inevitably exist.

Nurses need to ensure that patients, carers and clients feel that they can take an active part in making choices about their care. Some people do not have the confidence or the communication strategies to express their wishes. Some have been brought up not to question professional decision making and they feel that they have to accept what is offered. As the choices and expectations of different generations change, we as nurses need to be able to adapt to these changes.

A UK Department of Health report says that:

> Choice gives patients the power they need . . . Where patients find it difficult to express preferences it is the role of staff to take steps to ensure that patients can benefit from greater choice. Choice in public services is sometimes presented as the preoccupation of the wealthy and the educated, yet the evidence shows that it is the poorest and least educated who most desire greater choice. (DOH 2008, p. 38)

It is the nurse's role to try to encourage patient participation and work in partnership with those in their care, to encourage communication about their choices and to ensure that choices are real and not merely rhetoric.

Do we genuinely understand the meaning of working in partnership with our patients and clients?

CASE STUDY 6.2

Amanda really enjoyed working with people with learning disabilities and had chosen this option right from the start of her nursing career. She knew that many people shied away from people who were 'different' and also that communicating with her clients was often difficult for those with no experience of talking to people who expressed themselves in different ways. She found this to be a particularly interesting part of her role and finding alternative ways to bond with her clients was an ongoing and stimulating part of communicating with them.

Today was busy as usual and she knew that Pat wanted to buy a present for her friend Jane. Amanda often went out for a walk with Pat, but it would take longer if it involved buying a present too. She knew that

this would be a time-consuming activity, and one that she could much more easily accomplish by buying something herself for Pat to give to Jane. However, it was important for Pat to interact with as wide a range of people as possible. She had very few friends, so choosing a present herself was very important to her.

Having found out that Pat thought Jane would really like some new earrings, Amanda took Pat to a shop that sold inexpensive earrings and had a wide variety of choice. Pat was overwhelmed by all the pretty, sparkly earrings on display. She thought that they were beautiful. Amanda asked Pat what colour earrings she thought that Jane might like, whether she wanted long or short ones and how much she wanted to spend. Having decided that long sparkly blue ones were in keeping with Jane's way of dressing, they set about trying to find ones that Pat thought Jane would like best. After a great deal of deliberation Pat chose a pair that were not very expensive and there was a matching pendant that Pat could buy too, within her budget, and Amanda drew her attention to this. Pat was really pleased with this choice. Amanda could see that Pat's attention was drawn to some other purple glass earrings and she knew that Pat loved purple. Amanda looked at the price and saw that they were on discount and could actually be bought, still within Pat's budget. Amanda picked up the purple earrings and held them against Pat's ears and moved a mirror so Pat could see how they would look on her. Her face lit up and she said 'beautiful'. Amanda said to Pat that she did indeed look beautiful and said that she had enough money to buy these too. Pat was so excited that she started to jump up and down. People in the shop started to look alarmed and move away, but Pat was so excited that she did not notice. Just then a little girl, about five years of age, pulled on Pat's sleeve and said, 'I think those look lovely on you'. Her mother came from behind the counter and agreed, then smiled at Pat and asked if she would like them to be put in a pretty box. Pat nodded and gave her the blue pendant and earrings and it was clear she wanted to wear the purple ones.

Despite the developing queue to pay, the owner of the shop patiently explained how much money she needed from the large number of coins that Pat had. Amanda wished everyone was so understanding and accepting of those who had learning disabilities. She felt renewed by her faith in people and was really glad that she had spent the extra time in the shop that Pat had needed to make the decision about the present for her friend.

Discussion

Amanda is clearly working in partnership with Pat. She understands what is important to Pat, how some people with whom she comes into contact might judge her, and, even more essentially, what is important to her. Amanda is a busy practitioner who knows that she could sort out the present buying much faster if she took more control of the situation. However, it is important that it is Pat's choice and she makes the decision; Amanda is there really just to facilitate this. This case study clearly demonstrates a high level of sensitive partnership working.

Papadopoulos and Lees (2002) say that 'partnership demands that power relationships are challenged and that real choices are offered' (p. 261). Amanda was very clearly passing over power and the decision making to Pat in order that Pat could make the decisions herself.

Amanda is not expecting Pat to comply with decisions that have already been made; the partnership she is demonstrating indicates that their relationship is based firmly on concordance. Concordance involves a negotiation between equals based on a therapeutic relationship, which will be discussed in more detail in Chapter 7. Cuff (in Burley, *et al.* 1997) says that a therapeutic relationship involves the sharing in partnership of:

- information
- planning and decision making
- responsibility
- control and power.

Wallis (2007) writes about a young man living with a life-limiting and debilitating disease, who wanted to experience sexual activity before he died. The hospice facilitated this in his own home despite the fact that they were aware that he really wanted an emotionally fulfilling relationship and he could be disappointed with just sexual activity. The fact that he wanted to make his own choice was seen as paramount. A senior member of church felt that the decision to allow this to take place demonstrated true humanity and compassion. His disability prevented him from independently making his own choice and the hospice respected his autonomy and his right to make his own decision. This young man felt empowered by his part in the decision-making process and said, 'My experience taught me a lot and gave me a sense of normality – to a degree. It also helped me to realise that I could make things happen if I really wanted them enough' (Wallis 2007, p. 4). Although the experience lacked the emotional element that he wanted so much and he did not necessarily want to repeat the experience, it was of paramount importance

to him to feel in control of his own destiny and life experiences. Therefore, the therapeutic relationships that facilitated this did involve partnership in relation to information, planning, decision making, responsibility, control and power.

Both Case study 6.2 and the experience that Wallis writes about demonstrate concordance, which is evidenced by respect for the patient's perspective, promotion of patient autonomy and self-determination. Therefore, the patient or client is actively engaged in the decision making. Problem solving, negotiation and partnership are key elements of working in partnership. Hornby and Atkins (2000) say that certain attitudes are essential for working in partnership; for example, reciprocity, flexibility and professional integrity. Again, both in the case study and in Wallis' article, power and control were devolved in a reciprocal manner, there was flexibility and the professionals involved demonstrated professional integrity.

Working in partnership is not always easy and relies heavily on the nature and strength of the relationship between nurse and patient or client.

> For older people who are not yet self-agents in their care, providing the clinical and social environments for them to grow and learn is essential. The way to do this is not to assume we know what they want to learn, but rather to offer a participative partnership that facilitates their control of 'what' and how it is offered. (Koch, Jenkin and Kralik 2004, p. 490)

It is not just older people who have difficulty working in partnership in making decisions about their care. It is important to realise that there is a clear power imbalance when a person is receiving care from others, and possibly has less knowledge about their health condition and what services are available. People need to feel empowered in order to make choices. Wilkinson (2007) says that people should have access to knowledge of care choices and the treatment success from different people's personal experiences, as well as their rights of complaint and how they can take part in satisfaction surveys. There are new options that are becoming more accepted by patients and healthcare professionals, such as some complementary therapies and exercise programmes rather than medication, but patients might be less aware of these options.

Having discussed the importance of working in partnership with patients and clients and what it actually means, it is now important to discuss ways in which we can increase patient participation in the choices about their care.

THOUGHTS FOR YOUR PRACTICE

- Can you think of a time when a patient's choices were compromised?
- On reflection, do you think that more choices were available?
- If so, how could you have encouraged those choices to have been more real?
- Have there been times when you have not been able to meet someone's choices, when you would have liked to facilitate this?
- If so, how did you explain this to the person involved?
- How could you further enhance your ability to encourage patients to express their choices?
- How could you encourage others to challenge their own practice in this way?
- Do you feel that there are ways in which you could further decrease the power imbalance between you and your patients?
- How could you share your thoughts with others?
- Think of an example when your relationship with a patient has been truly concordant and one where it has not. What made the difference between the two situations?
- What have you learnt from this for future practice, and how can you share this with others?
- Can you think of ways in which you can develop your skills further in relation to working in partnership with patients and clients?
- Is there anything about partnership working that you have learnt that could be adopted by your practice team?

How can we increase patient participation in choices about their care?

CASE STUDY 6.3

Zack was restless and angry. He never knew where this anger came from and was aware that the reason he was in the forensic mental health unit was because anger took him over, unexpectedly, at times. He never knew how he might react when these intense feelings hit him. He had harmed someone in the past during one of his bouts of anger. His sentence was to be carried out here in the forensic unit, rather than in prison, because it was felt that his problems were due to mental illness.

Zack did not want to hurt anyone ever again, and it was obviously

safer for other people for him to be here. Although he felt that he was in a therapeutic environment and not just a custodial one, this sometimes made his lack of freedom more pronounced. He did not have choices about how he spent his time and the system determined what time he got up, when and what he ate, when he was allowed to have exercise and when he went to bed. He felt like a caged animal with no rights, no choices and no ability to make decisions for himself.

Discussion

Zack was clearly in a situation where he had to be contained to protect the safety of others. Therefore, he had to comply with what the system dictated and could take no part in decisions that involved him in most areas of his life. Other people might feel the same way despite the fact that they are not legally required to be somewhere. For example, there are many people who are not able to care for themselves at home and, therefore, are cared for in a more formal setting. They might also lack many of the choices that Zack is lacking.

Older people with mental health problems might be in residential care, but their privacy should be respected as should their priorities at all times. Knocking on the door to someone's private room should not just be a formality where the nurse knocks and walks straight in. The individual concerned should have the opportunity to answer and invite the nurse to enter, or ask them to wait a moment, in the same way as we do in our own homes. A nurse should always respect what someone wants to be called rather than make assumptions. They might not want to be called by their first name, or they might want their occupation in life to be recognised by the terms Father, Reverend, Major or Doctor, and this again should be respected. Other people might want a choice about whether they have a bath or a shower, how often this is, and when it takes place. As long as there is a bath or shower available, staffing levels allow and hygiene is being maintained, then these choices should be available. However, too often decisions are made about what is easier for the service, despite the fact that choice is possible and would not be disruptive within the environment in which the person is being cared for. Mealtimes can be another time when no choice is available. Some people might choose to miss breakfast and have a lie in, and this would not be detrimental to their health. Others might not feel well enough to eat a meal, but might be able to tolerate a milkshake or a smoothie, and this could be possible within the resources available. In order for any of these things to take place, people have to be given options and genuinely asked what they would

prefer in order to make informed choice a reality.

As nurses, it is essential to realise how important choice is in relation to quality of life and what it means to individuals. Bowling and Gabriel (2007), in their study of older people in the UK, highlight 'health' as a key aspect of what quality of life means to individual older people. They found that people valued choices in life and saw these as 'empowerment, freedom, social participation and doing what they wanted to do' (p. 844). In a Taiwanese study, Yu-Ching, Ruey-Hsia and Shu-Hui (2006) supported this and found that older people in nursing homes said that empowering care was the most important predictor of quality of life. Choice is central to empowered care and this will be discussed further in Chapter 7.

As nurses, we face many dilemmas in nursing care, some of which surround the emotive areas of end-of-life and resuscitation choices. Dying with dignity is something we would all aspire to, and it is likely that we would see having choices about decisions in our final days as central to a 'good death'. We cannot predict how or when we will die in most cases – all we know is that our lives are finite. The point at which death becomes inevitable might not be immediate and might come at a point where we are unable to make choices for ourselves. Therefore, we would hope that nurses who are involved in our care would be sensitive, empathetic and respectful of us, and would be actively trying to protect our dignity. Someone who is in a permanent vegetative state, and has been for 10 years, might never have wanted their lives prolonged. However, it is impossible for someone who is unable to respond to make a choice about ending their life, or what measures should be taken if their condition worsens. This could involve not actively treating infections or increasing medical interventions, or not resuscitating someone. There have been key cases, widely reported by the media, around not prolonging life, which have involved withholding food or fluids. Some nurses and healthcare professionals have questioned the humanity of this; there is a narrow line between not prolonging life and actively helping someone to die. The British Medical Association (BMA 2002) has produced guidelines in relation to decision making for resuscitation and this emphasises the importance of a partnership approach involving the patient, their close friends and relatives and the multi-professional team caring for the person.

> You and your doctor will decide whether CPR should be attempted if you have a cardiopulmonary arrest. The healthcare team looking after you will look at all the medical issues, including whether CPR is likely to be able to restart your heart and breathing if they stop, and for how long. It is beneficial to

> attempt resuscitation if it might prolong your life in a way that you can enjoy. Sometimes, however, restarting people's heart and breathing leaves them with a severe disability or only prolongs their suffering. Prolonging life in these circumstances is not always beneficial. Your wishes are very important in deciding whether resuscitation can benefit you, and the healthcare team will want to know what you think. If you want, your close friends and family can be involved in discussions. In most cases, doctors and their patients agree about treatment where there has been good communication. (BMA 2002, p. 5)

We cannot always assume that all relatives or next of kin are striving for what the patient would have wanted, although this is often the case.

In order for compassionate and caring decisions to be made in relation to end-of-life issues, it is important for nurses to make sure that decisions are not based on their own beliefs and principles, but on an ethical basis that is as objective as possible. Nurses should aim to maximise and honour a person's choices and bear in mind that patients should, whenever possible, be treated as partners in any decisions concerning their needs and priorities.

THOUGHTS FOR YOUR PRACTICE

- How do you involve patients and clients in decisions about their care?
- How do you ensure that you offer as great a range of choices as possible?
- Do you feel that there are times when you put service needs before the choices of patients or clients?
- How do you work in partnership with people to find out what quality of life means to them?
- Do you ever feel that your own personal beliefs influence the way you present choices to patients or clients?
- How can you try to identify when this happens and how can you refocus possible choices around the patient's agenda?

KEY THEME TWO – PRIORITIES

CASE STUDY 6.4

Katy had spent the whole morning rushing around. She really enjoyed the diversity of her school nursing role, but there was a lot to fit into the relatively short day, when children and young people were more available because they were in school. She had been supervising an immunisation session that morning. She was trying to ease anxiety levels among the young people, who were likely to try to do the opposite, as well as ensuring the session was as efficient as possible. This was always a challenge.

She had then driven the short distance to another school to see Adam, who had been diagnosed with diabetes a few months beforehand. Adam was eight years old and he was already able to use the blood glucose monitoring machine and understand the readings to a level that he could work out the insulin dose he needed. She thought that he had done very well in the circumstances. He was able to give his own injections, but he had not got enough confidence yet to give the injections on his own and nobody at the school felt able to take on this role. Katy was genuinely impressed with how much Adam had achieved as he also had to cope with accepting the fact that he had a health condition that would be with him for life. However, she felt that she was there more as a reassurance than as a nurse. She knew that soon Adam would have enough confidence to do this on his own, but, although she saw this as a priority, at the moment the daily visits to the school were putting quite a pressure on the school nursing service. She was also aware that there were increasing pressures on the service including more children developing long-term conditions, more mental health issues among young people and younger children, a rising teenage pregnancy rate, increased incidence of sexually transmitted infections in the school-age population and more children with special needs. The service was under immense pressure, and priorities would have to be made from the service point of view, which would not necessarily be based on the needs of the children and young people in schools she covered.

Discussion

This case study highlights the dilemma that a nursing service has in trying to meet an increasingly wide diversity of needs within a financially constrained healthcare environment. Adam has done very well to progress to the point where he was able to work out his own insulin dose, draw it up into a syringe and inject it himself. Understandably, he is still lacking confidence, and Katy might have been visiting to carry out more of the care herself if he had not become independent so fast. The fact that he is largely self-caring means that her skills are not needed to such a great extent. However, this means that it is less easy to justify her nursing time in Adam's situation. Her experience enabled her to realise that his developing confidence might be easily damaged and that spending time at this point was not only a priority for him, but for the school nursing service, because he would become totally independent much more quickly.

In the previous section, we discussed the importance of offering choice to patients and clients. However, the reality of healthcare provision is that choices need to be balanced with service resources, targets and priorities. Therefore, in the following section, we will be discussing whether we know what our patients' and clients' priorities are and whether we actually base our practice around these.

Do we know what the priorities of our patients and clients are?

CASE STUDY 6.5

Brian had known for some time that his drinking was out of control. He was aware of what an important part alcohol was playing in his life. If he was not actually drinking, he was either recovering from the effect of his last drink or thinking about when his next drink would be, sometimes both at the same time. This was not going to be a long-term solution to his loneliness and distress following the death of his beloved wife Val. They had always been so close and had done everything together, and her illness had been so sudden and so short that he had found himself on his own before he had really known what was happening. He knew that Val would be very sad if she could see how his life was at the moment, and he knew that he owed it to her, as well as himself, to stop drinking before he lost his job and probably his home.

He had made an appointment to see Hamed, the Occupational Health Nurse, with some trepidation. After all, Hamed was employed by

the company too, and he really was not sure about whether this could be a confidential discussion or not. Brian knew that he was not putting anybody else at risk within his workplace by his drinking, but he was damaging his own health.

Hamed greeted Brian in an informal manner and immediately explained that any conversation between them would be confidential, unless there were any safety issues involved, in which case they would discuss a way forward that would hopefully solve the immediate situation. Only in extreme circumstances would Hamed have to report a situation to someone within the company.

Brian immediately felt more relaxed. He had met Hamed only on the odd occasion before, but had never talked to him on a one-to-one basis. He knew that Hamed was Muslim and, therefore, was unlikely to drink at all, but he felt that Hamed was someone who was unlikely to judge him for the fact that he was drinking.

Hamed said that he could see that Brian was unhappy and Brian told him about how much he missed Val. To his embarrassment he started to cry, but Hamed carried on talking gently to him about the person Val had been, what their relationship had been like and how he was coping with his immense loss. Brian knew then that Hamed would understand and told him how worried he was by his drinking. Hamed asked how much he was drinking and did not seem shocked by the reply. Brian told him how much he wanted to stop drinking, but that he needed help. Hamed was reassuring and said that it was not uncommon for people to develop negative coping strategies at times of stress or bereavement. He gave him some numbers to ring for an alcohol service and for counselling and then said that he would like to keep in contact too, so that he has someone to support him in the work environment. Brian felt so relieved, not only because help and support were available and he thought the counselling was a good idea, but also because Hamed was prepared to support him while he was at work. He felt that he really would be able to fight his need for drink with appropriate support.

Discussion

When he went to see Hamed, Brian's priorities were about being able to trust him. He needed him to be non-judgemental, sensitive and supportive, but he also needed the conversation to be confidential. Hamed was aware of this and he started off by discussing where confidentiality started and ended. Nurses

need to be aware of the importance of having this conversation at the start of their relationship with someone, because wrong assumptions can be made. A patient can assume that everything will remain confidential, despite the fact that they have raised issues that put others at risk. If a nurse, midwife or health visitor discusses how they have to protect the safety of vulnerable people and children and therefore confidentiality cannot be protected in situations where there is obvious risk, then everyone is clear from the start. In occupational health settings, a nurse has to be able to make difficult decisions about the safety of others. If Brian's drinking was putting others at risk, because he was driving or operating machinery, Hamed would have needed to take this into account in relation to the confidentiality of their discussions. Therefore, the fact that Hamed raised this at the start of the conversation had the effect of reassuring Brian and made it possible for their future conversations to be based on an informed understanding.

Hamed then started to develop a trusting and supportive relationship with Brian. His non-judgemental and supportive approach was key to Brian feeling that he could discuss his problems openly, including his use of alcohol as a negative coping strategy. Therefore, Brian could start to trust Hamed. This trustworthiness also involved Brian knowing that Hamed was operating in an evidence-based way, and was knowledgeable about up-to-date services, treatments and options. A trusting professional relationship is also based on a nurse being professional in appearance and attitude, which is important for patient confidence and helps to reduce worry and concern. This was clearly evident in the developing relationship between Brian and Hamed.

Hamed's relationship with Brian was based strongly on psychological support, good communication, empathy, sensitivity and kindness. He was aware of available resources and could coordinate these in a way that was meaningful for Brian's situation. Hamed also stressed his accessibility and availability, and he offered ongoing support, which allowed Brian to feel that there would be continuity of care. He was clearly there to help Brian to achieve his goal in relation to coping with his use of alcohol. During their consultation, all of these components of care were based clearly on Brian's needs and priorities, without compromising Hamed's professional nursing practice.

This focus on patient, carer and client priorities was clearly identified in an Australian study by Gullick and Shimadry (2008), who asked for patient and client views on their experiences to improve quality of care. They used the Picker criteria of the nine valued domains of healthcare (Coulter 2006), which are:

- fast access to reliable healthcare;

- effective treatment delivered by trustworthy staff;
- involvement in decisions, and respect for preferences;
- clear, comprehensible information throughout the journey;
- attention to physical and environmental needs;
- emotional support, empathy and respect;
- involvement of, and support for, family and carers;
- smooth transition to, and support for, self-care;
- continuity and coordination of care.

In their study, Gullick and Shimadry (2008) found that the three most positive dimensions, according to the patients and carers, had been fast access to reliable healthcare, effective treatment delivered by trustworthy staff and the involvement of, and support for, family and carers.

The most negative experiences had been in relation to lack of clear, comprehensible information, lack of coordination and continuity of care and lack of attention to physical and environmental needs. Exclusion from care planning, lack of partnership, lack of communication and consultation were particularly highlighted.

In Brian's situation, he was respected and involved in decisions about his care within a trusting and therapeutic relationship. Hamed communicated his understanding of how the loss of his wife had devastated Brian and had a negative impact on his health and lifestyle choices. Hamed had been accessible to Brian at a time when Brian felt able to discuss his situation, and had been emotionally supportive to him. Furthermore, Hamed offered him continuity of care via his ongoing relationship with Brian.

The importance of continuity of care is highlighted in a Canadian study by Haggerty, *et al.* (2003). Continuity is mainly viewed as the relationship between a single practitioner and a patient that extends beyond specific episodes of illness or disease. Continuity implies a sense of affiliation between patients and their practitioners, often expressed in terms of an implicit contract of loyalty by the patient and clinical responsibility by the provider. Two core elements are:

- care of an individual in how individual patients experience integration of services and coordination;
- care delivered over time, which can be variable.

Haggerty, *et al.* (2003) say that for continuity to exist both elements must be present, and care must be experienced as connected and coherent. This was clearly the case in Brian's situation and his priorities had been recognised

and met by Hamed, who had been able to identify Brian's priorities since the beginning of their conversation.

THOUGHTS FOR YOUR PRACTICE

- How do you know what your patient's priorities are?
- How do you ensure that you focus on these throughout your conversations with patients and clients?
- Do you sometimes feel that time constraints and your clinical priorities take precedence over your patients' priorities?
- How can you ensure that your patients' priorities remain paramount within the care they receive?
- Do you have explicit discussions about the nature of confidentiality within conversations with patients and clients?
- Do you have these discussions early enough in your professional relationships with people to ensure that there is clarity for all concerned?
- If not, how do you need to build this into your practice in a different way?

Do we genuinely base our practice around patient and client priorities?

CASE STUDY 6.6

Jenny was lying in bed behind the screens feeling terrified. She had never had an operation before and she was on her own and was feeling more like a child than the 16-year-old that she actually was. She was on her own and just wanted her mum, but of course that was not possible because of the reason she was here. She had felt that a termination of her pregnancy was the only way out of her desperate situation, but now she was not so sure.

She had not told her parents about that terrible night and she had been in denial for some weeks once she had finally known that she was pregnant, so this was probably the last opportunity for her to have a termination. She had ultimately plucked up the courage to tell her doctor, who had made an urgent referral to the hospital. Everything had gone very quickly from there, and now here she was waiting for the operation to take place.

They had asked her if she was sure that this was the decision she wanted to make and she had been absolutely sure. After all, how could you keep a baby who was not born out of love or even passion, but from power and violence? She felt that it must have been in some way her fault, that she had been giving out the wrong signals and that, therefore, she alone should suffer the consequences. She had been drinking that evening, but not enough to dull her senses or her decision making. She had gone to the toilet and, on the way out of the bathroom, her way downstairs had been blocked by a group of boys who she knew from school. They were in the year above and she had always secretly fancied Rob, so it must have been her fault what had happened then. They were all laughing and joking as they pushed her and Rob into an empty bedroom. Rob looked at her and she knew that he had taken something more than alcohol, although he had been drinking quite a bit too. His eyes were vacant as he pushed her down on the bed and he just ignored her efforts to get off the bed or her attempts to make him stop. She tried being angry, pleading with him, hitting him and then just cried as she accepted the inevitable. He just walked out of the room afterwards and she heard the group laughing as they went down the stairs.

She had lain there, crying, for some time and then ran down the stairs, ignoring her friends who were asking if she was alright. She did not know how she had got home, but she did, and she ran straight up the stairs and had a shower, then a bath, then another shower, but nothing made her feel clean. In the days afterwards, she had become withdrawn from her friends, brushed off her parents' concerned questions and hoped that she would not get pregnant or start getting symptoms of a sexually transmitted infection. She knew that her parents would have wanted her to go to the police and she could not bear that – all the questions and humiliation and perhaps silent blame.

So here she was, alone and crying, when Fiona, the nurse who had admitted her that morning, came to say that it would not be long until she went up to theatre.

Fiona knew as soon as she saw Jenny that something was very wrong. It was a busy list and her priority was on ensuring that everyone was prepared and ready to go up to theatre at the allotted time. However, she could not ignore Jenny's distress and had felt from the time she had met her that something was wrong. Telling Jenny she would be back in a minute she went to speak to a colleague and then back to talk to Jenny.

When Fiona went home that night she could not stop thinking about her day and about Jenny. Having said to her colleague that she needed to spend some time with Jenny because she felt that she could be in the process of making the wrong decision by having a termination, she then spent a long time talking to Jenny. She postponed the operation for the day and then after hearing of her horrendous experience, she persuaded Jenny to try to tell her mother. Jenny's mother arrived very distressed at the fact that Jenny was in hospital at all, and she became more distressed when she heard what had happened to her. Although she was strong for Jenny at the time, she and her husband had needed support later in the day. Fiona had coordinated discussions with her doctor, who had come down at the end of the theatre list, and had been very supportive and sympathetic. With Jenny's consent, she had also phoned the police who had arrived in the form of a sensitive officer who specialised in domestic abuse and crimes of a sexual nature. By the end of the day, Jenny was managing a brief smile and actually gave Fiona a quick hug to thank her. She went home with her parents and Fiona carried on with all the usual ward demands of pre- and post-operative care. She knew that her colleagues had had to cope with all these demands with one less team member, which had put them under immense pressure, but as a team they felt that they had made the right decisions and focused on the right priorities during a day that had brought increased and unexpected challenges.

Discussion

Jenny's situation is very distressing, and the fact that she is just about to go to theatre for her termination when this case study takes place puts additional pressure on the situation as there are clear time constraints. Fiona needs to act immediately if she to prevent a termination talking place that might not be the decision that Jenny actually wants. This involves sensitive and dynamic decision making, problem solving and prioritisation. It would be very easy for Fiona to perceive Jenny's distress as pre-theatre stress and carry on prioritising the day's work, ensuring that everybody is prepared adequately for their operation on time. However, being a nurse involves being dynamic in changing situations and this means reprioritising as necessary. These decisions need to be made based on conflicting professional demands, and this should include balancing the priorities of different patients and clients.

Fiona needs to ensure that the ward priorities are met and this involves

discussion with other team members. This allows her to find time in a busy ward situation to prioritise Jenny's needs. The team supports Fiona in redefining her priorities, but even in relation to Jenny herself there are conflicting priorities. Fiona needs to postpone Jenny's operation (ensuring that this is also what Jenny wants) and contact relevant personnel. She also needs to seek Jenny's consent to arrange additional support for her – primarily her mother in this case. If this was inappropriate then other members of the multiprofessional team, such as a social worker or a member of the clergy, might be acceptable to her. Social and medical needs all have to be balanced alongside organisational needs of the ward and theatre. This is a very skilled role and the situation could have ended in many different ways, which may have resulted in Jenny's needs and priorities not being central to decisions made.

In other situations, individuals' priorities cannot always be predicted and therefore need to be discussed. For example, people with long-term conditions are living longer, and children with life-limiting illnesses are surviving into adulthood. It is crucial, therefore, to 'remember that their priorities in life are likely to be different from those of healthcare professionals. Their personal stories tell of an alternative approach to living with chronic illness in which decisions are carefully considered within the life context of individuals' (Badlan 2006, p. 269).

In some countries, individuals can make different decisions about how the resources for their care are spent. This involves them knowing what services are available and how to access them. It can be wrongly assumed that everyone genuinely wants to self-care, when some individuals might not have the confidence or the motivation to do so. In addition, the priorities of the person with a disability or long-term condition might not be the same as that of their carers. When their friend or relative is away from the home, a carer might need that short space to have some precious time for themselves. If this does not happen, the whole care support system might fall apart. Therefore, priorities need to be carefully managed to ensure that all needs are met as far as possible, while still staying within the prearranged budget. The person with the disability or long-term condition might not be able to indicate what their choice would be, and in these cases a nurse might need to act as an advocate. This will be discussed further in Chapter 7.

Annells and Koch (2001) support the New Zealand study of Carter, *et al.* (2004), which states how important it is to accept people's priorities that are based on their feelings, values, norms and beliefs, because this is essential in ensuring that patient choice is central to decision making. This could be crucial to end-of-life decisions where, for example, a patient wants to prioritise

dying at home, which might not fit with their daughter's priority of trying to keep the home situation as normal as possible for her children, as they are about to lose a close family member. Again, great skill is needed on the nurse's part to ensure that a compromise can be reached where all feel comfortable with the decision.

Therefore, it is important to work in partnership with individuals and communities so they can feel able to express their choices and priorities. However, it is also important not to raise expectations about what is possible to a point where people expect and demand services that cannot be provided within the resources available. Access to health information can be unreliable and misleading and patients' knowledge, competence, desires and limitations need to be respected. Staines (2008) says that patients can demand inappropriate treatments and products and can become angry and offensive when they are making their demands. Individual views should be respected, but this must be a two-way process as people need to realise that finances are finite, and also that opinions they have read might not be evidence-based and might not be appropriate for them or their condition.

As nurses, we need not only to seek ways of finding out what patients actually want or need, but also to balance these needs with what can realistically be provided within the healthcare systems in which we practise.

THOUGHTS FOR YOUR PRACTICE

- Think of a time when your organisational priorities have wrongly taken precedence over a patient's priorities.
- Do you think that on reflection there could have been better ways to take both sets of priorities into consideration?
- Do you feel that sometimes patients have unrealistic ideas about services or care that could be provided?
- If so, how do you try to address this?
- How do you increase someone's ability to make informed decisions about their health?
- How to you attempt to work with patients and their carers to try to resolve differences in their priorities and needs?

SUMMARY – LINKS TO COMPASSION AND CARING

In continuing our discussions of what compassionate care means in nursing practice, in this chapter we have focused on further aspects of person-centred care. This discussion has centred on the concepts of **choice** and **priorities**. Choice is important because it gives people power when they are in situations where they feel disempowered. Prioritisation is necessary in a resource constrained healthcare system where money needs to be spread as equitably as possible, bearing in mind the diversity of health needs to be met.

As nurses, we need to work in partnership with people to ensure that, as far as possible, these choices are real and not rhetoric and that people have as much information as they need to make informed decisions. This means that we need to change the power relationships so that we can work in concordance with people in our care. Nurses need to base their discussions on ethical principles, where they genuinely respect the beliefs and values of others, rather than assuming that everyone has the same priorities in life that they do.

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