Answer Guidance

# Chapter 13: Patient, service user, family, and carer perspectives

## Activity answer guidance

### Activity 13.1

Take a few minutes to identify all the terms you have heard used to refer to those people who use the health service.

Are there any you feel are better than others? Why is this?

#### Answer guidance:

*Some words can be considered passive, for example, “patient,” while other terms such as “client” or “service user” imply shared responsibility and equal power. Words tend to convey the environment in which the care takes place. For example, “inpatient” is a common term used to describe someone in a hospital. Therefore, the term ‘patient’ is often associated with an illness or condition.*

### Activity 13.2

Service user, patient, client, survivor, or user:

How do you refer to those you deliver care to?

Why is this?

Do you think the same findings would emerge if other groups of people who use health services were asked the same questions?

What are your reasons for this conclusion?

#### Answer guidance:

*The terms used to describe service users tend to differ across professional groups and specialties. In the main, this is a result of professional identity and the extent to which the professional and service user share power within the relationship. For example, because of the illness connotations, it would be unusual to hear a mental health practitioner describing a service user as a “patient.”*

### Activity 13.3

Reflect on the care you have recently provided for one of your patients:

• How did it compare with the features of person-centred care identified by Manley et al. (2011)?

• What more could have been done to make the care and support more person-centred?

• What more could have been done to make the service more person-centred?

#### Answer guidance:

*Your reflection might show some or all of the features of person-centred care identified by Manley et al. If it didn’t you might want to analyse what was different and how you, as a student, might improve the situation. The reflective account should help you to look more closely at the relationships within the service and the factors (power, compassion, communication) which facilitate effective patient-centred care.*

*Manley et al. (2011) refer to “person-centred care,” and identify the following features of person-centred care:*

• *knowing the patient as a person*

• *enabling them to make decisions based on informed choices about what is available*

• *shared decision-making rather than exerting control over the patient*

• *providing information that meets the individual needs of the patient*

• *supporting the person to express their choices*

• *ongoing evaluation to ensure that care remains appropriate for the individual.*

## Case study answer guidance

### Case study 13.1: Mark

‘I was diagnosed with HIV 20 years ago so I’ve experienced many changes, not just in the treatment options available but also in the attitudes of healthcare workers towards people with HIV. I was given my diagnosis in a sexual health clinic and although everyone was very pleasant, I found attending the sexual health clinic reinforced my feelings of being ‘dirty’ or having “done something wrong.” I was encouraged to join support meetings and attend service user groups but, from a purely personal perspective, I didn’t really want to talk about my sexuality or meet other people with the same condition. I just wanted to be treated as an individual and get on with my life.

Maybe nurses need to question their assumptions about the type of support that people with HIV need and be aware that just because people share a diagnosis, they won’t automatically have something in common. While some people with HIV want to focus on their condition, others try to ignore the virus and only think about it when a health check is due.

For me, it’s important that when I have my hospital appointment it feels like an informal, friendly catch-up with a familiar face. Remembering my likes and dislikes, treating myself as an equal, and valuing my opinions about the care I would like to receive are important to me.

Consider what Mark says about how he would like support to be provided. How can nurses support groups of patients while also addressing individual needs?

#### Answer guidance:

*It is important to treat everyone as an individual with unique likes, dislikes, fears, and anxieties. Spending time getting to know the person, finding out about them, and understanding what they feel is important will help you to encourage autonomy and create a therapeutic relationship.*

### Case study 13.2: Sarah

We found out that Sarah had learning difficulties when she was 3 years old. As she was our first child, we hadn’t realised she wasn’t doing the things she should. We knew she wasn’t doing as much as the babies of some of our friends, but everyone told us she was “placid” or “contented.” It took a long time for Sarah to be diagnosed with learning difficulties and even now we don’t have a name for her disability; we just know that she needs a lot of help with things the rest of us take for granted. When Sarah was 4, she was admitted to the hospital for tests (she has epilepsy). We were very anxious as she’d never been in hospital before and is easily upset.

Whenever we asked the nurses anything about her condition or the tests they were doing, we were told we needed to speak to a doctor. This was very frustrating as I wanted to be with my wife in case the news was bad, but I’m self-employed and didn’t want to keep taking time off and losing money. The annoying thing was that when we saw the paediatrician, she said there wasn’t anything new to tell us. Why couldn’t the nurses have told us this? We knew if the news was bad the nurses couldn’t tell us, but they might have given us a few words of reassurance or encouragement. There needs to be more transparency about what nurses can or can’t tell you.

The other problem we have is that although we know what Sarah can, can’t, or won’t do, whenever she goes into the hospital her routine is changed. She will soon be a teenager; as she gets older it is more difficult for my wife and me to lift her, so it’s really important to get her to do as much for herself as she can, but every time she comes home we have to start again. It feels like we are working against the hospital.

• How could the nurses work with the family to promote better communication?

• What could be done to maintain Sarah’s routine as much as possible while she is in the hospital?

#### Answer guidance:

*Sarah’s situation could have so easily been resolved with effective communication. Planning care collaboratively with Sarah’s parents would have improved this situation. As her primary carers, Sarah’s parents would have been able to advise on Sarah’s daily routine, likes and dislikes, etc. thereby ensuring Sarah received holistic care while reducing tensions between the family and the hospital. Recognising and valuing Sarah’s parents as key members of her support team would have helped achieve this and also ensure a smooth transition between hospital and home.*

### Case study 13.3: Jag

“My name is Jag, I am 16 years old and recently I have been diagnosed as having diabetes. I had been feeling very tired and unwell for some time and my mum put this down to the fact that I had been growing a lot recently, doing a lot of sports and also working hard at school for my exams. However, when it seemed to be going on she decided that I needed to go to the doctor. They did some tests and also sent me to the hospital where I was told that I had diabetes. I was really shocked when they told me this because I thought that diabetes was something that only happened to older people who were overweight. I was also really scared as I thought it was going to stop me from doing a lot of things I enjoyed. I didn’t want to be seen as different or “ill.” However, the specialist nurse saw me both on my own and with my mum. She explained to me the type of diabetes I have and also what it would mean to my day today. She explained in a way that I could understand but didn’t treat me like a child which was good: she stressed that I would need to take responsibility for managing my condition but there would be a lot of support for me. As I like being active she explained to me the importance of making sure that I eat the right foods, monitor my blood glucose levels, and told me what to do if the levels go too high or go too low. Like most teenagers, I like using my mobile phone a lot so we sorted out together how I could use my phone to set reminders to do things like checking my blood glucose and taking my insulin. My mum also explained these things and told her what she needed to do to help support me. This was really helpful as although it was good to be treated as an adult it was also good to know that there was someone else at home who understood what I needed to do. So far I have managed quite well—although it has meant a lot of changes the fact that things were explained to me has helped a lot. Also, I know that if at any time I have got any questions or concerns I can always get in contact with the nurse as she gave me her phone number and email address and I have these on my mobile phone. It feels as though we have a partnership which helps me deal with my diabetes.’

• How do you think this nurse has empowered her patient?

• What elements of care could you emulate in your own practice?

#### Answer guidance:

*In this scenario the nurses demonstrate the key elements needed for person-centred care described by Manley et al. Success involved working in partnership with Jag, making sure Jag understood the diagnosis, having the skills and knowledge needed to help Jag learn how to manage the condition but reassuring Jag there was support from Mum and the nurse if and when it was required. By empowering Jag, the nurse promotes autonomy, leading to improved adherence and better diabetes control.*

*Being knowledgeable, acting as an advocate, and allowing the service user to set the pace of care, are all essential nursing skills.*