

KEYWORDS INFECTION CONTROL | PATIENT EXPERIENCE | OLDER PEOPLE | GASTROINTESTINAL

Using the lived experiences of patients with *Clostridium difficile* infection to improve care

Interviews were conducted with older people who have *C difficile* infection to increase understanding of their needs and experiences from their own perspective

AUTHORS Maurice Madeo, MSc, RN, is deputy director for infection prevention and control; Miriam Boyack, BSc, RN, is infection prevention and control practitioner; both at Doncaster and Bassetlaw Foundation Trust.

ABSTRACT Madeo M, Boyack M (2010) Using the lived experiences of patients with *Clostridium difficile* infection to improve care. *Nursing Times*; 106: 36, 10-13.

Aim To better understand the lived experiences and needs of patients who have *C difficile* infection.

Method Interviews were conducted with 15 patients in an acute hospital using an interpretative phenomenological approach.

Results Experiences vary and depend on the severity of each individual patient's condition, among other factors. Four main themes were identified: physical suffering impacting on activities of daily living; lack of control over bowel function; a lack of understanding of the illness; and issues around privacy and dignity.

Conclusion Nursing and medical staff need a better understanding of the experiences of patients who have *C difficile* in order to provide them with the knowledge, reassurance and dignity they need.

INTRODUCTION

The number of people aged 65 years and over has more than doubled since the 1930s and is expected to rise further over the next 20 years (Department of Health, 2001). Projections also suggest that the number of people aged 85 and over will more than double within the next 30 years. This will have a significant impact on the way healthcare staff plan and deliver care, as older patients are more likely to develop complications during hospitalisation (DH, 2004). This risk was reflected in the latest UK healthcare associated infection prevalence study. Almost half of the patients surveyed were aged 75 or over, with older patients more likely to develop an infection (Smyth et al, 2006).

C difficile is one of the most common

infections in older patients. In 2007, there were over 55,000 cases, which represents a 50-fold increase since 1990. More recent data suggests the figure has since fallen to around 30,000 cases annually (National Audit Office, 2009). Over 80% of those who develop *C difficile* are aged 65 years and over, and reducing the rates of this infection is a national priority (DH, 2008).

BACKGROUND

C difficile was first identified as a cause of disease in 1978 (Larson et al, 1978), but the bacterium can be present in the gut without causing any symptoms (Kelly et al, 1994). An estimated 20% of people aged over 65 harbour *C difficile*, increasing their risk of disease when exposed to antibiotic treatment (Bartlett, 2006). *C difficile* is now recognised as an important healthcare acquired pathogen.

The bacterium can produce toxins that cause extensive tissue damage to the walls of the intestine. Symptoms include diarrhoea, abdominal pain and, in some, bowel perforation. It can cause a wide spectrum of disease, ranging from asymptomatic carriage and mild to severe diarrhoea to life threatening pseudomembranous colitis (Hall and Horsley, 2007), and patients' experiences will differ.

The infection is associated with considerable morbidity and mortality (NAO, 2009; McFarland et al, 1999) – in Maidstone and Tunbridge Wells hospitals, up to 90 mostly older patients may have died as a direct consequence of contracting it (NAO, 2009).

Few studies describe the experiences of patients with HCAs such as *C difficile* and those that do exist tend to focus on MRSA or the psychological effects of isolation (Criddle and Potter, 2006; Mattner et al, 2006). Previous studies have shown that the reactions of patients who acquire an HCA are varied and influenced by many factors, such as the media, educational materials, staff knowledge of infection control, cultural beliefs and previous hospitalisation (Merle et al, 2005).

AIM AND METHOD

This study set out to increase understanding of the needs and experiences of patients with *C difficile* infection, from the perspective of older people in hospital.

We used an interpretative phenomenological approach to describe and interpret the patients' lived experience (Berg et al, 2006). Although there is no universally accepted method for data collection and analysis for this type of study (Draper, 1997), Van Manen (1990) offers six research activities to assist data analysis:

- Turning to a phenomenon that seriously interests us;
- Investigating the experience as we live it;
- Reflecting on the essential themes that categorise the phenomenon;
- Describing the phenomenon through the art of writing and rewriting;
- Maintaining a strong and orientated relation to the phenomenon;
- Balancing the research context by considering parts and whole.

Data analysis began as soon as the first interview was transcribed from audiotapes. The whole text was examined for themes; parts of the text and the two interpretations were then compared to identify conflicts and to ensure full understanding.

Patients aged over 65 with laboratory diagnosed *C difficile* infection and who had been in hospital for more than two days were recruited using a purposive sampling technique. All participants had been inpatients in the same large acute hospital between October 2008 and March 2009.

In all, 15 patients (four women and 11 men), aged 65-89, were interviewed twice by the same researcher, first to explore their experiences and then to discuss the transcripts and give them the opportunity to clarify or amend any of the findings.

RESULTS

The transcripts were read numerous times and textual analysis was conducted using the computer software package NVivo version 7.

This led to the identification of four key themes:

- Physical suffering;
- Lack of control over bowel function;
- Understanding of illness;
- Privacy and dignity.

Physical suffering

All 15 participants mentioned the negative effects of the infection on their normal activities of daily living, including reduced appetite, abdominal pain, lack of energy and fatigue.

Four reported a significant loss of appetite during the acute phase of the infection, which, for them, signified deterioration in their health and was a marker of illness severity.

“... if I have something to eat it will upset my stomach tonight, and it does, you get frightened and they come and say to you ‘Would you like anything to eat?’, ‘No please I’ll just have a glass of hot water’ ... that’s what I’ve been doing. I’ve been frightened to eat.” (P1)

“The main thing I noticed was the complete lack of interest in my food which is not like me at all considering the food here is surprisingly good.” (P5)

“... nothing tastes right, my mouth is so dry and it tastes horrible but it could be me. I eat porridge and have rice and custard, things like that. I can’t drink that orange cordial – just a whiff of that and it goes straight through me – so I now avoid it, just stick with water but that tastes a bit like minerals so [is] not pleasant to drink.” (P11)

“I’ve gone off my food since this infection, not sure why that is. It may be because every time I attempt to have something to eat, I get these cramping sensations and some of the time it triggers me wanting the commode.” (P14)

One of the key features of *C difficile* infection is its potentially debilitating effect on the patient due to the production of toxin A (a potent enterotoxin that causes fluid secretion, mucosal damage and inflammation of the gut) and toxin B (a cytotoxin that causes the characteristic explosive diarrhoea) (Hall and Horsley, 2007).

Five participants reported symptoms of fatigue, which were directly attributed to the infection.

PRACTICE POINTS

- Patients with *C difficile* infection face four main issues: physical suffering; lack of control over bowel function; understanding of illness; and privacy and dignity.
- Most patients struggle with the experience of diarrhoea during the acute phase but are unlikely to discuss their concerns.
- Good staff–patient communication is needed to ensure patient dignity and their overcoming feelings of shame and embarrassment.
- Patients would benefit from more written and verbal information about *C difficile*.

“You run to the loo, lose your appetite and then got no strength, lethargic. I’ve got a radio and TV from my family, you just start to look at a TV that is not even switched on. You are that lazy that you cannot be bothered and having problems concentrating ... I think the infection saps you that much that you would rather doze off if you can, rather than do anything else.” (P2)

Lack of control over bowel function

The majority of participants discussed the horror of being unable to control their bowels. They described it in a number of ways, such as the frequency of bowel movement, the distance to the toilet, feeling like a nuisance to nursing staff, and being embarrassed by the smell produced.

“It seems to take charge, you get the warning that you all get [to go to the toilet], if you don’t get that you’re in trouble, but if you’re normal, you get the warning and you say right I’ll do this and that and the other and then I’ll go, but with this condition it’s unbelievable...” (P2)

“The main thing is diarrhoea of course, I’ve had diarrhoea before in my life but I’ve very rarely known it to go on for so long as this. Usually, when I get diarrhoea, it goes on for a few hours but this has been going on for a few days ... I’ve been passing a motion every two to three hours for several days but recently it’s got much better.” (P5)

“I had diarrhoea seven times a day and sometimes I went every two hours and occasionally twice in half an hour. You know it took me all my time to get out of bed to get onto the commode, because I did not want to mess the bed.” (P8)

“The diarrhoea started about 10pm. From that bed to that toilet does not seem very far right now but when you have diarrhoea believe me, it is ... I just made my way to the toilet six to eight times and did not manage to get any sleep at all during the night.” (P15)

A number of patients knew their bowel movements were abnormal not only because of increased frequency but also because of the smell associated with the infection. *C difficile* infection is generally associated with a distinct barnyard odour (DH, 2008).

“... the smell is absolutely atrocious, that’s what made me suspicious at first. Also the colour was different again ... and that’s what I said to the nurse, that there is something wrong here. She gave me a sample pot and that’s how it started.” (P7)

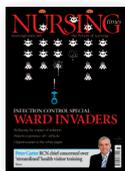
“My stools are still smelly and it still lingers; maybe other people can’t smell it when they come in but I can smell it all the time and it’s not very nice. A chap came in yesterday to clean the toilets, naturally I felt guilty, I said what are you doing, he said I’m just giving the toilet a good clean. Maybe it is a thing that they always do, but I felt guilty because he was doing it. I thought it was to get rid of the smell...” (P10)

“The problem is there is no ventilation in the toilet so you have to clear the smell yourself, so basically I was doing the door, wafting it open and closed to get some draft, that’s why the window is always open. No one else does go in there, only the cleaner, and I sort of apologise to the cleaner...” (P15)

Understanding of illness

Patients are heavily influenced by the media, especially newspapers and television, when it comes to HCAs (Madeo et al, 2008).

Levels of understanding of microorganisms will vary and depend on factors such as the level of education, personal experience and workplace knowledge (Merle et al, 2005). The level of understanding about the infection varied among the 15 participants. Some expressed concern with the diagnosis and the impact it would have on their recovery. There was also generally a poor understanding of how the infection was acquired – only one respondent made the link between the use of antibiotics and increased risk of developing *C difficile* infection.



practice research report

"I was worried about the infection as I had not heard of it before. I thought, well, was it going to affect the scars and the operation I've just had, will I have to go back to theatre and have another operation? It did frighten me ... I think it's the operation that gave me the infection. I think at one point they had to take my stomach out while they did this operation and then put it back ... that's where you get your bugs from." (P1)

"The staff on the ward are fantastic. They have a job to do and it's done very well. This kind of thing is very quickly forgotten by people because it's probably not a very nice subject talking about diarrhoea and the illness and the like. I think it should be looked at and people should be made more aware of it because, when you come to hospital, you do not realise what it is, how it goes and where it goes to. There is a lack of information about the condition as I certainly have not had anything..." (P12)

Some participants said they had received sufficient information about their condition and seemed to have a better understanding of it after this.

"The doctor told me this morning they have given me some antibiotics for my chest infection and this may have caused the bug in my gut to get worse and she said if that happens we'll stop the antibiotics for the chest infection..." (P4)

"They tell me if they get a microbiologist on board then they can cure this *Clostridium difficile*. The sooner they do that the better, so I can get my appetite fully back. I did not know that much about the infection, but I have learnt a little more since then, that the antibiotics kill off the good bacteria in my bowel..." (P12)

Privacy and dignity

The literature suggests that patients who are infectious and isolated are prone to loneliness and depression as well as feeling stigmatised (Oldman, 1998).

One of the negative effects of isolation is the removal of familiar objects and routines, which may evoke fear, anxiety, depression, and rapid mood changes. It has also been noted that patients suffering from an infection commonly experience some of these psychological manifestations.

Participants in this study had mixed feelings about being placed in isolation, the

effects of which seemed dependent on the severity of their symptoms and their ability to cope with being alone.

"The biggest bonus of being in this room now is if I need to dash I can go in private, without disturbing anyone now ... I can live with myself, although I did enjoy the company in the other place as there were a bunch of men of a similar age and we could have a laugh and a joke. It's company, isn't it? But it was such a walk to the toilet – 30 to 40 yards and, when you are going 10 times a day or more, I think they [other patients] would be getting fed up of me." (P2)

"I was on the ward with four other patients and it was really nice because I do like company and one afternoon they shunted me out of the ward and shunted one of the other women out of the single room for me. When I asked the reason why they said I had got this bug and it was causing the diarrhoea and naturally they did not want it to infect anybody else, and that's how I got to be moved in here. I hate being on my own. Then again, the nurses are good, they do come and keep you company sometimes but they have not got the time to come and mess about with me when they are doing their jobs, have they?" (P10)

Many respondents with moderate to severe diarrhoea found the experience affected their dignity. Patients are more reliant on healthcare staff during this acute illness phase, resulting in some feeling helpless and embarrassed (Wilson, 2007).

"The nurses have to come and put me on the bedpan or commode now because I've only got one leg. When I've had my bowels open they have to clean me up, change my sheets if I've made a mess of the sheets. They try and explain to me that it does not matter and it's not my fault but it does not sink in that the nurses understand what I'm going through so I end up feeling really ashamed of what I am doing, a man of my age messing the bed ... I'm not blaming the nurses, when they come to clean me up, if they pass a comment about the smell because I can understand it. It used to make my eyes water at first and some of them are only young so I suspect they are not quite used to things like that yet. If the staff had not been as good as they are, I don't know what I would have done." (P1)

"From my own point of view I wish they could do something about the diarrhoea quickly. From the nurses' point of view, what I don't know is how much of this is part of their job because they seem to be able to take it into their stride. There are some nurses who will talk to me when I'm being cleaned up and some that just get it done as quickly as possible and leave. Some will say 'Don't you worry about it' and give you reassurance and there are others who just get the job done and leave. I think it depends on the time of the day and probably the amount of work they have got to do but mostly they are very encouraging and caring, but I can't help but feel a degree of humiliation when I'm incontinent." (P12)

DISCUSSION

During the interviews, most participants made comments about diarrhoea, suggesting that it affected their patient experience. Unlike with other forms of illness, patients often find it difficult to talk about diarrhoea (Collins and Norton, 2004). It creates feelings of shame, embarrassment, fear of accidents, poor self image and low self esteem. It is not surprising that patients may fail to mention these problems to staff as they do not want to burden them further (Abayomi et al, 2005). Good staff-patient communication may help to remove some of these communication barriers and enhance patient confidence (Jefferies, 2010).

Modern medicine is often accused of being more concerned with the disease process than with dealing with the person as a whole (Taylor and Field, 1997). This is well demonstrated with the emphasis on containment and treatment of the infection (DH, 2007) rather than the emotional and social wellbeing of the patient. Healthcare workers need to be aware of the possible consequences that such an illness may have on the patient so measures can be taken to reduce their impact.

CONCLUSION

This study explored many of the issues that face patients with *C difficile* infection and identified four themes – physical suffering, lack of control over bowel function, understanding of illness, and privacy and dignity – that need to be addressed. *C difficile* infection is relatively common and healthcare workers need to understand how to manage patients who have it.

The presence of diarrhoea remains an embarrassing condition for patients, which can result in physical and emotional

deterioration. Greater awareness among nursing and medical staff, as well among the general public, is needed to improve the patient experience.

IMPLICATIONS FOR PRACTICE

It is clear that patients need to be provided with verbal and written information about C difficile.

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Patient dignity needs to be ensured by easy access to toilet facilities, especially for those with mobility problems. Other simple steps to ensure privacy and dignity include making sure the door or curtain is fully closed when the patient is using the toilet, provision of a nurse call bell and immediate help with hygiene needs in patients who are incontinent.

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As many patients will become malnourished due to the symptoms of a C difficile infection, early referral to a dietitian and careful monitoring of fluid and food intake are important.

Patients with C difficile infection also need adequate rest periods as interrupted sleep often leads to weakness and fatigue and may delay their recovery. ●

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