

# C. Diff – What matters to me...

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## Introduction

Patients and relatives interviewed as part of the Vale of Leven inquiry into an outbreak of Clostridium difficile infection (CDI) in 2007 expressed concern regarding the information they received.

In response to these findings and in an effort to enhance information provision and patient understanding of CDI, it was agreed that in NHS Dumfries and Galloway all patients with CDI would be visited by an Infection Prevention and Control Nurse (IPCN) if they are in hospital and telephoned at home if they are in the community when their infection is diagnosed.

This study investigated patient and relatives perspectives of Clostridium difficile infection and serves as an evaluation of the IPC service provided.

## Methods

The key questions to be answered by the study were:

1. How do patients who have experienced CDI describe the impact of contact with an Infection Prevention and Control Nurse?
2. How does contact with an Infection Prevention and Control Nurse (IPCN) influence patients and their relatives understanding of CDI management?
3. How do patients and their relatives describe the impact of CDI on their daily life?

An exploratory qualitative design was adopted, utilising semi-structured telephone interviews with volunteering participants.

Letters inviting participation in the project were sent to 35 patients: 8 responded initially and a total of four patients and two partners were interviewed.

All interviews were digitally recorded and fully transcribed. Thematic analysis of transcripts was conducted, using NVivo® software to manage data.

## Findings

People use the term C.diff when referring to Clostridium difficile infection and are largely unaware of it until it affects them.

Patients and relatives value direct contact with those providing information on Clostridium difficile.

They don't remember who gave them the information but do remember how it was given.

Leaflets and links to information do help.

Contact with IPCNs when out of hospital is valued.

The impact of CDI is much wider than the physical effects.

Being given a card to aid prescribing by other healthcare providers can lead to feelings of stigma on the part of the patient.

### Awareness

"Never heard of it. It was a completely new thing to me"

"I suppose it is something that you don't hear about unless it affects you or infects somebody you know?"

"The first thing about it was I was surprised that I could get it, because I had been on antibiotics for too long. That really sort of made me think, that surely if antibiotics are meant to cure you... but yet I still had C.diff."

### Communication

"It was my C. diff guy from Dumfries that phoned me and every week and asked me how I am. He explained everything to me."

"I think that someone came up from infection control and told me. But when he came and told me about it he didn't come in, he stood at the door. Which I felt like it was another thing that made me feel untouchable."

"...well I didn't know what it was to start with, until you know, this infection nurse come with this leaflet the day after and said what it was, you know."

### Emotional reactions

"Clothes got marked. I didn't get any help or advice or anything from the hospital and I was so upset about it."

"I actually felt a bit ashamed of having it, so I didn't tell anyone about it, or anyone else. Which was further compounded when they sent me a card to say I had C. diff. I have to keep this card in my wallet for a year. That felt a bit sort of, demeaning. It reminded me of what I had been through really."

"when he was in hospital and had been in plenty of times, he wouldn't let anybody else shower him ...the one time that someone else showered him and do you know, he actually rang me and apologised before it happened."

### Hospital experience

"You know, I don't think he worried about it being in a single room. Because he weren't well."

"In a single you see you are on your own, so it was good. I was going to the toilet. Sometimes like a rocket. Cause when you got to go, you have got to go."

## Discussion

This was a small scale exploratory study with only six participants; four patients and two partners, and therefore the findings cannot be held to reflect the experience of all patients with C.diff who had contact with an IPCN. Despite this limitation, the findings do provide several pointers for further service improvement.

This study provides limited information regarding the impact of specialist IPCN advice and support for patients who experience C.diff. It is however, useful in shedding light on the wider experience of those with C.diff infection and can be used to improve general nursing care.

Face to face contact is valued and the person providing this must have an adequate understanding of C.diff and the communication skills to address the concerns and anxieties, both current and potential, of a patient with C.diff or their relative.

Lack of awareness, stigma and concern about soiling and its management are still identified as issues, even in a post Vale of Leven world where considerable efforts within the NHS board have been made to improve C.diff identification, care and support.

Locally we have reflected on these findings and practice has been changed with the intention of making the process of providing IPCN support and information more robust for all our patients.

This has included ;

- Providing access to a dedicated IPCT vehicle to undertake community hospital visits when a CDI patient is in hospital which has supported more prompt face to face contact with patients and their relatives.

- The standard operating procedure for action to be taken upon receipt of positive C. diff toxin positive results has been amended to include the need to record face to face or telephone contact with patients in our IPCT patient management system

In healthcare it is important to establish that what we think we do, we actually do!

## Reference

Vale of Leven Hospital Inquiry Report (2014)

<http://www.valeoflevenhospitalinquiry.org/Report/j156505.pdf>

