

ORIGINAL ARTICLE

Exploring the patient experience with recurrent *Clostridium difficile* infection in Ontario, Canada

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ABSTRACT

Background: *Clostridium difficile* (*C. difficile*) infection is a leading cause of hospital-acquired diarrhea, and many sufferers experience infection recurrence after treatment. Several aspects of the burden of *C. difficile* infection have been recognized, including a substantial morbidity and mortality and extensive healthcare costs. However, personal difficulties in the patient experience with recurrent *C. difficile* infection in Canada have not been thoroughly explored.

Methods: A mixed methods approach, involving the qualitative and quantitative analyses of a written survey that was distributed to 9 outpatients with recurrent *Clostridium difficile* infection in Ontario, Canada, was used to investigate themes related to patient-perceived quality of care.

Results: Important themes in the patient experience included knowledge and understanding of *C. difficile* infection, access to adequate care in times of need, and emotional and physical hardships in the lived experience with recurrent *C. difficile* infection. Each of these themes could be broken down into a number of subthemes. Within the knowledge and understanding theme, a prominent subtheme was confusion and uncertainty about symptoms. Regarding access to care, subthemes included timely care and access to novel treatments such as fecal transplantation.

Conclusions: These themes highlight patient attitudes and circumstances that are associated with difficulty and dissatisfaction with care. Supportive patient resources and clinical care strategies should include improved education about recurrent *C. difficile* infection and how to live with it, easy access to care when symptoms return, and counseling on management strategies for living with recurrent *C. difficile* infection.

KEY WORDS

Clostridium difficile, patient experience, hospital-acquired infection, patient satisfaction, quality of care

INTRODUCTION

C. difficile is an enteric bacterial pathogen that is spread via the fecal-oral route, causing a wide spectrum of disease, from mild diarrhea and cramping to fulminant colitis. One of the main morbidities of *C. difficile* infection (CDI) is recurrence of disease, which affects roughly 20 percent of patients and results in more complex, longer-term management (1, 2). Advanced age is a significant risk factor for recurrent CDI (3, 4). While antibiotics such as metronidazole, oral vancomycin, fidaxomicin and emerging treatments like fecal transplantation are available for treatment of acute infection, patients with recurrent disease are often stuck in a cycle of repeated episodes of disease once treatment is stopped (5-7). The burden of CDI on individuals as well as the Ontario population is well recognized, earning it a rank of nine in the top 20 diseases in the Ontario Burden of Infectious Diseases Study (8). Furthermore, a study of 19 hospitals across Canada showed that the healthcare-associated costs from hospital

readmissions alone due to CDI are approximately \$120,200 per facility per year (9).

Public awareness and fear of CDI is becoming more prominent due to its increasing prevalence and media coverage of outbreaks (10, 11). Though studies have shown that many patients would feel angry or afraid if they were to contract a CDI (12), no empiric research has been carried out to explore the patient experience with CDI in Canada. Through care of a large volume of CDI outpatients in Ontario, we have observed a number of challenges faced by individuals with recurrent CDI. Access to treatments and financial coverage for medications continue to be a struggle for many patients. Patients with recurrent CDI have encountered inadequate access to care, resulting in emergency room visits, a lack of information and educational resources, and limited follow-up. Many of these challenges are associated with a fragmented and unspecialized course of care that patients receive.

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More robust support of this population requires a better understanding of patient challenges and concerns through exploration of personal difficulties and patient perception of care. This qualitative study of the patient experience with recurrent CDI highlights aspects of the patient experience that have a negative impact on quality of care, in order to guide the development of resources and support for patients.

METHODS

A survey was developed by the authors. The survey included both close-ended and open-ended short answer questions intended to reflect various determinants of health: health literacy, personal practices and coping skills. Respondents were asked to rate their overall satisfaction with care for CDI. Additionally, the survey included a series of written open-ended questions, which allowed patients to expand on their illness experience. Paper copies of the survey were distributed to participants, and the surveys were self-administered, completed on average within 10 minutes. The survey was distributed by a study investigator (first author) who was not a member of the clinic staff. The second and senior authors were regular clinic staff.

A convenience sample of patients with a history of recurrent CDI who visited one infectious disease clinic in Toronto, Canada was targeted for the survey. This clinic serviced patients from across Ontario with recurrent CDI. All patients who attended the clinic for a CDI between February and May 2015 were asked to participate voluntarily. Prior to completing the survey each participant was given an information document describing the study, and informed consent was obtained. Survey responses remained anonymous. Institutional research ethics board approval was obtained prior to initiation of the study.

A mixed methods analysis design was employed. Standard descriptive statistics were used where appropriate to analyze quantitative data. Qualitative data was extracted from the patients' survey comments and answers to open-ended questions. Responses were organized and reviewed as they were received. Descriptive thematic analysis, which involved transcribing the written responses to an electronic format, organizing, and indexing them, was carried out by the first author to report on patterns or themes within the data. Open coding was used to label the concepts that arose and similar or related codes were arranged into thematic categories for analysis. Codes and themes were developed by one study investigator (first author), and reviewed by two other study team members (co-authors), who made additional suggestions. In particular, themes that reflected patient satisfaction or dissatisfaction, such as difficulties, barriers, causes of frustration, and expressed needs, were explored. No formal sample size calculation was carried out *a priori*. Survey responses were analyzed as they were collected and then reviewed in an iterative process. Thematic saturation was achieved after no new themes were developed from additional completed surveys.

RESULTS

All nine patients approached for this study agreed to participate. Table 1 summarizes the characteristics of the study participants. The age of participants ranged from 40 to 90 years (mean 76.8 years) but was skewed towards advanced age (median age 83), reflecting the greater susceptibility of the elderly to recurrent CDI (13, 14). Five of the participants had experienced more than four episodes of CDI.

Within the survey, patients wrote about their experience with CDI and its management. Due to the focused nature of the questions, thematic data saturation was achieved despite the low number of participants. Though the patients generally reported feeling satisfied with all forms of care that they had received during their most recent episode of CDI, they all described difficulties that they had faced and areas for improvement. Three major themes in the patient experience with CDI emerged: 1) knowledge and understanding; 2) access to adequate care; and, 3) the lived experience. Within each of these themes arose a number of subthemes (Figure 1).

1. Knowledge and Understanding

1A. Confusion and Uncertainty

When asked about what makes their experience with CDI difficult, many patients wrote about the confusion and uncertainty they had faced. They often had comorbidities, and the medications that they took had side effects, making it more difficult for patients to understand what was causing their symptoms. Difficulties expressed included:

"Confused about other conditions versus C. diff symptoms."

"When I get symptoms, not being able to identify the cause of the symptoms."

Patients were upset about being uncertain of when their symptoms will come back, and when they would need to seek medical help:

"Not knowing when it will come back and when to call the doctor."

Although the medication regimens for treating recurrent CDI can involve dosage tapers, patients reported no difficulty in understanding how and when to take their medications (Figure 2) and likewise this was never mentioned in the open-ended responses. Of note, patients at the study clinic were provided written instructions on how to take their medications, which may not reflect the practice of all clinics managing CDI patients.

1B. Infection Control

Many patients reported worrying about passing the infection on to others (Figure 2) and wanted to know how to prevent transmission. When asked about any feelings regarding CDI, one patient expressed concern:

"Knowing how contagious it can be."

Some patients did not have a complete understanding of the nature of *C. difficile* transmission. Though most patients understood that hand hygiene is important (Figure 2), when asked about spreading infection to others, one patient commented:

"This isn't a type of disease that passes to other people, is it?"

1C. Education Medium

Almost all surveyed patients felt that understanding their disease was important to them, and most patients agreed that they would read educational pamphlets about CDI and its management (Figure 2). When asked directly about how they would prefer to learn more about their disease, many patients stated that they favoured verbal and written education. However, some other requests included online education resources, as well as group talks for discussing CDI with other patients.

2. Access to Adequate Care

2A. Timely Care

Patients stressed the importance of timely responses from clinic staff and quick access to therapies. This was an important aspect of their care, since they did not know when their symptoms would return and were anxious about being prepared for it:

"Since the symptoms are unpredictable, knowing that I can access a doctor or treatment quickly would make a big difference."

Fast responses from their care providers seemed to have a strong positive influence on the patient experience:

"Very responsive if I call the clinic. Quite satisfied with the clinic."

2B. Avoiding Hospitals

Patients were concerned about any need for hospitalization. Some patients did not trust that hospitals adequately controlled and managed the infections, while others dreaded the hospital experience in general:

"Lack of proper procedures at [hospital named removed] in handling C-diff patients like me."

"Fear of hospitalization!"

2C. Access to Improved Treatments

When asked about what would help to improve their experience with CDI, many patients expressed a desire for improved or novel therapies. They requested information about treatment alternatives:

"Explanation of what options a patient has to be cured."

Many patients expressed interest in learning more about and accessing fecal transplantation. Limited access to this form of CDI treatment, which was until recently limited to clinic trials, is a cause of frustration to some:

"I strongly recommend that fecal transplant becomes available. Accelerate the study. Find some funding so that more people can be saved."

3. The Lived Experience

3A. Emotions and Concerns

Most patients reported that their CDI made them feel stressed, and that they were frustrated by their illness and treatment (Figure 2). Additionally, in their written responses patients describe a wide array of emotions that they have experienced throughout their infection, including feelings

of embarrassment, anxiety, debilitation, and frustration. Respondents often used strong wording to explain the difficulties that they experienced with infection:

"I was traumatized by the whole experience. The weakness, exhaustion, embarrassment, total dependence, the feeling that there is no cure for it – only management – this was horrifying."

The fear of having uncontrolled symptoms for a long period of time and never being cured of the infection was frequently reported. Many patients worried about their risks of developing another episode of CDI:

"Concern and worries for taking any antibiotics for dental work."

"I have an IBD, are people who have this more susceptible? What conditions make you more at risk for the infection?"

3B. Daily Functioning

Patients reported significant debilitation from the disease and often remained housebound, as they did not know when they would next need to use the toilet. Feelings of exhaustion and dependence were also frequently reported.

"How debilitating it is. I cannot leave the house most days. When on meds I get a few hours or sometimes days of reprieve but once off them the vicious cycle starts again."

"I never know when I have to go to the washroom. Accidents are hard to clean up, especially when you're in that condition and sapped of your strength"

3C. Coping Ability

All patients reported that they received support from family or friends when sick (Figure 2). Many described the help they got from their spouse:

"Yes, my wife, my right hand."

When asked to indicate whether or not their CDI made them feel stressed, one patient reported not feeling stressed, commenting that they have adjusted to the infection after having it for a long time. In contrast, another patient indicated strong feelings of stress, reporting that their disposition contributes to feelings of stress during infection:

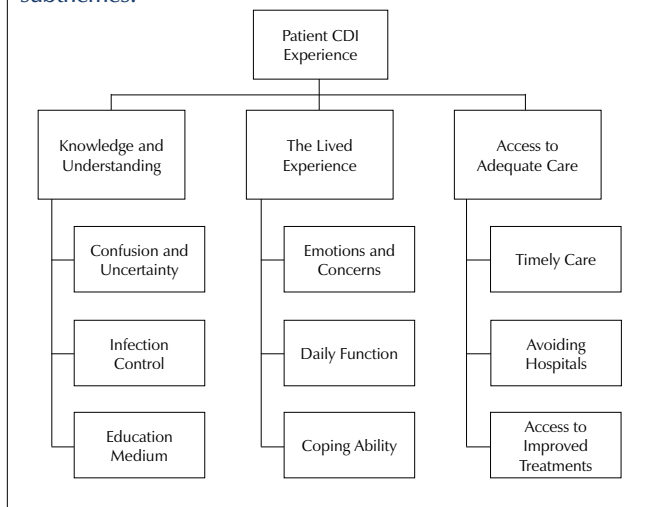
"I'm an anxious person."

TABLE I. Participant Demographics

Total Study Participants	N =9
Age	
Mean	76.8
Median	83
Minimum	40
Maximum	90
Sex	
Male	5 (55.6%)
Female	4 (44.4%)
Number of <i>C. difficile</i> Infection Episodes	
First Infection	0 (0%)
2-4 Infections	5 (55.6%)
More than 4 Infections	4 (44.4%)

FIGURE 1: Thematic Data Map

Three major themes emerged in the patient experience with CDI. These themes were further divided into numerous subthemes.



DISCUSSION

In this study, we provide empiric data on the personal difficulties associated with recurrent CDI. Similar studies of patients with other hospital-associated infections have highlighted a lack of verbal and written communication, confusion and anxiety, and discomfort with asking questions as pertinent features of the patient experience (15, 16). Patients that feel greater anxiety and perceive higher risks with respect to healthcare-associated infections generally demonstrate a limited understanding of the practical aspects of infection, such as what the causative organism is and how it is transmitted (16-18). People with higher education are more likely to have a good understanding of the

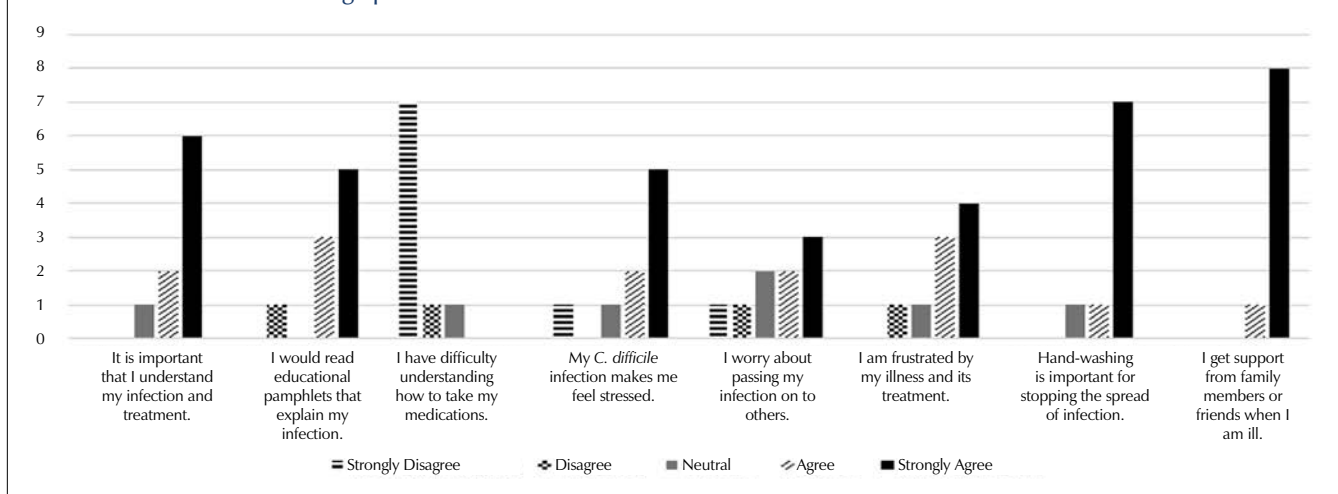
dangers and causes of healthcare-associated infections (19, 20). Patients with a past history of hospitalization or with a history of any healthcare-associated infection are more aware of the risks and consequences of CDI (21). Determinants such as these, which may include prior experiences and personal factors like health literacy and coping practices, are all an interconnected part of the patient experience with illness.

Many elements of a patient’s behavior and prior experiences impact their illness experience and satisfaction with CDI care. In our study, participants viewed their personal health-associated competencies as being important. A lack of patient knowledge and understanding contributed negatively to the CDI experience. Recurrent CDI patients were unsettled when they did not know what to expect from their infection. They wanted to understand their symptoms and know when to seek medical help. These sentiments were expressed in spite of patients having received regular verbal education on CDI at the clinic. Providing written educational materials describing the symptoms of CDI, contact information for care providers and guidance on how to react to specific types of symptoms, may help to address some of these issues. Although the CDI education administered by clinic staff also included a discussion on transmission risk and environmental management of *C. difficile* in the home, many patients remained unclear on how *C. difficile* is transmitted and the risks they pose to others. This highlights a need for ongoing patient education on the infection prevention and control aspects for CDI, both to address the excessive and unwarranted anxiety that some CDI patients feel about spreading infection, and to reinforce awareness of the risks and mechanism of disease.

This study indicates that having rapid access to medical care and medications is very important to patients. The implementation of dedicated CDI clinics, with teams of healthcare providers who have experience managing CDI patients and their medications, may address this need. With

FIGURE 2: Survey Responses

Patient responses to survey checkbox questions related to health literacy, practices, and coping abilities. Each bar represents the number of patients who answered either *strongly disagree*, *disagree*, *neutral*, *agree*, or *strongly agree*, to the survey questions indicated below each set of bar graphs.



thorough care and follow-up, as well as rapid access to medical consultation, unnecessary emergency room visits and hospital admissions may be avoided. Study participants also expressed interest in newer therapies, including fecal transplantation. As emerging therapies for CDI become more available, reliable information and guidance on how to access them would help to alleviate this area of patient frustration. Other negative aspects of the lived experience with CDI, such as problems with daily functioning during active infection, and emotional concerns such as embarrassment, may be more difficult to target through resource development. However, counseling and a thorough discussion of management strategies with the physician may help to make these difficult episodes more bearable for the patient.

Our study has a number of limitations. Study participants were selected through convenience sampling at one infectious disease clinic in Toronto, Ontario and participation in the study was voluntary, so there is a potential for selection bias in the sample population. Though clinic staff were not involved in administering or collecting the survey, it is possible that the results may have positive bias, as it was completed within the clinic. The sampled population was skewed towards advanced age, and elderly patients may be more comfortable receiving information in a different format compared to younger patients. Additionally, clinic visitors were mainly from urban areas, and recurrent CDI patients in more remote or underserved areas may experience additional difficulties related to travel distance, or other unforeseen challenges that have not been recognized by this study. Our study sample size was small; although it was not sufficient for carrying out an extensive statistical analysis of responses, we were able to achieve thematic saturation on the qualitative data. Our sample population consisted of patients with recurrent CDI, and so themes that might be prominent in the patient experience with an initial acute CDI, such as frustration due to misdiagnosis or delayed diagnosis, were not identified by our study. Finally, we sought to understand the patient experience with CDI in one Canadian jurisdiction, so some of our findings may not be transferrable to other regions with different models of health care delivery. However, we note that outside of the uncovered theme of “access to adequate care,” difficulties identified by study participants were not dependent on health care systems as much as personal experiences, making these findings broadly applicable beyond any one jurisdiction.

CONCLUSIONS

Many personal factors contribute to an individual's experience with CDI, including their own prior experiences, coping strategies, and understanding of infection. There are common themes in the patient experience that relate to dissatisfaction with care. These themes highlight patient needs and areas for improvement, such as improved education about CDI and how to live with it, easy access to care when symptoms return, and counseling on management strategies for living with CDI.

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C. difficile Clinic Patient Survey

This survey relates to your opinions on healthcare and your personal experience with *C. difficile* infection. It will take approximately 10 minutes to complete. You will be contributing to the understanding of the illness experience and helping to guide improvement of patient management. By completing this survey, you agree to participate in this research with the knowledge that you are free to withdraw your participation at any time.

Please state your age: _____

How many *C. difficile* infections have you experienced, including any current infection?

- This is my first infection
 2 - 4 infections
 More than 4 infections

Check the boxes to indicate how strongly do you agree with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Comments
It is important that I understand my <i>C. difficile</i> infection and its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I would read educational pamphlets that explain my infection and its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I have difficulty understanding how and when to take medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
My <i>C. difficile</i> infection makes me feel stressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I worry about passing my infection on to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I am frustrated by my illness and its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hand-washing is important for stopping the spread of infection to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I get support from family members or friends when I am ill.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Rate your overall satisfaction with the care that you are receiving or have received during this infection.

- Very Unsatisfied Unsatisfied Neutral Satisfied Very Satisfied

Please provide a response to the following questions, as applicable:

What do you find most difficult, frustrating, and/or stressful about your illness and its treatment?

What would help to improve your experience?

How would you like to learn more about your illness and/or its treatment (e.g., pamphlets, verbal explanations, online resources, etc.)?

Please provide any additional comments or feelings about *C. difficile* infection.