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**Identifying and integrating patient and caregiver perspectives for clinical practice guidelines on the screening and management of infectious micro-organisms in hemodialysis units**

**Running head:** Consumer input into dialysis guidelines

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## Abstract

**Introduction:** The integration of patient and caregiver input into guideline development can help to ensure that clinical care addresses patient expectations, priorities, and needs. We aimed to identify topics and outcomes salient to patients and caregivers for inclusion in the Kidney Health Australia Caring for Australasians with Renal Impairment (KHA-CARI) clinical practice guideline on the screening and management of infectious micro-organisms in hemodialysis units.

**Methods:** A facilitated workshop was conducted with 11 participants (patients [n=8], caregivers [n=3]). Participants identified and discussed potential topics for inclusion in the guidelines, which were compared to those developed by the guideline working group. The workshop transcript was thematically analyzed to identify and describe the reasons underpinning their priorities.

**Findings:** Patients and caregivers identified a range of topics already covered by the scope of the proposed guidelines and also suggested additional topics: privacy and confidentiality, psychosocial care during/after disease notification, quality of transportation, psychosocial treatment of patients in isolation, patient/ caregiver education and engagement, and patient advocacy. Five themes characterized discussion and underpinned their choices: shock and vulnerability, burden of isolation, fear of infection, respect for privacy and confidentiality, and confusion over procedural inconsistencies.

**Discussion:** Patients and caregivers emphasized the need for guidelines to address patient education and engagement, and the psychosocial implications of communication and provision of care in the context of infectious micro-organisms in hemodialysis units. Integrating patient and caregiver perspectives can help to improve the relevance of guidelines to enhance quality of care, patient experiences, and health and psychosocial outcomes.

**Keywords:** practice guideline, consumer participation, cross infection, patient satisfaction, renal dialysis

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## Introduction

Patients receiving in-center hemodialysis are both at increased risk of exposure to infectious agents and are more vulnerable to the diseases they cause. The increased risk of hospital-acquired infection (HAI) is multifactorial; including frequent and extended vascular exposure during dialysis, immune dysfunction, close proximity to other hemodialysis patients who may be carrying micro-organisms, high rates of hospital admission and contact with health workers who frequently move between patients and hemodialysis machines<sup>1,2</sup>. As a consequence, patients on hemodialysis are at increased risk of exposure to various infectious agents including multi-resistant bacteria (MRSA, VRSA), bacteremia, and blood-borne viruses including Hepatitis B virus (HBV), Hepatitis C virus (HCV), and human immunodeficiency virus (HIV). HAIs also have the potential to jeopardize the well-being of patients as a consequence of social isolation and restrictions on ability to travel, and to disrupt care of groups of patients within a dialysis unit<sup>3</sup>.

The value placed on different aspects of care in dialysis units differ substantially between patients and health professionals<sup>4-6</sup>. Previous studies of patients' perspectives in dialysis have indicated that whereas health professionals tend to prioritize clinical markers and outcomes highly, patients tend to emphasize procedural elements of care. Patients place particular value on education and involvement in their care and perceive these to be important for the prevention and control of infections<sup>7</sup>. The integration of patient input into guideline development has been widely advocated to help ensure that clinical care addresses patient expectations, priorities, and needs, but few examples exist<sup>8,9</sup>. In the process of developing a clinical practice guideline for the screening and management of infectious micro-organisms in hemodialysis units, Kidney Health Australia — Caring for Australasians with Renal Impairment (KHA-CARI), the guideline development organization for chronic kidney disease

in Australia and New Zealand, convened a workshop to identify the priorities of patients and their caregivers. The aim of this study was to identify topics salient to patients and caregivers to include in the guidelines, to ensure that the scope and content of the guideline adequately address the needs of patients and caregivers.

### **Materials and Methods**

A process flow diagram of the patient/ caregiver involvement model used in this project is included in the Supplementary material (Table S1).

#### ***Participants and recruitment***

We recruited participants from Concord Repatriation and General Hospital and Sydney Adventist Hospital in Sydney, Australia. Patients with current or previous experience with in-center hemodialysis (or their caregivers), were eligible to participate if they were over the age of 18 years, English-speaking and able to provide informed consent. We sought to include patients who had been screened, diagnosed, or treated for infectious micro-organisms; but for reasons of confidentiality, patients were not required to disclose this during recruitment. We used purposive sampling to ensure a range of demographic (age, gender) and clinical (diagnosis, co-morbidities) characteristics, and different experiences with regards to screening and management (including isolation) of infectious micro-organisms were included. Patients from both public and private hospitals were represented. Informed written consent was obtained from all participants prior to their inclusion in the study. The Ethics Committee of the Concord Repatriation General Hospital approved the study.

#### ***Data collection***

The scope of the draft guidelines was the screening and management of the carriage of infectious disease agents in people receiving treatment in hemodialysis units. The guidelines had four major topics – epidemiology, benefits and harms of screening, transmission-based precautions, and environmental controls. We developed the workshop question guide (Table S3) based on previous patient and caregiver workshops for clinical practice guidelines on autosomal dominant polycystic kidney disease<sup>10</sup> and early chronic kidney disease<sup>11</sup>.

We held the workshop on 16<sup>th</sup> June 2015 at a centrally located hotel meeting room outside the hospital setting to encourage uninhibited discussion. Patients were first informed of the scope of the draft guidelines and major topics. We then asked participants to reflect on their experiences related to screening and management of infectious micro-organisms in dialysis units, to identify topics to include in the guidelines, and to discuss the reasons for their choices. To ensure flexibility and breadth of discussion, topics could include interventions, outcomes or general concerns and priorities that could be addressed in the context of guidelines. One participant recorded the responses in point form on a flip-chart. Researcher AT facilitated the discussion and DC, MH, JP recorded field notes on the group dynamics and non-verbal communication. The workshop was digitally audio-recorded and transcribed verbatim.

### ***Data analysis***

We entered the transcript and flip chart into NVivo (QSR International. Australia, VIC, Melbourne, Version 10.0.638.0 SP6). Authors HM/DJT reviewed the transcripts and flipcharts line by line to extract guideline topics (including interventions) and outcomes identified by the participants. These were categorized into subtopics using the guideline structure developed by the guideline working group. The subtopics identified by patients and

caregivers were compared with those of the guideline working group. The primary coder (HM) inductively identified preliminary concepts relating to the reasons (i.e. beliefs, values and attitudes) for topic selection. These concepts were discussed among the research team (HM, DJT and AT) and revised to ensure the full breadth and depth of data was captured in the analysis.

## **Results**

### ***Participant characteristics***

Eleven participants attended the workshop discussion, of whom eight were patients and three were caregivers. The participant characteristics are shown in Table 1. Participants were aged between 30 and 89 years. Half the patients (4/8) were receiving center hemodialysis, and half were on home dialysis (4/8). Four of the eight patients had been diagnosed with at least one infectious micro-organism; including blood-borne viruses, multi-resistant organisms, and bloodstream infections. All three caregivers were female and spouses of patients in the workshop.

### ***Identification of guideline topics and outcomes***

The guideline topics identified and discussed by the workshop participants are shown in Table 2. Patients and caregivers focused on aspects of care which directly impact them. Participants identified many of the topics outlined but also identified additional topics which were not explicitly addressed in the scope of the proposed guidelines. An additional six topics were raised: privacy and confidentiality, psychosocial care during/after disease notification, quality of transportation (including managing cross infection), psychosocial treatment of patients in isolation, patient/ caregiver education and engagement, and patient advocacy.

### *Themes*

We identified five major themes, which reflected the reasons for topic and outcome selection by participants: shock and vulnerability; burden of isolation; fear of infection; respect for privacy and confidentiality; and confusion over procedural inconsistencies. Illustrative quotations for the themes are provided in Table 3.

*Shock and vulnerability:* Participants felt initially shocked, confused and anxious when they were diagnosed with an infectious micro-organism. Participants questioned the source of infection and were worried about passing infection onto others. They felt uncertain about their own and their family's capacity to cope with the implications of diagnosis for their health and on their future treatment. To reduce the anxiety associated with diagnosis, participants believed that guidelines should outline that all hemodialysis patients be educated about infectious micro-organisms; including transmission and the implications of infection for future treatment.

Furthermore, participants felt that guidelines need to address how the diagnosis of infectious micro-organisms should be communicated to patients, particularly specifying who is responsible for delivering diagnoses, and to ensure that the information provided with the diagnosis adequately addresses patients' concerns. Participants urged for guidelines to recommend that psychosocial support systems be made accessible to patients and caregivers to provide support and assist the psychological process of coming to terms with a positive diagnosis and its implications. It was noted by participants that clinicians may have limited time to discuss the consequences of diagnosis with patients and caregivers. Social workers, nurses and other patients were acknowledged as reliable alternative sources of information

and support. Participants felt that by addressing these aspects of care, the guidelines would ensure greater social and emotional wellbeing of patients and caregivers by providing reassurance and confidence, and ensuring that patients and caregivers are supported to cope with diagnosis.

*Burden of isolation:* Participants described being isolated in the dialysis unit as ‘agonising’, as they felt ostracized, lonely and bored, particularly because they had minimal to no contact with other patients or staff. One participant stated, “You feel as if... you’ve been convicted of murder and you’re in solitary”. While participants understood the necessity of isolation for reducing transmission, they felt staff could help “overcome the isolation by giving the patient something to do”. They suggested that “the evidence might say you have to isolate them, but the guideline should say what you should do to make sure that the [isolated] person isn’t feeling stigmatised, upset and alone.” Participants felt that the guidelines could address strategies for overcoming isolation and boredom, thereby reducing the burden of isolation. Others appreciated the quietness and privacy of the isolation ward.

*Fear of infection:* Participants were concerned about the risk of infection whilst being dialyzed and were fearful of passing on infection to others. The uncertainty and unpredictability of infection exacerbated their anxiety about the risk of transmitting infection. Participants wanted to understand the cause of infection and the implications for both the treatment of the infectious micro-organisms, and of dialysis-related treatment. One participant stated “they want to know where [the infection has] come from and what it’s going to do to them. You want to find out answers. It’s scary”. Participants suggested that guidelines should emphasize patients on hemodialysis and their caregivers receive comprehensive education about infectious micro-organism transmission and appropriate

prevention and control measures – “we should be made aware... of what lies ahead with infectious disease so that patients themselves feel comfortable and know enough about it”.

Participants were also worried about family members and other patients who may be more susceptible to infection. They did not want to be bear guilt and responsibility for the transmission of infection to others. Frequent screening was perceived as a “necessary evil” to reduce the risk of acquiring infection and/or transmitting an infection. Participants also believed that patients should be informed on how to manage their condition and minimize the risk of transmitting infection onto others – “it would be good to find out [how infection is transmitted] so that you can prevent it again”. They felt patients should be included in prevention and control efforts, for example, one participant stated “patients come up with really good ideas. Instead of you telling people what to do [to prevent transmission], sometimes they should be telling you”. Participants therefore felt that greater patient and caregiver knowledge and engagement would reduce anxiety by ensuring patients have a better understanding of their diagnosis, their potential risk to others and how to manage their condition.

*Respect for privacy and confidentiality:* Some participants felt that patient confidentiality and privacy was not adequately respected in dialysis units. One participant observed that “the doctor comes to your bedside [to tell you the diagnosis of infection], he’s got the screens around...but the other three patients in the ward can hear.” They believed that just “putting the curtain around” the patient was not sufficient for patient privacy. Some also noted that it was possible to overhear patient information being discussed from the nurses’ station.

Participants therefore felt the guidelines should advise the manner in which sensitive information is communicated, ensuring confidentiality and privacy when communicating with patients and among staff members.

Some participants felt they should have a right to know about whether another patient was positive for an infectious micro-organism so they could protect themselves. However, others felt this would impinge on patient confidentiality. One participant felt it was only necessary to disclose this information if there was a possible risk of infection to others. Another participant suggested that to reduce the stigma experienced by patients with respect to infectious micro-organisms, the guidelines should recommend that all patients be treated with equal caution. They stated, “You should just assume anybody could have it [infectious disease] and make procedures appropriately. That way it takes away a bit of the stigma.”

Some participants also felt that patients may withhold information due to a fear that disclosure may impact on the care they receive in an observable way. For example, one participant stated “there’s an issue where a lot of patients in a dialysis unit withhold saying too much for the fear that they’ll be moved out of the unit or treated in a different manner. So a lot of people want to say things, want things to happen, but are reluctant to say anything.” Participants therefore felt strategies for anonymously accessing information and making complaints could alleviate this problem, reduce the experience of stigma and engage patients in their own care.

*Confusion over procedural inconsistencies:* Participants expressed confusion over perceived variability in the procedures relating to hygiene, cleanliness and infection control within dialysis units and between different hospitals and units. Specifically, they noted the differences in procedures with respect to patient isolation, the cleanliness and hygiene of hemodialysis units and machines, and patient transportation to and from dialysis units. Participants also remarked that the focus on cleanliness and hygiene in dialysis units was not always clear to them. For example, while the importance of hand washing was emphasized to

patients, they observed that surfaces and equipment may not be routinely wiped down, and the wearing of uniforms by health professionals out of the hospital buildings was thought to increase the risk of cross infection.

Participants were uncertain of the prevalence of infectious micro-organisms in dialysis units, the risk of infection and transmission, and appropriate prevention measures. Moreover, they were uncertain of how frequently screening should be performed. Given this confusion, participants wanted greater clarity and consistency of procedures for the control and management of infectious micro-organisms within hemodialysis units, particularly with regards to cleanliness and hygiene, isolation, and transportation to and from dialysis units. They also felt the guidelines should state how frequently screening should occur, and felt this should be dependent on the relative risk that individual patients pose (including whether a patient is a carrier of a micro-organism and how often they move between different dialysis units). Participants felt that addressing these factors in the guidelines would reduce concern and lead to greater patient reassurance.

## **Discussion**

This study captured experiential perspectives of patients and caregivers related to the screening and management of infectious micro-organisms in hemodialysis units for the explicit inclusion into clinical practice guidelines. There was reasonable concordance between the topics and outcomes identified by the guideline working group and those identified by patients and caregivers in the workshop. However, patients and caregivers identified additional topics and outcomes not identified by the guideline working group. Procedural aspects of care were valued highly by patients and caregivers and should be addressed in guidelines. The rationale for the selection of topics and outcomes demonstrated

that patients and caregivers wanted greater respect for patient confidentiality, patient education and engagement, and psychosocial aspects of care, to minimize anxiety relating to prevention and management of infectious micro-organisms in hemodialysis units.

The findings add to the current literature on patient perspectives of care in dialysis units and are consistent with research that indicates there may be differences in the priorities and preferences of patients compared to those of health professionals<sup>4,6,12-14</sup>. In line with our findings, many of these studies indicate that procedural elements of care may have more salience over health outcomes to dialysis patients. Studies suggest patients particularly value interaction with healthcare professionals, the physical environment and atmosphere of the dialysis unit, the quantity and quality of information provided by staff to patients about their condition, respect for confidentiality and appropriate management of patient data, and the quality of patient transportation<sup>6,13,14</sup>. The need for multidisciplinary care in providing education and support for dialysis patients receiving a diagnosis of an infectious micro-organism has also been previously identified by patients<sup>7</sup>. Nurses, social workers and dietitians, as well as other patients, have been identified as trusted sources of information and support regarding infectious micro-organisms to combat the limited time that doctors have with patients<sup>7</sup>.

Patients and caregivers emphasized that guidelines should cover patient education and engagement in prevention and control efforts to reduce further transmission to others. Previous studies have highlighted the importance that patients place on education, and in particular, patients have identified early and frequent education on infectious diseases as important<sup>7,15</sup>. Despite expressing discomfort at advocating for their own safety due to a fear that this may impact the care they receive, patients have emphasized the importance of their own involvement in limiting the transmission of infectious micro-organisms<sup>7</sup>. This is in line

with current recommendations relating to infectious disease in hemodialysis units which state that patient education and involvement are important elements to prevention and control efforts<sup>1,16</sup> and may result in lower transmission rates<sup>17</sup>.

The psychosocial impacts of screening, diagnosis and treatment for infectious micro-organisms in dialysis units were prominent in the workshop discussion. In particular, the shock, vulnerability and fear associated with diagnosis, and the social isolation and boredom related to being in isolation were noted. A systematic review of the physical and psychosocial effects of patient isolation in hospitals found that isolation impacted on patient wellbeing, patient satisfaction, and direct patient contact<sup>3</sup>. The findings indicate that early patient education and communication with health professionals may reduce the negative psychosocial effects of isolation on patients. Our findings add to this understanding and provide unique insight into patient experiences of isolation in dialysis units, underlining the need to ensure psychosocial care is addressed in the management of infectious micro-organisms.

Of note, the evidence base for isolation in reducing HCV transmission is limited, and is not recommended by major authorities including the Centers for Disease Control and Prevention (CDC)<sup>1</sup> or Kidney Disease: Improving Global Outcomes (KDIGO)<sup>18</sup>. In light of this lack of evidence and the established psychosocial impacts of isolation, decisions to isolate HCV patients should be seriously considered, and should not replace adherence to strict infection control procedures.

Our study does have some potential limitations. Due to resource limitations, only one workshop could be convened, and this was specifically conducted to elicit patient and

caregiver perspectives for inclusion in clinical practice guidelines for the screening and management of infectious micro-organisms in hemodialysis units. While relevant perspectives were identified for integration into the guidelines, conducting a single workshop may have limited the breadth of knowledge and experienced obtained, particularly as infection prevention and control procedures can vary considerably across sites. Nevertheless, the findings appear to be broadly similar to other qualitative research on patient perspectives of care in dialysis units, lending support to the transferability of the findings beyond our setting.

Patients on hemodialysis and their caregivers emphasized the need to address patient confidentiality, education and engagement, and the psychosocial impacts associated with screening, diagnosis, and management of infectious micro-organisms. Integrating patient and caregiver perspectives in clinical guidelines can help to ensure that their needs are adequately addressed in the recommendations to improve quality of care, patient experiences, and health and psychosocial outcomes.

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**Table 1.** Participant characteristics (n=11)

<b>Characteristic</b>	<b>N (%)*</b>
<b>Participants</b>	11 (100)
Patient	8 (73)
Caregiver	3 (27)
<b>Sex</b>	
Male	7 (64)
Female	4 (36)
<b>Age</b>	
30-49	2 (18)
50-69	7 (64)
70-89	2 (18)
<b>Highest level of education attained</b>	
School certificate	4 (36)
Diploma	4 (36)
University Degree	2 (18)
Not provided	1 (9)
<b>Employment status</b>	
Full time	1 (9)
Part time/casual	2 (18)
Retired/ Volunteer	7 (64)
Not employed	1 (9)
<b>Marital status</b>	
Married	7 (64)
Separated	2 (18)
Single	2 (18)
<b>†Primary renal disease</b>	
Unknown/not stated	4 (50)
Polycystic kidney disease	2 (25)
Immunoglobulin A (IgA) nephropathy	1 (13)
Diabetic nephropathy	1 (13)
<b>†Current treatment</b>	
In-center hemodialysis	4 (50)
Home hemodialysis §	4 (50)
<b>†Years on dialysis</b>	
≤2	4 (50)
3-4	2 (25)
≥5	2 (25)
<b>†Comorbidities ¶</b>	
Diabetes	3 (38)
CVD	4 (50)
Hypertension	5 (63)
None	3 (38)
<b>†Screened for infectious micro-organism</b>	
Yes	7 (88)
No	1 (13)
<b>†Diagnosed with infectious micro-organism</b>	
Yes	4 (50)
No	4 (50)
<b>†Infectious micro-organisms diagnosed ¶</b>	
Blood-borne viruses	2 (25)
Multi-resistant organisms	2 (25)
Bloodstream infections	2 (25)
<b>‡Number of years being a caregiver</b>	
≤1	1 (33)
2-3	1 (33)
≥4	1 (33)

\*Percentages may not add to 100% due to rounding. † Patient characteristic only. ‡ Caregiver characteristic only. § Previous treatment in-center hemodialysis ranging from 3 to 12 months in direction. ¶ Some participants reported more than one comorbidity and/or diagnosis with infectious micro-organism.

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**Table 2.** Issues identified by patients and caregivers as being relevant to the guidelines for infectious disease in hemodialysis units

Patient and caregiver identified issues	Details and explanation	Relevance to Guideline Topics
<b>1) Epidemiology of infectious micro-organisms</b>		
Prevalence of micro-organisms Incidence of infection Incidence of transmission	Patients and caregivers were interested in how common micro-organisms in dialysis and hospitals units are, and how often infection occurs. They were interested in receiving information both about prevalence in individual dialysis units and hospitals, and also in dialysis units and hospitals more generally.	Incidence, prevalence, nosocomial acquisition
<b>2) Benefits and harms of screening</b>		
Frequency of screening	Patients and caregivers felt screening was necessary and should occur frequently. They felt the regularity of screening should be based on optimal containment of spread of infection, and on individual risk (more frequent if patient is positive for micro-organisms, travelling frequently etc.) Some patients reported clinical services had been delayed due to a positive test result.	Frequency of testing, rate of detection, rate of transmission, psychosocial impacts of isolation (stigma, isolation), impact on delivered services
Procedures to ensure privacy and confidentiality -disease notification -exchange of patient information between staff	Patients and caregivers wanted the guidelines to address aspects of disease notification including who should inform the patient (doctors, nurses, other health professionals) and where a diagnosis is given (in a private, confidential space). They also stated that it was possible to overhear the exchange of patient information between staff and wanted better procedures to protect confidentiality.	† Privacy and confidentiality
Psychosocial care -disease notification -ongoing support following diagnosis	Patients and caregivers felt that guidelines should address how a diagnosis is communicated, ensuring that patients receive information about their condition and have their questions addressed to provide reassurance and confidence. They also wanted more psychosocial support following a diagnosis of an infectious micro-organism. They recognized the limited time that doctors have with patients and recommended access to social workers and/or counselors in dialysis units to provide patients and caregivers with education and support about their condition. They suggested other patients could provide support by establishing informal support groups to share information and advice.	† Psychosocial care during/after disease notification

		3) Transmission-based precautions 4) Environmental controls
Transmission-based precautions Environmental controls	Patients and caregivers were interested in how transmission-based precautions and environmental control procedures influence rates of infection and/or transmission. Given perceived inconsistencies in procedures, patients and caregivers wanted to understand what procedures were effective in reducing the spread of infection.	Hand hygiene, use of personal protective equipment, management of HD machines, sterilization processes, nosocomial infection rates, environmental contamination rates, agents/procedures (used for staff, patients, HD machines, objects and environmental surfaces) rates of transmission to other patients and/or staff
Minimizing cross-infection during transportation	Patients and caregivers discussed transportation including the quality of transport and the cross-contamination risk associated with non-emergency patient transport versus taxi services	† Quality of transportation
Psychosocial treatment of patients in isolation	Patients and caregivers wanted the guidelines to address psychosocial issues related to patient isolation. They felt patients should be fully informed of the reasons for their isolation, and be given something to do whilst in isolation to abate boredom and social isolation.	† Psychosocial care of patients in isolation‡
Patient/caregiver education	Patients and caregivers wanted comprehensive education about infectious micro-organisms in dialysis units and the impact of infection on future treatment (dialysis related and infection-related). They wanted information on transmission so that they could understand their own risk to others and prevent further spread.	† Patient/caregiver education and engagement
Processes for patient advocacy	Patients and caregivers were concerned that disclosing information may impact on the care they receive from health professionals. They wanted access to an anonymous service through which they could access information and express any concerns. An anonymous phone line was suggested.	† Patient advocacy

†Topic not addressed under proposed guideline topics. ‡ Treated as a new topic as it is not explicitly stated in the guidelines, despite implicit indication. HD= hemodialysis

**Table 3.** Key themes and illustrative quotations

Theme	Illustrative quotations
Shock and vulnerability	<p>When they tell you, it just smacks you in the head, and you think - how the hell did I get that?</p> <p>I thought - where? How? I've been into hospital many times, so when did I contract it? How long have I had it? I had no idea.</p> <p>I didn't know what TB [tuberculosis] was. I had to do my own research. I was on the internet. How had I contracted it, how can I pass it on. I had to do all that stuff by myself.</p> <p>I'd rather speak to somebody than read. The more I read, the more worried I get. It just sounds worse than it really is.</p> <p>It doesn't just affect the patient; it's also the partner - the husband or the wife. It impacts the whole family.</p> <p>They might be going through it physically, but emotionally it's on the carers or the kids, the family.</p> <p>The doctor's not going to sit there for a good half an hour, or even 15 minutes to explain it. You'll be in so much shock you're going to want to talk about it. So they've got to have the back up to support the doctors ... there should be a social worker attached to the dialysis units.</p>
Burden of Isolation	<p>You can't converse with anybody, you're just by yourself. You feel as if you're in prison, as if you've been convicted of murder and you're in solitary.</p> <p>The worst part of isolation is you can't communicate with the outside world.</p> <p>You're in there by yourself with a bed and cabinet and a window to look out and that's it. The time is just agonising being in isolation. Time just drags on and on.</p> <p>You've really got nobody to talk to.</p> <p>The evidence might say you have to isolate them, but the guideline should say what you should do to make sure that the person isolated isn't feeling stigmatised, upset, alone</p> <p>You could overcome the isolation with giving the patient something to do, or to look at. Just so you're not in there by yourself with a bed and cabinet and that's it, and a window to look out. You need some sort of activity to help you along.</p> <p>I love it when I go into hospital and I've got the single room. I don't have to put up with anybody else's noise. I like the peace and quiet.</p>
Fear of Infection	<p>You go everywhere for your appointments. How do you know you're not coming out with something?</p> <p>For a while I didn't want to go near anybody. Because I didn't know whether I would pass it on.</p> <p>They want to know where it's come from and what it's going to do to them. You want to find out answers. It's scary</p> <p>We should be made aware when we are first going onto dialysis of what lies ahead with infectious diseases, what we can contract, so that patients themselves feel comfortable and know enough about it</p> <p>Education is important. That was the thing about AIDS and HIV. People were freaking out, because they weren't aware of how they could contract it and all that stuff. I think that would benefit other people to know what's going on</p> <p>My main concern would be if it can be passed on and how. I've got three kids and I'd be scared to pass it on to my kids</p> <p>It would be good to find out [how infection is transmitted] so that you can prevent it again. Take precautions to prevent the spread</p> <p>Patients come up with really good ideas. Instead of you telling people what to do [to prevent transmission], sometimes they should be telling you</p> <p>It's an act of God that you got it. Someone else has passed it onto you, so you've got no control over whether you pass it onto someone else</p> <p>I'm very careful now with any bloods. I don't want to touch anybody if they've got a cut or I've got a cut that I could probably pass it on</p>

Accepted Article

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I have a lot of elderly people living where I live. I would hate to think that I had passed something on to one of them  
 I think [screening is] excellent. It's reassuring for yourself to know you're not carrying a disease to another area  
 It's a necessary evil. It's something that's got to be done  
 If I was told that someone was a carrier, I'd immediately be saying to the nurses, get them out of the unit. Because there is potential that every person in that unit could contract it

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Respecting Privacy & Confidentiality

The doctor comes to your bedside, he's got the screens around and he says "you've got this and this and we're going to do this and this". But the other three patients in the ward can hear  
 When they put the curtain around, that's their way of saying - this is your privacy.  
 Whose role is it to inform the patient that they have this? And how?  
 How does the doctor tell them? I think it should be taken to an off room, a consultation room  
 We can hear the doctors talking to the nurses out at the nurse's station. You can hear the doctors saying "oh that patient has got this and this, and this is what we're going to do"  
 If I was a patient and someone next to me had something, I would love to know because at the end of the day I've got to protect myself  
 The only time you ever hear anything is when a patient has a positive result. Then they'll go around and tell everyone that's had contact with that person  
 Something that I can catch by being close to them or anything like that, I want to know. Because at the end of the day I've got a family that I need to protect and I need to protect myself. But not if it's hepatitis or something because it's not going to be transmitted unless it's blood  
 The staff need to know [the diagnosis] but I don't think other patients need to know  
 You should just assume anybody could have it [infectious disease], and make procedures appropriately. That way it takes away a bit of the stigma  
 There's an issue where a lot of patients in a dialysis unit withhold saying too much for the fear that they'll be moved out of the unit or treated in a different manner. So a lot of people want to say things, want things to happen, but are reluctant to say anything.  
 You need somewhere to go [to access information or make complaints], like an anonymous phone line

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Confusion over procedural inconsistencies

The fact that there are no guidelines at the moment - you think well maybe it's not that big of a problem  
 How prevalent is infection? How much does it occur in dialysis units? You hear of golden staph everywhere, at all hospitals. But is there a disease or not?  
 It's reassuring to know that there are procedures in place.  
 I find it really hard to figure it out. When he was diagnosed they could not stop talking about cleanliness. How do you tell me to wash my hands, clean up, make sure that's all sterilised, this and that, but the chair that I'm about to go sit on, somebody else has been sitting on there. How do you know if it's clean? Even the table where you put your coffee, that's not even wiped down  
 My mother went to hospital for an operation and they came back later on and said she had VRE. They said to me "we're going to have to put her in an isolated room because she's got this infectious disease". But about two weeks later they had her in a ward room with three other elderly ladies. So I said to the nurse, "you told me that she's got this infectious disease and you've got to keep her isolated from the other people in the nursing home". They said, "oh no, it's okay". I said, "well two weeks ago you were telling me she's got this thing and you got her all worried, got me all worried".

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