BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-021418
Article Type:	Research
Date Submitted by the Author:	27-Dec-2017
Complete List of Authors:	Silver, Sam; Queen's University, Nephrology Saragosa, Marianne; St. Michael's Hosptial, Nursing Adhikari, Neill; Sunnybrook Health Sciences Centre, Department of Critical Care Medicine Bell, Chaim; Sinai Health System, Medicine Harel, Ziv; University of Toronto, Nephrology Harvey, Andrea; St. Michael's Hospital, Nephrology Kitchlu, Abhijat; St. Michael's Hospital, Nephrology Neyra, Javier; University of Kentucky, Nephrology Wald, Ron; University of Toronto, Medicine/Nephrology Jeffs, Lianne; St. Michael's Hospital, Li Ka Shing Knowledge Institute
Keywords:	Acute renal failure < NEPHROLOGY, QUALITATIVE RESEARCH, Health & safety < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Nephrology < INTERNAL MEDICINE

Insights from Patients and Caregivers on Acute Kidney Injury and Post-Hospitalization Care: A Qualitative Study

Samuel A Silver MD MSc[1], Marianne Saragosa RN MN[2], Neill K Adhikari MDCM MSc[3], Chaim M Bell MD PhD[4, 5], Ziv Harel MD MSc[2, 6], Andrea Harvey BSc[6], Abhijat Kitchlu MD[6], Javier A Neyra MD MSCS[7], Ron Wald MDCM MPH[2, 6], Lianne Jeffs RN PhD FAAN[2, 8]

[1]Division of Nephrology, Kingston Health Sciences Center, Queen's University, Kingston, Canada
[2]Li Ka Shing Knowledge Institute of St Michael's Hospital, St. Michael's Hospital, Toronto, Canada
[3]Department of Critical Care Medicine, Sunnybrook Health Sciences Center, University of Toronto, Toronto, Canada
[4]Department of Medicine, Sinai Health System, University of Toronto, Toronto, Canada
[5]Department of Medicine and Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Canada
[6]Division of Nephrology, St. Michael's Hospital, University of Toronto, Toronto, Canada
[7]Division of Nephrology, Bone and Mineral Metabolism, University of Kentucky, Lexington, United States
[8]Lawrence S Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada

Abstract word count: 270
Manuscript word count: 2818
Running title: Patient Insights on AKI

Corresponding author:
Samuel A Silver
Division of Nephrology, Queen's University
76 Stuart Street, 3-Burr 21-3-039
Kingston, ON, Canada
K7L 2V7
Tel: 613-549-6666 ext:4895
Fax: 613-548-2524
samuel.silver@queensu.ca

ABSTRACT

Objectives: Hospitalization with acute kidney injury (AKI) is associated with short- and long-term adverse events, but patient and caregiver experiences with AKI are not well described. We sought to better understand patient and caregiver perspectives after a hospitalization with AKI to inform discharge strategies that may improve outcomes for this high-risk population.

Design: Qualitative study with semi-structured interviews

Setting: Tertiary care hospital in Ontario, Canada

Participants: Patients (n=15) who survived a hospitalization with Kidney Disease Improving Global Outcomes (KDIGO) stage 2 or 3 AKI from May to December 2016. We also interviewed five patient caregivers. We required patients to have no previous evidence of severe chronic kidney disease (i.e., prior receipt of dialysis, previous kidney transplantation, or pre-existing eGFR under 30mL/min/1.73m^2).

Results: We identified three over-arching themes: 1) prioritization of conditions other than AKI, reflected by the importance placed on other comorbidities and the omission of AKI as part of the ongoing medical history; 2) variability in comprehension of the significance of AKI, represented by minimal knowledge of the causes and symptoms associated with AKI, along with misinformation on the kidneys' ability to self-repair; and 3) anxiety from discharge planning and competing health demands, illustrated by complicated discharge plans involving multiple specialist appointments.

Conclusions: Patients and caregivers view AKI as a short-term and reversible condition, giving it little thought during the post-discharge period. As a result, reliance on patients and caregivers to report an episode of AKI to their outpatient physicians is unlikely to be

successful. Patient-centered tools and decision aids are needed to bridge the gap between a hospitalization with AKI and the safe transition to the outpatient setting.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Performed, analyzed, and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines
- Bias minimized by conducting all interviews with qualitative researchers who had no specific expertise in nephrology or involvement in patient care to influence patient and caregiver responses.
- Participants self-selected for interviews, which may not be representative of the entire population with AKI
- Single-center study

INTRODUCTION

Acute kidney injury (AKI) is a common condition that affects approximately one in five hospitalized patients [1, 2]. With in-hospital survival for AKI-associated hospitalizations improving [3], increased attention has been drawn to adverse events after an episode of AKI. These complications include kidney events such as recurrent AKI [4], incident or progressive chronic kidney disease (CKD), and end-stage renal disease (ESRD) [5], as well as systemic problems such as new-onset hypertension [6], cerebrovascular disease [7], and cardiovascular disease [8]. Given these increased risks, it is not surprising that survivors of AKI are at higher risk of rehospitalization and death relative to patients without AKI [5, 9].

Several gaps in care of AKI survivors have been identified, and addressing these may improve post-discharge outcomes. Fewer than half of physician discharge summaries document the presence of AKI [10, 11], and over 80% of hospitalized patients are unaware that they experienced an episode of AKI [12]. A United States Renal Data System (USRDS) report demonstrated that only three in five patients have their serum creatinine checked within 90 days of discharge [13], despite the Kidney Disease Improving Global Outcomes (KDIGO) guidelines recommending evaluation for kidney function at 90 days [14]. In the same USRDS report, fewer than one in six patients visited a nephrologist within 90 days of discharge [13], even though follow-up with a nephrologist after severe AKI has been associated with a 24% relative reduction in mortality [15].

As more attention is devoted to enhancing these care processes [16], information is needed on the priorities and perspectives of patients and caregivers after a hospitalization with AKI. Little is known about their level of understanding around what AKI entails, awareness of the long-term consequences of AKI, and post-discharge care preferences. Our objective was to describe the experiences and expectations of AKI survivors and their caregivers in the immediate post-discharge period to ultimately inform patient- and caregiver-centered strategies that may improve outcomes for this high-risk population.

METHODS

Design

We conducted a qualitative study with individual semi-structured interviews. We performed, analyzed, and reported this qualitative study in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ guidelines) [17]. The Research Ethics Board at St. Michael's Hospital approved this study.

Participants

We recruited patients and caregivers after an inpatient stay at a single, urban teaching hospital. Eligible patients were ≥ 18 years of age with KDIGO stage 2 AKI or greater. We also required the patient or his/her caregiver to speak English. We excluded patients likely to have received formal education on kidney health prior to study contact, such as kidney transplant recipients, patients already under the care of a nephrologist, patients with a baseline eGFR under 30mL/min/1.73m^2, and patients discharged from hospital on dialysis.

Recruitment and Data Collection Methods

We recruited patients using purposive sampling, which involved the initial identification of eligible patients by one of the investigators or nephrologists as part of an ongoing program to improve outpatient care for patients with AKI [18, 19]. These staff asked potential participants for permission to be contacted by the qualitative study team. The qualitative research staff then contacted participants with further study information, arranging an interview time for agreeable patients and/or caregivers. Research staff obtained informed consent before conducting any interviews.

Once a participant was enrolled in the study, researchers with experience in qualitative methods conducted in-depth semi-structured interviews using guides that included questions on demographics, general health, the index hospitalization, level of AKI knowledge, and post-discharge follow-up care **(Online Supplement, Figures 1 and 2).** We conducted the interviews from May to December 2016, as either in-person interviews at the time of outpatient appointments or as telephone interviews. We audiotaped and transcribed all interviews verbatim, with a mean duration of 25.1 minutes (range 6.5 to 43.5 minutes). We determined the final sample size by thematic saturation, where all emerging themes are fully accounted for and successive interviews did not reveal any new barriers or expansions on relevant themes [17, 20].

Analytical Plan

We summarized baseline characteristics using descriptive statistics. We expressed continuous variables as the mean (standard deviation; SD) or median (25th, 75th percentile), and categorical variables as a percentage.

Data analysis occurred in conjunction with data collection in an emergent, iterative process. Two research staff (MS and LJ) with experience in qualitative methods independently reviewed and coded all interview transcripts. Two investigators (SS and LJ) refined the final coding schema by comparing their coding of the transcripts with the emergent coding schema. We determined the emergent coding schema using a constant comparison technique and through consensus [21, 22], with no discrepancies amongst the different reviewers.

RESULTS

Participant Characteristics

We interviewed 15 patients and 5 caregivers; 3 caregivers were related to the patient participants. Of the 17 unique patients, the average age was 68.4 (11.6) years, 8 (47%) were female, 5 (29%) had CKD, 10 (59%) required critical care, and 2 (12%) received renal replacement therapy. The 5 caregivers interviewed consisted of 2 children, 2 nieces, and 1 spouse. **Table 1** provides a more detailed description of the participant characteristics. The interviews occurred a median of 68 (52-86) days after hospital discharge.

Emergent Themes

Three over-arching themes emerged from analysis of this narrative dataset: 1) prioritization of conditions other than AKI; 2) variability in comprehension of the significance of AKI; and 3) anxiety from discharge planning and competing health demands. **Table 2** provides selected quotations to support these themes.

Prioritization of Conditions other than AKI

This theme captures how participants were more concerned with other conditions than AKI and includes the following sub-themes: the importance of other comorbidities and the omission of AKI as part of the ongoing medical history.

Importance of Other Comorbidities

Many of the patients had comorbidities (e.g., diabetes, hypertension) or other medical issues (e.g., low hemoglobin, recent surgery) that they described as their main concern. Some participants identified a connection between these conditions and AKI, particularly the relationship between heart and kidney disease. However, most participants prioritized conditions other that AKI because these *"diseases progress over time."* Several participants explained that they overlooked the kidneys because AKI is *"an unseen issue"* that is *"transient and fixable."*

Omission of AKI from the Medical History

Having minimal concern for their kidney function after an episode of AKI was also reflected in participants' reluctance to include AKI as part of their past medical history. Participants provided several reasons for this omission, which included return to normal serum creatinine concentration, the cessations of dialysis, *"feeling better,"* and the presence of *"two kidneys."* A few patients even denied experiencing AKI. At a recent outpatient appointment with his or her primary care physician, one patient *"didn't even think they said anything about their kidneys"* when questioned about details of the recent hospitalization. Several participants observed that the healthcare team was more worried about the kidney function as an inpatient than as an outpatient, suggesting that AKI was a short-term and reversible condition that did not merit inclusion as a distinct condition in one's medical history.

Variability in Comprehension of the Significance of AKI

This theme reflects the varying levels of understanding the significance of AKI among the participants and includes the following sub-themes: not knowing the causes, symptoms, and signs of AKI and misinformation on the kidneys' ability to self-repair.

Not Knowing the Causes, Symptoms, and Signs Associated with AKI

Many participants *"did not have the faintest idea"* what caused their AKI episode. Suggestions offered by patients and caregivers included hypertension, hypotension, dehydration, surgery, medication, and infection, but very few patients expressed confidence in the mechanisms that they proposed. This uncertainty may be because most patients *"didn't go into the hospital because of a problem with [their] kidneys,"* and only discovered their kidneys were involved based upon serum creatinine testing rather than specific kidney-related symptoms.

When patients and caregivers did mention symptoms or signs experienced during a hospitalization, these were rarely attributed to the kidneys or AKI. One patient observed that *"when you don't have symptoms, you don't think about it."* Several participants identified urinary symptoms and signs including high output, low output, odor, color, dysuria, and catheterization. Pain was a commonly expressed symptom, particularly in the abdomen, back, and suprapubic area. A few patients also mentioned breathing changes and leg swelling, but they *"wouldn't be able to pinpoint it to the kidney at all."* Despite this confusion, most participants demonstrated an awareness that blood tests monitored kidney function. One patient summarized his or her understanding with *"I don't [know how you know kidneys are functioning better]. I only know my creatinine level."*

Misinformation on the Kidneys' Ability to Self-repair

The majority of participants viewed AKI as a "repairable" condition and even as a "self-recuperating machine like the liver." Those who believed permanent kidney damage from AKI was still possible were not concerned because of the presence of two kidneys.

Anxiety from Discharge Planning and Competing Health Demands

This theme captures the experiences of participants with discharge planning and their competing health demands and includes the following sub-themes: complicated discharge plans and multiple specialists involved in their care.

Complicated Discharge Plans

Participant experiences with discharge planning varied, but most expressed anxiety over the number of issues to address. Many participants shared that they were not provided any specific advice around kidney health at the time of hospital discharge. Rather, the focus of discharge planning was more general (e.g., maintaining a better lifestyle, eating healthier, mobility) and on other conditions (e.g., cardiac or post-surgical problems). Medications were a particular focus, with one patient noting that *"all the meds I had been taking prior to going into the hospital were altogether different than the ones that I had coming out of the hospital, all the prescriptions were different."* A few participants attributed poor discharge planning around diuretic management to the need for rehospitalization, mainly involving the discontinuation/reduction of diuretics during an AKI episode contributing to subsequent heart failure exacerbations.

Multiple Specialists Involved in Care

Regardless of the actual discharge plan content, study participants noted multiple health demands that required a series of follow-up appointments with medical specialists (e.g., nephrologist, cardiologist, surgeon) and health disciplines (e.g., physiotherapy). The high volume of appointments was handled well by some participants, but was a source of stress for others. In these latter cases, it was challenging for some participants to concern themselves with their kidney health while dealing with other conditions and the associated follow-up appointments.

DISCUSSION

After a hospitalization with AKI, our qualitative study found that patients and caregivers view AKI as a short-term and reversible condition with limited relevance to their global health. Reasons for these impressions include the concomitant presence of other important comorbidities, misconceptions of the significance of AKI, and the prioritization of other illnesses by healthcare providers. The post-discharge period is also complicated for these patients and their families, with kidney health rarely emerging as a primary concern.

There is limited information on the barriers to providing care for survivors of AKI, and so some insights may be gained from the setting of CKD. Frequently-cited CKD barriers include poor understanding of disease risks, lack of knowledge on management, and low prioritization of kidney disease among primary care providers [23, 24]. Our work suggests that some physicians view AKI episodes as transient and fixable, as reflected by the language utilized by patients and caregivers [25]. One study conducted semi-structured interviews with physicians and pharmacists experienced in the care of patients with AKI [26]. These participants identified AKI as a complex condition, with both knowledge and organizational challenges that disrupted workflows, communication, and coordination between healthcare providers. In many cases, participants described patients as messengers between practitioners, depending upon them to relay important details about laboratory monitoring and medication use during and after a hospitalization with AKI.

Our study builds upon this work by providing the patient and caregiver perspective on AKI. We observed that both groups rarely mentioned AKI as an important discharge issue, which is noteworthy because most interviews occurred approximately two months after an acute hospitalization with AKI. Even when prompted during interviews, only a minority of patients and caregivers included AKI as part of their past medical history. This latter sub-theme is particularly important, given the short- and long-term health consequences associated with an episode of AKI [4, 5, 8, 9]. These findings suggest that patients and caregivers may not be the ideal messengers to coordinate post-AKI care, contrary to the expectations of other healthcare providers described above [26].

We suspect that some of the lack of attention dedicated to AKI by patients and caregivers is related to our second theme, variability in comprehension of the significance of AKI. Not only was knowledge of the symptoms and signs associated with AKI low, but we also observed little certainty in the causes of AKI. These observations are also consistent with discharge summary content, where in one study monitoring advice after AKI was provided to 6/75 (8%) patients and causes of AKI communicated to 1/75 (1%) patients [10]. It is hard to expect patients and caregivers to prioritize a condition that they do not completely understand, especially given multiple competing health demands during the post-discharge period.

Current discharge communication initiatives after a hospitalization with AKI include infographics endorsed by the National Kidney Foundation in the United States [27] and the National Health Service in the United Kingdom [28]. The latter “Think Kidneys” program (https://www.thinkkidneys.nhs.uk/aki/) also sets standards for discharge summary content after AKI, which include identifying the cause of AKI, describing the course of AKI (e.g., baseline creatinine, AKI severity, and discharge creatinine), recommending medication adjustments, and identifying the responsible ambulatory care provider along with the timing of a follow-up appointment. However, with appropriate discharge summary completion for AKI below 50% [10, 11], this strategy is unlikely to be successful on its own. Moreover, our study suggests that relying solely on the patient or caregiver is also unlikely to result in successful care coordination.

Instead, our work supports the need for system-based efforts to educate patients and facilitate knowledge transfer after a hospitalization with AKI **(Table 3)**. Elements of a successful program should begin before hospital discharge, provide simple discharge instructions, and respect the multiple appointments faced by these patients and their caregivers. In addition to the discharge content endorsed by the "Think Kidneys" program, our study illustrates that patients and caregivers require teaching on the consequences of AKI (e.g., CKD, cardiovascular disease, recurrent AKI) and strategies to recognize and prevent subsequent episodes. Better education in these areas may change how patients and caregivers prioritize kidney health relative to other comorbidities. An innovative approach that addresses these elements is the concept of patient-oriented discharge summaries [29]. Co-designed by patients, caregivers, and providers, they are structured to provide important information in an easy-to-understand format without increasing healthcare provider workload (http://pods-toolkit.uhnopenlab.ca/). Further study is required to determine whether these templates can be modified to suit the specific needs of patients with AKI.

Our study has limitations. As with most qualitative studies, participants were self-selected for interviews and may not be representative of the entire population with AKI. Even though we interviewed participants from a diverse range of ethnicities and cultural backgrounds, we excluded patients/caregivers who could not speak English to avoid misinterpretation from language translation. We also targeted participants less likely to have received formal education on kidney health prior to study contact, and so we may have underestimated the knowledge and understanding around AKI. However, similarly low levels of disease comprehension apply to patients with CKD followed by a nephrologist [30, 31]. Finally, our results are from a single tertiary care hospital in Canada and may not be transferable to other populations.

Despite these limitations, we minimized bias by conducting all interviews with qualitative researchers who had no specific expertise in nephrology or involvement in patient care. In this way, the research team possessed few preconceptions about the research topic to influence patient and caregiver responses. All interviews also occurred as soon as logistically possible after discharge from hospital (usually within 60 days), preventing other healthcare providers or events from influencing patient and caregiver perceptions.

Our qualitative study found that AKI was a low priority concern for patients who survived an episode of AKI and their caregivers. Themes that explain these patient and caregiver experiences included concern with other health conditions, limited understanding of the significance of AKI, and complicated discharge plans with multiple appointments to balance. These findings should inform the design of patient-centered discharge plans after a hospitalization with AKI, suggesting that the onus is on the healthcare system to educate and arrange appropriate follow-up for this high-risk population. Sole reliance on patients and caregivers to communicate an episode of AKI to outpatient physicians is unlikely to be successful. With in-hospital survival after AKI improving, patient-centered tools and decision aids are needed to bridge the gap between a hospitalization with AKI and the safe transition to outpatient care in order to promote kidney recovery and prevent the many adverse consequences associated with AKI.

ACKNOWLEDGEMENTS: The authors would like to thank the study participants for their time.

SUPPORT: SAS was supported by a Kidney Research Scientist Core Education and National Training Program Post-Doctoral Fellowship (co-funded by the Kidney Foundation of Canada, Canadian Society of Nephrology, and Canadian Institutes of Health Research). JAN was supported by the Ben J. Lipps Research Fellowship Program of the American Society of Nephrology Foundation for Kidney Research. LJ was supported by the St. Michael's Hospital Volunteer Association Chair in Nursing Research and a Ministry of Health and Long-Term Care Early Nursing Research Award. These funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, or approval of the manuscript; or decision to submit the manuscript for publication.

CONFLICTS OF INTEREST: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

AUTHOR CONTRIBUTIONS: Study concept and design: SAS, CMB, ZH, RW, LJ; Acquisition, analysis, or interpretation of data: SAS, MS, NKA, AH, AK, JN, LJ; Drafting of the manuscript: SAS, MS, LJ; Critical revision of the manuscript for important intellectual content: SAS, MS, NKA, CMB, ZH, AH, AK, JN, RW, LJ; Study supervision: LJ. All authors approved the final version of the submitted manuscript. LJ had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. We certify that this manuscript nor one with substantially similar content has been published or is being considered for publication elsewhere.

DATA SHARING: No additional data available

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Table 1: Characteristics of the 17 unique patients (15 patient interviews and 2 caregiver interviews)

Demographics	Patient (n=17)
Age (years), mean (SD)	68.4 (11.6)
Women, n (%)	8 (47)
Ethnicity, n (%)	
Caucasian	10 (59)
Other	7 (41)
Comorbidities n, (%)	
Chronic kidney disease	5 (29)
Diabetes	9 (53)
Congestive heart failure	5 (29)
Coronary artery disease	5 (29)
Cancer	2 (12)
Characteristics of index hospitalization, n (%)	
Renal replacement therapy	2 (12)
Intensive care unit	10 (59)
Sepsis	4 (24)
Surgical procedure	10 (59)
Nephrotoxin	2 (12)
Length of stay (days), median (25th, 75th percentile)	15 (11-32)

Table 2: Selected participant quotations for each theme

Sub-Theme	Quotation
Theme 1: Prioritization of conditions other than AKI	
Importance of other comorbidities	"Going forward we don't have any concerns about his kidneys. It's more about his heart condition and how that's going to function and if that's going to keep on going." (Son 006)
	"My main concern is my blood pressure more than anything. They had told me my lungs would take a while to come back and they were really worried about my kidney because my blood pressure was so low. Apparently they had a problem during the operation, and not only did I get an incision down my front side, but the top of my right leg, I think they had to call another doctor in because there was no blood flow in my right leg. I don't know, she wanted me to get my kidneys checked because she told me that they took quite a beating in there and that was because of my low blood pressure. I was never really worried about my kidneys." (Patient 011)
	"Just you know, my keeping my blood in line and my hemoglobin is low you know I had to have a blood transfusion, I get really short of breath so that's my concern now. No (not concerned about the kidneys) because I don't have any symptoms." (Patient U-002)
Omission of AKI from the past medical history	"Kidney injury or kidney disease or kidney problems could be more immediate like a heart attack or uncorrectable damage that's been done. It's irreversible. I wouldn't list the kidney as a kidney damage that's an ongoing condition because I think he did go through it and now he's back and he's doing ok so I wouldn't say that he's got continuous kidney problems. I think that his kidneys are and they're functioning normally right now." (Son 006)
	"No I would not [list AKI as part of medical history] because I believe it will be repaired. Let's say you have this fantastic lung capacity and you start smoking and your lung capacity reduces and you quit and those ten years they say your lungs are very forgiving and could come back to their full capacity. I hope to be able to think that the kidney has that rebound effect." (Patient 001)
	"I was really lucky that my kidneys survived or didn't get affected. They got better I have no trouble urinating and as I'm on the lasix and I get rid of the fluid. My kidneys recovered with the care that I got. I'm positive in that I seem to have recovered so many functions in my body that were affected including my kidneys so I assume that I'll be fine as far as my kidney function goes." (Patient Care U-001)
	"During my time in hospital, it was a major part of the medical professionals around me. More often than not, the nephrologists were hanging around rather than anybody else. So you know, in terms of attention even, uh, directed by the medical professionals, it seemed to be, a bigger chunk of concern on their end of the spectrum." (Patient U-003)

Theme 2: Variability in comprehension of the significance of AKI	
Not knowing the causes, symptoms, and signs associated with AKI	“I had some blood infection and then my kidney was also affected by that, everything like other things were due to the surgery and all so anyway. I have no idea.” (Patient 004)
	“They took those nodes out and then I had one chemotherapy session after which my whole body crashed. Dr. X had explained to me that part of the kidney malfunction could well be that I have urine reflux. I wasn’t pushing enough urine through, so the base of the bladder could have an infection that was being passed to the kidneys, another time I was told it was autoimmune - the kidneys’ reaction and one time I was told herpes.” (Patient U-003)
	“I probably wouldn’t be peeing as much, or at all or perhaps the coloration of my urine might be a little different than normal. All the related to the urine as I would observe it. I don’t recall during my time in the hospital when I was having any difficulty with my kidneys that uh, I was able to observe anything different to be honest with you. I guess they were recovering and I didn’t notice anything different at all.” (Patient 014)
	“He would have to definitely not be feeling well, or not passing urine properly, or have pain. Any one of those symptoms, pain, he’s not sleeping, maybe his legs are swollen, or his hands are swollen so they could be a trigger, they could be a sign that something’s not right.” (Son 006)
	“I don’t know. I mean obviously I’m urinating regularly and my kidneys are function, and I am not in distress, so, it’s an unseen issue.” (Patient 002)
	“I don’t have any swelling anywhere on my body. I have no problem urinating so I think it must be okay.” (Patient 004)
	“The kidneys help you breathe. I want to make my kidneys better. So I’m not doing anything to cause any kind of crazy breathing whatsoever. “I’m gathering between the heart and the kidneys my breathing would go real shallow.” (Patient 007)
Misinformation on the kidneys’ ability to self-repair	“I don’t know if it’s 100% reparative, self-reparative, but if it isn’t, I’m OK with it because the kidneys you have two of them. We can live on one so both my kidneys have had damage I’m certain the combined contribution of both these organs would probably be sufficient enough to keep me going for the rest of my life.” (Patient 001)
	“I am not concerned because I believe we have two kidneys and my kidneys are probably healthy and I don’t think they were ever comprised to begin with and that the body is in itself a self-recuperating machine like the liver is. I heard that the kidneys are a self-recuperating organ.” (Patient 002)
	“I rather think of it as more transient and fixable. Whereas with the kidney disease, you know if I do things sensibly and take the right medications, and keep things flushing, um, you know I feel like I have a little, right or wrong, I feel like I have a little control over maintaining a positive and good state of health, as I can. Like I feel like I can be participatory. Whereas I think if somebody told me you have heart disease, I wouldn’t really know, I wouldn’t really feel that I could do anything to make it better. With a kidney injury, I feel like I can do things to participate in improving kidney health.” (Patient U-003)

Theme 3: Anxiety from discharge planning and competing health demands	
Complicated discharge plans	“I don’t think I’m taking anything directly relative to the kidneys but certainly to keep my diabetes under control, high blood pressure is well under control. An explanation sheet from the pharmacy about medications that I was taking, new medications and the reason I was taking those as opposed to the other medications. I’ve retained that sheet because it gives me a good explanation of the meds that I’m taking, what they’re doing and all that. All the meds I had been taking prior to going into the hospital were altogether different than the ones that I had coming out of the hospital, all the prescriptions were different.” (Patient 014)
	“It was oh you can go home next week. Oh it will be Tuesday and you know, I’m saying well what happens with this? I’m, I need stroke rehab, you know you’ve been giving me choices for rehab places to go to that has to have a stroke unit, and now suddenly I can go home and what’s changed? And what do I need? And who looks after me when I get there? And, do I organize the radiotherapy and uh, kidney clinic myself? Or how does that happen? So finally when I did get home, I had some uh, some paperwork that said I would be contacted by ABCD, ABC so far not D.” (Patient U-003)
	“I haven’t been advised of anything, just to reduce my blood pressure. Just physiotherapy for my hip. That somebody from the AKI would ultimately call me. I mean to be honest with you, after being made to stay in the hospital an extra day because of this kidney issue. It was clearly not my responsibility.” (Patient 002)
	“I said well wait I have not been told she is being discharged so then I was disturbed by that. I am coming to pick her up how don’t I know there is a discharge date. I was concerned and I thought well they know what they are doing. Then she went back to the hospital specifically because she needed lasix. That could have been prevented.” (Niece 009)
	“My health priorities were to certainly keep on the meds that I was prescribed, cause just everything changed as far as my meds.” (Patient 014)
	“Based on my discharge alone, from the hospital, I don’t know at this point whether my kidneys have improved more so. I don’t know the state of my kidneys.” (Patient 001)
Multiple specialists involved in care	“Discharge plan was follow-up with my kidney doctor, follow-up with my neurologist, follow up with a kidney specialist, a follow up with my cardiologist and a follow up with my psychiatrist.” (Patient 001)
	“The discharge plans were to get better and carry on from where I left off before it all started. They said I should see my family doctor and my heart doctor which I haven’t done yet.” (Patient 012)
	“The joy of keeping track of all of these doctors because I am now waiting to hear from Dr. X when she gets back from the holiday or that, because Dr. Y wants some further information. The [referral process] was very well handled because it was from one doctor to the other and the appointment was made and then I was given a sheet with the information with what I could and couldn’t do and when the appointment would be.” (Patient 003)

Table 3: Elements that may improve knowledge transfer after a hospitalization with AKI

Content	Communication	Format
Signs and symptoms of AKI (including none)	Teaching that begins before hospital discharge	Single page
Causes of AKI	Prioritization of comorbidities for the patient and caregiver	Large font
Severity (including need for dialysis)	Prioritization of medical appointments for the patient and caregiver	Frequent use of visual materials
Serum creatinine at discharge, along with the pre-admission baseline serum creatinine	Strategies to recognize and prevent AKI	Room for patient and caregiver notes
Medication changes		
Consequences of AKI		
Follow-up plan (including tests, appointments, and responsibility for arranging)		

FIGURE LEGENDS

Supplementary Figure 1: Guide for patient interviews

Supplementary Figure 2: Guide for caregiver interviews

Online Supplement

Figure 1: Guide for patient interviews

Figure 2: Guide for caregiver interviews

Figure 1: Guide for Patient Interviews

Preamble

- Use shortly after hospital discharge
- Goal is to determine patient knowledge/understanding of acute kidney injury and its long-term consequences
- The following questions and/or prompts have been developed by the investigative team to guide this discussion

Introduction

Remind the participant of the following:

- The interview is voluntary and consent is implied by participating in the interview
- The expected length is 30-60 minutes
- The session will be audio recorded for accuracy
- Participants may skip any question that they do not wish to answer
- Participants may pause or stop the interview at any time, for any reason

Demographic Information

- Age
- Gender

General Health Questions

- Tell me about your health?
- What is your understanding of your current discharge plan?
- What are your main concerns right now?

Questions Related to Acute Kidney Injury Hospitalization

- What were you admitted to hospital for?
- When you think of your recent hospital stay, what is the first thing you think of?
- What organs in your body were affected?
- Were your kidneys affected during this hospital admission? If so, how and why?
- How are your kidneys functioning now?

Acute Kidney Injury

- When you hear the term acute kidney injury or acute renal failure, what comes to mind?
- How do you know if your kidneys are working properly?
- Do you think of acute kidney injury the same way as a disease such as diabetes or heart attack? Please explain.
- If asked about your past medical history, would you list acute kidney injury? Explain.

Questions Related to Long-term Health

- Has this current admission affected your long-term kidney health? If so, what steps will you take so your kidneys improve?
- What are your main concerns when you leave hospital?
- What are your health priorities when you leave hospital?

- Whose responsibility is it to arrange follow-up care after a hospital stay? The inpatient team? Family doctor? Patient?

Closing

- Now that you have thought through all of these details about your hospital stay and your kidneys, can you describe your understanding of acute kidney injury and how it impacts you? In the short-term? In the long-term?
- Is there anything else related to this hospital admission and your kidneys that we have not covered?

Figure 2: Guide for Caregiver Interviews

Preamble

- Use shortly after hospital discharge
- Goal is to determine family knowledge/understanding of acute kidney injury and its long-term consequences
- The following questions and/or prompts have been developed by the investigative team to guide this discussion

Introduction

Remind the participant of the following:

- The interview is voluntary and consent is implied by participating in the interview
- The expected length is 30-60 minutes
- The session will be audio recorded for accuracy
- Participants may skip any question that they do not wish to answer
- Participants may pause or stop the interview at any time, for any reason

Demographic Information

- Age
- Gender
- Relationship with patient

General Health Questions

- Tell me about your family member's health?
- What is your understanding of their current discharge plan?
- What are your main concerns right now?

Questions Related to Acute Kidney Injury Hospitalization

- What was your family member admitted to hospital for?
- When you think of their recent hospital stay, what is the first thing you think of?
- What organs in their body were affected?
- Were their kidneys affected during this hospital admission? If so, how and why?
- How are their kidneys functioning now?

Acute Kidney Injury

- When you hear the term acute kidney injury or acute renal failure, what comes to mind?
- How do you know if your kidneys are working properly?
- Do you think of acute kidney injury the same way as a disease such as diabetes or heart attack? Please explain.
- If asked about your family member's past medical history, would you list acute kidney injury? Explain.

Questions Related to Long-term Health

- Has this current admission affected your family member's long-term kidney health? If so, what steps will you take to help their kidneys improve?

- What are your main concerns for your family member when they leave hospital?
- What are your family member's health priorities when they leave hospital?
- Whose responsibility is it to arrange follow-up care after a hospital stay? The inpatient team? Family doctor? Patient?

Closing

- Now that you have thought through all of these details about your family member's hospital stay and their kidneys, can you describe your understanding of acute kidney injury and how it impacts patients? In the short-term? In the long-term?
- Is there anything else related to this hospital admission and your family member's kidneys that we have not covered?

Dr. Samuel Silver
Division of Nephrology
Queen's University
76 Stuart Street
3-Burr 21-3-039
Kingston, ON, Canada
K7L 2V7
Tel: 613-549-6666 ext: 4895
Fax: 613-548-2524

December 5, 2017

Dear Drs. Groves and Aldcroft:

We are submitting the following manuscript for consideration as a Research Article in *BMJ Open:*

Insights from Patients and Caregivers on Acute Kidney Injury and Post-Hospitalization Care: A Qualitative Study

We conducted semi-structured interviews with fifteen patients and five caregivers after a hospitalization with acute kidney injury (AKI) from May to December 2016. We identified three themes: 1) prioritization of conditions other than AKI, reflected by the importance placed on other comorbidities and the omission of AKI as part of the ongoing medical history; 2) variability in comprehension of the significance of AKI, represented by minimal knowledge of the causes and symptoms associated with AKI, along with misinformation on the kidneys' ability to self-repair; and 3) anxiety from discharge planning and competing health demands, illustrated by complicated discharge plans involving multiple specialist appointments.

We believe this manuscript is particularly timely and important to a general medicine audience, given the increased attention to follow-up care after AKI and the lack of literature on patient perspectives in this area. Based on the themes we identified, relying solely on patients and caregivers to communicate an episode of AKI to their outpatient physician is unlikely to be successful. Rather, our work helps inform the patient-centered tools and decision aids that are needed to bridge the gap between a hospitalization with AKI and transition to the outpatient setting.

This manuscript has not been previously published and is not under consideration in the same or substantially similar form in any other peer-reviewed media. We hope that it meets with your approval.

Sincerely,

Samuel Silver

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher’s credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

BMJ Open

What insights do patients and caregivers have on acute kidney injury and post-hospitalization care? A single-center qualitative study from Toronto, Canada

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-021418.R1
Article Type:	Research
Date Submitted by the Author:	23-Mar-2018
Complete List of Authors:	Silver, Sam; Queen's University, Nephrology Saragosa, Marianne; St. Michael's Hosptial, Nursing Adhikari, Neill; Sunnybrook Health Sciences Centre, Department of Critical Care Medicine Bell, Chaim; Sinai Health System, Medicine Harel, Ziv; University of Toronto, Nephrology Harvey, Andrea; St. Michael's Hospital, Nephrology Kitchlu, Abhijat; St. Michael's Hospital, Nephrology Neyra, Javier; University of Kentucky, Nephrology Wald, Ron; University of Toronto, Medicine/Nephrology Jeffs, Lianne; St. Michael's Hospital, Li Ka Shing Knowledge Institute
Primary Subject Heading:	Renal medicine
Secondary Subject Heading:	Qualitative research
Keywords:	Acute renal failure < NEPHROLOGY, QUALITATIVE RESEARCH, Health & safety < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Nephrology < INTERNAL MEDICINE

What Insights do Patients and Caregivers have on Acute Kidney Injury and Post-Hospitalization Care? A Single-Center Qualitative Study from Toronto, Canada

Samuel A Silver MD MSc[1], Marianne Saragosa RN MN[2], Neill K Adhikari MDCM MSc[3], Chaim M Bell MD PhD[4, 5], Ziv Harel MD MSc[2, 6], Andrea Harvey BSc[6], Abhijat Kitchlu MD[6], Javier A Neyra MD MSCS[7], Ron Wald MDCM MPH[2, 6], Lianne Jeffs RN PhD FAAN[2, 8]

[1]Division of Nephrology, Kingston Health Sciences Center, Queen's University, Kingston, Canada
[2]Li Ka Shing Knowledge Institute of St Michael's Hospital, St. Michael's Hospital, Toronto, Canada
[3]Department of Critical Care Medicine, Sunnybrook Health Sciences Center, University of Toronto, Toronto, Canada
[4]Department of Medicine, Sinai Health System, University of Toronto, Toronto, Canada
[5]Department of Medicine and Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Canada
[6]Division of Nephrology, St. Michael's Hospital, University of Toronto, Toronto, Canada
[7]Division of Nephrology, Bone and Mineral Metabolism, University of Kentucky, Lexington, United States
[8]Lawrence S Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada

Abstract word count: 270
Manuscript word count: 3115
Running title: Patient Insights on AKI

Corresponding author:
Samuel A Silver
Division of Nephrology, Queen's University
76 Stuart Street, 3-Burr 21-3-039
Kingston, ON, Canada
K7L 2V7
Tel: 613-549-6666 ext:4895
Fax: 613-548-2524
samuel.silver@queensu.ca

ABSTRACT

Objectives: Hospitalization with acute kidney injury (AKI) is associated with short- and long-term adverse events, but patient and caregiver experiences with AKI are not well described. We sought to better understand patient and caregiver perspectives after a hospitalization with AKI to inform discharge strategies that may improve outcomes for this high-risk population.

Design: Qualitative study with semi-structured interviews

Setting: Tertiary care hospital in Toronto, Ontario, Canada

Participants: Adult patients (n=15) who survived a hospitalization with Kidney Disease Improving Global Outcomes (KDIGO) stage 2 or 3 AKI from May to December 2016. We also interviewed five patient caregivers. We required patients to have no previous evidence of severe chronic kidney disease (i.e., prior receipt of dialysis, previous kidney transplantation, or pre-existing eGFR under 30mL/min/1.73m^2).

Results: We identified three over-arching themes: 1) prioritization of conditions other than AKI, reflected by the importance placed on other comorbidities and the omission of AKI as part of the ongoing medical history; 2) variability in comprehension of the significance of AKI, represented by minimal knowledge of the causes and symptoms associated with AKI, along with misinformation on the kidneys' ability to self-repair; and 3) anxiety from discharge planning and competing health demands, illustrated by complicated discharge plans involving multiple specialist appointments.

Conclusions: Patients and caregivers view AKI as a short-term and reversible condition, giving it little thought during the post-discharge period. As a result, reliance on patients

and caregivers to report an episode of AKI to their outpatient physicians is unlikely to be successful. Patient-centered tools and decision aids are needed to bridge the gap between a hospitalization with AKI and the safe transition to the outpatient setting.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- First report of patient and caregiver experiences with acute kidney injury (AKI), which informs patient-centered strategies to improve care transitions after a hospitalization with AKI
- Semi-structured interviews allowed the researchers to thoroughly explore participants' understanding of AKI and its long-term consequences
- Participants self-selected for interviews, which may not be representative of the entire population with AKI
- Single-center study

INTRODUCTION

Acute kidney injury (AKI) is a common condition that affects approximately one in five hospitalized patients [1, 2]. With in-hospital survival for AKI-associated hospitalizations improving [3], increased attention has been drawn to adverse events after an episode of AKI. These complications include kidney events such as recurrent AKI [4], incident or progressive chronic kidney disease (CKD), and end-stage renal disease (ESRD) [5], as well as systemic problems such as new-onset hypertension [6], cerebrovascular disease [7], and cardiovascular disease [8]. Given these increased risks, it is not surprising that survivors of AKI are at higher risk of rehospitalization and death relative to patients without AKI [5, 9].

Several gaps in care of AKI survivors have been identified and addressing these may improve post-discharge outcomes. Fewer than half of physician discharge summaries document the presence of AKI [10, 11], and over 80% of hospitalized patients are unaware that they experienced an episode of AKI [12]. A United States Renal Data System (USRDS) report demonstrated that only three in five patients have their serum creatinine checked within 90 days of discharge [13], despite the Kidney Disease Improving Global Outcomes (KDIGO) guidelines recommending evaluation for kidney function at 90 days [14]. In the same USRDS report, fewer than one in six patients visited a nephrologist within 90 days of discharge [13], even though follow-up with a nephrologist after severe AKI has been associated with a 24% relative reduction in mortality [15]. There are multiple explanations for these potential gaps in care, including the lack of strong evidence to guide post-AKI care and the heterogeneity of AKI itself. Patients who experience AKI are often older and suffer from multiple medical comorbidities, with AKI sometimes representing a marker of the severity of other health conditions [4, 16]. In these cases, prioritization of other chronic diseases over AKI may be reasonable and beneficial for patients [17, 18].

As more attention is devoted to enhancing care processes after a hospitalization with AKI [19], information is needed on the priorities and perspectives of patients and caregivers who experience AKI. Little is known about their level of understanding around what AKI entails, awareness of the long-term consequences of AKI, and post-discharge care preferences. Our objective was to describe the experiences and expectations of AKI survivors and their caregivers in the immediate post-discharge period to ultimately inform patient- and caregiver-centered strategies that may improve outcomes for this high-risk population.

METHODS

Design

We conducted a qualitative study using a descriptive inductive design with individual semi-structured interviews. We performed, analyzed, and reported this qualitative study in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ guidelines) [20]. The Research Ethics Board at St. Michael's Hospital approved this study.

Participants

We recruited patients and caregivers after an inpatient stay at a single, urban teaching hospital. Eligible patients were ≥ 18 years of age with KDIGO stage 2 AKI or greater; caregivers also were required to be ≥ 18 years of age. We also required the patient or his/her caregiver to speak English. We excluded patients likely to have received formal education on kidney health prior to study contact, such as kidney transplant recipients, patients already under the care of a nephrologist, patients with a baseline eGFR under $30mL/min/1.73m^2$, and patients discharged from hospital on dialysis.

Recruitment and Data Collection Methods

We recruited patients using purposive sampling, which involved the initial identification of eligible patients by one of the investigators or nephrologists as part of an ongoing program to improve outpatient care for patients with AKI [21, 22]. These staff asked potential participants for permission to be contacted by the qualitative study team.

The qualitative research staff then contacted participants with further study information, arranging an interview time for agreeable patients and/or caregivers. Research staff obtained informed consent before conducting any interviews.

Once a participant was enrolled in the study, researchers with experience in qualitative methods conducted in-depth semi-structured interviews using guides that included questions on demographics, general health, the index hospitalization, level of AKI knowledge, and post-discharge follow-up care **(Online Supplement, Figures 1 and 2).** We conducted the interviews from May to December 2016, as either in-person interviews at the time of outpatient appointments or as telephone interviews. We interviewed patients and caregivers separately in cases where both agreed to participate. We audiotaped and transcribed all interviews verbatim, with a mean duration of 25.1 minutes (range 6.5 to 43.5 minutes). We determined the final sample size by thematic saturation, where all emerging themes are fully accounted for and successive interviews did not reveal any new barriers or expansions on relevant themes [20, 23].

Analytical Plan

We summarized baseline characteristics using descriptive statistics. We expressed continuous variables as the mean (standard deviation; SD) or median (25th, 75th percentile), and categorical variables as a percentage.

Data analysis occurred in conjunction with data collection in an emergent, iterative process. Two research staff (MS and LJ) with experience in qualitative methods independently reviewed and coded all interview transcripts. Two investigators (SS and LJ) refined the final coding schema by comparing their coding of the transcripts with the emergent coding schema. We determined the emergent coding schema using a constant comparison technique and through consensus [24, 25], with no discrepancies amongst the different reviewers. Strategies to ensure trustworthiness and credibility of the data included having three different coders to establish intercoder reliability and employing an iterative approach to analysis. In the latter case, the two primary investigators analyzed the data while the interviews were being conducted and then further probed emergent key themes with study participants as a form of member checking [26]. We did not use coding software due to the discrete number of interviews completed.

Patient and Public Involvement

We involved patients and caregivers in the design and conduct of this study, as outlined above. We will offer all participants a copy of the manuscript upon publication.

RESULTS

Participant Characteristics

We conducted 20 separate interviews: 12 with patients only, 2 with caregivers only, and 3 patient/caregivers pairs (conducted separately, so 6 interviews total). Of the 17 unique patients (12 patient-only interviews, 2 caregiver-only interviews, and 3 patient-caregiver pairs), the average age was 68.4 (11.6) years, 8 (47%) were female, 5 (29%) had CKD, 10 (59%) required critical care, and 2 (12%) received renal replacement therapy. The 5 caregivers interviewed consisted of 2 adult children, 2 nieces, and 1 spouse. **Table 1** provides a more detailed description of the participant characteristics. The interviews occurred a median of 68 (52-86) days after hospital discharge.

Emergent Themes

Three over-arching themes emerged from analysis of this narrative dataset: 1) prioritization of conditions other than AKI; 2) variability in comprehension of the significance of AKI; and 3) anxiety from discharge planning and competing health demands. **Table 2** provides selected quotations to support these themes.

Prioritization of Conditions other than AKI

This theme captures how participants were more concerned with other conditions than AKI and includes the following sub-themes: the importance of other comorbidities and the omission of AKI as part of the ongoing medical history.

Importance of Other Comorbidities

Many of the patients had comorbidities (e.g., diabetes, hypertension) or other medical issues (e.g., low hemoglobin, recent surgery) that they described as their main concern. Some participants identified a connection between these conditions and AKI, particularly the relationship between heart and kidney disease. However, most participants prioritized conditions other that AKI because these *"diseases progress over time."* Several participants explained that they overlooked the kidneys because AKI is *"an unseen issue"* that is *"transient and fixable."*

Omission of AKI from the Medical History

Having minimal concern for their kidney function after an episode of AKI was also reflected in participants' reluctance to include AKI as part of their past medical history. Participants provided several reasons for this omission, which included return to normal serum creatinine concentration, the cessations of dialysis, *"feeling better,"* and the presence of *"two kidneys."* A few patients even denied experiencing AKI. At a recent outpatient appointment with his or her primary care physician, one patient *"didn't even think they said anything about their kidneys"* when questioned about details of the recent hospitalization. Several participants observed that the healthcare team was more worried about the kidney function as an inpatient than as an outpatient, suggesting that AKI was a short-term and reversible condition that did not merit inclusion as a distinct condition in one's medical history.

Variability in Comprehension of the Significance of AKI

This theme reflects the varying levels of understanding the significance of AKI among the participants and includes the following sub-themes: not knowing the causes, symptoms, and signs of AKI and misinformation on the kidneys' ability to self-repair.

Not Knowing the Causes, Symptoms, and Signs Associated with AKI

Many participants *"did not have the faintest idea"* what caused their AKI episode. Suggestions offered by patients and caregivers included hypertension, hypotension, dehydration, surgery, medication, and infection, but very few patients expressed confidence in the mechanisms that they proposed. This uncertainty may be because most patients *"didn't go into the hospital because of a problem with [their] kidneys,"* and only discovered their kidneys were involved based upon serum creatinine testing rather than specific kidney-related symptoms.

When patients and caregivers did mention symptoms or signs experienced during a hospitalization, these were rarely attributed to the kidneys or AKI. One patient observed that *"when you don't have symptoms, you don't think about it."* Several participants identified urinary symptoms and signs including high output, low output, odor, color, dysuria, and catheterization. Pain was a commonly expressed symptom, particularly in the abdomen, back, and suprapubic area. A few patients also mentioned breathing changes and leg swelling, but they *"wouldn't be able to pinpoint it to the kidney at all."* Despite this confusion, most participants demonstrated an awareness that blood tests monitored kidney function. One patient summarized his or her understanding with *"I don't [know how you know kidneys are functioning better]. I only know my creatinine level."*

Misinformation on the Kidneys' Ability to Self-repair

The majority of participants viewed AKI as a "repairable" condition and even as a "self-recuperating machine like the liver." Those who believed permanent kidney damage from AKI was still possible were not concerned because of the presence of two kidneys.

Anxiety from Discharge Planning and Competing Health Demands

This theme captures the experiences of participants with discharge planning and their competing health demands and includes the following sub-themes: complicated discharge plans and multiple specialists involved in their care.

Complicated Discharge Plans

Participant experiences with discharge planning varied, but most expressed anxiety over the number of issues to address. Many participants shared that they were not provided any specific advice around kidney health at the time of hospital discharge. Rather, the focus of discharge planning was more general (e.g., maintaining a better lifestyle, eating healthier, mobility) and on other conditions (e.g., cardiac or post-surgical problems). Medications were a particular focus, with one patient noting that *"all the meds I had been taking prior to going into the hospital were altogether different than the ones that I had coming out of the hospital, all the prescriptions were different."* A few participants attributed poor discharge planning around diuretic management to the need for rehospitalization, mainly involving the discontinuation/reduction of diuretics during an AKI episode contributing to subsequent heart failure exacerbations.

Multiple Specialists Involved in Care

Regardless of the actual discharge plan content, study participants noted multiple health demands that required a series of follow-up appointments with medical specialists (e.g., nephrologist, cardiologist, surgeon) and health disciplines (e.g., physiotherapy). The high volume of appointments was handled well by some participants, but was a source of stress for others. In these latter cases, it was challenging for some participants to concern themselves with their kidney health while dealing with other conditions and the associated follow-up appointments.

DISCUSSION

After a hospitalization with AKI, our qualitative study found that patients and caregivers view AKI as a short-term and reversible condition with limited relevance to their global health. Reasons for these impressions include the concomitant presence of other important comorbidities, misconceptions of the significance of AKI, and the prioritization of other illnesses by healthcare providers. The post-discharge period is also complicated for these patients and their families, with kidney health rarely emerging as a primary concern.

There is limited information about the barriers to providing care for survivors of AKI, and so some insights may be gained from the setting of CKD. Frequently-cited CKD barriers include poor understanding of disease risks, lack of knowledge on management, and low prioritization of kidney disease among primary care providers [27, 28]. Our work suggests that some physicians view AKI episodes as transient and fixable, as reflected by the language utilized by patients and caregivers [29]. One study conducted semi-structured interviews with physicians and pharmacists experienced in the care of patients with AKI [30]. These participants identified AKI as a complex condition, with both knowledge and organizational challenges that disrupted workflows, communication, and coordination between healthcare providers. In many cases, participants described patients as messengers between practitioners, depending upon them to relay important details about laboratory monitoring and medication use during and after a hospitalization with AKI.

Our study builds upon this work by providing the patient and caregiver perspective on AKI. We observed that both groups rarely mentioned AKI as an important discharge issue, which is noteworthy because most interviews occurred approximately two months after an acute hospitalization with AKI. Even when prompted during interviews, only a minority of patients and caregivers included AKI as part of their past medical history. This latter sub-theme is particularly important, given the short- and long-term health consequences associated with an episode of AKI [4, 5, 8, 9]. These findings suggest that patients and caregivers may not be the ideal messengers to coordinate post-AKI care, contrary to the expectations of other healthcare providers described above [30].

We suspect that some of the lack of attention dedicated to AKI by patients and caregivers is related to their prioritization of other health conditions and variability in comprehension of the significance of AKI. It is important to interpret these perspectives in context. For example, these responses may be appropriate depending upon the severity of other illnesses and the degree of kidney recovery at hospital discharge. Prioritization of comorbidities is a recognized self-management strategy for elderly patients with kidney disease [31], and these observations underscore the heterogeneity of AKI and the complexity of integrating post-AKI care in a manner that considers patient multimorbidity and preferences [17, 18]. Even if other health conditions are appropriately prioritized over AKI in some instances, discharge summary AKI content can still be improved. In one study, monitoring advice after AKI was provided to only 6/75 (8%) patients and causes of AKI communicated to only 1/75 (1%) patients [10]. It is hard to expect patients and caregivers to prioritize a condition that they do not completely understand, especially given multiple competing health demands during the post-discharge period.

Current discharge communication initiatives after a hospitalization with AKI include infographics endorsed by the National Kidney Foundation in the United States [32] and the National Health Service in the United Kingdom [33]. The latter's "Think Kidneys" program (https://www.thinkkidneys.nhs.uk/aki/) also sets standards for discharge summary content after AKI, which include identifying the cause of AKI, describing the course of AKI (e.g., baseline creatinine, AKI severity, and discharge creatinine), recommending medication adjustments, and identifying the responsible ambulatory care provider along with the timing of a follow-up appointment. However, with appropriate discharge summary completion for AKI below 50% [10, 11], this strategy is unlikely to be successful on its own. Moreover, our study suggests that relying solely on the patient or caregiver is also unlikely to result in successful care coordination.

Instead, our work supports the need for system-based efforts to educate patients and facilitate knowledge transfer after a hospitalization with AKI **(Table 3)**. Elements of a successful program should begin before hospital discharge, provide simple discharge instructions, and respect the multiple appointments faced by these patients and their caregivers. In addition to the discharge content endorsed by the "Think Kidneys" program, our study illustrates that patients and caregivers require teaching on the consequences of AKI (e.g., CKD, cardiovascular disease, recurrent AKI) and strategies to recognize and prevent subsequent episodes. Better education in these areas may change how patients and caregivers prioritize kidney health relative to other comorbidities. An innovative approach that addresses these elements is the concept of patient-oriented discharge summaries [34]. Co-designed by patients, caregivers, and providers, they are structured to provide important information in an easy-to-understand format without increasing healthcare provider workload (http://pods-toolkit.uhnopenlab.ca/). Further study is required to determine whether these templates can be modified to suit the specific needs of patients with AKI.

Our study has limitations. As with most qualitative studies, participants were self-selected for interviews and may not be representative of the entire population with AKI. Even though we interviewed participants from a diverse range of ethnicities and cultural backgrounds, we excluded patients/caregivers who could not speak English to avoid misinterpretation from language translation. We also targeted participants less likely to have received formal education on kidney health prior to study contact, and so we may have underestimated the knowledge and understanding around AKI. However, similarly low levels of disease comprehension apply to patients with CKD followed by a nephrologist [35, 36]. A more complete understanding of AKI and post-hospitalization care could also have been provided by involving physicians and other healthcare staff in interviews or focus groups, but resource limitations precluded their involvement. Finally, our results are from a single tertiary care hospital in Canada and may not be transferable to other populations.

Despite these limitations, the use of semi-structured interviews allowed our research team to thoroughly explore participants' understanding of AKI and its long-term consequences. Our interview team was experienced with concepts related to post-hospital care transitions and the challenges faced by participants during this time [37, 38], thereby strengthening the credibility of our findings. All interviews also occurred as soon as logistically possible after discharge from hospital (usually within 60 days), preventing other healthcare providers or events from influencing patient and caregiver perceptions.

Our qualitative study found that AKI was a low priority concern for patients who survived an episode of AKI and their caregivers. Themes that explain these patient and caregiver experiences included concern with other health conditions, limited understanding of the significance of AKI, and complicated discharge plans with multiple appointments to balance. These findings should inform the design of patient-centered discharge plans after a hospitalization with AKI, suggesting that the onus is on the healthcare system to educate and arrange appropriate follow-up for this high-risk population. Sole reliance on patients and caregivers to communicate an episode of AKI to outpatient physicians is unlikely to be successful. With in-hospital survival after AKI improving, patient-centered tools and decision aids are needed to bridge the gap between a hospitalization with AKI and the safe transition to outpatient care that also respects the multiple competing health demands faced by patients post-discharge.

ACKNOWLEDGEMENTS: The authors would like to thank the study participants for their time.

SUPPORT: SAS was supported by a Kidney Research Scientist Core Education and National Training Program Post-Doctoral Fellowship (co-funded by the Kidney Foundation of Canada, Canadian Society of Nephrology, and Canadian Institutes of Health Research). JAN was supported by the Ben J. Lipps Research Fellowship Program of the American Society of Nephrology Foundation for Kidney Research. LJ was supported by the St. Michael's Hospital Volunteer Association Chair in Nursing Research and a Ministry of Health and Long-Term Care Early Nursing Research Award. These funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, or approval of the manuscript; or decision to submit the manuscript for publication.

CONFLICTS OF INTEREST: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

AUTHOR CONTRIBUTIONS: Study concept and design: SAS, CMB, ZH, RW, LJ; Acquisition, analysis, or interpretation of data: SAS, MS, NKA, AH, AK, JN, LJ; Drafting of the manuscript: SAS, MS, LJ; Critical revision of the manuscript for important intellectual content: SAS, MS, NKA, CMB, ZH, AH, AK, JN, RW, LJ; Study supervision: LJ. All authors approved the final version of the submitted manuscript. LJ had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. We certify that this manuscript nor one with substantially similar content has been published or is being considered for publication elsewhere.

DATA SHARING: No additional data available

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Table 1: Characteristics of the 17 unique patients*

Demographics	**Patient (n=17)**
Age (years), mean (SD)	68.4 (11.6)
Women, n (%)	8 (47)
Ethnicity, n (%)	
Caucasian	10 (59)
Other	7 (41)
Comorbidities n, (%)	
Chronic kidney disease	5 (29)
Diabetes	9 (53)
Congestive heart failure	5 (29)
Coronary artery disease	5 (29)
Cancer	2 (12)
Characteristics of index hospitalization, n (%)	
Renal replacement therapy	2 (12)
Intensive care unit	10 (59)
Sepsis	4 (24)
Surgical procedure	10 (59)
Nephrotoxin	2 (12)
Length of stay (days), median (25th, 75th percentile)	15 (11-32)

*17 unique patients (12 patient-only interviews, 2 caregiver-only interviews, and 3 patient-caregiver pairs)

Table 2: Selected participant quotations for each theme

Sub-Theme	Quotation
Theme 1: Prioritization of conditions other than AKI	
Importance of other comorbidities	"Going forward we don't have any concerns about his kidneys. It's more about his heart condition and how that's going to function and if that's going to keep on going." (Son 006)
	"My main concern is my blood pressure more than anything. They had told me my lungs would take a while to come back and they were really worried about my kidney because my blood pressure was so low. Apparently they had a problem during the operation, and not only did I get an incision down my front side, but the top of my right leg, I think they had to call another doctor in because there was no blood flow in my right leg. I don't know, she wanted me to get my kidneys checked because she told me that they took quite a beating in there and that was because of my low blood pressure. I was never really worried about my kidneys." (Patient 011)
	"Just you know, my keeping my blood in line and my hemoglobin is low you know I had to have a blood transfusion, I get really short of breath so that's my concern now. No (not concerned about the kidneys) because I don't have any symptoms." (Patient U-002)
Omission of AKI from the past medical history	"Kidney injury or kidney disease or kidney problems could be more immediate like a heart attack or uncorrectable damage that's been done. It's irreversible. I wouldn't list the kidney as a kidney damage that's an ongoing condition because I think he did go through it and now he's back and he's doing ok so I wouldn't say that he's got continuous kidney problems. I think that his kidneys are and they're functioning normally right now." (Son 006)
	"No I would not [list AKI as part of medical history] because I believe it will be repaired. Let's say you have this fantastic lung capacity and you start smoking and your lung capacity reduces and you quit and those ten years they say your lungs are very forgiving and could come back to their full capacity. I hope to be able to think that the kidney has that rebound effect." (Patient 001)
	"It's funny because I just got a Medic-Alert on Monday night and I thought it wouldn't hurt to have a Medic-Alert if something ever happened at least they would know what drugs I take in there and different things like having a central line. They ask you all that information you know, about your health and you know I don't even think I did say anything about my kidneys." (Patient U-002)
Theme 2: Variability in comprehension of the significance of AKI	
Not knowing the causes, symptoms,	"I had some blood infection and then my kidney was also affected by that, everything like other things were due to the surgery and all so anyway. I have no idea." (Patient 004)

and signs associated with AKI	"They took those nodes out and then I had one chemotherapy session after which my whole body crashed. Dr. X had explained to me that part of the kidney malfunction could well be that I have urine reflux. I wasn't pushing enough urine through, so the base of the bladder could have an infection that was being passed to the kidneys, another time I was told it was autoimmune - the kidneys' reaction and one time I was told herpes." (Patient U-003)
	"I probably wouldn't be peeing as much, or at all or perhaps the coloration of my urine might be a little different than normal. All the related to the urine as I would observe it. I don't recall during my time in the hospital when I was having any difficulty with my kidneys that uh, I was able to observe anything different to be honest with you. I guess they were recovering and I didn't notice anything different at all." (Patient 014)
	"He would have to definitely not be feeling well, or not passing urine properly, or have pain. Any one of those symptoms, pain, he's not sleeping, maybe his legs are swollen, or his hands are swollen so they could be a trigger, they could be a sign that something's not right." (Son 006)
	"I don't know. I mean obviously I'm urinating regularly and my kidneys are function, and I am not in distress, so, it's an unseen issue." (Patient 002)
	"I don't have any swelling anywhere on my body. I have no problem urinating so I think it must be okay." (Patient 004)
	"The kidneys help you breathe. I want to make my kidneys better. So I'm not doing anything to cause any kind of crazy breathing whatsoever. "I'm gathering between the heart and the kidneys my breathing would go real shallow." (Patient 007)
Misinformation on the kidneys' ability to self-repair	"I don't know if it's 100% reparative, self-reparative, but if it isn't, I'm OK with it because the kidneys you have two of them. We can live on one so both my kidneys have had damage I'm certain the combined contribution of both these organs would probably be sufficient enough to keep me going for the rest of my life." (Patient 001)
	"I am not concerned because I believe we have two kidneys and my kidneys are probably healthy and I don't think they were ever comprised to begin with and that the body is in itself a self-recuperating machine like the liver is. I heard that the kidneys are a self-recuperating organ." (Patient 002)
	"I rather think of it as more transient and fixable. Whereas with the kidney disease, you know if I do things sensibly and take the right medications, and keep things flushing, um, you know I feel like I have a little, right or wrong, I feel like I have a little control over maintaining a positive and good state of health, as I can. Like I feel like I can be participatory. Whereas I think if somebody told me you have heart disease, I wouldn't really know, I wouldn't really feel that I could do anything to make it better. With a kidney injury, I feel like I can do things to participate in improving kidney health." (Patient U-003)
Theme 3: Anxiety from discharge planning and competing health demands	
Complicated discharge plans	"I don't think I'm taking anything directly relative to the kidneys but certainly to keep my diabetes under control, high blood pressure is well under control. An explanation sheet from the pharmacy about medications that I was taking, new

	medications and the reason I was taking those as opposed to the other medications. I've retained that sheet because it gives me a good explanation of the meds that I'm taking, what they're doing and all that. All the meds I had been taking prior to going into the hospital were altogether different than the ones that I had coming out of the hospital, all the prescriptions were different." (Patient 014)
	"I haven't been advised of anything, just to reduce my blood pressure. Just physiotherapy for my hip. That somebody from the AKI would ultimately call me. I mean to be honest with you, after being made to stay in the hospital an extra day because of this kidney issue. It was clearly not my responsibility." (Patient 002)
	"I said well wait I have not been told she is being discharged so then I was disturbed by that. I am coming to pick her up how don't I know there is a discharge date. I was concerned and I thought well they know what they are doing. Then she went back to the hospital specifically because she needed lasix. That could have been prevented." (Niece 009)
	"My health priorities were to certainly keep on the meds that I was prescribed, cause just everything changed as far as my meds." (Patient 014)
	"Based on my discharge alone, from the hospital, I don't know at this point whether my kidneys have improved more so. I don't know the state of my kidneys." (Patient 001)
Multiple specialists involved in care	"Discharge plan was follow-up with my kidney doctor, follow-up with my neurologist, follow up with a kidney specialist, a follow up with my cardiologist and a follow up with my psychiatrist." (Patient 001)
	"The discharge plans were to get better and carry on from where I left off before it all started. They said I should see my family doctor and my heart doctor which I haven't done yet." (Patient 012)
	"The joy of keeping track of all of these doctors because I am now waiting to hear from Dr. X when she gets back from the holiday or that, because Dr. Y wants some further information. The [referral process] was very well handled because it was from one doctor to the other and the appointment was made and then I was given a sheet with the information with what I could and couldn't do and when the appointment would be." (Patient 003)
	"It was oh you can go home next week. Oh it will be Tuesday and you know, I'm saying well what happens with this? I'm, I need stroke rehab, you know you've been giving me choices for rehab places to go to that has to have a stroke unit, and now suddenly I can go home and what's changed? And what do I need? And who looks after me when I get there? And, do I organize the radiotherapy and kidney clinic myself? Or how does that happen? So finally when I did get home, I had some paperwork that said I would be contacted by ABCD, ABC so far not D." (Patient U-003)
	"The information is flowing from all of these sources back to both the cardiologist and the endocrinologist, and also my family doctor, so I've got three guys that are involved here looking after things and keeping me on the straight and narrow. I've got another follow-up appointment coming early next year with regard to the endocrinologist. Also going back to

	another session with the gal on the pacemaker. I'm managing it and my wife and I are managing it as far as the appointments go. They're all scheduled and usually at the end of one session I'm booking the next session right away." (Patient 014)

Table 3: Elements that may improve knowledge transfer after a hospitalization with AKI

Content	Communication	Format
• Signs and symptoms of AKI (including none) • Causes of AKI • Severity (including need for dialysis) • Serum creatinine at discharge, along with the pre-admission baseline serum creatinine • Medication changes • Consequences of AKI • Follow-up plan (including tests, appointments, and responsibility for arranging)	• Teaching that begins before hospital discharge • Prioritization of comorbidities for the patient and caregiver • Prioritization of medical appointments for the patient and caregiver • Strategies to recognize and prevent AKI	• Single page • Large font • Frequent use of visual materials • Room for patient and caregiver notes

FIGURE LEGENDS

Supplementary Figure 1: Guide for patient interviews

Supplementary Figure 2: Guide for caregiver interviews

Online Supplement

Figure 1: Guide for patient interviews

Figure 2: Guide for caregiver interviews

Figure 1: Guide for Patient Interviews

Preamble

- Use shortly after hospital discharge
- Goal is to determine patient knowledge/understanding of acute kidney injury and its long-term consequences
- The following questions and/or prompts have been developed by the investigative team to guide this discussion

Introduction

Remind the participant of the following:

- The interview is voluntary and consent is implied by participating in the interview
- The expected length is 30-60 minutes
- The session will be audio recorded for accuracy
- Participants may skip any question that they do not wish to answer
- Participants may pause or stop the interview at any time, for any reason

Demographic Information

- Age
- Gender

General Health Questions

- Tell me about your health?
- What is your understanding of your current discharge plan?
- What are your main concerns right now?

Questions Related to Acute Kidney Injury Hospitalization

- What were you admitted to hospital for?
- When you think of your recent hospital stay, what is the first thing you think of?
- What organs in your body were affected?
- Were your kidneys affected during this hospital admission? If so, how and why?
- How are your kidneys functioning now?

Acute Kidney Injury

- When you hear the term acute kidney injury or acute renal failure, what comes to mind?
- How do you know if your kidneys are working properly?
- Do you think of acute kidney injury the same way as a disease such as diabetes or heart attack? Please explain.
- If asked about your past medical history, would you list acute kidney injury? Explain.

Questions Related to Long-term Health

- Has this current admission affected your long-term kidney health? If so, what steps will you take so your kidneys improve?
- What are your main concerns when you leave hospital?
- What are your health priorities when you leave hospital?

- Whose responsibility is it to arrange follow-up care after a hospital stay? The inpatient team? Family doctor? Patient?

Closing

- Now that you have thought through all of these details about your hospital stay and your kidneys, can you describe your understanding of acute kidney injury and how it impacts you? In the short-term? In the long-term?
- Is there anything else related to this hospital admission and your kidneys that we have not covered?

Figure 2: Guide for Caregiver Interviews

Preamble

- Use shortly after hospital discharge
- Goal is to determine family knowledge/understanding of acute kidney injury and its long-term consequences
- The following questions and/or prompts have been developed by the investigative team to guide this discussion

Introduction

Remind the participant of the following:

- The interview is voluntary and consent is implied by participating in the interview
- The expected length is 30-60 minutes
- The session will be audio recorded for accuracy
- Participants may skip any question that they do not wish to answer
- Participants may pause or stop the interview at any time, for any reason

Demographic Information

- Age
- Gender
- Relationship with patient

General Health Questions

- Tell me about your family member's health?
- What is your understanding of their current discharge plan?
- What are your main concerns right now?

Questions Related to Acute Kidney Injury Hospitalization

- What was your family member admitted to hospital for?
- When you think of their recent hospital stay, what is the first thing you think of?
- What organs in their body were affected?
- Were their kidneys affected during this hospital admission? If so, how and why?
- How are their kidneys functioning now?

Acute Kidney Injury

- When you hear the term acute kidney injury or acute renal failure, what comes to mind?
- How do you know if your kidneys are working properly?
- Do you think of acute kidney injury the same way as a disease such as diabetes or heart attack? Please explain.
- If asked about your family member's past medical history, would you list acute kidney injury? Explain.

Questions Related to Long-term Health

- Has this current admission affected your family member's long-term kidney health? If so, what steps will you take to help their kidneys improve?

- What are your main concerns for your family member when they leave hospital?
- What are your family member's health priorities when they leave hospital?
- Whose responsibility is it to arrange follow-up care after a hospital stay? The inpatient team? Family doctor? Patient?

Closing

- Now that you have thought through all of these details about your family member's hospital stay and their kidneys, can you describe your understanding of acute kidney injury and how it impacts patients? In the short-term? In the long-term?
- Is there anything else related to this hospital admission and your family member's kidneys that we have not covered?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	20
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	1,8, 18
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	8
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Supplement
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Supplement
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7-9
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	7-8
Sample size	12	How many participants were in the study?	10
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	8
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7-8
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	10, Table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8, Supplement
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	8
Field notes	20	Were field notes made during and/or after the inter view or focus group?	8-9
Duration	21	What was the duration of the inter views or focus group?	8
Data saturation	22	Was data saturation discussed?	8
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8-9
Description of the coding tree	25	Did authors provide a description of the coding tree?	10, Table 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	9-10
Software	27	What software, if applicable, was used to manage the data?	9
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Table 2
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-14, Table 2
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-14, Table 2

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.