Patient-Reported Experiences After Acute Kidney Injury Across Multiple Health-Related Quality-of-Life Domains

Galen Switzer, Chethan Puttarajappa, Sandra L. Kane-Gill, Linda Fried, Kaleab Abebe, John Kellum, Manisha Jhamb, Jessica Bruce, Vidya Kuniyil, Paul T. Conway, Richard Knight, John Murphy, and Paul Palevsky

Key Points:
* Eighty-four percent of respondents reported that the AKI episode was very/extremely impactful on physical/emotional health.

* Fifty-seven percent reported being very/extremely concerned about AKI effects on work and 67% were concerned about AKI effects on family.

* Future research should incorporate more comprehensive HRQoL measures and providers should give more information to patients about AKI.

Abstract:
Background: Investigations of health-related quality-of-life (HRQoL) in acute kidney injury (AKI) have been limited in number, size, and domains assessed. We surveyed AKI survivors to describe the range of HRQoL AKI-related experiences and examine potential differences in AKI impacts by gender and age at AKI episode. Methods: AKI survivors among American Association of Kidney Patients (AAKP) completed an anonymous online survey in September 2020. We assessed: (1) socio-demographics, (2) impacts of AKI - physical, emotional, social, and (3) perceptions about interactions with healthcare providers using quantitative and qualitative items. Results: Respondents were 124 adult AKI survivors. 84% reported that the AKI episode was very/extremely impactful on physical/emotional health. Fifty-seven percent reported being very/extremely concerned about AKI effects on work and 67% were concerned about AKI effects on family. Only 52% of respondents rated medical team communication as very/extremely good. Individuals ages 22-65 at AKI episode were more likely than younger/older counterparts to rate the AKI episode as highly impactful overall (90% vs 63% younger and 75% older individuals; p = 0.040), more impactful on family (78% vs 50% and 46%; p = 0.008) and more impactful on work (74% vs 38% and 10%; p < 0.001). Limitations of this work include convenience sampling, retrospective data collection, and unknown AKI severity. Conclusions: These findings are a critical step forward in understanding the range of AKI experiences/consequences, and unknown AKI severity. Future research should incorporate more comprehensive HRQoL measures and healthcare professionals should consider providing more information in their patient communication about AKI and follow-up.

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Key Points

- 84% of respondents reported that the AKI episode was very/extremely impactful on physical/emotional health.
- Fifty-seven percent reported being very/extremely concerned about AKI effects on work and 67% were concerned about AKI effects on family.
- Future research should incorporate more comprehensive HRQoL measures and providers should give more information to patients about AKI.

Abstract

Background: Investigations of health-related quality-of life (HRQoL) in acute kidney injury (AKI) have been limited in number, size, and domains assessed. We surveyed AKI survivors to describe the range of HRQoL AKI-related experiences and examine potential differences in AKI impacts by gender and age at AKI episode.

Methods: AKI survivors among American Association of Kidney Patients (AAKP) completed an anonymous online survey in September 2020. We assessed: (1) socio-demographics, (2) impacts of AKI – physical, emotional, social, and (3) perceptions about interactions with healthcare providers using quantitative and qualitative items.

Results: Respondents were 124 adult AKI survivors. 84% reported that the AKI episode was very/extremely impactful on physical/emotional health. Fifty-seven percent reported being very/extremely concerned about AKI effects on work and 67% were concerned about AKI effects on family. Only 52% of respondents rated medical team communication as very/extremely good. Individuals ages 22-65 at AKI episode were more likely than younger/older counterparts to rate the AKI episode as highly impactful overall (90% vs 63% younger and 75% older individuals; p = 0.040), more impactful on family (78% vs 50% and 46%; p = 0.008) and more impactful on work (74% vs 38% and 10%; p < 0.001). Limitations of this work include convenience sampling, retrospective data collection, and unknown AKI severity.

Conclusions: These findings are a critical step forward in understanding the range of AKI experiences/consequences. Future research should incorporate more comprehensive HRQoL measures and healthcare professionals should consider providing more information in their patient communication about AKI and follow-up.
Introduction

Acute kidney injury (AKI) is a significant public health problem in the US with incidence rates estimated at 18 per 1000 individuals.\(^1\) AKI affects \~60\% of all ICU patients\(^2\) and complicates non-ICU hospitalizations, producing significantly worse short- and long-term outcomes. Approximately 20\% of patients with AKI are readmitted within 30 days after their index hospitalization with an elevated risk of acute myocardial infarction and congestive heart failure.\(^3\) The development of new onset of chronic kidney disease (CKD) or worsening of pre-existing CKD occurs in approximately 30\% of patients surviving an episode of AKI and is associated with increased risk of progression to kidney failure.\(^1, 3-7\)

There is also evidence that individuals who survive AKI have poorer quality of life and consume a greater proportion of health-care resources than their healthy counterparts.\(^8\) Our own findings as part of the VA/NIH Acute Renal Failure Network (ATN) study indicate that 27\% of AKI survivors had a severely compromised health utility index at 60 days, similar to what is considered by the general population to be equivalent to or worse than death.\(^9\) An additional handful of studies that have examined short and longer-term health-related quality-of-life (HRQoL) among AKI survivors have generally found that (1) there are both physical and mental health effects of AKI and (2) poorer AKI-related HRQoL is linked to greater mortality.\(^9-17\) In a systematic review, Villeneuve, et al., (2016)\(^18\) reported that HRQoL among AKI survivors who received renal replacement therapy in the ICU was lower than that of population norms, but did not differ from that of other ICU patients. The studies included in this systematic review and other investigations of HRQoL in AKI have assessed HRQoL and function using either generic HRQoL measures (e.g., SF-36\(^19\), EuroQoL,\(^18\) or Health Utilities Index\(^20\)) or measures designed to assess HRQoL in the context of CKD. While these measures provide valuable information about the general patient-reported health effects of AKI, they do not provide especially nuanced information about the physical, emotional, and social consequences of AKI. Specifically, this prior work has not identified the most impactful HRQoL elements of the factors of AKI experience, separated AKI’s impact on employment
versus return to usual activities, explored healthcare communication quality in the context of AKI and evaluated concern about medical costs. Furthermore, a systematic review of studies focused on a broad range of kidney diseases found that patient-reported HRQoL is often not the focus of these investigations and concluded that it is imperative to elevate it as a research priority to improve patient-centered care.

Our goals for the current investigation were to survey AKI survivors in order to (1) describe the range of AKI-related HRQoL experiences—physical/functional, emotional, social (e.g., family and work), healthcare communication and (2) examine potential differences in impacts of AKI by gender and age at AKI episode. We expected that findings from this diverse sample would provide information about important aspects of the AKI experience that may have been under-investigated in previous research and form a foundation for further refinement of instruments designed to assess HRQoL in the context of AKI.

Materials and Methods

Human subjects research protection

This investigation was reviewed by the Institutional Review Board at the University of Pittsburgh and was determined to be exempt from IRB oversight.

Participants and study design

This cross-sectional investigation included AKI survivors who were members of the American Association of Kidney Patients (AAKP) who responded to an online Qualtrics-based survey between 10/14/2020 and 10/26/2020. An anonymous survey link was distributed to all members by AAKP leadership via email and was followed by three email reminders. Although the AAKP includes individuals with a range of kidney diseases, the survey included a screening question to ensure that only AKI survivors responded to the full survey.
**Study measures**

Given the lack of existing validated measures to specifically evaluate HRQoL in AKI, our authors developed a novel survey in collaboration with content and psychometric/measurement experts who were all co-investigators. A key strength of the investigation is the involvement of AKI patient survivors (co-authors RK and PC) in the development and refinement of the item-sets that were used in the investigation and content validity review and revision by our full study team which included specialists in all aspects of AKI disease and treatment, HRQoL, patient-reported measurement, survey design/deployment, and biostatistics. The English-language survey was designed to minimize patient burden and had an expected time for completion of <10 minutes. The survey included three categories of participant characteristics: (1) socio-demographic, (2) impacts of AKI – physical, emotional, social (e.g., work and family), and (3) perceptions about interactions with healthcare providers (see supplementary materials for study questionnaire).

**Socio-demographic characteristics:** age at first AKI episode, current age, education level, gender, and race/ethnicity. For examination of associations between age at first AKI episode and other variables, age was trichotomized as 0-21, 22-65, and >65. **HRQoL impacts of AKI:** overall physical and emotional impacts of AKI (4-point; slightly to extremely impactful), AKI experience checklist (check all that apply; 16 physical/functional, emotional, and care-related plus “other”), top three impacts/difficulties of AKI selected from the list of 16 potential impacts, concern about family (5-point; not at all to extremely) plus an open-ended follow-up, concern about work (5-point; not at all to extremely) plus an open-ended follow-up, and quality of healthcare information communication (5-point; not at all good to extremely good).

**Statistical analysis**

Data were cleaned and exported from Qualtrics to IBM SPSS Statistics for Windows, Version 22.0 (IBM Corporation, Armonk, NY, USA) for analysis. Percentages were used to describe categorical
variables and means and standard deviations were used to describe continuous variables. Responses to open-ended questions were initially reviewed and grouped into themes by one of the authors (VK) and then reviewed separately for appropriate categorization of response by two additional co-authors (GES and JGB). The few differences in coding (< 5% of total) were resolved by discussion among these three authors. For bivariate comparisons – gender and age at AKI episode by key impact variables – we dichotomized the Likert scales (“very” and “extremely” versus the other three response categories). For these same analyses, age at AKI episode was trichotomized – 0-21 years, 22-65 years, and ≥ 65 years of age. Differences by gender and age at first AKI episode were examined using chi-square analyses.

RESULTS

Participants

In October 2020, members of the AAKP who opted to participate in quick-turnaround survey opportunities (N= 23,582) received an email invitation to participate in a short anonymous survey about experiences with AKI and 3 follow-up reminders. A total of 124 AKI survivors completed the survey during a 2-week window. Table 1 includes sociodemographic characteristics of study participants. The mean age at first AKI episode was 53 years with a median of 58 years, but there was wide variation (sd = 19 years; range = 2-82). Table 1 also reports the categorical version of the variable with the majority of respondents (78%) in the middle age category (22-65) at the time of their first AKI episode. Mean current age was 62 years with a median of 63 years (sd = 13 years; range = 23-84). Fifty-six percent of the sample was female and 77% was white. Fifty-five percent of respondents had completed a bachelor’s degree or more.

Overall impacts/experiences of AKI

Table 2 presents responses to questions about the impact of AKI. Eighty-four percent (CI 76%-90%) of respondents reported that the AKI episode was either “very” or “extremely” impactful on their physical and emotional health. In terms of specific impacts, >50% of respondents reported not feeling
well physically or feeling week or tired. An additional >30% reported (1) feeling unable to do daily activities, (2) feeling anxious or stressed, (3) feeling unable to do fun/recreational activities, (4) having trouble sleeping, (5) not feeling well emotionally, or (6) feeling down or depressed. Smaller percentages (15%-25%) reported (1) problems with coordination of care and with receiving information about AKI, (2) problems with dietary restrictions, and (3) concern about medical costs. When respondents were asked to select the top 3 AKI impacts from the list of 16 potential impacts, the most frequently endorsed responses were not feeling well physically (48%), feeling weak or tired (36%), and feeling unable to do daily activities (28%).

**Physical/functional experiences of AKI**

Physical impacts of AKI were the most frequently endorsed from the 16-item checklist. Four of the top 5 most frequently endorsed impacts (Table 2) referenced physical/functional limitations including not feeling well physically, feeling weak/tired, feeling unable to do daily activities and feeling unable to do fun/recreational activities. In addition, one of the main categories of responses when respondents were asked an open-ended question about “other”, not-listed impacts, was AKI symptoms, including nausea, trouble walking, and limited appetite. Examples of quotes representing these themes and themes from other experience categories are in Table 3.

**Emotional experiences of AKI**

Emotional impacts of AKI were also frequently endorsed by respondents. The three most commonly endorsed emotional impacts from the 16-item checklist were feeling anxious or stressed (36%), not feeling well emotionally (32%), and feeling down or depressed (32%). In addition, in their responses to open-ended questions, participants also reported depression about potential inability to return to and maintain an active lifestyle and fears about future loss of function in one or both of their kidneys (Table 3).

**Family-related AKI experiences**
Sixty-seven percent (CI 57%-76%) of respondents reported being very/extremely concerned about AKI illness effects on their families. This question generated the highest number of open-ended descriptive responses about the specific types of family impacts. Several themes emerged from these open-ended responses including (1) feeling rejected/misunderstood by family, (2) feeling like a burden on family, (3) not being able to support family, and (4) loss of independence (Table 3).

**Work-related AKI experiences**

Fifty-seven percent (CI 47%-67%) of respondents reported being very/extremely concerned about AKI illness effects on their work. Several themes emerged in the open-ended responses to the question about work-related impacts including (1) difficulty scheduling treatment, (2) concern about declining performance, (3) concern about losing job, and (4) concern about long-term disability (Table 3).

**Healthcare-related AKI experiences**

Only 52% (CI 42%-62%) of respondents reported that the medical team communicated AKI information – including information about treatment and longer-term lab tests and follow-up – very/extremely well. Key themes that emerged from the open-ended follow-up question were (1) overall lack of information and uncertainty about AKI, and (2) mismanagement and poor communication by healthcare professionals (Table 3).

**Differences by Gender and Age at AKI episode**

We examined potential gender differences and differences by age at AKI episode across four key quantitative questions – overall impact of AKI, impact on family, impact on work, and quality of healthcare communication (Table 4). Although no gender differences were significant at \( p \leq 0.05 \), female respondents tended to be more likely than males to rate the AKI episode as highly impactful (93% versus 76%; \( p = 0.064 \)) and less likely to indicate that the medical team communicated AKI medical information well (42% vs 64%; \( p = 0.056 \)). Individuals between ages 22 and 65 when the AKI episode
occurred (middle age category) were more likely than their younger and older counterparts to rate the AKI episode as highly impactful overall (90% vs 63% youngest age group and 75% oldest age group; p = 0.040), more impactful on family (78% vs 50% and 46%; p = 0.008) and more impactful on work (74% vs 38% and 10%; p < 0.001). Time since AKI episode (i.e., difference between age at first AKI episode and current age) was not associated with overall reported impact of AKI episode.

**DISCUSSION**

The central goals of this investigation were to describe a broad range of physical, emotional and social effects of AKI and to examine potential differences in these areas by gender and age at AKI onset. The few other investigations of HRQoL following AKI have generally been small, single-center, and limited primarily to assessment of physical and mental health effects of AKI using generic HRQoL instruments. Furthermore, the majority are small and single-center. A particular strength of this investigation was the involvement of AKI survivors in all project phases from the refinement of the survey instrument through interpretation of findings which allowed us to include areas of HRQoL that may be particularly affected by AKI and important to patients—e.g., effects on work and family— but under-investigated in previous research.

The vast majority of participants (84%) reported that the AKI episode was very/extremely impactful on their physical/emotional health. Not surprisingly, the most frequently cited impacts were physical—top three impacts were not feeling well physically, feeling weak/tired, and not being able to engage in daily activities. However, these physical impacts were followed closely in frequency of reporting by emotional impacts including feeling anxious/stressed, having trouble sleeping, and not feeling well emotionally. It should be noted that other investigators have found that despite the impact of AKI, longer-term HRQoL is often rated as satisfactory or acceptable in this group.

These physical and emotional impacts have been relatively well-established and a particularly novel aspect of our findings is the patient-reported impact of AKI on work and family. Responses to the
closed-ended questions about the impact on work and family indicated that nearly 60% of survivors were very/extremely concerned about the impact of AKI on work and nearly 70% were concerned about impact on family. The work-concern findings are consistent with findings from Morsch, et al.\textsuperscript{17} that only 28% of AKI survivors returned to work at 9 months following the episode. They are somewhat less consistent with findings from Morgera, et al.\textsuperscript{24} that indicated 69% of patients employed prior to the AKI episode were able to return to work – however our question was about work-related concern, not actual return to work and could have included concern about work-related limitations even if work was resumed. A small subset of respondents (~16%) reported concerns about healthcare cost coverage of their AKI hospitalization. This is lower than the rate reported by Khandelwal, et al.,\textsuperscript{25} (~43%) and may be due to the fact that that investigation involved ICU patients while ours likely involved a mix of AKI severity types.

Participants were also most likely to enter open-ended explanations and descriptions about AKI experiences in response to these questions and many of the responses clearly evoked deep emotions. In particular, feeling misunderstood/neglected by family, feeling like a burden, and not being able to attend family functions and perform adequately at work were issues described by multiple participants. Finally, only 52% of survivors rated communication with the medical team around AKI as very/extremely good. Open-ended responses cited poor medical management that may have led to the AKI episode and lack of communication/information about AKI itself and how to manage/treat it. Given the high risk of rehospitalizations, cardiovascular complications and risk for CKD among AKI patients, this perceived gap in communication/education should addressed. The importance of these three facets of the AKI experience in our research – effects on work, effects on family, and poor communication with healthcare professionals – is a novel finding and implies that these factors should likely be incorporated into patient-centered research in this area. Further, the themes that emerged from these open-ended
questions and the specific items within these domains reflect important aspects that should be considered for inclusion in the development of AKI specific HRQoL questionnaires.

Women and adults aged 22-65 at AKI episode (as opposed to younger and older age groups) tended to report that the AKI experience was more physically/emotionally impactful overall – this middle age group also reported more impact on work and family. This latter finding is not surprising given that this age group is more likely to be actively working and caring for family at home, but it does imply that interventions to improve HRQoL should recognize and focus on the extra impacts of AKI among this group. Women tended to report having worse experiences in communicating with the medical team, a finding that should be explored in more detail in future research.

There are a few limitations to this research. First, this was a convenience sample derived from the membership of the AAKP. It is highly likely that AAKP membership is more knowledgeable about AKI in general than their non-member counterparts and may also be more likely to have residual kidney impairment. They also likely have more formal education – 27% of the sample had graduate or professional degrees. This may have allowed our respondents to better understand and report some of the medical aspects of their experiences and perhaps that they had more severe or chronic AKI experiences. It could suggest, however, that a non-member population would be even less informed and more frustrated by their AKI experiences. We also have no objective measure of AKI severity among this group -- future work in this area could estimate severity by asking, for example, whether respondents required dialysis during their AKI episode and whether they currently have complete/incomplete/no return of kidney function to their best knowledge. Second, although we had good gender representation, the sample was not particularly racially/ethnically diverse – 77% of the sample was non-Hispanic white. This limitation is important to address in future research that would include broader race/ethnic diversity among AKI survivors. Third, the data are retrospective in nature, which may have affected respondents’ ability to accurately recall the AKI episode suggesting that
prospective studies of HRQoL in AKI are needed. Finally, although we asked specifically about symptoms related to AKI, many AKI patients have other comorbidities or acute illness at the time of AKI – as well as progression to chronic kidney disease for some patients – that may have independently contributed to symptom experiences.

Despite the potential limitations of the investigation, these findings are a critical step forward in our understanding of the range of AKI experiences/consequences. As such, they suggest that additional research using more nuanced and comprehensive HRQoL measures administered early in the AKI experience and followed longitudinally is essential. If these, or new items/measures are developed to further assess these understudied domains, it will be important to evaluate their psychometric properties, including content validity and reliability. Additionally, healthcare professionals should be more proactive and informative in their patient communication about AKI and in their post-AKI follow-up, and more effective means of patient education and communication regarding AKI are needed to address patient concerns.

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**Author Contributions**
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**Data Sharing Statement**
All data is included in the manuscript and/or supporting information.

**Supplemental Material**
Questionnaire
References


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<td>During/after AKI episode, how concerned were you about the effects of the illness on your FAMILY life?</td>
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<td>19</td>
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<tr>
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<td>42</td>
<td></td>
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<td>7.6</td>
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<tr>
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<td></td>
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</tr>
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<td></td>
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</tr>
<tr>
<td>Slightly concerned</td>
<td>5</td>
<td></td>
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</tr>
<tr>
<td>Not at all concerned</td>
<td>33</td>
<td></td>
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<td>How well did the medical team communicate about AKI- including information about treatment and longer-term lab tests and follow-up?</td>
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<td>24</td>
<td></td>
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<td>Extremely well</td>
<td>31</td>
<td></td>
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</tr>
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<td>Very well</td>
<td>21</td>
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<td>21.0</td>
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<td>18</td>
<td></td>
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<tr>
<td>Slightly well</td>
<td>15</td>
<td></td>
<td>15.0</td>
</tr>
<tr>
<td>Not at all well</td>
<td>15</td>
<td></td>
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¹ Missing values are not presented for this question because it was “check all that apply.”
Table 3. Qualitative themes and representative participant quotations.

| Physical/functional experiences | • “Nausea, couldn’t eat”  
| | • “Urinating very frequently but with small volume”  
| | • “Loss taste and was unable to walk even very short distances”  
| Emotional experiences | • “Depressed about future ability to maintain active lifestyle”  
| | • “Ability to return to same level activity prior to operation”  
| | • “I lost one of my kidneys and worry what if I lost the other one”  
| Family-related experiences | Feeling rejected/misunderstood by family  
| | • “My family have never been understanding about my kidney disease and they didn’t understand why I was so tired and feeling ill.”  
| | • “My grown kids were very unkind to me, they never came to see me or even phone.”  
| Feeling like a burden on family | • “Them taking on extra responsibilities connected to my health.”  
| | • “The way they had to go out of their way to help me.”  
| Not being able to spend time with family | • “Not being able to spend time with a dying family member.”  
| | • “Not being able to enjoy life with those I love.”  
| Loss of independence | • “Concerned that I might not be able to continue to be independent.”  
| | • “Getting out and doing errands by myself.”  
| Work-related experiences | Scheduling conflicts  
| | • “Not being able to work and knowing how my work would accommodate my dialysis schedule.”  
| | • “Scheduling treatment.”  
| Concern about declining performance | • “My lack of performing my job at the level of pre-AKI.”  
| | • “My symptoms affected my work performance.”  
| Concern about losing job | • “If I were to die or be unable to work, my husband and daughter would lose both my income and health insurance.”  
| | • “Being fired and having loss of medical coverage.”  
| | • “Being forced into retirement.”  
| Concern about long-term disability | • “Potential for having a permanent disability.”  
| | • “Progress to kidney failure and need to RRT.”  
| Healthcare-related experiences | Lack of information and uncertainty  
| | • “Didn’t get all necessary information”  
| | • “Nobody really knew the answer”  
| | • “I did not know enough to even ask basic questions. I did not know what kind of kidney disease I had.”  
| | • “Frustrating inaccuracies about renal diets”  
| Mismanagement and lack of communication | • “My doctors at the time didn’t explain the seriousness of the AKI.”  
| | • “Very poor diagnosis and care at initial stages of onset.”  
| | • “I learned by reading an unrelated appointment summary that my kidneys had suffered an acute injury caused by an adverse reaction to anesthesia during a complex back surgery.”  

<table>
<thead>
<tr>
<th></th>
<th>“Lack of understanding early on in diagnosing the medical condition and managing the kidney damage caused by it resulted in loss of kidney function and might have been avoided. Now on dialysis.”</th>
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<tr>
<td></td>
<td>“The damage was caused by the surgeons when they did a spinal fusion surgery”</td>
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Table 4. Overall impact, family and work concerns by gender and age at first AKI episode.

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<td>5.49</td>
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<td>75</td>
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<td>64</td>
<td>5.75</td>
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<td>47</td>
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*p ≤ .05; **p ≤ .01; ***p ≤ .001.
Screening Question
Have you ever had an Acute Kidney Injury?
No → Thank you for your time but we are only including individuals who have had AKI in this survey.
Yes

1. What was your age in years at the time of your first AKI episode?

2. How would you describe the impact of the AKI episode on your physical and emotional health?
   - Extremely impactful
   - Very impactful
   - Moderately impactful
   - Slightly impactful

3. Please think about the time during your AKI episode. Below is a list of some of the experiences people can have when they have an episode of AKI. Please select ALL the things from the list that were part of your AKI experience.
   - Not feeling well physically
   - Not feeling well emotionally
   - Having symptoms related to AKI
   - Feeling down or depressed
   - Feeling anxious or stressed
   - Feeling unable to do daily activities
   - Feeling unable to do fun/recreational activities
   - Having trouble sleeping
   - Having trouble with restrictions on what you could eat
   - Feeling weak or tired
   - Feeling unsupported by friends/family
   - Feeling like you didn’t have enough information about AKI
   - Having trouble getting information about AKI
   - Feeling like the doctors didn’t coordinate care – weren’t talking to each other
   - Having trouble getting information from healthcare providers
   - Having concerns about who was going to cover healthcare costs
   - Other (Please specify): _____________
4. Now, look back at the list of things you selected that were part of your AKI experience. Please select the THREE things from the list that had the most impact or caused the most difficulty in your life during your AKI experience.

- Not feeling well physically
- Not feeling well emotionally
- Having symptoms related to AKI
- Feeling down or depressed
- Feeling anxious or stressed
- Feeling unable to do daily activities
- Feeling unable to do fun/recreational activities
- Having trouble sleeping
- Having trouble with restrictions on what you could eat
- Feeling weak or tired
- Feeling unsupported by friends/family
- Feeling like you didn’t have enough information about AKI
- Having trouble getting information about AKI
- Feeling like the doctors didn’t coordinate care – weren’t talking to each other
- Having trouble getting information from healthcare providers
- Having concerns about who was going to cover healthcare costs
- Other (Please specify): _____________

5. During your AKI episode and shortly after, how concerned were you about the effects of your illness on your FAMILY life?

- Extremely concerned
- Very concerned
- Moderately concerned
- Slightly concerned
- Not at all concerned

   If they respond to #5 with anything other than “not at all concerned,” then have them routed to this question with an open text box. Otherwise skip to #6.

5a. Please describe the effects on your family life that you were most concerned about.
6. During your AKI episode and shortly after, how concerned were you about the effects of your illness on your WORK life?

   Extremely concerned
   Very concerned
   Moderately concerned
   Slightly concerned
   Not at all concerned

   If they respond to #6 with anything other than “not at all concerned,” then have them routed to this question with an open text box. Otherwise skip to #7.

6a. Please describe the effects on your work life that you were most concerned about.

7. How well do you feel your medical team communicated with you about AKI – including information about treatments and longer-term lab tests and follow-up?

   Extremely well
   Very well
   Moderately well
   Slightly well
   Not at all well

8. What is your current age in years?

9. What is your gender?

   Male
   Female
   Prefer to self-describe (Please specify): _____________

10. How much formal education have you completed?

    Eighth grade or less
    Trade school or business school instead of high school
    Some high school
    High school graduate or GED
    Trade school or business school after graduating from high school
    Some college
Received bachelor’s degree
Some graduate or professional school beyond the bachelor’s degree
Graduate or professional degree, (Please specify): _____________

11. Which of the following BEST describes the race or ethnic background to which you belong?
   Hispanic or Latino
   African American or Black
   Asian or Pacific Islander
   White or Caucasian
   Native American
   Mixed or Multiple Race or Ethnicity (Please specify): _____________
   Other (Please specify): _____________

12. Is there anything else you would like to tell us about your AKI experience?