### What Do Acute Kidney Injury Survivors Want to Know **About Their Condition: A Qualitative Study**

Clarissa J. Diamantidis, Erin Burks, Dinushika Mohottige, Jennie Riley, Cassandra Bowman, Joseph Lunyera, and Jennifer St. Clair Russell

Rationale & Objective: Acute kidney injury (AKI) in the hospital often occurs with other serious illnesses that take medical priority. Despite a persistent risk of adverse outcomes following hospital discharge, AKI survivors often receive inadequate education about how best to mitigate risks once home. We sought to identify AKI survivors' perceived barriers to shared and informed decision-making regarding their AKI diagnosis and self-management.

Study Design: Semistructured phone interviews were used to assess patients' perceived barriers and facilitators to AKI self-management after a hospital-related AKI event.

Setting & Participants: AKI survivors discharged from Duke University Hospital in Durham, NC, were recruited for interviews to discuss their AKI experiences. Those who received dialysis for AKI were excluded because their perceptions of AKI care were hypothesized to be much different from those of patients not requiring dialysis.

Analytical Approach: Twenty-four interviews were conducted between May and August 2018. Interviews were recorded, transcribed, and analyzed

Acute kidney injury (AKI) is an increasingly common complication of acute hospitalizations, with approximately 10% to 20% of all hospitalized patients estimated to have some degree of AKI during their hospital stay.<sup>1,2</sup> Hospital-based AKI often occurs in conjunction with other acute events, such as congestive heart failure exacerbations or sepsis.<sup>3</sup> Consequently, AKI often remains a lower priority than other competing, and typically symptomatic, illnesses.<sup>4</sup> However, the short- and long-term consequences of AKI are substantial. Survivors of AKI suffer exceedingly poor kidney outcomes, including persistent loss of kidney function, progression to kidney failure, and increased mortality.<sup>5-7</sup> Even those who recover kidney function following an episode of AKI may be at risk of adverse kidney outcomes in the future.

Despite a persistent risk of adverse outcomes following hospital discharge, AKI survivors are often not provided with adequate information and education about how best to minimize ongoing kidney risks at home. A diagnosis of AKI is often absent from billing codes and discharge documentation despite clinical evidence of the AKI event. One small study reported that <15% of survivors of an AKI-related hospitalization were given discharge instructions that included documentation of the AKI event, and none were offered AKI treatment or risk mitigation

by study team members to identify common themes and discrepancies and reach a final consensus.

Results: Five consistent themes emerged after thematic saturation: (1) patients were unaware of their AKI diagnosis; (2) patients lacked information about AKI and how to manage it at home; (3) patients identified a lack of understanding about AKI; (4) patients were concerned about dialysis; and (5) patients wanted to know how to prevent AKI in the future.

Limitations: Limitations include recruitment from a single center, all study participants receiving a nephrology consultation, and several patients being unable to participate because of persistent illness following hospitalization.

Conclusions: AKI survivors are unaware of their diagnosis, receive suboptimal education while hospitalized, and are not equipped with tools to mitigate risks following discharge. Patient-centered interventions promoting AKI awareness and selfmanagement may improve long-term outcomes for high-risk AKI survivors.

> recommendations.<sup>8</sup> Therefore, ambulatory care providers who rely on the medical record for details of their patients' hospitalizations may be unaware that an AKI event occurred. Further, it is unlikely that patients, who are commonly unaware of their AKI diagnosis, will report AKI to their primary care provider; thus, mitigating strategies cannot be implemented.<sup>4</sup>

> The objective of this qualitative study was to understand the experiences of survivors of an AKI-related hospitalization, to identify their perceived barriers to shared and informed decision-making as it relates to an AKI diagnosis and self-management, and to elucidate the best practices for the provision of patient-centered AKI care.

### **METHODS**

#### **Study Participants**

We conducted 24 semistructured telephone interviews in 2018 with AKI survivors recently discharged from Duke University Hospital in Durham, NC, in 2018 to learn about their experiences and perceived difficulties surrounding their hospital-based AKI diagnosis. Previously hospitalized patients on a medical or surgical service, who were aged  $\geq 18$  years, with a diagnosis of AKI based on inpatient nephrology consultation documentation and the ability to



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### PLAIN-LANGUAGE SUMMARY

We interviewed 24 discharged patients who developed acute kidney injury (AKI) while in the hospital to understand their experiences and perspectives on the care they received for their kidney health. All interviewed patients were seen by the inpatient nephrology service. Of the 24 patients, many had underlying kidney disease, and over half had severe AKI (stage 3). We found that most AKI survivors were unaware of their AKI and knew little about what caused it. Few were given education on how to manage their AKI at home, while many desired information on how to self-manage their illness. This study suggests that tools are desperately needed to help AKI survivors manage their kidney health after hospital discharge.

communicate proficiently in English were eligible to participate. Individuals who received inpatient or outpatient dialysis treatment were excluded based on the differential experience created by the need for dialysis. Patients were first introduced to the study after hospital discharge via a mailed institutional review board–approved letter describing the study with an opportunity to opt out. After 10 days, individuals were contacted by a study team member to ask for their participation. Phone consent was obtained from all participants. Participants received \$25 upon study completion of the telephone interview. The Duke Health Institutional Review Board approved the study protocol (PRO00080287), and the study team adhered to the principles outlined in the Declaration of Helsinki.<sup>9</sup>

### **Data Collection**

The interview guide was developed by the study team, which included an expert in instructional tool development (JSCR), and consisted of open-ended questions with the goal of eliciting patients' experiences with AKI care and overall AKI self-management. Before study initiation, the interview guide was tested with 3 AKI survivors to ensure questions were understandable by study participants and elicited responses related to the phenomena of interest.

Two study team members (JR and CB) conducted the semistructured telephone interviews with participants. The interviewers completed training in qualitative methods before interviewing participants. The semi structured telephone interviews were conducted between June and August 2018 and lasted between 25 and 60 minutes. Each interview began with an introduction to the interview process and purpose and finished with a demographic questionnaire. With the exception of 3 interviews because of participant refusal, all interviews were audio recorded and transcribed verbatim by a third party for analysis. For those not audiotaped, the interviewer took comprehensive

notes. Data collection continued until our analysis indicated thematic saturation and no new themes were emerging from the data.

Sample questions from the interview guide (full interview guide in Item S1) included: "did anyone in the hospital tell you that you had acute kidney injury, or AKI for short?," "what were you told about your kidneys during your time in the hospital?," "as someone who had acute kidney injury, what do you think would be helpful for patients to know about acute kidney injury?," and "given all that we have discussed, what do you think is the most important thing for patients with acute kidney injury to know?" For participants who were not familiar with the term acute kidney injury, interviewers reviewed a medical definition of AKI with the participant and answered any clarifying questions.

### Analysis

We applied the grounded theory approach to data collection and analysis.<sup>10,11</sup> Constant comparison was used to analyze the data once 3 interviews were completed, with additional interviews analyzed as they were completed.<sup>10</sup> Throughout the interview process, the interviewers (JR and CB) and qualitative researcher (JSCR) met to review the major themes emerging from the data. After 24 interviews, the point of saturation was reached (no new themes were emerging), and the study team independently created a summary of key words, findings, and quotes for each question asked of participants. Based on the summary of participant responses to each interview question, the interviewers (JR and CB) iteratively agreed to the themes present in the data. A third researcher (JSCR) was consulted for any tie-breaking decisions about a theme. The study team adhered to the Consolidated Criteria for Reporting Qualitative Research guidelines during data collection, analysis, and reporting of all results.

### RESULTS

We contacted 108 eligible patients, of whom 24 completed semistructured telephone interviews. Recruitment efforts were stopped after thematic saturation was reached (Item S1). Study participants were predominantly female (62.5%), aged 45 to 64 years (45.8%), non-Hispanic White (62.5%), and high school graduates (Table 1). The majority (62.5%) had underlying chronic kidney disease. Most cases of AKI were severe (stage 3) and attributed to volume depletion; the median duration of AKI was 16 days. All but 3 interviews (87.5%) were completed within 30 days of hospital discharge. Five major themes emerged as a result of the qualitative analysis (Table 2).

#### **Patients Unaware of AKI Diagnosis**

Almost two-thirds of participants we interviewed were unaware of their AKI diagnosis. When interviewers asked what the participant was told about their kidneys while in

#### Table 1. Baseline Study Characteristics

Demographics	n (%)
Sex	
Female	15 (62.5)
Male	9 (37.5)
Age, y	
18-44	3 (12.5)
45-64	11 (45.8)
≥65	10 (41.7)
Race/ethnicity	
Non-Hispanic White	15 (62.5)
Non-Hispanic Black	9 (37.5)
Hispanic	0 (0.0)
Education	
Less than high school diploma	1 (4.2)
High school diploma or GED	9 (37.5)
Some college	6 (25)
College graduate	5 (20.8)
Graduate/professional school	3 (12.5)
Comorbid condition	
CKD	15 (62.5)
Hypertension	14 (58.3)
Cardiovascular disease	8 (33.3)
Diabetes	7 (29.2)
AKI stage	
Stage 1	5 (20.8)
Stage 2	6 (25)
Stage 3	13 (54.2)
AKI etiology	
Volume depletion	9 (37.5)
Nephrotoxin exposure	6 (25)
Sepsis	3 (12.5)
Other/unknown	6 (25)
AKI duration in d, median (IQR)	16 (5, 90)

Abbreviations: AKI, acute kidney injury; CKD, chronic kidney disease; GED, General Educational Development; IQR, interquartile range.

the hospital, they recalled the discussion about several issues, including weak kidneys, kidneys failing, and chronic kidney disease. However, many said they did not recall much about what they were told about their kidneys. Several participants reported not asking their care teams follow-up questions about their kidneys because they were in too much pain, their caretaker asked questions for them, or they felt that AKI was not their primary issue.

# Patients Lack Information About AKI and How to Manage it at Home

Few participants recalled receiving detailed information in the hospital about their AKI and how to manage it at home. There was a lack of specific guidance around prevention of recurrent AKI. When asked about the best way to learn information about their kidneys, participants indicated that they would like to read information either in brochures or online, talk with a health-care provider, and/or watch a video on the topic. Most wanted to receive information while in the hospital or at discharge so they could review it at home, in a more relaxed environment.

# Patients Identified a Lack of Understanding About AKI

Patients were generally unsure of what AKI is, its causes, and what to expect, as substantial barriers to selfmanagement after discharge. For several participants, the medical terminology used was confusing. For each patient who was unfamiliar with the term "acute kidney injury," interviewers read the medical definition of AKI and answered any subsequent questions. Many participants were confused by the term "injury," thinking it related to being "punctured," hit, in an accident, having a fall, or having an infection.

### **Patients Concerned About Dialysis**

Many participants associated the term AKI with dialysis and stated concerns or fears related to possibly requiring dialysis in the future. Participants described themselves as being worried, shocked, stunned, scared, concerned, and anxious about possible dialysis-related pain, about future damage to kidneys, and about the dialysis process in general. However, a minority of participants expressed no concerns about their kidneys, citing confidence in their care team, "not being a worrier," or prioritization of issues such as experiencing homelessness. One participant described actively avoiding additional information about AKI because of the fear of possibly needing dialysis. Another described the logistical concerns of driving to and from a clinic because he did not drive.

# Patients Want to Know How to Prevent AKI in the Future

Participants desired a more detailed information on their AKI than they received while in the hospital. While almost all participants reported receiving information from their care team about diet, hydration, medications, and sometimes follow-up care, participants expressed interest in knowing more about AKI prevention specifically. Participants wanted to know what caused AKI, the warning signs and symptoms, what to do when you have AKI, and more information on healing the kidneys. While many patients did not ask their care team follow-up questions about their kidneys, some asked questions about their laboratory values, what caused their AKI, and what to do next, including changes to diet and avoiding dialysis.

### DISCUSSION

In this study of survivors of hospital-based AKI without the need for dialysis, participants identified several suboptimal aspects of their AKI care. Specifically, most AKI survivors were unaware of their AKI diagnosis following discharge and reported low knowledge of AKI causes and consequences, concern over AKI self-management expectations at home, and a lack of information regarding AKI

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### Table 2. Themes and Representative Quotes

Table 2 (Cont'd). Themes and Representative Quotes

Themes	Representative Quotes	Themes	Representative Quotes
Patients unaware of AKI diagnosis	"Yeah, they could have explained just what it was and try to give you some advice on how to help it or combat or something in the hospital. Like I said, they didn't, after they got the see the main thing I was in the hospital for was potassium levels, but they got the potassium levels straightened out [and] the kidney levels went back to my normal, so they didn't even say anything else about the kidneys. Then the next day I was sent home." – (SS0228) "Well, see I knew my kidneys were not like they were supposed to, but they say I had chronic kidney disease, so I knew that, but I didn't know about this AKI." – (SS0228) "You know, I'm gonna be honest with you, I was so sick I can't remember some stuff that was told to me and wasn't told to me when I was in there." – (SS0315)		delve too much into it or get too much information, mainly out of fear." – (SS0205) "You know dialysis is the one thing I do not want." – (SS0229) "Well, I was worried about what they did to this, when they told me I was gonna have to go on dialysis I was <i>[unintelligible]</i> back and <i>[unintelligible]</i> where I had to go, I was sad because I thought that my kidneys had crapped out completely but I was more concerned about how I was going to get back and forth to the kidney dialysis thing cause I don't drive and <i>[unintelligible]</i> got to work." – (SS0228) "they said that it could possibly lead to other problems, but they wasn't sure right then, but I don't think that it's gonna go to as far as I was thinking it was gonna go because my father was on dialysis so <i>[unintelligible]</i> when you say
Patients lack information about their AKI and how to manage it at home	"I haven't had any knowledge, anything about the kidneys except lay off the salt, drinks, something like that, but as far as you know, going in-depth about the situation, no, I didn't get no in depth." – (SS0234) "They didn't really tell me anything different to do" – (SS0355) "I assumed that they would instruct me [ <i>unintelligible</i> ] process about what I need to do and how I need to do it that they would prescribe the medication for. But what I need to do that they would tell me, and they didn't." – (SS0204)	Patients want to know how to prevent AKI in the future	"I'd like to know more about what I'm supposed to eat and what I'm supposed to eat and what I'm supposed to eat and what I'm supposed to do to keep from getting another one. I haven't been told any of that yet, so I'm gonna find out when I go back to the hospital, back to my next checkup." – (SS0392) "I still feel like I'm not getting enough fluids, like water, I'm worried, like am I drinking enough water, or if I eat something, is it the right thing or the wrong thing?" – (SS0266) "Just doesn't seem to be a
Patients identified a lack of understanding of what AKI is, its causes, and what to expect	"I don't know. I mean it wasn't injured, so I don't understand. To me, I would think that you know, it had been punctured or something you know, but it was just a matter of apparently my metabolism use out of wheak		specific that I'm aware of a specific reason or cause for it and why it happened and what you can do to really keep it from happening. I mean you know just I don't know." – (SS0346)
	and I guess I was out of whack – (SS0220) "They should break it down where a normal person would understand it. Don't use all these high medical terminology" – (SS0315)	prevention strategies. These all participants receiving an tation. Although study partic while hospitalized, many ass	findings were evident despite inpatient nephrology consul- ipants did not require dialysis ociated AKI with the need for
Patients concerned about dialysis	"I was always afraid you know, of possibly having to go on dialysis, so I just don't like seeing what it does to people you know, it scares me so I don't really like to you know,	dialysis, which caused appr sions. Taken together, these improvement in AKI care transitions, and in the ambu To our knowledge, this is AKI survivors following hose	rehension about AKI discus- findings support the need for in the hospital, during care latory care setting. s the first qualitative study of spital discharge that explores

(Continued)

patients' experiences with a hospital-based AKI diagnosis

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### Table 3. Best-Practice Recommendations for AKI Survivor Care Teams

Challenges Identified	Patient-Centered Approach	Anticipated Outcomes
In the hospital		
Patients and caregivers are not informed of AKI	Tell patients about their AKI diagnosis using patient- centered terms and reinforce it during rounds	<ul> <li>Allows patient to be involved in shared and informed decision-making</li> <li>Empowers patients with knowledge regarding kidney health and for future discussion and follow-up</li> </ul>
Patients and caregivers are not provided education about AKI	Provide patient-centered AKI education to patient and care partners and allow them to ask questions	<ul> <li>Allows patient to understand AKI causes, treatment goals, and consequences</li> <li>Involvement of care partners increases patient self-efficacy</li> </ul>
Poor documentation in medical record contributes to a lack of awareness among consulting providers and can lead to additional kidney insults	Document AKI in the daily medical record	<ul> <li>Makes consulting providers aware of AKI diagnosis</li> <li>Reduces risk of additional kidney insults</li> <li>Enables all providers and patients to understand whether recovery occurs and adjust medications and further treatments as needed (eg, isotonic volume administration etc)</li> </ul>
At discharge		
Documentation of AKI in discharge summaries is suboptimal	Document AKI diagnosis and treatment in the hospital discharge summary	<ul> <li>Facilitates communication about AKI diagnosis across care transitions</li> <li>Ensures kidney health and preventive strategies may be reinforced by primary care or outpatient team</li> </ul>
Patients are not aware when they should follow-up with providers	Schedule provider follow-up with laboratories (nephrology or primary care) within 30 days of discharge	<ul> <li>Timely posthospital assessment for AKI survivors has been linked with improved outcomes</li> </ul>
Documentation of AKI in discharge instructions given to patients is suboptimal	Provide AKI-specific follow-up recommendations in discharge instructions given to the patients	<ul> <li>Allows patients and care partners to review AKI diagnosis, associated medication changes, and outpatient recommendations</li> <li>Provides written documentation of AKI diagnosis that patient can bring to the outpatient follow-up visit</li> </ul>
In the ambulatory care setting		· · · · · ·
Patients and caregivers are not informed of AKI	Tell patients about their AKI diagnosis	<ul> <li>Allows patient to be involved in shared and informed decision-making and preventive strategies</li> </ul>
Transient cognitive impairment in the hospital is common and may impede the ability to retain the education provided in the hospital	Provide patient-centered AKI education to family and care partners, and allow them to ask questions with the opportunity for remote visits (eg, telehealth)	<ul> <li>Allows patient to understand AKI causes, treatment goals, and consequences</li> <li>Involvement of care partners increases patient self-efficacy</li> </ul>
Poor documentation in medical encounter contributes to a lack of awareness among consulting providers and can lead to additional kidney insults	Document AKI in the medical encounter	<ul> <li>Makes other care providers aware of AKI diagnosis</li> <li>Reduces risk of additional kidney insults</li> <li>Reduces risk of recurrent AKI</li> </ul>
Long-term consequences of AKI are inconsistently assessed	Repeat kidney function testing at 90 days with both blood and urine tests to evaluate for the evidence of new chronic kidney disease; consideration of tailored postdischarge AKI clinic implementation	<ul> <li>AKI is a risk factor for the development and progression of CKD; early detec- tion and management of CKD improves the long-term outcomes</li> </ul>

Abbreviations: AKI, acute kidney injury; CKD, chronic kidney disease.

and nephrology consultation. One prior study by Siew et al<sup>12</sup> examined patient knowledge of AKI through surveys in a cohort of hospitalized AKI survivors with stages 2 and 3 AKI and noted a similarly low degree of AKI

awareness among participants before discharge. Male sex and lack of a nephrology consultation were independently associated with low awareness, and most participants desired more information regarding AKI. Our study

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corroborates these findings among individuals with AKI receiving nephrology inpatient consultation and confirms these obstacles persist in the ambulatory setting once the acute issue has resolved. A similar study in 2018 by Silver et al<sup>4</sup> found that patients and caregivers endorsed fleeting concerns and competing demands in the postdischarge period, and emphasized the need for supportive tools in both care processes and health systems to reduce the overall burden on AKI survivors themselves in the outpatient setting. We found that AKI survivors desired detailed, concrete instructions for self-management of AKI, yet they were not provided such tools during their hospitalization.

Hospital-based AKI often occurs in conjunction with other acute events, such as congestive heart failure or sepsis.<sup>3</sup> Our participants' experiences support emerging evidence that suggests AKI often remains a lower priority than other competing, and typically symptomatic, illnesses, despite the long-term consequences conferred by an AKI diagnosis.<sup>4</sup> During the current coronavirus disease 2019 pandemic, for instance, AKI has been found to complicate approximately 50% of coronavirus disease 2019-related hospitalizations, and portends a significantly worse outcome for AKI survivors than individuals without AKI.<sup>13-15</sup> It is further anticipated that the long-term impacts of these events will influence kidney susceptibility for years to come. Therefore, it is imperative to improve AKI care to mitigate the longer-term consequences conferred by the current pandemic.

Further complicating the hospital-based care of AKI is the frequently reduced the ability of patients to retain information because of transient cognitive impairment during acute hospitalizations.<sup>16-18</sup> All of this is compounded by a high prevalence of poor or lacking documentation of AKI in the hospital records and discharge materials viewed by both providers and patients.<sup>8</sup> Therefore, if ambulatory care providers themselves are unaware of AKI, there is no opportunity to provide patients with educational tools to lower further risk once they are discharged, or to discuss postdischarge kidney health optimization. This is evidenced by ongoing outpatient health behaviors that increase risks of short- and long-term AKI consequences, such as the use of nonsteroidal antiinflammatory drugs, which remains common following an AKI event.<sup>12,19,20</sup> There is mounting evidence that tailored postdischarge AKI clinics serve an important role in improving AKI knowledge and self-management behaviors.<sup>21,22</sup>

We surmise that optimal interventions for patientcentered AKI care must target care components in the inpatient and outpatient settings and across care transitions, with the fundamental goals of increasing awareness of AKI, improving education and communication regarding AKI causes and self-management practices, and documenting AKI in the medical record and in patient-facing materials. In Table 3, we outline recommendations for patient-centered AKI care best-practice activities across care settings based on challenges identified in our work. We theorize that reinforcing information in multiple settings and across multiple learning formats (eg, digitally, in print) using adult learning theory principles to address varied health literacy levels, learning styles, and cultural sensitivities will improve patient self-efficacy to self-manage their AKI, mitigate potential contributory behaviors (eg, nonsteroidal antiinflammatory drug use), and improve overall AKI outcomes. We further suggest that the use of postdischarge AKI clinics leveraging patient-centered technologies, such as telehealth and asynchronous messaging, may mitigate issues related to the posthospital discharge patient burden when follow-up visit demands are coupled with the need for ongoing healing after a hospitalization. These interventions must also be tailored to address the unique structural barriers to care reported by some participants (eg, transportation, financial concerns, housing).

Our study has limitations worthy of mention. This study was conducted in a single center in the Southeastern United States, which may limit generalizability to other settings. It is also possible that participation in a study on AKI resulted in an elevated awareness of AKI and resulted in behavior modifications that are not representative of the general AKI population. Further, our participants had all received inpatient consultations by the nephrology team, likely because of the severity of their condition, and thus may not be fully representative of AKI survivors without nephrology care or with less severe stages of AKI. We also did not evaluate the need for intensive care, past AKI episodes, pre-established nephrology care, follow-up care, or travel distance, which may greatly influence the AKI experience. Further, we did not incorporate the viewpoints of caregivers in this study, which would likely yield important information regarding barriers and facilitators to AKI self-management for hospital survivors. Several eligible patients were unable to participate because of persistent illness following hospitalization, which may indicate our participants represent a healthier cohort than the general AKI population. Similarly, while most interviews were conducted within 30 days of hospital discharge, it is possible that recall bias may have influenced the study findings. However, study strengths include the qualitative nature of our study, which allowed participants to express their perceptions of care with limited bias; use of phone interviews rather than in-person interviews to facilitate broader participation with a reduced need for transportation; and the focus on AKI needs outside the hospital.

In conclusion, AKI survivors identified several modifiable barriers to patient-centered care in AKI. Several challenges identified across care transitions should be addressed so that AKI survivors can more effectively navigate the complexities of AKI self-management at home. Future qualitative studies on AKI should include a diverse population, inclusive of Hispanic individuals, other racial minority individuals, and non–English speaking patients; incorporate caregiver and provider perspectives; and examine elements to reduce the overall burden for AKI survivors discharged from the hospital. Through promotion of awareness, provision of education, appropriate communication, and proper documentation, AKI care teams have immense opportunity to integrate patientcentered care approaches into the management and treatment of high-risk kidney conditions.

### SUPPLEMENTARY MATERIAL

### Supplementary File (PDF)

Item S1. Interview questions

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