


**ORIGINAL RESEARCH:
EMPIRICAL RESEARCH–QUALITATIVE**

Living with dying: A narrative inquiry of people with chronic kidney disease and their family members

Anita E. Molzahn¹  | Laurene Sheilds^{2,3,4} | Anne Bruce² | Kara Schick-Makaroff^{1,5} | Marcy Antonio⁶ | Lacie White^{2,7}¹Faculty of Nursing, University of Alberta, Edmonton, AB, Canada²School of Nursing, University of Victoria, Victoria, BC, Canada³School of Public Health and Social Policy, University of Victoria, Victoria, BC, Canada⁴Learning and Teaching Support and Innovation, University of Victoria, Victoria, BC, Canada⁵Can-SOLVE CKD – KRESCENT New Investigator (Canadians Seeking Solutions & Innovations to Overcome Chronic Kidney Disease; Kidney Research Scientist Core Education & National Training Program) Faculty of Nursing, University of Alberta, Canada⁶School of Nursing and School of Health Information Science, University of Victoria, Victoria, BC, Canada⁷School of Nursing, University of Ottawa, Ottawa, ON, Canada**Correspondence**

Anita E. Molzahn, Faculty of Nursing, University of Alberta, Edmonton, AB, Canada.

Email: anita.molzahn@ualberta.ca

Funding information

Funding for the study was received from the Canadian Institutes for Health Research (grant #MOP 130248)

Abstract**Aims:** To describe how people diagnosed with chronic kidney disease and their family members describe uncertainty related to impending death.**Background:** There has been little research about the experiences of people with chronic kidney disease and their family members as they near the end-of-life. We need to understand these experiences to give holistic person-centred care.**Design:** A narrative enquiry was undertaken using a social constructionist perspective.**Methods:** Data were collected in two in-depth interviews, approximately 3–4 months apart, followed by a telephone follow-up 2–3 months later.**Results:** Eleven people with advanced chronic kidney disease and nine family members/significant others participated. For both participants in the dyad, a number of key themes/storylines were identified. These included recognition that: *@life has a boundary, living on the edge, I'm not afraid to die but... and remembering loss and death experiences@.***Conclusions:** This enquiry illuminated four key storylines of about death and dying with advanced chronic kidney disease for people with the illness and their family members. Discussion about past experiences with illness, loss, death, and dying can give an entry for discussion about end-of-life. The person with illness and family members often held very similar perceptions and desires, but healthcare professionals' contributions to understanding of the experience were not mentioned. Implications for clinicians include attending to peoples' awareness of death as a distinct opportunity, listening attentively and posing questions that genuinely invite concerns and wishes about end-of-life and living well.**KEYWORDS**

chronic illness, chronic kidney disease, dialysis, end-of-life, family, narrative enquiry, qualitative research

1 | INTRODUCTION

Chronic kidney disease (CKD) is one of the most common (Hill et al., 2016) and burdensome life-limiting illnesses (Davison et al., 2015). Costs of dialysis and symptom burden are high and survival is disappointing; annual mortality of people on dialysis exceeds 20% and withdrawal from dialysis is a common cause of death for people on dialysis (Davison et al., 2015). Yet, access to end-of-life (EOL) care is limited in the context of our “death-denying” culture (Davison et al., 2015; Gawande, 2014).

People with CKD and their family members often find it difficult to discuss death, dying and the uncertainty of living (Molzahn et al., 2012; Shields et al., 2015). People fall between the cracks of being defined as chronic or palliative, while family members struggle to support loved ones and give care. There has been little research that relates to experiences of people with CKD as they near the EOL and even less about the experience of family members/significant others. Further, it is rare to find studies where dyads consisting of both people with illness and their significant others are included and extremely rare to find longitudinal studies. We address these gaps in the literature by reporting experiences of people with advanced CKD and their family members over time.

1.1 | Background

With advances in treatments and technologies, people with life-limiting chronic illness may live relatively well for months and even years, but the threat to life causes considerable emotional distress. For instance, in a qualitative study, Öhman, Söderberg, and Lundman (2003) described experiences of people with serious chronic illness and their family members as “hovering between suffering and enduring.” In a study of non-cancer terminal people, Mahtani-Chugani, Gonzalez-Castro, Saenz de Ormijana-Hernandez, Marin-Fernandez, and Fernandez de la Vega (2010) found that people and health professionals continue to consider death a taboo topic. Parker et al. (2007) conducted a systematic review including 46 articles on people and caregiver preferences for information at EOL concluding that family members wanted more information as the illness progressed while people wanted less information. Both groups wanted a trusted honest empathic health professional to clarify information needs and encourage questions.

In the qualitative research relating to patient experiences with stage 5 CKD, concerns about the threat to life are seldom raised. It seems that there is a culture of not talking about death in dialysis settings, where the benefits of technology are emphasized (Moss, 2003). For example, in a phenomenological study, Rittman, Northsea, Hausauer, Green, and Swanson (1993), identified three themes: “taking on a new understanding of being,” “maintaining hope,” and “dwelling in dialysis.” The constitutive pattern, “control: the meaning of technology,” referred to control of renal replacement therapy. Similarly, Nagle (1998), who used hermeneutics to understand the meaning of technology for 11 people on haemodialysis, presented

Why is this research or review needed?

- As nurses, we need to understand the stories of people and their families as they approach end-of-life to give holistic person-centred care.
- Little is known about the perspectives of family members, in particular, yet they give valuable support to their significant others at this stressful time.

What are the key findings?

- People with chronic kidney disease and their family members recognize the risk of death and think about limited life expectancy, yet live life as fully as possible.
- Family members had a good understanding of the prognosis of their significant other. The perspectives of dyads were similar, at times verbatim, but in a few cases clearly diverged.
- Nurses and health professionals were not mentioned in the conversations of people with chronic kidney disease and their family members about death and dying.

How should the findings be used to influence policy/practice/research/education?

- Clinicians should listen attentively to people with advanced illness and their family members and pose questions that genuinely invite concerns and wishes about living well with serious illness and end-of-life.
- Past experiences with illness, loss, and death can be entry points for discussing awareness of the possibility of death and end-of-life care.
- End-of-life planning would benefit from inclusion of family members/significant others.

the paradox of experiencing dialysis as a “lifeline” but also as a source of suffering. Three themes, “coming to terms with loss and limitations,” “abiding with technology,” and “enduring the treatment environment” were expressed. Hagren, Pettersen, Severinsson, Lutzen, and Clyne (2001), in a qualitative interpretive study, found two main themes including “hemodialysis machine as a lifeline” and “alleviation of suffering.” The findings in these studies focused on adaptation to technology and not on physical decline and subsequent death.

In analysis of 200 CKD patient narratives, Molzahn, Bruce, and Shields (2008) found that the experience of receiving treatment for CKD was a liminal (betwixt and between) experience. A number of liminal spaces were described including living/not living, independence/dependence, restrictions/freedom, normal/not normal, worse off/better off, and alone/connected. In other narrative studies, some people openly discussed the likelihood of death, others did not speak of death

and dying, even with their family or healthcare providers (Molzahn et al., 2012; Schick-Makaroff, Sheilds, & Molzahn, 2013; Sheilds et al., 2015). As people get closer to EOL, these discussions become more important and studies of the EOL experience are critical.

Research on EOL in the CKD population has focused primarily on symptom management and advance care planning. For example, Murtagh, Sheerin, Addington-Hall, and Higginson (2011) described the illness trajectory of life in people with conservatively managed stage 5 CKD (with a mean age of 81 years). They found that mean symptom distress scores increased in the last 2 months of life. Davison (2011) argued that people with CKD have extensive and unique EOL care considerations and needs, emphasizing that a better understanding of peoples' experiences is required to maximize the effectiveness of a palliative approach. Recently, an international consensus conference was held (Davison et al., 2015) to develop guidelines for supportive care of people with CKD. The group acknowledged the complexity of caring for people with advanced CKD given the variability in illness trajectories, high symptom burden, and the need for supportive care often for months to years before death. They concluded that many questions remain to be studied relating to EOL care for this population.

In summary, the EOL experiences of people with advanced CKD are not well understood. While family members give considerable support, their perceptions about caring for someone with advanced CKD are not well documented. A better understanding of the experiences of these two groups can lead to better EOL care. Following people with CKD and their families over time provides opportunities to better understand how their perceptions and needs shift as death approaches.

2 | THE STUDY

2.1 | Aims

The research questions were:

- 1) How do people diagnosed with CKD describe uncertainty related to impending death?
- 2) How do family members describe the experience of caring for a person diagnosed with CKD and living with the uncertainties of impending death?

2.2 | Design

A narrative enquiry was undertaken using in-depth interviews to explore people's experiences of living with the uncertainties of illness and the likelihood of dying. A social constructionist perspective framed the approach to the study. It is founded on the premise that peoples' understandings and experiences of reality are sustained and shift through stories (Berger & Luckmann, 1967; Davis & Sumara, 2002; Gergen & Gergen, 2004). Narrative enquiry is a lens into the multiple narratives and cultural/social discourses that shape how individuals story experience.

2.3 | Participants

People with CKD and family members/significant others were recruited purposively because of the advanced life-limiting state of their illness through two western Canadian treatment centres. Advanced care nurses and a nephrologist were asked to identify participants who: had stage 5 CKD; were currently receiving treatment (haemo or peritoneal dialysis); were over the age of 18 years; had experienced exacerbations, complications or notable progression of disease; and had one or more co-morbidities. Exclusion criteria included: non-English speaking persons; significant cognitive impairment; and acute distress related to the diagnosis. Participants were told that the research team was interested in understanding the uncertainties of living with a serious illness. In one centre, names of people meeting the inclusion criteria were sent directly to the research team and in the other, potential participants were left with an information sheet inviting them to contact the research team. Because of the latter recruitment strategy, it is not clear how many potential participants declined participation.

In the screening process, participants were asked to identify a family member (or significant other) who would be interested in participating. They were not excluded if they did not have or chose not to identify a person.

2.4 | Ethical considerations

Research Ethics Committee approval was granted by the Institutional Review Boards of the educational institutions and administrative approval was obtained from the healthcare agencies. Participation in the study was voluntary. Informed consent was obtained at the time of the first interview and was ongoing. Pseudonyms have been used to protect confidentiality of participants and care was taken to preserve confidentiality between members of the dyad unless they chose to share their comments with their family member.

2.5 | Data collection

Data for this study were collected between November 2015–January 2018 in two in-depth interviews, approximately 3–4 months apart, followed by a telephone follow-up conversation 2–3 months later, with some variability to accommodate participants' illnesses. Because of the number of interviews and two geographic regions for the study, four interviewers, including a doctoral student and three research assistants assisted with data collection. All interviewers were female; two of the four interviewers were nurses and two had preparation in other health disciplines. All were experienced interviewers. They furthered their narrative interviewing skills through training workshops and dialogue with the research team. Weekly debriefing sessions between the interviewers and the investigators facilitated training, ensured quality, and familiarized the team with the data. Dialogue amongst the interviewers enabled them to obtain informal feedback, consider new strategies for interviewing and gain support after emotion-laden interviews. No members of the research team held prior relationships with the participants.

The first two interviews were face-to-face and took approximately 90–120 minutes each. The third interview was a follow-up telephone conversation approximately 20–30 minutes long and focused on clarifications and closure. All interviews were held at a mutually convenient time and location, usually in the participant's home but occasionally in the hospital or university. Whenever possible, participants in the dyad were interviewed separately to give the opportunity for them to speak freely and confidentially. However, four dyads requested that some or all of their interviews be conducted together. Interviews were semi-structured, began with broad general questions such as "Tell me about what it is like to live with a serious illness," followed by questions guided by the specific comments and stories of the participants and the study objectives. All interviews were audio-recorded and transcribed. Immediately after the interviews, field notes were recorded focusing on non-verbal communication, context of the interview, and changes in disease condition since the previous interview.

2.6 | Data analysis

Riessman's (2008) approach to thematic analysis was used. This included analysis in and across participants (person with illness and family members). The research team came to know each participant and dyad through reading, re-reading, and listening to the interviews. Two research assistants coded the data under the supervision of the research team. Differences in coding or questions about categorization were discussed with the entire research team and after dialogue, decisions were made by consensus. Theoretical saturation was achieved when participants' descriptions became repetitive and no new themes were identified. N-Vivo™ Version 11 software was used to facilitate coding of transcripts.

2.7 | Rigour

Trustworthiness, a criterion of rigour in the constructivist paradigm (Denzin & Lincoln, 2005), was established by purposeful sampling, where all informants were deliberately selected for the purpose of the study. Trustworthiness was further evaluated using the qualitative criteria of credibility, transferability, dependability, and confirmability. Credibility was established through prolonged engagement with the participants. The interviewers recorded field notes after each interview. A detailed audit trail (Denzin & Lincoln, 2005) was maintained; records of all design and data analysis decisions were recorded, including the theoretical and process memos of analytic decisions. Memoing and discussion of issues of analysis in our team were means to reflexivity and critical to the integrity of this project (Banister, 1999). Member checking was not conducted.

3 | FINDINGS

3.1 | Participants

Eleven people with advanced CKD and nine family members/significant others participated in the study. Participants with CKD ranged

in age from 45–80 years of age (mean = 65.5) and family members ranged in age from 41–76 years (mean = 55.3). Six of the 11 participants with CKD were male and five were female. Of the people with CKD, five were on peritoneal dialysis and six received haemodialysis. All of them had one or more co-morbidities. Over the course of the study and shortly thereafter, three participants with CKD died. The family members/significant others were mostly female (eight of the nine who participated). They included four spouses, three children, one parent, and one friend.

3.2 | Themes/Storylines emerging

For both the participants with CKD and their family members, a number of key themes/storylines relating to living with dying were evident in the data. These included recognition that: "*life has a boundary, living on the edge, I'm not afraid to die but... and remembering loss and death experiences.*"

3.2.1 | Life has a boundary

Despite the hope and survival offered by dialysis, both the persons with CKD and the family member participants acknowledged that life has a boundary and they were acutely aware that death was a distinct possibility for the person with advanced CKD. In a shared interview, Carol, a woman with CKD stated: "I have to realize I am not at the point to go on. You know I'm just waiting for my time." Her husband responded, "We are not anxious... We know that things will happen." Audrey, a spouse, said: "I think about the future and that the chances of me being a widow are probably pretty...pretty strong." Ethan told the story of seeing a friend die on dialysis. After this loss, he chose not to engage with other people on dialysis. Mary-Anne, who lost her father over the course of the study said: "I'm realistic in that I know that my dad has almost died half a dozen times.... so every day's a blessing." She described how her father had talked with a psychiatrist so that: "if someday he decides he's had enough...He actually has a choice in that. Which is extremely important for my dad." She also encouraged her young son to engage with his grandfather saying: "every time you see him [your grandfather], say good bye. You know, in your heart, say good bye forever."

Participants also recognized that terminating dialysis would result in death. Ethan commented: "I just found out, couple of days before the interview, that one guy basically went home to his farm to give up. He's gonna stop his dialysis. And a week later, he was dead." He described the impact this had on him and his reason for delaying his participation in the second interview, which occurred 7 months after the first: "You know, that... some of the questions were getting close to that type of thing. So it was a raw nerve at that moment."

For most family participants, discussions with their relative about risk to life made them consider their own mortality. They all recognized that their family member often thought about death and dying. Some family members had concerns about what would happen if they became ill or passed away first. Jane said: "I always hung my head

about planning for when [husband] dies. And then, I'm thinking ... You know what? What happens if I die? I have to plan about what happens if I die before him." This concern was also poignant for Sheila, who was caring for her daughter who had multiple chronic illnesses:

I am concerned what would happen to her if I died first... I hope she dies before me...otherwise her life is going to be extremely difficult because I am her number one support. So I couldn't bear to think what might happen.

3.2.2 | Living on the edge

Many of the participants talked about living close to the edge between life and death. Mary-Anne, who lost her father over the course of the study said: "I don't mean that I'm glad he's gone. That's not it at all. But we're – we're both free. He's free of all that and he suffered a long time." She also noted: "I think my dad knew what was coming." She was comforted in knowing that her 13 year old son had an opportunity to see his grandfather the day before he died and told the following story:

We were very lucky that [son] went in the day before he died and dad ah – he held his hand and dad, he never cried... Well, tears. And [son] came home and told me that Grandpa cried. So I explained that he's saying good bye. ... So, I went that night and he passed the next day. Like, it was like he needed to say good-bye. And I was very grateful for that.

In some situations, death seemed imminent to the participants, while in others, it appeared to be a more distant threat. Even when death seemed perilously close, the participants held possibilities for healing. For instance, Jillian said:

I think he was pretty much at his worst with, you know ... big wounds and big holes and big – big problems. And we've seen so much healing. And so many good positive changes that it's like well, we're kinda on the upward swing here.

Participants' values shaped their ways of living at the edge and the 'edge' was unique for each participant, at times shifting in the individual. Leah, a wife, spoke about living on the edge of hope and hopelessness:

I have hope again because of the changes that have been put in effect. And he had one really good dialysis and so, it's given me hope that he can continue to have it. ... he goes up, like this. And then something else will happen, right? And then, he'll go down. So it's like, how long is he going to stay like this? But my

whole fear with this mortality was that he would get to the point where they can't do dialysis on him.

When people asked George how his wife was doing, "the only thing I can say is sometimes good, sometimes bad... we are still hoping that there will be some remedy."

3.2.3 | I'm not afraid to die, but ...

The participants with CKD in the study commented that they were not afraid to die, but they did not want to suffer. They wanted to continue living to maintain close relationships in their life. Brianna, a participant with CKD, spoke with a trembling voice of her role as an aunt: "You have to be around for the kids...they don't have any family." Similarly, Emily expressed: "I'm not ready to kick off" ... and talked about her grandchildren at length, communicating their importance in her life: "I've got lots of grandkids! That makes it worth living." In another family, William's desire to continue to give financial support to his family made him want to "hang on."

Family members had the same goal. Sandra talked about her mother's wish for a death that was "a peaceful slumber ...and not have the pain." Mia recognized that she needed to support her mother's wishes: "You know... at the end of the day, she's the one that's suffering with it. You've gotta try and make her appreciate everything, it – whether it's gonna be, she's got 10 years left, 20 years left, or one year left, you've gotta live that year to the fullest."

When participants were asked about their uncertainty in living with CKD, many referenced their belief systems including Christian, Muslim, and other faiths and spiritual but not religious beliefs. Hazeem, who had CKD, said that he was not fearful of death, but was worried about his family and viewed death with certainty. He said: "being Muslim, God says ... in Quaran, how much time you will spend in this world has been decided and it cannot be curbed one-second further or one-second before." George, who was Catholic, reported that his wife who was living with CKD said: "...If only God can take me now.... Are you preventing God – to – doing what I want?" When he responded: "I'm still praying for a miracle," he reported that she said, "Can't you give me up?"

On occasion, the values between people and families were implicit but not spoken outright to one another. In the context of dyads, sometimes participants had thoughts that they were reticent to share with each other. In the case of one dyad (pseudonyms unstated for reasons of confidentiality), a spouse said:

I have never told [my husband] this, but I – I thought if – if he's not gonna come back and be the person that he wants to be, then I hope he passes on.... And probably, if I was being totally honest, I was – was also thinking, "Oh my God, you know, am - am I – how am I gonna feel if he's a total invalid?" If he's a – you know, someone who's... an invalid. I mean, at – but up until this point, he has not been an invalid. Um, how am I gonna handle that?

3.2.4 | Remembering loss and death experiences

Other losses and deaths experienced by the participants over their lifetime were described in depth and provided context for participants' perceptions about death and dying. The losses took a variety of forms. Some people talked about beloved pets which had died, others about lost kidney function and Ethan described losing a job, a pet, a parent, and a marriage at about the same time. Many of the participants described the death of one or more family members and/or friends. For instance, William and his daughter Mary-Anne both talked about the loss of a son/brother in a motor vehicle accident. This tragic loss affected them differently. William commented: "I don't have any faith...Pretty hard to deal with it rationally." On the other hand, Mary-Anne thought, "your brother's there [in the afterlife], he'll see – so it's not as bad as suffering would be."

These losses affected perceptions about death and dying in different ways. For some people, it made it easier to discuss the opportunity of death. Leah said that when her husband's best friend died, "it was hard. But then we just accept it. So it's like, we're all gonna die. We talk freely about, Yeah well, when I'm dead ...". Leah also said:

I think that it's also got to do with a lot of our friends and relatives that were really close, died very unexpectedly. And so, I think my thoughts on mortality kinda changed even before all of this just because you'd get a phone call and a friend had died. Or a relative had died – totally unexpectedly from something, right? And so, it's just...like, we never know.

Some participants had experienced multiple losses of close family members over a short time. These tragedies affected their approach to living with uncertainty. For instance, Mia, whose mother was on dialysis, discussed the tragic loss of her father when she was a child: "I mean you look at what happened to our family, my dad he was [under 40] when he died ...– you never know right? And I think that is how I maybe look at things: you just never know."

Remembering experiences of death and loss shaped how people and family members approached living with the uncertainty of illness. Evan described how his desire to: "keep on this path of living to an old age" was influenced by the way his father choose to navigate his illness experience and death:

I was a little disappointed in my dad. My dad had emphysema and he spent some time in hospital on oxygen gasping for breath and he said to me one time, 'I'm not going to go through that again'... So he was giving up in that his hospital experience was worse than what he was prepared to accept and I suppose there are situations when you're in pain and do that and I really don't have that problem at all... I suppose that's where you take your role model from, when you can see what other people are doing...

Yeah that was just something that was in the conversation which said (pause) 'I don't like the sound of that particularly'.

These deaths affected them for years. Some participants experienced losses during the course of the study that made them more emotional when considering their own mortality or that of their family member. Sandra, a 54 year old daughter, talked about her concern about becoming an orphan when her parent died. Some family member participants talked about other losses and how they were able to get through their grief. This made them realize that they could deal with the eventuality of death in their family member and that some positive memories would last.

4 | DISCUSSION

We found that the participants with advanced CKD and the family participants were very aware of the limited life expectancy associated with the illness, yet they still held hope for improvement and a commitment to living well for as long as they were alive. The participants with CKD commented that they were not afraid to die, but they did not want to suffer. They expressed this desire to their family members and without exception, the family members had the same goal. Sandra talked about her mother's wish for a death that was "a peaceful slumber ...and not ... the pain." These wishes are consistent with observations from previous qualitative research in the CKD population (Molzahn et al., 2012; Shields et al., 2015) and in the palliative care literature (Ferrell, Coyle, & Paice, 2015).

To address the needs of people with advanced CKD and their families, early palliative care services would be beneficial. Palliative care is an approach that focuses on improving "the quality of life of people and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (WHO, 2018). A palliative approach, that uses "principles of palliative care [that] are adapted and integrated into contexts of care that do not give specialized palliative care services, regardless of the healthcare sector where the service is provided" (Sawatzky et al., 2016, p. 1), seems particularly appropriate given the organization of renal care services. "Supportive care" is a term recently used in the literature relating to EOL with CKD that offers language that is preferred by people and health professionals in this setting (Davison et al., 2015). Given the findings of this study, additional professional development of renal programme nursing staff relating to a palliative approach and supportive care is warranted.

Living and dying with a life-limiting illness such as CKD is clearly a family experience and not only the experience of the individual. Goff et al. (2015), in their study of people with CKD and their families, noted that many participants in their study requested family involvement in advance care planning. The participants in this study also noted the value of having these conversations. For many of the

dyads in this study, it seemed that family members had a good understanding of the prognosis of their significant other. Some dyads even used similar, at times verbatim, language to describe their experiences, perhaps because of shared experiences, or discussion about their concerns. The perspectives were frequently intertwined, but in a few cases clearly diverged from each other. There were also unspoken aspects to the communication between them, as previously noted by Schick-Makaroff et al. (2013). Interventions to facilitate EOL planning would benefit from inclusion of family members for support and to enhance communication.

The challenges associated with long-term caregiving in CKD are significant for family members. They must deal with the complex aspects of the treatment regimen and the uncertainty associated with health crises and sometimes near-death experiences. This is similar to other life-limiting illnesses such as cancer where family caregivers give symptom management and care coordination in the home (Ullgren, Tsitsi, Papastavrou, & Charalambous, 2018). This study begins to illuminate the uncertainties that family caregivers face with advanced CKD.

Guidelines and recommendations relating to supportive and EOL care for people with CKD have been developed (Davison et al., 2015). These are important initiatives that will need further development as new knowledge emerges. While symptom management and prognostic indicators were identified as important areas for care and future research (ibid), the value of realistic open communication about EOL does not easily lend itself to guidelines. Participants in this study varied in their approach to talking (and not talking). Flexibility, authenticity and openness are needed to enable people to converse in their own ways. It is not necessary that healthcare providers have the answers to the difficult questions about death and dying. Genuine presence and partnership in setting goals of care can help people with life-threatening illnesses and their family members navigate the difficult existential questions relating to living and dying. Creating space for conversation about EOL also aligns with values inherent in a palliative approach (Sawatzky et al., 2016) and holistic care (Noble, Brown, Shields, Fogarty, & Maxwell, 2015).

The stories about living and dying with advanced CKD represented a wide range of perceptions. Each individual's unique experience influenced their values and beliefs about living and dying. Goff et al. (2015) also observed that life experiences, personality traits, and relationships may affect perspectives on advance care planning. Discussion about past experiences with serious illness, loss, death, and dying of family members and friends could give an entry point for discussion about EOL.

Although we asked participants what would have been helpful to them, we were struck that we heard no stories where nurses or other professionals engaged in discussion about death and dying with the participants. It seems that their impact was not worth noting by the participants in the otherwise rich interviews. Similar observations have been made in other studies (Goff et al., 2015). The absence of these stories suggests at the very least a disjuncture between people living with illness and their healthcare providers.

The longitudinal design of the study was a particular strength of the study, enabling us to deepen relationships and see how stories changed/remained consistent as the illness progressed. This study also extends previous work by exploring the stories of people with advanced CKD as they approach EOL and by including the perspectives of family members. The thick rich descriptions and poignant stories give exemplars that may be valuable to clinicians and researchers who see that the cases represent situations that they recognize.

Further research relating to the impact of EOL care in CKD on family caregivers is warranted. Supportive and/or palliative care programmes for people with CKD need further development and evaluation.

4.1 | Limitations

There are several limitations to the study. We are unable to generalize findings from the research to other populations, since the sampling strategy was purposive. Our sample may have been biased in that health professionals recommended participants. Two participants did not have a family member participate, thus we were unable to compare fully across families.

5 | CONCLUSION

The findings from this narrative enquiry illuminated perceptions about death and dying with advanced and complicated CKD for people with the illness and their family members. Key storylines evident in the data included recognition that *life has a boundary, living on the edge, I'm not afraid to die but...* and *remembering losses and death experiences*. The person with the illness and the family members often held very similar perceptions and desires, namely to avoid pain and minimize suffering. People often shared past experiences of death and dying. Exploration of these experiences could facilitate deeper understanding of EOL wishes. Healthcare professionals were not mentioned by participants, indicating opportunities to do more.

There are many implications of this study relating to the need for discussions about death and dying people with CKD and their family members. We need to understand the stories of people and their families as they approach EOL to give holistic individualized person-centred care. Although both family members and people with CKD recognized the risk of death, the concerns of both members in the family dyad were often unspoken. We recommend that clinicians caring for people at the EOL open dialogue by listening attentively and genuinely to cues emerging from discussion of past or present illnesses and ascertaining their unique concerns at EOL. Engaging family members in discussions provides much needed support for them and the person with illness.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [<http://www.icmje.org/recommendations/>]):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

ORCID

Anita E. Molzahn  <http://orcid.org/0000-0002-9835-9147>

REFERENCES

- Banister, E. (1999). Evolving reflexivity: Negotiating meaning of women's midlife experience. *Qualitative Inquiry*, 5(1), 3–23. <https://doi.org/10.1177/107780049900500101>
- Berger, P. L., & Luckmann, T. (1967). *The social construction of reality: A treatise in the sociology of knowledge*. New York: Anchor Books.
- Davis, B., & Sumara, D. (2002). Constructivist discourses and the field of education: Problems and possibilities. *Educational Theory*, 52(4), 409–428. <https://doi.org/10.1111/j.1741-5446.2002.00409.x>
- Davison, S. N. (2011). Integrating palliative care for patients with advanced chronic kidney disease: Recent advances, remaining challenges. *Journal of Palliative Care*, 27, 53–61.
- Davison, S. N., Levin, A., Moss, A. H., Jha, V., Edwina, A., Brown, E. A., ... Obrador, G. T. (2015). Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *Kidney International*, 29. <https://doi.org/10.1038/ki.2015.110>
- Denzin, N., & Lincoln, S. (2005). *The Sage handbook of qualitative research*. Thousand Oaks: Sage.
- Ferrell, B. R., Coyle, N., & Paice, J. (Eds). (2015) *Oxford textbook of palliative nursing* (4th ed.). Oxford, UK: Oxford University Press.
- Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*. New York, NY: Metropolitan Books.
- Gergen, K., & Gergen, M. (2004). *Social construction: Entering the dialogue*. Chagrin Fall, OH: Taos Institute Publications.
- Goff, S. L., Eneanya, N. D., Feinberg, R., Germain, M. J., Marr, L., Berzoff, J., ... Unruh, M. (2015). Advance care planning: A qualitative study of dialysis patients and families. *Clinical Journal of American Society of Nephrology*, 10, 390–400. <https://doi.org/10.2215/CJN.07490714>
- Hagren, B., Pettersen, I. M., Severinsson, E., Lutzen, K., & Clyne, N. (2001). The hemodialysis machine as a lifeline: Experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing*, 34, 196–202. <https://doi.org/10.1046/j.1365-2648.2001.01745.x>
- Hill, N. R., Fatoba, S. T., Oke, J. L., Hirst, J. A., O'Callaghan, C. A., Lasserson, D. S., & Hobbs, F. D. R. (2016). Global prevalence of chronic kidney disease—A systematic review and meta-analysis. *PLoS ONE*, 11(7): e0158765. <https://doi.org/10.1371/journal.pone.0158765>
- Mahtani-Chugani, V., Gonzalez-Castro, I., Saenz de Ormijana-Hernandez, A., Marin-Fernandez, R., & Fernendez de la Vega, E. (2010). How to provide care for patients suffering from terminal non-oncological diseases: Barriers to a palliative care approach. *Palliative Medicine*, 24(8), 787–795. <https://doi.org/10.1177/0269216310380296>
- Molzahn, A. E., Bruce, A., & Shields, L. (2008). Learning from stories of people with chronic kidney disease. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*, 35(1), 13–20.
- Molzahn, A. E., Shields, L., Bruce, A., Stajduhar, K. I., Schick Makaroff, K. S., Beuthin, R., & Shermak, S. (2012). Perceptions regarding death and dying of individuals with chronic kidney disease. *Nephrology Nursing Journal*, 39, 197–204.
- Moss, A. (2003). Too many patients who are too sick to benefit start chronic dialysis nephrologists need to learn to “just say no”. *American Journal of Kidney Diseases*, 41, 723–727. [https://doi.org/10.1016/S0272-6386\(03\)00131-8](https://doi.org/10.1016/S0272-6386(03)00131-8)
- Murtagh, F. E. M., Sheerin, N. S., Addington-Hall, J., & Higginson, I. J. (2011). Trajectories of illness in stage 5 chronic kidney disease: A longitudinal study of patient symptoms and concerns in the last year of life. *Clinical Journal of American Society of Nephrology*, 6, 1580–1590. <https://doi.org/10.2215/CJN.09021010>
- Nagle, L. M. (1998). The meaning of technology for people with chronic renal failure. *Holistic Nursing Practice*, 12(4), 78–92.
- Noble, H., Brown, J., Shields, J., Fogarty, D., & Maxwell, A. P. (2015). An appraisal of end-of-life care in persons with chronic kidney disease dying in hospital wards. *Journal of Renal Care*, 41(1), 43–52.
- Öhman, M., Söderberg, S., & Lundman, B. (2003). Hovering between suffering and enduring: The meaning of living with serious chronic illness. *Qualitative Health Research*, 13, 528–542. <https://doi.org/10.1177/1049732302250720>
- Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., ... Tattersal, M. H. N. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life limiting illness: Patient/caregiver preferences for the content, style and timing of information. *Journal of Pain and Symptom Management*, 34, 81–93. <https://doi.org/10.1016/j.jpainsymman.2006.09.035>
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.
- Rittman, M., Northsea, C., Hausauer, N., Green, C., & Swanson, L. (1993). Living with renal failure. *American Nurses Nephrology Association*, 20, 327–332.
- Sawatzky, R., Porterfield, P., Roberts, D., Lee, J., Liang, L., Reimer-Kirkham, S., ... Thorne, S. (2016). Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis. *Advances in Nursing Science*, 40, 261–277. <https://doi.org/10.1097/ANS.0000000000000163>
- Schick-Makaroff, K., Shields, L., & Molzahn, A. (2013). Stories of chronic kidney disease: Listening for the unsayable. *Journal of Advanced Nursing*, 69, 2644–2653. <https://doi.org/10.1111/jan.12149>
- Shields, L., Molzahn, A., Bruce, A., Schick Makaroff, K., Stajduhar, K., Beuthin, R., & Shermak, S. (2015). Contrasting stories of life-threatening illness: A narrative inquiry. *International Journal of Nursing Studies*, 52, 207–215. <https://doi.org/10.1016/j.ijnurstu.2014.10.008>
- Ullgren, H., Tsitsi, T., Papastavrou, E., & Charalambous, A. (2018). How family caregivers of cancer patients manage symptoms at home: A systematic review. *International Journal of Nursing Studies*, 85, 68–79. <https://doi.org/10.1016/j.ijnurstu.2018.05.004>
- WHO. (2018). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

How to cite this article: Molzahn AE, Shields L, Bruce A, Schick-Makaroff K, Antonio M, White L. Living with dying: A narrative inquiry of people with chronic kidney disease and their family members. *J Adv Nurs*. 2019;75:129–137. <https://doi.org/10.1111/jan.13830>

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in JAN:

- **High-impact forum:** the world's most cited nursing journal, with an Impact Factor of 1.998 – ranked 12/114 in the 2016 ISI Journal Citation Reports © (Nursing (Social Science)).
- **Most read nursing journal in the world:** over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 3,500 in developing countries with free or low cost access).
- **Fast and easy online submission:** online submission at <http://mc.manuscriptcentral.com/jan>.
- **Positive publishing experience:** rapid double-blind peer review with constructive feedback.
- **Rapid online publication in five weeks:** average time from final manuscript arriving in production to online publication.
- **Online Open:** the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).