



Research Article

Understanding the Lived Experience of Frailty in the Chronic Kidney Disease Context Using Social Cognitive Theory: An Exploratory Qualitative Study

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Abstract

Purpose: Frailty has been characterized as a state of accelerated aging with increased vulnerability to adverse outcomes. The lived experience of individuals with CKD and frailty has yet to be examined. This study aims to understand frailty in the advanced chronic kidney disease (CKD) context and impact on decision-making. **Methods:** Participants with advanced CKD and Fried Frailty phenotype and their caregivers were invited to participate in in-depth interviews or focus group to gain a rich description of key informants' experiences of frailty. Interviews were recorded, transcribed and coded for meaningful concepts and analyzed using inductive thematic analysis using a constant comparative method of data analysis employing Social Cognitive Theory. **Results:** Two focus groups, six individual semi-structured interviews and three interviews were analyzed prior to saturation of themes. Experiences of frailty were described across four domains: the self, the body, the mind, and impact on relationships; yielding themes of: the normative influence of capacity, reliance on help (personal or equipment), the dynamic state of frailty, erosion of identity, unresolved symptom burden, non-routine recovery, contracted social sphere, the mind-body continuum, and proximity to death. Experiences of frailty were punctuated by falls, comorbidity, and prolonged hospitalizations. **Conclusions:** Frailty is a pejorative, personal, subjective experience defined by deterioration from a previous normative baseline and reliance on aids and caregivers. Patients and their caregivers strive to maintain the status quo, experiencing life "day by day," and "taking baby steps". The dynamic state of frailty needs to be considered in decision-making and future planning.

Keywords: Kidney disease, Dialysis, Frailty, Qualitative, Symptom burden, Decision-making

Abbreviations: CKD: Chronic Kidney Disease, HD: Hemodialysis, SRQR: Standard for Reporting Qualitative Research, FAINM: Free Association Narrative Interview Method, SCT: Social Cognitive Theory

Introduction

Frailty has been characterized as a state of accelerated aging with increased vulnerability to adverse outcomes and non-routine recovery from relatively minor insults [1, 2]. Frailty literature suffers from heterogeneous definitions and assessment contexts, both in the mainstream geriatric literature, but especially so within nephrology research and clinical settings [3, 4].

Best practice recommendations endorse frailty screening for high-risk nephrology populations where frailty is known to be prevalent [5]. This reflects an understanding that the presence of frailty is a more consistent predictor of illness outcomes than estimated glomerular filtration rate, dialysis modality, age or comorbidity, and thus offers opportunity for improved prognostication and advanced communication with patients living with advanced CKD [6-8]. Evidence suggests transplant centers that assess frailty demonstrate superior patient outcomes, including guiding the provision of social and home support, facilitating “prehabilitation” prior to transplantation and tailoring of immunosuppression [9, 10]. Qualitative studies examining the lived experience of frailty in geriatric populations have uncovered themes of progressive deterioration, vulnerability and impaired resilience, loss of social identity, personhood and agency as well as loss of physical function including energy loss and fatigue, weight loss, impaired mobility and loss of vision and hearing abilities [11]. Frailty emerges as a personal, subjective experience that is both triggered and exacerbated by negative emotional states such as worry, sadness and fear [12]. Such findings are obscured by methodological limitations, including recruitment of participants predominantly defined by age and disability criteria and may not reflect the experience of frailty per se, but rather the embodiment of incapacity. One Australian study, operationalizing the FRAIL questionnaire screening tool examined the perception of frailty among older adults living in community, assisted living and residential aged care settings. This study reported that older adults question the necessity and logic of an objective measure of frailty and are reluctant to participate in frailty screening unless it is likely to culminate in action, reflecting key principles of public health screening initiatives [13]. Importantly, respondents emphasized the need for frailty screening to be undertaken sensitively due to the negative perceptions of the term frailty and the potential adverse effects of frailty labelling [13]. This theme of stigma associated with the term frailty is widespread within the qualitative literature [12]. To date, no studies have examined the lived experience of frailty in the CKD context. Should frailty screening move towards implementation in the CKD setting, it is imperative that screening approaches are acceptable to this vulnerable patient population [14].

Understanding the patient perspective of frailty is also critical to offering holistic patient-centered care while empowering a patient to share their deeper knowledge. Current clinical approaches to frailty allocate little time or value in exploring patient perspectives. Exploring patients’ lived realities assists in provision of goal-directed care and scaffolding future changes in health status. Indeed, rehabilitation strategies for patients with advanced CKD and frailty have been limited in their ability to overcome patient-perceived barriers to participation, resulting in challenges with recruitment, high rates of drop-out and non-adherence [15, 16]. While exercise interventions in the dialysis context support longer interventions of >12 weeks duration [17], pilot studies examining frailty in nephrology populations speak to the challenges of recruitment and retention in this patient population [18]. Understanding the lived experience of frailty likely offers benefits that extend beyond rehabilitation goals and into preferences for living and dying well in spite of frailty.

Incident frailty and functional decline in the CKD and dialysis context have particular implications for caregivers, where caregiver burden is already recognized to be substantial [19, 20]. Through qualitative enquiry, this paper will examine the lived experience of frailty as experienced by both patient and caregiver.

We hypothesise that frailty is a recognizable concept to participants living with this condition, and that people with frailty can offer insights into how frailty should be approached and managed by health services. Research methodology and findings are reported in line with Standard for Reporting Qualitative Research (SRQR) [21].

Aims

- To understand the lived experience of frailty in the advanced kidney disease context and how this impacts interactions with healthcare providers and medical decision making.
- To examine patient perspectives of frailty screening in the CKD context.
- To explore caregiver experiences of CKD and frailty.

Methods

Participants and Research Context

Participants from the CKD Frailty study [22] with Fried Frailty Phenotype and their caregivers were invited to participate in a focus group workshop or interview to seek patient experiences and preferences regarding frailty and frailty assessment in the setting of advanced kidney disease. The Fried phenotype defines frailty as the presence of three or more of the following criteria: unintentional weight loss, physical inactivity, exhaustion or fatigue, weakness and slowness [1]. Inclusion criteria included English-speaking adults with advanced chronic kidney disease (defined as eGFR <20ml/min) or undergoing maintenance hemodialysis (HD). Exclusion criteria were acute kidney injury, receipt of functioning

kidney transplant, diagnosis of dementia or cognitive impairment. Open-ended interviewing was employed in a focus group setting in small meeting rooms within the renal outpatients' area of The Canberra Hospital. Focus group interviews were facilitated to contain a minimum of two and a maximum of six participants per group. Where interested participants were unable to attend a focus group interview, they were offered a one-on-one interview, either in-person or over the telephone, utilizing the same open-ended interview approach. Purposive sampling of diverse patient demographics was utilized. The opportunity to interview across different patient groups allows and invites a range of perspectives and experiences, adding strength to the research outcomes. Sample size was informed by the principles of ethnography indicating smaller data collection facilitates in-depth study of the topic, along with principles of theoretical sufficiency which indicate that a homogenous sample usually allows for meaningful analysis and credible conclusions [23-25]. Participants were offered taxi vouchers for participation. Interviews were conducted between January and April 2023.

Study design

This examination adopted an exploratory qualitative descriptive methodology to gain a rich description of key informants' experiences of frailty, participation in frailty screening and produce an authentic report of participant's experiences and expectations of care. A Free Association Narrative Interview Method (FANIM) [26] was adopted, recognizing that this participative and conversation-style approach is most appropriate in a patient population that may become cognitively tired and require prompts to recall their thoughts [27]. Semi-structured focus group interview sought patient understanding, identification with, and experience of frailty, including acceptability of screening for frailty. This approach enabled focused and in-depth exploration of topics and subjective experiences. Questions utilized open-ended format with flexible design to allow interviewees to follow train-of-thought ideation, expand on concepts and promote unplanned dimensions to the topic of interest. Interviews were conducted by an experienced researcher using a topic guide developed from literature review on this topic [4, 28]. Focus groups were up to one hour duration. Interviews were audiotaped and transcribed verbatim. The de-identified transcript was coded for meaningful concepts and analysis grouped similar concepts into emergent themes using a constant comparative iterative method of data analysis [29]. Focus groups and interviews were continued until no new ideas emerged and theme saturation was achieved.

Qualitative Approach and Research Paradigm

Social cognitive theory (SCT) was used as a conceptual framework to organize the data and allow participants to relay their experiences through interpretation of their accounts. SCT theories that personal beliefs and attitudes, environmental factors (both physical and social) and behaviors reciprocally interact to influence further behaviors including expectations, self-efficacy, self-monitoring and social support, all felt to be relevant to chronic

disease management and rehabilitation participation. SCT has been used as the analytical framework within other reports of exercise participation in patients with CKD [30]. Reliability and validity were ensured through development of a codebook. SR performed coding comparison query.

Qualitative Data analysis

Data responses were de-identified. NVivo12 Plus software [31] was used for qualitative data analysis using inductive thematic analysis, identifying themes at a semantic level, appropriate to health services research to allow a rich and complex account of the phenomenon studied. Analysis followed the steps instructed by Braun and Clark: familiarization with data, initial coding, searching for themes, reviewing themes using the constant comparison method, axial coding and finally defining themes for final analysis and report [32].

Consent

Consent for participation in the focus group or interview was sought as informed consent. Patient Information and Consent Form was provided to ensure participants understood the nature of the qualitative enquiry. Consent was documented by signing consent form upon commencement of the interview or verbal agreement where interviews were conducted over phone. Participants were able to withdraw consent up to 2 weeks after conclusion of the focus group discussion, whereupon their discussion contributions would be redacted from the interview transcript. Participants were instructed to respect the privacy and confidentiality of the group and not discuss issues or personal details of the focus group participants outside of the focus group.

Ethics Approval

Ethics Approval was provided by The Australian National University and The Canberra Hospital Human Research Ethics and Governance Office 2020.ETH.00038

Researcher Characteristics and Reflexivity

The study team consisted of the principal investigator, principal qualitative researcher and a research assistant, all female. The principal investigator is a practicing nephrologist and renal supportive care physician working within the department of renal medicine at The Canberra Hospital with several years of qualitative and quantitative research experience. The principal qualitative researcher is a practicing palliative medicine physician with many years of qualitative and quantitative research experience. The research assistant has a background in exercise physiology and has experience working with and delivering rehabilitation to people with frailty.

Results

Twenty-six participants with frailty were approached for participation in focus group discussion or in-depth interviews; twelve participants declined due to competing health concerns including fatigue or fall and clinic burden.

Two focus groups (N=4, N=2) and six individual semi-structured interviews with participants who had Fried frailty phenotype were conducted and analysed prior to saturation of themes. Three caregiver semi-structured interviews were conducted. Three participants indicated willingness to attend for focus group participation but failed to attend: one withdrew due to concerns of privacy and opted for in-depth interview instead, the other reported he forgot the appointment and subsequently withdrew from participation, the third patient withdrew without providing a reason. No participant withdrew consent following participation in interview or focus group (Table 1).

	Participant number	Age (years)	Sex	Modality	Self-described Ethnicity	Caregiver relationship
Individual in-depth interviews						
	Patient 1 + Caregiver 1*	79	F	CKD	Welsh	Husband
	Patient 2	72	M	CKD	Australian	N/A
	Patient 3	73	F	HD	Australian	N/A
	Patient 4	88	M	HD	Polish	N/A
	Patient 5	64	M	HD	Australian	N/A
	Caregiver 2	81	F	CKD	Serbian	Daughter
	Patient 6 + Caregiver 3*	63	M	CKD	Australian	Wife
Focus Group 1						
	Patient 7	50	M	CKD	Māori	N/A
	Patient 8	59	F	HD	Greek	N/A
	Patient 9	61	F	CKD	Lebanese	N/A
	Patient 10	72	F	CKD	Australian	N/A
Focus Group 2						
	Patient 11	72	M	HD	Australian	N/A
	Patient 12	74	M	HD	Aboriginal Australian	N/A

*demographic details of caregivers not collected; all patient participants scored ≥ 3 on Fried Frailty assessment; CKD: chronic kidney disease; HD: haemodialysis

Table 1: Demographic details of participants

Experiences of frailty were described across four domains: the self, the physical body, the mind and impact on relationships; yielding themes of: frailty as a disruptive experience that contrasts to the normative influence of capacity, the defining feature of reliance on help (caregiver or equipment), the dynamic state of frailty and transitions in frailty state, non-routine recovery, erosion of identity and enjoyment, unresolved symptom burden, a contracted social and geographic sphere and the mind-body continuum exploring the mental (cognitive and psychological) aspects of frailty. Experiences of frailty were punctuated by falls, comorbidity and prolonged hospitalizations.

Theme 1: Experiences of frailty: a disruptive episode that contrasts to the normative influence of capacity.

Frailty was universally described as a negative and stigmatized condition, affiliated with aging and threatening future health and wellbeing. Descriptions of frailty drew on culturally stereotyped images of advanced age, stooped, unsteady or assisted in mobility and impaired by malnutrition and functional dependence;

Frail and age usually go together. Someone who is very thin, has to use mobility aids, has poor dietary [habits] Yeah...and usually old... And has suffered. And is suffering more. (Patient 10)

Participants reported on the lived experience of reduced power, suggesting not only impaired strength but also diminished authority and presence. One caregiver described her observations of sarcopenia, and the accelerated and pathological aging that has accompanied the experience of CKD,

That's what I noticed over the last couple of years. [He's] become very frail because I've actually watched the muscle wasting go to his legs and... his muscle wastage – it's big. [He] used to have legs like tree stumps. Good muscly legs um, used to have the guns as they call them. [He] doesn't have any of that anymore. [He] used to have a 56-inch chest. He was quite broad, and I've watched – he has become very frail. It's like watching a 90-year-old man walking around... he's a shell of a man. (Caregiver 3)

Frailty was associated with diminished quality of life and perceived as “unfair”;

And where he used to love to walk the dog, is no more. His life's... Quality of life to him is not there.... All the things that we take for granted... in a word, it's unfair. (Caregiver 3)

Frailty was aligned with loss of independence and suffering:

I ended up in hospital, you know, in a wheelchair. And that was, that was pretty bad. I felt like I lost my independence. And I think that's what the main thing is, losing your independence, you know, and suffering from pain and...

Despite its negative connotations, the conceptualisation of frailty proved useful to participants, putting into words a shared experience;

Interviewer: Sometimes we use the word frail. What does that mean to you?

Patient 6: Frail'll be a good one.

Other participants refused the diagnosis of frailty, despite acknowledging limitations in functional capacity and a sense of inevitability;

It makes me a little bit upset... ..that I can't do it anymore, but I don't think of myself as frail yet.

In this way participants expressed ambivalence at the value of frailty screening, drawing on their own definitions in preference to clinical diagnoses.

The lived experience of frailty was reported as a state of resignation wherein people with frailty were forced to “accept their limitations”; ‘But it's just a matter of knowing what my current limitations are, you know, and – and working within them’ (Patient 5), suggesting a sense of resilience and deeper knowledge of frailty rehabilitation strategies. Frailty was conceptualized as a need to pay greater attention and protection to the physical body, to not “overdo something” and to “pace yourself.”

Frailty was defined against a functional norm wherein day to day activities were able to be completed independently;

Well I was doing, I was doing everything then. I was um well like – like you – vacuuming the house... And dusting and doing the washing and doing some cooking... (Patient 1)

In this way frailty was articulated as a loss of being able to manage the home environment and loss of functional independence;

I couldn't shower myself, I couldn't stand up in the shower, and I couldn't walk very far. (Patient 3)

Maintained functional independence was presented by caregivers to refute the diagnosis of frailty;

She seems fine. Um, she's – she's um, she's still continuing with all her activities, um, still able to do everything on her own, look after the house, do the cooking, the rest of it. Um, whatever routine she has, she still goes to the shops, um, when she can, um, visits friends, does all of that... (Caregiver 2)

Participants interpreted the return of functional independence as evidence of frailty recovery;

I'm over, over this, you know, I'm a few steps past frailty. But I'm still not, um, robust. But if I manage myself properly, if I have - if I drink and eat well, and do things like that, I can manage to look after myself...I can manage to go shopping. I take myself to dialysis and bring myself home... Um, so I'm quite encouraged by what I'm able to achieve for myself. (Patient 3)

Participants described ability to manage the day-to-day and anticipated routine as a source of strength and resilience. Where tasks could be extended into episodic efforts to accommodate reduced endurance, they were maintained in the face of frailty. Where tasks became overwhelming, participants reported grudging acceptance of outside help, in the form of people or aids, to facilitate as much independence as possible.

Theme 2: Reliance on help

Frailty was recognized as a state of dependence and risk of institutionalization;

It's just when you're used to doing everything yourself... And you got to depend on people. That's when it gets you (Patient 11)

Well, I've known a lot of older people that have been definitely frail, and I mean frail, like, a battle to even eat their own meals. No, I'm not that bad yet, but I can see myself getting like that. I – I – I dread the day that I have to go into an old people's home. (Patient 2)

Participants with frailty expressed their discomfort with reliance on help or equipment;

Terrible, I hate, you know, getting anyone to help me, because I've been independent all me [sic] life. You – you had to be when you're in the bush. (Patient 2)

I don't really like using it [my four-wheeled walker]...it's like I'm admitting I'm too old, or, or whatever, I, I don't know. (Patient 11)

Progression of frailty was understood as greater reliance on medical equipment;

At times like, I shower, go to get dressed and I'll feel like I need to be on oxygen (Patient 6)

Equally, participants perceived improvement when they became less reliant on available equipment;

So I just use the wheelie walker for that. I haven't used – I've got a scooter, a motorized scooter, but I don't know the last time I used that. (Patient 1)

Other participants celebrated the functional independence made possible by provision of appropriate equipment;

I've had a chair lift put in, and I've got a bed – the bed cost \$8,000. It's an adjustable bed, do you know the ones that you have in hospital? Yeah, it – it can do everything but mow the lawn. (Patient 2)

Frailty was defined as a dependence upon caregivers for help and the imposition of caregiver burden;

I don't necessarily want my problems to become other people's problems...You don't want to be the thing holding others back. (Patient 7)

Patients, too, had caregiving experiences and reflected on the impact of frailty on relationships, acknowledging caregiver stress and disrupted relationship dynamics;

My dad had had a stroke... He wasn't coping with the situation he was in... and my Mum was very arthritic, so she was an invalid. And, um, so frailty there for me meant if one more thing happened, I thought I would shatter into a million pieces. (Patient 3)

Other caregivers revealed the loss of equality in a marital dyad as the roles of patient and caregiver became entrenched;

Because in our relationship it's always been equal... Not any more (Caregiver 3)

Other participants reported a greater sense of appreciation for family bonds and the support they received during periods of poor health, describing a transposition of usual child-parent dynamics;

Well, my daughter was wonderful, my son and his family are wonderful, and they just kept keeping on. And I just took baby steps... (Patient 3)

Theme 3: Frailty as a dynamic state and experiences of transitions in frailty

Frailty was perceived as a dynamic state that could be overcome by rest and rehabilitation;

Frailty for me was in this time, was would I ever wake up and feel like I was alive. Because I felt so exhausted and weak and empty that I didn't know if I was ever going to get past that feeling... And I just took baby steps...One day would be good, the next day wouldn't, and so on. And one week would be better, then the next one wouldn't be so good. So, I just took time. I just had to just rest and take the time... (Patient 3).

Recovery from states of greater frailty was associated with a sense of optimism and hope for the future;

Well, in 2021 I didn't know whether I'd make it to 2022. Then 2022, at the beginning of [20]22 I was very, very fragile and unwell... so as it has progressed to where I am now, I'm quite quietly sort of excited that I might have a bit longer to live... (Patient 3)

Caregivers too, commented on the changeable and unpredictable nature of witnessed frailty;

I mean, she does surprise me sometimes, but um, when she's quite tired she does – I do see her as very frail. Um, but otherwise she's, she's not too bad, you know. I guess for me there's a frail scale... Most days she's on the lower end of the scale. Um, other days she, you know, does climb up the scale for weeks. (Caregiver 2)

Uncertainty linked to changes in health conditions was expressed as an externalization of the self and disengagement from health-seeking behaviors. Participant's use of language suggested frailty and comorbidity were experienced as a bystander to their own health, expressing a sense of bewilderment at medical events and complications, "Well apparently, I've got emphysema... They tell me I had three heart attacks" (Patient 11). Participants reported a sense of frustration accompanied by anxiety due to their physical limitations and foreboding that accompanied every medical interaction;

When I have an appointment at the hospital, you know, like I'll always bring, um, an overnight bag in case they tell me, oh, look, you're gonna have to go to the emergency... You know, in the back of my mind, it's always playing that, I go to an appointment, they're gonna say, oh look, you're gonna have to go to emergency... and I think to myself, yeah, it becomes like a phobia. But, but then I think maybe... if your general health is a lot better, then maybe

those sort of things start reducing and, you know, the prospects are having to be admitted is, uh, reduced. (Patient 7)

Theme 4: Non-routine recovery

Frailty was described as frequent experiences with non-routine recovery and disrupted recuperation;

I noticed recently, like, um, this might be a personal thing for me, but I find when I get sick it seems to take me longer to recover... And also when I do recover, I don't feel as though I'm getting back to where I actually was before I got sick. So let's say before I got sick I was at 100 per cent. I find I get back to maybe 85, 90. I don't quite get back to where I was. And progressively as, you know, as the years continue, I tend to find that that same - so where I was say, uh, I don't know, say seven years ago where it might have been 100 per cent, now my 100 per cent is only about 80 or you know, it's not the same. (Patient 7)

It's taken me a long time to get well. (Patient 3)

Participants with frailty reported frequent hospitalizations and prolonged illness experiences;

It all seems [it] started in [20]21 when I had the UTI and the sepsis... And I've just not fully recovered from that. (Patient 6)

Frailty experiences were normalized and expectations were adjusted based on past experience;

I had the doctor come and have a look at it today, and he said it'll take about six weeks. I said, yeah, I know [laughs]. I'm a slow healer. (Patient 2)

Theme 5: The erosion of identity and enjoyment

Participants revealed that frailty eroded their identity and personhood;

You know, I used to love cooking. You know Lebanese people love cooking. Now, I say to my husband, you're gonna have boiled eggs or toast. I don't have energy to cook like before. I love cooking. Now, no. No energy. (Patient 9)

His boss even told him he was the fixer... Any problem that needed solving, they used to send [him] in... And he can't do that now, he can't think his way through anything. (Caregiver 3)

Gender identities appeared particularly vulnerable to disruption by frailty;

Caregiver: He was the one that did all - most of the driving. As you know husbands, you go in the car and - they're the ones that are doing the driving anyway. So um, and [frailty] has limited his life of what he could do previous. I'm the alpha now. (Caregiver 3)

Interviewer: You're the alpha. Okay. What does that mean?

Caregiver: I'm the one that's taking on all the responsibilities. [He] has always been the solid one that's there. Typical male, he could take on a lot more than I could... So we thought. (Caregiver 3)

I'm not being sexist here but at times it can be harder for a male to

ask for help. You probably wouldn't hear that often, but it's true. You know, males, they don't like asking for help. (Patient 7)

Participants defined frailty in association with lost enjoyment, describing a state of progressive deterioration and a condition to be endured. Frailty was experienced as sense of estrangement from one's own body;

In [his] words, he doesn't like what his body's doing to him. (Caregiver 3)

Frailty was frequently depicted as a prelude to death, with participants who underwent dialysis reporting on the "empty chair" phenomenon when co-patients with frailty failed to return for their next treatment.

I've gotta tell you, you go to dialysis and you see all these frail people in dialysis and you just get depressed. You're in there and you're like, oh my God, you know, everybody's like sick, right? And then you walk in one day and you go, oh, where's that person now? Unfortunately, he died. It's really sad, right? (Patient 8)

Participants reflected on their roles as caregivers or community volunteers to people with frailty and the death that subsequently followed. For several participants the experience of frailty prompted contemplation about end of life;

I think the worst part was they [the people with frailty] had to live so long... At least we are at an age where, I know I am, I'm not gonna live... Yeah, forever. (Patient 10)

Frailty was described as a state proximal to death.

I don't think he's failed... I think his body's just giving up the ghost (Caregiver 3)

Frailty was perceived as aligned with aging, and a prompt for palliative care:

I'm 73 and I've already said that if I get to 80 and I'm still alive, I'll be palliative. I don't want anything. (Patient 10)

Participants with frailty expressed a sense of disorientation imposed by their current and future health status;

That's been one of my hardest, um, challenges to overcome.... The - the future, what does it look like? (Patient 3)

Frailty introduced uncertainty about the future and focused attention on the immediacy of day-to-day struggles; "Therefore we just live day to day" (Caregiver 3).

Theme 6: Unresolved symptom burden

Frailty was associated with unresolved symptom burden, with participants reporting difficulty sleeping, disrupted circadian rhythm and prominent fatigue;

I've got very poor sleep habits... I find at times I can be lethargic, don't quite have the same amount of energy as I used to... I'm really tired all the time. (Patient 7)

I wanna do my housework, I wanna do this, I wanna do that. And

then I can't. I don't have enough hours and... after dialysis, I come home, and I'm just wrecked. (Patient 8)

Many participants experienced pain, reflecting the comorbid burden of kidney disease;

Well I've got triple whammy... [the dialysis], the diabetes affects my legs. So, there's gout. Walking is very difficult. (Patient 4)

In this study population, symptom clusters were common, contributing to poor endurance and strength;

Ten minutes and I'm buggered. You know, my legs are aching – get short of breath. (Patient 11)

Descriptions of distress were common with participants reporting past and ongoing suffering,

I'm still suffering, this shoulder still hurts. (Patient 8)

Symptom burden was normalized, frequently under-reported to clinicians and accepted;

I'm experiencing a lot of the symptoms that you have. Um, I've asked the nurses and apparently, it's part of the, um, part of the process, right? Um, the itchiness in your skin, um, is the phosphate levels are too high... And this is part of the process. (Patient 8)

Within the setting of the focus groups, shared symptoms became a source of camaraderie and relationship-building; 'I think, um, we might be twins [laughter]' (Patient 7).

Theme 7: A contracted social and geographic sphere

Frailty was associated with contracted social and geographic sphere with themes of captivity and confinement;

So I virtually became housebound (Patient 3)

[He] is basically a prisoner in his own home (Caregiver 3)

All you do is just move around, bounce off the walls 'round the house [laughs]. (Patient 4)

Participants reported on reduced participation in social activities as clinical burden eclipsed recreation;

My biggest outing is really my doctor's appointment. (Patient 10)

We don't go out like we used to like even to go for a meal or sit and have a coffee or something. Um, not much of an option at the moment either because he gets um, dizzy ah, um, uneasy on his feet. (Caregiver 3)

Frailty and comorbidity emerged as an alienating experience that disrupted social support;

We were the socialites, and we were out all the time, right? With a lot of people, traveling. Do you know now, these people don't even call. They're fair-weather friends. (Patient 8)

The built environment emerged as a determinant of life participation and social accessibility;

If there's no rails there, no go. No way in the world can I get down there" (Patient 2)

Participants who lived in regional areas reported on the threat of the once-familiar bush and natural environment;

Oh, I'd just love to be able to walk...properly over uneven ground. It's impossible. I'd like – I don't know if you've tried to walk through tussocks... pig tussocks, there's no way in the world can I walk through tussocks. Or on grass, because I trip over. (Patient 2)

Social isolation was linked with falls and vulnerability and the need to rely on strangers for assistance;

I've had this [motions to walking stick] for about three or four years, it's because I fell over in the walking park, and in the parking area, [coughs]... One night I fell over... Then I was lying there like a speedbump in the middle of the road and the people that come and pick me up, [laughs]... You know I couldn't even get up. (Patient 12)

Falls emerged as key frailty experiences that prompted recognition and identification with the frailty condition and heralded the introduction of frailty symbols such as walking aids, personal alarms, home modifications and caregivers.

Theme 8: Frailty and the mind-body continuum; mental aspects of frailty

Alongside social frailty participants reflected on mental frailty, reporting disturbed mood and poor mental health;

But I think this kidney, this kidney disease depletes you of a lot of things, right? Well, and I don't know whether it's only, um, psychological, right, but I don't know, it makes you - it makes you - you know you're ill, right? But it, it, it just plays on your brain all the time and it makes you angry... You just feel depressed. (Patient 8)

Participants reported on the mind-body continuum, emphasizing that the experience of frailty included mental aspects of poor mood and impaired cognition;

I think frail is just as much a mental issue as it is a physical one. (Patient 7)

Cognitive isn't great. Um, I'll have a conversation um, I'll get part way through it and lose my words. At least part way lose complete train of thought. I... I might get confused very easily. (Patient 6)

Participants and caregivers described strategies for maintaining mental wellness in the face of physical frailty, reporting on the importance of humor and optimism;

You had to be strongminded to just pace yourself and get through it. (Patient 3)

You just take help or medication what if we can and don't worry much about it because if you start getting mentally upset, it's even get [sic] worse. (Patient 4)

Topic guide is available in Supplemental Materials

Discussion

This study represents a unique insight into the lived experience of frailty in a CKD context, building upon a small body of literature exploring attitudes to frailty. Consistent with previous work in the US, UK, Canada and Netherlands settings [12-14, 33], we found that frailty carries negative connotations and prompts deeply held cultural stereotypes. Frailty was a pejorative term which was perceived as “unfair,” associated with suffering, people with frailty self-described the experience of being “in-valid,” “wrecked” or being a “speedbump” obstructing other people’s momentum. Frailty was found to be undesirable, linked to caregiver stress and burden and aligned with suffering and death. Frailty in the CKD context threatened personhood, associated with being “depleted” or a “shell” of a previous identity. Frailty disrupted social, marital and family relationships. Some participants indicated frailty was described as a return to a state of infantilism. Frailty and kidney disease collectively imposed social isolation, geographic contraction and frequent hospitalization. Participants associated frailty as an inevitable part of aging and illness while demonstrating knowledge of the relationships with malnutrition, sarcopenia and immobility. In contrast to previous qualitative work, our study reports on the widespread acceptance of the diagnosis, with most participants self-identifying as ‘frail’ and recognizing its implications [34]. Nevertheless, frailty screening was met with uncertainty and ambivalence, prioritizing their own, often pejorative definitions of frailty. In this cohort of participants with advanced CKD and Fried frailty phenotype, we encountered an openness to self-identification of frailty as well as discussing frailty, medical complexity and death, which contrasts to the experiences of other qualitative researchers [14, 34, 35]. This finding suggests that frailty screening approaches should incorporate self-assessment components.

While many frailty assessment tools such as the Fried frailty phenotype, Rockwood’s Clinical Frailty Scale and the Frailty Index emphasize the physical domains of frailty, the lived experience of frailty is marked by social and geographic exclusion. Participants and caregivers reflected on withdrawal from social events driven by misunderstanding, precluded by illness and inaccessibility. Environmental constraints also contributed, implying the public health responsibility to review and priorities a built environment that meets the needs of its aging population. In our metropolitan and regional setting, natural environments were reported to exacerbate frailty-driven inaccessibility and social isolation, contrasting to experiences of frailty in rural Thailand where natural environments were celebrated for their opportunity for recreation and social activity [36].

Frailty was described as dynamic and often unpredictable, exacerbated by, or linked to a specific health event, and capable of crossing a critical threshold of irreversibility. Frailty was experienced as an abrupt and volatile change in health status that disrupted understanding of health and the body and demanding increased reliance on health resources and support systems. Not all participants reported progressive decline and several reported

experiences of increased capacity from a previously poorer state of health. Overall, frailty was conceptualized as a state of vulnerability characterized by falls, frequent hospitalization and delayed recovery. Furthermore, frailty recovery and rehabilitation were envisioned and anticipated. This contrasts to the more nihilistic attitudes of practitioners who question the reversibility of frailty in this patient population [37]. Frailty prompted consideration of mortality and death, but also was aligned with self-care and forbearance. In common with other reports, we found participants identified with the diagnosis of frailty but enlisted extended resources including family support and disability aids to accommodate functional limitations into new ways of managing daily living [11]. We found that independence and adaptations in activities of daily living challenge the diagnosis of frailty and offer resilience against functional dependence [27]. As reported by Skilbeck and colleagues, sustaining daily routines while renegotiating activities and priorities emerges as an exercise in personal agency [11]. This work confirms that meaningful frailty assessments must capture the positive and diverse ways in which patients with frailty operate their daily activities and self-care to optimize integrated care and support [11].

In our study falls were described as key frailty indicators, associated with contact with emergency services and hospitalization events, reliance on assistance and marking transitions in care. Participants described the sense of loneliness and vulnerability associated with a fall and, frequently, the inability to recover to the functional ability enjoyed before a fall. Falls contributed to avoidant behaviors including contracted social and geographic activity, which compounded the multidomain experience of frailty. It is notable that few of the frailty assessment tools available assess falls, but experienced clinicians from all disciplines identify falls as one of the most accessible and reliable indicators of frailty status [38]. Recent scoping review identifies that this frailty metric is highly valued by clinicians, but is frequently under-reported or dismissed by patients who appear to normalize falls within the frailty experience [3].

Importantly this study also emphasizes the significant symptom burden associated with CKD and ESKD and how this interacts with frailty. Participants frequently reported symptom burden as “part of the process” demonstrating a resignation to a poorer state of health and wellbeing. First described by Nixon and colleagues, there is an emerging recognition that frailty in CKD predicts high symptom burden well beyond that explained by differences in renal function and comorbidity [39]. Following on from this work, we also identified the frailty-related symptom cluster of breathlessness, loss of muscle strength and endurance, sleep disturbance and poor concentration. We propose that reports of symptom burden and particularly dyspnea/sleep disturbance/weakness/fatigue should prompt clinicians to assess for frailty and review care needs. Several participants reported reduced quality of life and ambivalence about the future, expressing both relief at “not living forever” with frailty/CKD as well as a state of critical indecision regarding future planning. Our findings indicate that

the dynamic and unpredictable character of frailty is a disruptive force, that can act to undermine advance care planning efforts and effective decision-making, as has been reported elsewhere[40]. In line with recognizing symptoms of frailty, our study identifies quality of life priorities for patients with frailty and CKD including life participation and energy, but also sleep and pain management. Participants reported common experiences of social isolation and diminished mental health. Within the dynamics of focus group discussion, we observed the value of shared experience and camaraderie made possible through peer-to-peer support. Effective interventions in the frailty and CKD space must prioritize social support and mental health care, offering social participation and psychological intervention for optimal wellbeing alongside medical management of uraemia.

This study also offers valuable insights into the unpaid and under-valued role of caregivers to participants with frailty/CKD. Caregivers act as brokers for healthcare access, promoting autonomy and sustaining community living. It is clear, however, that such support comes at great cost to the caregiver themselves, threatening marital and relationship dynamics as well as caregiver wellbeing. Effective interventions for frailty must acknowledge caregiver burden and provide tangible support to all members of the patient-caregiver dyad.

Nevertheless, the most important informational need for this patient population is around education about frailty and effective interventions for its management. Participants engaged with frailty assessment and discussion, demonstrating some knowledge about frailty mechanisms, but expressed knowledge gaps about frailty management. “Resting” and “accepting one’s limitations” emerged as the most frequently employed strategies in the face of frailty, indicating a poor understanding of the threat of physical inactivity and the potential of graduated physical activity and rehabilitation possibilities. Further work in this field should leverage consumer participation to explore participant preferences for rehabilitation and exercise approaches. Successful interventions for frailty are not only likely to be extended in duration [17], but individualized around dialysis and clinic burden as well as being multidisciplinary in nature, addressing informational, social and psychological needs.

There are acknowledged limitations to this study. Primary investigator AK is a member of staff at the research setting and thus shares a clinical relationship with some of the participants, through either nephrology clinics, inpatient encounters or Renal Supportive Care work. This may have influenced the participants’ willingness to disclose and/or discuss frailty and end of life care, accounting for some of the difference observed in other qualitative studies wherein participants generally rejected the frailty label. We also note that the methodology focused on enrolling participants with established frailty to offer a data-rich report of the lived experience, in recognition that participants with frailty are more receptive to discussing frailty than their non-frail counterparts, which may also account for this observed difference [14]. In addition, all three qualitative researchers AK, SR and KH are female and this may account for some of the gendered experiences disclosed, as has

been proposed by Beckwith and colleagues in their exploration of gender differences in experiences of hemodialysis in a similarly frail population [41]. Strengths of this study include its recruitment frame within a diverse and representative metropolitan/regional hospital setting, offering external validity. We were able to capture not only the lived experience of frailty as reported by patients, but also to examine the caregiver experience. Our focus group discussions created opportunity for peer-to-peer interactions and social learning. Taken together, these caregiver and patient perspectives draw attention to the socioeconomic determinants of health, the need to promote peer relationships and to scaffold health and wellbeing with adequate, consumer-informed support.

To our knowledge, this is the only existing study to describe the CKD experience of frailty. Our study conceptualizes frailty as a psycho-emotional-social experience that interacts with the physical manifestations of frailty and uraemia. We describe a prominent symptom burden and recognized symptom clusters, along with notably increased health care utilization patterns, with implications for health care planning. Nevertheless, the lived experience of frailty/CKD is imbued with a sense of optimism and resilience, which appears to contrast significantly to healthcare providers’ attitudes to frailty/CKD. Frailty screening emerges as an acceptable endeavor that should be accompanied by opportunities for self-identification in recognition of the resilience and adaptation strategies utilized by individuals living with frailty.

Conclusions

This study explores the views and experiences of people living with advanced CKD and frailty, offering insight into the social and psychological aspects of frailty, unresolved symptom burden and considerable caregiver burden associated with this state. Participants emphasized the dynamic experience of frailty and expressed expectations of improvement with appropriate time and care, in contrast to dominant clinical narratives of frailty. The opposite of frailty – resilience – emerges as a process of effectively negotiating, adapting to or managing significant illness and stress to “bounce back” in the face of adversity and reflects multidomain resources including psychological, social and environmental. There is ongoing tension between participants’ negative connotations associated with frailty and its clinical utility as a concept to open communication to future planning and care scaffolding. Sensitive discussion of frailty should explore the social determinants of health and acknowledge the considerable personal resources invested in its management.

Declarations

Ethics Approval was provided by The Australian National University and The Canberra Hospital Human Research Ethics and Governance Office 2020.ETH.00038. All participants provided informed consent.

All authors provide consent for publication. Participants provided informed consent for de-identified consent to publication.

Data analysed during the current study are available from the corresponding author on reasonable request.

The authors declare that they have no competing interests.

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Author's contributions

AK is a PhD candidate undertaking a thesis exploring frailty in the chronic kidney disease context. AK devised the methodology and authored the ethics submission. AK conducted frailty screening, developed the Topic Guide, conducted the focus groups and interviews, performed the analysis and developed the codebook. AK authored the manuscript.

SR contributed to the methodology, supervised the focus group and interviews, contributed to the analysis and data interpretation and performed a coding query comparison. SR provided draft revision and approval for the final version for submission.

KH conducted frailty screening, contributed to the focus group and interviews, provided draft revision and approval for the final version for submission.

NG contributed to the methodology, provided draft revision and approval for the final version for submission.

KP contributed to the methodology and ethics submission, provided draft revision and approval for the final version for submission.

AD contributed to the methodology and ethics submission, provided draft revision and approval for the final version for submission.

GT contributed to the methodology and ethics submission, provided draft revision and approval for the final version for submission.

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Topic guide is available in Supplemental Materials

Supplemental Materials: Topic Guide

Experiences of frailty and reduced physical ability

- How do you feel about your current state of health or fitness?
- What does the word frail mean to you?
- What does a frail person look like to you?
- How has frailty influenced your activities?
- How has frailty influenced your decisions?
- How has frailty impacted your plans for the future?

Experiences of frailty screening

How do you feel about being assessed for frailty?

Prompts and invitations

- That's very helpful, thank you
- You've given me a lot of good information there.
- I appreciate your willingness to share your experience. Every experience is unique and we've heard all kinds of things. There's no wrong or right answer to any of these questions. What matters is that it's your experience.
- It would be helpful to hear more about that.
- I can see that questions brings strong emotions. Take your time, or if you'd like we can change topics and come back to this later.

Signaling transitions

Thank you for your thoughts about..., let's talk now about ...