

Kidney360

Photovoice to Explore the Lived Environment and Experience of Adults with Frailty on a Kidney Transplant Journey --Manuscript Draft--

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Abstract:	<p>Background: Older adults with frailty and kidney failure face higher waitlist mortality and are more likely to be listed as inactive on the kidney transplant (KT) wait list. Photovoice is a qualitative participatory research method where participants use photographs to represent their environment, needs and experiences. It offers unique insight into the lived environment and experience of patients and may offer direction in how to improve functional independence, symptom burden, and kidney transplant outcomes in adults with frailty.</p> <p>Methods: This photovoice study was embedded within a larger intervention adaptation project. Participants with pre-frailty or frailty awaiting a KT or recently post-transplant took photos with Polaroid cameras and wrote short descriptions for 11 prompts. Each participant completed a semi-structured interview wherein their photos were discussed. The team coded and discussed photos and interviews to determine overarching themes and implications. Focus groups were used to triangulate visual data findings.</p> <p>Results: Sixteen participants completed both the photovoice and interview. Participants were a mean age of 60.5 years, 31.2% female, 43.4% self-identifying as Black, and 69% were frail. Outcomes were categorized into seven themes: functional space, home safety, medication management, adaptive coping, life changing nature of dialysis, support and communication. Visual data clarified and sometimes changed the interpretations of the text alone. Especially within the themes of home safety and functional space, safety hazards not previously recognized in the literature, like dialysis fluid storage, were identified.</p> <p>Conclusions: Photovoice contextualizes the living conditions and experiences of adults with frailty on the kidney transplant journey and could be a useful tool in geriatric nephrology and transplant. Addressing issues of home storage, organization, and accessibility should be explored as potential intervention targets. Incorporating participant values and goals into care decisions and interventional design should be further explored.</p>	
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Title: Using Photovoice to Explore the Lived Environment and Experience of Older Adults with Frailty on their Kidney Transplant Journey

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ABSTRACT

Background: Older adults with frailty and kidney failure face higher waitlist mortality and are more likely to be listed as inactive on the kidney transplant (KT) wait list. Photovoice is a qualitative participatory research method where participants use photographs to represent their environment, needs and experiences. It offers unique insight into the lived environment and experience of patients and may offer direction in how to improve functional independence, symptom burden, and kidney transplant outcomes in adults with frailty.

Methods: This photovoice study was embedded within a larger intervention adaptation project. Participants with pre-frailty or frailty awaiting a KT or recently post-transplant took photos with Polaroid cameras and wrote short descriptions for 11 prompts. Each participant completed a semi-structured interview wherein their photos were discussed. The team coded and discussed photos and interviews to determine overarching themes and implications. Focus groups were used to triangulate visual data findings.

Results: Sixteen participants completed both the photovoice and interview. Participants were a mean age of 60.5 years, 31.2% female, 43.4% self-identifying as Black, and 69% were frail. Outcomes were categorized into seven themes: functional space, home safety, medication management, adaptive coping, life changing nature of dialysis, support and communication.

Visual data clarified and sometimes changed the interpretations of the text alone. Especially within the themes of home safety and functional space, safety hazards not previously recognized in the literature, like dialysis fluid storage, were identified.

Conclusions: Photovoice contextualizes the living conditions and experiences of adults with frailty on the kidney transplant journey and could be a useful tool in geriatric nephrology and transplant. Addressing issues of home storage, organization, and accessibility should be explored as potential intervention targets. Incorporating participant values and goals into care decisions and interventional design should be further explored.

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INTRODUCTION

Over 700,000 Americans live with kidney failure, disproportionately affecting older adults.¹ Rates of kidney transplant (KT), the preferred treatment for kidney failure, have risen 5-fold for older adults since 1990 but outcomes vary.² Older adults are more likely to be listed as inactive on the KT waitlist, which is associated with a 2.2-fold increased risk of waitlist mortality.³

Symptom burden and functional status impact kidney transplant morbidity and mortality. High symptom burden increases the risk of waitlist mortality⁴ while maintaining functional independence lowers it.⁵ Additionally, frailty, which is associated with aging and defined as a syndrome of decreased physiological reserve,⁶ is an independent risk factor for KT waitlist mortality, increased health-care utilization and death after transplantation.^{7,8}

Exploring environmental factors may inform interventions to reduce waitlist mortality. One novel method to explore factors influencing the kidney transplant experience is photovoice - an empowerment qualitative research method that enables people to capture and reflect on their environment.^{9,10} (Figure 1.) This approach is successfully used in work with older adults^{11,12} and those with kidney disease.^{13,14} While qualitative studies of kidney transplant often focus on the internal psychological experiences¹⁵; photovoice expands this perspective to include the experience of one's lived environment, providing specific visual insight into the person-environment fit and constructing a 'day in the life' of these participants as a further way to elucidate the community needs.¹⁶⁻¹⁸ Guided by Social Cognitive Theory which posits that human functioning is a dynamic interplay between personal, behavioral and environmental factors^{19,20}, we used a phenomenological lens and the participatory nature of photovoice to empower participants to document images that represent their community. In this case, the 'community' is

individuals on the kidney transplant journey who are trying to stay active on the waitlist.

Therefore, the purpose of this paper was two-fold: (1) to use photovoice to explore the lived environment and experience of those with frailty on the kidney transplant journey to adapt a person-environment intervention to reduce inactive status and improve quality of life and (2) to highlight the use of visual data in the intervention adaptation process.

METHODS

Design and Recruitment

This photovoice study was embedded within a human centered design research project to adapt an existing person-environment intervention to the kidney transplant waitlist community. The entire research team received 2-3 trainings on the use of photovoice, especially as a way to describe one's home environment. Recruitment was nested within an existing NIA-funded longitudinal cohort study located at Johns Hopkins University (FAIR Cohort study; PI: McAdams-DeMarco), which examines physical frailty among KT candidates and recipients. The FAIR Cohort study has enrolled over 3,800 people evaluated for KT since 2010. For the photovoice study, we recruited individuals via telephone and used purposive sampling to ensure representation by physical frailty status (frailty and pre-frailty), waitlist status (inactive and active) and transplant stage (pre and post-transplant). During the initial pre-screening, the purpose of the study and the use of photos as a part of that was explained to the participants. Telephone consents were obtained, followed by formal, written consents when the research team dropped off the cameras that detailed the study process and procedures. A specific check box and signature within the consent form was included to use photographs and audio recordings from the project. An additional University specific photo release consent was also obtained to include specific photos in research-related presentations and publications. This study was approved by

the Johns Hopkins Institutional Review Board (IRB#00298781). For confidentiality, each participant was assigned a unique identifier that was only linked to their name on a password protected and encrypted server. Inclusion criteria included being pre-frail or frail at KT evaluation, as defined by the physical frail phenotype.⁶ We had no specific exclusion criteria. In particular, age was not a part of our exclusion criteria because of the accelerated aging trajectory present in advanced kidney disease.^{21,22}

Materials

The photovoice journal was developed by requesting participants take photos related to various topics (Table 1) and provide short written descriptions to accompany each photo. Topics were chosen by the research team with the particular intention of adapting a person-environment person-directed intervention to take place in the home. To ensure accessibility and ease of use, Polaroid cameras were provided to participants in lieu of their personal cameras. This approach aligned with established photovoice methodologies and facilitated the process for participants.⁹ The photojournals and consent forms were stored in locked containers at the University.

Process and Procedure

Phase I. Following consent from December 2021-June 2022, participants were contacted by a research team member to schedule a time to drop off photovoice materials. Upon arrival, the research team instructed participants on how to use the provided journal prompts as a guide to create their photovoice journal, some of the prompts were more concrete (e.g. concerning medications) and some were more abstract (e.g. concerning motivation). We had no parameters about how the participants decided what image to share for each prompt as we wanted their interpretation. Staff demonstrated proper use of the Polaroid camera to ensure participants could effectively capture their images and had participants demonstrate back.

Approximately two to six weeks following the initial drop-off of materials, participants were contacted to schedule a time for pick-up. Photovoice journals were scanned and uploaded for data analysis.

Phase II. Following completion of the photovoice journal, participants were mailed a photocopy of their journal and contacted to discuss their photos over the phone using a semi-structured interview guide. Interviews were conducted by MDH and MS, both trained in qualitative interview techniques, and were 30 -60 minutes long. Rapport with the interviewer was formed during the preparation and arrangement for the interview. Interviews helped to ensure that the interpretation of the photos were from the participant perspective. One example of a question asked was: *“Tell me in your own way about the photos you have taken and why you took them.”* We talked through each photo and ended each interview with the open-ended question: *“Is there anything else you would like to share with me about these photos or your experience.”* We also interviewed 4 people who were unable to complete the photovoice journal because they were too unwell (N=3) or found technology difficult (N=1).

Phase III. Two focus groups were convened in July 2022 including participants from Phases I & II as well as transplant community leaders, clinicians and caregivers. For the photovoice part of this project, the focus groups served to (1) review data collected (e.g. photos, interviews) and (2) ensure that data sufficiency was achieved to answer our research question.^{23,24}

Data Analysis

The interviews were transcribed verbatim using a professional transcription service and paired with the photovoice narrative. Interview data surrounding completed photovoice journals were examined using F4 Analyse data analysis software (audiotranskription.de, Marburg,

Germany). Transcripts were stored on a password protected encrypted server. They were independently coded by one coder, a doctoral-level nurse trained in qualitative methods and analysis including photovoice but without specialized experience of Kidney transplant patients. A second coder, a doctoral-level researcher-clinician with expertise in kidney disease, gerontology, and qualitative analysis, verified findings for 20% of interviews.²⁵ A data-driven thematic approach was used whereby a-priori codes were first identified by the team based on literature review and experience.²⁶ Then the first and second coder independently coded randomly chosen interviews working to identify themes, meeting to discuss emerging themes and compare experiences of reading the data. Memos of meetings were kept as part of an audit trail. The primary coder then continued to code bringing memos to monthly research team meetings.

Three team members (MDH, KK, KM) individually coded each photo for content. The research team then worked together comparing the photos and photo texts from participants, iteratively organizing themes and concepts that emerged from the combined narratives using an open coding technique to understand the lived environment and lived experience of the kidney transplant journey.²⁷ In this way the research team was able to: 1. generate knowledge about the lived environment and experience, and 2. identify areas that may be amenable to intervention to help participants on the kidney transplant journey. Themes identified through the visual data and interviews were then presented in focus groups to validate findings. This triangulation of data²⁸ (photos, semi-structured interviews and focus groups) gave us confidence that interpretation of the data was participant focused, minimizing bias from the research team.

RESULTS

Participant Demographics

A total of twenty-nine participants were recruited for the study, out of which sixteen completed both photovoice journals and subsequent interviews. Four completed interviews without photovoice journals due to illness or technology challenges. Of the 16 who completed the photo journals and interviews, the majority were self-identifying as Black persons (43.4%). The mean age of the participants was 60.5 years. Half were active on the waitlist (50%), most were frail (68.8%), most lived with a family member (62.5%) and most received dialysis at a center (56.25%). (Table 2.)

Participant Images and Logs

The participants provided a range of visual images encompassing different domains, including the home environment (i.e. stairs, home organization), items essential for medical management (i.e. dialysis machines, medications, mobility), support systems (i.e. family and healthcare workers), communication (i.e. with medical teams) as well as more abstract images related to their journey awaiting kidney transplant. The visual data could be categorized into seven themes: (1) functional space, (2) home safety, (3) medication management, (4) the life changing nature of dialysis, (5) adaptive and futuristic coping, (6) support and (7) communication. Figure 2 depicts our themes within the context of the Social Cognitive Theory framework. Within these themes, the photos added depth to the accompanying written statement. In some instances, a photo significantly clarified the accompanying statements and in other instances, the photo completely changed the interpretation of the written statement for the research team.

[Insert Figure 2.]

Participants identified difficulty with physical function within their homes and described ways they had attempted to overcome these functional limitations. They discussed adaptive equipment, storage, and organization challenges. The photo narratives that follow are representations of our findings.

Theme 1. (Figure 3A). Functional Space: Desk on Dresser

“This workspace... gives me all I need to, if I need to communicate or read/ exchange quickly via e-mail or MyChart with transplant team.” CKT004

This photo shows a computer workstation. The accompanying narrative reveals a participant who is actively involved with their care team and care plan. Examining this photo from a functional perspective, however, there are ergonomic improvements that could be made to facilitate optimal use by the participant who struggled with functional limitations.

Theme 2. (Figure 3B). Home Safety: The Grab Bar Example

“I am able to bathe by using hand grip to enter/exit shower and sit w/ bath seat.” CKT007

Grab bars and shower seats are very helpful functional tools for bathroom safety. This photo reveals the participant’s agency in creating a safer bathroom without the additional costs incurred from a professional service installation or remodel. This photo also showcases, however, a suction cup grab bar. This type of grab bar is known to loosen over time, creating an increasing fall risk.^{29,30}

Theme 2. (Figure 3C). Home Safety: Storage

“These photographs show how my environment has been affected [sic] by peritoneal dialysis. The hallway outside my bedroom is used to store about forty boxes of dialysis solution and peritoneal dialysis supplies each month...When I have my transplant, I’ll have more room.” CKT004.

This photo reveals another potential safety hazard of boxes piled high in a hallway. This statement also shows this participant's future coping focus. The focus is not on the boxes, but on the end goal of a kidney transplant to emotionally cope with the current storage problem.

The participant further explained about the storage issue: "And we try to keep it close-by, because the bags, well, for a 74-- I mean 73-year-old gets kind of heavy, so when it comes to that we'll maybe need some type of way-- a little roller cart-- what you call those things?-- that you can carry it and not have to lift it, ... Yeah. You just have to know how to store it, organize it and then use it."

Regarding a photo of boxes stacked in their living room, another participant stated "When guests come over they are bewildered by the supplies - its so much they are stored in the dining room. One man asked me if it was food for a special diet. Another woman asked when was I moving. So, having guests over can make for some awkward conversations. Most of my friends don't get it - at all. Nobody knows the trouble I've seen - nobody knows but Jesus, my wife, my parents, and doctors and nurses. Everyone else - clueless."

Two insights emerged from this photo narrative – the storage of supplies is not only a potential safety hazard but also elicits an emotional response and need for constant problem-solving.

Theme 3. (Figure 3D), Medication Management

"I take 15 medications on a daily basis, some in morning, some at night." CKT026

This photo reveals the large number of medications taken by this participant. It provides more than numeric data, however, showcasing another opportunity to create a more functional way for medication to be stored and dispensed.

Within the of “Lived Experience”, there were particularly salient images around participant values, the life-altering nature of dialysis treatment, and the integral role of effective coping strategies.

[Insert Figure 3 A-D]

Theme 4. (Figure 4A). Life Changing Nature of Dialysis

“I remember how it was to be free of the dialysis machine [before starting dialysis]. Being able to go places with no time restrictions. So, I always keep up my doctor’s appointments to make sure I’m on the active list. Most of all I want to be free of the machine [home dialysis].” CKT21

This photo shows the dialysis machine as the center of the photo, yet still at a distance representing this complex dynamic; the dialysis machine is central, but the photographer chooses to stay far away when capturing this image. The photo and quote recognize the life-saving necessity of dialysis therapy but also the demands that dialysis places on time, freedom and symptom burden.³¹

Theme 5. (Figure 4B). Adaptive Coping

"I enjoy listening to jazz so I decided to learn how to play a sax. When I need to think I play the sax." (CKT10)

In this photo, the saxophone is placed next to the dialysis machine but is at the center of the photo. When interviewed and asked to elaborate on this photo, the participant described how despite the problems and limitations of being a dialysis patient, taking on the challenge of learning how to play the sax was a demonstration of determination: “I vowed to never quit. Just never quit. If you say I can’t do it, I will prove to you that I can”. “Sax playing is tough but it’s

fun”. Many of the photos and photo narratives showcased the agency and adaptive capacity of these participants. Photos of teacups, walking trails, and flowers were all sources of coping.

Theme 6. (Figure 4C). Support

Responding to the photo journal prompt: “How confident are you in your ability to stay active on the transplant waitlist?” This participant responded: “Very confident . . . I have faith that one day I will receive the life-saving organ I need.” (CKT028)

This photo and photo narrative gives us insight into this participant’s futuristic coping ability. It also shows us how faith helped to support the participant and was an active part of their internal support. For many in our sample, faith played a vital *coping* role as well as a vital *social support* role that both practically and emotionally aided the participant. Many photos also showcased family members, dialysis or other health care team members as integral parts of their support network.

Theme 7 (Figure 4D). Communication

“Trying to communicate with my healthcare providers is like watching paint dry on the walls. Some days it was quick to get through, while other days it was a hassle to get through.” (CKT015)

Communication with the healthcare team was a source of support for some participants and a source of challenge for others. Understanding the emotional toll that communication difficulties can create is important to developing strategies to mitigate these challenges and improve patient-provider interactions.

Additional or Absence of Photos

It is important to note the absence or omission of some pages and responses. In our sample, individuals who expressed greater loneliness often lacked photos of peer or family support, for example.

Discussion

Photovoice proved to be a valuable method for gaining unique insights into both the lived environment and lived experience of people on a kidney transplant journey. Some photos clarified and reinforced the written statements. Other photos changed the interpretation of the written statement for the research team. In each example, the photo provided needed contextualization (compared to the words alone) to further understand the physical environment and represented numerous intervention opportunities to address these barriers.

Seeing the tower of dialysis fluid boxes for home hemodialysis, for example, challenges the traditional medical definition of success with regards to dialysis supplies. The high stacking of heavy boxes in a small hallway is a potential safety hazard. From the provider perspective, having the fluid successfully *delivered* to the home often defines success. However, the photos from our study challenge this notion, urging providers to expand their definition of success to include *how* the medical supplies are being stored within the home.

Another salient example is that of the suction cup grab bar. The participant clearly demonstrated agency to create a safer functioning bathroom, especially in the midst of debilitating fatigue and post-dialysis hypotension. The research team would have thought the bathroom was safe with the verbal endorsement of a grab bar, had the photo not been available. The photo provided additional necessary information to assess the safety of this bathroom and potentially offer safer alternatives.

Both of these examples speak to the larger issue of function. Older adults awaiting kidney transplant routinely have functional limitations. As a result, creating a safe space to live in is even more important for this group. This involves the intersection of geriatric and nephrology care, compelling us to take into account the environment within which these patients are living as a necessary part of holistic patient care. Along with home safety, home organization and ergonomic principles could also allow the home environment to function better with the potential of improving patient outcomes and quality of life.

This work informs research and intervention design focusing on the person-environment paradigm. One such intervention, known as Community Aging in Place, Advancing Better Living for Elders (CAPABLE), utilized a patient-directed approach and the skills of a nurse, occupational therapist and handy worker, which successfully led to improvements in disability, depressive symptoms, and pain, along with significant decreases in healthcare utilization in a sample of low-income older adults with multimorbidity^{32,33} and was successfully piloted in a home hemodialysis sample as well.³⁴ CAPABLE is currently implemented in 23 States and 43 sites nationwide. A CAPABLE adaptation may prove to be beneficial in this population and could function as a holistic type of prehabilitation.^{35,36}

Photovoice also showcased the adaptability and creativity of this group. It elicited emotions, motivations and feelings around faith, trust, hope, despair, fatigue among others which are consistent with other research findings.^{15,37} Generally, this group exemplified a keen ability to find meaning, joy and growth potential in their lives, specifically within their social networks and spiritual practices.

Our data, however, suggest that there is room for further development of best practices specifically around healthcare communication, consistent with other findings.³⁸ The photo of the

paint can (Figure 4D), for example, denotes the time needed for the paint to dry, much like the waiting needed to have a conversation with one's healthcare team. It also reminds us of the multiple paint layers needed to paint a room, similar to the multiple layers of healthcare information that need to be conveyed accurately to facilitate understanding. We recommend that communication techniques build upon the deep wells of personal values, meaning and goals that give this group strength to face the physical, emotional and mental challenges of dialysis.

These insights speak to the foundational importance for clinicians and research teams to incorporate patient values and goals into medical decision-making and holistic behavior change work. It requires clinicians and researchers to reach beyond the typical metrics we use as outcomes and standard of care to become truly patient-goal directed, tapping into the wealth of personal goals and values as motivational aides in the kidney transplant journey. This technique has been widely used in geriatrics and could offer value in the advanced kidney disease community as well.³⁹⁻⁴²

Another insight gained from photovoice is the power given to the participant not to provide a photo for a topic. When asked about this phenomenon, some people said they were tired, others said that they didn't have anything to say or didn't know what to photograph for it. In some instances, the absence of a photo corresponded with an absence or lack of that resource in the person's life. For example, most people provided photos of the people supporting them to depict their social support. When no photo was reported for that prompt, it was common that other prompts showed a sense of loneliness and isolation. In this case, not providing a photo also gave additional information.

We also endorse some limitations of this research. Four participants (all of whom were frail) were not able to use the camera. However, they were able to participate in the follow up

interview so that we could ask them what they would have taken a photo of and why. We had an attrition rate of 9 participants. Using a camera requires a certain amount of time, reflection and skill that can be difficult for a chronically ill or frail population, potentially introducing selection bias in the representation of the photographs.

Conclusion

In a time where contextualization and social determinants of health are being increasingly recognized as essential to proper and comprehensive care, photovoice offers a tool to empower the patient in this journey of communication and advocacy. Photovoice encourages the clinician and research community to consider the importance of the functional and lived environment as an essential assessment need in this community. In a novel way, photovoice also identifies numerous barriers that could be intervened upon to create better outcomes. It additionally encourages clinicians and researchers to consider the use of patient-directed goals in care delivery and research interventions.

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Table 1. Photovoice Topics
1. Difficulty with Physical Function
2. Environment
3. Pain
4. Mood
5. Medications
6. Healthcare Provider/Transplant Center Communication
7. Relationships and Social Support
8. Confidence in Staying Active on the Waitlist
9. Barriers to Staying Active While Waiting
10. Motivators to Staying Active While Waiting
11. Other Thoughts

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Table 2. Sample Demographics

	Total Sample (N=29)	Photovoice + Interview* (N=16)	Interview Only (N=4)	Withdrawn (N=9)
Age ¹ , mean (SD)	60.72 (12.76)	60.5	66.75	58.4
Sex (n, %)				
Male	17 (58.6)	11 (68.8)	0 (0)	6 (66.7)
Female	12 (41.4)	5 (31.2)	4 (100)	3 (33.3)
Race/ Ethnicity (n, %)				
Black	18 (62.1)	7 (43.4)	4 (100)	7 (77.8)
Hispanic	2 (6.9)	2 (12.5)	0 (0)	0 (0)
White	7 (24.1)	6 (37.5)	0 (0)	1 (11.1)
Other	2 (6.9)	1 (6.6)	0 (0)	1 (11.1)
KT Waitlist Status (n,%)				
Inactive	11 (37.9)	4 (25)	2 (50)	6 (66.7)
Active	11 (37.9)	8 (50)	1 (25)	2 (22.2)
Post-KT	7 (24.2)	4 (25)	1 (25)	1 (11.1)
Frailty Status (n,%) ²				
Frail	13 (44.8)	11 (68.8)	4 (100)	4 (44.4)
Pre-Frail	16 (55.2)	5 (31.2)	0 (0)	5 (55.6)
Dialysis Modality (n, %)				
Dialysis Center	16 (55.2)	9 (56.25)	3 (75)	4 (45)
Home (peritoneal or hemodialysis)	7 (24.1)	6 (37.5)	1 (25)	0
None	2 (7)	1 (6.25)	0 (0)	1 (10)
Not disclosed	4 (13.7)	0 (0)	0 (0)	4 (45)
Living Situation (n, %)				
alone	8 (28)	6 (37.5)	2 (50)	0 (0)
with family member	12 (41.3)	10 (62.5)	2 (50)	0 (0)
Unknown	9 (31)	0 (0)	0 (0)	9 (100)

Notes. KT: Kidney Transplant, SD: Standard Deviation

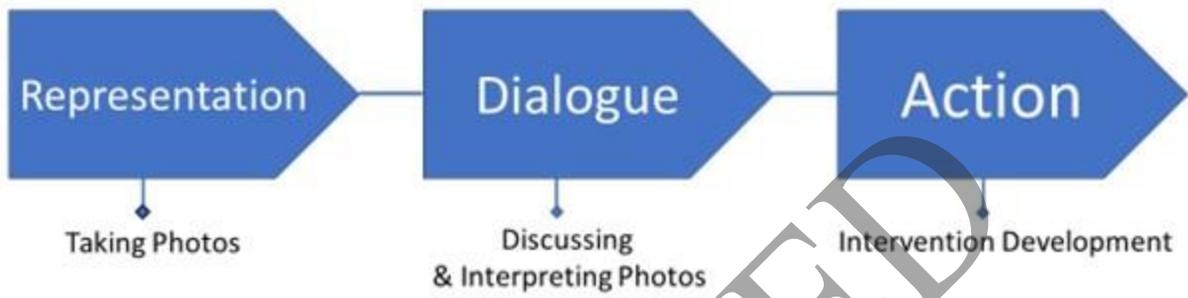
*Reported sample for this paper

¹Age when first listed for KT

²Pre-kidney transplant assessment of frailty status

Figure 1. Photovoice Conceptual Framework

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Figure 2. Photovoice Results within the framework of Social Cognitive Theory

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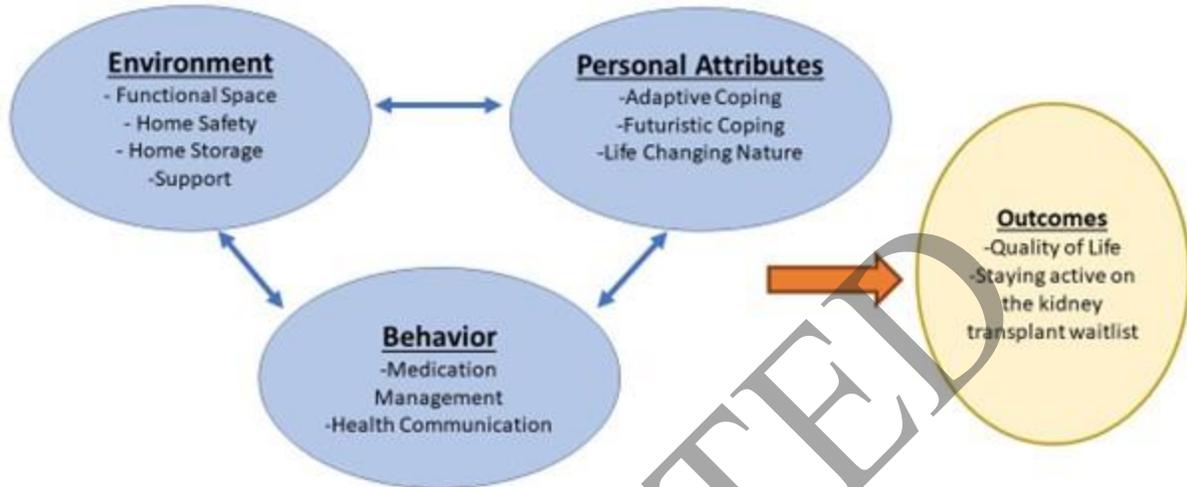
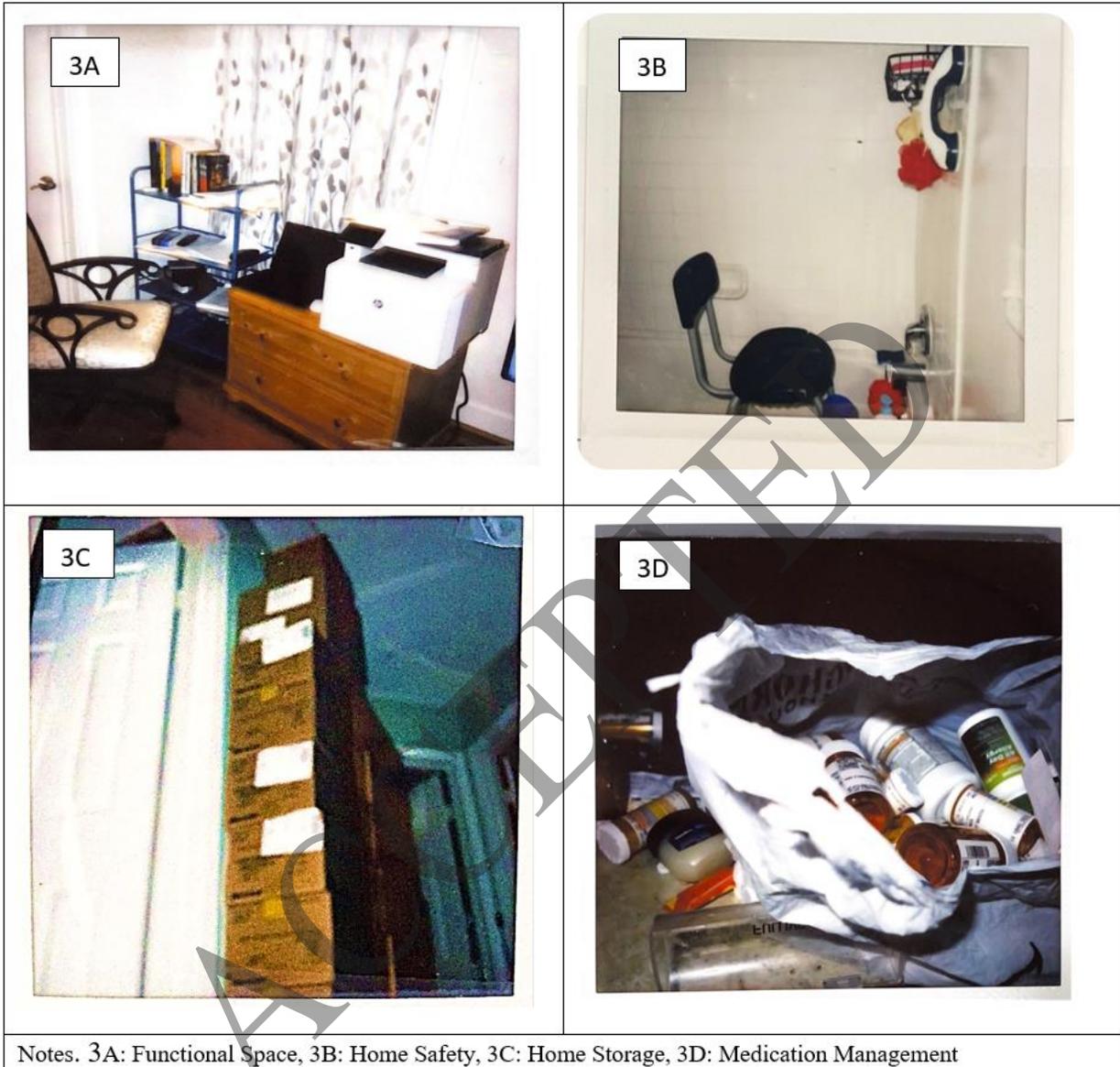


Figure 3 A-D. Insights into the Physical Environment



Notes. 3A: Functional Space, 3B: Home Safety, 3C: Home Storage, 3D: Medication Management

Figure 4 A-D. Insights into Lived Experience

