# My Story Has a Hopeful Future: Using Digital Journaling to Empower Youth Living with a Chronic Illness

Julia Constance Dunbar

A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2024

Reading Committee:

Wanda Pratt, Co-Chair

Ari H Pollack, Co-Chair

Alexis Hiniker

Program Authorized to Offer Degree:

The Information School

University of Washington

## Abstract

My Story Has a Hopeful Future: Using Digital Journaling to Empower Youth Living with a Chronic Illness

Julia Constance Dunbar

Co-Chairs of the Supervisory Committee:
Wanda Pratt
The Information School
Ari Pollack
School of Medicine and The Information School

Adolescents and young adults living with chronic illness experience more complications and challenges when transitioning to adult-oriented care. Despite various interventions to support medication management, goal setting, and collaboration with care teams, AYAs continue to struggle, affecting their health and life outcomes. In this dissertation, I investigated how designing to capture and integrate youths' stories into journey tools can support reflection and empower youth in their chronic illness journeys. I did this work in the context of youth who have undergone kidney transplantation as a focused example of a chronic illness journey.

I first examined the experiences of youth transplant patients and their caregivers as they recalibrated to normalcy post-transplant. As a result, I identified five dimensions of their

experiences. These dimensions represented the fluctuating nature of patients' and caregivers' experiences post-transplant. Informed by the rich understanding of their experiences, I contributed a conceptual framework that ties together multiple facets of patients' lives and represents the different needs and tensions that may arise throughout various parts of the transplant journey.

I then probed further into youth transplant patients' experiences to better understand their transplant journeys. Consequently, I characterized and discovered story categories that youth transplant patients and their caregivers discussed for each of the five dimensions of the framework. Additionally, I explored another essential element of youth's chronic illness journeys, medication management, and provided insights into medication management visuals to help support youth throughout their journey. From this work, I contributed new design insights for capturing youth kidney transplant stories and medication management to inform the design of chronic illness journey tools.

Lastly, I explored the impact of My Kidney TREK, a tool designed to capture youth kidney transplant patients' journeys in a real-world setting. Informed by design insights from my previous work, this tool provides youth with a comprehensive view of their kidney transplant journeys. I found that My Kidney TREK positively impacted patients' and caregivers' reflections on their transplant journey, demonstrating the value of incorporating stories within a chronic illness journey tool. Additionally, I discussed the design of the My Kidney TREK and provided recommendations to improve future chronic illness journey tools.

Regardless of their health challenges, youth with a chronic illness still have hopes for their futures and aspire to thrive throughout their journey. Capturing and reflecting on their chronic illness stories provides a more holistic picture of their journeys, highlighting barriers that interfere with harmonizing their healthcare and life needs. Ultimately, my work shows how using digital

journaling promotes self-efficacy as youth transition towards independence and empowers them to take more control of their lives. This research offers a promising avenue for improving the healthcare journey for youth with a chronic illness.

# TABLE OF CONTENTS

# LIST OF FIGURES

# LIST OF TABLES

# ACKNOWLEDGEMENTS

It is hard to know where to begin when writing this because there are countless people, organizations, and more who have supported me throughout my dissertation. Starting on a more formal note, this work would not have been possible without the grants awarded to Dr. Ari Pollack from the National Institute of Health NIDDK[1] and Institute of Translational Health Science (ITHS)[2].

From this work I have had the privilege to be able to hear countless stories from youth kidney transplant patients and caregivers, who have opened their hearts to tell me about their chronic illness journeys. Doing so can make these patients extremely vulnerable, and I sincerely appreciate them taking the energy to do so, enriching not only my work but also my personal view of the world. Additionally, I want to thank them for taking the time out of their busy schedules to do this work, which can hopefully continue to make a lasting impact with the youth kidney transplant community and other youth chronic illness communities. I would also like to thank the Seattle Children's Research staff members who have helped me to do this work, including the amazing research coordinators I got to work with, Cara and Chelsea, as well as the other clinicians, nurses, PAs, and more. I especially wanted to thank Jodi Smith, who has been involved in each study that is a part of this dissertation, offering great advice and guidance on the direction of this research.

Next, I want to thank my co-advisors and my committee members. Wanda and Ari, you both have become much more to me than co-advisors, I consider you both my mentors and friends.

[1] National Institute of Health NIDDK grant # K23 DK117017
[2] ITHS grant # UL1 TR002319 NCATS/NIH

Wanda, you have guided me throughout my PhD journey, teaching me not only valuable research skills, but have also instilled in me and my fellow lab mates the importance of each research participant's voice. Showing me and others that there is space for everyone within in research and that it is okay to be vulnerable and that, in fact, it can be a great strength. I will forever be grateful for your kindness, words of wisdom, and ability to make space for the hard and good times in this world. Ari, it has been so inspiring to work with such a fantastic researcher and clinician throughout this dissertation process. Your enthusiasm for learning has shown me that it is okay to have missteps and in fact you are a stronger researcher because of these missteps. I have learned how to pivot along the way and have built numerous other research skills with your guidance. I will forever remember our many walking meetings, white boarding brainstorming sessions, and conversations about our research and life. Your passion and willingness to help all of those that you mentor is inspiring, and I hope that one day I can be as good of a mentor as you were to me these past six years. Alexis, you have also been with me throughout my PhD as an instructor, research advisor, mentor, and PhD chair. During my research assistantship with you I grew as a researcher and mentor, and what I learned throughout that project was invaluable. Julie, your expertise and guidance as my GSR has helped make this dissertation work stronger and you have encouraged me to see the value in my work.

I have had so many other amazing mentors and collaborators throughout this work. Meg, my internship with Sage was pivotal in my growth and confidence as a researcher. In working on the Bridging the Gap project with you, I had the opportunity to build my research skills and interact with other researchers and youth from around the globe. I will always look back on my time on that project with a smile on my face. Shefali and Sonu, I wish I had more time to work with you both during my PhD. With that being said, I will always appreciate that you both made the effort

to stay in touch with me during my PhD, offering endless words of encouragement as well as amazing book and Christmas movie recommendations. In addition, all my other collaborators and co-authors, Jaime Snyder, Emily Bascom, Calvin Apodaca, Joseph William Tan Garcia, Carly Marten, Lily Jeffs, and so many more, thank you for your willingness to work through the hard times with me and provide productive criticisms to make this work stronger.

I would also like to extend a special thanks to the wonderful labs I have been able to be a part of. To the iMed lab, I always felt like I had a safe space to bounce my ideas around and have a fun time. I will inevitably once again forget someone, but I wanted to thank Hyeyoung Ryu, Lisa Dirks, Erin Beneteau, Calvin Apodaca, Emily Bascom, Yiran Zhao, Reggie Casanova-Perez, Nick Reid, and others. To the HIVE lab, you all truly helped me to push through and finish this dissertation, and I would not have finished without all your support. Thank you to Cara Currier, Chelsea Ng, Emily Bascom, Joseph William Tan Garcia, Lily Jeffs, Sanaa Syed, Sabrina Mangal, Nathan Pan, and others. Being a part of these labs brought me so much joy and helped me to become a stronger researcher and mentor.

To my fellow PhD cohort members, it has been amazing to go through this journey with you all. I wanted to say a special thanks to several people in my cohort: Yim Register, Ishita Chordia, Lisa Dirks, and Al Oleson. Yim, I feel so grateful that this program has brought me such an awesome friend, I appreciate you always making time to talk with me when I have struggled and for making me laugh throughout the process. Ishita, I am not sure I could have finished this program without having you in my corner, we helped each other during times of doubt and have both grown throughout this time. Lisa, you have always provided me with space to vent and have inspired me when I was feeling stuck. I will always be grateful to have you as a friend and fellow

researcher. Al, you have provided a sense of calm within our cohort, and I appreciate all of the times you made space to talk with me when I was feeling anxious.

Lastly, I want to thank my other communities, family, and friends who are outside of the PhD world. To my tennis community, I often leaned on tennis and my tennis friends when I was feeling frustrated with my PhD process, thank you all for providing me with an outlet to make this journey that much easier and fun. To my Seattle and long-distance friends, thank you all for your endless supportive texts & phone calls, fun food & adventure outings, and reminders that there is a world outside of this dissertation. To my amazing dog Ellie, thanks for the endless cuddles and forcing me to go outside and walk when I was in the weeds. To my family, I have always been able to lean on you for support and endless love, thanks for asking about my research and listening to me as I ramble. Mom and dad, your endless love from when I was born, through my cancer journey, and through my life journey has meant so much more to me than you could ever have known, thank you and I love you. Jim, your endless love and support are a big reason why I have been able to get through this PhD, I love you more than I can say.

# DEDICATION

For little Julia, Mom, Dad, and Jim.

# Chapter 1. INTRODUCTION

Being diagnosed with a severe chronic illness as a child has a significant impact on the lives of both the youth who are diagnosed and their families [1–6]. When youth are diagnosed with a chronic illness, they and their families are thrust into a new, rapidly changing reality. As the family transitions out of the initial shock of diagnosis, they will start to realize the lifelong implications of what being diagnosed with a severe chronic illness means. The families' focus must drastically shift from the routine daily activities of childhood to a new and unfamiliar landscape of medical appointments, medications, and unclear outcomes. However, these youth's original activities, needs, and dreams continue despite their new health challenges.

Having a chronic illness as a child adds a new level of complexity, layering a variety of different biological, social, and organizational elements. Successfully interweaving these different components can be complex for youth and their caregivers, resulting in conflicts between youth's healthcare and non-healthcare life needs (in short, life needs). For example, a youth may struggle to take their medications on time or at all (i.e., a healthcare need), as it can interfere with their social relationships (i.e., feeling awkward having to take their medications in front of their peers) or activities (i.e., playing sports or video games). These conflicts can have a significant impact on their health and well-being and require that youth adjust to this new reality of living with a chronic illness. Youth and their families will begin adjusting to their new state of normalcy [1] as their healthcare and life needs harmonize.

In this dissertation, I have worked with youth who have received a kidney transplant due to kidney disease, a life-threatening chronic illness [7–10]. While many youths, after receiving a kidney transplant, eventually get to a point where they feel normal again [11], most struggle on

their journey towards normalcy (i.e., when their healthcare and life needs feel in harmony). As a result, Adolescents and Young Adults (AYAs) who have received a kidney transplant often struggle to take their required post-transplant medications on time, a significant cause of kidney rejection and premature kidney failure [12–15]. The journey after transplant is not uniform and linear but instead fluctuates between times when youth struggle with their chronic illness and other times when they successfully integrate their healthcare needs with their life needs [3].

Understanding and ultimately addressing the conflicts between the healthcare and life needs that affect youths' normalcy requires a collaborative and comprehensive view of a youth's journey living with a chronic illness. In the past decade, there has been a push in medical, health informatics, and HCI fields towards more patient-centered care [16,17] as well as understanding patients' chronic illness journeys [18–20]. Even with this push, there is still a need to explore the intricacies of chronic illness journeys further to support youth in better understanding their holistic journey. Capturing youth's journeys may provide them with the necessary tools to reflect and identify challenges and successes and ultimately support better collaboration with their caregivers and clinical care team for improved harmony and normalcy.

However, to support such collaborative reflection, youth need a way to capture and review their journeys with others. Stories may provide a valuable source of information for youth kidney transplant patients, their care team, and their caregivers by painting a more detailed and vivid picture of the events or experiences these youth experience during their transplant journey. In addition, comparing stories over time shows the evolution and progression of one's kidney transplant journey. While researchers within various disciplines have explored the collection of individually curated data, such as personally tracked data [21–23], this type of data tends to be more quantitative. It often does not align or connect with youth's personal and narrative life

experiences. HCI researchers and researchers within other fields have explored mediums where patients may have more direct access to stories, such as online communities [24–28]. However, these spaces often lack the structure required for people to find relevant stories or specific topics. Therefore, there is a need for new tools to help individuals, especially youth, find stories applicable to their chronic illness journey to make sense of their experiences.

Designing tools to capture youth's kidney transplant journeys can help youth, their caregivers, and their care team better collaborate and understand their experiences throughout different points of their transplant journeys. It also provides all stakeholders with a way to reflect on the intricacies of an individual's journey and identify times when their healthcare and life needs conflict. In this dissertation, I explore youth kidney transplant patients' and caregivers' needs for tools to capture a more holistic view of their transplant journeys to help identify barriers, promote self-efficacy, and eventually live the lives they want to live. Below, I present my dissertation aims and research questions, dissertation setting, positionality statement, and end with an overview of this dissertation.

## 1.1 Dissertation Aims and Research Questions

**Aim 1: Understand Youth Transplant Patient's and Caregivers' Experiences.** The goal of this AIM is to gain a deeper understanding of youth kidney transplant patients and their caregivers' transplant experiences as they recalibrate to normalcy post-transplant (Chapter 3). By gaining a deeper understanding of youth and caregivers' experiences, I may uncover the needs that youth and their caregivers experience throughout their transplant journey. Research questions that guided this AIM included:

- RQ1 - Empirical: What are the information needs of youth transplant patients and their caregivers to help them understand and ultimately improve their transplant experiences?

- RQ2 - Conceptual: How can we frame the different needs and tensions that arise for youth and caregivers throughout the transplant journey?

**AIM 2: Inform the Design of a Transplant Journey Tool.** For this AIM, I set out to probe youth kidney transplant patients and caregivers further about their transplant experiences to inform the design of a kidney transplant journey tool (Chapter 4). To inform the design of a kidney transplant journey tool, I explore another essential element of youth's chronic illnesses journeys: medication management (Chapter 5). Designing to capture youth transplant patients' stories and other more discrete components like medication management may paint a clearer picture of youth's overall journeys. Research questions that guided this AIM included:

- RQ3 - Design: How can an existing framework help inform the design of a tool to support the collection of youth and caregivers' transplant journeys?
- RQ4 - Design: What are design insights for medication management visualizations to aid youth and caregivers in better understanding their medication management throughout their journey?

**AIM 3: Assess the Design and Impact of a Kidney Transplant Journey Tool.** In this AIM, I investigate a Kidney Transplant Journey tool with youth kidney transplants and caregivers in a real-world setting. To assess the design and impact of the tool, I will examine youth transplant patients' and caregivers' reflections after interacting with the tool and analyze youth's perceptions of the Kidney Journey Stories (KJS) component of the tool (Chapter 6). Research questions that guided this AIM included:

- RQ5 - Empirical: How did using the My Kidney TREK technology probe impact youth kidney transplant patients' and caregivers' overall reflections on their transplant journeys?
- RQ6 - Design: What are kidney transplant patients' and caregivers' perceptions of the My Kidney TREK Kidney Journey Stories component and design recommendations for future iterations?

## 1.2 Dissertation Setting

This dissertation comprises four studies. I recruited youth kidney transplant patients and their caregivers across each study. Participants were primarily recruited from Seattle Children's Hospital transplant centers located in Seattle in the United States. A handful of participants were also recruited via the Improving Renal Outcomes Collaborative (IROC) Community Engagement Workgroup (CEW) [29] (Chapter 3) as well as The Johns Hopkins University transplant center located within Baltimore in the United States (Chapter 5). All sites treat widespread youth populations from diverse geographic and demographic backgrounds [30].

Across all four studies, we had a wide age range of youth participants between 7 – 22 years old; I chose to do my research with youth because I believe they have unique information needs that differ from the information needs of adult patients and their adult caregivers. Adolescence and young adulthood is a critical period of life for any youth, but especially for those with a chronic illness. AYAs with chronic illnesses are becoming more aware of their illness and the implications of what this means as they mature into adulthood, such as the need to transition to self-management [31–35]. AYAs tend to be at higher risks for adverse health outcomes after a kidney transplant compared to their adult peers. Thus, it is critical that they are involved in this type of research. All youth participants had to meet the following criteria to be eligible: had a kidney transplant (All Chapters), were English speaking (All Chapters) or Spanish speaking (Chapter 5), had non-failing

kidney function (i.e., a GFR >30 ml/min/1.73m2) [36] (All Chapters), and be at least three months (Chapters 3, 4, and 6) or six months post-transplant (Chapter 5). We received informed assent and or consent from all youth and caregiver participants (to see an example of an assent form for one of the studies, see Appendix B; Figure B2). All study procedures were approved by Seattle Children's Hospital, the University of Washington, and other participating hospitals' Institutional Review Boards.

## 1.3 Positionality Statement

As a baby, I was diagnosed with Wilms tumor, which is a form of childhood cancer that affects your kidneys. Soon after diagnosis, I went through surgery to have my affected kidney removed, followed by several months of chemotherapy. After the surgery and chemotherapy my cancer went into remission, and I continued to have regular check-ups throughout my youth to ensure I was still in remission. Even though I was young when I went through my cancer treatments, I still have memories from these years that have influenced who I have become today. As I grew up, I also heard stories from my parents and family members about that time in my life, and I can see how it has affected not only my journey but also those of others in my life. Over the years, I have grappled with complex feelings about being a cancer survivor, but now I recognize that it will always be a part of who I am. My personal experiences have motivated me to explore and do research with youth who have complex health experiences, and even though I have not been through the same experiences that the youth population I have worked with have been through, I empathize with their experiences due to my own. Doing work with youth kidney transplant patients and their caregivers has, at times, been difficult for me to do because of the memories and emotions it has stirred up. However, I have been and continue to be honored to be a small part of these youth and their caregivers' chronic illness journeys.

## 1.4 Dissertation Overview

This dissertation explores how to support youth transplant patients and their caregivers in reflecting on their chronic illness journeys, with the goals of identifying barriers to harmonizing their health and life needs and promoting self-efficacy.

In Chapter 2, I pull from literature in several domains, including, but not limited to, Clinical Informatics, Personal Health Informatics, and Human-Computer Interaction (HCI). From these domains, ongoing discoveries highlight the experiences and outcomes of youth with chronic illnesses. In this chapter, I review literature from each domain and discern gaps in how to design better technology to support youth kidney transplant patients.

In Chapter 3, I describe the results and analyses from an interview study with ten youth transplant patients and nine of their caregivers. This study highlights the needs and perspectives of youth transplant patients and their caregivers as they recalibrate to normalcy post-transplant. I propose a conceptual framework that can be used to help youth transplant patients understand their transplant experiences, illustrating the tensions patients experience throughout their transplant journeys.

In Chapter 4, I describe the methods and findings from a semi-structured interview study with 11 youth kidney transplant patients and 12 caregivers. Building from my previous chapters' findings, I sought to probe participants about specific parts of their transplant journeys. I found that probing participants about specific parts of their transplant journey gave them the structure to tell rich stories about their experiences. Based on the findings, I discuss informing the design of a tool to capture youth transplant patients' journeys.

In Chapter 5, I describe part of a study with 30 youth kidney transplant patients and their caregivers who participated in a series of design sessions. In the findings, I explore the medication

management drawings of the patients and caregivers and then discuss how medication management visualizations should be designed to reflect the complexities of medication management better.

Chapter 6 describes my final dissertation study, a pilot technology probe study with 13 youth kidney transplant patients and ten caregivers. I provide details about the technology probe's design and study methods and describe the study findings. I also discuss design considerations and recommendations for the Kidney Journey Stories component and its elements from these findings.

In Chapter 7, I highlight my dissertation's contributions and how they address the research aims I laid out at the beginning of my dissertation. I also discuss the limitations of my dissertation studies and directions for future research and conclude with a statement about my dissertation work.

# Chapter 2. RELATED WORK

Ongoing research in medical, health informatics, and HCI fields continues to explore the difficulty of living with a chronic illness as a youth. In my related work section, I will explore work from each of these domains and highlight some of the different complexities of growing up with a severe chronic illness. A few related work sub-sections below are copied verbatim from two of my first authored publications [3,37].

## 2.1 Considerations That Can Challenge Adolescent and Young Adults (AYAs) with Chronic Illnesses Successful Transition to Self-Management

This dissertation centers on working with youth who have a severe chronic illness, known as chronic kidney disease. For any youth with a chronic illness transitioning to self-management and eventually adult-oriented care is an important part of their journey to understand. As youth with chronic illnesses transition towards adulthood many different challenges can impede their transition, including but not limited to different biological, social, and structural considerations. Blum et al. define the transition process for AYAs with chronic illnesses as the following, "...the purposeful, planned movement of AYAs with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems (primary and subspecialty care)" [38]. Several frameworks have been developed to understand the different biological, social, and structural considerations that can affect youth's successful transition to self-management and throughout my dissertation work I have often referred to these frameworks to better inform my understanding of youth's chronic illness journeys. Two frameworks that I would like to highlight include Betz. et al's healthcare transition model for research and practice (see Figure 1A) [39] as well as Schwartz et. al's social-ecological model of readiness for transition to adult-oriented care (see Figure 1B) [40]. Schwartz et al's model stems from work by Bronfenbrenner [41], a researcher whose work has had far reaching implications into a variety of healthcare domains [42–44].

Two key biological considerations that can challenge the successful transition to self-management for youth with chronic illnesses include: (1) stages of development/patients age and (2) health status, risks, and outcomes. If youth are not properly supported during different developmental stages it can lead to increased dependence on caregiver-management and create a

lack of self-management skills, which can lead to poor clinical outcomes [39,40]. Moreover, researchers within a variety of domains have developed frameworks that explore the impact of AYA's different developmental stages, such as in neurodevelopment [45], applied developmental science [46], and even child-computer interaction [47]. Youth's health status and risks have also been shown to impact their transition to self-management. Schwartz et al. discuss how several factors, such as late effects (i.e. a health issue that appears after diagnosis or after treatment has ended) or disease history can become barriers to the transition process, often delaying patients' transition from caregiver led management to self-management [40].

In addition to biological considerations that can affect youth's successful transition to self-management, key social considerations include: (a) family/social support, (b) socio-demographics/culture, and (c) psychosocial functioning [39,40]. The caregiver (e.g., parent) and patient dyad as well as the patient, caregiver, and clinician triad are well acknowledged relationships that are imperative to youth's transition towards self-management. Youth with chronic illnesses rely heavily on their caregivers for support and guidance throughout their chronic illness journey and as they transition to adult care it can be difficult for both youth and their caregivers to make this transition [39,40,48–54]. Due to this heavy reliance on their caregivers youth can lack skills, such as decision-making skills that affect their transition to self-management and adult-oriented care. Work within clinical and health informatics spaces has explored how the implementation of shared and collaborative decision making can help youth transition to self-management [48,51,55,56].

Multiple socio-demographic and cultural factors, such as ethnic/racial identity, socio-economic status, and community factors can influence different variables throughout the transition process creating barriers and negatively affecting access to care [39,40]. Psychosocial factors also

influence the transition to self-management, including the higher likelihood for AYAs with chronic illnesses to experience psychosocial disorders, such as depression or anxiety, due to their chronic illness [40,57–59]. Lastly, other key structural considerations, such as the healthcare system (e.g., access to insurance) or a youth's environment (community resources and educational systems) affect youth's transition to self-management as well [39,40]. These frameworks and literature provide insight into some of the key considerations that can affect youth's successful transition to self-management. A successful transition into self-management and adult-oriented care is a cornerstone of many of these youth's journeys. Capturing times during pivotal periods of their journey can help youth to understand and identify conflicts they are experiencing.

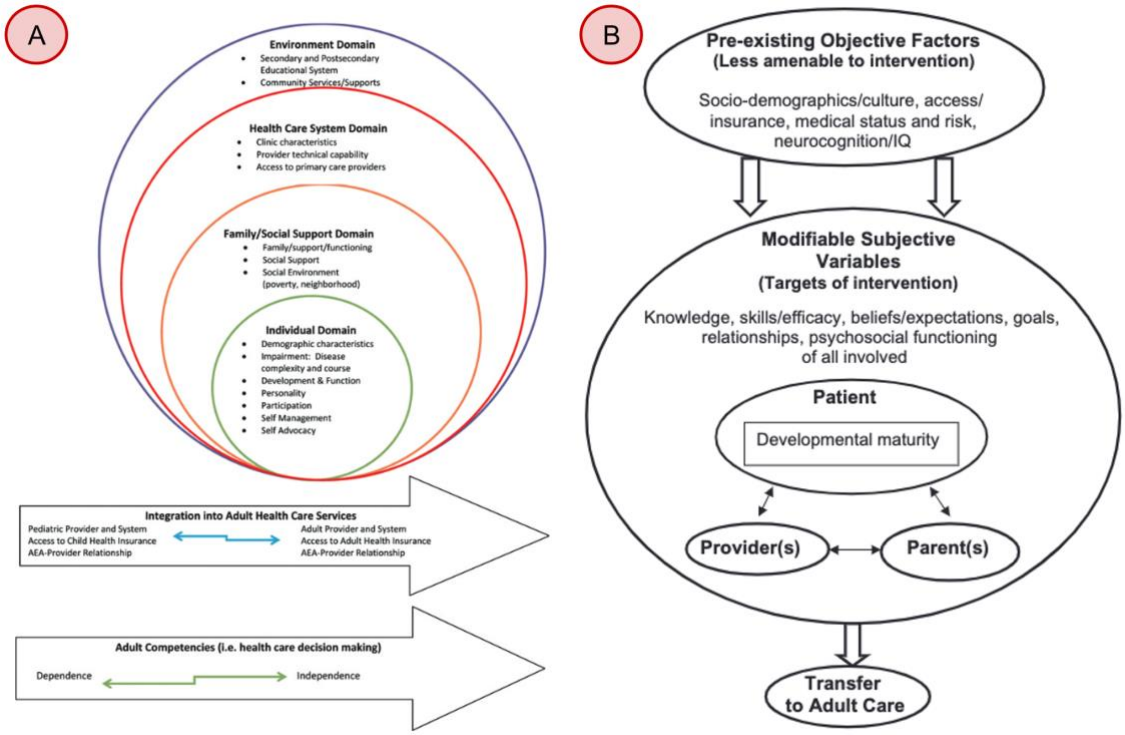



Figure 1 - (A) Betz et al.'s HCTRTC HCT model [39] (B) Schwartz et al's Social-ecological model of AYA (adolescents and young adults) readiness to transition [40].

## 2.2 Illness Uncertainty and Nonadherence Amongst Youth Kidney Transplant Patients

Kidney transplantation is the treatment of choice for pediatric patients with kidney failure because of the benefits to growth, development, and QOL [60,61]. Poor adherence to post-transplant medication management is a major cause of kidney rejection and kidney loss [12,62–67]. Nonadherence, which is estimated to be highest among adolescents and young adults (AYAs) [65,68,69], is often affected by many factors, both clinical and nonclinical.

Although the factors that contribute to nonadherence and reduced self-management are multifactorial for AYAs, decreased psychosocial functioning plays an important role [70]. Children living with a chronic illness are two to four times more likely to develop psychiatric disorders and social adjustment problems [71–73]. One contributing factor to decreased psychosocial functioning, illness uncertainty, has also been associated with nonadherence after a kidney transplant [74,75]. Illness uncertainty results from ambiguity, vagueness, unpredictability, or lack of information regarding an illness. This type of uncertainty limits one's ability to adequately interpret and respond to various situations and challenges [76]. Unfamiliar experiences also increase anxiety and worry for patients and their caregivers, especially when they do not have the ability to understand and process these situations [77]. Nonadherence can be seen as a direct result of the unmet information needs of patients and caregivers [78–80].

To improve outcomes for pediatric kidney transplant patients, a more comprehensive approach to understanding and addressing nonadherence is necessary [81–83]. Such an approach requires that all stakeholders develop a better understanding of the clinical and nonclinical factors that affect one's post-transplant journey. By gaining more insight into youth’s transplant journeys, clinicians and patients can potentially identify and address previously unrecognized modifiable

factors that can negatively impact clinical outcomes. Post-transplantation, individuals need to contextualize their own experiences and facilitate a positive self-image, with the goal of regaining a sense of self-directed normalcy [84]. While developing a stable and affirmative sense of self is key to helping patients feel their version of "normal" again, there is limited research describing the journeys individuals take after transplant to recalibrate a healthy sense of self. As part of this dissertation, I set out to explore the information needs required to help pediatric patients and their families understand their post-transplant experiences as they recalibrate their understanding of normalcy throughout their transplant journey.

## 2.3 Designing Technologies to Support Youth with Chronic Illnesses in Their Self-Management, Decision Making, and Transition Towards Independence

Living with a severe chronic illness as a youth requires managing many different puzzle pieces to ensure that they receive the best possible care while at the same time trying to enjoy their childhood. A variety of factors that affect youth with chronic illnesses include their physical growth/development [85], psychosocial development [86–88], and transitioning to adult-care [89–91]. Prior personal health informatics and HCI research has explored how technology supports people living with a chronic illness, with much of this work still focused on the needs of adults [25,92–96]. While some researchers have begun to explore the complexity of leveraging personal health informatics and HCI technologies to support youth with their chronic illness management, decision making, and transition towards independence, many opportunities to improve outcomes still exist.

As caregivers (often parents) are heavily involved in their child's care throughout their journey, HCI researchers have explored and designed a variety of technologies that support

collaboration between youth and their caregivers [97–100]. This work has examined a variety of technologies that affect youth and caregivers' collaboration, for example Britto et al. examined parental perceptions of a patient portal for managing their children's chronic illness. Hong et al. explored how technology can be used to support adolescents' with chronic-illnesses participation in their own care as well as how to support partnerships with adolescents, their families, and their clinical caregivers [101]. Additionally, Hong et al. and Lakshmi et al. have contributed other work to the field of HCI, exploring the designs of interactive Visual ODL dashboards with pediatric cancer patients, their caregivers, and their clinicians [102,103].

Other personal health informatics and HCI researchers have also explored how technology supports youth in having a more active role in participating in their healthcare as well as communicating with their hospital care team (e.g., their clinicians) [99,104,105]. Furthermore, personal health informatics and HCI researchers have focused on the needs of hospitalized youth, including designing patient portals to best align with patient needs and support engagement in their healthcare [106], identifying opportunities and challenges when designing peer support technology within a hospital setting [107,108], and developing technology to support youth goal setting and collaboration [109].

This is just a subset of work that has explored how technologies can support youth with chronic illnesses in their self-management, decision making, and transition towards independence. The underlying thread of most of this work is to better understand how technology can assist and support youth through their chronic illness experiences so that they can be successful in the long term. For youth to be successful, it is important to take into consideration not only how to support their health, but also how to keep them on track for the lives they want to live. While some of the work above does consider how to harmonize a youth's various healthcare and life needs, gaps

remain in better understanding, capturing, and identifying barriers and conflicts that occur throughout youth's chronic illness journeys.

## 2.4 The Importance of Capturing a Comprehensive View of the Chronic Illness Journey

Living with a chronic illness has a profound effect on an individual's quality of life, especially youth [110–115]. A key challenge in understanding the impact chronic illness has on an individual is identifying and tracking appropriate outcomes. While tracking clinical outcomes such as lab results, growth parameters, or vital signs are key for understanding the biological factors associated with a chronic illness, they do not necessarily reflect or capture the outcomes or needs that matter most to patients and families. There has been an uptick in collecting patient-generated data and patient-reported outcomes (i.e., data tracked by patients themselves) [116–119] within the past decade. Even though this data is tracked by patients themselves, most of the data still tracks health outcomes and does not necessarily reflect or capture the goals or needs that matter most to patients and families.

However, researchers have recently started exploring other types of outcomes. Researchers who are a part of the Standardized Outcomes in Nephrology (SONG) initiative are working towards developing a core set of outcomes based on shared priorities of different stakeholders e.g., patients, caregivers, clinicians, researchers, and more [120]. As part of their findings, the SONG researchers have identified a high-priority outcome domain for youth who have kidney transplants called "Life Participation" [121–123]. They define life participation as, "the ability to participate in meaningful activities of daily living," such as going to school, playing sports, or spending time with family and friends [120]. Even though researchers are starting to explore new types of

outcomes, such as life participation, there are still gaps to be filled in understanding and exploring the capturing of both healthcare and life needs.

Access to information reflecting patients' healthcare and life needs may give patients, their caregivers, and their clinicians a more comprehensive perspective of youth's chronic illness journeys. Some CSCW and HCI researchers have begun to delve into the intricacies of illness journeys, however, a majority of this work has been focused on adults and people living with cancer [124–127]. Nikkhah et al.'s CSCW paper on journey work does include pediatric cancer patients, but their findings discuss caregiving coordination journeys within the pediatric cancer journey [128]. There are still gaps to be addressed within this space to further explore different populations of youth with chronic illnesses, in our case youth who have had kidney transplants due to a severe chronic illness, requiring acute and chronic illness care. Further exploration into this space can also help to gain a better understanding of how to capture information that may directly help youth gain a deeper understanding of how their healthcare and life needs align or conflict throughout their journey. Capturing a more comprehensive view of a youth's journey may also provide them with the necessary tools to reflect on and identify barriers throughout their journey so they can better collaborate with caregivers and clinical care team. One source of information that is gaining popularity within health contexts, but still requires further exploration with youth patients, are stories, which is a primary focus of this dissertation.

## 2.5 Capturing Stories to Reflect on Youth's Chronic Illnesses

The use of storytelling, stories, and narratives has been explored in a variety of research fields over the years. Stories are a valuable source of information because they provide details about an individual's experience as well as depict the evolution of an individual's journey over time. They are also valuable because they can capture things, such as feelings, emotions, and values, which

are key to providing information to help contextualize and frame events. In recent years applications such as StoryWorth [129] or Remento [130] have become more mainstream, aiming to preserve loved one's memories, so their stories can be collaboratively shared between family members. Stories have and continue to be a valuable way to communicate information between people and as a research community we continue to explore the value of storytelling amongst different communities and how technology can support the capturing and transferring of stories.

Storytelling has been explored in a variety of different research domains, including the intersection of storytelling and clinical medicine, known as narrative medicine [131–136]. Narrative medicine has been used to not only support patients but also support clinicians in better understanding patients' lived experiences [131,133–135], thus illustrating how stories can be used as a collaborative source of information to help understand and reflect on a more holistic view of patients' journeys. An example of how stories have been successfully integrated and used to promote patient-centered care within a hospital system is the VA's My Life, My Story program [133,135]. In this program veterans participate in interviews and from their interview their "life history" is cultivated, which is then summarized and integrated into the VA healthcare system for clinicians and patients to have access to [131]. This work done with the VA illustrates the value that stories can provide in a healthcare setting. However, there is still work to be done to further explore non-adult experiences, such as youth chronic illness experiences, and how technologies can be designed to capture stories throughout the entirety of a chronic illness journey.

At the intersection of stories and technology, researchers continue to explore a variety of ways in which technology can help elicit, capture, and tell individuals' stories. Gordon et al. report on an automated story extraction system that involves capturing stories that people tell each other during conversations within the context of knowledge management [137,138]. Epstein et al.

discuss tracking tools and how these tools can better support individuals in telling their story using their data [139]. Pavel et al. delves into the challenges of capturing different and large amounts of data to display to individuals and approach it through a story-inspired paradigm [140]. Other researchers investigate and expand on ways to support storytelling [141], elicit stories [142], and even how to use stories to support goals [143,144].

Another avenue of exploration is when to capture an individual's transplant stories (past, present, or future stories). Most of the time when we think of capturing stories, we think about capturing experiences that have already happened or just happened (i.e. past and present stories). However, research done by Hershfield et al. has shown that people have difficulty aligning their current and future selves as one in the same [145–148]. Hershfield and others explore the idea of future self-continuity, "the sense of similarity and connection that is felt between one's current and future selves" [149], mainly within the domain of finance [150–152] as well as a few other domains [149,153]. This idea of future self-continuity is important for youth with chronic illnesses because they still have a majority of their life to live and understanding how their current/past decisions and experiences impact their future is critical. Some CSCW and HCI researchers have also explored the concepts of future self-continuity or future-self in a handful of studies, such as in the designs of future-self avatars for learning [154] and nutrition [155] or studying the effects of future self-continuity within VR in delaying immediate gratification [156]. Even though capturing and documenting past stories may help patients to reflect on their past so that they can grow in their future, making active choices in the present to help their future selves can still be difficult for individuals. Encouraging youth to think about their future in alignment with their past may also be an important consideration when encouraging participants to think about their transplant journey.

Stories can also be made up of different forms of data including, but not limited to written words, photos, audio recordings, or a combination of all the above. Within the context of having a chronic illness, stories about youth's experiences are more typically spoken via word of mouth from patient to caregiver, patient to care team, or patient to patient. Capturing youth's stories via written word or images within a format that can help them is less common. However, capturing individuals written stories and images over time could be a valuable source of information for these youth. How to best capture these stories so that youth can best leverage them is more challenging. It will be important to provide a structure for capturing youth stories that help them create a comprehensive picture of their chronic illness journey.

Clinical researchers within the past decade have increasingly sought to better understand youth transplant patients' experiences directly from youth themselves, enhancing our understanding of youth and their families' kidney experiences [157–161]. However, there is still a need for a better understanding of youth's complex kidney transplant journeys. In this dissertation, I will show how capturing stories can provide a more comprehensive (holistic) view of pediatric patients' transplant journeys and that designing to capture youth chronic illness journeys can help youth reflect on their experiences, identify barriers to their needs, and work towards self-efficacy.

# Chapter 3. UNDERSTANDING YOUTH KIDNEY TRANSPLANT PATIENTS' AND CAREGIVERS' EXPERIENCES

In this chapter, I switch between using the terms "I", "we", and "our" throughout because several areas of the Chapter are verbatim from the Journal of Pediatric Transplantation Volume 26, Issue 7, November 2022 [3] publication of this work. I would like to acknowledge that the data collection in this study was completed by Dr. Ari Pollack. I subsequently lead the analysis, formulated the

findings, and was first author on the published paper. I acknowledge the shared contribution of all authors in the original publication and would like to extend a further thank you to our third analyst Emily Bascom.

Even though having a kidney transplant is the treatment of choice for children with kidney failure, it can cause anxiety for patients and their families resulting in decreased psychosocial functioning, adherence (i.e. medication management), and self-management. We set out to identify the information needs required to help pediatric patients and their families understand their post-transplant experiences as they recalibrate to normalcy throughout their transplant journey. In this chapter, I answer the following questions: **RQ1 - Empirical:** What are the information needs of youth transplant patients and their caregivers to help them understand and ultimately improve their transplant experiences? and **RQ2 - Theoretical:** How can we frame the different needs and tensions that arise for youth and caregivers throughout different parts of the transplant journey?

I answer these questions by presenting findings from an interview study with 10 caregivers and nine youth kidney transplant recipients. I identified five specific themes (i.e. tensions) our participants associated with recalibrating their version of "normal" throughout the transplant journey: (1) exchanging information (information consumers vs. information contributors), (2) transitional management (family management vs. self-management), (3) building confidence (worry vs. confidence), (4) telling one's story (hiding vs. self-expression), and (5) normalizing kidney transplantation (feeling different vs. feeling similar). These five tensions form one's Kidney Identity, shifting from negative to positive throughout the transplant journey, illustrating a more abstract and complex account of kidney transplantation over time. Based on these findings, I present a conceptual framework that may help to provide a model and language to support patients and families throughout their transplant journey.

## 3.1 METHODS

### 3.1.1 *Study Population and Recruitment*

English-speaking pediatric kidney transplant recipients (7–21 years of age, who were at least 3 months post-transplant) and one family member were recruited from Seattle Children's Hospital, a large-volume pediatric transplant center in the United States, and the IROC CEW [29] (Table 1). IROC is a network-based learning health system working to improve the lives of children living with kidney disease, and the CEW is a group of engaged parents, patients, and other caregiver partners within the collaborative. Potential participants from the transplant center were identified via convenience sampling by identifying individuals with a scheduled transplant clinic visit. A recruitment flyer with study details was provided to the CEW group, and individuals were asked to contact the study team if interested. Based on previous experiences with qualitative research, Dr. Pollack had a goal to recruit 16–24 participants. Continued recruitment of participants was conducted until no new topics or themes arose from the interviews (i.e., data saturation). Nineteen individuals (10 pediatric transplant recipients and 9 caregivers) were interviewed (Table 1).

Table 1 - Study 1 Youth Transplant Patient and Caregiver Demographics

| Characteristic | Value |
|---|---|
| Age in years – median (range) | |
| Transplant participants | 14.2 (7–20) |
| Caregivers | 50.0 (37–75) |
| Gender – *n* (%) | |
| Transplant participants | |
| Male | 7 (70%) |
| Female | 3 (30%) |
| Caregivers | |
| Male | 3 (33%) |
| Female | 6 (67%) |
| Years since transplant – median (range) | 8.5 (2–14) |
| Patients requiring dialysis prior to transplant | 6 (60%) |
| First transplant | 10 (100%) |
| Donor type | |
| Living | 8 (80%) |
| Deceased | 2 (20%) |
| Etiology for kidney failure | |
| Acute kidney injury | 1 (10%) |
| Congenital anomalies of the kidney or urinary tract | 4 (40%) |
| Genetic kidney disease | 1 (10%) |
| Unknown | 4 (40%) |
| Race and ethnicity (participants could select more than one) | |
| White | 16 |
| Black or African American | 1 |
| Asian | 2 |
| Other | 2 |
| Hispanic | 0 |

### 3.1.2 *Study Procedures*

Each participant participated in one 30- to 90-min interview in the clinic or online via Zoom [162]. Youth and caregiver participants completed their interviews separately, unless participants were under the age of 12, then they were given the option to have a parent present during the interview. If youth participants under the age of 12 had a caregiver present, the caregiver was asked to participate only if they were asked a question directly by the youth participant.

Both youth and caregiver participants were asked to submit up to five photographs per topic that captured their feelings or experiences on the following four topics: (1) worry, (2) confidence, (3) similarity to their peers without kidney disease, and (4) differences from their peers without kidney disease. These four topics were chosen to help guide participants to think about and compare what they may view as normal and not normal throughout their transplant journey. The interviews were designed to understand the lived experiences of the study participants after receiving a kidney transplant, and this motivation was explained to participants prior to consent as well as during the interviews [163]. To structure and guide the interviews, Dr. Pollack utilized photo elicitation, a qualitative method that uses images to prompt individuals to talk about their personal experiences and values and develop an understanding of participant perspectives [164,165]. Individual participants were provided $25 gift cards at the completion of the study. The study was approved by Seattle Children's Hospital and University of Washington's Institutional Review Boards.

### 3.1.3 *Analysis*

Interviews were audio recorded, transcribed, and qualitatively analyzed [166–168] using a thematic analysis approach to identify common themes. I led and structured the analysis of the data. Using MAXQDA 2020 [169], I completed an initial deductive analysis [170] of the

transcripts with another member of the research team (EB who joined later on in the process) using four a priori codes based on the photo-elicitation exercise: (1) worried, (2) confident, (3) similar to their peers without kidney disease, and (4) different from their peers without kidney disease. I completed an initial deductive analysis with the four a priori codes to help maintain alignment with the purpose of the research, such as to understand the information requirements needed to capture what normalcy means to the patients and caregivers. The photographs submitted by participants were not analyzed, but only used to help structure and guide the interviews as described earlier. After completing the initial deductive analysis, we explored additional themes in the subsequent rounds of inductive analysis [171]. From the inductive analysis, 10 new codes emerged, which resulted in a total of 14 codes (4 a priori codes and 10 inductive/emergent codes) (see Appendix A).

After thematic saturation was hit (i.e., no new themes emerged from the transcripts), the 14 codes were then iteratively organized into a hierarchical coding framework, which was discussed between several members of the research team (myself, EB, AHP). During the iterative organization of the codes, the research team (myself, EB, and AHP) looked to see which codes could be combined and ultimately fall under one higher level branch of the hierarchical coding framework (see Appendix A; Figure A1 for an example). After a series of discussions, the research team (myself, EB, and AHP) reached a consensus on a final coding framework that consists of five high level codes, which make up the core of the "Kidney Identity" framework (Figure 2). Finally, after the framework was completed, I did a final round of analysis to identify any additional factors that may have influenced each of the five high level codes (Figure 3) and discussed these with the research team (myself, EB, and AHP). Participants did not provide feedback on the findings.


Figure 2 - Kidney Identity Figure - This figure depicts the Kidney Identity and its five tensions: (1) exchanging Information, (2) managing transitions, (3) building confidence, (4) telling my story, and (5) normalizing the journey, where each petal of the Kidney Identity flower displays one of the five tensions. Within each petal there are different sides of the tension, which can fluctuate throughout a patient's kidney transplant journey.

| | | Shared Factors | | | |
|---|---|---|---|---|---|
| | | Developmental Factors | Community/ Support System | Social Milestones | Identifying Quality of Life Expectations or Metrics |
| Tensions | Information Exchange | X | X | | |
| | Transitional Management | X | X | X | |
| | Building Confidence | | X | | X |
| | Telling Your Story | | X | X | X |
| | Normalizing Kidney Transplantation | X | X | X | X |

Figure 3 - This figure depicts each of the five tensions that make up the Kidney Identity and the shared factors that move patients along each tension.

## 3.2 RESULTS

I identified five specific themes (i.e. tensions) our participants experienced as part of the post kidney transplant journey: (1) exchanging information (information consumers vs. information contributors), (2) transitional management (family management vs. self-management), (3) building confidence (worry vs. confidence), (4) telling one's story (hiding vs. self-expression), and (5) normalizing kidney transplantation (feeling different vs. feeling similar) (Figure 2). I refer to these as tensions because they reflect moments of both positive and negative changes throughout the kidney transplant journey. Next, I describe each of these tensions, highlighting how they fluctuate throughout the kidney transplant journey. Quotes from transplant patients are identified by T# and their primary caregiver as P# and are organized by theme-specific tables (Table 2).

### 3.2.1 *Exchanging Information: Information Consumers versus Information Contributors*

Receiving a diagnosis of kidney failure can be overwhelming for patients and families. The complexity of kidney transplantation makes it difficult for pediatric kidney transplant recipients to advocate or make decisions for themselves. Families often need substantial support navigating treatment options and care plans. Often, the information families receive from their hospital and care team does not adequately meet their needs, resulting in many families utilizing online resources or communities, where they learn from other families with similar experiences (P7). Caregivers expressed the value of hearing both positive and negative experiences of others. Caregivers explained that during the training they go through to prepare for their child's kidney transplant, they rarely hear positive stories, which they believed could help them feel more confident about what their child is going to go through (P14). Other caregivers remarked that online support groups helped them realize they were not alone in their experience and *"...this isn't just [my] child [having gone through a transplant]"* (P14).

In addition, caregivers described how online transplant support groups supplemented the information they received from their hospital-based care teams, especially when exploring the day-to-day routines for their child. Many of the caregivers wanted to leave, *"no stone unturned"* (P7), when it comes to advocating for and improving the health of their child. Interestingly, as their child's care plan stabilized, their use of online resources decreased (P7). However, whenever a patient's condition or care plan changed, the family often returned to these groups to gain additional insight and support. As patients and families progressed along their transplant journey, they became more familiar with expectations and the requirements to maintain the patient's health and well-being, contributing to their own expertise. Developing patient expertise [172] supported the transition from individuals being primarily information consumers to being information contributors, sharing knowledge they have acquired as part of their transplant journey with others (P3).

Furthermore, age and experience influenced information exchanging behaviors and needs. As pediatric patients matured and became more aware of their clinical condition, they became both information seekers and providers, much like their caregivers (T9, T13.2, T11). Patients used their own post-transplant experiences to provide support to others undergoing similar treatments. Multiple participants described the value in sharing their experiences and hearing the experiences of other transplant patients at a summer camp for pediatric patients with various chronic diseases (T5, T13.2).

### 3.2.2 *Managing Transitions: Family management versus Self-management*

Throughout the kidney transplant journey, pediatric patients require different types and levels of support from their primary caregivers to maintain their health and stay on track with their care. Not only did our patients describe the support they received from their parents or caregivers (T4,

T14), these caregivers explained how they, in turn, relied on the support of other family members to help manage the complexity and time-consuming nature of the child's diagnosis. This reflects a family-oriented approach many caregivers took toward their child's illness (P3). As a result, clinical setbacks impacted the entire family, and were addressed together as opposed to something the patient managed alone.

As patients became more familiar with the tasks required to maintain their health, they transitioned from relying on their family to becoming more self-sufficient. Patients and caregivers described how the youth transplant patients took on more responsibilities to manage their routine and complex needs over time (P11, T4, P15, T11, P3). These self-management tasks ranged from simple tasks, such as setting medication reminder phone alarms, to more complex tasks, such as goal setting (T11). As expected, transitioning to self-management happened in conjunction with significant developmental and social milestones in a patient's everyday life, especially as youth recognized the impact of their kidney transplant on activities such as going to school, playing sports, participating in parties, or attending concerts (T13.1). Interestingly, the transition from family management to self-management was not unidirectional, with fluctuating levels of self-management (T4). For example, if a patient forgot to take their medications, parents described how they turned these mistakes into learning opportunities focusing on the importance of personal responsibilities (P11).

### 3.2.3 *Building Confidence: Worry versus Confidence*

Understandably, a diagnosis of end-stage kidney disease can generate significant worry and anxiety about a child's prognosis, life expectancy, and potential QOL (P14). The high frequency of anxiety and worry resulted in individuals adapting and getting used to their constant worries (P15). The fear of graft failure tended to surface with any new health concern (T14). The

complexity of navigating a child's healthcare needs, such as making and attending frequent appointments, administering medications, and coordinating laboratory testing provided additional sources of worry and stress (P14).

As individuals learned to cope and process their fears, they transitioned from worrying about every detail to accepting and being more comfortable with their lives after transplantation, resulting in less anxiety (P15, P4, P5). Community support from other transplant patients played a key role in helping individuals process new fears or complications (T3, T9). Having an understanding and empathetic support system, especially from those who have similar experiences (e.g., friends at camp), was extremely important for maintaining a positive outlook on their illness after experiencing setbacks. These relationships provided the support necessary for individuals to be more comfortable with their illness and build confidence. As our participants gained more confidence, previously stressful and anxiety provoking items (e.g., transplant scars) led to feelings of empowerment (T5). Although the seriousness of a kidney transplant initially led to feelings of worry and anxiety, as patients became more comfortable with their illness and found community among other transplant patients, their worries were mitigated. They became more confident and even proud of their transplant story.

### 3.2.4 *Telling One's Story: Hiding versus Self-expression*

When navigating youth and adolescence, an important part of discovering one's current or future identity is learning how to express oneself by communicating personal stories. Patients described that during their preteen to teen years, juggling who they want to be with other people's expectations or assumptions was difficult (T5). Individuals also stated that the added layer of complexity around having an illness made it more challenging to tell their story, develop boundaries around how much of their illness defines their story, and decide with whom they want

to share their stories (T7). Patients discussed feeling a need to hide their illness based on previous negative experiences and interactions. In addition, physical feelings such as pain interfered with our participants' desire to share their stories with others (T13.1).

However, as patients progressed along their kidney transplant journey, many started to feel more confident in expressing themselves and communicating details of their transplant story with others (T3, P5, P14). Individuals became more comfortable sharing the physical aspects of their illness, such as letting others see their scars or kidney guards (T13.2). When patients did not have the ability to express themselves and tell their story through words, they used alternative methods, such as playing the guitar (T5). Finally, patients stated the importance of having a community of supportive people who not only understood their experiences, but also helped them with their own self-expression (T5). While patients often began their journey unsure of themselves and what to expect from their illness, as they grew with their illness, their increased self-expression built confidence in the person they have become.

### 3.2.5 *Normalizing Kidney Transplantation: Feeling Different versus Feeling Similar*

At different points in their transplant journey, participants discussed their struggle to find a sense of their own "normal." One parent described hearing their child's diagnosis and quickly having multiple questions about what their life would be like, *"We had all these questions about normal kid things and we're not even a sports family, but would he be able to do sports if he wanted to?"* (P7). The uncertainty of what was to come for the patient often left the patient and their family feeling isolated (P9). The everyday requirements that come with maintaining one's health after a kidney transplant further exacerbated feelings of being different from their peers without a chronic illness; participants described having to take medication daily to save their life when their peers may only need to take medication when they develop a cold (T3). Participants described

insecurities about the physical restrictions and daily requirements of their illness, and that when others brought up or pointed out their differences from peers, this only reinforced those fears (T3).

In addition, participants described experiences that helped them feel more similar to their peers without chronic illness. T3 described the importance of being able to eat whatever they wanted following their kidney transplant, as they were no longer constrained by the strict dietary restrictions they had while on dialysis. As participants aged and matured, they stopped worrying about what others thought of them (T13.2). Finally, finding community with other transplant patients helped foster a sense of and build confidence in their identity (T11). Although having a kidney transplant can have a lasting impact on both patients' and their families' lives, as they all become more comfortable with the patient's condition, they begin to develop their new "normal" (P15, P11, T15, P13).

Table 2 - Kidney Identity Tension Quotes

| | |
|---|---|
| **Exchanging information** | |
| Information consumers | P7: "Early on... I found a lot of online groups, Facebook groups, and a Google group for parents of kidney kids that were super helpful." |
| | P14: "[they] didn't hear a lot of the positive stories... and it probably would have made it a little less stressful if we had heard a few positive stories." |
| Transition from information consumers to contributors | P7: "I think at first... I was taking in information, and then I was more of a contributor... [Hearing other family's stories is] not as big a part of my life anymore as it used to be, but still helpful... I mean, [online support groups are] just where I've learned a lot and share a lot of my knowledge." |
| | T9: "How much they have been a part of it, and just to look at the whole thing as a whole and to see what joy they have created, what a life that they have created, and that's what I want to give back. That's why I want to go into alternative medicine because it's the doctors. It's the doctors, the love that I felt from them and the connection that I felt with them. It's the thing that has formed my life completely." |
| Information contributors | T13.2: "I went the whole three years, and I was able to talk to the younger people there who had kidney transplants. I could talk them through it and teach my own way. I also looked up at the people older than me so they could tell me about their experience." |
| | P5: "So I will tell this story... to get people to take some money out of their pocket [at charity events], because there are kids who need it." |
| | T11: "I'd probably tell them about how I got mine out, and how they could possibly get theirs out if they didn't like it. I would also tell them how much work I had to do to get there of course." |
| | P3: "Anything that we can do to make it easier for the next family, I'm always willing." |
| **Transitional management** | |
| Family management | P3: "It's the whole family... because it doesn't just affect me and T3, it affects everybody in the family... [T3 is] really, really, really good 'bout it and it's not just him and me, the whole family's involved. His brother is a big part of it because T3 can't hear very well... He can't hear the alarms. So, he has to rely on somebody else to help him." |
| | T4: "Majority of the time my dad always tells me whatever my medicines are, or when I go to my mom's, they always tell me across the room, 'Hey, it's time for your medicines.'" |
| | P4: "The problem with teenagers is, I've been told, they forget, and they don't think of it much anymore...and that's what causes the biggest problem for the rejection of an organ in the body... I am constantly worried when he is not around me because I feel that I have as a father responsibility to make sure that my son [is okay]. He's a teenager... I have to keep eyes on him to make sure [he is okay]." |
| | T14: "Because, well, I was going to die, but then luckily since Dad gave me his kidney. I stayed alive..." |
| Transition from family management to self-management | P11: "T11 has been more and more responsible for her meds. We've taken off our alarms. She has an alarm on her phone now. She missed her meds once and it was the next day. It's not like we can go back and make them up again. I'm not going to freak out about it that much. It's like, 'All right, we missed one, we'll talk about it, we'll move forward.'" |
| | T4: "They've been supporting me and helping me all my life, so right now I'm just starting to take baby steps to support myself." |
| | P15: "It was just a couple of years ago I had to talk to everybody about cutting up his food for him and feeding him. I'm like he's beyond that, you know he doesn't need that... but I think for so long they were used to doing so much for him and helping him... they're doing it out of love for sure but it's just... And he allows it to happen." |
| Self-management | T11: "You made a specific goal, and it was specific, and you work toward it and you got it... So, you really learned how to take care of yourself to the point that we were like, we don't need this because you can take care of yourself without it." |
| | P3: "What is so hard about that? Most people get up in the morning and make a pot of coffee. It's no different than getting up in the morning and taking that handful of medication. You have to do it to feel right. You drink that cup of coffee to feel right, take that handful of medication to feel right. It's a simple thing. It's a routine." |
| | T13.1: "Really, just making sure I have medicines with me. Even if I'm only going out for a little bit, just to hear like, hey, I want to hang out more. So, I have my meds with me. I have water with me." |
| **Building confidence** | |
| Worry | T7: "It's a form about before surgeries, and I'm scared before surgeries sometimes." |
| | P14: "This was the only school picture I could find... There's this level of worry sending them off to school. At the beginning of the school year, there's a lot of worry about, okay, we have to have all the papers in order. We have to jump through extra hoops. We have to have extra doctors' appointments; we have to adamantly communicate with a new teacher. We have to make sure that they fully understand this is medically necessary, you have to let him do this." |
| | T14: "Because I am worried that my kidney won't last long and that I'll have another transplant in a few years." |

(Continues)

Table 2 (Continued)

| | |
|---|---|
| Transition from worry to confidence | T3: "It helped me be more confident... Just talking to other people about getting disease... if I just tell people they'll understand. Back when I felt like nobody understood, but I know that people will if you just tell them." |
| | T9: "So from the very outset came that confidence, and also of this feeling like other kids with kidney transplants. So, this connection, right, started this thing that I needed to share this experience. I can't keep this to myself because that will kind of darken my life in a way about, 'Oh, I have to worry about this. I have to worry about that. I can't do this. I can't do that.' I have to share that." |
| | P15: "It's a constant worry but we've seen so much success that it's hopeful that the outcome is going to be a lot greater than we first expected, and I think you grow a lot, you learn a lot in the journey, and you just get to keep plugging away with it." |
| | P4: "I see if he doesn't have a fever then I will give him some water, he wants pain [medicine] to relax and I say 'Okay, well if you want, I can give you Tylenol that makes it better.' That is again, part of being worried... Then when he's happy, he's laughing in the other room... He's in his room, he's sitting there and watching TV or laughing because[the] movie is comedy or something like that, I feel okay." |
| Confidence | P5: "So, I'm happy to know that actually if he really wants to do something that he can. When it comes to schoolwork, he's not that good. But, when he goes to the videos of the online classes, he just goes through them. He totally gets it. He's half watching it and half doing something else, but he still gets it... they're very repetitive and very boring. But he still goes through them super-fast. That tells me if he wants to do it, he can do it. I'm not really... worried about him getting through life. Because if he wants it, he's going to do it." |
| | T5: "I'm proud to have these scars. I think they look awesome... I'm proud of them. I've been through a lot. I think my scars are a very good representation of that. I think when I have these scars, I feel empowered. I feel like I can take on the world when I look at my scars. I feel strong. I feel proud and happy." |
| | Interviewer: "How do you feel when you sing that song?"<br>T15: "I feel strong." |
| Telling your story | |
| Hiding | T7: "Cause not that many people have pee tubes"<br>Interviewer: "Oh okay. And, I remember last time you had mentioned that it's something you don't really like other people to know about, that you have, right?"<br>T7: "Mm-hmm..." (affirmative). |
| | T13.1: "After transplant, I felt more disabled, because I was in pain from the kidney transplant, and I was more worried. I was more staying away from people" |
| | T5: "People will put you in a group or people... won't always react positively. At times, you really have to act like you aren't (just) to fit in especially in high school. It's like, oh, I have lots of friends. I'm moderately cool... I'm friends with the top people. I'm one below that...You really have to act like everyone else especially in high school because otherwise you get alienated. You can't always be yourself in high school. You have to conform to everyone else." |
| Transition from hiding to self-expression | T3: "Over time I just kind of ignored it. I didn't really care what people thought of me if I was different. I still don't really care if people think I'm different. It's just kind of a thing over time where you just, you're like 'you're different, get over it.'...Back when I had the kidney transplant it made me feel really bad because my body just wasn't normal you know. I got over it." |
| | T13.2: "I guess at some point I just kind of stopped caring. Like I wouldn't hide in the bathroom and put it on and tuck it under my clothes. I would just be like 'You know, they're my friends, it's not like they're going to think any differently of me.'" |
| | P14: "There's part of this that makes me feel confident in that he knows what's going on. This is a normal part of his life. This is part of the story that he's going to write. And there's part of me that worries because of the story, that that's the part of his life..." |
| Self-expression | P5: "Yeah, exactly. So, but this, he's happy to be who he is. And he's not... I don't think he's doing it for anybody else. Think he's doing it for himself." |
| | T5: "Camp [is] a really cool place. It's a place for people who also have medical issues. It's just a teen retreat week... it's a place where everyone has these issues. It's a place where everyone can be themselves, and be not judged for it, and can be accepted really fully. Everyone's allowed to be really confident there. At this place you can be completely yourself. It will be totally okay. The guy... he's played for a really long time. He was really nice. He really boosted my confidence about music. He said I was really good for nine months, which is how long I've been playing. He's like, 'You're a really good artist. I think you can do something. You'll be somewhere.' I was like, 'Wow. That's really amazing.' He's crazy. He's so good on his sax. We just played music together. It was really nice." |
| | P1: "So he's got his keys because he's really into keys, and his mismatched...and whatever, probably popsicle all over his face. It's moments like that where I just go, 'Hey, he's just himself, and we're good. We're just going to let him be himself.'" |

(Continues)

Table 2 (Continued)

| | |
|---|---|
| **Normalizing kidney transplantation** | |
| Feeling different | P9: "This is public schoolers. Not only do you have a transplant, you've gone through these types of experiences, you're not a public school student, you've just had different experiences, and how to merge with a group like that. You're not into modern music or culture, modern culture." |
| | T3: "I feel different people might treat you differently. They might treat you in a special way, but... you just want to be treated like everybody else... You shouldn't have to be treated differently because you have a kidney disease. You shouldn't really have to, but sometimes you have to when it comes to things like physical sports and stuff like that. Not all the time... That's one way it can be pretty bad." |
| | T3: "My medicine makes me feel really different because I have to take them to protect my kidney. Other people, they just take medicine... to get over a cold or something. I have to take medicine to basically stay alive. It makes me feel really different from everybody else. I take these medicines that nobody else can take. I feel like that... it just makes me feel different taking these medicines." |
| Transition from feeling different to feeling similar | T13.2: "... just through puberty to maturity, I kind of grew to be, like, yes this happened, but I'm still me, I'm not that much different than anyone else." |
| | P15: "This was just... this was the kids before bed. Their big sister reading to them. This is something that I think definitely hits home for me... T15 was on dialysis for so long that he wasn't... when he was younger we weren't able to snuggle him or cuddle him or... he was always in bed earlier because he had to be hooked up to his machine, so things like that, it's just like a freedom that we kind of take for granted and when you're thinking about it and going back to it it's like, 'Wow, this is awesome that they can do this'." |
| | P11: "Well, stuff like this, I'm always like, 'She's so healthy!' Like, 'She's running!' She is doing these activities all these other kids can do. Participant doesn't remember it, but I remember when she couldn't walk to the park, or when she could barely walk half a block. Walking to the end of our alley and back was a big outing. To see her doing stuff like this and growing strong and active is just awesome." |
| Feeling similar | T11: "I was kind of in a place with lots of other people who had had the same thing [as] them. I just felt... like I fit in there." |
| | T15: "I'm not just a kid with a kidney transplant. I can also act like a regular kid." |
| | P13: "I remember thinking, man, she's like other kids. She's not a kidney kid 100%, she's actually going off to college and moving into a dorm. And that's a picture of her and her friend in my daughter's dorm room the day we moved her in." |
| **Kidney Identity quotes** | |
| | P13: "There's been a lot of times where it's difficult to accept people's help, accept people's recognition of our situation because... sometimes as a parent of kids with this situation, you feel like, I just don't want people to pay special attention to us, I just want people to treat my family like we're any other family. And then there's other times where you recognize that, wow, people really care a lot about us and want to do things for us and it's really cool, but depending on what frame of mind I'm in, I can switch between the two. Even in that same day, I might've thought that I just wish we didn't have to do this event at all. I wish people just wouldn't go out of their way and do that kind of thing for me because I just want to be normal. And then, maybe an hour later I might be like, man, look at this, this is just amazing." |

Table 2 Note - Quotes from participants for each of the five tensions. The colors of the table are referencing the shared factors which influence one's Kidney Identity tensions, which can be seen in Figure 3. Red: Developmental Factors; Yellow: Community/support systems; Orange: Social milestones; Green: Identifying QOL expectations or metrics.

### 3.2.6 *The Kidney Identity Framework*

The five themes/tensions experienced as part of the post kidney transplant journey form a patient's "Kidney Identity" (Figure 2): (1) exchanging information (information consumers vs. information contributors), (2) transitional management (family management vs. self-management), (3) building confidence (worry vs. confidence), (4) telling one's story (hiding vs. self-expression), and

(5) normalizing kidney transplantation (feeling different vs. feeling similar). This Kidney Identity provides a framework to describe the changes throughout the transplant journey from diagnosis to post transplantation. Interestingly, this transition is not unidirectional from negative to positive, but involves participants moving in both positive and negative ways. The Kidney Identity captures the complex accounting of a patient's transplant journey and reveals tension shifts that may have occurred throughout the process. For example, when patients experience more positive outcomes with their health, they begin to feel more confident, are more comfortable sharing their story and expressing themselves with others and become increasingly self-sufficient and independent. However, as setbacks occur in a patient's care or other areas of their life, they may regress in one or all the tensions.

In addition to the influence of clinical outcomes, nonclinical factors also drive the positive and negative changes that occur throughout the transplant journey. I identified four nonclinical shared factors (Figure 3) that influence these transitions across the five Kidney Identity tensions: (1) developmental capacity, (2) social milestones, (3) community/support systems, and (4) QOL expectations (i.e., what individuals expect for a baseline quality in their life, such as their ability to engage in activities) as well as how these expectations have changed. These additional shared factors further illustrate the complexity surrounding an individual's kidney transplant journey. These nonclinical factors provide additional insight into the positive and negative shifts that occur across the five different tensions of the Kidney Identity framework.

## 3.3 Discussion

This chapter provides additional evidence to support the holistic benefit kidney transplantation provides to youth with kidney failure. A patient's Kidney Identity ties together multiple facets of their life including clinical, developmental, and social. However, for many patients and families,

the kidney transplant journey is filled with uncertainty, making it difficult for individuals to know where they may need help or support. Therefore, the Kidney Identity provides a framework and language to support the information needs of patients and families as they recalibrate their understanding of normalcy throughout their transplant journey. Uncovering these unmet needs allows all stakeholders (patients, caregivers, and clinicians) to collaboratively address previously unrecognized barriers and work toward improved outcomes for patients and their families.

The relationship between QOL and clinical outcomes after undergoing kidney transplant is bidirectional: QOL is impacted as a result of changing clinical outcomes [173,174] and clinical outcomes change as a result of QOL [175,176]. In addition, social outlets like peer mentoring have been shown to improve clinical outcomes and increase self- management for pediatric transplant patients [177]. The Kidney Identity framework, its tensions, and the drivers that affect the tensions add to this body of work by demonstrating the complex nuances that can affect the transplant journey. By shedding further light on these nuances, our work has the potential to support pediatric transplant patients, their families, and clinical teams in knowing the challenges (clinical or non-clinical) that affect an individual's transplant journey and the associated clinical outcomes. A well-formed identity is integral to developing a sense of normalcy for adolescents after kidney transplant [178]. Similar to Liu et al., our work demonstrated the importance peer connections play in supporting individuals after transplant [179]. Yet, it is important to recognize that pediatric patients living with chronic illnesses often develop a sense of a "new normal" resulting from their illness journeys [179]. Highlighting these changes helps individuals to better adapt and not have unrealistic expectations. The Kidney Identity provides a framework to assess and track individuals as they experience fluctuations throughout their transplant journey, potentially providing additional opportunities for targeted therapeutic interventions to support those who are struggling.

One of the major challenges faced by youth, adolescents, and young adults after transplant is medication adherence. While multiple studies have investigated the factors that lead to nonadherence [80,82,179–181] and ways to improve adherence after transplant [182], nonadherence continues to be a problem [81,180]. While structured tools – such as barrier assessments – provide opportunities to help address common issues faced by individuals after transplant [15], individuals face challenges that are personal and unique [183]. Understanding and detailing an individual's Kidney Identity through each of the five tensions may provide additional opportunities to surface potential adherence barriers. In addition, as Dr. Pollack et al. has previously described [183], photo elicitation could be used as a tool in clinical settings to support this discovery. Our work, describing the Kidney Identity and the utility of photo elicitation, can help provide clarity for patients by identifying how aspects of their clinical care – such as medication adherence and self-management – are affected by the highs and lows of their transplant journey and changes in their Kidney Identity.

Recognizing the transitory nature of the Kidney Identity tensions after transplant provides additional context to the challenges adolescents face transitioning from a pediatric, family-oriented model of health care to an adult, independent model. Adolescents and young adults who have chronic illnesses are exposed to many factors during this period of transition from adolescence to young adulthood [184,185], which can affect the patient's clinical outcomes and other aspects of their life. Having knowledge of one's Kidney Identity and how this identity fits into the larger picture of life and illness transitions can provide more clarity to patients and their families, such as deciding on when to seek help, when to prepare for changes, or what they value during these tough times. In conclusion, the Kidney Identity framework can help individuals regain a sense of normalcy by surfacing the five Kidney Identity tensions and making them visible to all

stakeholders. It also has the potential to reduce uncertainty and provide additional context to support patients and families, leading to improved health outcomes.

## 3.4 CONTRIBUTION

In this chapter, I identified five specific tensions that youth kidney transplant patients and caregivers experienced as they recalibrate to normalcy post-transplant. I contribute a rich empirical understanding of youth kidney transplant patients and caregivers' transplant experiences. From this understanding, I developed a conceptual framework that could be used to help youth transplant patients understand their transplant experiences throughout their journey, illuminating the fluctuations patients experience throughout their transplant journeys. In the next chapter, I probe further into youth transplant patients' experiences and discuss capturing youth's chronic illness journeys through stories.

# Chapter 4. EXPLORING KIDNEY TRANSPLANT PATIENTS' JOURNEYS TO INFORM THE DESIGN OF A TRANSPLANT JOURNEY TOOL

In this chapter, I switch between using the terms "I", "we", and "our" throughout because several areas of the Chapter are verbatim from the Proc. ACM Hum. Comput. Interact. 8, CSCW1, Article 213, [37] publication of this work. I acknowledge the shared contribution of all authors in the original publication. Youth who undergo a kidney transplant can experience a fluctuation of successes and challenges throughout their chronic illness journey. Designing to capture their journey could help youth to reflect on their experiences, collaborate on their care, and be empowered to live their lives to the fullest. In this chapter, I answer the following question: **RQ3**

**- Design:** How can an existing framework help inform the design of a tool to support the collection of youth and caregivers' transplant journeys?

I answer this question by presenting findings from an interview study with 11 youth kidney transplant patients and 12 caregivers to elicit their transplant journey experiences. We found that probing participants about specific parts of their transplant journey gave them structure to tell us rich stories about their experiences. Based on our findings, I discuss informing the design of a tool to support the capturing of stories for youth with chronic illnesses. Designing such tool could help youth and their caregivers to identify barriers, support reflection, and promote self-efficacy. Youth with chronic illnesses already have to change so many aspects of their lives to accommodate their illness; however, by giving them a platform to capture their chronic illness journey, it could encourage them to take more control of their lives and better collaborate with others.

## 4.1 METHODS

### 4.1.1 *Study Population and Recruitment*

All participants were recruited from a single pediatric transplant center that is part of Seattle Children's Hospital located within the United States. We had access to participants because two members of the study team are also clinicians at the transplant center. Most participants were recruited via convenience sampling by identifying individuals who fit the eligibility criteria and were scheduled for an upcoming transplant clinic visit. After participants were identified based on the clinic schedule, a member of the research team sent a list of the potential participants to a clinician on the study team to confirm the eligibility of the candidates. All participants were then contacted for recruitment either via phone call, patient portal, or email (for an example recruitment flyer see Appendix B; Figure B1). I recruited 23 total participants, including 11 youth who have had a kidney transplant and 12 caregivers of these youth.

Our eligibility criteria for participants included: (1) had a kidney transplant (2) English-speaking, (3) 7+ years of age, (4) had non-failing kidney function (i.e. a GFR >30 ml/min/1.73m2) [186], and (5) be a minimum of three-months post-transplant. Our youth participants (n=11) ranged in age between 7 – 22 years (median age = 13). More specifically, between the ages of 7-10 we had (n = 4) participants, between 11 - 14 we had (n = 3), between 15 - 18 we had (n = 3), and between 19 - 22 years old we had (n = 1). It is not unusual for youth with complex health conditions to continue being treated at children's hospitals into young adulthood. Our youth participants identified with the following genders: Man/Boy (n = 9), Woman/Girl (n = 2), and Transgender (n = 1), while our caregiver participants (n = 12) ranged between the ages of 27 – 58 (median age = 47) and identified with the following gender: Woman/Girl (n = 11) and Not Reported (n = 1) (see Table 3). One caregiver participant did not report any of their demographic information, which is marked as Not Reported in Table 3. Only one participant dropped out of the study after being consented, this youth participant was not included in the youth participant count. In this chapter participants of all age ranges may be addressed as youth to keep wording consistent throughout.

Table 3 - Study 2 Youth Transplant Patient and Caregiver Demographics

| Demographics | *Patients (n = 11)* | *Caregivers (n=12)* |
|---|---|---|
| Age (In Years) | 7 - 13 = 6<br>14 - 18 = 4<br>19 - 22 = 1 | 25 - 34 = 1<br>35 - 44 = 4<br>45 - 55 = 4<br>55+ = 2<br>Not Reported = 1 |
| Gender | Man/Boy = 9<br>Woman/Girl = 2<br>Transgender = 1<br>*One participant selected two genders* | Woman/Girl = 11<br>Not Reported = 1 |
| Race | White = 8<br>Chinese = 1<br>Some Other Race = 1<br>Not Reported = 1 | White = 9<br>Chinese = 1<br>Some Other Race = 1<br>Not Reported = 1 |
| Ethnicity | Not of Hispanic, Latino, or Spanish Origin = 8<br>Mexican, Mexican American, or Chicano = 2<br>Decline to State = 1 | Not of Hispanic, Latino, or Spanish Origin = 10<br>Mexican, Mexican American, or Chicano = 1<br>Not Reported = 1 |

### 4.1.2 *Study Procedures*

Before the interviews, all participants completed a consent/assent session with a member of the research team (for an example Assent Form see Appendix B; Figure B2). I interviewed each participant (pediatric participants and caregivers separately) in one ~60-minute-long semi-structured interview online via Zoom [162]. Youth and caregiver participants conducted their interviews separately, unless the parent or child felt uncomfortable and requested that the caregiver be present for the pediatric participant's interview. For almost all interviews, youth and caregivers completed their interviews separately and did not have a caregiver step in during the interview, with the exception of one interview when a caregiver stepped in to help their child answer when they were confused. After interviews were completed, participants completed a Redcap [187] demographics survey (Table 3). Participants (youth and caregivers) were each compensated with a $25 digital eGift Card, which they received via email. All study procedures were approved by the hospital's Institutional Review Board.

### 4.1.3 *Data Collection*

In developing our interview guides and analytical approach, I explored literature related to chronic illness journeys [18,127,128,188,189] and youth kidney transplant experiences [157–161]. While other work has explored aspects that youth kidney transplant patients and their caregivers experience, I felt that the framework I developed in Chapter 3 provided the most comprehensive and holistic view for this specific population, and more importantly focuses on the youth's unique and important perspective. Therefore, I utilized this framework to inform our interviews with the purpose of diving deeper into participants' transplant experiences.

The framework from Chapter 3 ties together multiple facets of their (a youth's) life including clinical, developmental, and social [3]. The framework details five dimensions (stated

as tensions in Chapter 3) which describe common experiences for both youth and their caregivers throughout their (post) kidney transplant journey (as a reminder, I have included the five dimensions below):

- **Dimension 1:** Telling One's Story - hiding vs. self-expression,
- **Dimension 2:** Exchanging Information - information consumers vs. information contributors,
- **Dimension 3:** Transitional Management - family management vs. self-management,
- **Dimension 4:** Building Confidence - worry vs. confidence, and
- **Dimension 5:** Normalizing Kidney Transplantation - feeling different vs. feeling similar

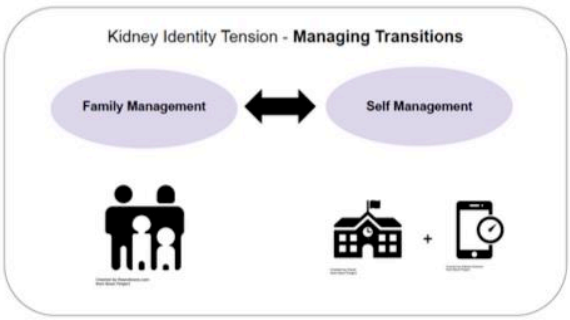
Qualitative semi-structured interview guides are often delineative of the topics that the interviewer wishes to explore [167,190,191]. Since our research question was, "How can an existing framework help inform the design of a tool to support the collection of youth and caregivers' transplant journeys?", I designed the interview guides to reflect the framework's dimensions to probe participants about their holistic transplant experiences (see Appendix B). In particular, I used the five dimensions of the framework to capture the positive and negative fluctuations youth often experience during their transplant journeys and potentially elucidate conflicts between their healthcare and non-health life needs. During the interview, I provided youth and caregiver participants with high-level visual representations of each of the five kidney identity dimensions (see Figure 4), via Zoom's screen-sharing functionality [162]. Alongside the visual representation, I also read out loud brief example scenarios of each dimension (see Appendix B). These scenarios incorporated examples from Chapter 3's findings [3] (see example scenario written below). For example, when describing the Transitional Management Dimension - family

management vs. self-management, I read the following two descriptions to youth patients about each side of the dimension:

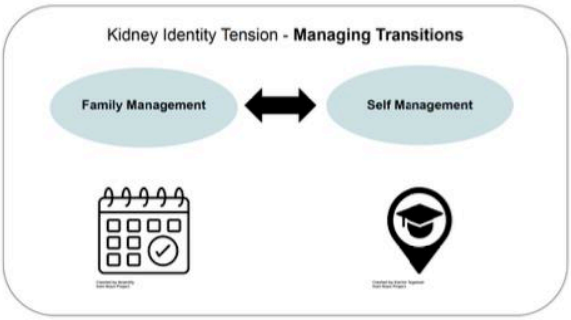
- **Family Management description:** Griffin is 11 years old and often relies on his parents to remind him about taking his different medications for his kidney. They set timers on his phone for him to follow and also check on him throughout the day to make sure that he takes them.
- **Self-Management Description:** Griffin is now 14 years old and starting high school. He is excited about starting high school, but also knows he will be involved in after school activities like theatre club and track which is usually when he would take his pills for his kidney. Griffin starts to make plans for the school year and how he will remember to take his medications, such as setting a timer on his phone.

To help explain the Kidney Identity Framework to participants, I used a metaphor, describing it as a pizza, "This identity is similar to a pizza, which has different ingredients, such as dough, pizza sauce, cheese, and toppings. Our identity that we will be talking about today has five different ingredients that make up this "kidney identity." I used the metaphor to help participants understand the concepts discussed during their interview and allowed them, particularly the youth, to feel comfortable talking about their holistic journey. In addition, I purposefully designed the metaphor as a fun precursor, to relax the participants and help them feel comfortable discussing the different, and at times emotional, aspects of their journey. After this explanation, I began the semi-structured interview questions, organized by dimension. I created separate interview guides for caregivers and youth participants with different example scenarios and descriptions for youth and caregiver participants (see Appendix B).

After reading participants the example dimension scenarios, we then moved on and began to ask participants interview questions. The interview questions focused on probing about specific parts of kidney transplant patients' and caregivers' journeys to better understand their experiences (see Appendix B). All semi-structured interviews were audio and video recorded and later transcribed for analysis.




(a) Transitional Management Dimension Card for Youth




(b) Transitional Management Dimension Card for Caregivers

Figure 4 - This figure depicts the two Transitional Management Dimension cards displayed to youth (figure 4a) and caregivers (figure 4b) during their interviews. These cards were simply meant to provide high- level visual representations of each of the five kidney identity dimensions to go along with the scenario descriptions.

### 4.1.4 *Analysis*

To begin analysis, I and another member of the research team reviewed 3/4 of the transcripts individually and took notes on reoccurring themes that were shared in the interviews, then subsequently met to discuss and compare observations. Following this initial pass, I went through the transcripts a second time and pulled quotes by Kidney Identity dimension that aligned with the first set of discussed themes. I sorted the quotes by dimension and then created digital FigJam sticky notes for each quote in FigJam [192]. Next, the research team met and categorized the quotes via affinity diagramming [193,194]. Each affinity diagramming session (one per Kidney Identity dimension) lasted approximately one to two hours, where two to four people from the research

team organized quotes. During each session each person was assigned, reviewed, and sorted a random subset of the quotes independently for 10 to 20 minutes; after individual sorting, the group discussed the individual categories of the quotes. After the group discussion, overlapping categories were identified and grouped together, and finally, I re-reviewed all quotes to make sure they were placed in the correct category.

## 4.2 RESULTS

We found that probing participants about specific parts of their transplant journey gave them structure to tell us rich stories about their experiences. In this section, we are characterizing the different types of stories that our participants discussed for each of the dimensions of the Kidney Identity framework (see Table 4). Quotes from youth pediatric transplant patients are identified by "Y#" and their primary caregiver as "C#", with the number being a unique identifier for each participant assigned by the research team.

Table 4 - Story Categories Captured from the Kidney Identify Framework Dimensions

| Kidney Identity Framework Dimensions | Story Categories |
|---|---|
| Telling People About Your Kidney Transplant Journey | - Stories about Barriers and Benefits to Sharing About Your Journey<br>- Stories about Community |
| Exchanging Information Throughout the Transplant Journey | - Stories about Lack of Interaction with Other Transplant Families<br>- Stories about Building Self-Efficacy |
| Transitional Management Throughout the Transplant Journey | - Stories about Responsibility and Planning for the Future<br>- Stories about Successes and Challenges of Transitioning |
| Building Confidence Throughout the Transplant Journey | - Stories about Fear<br>- Stories about the Road to Confidence |
| Normalizing the Transplant Journey | - Stories about Removing Healthcare Burdens and Reconnecting with Your Community<br>- Stories about Accepting Differences and Establishing a "New Normal" |

### 4.2.1 *Dimension 1 – Telling People About Your Kidney Transplant Journey*

***Stories about Barriers and Benefits to Sharing About Your Journey***

Several participants told us different stories about personal barriers they experienced in telling people about parts of their kidney transplant journey. Y8, Y9, and Y10 were nervous about how other people would react when they learned about their transplant journey, while C2 and C4 talked

about feeling unprepared to explain to people about their child's illness. Y2 told us a story about the awkwardness of trying to bring up his looming transplant into everyday conversation with his friends and now, reflecting on the moment, wishing he had brought it up sooner. Both caregivers and youth participants told us stories about the non-linear experiences they have had when trying to open up about the kidney transplant journey. For youth participants having these fluctuating periods of being comfortable talking about their transplant journey was often a part of their sense-making process. C5 told us a story about P5's sense-making process:

> *"I can definitely relate to this in a sense that his journey's been on a spectrum where it hasn't always been the same. He's gone through periods of what I would call hid- ing. Where it was a lot of why. Why can't I? And I think over time, obviously, those questions have all been answered and so he's just absorbed it and moved on and it has accepted, I think, in his own way, this is my normal." - C5*

On the flip side, Y13 and C13 always felt open to telling people about their kidney transplant journey experiences. Y13 told a story about how their fun-fact during school orientations was about their kidneys, *"It's like everyone else's fun facts in sixth grade orientation was like, "I'm reading this book. I visited this place."* Me, *"I had a kidney transplant when I was three years old, because both of them decided to fail on me and they never figured out why."* illustrating acceptance of their illness. Others like C10 told us how it's always been a part of Y10's story because they were born with their illness, *"I mean Y10 was born with kidney issues, so she's never known any other way."* Most of the youth and caregivers felt that they fluctuated in their willingness to talk to people about their kidney transplant experiences throughout the course of the transplant journey, however, as both youth and their caregivers reflected on their different periods of "hiding" and "self-expression" it was transparent that when they had moments of hiding it was often coupled with feeling uncertain, while moments of self-expression were often coupled with feelings of

understanding and control over their transplant journey. We can help caregivers and youth reflect on moments of hiding, so they can uncover barriers towards what is making them feel uncertain or in less control of their journey. As well seeing when and why they transitioned to moments of self-expression may reveal avenues to help them build towards and sustain staying on the self-expression side of the dimension.

***Stories about Community***

When probed about this aspect of their journey, youth participants and their caregivers told us several different types of stories around the category of community. Some caregivers and youth participants told us stories about their immediate family and how the youth's illness journey has become a part of their immediate family's own life as well (C9, C7, and P9). C9 told us a story about how this has become a part of P9's grandma's life and that it affects her day-to-day life:

> *"She has joined a Facebook group. So, she's always online, concerned about P9 and thinking about and looking for the latest medicines, treatments for keeping people in remission...So she gives me things that she's finding in her research...I'll bring it to X or Dr. X... So, it's affected her life." – C9*

Youth participants and their caregivers talked about how having to tell others about their kidney transplant journey helped them both build a better community network as well as it helped make their experiences more positive, because they had a community of people with whom to share their stories. C4 told us about how she was encouraged to join a certain type of pre-school and it led to her telling more people about their (her and her child's) kidney transplant journey more confidently, *"...And so you create a sense of community. And it was really that sense of community that started to empower me to speak up for what I needed to take care of Y4. Like, Okay, well he's a little different and I'm going to practice feeling empowered to say he can't have this ice cream or whatever it was."* Even though participants discussed the importance of telling

their story and how this can influence their relationship with their community, it was also noted that they lacked the ability to tell their story to other transplant families. The kidney transplant journey can be a long process for these youth and their families if they feel that they do not have the support of a community. Seeing how their journey has affected different parts of their community (e.g., immediate family) it may encourage youth and their caregivers to reflect on their experiences together and overall have more open conversations. Being able to reflect on their successful moments of building their community may also encourage these families to continue building support in moments when they are hesitant to discuss their journey.

### 4.2.2 *Dimension 2 - Exchanging Information Throughout the Transplant Journey*

***Stories about Lack of Interaction with Other Transplant Families***

When talking about exchanging information, something that we heard from almost all our youth participants was that they have rarely or *"...never talked to someone else who had a transplant"* (Y10). This left some of the youth feeling alone in their journey like Y4, *"...usually sometimes (I) feel like I'm the only one who has ever had a kidney transplant as a kid."* Caregivers also told us stories about feeling alone during stressful times of the kidney transplant journey and like C2 they expressed that it would have been, *"helpful"* to have heard about other transplant families who have been through similar experiences. A handful of the youth and caregiver participants did have experiences exchanging information with other people who have also been through difficult medical experiences, like Y13 who told us a story about the types of conversations they have with a friend who also frequents the hospital:

> *"We'll be at lunch and just normal conversation happening next to us at the table, and we'll just be like, "Hey, want to see the MRI I had?" It's just randomly talking about this stuff to each other, and it's kind of funny sometimes, when we're talking about it around other members of our friend*

*group because one of us will share this fact that's probably horrifying to people who don't visit the hospital a bunch..." – Y13*

Feeling understood such as Y13 did when they were able to exchange stories with their friend can be beneficial for this community since they often lack interactions with other transplant families. Other potential benefits for this population when sharing their stories with one another could be exchanging positives about the transplant journey and learning about new medical possibilities, like C4 who told us about their willingness to talk to others about different medical related things, *"...like how to navigate, and how to advocate, and how to partner with providers, and in the medical system, I've always been very open to sharing".*

Participants also talked about how if they shared stories with another transplant family or patient it may be beneficial, because they could compare experiences and learn from others across experience levels. C6 told us about some positive experiences she has had sharing their (her and P6's) transplant stories online, because they were able to *"compare some notes, compare experiences"*, which gave their family a *"new perspective"*. Hearing about others' transplant journey stories has the potential to help these patients and their families feel less alone, normalize different points of their journey, hear success stories, learn about new medical possibilities, and overall be able to compare and learn from others across different experience levels.

Even though a majority of both our youth and caregiver participants expressed interest in exchanging information with other transplant families, we did have some participants that were uninterested in connecting with others. These participants lacked interest for several reasons, including that they only wanted to experience things on their own (C1), they needed their child to be at a stable enough point of their journey (C7), they were worried people may feel bad when comparing transplant experiences (C7), or they were not at a state of being where they were ready

to share (C4). Several participants also expressed hesitation with the idea of connecting online with others, because they *"don't really do social media"* (C12), they don't consider themselves a *"computer person"* (C8), or they had mixed feelings towards connecting online with others because of past experiences.

***Stories about Building Self-Efficacy***

Another theme that emerged as a benefit when exchanging information was the potential for both youth and their caregivers to build self-efficacy. Shifting from receiving to sharing information will not always be a one-way street throughout the transplant journey, instead participants told stories describing how it is always a learning process. Y2 and C12 expressed to us how they think that they will always receive and share information:

> *"Yeah, I think it's really best to always do kind of both, I would say, to always get in- formation and improve on your own life through that information and also share to help other people." – Y2*

> *"For both of these really, because it's always and forever, that's kind of the diagnosis. This is forever. I'm going to have a young adult...I'm going to have to relinquish control, and that's still going to be hard. Harder in different ways than it will be for my other kids, to do that." – C12*

Due to their life long chronic illness, working towards self-efficacy is essential for these youth. In order to work towards self-efficacy, it will be important for them to reflect on how they exchange information throughout their transplant journey. Recognizing who, when, and what type of information is important to communicate about throughout their journey is essential in supporting youth as they work towards self-efficacy.

### 4.2.3 *Dimension 3 - Transitional Management Throughout the Transplant Journey*

***Stories about Responsibility and Planning for the Future***

When probed about the transitional management aspect of their journey, we received a lot of different stories from both youth and their caregivers about who is responsible for the youth's kidney health, how they are responsible, and what stage of self-management they are currently in. In their stories, participants emphasized the notion that transitioning to self-management cannot be done in a single move, but instead it is a learning process for everyone involved and can take many years. Many of our youth participants recognized that they still rely on their different caregivers to help manage their kidney health (Y3, Y4, Y5, Y6, Y9, Y10, and Y12). Some caregivers described themselves as the primary *"directors"* (C1) of their child's kidney health and that they will continue to be in the foreseeable future, because of the child's current developmental stage.

Youth, as they reached certain stages of their life, started to recognize though that they should also start to take on more responsibilities for their kidney health: *"My parents. So, my parents are responsible, but I should be too..."* (Y6). Several of the youth told us stories about the different stages of self-management that they are in, which ranged from drinking water and making sure to go to the bathroom (Y5), to taking their medications on time (Y13, Y8, Y10, Y9, and Y3), and attending doctor's appointments alone (Y8). However, learning to self-manage is not only about taking medication, but also about learning how to integrate their healthcare into their everyday lives, such as Y13 when they attend a school dance:

> *"...if I'm going out somewhere with my friends, like to a school dance for example, that I know is going over the 7:30 time period, I'll tuck my meds into a pocket, bring it along, and I'll pick one friend... I'll still have my phone with my alarm in my pocket and everything, but I'll pick one friend, whoever seems like they'll be the most responsible at the moment, and just be like, "Hey, I*

*know I have my alarm for 7:30 to remind me to take my meds, but could you just come find me around that time to make sure I've done it?" and I have never missed meds on a school dance night." – Y13*

It was clear from several participants' stories that as youth get older there is an expectation for them to become more independent, but doing so takes time and often requires parents and youth to start thinking about it from a young age. Such as C10, who told us her current and future thoughts about small steps towards independence for their child, *"...She's X age though, so she's a little young to have her own device...So maybe when she's a little older, we'll get her a smart watch or something we can send her reminders or I don't know, something to help her self regulate more..."* (Y10). Caregivers were not the only ones who told us stories about their different goals for transitioning to self-management, several youth also had different goals for self-efficacy, like Y5:

*"Yeah. I'd like to start taking my medicine on my own and set my own timers and all that...Well, I just sort of I want to be prepared to be more in independent for when I keep growing and eventually get out into the real world. So, yeah, I just want to learn to do things about myself eventually." –Y5*

Transitioning from family to self-management can be a tedious learning process for everyone who is involved. Our participants' stories illustrate that throughout the kidney transplant journey there is an ongoing conversation that must be had, so youth are supported but also encouraged to work towards self-efficacy. Capturing participants fluctuating experiences throughout their journey has the potential to help these families identify what stage of transition they are in, what successes they have had so far, what barriers they are coming up against, recognize if they should start prepping for success, and overall encourage open conversations between youth and their caregivers about who is responsible and how they can work towards their different management goals together.

***Stories about Challenges of Transitioning***

Working towards self-management does not come without barriers and the different worries that come along with those barriers. Youth participants of different ages and caregivers talked about different barriers they experience, including but not limited to barriers about: taking medications, drinking enough fluids, communicating with clinicians and other people about their kidney, and more. Youth of all ages and their caregivers recognize that there are different stages to transitioning to self-management and that each step matters. Several caregivers told stories about why they are worried about their kid transitioning to self-management in the future, such as if they will remember to take their medications and schedule appointments (C2). Even when the caregivers were excited to transition their child to self-management, they also had worries in the back of their mind, such as C5:

> *"Oh yeah. He is definitely ready for that and I'm excited to pass that baton. I think one of our concerns is that...mornings are very hectic and so he takes his meds before he leaves for school, and then before bed. And with the mornings being hectic and he's not a morning person, so sometimes it's all he can do to just remember everything to get out the door. And then at bedtime usually he's just ready to have sort of like free time where he's not having to follow a schedule or abide by a schedule. So, but I think that, for him, as long as he can put it into memory, he can be very routine. So I don't think it'll be a problem."*
> *– C5*

When talking about this specific aspect of their journey caregivers also brought up stories about how far their child has come and they reflected on feeling proud of their child, because of everything they have gone through and the different wins they have experienced along the way. C4 reflected on a story about seeing her son's personal growth and what that meant for his empowerment, *"I think where this really comes into play a lot is with empowerment in medical situations. Like medical trauma, PTSD, whatever you want to call it, is real for these kiddos. And so that's really been an evolution of him being able to take control of those situations and make*

*them feel a little bit more manageable, like with blood draws. So in that sense, he's been very hands-on. Yeah. And wanted to put the little rubber band on, and he chooses his own vein, and chooses his arm, so in that sense. But although that's kind of a different question, but he does show real, like he wants to be a part of that process."* By capturing these different wins and providing the ability for both youth and their caregivers to reflect on these different "wins" it can help provide them with a sense of positivity as well as encourage future growth towards self-management.

### 4.2.4 *Dimension 4 - Building Confidence Throughout the Transplant Journey*

***Stories about Fear***

Interestingly, when discussing the building confidence dimension most of the caregivers we interviewed had stories on the "worried" side of the dimension, but there were almost no quotes from youth participants about that side of the dimension. Each of the caregivers' stories all stemmed from different types of fears, such as fear of different kidney related health concerns or fear of the unknown. One acute fear that several caregivers reflected on was the day of their child's transplant (C1, C6, and C8). C1 told the story about Y1's day of transplant and her fear of complications, *"The biggest worry... Especially I was thinking on the day when Y1 gets to be admitted at the operation room, that something happened, because they told me that there might be complications or that he might need blood transfusion or something like that."* Part of the worry described by C1 is fear of the unknown, which was also a common fear amongst several other caregivers (C2, C3, C9, and C12).

Another fear that was expressed by some of the caregivers was the fear for their child's wellbeing when they were in environments not controlled by the caregiver. Even after youth received their transplants several caregivers as well as a youth participant told stories about the fear of being in an environment where they have less control, and their kidney might become

damaged. Such as C1 who worries when Y1 is at school, *"The only thing that worries me is that, during the day when he is at school...I don't want him to get hurt or to fall, or somebody kicks his stomach or something like that,"* or Y5 who worries when they do different activities, *"So, well, the only thing I really worry about is damaging my kidney if I do activities that are too crazy, and like I get into some accident".* Beyond fears about health concerns some caregivers discussed their fears of collateral damage to their child's life, such as C12:

> *"And then within the first few years after the transplant, I'd say maybe between two and four years. The worry is, you're like, "Okay. So my kid has this limitation, but he needs to feel the limitation so that he's safe, but not be limited in his life." – C12*

Even though caregivers told us stories about the many different types of fears they have for their child, they also told us stories about how their and their child's confidence has changed throughout the transplant journey.

***Stories about the Road to Confidence***

When telling stories about why they feel confident both youth and their caregivers talked about how they feel confidence in living through the journey. Y2 told us about how setting a kidney related goal and living through that increased his confidence, *"...because when you have milestones, maybe like getting to one year past transplant and having actually done it, that kind of boosts your confidence, because you look like, "Wow, I actually been able to do this for an entire year.""* C6 similarly talked about living through P6's kidney transplant journey:

> *"...but the confidence I think comes from a lot of just living through it. The trial and error, figuring out what work and keeping positive...It doesn't have to be a bad thing that you have kidney disease, and I truly believe that he's the person he is and the person he's becoming because of it." – C6*

Others told stories about feeling more confident, because they were getting back to their routine and feeling normal again. Y9 and C9 both told stories about going back to their normal eating habits and not worrying about the type of food Y9 has to eat, *"...having to drink more and like what I eat, for like sodium and potassium and stuff. Now I don't have to worry as much"* (Y9). While others like Y8 talked generally about *"doing the stuff"* they couldn't do before *"without any problem"* now.

Both youth and their caregivers also told stories about confidence in their self-efficacy. Caregivers like C1 talked about confidence in being able to take care of their child, *"...make me feel confident is that I have the ability to do what is best for my child''*. Youth like Y10 talked about gaining more confidence in things like taking their medications, *"For me medicine, I'm actually kind of confident because I don't spit it out anymore."* Our participants seemed to enjoy talking about all the ways they felt confident, because as they talked about it, it gave them the ability to reflect on how strong they are for everything they have been through, prove to themselves that they are able to get back to their version of "normal" as well as show them how they have gained self-efficacy throughout the journey.

### 4.2.5 *Dimension 5 - Normalizing the Transplant Journey*

***Stories about Removing Healthcare Burdens and Reconnecting with Your Community***

Youth and caregiver participants told us stories about their fluctuation of experiences related to normalizing their journey by establishing a new or comfortable routine. They told us stories about a variety of different healthcare burdens and how their lives have changed by having to deal with these burdens less or not at all post-transplant. Several participants brought up stories about the reduction of burdens when their child was no longer on dialysis, such as C9 who told us about how the everyday task of showering became easier when P9 was off dialysis:

*"That was a big issue. "Mom, I want to take a shower today." Hold on. Let me get everything ready. Tucking in the wires for dialysis...then you feel similar to everyone else in the family that doesn't have to put an Aquaguard on to take a shower and be careful and that was a big one." – C9*

For patients who have chronic kidney issues what they eat and if they feel good enough to eat can be severely impacted prior to transplant. Several participants including C1, C3, Y3, C9, and C13 all told stories about what it was like for them or their child to be able to eat more freely. Others told stories about how their burdens felt less when: they were able to go back home post-transplant, they frequented the hospital less, they didn't have to go in for labs as much, or when some of their everyday activities became physically easier.

Another aspect that was made easier by having reduced healthcare burdens, which helped participants feel back to their version of normal, was when they were able to reconnect with their different communities. C1, C5, and C12 all told stories about how pre-transplant their families had to change their routines and that as a family they couldn't get out as easily, even weekly activities like going to the *"grocery store"* (C12) was difficult. As opposed to post-transplant, some participants, like C10 expressed how they were able to get out more as a family, *"...we didn't have to say, "Okay, we have to go now because Y10 got to do her dialysis." So, we had a little more wiggle room as far as goes, being able to do things in the evening, that sort of thing."*

A few caregivers expressed that their children post-transplant started to rejoin the curve, such that their kids were catching up on different developmental milestones (e.g., with school). This was mentioned less frequently by caregivers, but for the caregivers who did mention it they were excited that their child was able to reconnect with their similar age-mates. A handful of participants also talked about reconnecting with some of their different communities because they were able to participate in more physical activities.

***Stories about Accepting Differences and Establishing a "New Normal"***

Another part of normalizing their transplant journey for both youth participants and their caregivers was when they accepted what made them feel different or established their "new" norms. Some participants told us how different parts of maintaining their or their child's kidney health became their "new normal" routines throughout different parts of the transplant journey. C5 expressed how dialysis *"started to become normal for us"* and they went on *"autopilot"*. Y8 *"...just felt normal*" a few years into taking their medications and seeing doctors regularly. C6 expressed how they are very intentional about *"...getting into the routine, making it the new normal"*.

Beyond establishing new normal routines, another part of normalizing the transplant journey for participants was accepting their differences as their version of normal. Y13 told us about how they have gotten used to talking about their kidney and answering different questions about it and that they have *"...heard these questions enough times, they just get bored at this point..."*. Other youth participants like Y2 and Y8 expressed that some parts of their kidney transplant journey used to be difficult for them to accept but now they *"...don't really care anymore"*. It is inevitable that both youth and their caregivers during different parts of their transplant journey will feel "different" but by bringing into focus what makes them feel their version of "normal" throughout both the difficult and stable parts of their journeys, this may be key to helping them discover barriers they may be coming up against, feeling a sense of community, and establishing what they want their "normal" to be.

## 4.3 DISCUSSION

The kidney transplant journey, similar to other chronic illness journeys, consists of many stories that encompass patients' experiences. Patients' stories provide youth, caregivers, and clinicians

with a holistic view of patients' transplant journeys. In our findings, we characterized the different stories youth and their caregivers told us when probed about different dimensions of their kidney transplant experiences. We found that using Dunbar et al's Kidney Identity framework (Chapter 3) to inform our interview guides helped our participants to reflect and tell us stories about their transplant experiences. Youth in the age ranges we worked with are not always the most forthright in speaking about their experiences, but using the framework helped to ground them at a high-level in the interview topics as well as be more open about their experiences. In the following sections, we will discuss how our findings can inform the design of a kidney journey tool to support the collection of kidney transplant journeys. We demonstrate how designing to capture kidney transplant stories may help youth patients, their caregivers, and their clinicians collaborate to identify barriers, support reflection, and promote self-efficacy for youth kidney transplant patients.

### 4.3.1 *Supporting Reflection*

Youth kidney transplant patients, caregivers, and clinicians regularly reflect on youth patients' health records and other quantitative data to determine a youth's health status throughout the transplant journey; however, their ability to contextualize what is happening during these different periods is lacking. After using an existing framework to successfully probe youth transplant patients and their caregivers about their kidney transplant experiences, our findings revealed that youth and caregivers have a multitude of stories to tell (e.g., stories about building self-efficacy or stories about accepting differences and establishing a "new normal"). Based on these findings, we conclude that designing a tool to capture the stories of youth kidney transplant patients and their caregivers can help support stakeholders to reflect on their kidney transplant journeys. Researchers have explored and continue to explore how technology can play a role in encouraging reflection

[195–197]. Lim et al. [198] has explored the facilitation of self-reflection among individuals with chronic conditions and [199] has designed tools to support health and wellness reflection.

We discovered that using the Kidney Identity framework and its five dimensions to inform our interview guides gave participants structure to reflect on specific aspects of their experiences, while still allowing them to share about a myriad of their experiences as stories. As participants shared their experiences for each of the "Kidney Identity" dimensions we noticed how participants, without prompting, discussed stories from different times of their transplant journey, including their past, their present, and even their future. This population of youth in particular may benefit from capturing "future" stories, because it can be difficult for them to understand and imagine how their current choices or decisions influence their future selves, such as described by Hershfield's idea of future self-continuity [200–203]. Therefore, a potential kidney transplant journey tool should allow stakeholders to capture stories during different periods of their kidney transplant journey, including future stories. Future stories could capture different topics, such as youths' dreams and aspirations about "when they grow up" or more mundane topics, such as successfully scheduling their own medical appointments or handling their prescriptions independently.

Importantly, future stories could also capture the fear and worry patients and/or caregivers have about growing up with kidney disease and living with a kidney transplant. A collection of current and future stories allows for collaborative reflection, leading to the development of strategies to help youth achieve their best possible future outcomes based on their current state. For example, should a future story identify the youth taking a more active role in their self-management, yet currently they still rely on their caregivers, a collaborative discussion can focus on concrete steps and actions which would help the youth gain more independent skills. In addition, if a future story captures undesirable events or fears, the team can reflect on and develop

prevention strategies. Therefore, a future kidney transplant journey tool to capture patients and caregivers written or audio recorded transplant journey stories should support self-reflection and promote collaboration between youth patients, caregivers, and clinicians to identify and address previously unrecognized barriers that interfere with their future goals and aspirations.

### 4.3.2 *Encouraging Self-Efficacy*

While sharing stories across stakeholders has the potential to support collaboration with others, interestingly, in our findings we noticed that the process of sharing their kidney transplant experiences actually supported their own reflection, leading to new insights about their kidney transplant journey and facilitated self-efficacy. As youth living with a chronic illness grow up, most eventually become independent and responsible for managing their health and other life needs [90,91,204]. This transition requires that youth engage in decision making and self-management, a frequent topic explored by clinical, CSCW, and HCI researchers alike [104,105,205–208]. Decision making and self-management are two examples of skills that affect youth's self-efficacy, i.e. youth's belief in themselves to act in ways necessary to reach their goals. Limited self-efficacy prevents their drive to pursue future independence and autonomy. Yet, for many youth, it can be challenging to see their own growth and progress. Therefore, capturing stories over time which highlight their individual successes, especially when they have overcome barriers, can facilitate perceived self-efficacy, which in turn facilitates self-management [209].

A key challenge to self-efficacy for youth living with a chronic illness is when their healthcare and non-healthcare life needs conflict. It can be difficult to decipher how health and life needs intertwine and affect one another throughout the course of an individual's journey. The rich stories describing the transplant journeys from youth and caregivers revealed many barriers between their healthcare and life needs and how these barriers interfered with self-efficacy. Yet,

the stories also demonstrated how these youth and caregivers are constantly striving to harmonize their life and healthcare needs and overcome barriers, but it can be difficult to identify these different needs and conflicts.

As a first step, capturing stores of conflict provides an opportunity to consider all their healthcare and non-healthcare life needs, within the same context, and therefore provides a more holistic understanding of their transplant journey. To facilitate this, participants need to organize their stories into relevant topics, especially those which are frequently known to highlight conflict. In addition, we suggest that participants have the ability to tag their stories by the categories we identified in our findings to provide additional context. By tagging their stories with these different categories, youth and caregivers can more easily seek targeted opportunities for collaborative problem solving (i.e. overcoming fear or building confidence). Providing youth with a better understanding of their healthcare and life needs may help them feel more confident in understanding the barriers they experience between their needs, and help build self-efficacy.

### 4.3.3 *Visualizing Information to Augment Stories*

We found that using an existing framework to probe participants about specific parts of their transplant journey gave them structure to tell us rich stories about their experiences. Expanding upon the success of using this existing framework to probe participants about their experiences, Dunbar et al's framework (Chapter 4) could also be used to capture a snapshot of their experiences in a different medium. Each of the dimensions resonated with participants, however, participants may not always have the time or energy to tell rich stories. To supplement the narrative stories of the transplant journey, visual features could be incorporated that capture the self-reported state of an individual within each of the five "Kidney Identity" dimensions. Other research has shown that such health visualizations can help participants understand their health outcomes [210–212]. By

moving a slider bar between the two tensions for each dimension (e.g. Building confidence: were they feeling more worried or more confident), provides another way to capture the story (Figure 5).

A participant could choose to capture their "Kidney Identity" slider bars either alongside their story or as a separate source of information on its own. The juxtaposition of the qualitative components of the narrative story with the quantitative elements of the visualization provides new opportunities for reflection, especially when compared over time. Even though stories provide in-valuable contextualized information into individuals' transplant journeys, we recognize writing or audio recording stories can be time consuming. Giving participants the option to capture their dimensions in another format either alongside their stories or on their own could be a way to instead provide a quick snapshot of moments during their transplant journey. At an individual level, participants could benefit from capturing their stories, but may also benefit from quicker snapshots of their journey over time. The proposed health visualization expands on Dunbar et al's framework (Chapter 3) by providing participants with another medium to capture information about their transplant journey over time, facilitating another way to help youth, caregivers, and their care team collaboratively identify barriers, support reflection, and promote self-efficacy for youth kidney transplant patients.

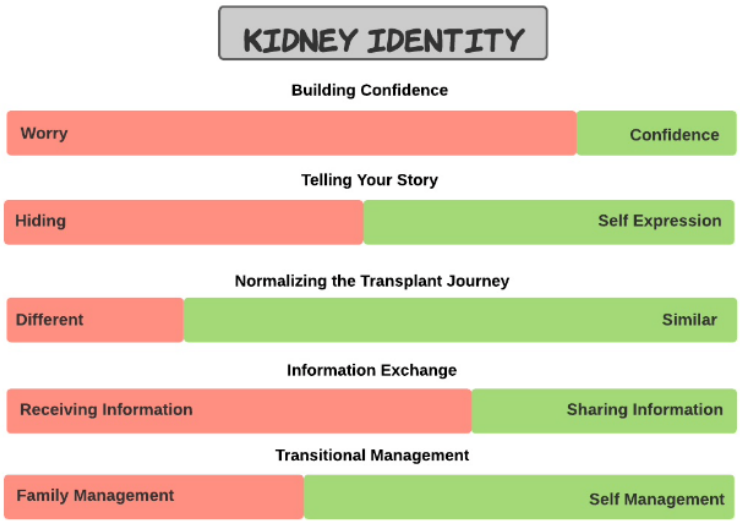



Figure 5 - This figure depicts an idea for a design feature that could be a part of a future Kidney Journey tool. The depicted design feature is an image of the five dimensions of Dunbar et al.'s Kidney Identity framework (Chapter 4) as horizontal slider bar scales. Each of the five slider bars are one of the five dimensions and the two sides of the slider bars are the two sides of the dimensions.

### 4.3.4 *Sharing Stories*

Even though our study shows numerous individual benefits to developing a tool for youth participants to capture their kidney transplant journey stories, we are still determining whether and how it may benefit participants to see or listen to other kidney transplant community members' stories. In our findings, we consistently heard from both youth and their caregivers that they have rarely or never interacted with other youth kidney transplant patients. Individuals with chronic illnesses often lack interaction with others in their own chronic illness communities and thus many adults with chronic illnesses turn to online communities [28]. Individuals join these different types of online communities (e.g., social media or vlogs) for a variety of reasons including, but not limited to, using them as a form of support for chronic illness management or to engage with others who have similar experiences as their own [25,93,213–215]. Online communities provide many

benefits to individuals who are on them, such as being able to share stories [216], but these online communities typically lack structure around how information is distributed, making it difficult for individuals to find content they are interested in or build relevant networks of people with similar experiences [27,217]. Also, these online communities are usually developed with adults in mind and lack appropriate moderation for youth.

Giving youth access to other transplant patients' stories may help them feel like a part of a kidney transplant community, which most of these individuals lack. Capturing stories from a variety of transplant patients will allow individuals to view other transplant patients' stories and recognize similarities or differences to their own story. Recognizing these similarities and differences may benefit these youth by making them feel less alone or helping them normalize their experiences. Since many of these youth lack the ability to interact with other youth with their same illness, they may not have a baseline understanding of what others go through. Accessing others stories may provide youth with interesting healthcare and life related information that can help youth normalize and compare their own experiences against others. In addition, it might help them identify previously unrecognized problems or challenges that they have adapted to, by identifying differences with other transplant recipients. Lastly, there is an opportunity to learn from other youth, specifically by seeing how others have approached and overcome similar barriers or challenges.

Although being able to compare their experiences may be beneficial for youth, such as being able to normalize or learn from others experiences, it also runs the risk of the youth negatively comparing themselves to others and creating unrealistic expectations [218,219]. We see potential in allowing youth to have access to other transplant patients' anonymous stories in a

future kidney transplant journey tool, but feel that this needs further exploration prior to implementation within a new tool.

## 4.4 CONTRIBUTION

In this chapter, I probed participants about specific aspects of their kidney transplant experiences to gain a deeper understanding of their transplant journeys. I found that the five dimensions of the Kidney Identity framework (Chapter 3) supported participants as they told rich stories about their transplant experiences, and more importantly, I highlight the conflicts and synergies between their health and non-health life needs. From these findings, I contribute empirical results in how to characterize youth transplant patients and caregivers transplant journey stories. I then surface new insights for designing tools to support youth kidney transplant patients in reflecting on their experiences and collaboratively identifying and communicating about health and life barriers. In Chapter 6, I use these new design insights to inform the design of my Kidney Journey tool.

# Chapter 5. DESIGNING MEDICATION MANAGEMENT VISUALS WITH YOUTH TO INFORM THE DESIGN OF A KIDNEY TRANSPLANT JOURNEY TOOL

Another component that forms part of many youth's chronic illness journeys is their medication management (i.e. adherence). Throughout their journey, youth work together with their caregivers and clinical care team to manage their medications, with the goal being for youth to manage their medications on their own successfully. Even though medication management has been identified as a key component in maintaining youth's health, many still struggle with managing their medications throughout their journey, impacting their overall health and wellbeing.

Adherence is often thought of as a dichotomy: individuals either did or did not take their medications. However, this may be oversimplifying something that is much more complex and nuanced. When youth with chronic illnesses and their families experience barriers in managing their medications, it is often due to a variety of different reasons. In this chapter, I answer the following question: **RQ4 – Design:** What are design insights for medication management visualizations to aid youth and caregivers in better understanding their medication management throughout their journey?

I answer this question by reporting on findings from the medication management task of a design session (that was part of a three-part design session study) with 14 youth kidney transplant patients and 16 caregivers. Participants were able to interact with other members of their transplant community and explore different aspects of their individual kidney transplant journeys, with the purpose of developing meaningful design insights for medication management visuals to support patients in understanding their medication management. The findings in this chapter further emphasize harmonizing health and life needs and highlight a need for medication management visuals to go beyond simply capturing if youth kidney transplant patients did or did not take their medications. Based on these findings, I discuss how medication management visualizations should be designed to better reflect the complexities of medication management.

## 5.1 METHODS

### 5.1.1 *Study Population and Recruitment*

All participants were recruited from two large transplant centers located in the United States: (1) Seattle Children's Hospital (SCH) transplant center located in Seattle, WA and (2) The Johns Hopkins University (John Hopkins) center located in Baltimore, MD. SCH's center is part of a large children's hospital, while Johns Hopkins is part of a large hospital that treats both adult and

youth patients. These two centers were selected because members of the research team are clinicians within these centers and could assist in recruiting participants.

I relied on my collaborators to inform individuals about the research project at Johns Hopkins transplant center. If an individual from Johns Hopkins was interested in participating in the study, they either called or emailed me to schedule a screening phone call to determine eligibility. The screening of the Johns Hopkins participants was completed by me and a few other SCH research team members. Recruitment at SCH was done via convenience sampling by identifying individuals who fit the eligibility criteria on a transplant clinic list (nephrology and transplant teams maintain a list of patients who have received a kidney transplant and are currently receiving care). All participants were initially contacted for recruitment either in-person at their clinic visit, where they were given a recruitment flyer or remotely, via a phone call or email. Initial recruitment via email or phone call was utilized in cases when email communication already occurred clinically, and a patient's email address was already known to the study team.

In this study I worked with youth between 10 – 21 years of age. I chose to include children within this range of ages because they are likely to have unique information needs that differ from adults. In addition, children and adolescents have higher risks for non-adherence (not taking their prescribed medications) after a kidney transplant compared to adults (ages 18+), and it is critical that they are involved in this type of research to explore potential interventions that reduce these risks. For this study both English and Spanish speaking participants were recruited (see Table 5), all Spanish speaking participants were recruited from SCH's transplant center. To assist recruitment with the Spanish speaking population, the research team and I partnered with the SCH research institute's clinical integration hub [220]. A member of their office helped with translation and interpretation services during both recruitment and study visits with these participants.

Participants completed the same study procedures, however, everything was translated and conducted in Spanish (see ; Figure C2 for an example of a translated recruitment flyer). Potential participants without internet access were excluded because having an active internet connection was required to participate in the study. All study procedures were approved by Seattle Children Hospital, Johns Hopkins, and University of Washington's Institutional Review Boards.

Table 5 - Study 3 Youth Transplant Patient and Caregiver Demographics
(not all participants reported their demographic data)

| Characteristic | Value |
|---|---|
| **Total Number of Participants – n (%)** | |
| *Transplant Participants* | 14 (46.7%) |
| *Caregivers* | 16 (53.3%) |
| **Age in Years – median (range)** | |
| *Transplant Participants (n = 12)* | 15 (10 – 21) |
| *Caregivers (n = 14)* | 49 (29 – 68) |
| **Gender – n (%)** | |
| *Transplant Participants* | |
| Man/Boy | 8 (61.5%) |
| Woman/Girl | 5 (38.5%) |
| *Caregivers (n = 16)* | |
| Man/Boy | 1 (0.06%) |
| Woman/Girl | 15 (93.8%) |
| **Race (participants could select more than one)** | |
| *Transplant Participants* | |
| White | 6 |
| American Indian or Alaskan Native | 1 |
| Black or African American | 1 |
| Chinese | 1 |
| Vietnamese | 1 |
| Some other race | 3 |
| *Caregivers* | |
| White | 9 |
| American Indian or Alaskan Native | 1 |
| Chinese | 1 |
| Vietnamese | 1 |
| Some other race | 4 |

| | |
|---|---|
| **Ethnicity (participants could select more than one)** | |
| *Transplant Participants* | |
| Not of Hispanic, Latino, or Spanish origin | 8 |
| Mexican, Mexican American, Chicano | 4 |
| Decline to state | 1 |
| *Caregivers* | |
| Not of Hispanic, Latino, or Spanish origin | 11 |
| Mexican, Mexican American, Chicano | 5 |
| First Transplant (n = 13) | 11 (84.6%) |
| Patients requiring dialysis prior to transplant (n = 13) | 11 (84.6%) |
| Family History of Kidney Disease | 3 (23.1%) |
| **Knows Someone Who Had a Kidney Transplant (n = 13)** | 5 (38.5%) |
| Donor Type (n = 13) | |
| Living | 4 (30.8%) |
| Deceased | 9 (69.2%) |

### 5.1.2 *Study Procedures*

At least one parent or caregiver gave consent to participate in the study and assent was received from all youth participants. All procedures completed in this study represented activities that patients would likely encounter through activities in their daily life or experience through standard of care. To equip participants for their design session, I emailed them a design session agenda and mailed them a physical design session toolkit (see Appendix C; Figure C1) before their session. Design toolkits included the following materials: hardcopies of task cards, a hardcopy of the design session agenda, colored markers, hardcopies of example visualizations, additional drawing/writing paper for tasks, and emoji stickers (see Appendix C; Figure C1). I, along with one or two other members of the research team, facilitated each design session. The role of the research team during these sessions included: hosting the Zoom room, explaining activities, moving participants in and out of breakout rooms, observing design sessions, and asking clarifying questions when needed. I and other members of the research team did not join group conversations,

unless we were specifically asked a question by the participants or if the dialogue became flat and we thought it was necessary to probe the group to keep the conversation moving.

All participants completed a 90-minute-long design session where they participated in a series of structured tasks with allotted break times (see Appendix C; Figure C1 for design session agenda given to participants). Caregivers and youth started their design sessions in the same room, but for most of their design session they completed their series of tasks in breakout rooms with only youth or caregivers (there were ~3 to 5 youth or caregivers in each breakout room). At the workshop's end, all participants returned to the main breakout room to present their final group drawings, followed by instructions on what they needed to return from their design toolkits. All youth and caregiver participants received a US $25 Amazon e-gift card for completing the 90-minute design session and were able to keep materials from the design toolkit such as markers, stickers, and papers.

***Medication Adherence Task***

This study was originally a three-part design session study, however, for the purpose of this dissertation I will only be describing procedures and reporting on findings from the medication management task of one of the design sessions. The medication management task had three parts to it, requiring participants to do the following: (1) find and discuss objects, (2) an individual drawing, and (3) a group drawing (see Appendix C - Research Team Protocol Outline for Medication Adherence Task). For this task participants used the following materials from their toolkits: a notecard with their task prompts (see Appendix C, Figure C3), example visuals, multiple blank pages for their drawings, and their markers/stickers.

First, I read a verbal prompt, asking participants to find two objects in their household: (1) an item that represents something that helps them be successful in taking their medications and (2)

an item that represents something that gets in the way of taking their medications (see Appendix C - Research Team Protocol Outline for Medication Adherence Task). I set a screen timer and told participants they had three minutes to find their two objects. After participants found their objects, I instructed them on the second part of their task, asking them to create two individual drawings using their objects for reference/inspiration in a 10-minute period. Lastly, for the final part of the task I asked participants to present their individual drawings to one another and then create a final group drawing, pulling inspiration from each of their individual drawings. Participants were given 15 minutes to complete their group drawings. At the end of this task all breakout room groups (youth and caregiver break out groups) returned to the main zoom room to present and describe their group medication management drawings to each other.

### 5.1.3 *Analysis*

All design sessions were audio and video recorded via Zoom [162] and transcribed for analysis using Rev, a transcription service [221]. I used a qualitative, thematic approach to analyze the de-identified design session transcripts and medication management task drawings in MAXQDA and MAXQDA Team Cloud (v.22.7.0 for Mac). I analyzed and guided the analysis process with three other members of the research team. Our analysis took part in four iterative rounds; for the first round of analysis I and the research team independently analyzed and coded one design session transcript. We then met after the first round of independent analysis to discuss emergent codes. After the initial round of analysis, we then completed three more rounds of analysis across one month, meeting in between rounds of independent analysis to discuss new emerging codes, categorize codes based on their meanings, and resolve any analytical discrepancies or interpretations. In total, eight design session transcripts were analyzed (four youth and four

caregiver groups). After analyzing all eight transcripts, the research team and I met three additional times to cluster and develop themes based on our codes.

## 5.2 RESULTS

Findings from these design sessions explore visuals created by youth transplant patients and their caregivers about their medication management throughout their journey. I identified several high-level categories that participants discussed and drew about in their medication adherence individual and group task drawings, four primary thematic categories for supporting their medication adherence and two for barriers to medication adherence. The four categories for supporting medication adherence included: (1) Technology, (2) Community, (3) Food, and (4) Planning & Communication. The two categories for barriers to medication adherence included: (1) Technology and (2) Life Distractions. Quotes and drawings from English speaking youth transplant patients are identified by Y# and their primary caregiver as C#; YS# or CS# are used for Spanish speaking participants.

### 5.2.1 *Individual Drawings about Medication Management*

Using their objects as inspiration, caregivers and youth alike created individual drawings about what has helped them succeed in taking their medications and what has gotten in the way. Participants were not required to directly include their objects as visual images, but most participants chose to incorporate their objects into their drawings and integrated additional visuals or text within their drawings as well. Participants' visuals within their individual and group drawings aligned with our identified thematic categories and their explanations of their drawings gave us additional insight into their medication management. Interestingly, participants' drawings

and explanations brought to the forefront once again the need for harmonizing youth's health and life needs, a similar thread identified in Chapters three and four of this dissertation.

We had several groups of youth complete this medication adherence task and they ranged in age between 11 – 21. We attempted to keep similar ages of participants together and our youngest group of participants were between the ages of 11 to 13. Several of our youngest youth participants had individual drawings that highlighted only one support or barrier, such as Y7 whose explanation and drawing fell under the support category of Food:


"**So, I guess any type of food, like granola bars or whatever. Well, this is a nut bar, but any food. I like to eat it after my meds not with my meds because I don't really think I need to take my meds with anything.** I just ignore the horrible taste and just take it up without anything." - Y7 (age 12)

A few of the youth and caregiver participants from the younger design group discussed how they used food as a tool to support them in taking their medications successfully. It is not uncommon for youth with chronic illnesses to experience frustrations with having to take daily medications. Youth in this younger age range (11 – 13) are usually just starting to work on their medication self-management alongside their caregivers and clinical care team. Even though they were at the beginning stages of working on their self-management, the younger youth participants in our study were each able to identify things that either helped or got in the way of taking their medications. As youth transition towards self-management throughout their journey, and especially at the beginning stages of self-management, they may benefit from visuals that are designed to support them in identifying patterns of success or challenges in taking their medications.

Unlike the youngest youth groups individual drawings, the older youth groups and caregivers' drawings often contained more than one type of support or barrier to medication management, emphasizing that not one specific thing (e.g., technology, food, community, etc.) contributes to youth's successes or struggles in managing their medications. For example, C9's drawing and explanation included the support categories of technology, community, and planning & communication:

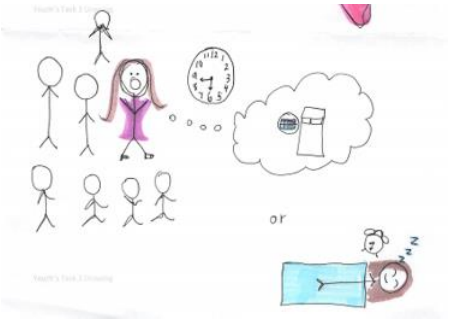

"**I put a cell phone with the alarm going off,** take my pills. I have one and Y9 has once so both of our phones make noise. **And then the other item is us talking, the family, the grandma calling, she texts me**, "Did you guys take the pills you got? Did you bring the pills? You're going to a basketball game today. Did you remember them?" **So, it's other people helping us to remember too, that care about Y9 and love our family, that friends and mostly grandma. And then that pill box.**"- C9

In their individual drawing and explanation, C9 discusses three things that all contribute to helping Y9 be successful in managing their medications: alarms on both of their phones, their family members reminding them to take their pills when out of the house, and Y09's pill box. C9's drawing and explanation highlight the complexities of managing Y9's medications during this stage of their life. Throughout different stages of their journey youth will experience different barriers and will need to shift their supports to be successful in managing their medications. Understanding their barriers and supports overtime can help them to develop medication management goals and routines as well as discuss any changes that need to be made as shifts occur.

Similarly, Y16's individual support drawing (older youth group, ages of 15 - 19) included more than one type of support category:

"So, for helpful, **I feel like my medicine thing**. And then this is one of the little portable ones that you just take with you. **And then also my watch is helpful at school because I'm not allowed to have my phone. So having a watch is helpful, so I have an alarm. Also, my friends remind me.** It's kind of weird, but anyways." - Y10 (age 16)

Y16 identified several supports, such as her watch as well as her pill boxes (one for at home and a portable one). Y16's description of her drawing underscores the added layers of planning and considerations that she takes daily to manage her medications. In addition, Y16 also mentions how her friends support her in remembering to take her medications, even though she finds it "*weird*" that they help remind her. Although Y16 mentions the positive support she can receive from friends, she also states how spending time with friends can be a barrier in managing her medications. In her second drawing, Y16 emphasizes how spending time with her friends outside of her house has caused her to forget her medications:

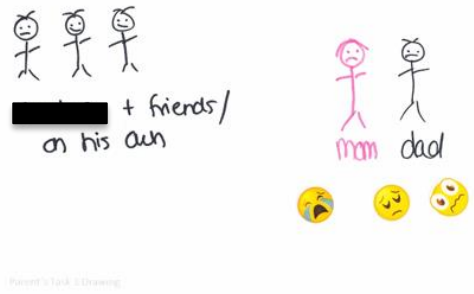



"…**And then for not helpful, it's me out with my friends** and then it's 8:30, and then I'm like, Oh my God, it's at my house. And then also **sometimes I just sleep through my alarm on the weekends**" - Y10 (age 16)

Y16's individual drawings and descriptions not only highlight the additional considerations she has in taking daily medications, but also underscores the challenges she experiences when trying to harmonize her health and life needs. Designing medication management visuals to highlight the challenges that youth experience in harmonizing their medication management and life needs may

help youth participants and their care team to identify where these needs conflict and then work together to find solutions.

Part of successfully transitioning to young adulthood with a chronic illness is learning how to minimize conflicts between managing one's health and life. We had several caregiver participants who expressed worries about their child finding the right balance as they get older, such as C6:




"**But something that I worry about is in the future and he's hanging out with his friends. He is more focused on being social rather than his own health...**I just know that would make us very worried. It would make us sad to even think of our son not taking care of himself when he's on his own or if he's out with his friends." (C6)

Other caregivers expressed similar worries about their child balancing their life and health needs as they get older. When prompted to draw about the supports and barriers towards taking their medication management, we consistently found that both youth and caregivers alike created visuals that tied together their medication adherence and their life. An essential part of supporting youth kidney transplant patients as they transition towards self-management is to help them understand the nuanced complications they may experience when managing their medications. Thus, designing medication management visuals that go beyond simply tracking if a youth patient did or did not take their medications, and instead highlight the nuances of their medication management experiences, may support patients to identify patterns or discover solutions by highlighting conflicting needs.

### 5.2.2 *Group Drawings about Medication Management*

Participants selected one of two directions that their group drawings could go in: (a) doing well with taking their medications or (b) not doing well with taking their medications. After the group chose the direction of their drawing, they then collaborated to make their drawing, pulling inspiration from their individual drawings. We had a total of 4 caregiver group drawings and 4 youth group drawings, across design sessions.

As youth with chronic illnesses transition from adolescence to young adulthood, the goal of many caregivers is to help them become more independent in managing their health needs. However, different barriers, including abstract barriers, such as "life distractions" may cause AYAs to struggle taking their medications on time or at all. Both caregiver and youth participants described one of the main barriers to their adherence as "life" distractions. This abstract concept of "life" distractions emphasizes the difficulties youth and their families can experience when trying to harmonize their health and life needs throughout their journey. Several youth and caregiver groups chose to focus their group drawings on not doing well with taking their medications. C5, C8, C9, and C10 (caregivers of the older youth group) drew a calendar that shows the many types of "life" barriers that contribute to their child not doing well at taking their medications:


"**We decided that for all of us, it was unanimous that it was things that keep you away from your home, where your pills are. So, it's life.** So, we did a calendar of a month, and just all these activities that are happening every single day, that distract you and keep you away from a routine. So things like: playing basketball or tennis, or going to a concert or going to the beach or riding your bike or going to dinner, hanging out with family, friends,

sleepover, all these things, going for lab work" – C10

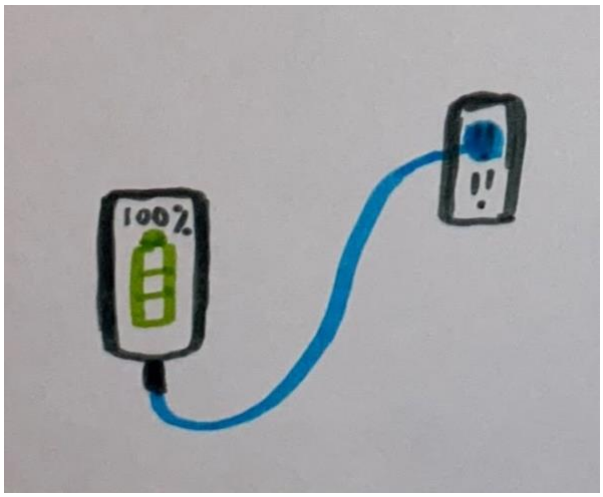
This consistent theme of "life" distractions was seen across participants' individual and group drawings. The youngest youth group chose to focus on doing well with taking their medications and incorporated images inspired from each of their individual drawings:


"So, the candy cane and the pizza has to do with food, because that helps me take my meds. This is supposed to be kidneys. I knew they're shaped like a bean, but I took the curve part too seriously. Then there is a syringe with the meds. There's a meds container and an alarm on a phone, for when you take your meds. And parents to help to remind you. **And then I put some different numbers. So, eight or nine is when you only have about very little distractions in your life, to keep you from taking your meds. Six is kind of the average, I believe. Because you might have at least four, you'll probably have at least four distractions. And 5.5 is pretty much if there are many distractions and you can't get it done very well, but you can still do it eventually."** – P7 (age 12)

In this drawing the youth group used several visuals and numbers to represent what helps them be successful in taking their medications. Their visuals aligned with a few of our thematic categories: food, technology, and community. This group collaboratively decided that when a youth is doing well with taking their medications the average number of "distractions" is 4 and if a patient has fewer distractions as well as more supports that number will increase to 8 or 9. Even though their drawing was about being successful taking their medications this youth group still chose to highlight their "distractions" in conjunction with their supports, illustrating that from their

perspective to be successful in managing their medications they need to lean on their supports and minimize their barriers or "distractions". This drawing additionally emphasizes the notion that youth will often have to deal with barriers or "distractions" and that is part of life, but designing visuals to support working towards a "higher" number can help youth to understand their current state of medication management and the importance of working towards a better balance between their needs.

The youth Spanish speaking group created a unique visual analogy design. Their visual analogy was of a phone battery. The analogy being if they don't take their medications on time and keep their phone charged their phone (i.e. taking their medications consistently) then it will become drained and not have power, affecting their kidney health. YS2 and YS3 collaboratively decided together what their design should be and what it means to them:




YS2: Something that makes you strong, **something where you feel strong and that you can handle everything, like that.**

YS3: **You think of it like charging your phone when you connect it to the charger.**

YS2: Yeah like that, something like that.

YS3: Okay

YS2: **And if you don't charge that phone, you're not going to have power, the phone is not going to have power…Something that keeps you focused on taking your medications.**

YS3 further explained their visual analogy stating, "*Yeah, it's a phone charging. And it's at a 100%. When we take our medicine on time…It means. Being everything. Protected. Keeping the kidney protected. And without our medicine, it's. Like cutting off not connecting the cable…It's connected*

*to the reminders that we put on."* This youth pair drew a successful visual analogy, illustrating the need for youth to take their medications consistently to keep their adherence battery charged. Adherence, even though seemingly simple, has many things that can impact if youth are successful in adhering to their medication management, as seen in many of the youth and caregiver's individual and group drawings above. It can be difficult for patients, especially youth, to understand and visualize nuanced concepts such as adherence. Therefore, designing visualizations that incorporate more relatable and relevant visual elements and information may help patients and their families to understand what helps them take their medications, as well as what gets in the way of taking their medications successfully.

## 5.3 Discussion - Designing Medication Management Visualizations to Support Youth in Identifying Actionable Insights

In the results, I present medication management drawings from four groups of pediatric kidney transplant patients and their caregivers. From these results, I will discuss how the findings can inform the design of a medication management visualization to be incorporated in a kidney transplant journey tool. Medication management visualizations should be designed to better reflect the complexities of medication management, so that they can help provide more nuanced information about youth's needs and help youth to identify actionable insights throughout their journey.

Adhering to taking medications is a complicated issue for Adolescents and Young Adults (AYAs) with chronic illnesses [35,65,70,181,222,223]. It is essential for youth who have kidney transplants to adhere to their post-transplant medications, however, adherence struggles continue to be a major cause for kidney rejection for these youth [65,83,222,223]. Even though researchers have explored different behavioral, psychosocial, and technological interventions [224–230] to

support youth with chronic illnesses, AYAs continue to struggle with medication adherence, and there is still a need to develop and design new solutions to support youth adherence. Building off the extensive work to support youth in their medication management, our results show that adherence isn't just as simple as taking your medicine or not, but rather supporting youth in understanding what helps them successfully take their medications or what gets in the way of their success.

Health visualizations have been used to help simplify large amounts of health data to support clinicians in understanding complex health information [231]. Moving beyond supporting clinicians, in more recent years there has been a shift in designing health visualizations to support patients in understanding their complex health data [232–235]. However, even with this increased focus on designing health visualizations to support patients, there are still gaps to be explored in designing health visualizations to support youth patients and their families. When designing medication adherence visualizations to support youth transplant patients successfully take their medications as prescribed and keep their kidney healthy, we need to move beyond just asking, "did you take your medicine or not?"

To support youth in understanding what helps them take their medications and what gets in the way of taking their medications successfully may require a more non-traditional visual approach, such as a visual analogy. Visual analogies utilize visual images as an analogy to convey complex information [236]. Non-traditional forms of visualizations, like analogies, may be a way to help youth patients understand seemingly simple but often complex information, such as successful medication adherence in a more novel and potentially more actionable way [234,237]. Our findings support this more graphic/visual form of presenting health information to participants.

Two of our youth participants (YS2, YS3) created a unique and interesting visual analogy that I believe has the potential to help other youth transplant patients and caregivers better understand their adherence successes and challenges throughout their journeys. The visual analogy created by these youth participants was of a phone battery. The analogy being if youth don't take their medications on time and charge their "adherence battery" than it will not have power and become drained. This battery visual analogy has the potential to be an approachable and youth friendly design.

The analogy itself is approachable to youth because even though not all youth have their own smart devices, many of them still interact with smart devices daily in their schools or at home [238,239]. Expanding upon the analogy, most devices need to be charged daily (i.e. taking their medications), supporting the idea that their adherence battery will need to be sustainably charged overtime. Furthermore, designing ways to help youth better understand what exactly supports or gets in the way of them managing their medications successfully could be incorporated. Based on our findings, I suggest incorporating a way for youth to add what "charges" (things that help them take their medications successfully) or "drains" (things that get in the way of taking their medications) their adherence batteries, thus supporting patients in reflecting on what supports or challenges them in managing their medications successfully (see Figure 6). This visual analogy has the potential to help participants reflect on the nuances that affect their medication management, such as if they have conflicting health and life needs.

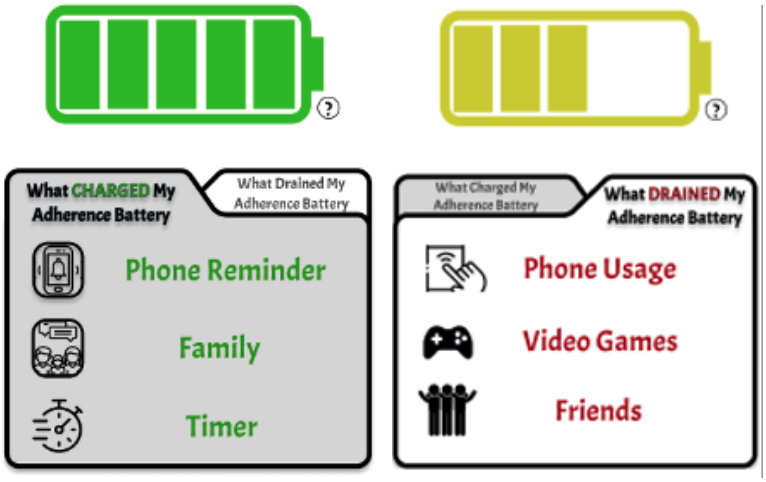



Figure 6 - Design feature incorporated in the My Kidney TREK technology probe (Chapter 6) inspired by findings from Chapter 5.

## 5.4 CONTRIBUTION

In this chapter, I add to and reinforce findings from existing literature on youth kidney transplant patients' struggles and successes of medication management throughout their transplant journey. In the results, I explore medication management drawings created by youth kidney transplant patients and their caregivers. Based on the results, I then discuss how medication management visualizations should be designed to better reflect the medication management complexities youth experience throughout their journeys. I provide design insights on how medication management visualizations can support youth in understanding their medication management nuances and identifying actionable insights throughout their journey.

# Chapter 6. PILOTING THE MY KIDNEY TREK TECHNOLOGY PROBE WITH YOUTH TRANSPLANT PATIENTS AND CAREGIVERS

In this chapter, I report on the initial exploration of the My Kidney TREK (Thinking, Reflecting, and Empowering Kidney Transplants Patients) technology probe [240–243]. Technology probes can be described as technological artifacts used in real-world contexts to reflect on the probe's impact and inspire ideas for new technologies [243]. The My Kidney TREK technology probe was designed to capture youth kidney transplant patients and their caregivers' kidney transplant journeys via three components: My Kidney Function, My Kidney Adherence (Chapter 5), and My Kidney Journey Stories (KJS) (Chapter 3 and Chapter 4). I answer the following research questions in this chapter: **RQ5 - Empirical:** How did using the My Kidney TREK technology probe impact youth kidney transplant patients' and caregivers' overall reflections on their transplant journeys? and **RQ6 – Design:** What are kidney transplant patients' and caregivers' perceptions of the My Kidney TREK Kidney Journey Stories component and design recommendations for future iterations?

I answer these questions by presenting findings from a study with 13 youth kidney transplant patients and 10 caregivers to assess the design and impact of the My Kidney TREK technology probe. In the following sections, I describe the study design and report on participants' reflections about their journeys after interacting with the technology probe and their impressions about the KJS component. There were many types of data collected from this study, but for the purposes of this dissertation, I am only going to be reporting on findings from the exit interviews since this data gives the most straightforward understanding of participants' assessment and the impact of the technology probe.

## 6.1 METHODS

### 6.1.1 *Study Population and Recruitment*

All participants were recruited from Seattle Children's Hospital Transplant Center, part of a large children's hospital in Seattle, WA. I had access to participants because several research team members are clinicians at Seattle Children's Transplant Center. Participants were recruited via convenience sampling by identifying individuals who fit the inclusion criteria and were scheduled for an upcoming transplant clinic visit. Participants were initially identified by me or a Seattle Children's Hospital research coordinator and then presented to Dr. Pollack (a member of the research team) during our weekly meetings to confirm the eligibility of each of the candidates. If there was uncertainty from Dr. Pollack about a potential participant, we reached out directly to the participant's primary nephrologist to confirm eligibility for recruitment. All participants were contacted for recruitment in person at the transplant clinic, via phone call, patient portal, or email. I recruited 23 total participants, including 13 youth who have had a kidney transplant and 10 caregivers (see Table 6).

Youth participants (n=13) ranged in age between 12 - 21 years (median age = 16). More specifically, between the ages of 12 - 14, we had (n = 5) participants; between 15 - 17, we had (n = 5); and between 18 – 21, we had (n = 3) (see Table 6). Youth participants (n=13) identified with the following genders: Man/Boy (n = 6), Woman/Girl (n = 5), Gender Fluid (n=1), and Nonbinary (n = 1), while our caregiver participants (n = 10, 2 participants did not report their ages) ranged between the ages of 36 – 56 (median age = 46) and identified with the following genders: Woman (n = 9) and Man (n = 1) (see Table 6). In this chapter, participants of all age ranges may be addressed as youth to keep wording consistent throughout.

Table 6 - Study 4 Youth Transplant Patient and Caregiver Demographics

| Characteristic | Value |
|---|---|
| **Total Number of Participants (n=%)** | |
| *Transplant Participants* | 13 (56.5%) |
| *Caregivers* | 10 (43.5%) |
| **Age in Years – median (range)** | |
| *Transplant Participants (n = 13)* | 16 (12 – 21) |
| *Caregivers (n = 10)* | 46 (36 - 56) |
| **Gender – n (%)** | |
| *Transplant Participants* | |
| Man/Boy | 6 (46.2%) |
| Woman/Girl | 5 (38.5%) |
| Gender Fluid | 1 (0.07%) |
| Nonbinary | 1 (0.07%) |
| *Caregivers (n = 10)* | 1 (0.06%) |
| Man/Boy | 1 (10%) |
| Woman/Girl | 9 (90%) |
| **Race (participants could select more than one)** | |
| *Transplant Participants* | |
| White | 8 |
| Black or African American | 2 |
| Asian | 3 |
| Some other race | 1 |
| *Caregivers* | |
| White | 6 |
| Asian | 3 |
| Some other race | 1 |
| **Ethnicity (participants could select more than one)** | |
| *Transplant Participants* | |
| Not of Hispanic, Latino, or Spanish origin | 12 |
| Mexican, Mexican American, Chicano | 1 |
| *Caregivers* | |
| Not of Hispanic, Latino, or Spanish origin | 9 |
| Mexican, Mexican American, Chicano | 1 |
| First Transplant (n = 13) | 13 (100%) |
| Patients requiring dialysis prior to transplant (n = 13) | 10 (76.9%) |
| Years Since Transplant - median (range) | 5 |
| Knows Someone Who Had a Kidney Transplant (n = 13) | 3 (23.1%) |
| Donor Type (n = 13) | |
| Living | 5 (38.5%) |
| Deceased | 8 (61.5%) |

### 6.1.2 *Study Procedures*

This study was intended to take youth participants and caregivers one month to complete (see Figure 7). In this study we had several points of data collection, such as the initial interviews, surveys, interaction with the technology probe & workbook, and an exit interview (see Figure 7). Even though we had several points of data collection for this study, in this dissertation I will only be providing information for the following: the My Kidney TREK probe, the Kidney Journey Stories component of the My Kidney TREK probe, the Story Survey, and the Exit Interviews. I am only providing details for these because the primary focus of this dissertation chapter is on the Kidney Journey Stories component of the probe and the analysis of the exit interview data. I will only be analyzing and reporting on data from the exit interview of the study, since this data set gives the most straightforward understanding of participants' assessment and the impact of the technology probe. If you would like more information about other parts of the study procedures, please see Appendix D.

Due to the length and having multiple points of data collection, we did run into several factors that contributed to participants needing additional time to complete the study, which included: difficulties scheduling interviews, needing additional time to complete study tasks, unexpected health issues/sicknesses, holiday breaks/vacations getting in the way, loss of access to technology, and forgetting to do certain tasks. For information about youth participants' consent and assent, please see Appendix D. Youth participants were compensated with a total of $145 of digital eGift Cards, and caregivers were compensated a total of $130 of digital eGift Cards. All study procedures were approved by the Seattle Children's Hospital Institutional Review Board and the University of Washington's Institutional Review Board. I will provide descriptions for the

following below: the My Kidney TREK probe, the Kidney Journey Stories component of the probe, the Story Survey, and the Exit Interviews.

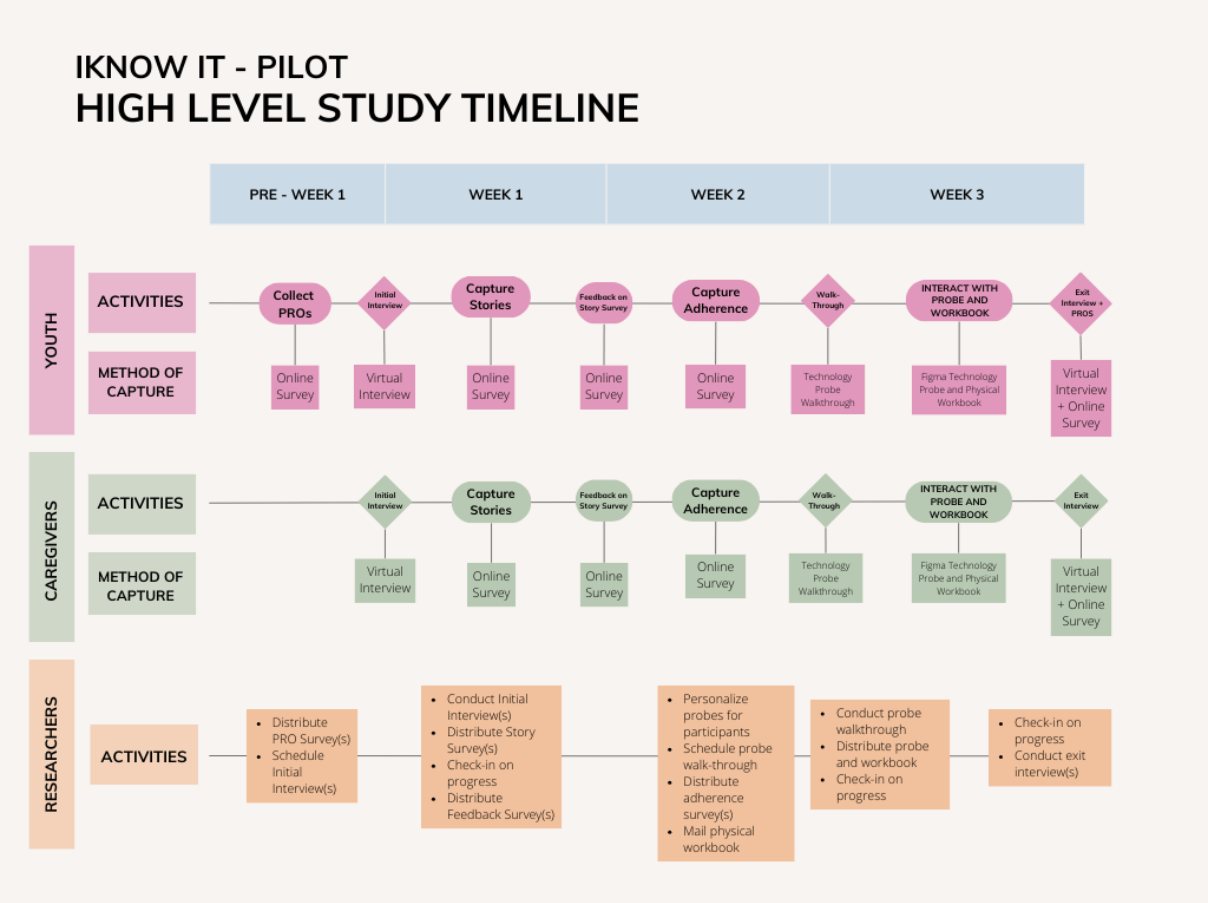



Figure 7 - Study 4 High Level Study Timeline

### *My Kidney TREK Technology Probe*

The My Kidney TREK tech probe featured three main components: My Adherence Component (taking medication on time) (design informed by Chapter 5), My Kidney Function component (design informed by prior work not included in this dissertation), and My Kidney Journey Stories (KJS) component (design informed by Chapters 3 and 4) (see Figure 8 for images of each components landing page). Each of the components was personalized with data provided by

participants during the early stages of the study: Story Surveys, Adherence Surveys, and Kidney Function lab results (which were pulled from their EHR). The overall probe functioned as a low-fidelity technology probe where participants were able to see their personal data that we input into the probe and use interactions to navigate the probe, but they were unable to input any new information into the prototype. Each of the three components of this technology probe were chosen because they are essential to youth's kidney transplant journeys. Individually, the elements provide important information about different aspects of their transplant journey, ranging from their kidney function (health-driven) to their Kidney Journey Stories (tying together components of their health and life needs). In culmination together, these elements can help support youth to benchmark their personal transplant experiences and create a more holistic picture of their journeys. Even though I helped design and create each of the components for the technology probe, I will go into more detail specifically about the Kidney Journey Stories (KJS) component since this is the primary component my dissertation is focused on.

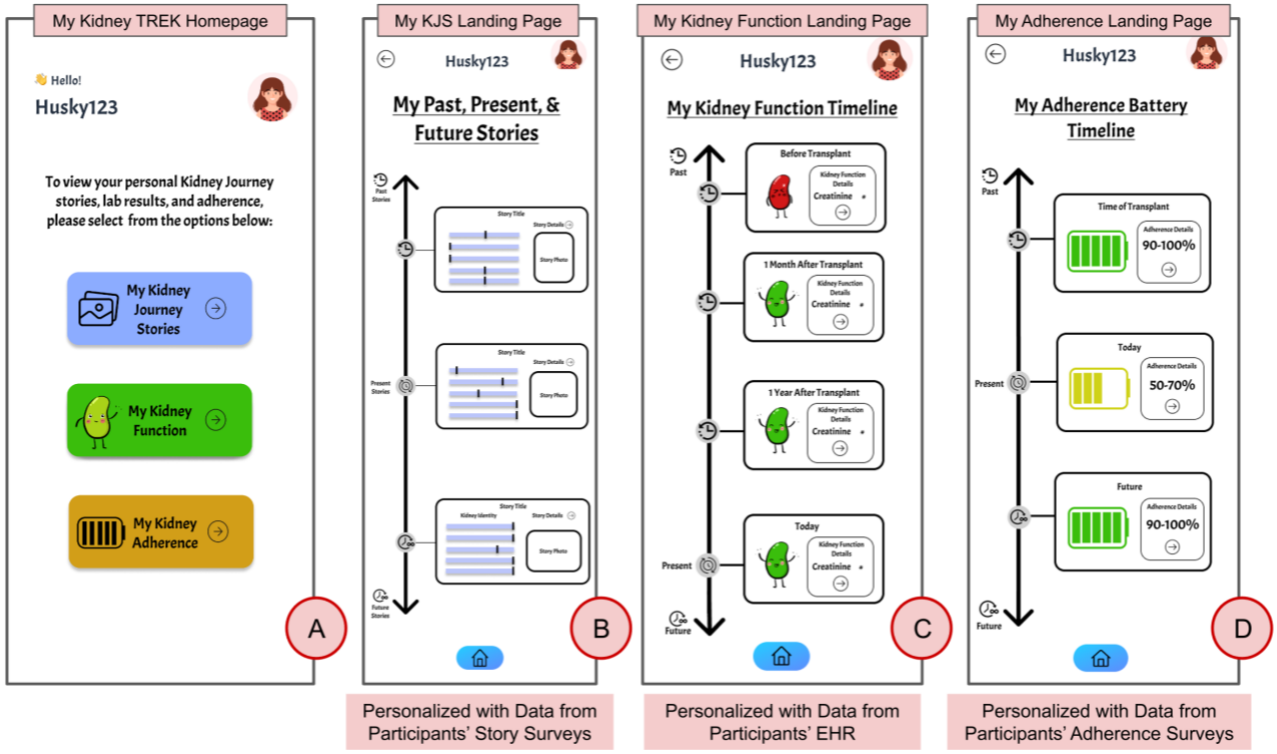


Figure 8 - (A) My Kidney TREK homepage with buttons to each of the three components landing pages, (B) Kidney Journey Story component timeline landing page, (C) Kidney Function component timeline landing page, and (D) Adherence component timeline landing page.

### *Kidney Journey Stories Component*

The KJS component was designed to provide youth kidney transplant patients with a comprehensive view of their kidney transplant journeys via stories. The KJS component allowed participants to view their past, present, and future stories that we gathered from them in the story survey. From the story survey we personalized this component of the technology probe with the following data: their photos, their written stories, Kidney Identity (KI) Slider bar visual, and their story categories (see Figure 10). The KJS component, like all the components, contained the following types of pages for participants to view: a landing page displayed as a timeline, individual pages with detailed information for that component, and a help/information page for that component (see Figure 9 for examples of different KJS pages).

On the landing page participants can view a snapshot of each of their stories on the timeline. These snapshots were designed to include the following personalized data: their photos, a Kidney Identity (KI) Slider bar visual, and their story titles (see Figure 10). The Kidney Journey Timeline allows participants to have a quick snapshot of all their personal stories in one place and, at a high-level, reflect on their journey over time. To look at more details about each of their personal stories participants were able to select which story they wanted to navigate to via the timeline and go to each one individually. The individual story pages were designed to include the following personalized data: their photos, their written stories, their story titles, a Kidney Identity (KI) Slider bar visual, and their story categories (see Figure 10). Participants were able to navigate between the individual story pages to compare their stories over time. Lastly, the KJS component contained

a definitions page (see Figure 9). This page includes the definitions of the five dimensions that make up the kidney transplant journey framework. The KJS component was designed to provide youth kidney transplant patients with a comprehensive view of their kidney transplant journeys via stories.

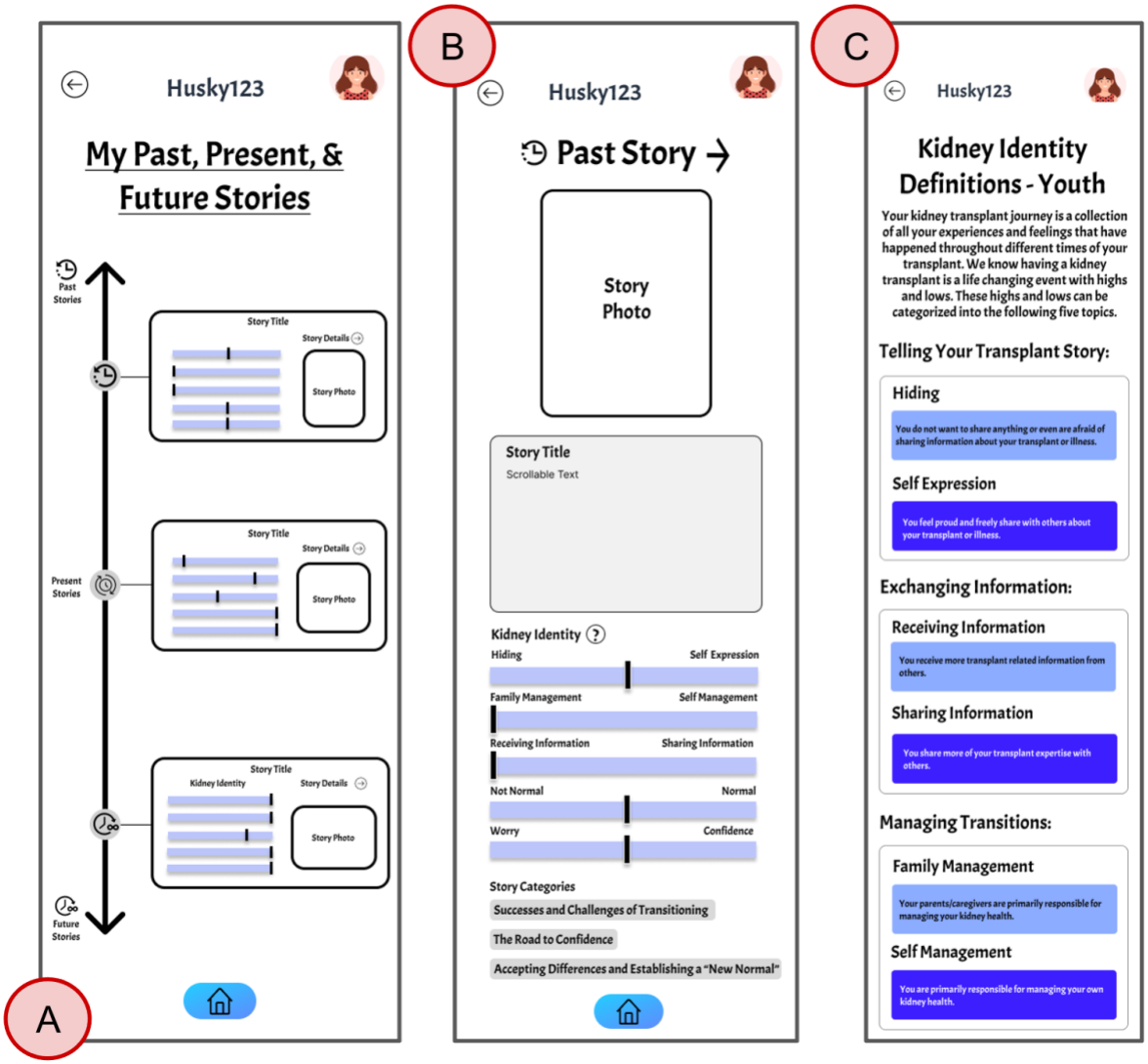



Figure 9 - KJS component of the My Kidney TREK technology probe. (A) Is the KJS timeline landing page, (B) individual personalized story page, and (C) Kidney Identity Definitions for the Kidney Identity visual.

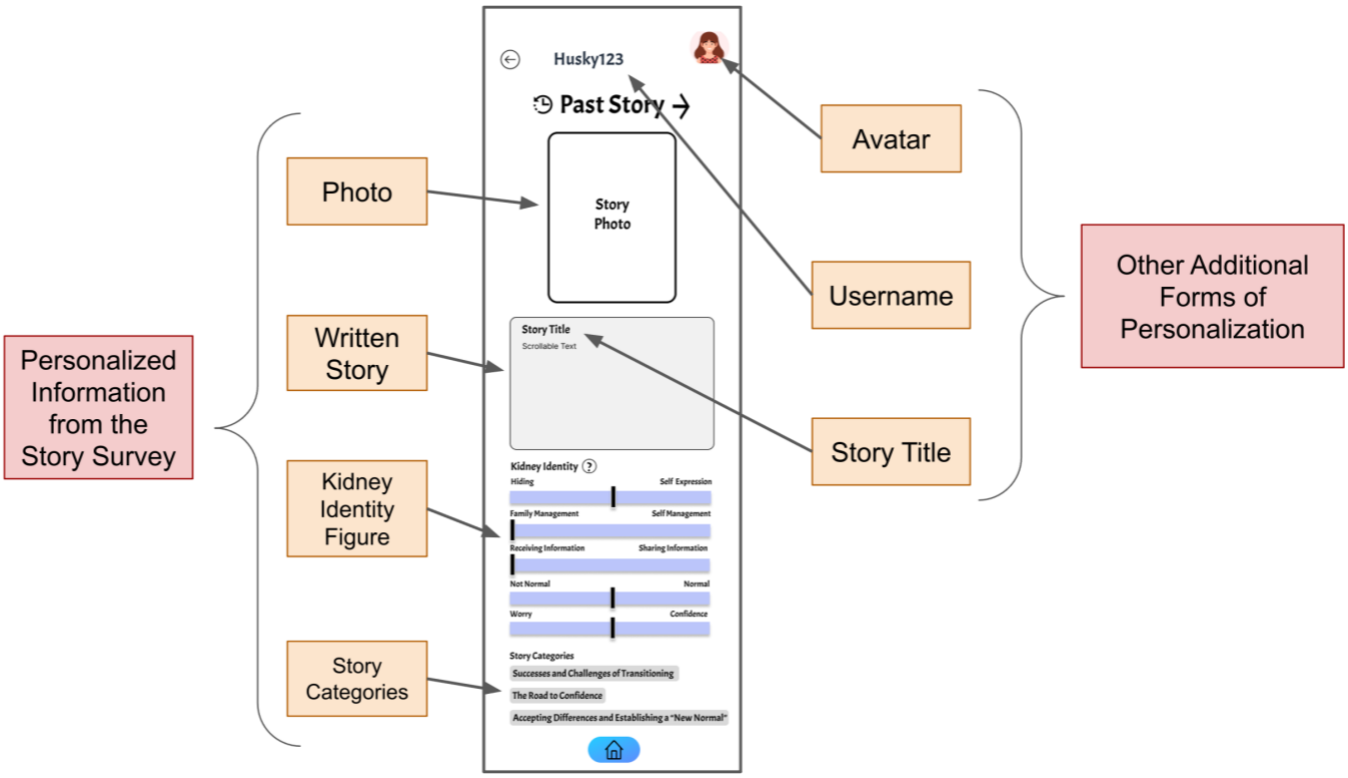



Figure 10 - KJS Component Individual Story Page, which contains the following personalized information from participants' story survey: photo, written story, kidney identity figure, story categories. In addition, it includes other forms of personalization, such as their avatar, username, and story title.

***Story Surveys – Used to Personalize KJS Component***

After completing the initial Interview, youth and caregiver participants were sent a RedCap [187] link to the Story Surveys via email or text. Youth and caregiver participants were given their own separate survey links. All participants were given one week to complete the story surveys, but many participants ended up needing additional time to complete their surveys because they either forgot to start the survey or wanted more time to complete the survey. Participants were contacted halfway through the first week and the day before the second week via email or text to complete their Story Surveys if they had not completed all sections of it. Youth and caregiver participants were compensated with a $25 gift card sent to them via email after completing their story surveys.

Participants' story surveys were used to personalize the Kidney Journey Stories component of the My Kidney TREK probe. In the story surveys, youth and caregivers were asked to provide three stories: one story from the past (around the time of their or their child's transplant), one story from the present (from the past week of their life), and one story from the future (envisioning a time when they or their child are independent). I chose to collect stories from different periods of participants' transplant journeys to give youth and caregivers the opportunity to be able to reflect on experiences throughout their journey, including the future. In the story survey, we collected the following types of data: photos, free text or recorded audio, slider scale data, and tagged data. I chose to have participants capture each of the different types of story data (text, photos, etc.) in the following order:

1. **Get Inspired:** Find a photo that matches the prompt for the given period (e.g., Past Story – find a photo from around the time that they had their kidney transplant to inspire their written story) (Chapter 3)
2. **Upload the Photo**
3. **Tell a Story:** Write or audio record their story inspired by their photo (Chapter 4)
4. **Reflect:** Answer a few questions for the given period in the form of a slider scale that represents the Kidney Identity framework (Chapter 3 and Chapter 4)
5. **Categorize:** Select categories that describe their story (Chapter 4)

For examples of what a participant would see for one of the three-story sections from the survey, see Appendix D; Figure D1. All story survey data was then used to personalize youth and caregiver's individual My Kidney Journey Stories (KJS) component of their technology probes (see Figures 9 and 10). Each of the different types of data gathered in participants' story surveys:

photos, written stories, Kidney Identity Slider bars, and story categories are all valuable types of information on their own, but when put together in the My Kidney Journey Stories component, could support youth and their caregivers in reflecting on their journeys.

Immediately after completing their story survey participants were prompted to complete a short ~ 5-minute feedback survey about the story survey. The story feedback survey only consisted of five questions, which focused on understanding how difficult the survey was for them to complete and what components of the survey they found interesting or useful. I will not be reporting on the story survey feedback findings in this dissertation.

### *Exit Interview*

After interacting with their personalized My Kidney TREK technology probes for one-week participants then completed a final exit interview. Participants' final exit interviews were conducted virtually via zoom, lasted between 45 – 60 minutes in length, and were audio & video recorded. Youth participants and caregivers had separate interviews, unless they requested for the caregiver to be present during the interview (only one youth and caregiver requested to have interviews at the same time). The semi-structured interviews consisted mainly of open-ended questions and were divided into two main sections of questions: (1) questions about the overall concepts of the My Kidney TREK tech probe and getting participants' feedback on the tech probe and (2) a hypothetical scenario about a future version of the app (see Appendix D for an example of the interview guide). The purpose of the exit interview was to: (a) understand participants' impressions of the design of the My Kidney TREK and each of its individual components and (b) understand the impact of the My Kidney TREK on participants' reflection of their journeys.

Several sections of the exit interview guide had questions that were developed to help us understand participants' impressions of the technology probe and the KJS component. Since the

KJS component is the primary component of focus for this dissertation, below I have highlighted the specific questions asked in the KJS section of the exit interview (see Appendix D for an example of the complete interview guide):

- What parts of the kidney journey stories component did you like and dislike?
- Did the kidney journey stories component help you to see any growth or change for yourself? What?
- Did the kidney journey stories component help you to identify any success or barriers to help keep your kidney healthy? What?
- Did you find more value in the process of writing your kidney journey stories or reading and reflecting on your kidney journey stories in the My Kidney TREK app, or both?
- If you were to redesign the kidney journey stories, which elements would you include or not include:
    - stories,
    - photos,
    - five-dimension sliders,
    - story categories
    - would you want to add something new?

### 6.1.3 *Analysis*

There are many valuable data sources from this study, but for this dissertation, I have chosen to focus my analysis on the exit interview data. The exit interview provides the most cohesive data to assess the design and understand the impact of the My Kidney TREK technology probe as a whole and for each of its individual components. For the analysis of this data source, several other members of the research team and I conducted a qualitative analysis of 13 youth and 10 caregiver

exit interviews. All exit interviews were audio recorded and transcribed for analysis in MAXQDA 24 (a qualitative analysis software). This data was analyzed in two phases: Phase 1 – thematic analysis and Phase 2 – affinity diagramming.

***Phase 1 – Thematic Analysis of Transcripts***

Before analysis with the research team began, Dr. Ari Pollack and I met to discuss and create a codebook that aligned with our research questions and assessment of the My Kidney TREK technology probe (see Appendix D; Figure D3 for the initial deductive codebook). After the development of the codebook, I lead three rounds of analysis with six members of the research team, including myself and Dr. Pollack, using the codebook. In the first two rounds of analysis, two research team members were assigned the same 2-3 random transcripts (youth or caregiver) to deductively apply the codes from the codebook and note any potential emergent themes to be discussed. After the first two rounds of analysis, the six research team members met to resolve discrepancies amongst applied codes and discuss any emergent themes that may want to be added to the codebook. Some emergent codes were added to the codebook after the first two rounds of analysis (see Appendix; Figure D4). In the third round of analysis, four members of the research team were assigned one random transcript each to test the codebook, and consensus was achieved. In the fourth round of analysis, I went through each transcript and double checked all codes applied aligned with the codebook.

***Phase 2 – Affinity Diagramming of Phase 1 Coded Data***

After completing our first analysis phase, the team met to determine if we thought an additional round of affinity diagramming of the Phase 1 analyzed data was necessary to help us further refine

our findings. Our team determined we would do an additional round of affinity diagraming for quotes that were coded for each of the three components: Adherence, Kidney Function, and Kidney Journey Stories, as well as the Reflection quotes. Each component had its own code and several sub-codes from the first phase of analysis. For example, Kidney Journey Stories (KJS) was a high-level code that then had the following sub-codes: KJS Likes, KJS Dislikes, KJS Neutral, and KJS Design Suggestions (see Appendix; Figure D4). I pulled all quotes from the transcripts that were coded for each component or as a Reflection and then created digital FigJam sticky notes for each quote under its assigned code in FigJam [192] (see Figure 11).

Next, the research team met four times to sort and categorize the (1) Reflection, (2) Adherence, (3) Kidney Function, and (4) Kidney Journey Story quotes via affinity diagramming [193,194]. Each affinity diagramming session lasted approximately one to two hours, where four to six research team members clustered quotes. During each session two people were paired together and assigned to review and sort a subset of the quotes together for 30 - 45 minutes; after sorting in pairs, the group discussed the emerging clusters. After the group discussion, pairs met on their own if they needed additional time to discuss and review the clusters they identified. They were also asked to write up high-level notes about what they identified and clustered.

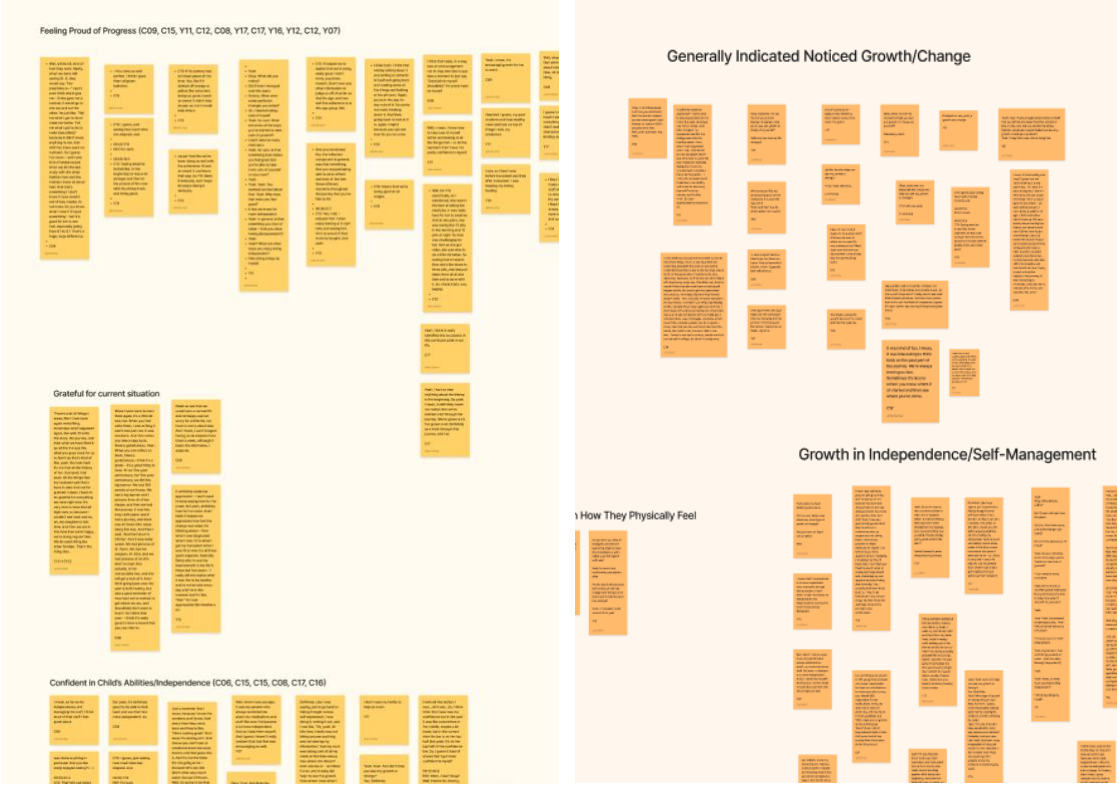



Figure 11 - Example screenshots of FigJam boards from the affinity diagraming analysis.

## 6.2 RESULTS

### 6.2.1 *Reflections From Participants After Interacting with the My Kidney TREK Probe*

As part of this study, I wanted to understand if the My Kidney TREK technology probe positively impacted participants. Youth and caregiver participants who interacted with the technology probe and its personalized content for each of the components reflected on many different aspects of their transplant journeys. We identified several high-level reflection themes from participants, which included positive reflections, growth/change, future reflections, and negative experiences and barriers. I found that the My Kidney TREK had a positive impact on participants' reflections on their transplant journeys.

***Positive Reflections***

Most of our participants spoke about different positive reflections they had about their transplant journey. Youth and caregivers told us about how they felt **proud of their progress** (Y07, Y11, Y12, Y16, Y17, C08, C09, C12, C15, C17)**.** Feeling proud of one's progress can help lead youth to feel more confident in their abilities and a desire to maintain their progress. Participants reflected on different types of progress that they have had throughout their journeys, including but not limited to progress in self-management, maintaining "good" kidney health, working towards personal life goals, and confidence. Both youth and caregivers were able to recognize positive self-management progress, such as Y11 (age 12), who spoke about how she doesn't "*need as many reminders*,*"* and this lets her know she is *"more independent."* Similarly, Y17 (age 13) spoke about how reflecting on her (kidney function) numbers showed her progress in her self-management and confidence, *"Well, I mean, I know how to take care of myself better and looking at all the things that…or all the numbers that I have… I'm pretty confident in myself."* In reflecting on their progress, other youth (Y07, Y11, Y12) and caregivers (C06, C08, C15, C16, C17) positively reflected on the **confidence they have in their own or their child's abilities/independence**.

C17 positively reflected on Y17's role throughout the journey, "*I think it really put into perspective Y17's role in the journey too for me, more so than mine because she really has over the years become much more independent in the process and her health."* Youth also positively reflected on identifying changes in their independence, particularly around their medication management like Y07 (age 16), "*Well, when I was younger, it was my parents who always reminded me about my medications and stuff. But now I've become a lot more independent, and so I take them myself, and I guess I haven't really realized that, but that was encouraging as well."*

Adolescent and young adult CKD patients, as highlighted throughout this dissertation, are at higher risk during times of transition; having a tool and stories to instill a sense of positive reflection of their journey may help youth to want to sustain progress towards positive health and life outcomes.

Connecting participant's past, present, and futures helped several youth (Y01, Y02, Y08, Y11, Y12, Y14, Y15, Y16, Y17, Y18) to have **temporal reflections** about their journeys, such as Y15 (age 17) who spoke about gaining a bigger picture about his transplant, *"I learned how I've gotten better after the transplant and what I used to be like before and just how much better it is now. Kind of gave me a bigger idea about that."* Similarly, Y02 (age 18) also enjoyed reflecting on the timeline of his journey, *"It shows the information of my before the transplant and into the current stage, and it's really cool to see what kind of health problems I had back then versus now and to see that kind of comparison, I guess, it's really cool to see how my kidney has gotten better."* Viewing their journey over time also helped participants to positively reflect on their **perseverance over time** as well as expressing **gratitude for their current state** of the journey:

> *"It definitely made me appreciate-- I don't want to keep saying how far I've come. But yeah, definitely how far I've come. And I think it helped me appreciate how fast the change was when I'm thinking about…from when I was diagnosed when I was 13 to when I got my transplant when I was 16 to now. It's all three years separate, basically being able to see the improvement in my life in these last few years…I really did not realize what it was like to be healthy and to not be sick every day until I'm in the moment and I'm like, "Huh." So I just appreciated the timeline a lot."* - *Y12 (age 21)*

As their chronic illness becomes a part of their everyday lives, youth and their families may put their past behind them, but in reflecting on their journeys, our participants were able to positively reflect on their past, connect to their present, and feel excited about their future.

### *Reflections on Growth and Change*

Youth and caregivers also reflected on different areas of growth or change that they or their child have had throughout the transplant journey. The adherence component, designed to highlight participants' successes and challenges in their medication management, helped participants reflect on youths' growth in **self-management and independence** throughout their journey. A few examples of self-management growth that participants identified included: taking their medications consistently, drinking water daily, and learning to fill prescriptions on their own (Y01, Y07, Y09, Y12, C01, and C16). For youth to feel confident in their self-management, they need to have self-efficacy (i.e., belief in their capacity to self-manage). Participants identified growth in their or their child's self-efficacy, recognizing growth in how they have become a more present contributor to their own health and that they have learned to advocate for themselves more (Y02, Y07, Y12, C17).

Additionally, some caregiver participants (C06, C12) reflected on difficult moments in their medication management journey with their child, leaving them feeling positive about their child's current state of medication management. Developing a routine is essential for youth who are managing their medications with their family's help or on their own. Y02, Y06, C16, and C17 reflected on growth in developing their routines, which are subject to change as youth and their families go through different seasons of life. In interacting with the technology probe, participants could reflect on and identify areas of self-management growth and change they have had throughout the transplant journey. Reflecting on all components of their journey can help youth identify barriers to their medication management, identify growth in their self-management, and develop a stronger sense of self-efficacy.

After interacting with the technology probe, participants were able to reflect on youths' **changes in health status** throughout their journey. The My Kidney Function component helped many participants to reflect on changes in youths' kidney function over time (Y03, Y11, Y12, Y14, Y15, Y16, C08, C09). Often, youth are told at their appointments how their kidney function is doing, but this can make it difficult for youth to truly understand their kidney function and connect the dots about how it has changed over time.

Many of our youth participants were excited to see their kidney function over time and felt positive about being able to keep their kidneys healthy, such as Y16 (age 16), *"I saw, so I how I was before transplant and then after transplant. I was keeping my kidney healthy."* Presenting complex information such as kidney function in an accessible way to youth is important. Doing so can help youth to recognize improvement in their kidney and overall health (Y08, Y14, Y15, Y17, C09, C16, C17), act if they notice something is different in their kidney function (Y12, Y15), and overall acknowledge the success of their transplant. C17, after interacting with the technology probe, stated, "*I think*, *obviously, the success is that we got a transplant for her, and her kidney health drastically improved."* In interacting with the technology probe, participants were able to reflect positively on the growth and change throughout the transplant journey.

***Future Reflections***

Participants were asked if they were more excited or nervous about their futures, and most participants felt excited about their futures after interacting with the technology probe, but some participants still expressed nervousness about their futures. Two caregivers (C06, C09) and one youth (Y09) expressed being **nervous about youth's capabilities or future independence**. It is normal for youth and caregivers to express worries about their future capabilities, especially if

some of those worries stem from not feeling confident in where they are at in the present. Using information presented to them from their probe, participants could reflect on their present and future worries and then use their reflections as a catalyst to start conversations with caregivers or clinicians about what they could do now to feel less worried about the future.

Others expressed being nervous about the future in general or being **hopeful but cautious due to their past experiences**. For example, Y02 (age 18) stated the following about being cautiously hopeful, *"A little bit of both. I'm excited because after the transplant, my health is better, and I'm hopeful to do more stuff and activities. Nervous because it could go completely in the opposite way and there's really no way to know what's going to happen. So, I'm just trying my best to do stuff that's within my control so that it would go to the way I want it."* Participants feeling cautiously hopeful aligns with having chronic kidney disease because, due to their illness, they will most likely need to have another transplant in their lifetime, as C17 articulates:

> *"I think it actually made me a little bit more…not necessarily nervous, but it did make me realize that her stages are already progressing and so this will be an ongoing journey. In the back of my mind, I think I always knew that, obviously, but it just really puts it point blank that it is an ongoing journey, which is a good thing. It's important to remember that and keep that in front of your mind." – C17*

Many worries about the future stem from individuals feeling in less control, unsure about missing information, or unsatisfied with their current balance between their health and life needs. After interacting with the technology probe, participants positively reflected on several of these aspects, potentially contributing to why many of the participants expressed excitement about their futures.

A few caregiver and youth participants conveyed being **excited about the current phase of their journey** they are in right now (C09, C11.1+C11.2, C15, Y15) because they feel like they are past some of the more difficult moments and are happy with their current health and life.

Others, after reflecting on their journeys, were **excited/confident about their future capabilities and independence** (C01, C06, C11.1+C11.2, C12, C15, C16, Y17). Caregivers expressed excitement about their child's future independence because they felt more confident after reflecting on their child's self-management growth.

Feeling excited and hopeful for the future were general sentiments expressed by both youth and caregivers. The technology probe had two components (adherence and KJS) that encouraged youth to think specifically about their past, present, and future. In thinking about their future selves in alignment with their past and present, some of our youth participants expressed feeling more positive about their futures, as conveyed by Y07 (age 16):

> *I guess I just have a lot of life before me. And like I said, the stories helped me reflect a lot. Because sometimes, it's easy to get discouraged with the transplant that, "Oh, my health is not good. I'm not going to be able to do a lot in the future." But the stories just helped me to…and the kidney adherence thing, too, just kind of encouraged me for the possibilities in the future. – Y07(age 16)*

It is understandable, with the complexities of managing a chronic illness throughout their childhood, that youth transplant patients will be nervous about their futures. However, even with all these additional considerations, these youth must still make space for what they need and dream of in their futures. It is valuable for these youth to think about their futures in alignment with their present so they can be excited about their futures and identify current misalignments in what is happening now with what they want for the future.

### *Reflections on Negative Experiences and Barriers*

In going through something as difficult as a kidney transplant, it is expected that youth and their caregivers will have difficult times throughout their journey. In reflecting on their journeys, several

participants told us about negative experiences and barriers that they have been through. Our caregiver participants reflected on the difficulties of past medical experiences, such as complications experienced post-transplant (C09). Additionally, in reflecting on their family's journey, caregivers reflected on difficulties with medication management, making lifestyle changes, planning ahead, and deviating from routine. Even though reflecting on negative experiences or barriers can be emotionally taxing for individuals, it can also be a cathartic output and a way to learn from past experiences. We expected that the technology probe may cause participants to reflect on difficult past experiences in addition to positive reflections, since transplant journeys are not linear and are filled with many moments of fear and worry. It is valuable for participants to identify challenging times, especially if they are experiencing difficulties in harmonizing their health and life needs.

### 6.2.2 *Design Impressions - My Kidney Journey Stories Component*

The design of the Kidney Journey Stories (KJS) component of the technology probe was informed by findings from Chapters 3 and 4 of this dissertation and is the primary component of focus for this dissertation from the technology probe. As informed by prior work, the four main elements that make up this component include participants' photos, written stories, the Kidney Identity (KI) slider bar visual, and story categories (see Figures 14, 16, 18, and 20 in the sections below as a reminder about how each of these four elements was incorporated into the design of the KJS component). This component was designed to provide youth kidney transplant patients with a comprehensive view of their kidney transplant journeys via stories.

All participants were asked which of the three components they would include or not include for a future version of the technology probe. For the KJS Component, 12 out of 13 youth

participants said they would include this component (with no changes or some suggested changes), and 8 out of 10 caregiver participants said they would include this component in a future version of the My Kidney TREK probe (see Figure 12 below). Additionally, participants were asked which of the four elements they would include, maybe include, or not include in a future version of the KJS component. In the sections below, I will report on participants' design impressions of the KJS component and which elements they would recommend including or not including in a future version of this component.

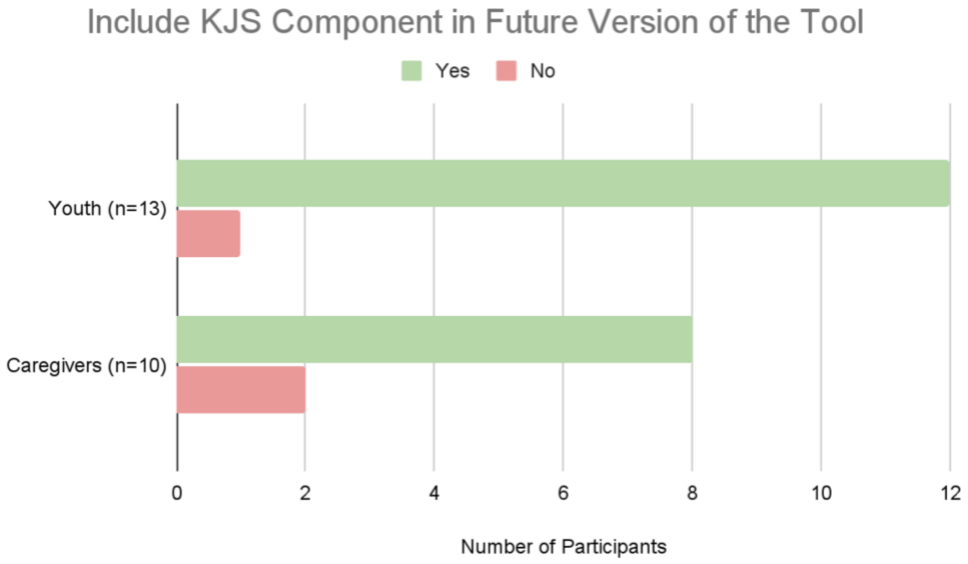



Figure 12: Number of youth and caregiver participants who would like to include or not include the KJS component in a future version of the My Kidney TREK.

***Kidney Journey Stories – Photo Element***

As designed, the photo element allowed participants to have one photo per story, which inspired participants' written stories; see Figure 14 at the end of this section to view the Photo Element highlighted within the KJS component. Youth participants were divided on whether they would

include (n = 7) or not include (n = 6) the photo element versus caregivers who resoundingly said they would include this element (n = 10) in a future version of the component (see Figure 13 below).

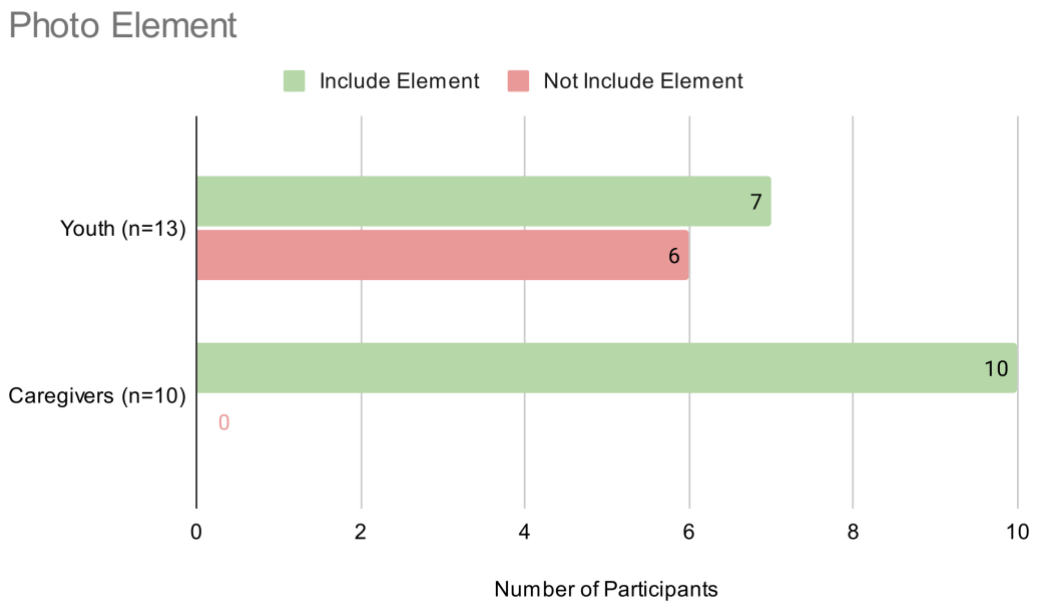



Figure 13: Number of Youth (n=13) and Caregiver Participants (n=10) who would include or not include the Photo Element in a future version of the KJS component.

Youth participants did not feel strongly about including or not including this element within the KJS component. Even though half of the youth participants said they would include this element, many did not elaborate on what they liked about it. One youth participant stated that the photos were "*helpful*" (Y15), while others thought it was "*cool*" to include (Y17). Moreover, Y07 and Y15 thought that the photos provided more context to their stories. Additionally, two youth expressed that they enjoyed finding photos (Y09, Y12). Even though half of the youth participants stated that they would include the photo element, their overall excitement towards it indicates that they would not care either way if the element was removed in future versions of the component.

Youth participants who did explicitly state that they would not include this element in future versions of the component gave several compelling reasons why, such as not being a fan of seeing photos of themselves or taking photos in general (Y01, Y03). Furthermore, they found it difficult to find photos (Y02, Y14), they felt the photos were a reminder of difficult times (Y03), and in general, they didn't think the photos "*added much*" to what was already there (Y02, Y06). This illustrates that the photos did not resonate as much with youth participants as we thought they might, suggesting this element may not be necessary in future versions. One participant, Y16, did suggest making the photos element "*optional*", supporting the notion that youth did not resonate with this element.

Unlike the youth participants, caregivers did like the photos element. Caregivers liked how the photos accompanied their written stories, adding more context and personalization (C08, C09, C15, C17). Writing a story from a blank slate can be difficult to do, and having a photo for inspiration or alongside a written story can provide a different way for participants to connect to the moment they are writing about. There is power in photos, as C08 conveys, *"...pictures are so powerful when you look at a picture and then what does it remind you of, and I think that that's yeah, I thought that the connection between the picture and the story was really important."* Beyond using a photo as inspiration to connect or elaborate on a story, three caregivers also discussed how finding photos was an enjoyable reflective exercise (C15) as well as a conversation starter, *"...so we open our photo library and we just we end up scrolling...we just talk about it with each other"* (C11.1 and C11.2).

Caregivers found value in including photos as part of this component, so much so that two caregivers stated a preference for having photos over their written stories (C01, C06). Others suggested being able to add multiple photos to a story (C11.1, C11.2, C12, C17), finding it difficult

to select just one photo and having the ability to scroll between multiple photos (C11.1, C11.2). Another design feature suggestion from a caregiver was having a pop-up picture to remind them of specific memories (C01). Seeing as youth and caregiver participants had drastically different impressions about the photo elements, further thought needs to be put into whether this element should be included in future versions of this component, and if so, how it can be improved. Individuals have different preferences on how they want to reflect on their kidney journey stories, suggesting the need for further thought on the best modalities (or elements) to include in the KJS component in future versions.

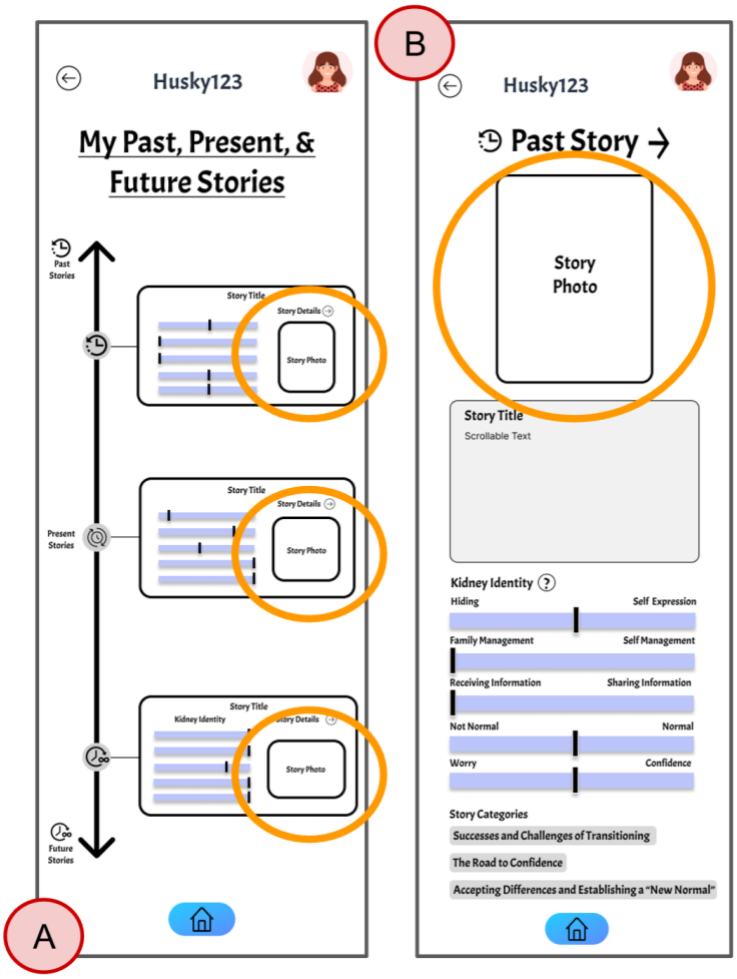



Figure 14: The Photo Element is circled on two of the Kidney Journey Stories Component pages: (A) the landing page and (B) the Individual Story Page. Figure 14A: The Photo Element

is included in the landing page for each of the past, present, and future story details. Figure 14B: The Photo Element is at the top of the individual story page before the Written Stories Element.

***Kidney Journey Stories – Written Stories Element***

As designed, participants reflected on three written stories (past, present, and future) with an accompanying story title for each story; see Figure 16 at the end of this section to view the Written Stories Element highlighted within the KJS component. Most youth (n = 12) and caregiver (n = 8) participants wanted to include the written stories element in a future version of the KJS component, with only 1 youth and 2 caregivers who were unsure or did not want to include the written stories (see Figure 15).

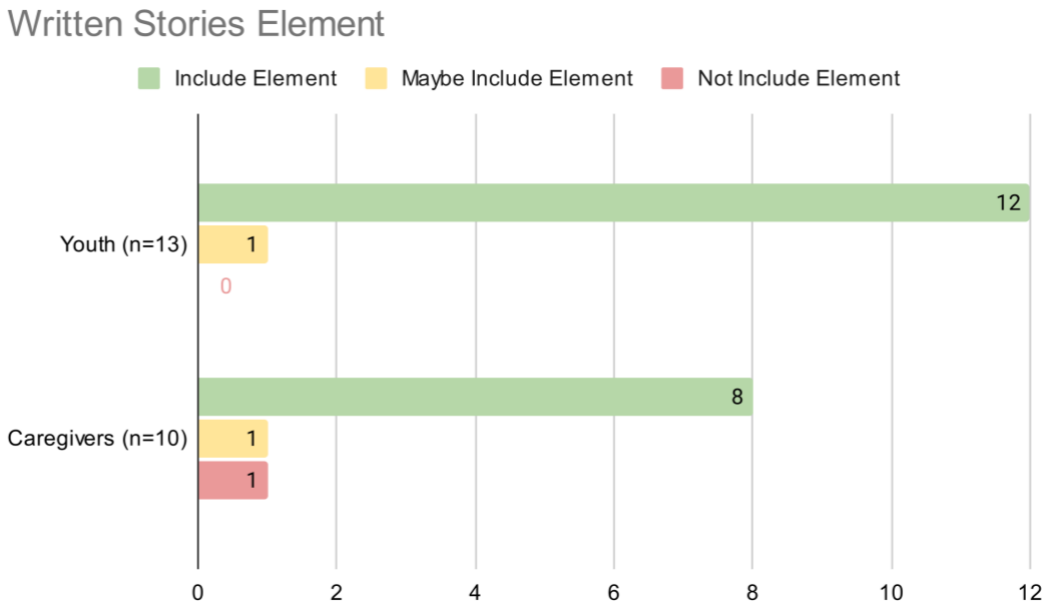



Figure 15: Number of Youth (n=13) and Caregiver Participants (n=10) who would include, maybe include, or not include the Written Stories Element in a future version of the KJS component.

Both youth and caregivers alike expressed how they enjoyed their stories, such as Y01 (age 16) who stated, "*I thought the stories part was definitely cool. How it was sharing the stories.*"

Some participants enjoyed both writing and reflecting on their stories (Y03, Y08, Y11, Y16, C08, C09, C11.1, C11.2 C12, and C16), while others preferred either the process of writing (Y02, Y07, C17) or the process of reflecting on their stories (Y06, Y09, Y14, Y15). A few youth participants told us that even though they enjoyed reflecting on their stories, they also found it difficult to write their stories. Although participants were divided amongst if they preferred writing or reflecting on their stories, most participants expressed finding value in having access to stories about their kidney transplant journeys.

Writing a story can be emotionally vulnerable, making it difficult for some participants to write and use their stories as a valuable tool of reflection. C08 told us about how it was difficult for her at first to write her stories, but ultimately, she found value in having them:

> *I think both. Yeah. When I went back to read them again, it's a little bit less raw. When you first write them, I was writing it and it was just raw. It was emotions. And then when you take a step back, there's gratefulness. Yeah. When you can reflect on them, there's gratefulness. I think it's a great…it's a great thing to have. At our five-year anniversary, her five-year anniversary, we did this big banner. We had 100 people at our house. We had a big banner and I pictures from all of her stages, and then we had this journey. It was this long craft paper, and it had a journey, and there was all these little steps along the way. And then I said, "And the future to infinity." And it was really sweet. We had pictures of Dr. X. We had her surgeon, Dr. X, and we had pictures of all of it. And I've kept that, actually, in her memorabilia box, and she will get a look at it. And I think going back over the past is both healing, but also a good reminder of how hard we've worked to get where we are, and don't want to lose it. So I think that was…I think it's really good to have a record that you can refer to. So yeah. – C08*

C08 was not the only participant who found value in their written stories. Participants found value in **reflecting on their journeys** through their stories. Stories can be a powerful reflective tool for many reasons, including being a way for participants to benchmark their experiences. Y16 (age 16) enjoyed being able to reflect and benchmark on their experiences stating, "*Yeah, it made me*

*see how I was feeling like before transplant, then after transplant, and present day."* Stories can also be used as a tool in the future to reflect and learn from past experiences:

> *But I think I would keep the stories because even though they seemed at the time, I was like, "I'm not really sure." Being able to look back at them and having that information is nice, especially because I have so little…I'm probably not going to have a written account of how I was feeling at this time ever again. So I think it was actually really nice, and I think I'll appreciate them more in the future. – Y12 (age 21)*

A few youth participants, such as Y11 (age 12), liked being able to tell their own stories: "*I got to tell it from my perspective.*" Stories can be an effective way for youth to express themselves, reminding them that their values, feelings, and thoughts matter and promoting self-efficacy. Participants also found value in their stories as a way to see the "*big*" picture of their journey and to feel positive about the future.

Not all the participants found value in having their written stories to reflect on. Two caregiver participants (C01, C06) understood how stories can be valuable for individuals but personally did not think the written stories were helpful for them. Some participants enjoyed the process of writing and others did not, suggesting room for improvement in capturing participants' written stories. Moreover, results for this element suggest that participants find value in having stories, but there is still room to improve clarity on how information from written stories is applicable to individuals and can provide them with actionable insights.

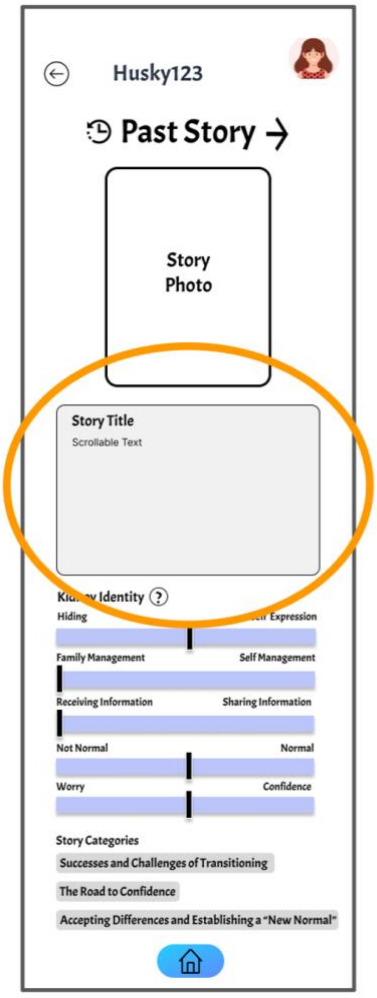



Figure 16: The Written Stories Element is circled on one of the Kidney Journey Stories Component pages, the Individual Story Page. It is in the middle of the individual story page after the Photo Element and before the Kidney Identity Slider Bar Element.

***Kidney Journey Stories – Kidney Identity (KI) Slider Bar Visual Element***

As designed, the KI Slider Bar visual was intended to provide a snapshot of the five dimensions that youth kidney transplant patients experience throughout their journeys; see Figure 18 at the end of this section to view the KI Slider Bar Element highlighted within the KJS component. All youth participants (n = 11) besides one stated that they would include this element in a future

version of the KJS component, while only 7 out of 10 caregiver participants would include the KI Slider Bar visual (see Figure 17).

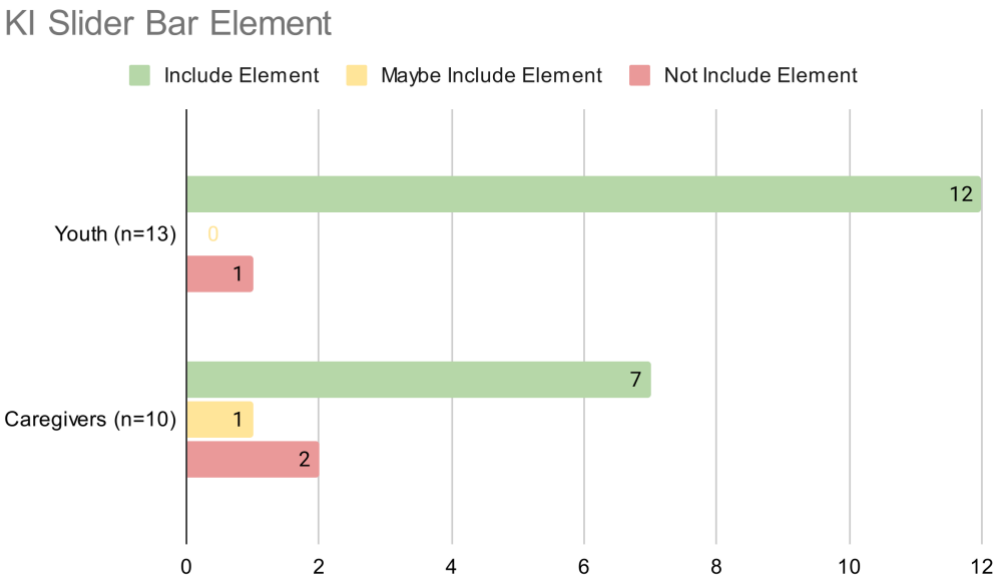



Figure 17: Number of Youth (n=13) and Caregiver Participants (n=10) who would include, maybe include, or not include the KI Slider Bar Element in a future version of the KJS component.

The KI Slider Bar visual was well-received by youth participants who liked the "*good design*" (Y01, age 16). Youth participants felt that the KI Slider Bar element's simple visual design helped them understand the five dimensions presented to them more easily. Furthermore, youth and caregiver participants spoke about how the KI Slider Bar visual helped them to **identify change** over time for each of the five dimensions. For example, Y17 (age 13) liked that she was able to identify changes in her confidence over time:

> *I liked the confidence part, like thinking about how confident you are with sharing it. Because I mean, it's important to feel comfortable with sharing that. And if you can...I don't know. If you know how confident you are with that, it's easier." – Y17*

The design of the KI Slider Bar visual was intended to be a way for participants to benchmark themselves over time for each of the five dimensions, and from participants' responses, it seems to have aided them in personal benchmarking. Y03 (age 13) talked about how they liked being able to "*see where they are at with something,*" and C06 liked seeing how the *"scale"* changed. In benchmarking their five dimensions, participants weren't only able to identify change, but some also indicated identifying actionable insights, such as Y12 (age 21), "*And I definitely did…I liked the slider bars a lot, and I think it definitely helped me realize that I had strengths and I had some weaknesses, and it really helped me reflect on the weaknesses and how to get better at them."* Y12 was particularly enthusiastic about the KI Slider Bar visual, also stating,

> *And I liked the bars, the scale. I think that was nice. And I liked the prompts between the bars. I thought they were really good and interesting and an interesting way to frame [My Kidney?] Journey because I'm not sure I would think about hiding versus self-expression. But then I was like, "Oh, I definitely was not telling anyone," versus now where I'm like, "Yeah, I have a kidney transplant." So I liked the bars for sure. And I think I liked the framing of future, present, and past. I think that's cool. – Y12 (age 21)*

In contrast, some caregiver participants disliked the KI Slider Bar visual (C01, C08, and C09), because they found it to be confusing or they felt that it did not add much additional meaning to them. C01 expressed that they felt the dimensions weren't as applicable to them now but that it "*might be interesting to do as a quarterly check-in*," indicating it could be valuable for personal benchmarking depending on the required frequency of filling it out. Interestingly, C01 also discussed how, for a "*kid who is managing on their own,*" it might be a good way to chart growth and feeling. Not many design suggestions were given to improve specific aspects of the KI Slider Bar visual from participants, besides one caregiver who suggested changing the colors on the figure depending on what we want to imply:

*If you don't want them to move from hiding into self-expression, then no, if there's not a a good and an area to work on for improvement then. No, you keep it a a blue color. But if you want to try to get people to move from hiding into self-expression. You'd want that the green in the red colors. or if you want them to move from worry to confidence. But if you're not judging or looking at that information to try and get the person to go, "Oh, okay, I maybe I shouldn't feel so not normal. And I should feel more normal than not normal" then it should be more orange or yellow and then moving to normal would be green. But it depends on what you want to share or what you want to imply, or what feeling you want the person to have. What goal do you want? The is the goal moving this way, or is it doesn't matter. – C15*

Even though the KI figure element was well received by most youth participants, additional design considerations are needed to aid youth and caregivers in extracting value from the benchmarking visual.

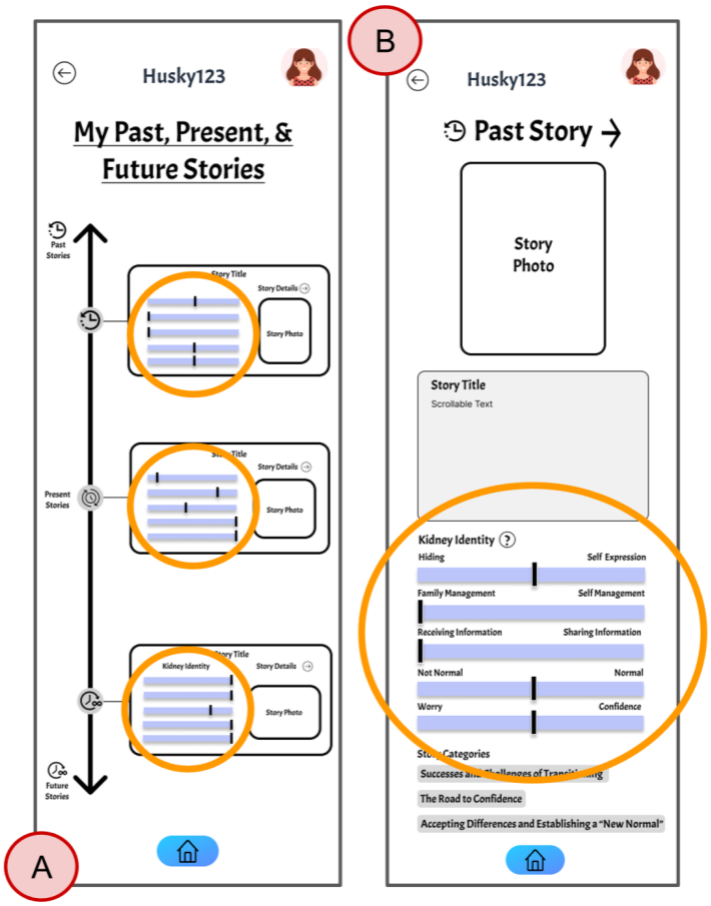


Figure 18: The KI Slider Bar Element is circled on two of the Kidney Journey Stories Component pages: (A) the Landing Page and (B) the Individual Story Page. Figure 14A: The KI Slider Bar element is included in the landing page for each of the past, present, and future story details. Figure 14B: The KI Slider Bar Element is near the bottom of the individual story page after the Written Stories Element and before the Story Categories Element.

***Kidney Journey Stories – Story Categories***

As designed, this element was intended to give participants a way to categorize their stories for each of their three stories (past, present, and future); see Figure 20 at the end of this section to view the Story Categories Element highlighted within the KJS component. 12 youth and seven caregiver participants stated that they would include the story categories in a future version of the KJS component, see Figure 19:

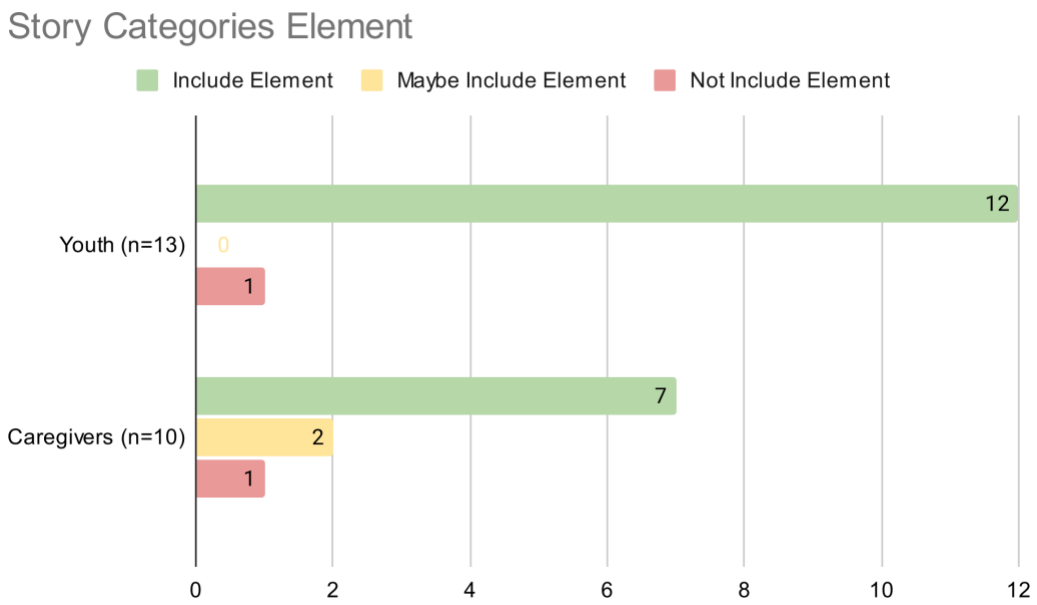



Figure 19: Number of Youth (n=13) and Caregiver Participants (n=10) who would include, maybe include, or not include the Story Categories Element in a future version of the KJS component.

Both caregivers and youth participants generally liked this element, stating that they found the categories "helpful" and "interesting." Having the story categories visually laid out below their stories supported participants, like Y11 (age 12), to "*know the theme of the story"* without having to read their full story. Moreover, some participants expressed that the story categories helped to give them **additional context** for other KJS elements.

Participants were able to select as many categories as they wanted for each of their stories, with most participants selecting more than one category. However, some participants found it difficult to fit their stories into a category(ies) (C01, C06, Y07). Participants were not given definitions for the different story categories, perhaps contributing to their confusion about which story categories to select. Y07 (age 16) additionally expressed that she felt the stories *"spoke for themselves",* suggesting that the categories did not provide her with meaningful insight.

Even though this element was overall well received by participants, our findings indicate that participants did not gain as much insight from this element compared to some of the other elements. A few participants (Y07, Y12, and C12) suggested that the story categories could be better utilized as inspiration to help participants write their stories, which we know was difficult for some participants. As currently designed, this element simply helps participants to identify the "themes" of their stories, but there is potential to improve the design of this element to help youth and their caregivers to extract more insight from the story categories.

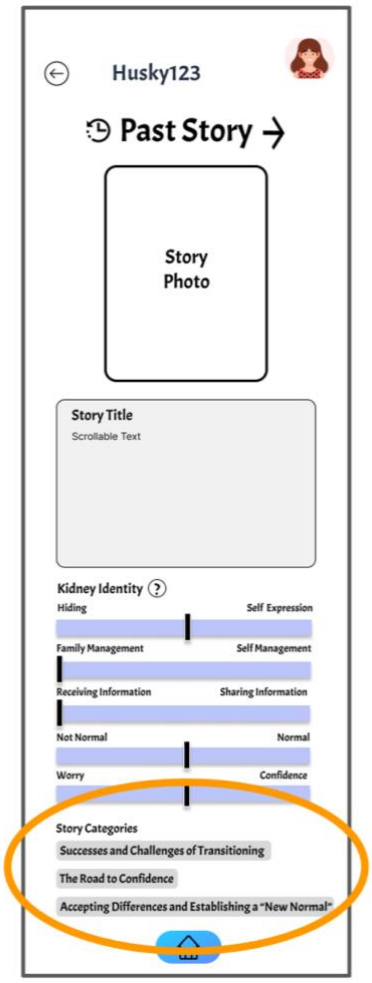



Figure 20: The Written Stories Element is circled on one of the Kidney Journey Stories Component pages, the Individual Story Page. It is in the middle of the individual story page after the Photo Element and before the Kidney Identity Slider Element.

## 6.3 DISCUSSION

I found that after interacting with the My Kidney TREK technology probe participants positively reflected on their kidney transplant journeys. In addition, I reported on the four elements of the Kidney Journey Stories component of the technology probe, highlighting likes, dislikes, and suggestions for each element. Based on our findings, I will discuss design considerations and recommendations for the Kidney Journey Stories component and each of its elements.

### 6.3.1 *Modality and Frequency of Capturing Patients Stories*

Stories can provide a wealth of information within a health setting, so much so that within medicine there is a domain known as narrative medicine [244–246]. Narrative medicine centers bridging the gap between patients and their clinicians through patients' stories [244,247,248]. Stories are not only a valuable tool for clinicians, but also a valuable tool for patients themselves. Many adult patients with chronic illnesses turn to their peers for support and to share about their experiences. Within the past two decades many patients have turned to online communities to share their stories [217,249–253]. Recognizing the power and value of stories, we designed the My Kidney Journey Stories (KJS) component to be one of the three primary components of the My Kidney TREK technology probe. Our findings support the value of capturing youth kidney transplant patients' stories to provide a more holistic view of their journeys overtime.

The KJS component contained four elements to provide youth and their caregivers with different ways to view, interact, and interpret their stories. Stories can be conveyed in a variety of ways, such as via written words or photos. In recent years capturing families' digital stories has become popular [129,130,254], offering users the ability to capture their stories via multiple modalities overtime. Acknowledging the difficulty and time it takes to write a story, it is important to give individuals options for how they would like to capture their stories. In the current design of the KJS component, youth transplant patients and caregivers were able to capture their stories via four elements: written stories, photos, KI Slider Bar visual, and story categories. Our participants enjoyed capturing their stories via the different modalities (i.e. elements), however, it was clear that some participants preferred certain modalities over others.

In future versions of the KJS component it will be important to allow participants to choose which elements (i.e. modalities) they would prefer to capture their stories. By giving individuals

the choice of how they choose to capture their stories it may keep them more engaged in the long term and support them in reflecting on their kidney transplant journey stories. Moreover, to keep patients engaged in capturing their stories, further consideration into how frequent a patient is expected to capture their stories will be important. For patients to extract concrete and valuable insights from their stories they need to reflect on them consistently overtime. However, considering the challenging nature of capturing stories, it will be important to not overburden patients by asking them to capture their stories too often. Future studies should explore testing the effectiveness of capturing stories at different frequencies. Above I discuss high-level considerations for the modality and frequency of story capturing, and next I will discuss design recommendations and feature ideas for each of the four elements within the KJS component.

### 6.3.2 *Design Recommendations and Feature Ideas to Improve the My Kidney Journey Stories Component*

***Photo Element***

Each element included within the KJS component has the potential to provide participants with valuable information, but our findings indicate there is room for improvement for each of these elements. For example, youth participants did not seem to care about capturing photos, but caregiver participants did. Even though photos have been shown to be a good way to prompt, understand, and reflect on patients' experiences [163,255–258], our findings show that youth participants in this study did not like the inclusion of personal photos for a variety of reasons. With this in mind, **I put forward the following two design recommendations for the photo element: (a)** photos should be optional to include alongside patients' written stories, and **(b)** additional personalization features should be added to the element. Individuals should be able to choose if they would like to include photos at the very beginning of the process, either when they upload a

story or in their settings. For example, when participants upload a story, they can select to include or not-include photos with their story. This could potentially be integrated as a radio button or toggle switch.

To encourage individuals to upload photos or to keep them engaged with their photos, I recommend incorporating additional features to this element that support personalization. Several caregiver participants suggested some unique design feature ideas that would add personalization to this element. Building from their ideas**, I propose the following photo-element features: (a)** a pop-up photo memory feature (supports reflection), **(b)** incorporate a favorite song that goes along with individuals' photos and stories (adds personalization), **(c)** a photo carousel for multiple photos (supports reflection and ease of viewing photos), and **(d)** ability to source photos from other places (e.g., google images) (ease of adding non-personal photos). These design feature ideas may help future users by supporting reflection, adding personalization, and making it easier for participants to view and add photos within the KJS component.

***Written Stories Element***

By and large our participants found value in having written stories, but there is still room for improvement for this element. Even though participants enjoyed reflecting on their stories, several youth and caregivers found it difficult to write their stories. Consequently, **I put forth the following design recommendations to improve the written stories element**: **(a)** clarify and develop better ways to prompt participants for their stories, **(b)** support users in extracting more actionable insights from their written stories, **(c)** provide additional options for participants to capture their "written" stories, and **(d)** additional features to support reflection and provide structure should be added to this element. Participants were prompted to write stories about

specific time periods during their transplant journey: past, present, and future. To develop better prompts for participants and to support them in extracting more actionable insights from their written stories, future versions of this element could utilize the kidney journey story categories or KI Slider Bar visual to prompt individuals. For example, the following story category could be used as a prompt: "Responsibility and Planning for the Future". Thus, helping future patients to hone-in on a story topic as well as reflect on meaningful topics that can provide more actionable insights for them.

The barrier to writing can be difficult for individuals, so providing patients with alternative options to capture and view their stories may be beneficial in future designs. Stories can be captured via a variety of mediums, including but not limited to written text, verbal (word of mouth or audio recording), and visual (photos or video recording). There may be benefits to capturing patients' stories via video and/or audio recording. HCI and health informatics researchers have seen success in using video and/or audio recording to capture individuals' health stories via methods such as digital storytelling [259–262], which uses videos as a main method of capture. In addition, researchers have also explored how patients have turned to methods of video and audio recording to capture their stories, such as health vlogging [263–265]. Further exploration into the feasibility and additional challenges of capturing video and audio recordings will need to be considered before integrating it within the KJS component, but there may be benefits to giving participants the option to capture their stories in these alternative mediums.

To support individuals' reflections on their stories and provide some additional structure, we had a few participants who suggested design features that could aid individuals in these capacities. Building from a few participant's ideas, **I propose the following design features: (a)** giving patients the ability to use highlighting/bolding/adding emojis to their written stories

(supports reflection and aids in identifying actionable insights) and **(b)** setting a word limit or time limit for captured stories (provides additional structures and supports ease of capturing stories). These design feature ideas can help future users by supporting reflection, identifying actionable insights, and making it easier for participants to capture their stories within the KJS component.

### *KI Slider Bar Visual Element*

Our findings show that the KI Slider Bar visual element was overall well received, especially by youth participants. To continue supporting individuals in extracting meaningful insights from this element, **I suggest the following design recommendations for the KI Slider Bar visual element: (a)** changing the colors of the KI bars to support youth patients in working towards a positive direction for each of the five dimensions, **(b)** utilizing the KI Slider Bar visual to prompt participants when writing or video/audio recording their stories, and **(c)** incorporating this element into only youth patients' future versions of the KJS component. Youth will experience fluctuations in their five dimensions throughout their transplant journeys, but ultimately, they will be working towards one side of each of the five dimensions of the framework. For example, with the transitional management dimension (family management – self-management), most youth will be working towards self-management. To help patients work towards the more positive side of each dimension, future versions should consider changing the colors of the dimensions. One of our participants (C15) suggested changing the colors of the dimensions to green and red because of these colors' strong symbolic connotations. Changing the colors to green and red may help indicate to patients which side of the dimension they should work towards. In the case of transitional management, this would mean family management is red, while self-management is green.

Since we had seen success with youth participants gaining insight from viewing the KI Slider Bar visual in this study as well as participants telling rich stories when asked about the dimensions in previous work (Chapter 4), there is potential for the KI framework to provide structure and assist patients in coming up with stories. This could be executed in a variety of ways, but one possible way to do this would be to first have patients fill out their KI slider bar visual and then, second, write a story based on what they filled out for one of the dimensions. Further brainstorming is needed to determine how to utilize the KI figure to prompt individuals for their stories.

Considering that this element was well received by youth participants, additional consideration needs to be put into who this element is best geared to support, youth or caregivers. The KI framework was originally conceptualized for both youth and caregivers, but this element may lend itself more to youth participants who can gain the most insights from interacting and reflecting on it. In a future version of the KJS component, it may be best to incorporate this element into youth transplant patients' designs, not caregivers.

***Story Categories Element***

Our findings for this element revealed that participants liked the story categories, but compared to some of the other elements, they did not extract as many meaningful insights. To help participants extract more meaningful insights from this element, **I propose several design recommendations: (a)** utilizing the story categories to prompt participants when writing or video/audio recording their stories, **(b)** creating a repository of stories by employing the story categories as labels, and **(c)** adding an additional feature to help clarify the meanings of each story category. The story categories already reflect meaningful topics related to youth and caregivers' transplant journeys

(Chapter 4); thus, they could be a great springboard to help participants write or video/audio record their stories. Currently, the story categories act as "themes" for participants' written stories, but they may be better utilized as prompts to inspire patients' stories.

Additionally, the categories could be used as labels to create a repository of different stories. For example, if a patient labels several stories under "Responsibility and Planning for the Future," a repository of stories for this label would be created for patients for reference. In future versions of the My Kidney TREK patients may be able to interact with and view stories from other patients, so having a labeling system could help patients find stories from other patients relevant to them. Haldar et al. successfully implemented a categorizing feature into their Patient Advice System to help patients find stories within the online community they developed [266]. Otherwise, finding relevant information can be difficult and burdensome for individuals within online health communities [27,217], emphasizing the benefits or providing additional structures to online communities [267]. Lastly, **I propose one additional design feature idea for this element: (a)** a pop-up (on hover) that provides a quick definition or example for each story category. This feature could help prevent confusion about the story categories' meanings and support patients when finding relevant stories.

## 6.4 CONTRIBUTION

In this chapter, I summarize the study design and components of a technology probe deployed with youth kidney transplant patients and their caregivers. The My Kidney TREK technology probe was designed to capture a more holistic view of youth kidney transplant patients' and caregivers' journeys via three main components. To understand if the technology probe had an impact, I examined participants' reflections after interacting with the technology probe. I identified four high-level reflection themes: Positive Reflections, Future Reflections,

Growth/Change, and Negative Experiences/Barriers. I found that the technology probe positively impacted participants' reflections on their transplant journeys and we now more fully understand how these digital journaling tools have the potential to be incorporated into patient care.

Through this study, I also demonstrate the value of incorporating stories within a Kidney Journey tool to support patients in having a more holistic view of their journeys. I highlight design choices made for the Kidney Journey Stories (KJS) component of the technology probe, which was informed by Chapter 4. I found that participants overall liked the KJS component, with most youth and caregiver participants stating that they would incorporate this component in a future version of the My Kidney TREK probe. I then report on participants' design impressions for each of the KJS component's four elements: Photo Element, Written Stories Element, KI Slider Bar Element, and Stories Categories Element. From these findings, I discuss design recommendations and feature ideas to improve the KJS component for future versions of digital journaling tools. In addition, I now have a collection of youth kidney transplant patient and caregiver journey stories (not analyzed as part of this dissertation), which can add to the rich empirical understanding of youth kidney transplant patients' and caregivers' journeys.

# Chapter 7. CONCLUSION

In this final chapter, I describe how the findings from the studies presented in this dissertation fulfill the three Dissertation AIMs from Chapter 1. I then summarize my contributions, discuss limitations and future work, and end with a concluding statement.

## 7.1 FULFILLMENT OF DISSERTATION AIMS

**Aim 1: Understand youth transplant patient's and caregivers' experiences.** In this AIM, I conducted a qualitative analysis of interview data to understand the experiences of youth kidney

transplant patients and their caregivers as they recalibrated to normalcy post-transplant (Chapter 3). From this analysis, I identified five tensions (dimensions) that illustrate a more abstract and complex accounting of kidney transplantation over time. These five dimensions form the basis of a conceptual framework, the Kidney Identity Framework, capturing a complex accounting of the kidney transplant journey and the tension shifts that participants can experience from diagnosis to post-transplant. Youth transplant patients may experience shifts within each dimension of the framework due to clinical and non-clinical factors, and as part of this work, I also identified four non-clinical shared factors, which influence the five dimensions and further highlight the complexities of the kidney transplant journey.

**AIM 2: Inform the Design of a Transplant Journey Tool.** In this AIM, I used qualitative and design approaches to inform the design of a Kidney Transplant Journey tool. This AIM expands across two chapters; in Chapter 4, I probe further into youth transplant patients' experiences and discuss capturing youth's chronic illness journeys through stories. Stories have the potential to provide all stakeholders with a way to reflect on the intricacies of their journeys and identify times when their healthcare and life needs are or are not in harmony. In Chapter 5, I explore another essential element of youth's chronic illnesses journeys: their medication management. In the findings of this chapter, there was once again an emphasis on harmonizing health and life needs, highlighting a need for medication management visuals to capture the why behind youth's struggles or successes in managing their medications. I surfaced design insights from both chapters to inform the design of a Transplant Journey tool.

**AIM 3: Assess the Design and Impact of a Kidney Transplant Journey Tool.** In this AIM I completed an initial exploration of the My Kidney T.R.E.K Technology Probe to examine youth's perceptions of the tool's Kidney Journey stories component and to understand the reflective impact of the tool on their overall transplant journey. I found that the technology probe had a positive impact on participants' reflections on their kidney transplant journeys, supporting them in different ways, such as identifying areas of growth and change and promoting self-efficacy. I also reported on the four elements of the Kidney Journey Stories component of the technology probe, highlighting likes, dislikes, and suggestions for each element. Based on participants' design likes, dislikes, and suggestions, I discussed design recommendations and feature ideas for the Kidney Journey Stories component. This work illustrates the power of capturing youth's chronic illness journeys.

## 7.2 KEY CONTRIBUTIONS

In this dissertation, I make the following empirical, design, and conceptual contributions:

### 7.2.1 *Empirical*

1. A rich empirical understanding of the needs and tensions that youth kidney transplant patients and caregivers experience as they re-calibrate to normalcy post-transplant (Chapter 3).
2. Empirical results on how to characterize youth kidney transplant patients and caregivers' chronic illness journey stories (Chapter 4).
3. Confirming existing understandings of youth kidney transplant patients' struggles and successes of medication management throughout their journeys (Chapter 5).

4. Empirical evidence that the My Kidney TREK probe had a positive impact on youth patients' reflections of their chronic illness journeys, demonstrating the value of incorporating stories within a chronic illness journey tool (Chapter 6).
5. An assortment of kidney transplant stories, that can add to the rich understanding of youth kidney transplant patients' and caregivers' journeys (Chapter 6).

### 7.2.2 *Design*

1. Insight into the value of capturing youth kidney transplant stories to support youth patients in reflecting on their experiences and to inform the design of chronic illness journey tools (Chapter 4).
2. Insight into how medication management visualizations can be designed to support youth in understanding their medication management nuances and identifying actionable insights throughout their journey (Chapter 5).
3. The My Kidney TREK probe as a technological artifact informed by design insights for capturing youth transplant stories (Chapter 4) and medication management visualizations (Chapter 5) to represent a more holistic view of youth kidney transplant patients and caregivers' experiences.
4. Design considerations and recommendations to inform future chronic illness journey tools, particularly a story-capturing component within a journey tool (Chapter 6).

### 7.2.3 *Conceptual*

1. A conceptual framework that represents the different needs and tensions that arise throughout the transplant journey, shedding light on the fluctuations patients experience throughout their transplant journeys (Chapter 3).

## 7.3 Limitations and Future Work

There are limitations to the work in this dissertation, below I will summarize limitations that apply across all the studies. Each of these studies primarily recruited youth and caregiver participants from Seattle Children's Hospital (SCH) located in the Pacific Northwest, besides a handful of participants recruited from IROC CEW [29] (Chapter 3) and Johns Hopkins University transplant center (Chapter 5). Thus, the population of participants recruited from SCH reflects the demographic and geographic population of that area and future work should engage populations of youth from different geographic areas. Additionally, even though we attempted to recruit participants from different race and ethnicities, most of our participants identified as Caucasian and English speaking; future work should engage more diverse populations.

Youth participants across the studies had a wide age range (especially for Chapters 3 and 4), which I recognize may have influenced our findings due to participants' developmental stages, life experiences, and other age-based considerations. I felt that it was important to include a variety of ages for these studies, with a focus on AYAs, because their perspectives are typically not addressed in this type of work. Also, participants reflected on their kidney transplant experiences in each of the studies, however, many of our participants did not recently have their kidney transplant. Thus, recall bias from participants could affect their perceptions.

All youth transplant patients who completed these studies had to be at a certain level of kidney function (i.e. a GFR >30 ml/min/1.73m2) [186], meaning we did not recruit participants who had failing kidney function, so our findings do not reflect participants at later stages of kidney disease. Participants who completed these studies may be considered more engaged in their care compared to the average youth kidney transplant patient. Future work should try and target youth

patients who are less engaged with their care. Despite these limitations, work I presented in this dissertation still offers contributions to the fields of clinical informatics, personal health informatics, and HCI.

### 7.3.1 *Continuation of the My Kidney TREK Technology Probe*

Opportunities exist to explore the direct continuation of work with the My Kidney TREK technology probe. I see several avenues for future work, but I will be focusing on two: (1) further exploration into the development of a high-fidelity prototype to use as a clinical intervention to improve outcomes after transplant and (2) comparing (i.e. benchmarking) youth's individual transplant experiences to other transplant patients' experiences. The work completed in Chapter 6 was a pilot study to understand the impact and assess the initial design of the My Kidney TREK technology probe. Findings from the study revealed the positive impact of the technology probe as well as different design avenues for exploration. Immediate next steps would be to analyze further the design feedback for the other two components of the technology probe: My Kidney Adherence and My Kidney Function. Before deploying a high-fidelity version of the My Kidney TREK, further steps should be taken to iterate on the designs with youth transplant patients and caregivers. Design iterations should be based on the design considerations and recommendations for each of the three components.

Other additional steps will need to be considered before developing a high-fidelity version of the My Kidney TREK probe to use as a clinical intervention, such as what specific outcomes the intervention may impact. I recommend that future researchers should continue to evaluate self-efficacy, self-management, and youth's assessment of their health status as part of the clinical intervention. Additionally, I recommend that to best evaluate the impact of a high-fidelity version of the My Kidney TREK, future researchers should consider conducting a longitudinal study over

several months. As part of the pilot study, we also gathered data for several PROs, such as participants' perceptions about their self-management. PRO findings from the pilot study should be used to help select effective PROs to utilize in future work. Furthermore, based on one of our limitations mentioned above, I think a future clinical intervention should target youth patients who are less engaged with their care.

In Chapters 4 and 6 of this dissertation, I discussed the possibility of using this tool as a way for patients to understand how their own outcomes and experiences compare to others. This would mean transitioning from the current design, focused on personal benchmarking, and instead shifting the design of the My Kidney TREK to accommodate benchmarking against other patients. The purpose of this would be to help participants understand what is "normal" during different stages of the transplant journey as well as learn from others' experiences. However, this could pose not only design complications but also complications for youth patients, who may be more susceptible to negative feelings if compared to others [218,219].

As part of this study but not reported on in this dissertation, I did gather information about patients' and caregivers' thoughts about comparison. The immediate next steps would be to analyze this data to understand if participants would like to compare themselves to others for each of the My Kidney TREK components. Based on these findings, additional iterative design sessions would need to take place to incorporate this into a high-fidelity version of the My Kidney TREK probe. I would recommend having youth transplant patients as part of the research team during these iterative design sessions.

### 7.3.2 *Exploring the Generalizability of the Kidney Identity Framework*

The Kidney Identity framework conceptualized in Chapter 4 of this dissertation contains five dimensions that shift from negative to positive throughout the transplant journey. This framework

represents a more complex account of kidney transplantation over time and can provide a model and language to support patients and families throughout their transplant journey. Although other frameworks and similar literature do touch on aspects of the chronic illness journey, I hypothesize the rich accounts of experiences we captured in Chapter 4 stemmed from the holistic nature of this framework. From the success of utilizing the framework to capture youth participants' stories (Chapter 4) as well as benchmark their experiences (Chapter 6), I posit that this framework may be generalizable to youth with other types of chronic illnesses.

Each of the five dimensions within the framework highlights youth's fluctuating experiences throughout their journeys and may be applicable to youth with other types of chronic illnesses: (1) Telling Your Transplant Journey Story (hiding – self-expression), (2) Exchanging Information (receiving information – sharing information), (3) Managing Transitions (Family Management – Self-Management), (4) Building Confidence (worry – confidence), and (5) Normalizing the Transplant Journey (Not Normal – Normal) (see Chapter's 4 and 5). As an example, it is known that youth with a variety of chronic illnesses struggle to adhere to taking their medications [223,226,268–270] and that youth particularly struggle with this as they transition to self-management [35,38–40,50,271,272]. Transitioning from family to self-management is a key dimension that impacts youth with many types of chronic illnesses. Understanding how youth fluctuate throughout their chronic illness journey between these two sides of the managing transitions dimension may help support youth in their transition towards independence. Thus, future work could include exploring the generalizability of this framework with other populations of youth with chronic illnesses, such as diabetes, cystic fibrosis, asthma, other types of transplantations, and more. Utilizing the conceptual framework to help capture youth patients' stories and benchmark their experiences throughout their journeys.

## 7.4 CONCLUSION

Stepping into the hospital once a year for an annual check-up is a normal occurrence for most people, but for someone living with a chronic illness frequent trips to the hospital, getting bloodwork done regularly, and taking medications are a part of their everyday. For youth with chronic illnesses, they are on a journey that will affect each stage and transition throughout the rest of their lives. Regardless of their health challenges, youth's original activities, needs, and hopes for their future continue. Throughout this dissertation I have explored the needs and tensions that youth kidney transplant patients experience throughout their transplant journey. One tension that youth can experience as part of their journey is when, how, and to what extent they want to tell their personal story(ies) about their illness, fluctuating between hiding versus self-expression. As youth grow with their illness, they will often shift towards self-expression, becoming more confident in themselves and their abilities.

Stories are not only a powerful means of expression but also a valuable source of information. As part of this dissertation, I discuss the benefits of capturing youth;s chronic illness journeys through stories, illustrating how stories provide details about youth's lived experiences and present a holistic picture of their journeys over time. Youth and caregivers told us a variety of stories, discussing things such as responsibility and planning for their futures as well as removing healthcare burdens and reconnecting with their communities. I then demonstrate the value of designing technologies to capture chronic illness journeys, by showing the positive impact interacting with my Kidney Journey tool had on youth patients' and caregivers' reflections of their transplant journeys. Centering youth's journeys can help to identify barriers towards harmonizing their health and life needs, when so often these youth are forced to put their health needs before their wants and desires. Moreover, reflecting on their journeys through stories is a good reminder

of how hard these youth have worked to get to where they are, instilling a sense of empowerment to take more control of their lives and to fight for the life they envision.

# REFERENCES


1. Liu LS, Inkpen KM, Pratt W. I'm Not Like My Friends: Understanding How Children with a Chronic Illness Use Technology to Maintain Normalcy. Published online 2015:1527-1539. doi:10.1145/2675133.2675201

2. Bernhaupt R, Mueller F "Floyd," Verweij D, et al. Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers. *Proc 2020 Chi Conf Hum Factors Comput Syst*. Published online 2020:1-16. doi:10.1145/3313831.3376426

3. Dunbar JC, Bascom E, Pratt W, Snyder J, Smith JM, Pollack AH. My Kidney Identity: Contextualizing pediatric patients and their families kidney transplant journeys. *Pediatr Transplant*. 2022;26(7):e14343. doi:10.1111/petr.14343

4. Hong MK, Lakshmi U, Wilcox L. Just-in-Time Design: In Situ Methods for Capturing and Articulating Adolescents' Illness Experiences. *Proc 7th WISH 2017 at the American Medical Informatics Association (AMIA) Annual Symposium*. Published online November 4, 2017:1-6.

5. Lee CP, Poltrock S, Barkhuus L, et al. "I'm so glad I met you." *Proc 2017 Acm Conf Comput Supported Cooperative Work Soc Comput*. Published online 2017:1763-1774. doi:10.1145/2998181.2998326

6. Mavis AM, Ertl A, Chapman S, Cassidy LD, Lerret SM. Vulnerability and chronic illness management in pediatric kidney and liver transplant recipients. *Prog Transplant*. 2015;25(2):139 146. doi:10.7182/pit2015551

7. 2022 C©, Company TE, LLC. NAPRTCS - North American Pediatric Renal Trials and Collaborative Studies. Accessed November 28, 2022. https://naprtcs.org/

8. Foundation NK. Welcome - the National Kidney Foundation. Accessed May 24, 2023. https://www.kidney.org/

9. McDonald SP, Craig JC, Association A and NZPN. Long-Term Survival of Children with End-Stage Renal Disease. *New Engl J Medicine*. 2004;350(26):2654-2662. doi:10.1056/nejmoa031643

10. Kidney Disease in Children | NIDDK. Accessed November 28, 2022. https://www.niddk.nih.gov/health-information/kidney-disease/children

11. Tong A, Morton R, Howard K, McTaggart S, Craig JC. "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatr Transplant*. 2011;15(3):285-293. doi:10.1111/j.1399-3046.2010.01470.x

12. Bleser LD, Matteson M, Dobbels F, Russell C, Geest SD. Interventions to improve medication-adherence after transplantation: a systematic review. *Transpl Int*. 2009;22:780-797. doi:10.1111/j.1432-2277.2009.00881.x

13. Dobbels F, Ruppar T, Geest SD, Decorte A, Damme-Lombaerts RV, Fine RN. Adherence to the immunosuppressive regimen in pediatric kidney transplant recipients: a systematic review. *Pediatr Transplant*. 2010;14(5):603-613. doi:10.1111/j.1399-3046.2010.01299.x

14. Hoegy D, Bleyzac N, Robinson P, Bertrand Y, Dussart C, Janoly-Dumenil A. Medication adherence in pediatric transplantation and assessment methods: a systematic review. *Patient Prefer Adher*. 2019;13:705-719. doi:10.2147/ppa.s200209

15. Varnell CD, Rich KL, Nichols M, et al. Assessing barriers to adherence in routine clinical care for pediatric kidney transplant patients. *Pediatr Transplant*. 2017;21(7):e13027. doi:10.1111/petr.13027

16. Ford S. Patient-centered Medicine, Transforming the Clinical Method. *Health Expectations: an Int'l Journal of Public Participation in Health Care and Health Policy*. 2004;7(2):181.

17. Levenstein JH, McCracken EC, McWhinney IR, Stewart MA, Brown JB. The patient-centred clinical method. 1. A model for the doctor-patient interaction in family medicine. *Family practice*. 1986;3(1):24-30.

18. Jacobs M, Clawson J, Mynatt E. A Cancer Journey Framework: Guiding the Design of Holistic Health Technology. *Proc 10th Eai Int Conf Pervasive Comput Technologies Healthc*. Published online 2016. doi:10.4108/eai.16-5-2016.2263333

19. Jacobs ML, Clawson J, Mynatt ED. My journey compass: a preliminary investigation of a mobile tool for cancer patients. In: *Proc.of the SIGCHI Conf. Hum. Factor Comput. Syst.* ; :663-672.

20. Nikkhah S, John S, Yalamarti KS, Mueller EL, Miller AD. Family Care Coordination in the Children's Hospital: Phases and Cycles in the Pediatric Cancer Caregiving Journey. *Proc ACM Hum-Comput Interact*. 2022;6(CSCW2). doi:10.1145/3555187

21. Dijk EK van, IJsselsteijn WA. Design Beyond the Numbers: Sharing, Comparing, Storytelling and the Need for a Quantified Us. *IxD&A*. 2016;29:121-135.

22. Neff G, Nafus D. *Self-Tracking*. MIT Press

23. Staff W. Know Thyself: Tracking Every Facet of Life, from Sleep to Mood to Pain, 24/7/365. Published online 2009. https://www.wired.com/2009/06/lbnp-knowthyself/

24. Huh J. Clinical Questions in Online Health Communities: The Case of "See Your Doctor" Threads. In: *Proc.of the 18th ACM Conf. on CSCW & Social Computing*. CSCW '15. ACM; :1488–1499. doi:10.1145/2675133.2675259

25. Huh J, Ackerman MS. Collaborative Help in Chronic Disease Management: Supporting Individualized Problems. In: *Proc.of the ACM 2012 Conf. on CSCW*. Vol 2012. CSCW '12. ACM; 2012:853–862. doi:10.1145/2145204.2145331

26. Massimi M, Bender JL, Witteman HO, Ahmed OH. Life Transitions and Online Health Communities: Reflecting on Adoption, Use, and Disengagement. In: *Proc.of the 17th ACM Conf. on CSCW & Social Computing*. CSCW '14. ACM; :1491–1501. doi:10.1145/2531602.2531622

27. Newman MW, Lauterbach D, Munson SA, Resnick P, Morris ME. It's not that i don't have problems, i'm just not putting them on facebook. *Proc Acm 2011 Conf Comput Supported Cooperative Work - Cscw '11*. Published online 2011:341-350. doi:10.1145/1958824.1958876

28. Preece J. Empathic communities: Reaching out across the web. *interactions*. 1998;5(2):32-43.

29. Center. CCHM. Improving Renal Outcomes Collaborative (IROC) Community Engagement Workgroup (CEW). 2024. Accessed June 11, 2024. https://www.irocnow.org/community-engagement#:~:text=Who%20We%20Are,equivalent%20to%20the%20general%20population.

30. Hospital SC. Facts and Stats. 2024. Accessed June 11, 2024. https://www.seattlechildrens.org/about/facts-and-stats/#:~:text=We%20had%20407%20total%20licensed,Medical%2FSurgical%20Unit%3A%20183

31. Betz CL, Ferris ME, Woodward JF, Okumura MJ, Jan S, Wood DL. The health care transition research consortium health care transition model: A framework for research and practice. *J Pediatric Rehabilitation Medicine*. 2014;7(1):3-15. doi:10.3233/prm-140277

32. BLUM RWM, M.D., Ph.D., et al. Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions. *Journal of Adolescent Health*. 2020;14(7):570-576.

33. Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Educ Couns*. 2017;100(1):76-92. doi:10.1016/j.pec.2016.08.011

34. Mavis AM, Ertl A, Chapman S, Cassidy LD, Lerret SM. Vulnerability and chronic illness management in pediatric kidney and liver transplant recipients. *Prog Transplant*. 2015;25(2):139146. doi:10.7182/pit2015551

35. Modi AC, Pai AL, Hommel KA, et al. Pediatric Self-management: A Framework for Research, Practice, and Policy. *Pediatrics*. 2012;129(2):e473-e485. doi:10.1542/peds.2011-1635

36. Inc. NKF. Estimated Glomerular Filtration Rate (eGFR). 2023. Accessed January 11, 2023. https://www.kidney.org/atoz/content/gfr

37. Dunbar JC, Pratt W, Bascom E, et al. It's About the Journey - Capturing Stories of the Fluctuating Experiences of Youth Kidney Transplant Patients. *Proc ACM Hum-Comput Interact*. 2024;8(CSCW1):1-26. doi:10.1145/3653704

38. BLUM RWM, M.D., Ph.D., et al. Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions. *Journal of Adolescent Health*. 2020;14(7):570-576. doi:10.1016/1054-139x(93)90143-d

39. Betz CL, Ferris ME, Woodward JF, Okumura MJ, Jan S, Wood DL. The health care transition research consortium health care transition model: a framework for research and practice. *J Pediatr rehabilitation Med*. 2014;7(1):3-15. doi:10.3233/prm-140277

40. Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Heal Dev*. 2011;37(6):883-895. doi:10.1111/j.1365-2214.2011.01282.x

41. Bronfenbrenner U. Ecology of the Family as a Context for Human Development: Research Perspectives. *Dev Psychol*. 1986;22(6):723-742. doi:10.1037/0012-1649.22.6.723

42. Deatrick JA, Thibodeaux AG, Mooney K, Schmus C, Pollack R, Davey BH. Family Management Style Framework: A New Tool With Potential to Assess Families Who Have Children With Brain Tumors. *J Pediatr Oncol Nurs*. 2006;23(1):19-27. doi:10.1177/1043454205283574

43. Civita MD, Dobkin PL. Pediatric Adherence as a Multidimensional and Dynamic Construct, Involving a Triadic Partnership. *J Pediatr Psychol*. 2004;29(3):157-169. doi:10.1093/jpepsy/jsh018

44. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving Chronic Illness Care: Translating Evidence Into Action. *Health Affair*. 2017;20(6):64-78. doi:10.1377/hlthaff.20.6.64

45. Colver A, Longwell S. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. *Arch Dis Child*. 2013;98(11):902. doi:10.1136/archdischild-2013-303945

46. Scales PC, Benson PL, Oesterle S, Hill KG, Hawkins JD, Pashak TJ. The dimensions of successful young adult development: A conceptual and measurement framework. *Appl Dev Sci*. 2016;20(3):150-174. doi:10.1080/10888691.2015.1082429

47. Hourcade JP. *Child-Computer Interaction*. Self; 2015.

48. Boland L, Graham ID, Légaré F, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci :* . 2019;14(1):7. doi:10.1186/s13012-018-0851-5

49. Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Educ Couns*. 2017;100(1):76-92. doi:10.1016/j.pec.2016.08.011

50. Kennedy A, Sloman F, Douglass JA, Sawyer SM. Young people with chronic illness: the approach to transition. *Intern Med J*. 2007;37(8):555-560. doi:10.1111/j.1445-5994.2007.01440.x

51. Wyatt KD, List B, Brinkman WB, et al. Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis. *Acad Pediatr*. 2015;15(6):573-583. doi:10.1016/j.acap.2015.03.011

52. Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Educ Couns*. 2017;100(1):76-92. doi:10.1016/j.pec.2016.08.011

53. Miller VA, Harris D. Measuring Children's Decision-Making Involvement Regarding Chronic Illness Management. *J Pediatr Psychol*. 2012;37(3):292-306. doi:10.1093/jpepsy/jsr097

54. Gutman T, Hanson CS, Bernays S, et al. Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study. *Am J Kidney Dis*. 2018;72(4):547-559. doi:10.1053/j.ajkd.2018.05.005

55. Opel DJ. A 4-Step Framework for Shared Decision-making in Pediatrics. *Pediatrics*. 2018;142(Suppl 3):S149-S156. doi:10.1542/peds.2018-0516e

56. Opel DJ. A Push for Progress With Shared Decision-making in Pediatrics. *Pediatrics*. 2017;139(2):e20162526. doi:10.1542/peds.2016-2526

57. Cukor D, Cohen SD, Kimmel PL. Psychosocial Aspects of Chronic Kidney Disease. Published online 2021:9-25. doi:10.1016/b978-0-12-817080-9.00002-6

58. Jhamb M, Steel J. Psychosocial Aspects of Chronic Kidney Disease. Published online 2021:213-228. doi:10.1016/b978-0-12-817080-9.00010-5

59. Amatya K, Moxey-Mims MM, Hooper SR. Psychosocial Aspects of Chronic Kidney Disease. Published online 2021:451-471. doi:10.1016/b978-0-12-817080-9.00020-8

60. Wong G, Howard K, Chapman JR, et al. Comparative Survival and Economic Benefits of Deceased Donor Kidney Transplantation and Dialysis in People with Varying Ages and Co-Morbidities. *PLoS ONE*. 2012;7(1):e29591. doi:10.1371/journal.pone.0029591

61. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of Mortality in All Patients on Dialysis, Patients on Dialysis Awaiting Transplantation, and Recipients of a First Cadaveric Transplant. *N Engl J Med*. 1999;341(23):1725-1730. doi:10.1056/nejm199912023412303

62. Jarzembowski T, John E, Panaro F, et al. Impact of non-compliance on outcome after pediatric kidney transplantation: an analysis in racial subgroups. *Pediatr Transplant*. 2004;8:367-371. doi:10.1111/j.1399-3046.2004.00158.x

63. Simons LE, Gilleland J, Blount RL, Amaral S, Berg A, Mee LL. Multidimensional Adherence Classification System: initial development with adolescent transplant recipients. *Pediatr Transplant*. 2009;13:590-598. doi:10.1111/j.1399-3046.2008.01038.x

64. Nevins TE, Thomas W. Quantitative patterns of azathioprine adherence after renal transplantation. *Transplantation*. 2009;87:711-718. doi:10.1097/tp.0b013e318195c3d5

65. Dobbels F, Ruppar T, Geest SD, Decorte A, Damme-Lombaerts RV, Fine RN. Adherence to the immunosuppressive regimen in pediatric kidney transplant recipients: a systematic review. *Pediatr Transplant*. 2010;14(5):603-613. doi:10.1111/j.1399-3046.2010.01299.x

66. Spivey CA, Chisholm-Burns MA, Damadzadeh B, Billheimer D. Determining the effect of immunosuppressant adherence on graft failure risk among renal transplant recipients. *Clin Transplant*. 2014;28:96-104. doi:10.1111/ctr.12283

67. Sellarés J, Freitas DG de, Mengel M, et al. Understanding the causes of kidney transplant failure: the dominant role of antibody-mediated rejection and nonadherence. *Am J Transplant*. 2012;12:388-399. doi:10.1111/j.1600-6143.2011.03840.x

68. Pinsky BW, Takemoto SK, Lentine KL, Burroughs TE, Schnitzler MA, Salvalaggio PR. Transplant outcomes and economic costs associated with patient noncompliance to immunosuppression. *Am J Transplant*. 2009;9:2597-2606. doi:10.1111/j.1600-6143.2009.02798.x

69. Dew MA, Dabbs AD, Myaskovsky L, et al. Meta-analysis of medical regimen adherence outcomes in pediatric solid organ transplantation. *Transplantation*. 2009;88:736-746. doi:10.1097/tp.0b013e3181b2a0e0

70. Shaw RJ, Palmer L, Blasey C, Sarwal M. A typology of non-adherence in pediatric renal transplant recipients. *Pediatr Transplant*. 2003;7(6):489 493. doi:10.1046/j.1397-3142.2003.00117.x

71. Cadman D, Boyle M, Szatmari P, Offord DR. Chronic illness, disability, and mental and social well-being: findings of the Ontario Child Health Study. *Pediatrics*. 1987;79(5):805-813.

72. Garrison WT, McQuiston S. Chronic illness during childhood and adolescence: Psychological aspects. *Diabetes Care*. 1989;3(6):696-702. doi:10.2337/diacare.3.6.696

73. Lavigne JV, Faier-Routman J. Psychological Adjustment to Pediatric Physical Disorders: A Meta-Analytic Review. *J Pediatr Psychol*. 1992;17(2):133-157. doi:10.1093/jpepsy/17.2.133

74. Maikranz JM, Steele RG, Dreyer ML, Stratman AC, Bovaird JA. The Relationship of Hope and Illness-Related Uncertainty to Emotional Adjustment and Adherence Among Pediatric Renal and Liver Transplant Recipients. *J Pediatr Psychol*. 2007;32(5):571 581. doi:10.1093/jpepsy/jsl046

75. Steele RG, Aylward BS, Jensen CD, Wu YP. Parent- and Youth-Reported Illness Uncertainty: Associations With Distress and Psychosocial Functioning Among Recipients of Liver and Kidney Transplantations. *Child Heal Care*. 2009;38(3):185-199. doi:10.1080/02739610903038768

76. Mishel MH. The measurement of uncertainty in illness. *Nursing research*. 1981;30(5):258 263.

77. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003;26(1):1-7. doi:10.1207/s15324796abm2601_01

78. Meyers KEC, Thomson PD, Weiland H. NONCOMPLIANCE IN CHILDREN AND ADOLESCENTS AFTER RENAL TRANSPLANTATION. *Transplantation …*. 1996;62(2):186.

79. Blowey DL, Hébert D, Arbus GS, Pool R, Korus M, Koren G. Compliance with cyclosporine in adolescent renal transplant recipients. *Pediatr Nephrol*. 1997;11(5):547 551. doi:10.1007/s004670050335

80. Dobbels F, Ruppar T, Geest SD, Decorte A, Damme-Lombaerts RV, Fine RN. Adherence to the immunosuppressive regimen in pediatric kidney transplant recipients: A systematic review. *Pediatr Transplant*. 2010;14(5):603 613. doi:10.1111/j.1399-3046.2010.01299.x

81. Steinberg EA, Moss M, Buchanan CL, Goebel J. Adherence in pediatric kidney transplant recipients: solutions for the system. *Pediatr Nephrol*. 2018;33(3):361-372. doi:10.1007/s00467-017-3637-0

82. Pruette CS, Amaral S. Empowering patients to adhere to their treatment regimens: A multifaceted approach. *Pediatr Transplant*. 2021;25(1):e13849. doi:10.1111/petr.13849

83. Dobbels F, Decorte A, Roskams A, Damme-Lombaerts RV. Health-related quality of life, treatment adherence, symptom experience and depression in adolescent renal transplant patients. *Pediatr Transplant*. 2010;14(2):216-223. doi:10.1111/j.1399-3046.2009.01197.x

84. Tong A, Morton R, Howard K, McTaggart S, Craig JC. "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatr Transplant*. 2011;15(3):285-293. doi:10.1111/j.1399-3046.2010.01470.x

85. Ferris ME, Miles JA, Seamon ML. Adolescents and young adults with chronic or end-stage kidney disease. *Blood purification*. 2016;41(1-3):205-210.

86. Dobbels F, Decorte A, Roskams A, Damme-Lombaerts RV. Health-related quality of life, treatment adherence, symptom experience and depression in adolescent renal transplant patients. *Pediatric transplantation*. 2010;14(2):216-223.

87. Steele RG, Aylward BS, Jensen CD, Wu YP. Parent-and youth-reported illness uncertainty: Associations with distress and psychosocial functioning among recipients of liver and kidney transplantations. *Children's Health Care*. 2009;38(3):185-199.

88. Watson AR. Psychosocial support for children and families requiring renal replacement therapy. *Pediatric Nephrology*. 2014;29(7):1169-1174.

89. Betz CL, Ferris ME, Woodward JF, Okumura MJ, Jan S, Wood DL. The health care transition research consortium health care transition model: a framework for research and practice. *Journal of pediatric rehabilitation medicine*. 2014;7(1):3-15.

90. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*. 1993;14(7):570-576.

91. Schwartz L, Tuchman L, Hobbie W, Ginsberg J. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: care, health and development*. 2011;37(6):883-895.

92. Barbarin A, Veinot TC, Klasnja P. Taking Our Time: Chronic Illness and Time-Based Objects in Families. In: *Proc.of the 18th ACM Conf. on CSCW & Social Computing*. CSCW '15. ACM; :288–301. doi:10.1145/2675133.2675200

93. Isika N, Mendoza A, Bosua R. "I Need to Compartmentalize Myself": Appropriation of Instagram for Chronic Illness Management. In: *Proc.of the Australasian Computer Science Week MultiConf.* ACSW '20. ACM; 2020:1-9. doi:10.1145/3373017.3373040

94. Mankoff J, Kuksenok K, Kiesler S, Rode JA, Waldman K. Competing Online Viewpoints and Models of Chronic Illness. In: *Proc.of the SIGCHI Conf. Hum. Factor Comput. Syst.* CHI '11. ACM; :589–598. doi:10.1145/1978942.1979027

95. O'Kane AA, Mentis H. Sharing Medical Data vs. Health Knowledge in Chronic Illness Care. In: *CHI '12 Extended Abstracts on Human Factors in Computing Systems*. CHI EA '12. ACM; :2417–2422. doi:10.1145/2212776.2223812

96. Pang CE, Neustaedter C, Riecke BE, Oduor E, Hillman S. Technology Preferences and Routines for Sharing Health Information during the Treatment of a Chronic Illness. In: *Proc.of the SIGCHI Conf. Hum. Factor Comput. Syst.* CHI '13. ACM; :1759–1768. doi:10.1145/2470654.2466232

97. Cha YJ, Saxena A, Wou A, Lee J, Newman MW, Park SY. Transitioning Toward Independence: Enhancing Collaborative Self-Management of Children with Type 1 Diabetes. In: *CHI Conf. Hum. Factor Comput. Syst.* ; :1-17.

98. Hong MK, Lakshmi U, Do K, et al. Using diaries to probe the illness experiences of adolescent patients and parental caregivers. In: *Proc.of the 2020 CHI Conf. Hum. Factor Comput. Syst.* ; :1-16.

99. Kaye J, Druin A, Lampe C, et al. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. *Proc Sigchi Conf Hum Factors Comput Syst Chi Conf*. 2016;2016:5337-5349. doi:10.1145/2858036.2858508

100. Britto MT, Hesse EA, Kamdar OJ, Munafo JK. Parents' Perceptions of a Patient Portal for Managing Their Child's Chronic Illness. *J Pediatrics*. 2013;163(1):280-281.e2. doi:10.1016/j.jpeds.2013.02.041

101. Hong MK, Wilcox L, Machado D, Olson TA, Simoneaux SF. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. In: *In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16).* ; 2016:5337-5349. doi:10.1145/2858036.2858508

102. Hong MK, Lakshmi U, Olson TA, Wilcox L. Visual ODLs: Co-Designing Patient-Generated Observations of Daily Living to Support Data-Driven Conversations in Pediatric Care. Published online 2018:476. doi:10.1145/3173574.3174050

103. Lakshmi U, Hong M, Wilcox L. Integrating Patient-Generated Observations of Daily Living into Pediatric Cancer Care: A Formative User Interface Design Study. *2018 Ieee Int Conf Healthc Informatics Ichi*. Published online 2018:265-275. doi:10.1109/ichi.2018.00037

104. Hong MK, Feustel C, Agnihotri M, Silverman M, Simoneaux SF, Wilcox L. Supporting families in reviewing and communicating about radiology imaging studies. In: *Proc.of the 2017 CHI Conf. Hum. Factor Comput. Syst.* ; :5245-5256.

105. Zhao Y, Kim Y, Apodaca C, et al. Supporting Goal-Based Collaboration for Hospitalized Children. *Proc Acm Human-computer Interact*. 2021;5(CSCW1):1-22. doi:10.1145/3449238

106. Haldar S, Mishra SR, Khelifi M, Pollack AH, Pratt W. Beyond the Patient Portal: Supporting Needs of Hospitalized Patients. In: *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. CHI '19. Association for Computing Machinery; :1–14. doi:10.1145/3290605.3300596

107. Haldar S, Mishra SR, Khelifi M, Pollack AH, Pratt W. Opportunities and Design Considerations for Peer Support in a Hospital Setting. In: *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems, CHI '17*. Vol 2017. Proceedings of the SIGCHI conference on human factors in computing systems . CHI Conference. ; 2017:867-879. doi:10.1145/3025453.3026040

108. Haldar S, Mishra SR, Kim Y, Hartzler A, Pollack AH, Pratt W. Use and impact of an online community for hospital patients. *J Am Med Inform Assn*. 2020;27(4):549-557. doi:10.1093/jamia/ocz212

109. Zhao Y, Kim Y, Apodaca C, et al. Supporting Goal-Based Collaboration for Hospitalized Children. *Proc Acm Human-computer Interact*. 2021;5(CSCW1):1-22. doi:10.1145/3449238

110. Anthony SJ, Hebert D, Todd L, et al. Child and parental perspectives of multidimensional quality of life outcomes after kidney transplantation. *Pediatr Transplant*. 2010;14(2):249-256. doi:10.1111/j.1399-3046.2009.01214.x

111. Dobbels F, Decorte A, Roskams A, Damme-Lombaerts RV. Health-related quality of life, treatment adherence, symptom experience and depression in adolescent renal transplant patients. *Pediatr Transplant*. 2010;14:216-223. doi:10.1111/j.1399-3046.2009.01197.x

112. Ingerski LM, Modi AC, Hood KK, et al. Health-Related Quality of Life Across Pediatric Chronic Conditions. *J Pediatrics*. 2010;156(4):639-644. doi:10.1016/j.jpeds.2009.11.008

113. Pinquart M. Health-Related Quality of Life of Young People With and Without Chronic Conditions. *J Pediatr Psychol*. 2020;45(7):780-792. doi:10.1093/jpepsy/jsaa052

114. Taylor RM, Gibson F, Franck LS. A concept analysis of health-related quality of life in young people with chronic illness. *J Clin Nurs*. 2008;17(14):1823-1833. doi:10.1111/j.1365-2702.2008.02379.x

115. Weng L, Dai Y, Huang H, Chiang Y. Self-efficacy, self-care behaviours and quality of life of kidney transplant recipients. 66(4):828-838.

116. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Heal Serv Res*. 2013;13(1):211. doi:10.1186/1472-6963-13-211

117. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pr*. 1999;5(4):401-416. doi:10.1046/j.1365-2753.1999.00209.x

118. Hartzler AL, Izard JP, Dalkin BL, Mikles SP, Gore JL. Design and feasibility of integrating personalized PRO dashboards into prostate cancer care. *J Am Méd Inform Assoc*. 2016;23(1):38-47. doi:10.1093/jamia/ocv101

119. Lordon RJ, Mikles SP, Kneale L, et al. How patient-generated health data and patient-reported outcomes affect patient–clinician relationships: A systematic review. *Heal Inform J*. 2020;26(4):2689-2706. doi:10.1177/1460458220928184

120. Initiative TS. Standardised Outcomes in Nephrology (SONG). 2024. Accessed June 7, 2024. https://songinitiative.org/

121. Ju A, Chow BY, Ralph AF, et al. Patient-reported outcome measures for life participation in kidney transplantation: A systematic review. *Am J Transplant*. 2019;19(8):2306-2317. doi:10.1111/ajt.15267

122. Ju A, Josephson MA, Jowsey-Gregoire S, et al. Establishing a Core Outcome Measure for Life Participation: A Standardized Outcomes in Nephrology – Kidney Transplantation (SONG-Tx) Consensus Workshop Report. *Transplantation*. 2018;102(Supplement 7):S562. doi:10.1097/01.tp.0000543427.80244.79

123. Kerklaan J, Hannan E, Baumgart A, et al. Patient- and parent proxy-reported outcome measures for life participation in children with chronic kidney disease: a systematic review. *Nephrol Dial Transplant*. 2020;35(11):1924-1937. doi:10.1093/ndt/gfaa132

124. Hayes GR, Abowd GD, Davis JS, Blount ML, Ebling M, Mynatt ED. Pervasive Computing. *Lect Notes Comput Sci*. Published online 2008:262-279. doi:10.1007/978-3-540-79576-6_16

125. Jacobs M, Clawson J, Mynatt E. A Cancer Journey Framework: Guiding the Design of Holistic Health Technology. *Proc 10th EAI Int Conf Pervasive Comput Technol Healthc*. Published online 2016. doi:10.4108/eai.16-5-2016.2263333

126. Jacobs M, Johnson J, Mynatt ED. MyPath: Investigating Breast Cancer Patients' Use of Personalized Health Information. *Proc ACM Hum-Comput Interact*. 2018;2(CSCW):1-21. doi:10.1145/3274347

127. Jones M, Palanque P, Schmidt A, et al. My journey compass: a preliminary investigation of a mobile tool for cancer patients. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. Association for Computing Machinery; 2014:663-672. doi:10.1145/2556288.2557194

128. Nikkhah S, John S, Yalamarti KS, Mueller EL, Miller AD. Family Care Coordination in the Children's Hospital: Phases and Cycles in the Pediatric Cancer Caregiving Journey. *Proc ACM Hum-Comput Interact*. 2022;6(CSCW2):1-30. doi:10.1145/3555187

129. STORYWORTH, INC. Storyworth - Everyone has a story worth sharing. 2024. Accessed June 10, 2024. https://welcome.storyworth.com/

130. Remento) HMTInc (dba. Remento: Capture family stories. 2023. Accessed June 10, 2024. https://www.remento.co/

131. Affairs USD of V. My Life, My Story - Whole Health. 2024. Accessed June 7, 2024. https://www.va.gov/WHOLEHEALTH/mylifemystory/index.asp

132. Lam JA, Feingold-Link M, Noguchi J, et al. My life, my story: Integrating a life story narrative component into medical student curricula. 18:11211.

133. Nathan S, Fiore LL, Saunders S, et al. My life, my story: Teaching patient centered care competencies for older adults through life story work. *Gerontology & Geriatrics Education*. 2022;43(2):225-238. doi:10.1080/02701960.2019.1665038

134. Nathan S, Schwartz AW, Topor DR. My life, my story: a narrative life history activity to humanize the veteran patient experience. In: *Cases on Instructional Design and Performance Outcomes in Medical Education*. IGI Global; :70-91.

135. Roberts TJ, Ringler T, Krahn D, Ahearn E. The My Life, My Story Program: Sustained Impact of Veterans' Personal Narratives on Healthcare Providers 5 Years After Implementation. *Health Commun*. 2021;36(7):829-836. doi:10.1080/10410236.2020.1719316

136. Walker E, Bruns E, Dhaliwal G. The VA My Life My Story Project: Keeping Medical Students and Veterans Socially Connected While Physically Distanced. *Fed Pract*. 2021;38:568-573. doi:10.12788/fp.0208

137. Gordon AS, Cao Q, Swanson R. Automated Story Capture from Internet Weblogs. In: *Proceedings of the 4th International Conference on Knowledge Capture*. K-CAP '07. Association for Computing Machinery; :167–168. doi:10.1145/1298406.1298437

138. Gordon AS, Ganesan K. Automated Story Capture from Conversational Speech. In: *Proceedings of the 3rd International Conference on Knowledge Capture*. K-CAP '05. Association for Computing Machinery; :145–152. doi:10.1145/1088622.1088649

139. Epstein DA, Dontcheva M, Fogarty J, Munson SA. Yarn: Adding meaning to shared personal data through structured storytelling.

140. Pavel D, Trossen D, Holweg M, Callaghan V. Lifestyle Stories: Correlating User Information through a Story-Inspired Paradigm. In: *Proc.of the 7th Int'l Conf. on Pervasive Computing Technologies for Healthcare*. PervasiveHealth '13. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering); 2013:412–415. doi:10.4108/icst.pervasivehealth.2013.252131

141. Rosner DK, Ryokai K. Spyn: augmenting knitting to support storytelling and reflection. *Proc 10th Int Conf Ubiquitous Comput - Ubicomp '08*. Published online 2008:340-349. doi:10.1145/1409635.1409682

142. Schulte BF, Hornecker E. Care Stories: Understanding People's Hopes and Fears for Technologies of Care through Story Elicitation. In: *Proc.of the 25th Int'l Academic Mindtrek Conf.* Academic Mindtrek '22. ACM; 2022:117–128. doi:10.1145/3569219.3569309

143. Saksono H, Castaneda-Sceppa C, Hoffman JA, El-Nasr MS, Parker A. StoryMap: Using Social Modeling and Self-Modeling to Support Physical Activity Among Families of Low-SES Backgrounds. In: *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. CHI '21. Association for Computing Machinery. doi:10.1145/3411764.3445087

144. Saksono H, Castaneda-Sceppa C, Hoffman J, Morris V, El-Nasr MS, Parker AG. Storywell: designing for family fitness app motivation by using social rewards and reflection. In: ; :1-13.

145. Oettingen G, Sevincer AT, Gollwitzer PM, eds. *The Psychology of Thinking about the Future.* Guilford Publications; 2018. https://www.guilford.com/books/The-Psychology-of-Thinking-about-the-Future/Oettingen-Sevincer-Gollwitzer/9781462534418/contributors

146. Hershfield HE. Future self-continuity: how conceptions of the future self transform intertemporal choice. *Ann Ny Acad Sci*. 2011;1235(1):30-43. doi:10.1111/j.1749-6632.2011.06201.x

147. Hershfield HE. The Self Over Time. *Curr Opin Psychology*. 2018;26:72-75. doi:10.1016/j.copsyc.2018.06.004

148. Hershfield HE, Maglio SJ. When Does the Present End and the Future Begin? *J Exp Psychol: Gen*. 2020;149(4):701-718. doi:10.1037/xge0000681

149. Rutchick AM, Slepian ML, Reyes MO, Pleskus LN, Hershfield HE. Future Self-Continuity Is Associated With Improved Health and Increases Exercise Behavior. *J Exp Psychology Appl*. 2018;24(1):72-80. doi:10.1037/xap0000153

150. Ersner-Hershfield H, Garton MT, Ballard K, Samanez-Larkin GR, Knutson B. Don't stop thinking about tomorrow: Individual differences in future self-continuity account for saving. *Judgm Decis Mak*. 2009;4(4):280-286.

151. Hershfield HE, John EM, Reiff JS. Using Vividness Interventions to Improve Financial Decision Making. *Polic Insights Behav Brain Sci*. 2018;5(2):209-215. doi:10.1177/2372732218787536

152. Hershfield H, Shu S, Benartzi S. Temporal Reframing and Participation in a Savings Program: A Field Experiment. *SSRN Electron J*. Published online 2019. doi:10.2139/ssrn.3097468

153. GELDER JV, LUCIANO EC, KRANENBARG MW, HERSHFIELD HE. FRIENDS WITH MY FUTURE SELF: LONGITUDINAL VIVIDNESS INTERVENTION REDUCES DELINQUENCY. *Criminology*. 2015;53(2):158-179. doi:10.1111/1745-9125.12064

154. Makedon F, Tsiakas K, Cnossen D, et al. FutureMe: Negotiating Learning Goals with your Future Learning-Self Avatar. *14th Pervasive Technologies Relat Assistive Environ Conf*. Published online 2021:262-263. doi:10.1145/3453892.3461008

155. Fuchs K, Meusburger D, Haldimann M, Ilic A. NutritionAvatar: designing a future-self avatar for promotion of balanced, low-sodium diet intention: framework design and user study. *Proc 13th Biannu Conf Italian Sigchi Chapter Des Next Interact - Chitaly '19*. Published online 2019:1-10. doi:10.1145/3351995.3352044

156. Faralla V, Innocenti A, Baraldi S, et al. The effect of future self-continuity on delaying immediate gratification. A virtual reality experiment. *European Conf Cognitive Ergonomics 2021*. Published online 2021:1-8. doi:10.1145/3452853.3452893

157. Gutman T, Hanson CS, Bernays S, et al. Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study. *Am J Kidney Dis*. 2018;72(4):547-559. doi:10.1053/j.ajkd.2018.05.005

158. Hanson CS, Gutman T, Craig JC, et al. Identifying Important Outcomes for Young People With CKD and Their Caregivers: A Nominal Group Technique Study. *Am J Kidney Dis*. 2019;74(1):82-94. doi:10.1053/j.ajkd.2018.12.040

159. Kalantar-Zadeh K, Li PKT, Tantisattamo E, et al. Living Well with Kidney Disease by Patient and Care-Partner Empowerment: Kidney Health for Everyone Everywhere. *Am J Nephrol*. 2021;52(1):1-7. doi:10.1159/000513952

160. Kerklaan J, Hannan E, Hanson C, et al. Perspectives on life participation by young adults with chronic kidney disease: an interview study. *Bmj Open*. 2020;10(10):e037840. doi:10.1136/bmjopen-2020-037840

161. Tong A, Morton R, Howard K, McTaggart S, Craig JC. "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatr Transplant*. 2011;15(3):285-293. doi:10.1111/j.1399-3046.2010.01470.x

162. One platform to connect | Zoom. Accessed February 12, 2024. https://zoom.us/

163. Pollack AH, Snyder J. Reflecting on patient-generated photographs of the pediatric renal transplant experience. *Pediatr Transplant*. Published online 2020:e13896. doi:10.1111/petr.13896

164. Mitchell C. *Doing Visual Research*. Sage Publications; 2011.

165. Rose G. *Visual Methodologies: An Introduction to Researching with Visual Materials*. Sage Publications; 2016.

166. Patton MQ. *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*. Sage Publications; 2014.

167. Creswell JW, Poth CN. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. Sage Publications; 2016.

168. Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory.* Sage Publications; 2014.

169. *MAXQDA 2020*.; 2020. maxqda.com

170. Hyde KF. Recognising deductive processes in qualitative research. *Qual Mark Res: Int J*. 2000;3(2):82-90. doi:10.1108/13522750010322089

171. Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *Am J Eval*. 2006;27(2):237-246. doi:10.1177/1098214005283748

172. Hartzler A, Pratt W. Managing the Personal Side of Health: How Patient Expertise Differs from the Expertise of Clinicians. *J Med Internet Res*. 2011;13(3):e62. doi:10.2196/jmir.1728

173. Wightman A, Bradford MC, Smith J. Health-related quality of life changes following renal transplantation in children. *Pediatr Transplant*. 2019;23(2):e13333. doi:10.1111/petr.13333

174. Adamczuk D, Blaim MR, Leszczyńska B, Tomaszewska MP. Life activity, disease acceptance and quality of life in patients treated with renal replacement therapy since childhood. *Adv Clin Exp Med*. 2019;28(7):871-878. doi:10.17219/acem/94070

175. Amatya K, Monnin K, Christofferson ES. Psychological functioning and psychosocial issues in pediatric kidney transplant recipients. *Pediatr Transplant*. 2021;25(1):e13842. doi:10.1111/petr.13842

176. Hamilton AJ, Caskey FJ, Casula A, Inward CD, Ben-Shlomo Y. Associations with Wellbeing and Medication Adherence in Young Adults Receiving Kidney Replacement Therapy. *Clin J Am Soc Nephro*. 2018;13(11):CJN.02450218. doi:10.2215/cjn.02450218

177. Jerson B, D'Urso C, Arnon R, et al. Adolescent transplant recipients as peer mentors: A program to improve self-management and health-related quality of life. *Pediatr Transplant*. 2013;17(7):612-620. doi:10.1111/petr.12127

178. Tong A, Morton R, Howard K, McTaggart S, Craig JC. "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatr Transplant*. 2011;15(3):285-293. doi:10.1111/j.1399-3046.2010.01470.x

179. Liu LS, Inkpen KM, Pratt W. I'm Not Like My Friends: Understanding How Children with a Chronic Illness Use Technology to Maintain Normalcy. Published online 2015:1527-1539. doi:10.1145/2675133.2675201

180. Hoegy D, Bleyzac N, Robinson P, Bertrand Y, Dussart C, Janoly-Dumenil A. Medication adherence in pediatric transplantation and assessment methods: a systematic review. *Patient Prefer Adher*. 2019;13:705-719. doi:10.2147/ppa.s200209

181. Griffin KJ, Elkin TD. Non-adherence in pediatric transplantation: a review of the existing literature. *Pediatr Transplant*. 2001;5(4):246 249. doi:10.1034/j.1399-3046.2001.005004246.x

182. Foster BJ, Pai ALH, Zelikovsky N, et al. A Randomized Trial of a Multicomponent Intervention to Promote Medication Adherence: The Teen Adherence in Kidney Transplant

Effectiveness of Intervention Trial (TAKE-IT). *Am J Kidney Dis*. 2018;72(1):30-41. doi:10.1053/j.ajkd.2017.12.012

183. Pollack AH, Snyder J. Reflecting on patient-generated photographs of the pediatric renal transplant experience. *Pediatr Transplant*. Published online 2020:e13896. doi:10.1111/petr.13896

184. Betz CL, Ferris ME, Woodward JF, Okumura MJ, Jan S, Wood DL. The health care transition research consortium health care transition model: A framework for research and practice. *J Pediatric Rehabilitation Medicine*. 2014;7(1):3-15. doi:10.3233/prm-140277

185. Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Heal Dev*. 2011;37(6):883-895. doi:10.1111/j.1365-2214.2011.01282.x

186. Foundation NK. Estimated Glomerular Filtration Rate (eGFR). Accessed June 1, 2023. https://www.kidney.org/atoz/content/gfr

187. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010

188. Hayes GR, Abowd GD, Davis JS, Blount ML, Ebling M, Mynatt ED. Pervasive Computing, 6th International Conference, Pervasive 2008 Sydney, Australia, May 19-22, 2008 Proceedings. *Lect Notes Comput Sci*. Published online 2008:262-279. doi:10.1007/978-3-540-79576-6_16

189. Jacobs M, Johnson J, Mynatt ED. MyPath: Investigating Breast Cancer Patients' Use of Personalized Health Information. *Proc ACM Hum-Comput Interact*. 2018;2(CSCW). doi:10.1145/3274347

190. Jamshed S. Qualitative research method-interviewing and observation. *J Basic Clin Pharm*. 2014;5(4):87-88. doi:10.4103/0976-0105.141942

191. DiCicco-Bloom B, Crabtree BF. The qualitative research interview. *Méd Educ*. 2006;40(4):314-321. doi:10.1111/j.1365-2929.2006.02418.x

192. Inc F. Figjam. 2024. Accessed 2024. https://www.figma.com/figjam/

193. Holtzblatt K, Beyer H. *Contextual Design: Defining Customer-Centered Systems*. Elsevier

194. Lazar J, Feng JH, Hochheiser H. *Research Methods in HCI*. Wiley Publishing

195. Baumer EP. Reflective informatics: conceptual dimensions for designing technologies of reflection. In: *Proc.of the 33rd Annual ACM Conf. on Human Factors in Computing Systems*. ; :585-594.

196. Choe EK, Lee B, Zhu H, Riche NH, Baur D. Understanding self-reflection: how people reflect on personal data through visual data exploration. In: *Proc.of the 11th EAI Int'l Conf. on Pervasive Computing Technologies for Healthcare*. ; :173-182.

197. Thudt A, Hinrichs U, Huron S, Carpendale S. Self-reflection and personal physicalization construction. In: *Proc.of the 2018 CHI Conf. Hum. Factor Comput. Syst.* ; :1-13.

198. Lim CY, Berry AB, Hartzler AL, et al. Facilitating self-reflection about values and self-care among individuals with chronic conditions. In: *Proc.of the 2019 CHI Conf. Hum. Factor Comput. Syst.* ; :1-12.

199. Blair J, Luo Y, Ma NF, Lee S, Choe EK. OneNote Meal: A Photo-Based Diary Study for Reflective Meal Tracking. *Amia Annu Symposium Proc Amia Symposium*. 2018;2018:252-261.

200. Hershfield HE. Future self-continuity: How conceptions of the future self transform intertemporal choice. *Annals of the NY Academy of Sciences*. 2011;1235(1):30-43.

201. Hershfield HE. The self over time. *Current Opinion in Psychology*. 2019;26:72-75.

202. Hershfield HE, Maglio SJ. When does the present end and the future begin? *Journal of Experimental Psychology: General*. 2020;149(4):701.

203. Oettingen G, Sevincer AT, Gollwitzer PM. *The Psychology of Thinking about the Future*. Guilford Publications

204. Betz CL, Lobo ML, Nehring WM, Bui K. Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook*. 2013;61(5):311-336.

205. Boland L, Graham ID, Légaŕe F, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implementation Science*. 2019;14(1):1-25.

206. Drotar DD. Collaborative decision-making and promoting treatment adherence in pediatric chronic illness. *Patient Intell*. 2010;Volume 2(Default):1-7. doi:10.2147/pi.s8820

207. Hong MK, Wilcox L, Machado D, Olson TA, Simoneaux SF. Care partnerships: Toward technology to support teens' participation in their health care. In: *Proc.of the 2016 CHI Conf. Hum. Factor Comput. Syst.* ; :5337-5349.

208. Wyatt KD, List B, Brinkman WB, et al. Shared decision making in pediatrics: a systematic review and meta-analysis. *Academic pediatrics*. 2015;15(6):573-583.

209. Holman H, Lorig K. Perceived self-efficacy in self-management of chronic disease. *Self-efficacy: Thought control of action*. 1992;1:305-324.

210. Turchioe MR, Grossman LV, Myers AC, Baik D, Goyal P, Creber RMM. Visual analogies, not graphs, increase patients' comprehension of changes in their health status. *JAMIA*. 2020;27(5):677-689.

211. Snyder J, Murnane E, Lustig C, Voida S. Visually encoding the lived experience of bipolar disorder. In: *Proc.of the 2019 CHI Conf. Hum. Factor Comput. Syst.* ; :1-14.

212. Turchioe MR, Myers A, Isaac S, et al. A systematic review of patient-facing visualizations of personal health data. *Applied clinical informatics*. 2019;10(04):751-770.

213. Frost J, Massagli M, others. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. *Journal of medical Internet research*. 2008;10(3):e1053.

214. Huh J, Liu LS, Neogi T, Inkpen K, Pratt W. Health vlogs as social support for chronic illness management. *ACM Transactions on Computer-Human Interaction (TOCHI)*. 2014;21(4):1-31.

215. Liu LS, Huh J, Neogi T, Inkpen K, Pratt W. Health vlogger-viewer interaction in chronic illness management. In: *Proc.of the SIGCHI Conf. Hum. Factor Comput. Syst.* ; :49-58.

216. Høybye MT, Johansen C, Tj\ornh\oj-Thomsen T. Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*. 2005;14(3):211-220.

217. Civan-Hartzler A, McDonald DW, Powell C, Skeels MM, Mukai M, Pratt W. Bringing the field into focus. *Proc 28th Int Conf Hum Factors Comput Syst - Chi '10*. 2010;2010:1675-1684. doi:10.1145/1753326.1753577

218. Arigo D. Social Comparison Theory in the Context of Chronic Illness: Predictors and Consequences of Target Selection among Individuals with Type 2 Diabetes.

219. Gerber J, Wheeler L, Suls J. A social comparison theory meta-analysis 60+ years on. *Psychological bulletin*. 2018;144(2):177.

220. Hospital SC. Research Integration Hub. 2024. Accessed June 24, 2024. https://www.seattlechildrens.org/research/resources/research-integration-hub/

221. REV. Where Every Word Matters. 2024. Accessed June 24, 2024. https://www.rev.com/

222. Steinberg EA, Moss M, Buchanan CL, Goebel J. Adherence in pediatric kidney transplant recipients: solutions for the system. *Pediatr Nephrol*. 2018;33(3):361-372. doi:10.1007/s00467-017-3637-0

223. Pruette CS, Amaral S. Empowering patients to adhere to their treatment regimens: A multifaceted approach. *Pediatr Transplant*. 2021;25(1):e13849. doi:10.1111/petr.13849

224. Curtis K, Lebedev A, Aguirre E, Lobitz S. A Medication Adherence App for Children With Sickle Cell Disease: Qualitative Study. *JMIR mHealth uHealth*. 2019;7(6):e8130. doi:10.2196/mhealth.8130

225. Foster BJ, Pai ALH, Zelikovsky N, et al. A Randomized Trial of a Multicomponent Intervention to Promote Medication Adherence: The Teen Adherence in Kidney Transplant Effectiveness of Intervention Trial (TAKE-IT). *Am J Kidney Dis*. 2018;72(1):30-41. doi:10.1053/j.ajkd.2017.12.012

226. Pai ALH, McGrady M. Systematic Review and Meta-Analysis of Psychological Interventions to Promote Treatment Adherence in Children, Adolescents, and Young Adults With Chronic Illness. *J Pediatr Psychol*. 2014;39(8):918-931. doi:10.1093/jpepsy/jsu038

227. Coyne KD, Trimble KA, Lloyd A, et al. Interventions to Promote Oral Medication Adherence in the Pediatric Chronic Illness Population: A Systematic Review From the Children's Oncology Group. *J Pediatr Oncol Nurs*. 2019;36(3):219-235. doi:10.1177/1043454219835451

228. Badawy SM, Thompson AA, Kuhns LM. Medication Adherence and Technology-Based Interventions for Adolescents With Chronic Health Conditions: A Few Key Considerations. *JMIR mHealth uHealth*. 2017;5(12):e202. doi:10.2196/mhealth.8310

229. Badawy SM, Thompson AA, Liem RI. Technology Access and Smartphone App Preferences for Medication Adherence in Adolescents and Young Adults With Sickle Cell Disease. *Pediatr Blood Cancer*. 2016;63(5):848-852. doi:10.1002/pbc.25905

230. Lau N, Waldbaum S, Parigoris R, et al. eHealth and mHealth Psychosocial Interventions for Youths With Chronic Illnesses: Systematic Review. *JMIR Pediatr Parent*. 2020;3(2):e22329. doi:10.2196/22329

231. Yang F. The Handbook of Applied Communication Research. Published online 2021:213-232. doi:10.1002/9781119399926.ch13

232. Turchioe MR, Myers A, Isaac S, et al. A Systematic Review of Patient-Facing Visualizations of Personal Health Data. *Appl Clin Inform*. 2019;10(4):751-770. doi:10.1055/s-0039-1697592

233. Arcia A, Benda NC, Wu DTY. Advancing the science of visualization of health data for lay audiences. *J Am Méd Inform Assoc*. 2024;31(2):283-288. doi:10.1093/jamia/ocad255

234. Faisal S, Blandford A, Potts HW. Making sense of personal health information: Challenges for information visualization. *Heal Inform J*. 2013;19(3):198-217. doi:10.1177/1460458212465213

235. Turchioe MR, Creber RM. Personal Health Informatics, Patient Participation in Precision Health. *Cogn Inform Biomed Healthc*. Published online 2022:371-396. doi:10.1007/978-3-031-07696-1_18

236. Casakin H. Visual Analogy, Visual Displays, and the Nature of Design Problems: The Effect of Expertise. *Environ Plan B: Plan Des*. 2008;37(1):170-188. doi:10.1068/b35073

237. Turchioe MR, Grossman LV, Myers AC, Baik D, Goyal P, Creber RMM. Visual analogies, not graphs, increase patients' comprehension of changes in their health status. *J Am Med Inform Assn*. Published online 2020. doi:10.1093/jamia/ocz217

238. Center PR. Teens and Internet, Device Access Fact Sheet. January 5, 2024. Accessed June 15, 2024. https://www.pewresearch.org/internet/fact-sheet/teens-and-internet-device-access-fact-sheet/#which-teens-have-access-to-digital-devices

239. Center PR. Teens, Social Media and Technology 2023. December 11, 2023. Accessed June 15, 2024. https://www.pewresearch.org/internet/2023/12/11/teens-social-media-and-technology-2023/

240. Haldar S, Kim Y, Mishra SR, Hartzler AL, Pollack AH, Pratt W. The Patient Advice System. *Proc Acm Human-computer Interact*. 2020;4(CSCW2):1-23. doi:10.1145/3415183

241. Mival O, Smyth M, Dalsgaard P, et al. Exploring Design Opportunities for a Context-Adaptive Medical Checklist Through Technology Probe Approach. *Proc 2017 Conf Des Interact Syst*. 2017;2017:57-68. doi:10.1145/3064663.3064715

242. Patel RA, Klasnja P, Hartzler A, Unruh KT, Pratt W. Probing the benefits of real-time tracking during cancer care. *Amia Annu Symposium Proc Amia Symposium*. 2012;2012:1340-1349.

243. Hutchinson H, Mackay W, Westerlund B, et al. Technology probes: inspiring design for and with families. *Proc Sigchi Conf Hum Factors Comput Syst*. Published online 2003:17-24. doi:10.1145/642611.642616

244. Charon R. Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust. *JAMA*. 2001;286(15):1897-1902. doi:10.1001/jama.286.15.1897

245. Zaharias G. What is narrative-based medicine? Narrative-based medicine 1. *Can Fam physician Med Fam Can*. 2018;64(3):176-180.

246. Kalitzkus V, Matthiessen PF. Narrative-Based Medicine: Potential, Pitfalls, and Practice. *Perm J*. 2009;13(1):80-86. doi:10.7812/tpp/08-043

247. Charon R. Narrative and Medicine. *N Engl J Med*. 2004;350(9):862-864. doi:10.1056/nejmp038249

248. Charon R. *Narrative Medicine Honoring the Stories of Illness*. Oxford University Press, Inc.; 2006.

249. Preece J. Empathic communities: reaching out across the Web. *Interactions*. 1998;5(2):32-43. doi:10.1145/274430.274435

250. Hinson KL. Framing illness through Facebook enabled online support groups. *Commun Des Q Rev*. 2017;4(2b):22-31. doi:10.1145/3068755.3068758

251. Huh J, Liu LS, Neogi T, Inkpen K, Pratt W. Health Vlogs as Social Support for Chronic Illness Management. *Acm Transactions Comput Interact Tochi*. 2014;21(4):1-31. doi:10.1145/2630067

252. Høybye MT, Johansen C, Tjørnhøj-Thomsen T. Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho Oncol*. 2005;14(3):211-220. doi:10.1002/pon.837

253. Frost JH, Massagli MP. Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *J Med Internet Res*. 2008;10(3):e15. doi:10.2196/jmir.1053

254. Greene C. 7 Best Tools to Record and Capture Family Memories & Stories. 2024. Accessed June 24, 2024. https://www.remento.co/journal/the-7-best-tools-to-capture-and-celebrate-family-memories-stories

255. Drew SE, Duncan RE, Sawyer SM. Visual Storytelling: A Beneficial But Challenging Method for Health Research With Young People. *Qual Health Res*. 2010;20(12):1677-1688. doi:10.1177/1049732310377455

256. Ploderer B, Aghdam AR, Burns K. Patient-Generated Health Photos and Videos Across Health and Well-being Contexts: Scoping Review. *J Med Internet Res*. 2022;24(4):e28867. doi:10.2196/28867

257. Haines-Saah RJ, Oliffe JL, White CF, Bottorff JL. "It is just not part of the culture here": Young adults' photo-narratives about smoking, quitting, and healthy lifestyles in Vancouver, Canada. *Heal Place*. 2013;22:19-28. doi:10.1016/j.healthplace.2013.02.004

258. Cho H, Silver N, Na K, Adams D, Luong KT, Song C. Visual Cancer Communication on Social Media: An Examination of Content and Effects of #Melanomasucks. *J Méd Internet Res*. 2018;20(9):e10501. doi:10.2196/10501

259. Fails JA, Coenraad M. Youth Design of Digital Stories to Promote Indigenous Voices. *Proc 18th ACM Int Conf Interact Des Child*. Published online 2019:728-731. doi:10.1145/3311927.3325353

260. Howard AF, Noga H, Parmar G, et al. Web-Based Digital Storytelling for Endometriosis and Pain: Qualitative Pilot Study. *JMIR Form Res*. 2023;7:e37549. doi:10.2196/37549

261. Wexler L, Gubrium A, Griffin M, DiFulvio G. Promoting Positive Youth Development and Highlighting Reasons for Living in Northwest Alaska Through Digital Storytelling. *Heal Promot Pr*. 2013;14(4):617-623. doi:10.1177/1524839912462390

262. Moutafidou A, Bratitsis T. Digital storytelling. *Proc 8th Int Conf Softw Dev Technol Enhancing Access Fight Info-exclusion*. Published online 2018:219-226. doi:10.1145/3218585.3218684

263. Fernandez-Luque L, Elahi N, Grajales FJ. An analysis of personal medical information disclosed in YouTube videos created by patients with multiple sclerosis. *Stud Heal Technol Inform*. 2009;150:292-296.

264. Chou WYS, Hunt Y, Folkers A, Augustson E. Cancer Survivorship in the Age of YouTube and Social Media: A Narrative Analysis. *J Méd Internet Res*. 2011;13(1):e7. doi:10.2196/jmir.1569

265. Liu LS, Huh J, Neogi T, Inkpen K, Pratt W. Health Vlogger-Viewer Interaction in Chronic Illness Management. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. CHI '13. Association for Computing Machinery; :49–58. doi:10.1145/2470654.2470663

266. Haldar S, Kim Y, Mishra SR, Hartzler AL, Pollack AH, Pratt W. The Patient Advice System. *Proc Acm Human-computer Interact*. 2020;4(CSCW2):1-23. doi:10.1145/3415183

267. Kraut RE, Resnick P. *Building Successful Online Communities: Evidence-Based Social Design*. The MIT Press; 2012. doi:10.7551/mitpress/8472.001.0001

268. Taddeo D, Egedy M, Frappier JY. Adherence to treatment in adolescents. *Paediatr Child Heal*. 2008;13(1):19-24. doi:10.1093/pch/13.1.19

269. Lask B. Motivating children and adolescents to improve adherence. *J Pediatr*. 2003;143(4):430-433. doi:10.1067/s0022-3476(03)00447-5

270. Rapoff MA. Assessing and Enhancing Adherence to Medical Regimens for Juvenile Rheumatoid Arthritis. *Pediatr Ann*. 2002;31(6):373-379. doi:10.3928/0090-4481-20020601-09

271. Betz CL, Lobo ML, Nehring WM, Bui K. Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nurs Outlook*. 2013;61(5):311-336. doi:10.1016/j.outlook.2013.01.008

272. Cha YJ, Saxena A, Wou A, Lee J, Newman MW, Park SY. Transitioning Toward Independence: Enhancing Collaborative Self-Management of Children with Type 1 Diabetes. In:

*Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*. CHI '22. Association for Computing Machinery. doi:10.1145/3491102.3502055

273. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software platform partners. 2019;95:103208. doi:10.1016/j.jbi.2019.103208

274. Definition of patient-reported outcome - NCI Dictionary of Cancer Terms - NCI. Accessed May 27, 2024. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/patient-reported-outcome

275. Forrest CB, Devine J, Bevans KB, et al. Development and psychometric evaluation of the PROMIS Pediatric Life Satisfaction item banks, child-report, and parent-proxy editions. 2018;27(1):217-234. doi:10.1007/s11136-017-1681-7

276. Ravens-Sieberer U, Devine J, Bevans K, et al. Subjective well-being measures for children were developed within the PROMIS project: presentation of first results. 2014;67(2):207-218. doi:10.1016/j.jclinepi.2013.08.018

277. Salsman JM, Lai JS, Hendrie HC, et al. Assessing psychological well-being: self-report instruments for the NIH Toolbox. 2014;23(1):205-215. doi:10.1007/s11136-013-0452-3

278. Corporation R. 36-Item Short Form Survey (SF-36). Accessed May 31, 2023. https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form.html

279. The Rand 36-item Health Survey 1.0.

280. Cohen S, Kamarck T, Mermelstein R. A Global Measure of Perceived Stress. *Journal of Health and Social Behavior*. 1983;24(4):385. doi:10.2307/2136404

281. Hodes RJ, Insel TR, Landis SC. The NIH toolbox: setting a standard for biomedical research. *Neurology*. 2013;80:S1. doi:10.1212/wnl.0b013e3182872e90

282. Kupst MJ, Butt Z, Stoney CM, et al. Assessment of stress and self-efficacy for the NIH Toolbox for Neurological and Behavioral Function. *Anxiety Stress Coping*. 2015;28:531-544. doi:10.1080/10615806.2014.994204

283. Kaye J, Druin A, Lampe C, et al. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. In: *In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16).* Vol 2016. Proceedings of the SIGCHI conference on human factors in computing systems. CHI Conference. ; 2016:5337-5349. doi:10.1145/2858036.2858508

284. Lakshmi U, Hong M, Wilcox L. Integrating Patient-Generated Observations of Daily Living into Pediatric Cancer Care: A Formative User Interface Design Study. *2018 Ieee Int Conf Healthc Informatics Ichi*. Published online 2018:265-275. doi:10.1109/ichi.2018.00037

285. Figma. How you design , align , and build  matters. Do it together with Figma. 2024. Accessed 2024. https://www.figma.com/

286. Inc. C. Canva: Visual Suite for Everyone. 2024. Accessed June 24, 2024. https://www.canva.com/

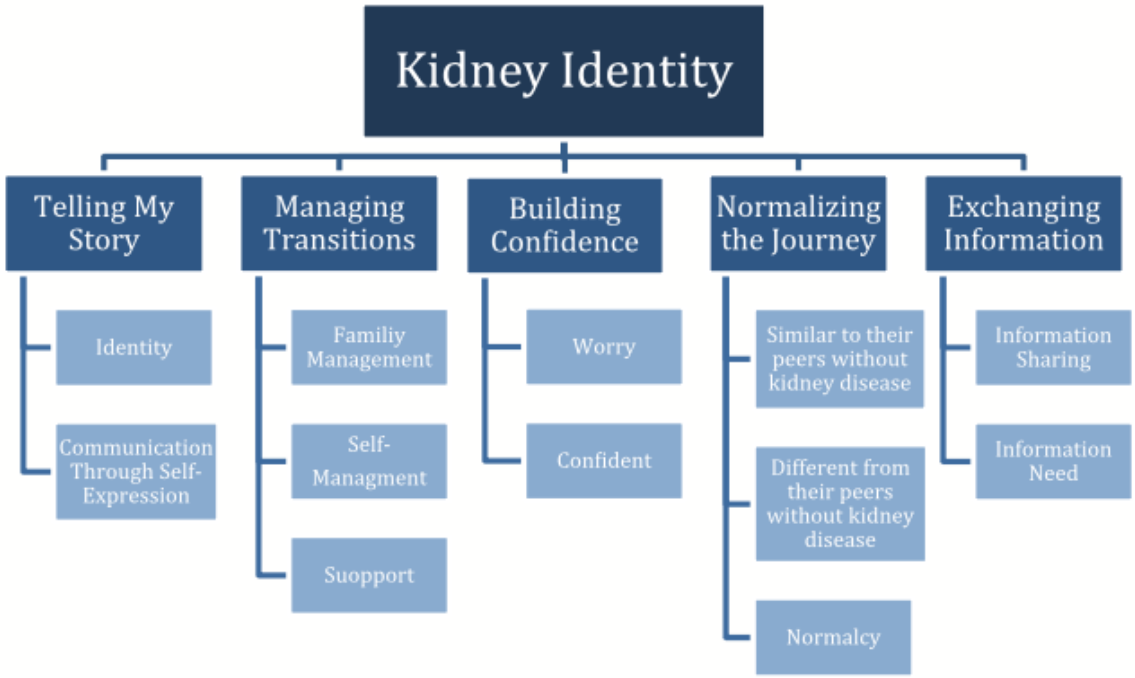
# APPENDIX A

**Fourteen Total Codes**

*Four A Priori Codes:* (1) worried, (2) confident, (3) similar to their peers without kidney disease, and (4) different from their peers without kidney disease.

*Ten Inductive/Emergent Codes:* (1) support, (2) guilt, (3) communication through self-expression, (4) family management, (5) self-management, (6) information sharing, (7) communication with clinician, (8) normalcy, (9) identity, and (1) information need.

**Figure A1 – Example iteration of the hierarchical coding framework**



# APPENDIX B

***Youth – Interview Guide***

**Youth Participant Interview Questions and Example Scenarios (approximate total time 60 minutes):**

A. Ice breaker question(s) ~ 3-5 minutes:
    i. If you had to describe yourself to someone what are three words you would use to describe yourself?
    ii. How do these three words describe you?
B. Questions to see if they have personally experienced each of the five tensions or dimensions (ingredients) and the shifts/changes ~ 25 to 30 minutes:
    i. Dimension - telling their (pediatric patients) transplant stories:
        a. Examples of the dimension (they will see the example card as the researcher reads this out loud to them):
            1. Example of Hiding:
                a. Charlie just had his kidney transplant and feels uncomfortable in his body and also telling people about why he has missed school, why he can't play soccer, or do other things. He doesn't feel comfortable yet explaining to his friends about all of his kidney "stuff", because it's too complicated.
            2. Example of Self-Expression:
                a. It's been a few years since Charlie has had his transplant and he now feels comfortable telling his friends about his kidney "stuff". When he has to explain it to his friends or even strangers, he now is excited to explain his kidney story and he realizes that his kidney "stuff" is a part of who he is, and it makes him proud to share his journey.
        b. Questions:
            1. How do you think your transplant journey has influenced your kidney story?
            2. How has your comfort in telling your transplant story changed over time?
            3. What factors do you think influenced this change?
    ii. Dimension - exchanging information:
        a. Examples:

1. Example of Receiving Information:
    a. Sarah is fifteen years old and is currently going through dialysis. She wants to know more about what a kidney transplant is like, so she reaches out to her friend on Instagram/Discord that she met and has had a kidney transplant. She asks her friend what having their transplant was like.
2. Example of Sharing Information:
    a. Sarah had her kidney transplant and is now a year post-transplant. She has made a few new friends who have also had kidney transplants on Instagram/discord and one of them reaches out to her asking if she has advice on what having her transplant was like.

b. Questions:
1. How have you learned from or been supported by other transplant patients?
2. How have you used your knowledge and experiences to support other transplant patients? Would you view yourself more on the receiving side of information or on the sharing side?

iii. Dimension - managing transitions:

a. Examples:
1. Example of Family-Management:
    a. Griffin is 11 years old and often relies on his parents to remind him about taking his different medications for his kidney. They set timers on his phone for him to follow and also check on him throughout the day to make sure that he takes them.
2. Example of Self-Management:
    a. Griffin is now 14 years old and starting high school. He is excited about starting high school, but also knows he will be involved in after school activities like theatre club and track which is usually when he would take his pills for his kidney. Griffin starts to make plans for the school year and how he will remember to take his medications, such as setting a timer on his phone.

b. Questions:
1. Who is responsible for managing your kidney health and how has this changed over time?
2. In what ways have you taken on responsibility for managing your own care?

3. What is one way you would like to become more independent in managing your kidney health?

iv. Dimension - building confidence:
   a. Examples:
      1. Example of Worry:
         a. Ginny is nine years old and is waiting to have her first kidney transplant. Ginny has been invited to swim with her friends at one of their houses. She is worried about swimming because she still has her g-tube and has to take extra precautions when she swims, so she goes to her friends but only swims for a little bit.
      2. Example of Confidence:
         a. It has been a while after Ginny's transplant, and she has been invited to a friend's birthday party which is going to be a pool party. Instead of being worried Ginny is now excited to go to her friend's birthday party, she gets to the party and swims in the pool for hours with her friends.
   b. Questions:
      1. How much do you worry about your health and wellness, and how has this changed since your transplant?
      2. How much confidence do you have in supporting your own health and wellness, and how has this changed since their transplant?
      3. What factors influence your levels of worry and confidence?

v. Dimension - normalizing the transplant journey:
   a. Examples:
      1. Example of Feeling Different:
         a. When Ellie first found out that she needed a kidney transplant, everything she needed to do to keep her kidney healthy felt annoying and frustrating. Her life felt disrupted and different than it used to be, which made her feel frustrated and she would wish for things to go back to normal.
      2. Example of Feeling Similar:
         a. Ellie is coming up on her 5th kidneyversary (i.e., 5 years after her transplant) and everything has just gotten so much easier for her. Taking her meds, getting labs, or even going in for a checkup have just become part of her routine, and is just part of who she is.
   b. Questions:
      1. At what point after transplant did your life feel normal again? Why?

2. What about the transplant experience made you feel different?

C. Questions about the overall kidney identity and dimension ~ 5 minutes:
   i. Do you feel like the kidney identity captures your transplant experiences?
   ii. Out of the five ingredients (dimensions) pick the top three which you can relate to the most.
      a. Why do you feel like you can relate to these three ingredients the most?
      b. What about the two ingredients you did not put in your top three was hard to relate to?
   iii. Are there other dimensions/ingredients that you think describes your transplant journey that we haven't discussed?

**Figure B1 – Example Recruitment Flyer**

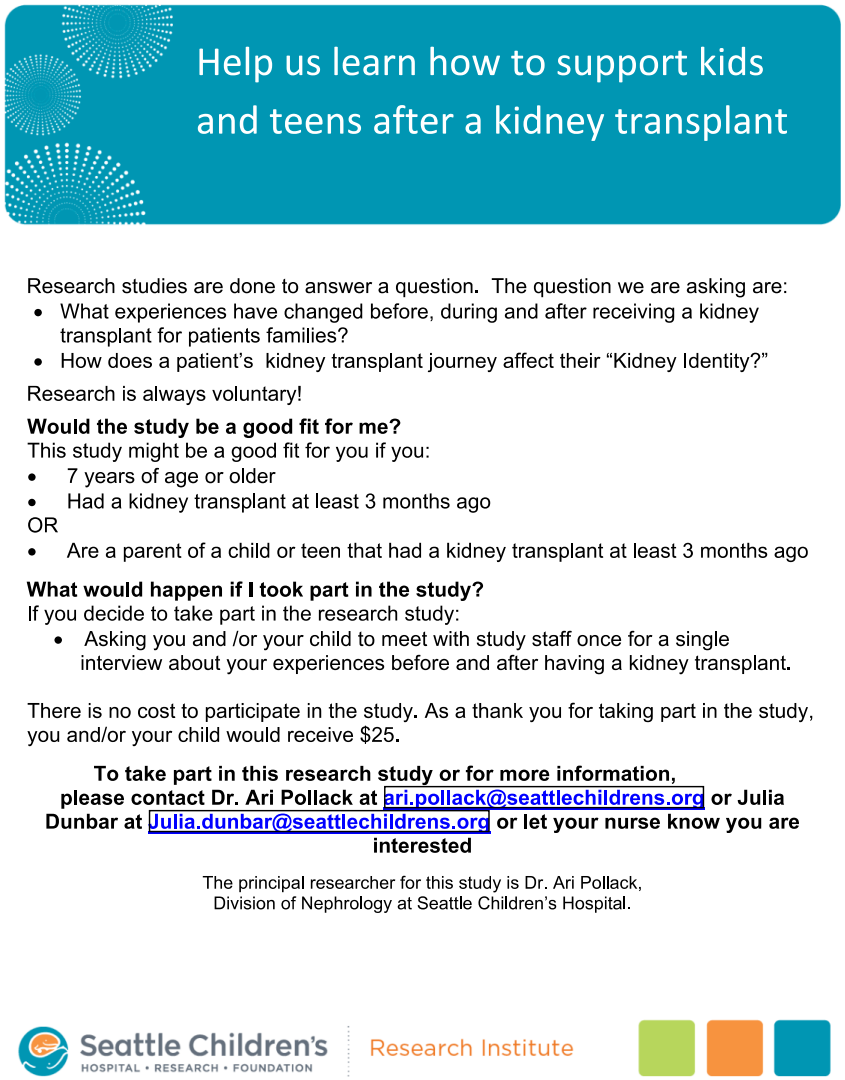


**Figure B2 – Example Assent Form**

*Page 1 of Assent Form*

# Assent Form

**What is a research study?**

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

**Important things to know…**

- You get to decide if you want to take part.
- You can say 'No' or you can say 'Yes'.
- No one will be upset if you say 'No'.
- If you say 'Yes', you can always say 'No' later.
- You can say 'No' at anytime.
- We would still take good care of you no matter what you decide.

**Why are we doing this research?**

We are doing this research to find out more about kids with kidney transplants and learn more about their kidney transplant journey.

**What would happen if I join this research?**

If you decide to be in the research, we would ask you to do the following:

- Talking: You would join us for one virtual or in-person interview with one of our research team members. A person on the research team would ask you some questions. Then you would say your answers out loud. You would also be giving your opinion on some images we have created. These sessions will be audio and video recorded.

*Pages 2 and 3 of Assent Form*

**Could bad things happen if I join this research?**

Some of the tests might make you uncomfortable or the questions might be hard to answer. We will try to make sure that no bad things happen. You can skip questions you do not want to answer.

You can say 'no' to what we ask you to do for the research at any time and we will stop.

**Could the research help me?**

We think being in this research may help you because you may like talking about what it is like to have a kidney transplant.

And someday we hope it will help other kids who have kidney transplants like you do.

**What else should I know about this research?**

If you don't want to be in the study, you don't have to be.

It is also OK to say yes and change your mind later. You can stop being in the research at any time. If you want to stop, please tell the research doctors.

To thank you for being in the study, we would give you $25. You should talk with your parents about how you would like to use this.

You can ask questions any time. You can talk to anyone on the research team. Ask us any questions you have. Take the time you need to make your choice.

**If we are talking to you over the phone or on your computer:** If you want to be in the research, please say out loud (Yes or No) that you are interested in participating in this research. We will mark it down that we talked about the research and that you want to take part.

**If we are seeing you in person:** If you want to be in the research after we talk, please write your name below. We will write our name too. This shows we talked about the research and that you want to take part.

***Name of Participant*** _____
(To be written by child/adolescent)

***Printed Name of Researcher*** _____

***Signature of Researcher*** _____

_____ _____
***Date*** ***Time***

**Original form to:**
Research Team File

**Copies to:**
Parents/Legally Authorized Representative

# APPENDIX C

**Research Team Protocol Outline for Medication Adherence Task**

- Medication Adherence Task ~ 28 minutes
    - We will have the participants open their task 3 envelope which will contain:
        - A notecard with the Medication Adherence prompt
        - Example visual analogy
        - Multiple blank pages for their drawings
    - Verbal Prompt: "For this task you each will have up to three minutes to get two more objects or items. The first object you get should represent something that helps you be successful with taking your medicines. The second object should represent something that gets in the way of you taking your medicine. You will have 3 minutes to find both objects or items." ~ 3 minutes
    - Researchers will set a screen timer for three minutes.
    - Verbal prompt: "Now that you all have both of your objects that help tell your stories of taking your medicines, we would like you all to create two drawings. For these two drawings we would like you to keep the objects you grabbed in mind.
        - For the first drawing we would like you to draw something that shows you taking your medicine successfully (i.e. taking it every day on time).
        - For the second drawing we would like you to draw something that shows you struggling with taking your medicine every day and on time.
        - You will have 10 minutes to make both drawings."
    - Researchers will set a screen timer for 10 minutes, reminding people halfway that they should be moving on from the first drawing to the second drawing.
    - Verbal prompt after 10 minutes is up: "Now that you all have your two drawings; in your breakout rooms, we would like you all to present your two drawings to your breakout group and discuss them. When you present your drawings, we would like you to explain them to your group, such that everyone totally understands what the drawings represent and the story they tell. When you are all done discussing the drawings you all should designate one person to draw the final breakout group drawing. The final breakout group drawing will combine your groups' ideas of either a) doing

well with your medicine or b) not doing well with your medicine, which will be assigned by the researchers before you all are sent out into the breakout groups. When you all comeback to the larger group we will wrap-up and each breakout group can present their final drawing." ~ 15 minutes

- During each participant's walk through of their drawings the research member in the group will ask any clarifying questions about the drawings as they see fit.
- Researchers will set a screen timer for 15 minutes
- One research member will join each group as an observer to record the breakout session, take notes, ask clarifying questions, and ensure participants follow instructions.

**Figure C1**

(A) Visual Schedule for Participants Included in Their Design Toolkits and (B) Design Tool Inventory Checklists

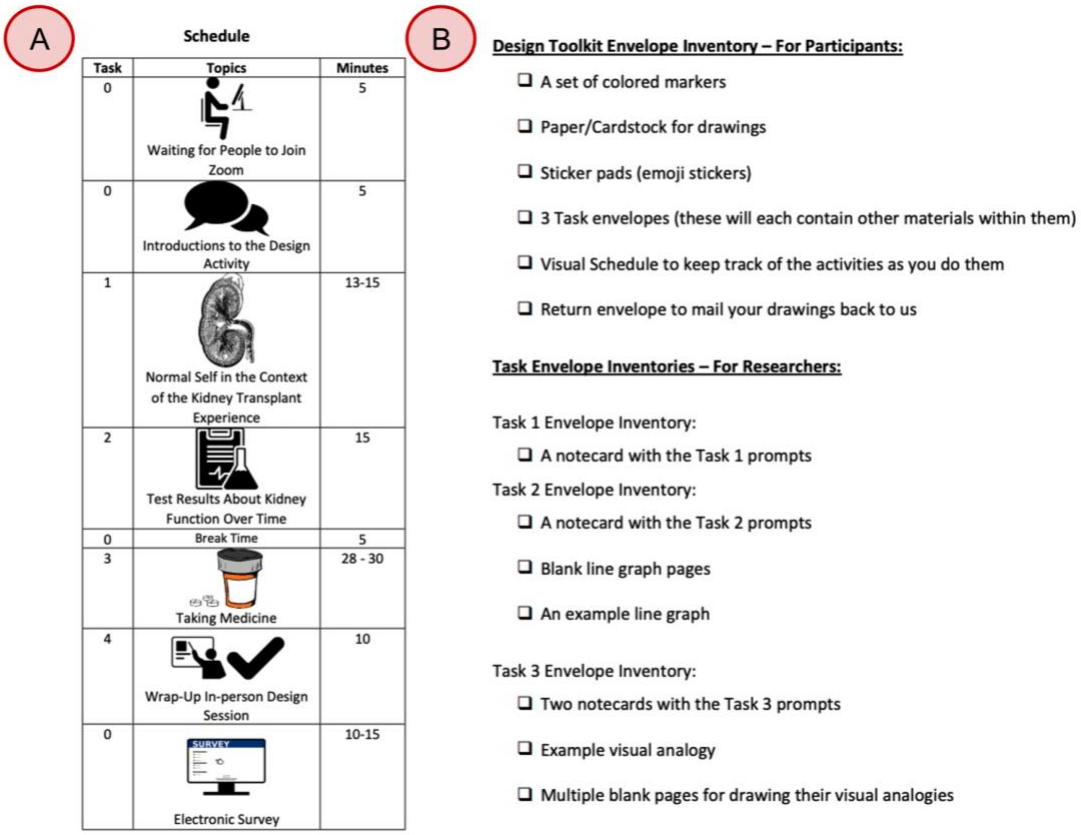
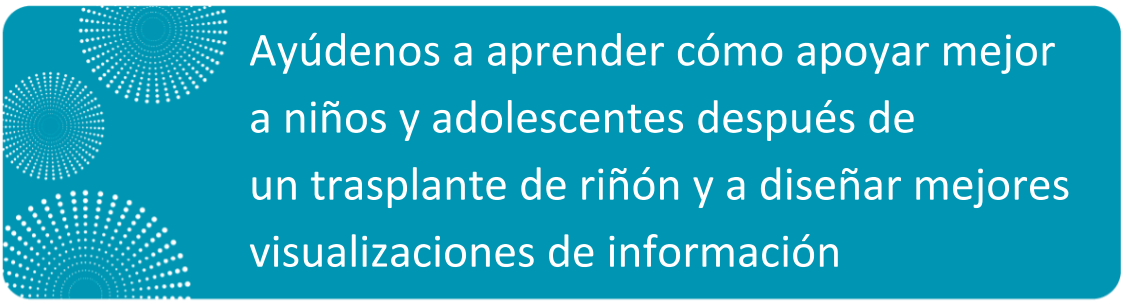


**Figure C2 - Example of a Translated (Spanish) Recruitment Flyer**




Los investigadores de Seattle Children's desean a) aprender más sobre las necesidades de información de los pacientes y sus familias y b) desarrollar mejores diseños para visualizaciones de información para apoyar a los pacientes y a sus familias en la comparación de experiencias de trasplante de riñón.

¡La investigación es siempre voluntaria!

**¿El estudio sería una buena opción para mí?**

Este estudio podría ser una buena opción para usted y para su hijo/a si su hijo/a:

- tiene 10 años de edad o más;
- ha tenido un trasplante de riñón al menos hace 6 meses;
- tiene acceso a Internet a través de una computadora, tableta o teléfono inteligente.

**¿Qué podría suceder si participara en el estudio?**

Si usted y su hijo/a deciden participar en este estudio de investigación:

- Usted y su hijo/a asistirán a varias sesiones remotas de diseño por Zoom
- Para la primera sesión de diseño, usted y su hijo/a completarán sesiones de diseño separadas, que incluirán debates en grupo y una tarea de sesión previa al diseño.
- Para la segunda sesión de diseño, usted y su hijo/a completarán sesiones de diseño separadas, o bien la sesión de diseño juntos, en la cual recibirán un kit de diseño, crearán diseños y participarán en debates grupales.
- Para la tercera sesión de diseño, usted y su hijo/a completarán una encuesta electrónica y participarán en una entrevista.

La participación en el estudio no tiene costo alguno. Como agradecimiento por participar en el estudio, usted y su hijo/a recibirán una tarjeta regalo de $25 al finalizar cada sesión de diseño, por un máximo de $75.

**Para participar en este estudio de investigación o para obtener más información, comuníquese con el Dr. Ari Pollack en ari.pollack@seattlechildrens.org o Julia Dunbar en julia.dunbar@seattlechildrens.org.**

El investigador principal de este estudio es el Dr. Ari Pollack, División de Nefrología del Seattle Children's Hospital.

Seattle Children's HOSPITAL • RESEARCH • FOUNDATION | Research Institute

**Figure C3 - Task Card Text Given to Participants**

**TASK 3 Part 1**

You each will have up to ***three minutes*** to get ***two objects.***

- The ***first object*** you get should represent something that helps you be successful with taking your medicine.
- The ***second object*** should represent something that gets in the way of you taking your medicine.

**TASK 3 Part 2**

Now that you all have your objects that help tell your stories of taking your medicine, we would like you all to create ***two drawings.*** You will have 5-10 minutes to draw these two drawings.

- For the ***first drawing*** we would like you to draw something that shows you taking your medicine successfully (i.e. taking it every day on time).
- For the ***second drawing*** we would like you to draw something that shows you not doing well with your medicine.

**TASK 3 Part 3**

In your breakout rooms, we would like you all to ***present your two objects*** to your breakout group as well as ***present your two drawings*** and how your objects inspired each drawing. You will have 10-15 minutes to draw the group drawing.

- When you are all done discussing them you all should ***designate one person to draw the final breakout group drawing.***
- The final breakout group drawing will combine your groups ideas of either:
    - a) doing well with your medicine or
    - b) not doing well with your medicine.
- Once the time is up you all will be going back to the larger group of youth patients/caregivers, please designate one person from your group to present the final group drawing to the larger group.

# APPENDIX D

**Consent/Assent and Communication with Participants During the Study**

Written or verbal consent and assent from all participants was received from all participants either in-person during a clinic visit, via phone, or via zoom. After or during the consent/assent session all youth and caregiver participants completed a demographics form via Redcap (a HIPAA compliant survey service) [187] or verbally. If completed verbally all demographic data was later input into Redcap by the research team.

All communications during the data collection phase of the study happened either via email, phone call, or text. Participants preferred method of contact was collected after their consent/assent session as well as information about who should be contacted about study tasks: only the caregiver(s) or both the caregiver(s) and youth participants. Most participants chose to be contacted via text or email as well as both caregivers and youth chose to receive study updates.

**PRO Measures (~ 10 – 15 minutes for participants to complete)**

Youth participants completed two rounds of PRO surveys, once prior to their initial interview and once before their exit interviews. I chose to have youth participants fill out the PRO measures twice during the study as to not overburden their time. Youth participants were sent their PRO measures as surveys via Redcap [187,273]. The PRO surveys took most youth participants between 10 – 15 minutes to complete. Youth participants were compensated with a $15 digital eGift Cards for each round of PRO surveys they completed.

Patient Reported Outcomes (PROs) are, "information about a patient's health that comes directly from the patient" [274]. We chose to have youth fill out PROs as part of this study to gather additional information directly from youth's perspectives related to their transplant journeys and to see if we would like to use these measures in future work. This study was not a clinical trial, and we did not intend to find any significant differences in youth participants PROs prior to versus after using the My Kidney TREK technology probe. In total, youth completed a series of seven

PRO measures. This included four PROMIS measures about life satisfaction, general life satisfaction, meaning and purpose, and self-efficacy in managing medications [275–277]. Additionally, participants completed three other PROs: RAND 36-item measure about QoL [278,279], Perceived Stress Scale (PSS-10) [280], and NIH self-efficacy measures [281,282].

**Initial Interviews (~ 20 – 30 mins)**

Youth and caregiver participants completed separate initial interviews unless they requested to complete them together (only one youth and caregiver requested to have interviews at the same time). Informed by my own past work and others who have worked with youth patients [2,109,266,283,284], I chose to allow youth participants to do their own separate interviews. Allowing youth participants to be interviewed on their own has been shown to encourage more open conversations with youth participants, since having caregivers present may influence what youth may talk about in an interview or caregivers may even speak over a youth participant inserting their own thoughts over that of the youth's. All initial interviews were completed overview zoom, lasted between 20 to 30 minutes, and were audio and video recorded. The initial interviews were designed as an ice breaker for participants to open-up and discuss their general kidney transplant experiences, participants also received a brief overview of the study timeline. At the end of the interview, participants (youth and caregivers) were instructed on what they needed to do for their story survey and were compensated with a $25 e gift-card sent to them via email.

***Summarized Version of Initial Youth Interview Protocol***

*Introduction*

Hi _____, thank you for participating in today's interview! The interview today will be approximately 30 to 45 minutes long and will be audio and video recorded. Before I go further, I would like to get your verbal consent/assent again that you are okay with today's interview being audio and video recorded. Are you okay with today's interview being audio and video recorded? (Wait for Affirmative Response). If they respond no, we will ask if we can take written notes instead of recording the interview (they already previously consented/assented, so we shouldn't have many no's).

Great, now I am going to start recording. For our interview today I will be asking you questions as well as doing a brief overview with you about what to expect for the rest of the study. When answering the interview questions, you can always feel free to skip a question and take as much time as you need to answer them, there are no right or wrong answers. You are free to leave the interview at any time. Before we get started are there any questions you have for me?

*Interview Questions*

We will begin with the interview questions that we expect to take between 10 - 20 minutes. First, we will begin with a few icebreaker questions.

*Ice Breaker Questions or Prompts*

1. Describe what a typical day looks like for you.
2. If you could invent something to make your or your caregiver's (parent, grandparent, etc.) life easier, what would it be?

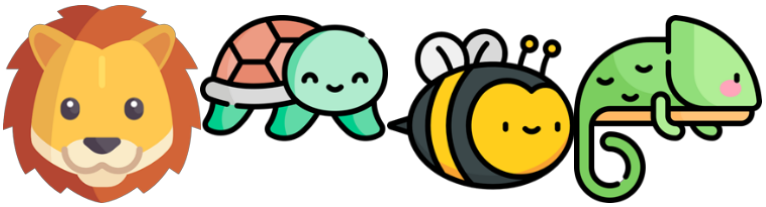
*Kidney Journey Questions*

For this study we will be learning about different components of your kidney transplant journey, which is the collection of all your experiences and feelings that have happened pre-transplant, during transplant, post-transplant, and even in the future. We know having a kidney transplant is a life changing event with highs and lows. Next, we would like to ask you some questions about different aspects of your kidney transplant journey.

1. Why did you need to have a kidney transplant?
2. How old were you when you had your kidney transplant?
3. How do you feel like you have changed since your kidney transplant?
4. What is something you are looking forward to in the future?
5. How do you know if your kidney is healthy or not?
6. What do your doctors measure to know if your kidney is healthy or not?
7. Do you know what your most recent measurement was?

As part of this study, you will be interacting with the My Kidney T.R.E.K Thinking, Reflecting, and Empowering Kidney Patients app. This app will be personalized for you and as part of this personalization we would like you to select a username and avatar. I am going to show you four options for an avatar now, please let me know which one you would like for you're my Kidney TREK app.

Display the following four avatar options to them (these options will be in their own document which we will screen share with them):



Great, now that you have selected an avatar what username would you like displayed on the app for you? --> Researcher will record the username they want

That is the end of the question portion of the interview today, is there anything else you would like to add? We can now take a few minutes break if you need one (give a short 3 - 5-minute break if needed, if not move onto the next section).

*Below is a summarized outline of the rest of protocol:*

- Brief Overview of the Rest of the Study Timeline
- Brief Story Survey Overview and Distribute the Story Survey Link
- Wrap-Up with Participant
- Separate Wrap-Up for Researcher(s)

***Summarized Version of the Youth and Caregiver Exit Interview Protocol***

*Introduction*

Hi _____, thank you for participating in today's interview! The interview today will be approximately 60 minutes long and will be audio and video recorded. Before I go further, I would like to get your verbal consent/assent again that you are okay with today's interview being audio and video recorded. Are you okay with today's interview being audio and video recorded? (Wait for Affirmative Response). If they respond no, we will ask if we can take written notes instead of recording the interview (they already previously consented/assented, so we shouldn't have many no's).

Great, now I am going to start recording. For our interview today I will be asking you questions as well as doing a brief over with you about what to expect for the rest of the study. When answering the interview questions, you can always feel free to skip a question and take as much time as you need to answer them, there are no right or wrong answers. You are free to leave the interview at any time. Before we get started are there any questions you have for me?

*Interview Questions*

Our interview questions today will be divided into two sections: (1) Questions about the overall concepts of the My Transplant TREK app and getting your feedback on the app and (2) a hypothetical scenario about a future version of the app. We expect this interview to take approximately 60 minutes long. Are you ready to get started?

*Questions About Overall Concepts of Tech Probe and Feedback*

Overarching Tech Probe Questions:

1. What parts of the My Transplant TREK app did you like and/or dislike?
2. How did the app change the way you thought about your journey?
3. What did you learn about yourself or your journey after using the app?
4. After reflecting on each of the components of the app do you feel more excited or nervous about your future?

5. Compared to more traditional forms of representing health data like a line or bar graph, did you find the visual elements of the app like the adherence battery more or less effective?

Adherence component:

6. What parts of the adherence component did you like and/or dislike?
7. Did the adherence component help you see any growth or change for yourself? What?
8. Did the adherence component help you identify any successes or barriers? What?
9. Did the battery visual motivate you to want to make any changes to help keep your kidney healthy or did it disincentivize you?

Kidney Function component:

10. What parts of the kidney function component did you like and/or dislike?
11. Did the kidney function component help you see any growth or change for yourself? What?
12. Did the kidney function component help you identify any successes or barriers towards maintaining your kidney health? What?
13. What did you learn from seeing your creatinine levels over time?
14. Did the kidney function visual motivate you to want to make any changes to help keep your kidney healthy or did it disincentivize you?

Kidney Journey Stories component:

15. What parts of the kidney journey stories component did you like and dislike?
16. Did the kidney journey stories component help you to see any growth or change for yourself? What?
17. Did the kidney journey stories component help you identify any successes or barriers to help keep your kidney healthy? What?
18. Did you find more value in the process of writing your kidney journey stories or reading and reflecting on your kidney journey stories in the My Kidney TREK app, or both?
19. If you were to redesign the kidney journey stories component which elements, would you include or not include:
    1. stories,

2. photos,
3. five-dimension sliders, story categories
4. Would you want to add something new?

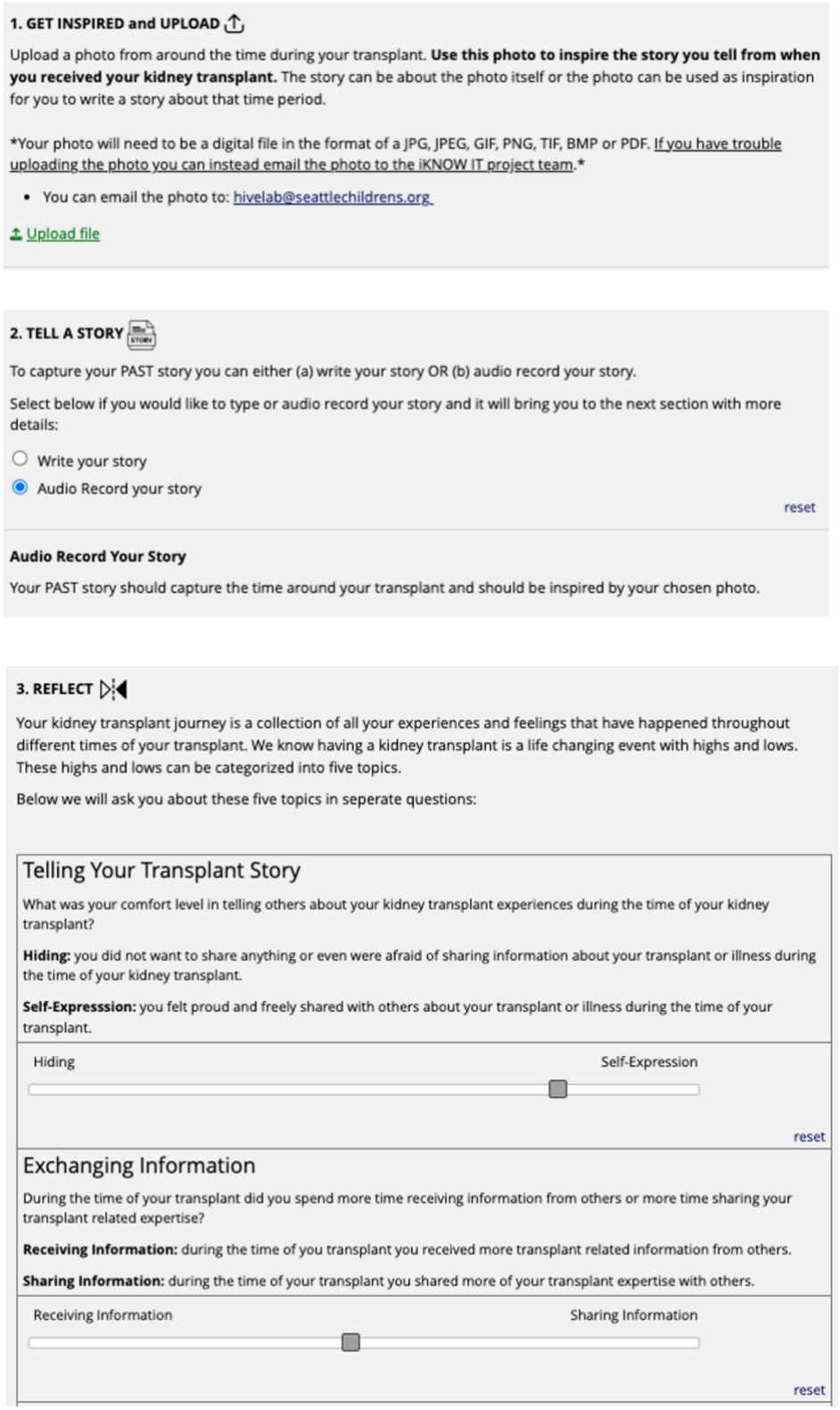
Comparing the three components:

20) If you were to redesign this tool which of the three components (adherence, kidney function, or kidney journey stories) would you include, not include, or change?

*Below is a summarized outline of the rest of protocol:*

- Kidney Function Visual Scenario/Questions
- Wrap-Up with Participant
- Wrap-Up for Researcher(s)

**Figure D1 - Example Youth Story Survey (~ 30 to 60 mins)**



**1. GET INSPIRED and UPLOAD**

Upload a photo from around the time during your transplant. **Use this photo to inspire the story you tell from when you received your kidney transplant.** The story can be about the photo itself or the photo can be used as inspiration for you to write a story about that time period.

*Your photo will need to be a digital file in the format of a JPG, JPEG, GIF, PNG, TIF, BMP or PDF. If you have trouble uploading the photo you can instead email the photo to the iKNOW IT project team.*

- You can email the photo to: hivelab@seattlechildrens.org

Upload file

**2. TELL A STORY**

To capture your PAST story you can either (a) write your story OR (b) audio record your story.

Select below if you would like to type or audio record your story and it will bring you to the next section with more details:

- ○ Write your story
- ◉ Audio Record your story

reset

**Audio Record Your Story**

Your PAST story should capture the time around your transplant and should be inspired by your chosen photo.

**3. REFLECT**

Your kidney transplant journey is a collection of all your experiences and feelings that have happened throughout different times of your transplant. We know having a kidney transplant is a life changing event with highs and lows. These highs and lows can be categorized into five topics.

Below we will ask you about these five topics in seperate questions:

**Telling Your Transplant Story**

What was your comfort level in telling others about your kidney transplant experiences during the time of your kidney transplant?

**Hiding:** you did not want to share anything or even were afraid of sharing information about your transplant or illness during the time of your kidney transplant.

**Self-Expresssion:** you felt proud and freely shared with others about your transplant or illness during the time of your transplant.

Hiding — Self-Expression

reset

**Exchanging Information**

During the time of your transplant did you spend more time receiving information from others or more time sharing your transplant related expertise?

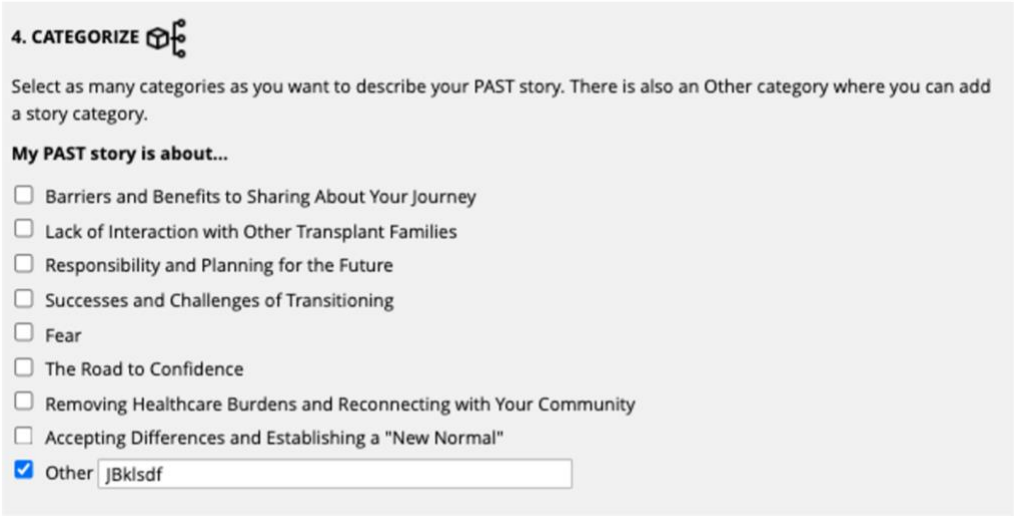
**Receiving Information:** during the time of you transplant you received more transplant related information from others.

**Sharing Information:** during the time of your transplant you shared more of your transplant expertise with others.

Receiving Information — Sharing Information

reset

**Figure D1 Cont. - Example Youth Story Survey (~30 – 60 mins)**




**Adherence Survey (~5 to 10 mins)**

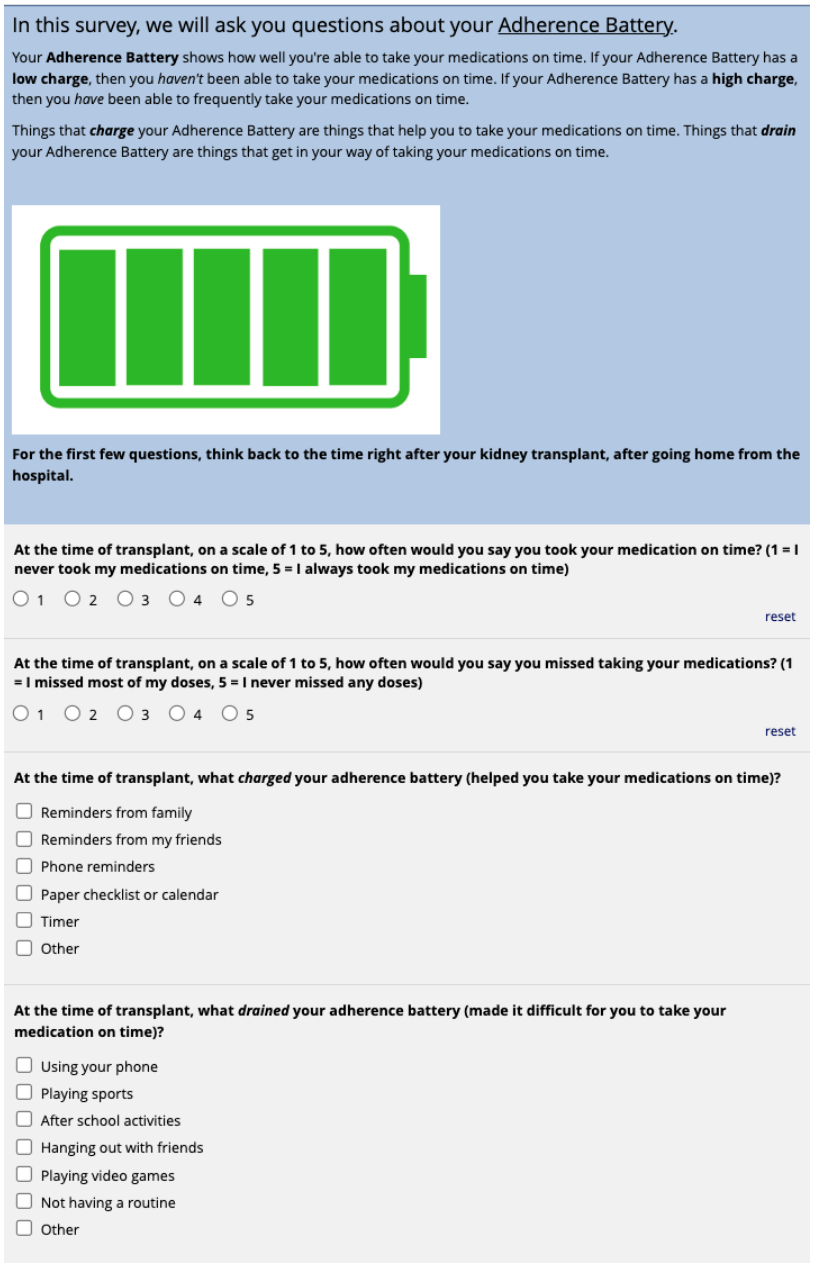
After participants completed their story surveys, they were then contacted by the research team via email to complete their adherence surveys via Recap [187] during the second week of the study. The main purpose of the adherence survey was to gather information about participants perceptions of their adherence from during the time of their transplant, during the past week, and what they would like it to be in the future. This survey used a battery analogy inspired from a participants design in Chapter 5. We included a visual of a battery for participants along with an explanation of what we meant by an adherence battery:

Your Adherence Battery shows how well you're able to take your medications on time. If your Adherence Battery has a low charge, then you haven't been able to take your medications on time. If your Adherence Battery has a high charge, then you have been able to frequently take your medications on time.

Things that charge your Adherence Battery are things that help you to take your medications on time. Things that drain your Adherence Battery are things that get in your way of taking your medications on time.

All adherence surveys were then used to personalize youth and caregiver's individual My Adherence components of their technology probes. For an example of what a participant would see for one of the three-adherence sections from the survey, see Appendix D; Figure D2. Youth and caregiver participants were compensated with a $15 e gift-card sent to them via email after completing their adherence surveys.

**Figure D2 - Example Youth Adherence Survey (Past)**



**My Kidney TREK Walkthrough and Workbook (~ 15 to 20 minutes)**

During the final leg of the study all participants completed the following: a short walkthrough of their personalized My Kidney TREK tech probe, interaction with their personalized tech probe and accompanying workbook, and an exit interview. The walkthroughs were ~ 15 to 20 minutes in length and were audio and video recorded. The walkthroughs were designed to show participants all components of their personalized technology probes & workbooks as well as give participants time to interact with their tech probe and ask any questions.

Each participant received a personalized technology probe to interact with for a week. Participants received their technology probe via a link to a Figma prototype [285], which participants were then able to access on any smart device (mobile, iPad, or computer). Each Figma prototype was secured with a password and could only be accessed by the individual participant and the research study team. During their walkthrough participates were asked to open their Figma link to both explore and troubleshoot if they had any technical issues. During the week they interacted with their tech probe participants were also asked to fill out an accompanying workbook. Participants were either mailed a hard copy of the workbook to go along with their personalized technology probe or emailed a PDF of their workbook. Participants were encouraged to first interact with tech probe and then use the workbook to reflect. Youth and caregiver participants were compensated with a $25 e gift-card sent to them via email after interacting with their tech probe and workbook.

The accompanying workbook to be filled out after interacting with the technology probe was designed to encourage reflection about the content of the My Kidney TREK tech probe. I created the workbooks using Canva [286] and developed each section of questions through several rounds of feedback with the research team and additional feedback from a youth kidney transplant patient research collaborator. I will not be reporting on findings from the workbook data in this dissertation.

- Workbook General Layout:
    - Intro Page
    - Contents Page
    - My Kidney TREK Probe Guidance Page
    - Workbook Section 1 – My Adherence
        - Intro to Section

    - Question/Prompt Pages for Section
- Workbook Section 2 – My Kidney Function
    - Intro to Section
    - Question/Prompt Pages for Section
- Workbook Section 3 – My Kidney Journey Stories
    - Intro to Section
    - Question/Prompt Pages for Section
- Bonus Page for Drawing or Additional Writing
- Conclusion

**Figure D3 - Summary of the Initial Deductive Codebook**

| Code System | Memo |
|---|---|
| MY Kidney TREK - EXIT INTERVIEW CODES | These are all codes developed for analyzing the My Kidney TREK study exit interviews. |
| Reflections | |
| Positive Reflection | Positive reflection on either self or their journey. |
| Growth/Change | Has reflected on personal growth or change throughout their journey. |
| Hypothetical Scenarios | |
| What to Compare | Participant discusses what they would like to compare (specific components) |
| How to Compare | Participant discusses how they would like to be compared if at all |
| Mixed Thoughts on Comparison | After shown scenario explains why they have mixed thoughts on comparison or like some ideas behind and dislikes other ideas. |
| Dislikes Comparison | After shown scenario explains why they dislike the idea of comparing their or their child's personal data. |
| Likes Comparison | After shown scenario explains why they like the idea of comparing their or their child's personal data. |
| Kidney Journey Stories | Kidney journey stories specific component codes |
| KJS Design Suggestions/Ideas | KJS specific design suggestions or ideas |
| KJS  Dislikes | KJS specific component dislikes |
| KJS Likes | KJS specific component likes |

| | |
|---|---|
| Adherence Component | Adherence specific component codes |
| Adherence Design Suggestions/Ideas | Adherence specific design suggestions or ideas |
| Adherence Dislikes | Adherence specific component dislikes |
| Adherence Likes | Adherence specific component likes |
| Kidney Function Component | Kidney function specific component codes |
| Kidney Function Design Suggestions/Ideas | Kidney function specific design suggestions or ideas |
| Kidney Function Dislikes | Kidney Function specific component dislikes |
| Kidney Function Likes | Kidney Function specific component dislikes |
| Overall Technology Probe | Any thoughts particpants have about the technology probe overall. Suggest adding inductive codes as identified. |

**Figure D4 – Summary of Final Codebook**

| Code System | Memo |
|---|---|
| MY Kidney TREK - EXIT INTERVIEW CODES | These are all codes developed for analyzing the My Kidney TREK study exit interviews. |
| Reflections | |
| Negative Experiences | |
| Future Reflections | |
| Future Nervous | |
| Future Excitement(s) (+) | Things they identified as being excited about for their or their child's future |
| Positive Reflection | Positive reflection on either self or their journey. |
| Growth/Change | Has reflected on personal growth or change throughout their journey. |
| Barriers | Reflecting on thei past and barriers identified. |
| Hypothetical Scenarios | |
| Reactions to Scenarios | How particpants reacted to the scenarios and feelings it brought up for them. |
| Likes Comparison | After shown scenario explains why they like the idea of comparing their or their child's personal data. |
| Mixed Thoughts on Comparison | After shown scenario explains why they have mixed thoughts on comparison or like some ideas behind and dislikes other ideas. |

| | |
|---|---|
| Dislikes Comparison | After shown scenario explains why they dislike the idea of comparing their or their child's personal data. |
| What to Compare | Participant discusses what they would like to compare (specific components) |
| How to Compare | Participant discusses how they would like to be compared if at all |
| Kidney Journey Stories | Kidney journey stories specific component codes |
| KJS Likes | KJS specific component likes |
| KJS Neutral | |
| KJS  Dislikes | KJS specific component dislikes |
| KJS Design Suggestions/Ideas | KJS specific design suggestions or ideas |
| Adherence Component | Adherence specific component codes |
| Adherence Likes | Adherence specific component likes |
| Adherence Neutral | Participant expresses over neautrality towards the component (no particualr likes or dislikes). |
| Adherence Dislikes | Adherence specific component dislikes |
| Adherence Design Suggestions/Ideas | Adherence specific design suggestions or ideas |
| Battery Visual | Participants general impressions, thoughts, and if they found the visuals motivating or not motivating. |
| Routine | Particianpts discuss their routine in terms of something they identified as something they need to focus more on based on what they reflected on in the adherence component. |
| Kidney Function Component | Kidney function specific component codes |
| Kidney Function Likes | Kidney Function specific component dislikes |
| Kidney Function Neutral | Participant expresses over neautrality towards the component (no particualr likes or dislikes). |
| Kidney Function Dislikes | Kidney Function specific component dislikes |
| Kidney Function Design Suggestions/Ideas | Kidney function specific design suggestions or ideas |
| Kidney Function Visual | Participants general impressions, thoughts, and if they found the visuals motivating or not motivating. |
| New Things Learned | Learned something new by interacting with kidney function component. |
| Overall Technology Probe | Any thoughts particpants have about the technology probe overall. Suggest adding inductive codes as identified. |
| Tech Probe General Impressions/Usability | Participants discuss their overarching general impressions about the tech probe and may bring up its usability. |

| | | |
|---|---|---|
| | Design Suggestion/Idea | Suggestions/ideas participants have for the tech probe overall. |
| | Tech Probe Visuals | |
| | Effective | |
| | Not Effective | |
| | Neutral | |