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An Investigation of Barriers and Facilitators to Living Kidney Donation

By:

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B.S., University of Louisville, 2020

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University of Louisville

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An Investigation of Barriers and Facilitators to Living Kidney Donation

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ABSTRACT

There is strong interest in increasing living kidney donation, as the need for kidney transplants is quite high. Although previous studies outline some barriers and facilitators associated with donating, living kidney donation comprises only a small percentage of overall kidney transplants and thus further research on factors influencing the decision to donate is needed to find ways to increase the donor pool. Ten semi-structured interviews of living kidney donors were completed and analyzed for common themes that either support the current literature or surface additional barriers and facilitators. In addition, a systematic review and analysis of social medial support groups for living kidney donors was completed to further the findings of barriers and facilitators to living kidney donation. Both sets of data were segmented into codable elements and then abstracted into recurrent, overarching themes, from which study findings were derived. Several barriers and facilitators emerged from both data sets and are organized using a sociotechnical systems framework. The facilitators included: (1) an informative, caring, and available care team; (2) having a healthy body prior to donation; (3) being in a good place financially before donating; (4) living kidney donation does not have to be to a friend or family; (5) on the flip side, knowing the recipient may encourage donation; (6) seeing a successful kidney transplant prior to donating; (7) hearing other people's successful transplant stories can be encouraging/motivating to a potential donor; (8) being well informed is an important part to making the decision to donate; (9) potential donor watches the recipient's health decline; (10) personal beliefs can further a person's decisions; (11) the kidney exchange is available for those are not a direct match to the intended recipient; (12) there is heavy testing done to ensure someone is a good candidate as a donor; (13) knowing and understanding the kidney exchange program;

and (14) being a part of a social support group for living kidney donors. The barriers included: (1) negative mental health during the process; (2) a kidney donor cannot take Advil/ibuprofen after donating; (3) outside pressure is not wanted by donors; (4) there are short term negative effects following the weeks and months after donation; (5) not being prepared for post-transplant expectations by their team; (6) mental health prior to donating can decline; and (7) not being able to find long-term studies on donors. Corresponding suggestions are offered for how to encourage others to consider donation and increase the living donor pool, as well as to ensure donor's health and safety during the process. This thesis was part of an Institutional Review Board (IRB)-approved study with the University of Louisville's Department of Industrial Engineering and School of Medicine.

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INTRODUCTION

The first successful kidney donation took place over sixty years ago in 1954 and occurred between living identical twins (Reese et al., 2015). Since then, kidney donation has saved several lives and is often the best way to save the life of someone in renal failure. Renal failure, or kidney failure, refers to the kidney failing to remove waste from the body as well as struggling to maintain a balance of electrolytes (Organ Procurement and Transplantation Network, 2020). Kidney donation provides much higher survival rates for those in renal failure than dialysis. More specifically, living kidney donation (LKD) is preferred and more effective than both deceased kidney donation and dialysis (Medin et al., 2000). Although LKD is the preferred treatment for someone in kidney failure, there are simply not enough living kidney donors, or donors in general, to help every person in need. According to the Health Resources and Services Administration under the US Department of Health and Human Services, in 2020, 77% of all kidney donations were through deceased donors. Researchers have begun investigating how to decrease that gap and encourage more living kidney donors. This thesis aims to reveal several factors that facilitate the decision process of becoming a living kidney donor. Additional research is needed on both motives and barriers of deciding to become a donor or not. Ultimately this thesis provides more insight into the experience of living kidney donors by framing the realm of LKD as a sociotechnical system. The sociotechnical framework, often used in human factors engineering studies, distinguishes three integrated parts of a work system: social, technical, and environmental subsystems (including internal and external) (Hendrick & Kleiner, 2001; Kleiner, 2008).

The social subsystem is comprised of the living kidney donors, their friends and family, the donor recipients, and the health care team. The social subsystem also includes these individuals' beliefs, attitudes, social networks, etc. The technical subsystem includes not just the health IT (donor health records), but also technology such as social media apps that connect donor support groups. Physical environmental and local contextual factors are part of the internal environment. The external environment includes any external influences such as available funding support for living kidney donors. Ideally, the social and technical subsystems, as well as the internal environment, are balanced, or 'jointly optimized', to function optimally. The sociotechnical systems theory is used to frame the findings from this thesis.

LITERATURE REVIEW

Living Kidney Donation

There are several reviews and studies that have investigated barriers and facilitators to LKD, with recommendations and ideas for how to potentially increase the number of donors. There have been studies and articles published that focus specifically on one theme of why donors may make their decision, as well as studies that look more broadly at several themes. Many common themes have emerged for donor motivation. A very common barrier to donating is the donor's fear of post-transplant health problems they may encounter. This has been identified as a psychological barrier in a study comparing potential donors to those who had already begun the donation process. The potential donors most often expressed a personal fear of health problems because of the transplant (Kranenburg et al., 2007). Another large barrier to donating is the financial consequences for the donor. According to the National Kidney Foundation, the transplant recipient's insurance will typically pay for the donor's medical expenses relating to any prior testing, the surgery, and post-operative care that will take place. (National Kidney Foundation, 2020). However, insurance does not usually cover several indirect and direct costs that are incurred by most transplant donors. For example, travel expenses, if necessary, may not be covered, and the donor's healthcare coverage may be adversely affected for health issues that could arise much later. These uncovered additional costs may influence a potential donor's decision. Previous research has shown that people with low socioeconomic status tend not to become living donors for these reasons (Tushla et al., 2015). Although providing financial incentives may seem feasible, The National Organ Transplant Act of 1984 prohibits organ purchases, since this could lead to a moral conflict of providing incentives in exchange for one to donate an organ. In a similar study to this thesis, living kidney donors were interviewed to find concerns surrounding donating related

to information-gathering practices. An overarching concern, one could say a barrier, relating to donating was the concern from family members about the health and safety of the donor. There was a statistically significant difference in the concerns about donating between the donors themselves and the donor's family members. (Ruck et al., 2018). That is, the donor's family members were significantly more likely to have concerns and fears than the actual donor. Irving et al. (2012) analyzed several qualitative research studies on organ donation and found eight themes that influenced the decision to become a donor: relational ties, religious beliefs, cultural influences, family influences, body integrity, previous interactions with the healthcare system, the individual's knowledge about the organ donation process, and major reservations about the process of donation. Ultimately Irving found that many made their decision based on their personal beliefs. The study identified that while previous research led to the notion that religious beliefs were often a barrier to donating, certain testimonies could be used as facilitators in a religious setting. Another conclusion reached was the notion that there was less resistance to living donation if it were being done for a family member. This is not surprising as there is an assumed dependency (either emotional and/or financial) on a family member as opposed to a stranger (Irving et al., 2012).

Social Media and Other Online Support Groups

Social media has become a well-known tool for people across the world to keep in touch, stay informed, and even meet new people. Most adults use some form of social media daily. Understanding how social media works and who uses it can be beneficial to many industries, including healthcare. A recent study by Eckler et al. (2010) tried to understand basic elements of how social media was being used in health care. They found many healthcare networks had already

begun creating a presence on social media to share their services offered. Ultimately, the authors found that social media had matured more and allowed for a larger, more influential platform (Eckler et al., 2010). Bennett (2012) has described five important uses of social media for hospitals to follow: (1) customer service, (2) community outreach (3) patient education, (4) public relations, and (5) crisis communications (Bennett, 2012). Similarly, another study (Chou et al., 2009) set out to understand the health-related factors associated with adults using social media. Not surprisingly, one of the only predictors of using social media was youth. At the time of that study, there was an association between poor general health, psychological distress, or cancer experience and being in an online support group (Chou et al., 2009). Naslund et al. (2016) aimed to better understand support for people with mental illness across various social media platforms. The researchers found there were positive outcomes for people with serious mental illnesses to interact with other people facing similar challenges; it was beneficial to hear other's outcomes and what to expect for someone going through something similar. Hearing other's experiences can be educational and even encourage one to seek healthcare (Naslund et al., 2016).

The benefit for sharing health information as well as seeking support from others in a similar health situation, is understandable. Facebook, a large social media site, is a popular platform where users can create groups to share ideas, concerns, and even support one another. There have been studies focused specifically on a certain health issue and using Facebook Groups as support for those patients. One focused on diabetes patients using Facebook groups to communicate with other patients. The researchers found four overarching themes from using the Facebook groups: information-sharing, patient-centered management, community building (or emotional support), and marketing/data collection (Greene et al., 2011). Similarly, another study focused on Facebook groups for hypertension and analyzed the main themes within the groups.

This study found that the majority of groups were created to promote awareness for hypertension, and then secondly, they were created to provide support to patients and their caregivers (Mamun et al., 2015). Very similar to that, another study analyzed the reason for the creation of Breast Cancer Facebook groups. The most common type of reason for these groups, in contrast, was fundraising, then followed by raising awareness. Looking at specifically support groups for breast cancer, they found that half of the support groups were created to support anyone affected by cancer, not just the patients themselves (Bender et al., 2011). Several organ donors as well as potential donors have turned to Facebook to look for support from fellow donors and hear their stories in hopes of confidence to either donate themselves or even find donors for loved ones. The research on Facebook support groups is minimal, and even more slim for finding barriers and facilitators of LKD. However, one study did find that 26% of participants reported that hearing other LKD experiences was of value to them (Ruck et al., 2018). Another article reported on a separate mobile application that was Facebook-based, which aimed to pair living organ donors with those in need (Bramstedt & Cameron, 2017).

METHODS

Participants

Ten participants (6 females, 4 males), all current living kidney donors, were recruited for this Institutional Review Board (IRB)-approved study to talk about their journey as a living kidney donor using a semi-structured interview process. Additionally, Facebook groups dedicated to support kidney transplant donors and recipients were used for further research into the donation decision process. The participants for this study were recruited from a list of recent living kidney donors (January 2017 to December 2019) at the University of Louisville's Trager Transplant Center. They were contacted either by phone or email. Once a donor expressed interest in participating, the interview was scheduled either in person and socially distanced, or virtually on a video or phone call. Virtual participation options were available due to the COVID-19 pandemic. After the interview was scheduled, the participant was sent the informed consent, (APPENDIX III) and confirmation of their interview time. During the interview, the participant's current age and age when they donated were recorded. The ages of the participants at the time of donation ranged from 23 to 66 years of age, with 7 of the 10 participants between 30 and 50 years of age. The mean age of the participants was 46.3 years old, while the mean age at the time of donation was 44.4 years old. The race of the participants was not recorded for this study.

Semi – Structured Interviews

The semi-structured interviews were conducted to further investigate barriers and facilitators to LKD. Semi-structured interviews were chosen because they are more flexible and are more open-ended for the participant to be able to bring up other important information on their own. It also allows the interviewer to inquire deeper and ask questions about a particular topic or idea that may

be arise. All participants were asked the same initial questions for a base level of consistency. Below, are the base questions used for each interview; the development of these questions was informed, in part, by the literature review.

0. What is your age now and your age when you donated?
1. What is or was your main motive for deciding to donate (or not donate) a kidney?
2. (*Future need*) Assuming you had the ability to make a future kidney donation, is there anyone [else] you would consider donating to if they needed a kidney in the future?
3. (*Religion/Belief*) What specific aspects of your religion or beliefs encouraged or discouraged you from donating a kidney?
4. (*Negative consequences*) Are there negative consequences that may have impacted your decision to donate a kidney?
 - 4a. How did you learn about those potential negative health consequences (e.g., physician, internet, word of mouth, self-perception, etc.)?
5. (*Financial*) Are there financial or logistical considerations that may have impacted your decision to donate a kidney (e.g., Unable to take time off from your job, Work-up expenses, etc.)? Please explain.
6. (*Fear of unknown*) Are there unknown factors that may have impacted your decision to donate a kidney (e.g., medication side effects)? Please explain.
7. (*Pressure from others*) Was pressure from friends and family a factor in your decision to donate (or not donate) a kidney (e.g., please help / please do not donate)? Please explain.
8. (*Need the candidate/recipient*) Do you have a dependency on the recipient that may have influenced your decision to donate a kidney (e.g, to raise kids, for income, etc.)?

9. (*Societal contribution*) Is the ability to contribute to society a factor in your decision to donate a kidney? Please explain.

10. Is there anything we have not covered yet that was important to you during your process in deciding to donate a kidney?

11. What advice would you give others who may be starting this journey and deciding whether or not to donate a kidney?

The semi-structured interviews provided qualitative data for analysis and identification of barriers and facilitators to LKD. The interview responses were broken down into smaller segments that were easier to then analyze for an overarching code of that segment. Segmenting is a popular method for analyzing qualitative data. It includes dividing the data into smaller, more meaningful parts. It can be a word, a sentence, phrase, or even a full paragraph. It does not have a set length, but rather just needs to have an overarching meaning or theme to the researcher (Johnson and Christensen, 2019). Below you can see a few examples of segments pulled from the interview data:

- “No. At the time, I was 100% employed by U of L and I had tons of sick time built up and things like that. So I was able to take off with full pay and not have any financial concerns.”
- “So, and it's a rare, celiac artery aneurysm or something, only 300, maybe, people in the world have ever had it. I have a team at the, I can't think of the name, but it's at U of L, that I come in every year and they map out the heart and they map out the aneurysm and they, so many, it's almost a blessing in disguise that I did it. I mean, there, not to get religious or theoretical, but I mean, there was always a higher calling for me to do it.”
- “I wanted to do it [living kidney donation] for, I don't know, maybe five years.”

Two researchers assigned one code (or two codes where applicable) to each segment separately, then met to identify and settle on each segment's assigned code. After coding the first two participant transcripts independently and then coming to consensus, a codebook consisting of 13 codes was created, each with an associated definition. The code book and their definitions can be seen in APPENDIX I. The codes that emerged were : *Care Team, Donor Health, Family/Friends, Job/Career, Long-term effect, Personal Journey, Personal Research, Recipient Health, Religion, Short-term effect, Surgery Outcome, and Kidney Exchange*. Once the codebook was created, the author and another researcher used the codebook to independently code the remaining 8 interviews and then come to a consensus to resolve any discrepancies. Each of these codes were filtered into their own category and analyzed individually. The author analyzed each code individually to find associated facilitators and barriers with another researcher confirming or suggesting edits to each. This type of auditing procedure by a second analyst is considered an acceptable alternative to using independent coders for ensuring validity of the analysis (Holden, 2012). From the 12 codes, several barriers and facilitators emerged.

Content Analysis of Facebook Support Groups

The author systematically reviewed comments and posts from March 2019 forward in two Facebook groups for living kidney donors. The first group was a public group, meaning any person with a Facebook profile can join, and does not have to "request" to be a part of the group. In a public group, anyone can also read and view any posts made without liking or joining the group. This group was titled "Living Kidney Donor Transplant" and had 342 members. The second group was a private group, meaning one must request to the group administrator to join and state one's

reasoning to join. This group was titled “Living Kidney Donors Support Group” and had 6,600 members. No demographic information was recorded.

The two Facebook support groups for living kidney donors were combed through for comments and posts relating to the process of LKD. There were several posts congratulating people for either becoming a living kidney donor or a recipient successfully getting a transplant as well as posts asking for help for loved ones in kidney failure. Lastly, there were several posts from donors posting that they had successfully scheduled their transplant date or immediately post-surgery saying that everything had gone well, where the community of other donors would congratulate and thank them for being a living kidney donor. However, there were also several posts asking previous donors how they felt and what they experienced throughout their donation journey, as well as donors posting updates on their recovery. These were the posts and comments the author pulled from as they related more to the overall donation process and could provide insight into barriers and facilitators of donating. These were then segmented as necessary so to code similarly to the interviews. The original code book for analyzing the interviews (APPENDIX I) was used while analyzing the two Facebook support groups as well. However, because the comments and posts being pulled for data segments were not derived from the same questions as the interviews, new codes were added to address other topics within the support groups. The additional codes added were *Advice*, and *Pre-Surgery Testing* (APPENDIX II).

RESULTS

Analysis of the Semi – Structured Interviews

The full list of barriers and facilitators can be seen in Tables I and II. The fact that there were more facilitators did not come as a surprise as everyone interviewed had already completed their transplant surgery, whereas prior research has included potential donors and donors, not just those who have already donated.

TABLE I

LIST OF FACILITATORS FOUND FROM SEGMENTING ANALYSIS

<u>Facilitator Found:</u>	<u>Associated Code:</u>	<u>Supporting Participants (N = 10)</u>	<u>Total Number of Segments (N = 332)</u>
An informative, caring, and available care team	Care Team	8	14
Having a healthy body prior to donation	Donor Health	4	32
Being in a good place financially before donating	Job/Career	4	31
Being able to take extra time off work for recovery	Job/Career	7	31
Living kidney donation does not have to be to a friend or family	Personal Journey	4	59
On the flip side, knowing the recipient may encourage donation	Personal Journey	2	59
Seeing a successful kidney transplant prior to donating	Personal Journey	3	59
Hearing other people’s successful transplant stories can be encouraging/motivating to a potential donor	Personal Research	4	36
Being well informed is an important part to making the decision to donate	Personal Research	4	36
Potential donor watches the recipient’s health decline	Recipient Health	6	20
Personal beliefs can further a person’s decisions	Religion	4	15
The kidney exchange is available for those who aren’t a direct match to the intended recipient	Kidney Exchange	4	6
There is heavy testing done to ensure someone is a good candidate as a donor	Surgery Outcome	3	7

1

¹ The column, Supporting Participants, relates to the number of participants who supported the facilitator found. The Total Number of Segments column refers to the total number of segments under that associated code.

TABLE II

LIST OF BARRIERS FOUND FROM SEGMENTING ANALYSIS

<u>Barrier Found:</u>	<u>Associated Code:</u>	<u>Supporting Participants (N = 10)</u>	<u>Total Number of Segments (N = 332)</u>
Negative mental health during the process	Donor Health	4	32
A kidney donor cannot take Advil/ibuprofen after donating	Long-Term Effect	3	17
Outside pressure is not wanted by donors	Personal Journey	4	59
There are short term negative effects following the weeks and months after donation	Short-Term Effect	6	17

2

With the understanding that a facilitator can also be framed as a barrier and vice versa, each code produced at least one facilitator or barrier, some producing multiple. The four codes that produced barriers were *Donor Health*, *Personal Journey*, *Short-Term Effect* and *Long-Term Effect*. The barrier that emerged for *Donor Health* was that the donors experienced negative mental health affects during the process. Four out of ten interviewees mentioned their mental health being affected negatively by the donating process. When talking about the donor’s *Personal Journey* through the donation process, it was clear that outside pressure was not wanted by the donors and can be a barrier to donating. Four participants expressed that they did not want pressure from family and friends, and thought it was important to have the option to potentially back out from donating all the way up until the surgery. The barrier that emerged from the code *Short-Term*

² The column, Supporting Participants, relates to the number of participants who supported the barrier found. The Total Number of Segments column refers to the total number of segments under that associated code.

Effect was that donors experienced negative effects throughout the weeks and months following donation. Six of ten participants mentioned being either extremely tired or suffering slight pain after donating. The last barrier that emerged from the data was a *Long-Term Effect* on the donor, being that a living kidney donor cannot take Advil or ibuprofen after donating. Three participants mentioned this being a negative consequence of donating.

Although four clear barriers were apparent from the data, several facilitators emerged as well. Each code created at least one facilitator, except for *Long-Term* and *Short-Term Effects*. For *Care Team*, an informative, caring, and available team was important to the donors. Eight out of ten participants referenced members of their care team during the interview. Another important factor was that several donors mentioned they had lived overall healthy lives prior to donating. So, having a healthy body before donation was the facilitator from *Donor Health*. When talking about their *Career*, being in a good place financially was important to several donors as well as being able to take extra time off work for recovery. Four participants expressed their financial situation prior to donating was an important factor and seven participants talked about how they were easily able to take time off work (or school) to properly recover. The *Personal Journey* a donor has from making the decision to donate through the surgery is quite extensive. Three facilitators came from this code. The first was that LKD does not have to occur between a friend or family member. Four interviewees explained they either had no relationship to their recipient or would donate to a stranger, if given the capability to donate again. Secondly, having a relationship or knowing the recipient can encourage donation. This seems more straightforward, but two participants did say they would need to know the participant when asked. Regarding the donor's *Personal Research* before donating, hearing other people's successful transplant stories can be encouraging to a potential donor. Four participants mentioned that they had done their own research to hear another

donor's journey through joining a social media support group, meeting a donor in person, or reading a blog about donation to help them feel comfortable for the surgery. Similarly in *Personal Journey*, seeing a successful kidney transplant can encourage live kidney donation. Three participants had mentioned they had seen a kidney transplant patient prior to beginning their donation process. Thus, seeing firsthand a successful outcome from a kidney transplant may encourage live kidney donation. Three participants spoke about the benefit of seeing kidney transplant patients prior to beginning their process. Similarly, four participants also expressed the importance of doing your own research if one is considering donating. Being well informed is an important part of making the decision to donate and can facilitate LKD. Seeing the recipient's health decline, although a negative experience, can also encourage donation from a potential donor. Six out of the ten participants mentioned that watching the decline and poor health of their recipient pushed them to donate. Additionally, five participants talked about the rewarding feeling of seeing the recipient's positive change in health post-transplant. Very similarly, when looking at the code *Surgery Outcome*, three participants expressed that the outcome of the surgery (regardless of if the recipient lived or not) confirmed their decision to donate. *Religion* and personal beliefs are a strong part of many people's life and how they make decisions. Of the six participants who talked about religion, four of them indicated that their religion was an important influence on their decision to donate. Thus, personal beliefs can further a person's decision to donate. The ability to do a *Living Kidney Exchange* when the donor is not a match for their intended recipient is a strong facilitator. In the five participants who brought it up, four said they would have done it had they not been an initial match.

Analysis of Social Media Support Groups

The support groups had a lot of similarities in the comments that mirrored what was said in the interviews; however, more barriers emerged from these data rather than facilitators. Tables III and IV shows the additional barriers and facilitators, respectively.

TABLE III

LIST OF BARRIERS FOUND FROM SOCIAL MEDIA SUPPORT GROUPS

<u>Barrier Found:</u>	<u>Associated Code:</u>	<u>Supporting Segments</u>	<u>Total Number of Segments (N = 125)</u>
Not being prepared for post-transplant expectations by their team	Care Team	7	8
Mental health prior to donating can decline	Donor Health	8	11
Not being able to find long-term studies on donors	Personal Research	3	8

3

³ The column, Supporting Segments, relates to the number of segments with the associated code, that support the barrier found. The Total Number of Segments column refers to the total number of segments under that associated code.

TABLE IV

LIST OF FACILTATORS FOUND FROM SOCIAL MEDIA SUPPORT GROUPS

<u>Facilitator Found:</u>	<u>Associated Code:</u>	<u>Supporting Segments</u>	<u>Total Number of Segments (N = 125)</u>
Knowing and understanding the kidney exchange program	Kidney Exchange	10	10
Being a part of a social support group for living kidney donors	Personal Journey	4	18

4

From the original codes, *Care Team* produced a strong barrier being that the donors may not feel prepared enough by their care team prior to donation. Seven of the eight comments relating to the care team mentioned that they did not regret donating but wished they either would have been more prepared for post-transplant expectations or had a better experience with the care team. A second barrier emerged from *Donor Health*, as mental health prior to donation can be poor for the proposed donors. This essentially echoes the *Donor Health* barrier found in the interviews, although this related solely to their mental health prior to donation, not encompassing the whole process. Eight of the eleven comments under *Donor Health*, as mental health prior to donation can be poor for the proposed donors. An interesting finding that came from the code *Personal Research* was that donors felt they lacked long term research prior to donating. There were eight comments relating to Personal Research and half of them related to concerns over long term effects on donor health.

⁴ The column, Supporting Segments, relates to the number of segments with the associated code, that support the facilitator found. The Total Number of Segments column refers to the total number of segments under that associated code.

For the code Kidney Exchange, a clear facilitator emerged in that knowledge of the kidney exchange could encourage donation. Nine of the ten segments under Kidney Exchange expressed that the donor had not initially been a match but ended up participating in a paired kidney exchange for their intended donor. Of these, six did a paired kidney exchange for a family member. In the code Personal Journey, there was a lot of encouragement to others, expressing that the rewards of being a donor are tremendous, as well as showing their gratitude towards the support group. Being a part of a support group prior to donating could facilitate LKD. Relating to Personal Journey, there were five comments about the support group itself. Of those five, four expressed gratitude and appreciation towards the group. The fifth comment expressed that while they learned a lot from the group, the information from the group ultimately increased their anxiety. There were several segments that were coded under Religion and all had positive connotations. This result echoes the facilitator found in the interviews, that all nine comments about religion were encouraging towards donation, whether that was to trust God, pray on their decision, or trust in their beliefs. Lastly, Short-Term Effects was the code that had the most segments assigned. There were 31 segments relating to Short-Term Effects on donors post-donation; 30 of these were from donors and one was from a potential donor dreading having symptoms post-operation. This was a very popular topic as one who is considering donating will inquire about this and one who has recently donated is usually open to sharing how they feel. There seemed to be a divide between the comments with a line being at two weeks post-surgery. Most tended to talk about how they felt either within two weeks or outside of it. Once that was clear, after combing through the segments, the author divided the segments into one of four categories, “Felt fine outside of 2 weeks”, “Did not feel fine outside of 2 weeks”, “Felt fine within 2 weeks”, “Did not feel fine within 2 weeks.” Interestingly, these data were split very evenly. Ten comments fell into each category of either

feeling fine or not feeling fine outside of two weeks. Five comments each fell into the categories feeling fine or not feeling fine under two weeks.

The code “Advice” surfaced quickly as many posts in the groups were asking for input from previous donors on different aspects of the donation process. One of the main pieces of advice that stood out was for donors to take it easy after donation. This code was not necessarily one that produced a facilitator or barrier, but it was important to note that many people joined the groups in hopes of receiving advice from previous donors. The other new code was Pre-Surgery Testing, which had a few posts dedicated to just that. This code did not necessarily produce a clear barrier or facilitator as well, but it did seem to be a point of interest for the people considering donation as it is a lengthy process. Half of the comments related to Pre-Surgery Testing, though were encouraging about the exam expressing that it “wasn’t too bad” and was also a very thorough exam for the donor.

DISCUSSION

Semi-Structured Interviews

The barriers revealed by this study can be helpful to understand and utilize when pursuing donor candidates and potential donors. With 40% of the participants mentioning that their mental health was affected throughout this process, it may be critical for all transplant centers to offer a counseling service during the whole process for donors, as well as for their families. One of the donors even said “...the stress for me was that intense. And I’ve been in a lot of stressful situations before, from an athletic standpoint, I’ve had a game riding on whether I’ve been up to bat with two strikes. And if we didn’t, if I didn’t get a hit, we weren’t going to win that game and our season was over. So, I’ve been in extremely stressful situations. For me, that [donation] was heads and tails beyond anything that I’d experienced.” Along with stress they may be feeling internally, the outside pressure coming from family and friends could negatively impact their mental health while making such an important decision. It is not surprising that the donors prefer not to have negative comments coming from those closest to them. Apart from the mental aspects, the physical effects the transplant had on the body was the cause of the other two barriers, being that the donor could not take ibuprofen again after the transplant, and also the physical pain for the few weeks or months following the transplant. Neither of these were surprising to hear as there is obvious discomfort with any procedure. However, preparing donors for the potential levels of pain and discomfort they may feel could help lessen that shock after surgery. As well, offering other medications or advice for how to deal with headaches, slight pain, and fevers that may have previously required ibuprofen would be beneficial. One donor who suffered migraines before and after the transplant expressed that they wished they had their neurologists input as well before donating to understand better how to deal with their migraines post-surgery. Another common health fear of donors as

discussed in Ruck et al. (2018) was that they may one day need a kidney. However, two separate participants in this study addressed that with the following quotes: “I was like, well, what if 20 years down the road I need a kidney? They said you jump to the front of the line, of the register. I said, okay. That made me feel better.”, and “And then there's chance that you could, the one kidney you have could fail and you'd go on the list. But the good thing about that is if you donate it, you go to the higher barter list. You're not waiting so long.” Both participants are referring to the fact that if you are a living kidney donor who then goes into kidney failure, you are awarded points to be put in a priority spot on the deceased donor list according to the National Kidney Registration.

Although four barriers emerged from the interview data, it was clear that the participants felt strongly about donating and were willing to share reasons why they ultimately chose to donate and what helped lead them to that point. When looking to increase the donor pool, these are important aspects to keep in mind. The interviews revealed another physical benefit to the donor when considering donation. The facilitator that emerged from the Donor Health category, “Having a healthy body prior to donation” led to an interesting find: four out of ten donors mentioned that the thorough testing process found health issues they had no previous knowledge of, and thus would not have discovered otherwise. Even if a donor does not choose to follow through with donation, this testing process can find underlying health issues one may not know about. One donor said “...when they did the tests, they found I had an aneurysm in my heart. Without the tests, they would have never found that. When it snowballed and so, I mean, everything has, I saved someone's life and in turn, they almost saved my life.” Encouraging routine checkups for adults is already common but getting this intense level of testing completed is advantageous to the donor's overall health. For many donors, being in a comfortable spot financially and taking time off from their job or career was an extremely important factor and one that others found as a severe

barrier if that is not the case (Tushla et al, 2015). Interestingly, one donor felt so strongly about companies giving living kidney donors separate time off that they reached out to their state legislator to request a tax deduction or tax credit for employers that offer a separate paid leave. If all employers offered a paid leave for organ donors, it should help lessen the financial stressors suffered by people that might have otherwise shied away from donating. When talking about religion, of the six participants who brought it up, four said that their beliefs held a role in encouraging them to donate. One participant had a story that could be inspiring to potential donors in their same scenario. That participant stated “I just know through my relationship with God, when the Holy spirit leads you to do something it's, I don't want to say it's a supernatural impression on your body, but it was something that I knew was from Him. There wasn't an audible voice that came down and said, ‘donate your kidney to [recipients name redacted]’, or there wasn't this flashing sign on Facebook that said, ‘you should do this.’ It was just a...I would say just the Holy spirit working for me and just prompting me to check the posts. And, and sometimes I think that God lays things on your heart just to see if you'll be obedient to his calling.” If stories like this were shared among their respective religious groups, it may encourage more people to seek out donation and understand its benefits. Understanding these participants’ journeys through donation have the potential to help increase the living kidney donor pool by utilizing the facilitators that came from their interviews.

Facebook Support Groups for Living Kidney Donors

Like the facilitators and barriers found from the interviews, the ones found from the Facebook support groups can be advantageous when hoping to increase the donor pool. The first

barrier that emerged from these data related to Care Team and the donor not feeling prepared enough for post-transplant expectations. This makes a lot of sense to come from this data set as it is a support group for previous and potential donors and provides an open source for donors to express how they felt and prepare others if in the same situation. Ensuring a uniform expectation for transplant centers across the United States may help this situation as well as encourage the potential donor join either a virtual or in person support group. The other two comments that did not directly relate to the barrier but were assigned to Care Team were, “Everyone on my team was AMAZING!!! They make you feel very comfortable” and the other related back to the barrier but did not specifically state they did not regret it, “I don’t understand why transplant centers don’t do a better job of preparing people. Anyone that thinks they’ll be up and back to normal after TWO DAYS has clearly not been well prepared...” These two extremes show obvious inconsistency within care teams in transplant centers. Creating a standard work for these centers would assist in narrowing the differences. As far as the literature shows right now, this is not something already in place. The fact that mental health prior to donating can decline was an important barrier to note as this process is already physically hard on the donors. One donor stated, “[I] just got a date of April 8 for my paired donation for my brother-in-law. When I joined this group, I was hoping to learn a lot and ease some of my anxiety. I absolutely have learned a lot from this group but, my anxiety has increased exponentially.” This group intended for support seemed to have the opposite effect for them. For the code Family/friends, there was one comment in particular that stuck out, “I’m donating in April to a close friend, and pretty much all of my family is unsupportive... and it’s driving me insane. It’s making me feel like crap, even though I am completely set and committed in my decision with no second thoughts.” This was important to highlight as it echoed the barrier discussed earlier about negative outside pressure from family and friends. Again, this

may be a good place to ensure donors have availability to mental health resources as necessary through the donation process. Lastly, the donors being unable to find long-term studies on donor health is a barrier to donating is surely a concern. One donor stated, “That was one reason I joined this group before donation to become informed on the health of those who donated years ago.” Providing donors with published, reliable studies may help them to feel more confident prior to donating as well as encourage others to pursue donating.

For the two facilitators, the one relating to Personal Journey holds a lot more weight for donating. Being a part of a social support group for living kidney donors can have very positive effects for the potential donors, as they can get firsthand experience of several people who have donated rather than hearing from their doctor, who although reliable, has not experienced it themselves. One comment really stuck out from a donor, “[I] am very grateful to this group, as I sit here in my u-shaped pregnancy pillow! This group’s guidance really prepared me for what to expect. I am feeling really emotional and just had to share my gratitude for everyone here that has donated and shared their experiences. I am amazed by those of you who have selflessly gone through this experience for recipients you don’t know...you have my utmost appreciation and admiration, wow.” Although each donor will have a different experience, it is encouraging to see the stories of those who successfully donate and help someone in need and are able to share their recovery and how they handled the journey.

Similarities and Differences between the Interviews and Social Media Support Groups

Both sets of data provided a good look into what living kidney donors experience as they go through the decision process of becoming a donor, and then their journey through donation and

recovery afterwards. There were several segments pulled from each that heavily reflected each other, and themes that emerged showing similar ideals about donating. However, there were differences as well.

The donors' mental health being negatively impacted during the donation process was a strong barrier that was reiterated through both data sets. This is important to note as mental health may be overlooked as donating an organ has such a heavy impact on one's physical health. Suggestions of prioritizing access to mental health resources and additional support groups could help reduce stressors on donors. For the facilitators revealed, religion provided a beneficial aspect for donors, either to consider donation, support their donation journey, or a reason to share their story post-donation. There was not one comment in either data set where a donor referenced their religion to negatively talk about donating. Donors continuing to share encouraging religious stories could have an impact on their religious community. The fact that the code "Advice" surfaced in the social media support group data set was interesting as one of the interview questions was "What advice would you give others who may be starting this journey and deciding whether or not to donate a kidney?" This question assisted in producing the facilitator of being well informed prior to donating. Although the code "Advice" did not produce a strong barrier or facilitator, the fact that a code was necessary to separate out segments shows that potential donors want to hear advice from previous donors and seek out the opinions and experiences of those who have donated. Similarly, donors often want to share their experience with donating regardless of feeling positive or negative about donating. Lastly, this was a more unique similarity, the pre-transplant testing and examinations were described as very thorough. There was a comment from both data sets that reflected the fact that this testing often ends up finding other health issues the donor does not know

about. This is an added benefit to the donor unrelated to donating but is a chance for the donor to get a complete examination of their current health status without paying for it.

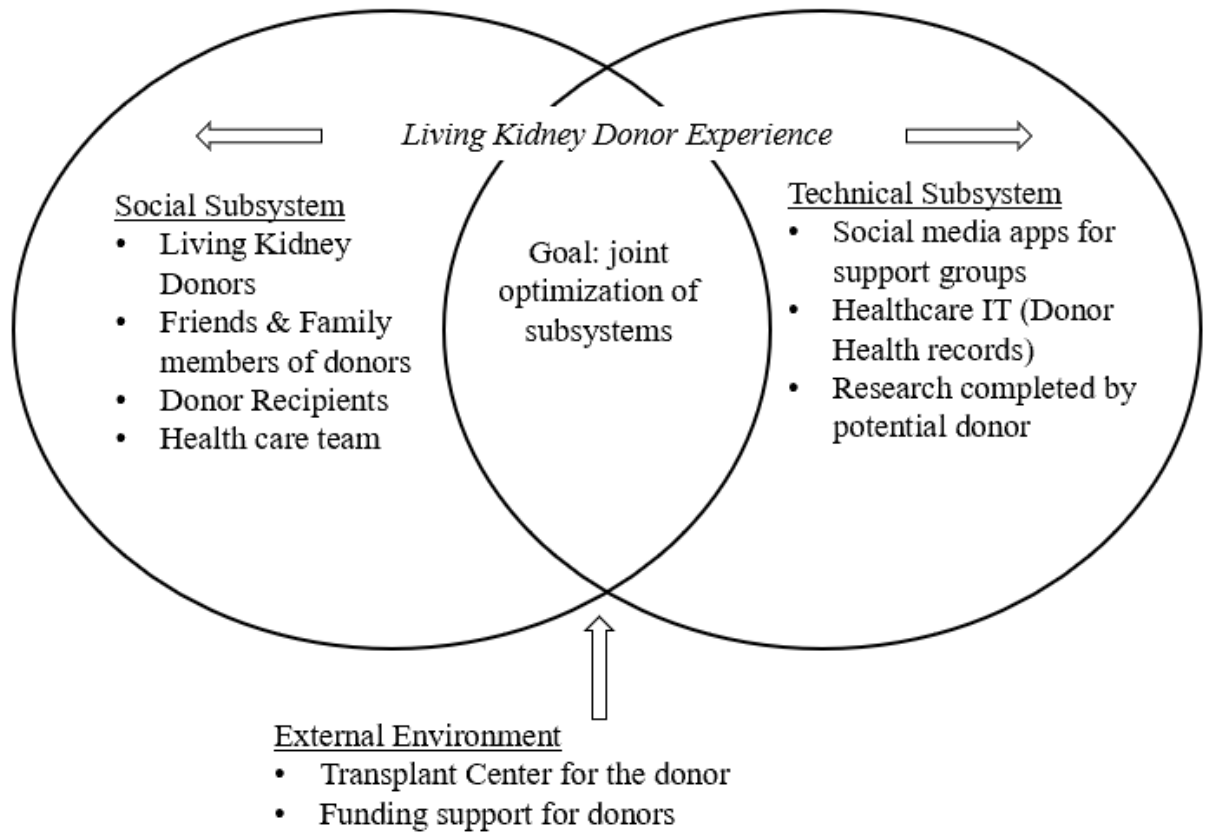
Differences arose between the two data sets naturally as the Facebook members were not asked the questions the interviewees were. There were more facilitators created from the interview data and more barriers found from the social media support group data. This was not concerning as all ten interviewees had already completed their transplant journey and were not potential donors; they were not currently living with fear and concerns that potential donors may be feeling. Having already donated, the concerns surrounding donating are not in the fore front of their thoughts, and instead focused on what did ultimately lead them to donating. Also, all ten participants for the interviews completed their transplant at the University of Louisville's Trager Institute for Transplants; the care team and overall process can be assumed to be more similar than those in the support groups as they interact with transplant centers across North America. Also, important to note, the interview data had roughly triple the number of total segments so it is no surprise that data set produced both more facilitators and barriers overall than the other data.

Sociotechnical Systems Framework

The findings from this thesis can be framed with the sociotechnical systems framework. Most of the findings are heavily grounded in the social subsystem. These include facilitators such as (1) having an informative, caring, and available care team, (2) having a healthy body prior to donation, (3) knowing the recipient, (4) hearing other people's successful transplant stories, (5) being well informed, (6) personal religious beliefs, and (7) being part of a social support group. Barriers within the social subsystem include (1) negative impact on mental health, (2) pressure from friends and family, (3) potential negative health effects, and (4) lack of understanding of

post-transplant expectations. This reveals a tremendous design opportunity to build support structures within the technological subsystem to help maximize facilitators and minimize barriers to LKD. For example, additional support groups can be enabled through thoughtfully designed apps. Existing support groups can be structured within social media, such as Facebook, through professionally and intentionally designed and organized user experience (UX) interaction design. For example, one Facebook support group seemed to have the opposite intended effect by increasing the anxiety of some. The interaction design and content of the support group could be better designed to more intentionally support donors and provide them with information that can ease their concerns. Additionally, virtual religious study groups are popular now after the COVID-19 pandemic, these platforms could be used for donors to share their story either by joining or posting their stories to the groups. The social and technological subsystems should be jointly optimized to help a donor through the entire donation process. Below Figure I illustrates the sociotechnical system and visually shows the joint optimization of the subsystems for a potential living kidney donor's experience through donation. Each of these subsystems plays a role in the potential donor's experience and ultimately their decision to donate or not.

FIGURE I



CONCLUSION

Initially this thesis was intended to be a project that sought to find facilitators and barriers to living kidney donation by examining interviews of living kidney donors. While this aspect was completed, the social media support groups for kidney donors presented an interesting source of information to provide more insight into the journey of becoming a living kidney donor. The facilitators and barriers found resembled others found in the literature review; however, this thesis uniquely combined two data sources that had not previously been joined to also investigate the sociotechnical system associated with a potential living kidney donor. This thesis used several human factors engineering methods including semi-structured interviews, peer auditing, and the use of the sociotechnical framework. The initial hypothesis was that several facilitators and barriers would emerge from the interview data, and while this is true, the ability to look at LKD as a sociotechnical system was an added benefit to those hoping to increase the donor pool.

The final results produced 15 facilitators and 7 barriers, an encouraging difference showing that there are several factors that further motivate donation. Many of these findings reiterated the conclusions found by current literature. As far as the author is aware, the finding that having plenty of time to recover off work was an addition to the traditional financial barriers of direct and indirect transplant costs. Hearing other donor's stories has been a known facilitator but seeing a successful kidney transplant and the effects on the recipient can also facilitate donation. There were several conclusions made about the current state of living kidney donation and suggestions for improvements that help foster positive experiences a donor may have. The mental health of the donor was raised multiple times and often talked about in addition to the physical health of the donor. Providing mental health support either in the transplant centers or on a support app for the

donor can help to relieve some anxiety and stressors surrounding donation. Encouraging participation in a social media support group may also ease anxiety for donors as hearing other's experiences has been noted as helpful to the donors. For the donor's physical health, it is important to stress the potential side effects that the donor may feel while also explaining each donor is different and may have their own unique reaction. Providing them with information of other ways to subside mild pain without ibuprofen and informing them prior to the surgery may help feelings of uncertainty and anger after donation. In that same realm, creating a universal guidance for transplant care teams may soften feelings of confusion and anger when they are seeking advice from donors who have been treated at other centers. When considering the financial aspect of donating, if more companies were to offer paid time off for recovery, this may help donors feel more comfortable and not rushed to return to work while still in discomfort. Lastly, if donors have a platform to share their religious views and can explain how their religion created an impact on their donation journey, it may provide encouraging content to others with the same beliefs.

Though there is still more research to do in this field, it was important to understand more of a donor's experience through their decision process to donate and what hindered or motivated them to do so. Ultimately the decision should be left up to the donor without extended pressure, but the resources necessary to make an informed decision should be there. To facilitate decision-making, potential donors should have more evidence-based information throughout their process and be able to hear first-hand experiences of other donors. Healthcare systems, in specific transplant centers, have the opportunity to capitalize on these facilitators and barriers and encourage the use of technical support groups for their patients. If utilized, these have the potential to ultimately increase the donor pool and awareness of living kidney donation.

FUTURE RESEARCH

Although this thesis has begun to analyze barriers and facilitators to LKD while using a sociotechnical framework and looking at social media as a new form of data, there is room for further work. First, collecting more data would be key, as this thesis only used interviews from 10 donors, and two social media groups. More interviews from donors at other transplant centers as well as finding people who had started the donation process but did not complete the transplant may help to understand some of the limitations from this research. Adding closed-ended questions to the interviews or sending out surveys in the social media groups could assist in providing more quantitative analysis as well. Using the additional data with quantitative analysis would be beneficial in conjunction with the analysis already completed. For example, one additional piece to look at would be whether these facilitators and barriers can be used as predictors for those more likely or less likely to donate. Using different statistical analysis tools such as an analysis of variance and regression analysis could be beneficial for understanding this.

APPENDIX I: Code Book

Final Code	Definition
Care Team	Any physician or clinical staff present during the patient's donation journey
Donor Health	State of health of the donor prior to surgery/donation, including mental health
Family/friends	Any mentions of family or friends as part of the patient's donation journey; especially the recipient-donor relationship as a family and/or friend relation
Job/Career	Job or career the donor has or had during their donation journey
Long-term effect	Continuing health effects on the donor post-surgery
Personal journey	The donor's time from pursuing donation to either post-surgery or post decision not to donate
Personal research	Any information sought by the donor during their donation journey
Recipient health	State of health of the donation recipient either prior or post-surgery
Religion	Any religious, spiritual, or personal beliefs
Short-term effect	Immediate health effects on the donor post-surgery
Surgery Outcome	Either the successful or unsuccessful surgery/kidney transplant
No code	Not enough info to assign a code or not relevant
Kidney Exchange	Living donors are swapped so each recipient receives a compatible transplant

APPENDIX II: Additional Code Book

Final Code	Definition
Advice	Any piece of advice giving to a donor or potential donor, whether wanted or not
Pre-Surgery Testing	The testing and examinations done prior to donating to ensure a potential donors health as well as checking them as a match to the recipient

APPENDIX III: Informed Consent Letter

UofL Institutional Review Boards
IRB NUMBER: 20.0440
IRB APPROVAL DATE: 06/10/2020

UNDERSTANDING BARRIERS TO LIVING KIDNEY DONATION

Date

Dear _____:

You are being invited to participate in a research study to understand reasons why one may want to donate or not donate a kidney.

Specifically, we will ask you to participate in a semi-structured interview to help understand these reasons for and against living kidney donation. These interviews will be audio-recorded. This study is led and conducted by Dr. Monica Gentili of the University of Louisville's School of Engineering. Dr. Jason Saleem from the School of Engineering and Drs. Hitarth Dave and Lina Mackelaite from the School of Medicine are collaborators on this study. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The data collected and information you provide will help us understand facilitators and barriers to living kidney donation. This information can then be used for designing effective policies and interventions to promote living kidney donation. Data from your completed interview will be stored at the Center for Ergonomics in Lutz Hall room 303 and secured in a locked cabinet and/or kept in a password protected computer. The entire interview will take approximately 45 minutes to complete.

This study requires the use of protected health information (PHI). Examples of PHI are identifiers such as your name or birthdate together with your health information. The Health Insurance Portability and Accountability Act (HIPAA) provides federal safeguards for your PHI. In this study we will use your name, telephone number, and email address along with your health information relevant to this study such as kidney donor status (previously donated or donation candidate). We will keep this data safe by on a password-protected computer with encryption and we will destroy all identifiers when they are no longer needed for the study.

You will be paid by an \$85 Visa gift card for your time, inconvenience, or expenses while you are in this study. Because you will be paid to be in this study the University of Louisville may collect your name, address, social security number, and keep records of how much you are paid. You may or may not be sent a Form 1099 by the University. This will only happen if you are paid \$600 or more in one year by the University. This will not include payments you may receive as reimbursement, for example mileage reimbursement. We are required by the Internal Revenue Service to collect this information and you may need to report the payment as income on your taxes. You can still be in the study even if you don't want to be paid.

Individuals from the Department of Industrial Engineering, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By answering the first question of the semi-structured interview you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop

Version Date: 06/05/2020

taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you have any questions, concerns, or complaints about the research study, please contact: Dr. Monica Gentili at (502) 852-0143 or Dr. Jason Saleem at (502) 852-2274.

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Sincerely,

Monica Gentili, Ph.D.

Jason Saleem, Ph.D.

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Vita

Rachel Crenshaw graduated from the University of Louisville with a Bachelor's degree in Industrial Engineering in May 2020. She is also currently seeking a Master of Engineering degree for May 2021. She has held leadership roles with the Institute of Industrial and System Engineers, Society for Health Systems, and Alpha Pi Mu. She was also awarded the 2021 Institute of Industrial Engineers Activity Award. Outside of school, she enjoys camping, hiking, and spending time with friends. After graduating, she is planning to continue her education at the University of Louisville to pursue her PhD.