



Through the Lens of Chronic Kidney Disease: A Qualitative Study of the Experiences of Young Women Living With CKD

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Abstract

Background: Young women may be particularly vulnerable to the negative psychosocial consequences of living with chronic kidney disease (CKD). To date, little is known about how women themselves experience and manage their illness.

Objectives: This study explored the experiences of young women living with CKD.

Design: Qualitative descriptive study.

Setting: Nephrology program in an urban setting in Ontario, Canada.

Participants: Women with category G1–3 glomerular-based CKD between 18 and 40 years of age.

Methods: Focus group discussions guided by semi-structured interview questions. Qualitative content analysis was used to analyze interview transcripts.

Results: Eleven women participated in 3 separate focus group discussions. Participants described living life *through the lens of CKD*, which was the central theme unifying their experiences of *encountering CKD*, *re-encountering CKD*, and *getting on with life*. Life decisions significant to women like pursuing a career or motherhood were often colored by CKD, particularly by illness-related challenges, such as unsatisfactory health care support and the physical implications of chronic illness. The women used a variety of strategies including seeking information and relying on supportive people to mitigate these challenges. Although these strategies sometimes enabled them to balance the demands of illness with other life priorities, the lack of resources directed toward their unique needs as young women with CKD often caused them difficulties in managing their illness.

Limitations: Participants were from one nephrology program in an urban setting and were well educated overall. Their experiences may not be reflective of young women in other settings or from diverse backgrounds.

Conclusions: The women's emotional well-being and life choices were considerably influenced by CKD. Although the women were often able to manage challenges associated with CKD, they acknowledged the need to seek additional professional resources to complement their own self-identified strategies. As the women sought out these supports, they identified gaps in resources specific to women with CKD. This article summarizes recommendations from their perspective.

Trial Registration: Not applicable as this was a qualitative study.

Abrégé

Contexte: Les jeunes femmes seraient particulièrement vulnérables aux effets psychologiques négatifs de vivre avec l'insuffisance rénale chronique (IRC). À ce jour, on en sait peu sur l'expérience vécue par ces femmes et sur la façon dont elles gèrent la maladie.

Objectif: L'étude s'est penchée sur l'expérience de jeunes femmes vivant avec l'IRC.

Type d'étude: Étude qualitative et descriptive.

Cadre: Le programme de néphrologie d'un centre urbain en Ontario (Canada).

Sujets: Des femmes âgées de 18 à 40 ans atteintes d'IRC glomérulaire de catégorie G1 à G3.

Méthodologie: Discussions sous forme d'entrevues semi-structurées en groupes-échantillons et évaluation des transcriptions par l'analyse qualitative de contenu.

Résultats: Les participantes (n=11) ont pris part à trois groupes de discussion distincts. Elles ont décrit leur expérience à travers le prisme de l'IRC, le thème principal des discussions, et discuté des *premières manifestations de la maladie*, des *épisodes récurrents* et de la *poursuite de leur vie malgré la maladie*. Les décisions de vie importantes, notamment la maternité et la



poursuite d'une carrière, ont bien souvent été teintées par l'IRC et ses défis, en particulier par le manque de soutien en matière de soins de santé et par les conséquences physiques de vivre avec une maladie chronique. Des défis qu'elles ont tenté d'atténuer par diverses stratégies, notamment par la recherche d'information et d'appui de la part de personnes de confiance. Bien que ces stratégies leur ont permis à l'occasion de créer un équilibre entre les exigences de la maladie et les autres priorités de leur vie, le manque de ressources répondant à leurs besoins particuliers a rendu la gestion de la maladie plus difficile.

Limites: Les participantes provenaient d'un seul programme de néphrologie en milieu urbain et étaient dans l'ensemble bien éduquées. L'expérience décrite pourrait ne pas refléter celle de jeunes femmes issues de milieux et de contextes différents.

Conclusion: L'IRC a considérablement influencé les choix de vie et le bien-être psychologique des jeunes femmes questionnées. Bien qu'elles arrivent généralement à surmonter les défis liés à la maladie, les participantes, en cherchant des ressources pour appuyer leurs stratégies, ont constaté des lacunes dans les ressources professionnelles destinées spécifiquement aux jeunes femmes atteintes d'IRC. Cet article résume les recommandations de leur point de vue.

Enregistrement de l'essai: Ne s'applique pas puisqu'il s'agit d'une étude qualitative.

Keywords

young women, chronic kidney disease, focus groups, qualitative research

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What was known before

Chronic illness can be intrusive to the lives of young adults. In particular, young women may be faced with difficult life decisions and a compromised quality of life.

What this adds

Young women in our study described how living with chronic kidney disease (CKD) influenced the entirety of their daily lives, affecting their relationships, decision making, and overall emotional well-being. The experience of living with CKD created a lens that colored the emotions and decisions of these young women because of its persistent and pervasive nature. Specifically, the young women in our study described a number of challenges they experienced in living with CKD, as well as strategies they used to mitigate these challenges, and supports they envisioned would be helpful.

Introduction

The experience of living with a chronic progressive illness such as chronic kidney disease (CKD) can have a profound effect on how young adults view themselves. It has been observed that young adults with a chronic life-threatening illness are forced to face developmental milestones traditionally experienced by individuals who are chronologically much older, including facing one's own mortality.¹ This may

be particularly true for young adults with CKD who must not only come to terms with their diagnosis but may also experience a sense of loss and uncertainty about the future and their ability to meet life goals.^{2,3} Research demonstrates that younger individuals with CKD experience poorer emotional well-being compared with older individuals.⁴⁻⁶ This may be attributable to a perceived disparity between expectations young adults may have for quality of life contrasted with the realities of living with a severe chronic illness.⁶

Living with CKD may be especially challenging for young women who have to deal not only with the uncertainty of long-term outcomes but also with the frequently occurring adverse effects of treatment. Specifically, medications often used to treat kidney disease, such as cyclophosphamide and corticosteroids, have disturbing side effects such as infertility, weight gain, acne, striae, and hair loss or growth, which can dramatically alter a young woman's appearance and threaten her self-esteem. Coupled with the need for ongoing medical management, the experience with CKD can seriously interfere with age-appropriate developmental tasks and challenge future aspirations for the self.^{1,7} At a very real level, the immediate awareness of facing a life-threatening illness with potentially invasive treatments may severely restrict a young woman's ability to meet her life goals.

Young women living with chronic illness are often faced with challenges such as establishing long-term intimate relationships, the development of a career, and the dilemma of whether childbearing is feasible or desirable.¹ This is

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particularly true for young women with CKD. Due to the high risk of complications of pregnancy associated with kidney disease,⁸⁻¹³ young women are often advised against pregnancy. Furthermore, the medications now used as standard of care for blood pressure control and kidney protection (inhibitors of the renin-angiotensin system) cannot be used if a young woman becomes pregnant,^{14,15} and other commonly used immunosuppressive treatments can cause teratogenicity.¹⁶ Thus, many young women with CKD face difficult life decisions about pregnancy and motherhood, which can result in emotional turmoil, including feelings of failure, decisional conflict, fear, and grief.¹⁷

Given these unique experiences and the observation that women with CKD report poorer health-related quality of life than their male counterparts,^{4,6} it is not surprising that the health care community is beginning to focus on issues facing women with kidney disease.^{7,18} Despite this, limited attention has been directed toward understanding the experiences of women themselves, and in particular young women living with CKD not requiring renal replacement therapy. The objective of this study was to explore issues young women are dealing with in relation to living with CKD and to identify strategies women use in managing their illness or might find helpful to assist them in the future.

Methods

Research Ethics Board approval was obtained from the participating institutions. Women between the ages of 18 and 40 years with mild-to-moderate glomerular-based kidney disease (glomerular filtration rate > 30 mL/min/1.73m²) who were under the care of a nephrologist at an urban tertiary care center in Ontario, Canada, were invited to participate in a focus group discussion. Eligible women were sent a letter of information about the study by mail. Potential participants lived within the catchment area of the urban care center and were able to participate in group discussions in the hospital setting. Those interested in participating sent their contact information directly to the research team, who were not involved in their care. Research team members contacted interested women to answer any questions and arrange a mutually agreeable time for focus group discussions. Written informed consent was obtained from all participants prior to participating in the discussion and was verbally reviewed with the group at the beginning of the session.

A total of 11 women participated in 3 separate focus groups. Focus groups were held in a conference room at the hospital where the women received care. Group discussions were facilitated by 2 study investigators experienced in qualitative research (H.B. and E.M.) and were guided by a semi-structured interview guide (see Figure 1). Focus group questions were designed to elicit women's experiences of living with CKD, including challenges they had encountered, as well as strategies the women used to manage their

1. As young women living with kidney disease could you please tell us what your experiences have been?
2. Is there anything in particular that is working well for you in terms of living with your illness?
3. Could you tell us how you understand your illness and your perception of its impact on your health?
4. Have there been aspects of living with your illness that you have found particularly challenging (personal health, family, work, social activities, relationships) during this time? Can you explain?
5. What strategies/supports have you used to help you during this time?
6. What additional supports do you think would be helpful?
7. If you had to give advice to a young woman who was recently diagnosed with kidney disease, what kinds of things would you tell her?

Figure 1. Focus group discussion guide.

illness. Participants were also asked to comment on any resources or supports they would recommend. Focus groups lasted approximately 90 minutes. Field notes were kept by either the facilitators or a research coordinator.

Group sessions were audiotaped and transcribed verbatim. Conventional qualitative content analysis¹⁹ was used to analyze interview transcripts for relevant themes. The initial categorization scheme was developed by a study investigator (H.B.) and a summer student who independently reviewed each transcript line by line to identify salient categories. An iterative, consensus-building process was then undertaken until a comprehensive coding framework was developed. Transcripts were then manually coded with this final framework. Analysis was undertaken to identify key themes describing the women's experiences by having team members (H.B., E.M., S.P.) review coded data, searching for intersections between and among the categories, and engaging in a dialogue among team members to synthesize key ideas and themes. An overarching theme and several sub-themes were identified and supported with relevant quotes from various participants in each of the focus groups.

Results

Participant characteristics are summarized in Table 1. The median age for participants was 34 years, and more than half of the women were born in Canada (55%). The vast majority reported being in a relationship. The majority reported being employed (91%), and overall, the women were well educated, with most reporting some education beyond high school. The women reported being aware of their CKD for between 1 and 16.5 years with a median of 6.9 years.

Through the lens of CKD was uncovered as the central theme unifying the young women's experiences of *encountering CKD*, *re-encountering CKD*, and *getting on with life*. Participants described challenges they experienced in living

Table 1. Participant Characteristics (n = 11).

Variable	Range	Median	IQR
Age	19-38	34	30.5-37
Years of education	12-19	17	16.3-17.8
Years living with kidney disease	1-16.5	6.9	3.6-10.5
	Percentage (n)		
Employed at the time of study	91 (10)		
Married or in common-law relationships	81.8 (9)		
Living with spouse and children	45 (5)		
Place of birth			
Canada	55 (6)		
Asia/East Asia	18 (2)		
United Kingdom	18 (2)		
Europe/Eastern Europe	9 (1)		
Parent's place of birth (n = 14) ^a			
Canada	36 (5)		
Asia/East Asia	36 (5)		
United Kingdom	14 (2)		
Europe/Eastern Europe	14 (2)		
Language spoken at home			
English only	55 (6)		
English and other language	46 (4)		
Other language only	9 (1)		
Self-reported cause of CKD			
Primary	27.3 (3)		
Secondary	54.5 (6)		
Unknown	8.2 (2)		

Note. IQR = interquartile range; CKD = chronic kidney disease.

^aSome participants reported different birth places for each parent.

with CKD, as well as strategies they used to mitigate these challenges. In addition, the young women had suggestions for additional resources and supports they perceived would be helpful. Each of these findings will be discussed in detail below. When reporting findings, the source of each quote is identified by focus group (F) and participant number (P) in parentheses.

Through the Lens of CKD

Participants described living life *through the lens of CKD*, which encompassed a perspective that young women brought to their daily lives within the context of CKD. The experience of CKD affected their relationships, decision making, and overall emotional well-being and necessitated the development of a perspective that enabled women to continue living their lives while managing their illness. The experience of CKD colored the emotions and decisions of these young

women because of its pervasive nature and persistence over time. As one woman described, and other women affirmed, CKD became a “framework” for living life with this illness:

It becomes the underlying secret framework for how to live your life underneath . . . And you need to know, you need people to know that it's there for you and it's there all the time—that little secret thing that's going on that colors all your decisions and the way that you're doing things and it has implications for a huge spectrum of events in your life. (FG1; P2)

Participants described how they had once anticipated leading a normal life where they could live day-to-day fulfilling expected roles and aspirations. However, living with CKD challenged these expectations as they first encountered kidney disease and re-encountered it when faced with challenges related to living with a chronic illness. These challenges included physical, emotional, and psychosocial concerns, as well as perceived inadequacies in information and support (see Figure 2). The centrality of CKD to the women's lives varied because it required attention at critical points and demanded the adoption of new strategies to help manage these challenges such as seeking information, keeping healthy, and relying on supportive others. As this process unfolded, these women realized that the illness would inevitably influence day-to-day living and significant life decisions, which consequently evoked many difficult emotions. On the contrary, when challenges were mitigated or addressed, the women were better able to focus their attention on fulfilling their roles and ambitions, thus getting on with life.

Encountering CKD. Encountering kidney disease involved being diagnosed with a disease that was not generally well understood. Often, the women's experience was colored by preconceived notions about kidney disease, which raised concerns for some about death and the threat of dialysis or a kidney transplant:

When you're first diagnosed it does feel like a death sentence . . . I'm like “35% [kidney function], so I'm dying right? So what do I expect? How long do I have?” (FG1; P1)

In contrast, other women questioned the seriousness of kidney disease until they realized that it had significant implications for their lives:

. . . She [doctor] wanted to start me on medication and I remember me being like, “uh no,” . . . and she's like, “. . . Or we could wait until you need a kidney transplant,” and that's really when it hit me. (FG1; P4)

This response was partly a consequence of a general lack of understanding of kidney disease by society and by the young women themselves. There was a sense that “It's not like

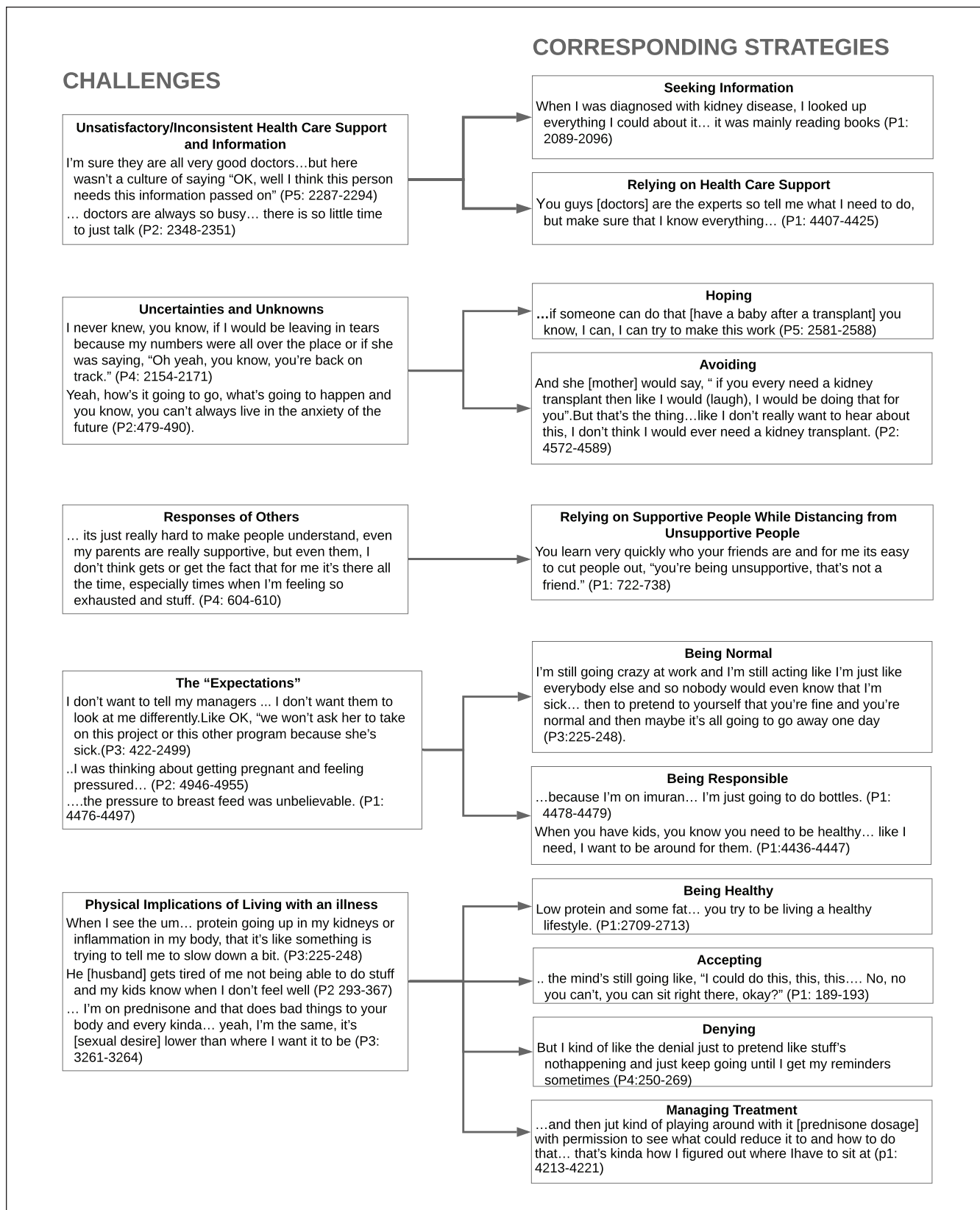


Figure 2. Challenges and corresponding strategies for young women living with CKD.
Note. CKD = chronic kidney disease.

kidney diseases are glamorous diseases . . . people aren't wearing ribbons and bands. It's not something that people intrinsically understand . . ." (FG1; P2).

Preconceived ideas about kidney disease often created feelings of fear and frustration, and the challenges these young women encountered after diagnosis, including uncertainties and unknowns about their current and future health, often put illness at the forefront of their lives. As they developed strategies, such as seeking information and relying on health care support to deal with emerging challenges, the young women were able to refocus on matters that were important to them and to get on with life. However, as illness-related challenges emerged or reoccurred, the women re-encountered CKD, pushing it into the forefront of their day-to-day lives.

Re-encountering CKD. Living with kidney disease involved realizing the chronicity of this illness and re-encountering CKD whenever challenges resurfaced and the women did not have sufficient strategies or resources to address these concerns. There was a tendency for illness to need attention because of the many challenges these women encountered (see Figure 2). Some challenges were shared, whereas some were unique to each woman. The challenges were not necessarily a direct result of the illness itself; some were the consequences of preexisting circumstances that influenced participants' illness experience. The challenges they faced were influenced by contextual factors that made the experiences of the women different from one another. These factors included the type and quality of social support they received, their past and present experiences with health care, and whether or not they had primary or secondary CKD.

Inconsistent information about kidney disease was a problem, as well as perceived unsatisfactory health care support. Uncertainties and unknowns regarding the nature of their illness and its effects were challenges which these women felt they had little control over, often creating negative emotions. Beliefs about kidney disease often created feelings of fear, as reflected by this participant: "And you know that the kidneys are going to be damaged again. That's scary, I find" (FG2; P3). In instances like these, the threat of kidney disease meant addressing it had to take priority over other matters. For example, one woman had to refocus on her health and steer away from her aspirations when "[doctors] say "I can't try, can't try [getting pregnant]" (FG3; P1).

The women re-encountered CKD partly due to the long-term implications of kidney disease. The physical implications of living with illness were experienced as CKD tested the women's energy levels, as well as their perceptions of self and their health. There was an apparent consensus that living with illness had physical implications not just on their reproductive potential but also on matters as simple as managing daily activities. For example, one woman felt she went from ". . . flying all the time and having that energy to all of a sudden having to slow down" (FG1; P1), and another

woman described "physically getting out of shape" (FG2; P4). Sometimes, circumstances permitted women to live their lives with illness in the background, such as when the illness was "asymptomatic," as one woman said, "until like other people here, I wanted to have a baby . . ." (FG2; P5).

Living with CKD challenged the expectations for personal roles and goals that most healthy young women often take for granted. The expectations these young women felt they had to fulfill were influenced by social pressure, as well as personal objectives to be productive young women. For example, CKD impeded career goals forcing one woman "to do as much travel as [she] can while [she] can . . . trying to make those life decisions about work . . ." (FG2; P1). A younger woman was concerned that her illness would also affect her decision about pursuing education:

I was in a pretty intense program at school, and you know, just all that. I've just always been on this sort of track three years at school . . . and that was my plan realizing that, I maybe [have] to take that a bit slower or modify that. (FG 1; P4)

Although a wide range of challenges provoked encounters and re-encounters with CKD, expectations for pregnancy and motherhood were concerns that predominated among these young women. For many, living with CKD challenged their hopes, ideas, and decisions about becoming and being a mother. For example, one woman questioned "what's the point to **be**, even" if she was unable to have a child because "one of the goals in [her] family and everywhere else is to have a child, to have a family . . ." (FG3; P2).

The women also described experiencing several emotions, such as frustration and depression, which were often triggered by the challenges they faced. Moreover, unsupportive responses from others often occurred because the people around these women did not comprehend their illness experience. For one woman, one source of frustration was "not knowing where to go and then going there and people not having the answers, necessarily" (FG 2; P5). For another woman, there were days when "nothing's going to make you better, make you happy, but you do have to go on" (FG 2; P3).

Getting on with life. Using various strategies and resources to manage illness-related challenges often enabled the women to temporarily shift their focus to the lives they envisioned as young women. This allowed them to prioritize roles and goals that were important to them as young women. These young women used a number of strategies to manage the challenges they experienced as a result of having CKD (see Figure 2). Some strategies were new and some were learned; some were active and some were passive. The strategies the women used were often directed at specific challenges. However, there were instances when a few women used certain strategies to deal with multiple challenges. For example, some women responded to the expectations and to the physical implications of living with illness by being responsible

Table 2. Suggested Resources.

Meaningful information for self and others	Individualized health care	A place for sharing and discussing experiences with others
Online support Information sheet	Dietary advice Counseling Multidisciplinary team	Support groups Mentoring Forums

about their health. A few women found it helpful to try “being normal” and “being responsible” when presented with personal and social pressures to fulfill certain expectations. Several women also perceived a need to be responsible for others (eg, children), which motivated them to try being healthy. Being healthy and managing treatment were among the strategies women used in responding to the physical consequences of their illness. For example, managing treatment to deal with the physical implications of illness helped one woman “[work] towards hopefully maybe having some children at some point . . . (FG 1; P3) and another woman to “[go] to university” (FG 2; P3).

While some young women described “acceptance” as an important strategy they used to manage the physical implications of their illness, others described initially denying the implications of their illness until they experienced “reminders.” Similarly, “avoiding” was a strategy used by a few women particularly when dealing with the unpredictable and frequently intrusive nature of their illness. On the contrary, some women described remaining positive and hoping. The women felt optimistic when preconceived notions about kidney disease or the challenges they faced were resolved and enabled them to maintain hope. For instance, upon seeing other women in the focus group who were able to have children, one woman expressed, “oh that is possible . . .” (FG2; P1).

Many women relied on supportive people who they could talk to about their illness, but distanced themselves from unsupportive people. A few women also described how they relied on health care support for both information and advice. It is important to note that some participants experienced positive experiences in their dealings with the health care system. For them, health care support sometimes presented as a strategy rather than as a challenge. Positive experiences involved coordinated health care services, timely follow-ups, communication and time for asking and answering questions, as well as care and support that considered the context of their lives as young women with CKD:

and everybody always- were just were really concerned and spent time with me and explained and whatever, so it was really a partnership in making sure that I stayed healthy . . . I liked how they coordinated and they’d be like, “ok, you’re going to have to see three doctors, but let’s just poke you once.” So then I would bring the requisition to everybody and then they would fill out one form so that I’m [not] going getting blood work every, you know, day . . . (FG3; P1)

What Would Help: Suggested Resources

In response to questions about what would help them in living with CKD, the women suggested several resources to complement the strategies they currently used. These recommendations are summarized in Table 2.

Meaningful information for self and others was recommended because clear information on CKD and its management was currently not available to them. One woman explained that “having information would be helpful and useful . . .it empowers you . . . And also, like understanding it right away in part I think takes away part of the fear of what it is” (FG2; P5).

The women also desired individualized health care. Specifically, they wanted support from “somebody who is focused on your disease but also your life. . .” (FG2; P4). This included a holistic focus on women’s experiences and needs:

Yeah there’s a real missing component, lifestyle, counseling, all those psychosocial bits and I think because the medical system doesn’t operate so much on as a team- like it does in certain aspects but not globally, it’s very, like you go and get it fixed. And that’s it. And they’re good at fixing you but everything else is ignored. So I think there has to be more of a team . . . like you know, social work, nursing, dietitian . . . that would be really helpful. (FG2; P4)

Finally, the women suggested that a place for sharing and discussing experiences with others would be valuable. For example, one woman believed that “it’s another way that having a web forum would be an important network as well because then you know, people are on the same page” (FG 2; P4). Another woman recommended that it would be particularly helpful if it is “somewhere people can go and discuss it when they’re not at end stage, when they’re just living and managing to keep them living” (FG 1; P2).

Discussion

Findings uncovered in this focus group study suggest that CKD colors young women’s day-to-day experiences, life choices, and emotional responses as they experience illness-related challenges and develop strategies to help mitigate these. The challenges reported by the young women with CKD in our study and their emotional and strategic responses are similar to

those reported with CKD²⁰ and other chronic illnesses. For example, physical challenges related to changes in energy levels and self and body image were reported by women in studies of individuals with other chronic illnesses.^{21,22} Similar to our findings, individuals from these 2 studies also expressed feelings of fear and frustration in addition to a variety of other emotions triggered by their illness experience. In addition, optimism and hope are strategies identified in the literature as commonly used by those living with chronic illness²¹ and are similar to coping strategies reported by individuals with CKD.^{20,23}

Young women in our study described how the impact of CKD on their lives shifted as they were able to manage illness-related challenges. Shifting priorities and perspectives have also been described in other chronic illnesses.^{22,24,25} For example, individuals with chronic illness often become absorbed in their illness experience because of the burden and loss associated with illness.²⁵ Several factors may contribute to the shifts in perspective, including personal and social identities, as well as relationships within an individual's social context that impact one's illness experience by navigating his or her attention.²⁵ In this study, the young women with CKD described their families, school and work, as well as their social roles as features of their social context that influenced and were influenced by their illness experience.

One social role impacted by chronic illness that was of utmost significance to participants in this study was that of becoming and being a mother. Benyamini²⁶ suggests that women have unique health concerns; in particular, "threats to the attainment of parenthood seem to be more serious among women." This suggestion resonates with the need to fulfill the goal of becoming a mother expressed by the majority of the young women in our study. As one participant put it, "what is the point to be . . ." if she was unable to become a mother, implying how kidney disease made her question the purpose and meaning of her life. It appears that the ability to be a mother was central to the identity of the majority of young women with CKD who participated in this study. Similar findings were uncovered in a recent synthesis of qualitative research exploring the perspective of women with CKD on pregnancy.¹⁷ Among the priorities and concerns identified in this review were aspirations for motherhood, as well as grief, fear, and concerns about not meeting expectations and letting people down.¹⁷

The young women in this study also cited concerns regarding the impact of their illness on their ability to function, for instance, at school and at work. Similar findings have been reported by others. For example, in a study by Caress et al²⁷ of 405 renal patients, younger individuals cited interruption of work by illness as a problem more than older individuals did. More recently, qualitative researchers have highlighted disruptions in educational achievements, fears about finding a job, and concerns about not being able to

meet life goals as serious psychosocial issues facing young adults with CKD and kidney failure.^{2,3} These findings highlight the importance of helping young people with CKD develop strategies and supports to navigate academic and employment opportunities.

Although the participants in this study may share similar experiences with young women who have other types of chronic disease, perhaps what makes managing kidney disease different are the signs not readily visible, such as proteinuria and hypertension, which are difficult to accept as grounds for having to maneuver life's course. An earlier study confirmed that individuals with early CKD have a difficult time acknowledging their illness and its management because of the absence of symptoms that confirmed their diagnosis of kidney disease.²⁸ In our study, the challenges the participants experienced were often exacerbated by the lack of information available on kidney disease and the inadequate health care support they received. A study by Sakraida and Robinson²⁹ found that individuals with both diabetes and CKD sought useful resources, but had difficulty obtaining satisfactory support and information from their health care providers. As one woman in our study expressed, kidney disease is different because it is not a "glamorous disease" and one that people usually don't know about. There is an apparent lack of awareness about CKD and a lack of resources and supports available for the specific needs of the young women in this study. Participants in a study by Tong et al²⁰ reported feeling isolated because of the lack of public awareness on CKD, which influenced their employment and social interactions.

The burden of illness on age and gender-based roles, goals, and expectations of the young women in this study, coupled with the nature of kidney disease and the current lack of resources available for them, makes their illness experience somewhat unique in these aspects. Although the impact of various chronic illnesses on perinatal and preconception care such as the choice of treatment has been documented, the needs and management of young women vary depending on their disease.^{30,31} There is a need for nephrology health professionals to assess the information requirements of young women on an ongoing basis and to devise opportunities to provide information and support to address women's unique needs. This should include consideration of a young woman's personal, professional, and academic goals, which may be best addressed by a multidisciplinary team. The young women with CKD in this study recommended a place for sharing concerns, reliable information on CKD, and individualized health care as resources that would assist them in balancing their illness and life priorities. Nephrology care providers could assist women in identifying credible sources of information specific to their unique concerns, as well as helping to interpret such information for themselves and others. On a broader level, health care leaders and policy makers should explore options to address

health care system barriers faced by young women and work on addressing the need for public education and awareness about CKD.

Limitations

The young women who participated in this study were from one nephrology practice in an urban center in Ontario and were recruited by mail. Furthermore, our participants were relatively well educated and volunteered to participate in a focus group discussion. Thus, their experiences and perspectives may not be reflective of those living in other parts of Canada or in more rural settings, or those with varying educational backgrounds. Future research could explore the experience of young women from different backgrounds and in various settings. In addition, given that some young women may not be comfortable in a group setting, other methods of data collection, such as individual interviews, could be used in the future to elicit diverse perspectives.

Conclusions

Young women with CKD can experience a number of physical, emotional, and psychosocial challenges that can significantly interfere with their ability to fulfill social roles and meet their personal life goals. By recognizing these challenges and supporting women's efforts to mitigate or manage them, health care providers can help position them to be successful in meeting their goals. Furthermore, providing information and support individualized to young women's unique concerns and needs may assist them in managing their illness and maintaining a sense of balance in their lives.

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Ethics Approval and Consent to Participate

This study was approved by the Research Ethics Boards at Ryerson University and Sunnybrook Health Sciences Centre. All participants provided informed consent.

Consent for Publication

All authors consented to publication of this work.

Availability of Data and Materials

Data and materials are not publicly available.

Declaration of Conflicting Interests

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References

1. Rancour P. Catapulting through life stages. When younger adults are diagnosed with life-threatening illnesses. *J Psychosoc Nurs Ment Health Serv.* 2002;40(2):32-37.
2. Bailey PK, Hamilton AJ, Clissold RL, et al. Young adults' perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies. *BMJ Open.* 2018;8:e019926.
3. Tong A, Henning P, Wong G, et al. Experiences and perspectives of adolescents and young adults with advanced CKD. *Am J Kidney Dis.* 2013;61(3):375-384.
4. Mujais SK, Story K, Brouillette J, et al. Health-related quality of life in CKD Patients: correlates and evolution over time. *Clin J Am Soc Nephrol.* 2009;4(8):1293-1301.
5. Porter AC, Lash JP, Xie D, et al. Predictors and outcomes of health-related quality of life in adults with CKD. *Clin J Am Soc Nephrol.* 2016;11:1154-1162.
6. Zimbudzi E, Lo C, Ranasinha S, et al. Predictors of health-related quality of life in patients with co-morbid diabetes and chronic kidney disease. *PLoS ONE.* 2016;11(12):e0168491.
7. McLean R, Shirazian S. Women and kidney disease: a Twitter conversation for one and all. *Kidney Int Rep.* 2018;3(4):767-768.
8. Zhang JJ, Ma XX, Hao L, Liu L-J, Lv J-C, Zhang H. A systematic review and meta-analysis of outcomes of pregnancy in CKD and CKD outcomes in pregnancy. *Clin J Am Soc Nephrol.* 2015;10:1964-1978.
9. Abe S. An overview of pregnancy in women with underlying renal disease. *Am J Kidney Dis.* 1991;17(2):112-115.
10. Nelson DB. Minimal change glomerulopathy in pregnancy. *Nephrol Nurs J.* 2003;30(1):45-50, 55-56.
11. Rahman FZ, Rahman J, Al-Suleiman SA, Rahman MS. Pregnancy outcome in lupus nephropathy. *Arch Gynecol Obstet.* 2005;271(3):222-226.
12. Purdy LP, Hantsch CE, Molitch ME, et al. Effect of pregnancy on renal function in patients with moderate-to-severe diabetic renal insufficiency. *Diabetes Care.* 1996;19(10):1067-1074.
13. Piccoli GB, Cabiddu G, Attini R, et al. Risk of adverse pregnancy outcomes in women with CKD. *J Am Soc Nephrol.* 2015;26(8):2011-2022.
14. Boix E, Zapater P, Picó A, Moreno O. Teratogenicity with angiotensin II receptor antagonists in pregnancy. *J Endocrinol Invest.* 2005;28(11):1029-1031.
15. Diav-Citrin O, Shechtman S, Halberstadt Y, et al. Pregnancy outcome after in utero exposure to angiotensin converting enzyme inhibitors or angiotensin receptor blockers. *Reprod Toxicol.* 2011;31:540-545.

16. Hoeltzenbein M, Elefant E, Vial T, et al. Teratogenicity of mycophenolate confirmed in a prospective study of the European Network of Teratology Information Services. *Am J Med Genet A*. 2012;158A(3):588-596.
17. Tong A, Jesudason S, Craig JC, Winkelmayr WC. Perspectives on pregnancy in women with chronic kidney disease: systematic review of qualitative studies. *Nephrol Dial Transplant*. 2015;30(4):652-661.
18. Piccoli GB, Alrukhaimi M, Liu ZH, Zakharova E, Levin A; for World Kidney Day Steering Committee. Women and kidney disease: reflections on World Kidney Day 2018. *J Ren Care*. 2018;44:3-11.
19. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
20. Tong A, Sainsbury P, Chadban S, et al. Patients' experiences and perspectives of living with CKD. *Am J Kidney Dis*. 2009;53(4):689-700.
21. Sullivan T, Weinert C, Cudney S. Management of chronic illness: voices of rural women. *J Adv Nurs*. 2003;44(6):566-574.
22. Whittemore R, Dixon J. Chronic illness: the process of integration. *J Clin Nurs*. 2008;17(7B):177-187.
23. Harwood L, Wilson B, Locking-Cusolito H, Sontrop J, Spittal J. Stressors and coping in individuals with chronic kidney disease. *Nephrol Nurs J*. 2009;36(3):265-276, 301.
24. Kralik D. The quest for ordinariness: transition experienced by midlife women living with chronic illness. *J Adv Nurs*. 2002;39(2):146-154.
25. Paterson BL. The shifting perspectives model of chronic illness. *J Nurs Scholars*. 2001;33:21-26.
26. Benyamini Y. Stress and coping with women's health issues. *Eur Psychol*. 2009;14:63-71.
27. Cares AL, Luker KA, Owens RG. A descriptive study of meaning of illness in chronic renal disease. *J Adv Nurs*. 2001;33(6):716-727.
28. Costantini L, Beanlands H, McCay E, Cattran D, Hladunewich M, Francis D. The self-management experience of people with mild to moderate chronic kidney disease. *Nephrol Nurs J*. 2008;35(2):147-155; quiz 156.
29. Sakrinda TJ, Robinson MV. Health literacy self-management by patients with type 2 diabetes and stage 3 chronic kidney disease. *West J Nurs Res*. 2009;31(5):627-647.
30. Misra DP, Grason H, Weisman C. An intersection of women's and perinatal health: the role of chronic conditions. *Womens Health Issues*. 2000;10(5):256-267.
31. Dunlop AL, Jack BW, Bottalico JN, et al. The clinical content of preconception care: women with chronic medical conditions. *Am J Obstet Gynecol*. 2008;199 (6 suppl 2):S310-S327.