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Interventions for and experiences of shared decision-making underpinning reproductive health, family planning options and pregnancy for women with or at high risk of kidney disease: a systematic review and qualitative framework synthesis

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ABSTRACT

Objective To determine intervention effects and synthesise qualitative research that explored women with or at high risk of kidney disease experiences of shared decision-making in relation to their reproductive health, family planning options and pregnancy.

Design A systematic review of interventions and a qualitative evidence synthesis.

Data sources We searched Cochrane, CINAHL, MEDLINE, Scopus, ProQuest, Elsevier, PubMed, ScienceDirect and Web of Science.

Eligibility criteria Shared decision-making interventions and qualitative studies related to reproductive health involving women with or at high risk of kidney disease published from 1980 until January 2021 in English (clinical settings, global perspective).

Data extraction and synthesis Titles were screened against the inclusion criteria and full-text articles were reviewed by the whole team. Framework synthesis was undertaken.

Results We screened 1898 studies. No evidence-based interventions were identified. 18 qualitative studies were included, 11 kidney disease-specific studies and 7 where kidney disease was a common comorbidity. Women frequently felt unprepared and uninformed about their reproductive options. Conversations with healthcare professionals were commonly described as frustrating and unhelpful, often due to a perceived loss of autonomy and a mismatch in preferences and life goals. Examples of shared decision-making were rare. Kidney disease exacerbated societal expectations of traditional gender roles (eg, wife, mother, carer) including capability to have children and associated factors, for example, parenting, (sexual) relationships, body image and independent living (including financial barriers to starting a family). Local interventions were limited to types of counselling. A new health system model was developed to support new interventions.

Conclusion There is a clear need to establish new interventions, test those already in development and develop new clinical guidance for the management of women with or at high risk of kidney disease in relation to their reproductive health, including options to preserve fertility earlier. Other health conditions with established personalised reproductive care packages, for example, cancer, could be used to benchmark kidney practice alongside the new model developed here.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The majority of included studies had minor or no methodological limitations.
⇒ We were able to include the perspectives of 411 women who had kidney disease or were at high risk of developing comorbid kidney disease.
⇒ We did not find any evidence-based interventions to support shared decision-making.
⇒ Perspectives of men and healthcare professionals were not included.
⇒ Studies reporting solely quantitative data were excluded.

INTRODUCTION

Women have unique healthcare needs including their reproductive health.[1 2] Chronic kidney disease (CKD) affects at least 195 million women worldwide and evidence suggests is the eighth leading cause of death in women globally.[3] CKD affects more women (14%) than men (12%).[4] Women are also more affected by health inequalities (eg, access to education, work, independent living, feeling safe) and the social and economic factors contributing to poor health (eg, deprivation, access to services) that being a woman is now considered a risk factor for developing CKD.[5–9]

CKD is classed by stages, from stage 1 mild to stage 5 kidney failure. Once a person reaches kidney failure they will need a kidney replacement treatment such as dialysis or transplant to live.[10]

A pregnancy in addition to being a risk factor for kidney disease[11 12] can also lead to loss of kidney function and even kidney failure in people with CKD.[13] Additional increased risks for women with CKD include, proteinuria, hypertension, decreased life expectancy, preterm birth, fetal growth restriction and pregnancy loss.[14 15] CKD is also a common comorbid condition of which general health management guidelines are critically lacking.[16] Certain types of kidney disease are also inherited and will pose additional risks, complications and burdens to infants through to adulthood, for example, most children on kidney replacement therapy will have an inherited kidney disease.[17] A woman can get pregnant at any stage of being high risk for or having CKD, while on dialysis or with a kidney transplant. Clinical or lay guidance on better, best timing to have a pregnancy are not straightforward.[18] Another potentially complicating factor is that women generally are having children later in life due to prioritising other life factors, for example, career and/or the rising costs of living including housing and childcare.[19] For these women starting family planning in later life poses heightened risks for their pregnancy, progressive kidney disease and fetal/neonatal well-being. For these reasons early discussions about reproductive choices are recommended allowing for carefully planned family planning with a multidisciplinary team who will consider a range of factors such as the risk of developing CKD, stage of CKD, general health and the women's preferences and future life goals.[20]

Shared decision-making

Shared decision-making is a globally recognised practice with interventions designed to empower patients by becoming more informed and involved in decisions which impact them and their clinical care.[21] The shift in practice is widely associated with undoing and removing medical practices associated with paternalistic dominance.[22] The fundamentals of shared decision-making include respecting patient autonomy, open dialogue which includes delivery of evidence-based information and communication of patient preferences. The goal is to work towards a decision that involves active participation of both health professionals and the patient. Evidence-based decision-making is the combination of clinical expertise, research evidence and patient preferences.[23] Shared decision-making has been widely implemented in long-term and complex conditions where more than one treatment is available, and is increasingly being adapted across more complex clinical settings, for example, intensive care.[24 25] The assumption is that shared decision-making is operating as business as usual and supporting both professionals and patients to make more informed decisions, improving patient outcomes and experiences of care. It is also linked to longer-term plans to deliver universal personalised care.[26]

A previous systematic review on this topic had a narrower focus on reproductive planning and pregnancy itself and included studies that were published up until April 2014.[27] The aims of the present systematic review and qualitative evidence synthesis was to determine how effective shared decision-making interventions are between healthcare professionals and patients when discussing pregnancy options. The second aim was to elicit and synthesise what women's experiences are of living with high risk of or CKD, pregnancy, family planning or deciding to have children. In order to do this, we undertook a systematic review of interventions to support women with or at high risk of kidney disease (including shared decision-making aids), and a qualitative thematic synthesis of qualitative studies exploring women's experiences of shared decision-making in relation to their reproductive health. We wanted the outcomes and findings from the review and synthesis to help healthcare professionals better support women in their decision-making to reflect both the women's perspectives and their medical needs.

METHODS

We used PICO for the systematic review of intervention effects and SPICE for the qualitative evidence synthesis and to set the context. Box 1 describes these in detail and the searching and screening processes.

Data extraction and synthesis

Systematic review of intervention effects

We planned to, if possible, undertake a meta-analysis following methods outlined in the Cochrane handbook of intervention reviews. If studies were not amenable to meta-analysis, we would have undertaken a synthesis without meta-analysis.

Qualitative evidence synthesis

Key study characteristics were extracted into a table and included, authors, date, study design, setting, aims, sample, participant demographics and key findings (online supplemental file 3, Key study characteristics). We used the five stage framework synthesis method (familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation). One author (BN) initially read and re-read the papers and identified an initial coding framework of codes derived from the papers that enabled extraction of relevant data to address the review questions and phenomena of interest, and to begin to translate these data into themes.[28] We used NVivo Pro V.11 to organise and code data.[29 30] LML then reviewed the codes alongside the coded data and began to assemble the codes into an overall narrative of women's experiences of living with CKD, pregnancy and shared decision-making. Initial coding of all papers was carried out by one author (BN) and reviewed and agreed by LML and JN and any discrepancies were resolved

Box 1 PICO and SPICE tools

Systematic review of intervention effects

PICO

Population—women with or at high risk of chronic kidney disease (CKD) of childbearing age. Not restricted to UK population.

Intervention—decision-making interventions for women regarding pregnancy or not. Interventions include patient decision aids, decision coaching and question prompt lists.

Comparison—women who have not used shared decision-making interventions in their reproductive decision-making (routine practice).

Outcomes of interest—how confident women feel in their decisions; all other outcomes measured.

The review question was:

What are the benefits of shared decision-making interventions for women with or at high risk of kidney disease who may be considering pregnancy, or who are currently pregnant, or who already have children?

Qualitative evidence synthesis

SPICE

Setting—global perspective.

Perspective—women with or at high risk of CKD.

Phenomenon of Interest—women's views and experiences of considering becoming pregnant, are currently pregnant, have been pregnant, have not chosen to have children or contemplating a second pregnancy. Views and experiences of individual decision-making, shared decision-making and shared decision-making interventions; acceptability and feasibility of shared decision-making interventions and implementation issues.

Comparison—comparing, eg, the views and experiences of women with CKD and those who have been transplanted; older women versus younger women, the perspectives of Black Asian Minority Ethnic (BAME) women with non-BAME women.

Evaluation—qualitative studies reporting attitudes, perceptions and experiences of shared decision-making or individual decision-making and actual decisions and their rationale. How women reflect on, make sense of and conceptualise their decisions over time.

The review question was:

What are women's views and experiences of living with a high risk of or CKD, shared decision-making, family planning and pregnancy?

Inclusion criteria

We used PICO to set the inclusion criteria specifically for interventions and SPICE to set the inclusion criteria for qualitative studies. Although frameworks continue to evolve we felt that the outlines provided by PICO and SPICE were sufficient to undertake the review.[61–63] Qualitative studies that had a qualitative method of data collection and analysis, including grey literature studies and PhD theses published in English. Studies of women with or at high risk of kidney disease. We included a sample of studies of women with comorbid conditions with high risk of kidney disease as recommendations do include discussions of family planning earlier but for many women (including our patient advisors—described in the patient and public involvement section), discussions about reproductive options after a diagnosis of established kidney disease is perceived as too late and care is often too focused on disease management.

Free-text data extracted from questionnaires had to be analysed with a qualitative method. Where studies included the perspectives of men and women, we only included the perspectives of women and only added the women to the total sample of participants in the synthesis.

We included studies from 1980 onwards as we wanted to map if women's experiences had changed over time.

Continued

Box 1 Continued

Exclusion criteria

Studies not written in English, published before 1980, studies about the perspectives of men or partners or healthcare professionals.

Searches

Electronic literature searching of the Cochrane database of trials, CINAHL, MEDLINE, Scopus, ProQuest, Elsevier, PubMed, ScienceDirect and Web of Science. Search terms included various names for CKD, pregnancy, intervention and/or qualitative methods (online supplemental file 1). Backward chaining through included studies and cluster searching of key researchers was undertaken. Experts were contacted and we also had a local repository of studies of interest that were screened.

Initial screening

Titles were screened against the inclusion criteria and duplicates removed in Mendeley.[29] Full-text articles remaining were reviewed by the three authors and the list of papers to be included was reached via discussion and whole team consensus (figure 2, Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram). We screened three PhDs and a further four papers where kidney disease was a highly likely comorbid condition.

Quality appraisal

Systematic review of intervention effects.

We planned to use the Cochrane risk of bias tool.

Qualitative evidence synthesis.

We used the Critical Appraisal Skills Programme qualitative checklist (online supplemental file 2) to assess methodological limitations of included studies. Following this appraisal, we decided to include all 18 studies to build an understanding of the phenomena of interest.

through weekly team meetings, discussion and rechecks of the primary data. Codes were reviewed again by LML to check for similarities and patterns and grouped into descriptive themes and subthemes, presented as a narrative and complementary table. Mapping and charting of emerging findings and the relationships between findings was undertaken to visualise, further interpret and agree findings. The aim was to illustrate patterns and tendencies across the papers but also were discrepancies or anomalies may apply and to articulate why this might be the case. We looked for common issues for women with or at high risk of kidney disease as well as developing findings specific to each group. We explored if women's experiences changed over time. This process was overseen by JN. Finally, the evidence was developed into an analytic theme by JN and LML with the intention of moving away from synthesising descriptive level findings at primary study level towards a (re)interpretation and transformation of evidence in relation to the review questions. We report this review using the ENTREQ guidelines (online supplemental file 4).[31]

Confidence in review findings

For the intervention effect review, we planned to apply GRADE.[32]

For the qualitative evidence synthesis, we applied GRADE-CERQual, an approach to better assess and

Table 1 Summary review of findings

	Studies contributing to the review findings with women with kidney disease	Studies contributing to the review findings with women at high risk of kidney disease	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Theme 1: For women with or at high risk of kidney disease societal expectations of traditional gender roles especially family planning were exasperated.								
Being high risk of or living with kidney disease, impacted on expectations of gender roles including motherhood negatively. This was especially evident in minority populations and in areas where women's rights were (significantly) underdeveloped.	5 papers: Nazario *et al*, Beanlands *et al*,[36] Tong *et al*,[27] Fatani,[28] Crowley-Matoka[40]	1 paper: Phuti *et al*[38]	No or very minor concerns about methodological limitations	Very minor concerns about coherence	Very minor concerns about adequacy	No concerns about relevance	High level of confidence	Six studies with no or very minor methodological limitations. Studies had rich data covering a global population, high, middle and low income with high number of female participants and depth data on experiences over women's lifetime.
For women with or at high risk of kidney disease, physical appearances such as scarring, weight gain/loss and multiple physical changes caused by medications (steroid use in particular which can change the shape of facial features and cause weight gain) and treatments de-feminised women. This was perceived as a significant burden for finding a partner, building stable relationships and the ability to have and mother children.	6 papers: Fatani,[39] Beanlands *et al*,[36] Crowley-Matoka,[40] Schipper *et al*,[41] Kerklaan *et al*,[42] Tong *et al*[37]	2 papers: Phuti *et al*,[38] Kazmerski *et al*[43]	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	No concerns about relevance	High level of confidence	Eight studies with high number of participants discussing treatment burden representing a global population from 2005 to 2020. No or very minor concerns for methodological limitations, coherence, adequacy and relevance.
For women with or at high risk of kidney disease, future planning including, independent living, education, career, finding a partnership, and prospects of having children particularly impacted younger women.	3 papers: Kerklaan *et al*,[42] Fatani,[39] Beanlands *et al*[36]	1 paper Kazmerski *et al*[43]	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	Very minor concerns about relevance	High level of confidence	Four studies explored younger perspectives, two studies explored the perspectives of men and women but only women's views were extracted. No or very minor concerns for methodological limitations, coherence, adequacy and relevance.
Living with or at high risk of kidney disease increased the financial burden for women and created various unmet support service needs and this negatively impacted on women's perception of capacity to have and raise a child.	3 papers: Kerklaan *et al*,[42] Fatani[39] Hollingsworth	2 papers Kazmerski *et al*,[43] Corbin[45]	No or very minor concerns about methodological limitations	Moderate concerns about coherence	Moderate concerns about adequacy	Moderate concerns about relevance	Moderate level of confidence	Moderate concerns about coherence, adequacy and relevance. Although discussed, none of the studies specifically set out to address impacts of financial and (as a consequence wider) unmet need. One study (Hollingsworth) reported on only one participant, and one study (Corbin) had a focus on clinical management. No or very minor concerns for methodological limitations.
Theme 2: For women with or at high risk of kidney disease, a perceived loss of autonomy negatively impacted all aspects of life but particularly reproductive discussions, pregnancies and family life.								

Continued

Table 1 Continued

	Studies contributing to the review findings with women with kidney disease	Studies contributing to the review findings with women at high risk of kidney disease	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Women reported that their needs were either not heard or taken seriously enough when trying to discuss their reproductive health needs with healthcare professionals including doctors and wider care services. Women felt judged at their desires to have children (by healthcare professionals, friends, family members and society) and that options were either taken away or never presented.	3 papers: Kurz,[46] Tong *et al*,[27] Wiles *et al*[47]	5 papers: Corbin,[45] Evans, Kazmerski *et al*,[43] Phuti *et al*, Thomas[49]	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	No concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence, adequacy and relevance. Studies discussed women's experiences in clinical and social settings and represented a global population including women from high income and deprived backgrounds and developed and underdeveloped healthcare systems.
Theme 3: What women with or at high risk of kidney disease wanted in their pregnancy planning and pregnancy care did not always match with what the professionals wanted and this led to negative experiences across their reproductive health pathways.								
Women with or at high risk of kidney disease consistently expressed a desire to have a 'normal' pregnancy and experience 'normalcy' post pregnancy in terms of wider care and support and motherhood, this included acknowledging their individual circumstances, preferences for having children (or not, and by what means) and ways to map this alongside the progression of their kidney disease and expected (changes) to treatment.	5 papers: Clarke *et al*,[50] Crowley-Matoka,[40] Kerklaan *et al*,[42] Beanlands *et al*,[36] Schipper *et al* [41]	3 papers: Evans, Kazmerski *et al*,[43] Thomas[49]	No or very minor concerns about methodological limitations	Very minor concerns about coherence	No concerns about adequacy	No concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence, adequacy and relevance. Studies focused on risk and risk management and women's experiences of this during pregnancy and had high numbers of participants from 2005 to 2020.
Women with or at high risk of kidney disease cited personalised care and support as key in having a positive pregnancy experience but frequently reported unmet need in post pregnancy care and psycho/social support.	6 papers: Beanlands *et al*,[36] Kurz,[46] Schipper *et al*,[41] Kerklaan *et al*,[42] Tong *et al*,[37] Wiles *et al*[47]	5 papers: Corbin,[45] Evans, Chuang *et al*,[51] Thomas,[49] Phuti *et al*[38]	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	No concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence, adequacy and relevance. The finding was close to the phenomena of interest in each study. Studies represented a global population from 1987 to 2020.
Transplant recipients had more complex needs in terms of thinking about potentially sacrificing their (new) kidney, and guilt for risking their 'donor sacrifice' despite longing for a child. Some women on the transplant list were concerned they would be removed from the list for wanting or planning a pregnancy.	5 papers: Crowley-Matoka,[40] Hollingsworth, Kerklaan *et al*,[42] Kurz,[46] Tong *et al*[27]		No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	Moderate concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence, adequacy and relevance. Three studies had a specific focus on outcomes post-transplant (one included all organs not just kidneys). One study focused on younger people (who were more likely to have transplants) and one had a general focus on women and kidney disease. There were high number of women participants and represented a global audience.

Continued

Table 1 Continued

	Studies contributing to the review findings with women with kidney disease	Studies contributing to the review findings with women at high risk of kidney disease	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
For women with or at high risk of kidney disease, factors associated with a high-risk pregnancy (eg, hospital appointments, early termination, onset of pre-eclampsia or potentially life-threatening health deterioration) were frequently discussed by doctors but women were left on their own to come to decisions. Women felt anxious from the outset about the need for increased monitoring and having a 'high risk' pregnancy. This was more likely if women had a previous negative pregnancy experience and/or outcome.	5 papers: Beanlands *et al*,[36] Clarke *et al*,[50] Hollingsworth,[27] [41]Schipper *et al*,[41] Tong *et al*[27]	4 papers: Chuang *et al*,[51] Corbin,[45] Evans, Thomas[49]	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	No concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence, adequacy and relevance. Nine studies were included and had high number of female participants representing a global population, many of whom had more than one pregnancy.
Theme 4: For women with or at high risk of kidney disease, the lack of personalised care in particular understanding women's preferences and life goals in relation to reproductive health meant that shared decision-making either never happened or was unhelpful.								
Some women with kidney disease felt that there was an urgency to have a pregnancy. Timing was presented as critical during consultations and many women felt that doctors were against a pregnancy even before starting discussions.	3 papers: Hollingsworth, Kerklaan *et al*,[42] Tong *et al*[27]		No or very minor concerns about methodological limitations	Moderate concerns about coherence	Moderate concerns about adequacy	No concerns about relevance	Moderate level of confidence	Moderate concerns about coherence and adequacy. Three studies representing high-income countries. One study followed only one participant and only one study had a focus on pre-conception counselling. No or minor concerns for methodological limitations.
For women with or at high risk of kidney disease, the lack of access to and balanced personalised information sometimes resulted in higher risk behaviours, eg, unplanned pregnancy. Women frequently wanted more information around inherited conditions and the risk of passing on their kidney disease as well as general lifestyle adjustments including diet which may support a healthy pregnancy.	4 papers Schipper *et al*,[41] Tong *et al*,[27] Kerklaan *et al*,[42] Clarke *et al*[50]	5 papers: Kazmerski *et al*, Chuang *et al*, Thomas, Evans, Lippe *et al*	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	No concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence, adequacy and relevance. Studies included a specific focus on pregnancy and pregnancy planning and represented women with multiple comorbid conditions.

Continued

Table 1 Continued

	Studies contributing to the review findings with women with kidney disease	Studies contributing to the review findings with women at high risk of kidney disease	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Some women with or at high risk of kidney disease associated their experiences of planning for pregnancy with a battle. Some felt their rights to have a child were not heard or listened to. Some actively sought out additional information to contradict their clinical team's advice. Many women felt that they knew more about what their body were capable of and felt that their pregnancy was an opportunity to prove their doctors wrong.	3 papers: Hollingsworth, Kurz,[46] Tong *et al*[27]	3 papers: Corbin,[45] Evans,[38] Phuti *et al*	No or very minor concerns about methodological limitations	No concerns about coherence	No concerns about adequacy	Moderate concerns about relevance	High level of confidence	No or minor concerns for methodological limitations, coherence and adequacy. Six studies contributed to this finding. Studies had a specific focus on pregnancy planning as well as reported detailed experiences of pregnancy as part of women's life experiences. Kidney disease was not the primary focus for this finding.
For women with or at high risk of kidney disease, their experiences of in vitro fertilisation/fertility treatment and alternate options for pregnancy (eg, adoption, surrogacy) were very often negative.	4 papers Nazario *et al*, Kerklaan *et al*,[42] Tong *et al*,[27] Schipper *et al*[41]	1 paper: Kazmerski *et al*[43]	No or very minor concerns about methodological limitations	Moderate concerns about coherence	High concerns about adequacy	High concerns about relevance	Very low confidence level of confidence	Serious concerns about coherence, adequacy and relevance. None of the studies had a focus on this specific topic. Non-pregnancy options for family planning were infrequently reported across the demographics and not a subject of investigation with any of the women. No or minor concerns for methodological limitations.
Women with kidney disease had positive experiences of a pre pregnancy counselling clinic.	1 paper: Wiles *et al*[47]		No or very minor concerns about methodological limitations	High concerns about coherence	High concerns about adequacy	High concerns about relevance	Very low confidence level of confidence	Serious concerns about coherence, adequacy and relevance. Only one study reported on an intervention, pre pregnancy counselling. Women had complex needs and varying outcomes. Although the clinic was reported as helpful more is needed to better understand what works well for women and their healthcare teams. No or minor concerns for methodological limitations.

Box 2 Descriptive themes

1. Theme 1: For women with or at high risk of kidney disease, it exacerbated societal expectations of traditional gender roles especially family planning (eg, wife, mother, carer) including capability to have children and associated factors, eg, parenting, (sexual) relationships, body image, independent living (including financial barriers to starting a family).
2. Theme 2: For women with or at high risk of kidney disease, a perceived loss of autonomy negatively impacted all aspects of life but particularly reproductive discussions, pregnancies and family life.
3. Theme 3: What women with or at high risk of kidney disease wanted in their pregnancy planning and pregnancy care did not always match with what the professionals wanted, and this led to negative experiences across their reproductive health pathways.
4. Theme 4: For women with or at high risk of kidney disease, the lack of personalised care in particular understanding women's preferences and life goals in relation to reproductive health meant that shared decision-making either never happened or was unhelpful.

integrate qualitative evidence into decision-making in health, social care and policy contexts. CERQual has four components: methodological quality, coherence, adequacy and relevance of evidence contributing to a synthesised finding. An overall assessment of confidence takes account of the individual component assessments to produce an overall rating on a range from high-to-very low confidence[33] (table 1).

Patient and public involvement

This review was undertaken as part of a wider mixed-method study investigating women with kidney disease lived experiences of shared decision-making in relation to their reproductive health that had extensive patient and public involvement throughout from women who were at various stages of CKD, family planning and parenting. A small group of women with CKD who were mothers (n=2) and wider healthcare professionals (psychologists and social workers) were involved in the development of the new health systems model by providing comments and reflections on drafts in progress.

Author reflexivity

The team undertaking this systematic review were all women and part of a wider study team undertaking primary research (surveys and interviews) into women with CKD experiences of care in relation to their reproductive health in the UK. This review was undertaken alongside the primary study and in part to help the team better understand the size and scope of the themes and concepts emerging from women's lived experiences. Weekly meetings were held to discuss outcomes from the review and ensure that there was agreement with the analysis and synthesis of the data extracted. The review team included a professor of health services research and child health with a portfolio of research across barriers, judgements and practices in the clinical setting, a PhD student looking at gender inequalities in sociology, and a medical student on a research placement with lived experience of kidney disease, shared decision-making in chronic conditions and complex care pathways.

RESULTS

Systematic review of intervention effects

No trials or evaluations of interventions were identified that were amenable to synthesis. We identified some local evaluations of counselling services, but they were not undertaken using designs that were suitable for synthesis as they did not generally measure outcomes. We did find one feasibility study protocol of a shared decision-making aid in development for use in making decisions about reproductive health for women with cystic fibrosis who commonly experience comorbid kidney disease, but the feasibility study had not started.[34]

Qualitative evidence synthesis

Summary of included studies 18 studies were included. The age range of 411 women was 17–77 years (online supplemental file 3). Although the quality of included studies varied, 16 studies were graded as valuable or above when addressing the review questions and all studies were included in the synthesis (online supplemental file 2). Included papers had an international perspective (USA n=6, UK n=3, Europe n=2, Canada n=2, Australia n=1, Brazil n=1, South Africa n=1, Saudi Arabia n=1, Mexico n=1, one study included participants in Australia, UK, Canada, India and Europe) and went back as far as 1987. Three PhD theses were included to address the lack of updated knowledge in the field and help fulfil gaps, in particular, minority perspectives and women whose rights were significantly underdeveloped. Four studies reporting pregnancy and reproductive concerns by women with chronic conditions where kidney disease was an important risk factor were purposively selected for inclusion. Including their perspectives was vital as most of these women would go on to develop kidney disease and most women with kidney disease were at some stage high risk. Comorbid conditions that have high risk of kidney disease and well as kidney disease itself and reproductive health exist on a continuum as women progress through life and from high risk to developing kidney disease.

Most studies reported data from interviews (n=15), one included questionnaires with free text, one analysed audio recorded consultations and one PhD applied a biographical approach. Eight studies aimed to explore and describe overall life perspectives of women, five aimed to better understand women's values, beliefs and expectations of pregnancy and their pregnancy care, two studies specifically examined women's experiences of decision-making, one study aimed to evaluate women's experiences of a counselling service and any impacts on pregnancy outcomes, one study looked at parents decision-making around genetic testing for polycystic kidney disease and one looked at women's experiences of transplant.

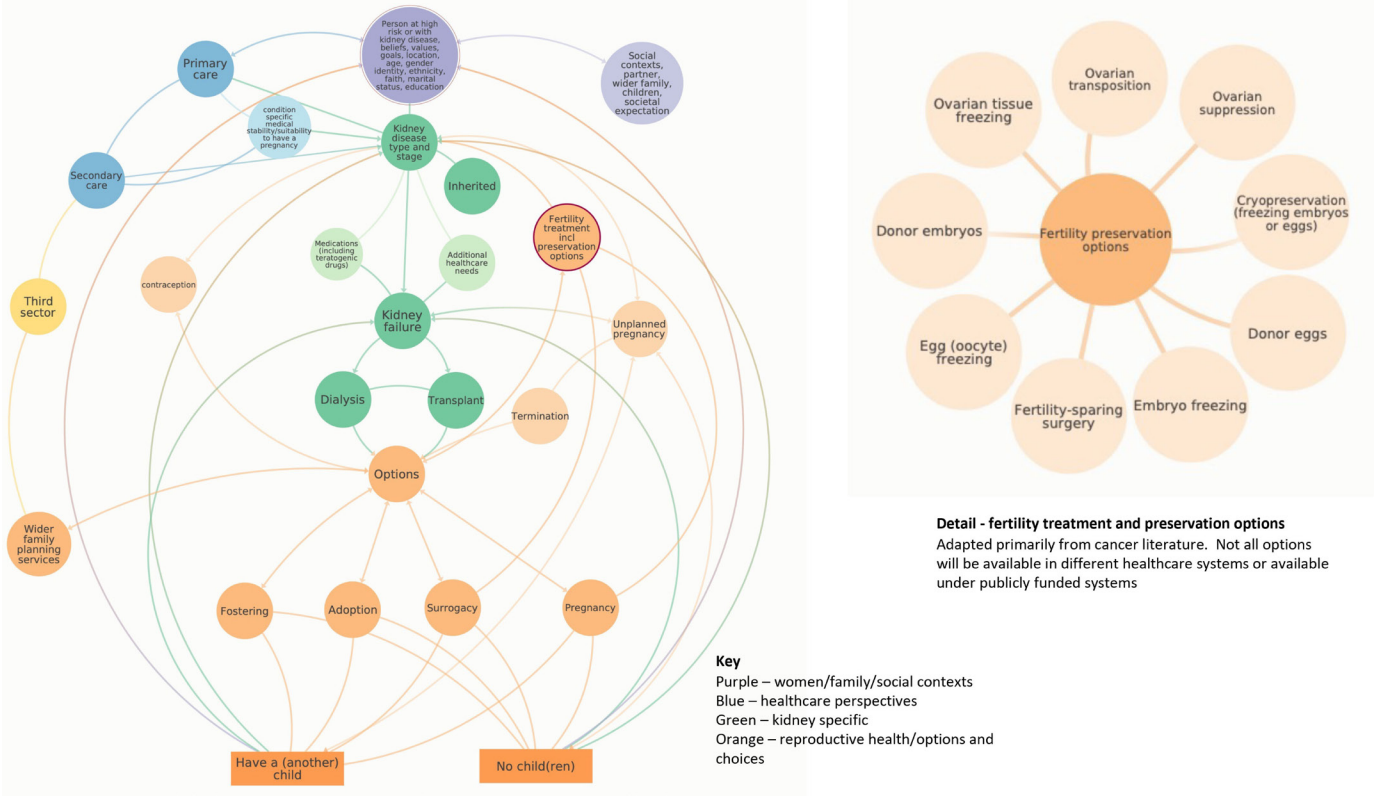

Figure 1 Reproductive options, choices and broader implications on decision-making—health system model.

We identified four major descriptive themes in women's experiences (box 2).

We discuss each of these major themes in further detail below. This summary of findings table with CERQual assessments is located in table 1.

Theme 1: for women with or at high risk of kidney disease, societal expectations of traditional gender roles, especially family planning, were exasperated

Uncertainty about capacity to have children and/or concern about being physically able to be a good mother negatively affected women's self-perception and social identity as women or prospective mothers. Fulfilling typically gendered roles, for example, being a wife, mother, carer was a worry for women not yet in one of these roles and a burden for many who were.[35–38]

Women who lived in countries where their rights were still developing and/or remain significantly underdeveloped (eg, Saudi Arabia and Mexico) felt the highest burdens in terms of kidney disease taking away their womanhood. Many had been shunned from family members, forced to divorce once kidney disease became more established and most felt that their kidney disease had taken away any future in terms of relationships, children and a family. Many of these women were illiterate and had received no formal education. It was also normal practice in Saudi Arabia to appoint a male member of the family as a legal guardian who made decisions on behalf of the women.[39 40]

> They always ask him why he can't find someone healthy. They are worried that I won't give them grandchildren. (female, kidney disease, Mexico)[40]

> I don't talk about my discomfort and fears with my family, especially my younger children. My divorce is already a source of problems for them because we no longer live together in our own home. I'm now living in my Uncle's house with my three daughters and my two sons live with their father. My daughters are already very busy helping me with household chores, and I don't want to complain to my sons when they visit me. I can't help but blame my condition for my divorce and the separation of my children. I always feel weighed down, because I can't share my feelings with them.[39] (Female, age 43, kidney disease, divorced, illiterate, never employed, Saudi Arabia)

Physical appearances such as scarring, weight gain/loss and multiple physical changes caused by medications (steroid use in particular which can change the shape of facial features and cause weight gain) and treatments de-feminised women.[36 38–43] Many felt that their physical appearance now and in the future would inhibit any physical relationships or potential future relationships.[38 39] This also impacted on women's general confidence and self-worth. Collectively these compounded women's self-belief in terms of their capacity to have children and/or be good mothers.[36 37 39–42]

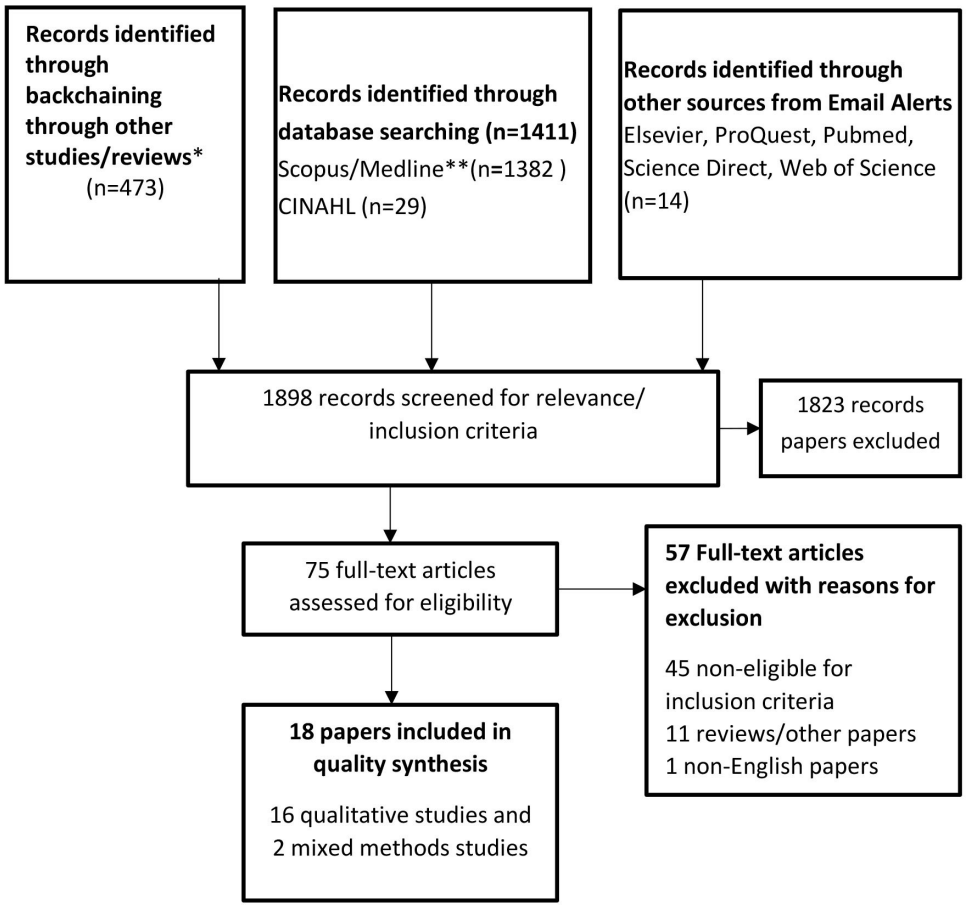

Figure 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. *Includes back-chaining through other reviews including Tong *et al* and an author search on Allison Tong. **Separate search with MEDLINE.

> …because of my body, my husband left me because he's not attracted to me. I'm not cute enough for him anymore. So those are the things that make me feel so down. (40 years old, high risk of kidney disease, separated mother of three, South Africa)[38]

> It is hard to look well when I don't feel well. All the changes taking place in my body makes it difficult for me to put on make-up and fix my hair. No matter what I do to look decent, I still feel ugly because I'm always tired. My family doesn't see that I'm trying my best; they think I can do better if I try harder. So what's the use in making all this fuss when no one recognizes my efforts? I only feel worse when they continue to push me to make myself look better for my husband and relatives. (Female, 36, kidney disease, married, 5 children, never employed, Saudi Arabia)[39]

Being high risk or living with kidney disease negatively impacted most women's views on finding a partner and building a stable relationship which would eventually lead to starting a family. The prospects of being unable to live independently in the future were additional concerns for women in terms of how they imagined themselves in the role of parenting. We found this was especially the case for younger women and those who had been denied or unable (due to ill health) to consider education goals leading to career pathways.[36 39 42 43]

> Conversations at parties stagnate when you say that you don't work. (Female, 56–65, high risk of kidney disease, South Africa)

Financial burdens—often caused by their illness left many women feeling unable to have children in spite of their health needs or desires to have a family.[39 42–45] This was often exacerbated by specific healthcare systems (eg, public or private).[35 37 41–43]

> I think financially is mostly where it's been an issue. I feel like I'm dependent on either the government or my dad or even my fiancé sometimes because I don't have the same education. I don't have a degree in order for me to get a good job. (Female, 22–25, kidney disease, across 6 high income countries)

> Some considered adoption or surrogacy but were 'shattered' because of the prohibitive financial cost, long waiting time, and 'convolute' legal requirements. Those who considered adoption felt hopeless when they were deemed ineligible because of their health condition, genetic disease, and inability to 'guarantee they would live long enough to raise a child. (author

interpretation, study involved 41 women, aged 22–56, CKD stage 3–5, Australia)[37]

Theme 2: for women with or at high risk of kidney disease, a perceived loss of autonomy negatively impacted all aspects of life but particularly reproductive discussions, pregnancies and family life

Problematic relationships with healthcare professionals were a key barrier in terms of even starting a conversation about having children. This included feelings of immediate needs not being heard, future preferences not listened to, and goals in terms of reproduction not taken seriously on balance with either high risk or established kidney disease. Factors which contributed to these feelings were, feeling that their doctor was against a pregnancy, feeling judged for putting them and/or their kidney at greater risk as well as wanting to be a mother in their condition. A perceived lack of support with their care team and a lack of continuity of care were additional factors contributing to women feeling like their capacity to make and be involved in decisions had been taken away.[37 38 43 45–49] These feelings tended to increase as women progressed through their disease condition.

> They told me not to get pregnant. They wanted to tie my tubes. Down-stairs in the medical clinic they stressed the risks. That is their opinion and I won't let that interfere. (female, Lupus and diabetes, high risk of kidney disease, high income country)

> They tried to convince me that I was having some kind of stress episodes. I said, "I know what an insulin reaction is, I've had diabetes for years. I know what it is, either that or I am losing my mind". They almost convinced me that I was going crazy…. I guess it upset me because I know what is going on with my diabetes and nobody would listen to me. That is what made me feel powerless, that is what made me feel so helpless. Even though I knew what was going on, nobody would listen to me. (female, high risk of kidney disease, diabetes, high income country)[45]

Theme 3: what women with or at high risk of kidney disease wanted in their pregnancy planning and pregnancy care did not always match with what the professionals wanted, and this led to negative experiences across their reproductive health pathways

Women wanted to be 'normal' and have the options that all other women have. Many women longed for a normal pregnancy and to be able to fulfil their roles as mothers in the family unit. They expressed a need for more support and understanding from their healthcare professionals, better and more integrated psychological and social support and tailored, personalised holistic care for their reproductive health.[36 40 42 43 45 46 48–51]

> 'I just want to be a normal woman. I want to be a mother and a real wife. And that's what a transplant can give me, so that is why we are going through all this now, so that we can be a family' (woman, kidney disease, low-income country).

Factors associated with a high-risk pregnancy were frequently discussed by doctors including increase monitoring through hospital appointments, early termination, onset of pre-eclampsia or potentially life-threatening health deterioration.[36 37 41 45 48–52] But women recalled they were often left on their own to weigh up these risks and come to a decision about a pregnancy. Women tended to feel anxious from the outset about the need for increased monitoring and having a 'high risk' pregnancy. This was more likely if women had a previous negative pregnancy experience and/or outcome.[36 37 41 45 48–51 53]

> I can't develop a time frame that enables me to plan the future. Most of the time I can't plan for the next 24 hours—that alone wears on you mentally!… The sad thing is that I always wanted three or four kids. And that has been—well, a bit of a disappointment for me, and I know disappointing for my husband as well.

> I didn't realize how big of an issue monitoring blood pressure would become in my life. The string of countless medications I have been subjected to has created a roller coaster of physical miseries. Each attempt to regulate my high blood pressure brought its own set of side effects such as drowsiness, headaches, dizziness, diarrhoea, sleeplessness, and anxiety. I feel like an experimental lab for blood pressure medication. (female, kidney disease, high income country)[52]

Theme 4: for women with or at high risk of kidney disease, the lack of personalised care, in particular understanding women's preferences and life goals in relation to reproductive health, meant that shared decision-making either never happened or was unhelpful

Many conversations with healthcare professionals were described as rushed and often women felt pressured to have a pregnancy (from what they perceived as their deteriorating health) in spite of many feeling emotionally and practically unprepared.[37 42 44]

> It was terrifying because it puts a time limit on things. It puts a rush on something that should be natural. (40 s, transplant recipient, high income)

Women were especially concerned about risks of passing on inherited conditions, need for continuous monitoring and poor outcomes for them and their baby, but reported information either lacking or unhelpful in terms of their reproductive options.[36 37 41 45 48–52 54] There was a lack of balanced practical information on ways to help women better prepare for a pregnancy, for example, lifestyle, diet and medication adjustments which at times led to higher risk behaviours and increases in unplanned pregnancies.[37 41 43 48 49 51 55]

> I found this quite stressful and frightening, the risks scared me so much. (female, kidney disease, questionnaire response)

Information and presentation of reproductive options was frequently reported as unhelpful as it lacked tailoring to women's specific needs, which were diverse.[37 41] Many studies reported high levels of misconceptions and an overall lack of understanding from the women's perspectives about fertility options including impacts on future health.[43 48 49 51 55]

Some women associated their experiences of planning for pregnancy as a battle. Some felt their rights to have a child were not heard or listened to. Some actively sought out additional information to contradict their clinical team's advice. Many women felt that they knew more about what them and their body were capable of, and felt that the their pregnancy was an opportunity to prove their doctors wrong.[37 38 45 46 48 52] Pre-pregnancy counselling clinics designed to address unmet needs were reported as helpful.[47]

> They felt without autonomy as each warning was a 'sledgehammer' and were reluctant to go against their physician's advice. Some were certain that physicians used 'scare tactics' because they 'saw being pregnant as a risk, not really as a human thing. (Author interpretation, kidney disease, high income country[37])

Women reported age and financial concerns as key influences in their negative experiences of alternate options to pregnancy, for example, adoption, surrogacy, fostering and wider fertility preservation options.[35 41–43 56] We found very little evidence that looked at women's experiences in later life and their views on having children or not, and their specific reproductive health needs, for example, menopause.

Sensitivity analysis of women with kidney disease compared with women at risk of kidney disease

The findings from women with or at high risk of kidney disease were similar but there were some discrepancies with the additional considerations for transplant recipients. Women who had a transplant (either from an unknown deceased donor or living donor from a relative) worried about risks to their new kidney and also expressed guilt about putting their 'gifted' kidney at potential risk. Women also reported anxieties about potentially being removed from the transplant list if they were to have a pregnancy.[37 40 42 46 52] There was little qualitative evidence regarding support (or interventions) to help women with these complex and emotional decisions specifically in relation to kidney transplant.

When papers were placed in a chronological timeline, no discernible differences in women's experiences were noted, which indicates that women's reproductive health is not routinely integrated into existing disease orientated clinical pathways.

Analytic theme developed from descriptive themes, and transforming the evidence to look for new patterns and insights beyond the primary studies

Reproductive shared decision-making is an ongoing fallacy

We were able to move from translation of studies to transformation of data across studies to develop new meaning and understanding of the phenomena of interest. Shared decision-making about women's reproductive health did not consistently happen because they were women who were not sufficiently empowered with knowledge and education (and in some cases basic rights) to enter into a shared decision-making process as an equal partner. Over time, women's experiences do not seem to have changed much. They still appear not to be heard or their voices acted on and clinical practice does not seem to have evolved to take account of women's reproductive health as well as their kidney disease. A gender-neutral disease orientated clinical pathway persisted that primarily focused on achieving condition or kidney stability and preservation that did not take account of women's reproductive hopes and dreams. Women were primarily seen as gender neutral biomedical beings that together with their doctors strived to achieve condition and or kidney stability. Women's hopes and desires concerning their reproductive health were not routinely flagged or acted on in standard clinical pathways. This contrasted with women's lived experiences of the female gender as a normative standard for expected societal and reproductive behaviour. The lack of effective shared decision-making interventions is likely to have a negative impact on women's reproductive outcomes.

Reproductive options, choices and broader implications on decision-making—health system model development

Based on findings from the review we developed a new health system model (figure 1) to (a) better represent the range of potential influences on decisions (b) draw attention to the multiple options that may be available in terms of reproductive health and (c) how women are more likely to experience them, that is, not linear or in any particular hierarchy.

figure 1 can be used by both women and healthcare professionals in decision-making and illustrates:

- Women, familial and social contexts to help prioritise the values and goals of women first rather than their disease condition.
- Key healthcare services, to better illustrate the range and number of specialists women are likely to engage with or where wider services may be better embedded into the healthcare pathway.
- Stage of CKD and treatment, to highlight that kidney disease is progressive, that multiple treatments are available and women will likely experience more than one.
- And linked to all of these to reproductive health options and choices which collectively illustrate potential pathways to embed shared decision-making

in relation to family planning earlier, more frequently and as part of routine care.

On the right-hand side of figure 1, we expand on fertility preservation options from the cancer literature. Not all of these options will be relevant or available to women but knowing the full range of potential options may help in women's decision-making and may help healthcare professionals in their reproductive options discussions.

The additional purpose of this model is to support the design of new and adapted shared decision-making interventions in clinical practice by highlighting what intervention developers may need to consider, where interventions might be implemented within the system, and consider where they are most likely to have an impact for women with kidney disease and their reproductive health needs and goals.

DISCUSSION

Women with or at high risk of kidney disease, like women generally, experience expectations of societal norms to fulfil certain roles, for example, wife, mother, carer. However, being at high risk of or living with kidney disease increases this burden and there are currently limited (if any) resources including psycho/social support networks which are picking up these unmet needs.

Women experience living with high risk or living with kidney disease as something which takes away and deprives. This is not just limited to health needs but includes their social status as women, choices, sexuality, preferences and life goals. Women with or at high risk of kidney disease want the same options and opportunities as anybody else but frequently encounter barriers in the clinical setting, in the family unit, the home and wider social contexts. Reproductive planning does not routinely commence when women are identified as being high risk of kidney disease and therefore women are progressing into late stage kidney disease and even kidney failure without ever discussing their reproductive health.

Noted gaps were the lack of evidence-based intervention studies and a somewhat narrow perspective on 'natural' pregnancy experiences compared with fertility preservation, or alternate options such as adoption, fostering, surrogacy for having a family. Perhaps the biggest finding from this review was how little services have changed in women's reproductive healthcare in more than 20 years. The health systems model developed indicates the need for more disruptive, system wide interventions, including training, system redesigns, new services additions, more linked networks of support, personalised resources and better evidence on what works, for whom and why.

Strengths and limitations

This is the first systematic review of interventions and women's experiences of shared decision-making in relation to their reproductive health in kidney disease. We followed Cochrane methods and processes and reported the findings in a transparent way. This review adds knowledge by highlighting the multiple options available for women including options not to have children, that options and choices can and do change overtime, and are influenced by a high number of personal views, experiences, health and social care services and systems. We applied GRADE CERQual to assess the confidence in synthesised findings, including the experiences of women at high risk, whose reproductive health needs considering and addressing before they progress to kidney disease. New findings also place the unmet needs of women with or at high risk of kidney disease outside of the purely health focused model of care and situates them within the context of inequalities and specifically how their risk of or actual kidney disease adds to this.[7 57 58] This review goes beyond descriptive findings that remain close to the primary studies. Some findings map onto to a similar but a more narrowly focused review on pregnancy experiences of women with kidney disease[27] including decisional burden, desires for a normal life and trauma exacerbated by healthcare professionals lack of knowledge and engagement with them as women first and people with kidney disease second. The new health system model developed as a result of the synthesis brings reproductive health—in particular options for having children—alongside the health pathway for women with kidney disease and aims to increase options by preserving opportunities. In this model, we demonstrate for the first time the complexity of decision-making for women, how this is likely to change overtime, the importance of introducing reproductive health conversations earlier, with frequent opportunities to revisit and provide with the right specialist services in place to offer personalised care and support. Importantly the model helps to synthesis existing qualitative evidence but within a health systems perspective, highlight gaps in knowledge (described below) and identify pathways to introduce real-world interventions across the care pathways, involve the multiple stakeholders and map the impact they are likely to have on women's decisions and experiences. In the qualitative evidence, we did not include the perspectives of healthcare professionals, men, partners or wider family and friends. We did not identify any studies to include in the review of intervention effects.

Unanswered questions and future research

There needs to be more research looking at minority perspectives. We consider ethnic minorities, the LGBTQ+community, women with more complex multiple comorbidity healthcare needs, older women, general women's health (eg, menopause, endometriosis) and their experiences of reproductive health and family planning an important gap and a key area for further research.

A significant gap was the lack of any interventions (eg, specialist staff, shared decision-making tools, training or upskilling) currently in practice or any evidence as to their effectiveness. We consider this essential for future research to develop and adapt new interventions

to address unmet needs and trial their impacts on the multiple stakeholders including partners and wider family networks where applicable.

Implications for clinicians and policymakers

Women's encounters with healthcare professionals are not routinely including discussion of reproductive options in ways that women find informative and helpful. Updated clinical guidance is welcome[20] but what is currently discussed in terms of options in a kidney context does not match with what is available or preferable in other long-term conditions, for example, cancer.[59 60] Policies and guidelines and how they translate into practice for non-pregnancy options (adoption, fostering) are not yet established nor are there examples of women's experiences in the literature. Women are frequently experiencing discussions about their reproductive health in generic and binary terms and opportunities for more personalised care with discrete pathways and packages of care are being missed.

CONCLUSION

Clinical practice for women with or at high risk of kidney disease is not evolving at a sufficient pace to incorporate their reproductive health needs, life goals and reproductive choices. There is a clear need to establish new shared decision-making interventions, test those already in development and establish new clinical guidance and policies for the management of women with or at high risk of kidney disease in relation to their family planning, including options to preserve fertility earlier. Other health conditions with established personalised care packages could be used to benchmark clinical care including links to wider services and networks of support.

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