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Nephrology Dialysis Transplantation

Full Review

A guide to reading and using systematic reviews of qualitative research

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ABSTRACT

There is an increasingly widespread policy momentum to increase patient-centred care and to improve quality of life outcomes within health services. Qualitative research methods are used to elicit in-depth and detailed insights into people's attitudes, beliefs, emotions and experiences-much of which may remain unspoken during clinical encounters. Questions about patients' beliefs and preferences for treatment can be addressed by qualitative research and inform evidence-based strategies for delivering patient-centred care. Systematic reviews of multiple primary qualitative studies bring together findings from different studies to offer new and more comprehensive understandings of social phenomena across various healthcare contexts and populations and are an emerging methodology in the literature including for care in chronic kidney disease. This article will provide a framework for the systematic review of qualitative research so readers can make sense of these study types and use them in clinical care and policy.

Keywords: patient-centred care, qualitative research, research methods, systematic review, thematic synthesis

SCENARIO

Mary is 55 years of age and has just been referred to you by her primary care physician. She has previously been diagnosed with IgA nephropathy and now has an estimated glomerular filtration rate of 20 mL/min per 1.73 m². During the consultation, you explain that she is likely to need kidney replacement

therapy within the next year or so. She is visibly distressed and expresses concerns about how this might impact her family and her ability to work.

For many patients with chronic kidney disease (CKD), decision-making about the various options for kidney replacement therapy is difficult and confronting. Kidney replacement therapy has profound consequences and lasting implications for the patient's well-being, relationships and lifestyle, as well as for their family. Often the decision to use one mode of therapy over another is determined by local infrastructural considerations such as availability, cost and expertise but could be shared more with the individual patients and their family by considering their values, goals and preferences. You might ask

- What are Mary's priorities and considerations which could influence her preferences for treatment?
- What are the concerns that Mary might have with respect to each treatment modality?
- How can I prepare Mary for the possible short-term and long-term impacts of kidney replacement treatment that she regards as most important?

You recall that one of your colleagues sent you an article on the views of patients' and carers' on making decisions about options for kidney replacement therapy by Morton *et al.* (2010) [1]. While it seems relevant, the article describes a relatively new methodology—systematic review and synthesis of qualitative studies. What are the key features of this methodological approach to understanding existing research and how can the findings of this study be used in your own clinical practice and decision-making?

INTRODUCTION

There is an increasingly widespread policy momentum to increase patient-centred care and to improve quality of life outcomes within health services [2–5]. Shared decision-making is considered a foundational aspect of patient-centred care [6], defined by the Institute of Medicine as care that is 'respective of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions [6].' Qualitative research methods are used to elicit indepth and detailed insights into people's attitudes, beliefs, emotions and experiences—much of which may remain unspoken during clinical encounters [7–9]. Questions about patients' beliefs and preferences for treatment can be addressed by qualitative research and inform evidence-based strategies for delivering patient-centred care.

Systematic reviews of multiple primary qualitative studies bring together findings from different studies to offer new and more comprehensive understandings of social phenomena across various healthcare contexts and populations; and are an emerging methodology in the literature [10–12]. Recently, they have also being used alongside systematic reviews of interventions. The Cochrane Collaboration Qualitative and Implementation Methods Group have published guidance on integrating qualitative evidence synthesis with Cochrane

intervention reviews of effects [13]. In nephrology, qualitative synthesis has addressed topics on end-of-life care [14], motivations and experiences of living kidney donors [15, 16], patients' experiences of kidney failure and dialysis [17–21], decision-making for renal replacement therapy [1, 22] and caregiver perspectives [23]. Systematic reviews of qualitative research have been cited as high-level evidence to underpin clinical practice guidelines recommendation on peritoneal dialysis [12] and have also been used to develop educational resources for living kidney donors [24].

This article will provide a framework for the systematic review of qualitative research so readers can make sense of these study types and use them in clinical care and policy.

KEY FEATURES OF SYSTEMATIC REVIEW AND SYNTHESIS OF QUALITATIVE RESEARCH

Methodology

There are different methodologies for systematic reviews of qualitative research (Table 1). The methodology used provides a framework, which informs the approach to literature search and selection, appraisal of primary studies and synthesis of results. Table 1 provides explanations for the common methodologies

Table 1. Summary of a selection of methodologies and approaches in synthesis of qualitative research^a

Approach	Thematic synthesis	Meta-ethnography	Critical interpretive synthesis	Meta-study
Intended output	To generate analytical themes that offer a new interpretation that goes beyond findings offered by primary studies	To develop higher-order interpretations (ideas, theories) based on findings reported in primary studies (third-order constructs).	To build a new theoretical conceptualization (synthetic construct)	To describe differences in research findings and to develop a new interpretation of the phenomena under investigation
Literature search	Comprehensive, systematic	NS	Theoretical sampling (to select studies that will inform theory development)	NS
Quality appraisal	Addresses aims, context, rationale, methods and findings, reliability, validity, appropriateness of methods for ensuring findings are grounded in participant perspectives	Assesses the relevance of study	Determines the degree to which the research findings inform theory development	Focuses on epistemological soundness (the theory of the nature and grounds of knowledge) and rigour of the research methods
Analytical principles and techniques	 Line-by-line coding of results and/ or conclusions from the primary studies Codes are organized into descriptive themes 	 Translation (i.e. comparing) of concepts from individual studies to identify first- and second-order constructs (reciprocal translational analysis) Exploration and explanation of differences and contradictions among studies (reputational synthesis) 	 Concurrent iteration of the research question Extract data and summarize papers Define and apply codes Develop a critique and generate themes 	 Analysis of findings Analysis of methods Analysis of theory Combine three components of the analysis
	Data are further interpreted to develop analytical themes			
		Theorizing based on synthesising translations and comparisons of the differences and similarities in the data (lines of argument)		

NS, not-specified.

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^aAdapted from ENTREQ [11], the selection of methodologies was used to illustrate the differences across the more commonly used approaches that are specific for synthesizing qualitative data.

used including thematic synthesis [25], meta-ethnography [26, 27]; critical interpretive synthesis [28] and meta-study [29]. Other approaches include framework synthesis [30, 31] and meta-aggregation. Realist reviews [32, 33] and narrative synthesis [34] can also be used but they are not specific for synthesizing qualitative data.

While systematic reviews of quantitative studies typically involve a comprehensive literature search, quality appraisal and synthesis of data, some methodologies for qualitative synthesis do not necessarily entail all three steps and vary in their approaches. These are outlined Table 1.

Literature search and selection

In synthesis of qualitative research, two approaches have been used for literature searching: a comprehensive search strategy to identify all studies that include the population and topic relevant to the research questions; and an iterative search strategy to find and select studies that will contribute to theory development—in other words, the search for additional papers ceases when no new data are found in subsequent papers.

Unlike for quantitative research such as randomized controlled trials, there are few well-validated search filters to identify qualitative research, which can make sourcing qualitative data challenging [35–37]. Qualitative studies are not well indexed in standard electronic databases such as MEDLINE and Embase, and there are a number of reasons for this. The term 'qualitative research' was introduced in MEDLINE only in 2003 and there is a range of methodological terms for qualitative research. In addition, the method may not be specified in the title of the qualitative study, or with insufficient detail about the qualitative methodology provided in the abstract.

We suggest that searches be conducted in electronic databases including MEDLINE, Embase, Cumulative Index for Nursing and Allied Health Literature (CINAHL), PsycINFO and other specialist databases (e.g. sociology, economics, education and nutrition) and journals relevant to the review topic. Searching multiple sources is needed as different databases are likely to yield different results [38, 39].

The search strategy may combine terms relating to the population, with the clinical or health topic, and terms relating to qualitative methodology and social phenomena (Table 2). Following our clinical example, we might wish to search for studies in people with advanced kidney disease [population] and medical decision-making [health topic]. A preliminary scoping exercise using simple keyword searches in PubMed or Google Scholar can identify qualitative studies on treatment decision-making in CKD, which would fit the inclusion criteria of the review. The search strategy could then be 'tested' for sensitivity, i.e. by ascertaining whether the strategy retrieves eligible studies identified in the preliminary search or known studies in the literature that would be eligible in the review. Reviewers may also search reference lists of included and relevant articles (this is called snowballing) and contact experts in relevant fields to identify any additional studies.

Referring back to the study referenced in the clinical scenario, Morton *et al.* [1] conducted a systematic review and synthesis of qualitative studies that explored patient and carer preferences for dialysis modality, transplantation or palliative

Table 2. Suggested search terms relating to qualitative methodology and social phenomena

- Qualitative research
- Interview
- Focus groups
- Thematic/theme
- Grounded theory
- Phenomenology
- Content analysis
- Ethnography
- Decision making
- Illness behaviour
- Knowledge
- Attitudes
- Social psychology
- · Decision-making
- Health belief
- Social belief
- Lifestyle
- Life changing events
- Quality of life
- Psychological adaptation
- Anxiety/depression
- Social support
- Social adjustment
- Communication
- Emotions
- Interpersonal relations
- Satisfaction
- Self-esteem
- Employment

care. Search strategies were conducted in MEDLINE, PsycIN-FO, CINAHL, EconLit and Embase from database inception. In addition, social work abstracts, social science, qualitative health and nursing journals were searched. To supplement this, the authors conducted searches in dissertation databases. Of the 18 studies included in the review, three were dissertations. This suggests that a broader range in the depth of insights may have been included in the synthesis.

Appraisal of primary studies

Assessment of primary qualitative research is contentious [40–42] as there is no universally accepted framework that can be applied to the wide range of methodologies, and little empirical evidence exists about what approaches improve the quality of the study, or what methodological characteristics influence the 'quality' of results (e.g. whether the results reflect the participants' perspectives). However, transparency of reporting can ensure that readers are able to make their own assessment of rigour and transferability of the findings to their own setting [43].

Although the application of quality criteria is still being debated, most syntheses of qualitative research include quality appraisal [11] and three main approaches have been described:

appraisal of study conduct (how well was the study conducted), assessment of the transparency of study reporting (how well the study was reported) and implicit judgement about the extent to which the findings from the primary study informs theory development (how well the study findings contribute to the theory developed in the synthesis). A number of frameworks have been developed to guide appraisal. The Critical Appraisal Skills Program (CASP) [44] and Consolidated Criteria for Reporting Qualitative Health Research (COREQ) [43] are most commonly used. CASP [44] has been used to assess study conduct and the reviewer using this tool decides whether the methods were appropriate in addressing the research questions, the rigour of data analysis and the value of the research findings. COREQ was designed to evaluate the completeness of reporting across three domains: research team and reflexivity (reflexivity is acknowledging the researchers' influence throughout the research process), study design (theoretical framework to guide the selection of methods or approach, participant selection, setting, data collection) and analysis and findings. Existing criteria may be modified and refined to suit the synthesis topic, population and range of study methods included in the review. When reading a systematic review, we can then decide on our confidence in the findings of the review based on the reporting of information in the original research. If study investigators in the primary studies did not consistently triangulate their findings among several researchers or data saturation (i.e. when little or no new information were identified in subsequent primary studies) was not sought or reached (e.g. in a grounded theory study), we might have lower confidence in the conclusions of the systematic review.

In Morton et al. [1], two reviewers independently applied the COREQ framework to assess all the studies included in the review. Discrepancies were resolved by discussion. The rationale was to make transparent the research methods reported by the authors of the primary studies so readers of the review could assess the trustworthiness and transferability of the findings. The studies were not excluded or weighted based on the quality of reporting. They noted that better reported primary studies contributed more to the final analytical themes; however, they did not suggest explanations for this observation. We can note in the systematic review by Morton et al. that of the 18 studies included in the review, 5 (28%) of the primary studies reported on whether they sought participant feedback or checked on the preliminary results to verify the findings, and 12 (67%) reported on the involvement of multiple investigators in data analysis. These findings might lead us to have a somewhat lower confidence that the findings of the primary studies reflected the breadth and depth of participant perspectives and experiences.

Synthesis

Synthesis is creating something new from separate elements—not simply summarizing the findings offered by the primary studies. Synthesis of themes within and across individual studies in differing clinical settings can produce new theoretical constructs, models or thematic schemas to explain the phenomena being investigated. The approaches to synthesis for each methodology are described in Table 1. Typically, the synthesis process involves coding of findings reported by the primary study,

identifying themes, comparing across studies, determining how studies are related, synthesizing themes and generating a new conceptual model or theory. There should be clarity about the sections of the articles that were analysed. Computer software can be used for data management (e.g. to store, group and retrieve codes) but cannot be used to do the interpretation and analysis of data.

Morton et al. [1] used thematic synthesis. The results and conclusions section from each study were imported in to NVivo 8 software to store, code and search the data. They conducted line-by-line coding of the findings from the primary studies, developed descriptive themes and generated analytical themes. However, the number of reviewers involved in the analytical process was not reported and it was not clear how they 'verified' that the full breadth and depth of data from the primary studies were integrated into the analysis. The authors identified four major themes about treatment decisionmaking: treatment choices— confronting mortality (choosing life or death, being a burden, living in limbo), lack of choice (medical decisions, lack of information, constraints on resources), gaining knowledge of options (peer influence, timing of information) and weighing alternatives (maintaining lifestyle, family influences, maintaining the status quo), and the links among themes were illustrated in a new thematic schema. They indicated which study contributed to the themes identified and provided selected quotations to demonstrate that the themes reflect patient and carer perspectives on treatment decisionmaking as reported in the primary studies.

In the systematic review by Morton *et al.*, it was noted that some patients across several clinical settings perceived a lack of individual choice in decision-making. For example, patients felt that they lacked information about some treatment options or they were not being offered treatment opportunities because of resource constraints, and believed clinicians were excluding these choices due to their own preferences. For our patient, Mary, these findings suggest that clinicians need to be aware of their own treatment biases when giving information and being aware of which aspects of treatment patients need the most information about—for example, the inability to travel if Mary values this highly, or the opportunity to have dialysis free days if this is Mary's strong preference.

GUIDING PRINCIPLES FOR APPRAISING SYSTEMATIC REVIEW AND SYNTHESIS OF QUALITATIVE RESEARCH STUDIES

The Enhancing Transparency in Reporting the synthesis of Qualitative Research (ENTREQ) Statement is the only guide-line currently available for reporting the systematic review and synthesis of qualitative research [11]. The statement includes 21 items addressing five domains: introduction, methods and methodology, literature search and selection, appraisal of primary studies and synthesis of findings. ENTREQ was explicitly designed to guide reporting but may also inform the appraisal of synthesis of qualitative research.

While the principles of credibility, dependability, transferability and confirmability have been proposed for guiding the

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appraisal of primary qualitative studies [45–49], they can also be applied to systematic review and synthesis of qualitative research. In this section, we outline the four guiding principles for appraisal and suggest strategies and techniques from the ENTREQ reporting framework that are relevant to each domain.

Credibility: can the findings be trusted?

Credibility is critical for establishing the trustworthiness of the findings [50]. In primary qualitative studies, credibility addresses how well the findings reflect the perspectives of the research participants [45, 48, 51]. In qualitative synthesis, this instead refers to the extent to which the synthesis findings represent the data and results reported in the primary qualitative studies. Strategies to enhance credibility include

- Investigator triangulation: Involving multiple investigators
 from various disciplines in the analysis can ensure that the
 breadth and scope of relevant data are captured in the synthesis. Also, briefing sessions among investigators can help
 to enhance the analytical process by providing opportunities to develop and refine ideas and interpretations, and
 for researchers to recognize and address their own biases
 and preferences [48, 51].
- Researcher reflexivity: Researchers should acknowledge and address the possible preconceptions and biases which may have unduly impacted on the decisions made during the process.
- Definition of data: The sections of the primary studies (e.g. participant quotations, results and conclusions) which will form the 'data' to be coded and analysed by the reviewers must be specified.
- Thick description: Detailed description of the findings (concepts, theories and themes) enables readers to assess whether the results encapsulate the depth and scope of the data in the primary studies.

Dependability: is the process logical and auditable?

Interpretive processes are fundamentally inherent in qualitative analysis. As such, it is not possible for another reviewer to reproduce exactly the same findings. Dependability refers to the transparency and auditability of the research process and ensures that the decisions made by the researchers are transparent. Also, this enables readers to ascertain whether there is a coherent link between the methodology and methods, data and the findings. Dependability may be increased by

- Explicit search strategies: The search strategies, databases, data sources and timeframes of the searches should be provided so the scope, relevance and sensitivity of the search in addressing the review question can be determined. Also, decisions to exclude studies should be justified.
- Appraisal process and tool: The rationale, process and tools used for appraising the primary studies should be provided.

- Inclusion and exclusion criteria: Specifying eligibility criteria enables readers to understand the nature and scope of the evidence-base used to address the research question of the synthesis.
- Computer-assisted data analysis software: The use of qualitative data management software can help to ensure that coding decisions can be recorded and traced.

Transferability: are the findings relevant to your setting?

Transferability refers to the potential relevance and applicability of the findings (e.g. concepts, theories, themes, explanations and descriptions) to other individuals, populations, contexts and healthcare settings [45, 51]. This is facilitated through

- Description of the study characteristics: Characteristics of the studies included in the review should cover information about the participants and setting in which the study was conducted.
- Thick description: Information on the context in which the findings were derived (population, setting and timeframe); and detailed descriptions of the findings—concepts, theories or themes need to be described so readers can assess the extent to which the results can be applied to their own population and context.

Confirmability: are the findings and interpretations linked to the data?

Confirmability seeks to demonstrate that the findings are derived from the data and not misconstrued or imagined by the researcher [50, 52]. Strategies to minimize inappropriate bias, distorted interpretation of the data and unsubstantiated findings include

- Investigator checking: Primary studies may be independently re-read by multiple investigators to confirm that the coding and analytical framework encompass all the data presented in the primary studies.
- Quotations from the primary studies: Quotations to illustrate the synthesis findings (e.g. themes) should be provided to demonstrate that the output is clearly supported by the results of the primary studies. The quotations may be from the participants of the primary studies or the interpretations of the authors of the primary studies.
- Study contributions: The contributions of each study could be linked to the findings. For example, the studies which contributed to each concept, theme or theory may be referenced.

The general principles discussed above offer a broad and multidimensional approach to appraising the synthesis of qualitative research. However, some of the techniques may not be applicable across the full range of qualitative synthesis methodologies. In addition to these principles, readers should also consider the question: 'Does the synthesis present rich, compelling and relevant results that go beyond a summary of the primary studies?' [11].

HOW CAN THE FINDINGS BE APPLIED IN PRACTICE?

In the context of clinical practice, qualitative findings can inform shared decision-making, enhance patient-provider communication, patient educational resources and clinical quality measures [8, 53].

We return to our case scenario where Mary faces complex, emotional and confronting decisions about kidney replacement therapy. After reading the systematic review by Morton *et al.* [1], you identify a number of themes which you could address in the consultation including her desire not to be a burden on the family, her need to understand practical lifestyle and quality of life implications of different modalities of kidney replacement therapy, Mary's potential reservations about initiating discussions with family and friends about living kidney donation and the potential preferences of Mary's family members.

The synthesis also delineated specific reasons influencing patients' preferences for dialysis modalities and may serve as a starting point for developing patient decision aids to facilitate informed decision-making around dialysis modality choice. For example, patients preferred peritoneal dialysis on the basis of selfmanagement, freedom and flexibility, and ability to travel, work and care for but they were concerned about the peritoneal dialysis catheter, infections and inability to store dialysis supplies. Reasons underpinning patient preferences for in-centre haemodialysis included the desire to receive care from trained healthcare professionals, predictability of a planned schedule, ability to go swimming and having easy access to the dialysis centre; while patient barriers were fear of needles, appearance of fistulas and vulnerability to infection. The range of issues identified in the review offer some insights into what may be potentially relevant to discuss with Mary when talking to her about treatment options.

Another point emphasized in the review was that family preferences and other patients' experiences had a powerful impact on patients' perception, decisions and preferences for renal replacement therapy. For example, the appearance of 'a swollen and disfigured arm following a fistula operation' [1] caused some patients to refuse haemodialysis. Or, seeing other patients' manage a peritoneal dialysis catheter successfully inspired confidence in patients to self-dialyse. This suggests that educational interventions or programmes for patients requiring renal replacement therapy and their families could involve trained patient educators who could share their experiences, coping skills and strategies and tips for managing their treatment. Another initiative to consider may be to establish peer support networks to promote knowledge, self-management, support treatment decision-making and improve treatment satisfaction. These findings could help dialysis services to become more responsive to patients' needs when they are receiving education about kidney replacement therapy and may be useful for policy and healthcare system design to enhance patient-centred care.

CONCLUSION

Systematic review and synthesis of qualitative health research can provide new and comprehensive understandings about people's values, attitudes and beliefs across different populations and healthcare contexts to inform patient-centred practice and policy in nephrology. This article offers guiding principles to assess the credibility, dependability, transferability and confirmability of this relatively new type of research evidence emerging in the nephrology literature. A better understanding of the approaches to guide critical appraisal may promote the access and use of synthesis of qualitative research studies for clinical practice.

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