

Multi-source synthesis of data to inform health policy

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Objectives: To propose a new method for comparing and integrating original qualitative data with systematic reviews of quantitative and qualitative studies, demonstrated by a study of the psychosocial needs of chronic fatigue syndrome (CFS) sufferers in Québec.

Methods: A systematic literature review was performed across various databases for English and French language studies, on the psychosocial aspects of CFS. Qualitative, quantitative, and mixed method studies published between January 1994 and July 2008 were included. Unpublished literature and reference lists of included studies were also searched. Themes identified in the literature were used to guide semi-structured interviews with seventeen CFS-sufferers, mostly recruited from a large specialist practice in Montreal. Interviews were transcribed verbatim and validated by a research assistant. Transcripts were coded using the identified themes. New codes were created when new issues arose. All themes were subsequently synthesized into overall categories using a constant comparative method.

Results: The literature search yielded thirty-one papers: twenty-eight primary studies and three systematic reviews. Twelve themes were identified and synthesized into four overall problem categories, such as "Lack of professional recognition." Interviews confirmed findings from the literature, but also revealed unidentified needs specific to CFS-sufferers in Québec. Policy recommendations were provided to address these needs.

Conclusions: Multi-Source Synthesis provides a systematic method for synthesizing data from original studies with literature findings, thereby broadening the knowledge base and the local relevance of decisions concerning specific patient populations.

Keywords: Systematic review, Mixed methods, Qualitative research, Research design, Needs assessment

The multi-source synthesis described in this paper was developed with the support of the Agency for Health Technology and Care Services Assessment in Québec (l'Agence d'évaluation des technologies et modes d'intervention en santé; AETMIS). The following people contributed to the study, for which multi-source synthesis was developed, Mathieu Plamondon, librarian (literature search); Micheline Paquin, library technician (literature retrieval); Catherine Lavoie, information officer (translation and transcription of interviews); Marie Glorieux, student assistant (interview transcripts quality checking); Jamie Huxley, copywriter and proof-reader (English language check).

It has been argued that a central reason for health technology assessment's (HTA's) relatively limited success in regulating use of undesirable technologies is the narrowness of the evidentiary basis on which it relies (8). Many decision-makers have realized that information about clinical efficacy and cost-effectiveness is insufficient; understanding the social and ethical implications of introducing new health technologies is also vital. Over the past 10 years, it has been increasingly acknowledged within the field of HTA that qualitative research can be used for examining the perspectives, meanings, values and interests of different stakeholders, including patients and informal carers. It may thereby enable an in-depth understanding of the context in which the health technology will be embedded (13). Consequently, producers of HTAs now often seek to incorporate data from the local context in which the technology will be implemented, requiring integration of very diverse types of data. Although this is a well-known reality of the daily work of HTA-producers, no systematic approach for integrating and contextualizing qualitative and quantitative research findings has yet been agreed upon.

Methods for synthesizing data from primary qualitative studies, such as meta-ethnography and comparative thematic analysis, have already been described (14;17;22). Recently, methods for comparing and combining results from literature reviews of qualitative and quantitative studies have also been proposed (23). However, the integration of both primary and secondary research in one single review remains a key challenge.

Drawing on the conduct of such an HTA report on the psychosocial needs of people suffering from chronic fatigue syndrome in the Canadian province of Québec, this paper aims to address this methodological gap. It will describe a method for combining findings from systematic literature reviews of both qualitative and quantitative studies, with data from a primary qualitative study.

BACKGROUND

In 2007, the Québec Ministry of Health commissioned AETMIS to conduct an HTA which examined the effectiveness as well as organizational, professional and economic aspects of techniques and interventions to diagnose and manage chronic fatigue syndrome (CFS; also known as myalgic encephalomyelitis or ME).

CFS is a condition characterized by pathological exhaustion (particularly after exercise), memory problems, flu-like symptoms, and headaches (5). Prolonged, extensive loss of physical and cognitive function is common. Furthermore, CFS-sufferers are often considered mentally ill or just plain lazy by both health professionals, friends and relatives, and this adds considerably to their suffering (6;9;11;21).

The cause(s) of CFS remains unknown, although it has been linked to certain viral infections, and there is currently no effective diagnostic test or long-term treatment. The

Québec Ministry of Health, therefore, specifically requested that the HTA conducted by AETMIS should identify care and services interventions relevant and useful in addressing the psychosocial needs of CFS-sufferers. This paper describes the innovative method developed and used by the authors to review evidence and integrate it with contextual data for this specific part of the full HTA. The following sections describe this method step-by-step.

MULTI-SOURCE SYNTHESIS

Framing the research

The executives of AETMIS decided that a social science approach would be useful for an in-depth examination of the psycho-social needs of CFS-sufferers. As the focus of the investigation was clear from the outset, a deductive approach was applied. This entails the application of a preliminary theoretical framework, which helps identify the core issues at play (equivalent to hypothesis testing within the natural sciences). A preliminary literature search revealed that loss of function and ability to fulfill daily roles was problematic for CFS-sufferers (21), and difficulties coping with stress could trigger or prolong the illness (1). Consequently, theories about the impact and management of loss of function, and theories on coping strategies were integrated in the theoretical framework.

Then, VHP and PD (in consultation with PL) formulated the following research questions: (i) What are the physical, emotional, and practical problems experienced by CFS-sufferers? (ii) How do CFS-sufferers cope with these problems? (iii) What are CFS-sufferers' experiences with treatment and support interventions in Québec; which types of interventions are (in their opinion) beneficial, and which are needed to provide better support?

To address the first and second questions, a systematic literature search was conducted, while conducting interviews with CFS-sufferers was seen as a relevant strategy to answer the third question, given the need for contextualized data.

Literature Review

A systematic literature search was carried out across carefully selected databases. The databases were chosen because they included publications from disciplines likely to examine the psycho-social aspects of CFS (see Table 1). An effort was made to locate nonpublished studies such as master theses, conference abstracts, etc. Nonscientific literature such as newspaper articles, newsletters from ME/CFS support organizations in Québec, and patient testimonials was also gathered, and later used for triangulation of the findings (see page 242). The databases were searched using the search terms provided in Supplementary Document 1, which can be viewed online at www.journals.cambridge.org/thc2011015.

Table 1. Databases and Journals Searched for Literature (18)

Databases	Anthrosource
	Banque sur la recherche sociale et en santé Campbell Collaboration Library of Systematic Reviews CBCA Complete CINAHL Cochrane Central Registry of Controlled Trials Cochrane Database of Systematic Reviews Database of Abstracts of Reviews (DARE) EMBASE ERIC Francis MEDLINE/PubMed PsychINFO/Psychlit Repère SAGE publications Social Services Abstracts (CSA) Social Work Reference Library (on CD-ROM) Sociological Abstract Sociology: a SAGE Full-Text Collection
Journals	Canadian Review of Sociology and Anthropology Journal of Patient Education and Counselling Medical Anthropology Medical Anthropology Quarterly
Non-scientific literature	Theses from anthropology, sociology and psychology on CFS-patients Relevant conference, symposium and colloquium proceedings and abstracts (e.g. International Conference on ME/CFS) Newsletters and other relevant publications from ME/CFS support organizations in Québec Patient testimonials from Québec patient organizations Internet search engines (Google Scholar)
Inclusion criteria	<ul style="list-style-type: none"> • English and French language • Published between 1994 (year of first published criteria for CFS [5]) and 2008 • Qualitative, case-control, cohort, or controlled before-and-after design • Experiences and/or needs for support and care of CFS-sufferers
Exclusion criteria	<ul style="list-style-type: none"> • Studies on the treatment of CFS with graded exercise therapy, cognitive behavior therapy and various pharmacological interventions (included in another part of the HTA). • Studies on prevalence, psychological and physical co-morbidities, diagnostic criteria, possible causes • Studies on physicians' perspectives on treatment of CFS

All titles and abstracts were screened by VHP as recommended in the PRISMA statement (16). Figure 1 shows a flow diagram of the retrieved and selected literature. A total of 72 papers were read in full by VHP. Study quality was assessed using a well-known checklist for qualitative studies (15), and tools from the Critical Appraisal Skills Programme for systematic reviews, case-control studies, and prospective cohort studies, respectively (20). Cross-sectional studies were assessed using an assessment tool developed by the Institute for Public Health Sciences at Yeshiva University (7). Twelve studies of low quality and twenty-nine studies which did not meet the inclusion criteria were excluded (18, pp. 84–88). In total, thirty-one papers were included; sixteen quantitative studies (including two systematic reviews) and fifteen studies using qualitative methods (including one meta-analysis).

Synthesis of Findings from Literature

Findings from the included quantitative and qualitative studies were synthesized using analysis techniques from pri-

mary qualitative studies, as suggested in various papers (2;17;22;23). Key concepts from the included studies were identified by VHP and “translated” into analytical themes using constant comparison (23). For instance, findings describing physical sensations and problems associated with CFS were described under various themes in the original studies. Using constant comparison, these themes were merged under the analytical theme “Functional limitations.” Findings from the quantitative literature were subsequently grouped under descriptive headings, for instance “Correlations between depression and CFS.”

The two lists of qualitative analytical themes and quantitative descriptive headings were then compared and merged under the analytical themes if they were reported findings on the same subject. For instance, findings from quantitative studies concerning unemployment rates, workdays and financial losses associated with CFS were presented under the analytical theme “Loss of work,” which reported findings from qualitative studies about the impact of CFS on sufferers' experiences of losing their work ability. The synthesis

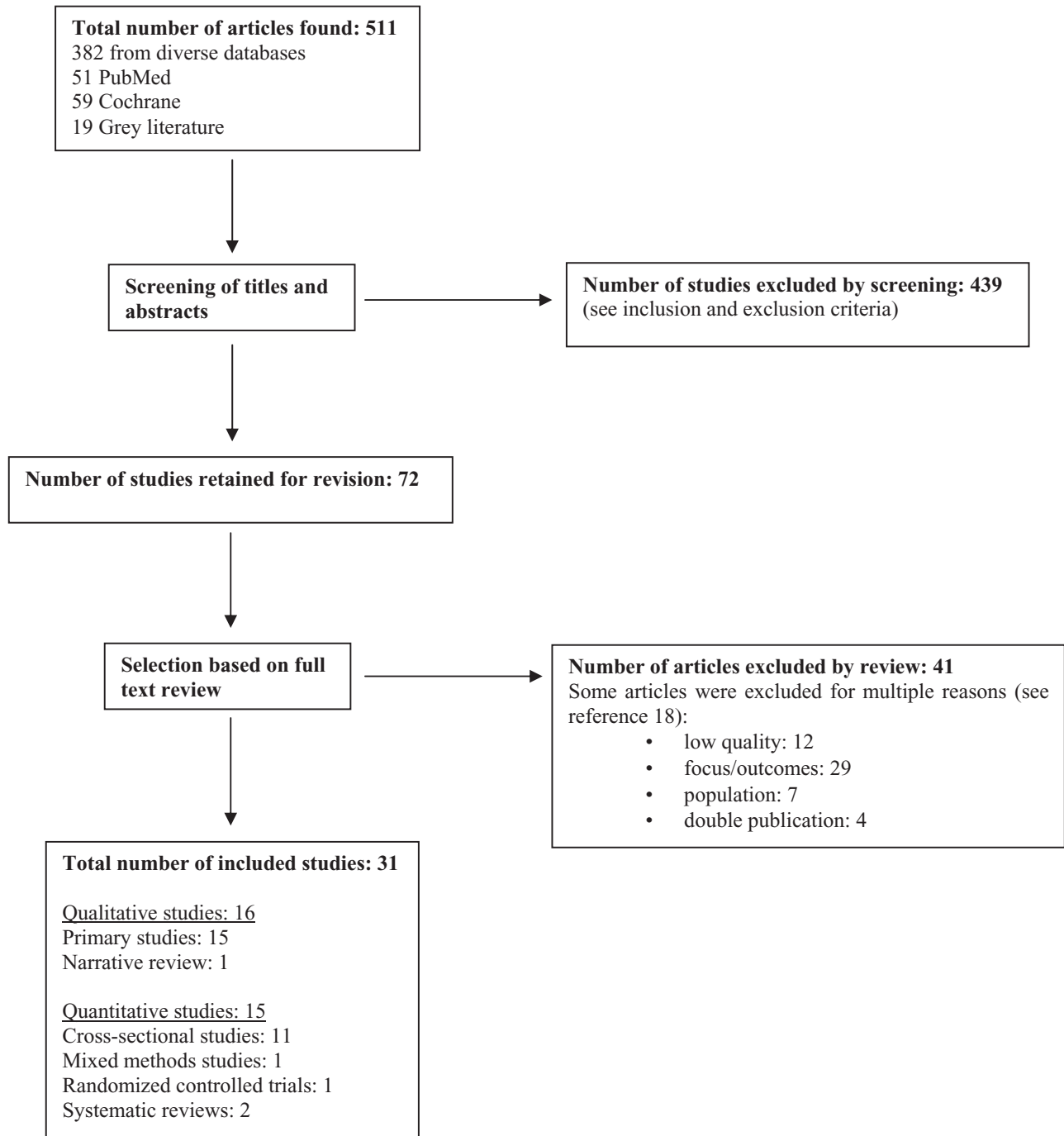


Figure 1. Flow diagram of studies retrieval and selection (18).

of qualitative and quantitative literature resulted in a total of twelve themes.

Design of Interview Guide

To determine the relevance of the literature findings within the Quebec context, the interview guide included questions about each of the twelve themes found in the literature. Furthermore, the interview guide included background questions

(time of diagnosis, received diagnostic procedures and treatments etc.) and questions on suggested care improvements for CFS-sufferers (Supplementary Document 2, which can be viewed online at www.journals.cambridge.org/thc2011015). As people with CFS often have cognitive problems, two CFS-sufferers from a local patient organization reviewed the interview guide to ensure the questions were relevant and the language was clear and comprehensible.

Collection of Primary Data

Individual interviews were conducted to get sufferers' personal experiences on their illness and their encounters with the social services and healthcare system.

Participants were recruited from a large, specialized practice in Montréal, where physicians distributed an information sheet to patients diagnosed with CFS. From a pool of thirty-eight volunteers, twenty interview participants were specifically selected to ensure variety across demographics and illness duration. In total, nineteen individual interviews were carried out (one person withdrew participation before the interview). Two interviews were subsequently excluded from the study as one participant had not been diagnosed with CFS by a health professional, and one sound file was technically unusable. Seventeen interviews were transcribed verbatim. Transcripts were subsequently checked against the recordings by a research assistant.

Coding of Primary Data

Findings from an analysis of interview data—usually described as “themes” in qualitative research—are topics which are considered of central importance to several interview participants. Themes are identified by “coding” the interview transcripts; they are often closely related to the theoretical framework (on which the interview questionnaire was based), but are also inductively identified through the data. For each of the twelve themes initially identified in the literature review, the corresponding interview content was copied into a separate document. Then during the coding process, new codes were created to address topics uncovered by predefined themes. For instance, during the interviews, it became clear that a theme from the literature, “Practical problems,” consisted of several distinct themes. This theme was, therefore, split into the sub-themes; “Work,” “Home life,” and “Finances.”

After the initial coding, the first ten interviews were re-coded to ensure that codes developed over the process were robust and consistent. The final list contained a total of thirty-seven codes, comprising the twelve themes from the literature and twenty-five themes that had emerged from the interview analysis.

Synthesis of Primary and Secondary Data

The analysis was conducted using a thematic approach. This involves grouping data in themes, then examining the whole data set to ensure that all the manifestations for each theme have been accounted for and compared (17).

The grouping of themes was performed by reading the selected interview sections in each theme document and comparing these documents to identify connections between themes. The identified connections were used to draw up an Analytical Map (Table 2) where all the identified themes were organized in relation to each other. Themes were grouped and regrouped on the analytical map until all theme documents

had been analyzed. This resulted in four overall categories each representing a “cluster” of interrelated problems, coping strategies and associated needs as they emerged in the interviews.

Triangulation with Nonscientific Literature

Triangulation means that different research methods are used to collect data about the same phenomenon. This increases the thoroughness of the analysis and robustness of the study findings (19). Synthesizing data from a systematic literature review with findings from interviews is in itself a form of triangulation, as several data collection methods are used to gather data. However, to ensure that the study findings would have local relevance, nonscientific literature retrieved in the literature search served as a context-specific triangulation. The retrieved nonscientific documents (see reference 18 for full list), such as newsletters from CFS patient organizations and newspaper articles about CFS were read by VHP, and any themes reported in these documents were noted. The nonscientific documents helped contextualize the interviewees' perspectives by comparing and contrasting them with those made public by the broader Quebec community of CFS-sufferers.

Conclusion of Combined Data Analysis

For each of the four identified problem categories, findings from the literature, interviews and nonscientific literature were compared, and similarities and differences highlighted. In this way, the core issues which were of particular relevance to CFS-sufferers in Québec became clear. For instance, the final analysis confirmed literature findings: physical and cognitive incapacities associated with CFS are distressing, potentially leading to unemployment and serious financial problems. However, the interviews showed that for CFS-sufferers from Québec, the loss of autonomy (physically and economically) which followed from these incapacities was perceived as deeply shameful and frustrating. Another important finding, owing to the synthesis of data from different sources, was that CFS-sufferers from Québec appear to make use of certain coping strategies which they consider beneficial and which are not described in the literature (18). The triangulation confirmed that these coping strategies were not only used by the interviewed participants, but were also mentioned in patients' organization newsletters and other nonscientific literature.

Policy Recommendations

Based on the analytical conclusions made for each category of problem, recommendations were made for changes in existing care and support services, and for possible new methods of support, which could address the problems identified. To this end, existing health care, social service policies, and laws were consulted to verify anecdotal interview statements and suggest changes. For instance, offering CFS-sufferers

Table 2. Analytical Map (18)

Problem category	Ways of coping	Support needs of sufferers
1. Reduced physical and cognitive capacity <ul style="list-style-type: none"> ● Physical functioning ● Loss of autonomy ● Work ● Finances 	<ul style="list-style-type: none"> ● Energy preservation (planning of activities, making physical adaptations to reduced mobility) ● Visualization (making lists, schemas, and use metaphors to communicate about the illness) ● Staying active (continue activity despite of symptoms) ● Listening to the body (rest is a necessity, not optional) 	<ul style="list-style-type: none"> ● Diagnosis (eliminate fears) ● Practical help ● Psychological support
2. Emotional burden <ul style="list-style-type: none"> ● Negative emotions ● Personal growth ● Reorientation 	<ul style="list-style-type: none"> ● Denial (of the illness and the symptoms, and even of bettering; “function on adrenaline”) ● Spirituality (prayer or meditation) ● Hope (focusing on the possibilities for cure or improvement) ● Venting (talking to others to overcome emotional stress) ● Acceptance (of the illness and altered life situation) ● Positive thinking (focusing on positive sides of the new situation) ● Reorientation (finding new meaning in life) 	<ul style="list-style-type: none"> ● Support group ● Psychological support ● Practical help
3. Social isolation <ul style="list-style-type: none"> ● Moral questioning in social networks ● Isolation 	<ul style="list-style-type: none"> ● Reorientation (finding new meaning in life) ● Avoiding stigma (pretending to be well, social withdrawal, not admitting to the illness, impression management, educating peers) ● Visualization (making lists, schemas, and use metaphors to talk about the illness) 	<ul style="list-style-type: none"> ● Advocacy for the illness in the general population ● Information (targeting relatives) ● Support group
4. Delegitimation and stigma <ul style="list-style-type: none"> ● Lack of professional recognition ● Stigma ● Insurance and social welfare ● Organization ● Diagnosis 	<ul style="list-style-type: none"> ● Non-medical treatment—looking for help and compassion elsewhere (alternative medicine, self treatment with vitamins, diet, massages, healing, or similar therapeutic measures) ● Active illness management—trying to “beat” or outsmart the system and find a way to get better treatment/care (making schemas for pills, preparing for consultations, registering bodily signs such as pulse, temperature, changing doctor if disagreements occur, educating doctor, filing formal complaints) 	<ul style="list-style-type: none"> ● Advocacy for the illness in the general population ● Education of health professionals and social workers ● Further research (into the nature of the illness) ● Specialized clinic/center ● Better organization of care ● Education of health professionals

more practical help with domestic tasks was proposed. This would allow them to conserve energy for work, child care or socializing, thereby increasing physical autonomy, social involvement and financial independence. The recommendations thus focused on interventions providing care and services suggested in the interviews (and to some extent in the literature review).

DISCUSSION

Scholars have increasingly called for, and proposed methods for retrieving and synthesizing studies that address patients’ perspectives and ethical issues (3;4;13).

When a given HTA report examines an intervention that is complex and may involve “multi-factorial outcomes rather than a causal chain” (2), a multi-source synthesis approach has the potential to contribute more significantly to policy-making, because it addresses specific knowledge gaps in the literature while simultaneously summarizing available evidence.

For the study of psychosocial needs of CFS-sufferers in Québec, the Multi-Source Synthesis method outlined in this paper proved very useful for contextualizing literature findings with local context data. Not only did the findings confirm several issues identified in the literature; the inclusion of interviews and nonscientific literature provided additional information about coping strategies used by CFS-sufferers in Québec and organizational issues specific to the Québec society (18). For instance, CFS-sufferers’ access to financial and social support was restricted because CFS was not categorized as a disabling health condition within the Québec social service system at the time of the study. Because these specific issues were identified, policy recommendations resulting from the analysis were “actionable” and more pertinent to the local context than recommendations based on a systematic literature review alone. It has been argued that access to a broader spectrum of evidence could help policy makers make difficult decisions in a more transparent and legitimate way, thus enhancing the probability of regulating use of health technologies (8). The relevance of using Multi-Source Synthesis in HTA is precisely that it combines such

transparency with more dynamic knowledge acquisition, thereby ensuring that decisions about medical technologies are made on a broader and more robust knowledge base.

Although it has long been acknowledged among HTA researchers that users' perspectives on healthcare services and technologies should be examined and incorporated into HTAs, such extensive evaluations are still not standard (12). One explanation for this could be the current paucity of well-described methods and practical guidelines for how to include such data. The Danish agency for HTA (DACEHTA) has recently published additional chapters for their methodological textbook, regarding the use of qualitative data for assessing patients' perspectives on health technologies (10). However, these chapters appear not to contain information about synthesis of literature findings with data from primary studies. Although many HTA producers are undoubtedly familiar with some of the processes described in this study, Multi-Source Synthesis offers a step-by-step approach to synthesis of data from multiple sources (Fig. 2). We, therefore, hope that this method can help HTA producers by saving them time and resources otherwise spent on developing original methods each time they conduct needs assessment studies, while simultaneously enabling increased use and utility of qualitative data in HTA. The use of more clearly described analytical techniques, such as Multi-Source Synthesis, would enhance transparency when synthesizing qualitative and/or contextual data, thus enabling comparison with between studies. Furthermore, the method incorporates an internal validation of the analytical results through triangulation with nonscientific sources. Thus Multi-Source Synthesis can enhance the robustness of qualitative and contextual data synthesis used within HTA, while at the same time increasing the meaningfulness of findings to decision-makers.

As with all methods, using Multi-Source Synthesis also has some limitations. It has been argued that combining findings from studies using qualitative and quantitative methodologies can make it difficult to develop theories about the findings, because of the different epistemological foundations of the two types of studies (3). Thus Multi Source Synthesis is probably not suited for theory development, but instead seeks to provide nuanced and contextualized descriptions of empirical phenomena. Furthermore, Multi Source Synthesis is mostly relevant for HTA's for which analysis of user needs or patients/providers perceptions can influence the effectiveness and appropriateness of management and treatment options. Whereas HTA's on medical techniques or drugs would rely more on data from clinical trials describing their clinical effectiveness, in which case a traditional meta-synthesis would be a more appropriate method. More practical limitations are that the method requires skill in qualitative data analysis and by nature is time-consuming, making it somewhat more costly than systematic reviews alone. However, investing in research which, while taking longer, ulti-

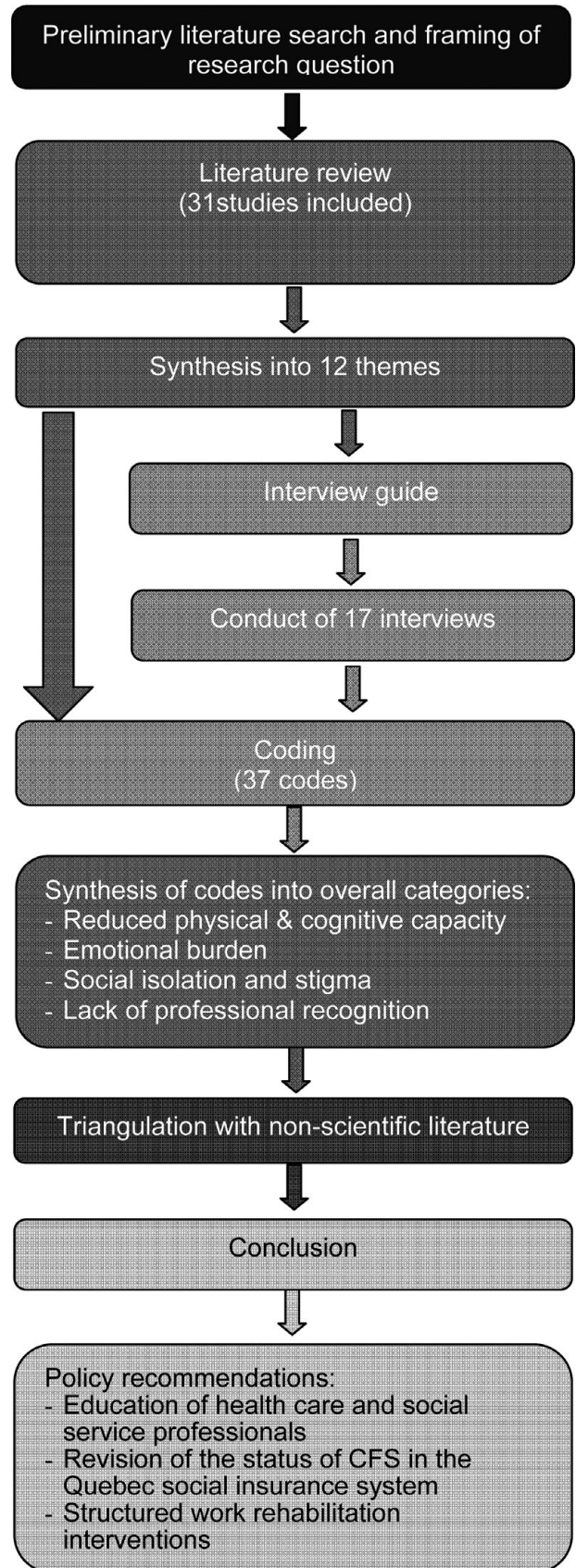


Figure 2. Overview of Multi-Source Synthesis.

mately provides more relevant answers to decision-makers' questions, is often worthwhile. This is particularly true when there is no data from the local context and patients' needs are left unaddressed.

The subjective nature of data selection can also be considered a methodological limitation. It is crucial to remember that findings from quantitative and qualitative studies often examine fundamentally different things. Consequently, it is not always possible to integrate data under one theme or headline. Outlying or contradictory findings should be presented openly so their relevance to the overall aim of the research can be discussed. Finally, it is important to keep in mind that using Multi-Source Synthesis is to some extent a pragmatic activity, which takes time and skill to master. As it is also a new method, it is, therefore, both likely, and desirable that it will be adjusted to different settings.

CONCLUSION

Multi-Source Synthesis offers a new method for systematically integrating quantitative and qualitative data from literature and primary studies. This method has some limitations in that it is time-consuming and requires skill and experience in collecting and analyzing qualitative data. However, the advantages of the method are substantial. It makes it possible to inform decision-makers directly on issues important to patients and other users/stakeholders in their local area, while simultaneously allowing for comparison with findings from other countries/areas. In this way, scientific knowledge can be made immediately relevant to the local area where new services or health technologies are to be implemented. Using Multi-Source Synthesis thus enables the provision of a solid knowledge base for decision-makers, while at the same time including the perspectives of local users and other stakeholders.

SUPPLEMENTARY MATERIAL

Supplementary Document 1

Supplementary Document 2

www.journals.cambridge.org/thc2011015

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CONFLICT OF INTEREST

All authors report they have no potential conflicts of interest.

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