Review

The experience and impact of chronic disease peer support interventions: A qualitative synthesis

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A R T I C L E   I N F O

A B S T R A C T

Objective: Our aim was to synthesise qualitative literature about the perceived impact and experience of participating in peer support interventions for individuals with chronic disease.
Methods: We carried out a meta-ethnography to synthesize 25 papers meeting specific inclusion criteria.
Results: Thirteen concepts were identified that reflected participants' perceptions of the experience and impact of intervention participation. These were brought together in a conceptual model that highlighted both positive and negative perceptions, while also indicating if specific experiences and impacts had greater pertinence for mentors, mentees, or were mutually experienced.
Conclusion: Although peer support interventions may establish uneven power relationships between mentors and mentees, there is also potential for initially asymmetrical relationships to become more symmetrical over time. Our synthesis suggests that emotional support is particularly valued when delivered under conditions that do not merely reproduce biomedical hierarchies of power.
Practice implications: This synthesis suggests that those developing and implementing peer support interventions need to be sensitive to their potential negative effects. They will need to manage the tension between the hierarchical and egalitarian aspects of peer support interventions, and consider the impact on both mentors and mentees.

1. Introduction

The burden of chronic disease continues to grow, due to aging populations, lifestyle factors, and improved treatment of acute illness [1]. Healthcare systems are struggling to contain this increasing burden, and however well-resourced a healthcare system, the burden of chronic disease management increasingly falls on patients and their caregivers. This is seen in the contrast between the limited patient time spent in consultations with professionals and the considerable time spent by patients themselves taking treatments, managing medications, diet and exercise, and monitoring biomedical indicators, such as blood sugars or blood pressure [2,3]. These time-consuming self-care activities are usually undertaken with intermittent supervision from health professionals. The importance of social support for effective disease self-management has long been recognized in mental health [4] and physical health [5], and often naturally occurs within families and communities.

Chronic disease management is a complex process, requiring multilayered input involving the individual, the health and other sectors, and broader society [6–8]. Self-management, an essential element, has been defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" [9]. The Chronic Care Model is perhaps the best known framework for the comprehensive management of this process [10,11]. However, until recently, few programs existed to support patients in their self-management roles. Examples are Lorig's Arthritis Self-Management program in the US [12], and the Expert Patient Program [13] and DAFNE (Dose Adjustment For Normal Eating) and DESMOND (Diabetes Education and Self Management for

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Ongoing and Newly Diagnosed) [14,15] in the UK. These are group-based programs, offering economies of scale and potential for peer support interventions. It is likely that self management, including peer support, will play an increasingly important role for the growing numbers of people with chronic diseases.

In this paper, peer support is considered a unique type of social support provided by those who share characteristics with the person being supported and is intentionally fostered within formal interventions. Dennis defined peer support as "the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behavior or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person" [16]. All three types of assistance are based on experiential knowledge rather than formal training. Dennis distinguished peer supporters who participate in formal interventions from "natural lay helpers" (those to whom people turn naturally within their own communities, but who do not usually have the same diseases as those they help), and from "paraprofessionals" (those who have been trained in their peer support role to such a degree that they identify more with the professional role than with the person being supported) [11]. Although peer support and mentoring are not synonymous [17], this paper uses the terms "mentor" and "mentee" to refer to peer supporters and those being supported, respectively.

Peer support interventions are highly variable in format (e.g., small groups, one-to-one in-person or by telephone, web-based chat rooms), amount of mentor training, and group composition (e.g., homogenous or mixed, disease type). There are few analyses of participants' experience of peer support interventions, and few conceptual frameworks exist linking the different elements of peer support. Peers may have the potential to influence health outcomes of other patients by addressing feelings of isolation, promoting a positive outlook, and encouraging healthy behaviour [16]. A better understanding of what actually takes place in peer support interventions is needed, to tease out how peer support works, in what circumstances and for whom. This paper synthesizes qualitative research about the experiences and perceived impacts of peer support interventions across multiple chronic diseases, and in so doing, works towards a conceptual model. It also aims to identify both positive and negative aspects of peer support, and examine which experiences and perceived impacts have relevance for mentors and mentees. Given the growing interest in developing evidence based peer support interventions for people with chronic illness [17], it is important to build on what is already known. We aim to contribute to the development and implementation of future interventions.

2. Methods

The technique of meta-ethnography was chosen for qualitative data synthesis as it is an interpretive method that preserves the qualitative nature of the material being synthesised [18]. Meta-ethnography encourages a clearer understanding of how concepts in different studies are related to each other. This mutual "translation" preserves the structure of relationships between concepts within any given study, thereby reducing the possibility of de-contextualization [19]. The value of meta-ethnography lies not only in its ability to retain the meaning of primary data, but also in its potential to enable a higher level of analysis and generate new conceptual models.

Meta-ethnography requires a literature search strategy, abstract selection, quality appraisal, and extraction, translation, and synthesis of concepts [19]. These stages were carried out by a team of 17 researchers including two people with arthritis (one of the chronic diseases included in the synthesis). Regular face to face,

tele- and video-conference meetings were held over 30 months. A customized web-based platform facilitated data extraction and analysis of the identified articles.

2.1. Search strategy

Seven comprehensive, on-line literature searches were conducted across the following disease categories: rheumatic disease, HIV/AIDS, cardiovascular disease (CVD), cancer, asthma, diabetes, and chronic disease. These diseases were identified by team consensus and by a desire to focus on physical diseases. Searched databases included MEDLINE (Ovid SP), EMBASE (Ovid SP), CINAHL (EbscoHOST), PsycINFO (Scholars Portal), ERIC (Scholars Portal), Social Sciences Citation Index (Scholars Portal), Social Work Abstracts (Scholars Portal), Cochrane Database of Systematic Reviews, The Cochrane Library (Wiley Interscience), and DARE (Centre for Reviews and Dissemination). There were no date restrictions. Studies were published in English. Manual reference searches were conducted from retrieved articles and tables of contents of relevant journals.

2.2. Abstract selection

Interventions that featured individuals with a chronic disease and a structured peer support intervention led or co-led by a peer were included. Studies needed to feature qualitative methods (see Appendix A for selection criteria). Original searches (October 2008–January 2009), were updated in March 2010 and April 2011. All abstracts were reviewed independently by two individuals for inclusion, with discrepancies between reviewers discussed, and agreement sought by consensus.

2.3. Quality appraisal

A pair of reviewers independently evaluated each selected article using a quality assessment tool [20] coding eligible papers into a data extraction form. A third researcher reviewed disputed papers. This process followed well established procedures; and those conducting meta-ethnographies have not usually published inter rater reliability coefficients for example [19].

2.4. Concept extraction and analysis

Concepts (ideas or metaphors with explanatory rather than descriptive potential) were identified within each included paper [18,19]. First order concepts refer to respondents' terms (direct quotations) expressing key ideas; second order concepts are authors' interpretations of participants' key ideas (for example, themes identified by authors). Third order concepts are reviewers' re-interpretation of these concepts, interpretations that must be congruent with interpretations of individual studies, while extending beyond with potentially richer explanatory potential [19]. During concept identification, reviewers extracted data on intervention format, disease, and type of participant (see Table 1), setting, mentors' roles, training, and socio-demographic characteristics, to contextualize results.

To identify concepts across included articles, each article was independently reviewed by three to four individuals. This enabled a rich interpretation of each article from multiple perspectives, thereby encouraging identification of a broad range of concepts. First and second order concepts in each article were identified and defined. Definitions allowed reviewers to establish whether a particular concept meant the same thing across papers and whether new descriptors were needed. Thirty-six concepts were first identified. Similar or related concepts were grouped together to produce 13 key concepts.