

## Review

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

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## ABSTRACT

**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.

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### 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.

**Table 1**  
Intervention format, disease, and participant type.

Participant type	Articles	Disease type	Format
<i>One on one (face-to-face)</i>			
Mentors	Hilfinger Messias [23]	HIV	Peer meetings took place every 2–3 weeks for a 6 month period.
<i>Group</i>			
Mentees	Barlow [34]	RA	Challenging arthritis course—the UK version of the Arthritis Self Management Program (ASMP) – comprises of 6 weekly sessions, each of 2.5 h in duration.
	Barlow [33]	Chronic disease	The Chronic Disease Self-Management Course (CDSMC) comprises 6 weekly sessions, each lasting approximately 2 h, guided by a manual, membership of the voluntary organization was not mandatory
	Barlow [36]	RA	The ASMP consists of six sessions of 2 h durations every week delivered in community settings by pairs of lay leaders.
	Barlow [22] Beckmann [37]	Chronic disease Cancer	CDSMC format Programs were delivered as outlined in the chronic disease self-management workshop leaders manual (Stanford Patient Education Centre, 1999). The program is usually offered as a six-week structured course for groups of 12 to 16 participants.
	Coward [39] Fu [41]	Cancer Asthma	8 weekly group sessions, 1.5 h/session Intervention followed the Chronic Disease Self-Management Program (CDSMP) course which consists of seven sessions, 2–2.5 h per session over 7 consecutive weeks, delivered to groups of 10–15 people in community settings according to the CDSMP leaders manual.
	Gifford [21]	HIV	7 weekly educational sessions of 2.5 h each, for a total of 17.5 h. Each group was composed of 10–15 HIV-positive individuals.
	Hyde [44]	HIV	Format differed. Included the AIDS project Los Angeles (offers educational forums and multi-session small-group workshops), Los Angeles Gay and Lesbian center's positive images consortia and tarzana treatment center (offers forums and multisession small-group workshops to both newly diagnosed and HIV-positive individuals who were diagnosed longer than 2 years), Los Angeles Shanti (offers LOVE positive seminars, multisession small-group workshops conducted across one weekend with a series of nine weekly follow-up support groups).
	Struthers [48]	Diabetes	The talking circle, a culturally appropriate, 12 week educational intervention
Mentors	Barlow [35] Hainsworth [42]	Chronic disease RA	CDSMC format The course comprises 6 weekly sessions, each of two and a half hours duration led by pairs of lay leaders.
Mentors and mentees	Dietrick [40]	Diabetes	12-h, 6-week, Spanish-language, promotora-led, diabetes self-management education program ("Learning about diabetes") or "promotora program." Two-hour class sessions were held each week.
	Stewart [47]	CVD	5 support groups (ranging in size from two to three couples) were held 1 h weekly for 12 weeks.
	Wilson [13]	Chronic disease	Two interventions were included; the lay-led Expert Patients Program (EPP) and an 8 week professional-led Back Fitness Course (BFC) The BFC comprised of weekly 2 h sessions; the EPP comprised of weekly 2.5 h sessions over 6 weeks.
<i>Telephone</i>			
Mentors	Whittemore [32]	CVD	12 week telephone peer support intervention
Bidirectional (no designation of mentor/mentee)	Heisler [43]	Diabetes	A prototype interactive voice response peer support system was tested with patient pairs.
<i>Mixed</i>			
Mentors	Brown [31]	Asthma	One-on-one face-to-face and telephone contact. An Initial consultation of up to 45 min was followed by a second face-to-face reinforcing session of up to 30 min duration, three weeks after the first consultation and 3 monthly telephone follow-up for 12 months.
	Marino [45]	HIV	Mix of group and one-on-one (telephone and face-to-face). Twice-monthly one-hour group meetings were held at a clinic, and phone calls from mentors to their assigned participants were made thrice weekly. Peers remained actively involved for an average of 11 months.
Mentees	Carlsson [38]	Cancer	Swedish patient associations for breast cancer patients offer support in both one-on-one and group formats
Mentors and mentees	Harris [24] Joseph [25]	HIV Diabetes	Format not described One hour face-to-face meeting and then telephone calls on a weekly basis for a 10–15 min discussion for 8 consecutive weeks
	Sheppard [46]	Cancer	Intervention was integrated within an existing Latino breast cancer community program and consisted of one in-person session at patients' homes and a phone follow-up one week later.
	Sutton [30]	Cancer	Mutual dyadic support intervention. Each dyad connected by telephone or by face-to-face meetings at least twice per week during the 8-week intervention.

**Table 2a**  
Article review summary.

Search	Abstracts reviewed	Total articles retrieved	Quality appraisal	Articles included
Rheumatic disease	1298	209	12	3
Cancer	4631	219	11	5
Diabetes	3853	365	7	3
Asthma	1947	205	1	1
CVD	3563	125	6	3
HIV	3579	96	10	4
Chronic disease	2618	193	11	6
Total	21,489	1412	58	25

Next, a key concept grid was produced, with data extracted on how each article containing the concept defined or related to it from the perspectives of study participants (first order), and study authors (second order). A record was kept of whose first order perspective was represented – mentors, mentees, or both. Finally, the research team produced third order definitions for each key concept through the process of translation [18]. The final synthesis was achieved by analysing and representing the relationships between the third order translations of the 13 key concepts.

### 3. Results

Of 21,489 abstracts identified, 1412 qualified for full-length article review, and 58 for quality appraisal. Of these, 15 disputed papers were reviewed by a third team member. Following the quality assessment guidelines established by Letts et al. [20], thirty-three papers were rejected, for reasons ranging from qualitative data being minimal, to lack of methodological rigour. Twenty-five papers (asterisked under references) were included. Table 2a summarizes the entire process, while Table 2b shows the reasons for rejection.

Table 3 shows concepts distributed across papers, by disease type. Most concepts were unrelated to specific diseases, an exception being “social isolation,” a subcategory of “isolation.” Isolation was experienced in various forms across all chronic diseases, but social isolation as associated with feelings of shame, rejection and social stigma, was most pertinent to HIV. The 13 identified concepts formed the building blocks of the conceptual model, shown in Fig. 1. This model represents a range of documented experiences and impacts during and after the process of providing and receiving peer support. It suggests a motivation for participants’ interest in peer support (isolation) and represents the distinct and overlapping ways in which mentors and mentees experienced the intervention during and after participation. During the intervention, notions of sharing had resonance for mentees, while experiential knowledge, reciprocity, helping, role satisfaction, and emotional entanglement had meaning for mentors. Both groups also related (albeit differently) to concepts such as sense of connection, isolation, and finding meaning. Once the intervention concluded, perceived outcomes across groups

**Table 2b**  
Quality appraisal.

Rationale for exclusion	No. of papers
Qualitative data lacking, limited, or lacked rigour	11
Absence of/inadequate analysis	4
Descriptive; no purposeful study conducted	1
Study yet to be conducted (e.g., focuses on aspects of setting up program)	4
Review	1
Not pertinent to scope of research topic	5
Did not meet inclusion criteria	6
Duplicate	1

included finding meaning; empowerment; and changed outlook, knowledge, and behavior.

#### 3.1. During intervention: mentors’ and mentees’ experiences

##### 3.1.1. Sense of connection

Mentors and mentees experienced mutual feelings of rapport. A shared disease fostered this bond, yet was often not enough to facilitate closeness. Facing similar challenges and disease experiences, personal and social characteristics, lifestyles and life experiences, cultural value systems, a shared commitment to the program, and reciprocal support, all helped to forge a sense of connection. The resulting supportive environment reduced feelings of isolation. Conversely, a perceived lack of similarity with peers (e.g., due to different social circumstances, value systems, ages, illness experiences) hindered rapport. Two interventions [21,22] featured a range of diagnoses, skills, and knowledge about the same chronic disease, but participants felt they benefited from this blend.

##### 3.1.2. Experiential knowledge

Mentors’ personal life experiences were seen as “an essential resource” for peer mentoring [23]. Mentors used these experiences to gain entry into mentees’ lives, build relationships, steer mentees toward economic, social, and health resources, and help them overcome fear and stigma. Mentors shared life experiences relating to the challenges and successes of living with disease, self-care and coping strategies, and navigating the healthcare system. Mentors’ instruction had higher impact than information-provision alone because of its grounding in personal experience and shared identity. Therefore, the mentor-mentee relationship was characterized as “a genuine relationship between equals, containing little power imbalance” [24]. Mentees perceived mentors as role models, sympathetic, understanding and easy to relate to, and as having authority, credibility, and more insight into their feelings and daily experiences than professionals. Mentors’ support and validation were grounded in a “personal understanding of how difficult it is to change behavior” [25]. At the same time, mentors were aware of the limits of experiential knowledge and the need to transcend it in order to understand experiences that may be unlike their own. Other limitations included mentors’ inability to answer medical questions, and maintaining confidentiality for peers in small communities.

##### 3.1.3. Finding meaning

Finding meaning referred to the process of finding value in one’s life within the context of a chronic disease diagnosis. It occurred during peer support, but was also a longer-term impact of intervention participation. A chronic disease diagnosis often entailed a loss of meaning, purpose and hope. A search for new meaning was an important part of hope and healing. Finding meaning involved reaching outwardly toward awareness of others and one’s environment; inwardly toward greater insight into personal beliefs, values, and dreams; temporally toward the

**Table 3**  
Distribution of concepts across articles, by disease type.

Disease type	Articles	Sense of connection	Experiential knowledge	Finding meaning	Isolation	Sharing	Helping	Reciprocity	Role satisfaction	Emotional entanglement	Changed outlook	Changed behaviour	Changed knowledge	Empowerment	
		During intervention										Post-intervention			
		Mentors and mentees					Mentee	Mentor	Mentors and mentees						
RA	Barlow [34]	✓			✓	✓					✓	✓			
	Hainsworth [42]	✓	✓	✓			✓		✓		✓				
	Barlow [36]	✓	✓		✓						✓	✓	✓		
Chronic disease	Barlow [35]		✓	✓	✓		✓		✓		✓	✓	✓	✓	
	Barlow [33]	✓	✓		✓		✓	✓			✓	✓	✓		
	Wilson [13]		✓		✓	✓					✓	✓	✓	✓	
	Barlow [22]	✓	✓		✓	✓					✓	✓	✓	✓	
Cancer	Carlsson [38]	✓			✓	✓							✓	✓	
	Sutton [30]	✓			✓		✓	✓			✓		✓		
	Coward [39]		✓	✓		✓				✓	✓	✓	✓		
	Beckmann [37]	✓			✓	✓					✓		✓		
	Sheppard [46]		✓										✓		
HIV	Harris [24]		✓	✓	✓		✓				✓	✓	✓	✓	
	Marino [45]	✓			✓		✓	✓	✓	✓	✓		✓	✓	
	Gifford [21]	✓			✓		✓				✓	✓	✓		
	Hyde [44]	✓	✓		✓	✓					✓	✓	✓		
	Hilfinger Messias [23]	✓	✓	✓	✓		✓	✓		✓			✓		
CVD	Whittemore [32]	✓	✓	✓			✓	✓	✓	✓		✓	✓		
	Stewart [47]	✓	✓		✓		✓	✓			✓	✓	✓		
Diabetes	Dietrick [40]		✓				✓	✓			✓	✓	✓	✓	
	Heisler [43]	✓		✓		✓		✓			✓	✓			
	Joseph [25]		✓				✓				✓	✓			
	Struthers [48]	✓				✓					✓	✓	✓		
Asthma	Brown [31]		✓		✓		✓		✓	✓			✓	✓	
	Fu [41]										✓	✓	✓		

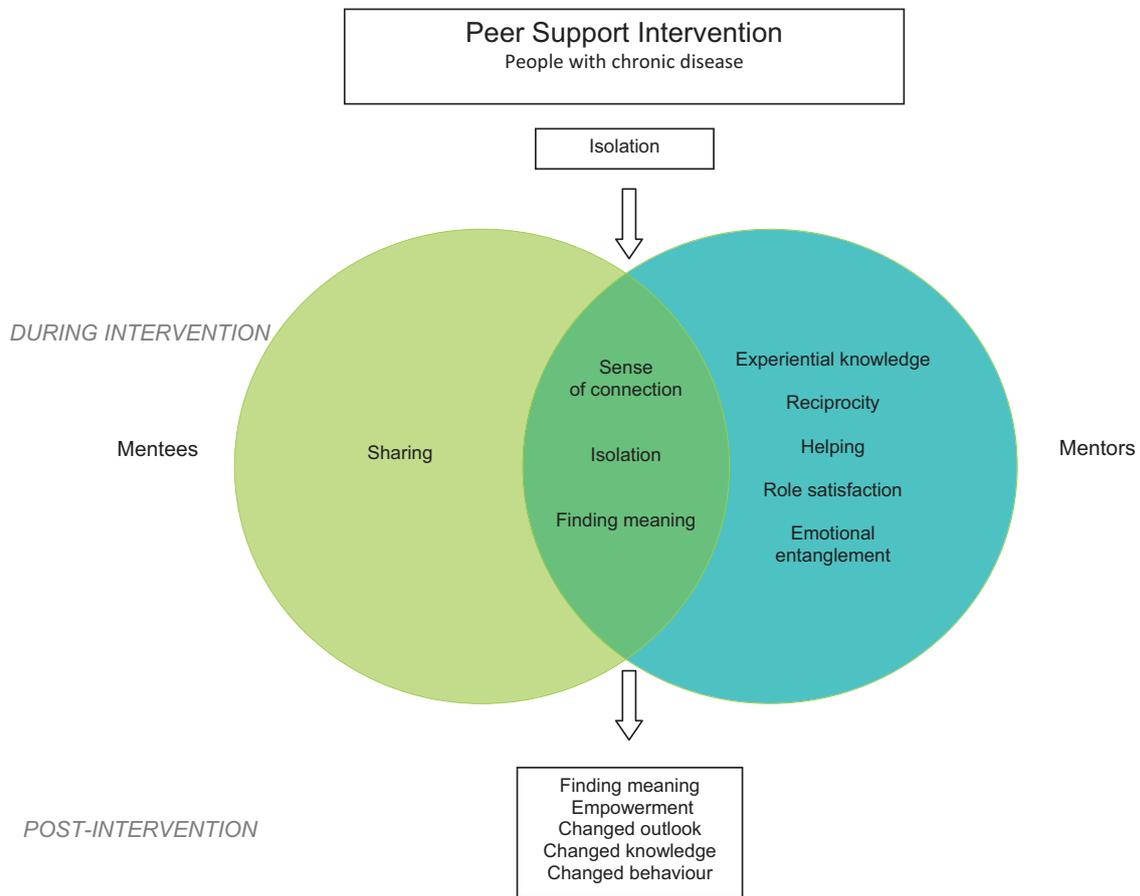


Fig. 1. The perceived impacts and experiences of peer support.

integration of past and future in a way that enhanced the present; and transpersonally towards an awareness of dimensions beyond the typically discernible world [26–29]. Through peer support, individuals re-evaluated their way of being in the world and redefined what was important to them.

#### 3.1.4. Isolation

Isolation referred to the sense of alienation, loneliness, and frustration that may be part of an individual's experience of disease and peer support. Experienced on multiple levels, isolation could result from receiving a chronic disease diagnosis, prompting the need for peer support, but, it could be both alleviated and reproduced during peer support interventions. Reducing isolation was an important outcome of successful interventions. Meeting and sharing experiences with similar others in a safe and non-threatening peer support context reduced feelings of being alone, normalizing the disease experience and promoting acceptance. Mentoring decreased mentors' own sense of isolation by allowing them to forge meaningful human connections and cultivate hope. Yet, participants could also experience isolation within peer support interventions, due to a mentor's unfamiliarity with a mentee's condition, or when individuals perceived partners had dissimilar lifestyles or personalities. Mentors working in healthcare settings could feel isolated due to lack of support and even hostility from professionals. Some participants informally extended the peer support network beyond the intervention itself; others were discouraged when organizers did not facilitate maintenance of these networks post-intervention.

#### 3.2. During intervention: mentee-specific experiences

##### 3.2.1. Sharing

Sharing by mentees referred to the exchange of experiences relating to living with disease, associated emotions, and coping strategies. While sharing was facilitated by a common disease, mentees found that sharing the consequences of disease was also possible across heterogeneous medical conditions. Sharing normalized participants' conditions, engendered feelings of peer belonging and acceptance, reduced isolation, and built community. While sharing energized participants, and fostered hope and empowerment, individual negativity could adversely impact group dynamics. The potential existed for negative social comparison, as well as a competitive culture of whose condition was worse.

#### 3.3. During intervention: mentor-specific experiences

##### 3.3.1. Helping

Helping involved the provision of assistance by mentors on an individual, communal, and institutional level. It included giving advice and assisting with problem solving, alleviating fear, advocacy, confronting health disparities, combating barriers created by fear and stigma, being a bridge between the healthcare system and community, encouraging the development of a "moral conscience" to reduce high risk behavior (in the case of HIV), and providing emotional, informational and appraisal support. Helping others enabled mentors to find meaning in their own disease. It could improve morale, self-esteem and well-being, thereby providing a sense of empowerment. Helping had a moral

dimension, with individuals attributing altruistic motives for their behaviors. Risks were involved, as when mentors felt left behind, unable to make change, or live up to their own advice. Helping roles may transform over the course of a peer relationship, becoming reciprocal over time.

### 3.3.2. Reciprocity

Despite expectations that peer-to-peer relationships would be unidirectional, asymmetrical, and hierarchical, being a peer mentor afforded opportunities for mutual sharing and benefit, an important facilitator of reciprocity. When sharing between mentor and mentee moved from health issues to social contexts, the relationship often changed and evolved into a more reciprocal one, so that mentors too benefited. Mentors had opportunities for personal growth and empowerment, found meaning and positive enforcement for their own behavioral goals, and got personal satisfaction from receiving and giving support. The intimacy of mutual sharing also carried risks, potentially leading to feelings of emotional entanglement, tension and conflict. Mentors felt a lack of reciprocity in relationships in which they did all the giving without receiving any support in return. Misunderstanding could occur when one partner believed the relationship to be reciprocal, while the other did not [30].

### 3.3.3. Role satisfaction

Role satisfaction referred to the extent to which mentors experienced fulfilment in their mentoring role. Mentors experienced satisfaction through the knowledge of being valued and adding value to the lives of others, and occupying a valued societal role. Witnessing improvement in mentees' health contributed to role satisfaction. Mentors had a sense of "mattering" by helping, and when their help did not make a difference or was not needed, mentors lacked personal fulfillment. Role satisfaction was negatively affected by burdensome administrative tasks, participant recruitment, and mandated rigid adherence to intervention protocols. Mentors could feel rejected when mentees dropped out of a study, did not turn up to scheduled appointments or return phone calls.

### 3.3.4. Emotional entanglement

Emotional entanglement was a risk associated with the emotional connections forged between mentors and mentees. It occurred when a mentee's personal or health problems became overwhelming and placed the mentor's well-being at risk; when mentors revisited negative emotions related to their personal experiences; when relational boundaries became blurred; and when severing peer relationships led to a sense of loss. Mentors' strategies to navigate these concerns included refusing to take on mentees if the relationship had the potential to threaten the mentors' health and well-being (particularly in the case of HIV), and maintaining availability after intervention completion to cope with the discomfort of severing relationships. With the provision of adequate support for mentors, resolving emotional entanglements could result in personal growth. Connecting mentees with other supportive networks prior to intervention termination may limit over-dependence on a mentor.

## 3.4. Post-intervention: mentors' and mentees' experiences and perceived impacts

### 3.4.1. Changed outlook

Changed outlook referred to the alteration in perspectives on dealing with life and disease as a result of receiving and providing peer support. It involved accepting one's disease identity and changing one's perception and attitude towards the future; individuals regained their old sense of self and became oriented

towards the future by acquiring hope and purpose. A changed outlook was accompanied by increased self-confidence, self-esteem, and sense of control, and was a precursor to behavior change. For mentees, outlook change involved a re-evaluation of priorities, with material things mattering less, and family and health increasing in importance. Outlook change was facilitated by social comparison, which provided new perspectives on one's situation, and by setting and achieving realistic goals. Mentors' future outlook also changed positively through their ability to help others, enabling them to regain a sense of self that had been negatively impacted by diagnosis. Mentors too could benefit from social comparison, allowing them to find meaning and hope in their own situation.

### 3.4.2. Changed behavior

The changing of old habits and developing new ones was linked to positive changes in emotional well-being and an individual's perception of and confidence in their ability to manage disease. For mentees, changing behavior involved developing a more active approach to healthcare and "making self-care a habit" [13]. This involved adopting self-management and self-care strategies such as responsible medicine use, test-taking, reducing high-risk behaviors, continued information-seeking, and educating others. Such changes could transform an individual's relationship with their doctor and the healthcare system. Lifestyles were transformed, extending to healthier eating and exercise habits, healthy friendships, a moral conscience, improving communication, and securing employment. Behaviour change was facilitated by goal-setting, contracting, role-modeling, and acquiring time-organization skills. Mentors, too, experienced behaviour change as the value of self-management techniques was re-affirmed. Their use of such techniques and their ability to deal with emotions increased, along with changes in their diet and exercise. This enabled mentors to inspire, empathize, and become more accepting of others, becoming positive role models.

### 3.4.3. Changed knowledge

Changed knowledge referred to a transformation in participants' knowledge about disease and related self-management skills. Mentors, other group members, and program resources were important sources of informational support for mentees. Participants gained knowledge of the disease, its self-management, and skills relating to diet, exercise, and medication. New knowledge could in turn be passed onto others, having a ripple effect that could have wider impact. Interventions could also act as a "reminder," reinforcing participants' existing knowledge of self-management techniques. Acquiring knowledge could empower participants to take on more responsibility for health information, resulting in new relationships with their physicians and also resulted in behaviour change. Mentors' knowledge also improved as they received information about the disease, medication, and community services, which in turn lessened their own fears and uncertainties. Not all participants experienced a transformation in knowledge, as when participants felt that intervention content was not detailed enough, too rushed, or not conducive to lay understanding.

### 3.4.4. Empowerment

Empowerment referred to the process of acquiring confidence and ability to cope, take control of one's disease and change one's outlook towards the future. Becoming empowered was facilitated by setting and achieving goals, gaining information, receiving advice, sharing experiences, and making connections with fellow peers, providers and others in the community. Empowerment entailed acquiring a sense of entitlement to talk about one's disease, and becoming increasingly interactive with healthcare

professionals and involved in treatment decisions. It was linked to increased self-confidence and personal strength, changes in lifestyle and outlook, and feelings of being inspired and energized. Helping others allowed mentors to put these feelings into action. However, Wilson et al. [13] cautioned that the expert self-managers produced by peer support programs were shaped within both empowerment and medical paradigms; therefore even as subjective, experiential knowledge of living with illness was fostered, the content and structure of interventions often reinforced traditional biomedical power.

### 3.5. Synthesis of concepts

This model may be summarized as a line of argument [18]. Across studies, isolation, or a sense of alienation, loneliness, or frustration prompted the need for peer support. During the peer support intervention, mentors and mentees experienced a sense of connection with each other, facilitated by mentees' ability to share disease and life experiences, and mentors' experiential knowledge of disease and its management. This connection helped both parties find meaning in life. For the mentor, participating in peer support afforded opportunities for reciprocal sharing and benefit. The potential to help another and to experience reciprocal support contributed to a sense of satisfaction. At the same time, mentors risked emotional entanglement, which could occur, for instance, when role boundaries became blurred, making it difficult to sever peer relationships. In addition, while a sense of isolation drove the need for peer support, isolation could also be reproduced within the peer support experience itself. As such, while peer support helped alleviate isolation by providing opportunities for mutual sharing in a safe and non-threatening environment, mentees could feel isolated if a mentor was unfamiliar with specific aspects of their condition, while mentors could feel unwelcome and unsupported by healthcare professionals. As a result of their participation in peer support, both mentors and mentees could experience a transformation in knowledge about disease and self-management skills, in their behaviour and outlook on dealing with life and disease. They could become empowered, adopting a more active approach to healthcare.

## 4. Discussion and conclusion

### 4.1. Discussion

While constructing a conceptual model representing participants' experiences of peer support interventions and their perceived impact, this research also highlights both positive and negative aspects of the peer support experience, and indicates which aspects of peer support interventions have meaning for specific participants.

*Intersubjective dynamics: broadening the spectrum:* Although participants' experience of peer support was largely positive, a range of negative experiences and impacts were observed. This provides insight into the specific contexts and intersubjective dynamics of peer support interventions that conditioned participants' experiences. For instance, while largely positive, *sharing* could facilitate communication and rapport, but it could also foster a competitive culture of "whose condition was worse" in the context of a generic intervention. Similarly, the successful forging of a *sense of connection* was dependent on the intersubjective relationships within specific peer dyads or groups; similar social contexts and value systems facilitated rapport. The manifestation of concepts such as *role satisfaction*, *helping*, and *isolation* were also dependent on specific intersubjective dynamics. While some experienced positive role satisfaction by feeling valued in their role as mentor, others felt that their help was unwelcome, as in the

case of mentors whose attempts to contact mentees were met with rejection [31,32]. *Reciprocity* was experienced differently both across and within peer support dyads, as partners could experience the same peer relationship differently. The negative aspects of these concepts, along with the concept of emotional entanglement, broaden the range of potential negative effects of peer support identified by Dennis [16].

*Stakeholder-specific experiences:* As noted above, while a number of concepts had meaning for both mentors and mentees, other concepts had pertinence for only one stakeholder category. While the prevalence of mentor-specific concepts may suggest that articles focused on reporting the experiences of this stakeholder category, a greater number of articles, in fact, examined peer support experiences from mentees' perspectives (Table 1). The broader range of concepts specific to mentors suggests that a diverse range of factors shaped mentors' experience of peer support, as in many cases, they were both providers and recipients of support. Concepts with relevance across participant categories may have different meanings for mentors and mentees. While mentees could find meaning by re-evaluating their lives in the context of peer support interventions, the very act of providing peer support might be a way of finding meaning for mentors. Hence, not only were interventions experienced in heterogeneous ways, but mentors and mentees could give meaning to seemingly shared experiences in different ways.

*Power relations:* Mentor- and mentee-specific concepts may assume different and uneven power relations as well. *Sharing*, a largely egalitarian concept, denoting the exchange of disease-related experiences by mentees with each other, is the only mentee-specific concept. In contrast, the mentor-specific concepts of *helping* and *role satisfaction*, are imbued with hierarchy and power. Helping refers to the unidirectional provision of assistance by mentors; role satisfaction is closely associated with it. While the rationale for peer support is based on the assumption that relationships between peers with experiential knowledge of disease are more egalitarian than relationships between patients and professionals, it would seem that peer support itself has the potential to replicate traditional power dynamics. Indeed, peer support interventions themselves establish such hierarchies by training mentors to provide help to mentees. Such training is intended to enhance mentors' capacity to provide something of value, which it is assumed the receiver lacks. However, the synthesis indicates that initially asymmetrical relationships have the potential to become more symmetrical over time. The mentor-specific concepts of *reciprocity* and *emotional entanglement* plot this transformation – both concepts denote a blurring of boundaries between mentors and mentees, having positive and negative effects. Given that mentors often had their own health problems, the reciprocal element of mentoring might be a necessary component of a sustainable intervention.

*Transcending hierarchy:* One of the papers included in the synthesis [13] concluded that although the Expert Patient Programme acknowledged and supported the experience of living with a long term condition, evidence existed that it simultaneously reinforced the medical paradigm. In contrast, this synthesis indicates that while the potential exists for peer support interventions to reproduce traditional hierarchies of power, so does the possibility of transcending these hierarchies through the development of egalitarian, affective relationships. If medicalized patients learn to suppress their emotions when talking to professionals, perhaps one particular value of peer support is its emotional component, when delivered under conditions that do not merely reproduce biomedical hierarchies of power. Hence, of the three aspects of peer support identified by Dennis [16], it is the value of emotional support for both mentors and mentees that emerges most clearly from this synthesis.

## 4.2. Conclusion

This study's contribution to the field is threefold: it expands the range of experiences and impacts associated with peer interventions, and identifies possible negative effects alongside their positive counterparts. It shows how different stakeholders may participate in the same intervention, and yet give different meanings to it; a process which inevitably conditions the perceived impact of the intervention. Lastly, it demonstrates how peer support interventions have the capacity to mimic the power relationships of biomedical models to which they seek to provide an alternative, while simultaneously having the capacity to transcend these hierarchies.

These insights have significant practice implications for the development of peer support programs for chronic disease in healthcare settings. Those developing and implementing peer support interventions need to be sensitive to potential negative effects of peer support. Such effects may be mitigated by understanding that individuals' social contexts and the intersubjective dynamics of dyads and groups condition the ways in which peer support is experienced. Facilitating a healthy rapport between peers, therefore, is integral to the success of interventions. Organizers must also consider the impact of peer support on both mentors and mentees with assuming homogeneity, as peers may derive meaning differentially from the same interventions. Finally, organizers need to manage the tension between the hierarchical and egalitarian aspects of peer support interventions.

At the time of development of the Chronic Care Model (CCM) by Wagner et al. [10], it was found that chronic care programs did not provide the essential element of modern self-management support [11]. Our examination of the recent literature has identified various ways in which peer support interventions can contribute to self-management and to the overall CCM goal of organising health care to improve outcomes for people with chronic conditions.

A strength of this synthesis was the range of disease areas covered, which increased the number of participants whose experiences were included, allowing for generalizations across diseases. Similarly, the multidisciplinary research team ensured that the synthesis reflected a range of viewpoints, including those of consumers. A limitation was that the captured impacts and outcomes were based on self-reported behaviors, thus conclusions about behaviour change resulting from peer support interventions need to be made with caution. Yet, it is this very subjective reporting of the experience and impact of peer support that provides insights into the circumstances under which peer support encourages new modes of thinking about and coping with disease.

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## Appendix A

### Selection criteria

1. *Participants*: Studies had to focus on peers (mentors or mentees), although studies featuring carers and family members in addition to peers were included. Peer mentors were required

to have experiential knowledge of chronic disease, but not necessarily the same chronic disease as their mentee.

2. *Disease*: Chronic disease referred to physical diseases of long duration such as arthritis, cancer, HIV/AIDS, cardiovascular disease, asthma, and diabetes.
3. *Structure*: Interventions met specified strictures relating to recruitment, participation, content, and delivery, (i.e., structured and planned interventions). Interventions could be delivered face-to-face, one-on-one, by telephone, online, or in groups. Interventions incorporating multiple formats were included. Peers could be paid or unpaid. Informal networks of spontaneously occurring peer support were not included.
4. *Content*: Given the research team's interest in developing a peer support intervention with an informational support component, selected articles had to feature informational support. However, multidimensional peer support, (with informational, emotional, appraisal, and instrumental support being provided simultaneously) could be included.
5. *Delivery*: Interventions were required to be delivered by peers alone or delivered by peers and professionals together. Solely professional-led interventions were excluded.
6. Qualitative methods of data collection and analysis were required. While mixed methods studies were included, only qualitative data were used. Primary qualitative methods could include interviews, focus groups, ethnographic case studies, participant observation, and observation. Data analysis could involve methods such as thematic analysis and constant comparison.

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