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Perceived Benefits and Factors that Influence the Ability to Establish and Maintain Patient Support Groups in Rare Diseases: A Scoping Review

Running head: Benefits and Factors Influencing the Sustainability of Patient Support Groups in Rare Diseases

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ABSTRACT

Background: Support groups are an important resource for many people living with rare diseases. The perceived benefits of participating in support groups for people with rare diseases and factors that may influence the ability to successfully establish and maintain these groups are not well understood. Thus, the objective of this scoping review was to provide a mapping of the available evidence on the (1) benefits or perceived benefits of participating in rare disease support groups and (2) barriers and facilitators of establishing and maintaining these groups.

Methods: CINAHL and PubMed were searched from January 2000 to August 2015, with no language restrictions. Publications that described the benefits or perceived benefits of participating in rare disease support groups or the barriers and facilitators of establishing and maintaining them were eligible for inclusion. Two investigators independently evaluated titles/abstracts and full-text publications for eligibility, and extracted data from each included publication.

Results: Ten publications were included in the scoping review. There was no trial evidence on support group benefits. All 10 publications reported on the perceived benefits of participating in rare disease support groups. Three reported on barriers and facilitators of establishing and maintaining them. Overall, 7 different perceived benefits of participating in rare disease support groups were identified: (1) meeting and befriending other people with the same rare disease and similar experiences; (2) learning about the disease and related treatments; (3) giving and receiving emotional support; (4) having a place to speak openly about the disease and one's feelings; (5) learning coping skills; (6) feeling empowered and hopeful; and (7) advocating to improve healthcare for other rare disease patients. Several facilitators (e.g., meeting via teleconference) and barriers (e.g., getting patients and/or family members to lead the group) of establishing and maintaining these groups were identified.

Conclusions: Rare disease support groups are an important source of emotional and practical support for many patients. There is no trial evidence on the benefits of these groups and limited evidence on the perceived benefits and barriers and facilitators to establishing and maintaining them.

KEY POINTS FOR DECISION MAKERS

- There is limited research on support groups for people with rare diseases, even though many people depend on them in the absence of disease-specific professional support resources.
- Perceived benefits of rare disease support groups identified included: (1) interacting with others with the same disease and similar experiences; (2) learning about the disease and treatments; (3) giving and receiving emotional support; (4) having a place to speak openly about the disease and one's feelings; (5) learning coping skills; (6) feeling empowered and hopeful; and (7) advocating to improve healthcare for people with the disease.
- Facilitators of establishing and maintaining rare disease support groups included: (1) meeting via teleconference; (2) providing leaders with training for their roles; and (3) having more than one leader. Barriers included: (1) getting patients or family members to lead the support group; (2) navigating difficult group discussions; and (3) uncertainty about one's role as a leader.

1. INTRODUCTION

Rare diseases are defined as conditions that affect fewer than 1 person in 2,000 [1]. There are currently approximately 7000 known rare diseases worldwide, with new diseases being identified each year [1-4]. People living with rare diseases experience many of the same challenges as people with more common medical diseases, including physical and psychological symptoms that require them to modify their family, professional, and social roles [5, 6]. Compared to people with more common diseases, however, those with rare diseases typically face substantial additional challenges due to gaps in knowledge about their disease and how to manage it [3, 4].

One major challenge for many rare disease patients is obtaining a correct diagnosis, which can sometimes take several years [3, 4]. Because little is known about many rare diseases, some patients need to consult multiple doctors and endure repeated medical tests before receiving a diagnosis. Once diagnosed, another major challenge involves obtaining appropriate treatment [3, 4]. Clinical research and practice guidelines are often limited or non-existent. Treatment and management services are typically scarce, and many patients have to travel long distances or wait long periods of time for care. The financial burden of living with a rare disease is yet another significant challenge for patients [3, 4]. Often, rare disease treatments are expensive, and patients or their caregivers may be forced to stop working. Other obstacles rare disease patients face include isolation and stigmatization [3, 4]. Many rare diseases are associated with changes in physical appearance that are uncommon or unfamiliar to the public, and patients may experience unwanted attention or rejection when interacting with other people.

In order to cope with the challenges of living with a burdensome medical condition, even a common, well-understood condition, many people seek support services [7, 8]. In the case of common medical diseases, these services are frequently offered by the healthcare system and are organized and delivered by professionals who are knowledgeable about the condition; in rare diseases, however, they are often not available or readily accessible [9]. In the absence of these services, people with some rare diseases have come together through grassroots efforts to mobilize their own support systems in the form of locally organized support groups [10].

The idea that support groups can provide important benefits to people living with a burdensome medical condition is based on the principle that people who face similar disease-related issues can empower one another through social contact and support [11]. Support groups can be configured in a variety of ways; they may be held face-to-face, online or via teleconference, they may be led by professionals or peers, and they may have a structured

or unstructured format [8-12]. Activities of these groups typically involve an educational or information-sharing component, as well as the giving and receiving of emotional and practical support.

A number of studies have assessed the benefits of participating in support groups for common medical diseases, such as cancer [13-15]. Participants in these studies have reported a number of benefits, such as obtaining emotional support, receiving information about their disease and treatments, and learning how other patients have coped with the condition. They have also reported that support groups help decrease isolation, foster a sense of community, and instill hope about the future.

Given the challenges faced by people with rare diseases, the perceived benefits of participating in rare disease support groups may differ compared to common medical diseases. Moreover, there are likely challenges that influence the ability to successfully establish and maintain support groups that are unique to a rare disease context. Understanding the benefits or perceived benefits of participating in rare disease support groups and factors that are important for initiating and sustaining these groups is necessary if access to effective support systems is to be increased. There are no studies, however, that have summarized the published academic literature on this topic.

Scleroderma, or systemic sclerosis (SSc), is an example of a rare disease where support groups play an important role for people with the disease [16]. SSc is a chronic multi-system connective tissue disorder characterized by abnormal fibrotic processes and excessive collagen production that manifests in thickening of the skin and damage to the internal organs, including the heart, lungs, and gastrointestinal tract [17, 18]. SSc normally occurs between the ages of 30 and 50 years, and approximately 80% of people with the disease are women [18, 19]; there is no cure for SSc [20].

Currently, there are approximately 200 SSc support groups across Canada and the United States, and the majority of these are led by peers [21, 22]. The Scleroderma Society of Canada and the Scleroderma Foundation in the United States help SSc patients locate support groups, but provide almost no information regarding starting a support group or formal training and support to peer facilitators. We are presently working with these organizations to provide the infrastructure that is required, including a training program for peer facilitators of support groups, in order to enhance access to support groups and the ability of these groups to consistently meet the needs of members. To help inform our work we conducted a scoping review. Specifically, the purpose of our scoping review was to systematically identify and map evidence on the (1) benefits or perceived benefits of participating in support groups for people with rare diseases and (2) facilitators and barriers of establishing and maintaining these groups.

2. METHODS

A scoping review is a "form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge" [23]. A scoping review is rigorous like a systematic review; however, unlike a systematic review, it addresses broader topics and charts all available evidence, regardless of study design or quality [24]. The methods for the present scoping review drew upon those initially recommended by Arksey and O'Malley [24] and subsequently refined by others [23, 25]. As recommended in these publications, we utilized a five-stage methodological framework: (1) Identifying the research question, (2) Identifying relevant studies, (3) Study selection, (4) Charting the data, and (5) Collating, summarizing, and reporting results [23-25].

2.1 Identifying the research question

To guide this scoping review, we defined the following research question: What are the (1) benefits or perceived benefits of participating in support groups for people with rare diseases and (2) facilitators and barriers of establishing and maintaining these groups?

2.2 Idenitfying relevant studies

In order to identify potentially relevant publications of support groups for people with rare diseases, we searched PubMed (from January 2000 through August 20, 2015) and CINAHL through the EBSCOhost platform (from January 2000 through August 26, 2015). A medical librarian developed the search strategy and performed the search. To develop the search strategy, we extracted all the names of rare diseases listed in Orphanet's Orphadata May 2015 "Rare Disorders and Cross-References" dataset (http://www.orphadata.org/cgi-bin/inc/product1.inc.php). The list included names of disorders, groups of disorders, subtypes, and synonyms and totalled 20,169 unique terms. To manage the size of the search, we excluded names of groups of disorders and synonyms, leaving 6,999 unique rare disorders and subtypes. We then combined these disorder names with terms relevant to support groups and self-help. The complete search strategy can be found in Online Resource 1.

2.3 Study selection

The results of the search were downloaded into the citation management database RefWorks [26], and duplicate references were identified and removed. Following this, references were transferred into the systematic review software DistillerSR [27]. We then assessed the eligibility of each publication through a two-stage process. First, two investigators independently reviewed the titles and abstracts of all citations identified through the search

strategy. If either investigator deemed a publication potentially eligible based on the scoping review inclusion criteria, then a full-text review was completed, again by two investigators. Disagreements after full-text review were resolved by consensus, with a third investigator consulted as necessary.

Eligible publications were required to describe the benefits or perceived benefits of participating in rare disease support groups or the facilitators and barriers of establishing and maintaining them. Consistent with standard scoping review methodology, we did not include any study design restrictions in our eligibility criteria [23-25]. Publications about support groups for people with rare diseases in any language were eligible for inclusion.

For the purpose of this study, support groups were defined as an ongoing gathering of individuals who share common experiences. Activities of support groups had to include the giving and receiving of emotional and practical support, and could also include educational activities. Activities of support groups could take place in person, online or via teleconference, and had to include ongoing real-time interaction between group members. Groups that only followed a structured learning curriculum with a defined beginning and end (e.g., self-management programs) were not considered support groups. Groups that provided psychotherapy were not considered support groups.

Eligible rare diseases were diseases listed in Orphanet's "List of rare diseases and synonyms in alphabetical order (May 2015)" and included in the Orphadata dataset [28]. This list includes diseases that are classified as rare based on their estimated prevalence in Europe. In cases where a publication reported on support groups in a non-European setting where the disease may or may not be rare (e.g., tuberculosis support groups in Africa), we determined the disease prevalence in the country in question using the World Health Organization's website [29]. If the support group was conducted in a country where the disease prevalence is less than or equal to 1 person in 2,000, then the publication was included. Publications about support groups that included people with rare diseases and others (e.g., family, friends, and other loved ones) were included if they reported information on people with rare diseases, specifically. Publications about support groups intended for people without rare diseases were excluded, even if some members may have had a rare disease.

2.4 Charting the data, and collating, summarizing, and reporting results

A descriptive analytical approach was used to chart and summarize the data. Two investigators independently extracted data from included publications and entered it into a standardized Excel spreadsheet. For each publication, we extracted: (1) first author name; (2) publication year; (3) country of study; (4) design of study;

(5) rare disease; (6) number of participants; (7) perceived benefits; (8) facilitators; and (9) barriers. Any disagreements were resolved by consensus, and a third investigator was consulted as necessary.

3. RESULTS

The database search yielded 912 unique titles and abstracts. Of these, 841 were excluded after title and abstract review, leaving 71 publications for full-text review. A total of 10 publications met the inclusion criteria and were included in the scoping review (see Figure 1).

3.1 Description of publications

The majority of included publications (n=8 studies, 80%) were primary research studies that collected qualitative or quantitative patient data [30-37], and two were experiential accounts [38, 39]. Of the eight primary research studies, four collected data using interviews or focus groups (sample sizes 3 to 30) [30, 33, 34, 36], and three used questionnaires (sample sizes 6 to 79) [32, 35, 37]. One publication, which was published only as a conference abstract, did not indicate the method of data collection [31]. Of the two experiential accounts, one was a personal reflection that described a woman's experience living with idiopathic pulmonary arterial hypertension and how attending a support group helped her cope with the disease [38]. The other was written by the Chief Executive Officer of the Acoustic Neuroma Association and discussed ways that people with acoustic neuroma may benefit from participating in support groups [39].

Seven publications (70%) were from North America [30, 31, 34-37, 39], and three (30%) were from the United Kingdom [32, 33, 38]. All publications were from 2000 or later, and none reported on support groups for the same rare disease. Characteristics of included publications are summarized in Table 1.

3.2 Perceived benefits of rare disease support groups

All 10 publications reported on the perceived benefits of rare disease support groups [30-39] (see Table 1). Seven overarching categories of perceived benefits were identified (see Table 2): (1) getting to know and befriending other people with the same disease who share similar experiences (n=9 studies, 90%); (2) learning about the disease and related treatments (n=8, 80%); (3) giving and receiving emotional support (n=5, 50%); (4) having a place to speak openly about the disease and one's feelings (n=4, 40%); (5) learning coping skills (n=4, 40%); (6) feeling empowered and hopeful (n=3, 30%); and (7) advocating to improve healthcare for people with the disease (n=1, 10%).

3.3 Facilitators and barriers of establishing and maintaining rare disease support groups

Three publications described facilitators of establishing and maintaining support groups [31, 32, 36], and one also described barriers [32] (see Table 1). All three publications were primary research studies. Facilitators reported included: (1) meeting via teleconference; (2) providing leaders with training for their roles; and (3) having more than one leader. Barriers included: (1) finding patients or family members to lead the support group; (2) navigating difficult group discussions; and (3) uncertainty about one's role as a leader.

4. DISCUSSION

Only ten publications, which used a variety of methods and described 10 different rare diseases, were identified [30-39]. Commonly reported perceived benefit of rare disease support groups were getting to know and befriending other people with the same disease and similar experiences, learning about the disease and related treatments, and giving and receiving emotional support. Three publications reported on facilitators and barriers of establishing and maintaining rare disease support groups for people with rare diseases [31, 32, 36]. Facilitators included: (1) meeting via teleconference; (2) providing leaders with training for their roles; and (3) having more than one leader. Barriers included (1) getting patients and/or family members to lead the support group; (2) navigating difficult group discussions; and (3) uncertainty about one's role as a leader.

A number of studies have examined the benefits of participating in support groups for common medical diseases, including several studies that have interviewed cancer patients about the benefits of attending cancer support groups [13-15]. Patients in those studies reported that support groups provide unconditional acceptance; emotional support; a sense of belonging and community; a place to freely and safely talk about the disease and one's feelings; and information about cancer, its treatment and how other patients have coped with the condition [13-15]. They also suggested that these groups decrease isolation and instill hope that one can survive the disease [15].

Although people living with common medical diseases and those living with rare diseases may face different challenges, the findings of the present review and results of studies of cancer patients have a number of similarities. Commonalities include agreement that an important perceived benefit of participating in illness-based support groups is the giving and receiving of emotional support. Similarly, in rare diseases and cancer, people attend support groups to obtain information about the disease and treatment, as well as to meet others going through similar experiences. These latter two points are especially important for people with rare diseases.

The most notable difference between the findings of the present review on rare diseases and the studies of cancer patients is that in the present study, a perceived benefit of participating in support groups was advocating to

improve healthcare for other rare disease patients. While this benefit was identified by only one of the studies included in the review, a number of previously published reports have also highlighted the importance of patient advocacy in rare diseases [3, 4, 40]. One possible explanation for this is that compared to common medical diseases, such as cancer, most rare diseases are often overlooked by clinicians, researchers, and politicians [3, 4]. As such people with rare disease and their families often become involved in trying to raise public awareness; in fact, because they must become their own advocates, rare disease patients and their families may be more proactive than patients with more common illnesses. Some become as knowledgeable or more knowledgeable about their condition as the health professionals who provide their care [4].

The findings of this scoping review suggest that support groups may be an important resource for many people with rare diseases, but establishing and sustaining support groups involves significant challenges. Rare disease organizations may be able to increase the accessibility of rare disease support groups by helping patients establish support groups, and the findings of our scoping review suggest factors that could potentially facilitate this process. For example, rare disease organizations may be able to implement training programs for potential leaders of support groups. There is not any evidence from well-designed and conducted trials on how to implement such a program or whether such a program would improve the experiences of support group leaders and members [41], but our group is currently in the process of developing a program for patient support group leaders in SSc. Providing ongoing training would be difficult for any single disease-based organization to carry out, but it could be done via umbrella rare disease organizations or partnerships between organizations. Additionally, rare disease organizations might consider providing support groups via teleconferencing or videoconferencing in order to help patients in geographically isolated areas or with physical disabilities. Future research should focus on identifying the potential benefits of participation in support groups and factors associated with participation and non-participation in these groups, as well as factors that can facilitate the establishment and maintenance of successful groups. Well-designed and executed trials that assess the effectiveness of support groups and training programs for peer leaders of these groups are needed. Since rare disease organizations may not have the capacity or resources to conduct such trials, it could be beneficial for them to partner with researchers in the field. For instance, our research team has partnered with key scleroderma patient organizations in order to test the peer leader training program that we are developing. Innovative trial designs, such as the partially nested design [42] and the stepped-wedge design [43, 44] may help

researchers and stakeholders test interventions in a way that is not disruptive to the stakeholders' primary goal of providing support services.

In addition or instead of synchronous support groups, rare disease organizations might also consider alternative sources that have been used by rare disease patients and caregivers for peer support, including Facebook groups, online discussion boards or forums, and patient conferences. Although online support resources facilitate only asynchronous support, they may provide many of the same benefits as the synchronous support groups discussed in this review. Commonly reported perceived benefits of these resources include meeting people with the same disease who have similar experiences, having a space to speak openly about the disease and one's feelings, giving and receiving emotional support, learning about the disease and related treatments, learning coping skills, and feeling hopeful [45-48]. Other benefits that are unique to online support resources are that they are available 24 hours a day, easy to disseminate, and less resource-intensive than traditional face-to-face synchronous support groups [45-47]. They are also accessible to patients who are geographically distant or homebound, such those who are too ill or whose symptoms are too severe to leave their home, as well as to patients who desire anonymity or privacy [45-47]. There are important limitations that may impact their effectiveness and should be considered. For example, online support resources may not be available to everyone, such as patients without a computer or Internet access and those with limited computer skills [45, 47]. Furthermore, since they often function without a facilitator, there may be little or no control over the quality of the information that is exchanged. There can also be a substantial time lag between when a person asks a question and gets a response, and exchanges may include negative or inappropriate remarks that may leave patients feeling vulnerable and unsupported [45, 47, 48]. Patient conferences, like online support resources, offer many of the same benefits as synchronous support groups [48]. However, limitations of patient conferences include that they are costly for the organizations running them, they may not be accessible to all patients due to financial or geographical constraints, and they are time-limited and do not provide a mechanism for sustained relationship building and support [48].

There are a number of limitations that should be considered when interpreting the results of this review. First, because we restricted our search to CINAHL and PubMed, it is possible that we may have missed important articles published in the grey literature, such as information from rare disease organization webpages. Second, although we had data extraction tools and two different investigators extracting data independently from publications, extracting accurate and complete data remained a challenge. There are a number of reasons for this,

including that some articles reported methods or results that were incomplete or unclear. Third, by definition, a scoping review does not address the issues of "synthesis," which limits the inferences that be drawn from this review [17]. Most of the included studies were relatively small studies that were done in different rare diseases and used different methodologies; some used questionnaires or patient interviews to obtain data, and some reflected the experience of the writer without collecting data. No trials have been conducted on the benefits and possible harms of support groups for people with rare diseases. We did not believe that we could validly draw conclusions about the frequency or importance of facilitators and barriers or compare disease groups. Fourth, although rare diseases have many similarities, including that they are often degenerative and incurable, difficult to diagnosis and manage, and greatly compromise the quality of life of patients, there is also significant heterogenetity among them [4]. For example, rare diseases can differ in terms of age of onset (e.g., childhood versus adulthood), prevalence (e.g., rare versus ultra rare diseases), and severity, and it is unclear how these factors may have influenced our findings.

5. CONCLUSION

In conclusion, support groups appear to be an important resource for many people living with rare diseases. However, there is limited research on the benefits of participating in support groups for people with rare diseases and the facilitators and barriers of establishing and maintaining these groups. The findings of this review will inform research that is needed on support groups in rare diseases and may inform rare disease organizations, such as the Scleroderma Society of Canada and the Scleroderma Foundation in the United States, on ideas for possibly enhancing access to support groups and improving the ability of support groups to meet members' needs on a sustained basis.

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Table 1. Publications included in scoping review

First author Year	Country	Study type	Study aim	Data source	Sample and rare disease	Support group characteristics	Perceived benefits of support groups described in study	Facilitators of establishing and maintaining support groups described in study	Bar establ maintai groups s
Alderson 2004 [33]	UK	Primary research study	To provide an understanding of the psychological sequel of androgen insensitivity syndrome (AIS) in phenotypic females in order to begin to inform psychosocial healthcare services	Two interviews with each participant	8 adult women with AIS	Held in person twice a year; leader characteristics not provided	• giving and receiving emotional support • learning about AIS • getting to know other people with AIS • having a place to speak openly about AIS and one's feelings • feeling empowered	Not applicable	Not applic
Barker 2009 [38]	UK	Experiential account	Not applicable	Personal experience	A woman with idiopathic pulmonary arterial hypertension (IPAH)	Not applicable	• getting to know other people with IPAH • having a place to speak openly about one's fears, including death	Not applicable	Not applic
Breau 2003 [34]	Canada	Primary research study	To identify and compare the needs of patients with prostate cancer or interstitial cystitis (IC) and to evaluate the role of self-help groups in meeting those needs	One interview with each participant	30 people with IC	Held in person once a month; led by a nurse practitioner	• receiving emotional support • getting IC- and treatment-related information • learning coping skills	Not applicable	Not applic
Castro 2008 [31]	USA	Primary research	To describe the design and	Methods not provided	42 people with cGVHD	Held over the phone once a week for four weeks;	• learning about cGVHD • being able to talk about the	• telephone support groups	Not applic

		study	evaluation of a telephone support group intervention for people with chronic graft-versus-host disease (cGVHD)	(abstract only)		led by advanced practice nurses from the National Institutes of Health	disease with others going through the same experiences		
Howard 2003 [35]	USA	Primary research study	To describe the structure, function, and outcomes of The Oklahoma Thrombocyto Penic Purpura-Hemolytic Uremic Syndrome (TTP-HUS) Study Group	Questionnaire	35 former TTP-HUS patients	Held in person three times a year; led by a doctor	• learning about TTP-HUS • having the opportunity to talk to a doctor who is knowledgeable about the TTP-HUS • talking to other people with TTP-HUS and knowing that one is not alone	Not applicable	Not applic
Jalovcic 2009 [30]	Canada	Primary research study	To capture the essence of women's experiences of participation in the Telephone Peer Support Group Program for Women with Spinal Cord Injury	One individual interview and three telephone focus groups with all participants	7 women with spinal cord injury	Held over the phone; leader characteristics not provided	• giving and receiving emotional support • learning up-to-date disease-related information • getting to know other people with the disease and knowing that one is not alone • having a place to speak openly about the disease and one's experiences with it • feeling empowered	Not applicable	Not applic
Moore 2008 [32]	UK	Primary research study	To describe the authors initial experience of establishing a support group for people with mesothelioma	Questionnaire	6 people with mesothelioma	Held in person once a month; led by four healthcare professionals (a patient information officer, a psychotherapist, and two lung cancer nurse specialists) and a peer	• getting to know other people with the disease and hearing about other patients' experiences living with the disease, as well as how they cope and manage it	• having more than one leader • having a collaborative partnership among the leaders	• getting and/or membe any or respon group • naviga group • uncerta one's r

Stewart 2001 [36]	Canada	Primary research study	To test the feasibility of a telephone support group intervention for men with hemophilia and HIV/AIDS and for their family caregivers	One interview with each participant	3 men with hemophilia and HIV/AIDS	Held over the phone once a week for 12 weeks; led by a mental health nurse and a peer	• receiving emotional support • getting informational support (e.g., learning about the disease and treatments) • feeling less alone • learning and employing coping skills	• leader training • having a guide of potential discussion topics	Not applic
Telfair 2000 [37]	Canada USA	Primary research study	To explore and describe the experiences of adolescents with sickle cell disease (SCD) who are active members of SCD support groups	Questionnaire	79 adolescents with SCD from 12 support groups	The majority of groups met once a month; all were led by a professional	• learning more about the disease • making new friends • advocating to improve healthcare for other people affected by the disease	Not applicable	Not applic
Vitucci 2012 [39]	USA	Experiential account	Not applicable	Personal experience	Chief Executive Officer of the Acoustic Neuroma Association	Not applicable	• giving and receiving emotional support • learning about disease- and treatment-related information • meeting other people who have gone through a similar experience and realizing that one is not alone • learning how other people cope with disease-related problems • feeling hopeful	Not applicable	Not applic

Table 2. Categories of perceived benefits of rare disease support groups and sources

Perceived benefit	n studies (%)	Experiential account	Original research study – qualitative	Original research study – questionnaire	Published abstract
Getting to know and befriending other people with the same disease who share similar experiences	9 (90%)	• Barker [38] • Vitucci [39]	• Jalovcic [30] • Alderson [33] • Stewart [36]	• Moore [32] • Howard [35] • Telfair [37]	• Castro [31]
Learning about the disease and related treatments	8 (80%)	• Vitucci [39]	• Jalovcic [30] • Alderson [33] • Breau [34] • Stewart [36]	• Howard [35] • Telfair [37]	• Castro [31]
Giving and receiving emotional support	5 (50%)	• Vitucci [39]	• Jalovcic [30] • Alderson [33] • Breau [34] • Stewart [36]	Not applicable	Not applicable
Having a place to speak openly about the disease and one's feelings	4 (40%)	• Barker [38]	• Jalovcic [30] • Alderson [33]	Not applicable	• Castro [31]
Learning coping skills	4 (40%)	• Vitucci [39]	• Breau [34] • Stewart [36]	• Moore [32]	Not applicable
Feeling empowered and hopeful	3 (30%)	• Vitucci [39]	• Jalovcic [30] • Alderson [33]	Not applicable	Not applicable
Advocating to improving healthcare for other patients	1 (10%)	Not applicable	Not applicable	• Telfair [37]	Not applicable

Figure 1. Publication selection process

Caption: A graphical representation of the flow of publications reviewed in the course of the scoping review.