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Members' experience of Lindsay Leg Clubs®: a thematic metasynthesis of published narratives in qualitative research

Abstract

Introduction: This paper aims to appraise and collate the published evidence on subjective members' experience of the Lindsay Leg Clubs. The Lindsay Leg Clubs are community institutions based on a psycho-social model of care which provide social support and education for people suffering from or at risk of chronic leg disease. The paper is based on a structured review, thematic metasynthesis and evaluation of qualitative research on members' narratives of their subjective experiences of attending the Lindsay Leg Clubs.

Methodology: A systematic review using the SPIDER search tool was applied to three databases. The search identified 190 papers. Following application of the inclusion criteria, 25 publications which contained narrative evidence of Lindsay Leg Club members' experience were included in the review and subjected to a thematic analysis following the principles of interpretative phenomenological analysis.

Results: The themes capturing collective members' experience were: Social support, Nurses' care and expertise, Empowerment and Education, Quality of life, Accessibility, Comparison to GP/community/hospital setting, Volunteers, Healing and Pain, Environment and Atmosphere, Relatability to other members and Refreshments.

Conclusion: This is the first review of the narratives of members of the Lindsay Leg Clubs from published evidence. The data pointed to an overall positive experience for members. It is acknowledged that additional sources of data, for example recorded videos, were not included in this synthesis. It would be interesting to examine this media to build on the evidence base.

Implications for Clinical Practice:

- Our results suggest that members should be offered the option of receiving treatment behind the screen and some waiting areas should be positioned so that such members do not have to observe treatment
- The findings indicated that members with hard-to-heal wounds should be offered additional psychosocial and clinical support.
- Leg Clubs should ensure that all venues have accessible toilets for members with disabilities

Introduction

Chronic wounds have an adverse impact on people's quality of life and increase the risk of mortality (1). Wounds in the lower limb that do not heal within a year or three months after appropriate treatment are defined as chronic leg ulcers (2, 3). Features such as pain, reduced mobility, sleep disturbance, time lost to caring for the ulcer including time off work, feelings of social distress, depression, anger, loss of confidence and fear are prominent in those with leg ulcers (4-6). The overall cure rate with conventional treatment is under 50%, and still there is a high recurrence

rate (7). Left untreated, these chronic wounds can progress, which puts people at risk of infections and thus sepsis, and even limb amputation. The number of amputations associated with chronic ulcers rose by 8.4% in just 8 years, many of these of which were preventable (8). Although diabetes is the leading cause of death associated with chronic ulcers, it is important to note that the mortality risk for those with leg ulcers of any aetiology is greater than controls (9). In addition, due to the high prevalence of chronic ulcers in the UK, affecting nearly 1% of the population and with a point prevalence of 3.2 per 10,000 (10), there is also a great financial burden associated. The cost of chronic wound treatment has been estimated to cost the UK around £100 million- £2 billion annually (10, 11) and is expected to reach up to £65 billion across the world by 2024 (12, 13).

The global prevalence of chronic wounds was estimated at 2.21 per 1,000 population (14) and is set to rise as we live longer (15) especially that they are particularly common among older adults (16) who might suffer from loneliness or social isolation aggravated by the Covid-19 pandemic (17). Therefore, there is a need for more sustainable and holistic approaches to the provision of wound care (18).

There is a growing body of research evidence for clinical and social benefits for individuals with leg problems who attend the Lindsay Leg Clubs (LLCs) – community-based movement providing treatment, education and support for people with, or at the risk of developing, leg ulceration (19, 20). Lindsay Leg Clubs are partnerships between wound care nurses, community volunteers and patients (known as members). They run from non-medical settings and operate under a

psycho-social model, providing a high quality of leg care as well as peer support and social engagement to often senior adults. Attendance is on a drop-in basis and can be for treatment and/or care, or simply to socialise with other members in the waiting area over refreshments provided by the volunteers. Treatment and care are collective and happen in an open area, with members seeing other members being treated. Given the well-documented high healing rates and lower costs associated LLCs-based wound care, as compared with traditional clinical care (21), part of the LLCs' vision is to 'make Leg Clubs part of the government and NHS strategy for leg ulcer management' (22) while continuing to expand globally.

In addition to quantitative evidence, continued expansion and integration of LLC care into clinical practice also requires a thorough understanding of the non-quantifiable, subjective experiences of members attending the LLCs. While positive qualitative commentary scattered across the nursing and social scientific literature abounds, thus far members' published narratives have not been formally appraised. To address this oversight, this paper offers a metasynthesis and evaluation of qualitative studies reporting on members' subjective experiences of the LLCs. First, it aggregates qualitative findings on LLC members' narrative experiences. Second, it synthesized the narratives thematically to generate an enhanced interpretation of the commonalities of these experiences (23). Third, it evaluates the quality of the available narrative evidence (24). Our guiding research question is: What are members' narrative experiences of attending LLCs?

Methods

To establish the scope for the review, the research team agreed to search for articles from 1995 (the year LLCs were established) to June 2021. The search was performed in June 2021. Most of the evidence on LLC members' experiences is described in qualitative and mixed methods publications (25). Such studies tend to have smaller sample sizes and, generally, richer but non-generalisable findings about behaviours and experiences conceptualised with use of subjective constructs; therefore, to standardise the strategy, we used the SPIDER tool developed by Cooke et al. (23). Its construction is shown in Table 1.

Table 1 here

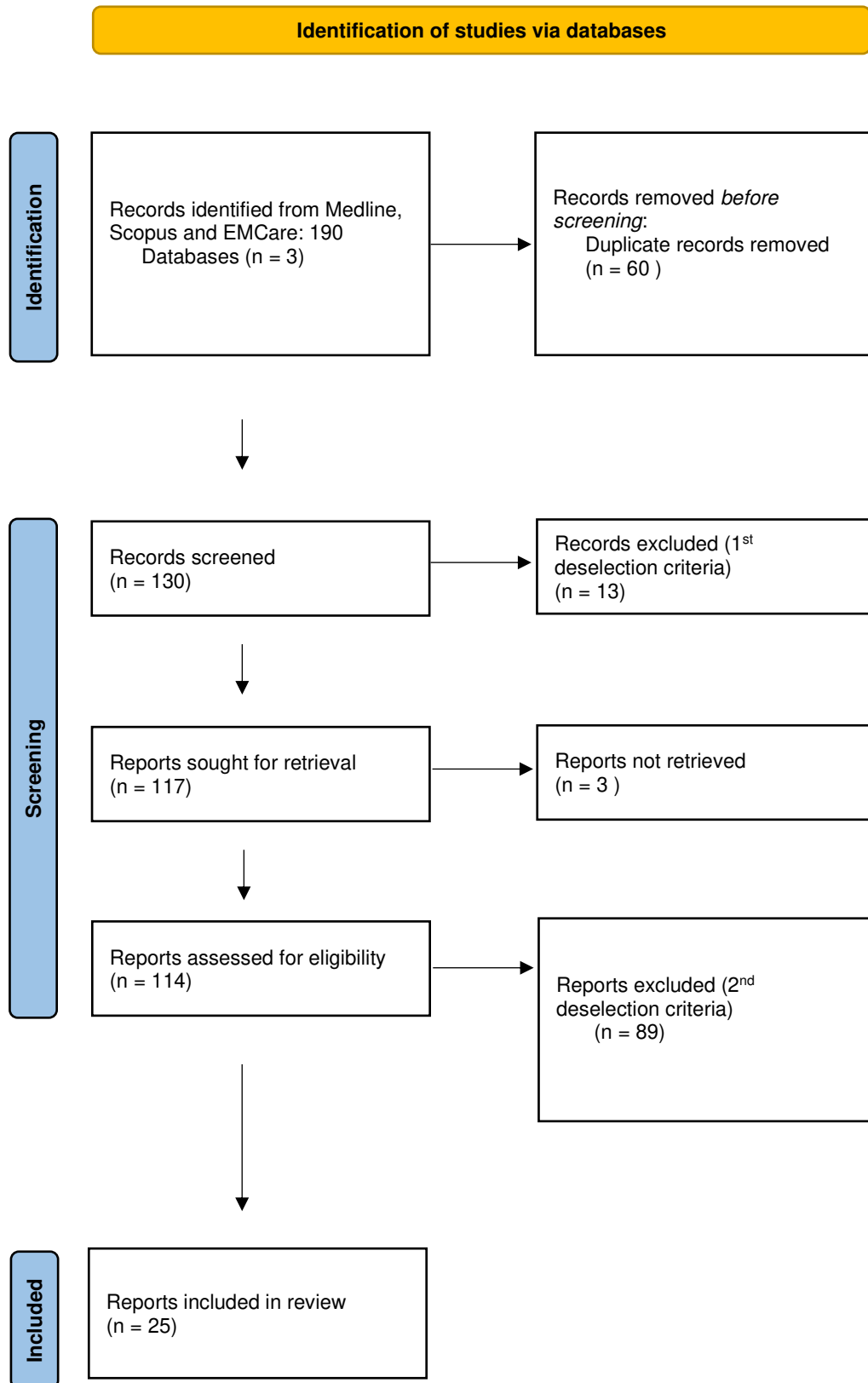
The search was performed on three databases – Medline via Ovid, Scopus and EMCare. Table 2 details the search terms used for the Medline database as an example. The first author conducted the search, which returned 190 publications. After removing duplicates, and further screening of the remaining 117 reports, 114 full text publications were inspected, retaining 25 publications that met the inclusion criteria specified in Table 2.

Table 2 here

The citations were entered into a Microsoft Excel spreadsheet by the first author and the second and third author validated inclusion of the papers. The inclusion criteria were devised to focus on retaining the publications that were both semantically and empirically relevant to the research question. First, the publications had to contain evidence on the topic of members' LLC experience (criterion 1). Second, this evidence needed to be presented as any type of qualitative narratives given the

complexity and variability of the pertinent evidence in the field of LLC research (criterion 2). Moreover, prior systematic reviews confirmed that the body of qualitative research literature on LLC is heterogeneous and of low to moderate quality (19). Therefore, the empirical criterion had to be broad to gather a rich data sample. Figure 1 shows the selection process based on the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) framework (26).

Figure 1



The full texts of the retained articles were then read by the first and third author to assess the rigour. The first author developed the codes for the thematic synthesis of LLC members' narrative experience. Quality assessment was conducted using Sandelowski's criteria (24). Defining characteristics for the criteria were devised to ensure relevancy in the context of LLCs (Table 3).

Table 3 here

The analysis followed the principles of interpretative phenomenological analysis (27, 28). First, references to members' subjective experience were entered into a Microsoft Excel database and coded. The codes compared across the data set, iteratively revised and grouped into thematic patterns as reinterpretations of common members' LLC experiences. The presentation of results follows these themes in their order of prominence. The summary of the analysis and quality assurance are summarised in Table 4, which displays the articles reviewed in a chronological order of their publication.

Ethical Considerations

This publication represents a secondary analysis of existing published data therefore no ethical approval to undertake the project was required.

Results

Table 4 summarises the publications included in the review in terms of the nature of qualitative research, the themes present and results of quality assessment.

Table 4 here

Thematic Analysis

Social support

The most widely reported aspect of members' LLC experience was the social support they received (25, 30-32, 34, 36, 37, 39, 40, 42, 45, 47-51). Meeting similar people in an environment of friendliness was the main source of this support (31, 32, 34, 39, 40, 42). Some members valued the company and a chance to talk and socialise (34, 36-38, 45, 47-51), others stressed developing close relationships akin to family (44, 47). Entertainment within the club was also mentioned, as members looked forward to Bingo (40) and to the singing that lifts their spirits (48).

Nurses' care and expertise

Members recognised the nurses' care and expertise, drawing attention to the clinical value of having a leg ulcer focus and working collectively (30, 31, 33-35, 41, 42, 44-46, 48, 52). Some appreciated how communal working was conducive to nurses' learning through informal clinical supervision (30). Others stressed nurses' dedication and care as excellent (31), highlighting how specialising in leg ulcer care (52) meant the nurses 'know what they are doing' (35) or 'know their job' (44), with some even calling them 'heroes' (46).

Empowerment and Education

Aspects of the empowerment of members with chronic wounds through health education were reported in nine articles. (25, 29, 33, 34, 39, 42, 43, 47, 49).

Pertinent members' experiences related to getting a sense of control over their treatment through open communication, having their concerns listened to, and benefitting from knowledge sharing in relation with the nursing team. One member was reported to become a 'partner in her care' (29), while other publications reflected on how ownership over parts of care led to a 'major change in behaviour (33). Members appreciated being 'kept up to date' on the progression of their healing (34) and having procedures explained and 'the reason for the procedures (42). The 'opportunity for everyone to learn from one another' (25) was also highlighted.

Quality of Life

Increased quality of life after attending LLCs was also repeatedly mentioned (29, 34, 39, 41, 44, 49-51), with member testimonies pointing to being 'in control of... life again' (29). Attendance at LLC was linked with benefits to physical and mental health; various members were reported to say that Leg Club attendance 'cheers me up if I am feeling down' (34) and 'puts me in a high frame of mind' (50) leading to greater motivation to lose excess weight (39).

Accessibility

Multiple papers recorded members praising the accessibility of LLCs (34, 41, 44, 45, 47, 48, 50, 52). Members liked that Leg Clubs were easy to get to (52) and that good parking (34) was present. The fact that appointments were not needed (45) gave members a feeling of acceptance (44). However, one member found that the toilets

in the venue where one Leg Club was held were unsuitable especially for people with disabilities (48), which suggests possible areas for further improving all Leg Clubs' accessibility.

Comparison to GP, community or hospital setting

Six studies extolled the positive experience of Leg Club attendance through contrasting it with traditional clinical provision of care (30, 35, 38, 44, 51, 52). One study highlighted the uniqueness of LLC was their informal, relaxed and welcoming nature (30), while another pointed to the value of a social chat while awaiting the treatment that is missing from hospital waiting areas (35). In another study emphasising the person-focused treatment provision, a member was reported to say her referral to the local LLC was 'the best thing that happened to her' (51). Members appreciated more time they could spend with a nurse in the Leg Club (34), not having to wait in at home (48), and that being treated by specialists in leg ulcer care gave them more options (52), like the first 'real treatment' of the wound (as contracted with medication prescribed by GPs) (42).

Volunteers

Multiple articles showed that an important aspects of members' positive LLC experience was the social support from the volunteers (31, 40-45, 51). For example, members praised them for being the conduits of social interaction over refreshments (51), 'extremely helpful, welcoming and supportive' (45) 'marvellous (40, 41), and for giving their time up 'willingly' and 'cheerfully' (31). Multiple members also went to become volunteers for the clubs (42, 43).

Healing and Pain

An obvious positive from LLC attendance for the members was improved healing and reduced pain (34, 35, 42, 44, 48, 49). Some members were even reported saying that their ulcers healed better and more quickly under Leg Club care (34, 35, 44). Others, however, complained that this was not always the case, with one member saying that 'one year on, it's still not healing' (48).

Environment and Atmosphere

Both the LLC environment and atmosphere were praised within the literature found (30, 34, 40-42, 44). The adjectives used for description ranged from 'relaxed, informal, welcoming' and 'supportive' (30) through 'welcoming and friendly' (34) to 'beautifully clean' ⁽⁴²⁾ and simply 'lovely' (44).

Relatability to other members

Five articles reported on the social gains to patients from being able to meet and relate to individuals who, like them, had leg ulcers (34, 44, 46-48). One member explained 'it is good to meet other members in the same position as yourself' (34), another that 'it was good to be in surroundings with people with similar problems, who were making progress' (44). The importance of chatting to 'other people who understand' (48) was also stressed, elsewhere linked to a reduction in the feeling of being stigmatized as 'everyone has the same' so there was "nothing to hide' (25). However, proximity to other members and their wounds was sometimes upsetting, as one member reported seeing how 'horrible legs can be' (25).

Refreshments

The availability of refreshments was referred to in multiple papers (30, 38, 47, 48, 51). This was mostly in a positive context of appreciation of a cup of tea and biscuits (51) as part of the 'warm welcome' (47).

Discussion

The aim of this synthesis was to systematically review and evaluate the rigour of qualitative research evidence on members' narrative experience of attending an LLC. Although prior systematic literature reviews have been conducted in the emergent field of Leg Club research (19, 53), the focus has been on reviewing the available evidence on clinical, psychosocial, safety outcomes for the members. This review is the first one to systematically appraise specifically the qualitative narratives of the members focused on their subjective experience of LLC attendance, captured in existing literature in the form of direct and indirect quotations as well as their stories retold by the authors of the publications. These narratives have been subjected to thematic synthesis to develop a nuanced understanding of aspects of members' reported positivity about the Leg Clubs. The themes that appeared most prominently related to social support, nurses' care and expertise, and empowerment and education. These themes parallel with the objectives of the LLCs (54), therefore this review provides evidence that the Leg Clubs are successful in meeting these objectives, at least from the perspective of the members who participated in the studies reviewed herein.

This thematic synthesis of the narratives of LLC members on their experience has emphasised that this experience has been mainly very positive. However, careful engagement with the evidence provided by members and duly captured by the authors of the publications reviewed has revealed areas for improvement, which can further increase members' experience of Leg Club attendance. For example, ensuring that all venues have accessible toilets, providing members whose ulcers are not healing with further psychological, social and clinical support and supplying screens for the treatment of members who desire privacy from other members could make for an even higher rate of satisfaction with LLCs.

Although all articles reviewed reported credible findings that offered faithful descriptions of members' attendance at the LLC, 15 of them presented findings whose 'fittingness', could have been improved by greater incorporation of adequate and appropriate data to warrant the claims (24). In this respect, direct member quotes were deemed to be of the highest rigour, but few studies contained such quotes and only one study (25) acknowledged that where such quotes were offered, they had been paraphrased rather than reported verbatim. Therefore, paraphrased quotes could reflect the researchers' recall bias, affecting the strength of the narrative evidence. Moreover, 10 case studies lacked a transparent a replicable design and therefore did not meet the criterion of auditability, while the ones that did meet the criterion, offered mostly that retold members' stories without saying much about how these members were recruited and involved in the research process (24). Nonetheless, any research in the field of LLCs needs to consider the potential vulnerability of the community that may prevent the conduct of distressing in-depth, recorded interviews, making any paraphrases the most suitable alternative (25, 55).

Information on LLC members' demographic data was also lacking. While age and gender are reported in single member case studies, duration and frequency of attendance is less so, and data on ethnicity is lacking. Insight into these factors may provide important evidence related to accessibility. More research is needed to sensitively explore their experiences further.

This review is not without limitations. First, only three databases were used for the search which may have limited the sensitivity of the search, however, these were deemed to be the most valid for the topic of investigation. Evidence reviewed was limited to papers published in journals as a marker of quality. However, it has to be recognised that other evidence on members' experiences is available on different platforms, such as the LLCs' YouTube channel¹. Second, except for one publication (37), the literature reviewed lacked evidence from LLCs outside the UK, thus an extensive comparison to LLCs in other countries (such as Australia, Germany, Finland and Italy) would be valuable as these have now established LLCs. Exploration of this could provide valuable insight into cultural aspects of experience to share.

Conclusion

The findings of this review demonstrate an overall positive members' subjective experience of attendance at the LLCs, captured in 10 themes. This is the first review that extracted knowledge from members' qualitative narratives. The results highlight

¹ https://www.youtube.com/channel/UC0_bQG1gr2T8BM3noyKRlg/videos

the need for further research to find ways of improving LLC accessibility and strengthening relationality between the members. Future work is also needed to boost the quality of available narrative evidence.

Implications for Clinical Practice

- Our results suggest that members should be offered the option of receiving treatment behind the screen and some waiting areas should be positioned so that such members do not have to observe treatment
- The findings indicated that members with hard-to-heal wounds should be offered additional psychosocial and clinical support.
- Leg Clubs should ensure that all venues have accessible toilets for members with disabilities

Further Research

- Future research to explore the demographics of members is necessary to understand their unique experience
- There is a need to undertake sensitive yet rigorous qualitative research that records members' narratives as closely to verbatim quotes as possible
- Future publications should carefully explain where the data came from and describe the study design in detail

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