

Members' experiences of Lindsay Leg Clubs®: A thematic metasynthesis of published narratives in qualitative research

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ABSTRACT

Introduction

This paper systematically reviews, evaluates and thematically synthesises evidence on members' experiences with Lindsay Leg Clubs. These are community institutions based on a psycho-social model of care that provides social support and education for people suffering from, or at risk of, chronic leg disease.

Methodology

A systematic review using the SPIDER search tool was applied to three databases and identified 190 papers. After applying the inclusion criteria, 25 publications containing narrative evidence of club members' experiences were included in the review and subjected to a thematic analysis based on 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 Leg Club members' narratives based on published evidence. The data pointed to their overall positive experiences. Additional sources of data, such as recorded videos, were not included, but it would be interesting to examine such media to build on the evidence.

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 there is still 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 eight years from 2005–2013, though many of these 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 associated financial burden. 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 since these wounds 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 the clinical and social benefits for individuals with leg problems who attend the Lindsay Leg Clubs (LLC) – community-based movement centres providing treatment, education and support for people with, or at the risk of developing, leg ulceration (19, 20). LLCs are partnerships among wound care nurses, community volunteers and patients (known as ‘members’). They are situated in 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, often to 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 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 with LLC-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, the 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 LLC 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 synthesises 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?

Table 1: Construction of the SPIDER search tool

SPIDER	Justification
S: Sample	Adults who have attended the LLC for treatment or care
PI: Phenomenon of Interest	Members’ subjective experiences of attending the LLC, how/why they had this experience and its impact on their decisions and behaviours
D: Design	Theoretical framework for qualitative data used, including evaluations, ethnographic papers and reported members’ stories, including individual case studies, if available
E: Evaluation	Evaluating the Patient Reported Experience Measures (PREMS) relating to the LLCs and member satisfaction
R: Research type	Qualitative (case studies, interviews, observations, ethnography) and mixed methods (surveys/questionnaires with open-ended questions)

METHODS

To establish the scope for the review, the research team agreed to search for articles from 1995 (the year LLCs were established) through 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.

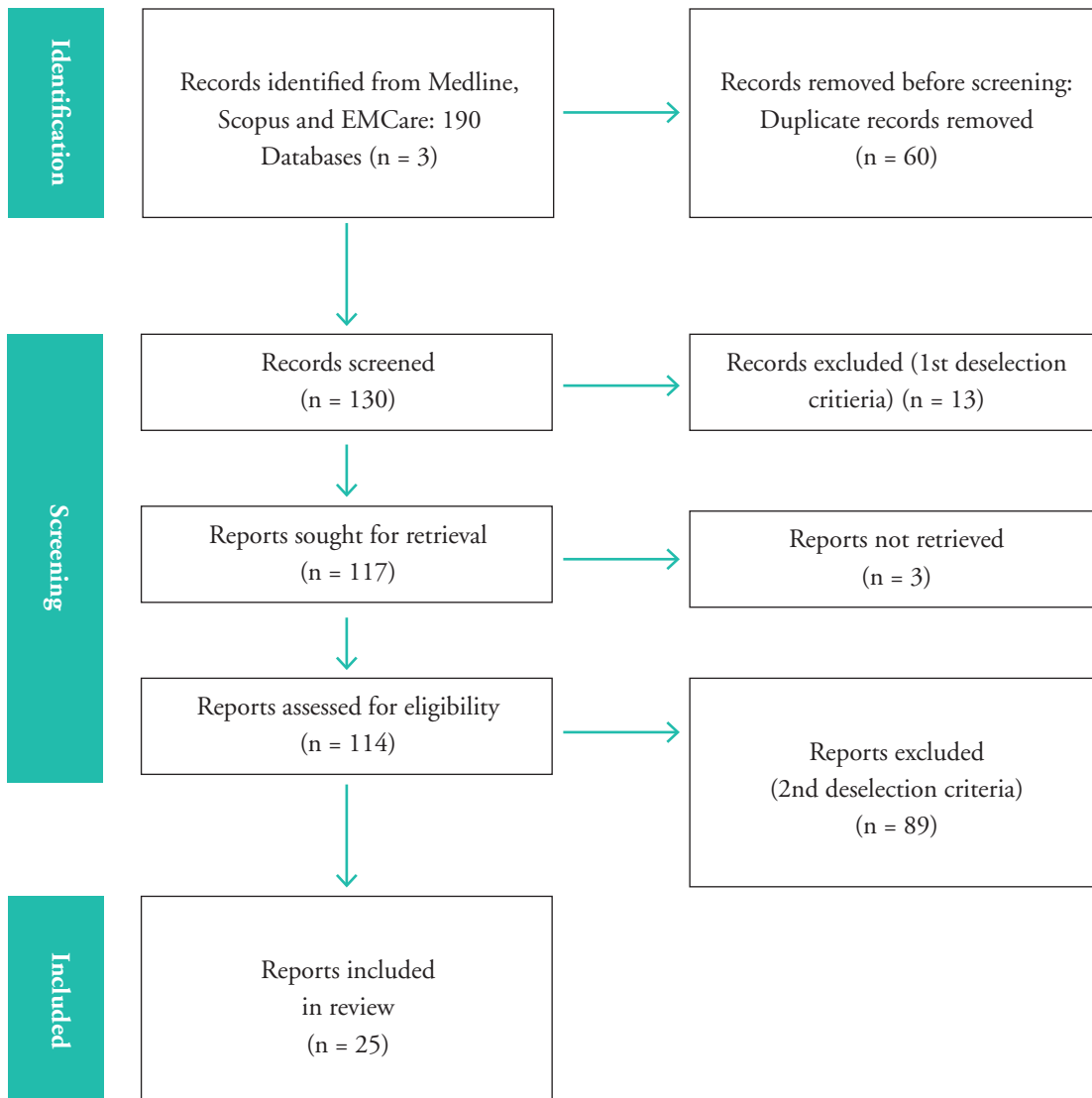
A search was performed using three databases – Medline via Ovid, Scopus and EMCare. Table 2 details the search terms used for the Medline database as an example. The first author conducted the search, which returned 190 publications. After removing duplicates, and further screening the remaining 117 reports, 114 full text publications were inspected,

retaining 25 publications that met the inclusion criteria specified in Table 2.

The citations were entered into a Microsoft Excel spreadsheet by the first author, and the second and third authors validated the papers’ inclusion. 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 experiences (criterion 1). Second, this evidence needed to be presented as any type of qualitative narrative, 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 LLCs 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).

Table 2: Literature search for Medline

Database: Medline via Ovid. Date range: 1995–2021. Language: English	
Search terms	Medline
	1. Exp Leg Ulcer/ 2. Exp Foot Ulcer/ 3. Exp Varicose Ulcer/ 4. (leg adj3 ulcer*) 5. (foot adj3 ulcer*) 6. (venous adj3 ulcer*) 7. Lindsay Leg Club Foundation 8. Lindsay Leg Club* 9. (Leg adj3 club*) 10. LLC 11. Member* 12. Patient* 13. Communit*
Search fields	Full texts
Removing duplicates	
1st deselection criterion	Thematic relevance to the research question (23)
2nd deselection criterion	Empirical evidence of members’ narrative experiences – first- and second-hand evidence, expressed in direct quotations from members or paraphrased by others, presented in qualitative research or mixed methods investigations

Figure 1: Identification of studies via databases

The full texts of the retained articles were then read by the first and third authors, to assess their rigour. The first author developed the codes for the thematic synthesis of LLC members' narrative experiences. A 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).

The analysis followed the principles of interpretative phenomenological analysis (27, 28). First, references to members' subjective experiences were entered into a Microsoft Excel database and coded. The codes were 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 the chronological order of their publication.

Ethical considerations

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

RESULTS

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

Thematic analysis

Social support

The most widely reported aspect of members' LLC

Table 3: Criteria for assessing the quality of evidence. Adapted from Sandelowski (1986)

Criterion	Application to publications reviewed
Credibility: Faithful description of phenomena that readers would recognise from own experience	Presence of members' direct or indirect quotes (verbatim or paraphrased)
Fittingness: Convincing grounding of meaningful findings in data (i.e., findings fit into contexts outside of the study situation)	Warranting interpretations of members' experience with appropriate evidence from members' quotes (enhanced with information on duration and/or frequency of member's LLC attendance)
Auditability: Clear 'decision trail' to enable other researchers to follow and arrive at non-contradictory conclusions	Knowing where the quotes or paraphrasing came from; where and when they were recorded (for example, at a specific Leg Club), by whom, and under what circumstances
Confirmability: All above criteria met, acknowledgement of researcher's subjective experience of and involvement in research	The criterion is mostly partially relevant, due to reviewer's interest in members' first-hand narratives, not their interpretations

experiences 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), while 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 singing together, which 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 work 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 gaining a sense of control over their treatment through open communication, having their concerns listened to and benefitting from knowledge-sharing in relation to the nursing team. One member was reported as becoming a 'partner in her care' (29), while other publications reflected on how ownership over parts of the care process led to a 'major change in behaviour' (33). Members appreciated being 'kept up to date' on the progress of their healing (34) and having procedures explained, in addition to '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 mentioned repeatedly (29, 34, 39, 41, 44, 49–51), with member testimonies pointing to being 'in control of... life again' (29). Attendance at an LLC was linked with benefits to physical and mental health; various members were reported as saying 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 LLCs' accessibility (34, 41, 44, 45, 47, 48, 50, 52). Members liked that Leg Clubs were easy to get to (52) and

Table 4: Findings from the articles included

Author(s)	Research type and amount of data	Themes	Quality assessment*
Lindsay, E., Hawkins, J. (29)	Single member case study. Retelling member's story, one indirect quotation	Empowerment, Improved QOL**	Cr:√ F:x A:x Co:x
Pollard, T. (30)	Editorial sharing of author's own experience of attending an LLC, most focus on LLC set-up, two sentences focused on impressions	Environment, Comparison to GP, Refreshments	Cr:√ F:x A:√ Co:√
Dalzell, L. (31)	Personal account of setting up an LLC. One direct quote from a member (3 sentences)	Social support, Nurses, Volunteers	Cr:√ F:x A:√ Co:√
Hampton, S., Lindsay, E. (32)	Single member case study. Retelling member's story, one indirect quotation	Social support	Cr:√ F:x A:x Co:x
Yarwood Ross, L., Haigh, C. (33)	Single member case study. Retelling member's story, one direct quotation	Empowerment, Education	Cr:√ F:√ A:x Co:√
Elster, M., Kingsley, A., Layton, T. (34)	Update reporting 16 direct quotes from informal member interviews and members' questionnaire	Education, Improved QOL, Environment, Nurses' expertise, Accessibility, Pain, Healing, Environment	Cr:√ F:√ A:√ Co:√
Dean, E. (35)	Single member case study, retelling member's story, two direct quotes	Nurse expertise	Cr:√ F:x A:√ Co:√
Foster, D. (36)	Report of LLC visit. Rephrasing (3 sentences with theme)	Social support	Cr:√ F:x A:√ Co:√
Renyi, R., Hampton, S. (37)	Report/update from LLC visit. 1 direct quote, rephrasing (1 sentence with theme)	Social support, QOL	Cr:√ F:x A:√ Co:√
Upton, D., Upton, P., Alexander, R. (38)	Multi-method survey with a fixed-response questionnaire and closed- and open-ended interview questions; 11 direct quotes from multiple members	Social support, Refreshments, Comparison to GP clinic, Healing, Nursing care, Accessibility	Cr:√ F:√ A:√ Co:√
Hampton, S. (39)	Single member case study, rephrasing (2 sentences with theme)	Social support, QOL, Education, Empowerment	Cr:√ F:x A:√ Co:√
Mew, M. (40)	Two-member case study, three direct quotes with a theme	Social support, Volunteers, Environment	Cr:√ F:x A:x Co:√
Hampton, S. (41)	Single member case study with a 1st person member's narrative, 5 sentences with	Volunteers, Refreshments, theme Environment/ atmosphere, Nurses, Accessibility	Cr:√ F:x A:√ Co:√
Hampton, S. (42)	Single member case study, two direct quotes, retelling member's story	Environment, Comparison to GP, Nurses, Social	Cr:√ F:x A:x Co:√
Higson, W. (43)	Retelling member's story, four sentences with theme	Education, Empowerment	Cr:√ F:x A:x Co:√

Table 4: Findings from the articles included

Author(s)	Research type and amount of data	Themes	Quality assessment*
Hampton, S. (44)	Single member case study, three direct quotes, retelling member's story (10 sentences with theme)	Nurses' expertise and care, Social, Comparison to hospital care, Environment, Relatability to other members, QOL, Accessibility	Cr:√ F:√ A:x Co:√
Hampton, S. (45)	Single member case study, one direct quote, retelling patient's story (four sentences used for theme)	Accessibility, Nurses' care and expertise, Volunteers	Cr:√ F:√ A:x Co:√
Mechen, C., Andrews, M. (46)	Single member's case study, two long direct quotes	Relatability to other members, Nurses	Cr:√ F:x A:√ Co:√
Galazka, A. M. (47)	Evaluation study, retelling and rephrasing the stories of 12 members	Social, Refreshments, Accessibility, Acceptance, Environment, QOL	Cr:√ F:√ A:√ Co:√
Gardner, S., Rooney, J. (48)	Single Leg Club case study, with added ten direct quotes from an implied survey (with open questions) of member's experience	Social, Relatability, QOL, Refreshments, Accessibility, Comparison to other services, Healing (neg), Accessibility (neg)	Cr:√ F:√ A:√ Co:√
Hampton, S., Timmis, J. (49)	Single member case study, with one long direct quote and retelling of member's story	Social, Healing, Nurses, Improved QOL, Empowerment, Education	Cr:√ F:√ A:x Co:√
Brooke, C. (50)	No design specified (case study of volunteering), three direct members' quotes	Social support	Cr:√ F:x A:√ Co:√
Hampton, S. (51)	Single member case study, one direct quote	Improved QOL, Comparison to GP	Cr:√ F:√ A:x Co:√
Spencer Veale, D., Timmons, J., Hampton, S. (52)	Single member case study, one direct quote	Comparison to GP	Cr:√ F:x A:√ Co:√
Galazka, A. M., Edwards, T., Harding, K. (25)	Realist evaluation, interview and observations, rephrasing (10 sentences with themes), multiple	Relatability, Education, Social, Comparison to GP/ hospital	Cr:√ F:√ A:√ Co:√

*Key: Quality Assessment based on the defining characteristics in Appendix 3; o Cr: Credibility o F: Fittingness o A: Auditability o Co: Confirmability. **QOL: quality of life

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.

Comparisons to GP, community or hospital settings Six studies extolled the positive experience of Leg Club attendance by contrasting it with traditional

clinical provision of care sites (30, 35, 38, 44, 51, 52). One study highlighted the uniqueness of the LLC was its informal, relaxed and welcoming nature (30), while another pointed to the value of a social chat while awaiting the treatment, an element that is missing from hospital waiting areas (35). In another study emphasising the provision of person-focused treatment, a member was reported to say her referral to the local LLC was 'the best thing that happened to her' (51). Members appreciated the greater amount of time they could spend with a nurse at the Leg Club

(34), not having to wait at home (48) and that being treated by specialists in leg ulcer care gave them more options (52), describing this as the first 'real treatment' of the wound (as contracted with medication prescribed by GPs) (42).

Volunteers

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

Healing and pain

An obvious positive aspect of members' LLC attendance 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 in the literature (30, 34, 40–42, 44). The adjectives used to describe them 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), while another said, '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, this was linked to a reduction in the feeling of being stigmatised, as 'everyone has the same' issue, 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) LLCs offer.

DISCUSSION

The aim of this synthesis was to systematically review and evaluate the rigour of qualitative research evidence on members' narrative experiences 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 and safety outcomes for the members. This review is the first to appraise the qualitative narratives of the members systematically and specifically, focused on their subjective experiences of LLC attendance, captured in existing literature in the form of direct and indirect quotations and their stories as 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 were 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 for meeting these objectives, at least from the perspective of those members who participated in the studies reviewed herein.

This thematic synthesis of the narratives of LLC members on their experiences has emphasised that this experience is 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 could further enhance members' experiences during 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 lead to even higher rates 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 a 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 and replicable design and therefore did not meet the criterion of auditability, while the ones that did meet the criterion mostly offered retold members’ stories without saying much about how these members were recruited and involved in the research process (24). Any research in the field of LLCs needs to consider the potential vulnerability of this community, which may prevent the conducting 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 were less common, and data on ethnicity was lacking entirely. Insights 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 its sensitivity; however, these sources were deemed the most valid for the topic of investigation. The evidence reviewed was limited to papers published in journals as a marker of quality, but it has to be recognised that other evidence on members’ experiences is available on different platforms, such as the LLCs’ YouTube channels. 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 countries have now established LLCs. Exploration of this could provide valuable insight into cultural aspects of experience worthy of sharing.

CONCLUSION

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

for further research to find ways of improving LLCs’ accessibility and strengthening relationality among 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 a screen, and some waiting areas should be positioned so that members do not have to observe others’ treatments.
- 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 exploring the demographics of members is necessary to understand their unique experiences.
- There is a need to undertake sensitive yet rigorous qualitative research that records members’ narratives using as close to verbatim quotes as possible.
- Future publications should carefully explain where the data came from and describe the study design in detail.

Acknowledgment

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Key messages

- This is a systematic review of qualitative studies reporting on members’ experiences of attending Lindsay Leg Clubs.
- This paper analyses the published qualitative evidence to thematically synthesise the experience of attending a Lindsay Leg Club, as expressed in members’ narratives.
- This review found overall positive members’ subjective experiences of the Lindsay Leg Clubs, captured across 10 main themes.

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