Leg Clubs® – Beyond the ulcers
Case studies based on participatory action research

Shuter P, Finlayson K, Edwards H, Courtney M, Herbert C & Lindsay E

Abstract

Based on participatory action research (PAR), the case studies in this paper examine the psychosocial benefits and outcomes for clients of community-based Leg Clubs®. The Leg Club model was developed in the United Kingdom (UK) to address the issue of social isolation and non-compliance to leg ulcer treatment. Principles underpinning the Leg Club are based on the participatory action framework (PAF) where the input and involvement of participants is central. This paper reports on a study carried out concurrently with a randomised controlled trial (RCT) and identifies the strengths of the Leg Club in enabling and empowering people to improve the social context in which they function. In addition, it highlights the potential of expanding operations that are normally clinically based (particularly in relation to chronic conditions) but transferable to community settings in order that that they become 'agents of change' for addressing such issues as social isolation and the accompanying challenges that these present, including non-compliance to treatment.

Keywords: Leg Club®, leg ulcers, peer support, social integration

Introduction

It is widely acknowledged that leg ulcer management is one of the most time- and cost-consuming activities in community nursing[1-4]. This situation is sometimes exacerbated by poor healing results due to non-compliance to treatment by leg ulcer sufferers who are often socially isolated. A correlation between non-compliance and social isolation has been identified in related literature[5,6].

In this context, community Leg Clubs® for the treatment of leg ulcers were developed in the United Kingdom (UK) by Ellie Lindsay[1]. Lindsay describes the unique approach of Leg Clubs where, "patients become stakeholders in their care provision in a community-based setting". Leg Clubs operate on a drop-in basis and have been described as a 'hub' where clients, staff, volunteers and educators come together to create a supportive environment with an emphasis on social interaction and peer support, concurrent with leg ulcer management by trained professionals.

Until recently, a scientifically controlled study to demonstrate the effectiveness of a community-based Leg Club over traditional community care in individuals' homes had not been carried out. Collaboration between the founder of the Leg Club, Ellie Lindsay, St Luke's Nursing Service (SLNS – now Spiritus) and Queensland University of Technology (QUT) presented an opportunity to address this gap in evidence-based leg ulcer management by conducting a randomised controlled trial (RCT)[7-9], and concurrently, this study based on participatory action research (PAR) to explore and enrich the results of the RCT.

Two Leg Clubs were established by SLNS in Queensland based on the UK model. Following approval from the research ethics committees of QUT and SLNS that conformed to the Statement on Human Experimentation, QUT undertook the RCT and concurrent PAR study. Computer-generated randomisation was carried out with leg ulcer patients who had volunteered to participate in the study. These volunteers were randomised to the Leg Club (intervention) or traditional community care (control). Participants randomised to the Leg Club enjoyed social interaction and peer support in addition to the normal care of their leg ulcers by specially trained community nurses, while the control group received traditional normal care of their leg ulcers in their homes by the same nurses.

Participant approval was sought and obtained from all participants and the cases described in this paper were drawn from the participants who had been randomised to the Leg Club. The sampling frame for this study was considered sufficiently large that the possibility of identification of specific individuals amongst many in similar situations was deemed highly unlikely.

The principles underpinning the Leg Club were based on the participatory action framework (PAF), where the input and involvement of participants is central. The PAR model that guided the operation of the Leg Club enabled the researchers to examine more closely psychosocial benefits and outcomes for members of the Leg Club and further explore results from the quality of life component of the RCT. These results indicated that attendance at the Leg Club resulted in improved morale and perceptions of social support compared to the control group.

Ms Patricia Shuter * DipHEd, MHthSc, MAppSc
Senior Research Assistant, School of Nursing and Midwifery, IHBI Queensland University of Technology, Victoria Park Rd, Kelvin Grove QLD 4059
Phone (07) 3138 6446
Email p.shuter@qut.edu.au

Dr Kathleen Finlayson BN, MNurs
Research Fellow, School of Nursing and Midwifery, IHBI Queensland University of Technology

Prof Helen Edwards DipAppSc, BA, BA(Hons), PhD
Professor and Head, School of Nursing and Midwifery, Queensland University of Technology

Prof Mary Courtney BComm, M Health Planning, PhD
Dean Faculty of Health and Social Development, University of British Columbia, Canada

Ms Cheryl Herbert DipAppSc, BAppSc, RN, RM, AdjAssProf
Chief Executive Officer, Health Quality and Complaints Commission
Formerly Chief Executive Officer, St Luke's Nursing Service (now Spiritus), QLD

Ms Ellie Lindsay DipHEd, BSc(Hons)
Independent Specialist Practitioner, 2 St Mary's Close, Gislingham, Eye, Suffolk IP23 8HW, UK

*Corresponding author

The Leg Club PAR process

Aim: To examine the ability of the Leg Club to bring about psychosocial changes that have the potential to empower members to improve the social contexts in which they live.

Method

The study was carried out based on the PAR concept of researcher as participant. PAR enables participants in the field of study to be actively involved in the research process that "requires participants to be seen as equals not only with the researcher but also with each other"[13]. The Leg Club, characterised by the informal but highly respectful collaboration between the organisations and the key roles played by clients, staff, volunteers and researchers in maintaining the egalitarian and inclusive culture of the Leg Club presented a valuable opportunity to carry out a PAR study that would enrich the results of the RCT.

The researcher is one member of the group interacting with clients and staff as a friend "working with the community members to implement the action and social change necessary to resolve a health problem"[14]. Kelly confirms the appropriateness of PAR for the Leg Club, emphasising the value and potential of small-scale studies as a key approach to exploring consumer issues, especially in relation to those who are normally disempowered or marginalised. Clients who attend the Leg Club represent different levels on the continuum between empowerment and disempowerment and embody a range of demographic characteristics. This includes the material spectrum from homeless to financially comfortable, people with psychiatric disorders and cognitive impairment and many levels of physical functional ability.

Results

The results were based on field notes and observations of researchers and informal conversations between the researcher as a member of the group interacting with staff, volunteers and Leg Club members.

The purpose of PAR is to better understand and ultimately improve practice through empowering participants to improve the social contexts in which they function[13,14]. Results of the Leg Club PAR indicate social outcomes that have moved beyond the clinical and social interaction within the Leg Club and indeed empowered clients to improve the social context in which they operate.

The results are presented in the form of two case studies. These case studies demonstrate the potential of the Leg Club model not only to improve social contexts for the clients, but to act as an catalyst or mechanism for individuals who would benefit significantly from respite-style care and would otherwise not

access it. A case study was considered an appropriate format in which to present the outcomes of this research because it is regarded as an appropriate platform when there is a need to understand the causal interrelationships of complex, dynamic personal and social factors[15] as existed in the Leg Club. The 'case' as a unit of study can take a number of different forms, including a group or groups of people[16]. In this study the individual Leg Club clients represent the 'cases'.

Case study one

The first case study is of a client who was an 80-year-old woman suffering from mild dementia and her 90-year-old husband and carer who lived in relative isolation. She had been randomised to the Leg Club but there was doubt and misgiving because her husband was uncertain about the implications of bringing her to a completely unfamiliar venue. The GP of this couple did little to allay the misgivings when contacted by researchers, advising "great caution" in introducing this couple to the Leg Club. A decision was made that the couple would be invited and welcomed to the Leg Club. Arrangements were made and they were picked up by a volunteer driver. From the first day, they were both warmly accepted by fellow clients, staff, volunteers and researchers. The woman's mild dementia was understood and did not present a barrier to meaningful communication. Observing her social integration into the Leg Club as she shared reminiscences and began to relax and enjoy the inclusive atmosphere was heart-warming. Her husband had also been well received and in time was able to relax and share travel experiences and day-to-day conversations with other clients and staff as he watched his wife integrate happily. Initially he had been quite protective of his wife and wary of the situation, but after some weeks expressed the thought that he felt his wife would be well cared for if she came to the Leg Club on her own.

She continued to attend the Leg Club alone and became increasingly happy to share her life stories. One volunteer, noting that she spoke about having done a great deal of crochet in her early life, decided to provide her with some wool and a large crochet hook and encourage her to take it up again. Another client who, despite being legally blind, did beautiful hand crafts including crochet and took it upon herself to be the crochet 'tutor' for this woman. After a painstaking explanation and assistance in beginning the work, the tutor went to have her leg ulcer treated. The surprise when she returned to find her friend crocheting, with nonchalance and dexterity, an almost complete square provided amusement and pleasure for the staff, volunteers, researchers and fellow clients.

In the meantime, the Leg Club had provided her husband with a morning's respite from caring for her. He was a dedicated carer and the demands of caring for a person with dementia are well documented[17-19]. These mornings gave him the opportunity to potter in his beautiful, pristine garden and carry out chores around the house. The volunteer driver who picked up his wife shared his pleasure and complimented him on his achievements. This provided him with some positive external social interaction.

This man sent a letter to the coordinator of the Leg Club acknowledging and thanking them for the valuable contribution that the Leg Club had made to their lives. As a final confirmation of the difference that the Leg Club had made to her life, the woman hugged the researcher following the Leg Club Christmas party and declared, "I have never been to such a wonderful party!" Sadly this woman died suddenly of a stroke shortly after this. She is missed by the Leg Club clients, staff, volunteers and researcher. However, knowing that her last months were enriched by being a member of the Leg Club is gratifying to staff and researchers alike. The experiences of this couple demonstrate the value of Leg Clubs as a setting where meeting the physical needs of a client can evolve into a holistic experience where the psychosocial needs of both client and family are met.

Case study two

One of the instruments used in the RCT evaluating the Leg Club was the geriatric depression scale. This is used with the undertaking that, should a client's score indicate a high level of depression, action would be taken. The value of this, in the broader context of the Leg Club improving the social contexts in which clients function, was illustrated when a gentleman who was a widower attended the Leg Club following an advertising campaign. The man was introspective and exhibited anxious behaviour, attended the Leg Club for a few weeks and then failed to return. An informal phone call enquiring as to his wellbeing was made and following this call he returned to Leg Club.

Following his return, the Leg Club coordinator was alerted to his very high score on the depression scale. This provided the manager with the opportunity to discuss issues that might be troubling him. Over a period of time they built up a rapport and his trust was gained. The Leg Club became a regular and pleasurable outing for him and his visits lasted longer. He was increasingly more relaxed and was happy to joke and share stories with everybody at the Leg Club. Through discussion with a researcher he made contact with the U3A and enrolled in a computer course, which improved his confidence and self-esteem.

A few months after his return to Leg Club, he developed pain and complications with his leg and reported that he was unable to obtain satisfactory support from the hospital where he went for treatment. The Leg Club nurses advocated for him, writing two letters recommending prompt and comprehensive treatment. His pleasure at the outcome of this advocacy which was respectful, prompt and comprehensive treatment at the hospital was satisfying for the Leg Club staff and researchers. He continued to attend Leg Club and his increased optimism and cheerful disposition ensure that he is a welcome participant in this positive and relaxed environment.

Discussion

These case studies, situated as they are within a PAR framework, highlight the value of the Leg Club beyond the management of leg ulcers. The success of the Leg Club in the light of this research cannot be viewed as a simple linear progression. The results indicate a dynamic social framework where power/knowledge relationships have been challenged and clients have been empowered to bring about positive change.

In the case of the woman suffering from mild dementia and her husband, the advice of the doctor was challenged. The course of events that followed enriched the lives of this couple as a result of interaction and collaboration with a group of people between whom the boundaries of knowledge and power had been blurred. The only motivation was to enhance the Leg Club experience and empower this couple to maximise the positive aspects of their lives together.

Similarly, the widower was able to find empathy and support at the Leg Club that empowered him to overcome his depression and anxiety. Through advocacy, the hospital was challenged and changed their approach towards him. The confidence and optimism that this generated, and the support of the Leg Club, enabled him to make plans and take action that enriched and continue to enrich his life.

Meyer[13] states that the purpose of PAR is to better understand and ultimately improve practice. This can be achieved because the findings of this type of research are more meaningful to practitioners as they more closely reflect reality by responding to events as they naturally occur in the field. The value of this study, in the light of this, is that it identifies the strengths of the Leg Club in enabling and empowering people to, "improve the social contexts in which they function"[13]. It highlights the potential of expanding operations that are normally clinically based (particularly in relation to chronic conditions) but transferable to a community setting so that they become 'agents of change' for addressing such issues as social isolation and community engagement, that will enhance the lives of marginalised and disempowered groups. Optimally such issues as non-compliance to any treatment through social isolation will no longer present a challenge to community health practitioners.

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