

Development of Self-Efficacy Tools for Parents and Professionals Caring for Children and Young People with Lymphedema (ILF Parent SE and ILF Professional SE)

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Abstract

Background: Self-management is a key aspect of lymphedema treatment and self-efficacy is a key factor linked to long-term adherence to treatment. The study aimed to generate self-efficacy scales to support the care of children and adolescents with lymphedema to support self-management.

Methods and Results: Parents of children with lymphedema and the professionals caring for them were recruited during a lymphedema educational camp. Six individual semistructured focus groups were undertaken in Italian, French, and English (three for parents and three for professionals) with simultaneous translation. Scale item generation was developed using interpretative phenomenological analysis and adopted Bandura's self-efficacy concept. Two self-efficacy tools were developed from research with 26 parents and 14 professionals. The parental tool (ILF parent SE) has 6 domains and 44 items: school; home and leisure; understanding the condition and treatment, and managing child and parent emotions. The professional tool (ILF Professional SE) has 4 domains and 21 items. This scale has two parts; the first indicates the level of professional autonomy in decision making, and the second covers assessment and treatment, patient understanding, and managing emotional reactions. Both tools adopt a 0- to 100-point scale using a 10-unit interval with 0 (cannot do) through to 100 (high certainty of being able to do). Initial face validity has been undertaken.

Conclusion: Self-efficacy has emerged as a complex issue faced by parents and professionals involved with children and young people with lymphedema. By being able to assess the challenges parents face in self-efficacy individualized programs can be developed that will assist families in managing this complex disease and lead to greater well-being. Increased professional self-awareness will help the development of mentorship programs to support professionals dealing daily with the stress of managing a rare disease in which the outcome may be uncertain.

Keywords: lymphedema, self-management, self-efficacy, scale development

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Background

THE CLASSICAL PILLARS of lymphedema management have always defined the importance of patient participation with treatment that requires them to commit to daily techniques such as skin-care regimes, specialized massage (manual lymphatic drainage), exercise, and different forms of compression therapy.¹ There is little doubt that these are a fundamental part of achieving control and prevention of complications that include cellulitis.² Despite this fact, very little attempt has been made to understand how people with lymphedema cope with their condition and face the daily challenges of self-management.³ In addition, there is little international clarity over what constitutes effective self-management for this complex population.

Many studies in lymphedema show that although the primary goal of treatment is the control of swelling, other difficulties include altered sensations, psychological distress, changes in body image, fatigue, and functional limitations. These may lead to a reduction in activity that further overwhelm patients, reduce their quality of life and overall sense of well-being.³ It is, therefore, likely that improvements in adherence to treatment will influence many aspects of life beyond symptoms associated with edema control. It is, therefore, of great importance that professionals understand in order that they can integrate these aspects into their clinical practice.

Psychosocial concepts such as lay beliefs, motivation, and self-efficacy have received little attention in lymphedema and yet may be fundamental in our understanding of why some patients are able to persevere with treatment and others are not.⁴ This is even more important for children and adolescents with lymphedema in whom it is a rare disease. It is well recognized that adolescence can be a traumatic period of life and an important transition during which they develop an enduring sense of self and personal identity⁵

Defining Self-Efficacy

Social cognitive theory addresses the developmental changes that occur during life and is influenced by the milieu of personal and ever-changing environmental factors.⁶ Self-efficacy is a complex phenomena that explores how individuals make subjective judgments about the capacity and capability they feel to be able to undertake a course of action that will result in a specific goal. Bandura's seminal study on self-efficacy reflects that life is not a situational entity but rather is a succession of transitions that need to be negotiated and shape our individual and collective future.⁷ It is recognized that personal self-efficacy is a fundamental bridge of human kind and influences motivation, well-being, and a sense of accomplishment. Unless people believe they can achieve results they do not have the incentive to persevere.

Many factors influence the outcomes of treatment, including the judgments people make about how well they will be able to perform activities in complex situations and their ability to solve problems when facing these issues.^{8,9} Considerable research has shown the complexity of supporting self-management programs for children and adolescents who are living with different chronic conditions. Self-efficacy beliefs are known to contribute significantly to emotional well-being and quality of life and also influence motivation and cognitive functioning, which in turn affects their ability

to accomplish complex tasks¹⁰ People with low self-efficacy quickly feel their efforts are futile when they face challenges causing them to give up, whereas those with high self-efficacy see the challenge as an opportunity for self-development, and that with perseverance the problem will be solved. Research has shown the importance of the culture and context in developing self-efficacy in young people; therefore, in studies such as the one reported in this article, we have attempted to address this aspect rather than assuming a homogenous group of parents and professionals. Research in the United Kingdom has shown that parents of children with lymphedema frequently suffer a long delay of several years in obtaining a correct diagnosis and retain negative memories of the difficulties of this journey.⁴ This leads to mistrust in professionals. However, the same research indicated the relief parents felt when reaching an expert center that could support them. Parents of children with a rare disease face the additional challenge of providing a normal childhood while assisting their children into adulthood in the face of an uncertain future.

Defining Self-Management in Chronic Illness

Estimates of the number of children who suffer with chronic conditions vary.¹⁰ The definition of chronic illness states the condition must have been present for >6 months and may be a result of genetic or environmental factors or a combination of both. In many instances the cause of lymphedema in children has yet to be defined, although the genetic field in this area is growing rapidly and insight continues to evolve of the possible causes.¹¹ Irrespective of this fact, long-term conditions differ in their severity and impact, but all require a degree of daily management and self-monitoring, which is defined as "self-management."

Research indicates that a more accurate term than "self-management" is "supported self-management".¹² Children, especially infants and very young children, require support and cannot self-manage alone but depend on parents and caregivers. Research strongly supports the need for an individualized approach that engages the child and family and takes account of the child's age and stage of emotional and cognitive development.¹³ Children's views may also differ significantly over time from that of their family particularly during adolescence. Self-management programs must be provided in a positive way to assist in achieving changes in behavior and attitude to treatment. Children develop at different speed that will influence their ability to foster self-management skills. These views are widely supported in the literature¹⁴

Self-Management in Lymphedema

A systematic review of activities or treatments in lymphedema revealed the lack of research in children and young adults with lymphedema.³ The results showed the importance of self-management and the poor evidence base that currently exists. The dichotomous view that professional treatment of lymphedema is separate from patient self-management is difficult to reconcile as both are required for effective management. Traditional aspects of treatment, including compression therapy, are based on the procedures used by professionals in adults, which are then taught to children and parents without adaption. These techniques are largely based

on adult recommendations without clear articulation of what should be adapted for children despite them facing different challenges. These aspects contributed to the requirement of research to explore these issues and ultimately improve self-efficacy in parents and professionals caring for these young people.

The aim of this study was to use qualitative methods to generate items for two scales, a parent and a professional self-efficacy scale related to caring for children and adolescents with lymphedema. The study was included within a wider study to explore the enablers and barriers to self-management in children, adolescents, parents, and professionals, which has already been reported¹⁵⁻¹⁷

Research Setting

Parents with children and adolescents with lymphedema and the professionals caring for them were recruited while attending an international educational camp for children with lymphedema in Turin, Italy (2017). The model of camps for children with lymphedema was developed in an expert center in Montpellier by the senior author of this article and has been extended to offering a camp to children from different countries.

The sample in this study included parents and professionals from Italy, France, Canada, Eire, and South Africa.

Ethics

Approval for this study was given by the University of Nottingham Faculty of Medicine and Health Science Ethics Committee. Formal ethical approval was not required in Italy as it was not an intervention study. The research was performed in accordance with the 2013 Helsinki Declaration.¹⁸ All participants gave informed consent and were made fully aware of their right to withdraw from the study if they wished to do so.

All study information was translated and back translated into the different languages to ensure accuracy with English, French, and Italian. Parents and professionals were involved in the development, review, and translation of the study material and to ensure it was suitable for a lay audience.

Methods

Parents and professionals were invited to participate within focus group undertaken in their native language (French, English, or Italian). Parents and professionals attended separate focus groups. There was no limit placed on the size of the groups as we were keen to hear the views of all who wanted to participate.

Moderation was carried out by two researchers, which were simultaneously translated so that participants could speak in their native language. The researchers wore headsets to ensure they understood the translation.

Procedure

After informed consent, participants introduced themselves and discussed their roles in relation to the children with lymphedema who were attending the camp. Semistructured focus groups involved initial questions that included the following areas: views about self-management in lymphedema, the challenges they faced, and how they addressed

these every day. This discussion included exploring their attitudes and feelings about their own self-efficacy beliefs. Parents were asked about their perceptions of self-efficacy in managing their child at home and at school and were asked about the challenges they viewed as their child developed. Professionals were asked about their views on preparing parents to care for their child with lymphedema and their own professional perceptions of their self-efficacy in supporting children and families.

At the conclusion of each focus group the moderators summarized the main points and invited further comments about anything that had not been addressed. All focus groups were audio tape recorded and lasted up to 1.5 hours. At completion both moderators completed a reflective diary of the event, which included their initial impressions and questions that may have been otherwise lost.

Data analysis

Interpretative Phenomenological Analysis methods were used.¹⁹ The first transcript was read several times, the left-hand margin being used to annotate what was interesting and significant and to create a thematic structure. These themes were then taken back and checked against the original transcript. Emergent themes were listed on a sheet of paper and studied for connections between them and were then clustered to produce a set of superordinate concepts that were continually checked with the transcripts. From this a coherently ordered table of themes was established and given names with a concurrent identifier to aid the organization of the analysis and facilitate checking back to the original transcript. During the analysis themes were dropped if they did not fit well into the emerging structure or were not rich in evidence. Themes from the first transcript were then used to ordinate the analysis of subsequent transcripts. As such, repeating patterns were established, but the emergence of new issues was also recognized. Data from each country focus group were then compared across the three transcripts to explore the cultural differences emerging.

An additional researcher undertook independent thematic analysis using the verbatim transcripts. Both researchers discussed the themes and subthemes they had identified, and agreement was sought when meaning was deemed the same, but the language used was different so that informed consensus was achieved.

Results

A total of 26 parents participated in the three focus groups (Table 1) and 14 in the professional groups (Table 2) with representatives from medicine, nursing, physiotherapy, and clinical psychology.

TABLE 1. SUMMARY OF ATTENDANCE IN PARENT FOCUS GROUPS (N=26)

Language	N=26
English	4
French	10
Italian	12

TABLE 2. SUMMARY OF ATTENDANCE IN PROFESSIONAL FOCUS GROUPS AND PROFESSIONAL ROLE (N= 14)

Language	N= 14	Physician	Physiotherapist	Nurse	Psychologist
English	3	1	—	2	—
French	6	2	2	1	1
Italian	5	1	4	—	—

Summary of findings from the parent focus groups

Results. Results from this thematic analysis have been previously published.¹⁵ Four superordinate themes emerged from the parent analysis: the journey, treatment management, independence, and psychosocial impact. Ten subthemes were identified: bandaging/compression, professional support, holistic care, fear, self-efficacy, acceptance, friendship, guilt, distress, and hope.

Conclusion of parental findings

The research indicated that the parents understood the importance of their child taking on treatment and becoming independent. This required them to develop skills in effective problem-solving. The parents recognized many difficulties for the child and themselves in achieving this. The research indicated that success with treatment could be a motivating factor, and this encouraged them to persevere when faced with their child’s resistance.

Creative approaches using play activities were used by parents of younger children to help their child engage in self-management. However, this was often difficult as it was intrusive to family life and excluded siblings. The research showed that younger children found the self-management boring and restrictive and could also limit what parents allowed them to do due to the fear of injury or exacerbation of the lymphedema. There was a range of parental views on this with parents of newly diagnosed children having more concern than parents of older children who had learnt to adjust and through experience to trust their judgments about what was safe for their child. Difficulty was expressed about the transition that occurred in adolescence and how to deal with letting their child take responsibility for their self-management and concerns that failure to continue with treatment would lead to complications such as cellulitis, which was a fear for parents and professionals.

Siblings were seen to play an important part in supporting the child affected by lymphedema both at home and school; however, very little emerged about how siblings felt about the role they adopted. Parents expressed an understanding of how lymphedema impacted on the whole family and they were often concerned this was detrimental to their other children. Families varied in the degree to which self-management was embedded in family life and the rigidity in which they carried out the techniques they were taught. Parents expressed their longing for cure or at least to have an ability to control the swelling and prevent deterioration. This motivated some parents to search for doctors who they believed could eradicate the lymphedema despite being told evidence to the contrary. Some parents wished to explore unproven treatments such as diets that were not necessarily recommended by professionals.

Parents did not describe themselves as self-efficacious despite the research showing that they were able to solve

complex problems; however, the data are complex. Parents used problem-solving and many held the belief that they could influence their child’s illness and thereby improve their overall well-being. The problem-solving included being able to find solutions for the daily treatment challenges they faced. Success was celebrated and was a strong motivator to persevere. Parents of adolescents strove to be able to transfer self-management to their children and acknowledged this was difficult and would involve an element of trial and error and inconsistency. This was particularly difficult when they felt their child had not come to accept their condition and when the degree of swelling influenced the child’s daily life. Parents were aware that a “normal limb” was of great importance for aesthetic reasons as well as the challenges of obtaining fashionable shoes and clothes. Parents focused on the need for their child to undertake a normal life and participate in activities. This was set against the fear of complications if they undertook activities they appraised as high risk. The situation was exacerbated for parents who had been rigidly taught by professionals. Many parents described their advocacy role in helping their child manage at school and to promote healthy home activities and relationships.

Parent self-efficacy questionnaire

The findings from the research have been developed into parental self-efficacy questionnaire presented in (Table 3).

Summary of the professional superordinate categories and themes

Results. Analysis of the data from the professional focus groups produced three superordinate themes: professional concepts of self-management, professional practice, and redefining the cornerstone of lymphedema care. An additional seven subthemes were readiness to self-manage, professional perspectives on self-management, defining success and treatment failure, emotional burden, traditional views on complex decongestive therapy (CDT), new ways to practice and sole practitioner versus multi-disciplinary teams. This thematic analysis has been published in full.¹⁶

Conclusion of professional findings

Professionals struggled to define self-management but identified the need for the family to be independent from continuous professional care and the importance of the child having as normal a life as possible. Different views were expressed about how and when this could occur with some able to tolerate more uncertainty than others. Therapists discussed self-management in relation to practicing techniques that are included as part of CDT, and the challenges of parents taking on these roles. Adherence to these procedures

TABLE 3. PARENT SELF-EFFICACY QUESTIONNAIRE (ILF PARENT SE TOOL)

This questionnaire is designed to help us get a better understanding of the kinds of things that create difficulties at school and home for parents with a child who suffers with lymphedema.

Please rate how certain you are that you *can do the things* discussed below by writing the appropriate number. Your answers will be kept strictly confidential and you will not be identified by name.

Rate your degree of confidence by recording a number from 1 to 100 using the scale below:

0	10	20	30	40	50	60	70	80	90	100
<i>Cannot do</i>			<i>Moderately can do</i>				<i>Highly certain can do</i>			
<i>Confidence (0–100)</i>										

Efficacy to influence decision making at school

- I can influence the decisions made about my child
- I can express my views on important matters
- I can ensure they join in normal academic activities
- I can ensure they join in sports activities
- I can ensure they join in extracurricular activities
- I can ensure my child's teachers understand the risk of certain activities
- I can reduce the risk of injury at school
- I can obtain help if they experience bullying
- I can help them manage other children's reactions to their condition
- I can help them reach their full potential at school

Efficacy to influence home and leisure activities

- I can get them into activities with other children at home
- I can ensure they join activities with their siblings
- I can ensure their siblings understand their condition and treatment
- I can stop them undertaking high-risk activities
- I can find ways to manage treatment within daily life at home
- I am confident to modify treatment if this interferes with home life
- I am confident that I can find clothing my child enjoys
- I am confident that I can find shoes that are suitable for my child

Efficacy to ensure my child understands their condition and treatment

- I can explain my child's condition to them in ways they understand
- I can identify accurate information to help them understand their condition
- I can ensure the professionals explain the condition to my child
- I can deal with questions that my child has about their condition
- I can ensure the family understands my child's condition

Efficacy to ensure my child undertakes self-management of their lymphedema

- I can ensure they wear their bandages
- I can ensure they wear their compression hosiery
- I can ensure they undertake exercise
- I can ensure they use massage
- I can find solutions if my child does not want to participate in treatment
- I can find ways to modify my child's treatment at home
- I can find ways to make my child's treatment a fun activity
- I can find ways to ensure my child is able to do things independently

Efficacy to manage emotional reactions in my child

- I can help my child cope with their condition
- I can manage my child's emotions if they are upset over treatment
- I can help my child when they feel down
- I can help my child look at positive things in their life

Efficacy to manage my emotional reactions

- I can stop myself from worrying about things with my child
- I can cope with the uncertainty of my child's condition
- I can take my mind off upsetting experiences with my child
- I can stop myself from being upset by everyday problems with my child
- I can keep tough problems with my child from getting me down
- I can overcome discouragement
- I can gain help from professionals when I am down about my child
- I can gain help and support from other parents
- I can find ways to distract myself from problems

was often described in a causal relationship to treatment success or failure and was attributed to the level of parental engagement. Attitudes to the strictness that parents should adopt in self-management varied considerably. Some reported that continuous adherence to a set of techniques was directly linked to the control of swelling, whereas others were more relaxed in their assessment of this.

Professionals found that integrating self-management techniques into their treatment time was time consuming and required a continuous relationship and engagement with families. Professionals held a strong belief in the need for a therapeutic relationship based on trust that could not always be rapidly or easily established. The challenges of having adequate time for families were discussed by professionals from all disciplines and countries.

The views held by professionals were diverse and ranged from paternalistic attitudes to following professionally prescribed treatment regimens to flexible approaches that sought solutions with the families. There was international recognition of the importance of providing correct information. Professionals expressed the difficulties they faced in dealing with uncertainty and their lack of self-efficacy in addressing questions from parents that they could not answer. This led to strong emotional reactions and was expressed by practitioners working alone and within teams.

Professional self-efficacy questionnaire (ILF Professional SE tool)

The findings from the research have been developed into a professional self-efficacy questionnaire (Table 4). The first part requires information about the type of professional completing it. The legal practice frameworks in different countries influence what professional groups can prescribe treatment (CDT) and the degree of freedom therapists have in making adaptations if they consider this is necessary, without consulting the original medical prescriber. In some countries therapists play a passive role in implementing the treatment prescription, whereas elsewhere they have more autonomy. In some countries, such as the United Kingdom, physiotherapists and nurses may have full prescribing rights with services being entirely therapy led. These differences may alter the beliefs about the degree of self-efficacy professionals feel in providing treatment if they feel they have little control over decisions. These aspects have been incorporated within the design of the questionnaire.

Conclusion

Self-efficacy has emerged as a complex issue faced by parents and professionals involved with children and young people with lymphedema. Design of the self-efficacy tools in this study were based on Bandura's recommendations.⁷ Efficacy items have been designed to reflect perceived capability and, therefore, "Can" is used to frame each question. The tool has also been designed to address specific issues that have emerged from the research. Each item requires a judgment is made about the belief in the ability they have to complete the task and a 0- to 100-point scale has been adopted as this has been shown to be more discriminant than smaller values to define differences in the population.²⁰ The tool uses a 10-unit interval scale with 0 indicating they *cannot do it* through to 100 in which they have a *high certainty of*

being able to do this. The tool will include preliminary instructions and include asking those completing the questionnaires to judge their considered current capability and not a future potential issue that they may not have faced.

To avoid the effects of motivational self-assessment and reporting bias safeguards have been recommended, including completing the questionnaire in private and allocating a code rather than a personal identifier.²⁰ The participants will be told their responses will be confidential to the research staff only and that they will make an important contribution to the research, which will ultimately help to improve the care of children and young people with lymphedema.

Plans for further validation

Face validity for the questionnaire in English has already been undertaken with 10 parents of children with lymphedema in the United Kingdom. A panel of professional experts from different countries who are involved in treating children with lymphedema have been asked to review the relevance of the items contained within the tools having been given the working definition of the construct we are studying. The reviewers were asked about the relevance of the items and its clarity and conciseness. The reviewers were also asked about any other ways that could be used to understand the phenomenon within the item.

Further research will include linguistic translation of the questionnaires in different languages. During the scales validation it will be assessed to identify potential flaws or problems. This will include assessment for social desirability that occurs when respondents wish to present themselves in a more positive manner that may distort the findings. Construct validity will be assessed alongside the tools' validation in large sample sizes.

Development of a clearer conceptualization of the challenges of self-management in lymphedema and the self-efficacy beliefs that underpin it will allow for the development of programs of support that will help children and their parents manage the day-to-day challenges they face.

Author Disclosure Statement

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