

AN ASSOCIATION FOR PEOPLE CONCERNED WITH LYMPHOEDEMA: THE BENEFITS OF BELONGING*

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ABSTRACT

Lymphoedema is a relatively neglected chronic condition with inadequate treatment provision and significant psychosocial consequences. A membership survey of a self-help organization in Queensland providing information and support and organizing meetings for people concerned with lymphoedema produced evaluative feedback. Comprehensive evidence of the benefits of belonging to the organization was gathered from the responses to a set of open-ended and closed questions. The contribution of this non-government organization to the health and welfare of people with lymphoedema by providing services and representation and facilitating association, is illuminated and affirmed by this evidence.

We have learned a great deal about how people experience chronic illness, but little attention has been paid to lymphoedema. This may in part be because the condition is often secondary to the impact or treatment of some other disease or condition. There is a "lack of research on the psychosocial impact of the disease" (Gillham, 1994) and comparatively, an absence of "means to identify the nature and degree of lymphoedema-related problems" (Todd, 1999). The condition results from inadequate drainage of lymph and causes unsightly, uncomfortable swelling, most often in the arms or legs. The changes brought about by the swelling carry a risk of skin infection and acute inflammation. Other consequences

*This work was carried out when both authors were at the University of Queensland.

of lymphoedema are pain, lack of energy, and loss of mobility. Primary lymphoedema is likely to be the result of an abnormality of the lymphatic structure. In developed countries, the main cause of secondary lymphoedema is malignancy and its treatment, for instance, surgical removal of lymph nodes in association with breast cancer. No curative treatment is available, but physical therapies can control the condition and result in reduced swelling and discomfort, and increased mobility. The extent and availability of treatment varies very considerably, from none at all to intensive therapy over several weeks (Gillham, 1994). As part of the treatment, patients are fitted with containment garments and encouraged to exercise and to carry out daily massage to keep the condition under control.

Lymphoedema is not a high profile medical condition, and this makes the role of a self-help group all the more significant in combating isolation among people with the condition, providing various services and advocating for improved treatment. In November 1999, a survey of the membership of the Lymphoedema Association of Queensland (LAQ) was carried out using a questionnaire distributed with the association's quarterly newsletter. The survey aimed to provide feedback about members' views and use of the association's services, to document the impact of the condition on individual lives, members' experiences of treatment provision, and the extent of self-treatment carried out by members. This article describes the benefits of membership mapped out in the analysis of responses to a set of open ended and closed questions.

RESULTS

One hundred and seventy-five members returned completed questionnaires. This number was 45 percent of the names and addresses listed in November 1999 on the association's membership database which was likely to have contained a significant proportion of non-active members and old addresses. Of these respondents, 137 (78 percent) had lymphoedema, and all except 11 (6 percent) were female. Among those respondents with lymphoedema, only 10 were male and the majority (56 percent) said that their lymphoedema was not "related to any other ongoing condition." The proportions of the responding members who had lymphoedema and who were male were roughly representative of the total membership—74 percent with lymphoedema and 4 percent male, according to the LAQ database (Table 1). The small number of males reflects the predominantly secondary nature of lymphoedema in Australia and its association with treatment for breast and gynaecological cancer, as well as the greater proportion of females than males joining self-help groups. Over half (91, 56 percent) had joined the association within the last four years, 42 percent (68) in the last two years; a further 30 percent (52) had been members for four to seven years, the rest for up to 10 years.

An open-ended question early in the questionnaire (question 4) asked about "the benefits of membership" for the respondent. Later in the questionnaire other

questions (questions 6, 7, and 8) asked for details of experience associated with membership and possible benefits, such as attendance at meetings, contact with other people with the same condition, and useful sources of information. Analysis of the answers to the open question about the benefits of membership (question 4) produced five main dimensions (or themes) in the range of answers: identification with others, information, practical help, emotional support, and helping others (Table 2). Individual answers often contained more than one dimension and occasionally combined as many as four, such as in this reply:

Helping to understand the condition and attended Brisbane Assoc.; being able to discuss problems with other members and advice on generally living with lymphoedema. Updating of treatment and advances of treatment and helpful advice from the committee members at any time—sharing experiences and knowing you are not alone with (the) condition and sharing humorous situations.

The most frequently mentioned benefit was the receipt of information. This dimension of answers included the acquisition of knowledge of the nature condition and its treatment, “education,” and learning about meetings, the latest

Table 1. Response of the Membership

	Survey response			LAQ database	
Total members	175	45%	of members on database	390	100%
Members with lymphoedema	137	78%	of responders	288	74%
Male members	11	6%	of responders	17	4%

Table 2. Perceived Benefits of Membership

Answers to question:	Dimension of benefits mentioned				
	Identification	Information	Practical help	Support	Helping others
4	42	113	32	27	8
7	15	16	8	11	1
Total mentions	57	129	40	38	9

treatments and resources. Mention of the association's newsletter was included in this dimension on the grounds that, although it could be the medium for other possible benefits, its main function was to provide information. Typical answers described benefits in this dimension as:

Increase in knowledge regarding the treatment of lymphoedema, and where to go for assistance.

Information and the opportunity to attend talks, etc.

Another dimension of the answers, which had an informational element, was the benefit of practically-related help and advice. This might come from others' experience of managing problems and was specific rather than general knowledge, such as in the following answers:

Finding out things from other people, from them having lymphoedema.
Discussing with them (members) their problems and learning how they have solved these problems.

The discount on support garments was a form of assistance that association members could receive, was frequently mentioned, and included in this dimension.

An important benefit of membership came from the simple knowledge that there were other people with the same condition with whom one could be in contact. This made possible feelings of identification, the reassurance of not being alone, and sometimes friendship through meeting. This benefit was expressed as:

To know I am not alone.

It's reassuring to know there are other sufferers out there that I can be in touch with.

Meeting with other sufferers and finding I have similar problems as them.

A further benefit which could follow from meeting others with the condition, was a feeling of being better off in comparison to them—that is, a positively oriented reassessment of one's own problem. This benefit was expressed by two respondents in the following terms:

Companionship and feeling of not being alone and there is always someone worse off than yourself.

. . . Meeting other members has helped me be aware of how fortunate I am and that mine is moderate and under control . . .

A few health professionals who did not themselves have lymphoedema, also mentioned the contact with others in terms of opportunities for "networking" at meetings as a benefit.

Talking and meeting with other members could result in the benefit of emotional support and understanding—as in this reply:

Contact and subsequent reassurance when questions or concerns arise.

Talking with people who understand your problem.

This benefit was mentioned rather less frequently than identification and often simply using the term “support.” A few respondents, including some professional members, mentioned the opportunity of helping others in their answers to this question about the benefits of membership.

Thirty-two respondents did not fill in a reply to this completely open-ended question. It may well be that some hesitated to formulate an answer but would have endorsed suggested benefits had they been offered. Such prompting, however, would have changed the nature of the evidence of benefit that was produced by the open-ended question allowing respondents to articulate their answer using their own words. Of those who did not reply to this question, five mentioned benefits and three practical difficulties about getting to meetings in answer to a later question; six others did not themselves have lymphoedema. Three people were evidently ambivalent about the benefits of membership, writing “not a lot,” “nothing special,” and “not sure.”

Contact with Others with Lymphoedema

Survey responders were asked if they regularly talked to anyone else with lymphoedema, either on the phone or in person (question 6). Among those responders with lymphoedema, 29 percent talked on the phone and 41 percent talked in person to someone else with the condition, and over half of these members replied that they did not know the person(s) they talked to before joining LAQ. The remaining survey responders with lymphoedema (54 percent) did not talk regularly to another person with the condition.

Attendance at Meetings and Groups

A little under half the survey responders (80, 46 percent) had attended a LAQ meeting at some time. Most of these members had attended meetings occasionally (64 percent), but over a third (36 percent) replied that they attended often, and the large majority (84 percent) had found the meetings helpful. Over a third of survey responders (37 percent) had attended a LAQ support group, with over half (52 percent) of these members attending regularly. The catchment area for this Queensland based association was potentially very large, including rural and remote parts of the state. The membership was largely concentrated on the south-east corner of the state, but even so, regular attendance at evening meetings or daytime support groups would have been determined by the travel distances involved and the employment of the respondent.

LAQ members were invited to comment after these sections of question 7 on whether they found the meetings helpful. All the members with lymphoedema who attended support groups said they found it helpful. Some of the comments

related to practical difficulties about getting to meetings because of their timing or where they were held. A few members complained of the negativity they found (three members), or made suggestions for how things might be done differently (two other members). Many others however, commented in terms of the benefits of attendance. The range of these comments had the same dimensions as the answers to the question which asked directly about the benefits of membership, however the pattern was slightly different with relatively more members writing in terms of identification with others and support, than in answer to the earlier question (Table 2).

The people are just like me there for help.

. . . companionship with people who understand . . .

The greatest help and support I have received has been from listening to and sharing the experience of others with this condition.

Again some answers contained more than one dimension and a few expressed several, as in the following comments on the helpfulness of attendance at general or support group meetings:

Increased knowledge—increased awareness—encouragement . . . more understanding of individual stresses—financial, emotional, physical needs—great interaction between sufferers.

Listening to others—knowledge gained from members, health professionals and doctors. Sharing with others with similar conditions. Joining and mixing with them, learning different and varied aspects plus enjoying the speakers in their different expertise.

Attendance at meetings provided me with additional information and helped me to focus on the benefits of the treatment keeping me motivated in my daily self management program. The interaction and exchange of information with other members helped to relieve my feelings of isolation and added to my knowledge of how to cope with the condition—great speakers helped to give me a great knowledge of how the treatment works.

The acquisition of information was again the most frequently mentioned benefit, and for some this would be the prime reason for attendance:

I received a lot of information. I found once I had that I was satisfied.

Sources of Information

Survey responders were asked what had been the most useful sources of information about lymphoedema. The sources mentioned fell into four main types: written or visual material; health care practitioners; meetings and seminars; and people with lymphoedema (/patients). By far the most often mentioned written information source was Node News (LAQ newsletter). Also mentioned were

pamphlets produced by LAQ and by the Cancer Fund, videos, books, Internet sites, and articles in professional journals. Health care practitioners were the source of information mentioned most frequently, either in generic terms as in a “hospital clinic” or specifically naming a particular person or clinic. Physiotherapists, occupational therapists, general practitioners, specialists, clinic nurses, and community nurses were all mentioned. People with lymphoedema (/patients) were a source of information for health care practitioners as well as for each other—often in support groups.

DISCUSSION AND CONCLUSION

Contact with other people who have the same condition or problem is a prime benefit of belonging to a self-help/support group. It makes possible the feeling of identification with others, which helps to dispel the aloneness of a long-term medical condition, and this in itself may be reassuring. It also facilitates access to the kind of understanding, emotional support, and experiential knowledge that someone else who also has the condition is best able to provide (Katz, 1970; Killilea, 1976; Richardson & Goodman, 1983). The benefits of this kind of contact were reflected in the answers of LAQ members to the question which asked about the benefits of membership for them. The term “being in the same boat” is an often used metaphor for this kind of identification and gives the idea of mutual need and purpose and fellowship on the sea of life (Posner, 1988). Meeting other people at meetings and groups can help to create a personal support network and provides opportunities for sharing experiences and ways of managing the condition. Even when a member is unable to make contact with others in person, the knowledge that there is someone to turn to with anxieties or problems allows the perception of support. There is much evidence that support contributes positively to health and to the management of chronic conditions (Green, 1993). By organizing meetings and support groups, providing a telephone helpline, and circulating a newsletter to members, LAQ is playing a vital role in facilitating such support.

The importance of LAQ’s role in the provision of up-to-date information and education about lymphoedema and its treatment is evident from this survey data. Receiving information was by far the most frequently mentioned benefit of membership. This information could take the form of knowledge about treatments available and their rationale, lead to understanding of the nature of the condition, or be practical, experiential information about aspects of management, sometimes referred to in comments as “swapping notes” with other members. This provision was valued not just by members who themselves have the condition, but also by health professionals with an interest in lymphoedema. Lymphoedema is seldom featured in the usual sources of health-related information, making this educational role vital for people learning to live with the condition. As Killilea (1976, p. 72) concluded from a survey of the literature on self-help organizations,

Information . . . is an important element in almost all mutual help organizations. What constitutes "help" is often a new definition of the problem and specific information about practicalities learned through experience and shared with others because it "works." This kind of information is usually not readily available from books, professionals, or formal caregiving institutions.

The opportunity to help others in the same situation as oneself is a recognized benefit of belonging to a self-help group and was termed "serial reciprocity" by Richardson and Goodman (1983). These authors observed that members tend to be the receivers of help when they first join a group, but later on may themselves provide help and support to newer members. In the case of this group, health professionals among the survey responders viewed membership as enabling them to help their patients better, by keeping up-to-date with treatments, passing on information/and understanding the patient's viewpoint. A few members with lymphoedema also mentioned helping others. This help could be either direct support or through advocacy of the association. One member wrote:

. . . I feel that this condition has been swept aside by many in the medical profession and this association provides an opportunity to publicise the problems.

The combination in the membership of LAQ of those involved with lymphoedema for professional reasons and those who themselves had the condition, mirrors the interweaving of formal and informal care required to manage this condition maximally. The low profile of lymphoedema and the variable attention given to the provision of treatment services, makes the role of any non-government organization in providing services and in representing people with the condition all the more important. The tangible and less tangible benefits of belonging to such an organization have been documented and illuminated from responses to a combination of open and closed questions which have mapped the valuable concomitants of this self-help activity.

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REFERENCES

- Gillham, L. (1994). Lymphoedema and physiotherapists: Control not cure. *Physiotherapy*, 80(12), 835-843.
- Green, G. (1993). Editorial review: Social support and HIV. *AIDS Care*, 5(1), 87-100.
- Katz, A. (1970). Self-help organizations and volunteer participation in social welfare. *Social Work*, 15(1), 51-60.

Killilea, M. (1976). Mutual help organizations: Interpretations in the literature. In G. Caplan & M. Killilea (Eds.), *Support systems and mutual help: Multidisciplinary explorations* (Chapter 2). New York: Grune & Stratton.

Posner, T. (1988). Sailing single-handed: Autonomy in the control of diabetes. *International Disability Studies*, 10(3), 123-128.

Richardson, A., & Goodman, M. (1983). *Self-help and social care: Mutual aid organisations in practice*. London: Policy Studies Institute No. 612.

Todd, J. (1999). A study of lymphoedema patients over their first six months of treatment. *Physiotherapy*, 85(2), 65-76.

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