Volunteer, lay tutors’ experiences of the Chronic Disease Self-Management Course: being valued and adding value

J. H. Barlow¹,², G. V. Bancroft¹ and A. P. Turner¹

Abstract

Chronic disease is a public health issue that could be addressed, in part, by increasing the ability of individuals to better manage their condition and its consequences on a day-to-day basis. One intervention designed to facilitate this is the Chronic Disease Self Management Course (CDSMC) that is delivered by volunteer, lay tutors who themselves have a chronic disease. Although there is growing evidence of course effectiveness for participants, the experiences of tutors have been neglected. This study aims to address this omission. Telephone interviews were conducted with 11 (six male) tutors: all interviews were transcribed and thematically analysed. Being a volunteer lay-tutor was perceived to be an enjoyable and valuable experience despite the challenges associated with course delivery, such as organizational demands and managing the diverse needs of mixed groups of chronic disease participants that led to a tension between disease-specific needs and the generic approach of the course. Being valued and adding value to the lives of others were key benefits of being a volunteer tutor, along with increased confidence that they were doing something positive for others. Course delivery prompted the initiation and maintenance of tutors’ own self-management behaviours.

Introduction

Voluntary work has been associated with improved physical health (Moen et al., 1989), a sense of achievement (Barlow and Hainsworth, 2001), greater life satisfaction (Harlow and Cantor, 1996), larger social networks (Oman et al., 1999), lower psychological distress (Hainsworth and Barlow, 2001) and changes in self-esteem (Omoto et al., 2000). Moreover, volunteering in moderate amounts results in a lower risk of mortality (Musick et al., 1999) and a meta-analysis of 37 studies found that 70% of older volunteers enjoyed a higher quality of life than non-volunteers, with greater benefits being associated with face-to-face helping (Wheeler et al., 1998). Volunteering can have societal as well as individual benefits. Based on estimates of the economic value of volunteering in the UK, it is calculated that £400 million is spent on volunteering and, from this, there is an estimated economic return of £12 billion—an investment ratio of 1:30 (Institute for Volunteering Research, 1999). Despite these benefits, evidence suggests that the level of volunteering in the UK has declined over the past 6 years from 51% of the adult population in 1991 to 48% in 1997 (Davis Smith, 1997). Research documenting the motivations for volunteering and the benefits arising from volunteering remains limited (Omoto et al., 2000).

In contrast to the downturn in volunteering in general, volunteering in the context of chronic disease management is receiving increased attention. Chronic disease is an important public health issue that could be addressed, in part, by increasing the ability of individuals to better manage their condition and its consequences on a day-to-day basis.
The majority of chronic disease self-management training has been disease specific and delivered by health professionals (Barlow, et al., 2003). One disease-specific course delivered by pairs of volunteer, lay people who themselves have a chronic disease is the Arthritis Self-Management Programme (ASMP) (Lorig and Holman, 1993). The majority of ASMP participants have co-morbid conditions and it was the commonalities of disease management across chronic conditions that led to the development of a generic Chronic Disease Self-Management Course (CDSMC) that again is delivered by volunteer, lay tutors (Lorig et al., 1999).

Evidence from randomized controlled trials shows that both the ASMP (Lorig and Holman, 1993; Barlow et al., 2000) and the CDSMC (Lorig et al., 1999) are effective in terms of increasing self-management behaviours, and improving aspects of physical and psychological health status. A non-randomized study based on a more heterogeneous sample of participants in the UK (Wright et al., 2003) reports similar improvements. The outcomes of these two interventions are independent of tutor status (i.e. lay volunteer versus health professional) (Cohen et al., 1986; Lorig et al., 1986). In the UK, delivery of the CDSMC was pioneered by voluntary organizations and has since been adopted as the foundation for the Department of Health’s Expert Patient Programme (EPP) that is being rolled out across primary care in England.

The CDSMC comprises six, weekly sessions, each lasting approximately 2 hours and is delivered in community settings by pairs of lay tutors. Each session is guided by a manual to ensure consistency of content. The CDSMC covers generic topics including: an overview of self-management principles, exercise, pain management, depression, nutrition, communication with family and health professionals, and contracting (i.e. setting realistic goals). Participants are encouraged to apply these generic skills to their own situation. The CDSMC utilizes the tenets of self-efficacy theory (Bandura, 1977), providing mastery experience, role modelling, persuasion, and reinterpretation of physiological and affective states to assist participants in making changes.

Volunteer, lay tutors were trained at residential events lasting 3 days by ‘master’ trainers. Care was taken to ensure that training venues provided satisfactory access for people with chronic disease and opportunities for trainees to practice their own self-management (e.g. swimming). Ideally, potential tutors will have completed a CDSMC prior to tutor training. Training includes CDSMC content, presentation skills, dealing with challenging participants, and the administrative and managerial tasks associated with being a tutor. Each volunteer tutor receives a Leader’s Manual and a copy of the Help Book that accompanies the CDSMC. Tutors agree to deliver at least two courses following training.

Although the impact of the CDSMC on course participants has been investigated, the perspectives of tutors, both in terms of their experiences of course delivery and the perceived impact on their own use of self-management techniques, have not been examined. The present study aimed to address these omissions. Given that the recruitment and retention of tutors is critical to the successful delivery of the CDSMC, it is important that the views and experiences of tutors themselves are considered. The CDSMC can be considered an example of structured volunteering whereby the format of volunteering is prescribed; volunteers are trained to deliver a structured course using a detailed manual; and both helper and recipient are likely to gain from learning about managing their condition (Barlow and Hainsworth, 2001).

**Method**

**Sample**

The study was set within the context of The Living with Long-Term Illness Project (LILL), developed by the Long Term Medical Conditions Alliance (LMCA), an umbrella organization for over 100 national voluntary organizations. A key aim of LILL was to increase the number of self-management programmes available to people living with long-term medical conditions (Cooper, 2001). This was achieved by training volunteer, lay tutors to deliver the CDSMC. A list of tutors (n = 24) who had
recently completed delivery of the CDSMC and were willing to be interviewed was collated by LMCA. A purposive sample was drawn from this list to give a range of chronic diseases, age and gender. A total of 11 tutors [six males, median age 56 years (range 42–67 years), median disease duration 17 years (range 2–56 years)], with the following conditions, depression, diabetes, endometriosis, haemophilia (×2), liver disease, myalgic encephalomyelitis (ME) (×2), osteoporosis, polio and sudden deafness took part. The two haemophilia tutors had delivered the CDSMC together. At the time of the interview, five tutors had delivered more than one course. All 11 tutors had done some community work in the past such as working for voluntary organization (e.g. on telephone help-line), reading to children in schools, setting up support groups and working for the Citizens Advice Bureau. The LMCA only records data pertaining to the voluntary organization the tutor delivers courses for and not personal data such as age or condition.

**Data collection**

Data were collected via telephone rather than face-to-face interviews due to the geographical dispersion of the participants. There are obvious limitations of telephone interviews compared to face-to-face interviews for establishing and maintaining rapport between interviewer and respondent. A further limitation of telephone interviews is the inability to attend to the interviewees’ facial and bodily gestures. Non-verbal communication may indicate the strength and depth of feelings accompanying verbal statements, which can provide a context for subsequent analysis (Kavale, 1996).

A schedule, which the authors have used previously (Barlow and Hainsworth, 2001; Hainsworth and Barlow, 2001) among volunteer ASMP tutors, was used to guide the interview. The interview format was sufficiently flexible to allow participants to raise and discuss other issues, which had personal relevance. At the beginning of each interview, participants were informed about the purpose and their consent to be audio-taped was obtained. The purpose of the interviews was to ascertain the tutors’ experience of course delivery and their current use of self-management techniques. We felt the latter was important as the tutors act as role models for course participants. We did not ask tutors to voice their thoughts and feelings about course participants *per se*, rather the focus was on their own experiences as tutors.

Data were analyed using content analysis to identify themes following the preliminary stages of coding suggested by Smith *et al.* (Smith *et al.*, 1999). First, the interview transcripts were read and interesting or significant points were noted in the left margin. After a second reading, emerging themes were noted in the right margin (i.e. key words encapsulating the essential quality of what was being said in the text). In the second stage of analysis, emerging themes were grouped and validity was checked by referring back to the original transcript and ensuring connections were evident. A master list of themes was then produced. The second transcript was analysed using the master list and any new themes were compared to the earlier transcripts. Two researchers analysed the data independently and a consensus over categorization of data was achieved through discussion with a third researcher. The quotes included in the paper are typical of the views expressed and are used to exemplify emerging themes.

**Results**

**Experience of course delivery**

*Being valued and adding value*

Six tutors felt they benefited from working with and meeting similar others with chronic disease, and feeling valued. Tutors received feedback from participants who expressed their appreciation either in person or in writing after the end of the course. Tutors felt they added value to participants’ lives by passing on self-management techniques. They valued observing participants initiate positive life changes as they learned to take responsibility for their condition.

They’d send letters or talk to you at the end of the course and you think, wow, it’s really changed your life. ...it’s quite amazing. [ID 2]
There was a woman who realized from being on the course that the reason she had so many problems was because she was HIV positive. They [her children] were getting to an age where things were difficult to explain to them without them knowing. At the end of the course, she actually approached them to tell them that she had HIV. [ID 4]

There was a lady in her 70s, who has polio, uses a wheelchair full-time. She was motivated to begin driving again. We were blown away! [ID 6]

Just giving, really just giving other people the opportunity to move their illness forward in the way that I had that opportunity. It’s a tremendous buzz when you see someone who on the first session is clearly, really struggling just to cope with surviving and on the last session goes out, you know, I won’t say a completely different person, but, someone who, perhaps for the first time since they had the illness actually believes in themselves and believes that they have got some control over their destiny. [ID 7]

What I enjoy most is that it is constantly developing as well. I enjoy the reaction of the participants. I enjoy being extremely nervous when I start a course. You know, will they get anything out of it, am I going to be crap. I enjoy the challenge of it, I enjoy the appreciation from participants, from the charities that you work for. [ID 10]

**Increased confidence**

One of the reasons for becoming a tutor was the desire to re-engage in a valued societal role following enforced, illness-related early retirement. Many tutors gained in confidence by being able to help others and feel part of a supportive network. They now felt that they had a purpose to their lives.

I think it increases your confidence because when you’re ill and you give up work, it eats away at your confidence and it helps to make you feel normal again, so you’re back in the land of the living. You’re not this strange being who has got an illness and doesn’t seem to be on the same planet as everyone else. So it brings you back into society. I have a greater appreciation of the difficulties people go through. I think it’s enriched my personality. I feel I inspire people as well and I feel I’m actually doing something to help people. It’s very, very rewarding. [ID 1]

It’s something [being a tutor] I never ever thought that I would be confident enough to do. It has changed me, my wife says that I am a much more positive person now and I have to say I am not as shy as I was. [ID 4]

I mean I totally lost confidence in myself. It’s not until you have something like that [disease] you become completely destroyed. You can’t do anything you are like a baby, almost all the skills you have had before have gone. It’s like you don’t know who you are. I did have something to offer when I started being a tutor it was like ‘oh this is what normal people do’. [ID 7]

**The challenges of course delivery**

The majority of tutors found the most difficult aspects of being a tutor were having to rigidly adhere to the course protocol and keeping participants focused on the sessions. Seven tutors cited the administration work, organization, marketing and management aspects of tutoring as disadvantages of their role. One tutor felt as if he was working in a full-time, unpaid job, whereas another found the travelling and moving around ‘exhausting’. A number of tutors had met with difficulties when attempting to recruit course participants. Furthermore, two tutors found it frustrating when there were no other tutors in their area as it meant they were unable to deliver a CDSMC. They felt isolated as a result of not being close to other tutors. Despite these disadvantages, tutors appeared to enjoy the challenge.

It’s quite exhausting, because of all the marketing. Although you only do the courses for 6 weeks, you’re busy setting up with the charity where you’re going to do it, you’re doing all the marketing, you’re talking to doctors and GPs and everything. Really it’s a full time job. It can go on every day of the year. I also find the travelling to the venue and the amount of attention that you
focus on your participants for that afternoon—I do find it exhausting, I’m exhausted when I come home because I don’t have great physical strength at the moment. [ID 1]

I no longer have a co-tutor to run the course with. I guess it’s just a bit of isolation. There are people all over the country, maybe we can create a network within each local area? [ID 2]

**Generic versus disease-specific issues**

The tension between generic versus disease specific needs was referred to by all tutors and was the subject of contrasting views. Two tutors thought that disease specific information would be a worthwhile addition to the generic approach of the CDSMC and suggested that this could be achieved by an optional, additional session at the end of the CDSMC or by simply drawing attention to disease specific information placed on the resource table. In contrast, three tutors thought that disease-specific information should not be included or provided, as this ‘conflicted’ with the ethos of a generic course. They further explained that participants are encouraged to be responsible for obtaining specific illness-related information themselves.

You don’t want to supply them with anything. You can go down the medical path then and you don’t want to be doing that. You’re not qualified to do it. You’re teaching them to go out and find out as much as they can and be informed without giving them anything specific. So that’s for them to go and talk to the other participants and the doctors. [ID 1]

I think adding disease specific information creates this thing where your condition is something special. I just think that teaching material on the course, the way it is kept generically non-specific, is very, very strong. You need to know stuff about your illness and having that information and knowing about treatment but the management information is separate to that. [ID 5]

Some tutors felt that not all sessions were relevant for all chronic diseases. For example, one tutor felt that pain distraction techniques and exercise were not beneficial to participants with diabetes, as ‘most are not in pain and are already exercising regularly’. Several tutors felt that exercise was inappropriate due to the physical restrictions of some of their course participants. One tutor believed that although exercise should be included, contraindications should be addressed. Finally, several tutors thought that living wills was not an appropriate topic where the course comprised participants with non-life threatening conditions.

I find the exercise quite difficult to deliver sometimes with people who have MS [multiple sclerosis] and polio because they’re restricted. I mean obviously they go to the physio and they have their own set of exercises but it’s quite difficult. This is the first time I’ve delivered to MS and polio people and found it difficult not to say ‘to walk’. It was difficult. In the end I said things like ‘just follow your routine and try and do as much as your physio recommends, try and ensure you do what she tells you to do, but there’s such a lot of exercise in that. [ID 10]

I would also like to see a separate section on the illness so that you can give people information. Information can actually empower you to make more informed decisions. [ID 8]

**Tutors’ use of self-management techniques**

Three tutors had been participants on a CDSMC and this had motivated them to become tutors in order to pass on their knowledge. The other eight tutors had learned about self-management during their training. Five tutors found that being a course tutor had increased their awareness and understanding of self-management techniques. Two tutors (former participants) felt they benefited from revisiting the course and being reminded of self-management techniques. All 11 tutors were currently practicing more than one self-management technique (see Table I). Distraction, and positive reinterpretation were used to manage pain, and relaxation, action planning and problem solving were mentioned frequently. Tutors found that they
were more accepting of their own situation. Their increased repertoire of self-management techniques and ways of dealing with emotions, such as anger, appeared to help in this regard. Moreover, tutors felt they were better able to empathize with others, could inspire course participants and were viewed as positive role models.

I use lots of techniques for pain relief. I am always using self-belief statements and the rest of it. If I’m feeling a bit low or the pain is particularly bad, just believing in myself in that sense, but I also use the pacing and target setting. [ID 7]

Oh I am always doing action plans and always problem solving. I think problem solving is really useful and I do the relaxation and one or two distraction techniques when I need to, when I have a bleed that sort of thing. [ID 3]

I’m more accepting of myself. I have always driven myself very, very hard. If have a bad day now, I don’t beat myself up about it or get angry about it. So for me its really learning about pacing and accepting without giving in, I think that is the key. [ID 4]

Discussion

The limitations of using a qualitative approach are often centred upon objectivity, validity, generalizability of findings, sampling techniques and sample size. Because of considerations of time and resources, qualitative studies are usually based on small, unrepresentative samples. Krueger (Krueger, 1998) argues that qualitative research is not intended to generalize, rather, it is employed in order to generate rich meaningful insights and greater understanding of the topic under investigation. Thus, the ‘quality’ of qualitative research is not dependent upon sample size. Although nearly half of all the LILL tutors that were trained at the time of the study were interviewed, the sample could be biased towards those with positive experiences. However, many tutors expressed dissatisfaction with the administrative aspects of the course and referred to difficulties in course delivery (e.g. keeping participants on task). These negative aspects accord with previous studies [e.g. (Hainsworth and Barlow, 2001)]. In addition, some tutors had difficulty in managing the tension between the generic approach of the CDSMC and participants’ individual,

Table I. Self-management techniques currently practiced by tutors

<table>
<thead>
<tr>
<th>Self-management technique</th>
<th>Number of tutors practicing self-management technique</th>
<th>Self-management technique used by tutor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assertiveness</td>
<td>2</td>
<td>Haemophilia2; ME2^a</td>
</tr>
<tr>
<td>Action planning</td>
<td>6</td>
<td>Liver Disease; ME2; Osteoporosis; Haemophilia1; Haemophilia2; Sudden Deafness</td>
</tr>
<tr>
<td>Breathing</td>
<td>3</td>
<td>Depression; Endometriosis; ME1^a</td>
</tr>
<tr>
<td>Communication</td>
<td>2</td>
<td>ME1; Polio</td>
</tr>
<tr>
<td>Distraction</td>
<td>2</td>
<td>Endometriosis; Haemophilia1</td>
</tr>
<tr>
<td>Diet</td>
<td>1</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Exercise</td>
<td>1</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Pacing</td>
<td>1</td>
<td>ME2</td>
</tr>
<tr>
<td>Problem solving</td>
<td>4</td>
<td>Haemophilia1; Haemophilia2; Osteoporosis; Polio</td>
</tr>
<tr>
<td>Relaxation</td>
<td>6</td>
<td>Depression; Diabetes; Liver Disease; Haemophilia2; ME2</td>
</tr>
<tr>
<td>Self-talk</td>
<td>2</td>
<td>Diabetes; ME2</td>
</tr>
<tr>
<td>Visualization</td>
<td>1</td>
<td>Sudden Deafness</td>
</tr>
</tbody>
</table>

^aME1 = Action for ME Tutor; ME2 = ME Association Tutor.

Chronic Disease Self-Management Course tutors
disease-specific needs. This issue may require additional attention during the tutors’ training. A further limitation of this study was that the majority of tutors had not previously attended the CDSMC before tutor training. Thus, we were unable to tease out the effects of volunteering from those of learning new self-management skills. Future studies should attempt to engage tutors who are reticent about being interviewed and should include tutors who decide to stop delivering self-management programmes. The latter group’s reasons for curtailing their involvement might help to develop a support and training strategy that both aids recruitment and retention of future volunteers. Future research could also explore the barriers to becoming a CDSMC tutor.

The cross-sectional and qualitative design of this study means that there still remain questions regarding the relationship between volunteering and health: specifically, whether volunteering leads to better health and well-being or whether improved health and well-being leads to volunteering. In a longitudinal study, where data were collected before and after delivering the ASMP, tutors reported improvements in self-efficacy and psychological distress (Hainsworth and Barlow, 2001). Randomized controlled studies based on standard measures of health status are needed in this respect and would help to clarify the potential benefits of peer-led health education for both tutors and participants with chronic disease.

The findings reported here are largely in accord with previous studies of volunteer tutors on the arthritis specific self-management programme (Barlow and Hainsworth, 2001; Hainsworth and Barlow, 2003). The most common motivational factor for becoming a tutor was a desire to feel valued by helping other people and for many tutors’ this is what they experienced while delivering the CDSMC. Tutors benefited from an act of altruism that was valued by participants and were further rewarded by witnessing participants make improvements throughout the 6-week course and beyond. The positive feedback received by tutors helped them to feel valued, and increased their own self-confidence. Delivery of the course served to remind tutors of self-management techniques, which they put to good use in their own lives, particularly relaxation, action planning and problem solving. Tutors felt that use of self-management helped them to feel more accepting, and able to inspire others. The presence of tutors who have a chronic disease and who act as role models for participants has been shown to be one of the key mechanisms for promoting successful outcomes among participants.

This study has extended previous findings by showing that benefits accruing from tutoring do not appear to be dependent on the similarity of tutors and participants in terms of having the same chronic disease, and nor are they restricted to female tutors.

Some participants were mindful of the administrative tasks that accompanied the setting up and delivery of the CDSMC. Moen et al. (Moen et al., 1989) have identified volunteer role strain where too many roles result in poor health outcomes. Recruitment of participants has been noted elsewhere as a major concern for tutors (Lorig et al., 1998) and it is important that they are fully supported throughout one of the less enjoyable aspects of delivering the CDSMC. Another concern encountered by some tutors was the prescriptive nature of the CDSMC, which is a safeguard to ensure consistent standards are maintained regardless of who is delivering the course. Despite this drawback, tutors felt that course delivery was an enjoyable challenge.

There was a tension between disease-specific needs and the generic approach prescribed by the course. Tutors had to manage this tension within the course setting. Sessions that provoked the most disparity of views were those on exercise, living wills and pain management with some tutors believing that these sessions were not relevant to all chronic disease participants. Indeed, several tutors expressed a degree of unease at having to deliver exercise sessions to people that they felt were physically restricted. Only one tutor was using exercise as a self-management technique. Additional training on this topic may be of value in the future. The impact of the tension between disease-specific and generic needs on course delivery and
outcomes remains unknown. However, it is interesting to note that Wright et al. (Wright et al., 2003) failed to find evidence of improvement on exercise among a heterogeneous sample of CDSMC participants. This contrasts with the consistency of exercise improvement reported in previous studies restricted to four or five chronic diseases [e.g. (Lorig et al., 1999)] and the arthritis specific studies (Lorig and Holman, 1993; Barlow et al., 2000). Quantitative studies are needed to examine the implications of generic course content for outcomes among specific chronic disease groups. Equally, further qualitative studies are needed to shed light on participants’ experiences and to examine the content of within course interactions, for example, and how these may change when courses are delivered to a mixed group of chronic disease participants compared with a homogeneous group with one common chronic disease. Regarding the latter, observations of the CDSMC delivered by and to people who had had a myocardial infarction (MI) suggest that discussions focused on specific issues, such as the actions needed if MI symptoms recurred (Barlow, 2004). Thus, although the CDSMC offers training in generic skills, the chronic disease experiences of tutors and participants influenced the content of course interactions.

Schwartz and Sendor (Schwartz and Sendor, 1999) have proposed that an altruistic act needs to be reinforced to sustain psychosocial improvements. In the absence of payment, it is important that the psychosocial benefits accruing from volunteering are maintained. Delivering the CDSMC to participants who demonstrate little or no improvements and consequently provide no positive feedback might result in demoralized and demotivated tutors. The positive findings reported here might be due to the novelty of successfully delivering the course. Several tutors had delivered only one CDSMC and it may be that the enjoyment and benefits of seeing participants improve may diminish or disappear over time to be replaced with the more mundane concerns of course administration, tutor burnout or a flare-up of the tutors’ own chronic condition. However, a study involving multiple sclerosis volunteer telephone supporter workers found that psychosocial improvements (e.g. coping, anxiety, depression, acceptance) was greater in the second year of helping compared to the first year and that there were stronger and more improvements for the peer supporters than there were for the patients they were supporting (Schwartz and Sendor, 1999).

In conclusion, being a volunteer, lay tutor was perceived as an enjoyable and valuable experience despite the challenges associated with course delivery such as organizational demands and managing the diverse needs of mixed groups of chronic disease participants. Being valued and adding value to the lives of others were key benefits of being a volunteer tutor.

Acknowledgements

Data collection was supported by a grant from the Department of Health to Barlow, Wright, Cooper and Wilson. The authors extend their thanks to the LILL Project organizations (British Liver Trust, British Polio Fellowship, Depression Alliance, Diabetes UK, Endometriosis Society, Haemophilia Society, LINK Centre for Deafened People, ME Association, Action for ME, Osteoporosis Society,) who delivered the CDSMC, the tutors, Jane Cooper (LMCA) and participants who freely gave their time.

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Received on March 4, 2004; accepted on June 4, 2004