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Volunteerism among older people with arthritis

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ABSTRACT
Research attention has turned towards investigating the motivations and experiences of those who volunteer under conditions that benefit both giver and recipient. The purpose of this paper is to examine the motivation of 22 older volunteers as they embarked on training to become lay leaders of an arthritis self-management programme. Data were collected through semi-structured telephone interviews at two points in time, before training and six weeks after training. Volunteerism was motivated by three key needs: to fill the vocational void left by retirement, to feel a useful member of society by helping others and to find a peer group. These key motivations remained important throughout the six weeks of the study. The costs of volunteering were perceived as time, responsibility, invasion of social life, failure, anxiety, and the duration and intensity of training. Nonetheless, older volunteers valued finding a purpose, reported less pain and an increased desire to 'get on with life'. Results suggest that volunteering in later life can help to offset losses associated with retirement and decline in health. Further research, incorporating standard measures of health status, is needed if the impact of volunteering on the health of this study population is to be more fully understood.

KEY WORDS – Older volunteers, motivation, arthritis self-management, health status..

Introduction

It is now recognised that volunteering can benefit both recipient and giver (Musick *et al*. 1999; Oman *et al*. 1999) including improved health, greater life satisfaction, larger social networks and increased altruistic behaviour (Oman *et al*. 1999; Wasserbauer *et al*. 1996). Volunteering can enable older adults to redefine their role in society, overcoming losses due to retirement or decline in health status (Wasserbauer 1996). For example, helping others has been associated with improved

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morale, self-esteem, positive affect, and wellbeing (Midlarsky and Kahana 1994). In contrast, several earlier studies failed to find evidence of health status benefits among volunteers (*e.g.* Lee and Markides 1990; Kornblum 1981). Thus, research evidence regarding the benefits of volunteerism is inconclusive (Fischer and Schaffer 1993). One difficulty yet to be resolved concerns causality. It is not clear whether volunteering leads to health benefits or whether people who volunteer are likely to be those in better health and with greater life satisfaction. Despite this unresolved issue, the skills and experiences that older volunteers can pass on to others are receiving greater recognition, and older volunteers are being actively sought (Rouse and Clawson 1992).

Motivation to volunteer is multi-factorial. Fischer and Schaffer (1993) identified the following categories of motivation in the literature: altruistic, ideological, material, status, social relationship, leisure time and personal growth. When compared to younger volunteers, they suggest that older volunteers are less motivated by material rewards and status (education for career development), but are more likely to be motivated by having free time and by religious concerns.[1] The most commonly reported motivational factor is altruism: the desire to help others, feel useful and have a sense of responsibility (Fischer and Schaffer 1993). Several authors however suggest this response is part of the vocabulary of motives and is the expected and automatic answer that may mask volunteers' actual motives, such as personal reward, companionship or empowerment (Baldock 1998; Fischer and Schaffer 1993; Francies 1983). One way in which motivation to volunteer can be addressed is to examine the circumstances under which people volunteer, rather than asking them why they engage in this type of activity (Fischer and Schaffer 1993). Reasons for terminating voluntary work can also provide useful insights into volunteers' original motivations. For example, in a study of a self-help group run by older volunteers, Morrow-Howell and Mui (1989) found that volunteers left when their original motivations for volunteering (*i.e.* altruism) were not met. Similar findings have been discussed by Kuehne and Sears (1993).

The increasing interest in the value of volunteerism among older people is timely. The greying of the demographic profile is accompanied by a predicted increase in the prevalence of chronic conditions. The prospect of increased numbers of older people who are learning to live with chronic illness has many implications, not least in terms of the pressures that may be placed on health and social care services. Given that the benefits of volunteerism extend to both giver and recipient,

building upon the life experiences and skills of those older volunteers who live with chronic illness, is one step towards addressing this issue.

The links between enhanced confidence in managing chronic illness, and increased interest in enhancing the quality of life of others in similar situations, first came to our attention in our work with older people with arthritis attending self-management and personal development courses. Having experienced increased confidence and self-determination in their own lives, older people with arthritis reported increased motivation to become involved in community activities, and some were motivated to become lay leaders of courses themselves (Barlow *et al*. 1997; Barlow and Williams 1999).

Reissman (1965) used the term 'helper-therapy principle' to describe role-reversal in which 'recipients' become 'helpers'. Volunteers derive benefit from teaching others to cope better. The valuable contribution that older people can make to their peers and their community is increasingly recognised with initiatives aimed at improving wellbeing and quality of life, ensuring that 'adding years to life also means adding life to years'. One example, is the Ageing Well UK Programme (organised by Age Concern UK) that trains people aged 50 or more to act as healthy ageing mentors to their peers. In the USA, programmes involving older volunteers include Foster Grandparents, Senior Companions, and the Retired Seniors Volunteers Program.

The purpose of this paper is to examine the concept of volunteerism among older people with arthritis. The intention is to broach important issues rather than to identify the proportion of volunteers who hold particular views. Specifically, we have sought to understand the underlying motivation of volunteers as they enrol and undergo training to become lay leaders on an arthritis self-management programme. Thus, soon after volunteering, their motivation was challenged by participation in a training programme known to be intense, tiring and challenging (Barlow and Williams 1999). Moreover, the training course was residential, and so volunteers were faced with the prospect of travelling away from the safety of their home environment and staying in an unfamiliar setting. The circumstances of volunteering have the potential for added value; participants may benefit from volunteering and from learning new skills to enhance their own disease management.

Participants and method

A total of 23 people with arthritis (all aged 50 years or more and from across England and Wales) were recruited through advertising within

and beyond Arthritis Care (the leading voluntary organisation working with and for people with arthritis). One participant withdrew because of ill health resulting in a final sample size of 22.

The 'Challenging Arthritis' course

Challenging Arthritis (CA) is the UK name for the Arthritis Self-Management Program (ASMP) that was designed in the USA for people with mild to moderate arthritis (Lorig and Holman 1993). In the UK, CA is organised on a nation-wide basis by Arthritis Care. The course is delivered in community settings (*e.g.* village halls or school halls) by pairs of lay leaders, the majority of whom have arthritis themselves. The CA course comprises six weekly sessions, each of two and a half hours' duration.

CA draws on the central tenets of self-efficacy theory (Bandura 1997). This includes the concept of role modelling; so tutors need to have experience of arthritis themselves. Topics covered include an overview of self-help principles, exercise, cognitive symptom management, communication with health professionals, and setting realistic goals. The course emphasises skills mastery, modelling and problem solving. The primary aim is to enhance arthritis self-efficacy defined as perceived ability to control various aspects of arthritis (*e.g.* pain, fatigue). Thus, participants are encouraged to become active agents in the management of arthritis, perceiving themselves as capable of successfully enacting the self-management strategies that best suit their needs in a given situation and at a given point in time. The aim is to help people move away from the traditional passive patient role associated with the medical model of care and to regain a sense of control in their lives.

The lay leaders play an important role in this process by acting as role models for participants, the majority of whom are over 50 years of age. Lay leaders are trained by Arthritis Care at residential training events. Each leader is provided with a Leader's Manual and a copy of the Help-Book that accompanies the CA course. This study recruited participants from three training courses for lay leaders run in three locations (Leicester, Shrewsbury and Skipton).

Study design and data collection

The experiences of 22 participants were examined through descriptive data collected by semi-structured telephone interviews at two points in time: before attending training and six weeks after training. This

qualitative approach enabled participants to freely express their views about their motivation for volunteering, their expectations, concerns and the perceived costs and benefits involved. In view of the small sample size, the intent of this study was to examine the range of views held by participants rather than their frequency. Each of the 44 interviews was recorded with the permission of the participant and was then transcribed in its entirety. Demographic data were collected at the start of the study using self-administered questionnaires.

Analysis

Qualitative data were analysed using a 'middle-order' approach (Becker and Geer 1982). This method of data categorisation enables the analysis to move between the identification of broad themes and a more grounded approach. All the interviews were read several times and simultaneously coded to explore potential content-related and conceptual themes. Prevalent themes were identified and broad categories formed which were then subjected to more detailed data investigation of sub-categories nested within the broad categories. The quotes included in the following section are typical of the views expressed and are used to exemplify emergent themes.

Results

Of the 22 participants, 20 were women and 20 were married or living with their partner; 14 had osteoarthritis and nine rheumatoid arthritis. Their mean age was 57.9 years (SD 5.3 years) and on average they had had the disease for 13.4 years (SD 9.2 years). Thirteen were unable to work as a result of arthritis. First, we consider their reasons for joining the training course, their expectations and their concerns.

Motivation to volunteer

Seventeen participants had had previous experience of volunteering, although for some this had been a number of years ago. Volunteerism included work with people with physical and learning difficulties, work with the homeless, the church, and community centres. Eleven volunteers had previously attended a CA course, although this was cited as a motivation to volunteer for only five people. The self-management techniques learned on CA had prompted the desire to share with others knowledge and information about coping with arthritis. Equally important, was the desire to meet similar others and

to help people. Eight participants expressed a strong need to replace their previous employment, now that they had retired, with a form of volunteering that would also continue to meet their intellectual needs. Similarly, three participants hoped that volunteering would provide a sense of direction and a purposeful activity that would have the added bonus of benefitting others. For the majority of participants (15 out of 22), becoming a volunteer was viewed as both challenging and exciting: they were looking forward to the experience.

I retired from teaching early (three years ago) and I wanted to do something that would help others but did not have a tying commitment like part-time teaching does.

I haven't actually accepted that I have retired yet. Doing the voluntary work with Arthritis Care will help me with my intellectual needs as I had with my college lecturing.

I think it's a light in my life in a way, as I see how others cope, perhaps not so well, and I can add a little of my knowledge to help them get over it.

Expected benefits of volunteering

The main benefits expected by participants paralleled their motivation to volunteer and were described in terms of helping others and the community (n = 16), companionship and peer group support (n = 10). In addition, ten volunteers expected to acquire coping skills and to feel a sense of personal satisfaction.

Making me feel I'm a part of things; giving me a sense of direction. I feel as if I am performing a service and helping someone; getting together with people who are in a like-minded position; to feel a member of the human race.

A sense of worthiness plus the fact that if you can help people to help themselves, it can give everybody a buzz in the nicest possible way.

I like helping people and love organising as it keeps my mind busy. I can't get my body going but I can get my mind busy.

I am looking forward to the contact with other people who are in a position comparable to my own, something which is a key factor as far as I am concerned as before I have been very isolated.

Some volunteers had expectations about the content of the CA course *per se*. Hence, they were hoping to gain a greater understanding about arthritis and to increase their coping skills repertoire (n = 13). Other expectations centred on developing course delivery skills such as presentation and recruitment strategies (n = 12).

Expected costs

Possible costs of volunteering were described mainly in terms of time commitments (n = 9). Individual views centred on dealing with communication difficulties (general and with organisations), lack of confidence in specific abilities (*e.g.* presentation skills) and the vulnerability associated with the role of a lay leader. The last of these encompassed feelings of anxiety, uncertainty, responsibility, coping with difficult group interactions and the prospect of personal failure (*e.g.* not recruiting sufficient CA participants).

Training needs

Many volunteers had had previous experience of organising and recruiting people on to courses or events associated with their work, and few reported any specific training needs before attending the CA training event for lay leaders. They were confident that any concerns would be addressed and felt they had access to appropriate support networks and contacts following completion of their training and when running a CA course. Nonetheless, three volunteers believed that it would be important to have practical support (*e.g.* mobility, illness cover, local information), and three highlighted the importance of emotional support being available when needed (*e.g.* guidance, reassurance, counselling). Although apprehensive, the majority of volunteers (17 out of 23) were looking forward to the training course and to meeting new people. It was viewed as an 'adventure':

Organising the course looks like a challenge and I quite like a challenge! I am both excited and nervous.

Benefits from the Training Course

Six weeks after completing the training course, volunteers felt that the main benefits they had gained were either social or skills based. Nine volunteers described having enjoyed meeting other people, including those worse off than themselves, and nine stated they had gained greater knowledge about arthritis and how to manage it. Other benefits were described as feeling less isolated (n = 5) and developing presentation skills (n = 5). One person felt they were more able to control their symptoms of arthritis.

I felt the two benefits that I had were the ending of isolation and to have suffered less pain and coped better with any pain I have had.

Similarly, it was the social component to the training that was perceived as most enjoyable, particularly meeting other similar people (n = 11). Group involvement and the caring attitudes of others were also important (n = 5). For some older volunteers, it was simply 'the taking part', feeling that they were back in a 'work' environment, and the realisation that they had the ability and skills to become a trainer.

… it was nice to go up there and pick up some things I hadn't done for ten years and I was quite pleased the way that it came out naturally … and I was so pleased that I'd got some of it left in me and it did me good. Made me feel younger.

The fellowship between the trainers and other people on the course, we all knitted together quite well which was nice.

… you get a great feeling of camaraderie and knowing that other people are doing it and everybody thinks the same. And you know you've gained a network, a lot of us exchanged addresses and telephone numbers and it was really good, we've been in touch since.

Some people felt that they were repeating topics, which they had been taught on the CA course. Nonetheless, they reported that new information about arthritis had been gained, existing knowledge had been reinforced and presentation skills had been acquired. Participants felt they had drawn on the strength and willpower of other course volunteers.

… then suddenly it's, my God! I've suddenly learnt all these things, it's a process, like the sea, it washes over you as the tide comes in and the tide goes out and you don't think about it and then something else triggers it off. It's a learning process which is continual.

Following their training, volunteers began to apply the skills they had acquired to their everyday lives. For example, five reported practising relaxation techniques, four were more aware of Arthritis Care, and three were using communication skills, including being more assertive with health professionals.

I am practising contracting in an effort to try and set a good example to the people that I will be delivering the course to. Generally, trying to have more of a positive attitude about pain management.

Costs

The most disliked aspect of the training was its intensity (n = 11). The duration of the training course was felt to be too long ('four days just totally wears you out'). Paradoxically, volunteers felt that some

sessions were 'rushed through' in order to cover all the topics and little time was given for relaxation or breaks.

We were all shattered when we came back! … It was quite time consuming.

It was a long day … when you're in pain and you've got to get your mind going as well it really wears you down.

The only thing that I felt wrong with it was the fact that everything was crammed in and we had little time to ourselves.

In the view of nine participants, time commitment remained the main cost involved in becoming a volunteer. Other individual concerns centred on difficulties with addressing 'taboo' issues (*e.g.* sex), role confusion and setting boundaries. The last of these encompassed dealing with 'difficult' participants, the invasion of privacy (*e.g.* phone-calls to home), the potential conflict between voluntary work and state benefits, and more practical difficulties associated with arthritis.

Volunteering

In accordance with views expressed before attending the course, eleven volunteers described the main benefits of becoming a volunteer trainer as being able to help others through the exchange of information about the self-management of arthritis. Eight volunteers, however, acknowledged that they would gain personally through increased knowledge, insight and coping skills in relation to arthritis. Further benefits included being involved in a worthwhile and challenging activity, regaining former status, and realising that they were not alone.

I just want to go out and say to people, look we've all got something like you've got and we want to help you because we've done it ourselves.

… to be quite honest I think I've been in the wrong job all my life, because I find this more satisfying … working with people and helping people.

Ten volunteers were still enthusiastic and looking forward to becoming a lay leader. They believed that they had been given a new lease of life and a purpose. For some, this distracted them from their painful symptoms; one volunteer was experiencing less pain and another had noticed a reduction in her stress and depression.

Done me good as a person. Because I don't feel old, I'm 62 … if you keep the brain going, the rest of you goes with it … it came along at the right time and the people I've met are smashing.

It's been a Godsend for me really … It's keeping my mind off the pain. It's a challenge to myself really.

For three, there was frustration at not being able to 'get on with it' and run a course immediately. Others were nervous about becoming a volunteer, worried that they might let someone down, and questioning whether they had sufficient knowledge. A number of volunteers had started to lose the enthusiasm that had been generated on the training event. There was a desire to 'get the first one over with' and to run a course as soon as possible. As one person remarked:

It should be easy enough to go through and do it, unit by unit. All dressed up and nowhere to go!

Volunteers felt fairly confident in the organisational aspects of running a course provided they had enough time in which to prepare and access support if required. Getting the course organised was more daunting for volunteers who did not have previous experience in this area. Feelings about delivering the first course were divided, with some volunteers (n = 8) expressing little worry whereas others were nervous, 'scared stiff' and felt that they needed to learn more.

On the whole, volunteers felt their training needs were being met. Nonetheless, a number of issues were raised including the availability of supervision and advice, training for ethnic minority groups and clarification of organisational issues. Most people felt well supported, by other team members involved in running courses and through Arthritis Care (n = 10).

In many ways I have found the support quite overwhelming. Having been without support for so long it is a new experience for me and it is taking a lot of getting used to.

Volunteering in practice

At the time of this second interview, two volunteers had already delivered their first course. Despite having felt nervous, their experience was described as enjoyable. These volunteers realised they were able to lead effectively and had observed changes in course participants.

It's a very good feeling delivering the course. I actually came home and said 'ooh I'm really good at it' … it's something that I can do really well.

I never expected people to change the way they have done and it's quite overwhelming really. We have four people on that course and you know their lives have been dramatically changed by taking the course and they're actually saying that and you can see the changes in them and that's a tremendous feeling.

Discussion

Volunteerism among the group of older people in our study was motivated by three key needs: to fill the vocational void left by retirement, to feel a useful member of society by helping others, and to find a peer group. These key motivations remained important throughout the six weeks of the study. In contrast to Fischer and Schaffer's suggestion that older volunteers are less motivated by status, one of the strongest motivations for volunteering among our sample centred on the status gained through the role of a lay leader. Loss of employment can leave some older people feeling isolated, lacking a sense of purpose and without a peer group. The older volunteers in our study were able to overcome losses caused by retirement and decline in health and had redefined their role in society (Wasserbauer 1996). Training to be CA volunteers is in keeping with the ethos of lifelong learning. Equally, older volunteers wanted to meet similar others and to form social relationships. In the course of learning new skills, volunteers had acquired a relevant peer group with whom they were able to share their anxieties and concerns. The value of sharing information and experiences with similar others is a hidden benefit of many group interventions (see *e.g.* Barlow *et al.* 1997), and was evident among the volunteers in our study. Several reported having increased leisure time as a consideration. Ideological motivations (belief in a worthwhile cause) were not explicitly mentioned. However, implicit beliefs in the value of disseminating self-management skills appeared to be an underlying motivation for many of our sample, especially those who had already attended a CA course and wished to pass on their new skills to their peers. For those new to CA, the circumstances of volunteering provided added value as participants appeared to enhance their own self-management ability.

After training, the benefits of volunteering remained consistent. Volunteers felt that they had acquired a purpose to their lives and had enjoyed meeting similar others. Indeed, some volunteers had remained in contact with each other thus forming a new social network and reducing isolation. The impact of volunteering on social network size is in accordance with findings of Oman *et al.* (1999). The group training experience had enabled volunteers to draw social comparisons with their peers and had the added benefit of providing insight into how to manage better their own arthritis and to develop new skills (*e.g.* presentation skills). Volunteers thrived on feeling 'at home' in a training environment reminiscent of their past working lives.

The costs of volunteering were conceived as the time commitment, responsibility, invasion of one's social life, chance of failure and anxiety about the lack of specific skills (*e.g.* presentation skills). Whilst some of these concerns were addressed in the training courses, they were consistently cited as the inevitable costs of volunteerism.

The intensity and duration of the training event were disliked and were considered to be part of the cost of volunteering. However, this did not dampen volunteers' enthusiasm to commence their lay leader activities. Indeed, many expressed annoyance at not being able to deliver a course soon after training. They felt that their knowledge would be dissipated before they had the opportunity to apply it. For the two volunteers who had managed to commence delivery of their first courses, observation of positive change among course participants served as a reinforcement for volunteerism, with lay leaders satisfied that they were 'helping others.'

The participants were being trained to become lay leaders of a community-based, self-management programme. This form of volunteerism can be conceptualised as structured volunteering, in that the formats of volunteer actions are prescribed. Hence, volunteers are trained to introduce a specific set of skills to their peers, following a training manual. This structure is necessary in order to assure the quality of each course. It also provided older volunteers with the feeling that they were part of an organisational structure similar to a work environment. Soon after volunteering, their motivation is put to the test by the need to attend a residential training programme. This involves leaving their home environment, learning new skills and meeting new people.

Although, most participants found the training intense and tiring, they felt empowered by their newly acquired knowledge, and most were enthusiastically waiting to deliver their first courses. Many had begun to apply their new-found knowledge about self-management to their own situation, reporting less pain and more willingness 'to get on with life'. Moreover, they had found a relevant peer group with whom they could exchange experiences.

A number of caveats to the study need mentioning. The sample size was relatively small and comprised mainly women of white/European origin; results, therefore, should be interpreted with caution. The study was exploratory and based on qualitative data generated through interviews. Our aim was to examine the range of views expressed by older volunteers and to identify the issues they perceived as important. More extensive studies, incorporating standard measures of health status, are needed to determine the impact of 'added value, structured

volunteering' on the health status of older adults with arthritis. With the exception of two volunteers who had begun to deliver CA courses at the time of the second interview, findings are limited to their subjective responses to volunteer training rather than the application of new skills in volunteer work. One future difficulty will be to disentangle the effects of volunteering from the effects of learning new self-management skills, given that both pursuits have been shown to result in improved psychological wellbeing (Barlow *et al.* 1997; Barlow *et al.* 1998*a*, 1998*b*; Midlarski and Kahana 1994). It should be noted that 17 out of the 22 participants reported previous experience of volunteering. Although we framed our questions in terms of the CA training, their views are likely to have been influenced by this previous experience. Finally, although the age range of participants is typical of those attending CA in the UK, most were under 65 years of age. Hence understanding more about the benefits of the potential involvement of those over the age of 65 remains a priority.

A strength of the study was the collection of data over time, which allowed the concept of volunteering to be examined before, and six weeks after, their participation in a challenging training course. Few studies have directly addressed the training experience and needs of volunteers. Furthermore, results were largely in accordance with previous studies (*e.g.* Oman *et al.* 1999, Wasserbauer 1996), and were grounded in the views of older people whose voices were clearly heard expressing their motivations to volunteer. Our findings extend previous work by showing that status is important for some older volunteers who seek to replace the void left by loss of vocational activity with structured pursuits that have the added value of benefiting both giver and recipient.

One issue remaining to be addressed concerns the value placed on volunteerism among older people. Their efforts are worthy of applause and demand an appropriate reward, financial or otherwise. It is all too easy for volunteers' contributions to become accepted as the norm, with no one person, or persons, designated as responsible for ensuring that volunteers receive the 'pat on the back' they so richly deserve. Furthermore, the type of structured volunteerism targeting older adults, in which recipients become helpers, has policy implications. The case of seniors as volunteers has been elegantly discussed by Baldock (1999) with reference to the USA, Australia and the Netherlands. Clearly, this broad issue, and the specific contexts in which they may become engaged (such as CA), warrant further policy-related study.

NOTE

1 The latter is conceptualised as part of the ideological motivations category, along with belief in a worthwhile cause.

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