

Consumers and health professionals' perceptions of Participatory Action Research in developing a health resource

Hilda Mulligan *PhD*

Senior Lecturer, Centre for Health, Activity, and Rehabilitation Research, School of Physiotherapy, University of Otago, New Zealand

Amanda Wilkinson *PhD*

Research Assistant, Centre for Health, Activity, and Rehabilitation Research, School of Physiotherapy, University of Otago, New Zealand

Ashlee Lusty *BPhy**

Annelou Delorme *BPhy**

Silas Bong *BPhy**

*At the time of this study were undergraduate students at the School of Physiotherapy, University of Otago, New Zealand

ABSTRACT

Multiple Sclerosis (MS) has a relatively high prevalence in New Zealand (NZ), which was the setting for this study. Fatigue is a common and one of the most disabling symptoms of MS. Recent research focus has been on developing other ways to manage fatigue than via medication. Participatory Action Research (PAR) is an innovative method of including consumers in the research process. The aim of this qualitative study was to explore perceptions of consumers and health professionals of PAR methodology in the development of a self-management programme for fatigue in MS and to identify considerations for health professionals when working with consumers in the development of health resources. Nine of the ten participants in the PAR group agreed to be interviewed. Semi-structured, individual interviews were audiorecorded and transcribed, then analysed thematically. The themes of 'Having a voice', 'Accomplishment' and 'The process' were all linked by an umbrella theme of 'Empowerment'. Consumers and health professionals perceived that the PAR experience was positive and valuable because it facilitated the sharing of knowledge between health professionals and people directly affected by MS. We believe PAR is a useful tool to facilitate a patient centred approach in developing relevant health resources.

Mulligan H, Wilkinson A, Lusty A, Delorme A, Bong S (2015) Consumers and health professionals' perceptions of Participatory Action Research in developing a health resource. New Zealand Journal of Physiotherapy 43(3): 93-97. doi 10.15619/NZJP/43.3.04

Key words: Participatory Action Research; multiple sclerosis; consumers; health resources

INTRODUCTION

Multiple Sclerosis (MS) has a high prevalence in New Zealand (NZ), which was the setting for this study (Taylor et al 2010). Recent literature suggests that 75-90% of people with MS experience fatigue (Matuska et al 2007). This fatigue is described as overwhelming and like a heavy body tiredness that occurs without warning, at any time of the day (Schapiro 2005). It interferes with activities of daily life. Recent focus has been on developing other ways to manage fatigue than via medication. These include being physically active (White and Dressendorfer 2004), or via cognitive strategies for energy conservation and self-management (Mathiowetz et al 2001, Matuska et al 2007, Twomey and Robinson 2010, Vanage et al 2003).

The dearth of an organised approach to fatigue management for people with MS in NZ prompted a physiotherapist to create a rudimentary course based on the concepts of self-management, intended to enable individuals to be equipped to successfully manage their symptoms on a daily basis (Barlow et al 2009, Lorig et al 1999, McGowan 2012). Formative evaluation of that course and four successive courses showed that they were well received (Snowdon et al 2013). Attendees suggested that it would benefit other individuals with MS in NZ but that they had ideas for improving its format and content. Building on this feedback led to the decision to further develop the programme in a formal manner, via research.

Participatory Action Research (PAR) was chosen as a methodological framework through which to develop the

programme. This was because the ethos of PAR should enable the process and its outcomes to remain in the hands of those to whom it really matters, in this case people living with MS (Ehde et al 2013, Seekins and White 2013).

PAR is a problem-solving process involving a group of people coming together with the intent of addressing a common issue and using a cyclic pattern of planning, action, evaluation and reflection. PAR differs from other research approaches in that it empowers consumers by providing a voice for them as active research participants (Baum et al 2006, Whyte 1991). Participants plan and execute actions according to knowledge and personal experiences, which they analyse and reflect upon towards further planning and action. The continuous cycle of reflection and action, as well as the relationships built between members of the group, are argued to be its strength, providing ownership and empowerment for all members of the group (Ehde et al 2013, Kemmis and McTaggart 2008, McTaggart 1991, White and Verhoef 2005).

The PAR group was formed by the physiotherapist who had offered the fatigue management course, using purposive sampling. Six attendees from the previous courses were invited to become part of the PAR group. This was because they had expressed particular interest in further development of a fatigue management programme so that it could be made available to other people with MS in NZ. Two healthcare professionals were also invited, one (a physiotherapist) for research expertise, and another (an occupational therapist) for clinical expertise in fatigue management. Six meetings were held. Discussions at the

meetings were audiorecorded, transcribed and read through for topics after each meeting by two health professionals from the group, who presented the topics at the beginning of the next meeting. Reflection and collaborative discussion by the group on the topics then facilitated setting of an agenda for that meeting. This provided a clear outline of the topics that needed to be discussed during the session, as well as the actions that were required by members of the group before the next meeting. Examples of actions were the writing of personal stories about fatigue, taking of photographs to illustrate the stories, research into fatigue management strategies, design of worksheets, and formatting of chapters for the workbook. Because fatigue was often a factor for participants with MS, especially towards the end of a meeting, email was established by the group as another way for people to communicate their ideas in their own time, and outside of the face-to-face meetings. The outcome of the PAR process was 'Minimise Fatigue, Maximise Life: Creating Balance with MS', a six week fatigue management programme for MS, with an accompanying 84 page take home work book and a facilitators' training manual (Multiple Sclerosis and Parkinson's Society of Canterbury (Inc.) 2013).

This paper reports on a study that aimed to: a) obtain an understanding of the perceptions of consumers and health professionals about the use of PAR methodology in the development of a self-management programme for fatigue in MS; and b) identify considerations for health professionals when working with consumers in the development of health resources. The study used a qualitative approach, with interviews to collect the data (Patton 2002).

METHODS

We contacted all of the members of the PAR group by email, about one month after the end of the PAR project, to provide information on this study and invite them to contribute their perceptions and opinions. Nine of the ten individuals who made up the PAR group agreed and provided signed consent to be a participant. Ethical approval for the study was gained from the relevant University Ethics Committee (12/173).

Data Collection

Semi-structured individual interviews were scheduled at a convenient time and location for each participant. These took place in participants' homes, workplaces, and the local library or Multiple Sclerosis Society rooms depending on the individual's preference. Three members of the research team (AL, SD, SB) conducted the interviews using open-ended questions (see Table 1 for questions). The interviews, which ranged from 30 minutes to an hour in length, were audiorecorded and then transcribed verbatim (AL, SD, SB). Personally identifying information was then removed and transcripts were numbered to maintain participant anonymity.

Analysis

We analysed the data thematically using an inductive approach to facilitate analysis, synthesis and description of the data (Thomas 2006). Data from the first two interviews, one from a health professional and one from a participant with MS, were used to develop an initial coding template. To do this, members of the research team independently read a hard copy of the interviews closely several times to gain familiarity with the text. Specific segments of text that were pertinent to the research

Table 1: Semi-structured interview questions

1.	Could you explain to us what your understanding of PAR is?
2.	How did you all come together as a group?
3.	Could you describe a typical meeting for me and describe any specific aspects that occurred or were important to you?
4.	Could you tell me about any issues that came up during the meetings and how these were dealt with?
5.	Could you tell us about your role in the group?
6.	If you were going to do it again, what would you change?
7.	What did you learn?
8.	How did this approach make you feel?
9.	What did you enjoy the most/least?
10.	Is there anything else that you want to comment on or tell us about?

aims were highlighted. These were assigned descriptors which described the segments as distinct categories. The research team then came together to discuss the individual coding and interpretation of the data, and to agree on the coding and meaning of the different categories identified. This led to the development of a list of 48 labelled categories. This coding template was then used to analyse the remaining interview transcripts, with the addition of new categories as these were identified. Data saturation was reached after interview five, with no new categories emerging in the last four transcripts. Over a number of occasions, the research team then synthesised the categories into themes. We then sent participants the themes together with each theme's contributing categories and asked for their feedback on whether this reflected their perceptions about their PAR experience. We received communication from seven out of the nine participants, with all of them agreeing to the categories and themes.

RESULTS

The final PAR group included six people with MS (five were female), three healthcare professionals (all female, two physiotherapists and an occupational therapist) and a male physiotherapy student on clinical placement with one of the healthcare professionals. Participants with MS used a variety of mobility aids, from motorised wheelchair to walking stick.

The term 'Empowerment' emerged as an umbrella theme drawing together three themes of 'Having a voice', 'Accomplishment' and 'The process'. The themes and their categories are displayed in Table 2 and described below supported with quotes taken from the data. Participants are identified as a participant with MS (e.g. PwMS 1) or a health professional (e.g. HP 1).

Table 2: Themes and categories

Empowerment		
Having a voice	Accomplishment	The process
Freedom of expression	The thrill, joy, pride and ownership in end product	Logistics and organisation
Social interaction	Personal growth	Suggestions for the future
Perception of equality		

Umbrella Theme: Empowerment

This umbrella theme of empowerment captures how the process of PAR facilitated all participants to contribute their own ideas and opinions within a group but at the same time hear and learn from others. The participants with MS and health professional participants were empowered through knowing that their contributions toward the development of the self-management programme would successfully meet a need within the MS community.

It sort of made me feel useful. I can do something. When you've had to give up your job, because you can't do it anymore, it's nice to know that you're not totally useless. You're not a disease; you're still the person you were before. And it was fun. [The PAR process], it's just sort of self-fulfilling positivity. I guess people feel part of something, they've owned something and that makes it a really positive process. (PwMS 3).

In addition, the health professionals spoke about gaining deep knowledge of what is meaningful to individuals living with MS. This they perceived would be transferrable to their clinical practice.

Theme: Having a voice. This theme showed how individual members of the group identified as a group and interacted together; yet also encompassed how participants felt able to make individual contributions and were valued for their input. There was a sense of validation from within the group; people were comfortable to share their ideas for everyone to discuss. There were no boundaries to what they could share and there was no perception of hierarchy within the group, more that everyone had something valuable to contribute.

I think people felt free to say what they thought and it was always received very positively (PwMS 4).

Participants appreciated the respectful interactions between group members that allowed time and space for voicing of opinions. For example, naming the programme was revisited many times, with more than 15 possible options put forward by group members. A final decision was only reached at the last group meeting.

I think a very specific memory has to go to choosing the name. We talked about the name so many different times (HP 4).

Theme: Accomplishment. This theme encompassed the ownership and overall pride in the perceived quality of the final product, coupled with the personal growth that had occurred in its completion. Participants mentioned the overwhelming satisfaction they felt when they were able to hold the high quality resource book and see its contents right in front of

them. There was an excitement about being able to see one's own ideas and discussions turned into reality. Not only were participants proud of the group effort but many commented on how satisfying it felt to know that the resource would help so many other New Zealanders living with MS.

I was really pleased to be part of it. Because it [the original course] did so much for me; to be able to improve it and make it better for other people gave me a good feeling. It's great to help other people. To work together as a team to make it all happen. It's very inspiring. Yeah, I really enjoyed it (PwMS 5).

In addition, by sharing knowledge, experiences and opinions about MS with each other, participants with MS had been able to learn about themselves in the light of living with MS. Participants felt that hearing other people's opinions made them see their own situations differently. The process of sharing information helped the participants with MS to learn more about what they themselves were experiencing.

Health professional participants grew in their understanding and respect for the expertise of individuals living with MS. They perceived that participation in the group (and hearing about the impact of MS and its accompanying fatigue) had been a most useful tool for them to realise they had held incorrect assumptions of what may be helpful for people with MS.

We hadn't even scratched the surface about what is it really like to live with MS and what's useful to know . . . And I thought I was the expert (HP 2).

Theme: The process. This theme encompassed participants' views on the organisation and setting up of the PAR group, the way that meetings were run, and the process of developing the fatigue management programme. Many participants mentioned how the setting of 'ground' rules about listening to and respecting others in the group while also being able to voice their own opinions and suggestions was useful in the first meeting. Participants perceived that PAR consisted of teamwork, making group decisions, continuous reflection and equality.

All the participants are coming together, making decisions all as equals, all having an action or a role to do to contribute, and then coming back again for the next stage of it (PwMS 1).

Group members were open-minded so that everyone was able to express their ideas. Participants identified that discussion often deviated but that any group member was able to bring the discussion back on track.

We would get through those things [what had been decided was to be on the agenda] but there was a huge amount of other stuff that crept in. Thoroughly enjoyable, I must say, discussions ... It wasn't like a meeting; we started with something and somebody would say "I think this" so it would head off down the tangent ... Then somebody would sort of say, "well, so do you think?", and we'd go back to the main question (PwMS 2).

Participants felt there was a good cross section of skills and experiences within the PAR group. They observed that the group worked as a team to make decisions but used individual strengths of group members where appropriate for actions required. Participants talked about the extent to which they and other members of the group had given of themselves, their time and particular expertise.

I think [the group] was a good mixture. I think if you were going to do this sort of thing with various people, it is important to have a group ... [where] everybody works together, very open about things (PwMS 6).

Participants identified that they had joined the group without selfish motives; they had wished to share their knowledge and experience to provide a greater depth to the programme. They reported no task had required allocation and tasks were optional with no expectation for any one individual to take on more than they wished to. Despite participants commenting on this, many noted that they had given far more than what they had initially thought would be required. However, participants also noted how they were able to work at a pace that suited them and use their strengths and skills to be of most value to the group.

Some practical suggestions for improving the process of using PAR were identified in the interviews. One issue was with the size of venues for the meetings. These were reported to be not large enough to easily accommodate individuals with walking frames or wheel chairs, which had led to time consuming efforts to get everyone seated at the beginning of the meetings. This was, however, not perceived as having an impact on the group dynamics per se. Additionally, due to the length of time between meetings, participants reported experiencing a loss of momentum. They suggested that meetings should be held more frequently than monthly. Some participants suggested it would have been helpful to have specific time at the beginning of the first meeting to get to know one another before embarking on the important business of the research.

Despite these issues, participants reported gaining enjoyment from the process of the meetings. Participants with MS felt the meetings were personally validating, as well as being intellectually stimulating. Because of the group process, energy and enjoyment were evident within the group, and because of that, work was able to be completed. Participants felt that through the group, they were able to accomplish a lot and build more momentum than they would have done on their own.

I would have never have achieved this on my own (HP 1).

With a group, you can just create the energy and the momentum to do a lot more than what you perhaps thought was possible (PwMS 3).

DISCUSSION

The purpose of this study was to obtain an understanding of the perceptions of consumers and health professionals about the use of PAR methodology in the development of a self-management programme for fatigue in MS. Additionally we aimed to identify factors for health professionals to consider when working with consumers in the development of health resources.

The core idea of PAR is to combine the skills and strengths of all participants in an equitable manner (Ehde et al 2013, McTaggart 1991). Our study strengthens this idea, through our participants reporting that the experience was positive, valuable and validating. All members of the group gained knowledge about MS and fatigue in particular while working with others toward a common goal by using their individual strengths and skills. Our findings identified that the use of PAR facilitated equality between those with MS and the health professionals involved, allowing all to contribute to the development of the self-management programme for fatigue in MS. Thus, such an approach provides validity for the end product, because its development included persons living with MS and not only health professionals.

Our study further informs the use of PAR as a methodological approach for development of health resources. The PAR approach (Kemmis and McTaggart 2008) has not yet been used extensively in the area of health compared to its more common application in the social and political setting (Tsey et al 2002). We suggest that the PAR approach could potentially be used to advantage in developing health resources or interventions for people with debilitating long-term conditions other than MS, examples being Parkinson's disease, stroke and traumatic brain injuries. Indeed it is apparent from our findings that it is the individuals with a specific condition who hold the expertise about their condition (Thorne et al 2000, Townsend et al 2006). Making use of the PAR approach could assist health professionals to access this expertise and form an empowering partnership (Seekins and White 2013).

Issues for health professionals to consider when using PAR with people with long-term conditions are the following: to have an initial group bonding meeting for group members to introduce themselves and get to know others in the group. This would assist in establishing connections and group cohesiveness. Plan for space and access for participants who use mobility equipment. In addition loss of momentum would be avoided and the process allowed to move faster if meetings were scheduled more often than monthly, or if a summary of meeting transcripts were sent in advance of the next meeting, for example via email. This would allow prior preparation and thought before the next meeting.

A limitation of this study is that the interviews were undertaken at one point in time, about a month after the end of the project. Different data may have been received if interviews had been conducted at different time points during the project. Indeed it may have been most insightful to have conducted a series of interviews during the process of the project, as this may have identified issues early on which could have then been addressed during the project.

CONCLUSIONS

In conclusion, this study has demonstrated PAR to be a positive and rewarding experience for consumers and health professionals. The nature of PAR is to bring people together to work effectively as a team towards a common goal. The depth that can be obtained through this type of research is far more than one can achieve individually. We have shown the usefulness of the approach in developing meaningful resources for use in the health sector.

PAR gives a voice to those who live with long-term conditions, thereby enabling personal growth, as well as the opportunity to help others. This is empowering. There is a growing need for more patient centred approaches in health care and we believe PAR may be an appropriate option in this regard, allowing health professionals to truly develop partnerships with health consumers, in order to develop meaningful and valid health resources. Furthermore, it is our role as health professionals to develop services that are meaningful and effective for our patients or clients. We anticipate that the programme developed through this study is a step towards fulfilling this need.

KEY POINTS

- Participatory Action Research (PAR) is an innovative approach to empowering and including consumers in the development of a health resource.
- PAR can facilitate the sharing of knowledge between health professionals and the consumers for whom a particular health resource really matters.
- While PAR is a useful tool to facilitate a patient centred approach, it may require a flexible approach to the cycles of PAR to enable consumers to be involved.

PERMISSIONS AND DISCLOSURES

The authors received no financial support for the research, authorship and/or publication of this manuscript. The first author was a member of the PAR team.

ACKNOWLEDGEMENTS

We wish to acknowledge our participants for their contributions and willingness to assist in this evaluation of the use of PAR in the health care sector.

ADDRESS FOR CORRESPONDENCE

Hilda Mulligan, Centre for Health, Activity, and Rehabilitation Research, School of Physiotherapy, University of Otago, PO Box 56, Dunedin 9054, New Zealand. Telephone: +64 3 364 3657. Email: hilda.mulligan@otago.ac.nz

REFERENCES

- Barlow J, Edwards R, Turner A (2009) The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis. *Psychology & Health* 24: 1167-1180. doi:10.1080/08870440802040277.
- Baum F, MacDougall C, Smith D (2006) Participatory action research. *Journal of Epidemiology & Community Health* 60: 854-857. doi:10.1136/jech.2004.028662.
- Ehde D, Wegener S, Williams R, Ephraim P, Stevenson J, Isenberg P, Mackenzie E (2013) Developing, testing, and sustaining rehabilitation interventions via Participatory Action Research. *Archives of Physical Medicine and Rehabilitation* 94: S30-42.
- Kemmis S, McTaggart R (2008) Participatory Action Research. In Denzin NK, Lincoln YS (Eds) *Strategies of qualitative inquiry* (3rd edn). Los Angeles: Sage Publications, pp 271-329.
- Lorig KR, Sobel DS, Stewart AL, Brown BW, Jr., Bandura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Medical Care* 37: 5-14.
- Mathiowetz V, Matuska KM, Murphy ME (2001) Efficacy of an energy conservation course for persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation* 82: 449-456. doi:10.1053/apmr.2001.22192.
- Matuska K, Mathiowetz V, Finlayson M (2007) Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *American Journal of Occupational Therapy* 61: 62-69.
- McGowan PT (2012) Self-management education and support in chronic disease management. *Primary Care; Clinics in Office Practice* 39: 307-325. doi:10.1016/j.pop.2012.03.005.
- McTaggart R (1991) Principles for Participatory Action Research. *Adult Education Quarterly* 41: 168-187. doi: 10.1177/0001848191041003003.
- Multiple Sclerosis and Parkinson's Society of Canterbury (Inc.) (2013) *Minimise Fatigue, Maximise Life: Creating balance with multiple sclerosis*. Christchurch, New Zealand: Multiple Sclerosis and Parkinson's Society of Canterbury (Inc.).
- Patton MQ (2002) *Qualitative Research & Evaluation methods* (3rd edn).
- Schapiro RT (2005) Managing symptoms of multiple sclerosis. *Neurologic Clinics* 23: 177-187. doi: 10.1016/j.ncl.2004.09.001
- Seekins T, White G (2013) Participatory Action Research designs in applied disability and rehabilitation science: Protecting against threats to social validity. *Archives of Physical Medicine and Rehabilitation* 94: S20-29. doi: 10.1016/j.apmr.2012.07.033
- Snowdon J, Mulligan H, Tapper L (2013) Self-management of fatigue for people with multiple sclerosis: The 'Manage Fatigue, Maximise Life' programme. Proceedings of the PhysioForward, Centennial Conference, p 53.
- Taylor BV, Pearson JF, Clarke G, Mason DF, Abernethy DA, Willoughby E, Sabel C (2010) MS prevalence in New Zealand, an ethnically and latitudinally diverse country. *Multiple Sclerosis* 16: 1422-1431. doi: 10.1177/1352458510379614.
- Thomas DR (2006) A General Inductive Approach for Analyzing Qualitative evaluation Data. *American Journal of Evaluation* 27: 237-246. doi: 10.1177/1098214005283748.
- Thorne S, Nyhlin K, Paterson B (2000) Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies* 37: 303-311. doi:10.1016/S0020-7489(00)00007-9.
- Townsend A, Wyke S, Hunt K (2006) Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness* 2: 185-194.
- Tsey K, Patterson D, Whiteside M, Baird L, Baird B (2002) Indigenous men taking their rightful place in society? A preliminary analysis of a participatory action research process with Yarrabah Men's Health Group. *Australian Journal of Rural Health* 10: 278-284. doi: 10.1046/j.1440-1584.2002.00491.x.
- Twomey F, Robinson K (2010) Pilot study of participating in a fatigue management programme for clients with multiple sclerosis. *Disability and Rehabilitation* 32: 791-800. doi: 10.3109/09638281003656578.
- Vanage SM, Gilbertson KK, Mathiowetz V (2003) Effects of an energy conservation course on fatigue impact for persons with progressive multiple sclerosis. *American Journal of Occupational Therapy* 57: 315-323.
- White L, Dressendorfer R (2004) Exercise and multiple sclerosis. *Sports Medicine* 34: 1077-1100.
- White M, Verhoef M (2005) Toward a patient-centered approach: incorporating principles of participatory action research into clinical studies. *Integrative Cancer Therapies* 4: 21-24. doi:10.1177/1534735404273727
- Whyte WF 1991 *Participatory action research*. Sage focus editions, Vol. 123. Thousand Oaks, CA: Sage Publications.