How to use participatory action research in primary care

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Objective. The aim of the article is to demonstrate the usefulness of participatory action research (PAR) in primary care. The author used PAR firstly to develop a deeper understanding of mutual participation in the doctor–patient encounter and secondly to apply this learning in a rural cross-cultural practice setting.

Method. PAR was done with four patient groups. Four patients with terminal illnesses formed groups with their family members, neighbours and friends. Seven meetings were held with each group over a period of 6 months. The meetings were conducted in Tsonga, which is the local vernacular. All the meetings were audio-taped. The primary question for each meeting was how the group could work together to achieve the best possible health outcome for the patient. Additionally, the author, who facilitated the meetings, kept a reflective diary, including field notes over the research period. One member of each group kept a written record of each meeting. Three free attitude interviews were conducted with the author over the research period to elicit the development of his understanding about mutual participation in the doctor–patient encounter. The recorded meetings and interviews were transcribed and translated and themes subsequently identified using the transcripts. The reflective diary was analysed similarly. A model was constructed to depict the themes and their interrelatedness. The model was interpreted and conclusions were drawn.

Results. The PAR process had a positive effect on the doctor–patient encounter. PAR greatly resembles a mutual participatory doctor–patient encounter. The research facilitator had certain basic tenets in order to facilitate participation. The patients who participated actively benefited most. Basic interviewing techniques were used to facilitate the mutual participation in PAR.

Conclusions. PAR is very applicable in primary care. The principles of PAR such as mutual collaboration, reciprocal respect, co-learning and acting on results from the enquiry are essential in the doctor–patient relationship. Self-awareness, the ability to self-critique and reflect in a deep manner using such tools as a reflective diary are essential for nurturing the development of effective primary health care workers and consequently care structures for the patients and their families.

Keywords. Mutual participation, participatory action research, primary care.

Introduction

Participatory action research (PAR) is a research process that focuses on improving the quality of service by means of a self-reflecting process, exploring and solving problems.\(^1\)\(^2\) The basic structure of PAR is an ever increasing spiral process of planning, acting, observing, reflecting, developing theory and re-planning.\(^1\)\(^3\)\(^6\) (see Fig. 1.) Participation, collaboration and mutuality of all participants on all levels of the research is the ideal, namely identifying the problem, defining the problem, planning the research, collecting the data, interpreting the data, planning the intervention, evaluating the intervention and re-evaluating the problem in light of the new information generated from the action implemented, and finally disseminating the information.\(^3\)\(^7\)\(^8\)\(^9\)\(^11\)

PAR works with a community, which is a group of people who share a common interest and not necessarily a common geographical location. Empowerment and social change are important goals of PAR. Equality in sharing control and power is a basic value of PAR. Through participation in the research process, it is hoped
that disempowered participants will lose their fear and shame and gain self-confidence, self-esteem and control, and thereby develop an understanding of their own value. PAR is highly relevant for work with oppressed and disempowered communities with self-help groups and for health education.6,7,10–13

The researchers become essentially facilitators or catalysts, and participants become co-learners in PAR; nobody is considered the expert.5 Insiders and outsiders work together as equals to solve problems. PAR is subjective and therefore not always neutral.9 PAR involves commitment from all participants and requires mutual respect, trust, humility, adaptability and a holistic approach to problem solving.1,6,7,10–13 Listening, dialogue and negotiating consensus are strategies to achieve mutualuality and empowerment.

Data collection in PAR is done by means of participant diaries, field notes, reflective diaries, minutes of meetings, recorded meetings, free attitude interviews, focus group interviews and survey questionnaires.1,3,5,8,13–15 Reliability of results is improved through honesty, transparency and openness of the researcher.3,14,16 The skill of self-awareness and reflection is essential to be truly open and honest.6 Acknowledging subjectivity and the fact PAR is not neutral enhances truthfulness.3,17 Internal validation, external validation, peer-critique (devil’s advocate) and triangulation are all techniques to improve reliability.16

Learning and the creation of knowledge are co-generated in PAR and take place on several levels.1,5–7,12 The first level is developing the skill of working in a team or partnership. The second level is developing the ability to identify problems, reach a common understanding and create solutions to those problems in a local setting. The action that comes from trying out suggested solutions (implementation of plans) leads to a third level of learning (or knowledge), namely competence. Competence is when the technique to implement a specific solution has been mastered. When documenting the implementation process of effective solutions, a fourth level of knowledge is created. The documented process has the potential to be utilized in other settings. The final level or dimension of learning in PAR is empowerment.6 Empowerment is achieved when participants discover they have the ability within to solve their own problems. As stated previously, the PAR process is an open spiral process and requires constant revisiting of previous levels with newly generated knowledge from actions taken, which then help to reshape the problem and resolve it at a deeper level.

PAR is a research form that is very suitable for primary care. PAR has contributed positively in the past to primary care.3,18-21 In this study, PAR methodology was used. The participants were from a rural village in the Limpopo Province of South Africa. People from this village are mostly of low socio-economic status, with poor levels of literacy. The purpose of the study was to develop and evaluate an application model for mutual participation in the doctor–patient relationship, with special reference to disadvantaged (poor), rural, cross-cultural South African practice. This article was written in order to illustrate how applicable this research method is in primary care and its usability in such a setting.

Method

Selection of participants

In this study, PAR was done with four patient groups. Four patients with terminal illnesses formed groups with their family members, friends and neighbours. Seven meetings with each group were audio-taped over the research period of 6 months. Each group consisted of the primary patient, the author (and research facilitator) who was their regular doctor, plus family members, friends and neighbours. In three of the groups, a home-based care volunteer formed part of the group. The groups ranged from four to eight participants in each group.

Method of data collection

The four groups met on a monthly basis. The author facilitated the meetings and acted as the research facilitator for all four groups. The meetings were conducted in Tsonga, the first language of all the participants except for the author. (The author is fluent in three languages, one of which is Tsonga.) All meetings were audio-taped. The first set of meetings took place in June 2000. The last set of meetings took place in the first week of December 2000. The meetings took place at the ‘patient participants’ respective homes. This decision was negotiated with each group individually. During the first meeting, the purpose and process of the research was explained. The research process was started with the following statement: “I want you to help me to understand better how we can work together as partners to improve the life of our patient, in view of the fact that his/her condition is incurable and chronic. I want to understand this better because as a doctor I cannot work miracles, I may have scientific knowledge, but do not know how it should be applied to a specific person’s life because each person...”
is different and this knowledge will work differently for every person. This is even more so for our patient as his/her illness cannot be cured by medical scientific intervention. Therefore, the question is: how can we work together to achieve the best for our patient?”

Each group was encouraged to give ideas on patient management. Action plans were formulated. The plans were tried out. Decisions were made by consensus of the whole group. The transcribed recording of each meeting was summarized and themes identified through the cut-and-paste method on computer. The summaries and identified themes were verified with the individual groups at the following meeting. Minutes were kept by a group member and were also read at the beginning of each meeting. Feedback on the effects of the implemented action plans was given during the following meetings. The effect of actions taken was discussed at these meetings. The patient’s clinical condition was also evaluated at each meeting. The author’s dual role of research facilitator and the patient’s usual doctor enabled regular assessment of the patient’s condition; this information was compared with the group’s ideas about the patient’s condition. The group also discussed the effect of implemented (or non-implemented) action plans on the patient as a whole. The author made field notes (mostly after the meetings) and kept a reflective diary during the research period. The group was facilitated to continue generating more ideas and plans for action. This process went on for five meetings. After four meetings, it was noticed that very few new themes were being generated. What happened, however, was that the same themes were discussed repeatedly, but on a deeper level.

The sixth meeting of each group was a free attitude focus group interview, asking the group to describe the changes in the patient's condition. The purpose of this interview was to see if there was any reference to participation and understanding of the effect thereof on the group. The results of these interviews as well as the results from all the previous meetings were validated during the seventh meeting. The participants agreed with all the themes identified. In the local Tsonga culture, it is not considered polite to disagree with a respected person, but information may be added to enhance his/her understanding. The participants added their understanding of the themes, which consequently helped the research facilitator develop a deeper understanding of the presenting themes. Misconceptions were also corrected in this process.

It must be mentioned that it was very difficult to involve the participants in data analysis in the true sense of the word, as it should be in PAR. This was due to the participants being either illiterate or only being literate in the local vernacular. In this research, the participants were only involved to the level of verifying and elaborating on the summaries and themes from the interviews in their own groups.

The reflective diary, which the author kept throughout the research period, was to record his observations of what happened during the research meetings, communications with others about the patient and his/her illness as well as thoughts about the concepts and process relevant to the research topic.

There were also three free attitude interviews done with the research facilitator (author). The first interview was in August 1998 during the protocol phase of the research. The exploratory question during this interview was: “How do you understand your own desire to help your patients?” This was done to enhance self-awareness. The next two interviews essentially evaluated the author’s perceptions about and understanding of the PAR model, its application and effect on the doctor–patient relationship. These interviews were conducted in English. The second interview in July 2000 was conducted after the second set of interviews with the different patient groups. The third interview was held in November after the set of free attitude interviews (sixth meeting) with the different groups was completed. The purpose of these interviews was to give the research facilitator the opportunity to increase personal awareness about perceptions regarding participation at different times during the research period.

**Method of data analysis**

The meetings were all transcribed and translated into English from Tsonga. The Tsonga transcriptions were done by one of the participants from each group. The research facilitator checked the transcriptions and translated the text into English. Analysed transcripts of the meetings identified themes from the English manuscript; these were then verified with the Tsonga text. The themes in all the meetings were identified with the cut-and-paste computer method. The research facilitator specifically searched to identify themes that described action plans as well as themes related to participation. The participants who formed the patient groups were involved in the analysis and verification only to this point due to literacy and language barriers. Themes from the author’s reflective diary and the three free attitude interviews of the research facilitator were identified through the cut-and-paste computer method. This was the first level of analysis.

Thereafter, the author reviewed the data again and described the process of each interaction that took place during the different meetings. Each sentence in the different meetings was examined and the process of the interaction described. The interaction processes in each group were described. This was the second level of analysis.

The descriptions of the interaction processes and themes from the different meetings with patient groups were combined with the list of themes from the author’s reflective diary and free attitude interviews. A combined list of themes was thus created. This list of themes was
compared with those themes which emerged from the transcribed patient group meetings, to ensure that no theme was overlooked.

The combined list of themes was used to construct a visual schematic model that demonstrates the interrelatedness of the different themes. Thereafter the model was described (see Fig. 2.) This was the third level of analysis.

Conclusions were drawn from this description and the conclusions were compared with other research and literature in general. This was the fourth level of analysis.

Reliability, bias, validity and truthfulness

The first way to enhance reliability was through the active attempt of the research facilitator to be open towards ideas from all other participants. The author focused actively on facilitation skills such as active listening, using regular reflection in the research diary to complement this process to ensure reliability of findings. Possible bias may have been introduced by the research facilitator’s preconceived ideas about mutual participation. The free attitude interviews with the research facilitator attempted to raise awareness concerning these ideas.

The themes identified from the different meetings were validated with the different groups during following meetings. To validate findings, the research facilitator compared themes from the transcribed meetings (level 1 analysis) with results of the process analysis (level 2 analysis). Theories generated during level 3 analysis were verified with individual participants (home-based care workers) or other key informants (colleagues). This was not done in the groups due to language barriers.

Ethical considerations

All participants gave written informed consent to participate in the study. The tapes were transcribed and translated by participants in the meetings and not outsiders. This ensured confidentiality.

Permission to carry out the study was obtained from the Research, Ethics and Publications Committee of Meduns, Department of Health and Welfare of the Limpopo Province as well as the Local Health Authority of the Greater Tzaneen Municipality.

Results

The purpose of this article is to illustrate how PAR has been used in primary care. The details of the results will be reported in another article. Here follows a very short summary of the results from the research.

The positive effect of open functional relationships and the negative effect of conflict and distrust in relationships on health (as well the PAR process) within the group (research group and/or patient’s family group) and with people outside the group were strongly suggested in this research.

Certain basic tenets of the doctor are helpful to implement a mutual participation model in health care: the doctor is required to value and respect the patients as well as their abilities and contributions to ensure this process is effective. There needs to be a preparedness to learn from patients with the aim of generating personal growth and development of self and the patient. It is important to value a holistic view of medicine and be aware of the limitations within Western medicine.
doctor or health provider has to be aware of the personal benefits from helping patients: the influence of their status on the therapeutic relationship and that this status could be due to their knowledge and position in society. These tenets helped the research facilitator to achieve participation during the PAR project.

Basic interviewing techniques, such as reflection, summaries and giving the opportunity to ask questions, had a positive impact on the process. It is important constantly to encourage participation by asking all participants repeatedly for their ideas, opinions, suggestions and plans.

Active participation by the patient such as the giving of opinions, taking of responsibility, taking action to contribute to their health and being honest and open about concerns and unresolved conflict had a positive effect on the well being of the patients as well as the PAR process.

Attitudes such as feelings of rejection, helplessness, being defensive, blaming others for their misfortune and being disenabled had a negative effect on the well being of the patient and on the PAR process.

Discussion

PAR is an excellent method to use in primary care, and even more so in a cross-cultural setting where there are tremendous differences between carer and patient.

In their article ‘Participatory research maximizes community and lay involvement’, Macaulay et al. describe clearly three primary features of participatory research including: collaboration, mutual education and acting on results developed from research questions which are relevant to the community. Participatory research is also based on a mutually respectful partnership between researchers and communities. Partnerships are strengthened by joint development of research agreements (design, implementation, analysis and dissemination of results). Macaulay et al. also make it very clear the PAR method is very appropriate for work with disadvantaged communities because the research methodology specifically addresses aspects of empowerment necessary to make decisions and therefore transform the group to lose fear and gain confidence and self-esteem. PAR stresses the importance of the relationship between the group and the researcher; this should be of direct benefit to the group and consequently focuses on the involvement of the group. McNiff stresses that PAR implies that real knowledge has no value unless it has practical implications. The development of answers from daily practice is an integral part of PAR.

The creation of knowledge in PAR is on various levels. Knowledge is created amongst all by new insights, competence and skills. In this research, the author gained competence in skills applying to mutual participation by involvement in this PAR project. The author learnt to apply a mutual participation model in a rural, cross-cultural setting, by repeatedly implementing what

was gained through the literature, and continually applying that which worked in practice during the research period. Gaining competence is described as one of the ways in which knowledge is created in PAR. Through implementing different ideas, the author discovered new insights about participation. The immense value of the following ancient truth was also rediscovered: the importance of believing in the inherent value of all people (including patients) and respecting them for that. This is the very essence of the doctor–patient relationship (or any helping relationship). Any attempt to establish a helping relationship would be futile and hypocritical without this value as a fundamental truth. To value and respect others should always be possible, even if working under the most inadequate circumstances. This essential truth has lost its importance with the new technical developments in biomedicine. The author re-discovered this through the process of reflection and keeping a reflective diary. Reflection, self-awareness and keeping a reflective diary are all skills very essential to the practice of medicine (or any caring profession) as well as the PAR process.

Ideally, in PAR, all participants are co-researchers and should participate at all levels of the research. Unfortunately none of the participants were able to speak or write English. The consequence was that they were unable to participate in the documenting of the research. Those who are able to write participated in collecting data in the vernacular (Tsonga); however, they were involved in the first level of the analysis.

The author as well as most of the participants enjoyed the PAR process. The times specifically allocated for personal interaction within these groups were significantly appreciated by the patient participants. This could be understood in light of their terminal illness. Opportunity for such interaction elsewhere was severely limited. There is anecdotal evidence that the PAR process, participation and group interaction had positive influences on the patients condition.

Having discussed many of the advantages of using PAR in a rural community, there is a need to discuss some of the difficulties. This process requires extensive time and patience in a cross-cultural rural setting. The language and literacy differences made communication difficult as well as time consuming. These differences subsequently had an impact on the truthfulness of the data. The data collection and the analysis processes were also extremely time consuming.

Conclusion

PAR is very applicable in primary care. The principles of PAR such as mutual collaboration, reciprocal respect, co-learning and acting on results from the enquiry are all essential in the doctor–patient relationship. Skills such as self-awareness, the ability to reflect and keeping a reflective diary have the potential to nurture the development of primary health care workers.
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