

Putting Participation into Practice

Marincowitz GJO, MBChB (UFS), M Fam Med (Medunsa), MD (Medunsa)
Department of Family Medicine and Primary Care, Limpopo Province Unit,
Medical University of Southern Africa (Medunsa)

Correspondence: Dr G Marincowitz, Department of Family Medicine and Primary Care, PO
Box 222, Medunsa, 0240, South Africa, e-mail: rhinorth@mweb.co.za

Keywords: participatory action research, primary care, mutual participation

SUMMARY

Background: The aim of the article is to share the findings of participatory action research performed to develop a mutual participatory doctor-patient relationship model, and to apply this model in a rural cross-cultural primary care setting.

Method: Participatory action research was performed with four patient groups. Four patients with incurable illnesses formed groups with their family members and significant others. Seven monthly meetings with each group were audio recorded. The question asked at each meeting was "How can the group work together to achieve the best possible health outcome for the patient?". The recorded interviews were transcribed and translated from the local vernacular (Tsonga) into English. Themes were identified from the transcripts, field notes and a reflective diary. A list of combined themes was compiled and a model was constructed to depict the themes and their interrelatedness. The model was interpreted and conclusions were drawn.

Results: To apply a mutual participatory model in a rural cross-cultural practice, the physician is required to operate from certain basic tenets. The patients have to participate actively to benefit optimally, and basic interviewing techniques are helpful to facilitate mutual participation.

Conclusions: It is not easy to implement a mutual participatory model in a disadvantaged, rural practice, but it is possible. We need a paradigm shift in health care, from "helping" patients (which may nurture dependence), towards facilitating the personal growth and development of patients (to nurture self-reliance).
(*SA Fam Pract* 2004;46(5): 31-36)

INTRODUCTION AND BACKGROUND

Different models of participation in the doctor-patient relationship have been described in the past. Szasz and Hollender's models are well known and include the activity-passivity model, the guidance-cooperation model and the mutual participation model.¹ Mutual participation as the basis of the doctor-patient relationship has been the ideal for many years and is recommended by many role models in family medicine and primary care.^{1,2}

Another way to look at mutual participation is to see the doctor-patient relationship as a partnership.³ In

terms of this partnership, the doctor and patient share decision making and responsibilities.⁴ In contrast to the mutual participatory model is the activity-passivity model (or non-participation), according to which the clinician gives the instructions and the patient only has to comply.¹

The literature now supports a link between patient participation and improved health outcomes.^{5,6,7,8,9} Laine even argues that, as physicians, we are ethically bound to use this model because of its positive effects on health outcomes.¹⁰ Other concepts that are linked to improved health outcomes are self-care, self-sufficiency and the patients' ability

to take responsibility for their own health care, to participate in health activities and to see themselves as partners in the therapy.^{3,9,11,12} This explains why primary care workers should actively apply mutual participation when working with patients.

I work in a remote health centre in the Greater Tzaneen Municipality of the Limpopo Province of South Africa. I want to share the results of a research project in which I participated in this rural area. I asked four of my regular patients with serious incurable illnesses to participate. The aim of the study was to develop a mutual participatory doctor-patient relationship model, and to learn how

to apply this model in a rural, cross-cultural primary health care setting. I believe the participation model developed and described for patient family groups is transferable and applicable to the doctor-patient relationship. Some of the findings of this study were generated from my reflective diary and are therefore personal. When discussing my personal reflections in reference to current academic literature, I will refer

to myself in the first person. Written consent was obtained from all the participants, as well as from the Research, Ethics and Publications Committee of Medunsa and the Limpopo Provincial Department of Health and Welfare.

METHOD

Participatory action research (PAR) was undertaken with four patient groups. Patients with serious incur-

able illnesses formed groups with their family members, the home-based care worker caring for them and some close friends. Seven meetings with each group were audio recorded over the research period of six months. On the patients' request, the meetings were held in their respective homes and the language spoken was the local vernacular, Tsonga. The question at each meeting was "How the can the group

Table I: Combined list of themes

		Health workers (including the family physician/researcher)	Patient (including family)
P O S I T I V E E F F E C T	T E N E T S	<p>Basic tenets for the family physician: A family physician needs to:</p> <ul style="list-style-type: none"> • Take a holistic view of illness. • Focus on the personal growth and development of the patient. • Understand the personal gains connected to "helping" patients. • Understand the effect of status and education on the relationship between a family physician and his/her patients. 	
	A C T I V I T Y	<ul style="list-style-type: none"> • Maintain relationships. • Confirm and respect the participants' (especially the patient's) values, opinions, actions and abilities. • Provide encouragement and support. • Focus on the patient's responsibility. • Focus on what is possible and what is positive – It gives hope. • Encourage truthfulness, honesty and openness. • Raise awareness about unresolved conflicts and concerns. • Focus on religion, prayer and trust in God. 	<ul style="list-style-type: none"> • The patients expressed their ideas, wishes and plans, asked for explanation and clarification about their own role and asked for opinions, ideas and solutions. • One patient expressed a strong desire to do things for herself. • The ability to take responsibility and make a commitment • The ability to address conflict in the family (reconciliation).
	T E C H N I Q U E S	<p>I, as the researcher, used a number of interviewing techniques to encourage contributions in the meetings:</p> <ul style="list-style-type: none"> • Asked for clarification • Gave reflective summaries • Encouraged the asking of questions • Provided summaries of the previous meetings. <p>Techniques that were specifically important include the following:</p> <ul style="list-style-type: none"> • I motivated and encouraged all participants to participate in the meetings by repeatedly asking about their opinions, ideas, suggestions, plans and solutions. • I acknowledged the pain and gave the patients the opportunity to ventilate their concerns about and experience of the pain. • I gave choices to the patients. • When plans were formulated, I focused on actions, solutions and concrete plans with short-term objectives. • The participation in the group, cooperation and the implementation of plans were negotiated. • Feedback was given about the implementation of action plans. 	
N E G A T I V E	E F F E C T	<ul style="list-style-type: none"> • Ignore cues. • Incongruence. • Nurturing dependence. • Being different. • Being neutral. • Negative feelings. • Blaming the patient. 	<ul style="list-style-type: none"> • Disabled. • Focus on helplessness. • Unwillingness to take responsibility. • Unresolved conflict in the family. • Focus on outside solutions (sometimes unrealistic expectations). • Fixation on the problem. • Blaming another person. • Defensiveness. • Feelings of rejection. • Passive resistance.

work together to achieve the best possible health outcome for the patient?" Each group was encouraged to give ideas on patient management. Action plans were formulated and tried out. Decisions were made after consensus had been reached by the whole group. The transcribed audio recording of each meeting was summarised and themes were identified through the cut-and-paste method on computer. Summaries and identified themes were verified with the individual groups at the following meeting. Minutes were kept by a group member and were read at the beginning of each meeting. Feedback on the effects of the implemented action plans was given during subsequent meetings, and the effect of actions taken was also discussed. The patient's clinical condition was evaluated at each meeting, while the group also discussed the effect of implemented (or non-implemented) action plans on the patient as a whole. I made field notes (generally 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 continued for five meetings. After four meetings it was noticed that very few new themes were generated. What happened, however, was that the same themes were discussed repeatedly, but on a significantly deeper level.

The sixth meeting of each group was a free-attitude focus group interview. The purpose of this interview was to understand the groups' perceptions regarding the effect of the participation process on the patients' health. The results of these interviews, as well as the results from all previous meetings, were validated within the different groups during the seventh meeting.

A reflective diary was kept throughout the research period to record my thoughts on the research meetings. I documented communi-

cations with others about the patients and their illnesses, as well as my thoughts about the concepts and processes relevant to the research topic.

One of the co-researchers (GSF) did three free-attitude interviews with myself as the research facilitator. The purpose of these interviews was to increase awareness about my perceptions regarding participation at different times during the research period.

The data was analysed as follows: The recorded meetings were all transcribed and translated into English from Tsonga. The analysed transcripts of the meetings were used to identify 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 text was specifically searched to identify themes that described action plans and themes describing participation. The participants could only be involved to the level of verifying and elaborating on the summaries and themes from the interviews in their own groups, as further analysis by them was hindered because of literacy and language barriers. Themes from the reflective diary and the three free-attitude interviews were also identified through the cut-and-paste computer method.

The transcribed records of the meetings were then re-analysed to describe the process of each interaction that took place during the different meetings. The descriptions of the interaction processes and themes from the different patient-group meetings were combined with the list of themes from the reflective diary and free-attitude interviews. A combined list of themes was thus created.

The combined list of themes was used to construct a visual schematic model that demonstrates the interrelatedness of the different themes.

The model was interpreted and conclusions were drawn.

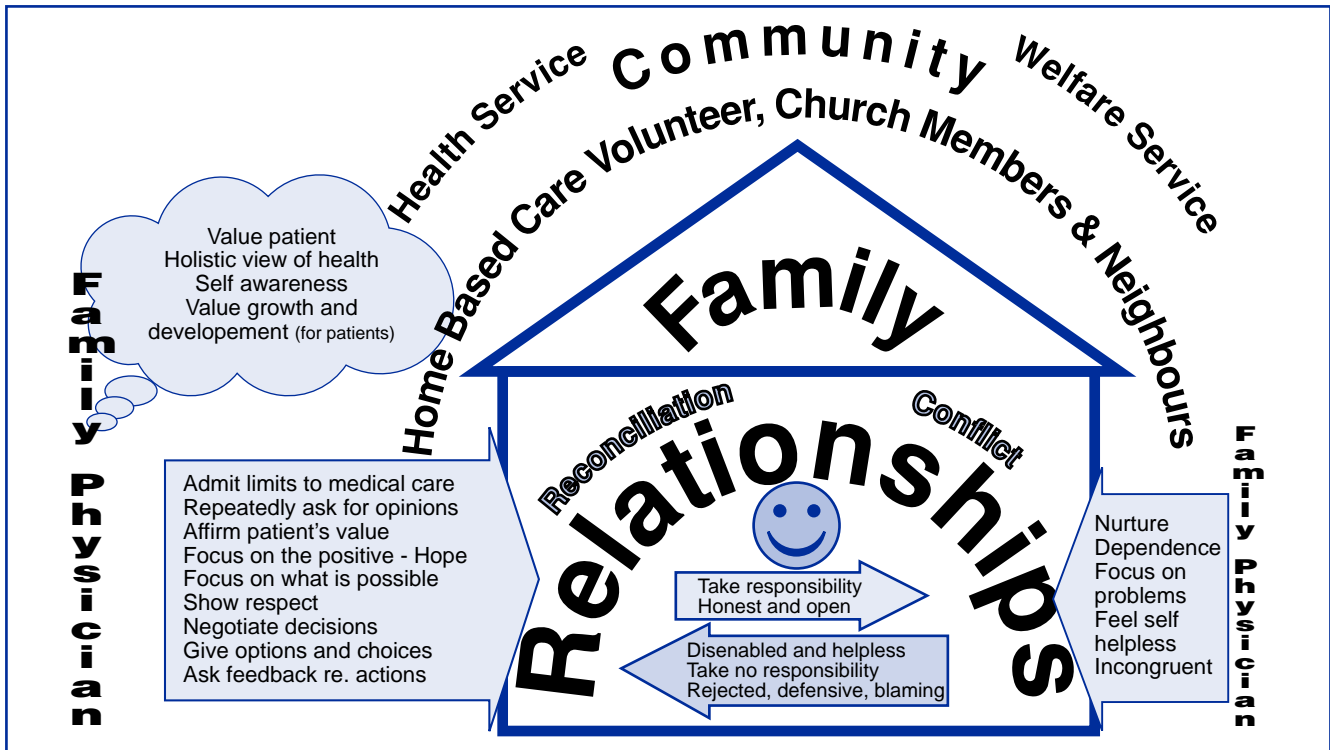
RESULTS

The results are summarised in the combined list of themes presented in Table I. A model of the combined list of themes is depicted in Figure 1, followed by a discussion of the model. The discussion highlights some differences between the findings of this research project and the literature.

The positive effect of supportive relationships and the negative effect of conflict and distrust in relationships on health were suggested by most of the participants. In each group, the patients and family members repeatedly stated that the support visits of the home-based care worker and the support they received during the meetings had a positive effect on their well-being. They repeatedly said "these visits must continue". One family experienced heightened levels of internal conflict and a participant stated: "It is not going well with our sister because there is no peace in this house".

Certain basic tenets emerged that would help the family physician to implement a mutual participation model. The majority of these tenets were identified during the analysis of the reflective diary. One of these tenets is that, when patients' abilities and contributions are respected and valued, a positive effect on their participation and their experience of well-being can be identified. Other important tenets include a preparedness to learn from patients, and being aware that, as health workers, we also benefit from helping patients. It is necessary to have a holistic view of medicine, to be aware of the limitations of Western medicine and to aspire for the personal growth and development of patients. Being aware of the influence of status on the therapeutic relationship helped me to apply the mutual participation

Figure 1: A model of the combined list of themes



model. The health worker's status often comes from his/her knowledge and position within society.

The transcribed manuscripts of the group meeting were reviewed to identify facilitation processes that encouraged participation. Basic interviewing techniques, such as reflection, summaries and giving opportunities to ask questions, were identified as having impacted positively on group participation. From the manuscripts it became clear that participation usually started after the participants had repeatedly been asked for their ideas, opinions, suggestions and plans.

Some of the actions of the caretaker team had a negative effect on the participation and well-being of the patients. Examples of these include ignoring cues from the patient, incongruent actions, nurturing dependence, being different from the patient, a pretence of being neutral, negative feelings towards the patient and blaming the patient. One patient entered into a relationship with a woman against the advice of the group. None of the group were em-

pathetic towards him, and all of them had different views on the matter. Group members blamed him for the decision and the subsequent deterioration of his health. In two of the groups, group members who were not family members took responsibility for providing food for the patients. Those patients became dependent on these contributions, which resulted in the patients themselves and their family members participating less during the discussions.

Active participation by the patient and his/her family, for example giving opinions, taking responsibility and taking action to contribute to their health, contributed to their overall sense of well-being. Open and honest discussion of concerns and unresolved conflict, including attempts to reconcile the issues, also had a positive effect on patients. One patient's daughter described the patient as "stubborn" because she would not allow them to help her. She "wanted to do things for herself". Her ability to walk without support greatly improved over the research

period. In one group, the patient was reported to be better when he became actively involved in visiting other sick people with his friends. In the family mentioned earlier in which conflict was experienced, the patient reported to be better after the eldest sister called the whole family together and discussed the conflict between the patient and other family members. The family meeting took place after this sister honestly admitted that there was conflict in the family. During the last meeting with this group, the participants reported that the patient was better because they had worked together as a group. In three of the groups, participants reported improvements in their sick family members who acted on the groups' recommendations, e.g. attending church services.

Attitudes of rejection, helplessness, being defensive, blaming others for their misfortune and being disenabled had a negative effect on the well-being of patients. The patient who had entered into a relationship against the advice of the group felt rejected after the group confronted

him about his relationship. He reacted by being defensive toward the group and blaming his ex-wife and children, who had subsequently left him, for his misfortunes. He stated he was “unable to do anything for himself”. After this incident, the patient’s condition deteriorated rapidly.

Discussion of Figure 1

The patient is depicted in the home with the family. The small arrow over the patient indicates what the patient and family contribute to enhance the process of participation. The small grey arrow shows what makes participation difficult. The arrows also symbolise the effect on the health of the patient. The untinted arrows symbolise that which improves participation and health, while the grey arrows symbolise that which hampers participation and which is detrimental to health and well-being. Everything that happens to the patient involves relationships. This is a very central theme in the model, as indicated by the size of the letters. Supportive relationships have a positive impact and relationships riddled with conflict have a negative impact on patients. Reconciliation is a way to change a conflictual relationship to a supportive, nurturing one.

The home-based care volunteer, the nurse, church members and neighbours surround the patient and the family. The community at large forms a second circle around the family nucleus. The health and welfare services, of which the family physician forms part, constitute the outer circle. The cloud callout shows the tenets that would help a family physician and other health workers to implement a mutual participation model.

The large arrow on the left displays that which assists the health workers to implement this model. These aspects also have a positive effect on health. The big grey arrow on the right shows that which may hamper the process.

DISCUSSION

Several of the tenets that were mentioned have been also mentioned by other authors. Tervalon and Murray-Gracyia stress the importance of humility and self-critique to redress power imbalances between the doctor and patient¹³. They also feel it is very important for physicians to be aware of the position of power that they have over their patients, especially with regard to the poor and in a cross-cultural setting. Brody states that an increased awareness of the limitations of clinical medicine helps the physician to be less authoritative¹⁴. Illich argues that expanding the role of medicine decreases patient autonomy and that patients consequently become more dependent on medical care.¹⁵

A number of specific techniques were helpful when applying the mutual participatory model. The most striking of these techniques was that I, as the research facilitator, repeatedly asked the participants and patients their opinions. In many instances, the participants initially answered that they had no input to make, but later started to contribute. I came to the conclusion that communication in the rural, disadvantaged society in which the study was performed operates in a circular or spiral pattern and not in a linear manner, as is typical in Western communication. The communication builds as it goes in circles. I found a similar pattern in the development of themes in the different meetings. During most meetings, the same themes were discussed repeatedly, but the depth increased. Joyce Scott describes a similar phenomenon in her book “Tuning in to a different song”, about African worship songs.¹⁶ She describes how African worship songs are mostly repetitive in nature, whereas Western songs concentrate more on content in a linear and non-repetitive way. She believes that the difference between the two paradigms is that Western worship songs

focus mainly on the theological content, whereas African worship songs focus on experiencing the meaningfulness of the song. I found that this description clarifies the differences in communication between people from African and Western cultures. The only way I could attain participation was by repeatedly asking for opinions. I was not able to persuade participants to participate by asking them once. It was as if the participants wanted to be sure I really wanted their participation and truly valued their opinions. Brody makes the point that persistence may be necessary to reassure the patients that their contributions are appreciated and valuable.¹⁴

The techniques to enhance participation described in this study are echoed in other articles. Chewing and Sleath describe how giving choices in treatment options is an important step towards collaboration in the client-centred model.¹¹ Perlmutter and Langer also found that providing choices gives patients a sense of control.¹⁷

A theme that repeatedly emerged was the need to encourage and support patients through compassion and respect. I felt this enabled the patients to participate more fully. The beneficial effect of support has been widely recorded.^{18,19}

I believe the most important aspect from the patients’ perspective is for them to take personal responsibility and commit themselves to participate positively in their own health. Supporting this view, Solomon et al. describe having a sense of responsibility as one of the factors associated with longevity in AIDS patients.⁹ In their “Hardiness in Health” study, Kobasa et al. found commitment to be one of the three basic components of resilience in health.²⁰ Greenfield et al. found that positive participation correlated with good health outcomes.⁶ Solomon et al. found that taking responsibility and the ability to view the physician

as a collaborator were associated with good health outcomes in the patient.⁹

Through the reflective processes of this research, I rediscovered for myself the immense value of an ancient truth, namely the importance of believing in the inherent value of all people (including patients) and respecting them for that. Personally, I feel this is the very essence of the doctor-patient relationship (or any helping relationship). Without this value, any attempt to establish a helping relationship will be futile and hypocritical. To value and respect others should always be possible, even if we work under the most inadequate circumstances. I feel this very essential truth has lost its importance as a result of the technical developments in biomedicine.

It was not easy to implement a mutual participation model in a rural cross-cultural setting in which most patients are disadvantaged, and it required commitment and perseverance from all the members of the team, including myself. Laine¹⁰ and Tervalon and Murray-Garcia¹³ have confirmed the difficulties associated with this process, but also stress its importance. I believe the major difficulty in implementing this model was due to the imbalances in personal power and status.

Ideally, in the process of participatory action research, all participants should be co-researchers and should participate at all levels of the research.²¹ Unfortunately, none of the participants was able to speak or write English. They consequently could not participate in the analysis and documentation of the research. However, those who were able to write participated in collecting data in the vernacular (Tsonga).

CONCLUSION

It is not easy to implement a mutual participation model in a disadvantaged, rural practice, but it is possi-

ble. As family physicians and health workers, we need a paradigm shift in health care: from "helping" patients (which may nurture dependence) towards facilitating the personal growth and development of patients (to nurture self-reliance).

It is important that a mutual participation model should be implemented in daily practice when training undergraduate and postgraduate generalist physicians and other health workers.

ACKNOWLEDGEMENTS

I wish to acknowledge all the co-researchers in this study and thank them for the important role they played. The co-researchers were Prof. GS Fehrsen of the Department of Family Medicine and Primary Care, Medunsa, Prof. JB Schoeman of the Department of Psychology, University of Pretoria, Mrs A Dzimbiri, a home-based care worker from Nkambako Village, Tzaneen, Ms M Manganyi and her family members from Nkambako Village, Mr R Mboweni and his family members from Jopie Village, Tzaneen, Mr MS Masinge and his sister, friends and neighbours from Nkambako Village, and Mrs M Malungana and her family members, also from Nkambako Village.

REFERENCES

1. Christie RJ, Hoffmaster CB. Ethical Issues in Family Medicine. New York: Oxford University Press; 1986. p. 19.
2. McWhinney IR. A Textbook of Family Medicine. New York: Oxford University Press; 1989. p. 118-27.
3. Coulter A. Partnerships or paternalism? *BMJ* 1999;319:719-20.
4. Stewart MA. Healing partnerships between patients and family doctors: an aspect of quality of care. Plenary address presented at WONCA, Dublin; 1998.
5. Biley F. Some determinants that effect patient participation in decision-making about nursing care. *Journal of Advanced Nursing* 1992;17:414-21.
6. Greenfield S, Kaplan S, Ware JE. Expanding patient involvement in care: effects on patient outcomes. *Annals of Internal Medicine* 1985;102:520-8.
7. Kaplan SH, Gandek B, Greenfield S,

- Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style: results from the medical outcomes study. *Medical Care* 1995;33(12):1176-87.
8. Rost KM, Flavin KS, Cole K, McGill JB. Change in metabolic control and functional status after hospitalization: Impact of patient activation intervention in diabetic patients. *Diabetes Care* 1991;14(10):881-9.
9. Solomon GF, Temoshok L, O'Leary A, Zich J. An intensive psychoimmunologic study of long-surviving persons with Aids. *Annals New York Academy of Science* 1987;496:647-55.
10. Laine C. Should physicians discourage patients from playing the sick role? *CMAJ* 1997;157(4):393-4.
11. Chewing B, Sleath B. Medication decision-making and management: a client-centered model. *Soc. Sci. Med* 1996;42(3):389-98.
12. Hagland M. Power to the patient. *Hosp Health Netw* 1996;70(20):24-6.
13. Tervalon M, Murray-Garcia J. Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *J Health Care Poor Underserved* 1998;9(2):117-25.
14. Brody DS. The patient's role in clinical decision-making. *Annals of Internal Medicine* 1980;93(5):718-22.
15. Illich I. Limits to Modern Medicine. 1st ed. London: Marion Boyars; 1976; p. 13-36.
16. Scott J. Tuning in to a different song: Using a music bridge to cross cultural differences. University of Pretoria: The Institute of Missiological and Ecumenical Research. 2000; p. 17-21.
17. Perlmutter LC, Langer EJ. The effects of behavioral monitoring on the perceptions of control. *Clinical Gerontologist* 1982;1:37-43.
18. Fawzy IF, Fawzy NW, Hyun CS, Elashoff R, Guthrie D, Fahey JL, Morton DL. Malignant melanoma: effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Arch Gen Psychiatry* 1992;50:681-9.
19. Nudes JA, Raymond SJ, Nicholas PK, Leuner JD, Webster A. Social support, quality of life, immune function and health in persons with HIV. *J Holist Nurs* 1995;13(2):174-98.
20. Kobasa SC, Maddi SR, Puccetti MC. Personality and exercise as buffers in the stress-illness relationship. *J Behav Med* 1982;5:391-404.
21. Macaulay AC, Commanda LE, Freeman W, Gibson N, McCabe ML, Robbins CM, Twohig PL. Participatory research maximises community and lay involvement. *BMJ* 1999;319(7212):774-8.