

MUTUAL PARTICIPATION IN THE HEALTH WORKER-PATIENT RELATIONSHIP

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ABSTRACT

The importance of a mutual participatory model in medical care and decision making is supported by literature that now shows a link between patient participation and an improved health outcome. Illness (and the sick role) constitutes a state of diminished autonomy and mutual participation may help patients to regain control.

Patients who participate most frequently are under 65 but above 30 years old, are better educated, have a higher income and profession and a higher socioeconomic status. Patients are keener to participate in decision making when more serious illnesses are present and when they have had prior experiences with a serious illness. They participate more fully if they feel that they are well enough, have enough knowledge and are allowed to participate. Patients are able to participate to a greater extent when they see themselves as experts in experiencing the illness. It is therefore important to encourage active participation by those patients who are less likely to participate.

It is important for health workers to have at least the following personal values and skills, which will enable them to encourage and foster active participation: humility, the ability to relinquish the role of the expert, an awareness of their position of power and the ability to value even the poor are needed to set the scene for participation.

It is important that health workers acknowledge the patients' right to self-determination and autonomy. Empathic listening, unconditional positive regard, sensitivity for the patients and their values and an ability to tolerate ambiguity create an atmosphere conducive to mutual participation.

When health workers become aware of differences in opinion or in the balance of power, this should be acknowledged and discussed and a mutual understanding should be negotiated. Health workers have the potential to manipulate "mutual decision making" with the information they give. It is therefore essential to be open and honest about biases and opinions.

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Introduction

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

In the 1980s, health policy in many countries was strongly influenced by the promotion of consumerism as part of the market ideology.

The problem with consumerism was that it encouraged people to make demands, but failed to emphasise reciprocal responsibilities. Because of a growing awareness of this deficiency, partnership (mutuality) has largely replaced consumerism. The mutual participation model is built on a relationship in which the physician and patient work together, take joint responsibility and decide jointly.³

Different terms are used in the articles reviewed here for the physician and the patient. The physician could also be called a doctor. Those authors who aim at an audience larger than physicians also use the

term health workers or health providers. Some authors use the term clients interchangeably with patients. I believe that the term *client* belongs to consumerism and the term *patient* would fit the partnership paradigm better. I also feel that the term *health worker* is more inclusive, considering that, in the environment in which I work, there is no absolute distinction between the duties of doctors and those of nurse clinicians in primary care. The concept of mutual participation is relevant for all of us who are part of the primary health care team. For the sake of simplicity I have predominantly used the terms

patient and health worker in this article.

Mutual participation is not easy to achieve, particularly for those of us who work with patients from different backgrounds and cultures to those of ourselves. Giving more autonomy to the patient is the basis of the "Batho Pele" principles of our present public service system. I tried to answer the question of how best to develop a mutual participatory relationship with my patients through a search of the available literature on the topic. Articles coming to similar conclusions as those of myself in this paper have been published before.^{4,5} The focus has been mainly on shared assessment and management. Mutual participation reaches wider than shared decision making and also involves mutual understanding, not only of the problem, but also of its context and the impact of the problem on the patient's life.⁶ A mutual participatory relationship has to start before the consultation and requires a number of prerequisite tenets in a health worker. I will make an attempt to focus on these as well. I also looked for information that would be relevant to my own practice, which is based in a developing, rural South African and cross-cultural setting.

Method of literature search

Searches were done on Pubmed (Medline), Ebscomed, BMJ, the African Health Anthology and Hans Snijkers Institute databases, and included articles from the past 10 years. The following key words were used: Mutual participation in the physician-patient relationship, participation in decision making, doctor-patient partnerships and alliances, patient involvement in medical care and shared responsibility in medical care. The Pubmed Database was also searched for German, French and Spanish references. The relevant articles were selected and the abstracts were studied. Related articles were also checked for other relevant material, the references of the most relevant articles were reviewed and relevant articles were selected. Arti-

cles that could be obtained through the Medunsa Library, both from journals that were available locally and through interlibrary loans, were reviewed.

Ideas from the literature

It has been argued that illness (and the sick role) is a state of diminished autonomy.^{5,7,8,9} From this it can be concluded that the role of the health worker is essentially to support and encourage the patient until his/her autonomy is restored. Voltaire said that the role of the physician is to keep the patient amused until he gets better by himself. Participation in decision making is essentially implicated in the principle of autonomy. The responsibility for choice lies with the patient. The patient's choices should be encouraged and respected, as these choices are manifestations of the patient's autonomy.¹⁰ If a patient wishes not to participate, his/her wish should be respected. Communicating such a wish is in essence participation.

Another way to look at mutual participation is to view it as a partnership.³ Partners work together to achieve a common goal. Their relationship is based on mutual respect for each other's abilities and they recognise the benefits of their partnership. They share decision making and responsibilities. The key to successful health worker-patient partnerships is therefore to recognise that patients are also experts in their experience of their illness.⁶

It is helpful if health workers are well informed about the condition and the treatment options, but it should be kept in mind that the patient knows his/her own experience of illness, social circumstances, habits and behaviour, attitudes to risk, values and preferences.^{6,11} The new emphasis is on self-help, shared information, shared evaluation, shared decision making, and shared responsibilities. This requires health workers to be informed about treatment options and outcomes and the limitations of medical care. Elwyn *et al.*⁴ suggest the following steps to achieve shared decision making:

understand the patient's context, elicit the patient's preferences, transfer technical information, help the patient to weigh risks versus benefits of treatment options and share the treatment recommendation with the patient or affirm the patient's choice.

Moira Stewart describes this "healing partnership" very well: The first step to such a partnership is through listening. People who believe that they are being heard become better sooner. Other aspects of the relationship include caring, empathy, support and compassion. Trust and control are also vital. A healing partnership involves the following process: "Listening, trust, willingness to change, skills that finally lead to the power (for patients) to take control over their own lives". The last step is the finding of common ground. She believes that mutual goal setting is essential in the empowerment process. The empowerment process has the following steps: "Trust, connecting, caring, mutual knowing and mutual caring".¹²

The literature supports some link between patient participation and an improved health outcome.¹²⁻¹⁹ It is argued that an improved health outcome and participation are linked by a sense of control.^{12,18,20,21} This being true, we are bound to encourage active patient participation and to discourage patients from taking on the sick role for longer than necessary if we have their best interests at heart.²² The participation of patients in their own care is a better process indicator of a successful outcome than patient satisfaction.¹⁹

I would like to discuss two randomised control trials done on the effect of patient involvement in care. The first article is by Greenfield *et al.*, who trained one group of patients in information-seeking skills, while a control group had a training session on information about their illness.¹⁴ They found that the patients from the experimental group had significantly fewer physical and role limitations after six to eight weeks. It was therefore postulated that there is an association between better

interpersonal patient-physician interaction and an improved health outcome.

Rost *et al.* did a randomised controlled trial on diabetic patients.¹⁷ The study showed that an intervention to improve physician-patient communication improved the patients' participation in their medical care and, with it, their functional status. The intervention included a session during which a nurse demonstrated to the patients the advantages of participation, as well as skills to improve communication, seek information and ask questions. The fact that this study is a carefully done randomised controlled trial improves its reliability.

To conclude the argument that mutual participation improves outcome, I wish to refer to a systemic review article. Guadagnoli and Ward investigated whether patients want to participate in decision making and what the benefits of patient participation are.¹⁵ They reviewed 14 studies about patient desires concerning participation in decision making and concluded that it seems as if patients (are more likely to) want to be involved in decision making if they have sufficient information. They did not come to any conclusion regarding the benefit of patient participation in decision making. Fifteen studies were reviewed: nine indicated a better outcome of medical care with patient participation and the other six showed no significant difference. However, they felt that no conclusion could be drawn on the issue because of methodological flaws in the studies. The authors stated that they believed patient participation was justified on humane grounds alone and that it was in line with the patient's right to self-determination. They also accept the fact that some patients are not ready for participation in decision making.

Mutual participation has the potential to help us to deal with patients who are dependent and who do not want autonomy.²³ When the patient takes on the sick role, he seeks assistance from a person he believes might help him. A mutual participa-

tory relationship implies give and take from both sides. A mutually agreeable plan of action should be developed. The same principles are relevant for dependent patients. The health worker must show his/her concern. If the health worker develops negative feelings towards the patient, these must be discussed. Powers suggests that a mutually agreeable follow-up plan (specific regular appointments) should be negotiated.²³ Such a long-term relationship has the potential for satisfaction for both patient and health worker. The patient may be reassured and get medical and psychological support, while the health worker will be more effective and burnout will be prevented.

To be able to encourage and foster active participation, the health worker should have certain personal values: humility, the ability to relinquish the role of the expert, an awareness of his/her position of power, the ability to value even the poor, self-awareness and a commitment to self-criticism are needed to set the scene for participation. Cultural humility incorporates a lifelong commitment to self-evaluation and self-criticism, and to redressing the power imbalances in the patient-health worker dynamic. Self-reflection and patient-focused interaction are essential parts of becoming effective partners with the community.²⁴ Honesty, openness and integrity are basic ingredients of a mutually participatory relationship.²⁵⁻²⁷ Humaneness, empathy and compassion with patients also foster participation.^{8,12,21,28,29,30} As Rogers puts it, the starting point for such a participatory relationship is empathy, congruence and an unconditional positive regard.³¹ Mutual trust and respect between the health worker and patient are essential for a mutual participatory relationship.^{6,12,16,28,29,30,32-34} The health worker should also acknowledge the patient's right to self-determination and autonomy.^{10,15}

Factors that maintain the imbalance of power between health worker and patient make it difficult to achieve mutual participation in de-

cision making. These include a lack of maturity, skills, knowledge, training and time in the health worker, psychological barriers from the patient, as well as the belief that more information may make the patients more anxious or the perception that the health workers are urging them to participate out of uncertainty. Health workers may fear loss of control in the relationship. The social gap between health worker and patient may also be a contributing factor.^{4,5} Differences in opinion or power should be acknowledged and discussed and a mutual understanding should be negotiated.^{5,23,24,27,29,35} Participation is frequently problematic in a cross-cultural setting. The lack of awareness and sensitivity to cultural values increases the social difference and breaks down communication between patients and health workers.²⁸ It would be helpful for health workers to be aware that they could potentially manipulate the "mutual decision making" with the information that they give. To curb this danger, it is essential to be open and honest about their own biases and opinions.^{27, 36}

Patients who participate most frequently were found to be younger than 65 but older than 30, better educated, with a higher income and profession and a higher socioeconomic status.^{16,20,37,38} According to Biley, patients participate more readily if they feel that they are well enough, have enough knowledge and are allowed to participate.¹³ In a study by Barry and Henderson, patients were found to be more likely to participate if they believed that their expertise was relevant to the decision.³⁹ They were more likely to participate when things were getting worse. Health workers were also more likely to follow a patient-centred approach when patients had a chronic condition. Chewing and Sleath found that, when patients saw themselves as experts in experiencing the illness or if they perceived that their expertise was relevant, they felt more able to participate.²⁰ This knowledge should encourage us to pursue active participation,

especially with those patients who are less likely to participate.^{16,22,33,37}

Self-care, self-sufficiency and the ability of a patient to take some responsibility for his/her own health care, take part in health activities and to take the role of a partner in the therapy are essential in mutual participation.^{6,18,20,29,40-42}

Solomon et al. related similar issues with regard to longevity in AIDS patients.¹⁸ They found that seeing the physician as a collaborator, having a sense of personal responsibility, a commitment, a sense of meaning and purpose in life and in the disease itself, with prior mastering of a life-threatening situation as well as engaging in an exercise programme, were strongly associated with better health outcomes. This is in contrast to patients with poor outcomes, who were found to be passive, appeasing, helpless and focussed on others for help and had unexpressed emotions. Although the above are not clearly defined as participation in the consultation, it is evident that active participation from the patients' perspective is similar to these findings.

Conclusion

The literature supports a notion that there is some association with an improved health outcome in a mutually participatory health worker-patient relationship. As we are ethically bound to give our patients the treatment with the best outcome, we are also bound to use this model in the consultation. As health workers, we have to make a special effort to encourage patients who are likely to participate poorly to be more active. In order to achieve this, we may need to learn to be humble, relinquish our role as experts, value even the poorest in our communities, negotiate differences and be aware of our own positions of power and our potential to manipulate the relationship.

Competing interests

None declared

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