

## **Patient directed research in a South African setting: what does it comprise?**

### **Examples from HIV/AIDS and IDDM research**

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*De deelname van patiënten aan gezondheidsonderzoek is tegenwoordig de kern van een beleidsdocument in Zuid Afrika. Het vermogen van de patiënt om als een autonome participant in deze context te handelen is ingegeven door andere factoren zoals de vraag naar rechtvaardige verdeling, de behoeften van de gemeenschap en de betrokkenheid van anderen die met ziekte te maken hebben, zoals de verzorgers. Dit paper bediscussieert de implicaties van de focus op het patiëntenperspectief in relatie tot de vraag naar een meer allesomvattend gezondheidsonderzoek in dit land. Voorbeelden van onderzoek met mensen met HIV/AIDS en IDDM worden gebruikt om enkele urgente vragen met betrekking tot het debat over de betrokkenheid van patiënten te begrijpen vanuit een Zuid-Afrikaans perspectief.*

*[patiënt, perspectief, autonomie, onderzoek, rechtvaardige verdeling, participatie]*

*All animals are equal, but some animals are more equal.*  
(Orwell 1945: 79)

The right of patients<sup>1</sup> or clients to have a voice in decisions concerning their treatment is increasingly accepted in many parts of the world. This emphasis on the patients' perspectives is closely related to the acknowledgement of their right of access to good quality care and to play a watchdog role concerning health services rendered to them. In a paper titled, *De patiënt als medeonderzoeker. Van vraaggestuurde zorg naar vraaggestuurd onderzoek*, Blume and Catshoek (2003) raise the issue of patient participation and of soliciting patients' views and input in health research. It is an approach that emphasizes patients' autonomy, rights and empowerment and, by extension, their participation as research partners rather than as study objects. Yet, as in the case of Orwell's *Animal Farm* (1945), while all patients are assumedly autonomously self determining, have the right to health care, and should be able to make their views known in relation to research, some are in actuality more 'autonomous', have more rights and are more able to fully participate as partners in research than others.

The aim of this paper is to problematize some of the issues discussed by Catshoek and Blume (2003) concerning patient participation in health research. The authors reiterate the well-known fact that patients and health care providers often view illness and health care differently. It is accordingly imperative that studies on illness, health and health care should find ways to recognize the perspective of the patients or consumers.

Unlike the medical sciences, medical anthropology has a long history of approaching both health and illness from the perspective of the patient or the sufferer (Blume and Catshoek 2003). Such studies were located amongst people of European and non-European descent and gave attention to the meanings they attached to their illness themselves, their related beliefs and practices (cf. Mattingly & Garro 2000; Farmer 1999; Pool 1994; Kleinman 1988). In this kind of research the anthropologists themselves usually broadly set the aims and main research questions, although these often changed during the research process. Efforts were made to get insight into the sufferer's own understanding and experience of health and illness. This was done through observation, the use of personal narratives, phenomenological narratives, case studies, life histories, semi-structured and unstructured interviews and such. Medical anthropologists often tried to make the main findings accessible to the respondents by giving them the final documents to read and comment upon. If the participants were not literate, workshops, meetings and discussions about the research results were often used to get some feedback from them. While such approaches often called the respondents 'participants' they nevertheless involved big differences in power between researcher and researched. Researchers usually set the agenda for studies and ultimately analysed and published the results.

For the purposes of discussing the inclusion of patients' perceptions or views in and through research, Blume and Catshoek (2003) approach the patient or consumer-as-participant as reasonably autonomous, and they link this aspect to empowerment. It seems that the above are more successfully promoted where organized bodies of shared interest, such as patient organizations, exist and can speak on the behalf of members and fellow afflicted. In this way the concerns of patients suffering from a similar condition can be politicised through advocacy. Yet, it is also problematic to group people together on the basis of their illness condition (ibid). This is because illness experience can be quite diverse and individualistic.

At the same time, patients' autonomy and the ability to exercise their rights might often be more assumed than real – for example in the case of migrants in European countries, like the Netherlands (cf. Vulpiani et al. 2000), or state patients in resource poor non-European countries (cf. Polu & Whiteside 2004). In some cultural settings all patients do not necessarily act as individuals in relation to decisions concerning their own health. Patients also do not all have equal access to, or a voice in, patient organizations. The ability of such organizations to lobby for patients' interests and rights might equally depend on the extent to which the condition or illness they focus on is regarded as important, funded, politicised and publicized.

Patient autonomy is thus an ambiguous and complex matter. As indicated above, one way to understand patient autonomy is as a part of empowerment (see Blume & Catshoek 2003: 186-187). This link is also implied in related policy documents in

the South African setting. One example is the Patient Right's Charter (1995), which provides a broad framework for patient participation and choice in health care and policymaking.

The Charter nevertheless states in the preamble that it is subject to the "financial means of the country", and it is mostly concerned with the right to access to good and equitable health services and treatment. It also emphasizes the necessity of patient (or client) participation and views in research. Yet the notion of patient autonomy is ambiguous. While researchers or policy makers can approach the patient as an autonomous participant, to do so, might imply viewing him or her in a decontextualized way.

As indicated above, in South Africa the issue of individual rights and autonomy of the patient intersects with other factors and, by reading documents closely, it becomes apparent that in spite of all the rhetoric, all patients are not equally autonomous in reality. The wider concern with equity, for instance, is an extension of the fact that not all will necessarily have the same autonomy to decide on issues related to their health or illness. This is so because health concerns that are taken for granted in, for example the Netherlands, such as adequate potable water, sanitation, waste disposal and air quality does not apply equally to all in South Africa. People may in theory have an autonomous right to the above, but it does not mean that they can actually access it or exercise this right. The lens of the patient's perspective is accordingly bifurcated by other factors.

AIDS activism and debates about health and access to health resources, as well as care for insulin dependent diabetes mellitus (IDDM) sufferers, highlight the complexity of the notion of patient autonomy, rights and voice in research. By drawing on two examples involving patients suffering from chronic diseases, i.e. HIV/AIDS and IDDM, I will show how notions and practices of patients' perspectives and participation can be restricted. Attention will be given to a variety of factors that impinge on and intersect with the issue of patient autonomy and the inclusion of the patients' viewpoint. Finally, reference is made to recent debates and proposals concerning the involvement of patients, clients and other stakeholders in health research in South Africa.

### **Patient autonomy, rights and participation in research**

As in the Netherlands, patient rights are increasingly stressed in South Africa, particularly for clients of state health services. These people either do not have access to medical schemes or their schemes are inadequate. As a result they are dependent on public health facilities and services. State patients are encouraged to become familiar with and insist on the rights contained in the Patient Rights' Charter (1995). It provides a broad framework for patient participation and choice in health care and policymaking. This document also provides for the involvement of patients in the setting up of research projects, establishing research goals and in participation in the research process itself. Ultimately it is concerned with the right to access to good and equitable health services and treatment. The inclusion of the patients (or clients), their input and views in research is implied in this.

According to a document, Health Research Policy in South Africa 2001, research is a scarce resource that should be shared equitably. The policy document was influenced by the enormous increase in research concerning almost every issue related to HIV and AIDS. A growing concern was that, despite the vast amount of research, very few of the results seemed to reach or benefit the general population.

The main concern of this policy document is with equity. To draw up the document the government tried to involve as many stakeholders as possible in the process of research and policy development. This is part of the State's effort to be transparent in governance and the surrounding processes. Before new policies are designed or Bills tabled in parliament the Parliamentary Health Portfolio Committee advertises and asks for individual as well as group-, interest- and institutional submissions to be provided, for discussion at public hearings. Submissions can be made orally or in writing. A wide array of individuals and groupings often attend the discussions. Patients give often deeply personal testimony of their own experiences of suffering while support groups, non-governmental organisations and institutions submit comprehensive submissions based on extensive research and aimed at policy changes. In this way an effort is made to involve a much broader base of the population in establishing foci, concerns and aims for future action and guidelines. When a policy document has been completed, it is made public for similar scrutiny and input.

The research policy document (2001) stresses that the views and experience of patients and other stakeholders must be actively sought and the ability to conduct research should equally be shared. Thus, research should involve efforts to develop the research capacity of members of the researched community, that is the patients and their families, and especially of the poor and of women. The researched community is supposed to be a partner in problem definition, research implementation, analysis and the allocation of funding for particular aspects of research. To do this, researchers are expected not only to involve patients as researchers, but also train them to do research, to analyse, monitor and evaluate the results in conjunction with other stakeholders. Research results also have to be disseminated in a way that can be understood by patients and should, whenever possible, be implemented.

The ultimate aim of the policy document is genuine participation for all stakeholders and to give not only patients, but also wider communities or clients concerned, the ability to participate in the planning of research projects, in doing it, analysing it and participating in the dissemination of results and the implementation of recommendations.

This is however a far more complex issue than it seems and will be discussed later in the paper. In the next section I will focus on how notions of autonomy, rights and patient involvement relate to the case of HIV/AIDS and antiretroviral research in South Africa.

#### *Case 1: HIV/AIDS and Anti-retrovirals*

Efforts to approach patients as autonomous research participants in studies on different aspects of antiretrovirals (ARV), medical, cultural and social, are complicated by a number of other issues. In this regard Herman (2003: 1) argues that for medical practi-

tioners in research, patient autonomy, and by extension treating the patient as autonomous research partner or participant in a medical setting, closely intersects with ethical requirements. These include the expectation that professionals should first do good and secondly should not do harm. A third component now involves the equitable allocation of resources, including research, without discrimination. The final aspect is that patients are entitled to the best possible treatment and should try to insist on it.

Many anthropological studies in South Africa have given attention to socio-cultural issues that impact on the ways in which people understand and experience HIV/AIDS, for example as inevitable and thus to be shared as a distorted form of *ubuntu*, as the result of witchcraft, as something that infects the 'other' and even concerning beliefs that intercourse with a virgin can cure AIDS. Some studies also focus on the possible involvement of traditional healers in preventing HIV infection (cf. Leclerc-Madlala 2002). Others include historical political factors in their analyses (Epstein 2003). The way in which different aspects are brought into focus in particular ways in different settings was highlighted in the ARV debate and related studies (Fassin & Schneider 2003; Schneider & Fassin 2002; Seidman 1999).

Unlike the studies with a focus on the individual in a group context as above, activism by patient organizations and NGO's such as Treatment Action Campaign (TAC) concerning access to ARV's and the most current related research results emphasized patient autonomy, i.e. the need to exercise the rights and choice of individual patients. Such rights involve patient participation in any process concerning health care, including research. This approach was strongly juxtaposed, for example, against wider concerns by some government health professionals, in research and implementation. They were equally worried about the long-term safety, negative effects, the possibility of the development of drug-resistant strains, and the affordability and sustainability of such a course of action (Fassin & Schneider 2003).

Assumptions about patient autonomy in TAC campaigns always strongly focused on concern for distributive justice, because HIV-positive members of medical aid schemes have had access to ARV's, while the poor, who makes up the majority of the population, did not. Thus, the emphasis of the Treatment Action Campaign was on patient autonomy and justice, while the concern of the government, even in research, was more with non-maleficence and beneficence. These issues inevitably tinted whatever lens was adopted to examine and analyse research concerning HIV/AIDS and antiretrovirals in South Africa.

In this regard the issue of equity was especially vexing as is demonstrated that the assumption of patient autonomy was often largely hypothetical. This concern can equally be of import elsewhere, for example in many developing countries, where most of the HIV-infected people are to be found. Here the ongoing dilemma of the cost, the ability to distribute and provide antiretroviral treatments effectively, given limited health sector budget allocations, might decrease equity and justice not only in research but also in practice.

As in South Africa resources are stretched to the utmost limit and there is a constant need in the public health sector to balance the individual's autonomous ability to exercise the right to treatment and participation with the responsibility of physicians and

policy-makers to protect public health (Herman 2003). The WHO and UNAIDS Guidance Modules on Antiretroviral Treatments (1998) also give specific attention to the concerns regarding cost, accessibility, and the need to balance demand for antiretroviral drugs with the cost-effectiveness of other care and prevention interventions. Thus patients' autonomy and their perspective in practice and in research are placed within the wider frame of the community and society.

By contrast HIV/AIDS activists have asserted the right of all HIV-infected people to have access to antiretrovirals and the results of related studies. In relation to HIV/AIDS research, besides autonomy, there is the contingent issue of the right to confidentiality. According to Herman (2003: 1):

These two aspects place the right of autonomy above the public good and have resulted in restrictions in the use of traditional public health approaches, such as surveillance, in managing the HIV/AIDS epidemic. Advances in the management of electronically collected and stored data have redefined the individual as a data set, causing a fundamental rethinking of the principles of confidentiality and informed consent.

A way out of this paradox has not yet been found. In the interim Herman (2003) stresses that vulnerable groups, including women, children, the elderly and prisoners should have access to antiretrovirals and must, by extension, be included in research, its planning, execution, results and its subsequent implementation. Yet, if they are vulnerable, their autonomous choice to participate can also not be taken as self-evident.

It is too early to measure the impact of the Government's recently announced policy on ARV availability, but until November 2003 the largest such programme, funded by Medicine Sans Frontiers (MSF), was for 1,200 indigent public sector out-patients in the Western Cape. All of them had to be willing to publicly declare their HIV status. This prerequisite was intended to raise awareness of the virus in the surrounding community, yet it can also potentially impact negatively on the willingness of patient to participate in research. This approach also raises issues of confidentiality as indicated by Herman (2003: 1) above.

#### *Case 2: People with advanced IDDM from disadvantaged areas in Cape Town*

The second case I want to use to illustrate the complexity of autonomy, rights and patient participation in research, involves my own studies on people with advanced IDDM. In 1993-1994 I conducted fieldwork in the medical wards of a tertiary teaching hospital in Cape Town, as part of a multi-disciplinary team conducting a 'Level of Care Intervention Study'. The aim of the study was to individualise patient treatment without affecting the quality of care. It was the first time an anthropologist was allowed to participate in a study within a tertiary health institution. Since then studies have been done in community health facilities, but not within the wards of a teaching hospital. In this regard the study was and remains unique. The research was driven by a protocol designed by a multi-disciplinary team that included medical, nursing and human resources professionals from the tertiary hospital as well as the Medical Research Council of South Africa (MRC).

The study itself and its approach to patients was in a very positivist manner constructed as a neutral objective process to find and document the true facts as 'discovered' in the research setting. Patients were included, but not as research partners. They gave consent to being respondents in the study, rather than to truly participating in it. The vast majority of the patients were unable to afford medical aid and were state patients. They were mostly black and Afrikaans or Xhosa speaking. I used an interpreter in my interaction with the latter. The racial, economical and gender make-up of the patients on the ward were very similar to what is today.

In the course of nine months I spent almost every day on the medical wards and interviewed hundreds of patients. During this period I became intensely aware of the way in which the production of knowledge through research was constructed by the rest of the medical research team. According to Lett (1997: 3) scientific epistemology assumes that knowledge is objective, absolute, based on extensive, empirically generated, verifiable evidence and facts generated through certain proscribed procedures, logically analysed and which can be tested and replicated. In turn, "the goal of scientific inquiry is to produce causal explanations that are predictive" (Lett 1997: 3). This was also the trend with the LOCIS research above.

I interviewed patients about the quality of care they received, whether they understood what the doctors and nurses were telling them, whether they had given informed consent to their treatment and, because of my own interest, how they themselves understood their condition of ill health. As I was not a health professional the patients soon realised that I had little power on the wards and this had a positive effect on their willingness to share confidences. At the same time there were many other 'realities' on the wards that this kind of study could not even begin to disentangle. Because I spent so many months on the wards I started to grasp at least four important issues related to research involving patients. These included the patient's own narratives and experience of illness and its meanings, the role of the family, the impact of the institution itself and the influence of wider socio-economic circumstances on the understanding and experience of the patient and his or her family. Yet, for the purposes of the LOCIS project, I 'translated' patients' perspectives through the lens of the study itself – not from the perspective of the patients.

In 1997/98 I decided to examine health, illness and the interface with the health care services from the point of view of IDDM patients themselves. This research was finally completed in 2000. I was able to trace 30 of the people who had been patients in the medical wards during the previous research at the teaching hospital. They were all black state patients and spoke either Afrikaans or English well enough for me not to have to use an interpreter. All the participants suffered from advanced chronic illness and complications as a result of IDDM.

The research funding that I could access the time would have bound me to a study where I had to set out the aims and main research questions to suit the larger agenda of the funders. Potential funders saw the fact that I wished to give the participants and myself more freedom to engage with issues they themselves regarded as important, as highly problematic and unscientific. I decided to not seek funding for the research, and began a long and protracted process to design a study guided by the patients, and their

families. Because of their poor health and economic circumstances it was not possible to engage all in discussions at the same time. I subsequently became involved in very time consuming interactions with each family. This concerned the research aims and questions which I then related it to the opinions and needs of all involved. During my initial research and subsequent discussions with the participants it became clear that they wished to give attention to their own understanding of their ill health, the meanings they attached to it and their embodied experience of their condition. Thus I spent long periods of time with the acutely chronically ill patients and their families in five institutional settings while they engaged with the health care system. In this process the patients became more like participants. To avoid confusion I nevertheless continue to call them patients in the remainder of this text.

From my first research interface with these people I was already aware that the experience of advanced and debilitating chronic illness did not only involve their own subjective experiences, but was equally clinically, economically and socially encountered. An important focus, guided largely by the occurrences in the lives of the patients and their families, was their encounter with the health care system. They interacted frequently with the health services and wished me to try to bring some understanding and coherence to this process, which was often very fragmented for them. To do so I had to also look at wider social, economic and political factors that impacted on their access to the health services and their experience of it (Gibson 2001).

As the patients often had recurrent incidents of hypoglycaemia, they were frequently hospitalised and they interacted with health care givers and the health care system at multiple levels. Patient understanding and experience was accordingly also informed by their interface with institutionalised health care. For this reason the understanding of the health care practitioners was also important.

I conducted semi-structured interviews with 10 doctors and 10 nurses at the different facilities to which patients had been referred. I did not have access to patient records but I discussed the diagnoses of patients with health care professionals, with the permission of the patients concerned and of their families. As I spent time with the sick people when they used the health care services it became clear that I could make better sense of it by incorporating the views of the family, and especially of the family caregivers into such an effort of understanding.

I learned about the complex symbolic meanings attached to having 'sugar' or a surfeit of sweetness in a cultural setting where commensality had deep social and familial connotations and represented not only the sharing of sustenance but also of fellowship, support, hospitality and caring. IDDM sufferers told that having to refrain from eating certain foods was experienced as exclusion. With the participants I tried to negotiate an understanding of the linkage between sweetness and bitterness and its wider social connotations of being part of a necessity to balance the bitter and sweet aspects of life, of forced removals, state, neighbourhood, family violence and ongoing physical need with laughter, humour and the 'realities of life'. Ultimately this study highlighted the unpredictability and lack of control I as a researcher had over the way in which the study progressed. Six of patients involved in the study died during the time of research and, like their families, I had to increasingly consider mortality and learn to deal with it.



From being a researcher I became a mourner. I could not simply withdraw from the families because my main participants had died. Like the survivors, I had to turn from looking at health and health care to also grapple with dying and death.

The issue of patient autonomy was particularly complicated in different settings. This was especially the case with the male patients. Their encounter with illness greatly impacted on the lives of their wives or daughters. At the same time socio-economic and political issues affected the family as a whole. Caregivers struggled to make ends meet, and their lives were constrained by and focused on the wellness and illness of the patients. Patients' agency and participation in the research waxed and waned according to their health condition. Although I could 'stitch' together a patient narrative of illness and a patient view, this was always a partial understanding. I had to include the narrative and experience of the family health caregivers, who were extremely alert to the bodies of the patients, and yet could not always influence their behaviour. The illness was theirs as much as that of the patient and the caregivers experienced the suffering deeply. When a patient's condition deteriorated, they had to rush him to the hospital, where staff scolded them as if they were directly responsible. Afterwards patients and caregivers often spent most of their days at the hospital. Because of the ill health of a spouse the women could not work. Accordingly the health or ill health of each patient was as much the concern of their wives, daughters or daughters-in-law. These caregivers collected the medication and saw that it was properly administered, bought the food, cooked the 'correct' meals, saw to it that the patient ate at the correct times and watched the sufferers closely for signs of change in their physical or emotional condition. Their lives were hemmed in by the patient's dependence (Gibson 2000).

Socio-economic circumstances also exerted a considerable influence on patient autonomy in other ways. They could not equally participate in society because many of them lost limbs as a result of advanced diabetes and they lacked mobility. If they were fortunate enough to have access to a wheelchair, the roads were often untarred or there were no proper pavements. The simple act of getting to and from the health facility was a huge undertaking. Taxis were expensive and did not always operate on a route going past their houses. They could call an ambulance, but these were often tied up with more acute emergencies.

Whatever agency they or even their family may have had – it was frequently diminished by their encounter with the public health system. Even health care givers themselves were forced to deal with the lack of own choice they sometimes faced in the treatment of patients when the coping ability of the system was acutely strained. This often destroyed any semblance of equity or of individual choice. Whereas the debate about patient participation is often largely intellectual, harsh conditions and the reality of poverty and lack of funds meant many shifts in what we might call autonomy.

Yet, unlike the case of HIV sufferers who will in the future have access to antiretrovirals, there has been little improvement in the situation for state patients with IDDM. While the human right to antiretrovirals can become a reality, the (lack of) rights of very ill IDDM sufferers to have kidney dialysis has remained unchallenged.<sup>2</sup> This, in turn, affects their ability to participate not only in research, but also in wider society. Thus ultimately not all patients with chronic illness were equally autonomous.

The current question in South Africa is ultimately how to achieve equity in research, while also including the patient and other stakeholders. In the last section I will examine possible issues to for the future in this regard.

### **Concluding issues for future consideration**

In this paper I tried to show that patient autonomy is a complex issue that can be influenced by local socio-economical and political factors. In South Africa these aspects can also impact on the quality of the care they receive. As a result of scarce resources health service providers always have to weigh the needs and rights of individuals against that of wider society. Thus the notion of the patient as autonomous participant might not always hold true. This trend can nevertheless shift when patient organizations and NGO's succeed in politicising and publicising the cause of particular patients, as was the case with HIV/AIDS and the claim of access to antiretrovirals. It is my contention that the somewhat ambiguous nature of autonomy, rights and the different ways in which conditions of ill health are put on the research agenda can also be of import in the Netherlands. This might be relevant when researchers wish to involve *autochtone* patients and migrants as partners in studies. Analogous to South Africa, it could also be necessary to not only study the quality of care to the above patients or their subjective experiences, but to equally try to understand it as clinically, economically and socially situated. Such an approach might also force Dutch researchers to critically think about their own assumptions concerning autonomy, the ability to exercise rights and even their own positions of power in relation to the patients. At the same time, it will be necessary to find different ways to make such patients full research partners.

An effort to find the patient's point of view can have unexpected outcomes. As shown in the case of IDDM research, patients sometimes have priorities for research issues that differ from health care providers. While the LOCIS research was focused narrowly on quality of care, the patients, when given the opportunity, wanted to show how fragmented and complex their interface with the health care services was. They were interested in showing and understanding how they and their families experienced it, made sense of it and tried to find ways to deal with – not only in relation to the health services, but to their illness in everyday life. Such research nevertheless calls for an extensive personal investment in time and effort from both the anthropologist and the other participants.

As with Catshoek and Blume's (2003) call for greater patient participation in research, the Health Research Policy in South Africa (2001) nevertheless stresses a more inclusive research process. The difference is that research is seen as a scarce resource that should be shared equitably. Such a broad approach is not as simple as it seems. It raises new questions about what and who the community and stakeholders are, and how they can be involved in an equitable and helpful way. A process of community involvement in South Africa can be very time-consuming and expensive, especially if they are to participate from writing the research proposal onwards.

As my discussion on the research with IDDM patients shows, participating in such a process is taxing for patients, their families and the communities they live in. This is especially so where there is poverty. Potential participants might doubt the value of investing themselves in a project that does not have immediate results. When this happens, the legitimacy of the views and aims of those who do participate can be equally problematic (Frohlich et al. 2001; Cornwall & Jewkes 1995).

Yet changes in health care research practices in South Africa increasingly demand the involvement of a wider range of stakeholders. These include funding organisations, researchers, patients, patient organizations, the community, non-governmental organizations and activist groups. To achieve this, the approaches and methods used, may also need to be reviewed. For this purpose it can be useful to look at some of the approaches used in Rapid Assessment Procedures and Rapid Rural Appraisal to set up structures and methods that can give equal weight to all stakeholders, including the patients and wider community. This will entail being more responsive to the needs of participants, being aware of the complexities of gearing research to address their needs and concerns and finding ways to incorporate this into standard criteria used to judge advanced academic understandings of the subject. Researchers will need to use more participatory methodologies that enable them to take the perceptions and opinions of 'target populations' and patients into account.

Young (1992) argues that views differ on how such perceptions should be translated into decisions and change. Chambers (1992) and others opine that those who will be affected should be included as participants in research, decision-making and the implementation of results. Approaches using participative methods for health research (Scrimshaw & Gleason 1992) have demonstrated that poor non-literate people can conduct studies. While some approaches involve patient participants and other stakeholders at almost all levels, many researchers feel they nevertheless need to retain control over the research project and its implementation, the utilization of some of the results and of making decisions at levels outside the community (Young 1992).

According to Young (1992) participation as a concept has gained acceptance but is still evolving in terms of the stresses resulting from the methodology or how it should be applied in research and in institutions. The dynamic of linking scientific enquiry to the researchers and untrained co-research participants has become crucial to ensure equity. Yet it is important that the patients' perspectives and participation should be combined with the views and input of those who operate and have influence within the wider structures of power. This is of particular salience as they can negatively or positively influence the implementation of research outcomes. They can also include or ignore it in policy decisions and planning. In this regard George (1986) refers to research concerning food security and hunger. He stresses the importance of looking not only at the experiences and views of the sufferers, but also at the effects and influences of those in power and to include them in such studies.

Such an approach strengthens the South African contention that research must involve a wider range of stakeholders, because of the ripple effect it will have on stakeholder communities, and because it will be opened to wider scrutiny than ever before. Research techniques that can bridge the gaps between those who hold the resources,

beneficiaries or sufferers, academic 'purity' and practical action should be pursued (Young 1992; WHO 1988). Ultimately such an approach raises the complexities inherent in the planning, organizing and conducting of studies. For research to attain such considerable scope, good management is as important to its success as is the quality of the research undertaken. Communicating this wider scope and its import from the design stage becomes crucial in order to overcome resistance to participation. Young (1992) stresses spontaneous participation is not common – it must be organized and sustained. This means that researchers must also be able to communicate effectively and to be able to manage projects. Such skills are not usually viewed as essential for doing conventional research. The research must be designed and executed so that the individual patient and other interest groups can more fully participate within the ambit of a more comprehensive and participative research approach.

## Notes

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- 1 For the purposes of this paper, and as often reflected in discussions in South Africa, a patient is viewed as a person who requires medical care and a client is a person who seeks medical advice. Accordingly patients can be clients and clients can be patients and the terms are often used interchangeably
- 2 In a landmark constitutional court case against the government in 1998 the claim of a chronically ill man to dialysis as a human right failed. The argument was accepted that access to life-prolonging resources provided by the state depends on whether it is available and an emergency, not a chronic condition.

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