

Patient involvement in treatment decision making among women with breast cancer: Creating person-centred and equitable health service systems

**Anthony Batte and Professor Richard Odoi-Adome
Faculty of Medicine , Makerere University Kampala-Uganda**

**Paper produced as part of a
Capacity building programme of the
Regional Network on Equity in Health in
east and southern Africa (EQUINET)**



May 2006

**Produced with the support of the
EQUINET student grant scheme and IDRC (Canada)**

Table of contents

Executive summary.....	3
1. Background.....	4
1.1. Breast cancer in Uganda	5
1.2. Treatment decision making in patients with breast cancer	5
2. Hypothesis and objectives	6
3. Methodology	6
4. Results.....	7
4.1. Demography	7
4.2. Information given to patients during interaction with the doctor	9
4.3. Participation in treatment decision making	9
4.4. Ways of improving patients' participation in treatment decision making ...	10
5. Discussion	11
5.1. Knowledge of right to participate in treatment decision making process...	11
5.2. Information given to patients during interaction with the doctor	12
5.3. Patients' participation in the treatment decision making process.....	12
5.4. Ways of improving patients' participation in treatment decision making ...	13
6. Conclusion	13
References	15

Through institutions in the region, EQUINET has been involved since 2000 in a range of capacity building activities, from formal modular training in masters courses, specific skills courses, student grants and mentoring. The capacity building activities in EQUINET are integrated within the existing areas of work of the network or build cross cutting skills demanded across themes by institutions in the network. The papers and reports produced in these training activities are products that are used to support or target mentoring. This report has been produced within the student grant programme and is disseminated in this context. It is not a formal EQUINET discussion or policy paper.

Executive summary

Patients' participation in the treatment decision making process is one of the patients' rights considered under the patient's autonomy in the health care delivery process. It is of great value therefore for health care providers and other parties involved in the health services provision to create space for patients' involvement in their treatment.

The purpose of this study was to assess patients' involvement in treatment decision making among women with breast cancer in Mulago hospital, Uganda's national hospital. One hundred fifty five patients were interviewed using self administered questionnaires. Data was analysed using SPSS 12.0 software version for windows.

While 58.9% reported that they think they were given enough information about the treatment interventions they were to undertake, a large proportion (41.1%) were not satisfied. Most patients (80%) reported that they think they were not given chance to participate in treatment selection. Many of the respondents (51.6%) think patients have no right to participate in the treatment decision making process, while 43.9% of the respondents think the patients have a right to participate in their treatment decision making process. The health providers should be sensitised on the role of patients participation in treatment decision making to ensure that patients are given chance to get involved in the decision making process. Patients should also be sensitised of their rights to participate in the treatment decision making process.

1. Background

Patient autonomy and participation in treatment decision making are some of the ethical issues that have been encouraged over the years. Patients, especially women need to be provided with information about their treatment options, related side effects and treatment outcomes so that they can make appropriate treatment decisions. Reasons for participation are varied, a number of them being inherent to individual patients. A number of studies have demonstrated that women feel information provision is important because it helps them to understand their diagnosis and make treatment decisions (Butow et al, 1997; Coulter, 1997; Thibodeau et al 1997; McWilliam et al, 2000). Other reasons for seeking information include gaining a sense of control over their situation, reducing anxiety, changing behaviour and formulating a plan for the future (Henman et al, 2002).

However, there is some evidence that patients and health professionals often do not agree on treatment preference in the areas of cardiovascular disease, cancer, obstetrics and gynaecology, and acute respiratory illness. The magnitude and direction of these differences vary and may depend on the condition of interest. Leigh et al (2001) reported that decisions are more likely to be made in the initial consultation if patients are not informed that they can delay decision-making and consider their options. They argue that if women feel rushed they may be less actively involved during treatment decision-making because they have not developed sufficient levels of rapport and understanding with the medical practitioners. Cathy et al (1999) have noted that women may not want to play active roles and may assume a relatively dependent relationship with the medical practitioners. Denial, fear and a sense of loss of control may exacerbate this attitude during initial interactions with the medical practitioners. It is further argued that women may not digest or understand all of the information provided because they are still dealing with a range of emotions relating to their diagnosis.

In the current health care systems, time and funding constraints can act as disincentives for doctors to explore and respond to patients' preference regarding the type of partnership they would prefer in the process of treatment decision-making (ibid). Education may enhance patient participation in treatment decision-making. According to Street et al (1995), college-educated patients younger than 65 years of age were more active participants in these consultations than were older, less educated patients. In addition, patients showed more involvement when they interacted with physicians who encouraged and facilitated patient participation. The method of education did not affect patient involvement although patients tended to learn more about breast cancer treatment after using the multimedia program than after reading the brochure.

Presenting patients with treatment choices has been shown to have positive benefit in reducing psychological morbidity (Davison et al, 1997; Fallowfield et al, 1994). The areas where the process can be enhanced include:

- the way individuals are invited to participate in the process (making the need for value judgments and sharing of responsibility explicit);
- the extent to which they are assisted to an adequate understanding of the treatment alternatives and their implications; and
- assistance to identify their preferences and to anticipate how these might change over time (Kenny et al, 1999).

Cancer is one of those chronic illnesses in which treatment decision making by the patients may be of great value. Women who are making treatment decisions for early stage breast cancer interact with a number of people when considering their treatment options and the impact breast cancer will have on their lives (Halkett et al, 2005).

It's thus important that a patient agrees upon the suitable kind of treatment to undertake since most of the chronically-ill get long term or lifetime treatment. Since successful treatment results depend on the patient's compliance, treatment success is improved upon by their selection of preferred treatment intervention in such cases as cancers.

1.1. Breast cancer in Uganda

Cancer is among the leading chronic diseases worldwide, accounting for an estimated 7 million deaths (12% of all deaths) worldwide in 2000 (WHO, 2001). In developing countries, breast cancer incidence and mortality rates are rising in most populations, with changes usually more marked in younger women (Parkin, 1994). In Uganda, breast cancer is the third most common cancer in women, after cancer of the cervix and Kaposi's sarcoma. The incidence in Uganda doubled from 11:100,000 in 1961 to 22:100,000 in 1995 (The Uganda Breast Cancer Working Group, 2003). According to Wabinga et al (1993) the incidence among females in Uganda is 11.4%. Unfortunately the cases are often seen in late stages when treatment-decision participation should be carefully weighed to benefit the patient.

1.2. Treatment decision making in patients with breast cancer

Studies have shown that when women are first diagnosed with breast cancer, they may react to their diagnosis with feelings of fear, anxiety, shock and disbelief (Thibodeau et al, 1997; van Der Molen, 2000). Thus decision-making for breast cancer treatment can be exceedingly complex. It depends on multiple variables: the woman's decision-making style, age, coping mechanisms, stage of disease, risk of recurrence, consideration for adjuvant therapy, state-of-the-art treatment recommendations, and personal preferences (Knobf, 1994). In addition women may have difficulty dealing with their emotions because they feel confused and are concerned about their futures.

In a study done by Degner et al (1997) of 1012 women with breast cancer, 22% wanted to select their own treatment, 44% wanted to collaborate with their doctors in the decision, and 34% wanted to delegate this responsibility to their doctors.

According to a survey done in Minnesota (Keating, 2002), only about half of patients reported an actual role in decision-making that matched their desired role. These patients were more satisfied with their treatment choice than other patients, suggesting that women with early-stage breast cancer may benefit from surgeons' efforts to identify their preferences for participation in decisions and tailor the decision-making process to them. This implies that efforts geared towards patients' participation in decision-making create a more people-centered and people driven health service delivery system, a strategy for improved health. Unfortunately in Uganda there is no data to date on the extent to which breast cancer patients participate in treatment decision-making. The purpose of this study was therefore to assess patients' involvement in treatment decision making among women with breast cancer in Mulago hospital, Uganda's national hospital. The information generated from this study could then be used in all

interventions made towards revitalizing and building a national people's health service delivery system which is people centred and people driven equitable health system.

2. Hypothesis and objectives

The study hypothesised that:

- many patients do not know their ethical obligation to participate in treatment decision-making; and
- patients who are given opportunity and satisfactory information about the treatment and their illness, will participate more in their treatment decision-making than those denied the information and opportunity.

The general objectives were therefore to:

- assess patients' involvement in treatment decision-making among women with breast cancer; and
- identify ways to improve involvement of patients in treatment decision-making among chronically ill patients since this may influence treatment outcomes of medical interventions.

Specifically the study sought to:

- determine the proportion of patients aware of their right to participate in treatment decision-making;
- determine the proportion of patients satisfied with the information provided to them before consenting to a given therapy;
- assess whether patients are given chance to participate in treatment decision-making; and
- identify ways to improve patients participation in the treatment decision-making process.

3. Methodology

The study was carried out in Mulago hospital, Uganda's national referral, teaching and research hospital as well as a district hospital for Kampala (capital city of Uganda). The hospital attends to 1800 outpatients per day and more than 100 breast cancer patients per month. Mulago hospital has a cancer department referred to as the Uganda Cancer Institute. The institute is divided into the Lymphoma treatment centre and the solid tumour centre. The solid tumour centre deals with treatment of different cancers, among which is breast cancer. The research interviewed patients who had been diagnosed/ were being treated for breast cancer from this centre. The selection criteria included:

- all patients who had been diagnosed with breast cancer on the days of the survey;
- all those who had come for treatment/ follow- up on the day of the survey but had been visiting the clinic for not more than one month and had been diagnosed with breast cancer.

These were interviewed in reference to the visit on which the diagnosis was made. The period of visit was made to be not more than one month because it was assumed that the patients could easily remember all that took place on the day of diagnosis.

To interview any of these patients, patients' files were checked to ensure they had been diagnosed of breast cancer. Questionnaires were offered to the patients after visiting the

doctor at the centre. Patients who had been admitted on the wards during this period and fell in the above criteria were also asked to respond to the questionnaires.

One hundred and fifty-five patients were interviewed. The number of patients was determined using Kish and Leisle Formula (where the prevalence of breast cancer in Uganda is 11.4% (Wabinga et al, 1993);

$$n = \frac{Z^2 \times p(1-p)}{d^2}$$

Where:

n is the sample size

is the Z- score corresponding to 95% confidence levels = 1.96

d is the sampling error observed = 0.05

p is the prevalence of breast cancer in Uganda

Respondents were sampled from the cancer clinic/ ward after consultation with the doctor. These were patients whose files had been checked and who had been diagnosed with breast cancer. Trained research assistants - medical students with knowledge of medical ethics and patient care - then administered the questionnaires.

A semi- structured questionnaire was used to collect quantitative data. Indicators collected were:

- proportion of patients aware of their right to choose or change their mind about the proposed medical intervention;
- proportion of patients informed that they are free to agree or reject the proposed intervention;
- proportion of patients given chance to discuss and reach a treatment decision in their favour or best interest;
- number of patients satisfied with the information provided to them before consenting for a given choice of treatment; and
- identified ways to improve patient involvement in treatment decision-making process.

Respondents consented following explanation of the study purpose. Confidentiality to the collected information was maintained. Data was coded and analysed using a computer software package, SPSS 12.0 Version for windows.

There were a number of limitations in the research:

- It was carried out among patients on the wards and the centre which could have biased their responses mostly on judgment of health workers attitude or behaviour.
- It was done among patients some of whom were in pain, a factor that might have affected their responses.
- The questionnaire was not able to obtain some indicators such as the effects of information and consultation time on the decision making process.

4. Results

4.1. Demography

Most respondents were in the age group of 40-49 years of age (25.5%) followed by 50-60 years of age (20.6%). Few respondents were below 20 years of age. A significant

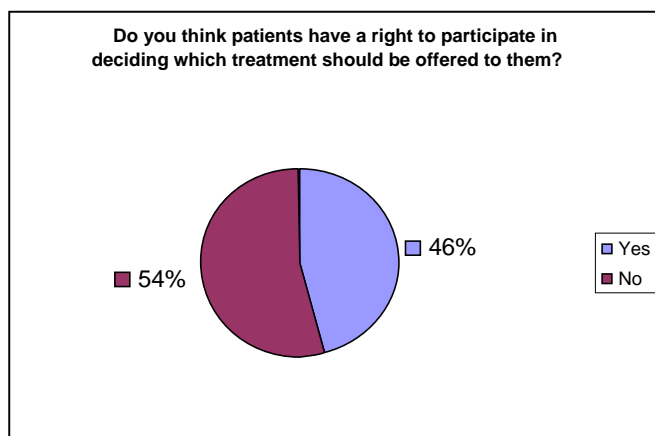
number of patients had never attended school (25.8%) and many had only attended a primary school (48%). Others had only attained secondary education (20.6%) while only 5.2% had either gone through a tertiary institution or graduated from a university. The table below shows the detailed demographic information.

Table 1: Demographic information of the respondents

Age of respondents	Frequency	Percentage
Below 20 years	14	9.0
20-29 years	18	11.6
30-39 years	26	16.8
40-49 years	39	25.2
50-60 years	32	20.6
Above 60 years	26	16.8
Level of education attained		
Never attended school	40	25.8
Primary education	75	48.4
Secondary education	32	20.6
Tertiary education	6	3.9
University Graduate	2	1.3
Marital status		
Single	62	40.0
Married	52	33.5
Widowed	29	18.7
Divorced	12	7.7

Many respondents (51.6%) think patients have no right to participate in the treatment decision making process while 43.9% of the respondents think the patients have a right to participate in their treatment decision making process.

Figure 1: Chart showing the perception of respondents to right to information



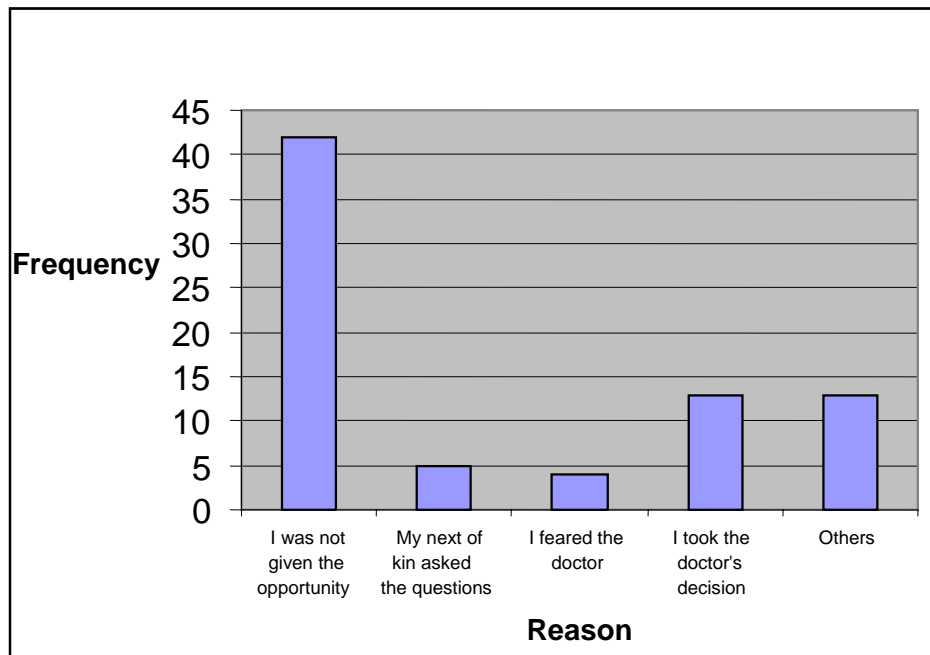
Respondents who reported that patients had a right to participate in the treatment decision-making process were more likely to report to have participated in the treatment decision-making than those who had reported that patients have no right to participate in the treatment decision-making (Odds ratio (1.01<OR< 7.05)).

4.2. Information given to patients during interaction with the doctor

Of the respondents interviewed, 85.2% had been told their illnesses by the doctors (breast cancer) while 14.8% had not been told what they were suffering from. Among patients interviewed, 58.9% reported that they think they were given enough information about the treatment interventions they were to under take, while 41.1% think they were not given enough information by the doctor. When asked what more information they would have liked to receive, the patients reported they wanted more information on the outcomes of the intervention, side effects, advantages of the intervention, alternative treatment interventions available and information such as the duration of the treatment.

When the patients were asked whether they had questions to ask the doctor, 45 % (68/151) said they had questions while 55% (83/151) said they did not have questions. Of those who had questions for the doctor, 25.7% said they asked the questions while 74.3% reported not to have asked the questions. The respondents who did not ask questions gave different reasons for not asking the questions (see *Figure 2*). These reasons included lack of opportunity to ask the questions, fear of the doctors, some of their questions were asked by their next of kin, and others took the doctors' decisions.

Figure 2: Reasons some patients were unable to ask questions



4.3. Participation in treatment decision making

Most patients (80%) reported that they think they were not given chance to participate in the selection of the treatment intervention they were to receive. It was found that 77.4% reported to have taken up the intervention because the doctor chose it for them; only 11.6% chose it because it's the intervention they preferred. Others chose the intervention because they did not know about other forms of interventions available; 4.5% and 5.2% said it's their next of kin that chose it for them.

Many respondents think it's important for patients to participate in treatment decision making process (51%) while 47.7% think it's not important for patients to participate in the treatment decision making process. One of the respondents said

It's the duty of the doctor to decide on which treatment I should receive, since I am not a doctor, I have nothing to contribute towards treatment. When we are sick we come to the doctor, so the doctors should get us the best preferred options which they thinks are best fit for our illnesses.

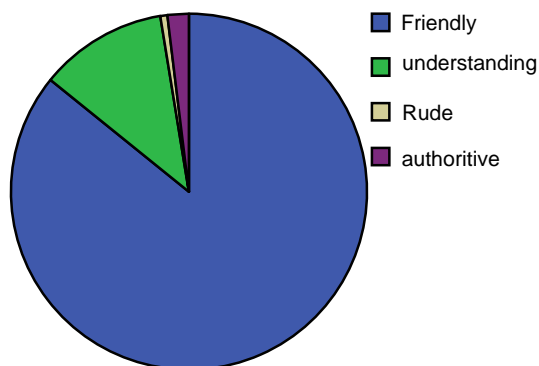
Those who preferred taking part in their treatment decision making process stressed that it gives chance to patients to choose interventions which are most comfortable for them. One of the patients stated that;

Since I am the one to take the one who is sick then I should be given chance to chose the treatment I am comfortable with.

Other factors that could influence patient participation in treatment decision-making

Many of the interviewed respondents (73.5%) reported to have spent enough consultation time with the doctor, while 26.5% reported that the consultation time they spent with the doctor was not enough. In general patients described the doctors' attitudes as being friendly or understanding. *Figure 3* shows the proportion of the patients who describe the doctors as friendly, understanding, rude or authoritative

Figure 3: Respondent perception of health worker attitude towards the patient



4.4. Ways to improve patient participation in treatment decision-making

Respondents suggested different ways in which they think their participation in the treatment could be improved, including:

- Doctors should provide enough information about the treatment options and the illness affecting the patient, for them to get involved in the process. One of the patients said:

Doctors should tell us about the available treatment alternatives and how they work for us to be able to choose and get a better understanding of the decisions we have taken.

- Health workers should improve their attitudes and communication skills such that patients feel free to express their views and taking decisions. One patient said:
Some of the doctors are rude that you even fear to say a word but if they are friendly and polite then it would be easier for us to either ask questions or give ideas on what treatment is best for us.
- Doctors should give enough time to patients for them to express their views and ask patients to contribute in the process. A patient said:
Its upon the doctors give us options and ask us for what we prefer but sometimes the doctor only asks you questions and he write the prescription down, the he sends you to go and take the written drugs.

5. Discussion

A large number of respondents were above 40 years of age. This is possibly due to the high prevalence of breast cancer among women over 40 years. In addition, most respondents have either never gone to school or they ended in primary school. This could possibly have compromised on their level of participation in treatment decision-making, since low education levels may imply having little knowledge about the different illnesses and rights to ethical roles like participation in treatment.

Previous studies have shown that a variety of demographic influences affect treatment decisions including: education levels, age, geographical location and cultural backgrounds (Wallberg et al, 2000). The treatment choice for older women appears to lean towards less painful treatment and less invasive techniques. Older women may consider their life expectancy, the efficacy of treatment, toxicity and presumed effects on their quality of life in different ways compared with younger women (Kutner et al, 2000). Women may choose a treatment that is more convenient considering their geographical location in relation to available treatment options. In this study most of the respondents came from within 30 km of Mulago hospital

Many of the respondents were not married even though no significant conclusion could be drawn from this. Correlation of the demographic data with the responses from the patients did not reveal significant values possibly due to the small sample size. However marriage has been noted to influence how women respond to challenging environments. Culturally in Uganda husbands decide treatment options for the household.

5.1. Knowledge of right to participate in treatment decision-making

Just over half of the respondents (51.6%) were not aware of their right to participate in the treatment decision making process. This could be one factor that led to their low participation in the process since it was seen that those who knew that they had this right, were more likely to participate in the process than those who did not know. The health workers' idea of the patient's right to participate in treatment decision-making is only beginning to emerge. Traditionally doctors tend to ignore that patients can add value to treatment outcome. This is especially so in developing countries where physicians have little training in communication skills.

5.2. Information given to patients during interaction with the doctor

According to the study, many patients reported they received enough information from the doctors but still a significant percentage (41.1%) reported not to have received enough information. In a study carried out in among family physicians in the Vancouver area of British Columbia, it was found that few physicians are able to provide/ avail information on treatment choices (including risks and benefits, consequence of no treatment, support for shared decision-making) (Godolphin et al, 2001). On the other hand, not all patients usually want to get information. Petrisek et al (1997) observed that older women were less likely than their younger counterparts to have desired participation in therapy selection, sought out medical information.

This may mean that even though many patients in this study reported receiving enough information, the information might have been too lacking to facilitate an informed and shared decision-making process. Those respondents who said that they had not received enough information pointed out key information they would have liked to receive from the doctors. This information included outcomes of the intervention, side effects, advantages of the intervention, alternative treatment interventions available and other information such as the duration of the treatment. Earlier studies indicated this kind of information is relevant to facilitate an informed and shared decision-making process (Godolphin et al, 2001)

5.3. Patients' participation in treatment decision-making

From the above results, it can be seen that patients are not given chance to participate in the process. This is displayed by the high number (80%) of the respondents who think were not given chances to participate in treatment decision-making. However, many patients think that it is the duty of the doctor to choose which intervention should be offered to a given patient. This is shown by the number of patients who pointed out that they have little knowledge as compared to the doctor, for them to participate in treatment decisions. This is similar to the paternalistic model described by Cathy et al (1999), in which the patient passively acquiesces to professional authority by agreeing to the doctor's choice of treatment. This may also be contributed to the number of patients (51.6%) who think patients have no right to participate in the treatment decision-making.

Patient participation is often determined by the inherent ideas of patients whereby they do not like to participate in the decision-making process. In a study of 1012 women with breast cancer, 22% wanted to select their own treatment, 44% wanted to collaborate with their doctors in the decision, and 34% wanted to delegate this responsibility to their doctors (Degner et al, 2001). These findings therefore mean that some patients prefer not to take up active roles in treatment decision making process.

However, a moderately large number of patients (51.7%) consider their participation in the treatment decision making process to be important; this to some degree means that these patients if given chance, they would possibly participate in treatment decision-making. It can also be seen that patients' great expectations from the doctor influence their idea that they should not participate in the process and thus they think they have nothing to contribute but to only take up a receptive role.

Many of the different factors which would hinder the communication process between the doctor and the patient, were well addressed by the doctors. For example, many patients described the doctor's attitude as friendly or understanding (97.4%). They also reported that they spent enough consultation time with the doctor (73.5%). Thus these may not be the factors hindering their participation in decision-making.

5.4. Ways to improve patient participation in treatment decision-making

Patients mentioned different ways of improving their participation in treatment decision-making. Many of these factors focused on doctors who should create an environment in which the patients are invited into the decision-making process. Patients also indicated doctors should sensitise them and provide enough information related to their illness and treatment for them to be able to contribute well to treatment decision-making.

The findings in this study should be interpreted in light of several limitations. First, although we studied care for women in a large National Referral Hospital, the generalizability of the findings to other areas and to current practice requires further study. Furthermore, despite good response rates to the survey, women interviewed were somewhat younger and healthier than those not interviewed. It can not be sure that the findings are generalisable to all women with breast cancer, nor can it exclude the possibility of response bias. Second, this was a retrospective study. Although prospective collection would have been preferable, this was not possible. The patients' actual roles in decision making are self-reported. Although patients were specifically asked to describe their role with their doctors, it was not possible to observe the interactions or ask the doctors to describe the patients' decision-making roles. Summarizing this study it can safely be said that treatment decisions and the experience of breast cancer may have a significant impact on the women's lives and can influence different aspects of their lives. These include their own values and priorities; the people that they have relationships with; and how they react to their breast cancer diagnosis.

6. Conclusion

Most patients in this study felt that they were not given a chance to participate in treatment decision-making. They took up a specific intervention because the doctors had chosen the interventions for them. Many patients think they do not have a right to participate in the treatment decision making process.

Many patients described the doctors' attitudes as either friendly or understanding and reported having spent enough consultation time with the doctor. They also reported to have been given enough information by the doctor, about their illness.

We would, on the basis of the findings in this study suggest options to improve patients' participation in the treatment decision making process:

- Health workers should be sensitised about the importance of patient participation in treatment decision-making to ensure patients are given chance to be involved in the process.
- Government and other parties involved in health care delivery should sensitise and inform the public about patient rights to participation in treatment decisions and

ensure that people empowered with the knowledge and ability to ensure that they participate in decisions on their treatment process.

- Health workers should ensure they provide enough information to the patients to facilitate an interactive session with their patients and to ensure that patients take informed decisions on any given kind of medical intervention.

References

- Beaulieu MD, Hudon E, Roberge D (1999) 'Practice guidelines for clinical prevention: Do patients, physicians and experts share common ground?' *Canadian Medical Association Journal* 161:519-23.
- Beisecker AE, Helmig L, Graham D, (1994) 'Attitudes of oncologists, oncology nurses, and patients from a women's clinic regarding medical decision-making for older and younger breast cancer patients,' *Gerontologist* 34:505-12.
- Butow P, Maclean M, Dunn S, Tattersall M and Boyer M (1997) 'The dynamics of change: Cancer patients' preferences for information, involvement and support,' *Annals of Oncology* 8: 857-863.
- Cathy C, Whelan T and Gafni A (1999) 'What do we mean by partnership in making decisions about treatment?' *British Medical Journal* 319(7212): 780-782 (18 September 1999).
- Cathy C, Whelan T, Gafni A, Willan A, Farrell S. (2003) 'Shared treatment decision-making: What does it mean to physicians?' *Journal of Clinical Oncology* 21(5): 932-936 (March 2003).
- Coulter A (1997) 'Partnerships with patients: The pros and cons of shared clinical decision-making,' *Journal of Health Services Research and Policy* 2: 112-121.
- Davison BJ and Degner LF (1997) 'Empowerment of men newly diagnosed with prostate cancer,' *Cancer Nursing* 20 (3):187-196.
- Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J (1997) 'Information needs and decisional preferences in women with breast cancer,' *Journal of the American Medical Association* 277:1485-1492.
- Fallowfield LJ, Hall A, Maguire P, Baum M, A'Hern RP (1994) 'Psychological effects of being offered a choice of surgery for breast cancer,' *British Medical Journal* 309:448.
- Godolphin W, Towle A and McKendry R (2001) 'Evaluation of the quality of patient information to support informed shared decision-making,' *Health Expectations* 4(4): 235.
- Halkett GKB, Arbon P, Scutter SD, Borg M (2005) 'The experience of making treatment decisions for women with early stage breast cancer: A diagrammatic representation,' *European Journal of Cancer Care* 14: 249-255.
- Henman M, Butow P, Brown R, Boyle F, Tattersall M (2002) 'Lay constructions of decision-making in cancer,' *Psycho-Oncology* 11: 295-306.
- Keating NL, Guadagnoli E, Landrum MB, Borbas C and Weeks JC (2002) 'Treatment decision making in early-stage breast cancer: Should surgeons match patients' desired level of involvement?' *J Clin Oncol* 2002 Mar 15; 20(6):1473-9
- Kenny P, Quine S, Shiell A, Cameron S (1999) 'Participation in treatment decision-making by women with early stage breast cancer,' *Health Expectations* 2(3):159-168.
- Knobf MT (1994) 'Decision-making for primary breast cancer treatment,' *Medsurg Nursing* 3(3):169-174, 180.
- Kutner J, Vu K, Prindiville S, Byers T (2000) 'Patient age and cancer treatment decisions,' *Cancer Practice* 8: 114-119.
- Leighl N, Gattellari M, Butow P, Brown R, Tattersall M (2001) 'Discussing adjuvant cancer therapy,' *Journal of Clinical Oncology* 19: 1768-1778.
- McWilliam C, Brown J, Stewart, M, (2000) 'Breast cancer patients' experiences of patient-doctor communication: A working relationship,' *Patient Education and Counseling* 39: 191-204.
- Parkin DM (1994) 'Cancer in developing countries,' *Cancer Surveillance* 19-20:519-61.
- Petrisek AC, Laliberte LL, Allen SM, Mor V (1997) 'The treatment decision-making process: Age differences in a sample of women recently diagnosed with nonrecurring, early-stage breast cancer,' *Gerontologist* 37(5):598-608.

Street RL, Voigt B, Geyer C, Manning T, Swanson GP (1995) 'Increasing patient involvement in choosing treatment for early breast cancer,' *Cancer* 76(11):2275-85.

The Uganda Breast Working Group (2003) 'Breast cancer guidelines for Uganda,' *African Health Sciences Journal* 3(1).

Thibodeau J, MacRae J (1997) 'Breast cancer survival: A phenomenological inquiry,' *Advances in Nursing Science* 19: 65–74.

van Der Molen B (2000) 'Relating information needs to the cancer experience: Themes from six cancer narratives,' *European Journal of Cancer Care* (England) 9: 48–54.

Wabinga HR, Parkin DM, Wabwire-Mangen F and Mugerwa JW (1993) 'Cancer in Kampala, in 1989-91: Changes in the era of AIDS'. Department of Pathology, Makerere Medical School: Kampala.

Wallberg B, Michelson H, Nystedt M, Bolund C, Degner L, Wilking N (2000) 'Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients,' *Acta Oncologica* 39: 467–476.

World Health Organization (2001) 'Cancer incidence, mortality and survival by site for 14 regions of the world,' *Global Programme on Evidence for Health Policy Discussion Paper 13*. WHO: Geneva.

Acknowledgements

This study was implemented under the EQUINET student grant programme. The author acknowledges supervision of Dr R Odoi, peer review from Dr TJ Ngulube and Dr R Loewenson and edit from R Pointer, R Loewenson.

Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned with equity motivated interventions that seek to allocate resources preferentially to those with the worst health status (vertical equity). EQUINET seeks to understand and influence the redistribution of social and economic resources for equity oriented interventions, EQUINET also seeks to understand and inform the power and ability people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.

EQUINET implements work in a number of areas identified as central to health equity in the region:

- Public health impacts of macroeconomic and trade policies
- Poverty, deprivation and health equity and household resources for health
- Health rights as a driving force for health equity
- Health financing and integration of deprivation into health resource allocation
- Public-private mix and subsidies in health systems
- Distribution and migration of health personnel
- Equity oriented health systems responses to HIV/AIDS and treatment access
- Governance and participation in health systems
- Monitoring health equity and supporting evidence led policy

EQUINET is governed by a steering committee involving institutions and individuals co-ordinating theme, country or process work in EQUINET:
Rene Loewenson, Rebecca Pointer TARSC; Firoze Manji, Patrick Burnett Fahamu; Mwajumah Masaiganah, Peoples Health Movement, Tanzania; Itai Rusike CWGH, Zimbabwe; Godfrey Woelk, University of Zimbabwe; TJ Ngulube, CHESSORE, Zambia; Lucy Gilson, Centre for Health Policy South Africa; Di McIntyre, Vimbai Mutyambizi Health Economics Unit Cape Town, South Africa; Gabriel Mwaluko, Tanzania; John Njunga, MHEN Malawi; A Ntuli, Health Systems Trust, Scholastika lipinge, University of Namibia, South Africa; Leslie London, UCT, NomaFrench Mbombo, UWC Cape Town, South Africa; Riaz Tayob, SEATINI, Zimbabwe; Ireen Makwiza, Sally Theobald, REACH Trust Malawi.

This report is produced under a training programme as part of a skills building exercise. It does not reflect the views of EQUINET and is not a formal EQUINET discussion or policy paper.

For further information on EQUINET please contact the secretariat:
Training and Research Support Centre (TARSC)
47 Van Praagh Ave, Milton Park, Harare, Zimbabwe
Tel + 263 4 705108/708835 Fax + 737220
Email: admin@equinetafrica.org
Website: www.equinetafrica.org