

Gender discrepancies in the HIV/AIDS Community Home-Based Care Programme in Kanye, Botswana

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Abstract

The aim and objective of this paper is to discuss the gender discrepancies associated with caregiving based on empirical findings from the Kanye HIV/AIDS Community Home-Based Care (CHBC) Programme. The research study was explorative and descriptive in nature and qualitative in design. It used focus group discussions among the caregiver respondents and one-on-one interviews with the CHBC nurses. The findings indicate that the caregiving role among women, and spilling over to girl children, is a result of socialisation that is deeply ingrained in the belief systems of cultures and communities, presents a state of gender exploitation and a human rights denial, is reinforced by the forces of patriarchy, and contributes immensely to the feminisation of poverty. The study recommends gender mainstreaming and analysis in all the institutions of social development, as well as poverty mitigation measures and education to surmount the effects of gender imbalances, gender inequality and gender inequity.

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Introduction

Problem statement

The gender imbalance that has attracted local, regional and international concern and that has left the arduous task of caregiving to be shouldered by women has compelled the researcher to examine the situation empirically in the Kanye HIV/AIDS Community Home-based Care (CHBC) Programme. The research findings are likely to inform advocacy strategies and interventions to mitigate the impact of this state of caregiving and possibly put in place measures to attract the male gender to participate in the caregiving process.¹ The fact that women, especially the primary caregivers, have not been considered for any meaningful motivation and incentives has necessitated a thorough examination of the CHBC Programme.² This was necessary because the government considers the programme an important one, especially after institutionalising it and placing it within the existent healthcare structures.³ The researcher believes that the operational challenges inherent within the CHBC Programme need special focus. This focus is likely to bring to the fore factors, that if addressed, can improve the circumstances under which women, especially the primary caregivers, operate. The human rights of the primary caregivers, as they are not covered by any policy of compensation in case of occupational hazards, have also

attracted attention, creating a forum for advocacy to the government and other bodies.⁴

Operational definitions

The words "client", "patient" and "HIV/AIDS clients" are used interchangeably to mean one and the same thing.

Gender

There are factors, roles and tasks that societies associate with either men or women that affect the way in which they share caregiving, for example having women predominantly handle caregiving while men are free. These factors, roles and tasks are determined by the culture, traditions and customs of a society.

Gender imbalance

"Gender imbalance" refers to power differences between men and women that cause women predominantly to take responsibility for caregiving, without the power to negotiate help from men.

Gender analysis

"Gender analysis" looks at the roles of women and men, their relationships and issues of access to and control over resources. It asks some basic questions, such as: Who does what? What do women do and what do men do: who has access to social and economic resources, and who

has control over these resources? The purpose of gender analysis is to effect interventions that can address gender inequalities and inequities.

Gender inequality

“Gender inequality” refers to socially determined power differences between men and women that cause women to occupy a lower position in society, therefore not being able to negotiate for men’s participation in caregiving tasks.

Gender inequity

“Gender inequity” refers to the differences in the value of the positions and resources that women can access compared to men after achieving gender equality.

Patriarchy

“Patriarchy” refers to culturally and traditionally attained power by men that they use to oppress women socially and economically.

Masculinity

“Masculinity” is the biological physical strength of men compared to women, enabling them to handle more strength-demanding tasks as opposed to women’s lighter tasks.

Engendering

“Engendering” is the social process of making gender.

Background

Gender is an important concept today, as societies grapple to achieve gender equality and equity. This will enable both men and women to enjoy life and to contribute to socioeconomic development meaningfully. However, the presence of gender imbalance affects all institutions of social development, including caregiving, proving that “development, if not well gendered, is endangered”.⁵ While the concept of gender is generally and erroneously taken to be an issue of sex between men and women, gender actually has to do with what roles societies have assigned to men and women respectively.

Gender also has to do with how societies have socialised men and women to act, to behave and to believe, ingraining and instilling in them certain societal and cultural values, stereotypes, customs and traditions, making any attempt to advocate for a change process a difficult and an uphill task. Gender is a social construct and is the result of values inculcated in individuals as they move through the various social, psychological and cognitive stages of life.⁶ According to Kimball,⁷ gender traits do not reside within the individual but rather are constructed in a cultural context and through interpersonal interactions. Individuals do not have gender; rather, they do gender.⁸ It is assumed that if young boys and

girls are put in the same social context and are exposed to the same social forces, they will behave similarly.⁹ This statement is, however, debatable and requires serious and convincing examination. Many people, including this author, think that besides the differences brought about by different aspects of the social environment, there are indeed inborn differences between men and women.

Across diverse regions of the globe, gender power appears to be skewed, with the result that power, resources and decision-making capacity are in the hands of men at the expense of women. According to The United Nations Development Programme (UNDP),⁵ “in no society today do women enjoy the same opportunities as men.” This is due to gender inequality and inequity and explains women’s vulnerability, that leads to their poverty. This feminisation of poverty is the tragic consequence of women’s unequal access to economic activities. A paradigm shift by men regarding gender dynamics and a realisation of how they contribute to disempower women would be one of the pivotal steps in addressing the feminisation of poverty.

Several studies in Botswana suggest that the environment of caregiving is riddled with many constraints, such as inadequate assistance (generally from communities), inadequate caregiving tools and inadequate motivation and psychological well-being. The burden of caregiving sometimes spills over to the girl child.¹⁰ The girl child is often forced to perform adult caretaking duties, such as feeding and bathing the sick and cooking for the rest of the members of her household. In this context, caregiving infringes upon her human rights by denying her access to school and forcing her to assume adult roles prematurely, that her physical, psychological and emotional capacity may not yet be ready for.¹¹

The aim of this article is to discuss the gender dimensions associated with caregiving in the Kanye HIV/AIDS CHBC Programme.

Method

Research design

A qualitative design was used in the study, as it sought to explore the thinking, feelings and attitudes of the caregivers regarding gender discrepancies and imbalances that militate against caregiving productivity. According to Creswell,¹² qualitative research is concerned with the meaning of how people make sense of their lives and experiences. As the area of caregiving has not been studied adequately, especially as it relates to gender, this study called for the exploratory skills embedded in the qualitative design. Participant observation was also used to capture the mood and temperament of the caregivers.

Research instruments

Two similar interview guides were used, one to steer 10 focus group discussions with caregiver respondents, and the other one to facilitate one-on-one in-depth interviews with the five CHBC nurses. The nurses formed the caregivers' supervision team. Other than the profile section that required the respondents to give their profile data such as age and gender, all the questions in the interview guide were open-ended. This allowed the participants to give their thoughts, opinions and attitudes freely. The instruments had been tested and refined during a pilot study.

Sample selection criteria and data collection procedure

Although all the caregivers, both community and primary, formed the sampling frame, it was only the 140 registered primary caregivers as they appeared in the CHBC register who were selected, using convenience sampling, to be the units of analysis of the study.¹³ Eighty-two (59%) registered primary caregivers turned up for the focus group discussions, making 10 focus groups of 6–12 individuals. All the discussion sessions lasted between 60 and 90 minutes. The CHBC register in each clinic helped to identify the number of primary caregivers served by each clinic and hence made the sample grouping for the focus group discussions easier. The community caregivers (referred to as "volunteers" in the Botswana context) also helped to clarify the number of caregivers that they were supervising and supporting in their caregiving roles. This eased the process of involving and encouraging the caregivers to participate in the study.

Also, all four CHBC nurses in the programme, and their coordinator, were selected, still using the convenience sampling method to participate in the study. They were picked because of their mandate of supervising the CHBC programme and the caregivers. The caregivers' selection criteria and grouping, disregarding age and gender, were based on the caregivers' clinic or health post proximity, with some clinics having more than one focus group discussion. The caregiver respondents were collected from the Kgwaliheng, Kanye Main, Mafhikana, Dada and Mmamokhasi clinics and the Dilolwe and Sebogo health posts, and taken to the Miracle Family Christian Centre premises where the focus group discussions were held. The CHBC nurses were each interviewed at her workplace. Jotting down notes, probing, questioning and audio taping information from the respondents formed the strategy of collecting the data.

Ethical and legal requirements

All the relevant legal and ethical issues were taken into consideration. The researcher, with the help of the CHBC managers, conducted briefings before the study, during which the study objectives and goals were explained and the participants were asked whether they would consent to participate in the study through signing consent forms. They were assured of data confidentiality and anonymity and of being treated with respect and consideration.¹³ The respondents were also informed of their rights and freedom to withdraw voluntarily if they wished, or if they felt uncomfortable with the research proceedings. The researcher had complied with all the research permit application procedures of the Human Research and Development Committee and was therefore issued with a research permit. He then had to write a letter to the Southern District Council asking for permission to enter into the field to collect data.

Data analysis and interpretation

To carry out data analysis, the information from both the focus group discussions with the primary caregivers and the one-on-one interviews with the nurses was taped and then transcribed. The huge piles of crude data were sorted, rearranged and reduced to manageable categories, themes and subthemes, using a coding process. Tables and graphs were used to present the data and the findings.

Data bias reduction

As a data bias reduction strategy, the results of the pilot study, involving five caregivers, had served to remove ambiguities in the measuring instruments and had helped to focus the study. This contributed positively to data reliability and validity. Double translation of the instruments, i.e. translation from English to Setswana and then from Setswana to English by two independent translators, and the two parties settling any differences, also contributed to the reduction of result bias. To strengthen data reliability and validity, the two interview guides used only differed slightly, and the two sets of responses confirmed and cross-checked each other.

Research domain

The data for this article were obtained from empirical research done in December 2005 and January 2006 at Kanye village. The village has a population of 40 628 persons according to the 2001 Botswana National Census,¹⁴ and is well endowed with adequate health facilities in that it has a big Seventh-Day Adventist referral hospital, five clinics and two health posts. The research domain was chosen, as the area was experiencing a high death toll among the CHBC clients.¹⁵

Results

Profile of the volunteer caregivers

The caregiver respondents' ages ranged from 18 to 85 years (Table I). While 46 (56%) caregivers were aged over 50, those above 60 years (28) constituted 34% of the total caregivers. The study revealed a serious gender discrepancy, with 80 (98%) caregivers being women and only two (2%) being men.

The caregivers agreed that if the men in their society would agree to assist in caregiving, this would help alleviate the serious problem that caregiving was facing regarding labour and possibly economics. Those caretakers above 60 years displayed both physiological and physical characteristics indicative of being stressed, depressed, demoralised, worn out and poor. This was exacerbated by the fact that 30 caregivers (36%) were taking care of two or more clients (Table II). This was an exhausting and overwhelming experience and constituted a heavy caseload, especially when the caring environment was not supportive. Generally, caregivers expressed being overwhelmed, as they were receiving little support from other family members and the community at large. Some caregivers burst into tears as they explained the challenges of being left alone to take care of their families and relatives. One had this to say: "I cannot get time to go and look for a job as I'm alone caring for my father. They all went for good, leaving me to struggle with caregiving."

On the economic front, 88% of the caregivers had no income to support themselves and they indicated that they were full-time volunteers in caregiving: "We do nothing except caregiving" (Table III).

Regarding literacy, 74% of the caregivers had either never been to school or had only primary-level education (Table IV). Only 5% of the caregivers had tertiary education. The caregivers indicated that illiteracy contributed to low caretaker productivity. This was exacerbated by poverty as the researcher observed that most of the caregivers with low education indicated that they were poor. Low productivity could also be explained by the fact that most of those who had never been to school were also elderly and said that they had difficulty in accessing education on caregiving and following the disease progression of their clients.

Ageing and low educational status affect the quality of caregiving

The findings indicated that though the effects of huge gender disparities in caregiving influenced caregiving effectiveness and productivity, the caregivers' advancing age and their low educational status immensely affected caregiving effectiveness, efficiency and quality. This is

Table I: Caregiving by age and gender

Age range	Women		Men		Total	
	Frequency	%	Frequency	%	Frequency	%
80–89	1	1			1	1
70–79	9	11	1	1	10	12
60–69	17	21	0	0	17	21
50–59	18	22	0		18	22
40–49	16	20	1	1	17	21
30–39	8	10	0		8	10
20–29	9	11	0		9	11
0–20	2	2	0		2	2
Total	80	98	2	2	82	100

Table II: Number of clients per caregiver

Number of clients per caregiver	Women		Men		Total	
	Frequency	%	Frequency	%	Frequency	%
1	51	62	1	1	52	63
2	19	23	1	1	20	24
3	4	5	0	0	4	5
>3	6	7	0	0	6	7
Total	80	98	2	2	82	99

Table III: Caregivers' involvement in income-generating activities

Income-generating work	Women		Men		Total	
	Frequency	%	Frequency	%	Frequency	%
Yes	8	10	2	2	10	12
No	72	88	0	0	72	88
Total	80	98	2	2	82	100

Table IV: Caregiving by gender and educational level

Educational level	Women		Men		Total	
	Frequency	%	Frequency	%	Frequency	%
Never been to school	28	34	1	1	29	35
Primary level	32	39			32	39
Secondary level	16	20	1	1	17	21
Tertiary level	4	5			4	5
Total	80	98	2	2	82	100

because the elderly women, despite their experience in caregiving, found it difficult to understand the dynamics of caregiving, especially changes in disease progression. The caregiver participants, who were predominantly women, also indicated that their contribution was hampered by inadequate assistance from men who could help in some tasks, such as changing the clients' clothes, positioning them and lifting them in and out of bed. The caregivers also reasoned that men are generally better endowed with financial resources than women and that their interest and

participation in caregiving could possibly provide economic support to the clients. Their feeling was, “Our caregiving capacity is affected by our age and the lack of helping hands from men.”

Further comments indicated that if there were frequent on-the-job training, this would probably increase the capacity of especially the elderly caregivers.

Caregiving is predominantly left to women and girl children

Virtually all the research respondents expressed dissatisfaction because caregiving has been left to women alone, with the duties being passed on to girl children. This they said was like a punishment to them. While men and boys were freed by culture and socialisation from involving themselves in caregiving, women and girl children were sometimes suffering burnout. Caregivers also saw the burden of caregiving as one of the reasons for the poverty of women. They complained as follows:

“The tasks of caregiving have been left to us women and our girl children. In this era of AIDS, it is too heavy a burden on us.”

“Leaving the caregiving tasks to women contributes heavily to the feminisation of poverty.”

“It’s a shame for communities to place the burden of caregiving on children.”

“The government and CHBC authorities should not allow the sick to be taken care of by children.”

The role of women as caregivers is reinforced by patriarchy

Sixty caregivers (73%) agreed that the issue of women as caregivers finds its roots in the concept of patriarchy. This is a mindset embraced and perpetuated by many cultures and traditions, asserting men’s supremacy over women and children. For those caretakers who were Christians, as most of them indicated, it was apparent that the Bible had a hand in strengthening patriarchy because according to biblical principles, men were given authority over women by God. The caregivers furthermore reasoned that role demarcation and differentiation has a biblical origin with women being apportioned relatively lighter tasks, nurturing the sick being one of them, while men take on relatively harder tasks. The following ideas were shared by many: “Caregiving tasks, among other lighter tasks, have been allocated to women by God”; and “God is the one behind role demarcation and gender differentiation. We can attempt to make change but not much.”

The role of women as caregivers is fostered through culture and socialisation

All the study respondents blamed culture and socialisation for determining that caregiving was a task for women. Some women indicated their disbelief in this and asserted that men should help in caregiving. Men should not expect women to be solely responsible for caregiving. All the respondents agreed that it was time that cultural beliefs, practices and stereotypes underwent a paradigm shift to face the reality of the HIV/AIDS pandemic. The following idea was echoed by many of the caregivers: “It is our culture and socialisation that dictate that caregiving is a task for women alone.”

The poverty of women caregivers affects caregiving productivity

All the caregivers, who were predominantly women, indicated that caregiving was adversely affected by the poverty of women. This they ascribed to the fact that men were not assisting them in their caregiving tasks, nor were they receiving adequate assistance from family and community members. The following came out strongly in the discussion groups: “The family members, relatives and men only help very little”; and “We are poor and need help. The help from men is necessary.”

Discussion

The findings that most caregivers in the Kanye CHBC Programme were elderly women and that a huge gender imbalance existed are matched by those of Jacques and Stegling¹⁶ in Kweneng, Botswana, who found that three clients were cared for by women caregivers who were not able to discharge their roles because of old age or disability. Mojapelo et al¹⁷ found that 89% of the caregivers in their study were women. This gender imbalance in the provision of care needs to be addressed, as it impacts negatively on the quality of caregiving. If caregiving is left to women alone, especially the elderly, family structures could be stretched beyond their capacity, leading to low productivity in caregiving.¹⁸

Gender imbalance in caregiving has been criticised by feminists who see it as unfair and oppressive to women, because women have other domestic chores that add to the burden of caregiving. This imbalance has also worsened women’s poverty.⁵ The burden of caregiving is also likely to cause stress and burnout in the caregivers.¹⁹ Notably, the traditional gregarious community spirit that used to prevail among African families is slowly dying out and is being replaced by the nuclear family setup that narrows down the kinship network that could help with caregiving. This could be due to the effects of modernisation, westernisation, Eurocentrism and, to some extent, globalisation.²⁰

Ways and means should be found of involving men and younger people in caregiving to help the ageing caregivers. There is a need to review caregiving policies to make room for incentives that can attract men and younger people to caregiving.

Regarding the educational level of the caregivers, other studies showed more or less the same trend and pattern of a large number of caregiver volunteers being either illiterate or semiliterate. In a study by Phorano et al on caregivers in Maun and Kweneng, 33% of caregivers had only a primary education.²¹ Since HIV/AIDS is a dynamic disease, caregivers with lower education status may not be able to keep pace with changes and new demands. This could help explain the lower standards, inefficiency and ineffectiveness that have characterised most caregiving programmes in Botswana.²² To offset the impact of illiteracy, on-the-job training by care managers in collaboration with the government, is needed in the Kanye CHBC Programme. This will ensure that the knowledge and coping capacities of the caregivers are improved.^{23,24}

The Kanye study revealed that though no minors turned up for the interviews, there were many girl children carrying out caregiving tasks, some having been forced to leave school and take over as caregivers and heads of households. In many developing countries caregiving has driven many girl children to leave school to take up adult roles, even if there are older boy children in the family who are not attending school. In the opinion of this researcher, this constitutes a human rights denial and abuse. According to the UN Convention on the Rights of Children,¹⁰ all children are entitled to and have a right to education.¹¹ In a study on caregiving by Mojapelo et al in Kweneng, four HIV/AIDS clients were taken care of by girl children.¹⁷ Socialisation and societal stereotypes that cause the girl child to believe that a woman is primarily a mother and a caretaker, have hugely contributed to making the girl child suffer skewed gender thinking, to the detriment of her social development.²⁵

The Kanye study found patriarchy to have a great impact on caregiving. Patriarchy, sanctioned by many cultures and traditions, means control of women and children by men. The concept is also reinforced by biblical principles and the belief that men have been given power by God to control women.²⁶ In Biblical terms, women are the "neck" while men are the "head". "Wives, submit to your husbands as to the Lord. For a husband has authority over his wife, just as Christ has authority over the Church."²⁶ Therefore patriarchy has bestowed socioeconomic and political powers on men to control women and children, further contributing to gender inequality and inequity.¹

Marxian thinking like that of Friedrich Engels sees patriarchy as being rooted in the development of private ownership of

animals, tools and land and in humanity's attempt to control more of the surplus production.²⁷ However, feminist scholars such as Kelesetse²⁸ contend that caregiving in CHBC by women is a societal exploitation of the female gender.

The Kanye study pointed to culture and socialisation as factors influencing the direction of caregiving. Culture represents societal values, norms and practices that are passed down from one generation to another. Culture has always been the mirror of society, representing society's thinking, cherished values and do's and don'ts, and it sets the pace for change in any society.¹ In most societies, it is culture that dictates how power is to be shared between men, women and children, and how boys will be treated and valued relative to girls.^{1,5} Most cultures appear to believe in the supremacy of men over women and of boys over girls.⁷ Different cultures have been dominated by patriarchy and masculine values, which have been deeply ingrained in customs and traditions to define the roles of men and women.²⁹ Household chores, hospitality and taking care of the sick are usually assigned to the female gender. However, the advent of HIV/AIDS demands a departure from this practice, calling for gender role swaps, gender realignment and dismantling of the gender stereotypes that solidly relegate a particular task to a particular gender.^{1,30}

Campaigns should be launched supporting gender role swaps, gender liberalisation and gender freedom, encouraging boys and girls to take on any role or pursue any course that traditionally may have been the preserve of a particular gender. This will no doubt usher in a new paradigm, enabling men to take on caregiving roles with ease.

The Kanye research findings established that 98% of the caregivers were women and that over 90% of them did not pursue any income-generating activity. Women caregivers reported that they were poor and were not able to support their clients and themselves adequately. According to the UN, women in many social contexts around the world are responsible for all household chores, including child care and care of sick family members. It has been argued that this has contributed to the feminisation of poverty.⁵ Similar studies by Khan and Stegling found that caregivers were poor and were not adequately supported by their close kin.³¹ The report of the UN Secretary General's Task Force on Women, Girls and HIV/AIDS in South Africa points out that there is little assistance, recognition or compensation for caregivers who may be the subjects of exploitation and severe stress.³²

The government needs to come up with poverty-mitigating measures in the CHBC programmes. For instance, caregivers could be assisted to pursue income-generating activities as they are providing care.

Conclusion

The fact that caregiving is dominated by women demonstrates the process of gender imbalance, inequality and inequity. This process is a result of culture, traditions and customs that have been influenced by the values of patriarchy and masculinity, assigning fixed roles to men and women. However, the reality of the HIV/AIDS situation necessitates that these cultural forces and stereotypes be challenged and be replaced by a mindset that will encourage both men and women to co-participate in caregiving. Gender campaigns that enlist gender analysis and gender mainstreaming are likely to force a paradigm shift towards a more equitable participation of men and women in caregiving. Societal thinking, beliefs and norms that encourage care to be only a women's task can be corrected through education and gender mainstreaming in all social institutions.

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