

Community Caregivers

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Community Caregivers within the South African Health Care context

Various terms including Community Caregiver (CCG), Community-Based Health Worker, Home-Based Carer, Ancillary Health Care Worker, DOTS Supporter and Onompilo, are used to describe those who work in the community, carry out one or more functions related to health care delivery but usually have no formal, professional health care qualifications. Since the WHO declaration of Alma Ata in 1978 focused attention on Primary Health Care (PHC), CCGs have worked in the community, playing a key role in empowering people with health care knowledge and facilitating access to PHC services. It has taken more than twenty years for CCGs to gain some recognition by the formal health care sector and for standardised training, career pathways and formal support to be considered.

The impact of HIV/AIDS has meant that there has been a dramatic increase in the number of people requiring care and support. With escalating costs of care and hospitals not able to cope with the demand for beds, the aim has been to decentralise care to community level, placing the responsibility, the costs and the burden on Non-Government Organisations (NGOs), Community Based Organisations (CBOs) and family carers. The reality is that many patients who are discharged from hospital do not have family members to care for them within a home setting or, if the primary caregiver has to go to work, the sick person is left alone. Even when family members are available, many do not have the required skills and knowledge and some are simply unwilling to care, perhaps fearing they, themselves, will become infected.

Human rights are normally divided into two groups, namely civil and political rights and then socio-economic and cultural rights. Examples of civil and political rights are the right to life, the right to dignity, freedom of speech, freedom of association and freedom of movement. Examples of socio-economic and cultural rights are the right to have access to sufficient food and water, the right to have access to social security, the right of access to housing and the right to education. The purpose of socio-economic and cultural rights is to ensure that all persons have access to resources and services that are needed. Socio-economic and cultural rights are important for the very poor and vulnerable people in our society. The government provides these rights according to what it can afford. Very often people say that socio-economic and cultural rights are provided within the available resources of the government.

The costs of private doctors, hospitals and medical aids are very expensive and some people cannot afford to pay these costs. Section 27 of the South African Constitution guarantees everyone the right of access to health care services including reproductive health care services. Children are regarded as being vulnerable and every child is given the right to basic health services. This section places a duty on the state to provide children with basic health care. Section 28 also places a constitutional duty on parents, who are financially able, to provide for their children's basic needs. The constitution also provides that no one may be refused emergency medical care. Emergency health care must be distinguished from access to health care

Terms you will read in this chapter:

Crucial prerequisites: essential requirements

Decentralise care: to move care from a health care facility into the homes and community

Disparities in remuneration: a lack of equality in payment for services

Enrolled nursing auxiliary: a person with one year of nursing training who works under the supervision of a professional nurse

Ethical responsibility: responsibility to act in a correct, moral manner

Interdisciplinary team: a team of people with various clinical skills from the hospital, hospice, clinic and community

Primary carers: the main caregivers, usually family or community members

Reciprocal benefits: something that benefits both parties

Reimbursement: to pay someone back for money spent or as compensation

Stipend: money paid in place of a salary for services in the caregiver setting, often below a living wage

service which is a socio-economic right. In *Soobramoney vs Minister of Health, KwaZulu-Natal* (1997), the court decided that the Government does not have to provide free health care services to everyone. The court said that if a hospital or clinic has a limited budget, the hospital may prioritise who will receive treatment.

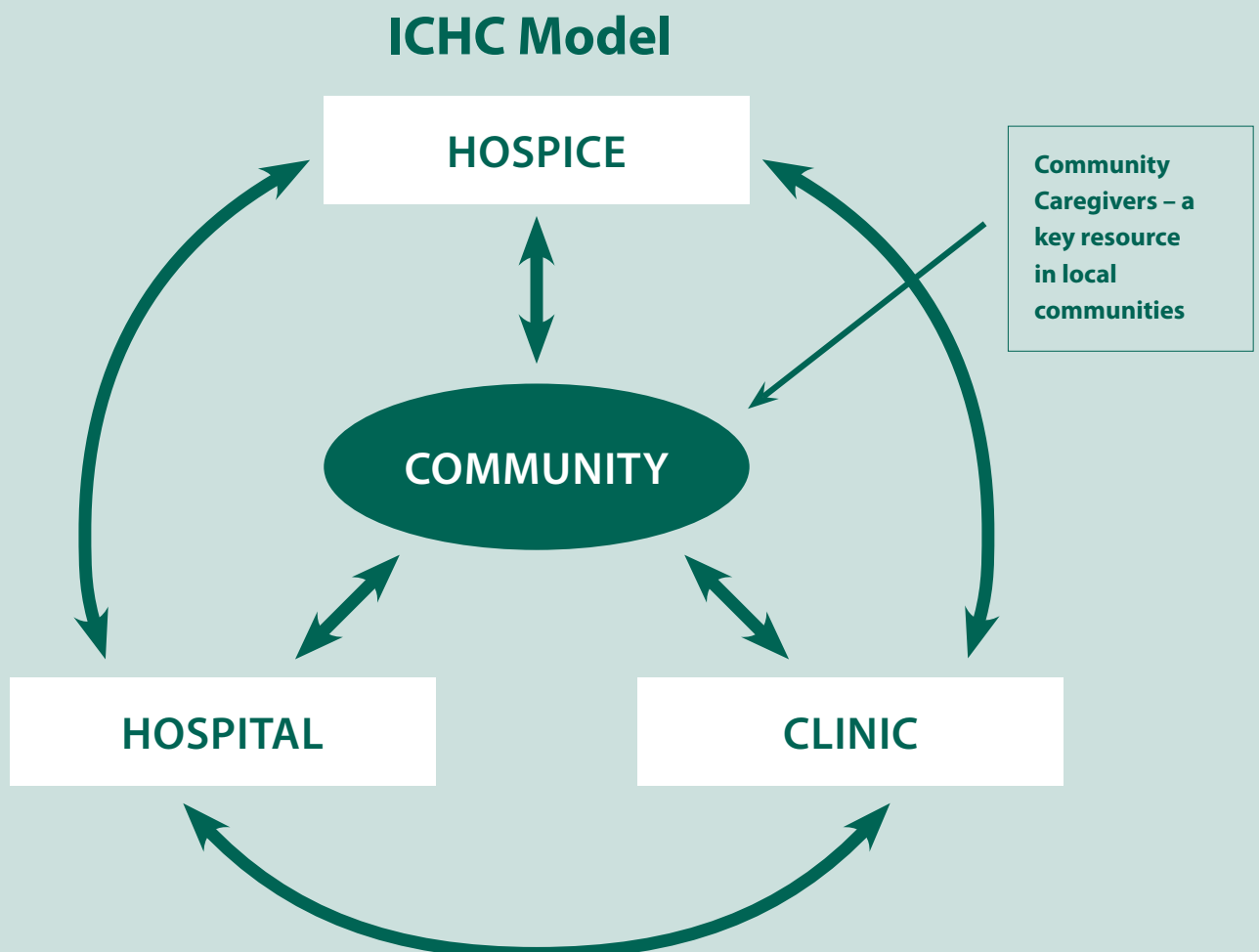
Any decision taken by the hospital or clinic must be reasonable and justifiable in the circumstances. In terms of the court's decision in the *Minister of Health and others vs Treatment Action Campaign* (2002), the Government must aim to have plans in place that will ensure the progressive realisation of the rights of access to health care.

Despite the rights provided for in the Bill of Rights, stigma is still rife within many communities. People living with HIV/AIDS (PLWHA) are often discriminated against and neglected by their families. Many people present late for treatment at PHC clinics, leading to added pressure on home care organisations. In some cases, where sick people are left on their own, CCGs have become the primary carers, assisting with household chores and even spending their own money to provide food or transport to PHC clinics. The effectiveness of shifting the responsibility for

the care of PLWHA to home care organisations, staffed by inadequately trained volunteers working without professional supervision or support needs to be questioned.

An additional problem now being faced by many home care organisations is that they are providing care and support not only for an increasing number of orphans but also for children who are HIV positive. Much time is spent in facilitating the placement of children, helping to secure relevant grants and seeking programmes providing paediatric care. In response to this need, HPCA has recently created a paediatric portfolio to focus on the need to provide training for those, including CCGs, providing palliative care for children and to expand existing hospice services to include programmes that will meet the specific needs of children.

Within a palliative care context, CCGs form part of an interdisciplinary team whose focus is on providing holistic home-based care in line with the World Health Organisation (WHO) definition of palliative care. The Integrated Community Home Care Model, promoted by the Hospice Palliative Care Association, regards CCGs as a key resource within the community.



Care giving activities

CCGs visit homes in the community each day, often walking long distances in the heat or the cold, to assist with:

- Physical care such as bed bathing, mouth care, wound care, cleaning those with frequent bouts of diarrhoea, etc.
- Emotional support
- Training family members how to care for PLWHA
- Securing relevant grants
- Referrals to clinics, hospitals and hospice programmes

When CCGs become well known in their communities, there is a danger that the demands made on them, often after hours, exceed their skills and ability to cope. Their own families begin to suffer and the cost of care becomes too great to sustain.

Although many CBOs claim to provide palliative care, lack of resources within these programmes usually means that care is limited to basic nursing or supportive care. In order to provide palliative care in line with the WHO definition, it is essential that the following are in place:

- CCG training which needs to include home care, palliative care both for adults and children, infection control, psycho-social support as well as record keeping
- Job descriptions, contracts and remuneration
- Adequate equipment and supplies
- Professional supervision
- A referral system which ensures the availability of medication
- Caregiver support and on-going training

Friedman points out that often 'lip service is paid to the importance of community based programmes without a willingness to provide the type of support lent to hospital and clinic based services'. Where CBOs are expected to operate without any of the essentials mentioned above, it is little wonder that only very basic support can be provided.

Although they are collectively responsible for the bulk of the hands-on care provided to people sick with HIV/AIDS by home care programmes in South Africa, lay community caregivers are currently not regulated by any professional council. This means that their work has to take place without the guidelines that a mandatory scope of practice provides. The ethical responsibility of promoting safe practice therefore falls upon the organisation to which they belong. The South African Nursing Council recognises the following categories of nurses:

1. The registered professional nurse who on completion of a minimum of three years training linked to a tertiary education institution is awarded a diploma or degree and is allowed to practice independently within a prescribed scope of practice.

2. The enrolled nurse who on completion of two years of dedicated training works within a scope of practice that allows for only very basic nursing interventions to be provided without supervision by a registered nurse who retains accountability for the activities she has delegated.
3. The enrolled nursing auxiliary who after one year of training is not permitted to provide even basic nursing care without professional supervision.

It is therefore apparent that to safeguard themselves as well as those entrusted to their care, community caregivers should be given adequate training, reimbursement, professional supervision and a proper job description.

Professional supervision

In order for any organisation to claim to provide palliative rather than supportive care, those providing home-based care need to be able to deal with issues of pain and symptom control. While CCGs play a key role in identifying and referring distressing symptoms, pain management is beyond their scope and it is, therefore, essential that CCGs are supervised and supported by professional nurses. The supervision of trained non-professional caregivers by registered nurses has assumed paramount importance in Africa. It is ethically inconceivable to accept that this category of health care worker should be allowed to function independently. It is the professional nurse who is responsible for the first assessment of the patient and for developing the care plan which the CCGs are involved in implementing. She is also responsible for supervising, supporting and teaching the CCGs so that together they provide holistic patient care and family support.

In 2006 HPCA conducted a brief survey exploring challenges and barriers to non supervised care giving by less formally trained palliative care personnel as well supervision and mentorship skills of professional nurses. This was a collaborative venture with Palliative Care International based at Sir Michael Sobell House in Oxford in the United Kingdom.

During interviews with caregivers the areas of concern they raised included:

- Lack of structured and formalised relationship with the primary health clinics and lack of time and commitment to supervision on the part of clinic nurses.
- Lack of medical supplies to use when working with patients.
- Reluctance on the part of nurses to accompany caregivers on home visits.
- Difficulties in report writing.

For the professional nurses the challenges included:

- Limited knowledge of scope of practice and need for referral.
- Difficulties with accountability and monitoring.
- Limited report writing skills.
- Disparities in remuneration between paid caregivers and volunteer caregivers who do the same job.
- Caregivers who are HIV positive themselves are at times not productive, resulting in an uneven distribution of care responsibilities.

When one considers the issue of professional supervision and the benefits it provides for CCGs, it is important to ensure that organisations train and support professional nurses in this role. Many nurses are unfamiliar with the scope of practice of CCGs and they also report that while it is easy to give praise, it is a challenging task to discuss and deal with areas of conflict. Although the National Department of Health recognises that there is a need for some kind of control or supervision of community caregivers, the model of linking them to a clinic does not appear to be working as there are no clear guidelines to direct the process and, in reality, clinic staff members are too busy to take on this supervisory role.

Who pays for care?

While some Community Based Organisations (CBOs) receive funding from the Departments of Health or Social Services at national or provincial level, there remain many informal CBOs providing a range of health care services within their communities without any form of remuneration. Even when care is provided by volunteers, it would be a mistake to regard it as a cheap option. The physical and emotional costs for those, usually women, providing care that is unpaid and under-valued are enormous. Whether it is acceptable to encourage unemployed people in poor communities to work as volunteers remains a contentious issue. As Friedman points out:

It is not surprising therefore that worldwide, most schemes which involve voluntarism are situated in predominantly industrialised countries or among upper/middle classes in developing countries, where people can afford to volunteer. Crucial prerequisites to this volunteering are time and money. A secure economic and social life makes voluntarism possible, even attractive... The reverse applies among volunteers from poorer settings where they are driven by the hope that it will lead to paid work or some other benefits ... Based on the burden that voluntarism tends to place on the poor, many view the intentional use of this strategy by health services as a form of exploitation.

Friedman also makes the point that in small rural communities, there might be reciprocal benefits in helping one's neighbour, but within an urban setting, driven by a cash economy, survival depends on some sort of monetary payment. As Margaret Legum, the Chairperson of the SA New Economics Network points out:

They [Governments] can intend, and effect, that people are paid closer to what they are worth, rather than what they must take because they have no alternative.

Organisations providing care to PLWHA and orphans and vulnerable children (OVCs) are unable to charge a fee for service and therefore are reliant on funding from donors, many of whom are reluctant to fund salaries. This point is illustrated by one care provider who recounted that when they included stipends in their proposal, the donor insisted that this budget item be removed or else the funding would not be granted.

At the time of writing, HPCA member hospices either employ CCGs directly or channel government stipends to the CCGs. Remuneration can therefore vary between a stipend of R500 and a salary of approximately R2000 per month. Viewing CCGs as employees means that they then have contracts, job descriptions and are bound by the policies and procedures of the organisation. This is particularly significant when one thinks of areas such as confidentiality, a key concern to PLWHA. An additional advantage is that attrition rates are lower, reducing the need for constant initial training of new CCGs. It is imperative that the CCGs be educated about the patient's right to privacy. Where the CCG works for an organisation and breaches the privacy of a patient during the exercise of her duties, the organisation may be held liable for the damages suffered by the patient. Section 14 of the Constitution provides that everyone has the right to privacy. Legal rules require that doctors, nurses, dentists, psychologists and other health care workers keep patient information confidential. Details about a patient's health status can only be disclosed to someone else, provided the patient has provided his or her informed consent. In a landmark court ruling, *Jansen van Vuuren vs Kruger* (1993), the court ordered a medical doctor to pay damages to a patient where the doctor disclosed a patient's HIV status to another person without the patient's consent. Lay counsellors also have to respect a patient's confidentiality even though they are not registered with a professional body. The common law of South Africa provides that all persons have the right to privacy and this requires all persons to respect the privacy of information belonging to another person.

In South Africa, a patient's information can only be given to another health care worker if:

- The patient consents
- A court orders a health care worker to disclose the HIV status of the patient.
- An act of Parliament requires a healthcare worker to make a disclosure.
- After the death of a person, where the next of kin has given permission.
- A health care worker is allowed to disclose the status to another health care worker if the disclosure is for a legitimate purpose within the ordinary scope of the duties of the health care worker and where the disclosure is in the best interest of the patient.

One area of confusion is that when stipends are paid via hospices, there are conflicting messages from the Department of Health, which insists that the CCGs are volunteers, and the Department of Labour, which maintains that they are employees. The Department of Labour's Expanded Public Works Program is one of the government's short-to-medium term programmes aimed at the provision of additional work opportunities coupled with training. Allowance is made for Expanded Public Works Program projects to pay below the minimum wage as gazetted in the Code of Good practice for employment under the Special Public Works Programme, as this is a form of training on the job. However, there is a concern that the lower rate of pay is applied not only to CCGs in training but also to experienced CCGs who have completed training.

An employee is defined in the Labour Relations Act 66 of 1995 as any person, excluding an independent contractor, who works for another person or for the State and who receives, or is entitled to receive, any remuneration and any other person who in any manner assists in the carrying on or conducting the business of the employer. Persons who do not receive remuneration will be excluded from the definition of employee. However, remuneration includes payment in kind, non-cash payments or benefits given in return for services rendered. Payment in kind would include providing accommodation, food and other supplies. A person working in a charitable institution will only be regarded as a volunteer if such a person does not get paid. In terms of the scenario sketched above, where CCGs are either employed directly by the organisation or receive government stipends which are channelled through the hospice, the relevant individuals will be regarded as employees in terms of the law and will be entitled to the protection afforded by the South African labour legislation.

Issues of gender

Because women's activities are generally invisible in national income accounting systems, there is an assumption among ordinary people as well as policy makers that the supply of women's labour is unconstrained and flexible. It is assumed that women can adjust their time easily and rapidly between market work and household production. Thus, it is often assumed that in response to crises or illnesses, women's labour will be the adjusting variable. When women are the primary carers in the household or work as volunteers in an organisation, the value of the time and effort required to perform this unpaid work is not taken into account in economic terms, despite its key contribution to communities and to the economy.

An evaluation of home-based care in southern Africa found that 91 per cent of caregivers are women. In addition to the burden of care, women have had to forego earning opportunities, resulting in a continued state of poverty within the family. Even when a CCG does receive a salary, it is often the only income supporting the family and is low in comparison to rising costs. In addition, there is often uncertainty about continued funding for CCG stipends or salaries, creating anxiety regarding the lack of job security.

Many young girls are forced to leave school to care for a sick family member, thus forfeiting the chance of an education and future employment prospects. In terms of Section 29 of the Constitution everyone has the right to basic education. Where young children are forced by circumstances to leave school to look after ill family members these learners have no hope of exercising their right to education. In terms of the South African Schools Act 84 of 1996 a child is compelled to attend school from the year in which the child reaches the age of seven to the last school day of the year in which the child reaches the age of 15 or the ninth grade, whichever occurs first. The problem with these rules is that the Department of Education is not monitoring whether the children who are compelled in terms of the law to attend school are in fact in school. If the Department monitored the situation one would have a much clearer understanding of the number of children who are not attending school. One also needs to recognise the impact of placing the emotional burden of care and household duties on children who are too young to assume these responsibilities. Involving more boys and men in care responsibilities would make a significant contribution to changing traditional attitudes towards what are perceived as gendered responsibilities and lessening the burden on girls and women.

Regardless of how well trained CCGs are, it can be awkward for a young black woman to provide care to an older man because of cultural norms and expectations. It is particularly unacceptable for her to suggest to a man that he engage in safe sexual practices. In the rare cases where there is a male caregiver on a hospice team, it is not unusual for him to feel that he should assume seniority and ask his female counterparts to do the more menial tasks simply because of his gender.

Caring for carers

‘Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general?’

There is a crucial need to recognise that CCGs need support to deal with their own emotional needs. The fact that many of those providing care are, themselves, HIV positive, with similar needs to their patients, means that the need for support is even more important.

Dealing with stigma and discrimination, the emotional stress of repeated losses, the physical strain of having to walk long distances to reach patients, the lack of adequate training, protective clothing and gloves all contribute to stress and fatigue.

Caring for caregivers can consist of many interventions to reduce stress, such as providing training so that CCGs feel more confident, providing leisure time, providing reasonable payment so that financial burdens are lessened and by organising debriefing and teambuilding sessions. CCGs could also be empowered by allowing them to participate in the decision making process.

Career pathways

The National Qualifications Framework (NQF) makes provision for various levels of training for Ancillary Health Care workers, including home care, palliative care, caring for people with disabilities as well as health promotion. While Standards have been developed, the process of accrediting training providers and introducing skills programmes has been very slow. It is hoped that when the system is fully functional, there will be career options for those currently working as CCGs.

Summary

Community Caregivers (CCGs) play a vital role in the provision of care to many who would otherwise have little access to any form of assistance. However, this care comes at a cost to the patient, the family, CBOs and CCGs and it is essential that government and donors acknowledge the critical role that caregivers, particularly women, are playing and provide the financial support needed so that palliative care for all who need it becomes a reality.

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