Editorial - The Role of Carers

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An article appears in this edition of the Malawi Medical Journal which articulates very clearly the gains which can accrue to the health sector if grandmothers were empowered to become consistent partners, especially in the provision of Maternal and Child Health and/or Reproductive Health services in Malawi, as studies have shown in other parts of the sub-Saharan Africa. This is in recognition of the pivotal role grandmothers play in influencing decisions, including those relating to health seeking behaviour, within their extended families. This is true, especially in the traditional rural settings where family structures remain intact. In these settings, there may also be significant others who influence the role of carers in healthcare, as will become apparent later.

In urban areas however, where these traditional family structures have been disrupted, solely younger couples play the role of caregivers in the home, at times with influence from some 'sympathetic' older neighbours. Here, many caregivers therefore lack experience and critical support when confronted with a sick child or adult family member.

The necessary support may be social, psychological or financial. The trauma resulting from lack of such support may be quite intense and could explain such common observations as delays in seeking formal medical care, refusal to accept hospitalisation or even absconding from hospital before completion of prescribed inpatient care and failure to complete or sustain long term therapy. This trend is usually evident in public health facilities, which cater for the poorer sections of our communities in the urban and in rural areas, as opposed to the private fee-paying facilities in urban areas.

A lot of such behaviour becomes incomprehensible especially to those of us planning and executing such medical care. We are disappointed or even angered by such apparent irresponsible behaviour, most times without being able or wishing to understand reasons influencing such decisions. Ignorance, fear, superstition, negative rumours, poverty, become some of the items on our long list of postulated reasons for such decisions, often not knowing in which order of importance.

We understandably are unhappy with those that report late to our health facilities, or even ridicule the many skin scarifications on what are perceived to be affected parts of the patient's body. The many charms tied around the child's neck, wrist or waist usually come in our way as we struggle to secure an intravenous access. The numerous severely acidotic babies with distended abdomens with or without a history of diarrhoea and ingestion of some herbal medications are particularly distressing to us, as oftentimes their prognosis is grim even under our ICU care.

Is there something the health sector has completely failed to do in order to influence the role of caregivers, or are some of the deterrents to improved care so much part of our communities' make-up that it is inconceivable to reverse the apparent negative practices and trends? When opportunities arise in our busy health facilities do we have ample time to interact with these individuals who complement what we do in our health institutions, and are therefore so critical to improved outcome of our medical care efforts?

It is perhaps true to say that some attempts are being made both by government and individual health care workers to try and improve the role of caregivers. Some of these efforts are made using a multisectoral approach by involving other social sectors outside the formal health sector, as is evident with the many community-based initiatives tackling the HIV/AIDS problem in the country.

In Malawi, the Ministry of Health has for some time promoted the role of health surveillance assistants (HSAs) as a bridge between communities and the formal health sector. By working with village committees and with support from their nearest health facilities, HSAs are engaged in promotive and preventive health services through improved water and sanitation, they conduct childhood immunisations, manage 'minor' ailments within communities and counsel caregivers for the many health problems facing communities. Their suitability for the many responsibilities piled upon them is an area that has called for regular review of their educational qualifications, training as well as other logistical support needed for them to discharge their duties effectively.

The department of paediatrics in the Queen Elizabeth Central Hospital in Blantyre locally developed critical care pathways as a simple but standard patient management tool, especially for the very sick patients. Critical care pathways also act as an inpatient care record. One important feature of this tool is the designated space for clinicians to record, during ward rounds or at any time they review the patient, that they have shared with the carer the management plan for their patient. This is an attempt to inform the carers about their patient's management plan while at the same time addressing any issues that they may bring up regarding the patient while in hospital or later.

Let me share what may appear to be an unusual but important role for a carer. I was once asked to review a critically sick patient who had been transferred to the procedure room. Before I could even assess the patient, he died. For a moment I did not know what to say to this poor mum. As I stood there, obviously stressed and not knowing what to say to the mother, she said to me 'Basi a dokotala, ndi chifuniro cha Mulungu!' (It is ok doctor, that is God's wish!). This mother, although sounding fatalistic to many because death of an infant may not be an unusual thing perhaps, in our setting, her apparent faith when she saw the anguish on my face encouraged me, and I held her hand for a while in silence.

Recently, I decided to visit in the village, a terminally sick young mother of three who had been discharged from one of our referral hospitals with cancer. Sitting helplessly beside her was her mother who told us her daughter had been discharged because 'she was now cured'! It was clear to me as she described her daughter's illness and sounding rather sarcastic, that the family had been told about the diagnosis and the poor prognosis, but perhaps they were sent away with little pain relief. As the patient lay on the mattress, conscious but restless, I attempted to palpate her abdomen. Finding a huge irregular liver and the firm mass above her left eye, I picked up courage and asked whether they had been told that

she had cancer. Mother then confirmed this and she began to say, genuinely I think, how helpful everybody at the central hospital had been. They had tried to save her daughter, being a young mother with negative serostatus for HIV. I felt that her apparent sarcasm was perhaps only a way of consoling herself in this desperate situation. I had very little to offer them, other than some advice on how to position her when trying to give her fluids orally. Mother audibly appreciated this. Few days later the young mother died, and it was one more funeral that I attend.

Few weeks earlier, a 10-month old baby died of severe pneumonia in one of the rural health centres nearby, after a couple days of treatment. Burial was delayed for two days, as his maternal side wanted someone to confirm that his paternal relations had killed the baby! We don't know how the matter was settled but there is now new 'evidence', we are told, that in fact it is one of his mother's relatives who killed the baby. I am sure that this is not an isolated instance of claims and counterclaims of this nature. It explains the many charms that we see in hospitals protecting our patients from these evil forces.

The role of carers in our communities is quite complex and is influenced by many different forces. The health sector is but one of them. Socio-economic and cultural factors, including witchcraft are the other. The health sector in Malawi has recognised this and will need to continue to do so, and for a long time to come. In which case, it is important to appreciate the challenges faced by the health extension workers in our communities as more and more responsibilities are created for them. Community elders, including grandmothers would not be immune to these challenges.