

Home-based care: caring for people in the community – challenges and opportunities

^aJack E, MA, MBBS(UK), MRCP, MRCGP ^aJenkins L, MBChB, MFamMed, FCFP(SA) ^bEnslin D, MBChB student
^aDepartment of Family Medicine (George Complex), Stellenbosch University, South Africa
^bElective period at George Complex

Correspondence to: Dr Louis Jenkins, e-mail: ljenkins@pgwc.gov.za

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Introduction

The Department of Family Medicine in the George Complex shares in the healthcare of about 600 000 people in the Eden and Central-Karoo districts.

One of the roles of the department is to provide clinical backup to our colleagues working in the community. To this end, we regularly join the home-based carers on a weekly morning round. A recent visit provided a fascinating insight into the challenges facing home-based carers, and community care more broadly, but also highlighted the excellent opportunities for intervention when providing care to people in their own homes. Based on these insights and interviews with home-based carers and the group partly funding their work, we lay out some suggestions on how these challenges could be met.

Case descriptions

The team comprised a staff nurse, two home-based carers, a medical officer and a third-year medical student from Pretoria who had taken her elective in our department. Safety is a major concern to the home-based carers, and one that they spoke of frequently. They never travel alone and have to deal with verbal harassment as they perform their work. To that end, they weren't prepared to take the responsibility for our travelling in their car, so we duly followed through the maze of dirt roads that intertwine the informal settlement of Thembaletu. The journey itself was far from the most dangerous part of the morning. We followed for 15 minutes and reached the end of a cul-de-sac.

We were to visit a 19-year-old girl recently discharged from the local tuberculosis (TB) hospital, having completed her intensive phase of treatment for TB meningitis. She lived in a cramped one-bedroom place made from corrugated sheets and lined with black bin liners. She was accompanied by an aunt and six young nieces and nephews. We introduced ourselves and crowded into her home. The consultation was led by the staff nurse, with help from the two carers. The patient was hit with a volley of closed questions, based on a pro forma questionnaire. Enquiries about her compliance, clinic attendance and diet were duly met with "Yes, sister", "No, sister", and there was certainly a sense of tension there.



Her weight was checked, and we moved on. As we left, I asked the nurse whether the children had been screened for TB or started on prophylaxis. She didn't know.

Some of the reasons for the tension in the previous consultation became more obvious with our next visit. We met another aunt who lived in a larger brick house around the corner. She was caring for a baby, and I was pleased to be able to help by looking at the baby's eye that the aunty and nurse were concerned about. There was a good rapport between the carers and the aunty. It transpired that this baby was the child of our first patient. The baby was being cared for away from the mother as a result of her TB diagnosis, and the mother would come and visit the baby from time to time. Through their discussions here, it became apparent that our first patient had frequently neglected to take her TB medication, and the nurses were rightly concerned about this, as was the aunty, who seemed to be a matriarchal figure for the neighbourhood. Plans were made to restrict the mother's access to her child further if she didn't take her medicine.

On our next visit, our two Xhosa-speaking carers entered the house first. They wanted to seek permission for us to be able to visit a palliative care patient, particularly as they had a doctor with them on the round. The patient had been diagnosed with HIV and stage IV cervical cancer. They came out and explained that the lady wasn't there. She had

returned to her homeland in the Eastern Cape. She wanted to seek help from her traditional healer before she sought help from the oncologist.

Working in South Africa, one often comes across this juxtaposition of traditional healers and “modern medicine”. It can lead to frustration, as one sometimes finds one’s efforts to help the patient being thwarted or impeded. The carers passed no judgement whatsoever; they simply made a plan to revisit the lady if and when she returned.

During the course of our visits we discovered that the nurse who was leading us was leaving her current post. Upon enquiry, she told us her husband had a job elsewhere in the country and she was taking the opportunity to move into the private sector to run a care home. I asked how she felt about her current job. She sighed and replied, “We don’t make a difference.” I asked why not. “The patients won’t take their medicines”, she replied. She reckoned that, in the last year, the number of patients not complying with their TB treatment had increased from 8% to more than 20%, “And now there’s MDR we never used to have that.” She postulated that the main reason for this was the difficulty that community members still faced with the stigma attached to HIV/AIDS and indeed TB.

Our last visit was particularly insightful. We attended another one-bedroom place, very similar in size to the first home we had visited. It was much tidier and lighter, this time lined by brown cardboard boxes to keep out the cold. It also had a light bulb. A bright 26-year-old girl, Mina, greeted us. She was caring for her mother, Gina, and her 14-year-old brother who wasn’t at school. She had moved from Port Elizabeth when she heard that her mother was sick again. The nurses got on well with her and found her remarkable because she was in her mid-20s, without children and using contraception until things were settled with her boyfriend.

The consultation was much more open in style, and we were pleased to hear that Gina (in her 40s) was making progress. She had had a stroke two years previously, leaving her with a right hemiplegia. She had recovered somewhat from this but had been laid low again by a bout of pulmonary TB. She had just been discharged from the local TB hospital. We worked our way through the questions on the new patient pro forma. This time the answers were much more expansive, and there was chance for dialogue. Gina’s weight was up, she was starting to walk, she was HIV negative and she was taking her tablets regularly. The nurse then asked to see her tablets.

Gina revealed her TB medication and then a packet of lamzid and efavirenz. The home-based care team all paused, clearly aware of the contradiction that we had just been presented with. No-one seemed willing to discuss this, and I looked to the nurse who had been leading our consultations and said under my breath, “They’re ARVs.” I was startled by the reply, “That’s your world.”

I was glad to take the opportunity to find out what was known about these tablets. I asked the daughter whether she knew what they were. She said she thought they were for TB but also said she thought they were called ARVs. I asked Gina, who replied she didn’t know what they were for either. I

gained her permission to explain before telling Mina that Gina was HIV positive and that this was her treatment. It became clear that in this instance the counselling process had broken down. On a couple of occasions at the TB hospital and the local clinic, the daughter had asked what they were for. She was told, “For TB” and “We can’t tell you without your mum’s permission.” Mina cried, but there was relief, and it was useful to have an open dialogue about what needed to happen next.

On reflection, several things struck me about this consultation. Mina was the rock on which the family was built; her mother’s well-being depended on her. I felt that whilst Gina was still frail, the opportunity to disclose her HIV status and the increased likelihood of her receiving effective treatment had dramatically improved her prognosis and, one also hopes, her quality of life. Several things had stood in the way of this opportunity: Gina’s right to confidentiality, the stigma attached to HIV and the fact that although I suspected Mina knew more than she was letting on, the medical profession had failed her on this occasion. In particular, the vital counselling process that should take place when one is diagnosed with HIV (or any other chronic disease) had not been effective.

Discussion

The morning showed the varied case load that the home-based carers manage, including some problems facing many communities in South Africa. The carers’ work is dominated by looking after patients with HIV and TB and facing up to the issues of compliance, as seen in the first visit to the young lady recovering from TB meningitis, and disclosure, as seen when they visited the last patient, Gina, and her daughter. This can have an effect on the morale of the individual carers, as our discussion with the staff nurse highlights. However, these cases helped us to highlight some specific challenges faced by the home-based carers.

Challenges

Safety

Safety is a major concern and limits the amount of work the carers can perform. Each carer has up to 15 clients on his or her books, and carers are generally matched with patients who live in the same zone as they do. The carers have to work in pairs for their own safety, as they have been harassed as they walk from patient to patient. Working in pairs clearly reduces the total number of patients that can be visited by each carer.

Training

The home-based carers are involved in managing a wide range of conditions. Our description of a morning spent with the carers demonstrates this; their task includes anything from supporting the treatment of TB and HIV to helping to care for those in need of palliative care. The Department of Health also lists prevention and early identification of disease as part of their role.¹ The current home-based care courses, such as those offered by St John’s Hospice Care, fall into two categories: a basic five-day course (40 hours) or the advanced course over 3–4 weeks (120 hours).

The cases we describe suggest that the training and empowerment of home-based carers need to be augmented. In these cases the carers stuck to a necessary pro forma but were perhaps inhibited by this, or perhaps through lack of training and empowerment missed some opportunities, particularly in their aim of disease prevention. On visiting the first patient, no attempt was made to discuss the need for the prophylactic treatment of TB in the young children living with our patient. There was also a reluctance to address the issue of Gina's non-disclosure of her HIV diagnosis.

Accessing and identifying those in need

There are 20 carers covering the township of Thembaletu. Although precise population data are not available, it is thought that the population of Thembaletu is at least 50 000. The patients are categorised so that some are visited weekly, some twice a week and some every day. Patients are referred from clinics, George Hospital, Harry Comay TB Hospital, Bethesda Hospice and less often via word of mouth in the community. The majority of the carers' patients have already come into contact with the healthcare services. Clearly there is a need for the care of those suffering from chronic disease, but given the number of carers covering the area, their ability to engage in health promotion and case seeking is limited.

Stigma

One of the problems the home-based care workers highlighted was the stigma their visits can cause. The carers are generally assumed to be 'HIV nurses'. This can make families reluctant to receive the home-based carers. Perhaps this played a role in our planned second case in which the patient we had hoped to visit was said to be away.

Opportunities and suggestions for the future development of home-based care

Understanding the culture and social structure of the community in which one is working is extremely important in reaching the widest range of patients in a way that is meaningful to them. The home-based carers who are a part of the community they serve are ideally placed to help those with chronic disease, to act as a point of access to healthcare services for those in need and to be a vital source of information for the community.

To be able to do this more effectively, the carers must feel empowered. Generally, given the complexity of their task and the challenges faced by carers, we feel their training must be enhanced. Whilst the proformas used provide a useful starting point for the carers, it would be excellent if, through greater understanding of conditions such as TB, the carers could become proactive in terms of seeking out and preventing cases. The majority of carers in our area are Level 1 (i.e. they have received the basic 40 hours of training); in terms of career progression for them, the only step up is to a Level 2 carer (i.e. completing the 120-hour course). It would provide carers with an incentive to gain further training and expertise if some further levels of care could be added.

Supporting the carers is essential. At present, the carers report daily to a staff nurse, who in turn reports weekly to the clinic

sister. The individual carers don't have a regular meeting with the clinic staff. To that end, the family medicine department at George Hospital provides a doctor to attend the rounds weekly. This hopefully helps the carers, providing a chance for feedback and teaching, and from our morning it seemed to influence the patients visited that morning. In particular, we were taken to see a baby with an eye problem, and the visit to see the lady with cervical cancer was arranged specifically because there was a doctor with the carers.

This partnership also benefits the family medicine department. The doctors in the regional hospital gain insight into the patients presenting to the hospital, getting a much more holistic view of the patients seen daily, far from their home in the hospital setting. It also offers a better understanding of the needs of the community as a whole. We have also learnt which patients the home-based carers can help best. Recently, the carers have asked for more referrals and have given us a direct fax number to facilitate this process. We would welcome a development of this process but also feel that a more 'joined-up' approach involving the doctors and nurses based at the clinic, the family medicine department based at the hospital and the home-based carers based at the offices of the nongovernmental organisations who fund them. A weekly meeting at the local clinic for the carers and representatives of the above groups could help co-ordinate referrals and also provide an opportunity for feedback and education.

As the efficacy of home-based care improves and as society becomes more accepting of HIV/AIDS, one hopes that the stigma associated with home-based care will also pass. This, combined with better training, will hopefully prompt the local community to come to value the home-based carers and to make use of them as a resource. This will also broaden access to the carers.

Home-based care is a cornerstone of the South African Government's policy on fighting HIV and TB. It intuitively seems like a positive development, but there is certainly a dearth of data as to whether it has an impact on outcomes, such as the default rate of TB medication, or on individuals' behaviour. More research is needed in this field to help develop home-based care in the most effective way.

This snapshot of a morning with a home-based care team illustrates the unique opportunities that they have to intervene in the health of an individual and a community. It also highlights the challenges faced by the home-based carers and the challenges faced in providing them with effective training and a safe, well-resourced working environment. The article goes on to suggest some ways in which the home-based care service could be enhanced locally, with implications for national policy, and calls for more research into the outcomes that home-based care can achieve, so that the potential benefits offered by home-based care can be fully realised.

Reference

1. Department of Health. National Guidelines on Home-Based Care, 2001. Available from <http://www.doh.gov.za/docs/factsheets/guidelines/homecare> (Accessed 14/05/2010).