Mutual Isolation and the Fight for Care: Exploring Home-based Healthcare in two South African Communities

Izak van Zyl, Anton Delen, Siphokazi Tswane

Home-based Healthcare Research Unit, Faculty of Informatics and Design, Cape Peninsula University of Technology, Cape Town, South Africa

Abstract and Objective

The 'duty' of home-based care is often imparted on non-government institutions that employ nurses and caregivers to provide care. These organisations are hampered by a capital barrier in that they rely on grants and donations. Therefore they are often not financially sustainable. This generally results in caregivers and nurses being underpaid and –resourced. A lack of resources translates into fractured coordination and systems when administering care. It has become crucial to redirect these systems so as to be more practical and effective. Yet this process cannot commence without understanding the many dynamics that shape the home-based healthcare context. A bottom-up ethnographic approach is therefore necessary to inform a proper care 'solution'. For this analysis, two communities in the Western and Eastern Cape of South Africa were assessed in their home-based healthcare endeavours. It was found that the care context is volatile and that caregivers require more resources to guarantee continued service. These findings are significant for understanding the 'grassroots' of home-based healthcare in South Africa for the possibility of developing a (technological) solution to care.

Keywords:

Home-based healthcare, Caregivers, Information flows, Fractured coordination, Care solution, Care context, Care network.

Methods

Two HBHC regions were engaged as participants. The first is the greater Stellenbosch area, and specifically Kayamandi, in the Western Cape, managed by Stellenbosch Hospice as primary care facilitator. The second is Motherwell in the Eastern Cape, administered by Olive Leaf Foundation as principal HBHC provider. Participants in these networks were questioned by means of structured and unstructured interviews. Data was collected through video- and sound recordings, as well as written notes. Caregivers, care coordinators, and patients were the primary participants in the study.

Results

Patients in both communities face the harsh realities of impoverished contexts. Despite that, patients adore and revere their caregivers, and follow their care plans religiously. Not to mention, care has been very effective in these communities. A number of patients were visited that in fact recovered well due to their continued, thorough treatment schedules. That said, home-based care functions in a precarious environment – one that persistently undermines its (potential) value to patients in need. The fight for care ensues.

Given that patient files and information flows are at the core of the home-based care systems in both Kayamandi and Motherwell, their proper handling is vital. It is apparent, regrettably, that patient files are continually mismanaged due to extraneous circumstances. Their handling poses a real problem for both care providers and patients. Moreover, (technological) alternatives to this paper-based standard are not readily accessible. In Kayamandi specifically, caregivers try to employ mobile phones. But given the unstable circumstances, the phones often get damaged, stolen or lost.

Conclusion

Caregivers and –receivers function in a cycle of mutual isolation, where both parties scrap to provide and access care. This cycle is especially characterised by an unstructured, sporadic approach to information (patient data) collection and dissemination. The possibility for sound technological measures arises, particularly concerning the strengthening of current systems and consequently, the overall betterment of care. Yet, the described volatile context(s) may hamper the development, integration and acceptance of any technological endeavour (intervention). It is thus crucial to facilitate a bottom-up approach, where community participation is central in aligning a new, differing system of information gathering and utilisation.