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Full Length Article

Needs and challenges of lay community health workers in a palliative care environment for orphans and vulnerable children

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ABSTRACT

Introduction: The escalation of HIV/AIDS infections in the last decade has increased the need for palliative care community organizations to care for orphans and vulnerable children, who are in dire need of support. Many of these organizations depend on the services of lay community health workers to provide constant care to those in need of it in their local communities. The focus of this study is to explore the role of lay health workers in a community organization located in rural Bronkhorstspuit, Gauteng Province of South Africa. That provides palliative care for orphans and vulnerable children diagnosed with HIV/AIDS. Their roles were analysed critically through a job-demands and job-resources theoretical framework.

Methods: A descriptive phenomenological case study design was employed to collect data through twenty five individual interviews, two separate focus groups consisting of ten participants in one group and eleven participants in the other group, observations and document analysis. Data were processed through a rigorous thematic analysis.

Results: The findings pointed out specific knowledge and skills these lay community health workers needed in order to be satisfied with, and successful in, their administration of palliative care to orphans and vulnerable children. Participants identified the following organizational challenges that were deemed to be impacting negatively on their work experiences: the lack of career pathing processes; sufficient career guidance; and inadequate employment processes, such as staff retention, succession planning, and promotion. **Conclusion:** Through the findings, a framework for enhancing the work experiences of the lay community health workers was developed. The uniqueness of this framework is that the focus is on improving the work lives of the lay community health workers, who have serious skills-resourcing needs. There were specific concrete strategies that the organization could adopt to support the knowledge and skills requirements of the lay community health workers in relation to the needs and challenges that will enhance their efficiency in the palliative care environment. The findings and framework that emanated from this study could be used to support lay community health workers in their respective organizations to be more effective in the support they provide to orphans and vulnerable children. Because South Africa is afflicted by the HIV/AIDS epidemic, this framework can be

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used in similar organizations that are working with lay community health workers with skill-resourcing needs not only in the health sector, but also in other sectors, such as in education and agriculture.

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1. Introduction and background

According to the Human Sciences Research Council (HSRC), South Africa ranks first in worldwide HIV incidents (HSRC, 2014). The social and economic effects of this illness are complex and potentially shocking to families, communities and economies. Therefore, the impact of HIV/AIDS requires people to work together to address the international, national, regional and local challenges collaboratively (United Nations Millennium Declaration, 2000). The increasing number of orphans and vulnerable children (OVC) increases the challenges faced by the family unit and the broader community. This increases pressure on government to come up with adequate support programmes to address these challenges.

However, the government cannot manage these responsibilities on its own, hence they invite external stakeholders, such as non-governmental organisations (NGOs), non-profit organisations (NPOs), and community organisations to come on board to provide the necessary support and care for the OVCs. Government advocates that ideally all children should remain in their family units, even if this is not always possible. Due to this the government encourages organizations to provide support and care for the OVCs. This should be reason enough for community organizations to play a more critical role in the care of OVC, however, this is not the case because the survival of community organizations is dependent on the services of lay community health workers (LCHWs). Hence, this study focuses on the demands and resources of the LCHWs' job profile from an organizational level by using the job-demands and job-resources (JD-R) model as predictors. For this reason, the JD-R Model was selected as a framework to explore the needs and challenges of LCHWs (Bakker & Demerouti, 2007). Specific job demands and job resource components can be related to this study, because they can be used to predict certain behaviours in LCHWs, including work stress, burnout and work engagements, and the consequences of these variables on organizational performance (Bakker & Demerouti, 2007). The JD-R model (Bakker & Demerouti, 2007) further proposes that employee well-being is related to a wide range of workplace variables that can be conceptualized as job demands, such as the physical, social, or organizational aspects of the job that require sustained physical or psychological effort; or job resources, such as personal growth, learning and development, irrespective of the occupational context under study. Thus, the JD-R model serves as a framework to explore the needs and challenges LCHWs experienced in their work as providers of palliative care. This study examined what is expected from LCHWs in terms of competencies, abilities and

their coping mechanisms, based on their regular interaction with terminally ill and vulnerable children. The study made it clear that these situations have a psychological impact on the LCHWs. It was critical to get a deeper understanding of their needs and challenges. While there is growing evidence that LCHWs can help improve certain health outcomes (Lewin et al., 2005), research suggests that community health programmes often fail because of the lack of support, knowledge and skills offered to LCHWs (Gilson, Doherty, Loewenson, & Francis, 2007). This study shows that the sustainability of palliative care community organizations depend on an organization's ability to equip LCHWs with the knowledge and skills required to perform their jobs effectively.

2. Problem statement and objective

LCHWs serve a critical function in the communities, in which they work, providing a service to the most marginalised poor communities where none might otherwise have been available (Daniels, van Zyl, Clarke, Dick, & Johansson, 2004). They are recognized as natural helpers who play an important role in connecting the public and primary care to the communities they serve (Herman, 2011). This is unique, since LCHWs generally have a natural flair for trust, rapport, understanding and the ability to communicate with the community. Regardless of the high job demands and limited resources, these individuals are passionately committed to their jobs, their organization and to OVCs. The LCHWs enthusiasm towards their work helps them overcome the daily challenges and give them a sense of significance and worth in the role they play as carers (Bakker & Demerouti, 2008). They provide valuable work by improving the quality of health care given to patients, according to Kennedy, Milton, and Bundred (2008).

In fact, LCHWs' services are so essential in community organizations that the United States Agency for International Development (USAID, 2012), lobbied that they should have definite responsibilities and be well-supported by health services and non-governmental organizations working with them. Community organizations benefit immensely from the services rendered by LCHWs, because they have the untapped potential to provide care and support to OVCs beyond basic treatment. This is according to the primary health-care declaration of the World Health Organization (WHO, 2000) who emphasize that knowledge can be efficiently applied by laypersons and that it is not necessary to relying on specialized services from technically trained professionals. Researchers Van Ginneken, Lewin, and Berridge (2010) explain that if community organizations wish to improve on the cost-

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