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SUPPORTING CHILD CARE GIVERS: EXPERIENCES FROM THE PALLIATIVE CARE ASSOCIATION OF UGANDA'S (PCAU) ROAD TO HOPE PROGRAM

Rashidah Nakabugo Adams^a, Rose Kiwanuka^a, Mark Mwesiga^a, Denis Kidde^a and Roberta Spencer^b^aPalliative Care Association of Uganda, Uganda^bCentre for Hospice Care Indiana, Uganda

Aims of the Project:

- To contribute to children's future through supporting their formal education.
- To provide psychosocial support to child care givers and their families based on their specific needs.
- To advocate for and promote the rights of child care givers in their communities. Problem statement

Children give up key roles when they become child care givers to sick/dying parents. One of these significant areas is their education. Along with Caregiving they look for food, walk miles to obtain medications and attend to the daily running of their home. PCAU, together with the Center for Hospice Care, USA, established the Road to Hope Program in 2012 to address the educational needs of these children.

Methodology: Children are identified through palliative care practitioners in different health facilities. They are selected annually, consideration given to the most vulnerable. An assessment of a child's status is completed. Regular follow-up/monitoring is undertaken to ensure sustained wellbeing of the children.

Results: PCAU is currently supporting 42 children with school fees and psychosocial support. Health workers are relieved of stressful concerns about these children and parents are relieved to know there is something for their children's future. There is a greater engagement between the PC practitioners and the community resulting in increased visibility for PCAU.

Conclusion: Child care givers are a unique group neglected in the wider palliative care response. Palliative care providers should provide specific support to meet their needs in order to complete the cycle of care. They should also be exposed to equal opportunities as other children.

Lessons Learnt:

- The program has improved the children's quality of life through empowering them to share, speak out and express themselves better.
- Children are more outgoing, their self-esteem has improved and their hopes are restored.
- Given equal opportunities, child care givers can become important people in society. Recommendations

Palliative care programs should consider addressing the rights and special needs of the child's caregivers in palliative care at policy level.

Biography

Rashidah Nakabugo Adams has done her graduation from Makerere University. After completion of her graduation, she attended a number of training programs. Presently she is working as a Programs Officer in Palliative Care Association of Uganda.

adamsrashidah89@gmail.com