Mental health of unpaid caregivers

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To take care of her mother and educate her children, Nakabazzi hires herself out as a labourer to dig in people's gardens. PHOTOS/ GILLIAN NANTUME

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Worldwide, women disproportionately serve as unpaid caregivers, caring for children, the elderly, and people with disabilities. In most cases, this workforce sacrifices their education and careers due to the significant time, physical, and emotional burden of caring for their charges. For over five years, an HIV-positive mother in Rakai District has been trapped in an immobile state after suffering a stroke. Her daughter left her marriage to become her mother's full-time caregiver, as **Gillian Nantume** reports.

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>
> Prossy Nakabazzi caregiver

In Kiyovu village, Lwanda Sub-county, Rakai District, 59-year-old woman named Ruth Nalwadda lies in an almost vegetative state, awake but immobile, unaware of herself or her surroundings.

Before she suffered a stroke in 2019, she had owned a small makeshift restaurant in her village. This was an income that supplemented her subsistence farming. She was living positively with HIV.

Her eldest daughter, Prossy Nakabazzi, says her mother's health took a turn for the worse after a neighbour died.

"The death shocked her. One day, I travelled away from home, and when I returned, she had collapsed. She was unable to walk. I took her to a nearby clinic, and we were informed that she had high blood pressure," she says.

After carrying out some tests, the doctor informed Nakabazzi that her mother had suffered a stroke and referred her to Masaka Regional Referral Hospital for a brain scan.

"The scan did not show that there had been any damage to her brain. The doctors recommended medication and physiotherapy. Since 2019, we have routinely returned to the hospital for medical reviews. On one of those occasions, we discovered that my mother was suffering from diabetes as well," Nakabazzi explains.

Although the 37-year-old woman has five siblings, she had to abandon her marriage to become her mother's primary caregiver. Today, she looks after her mother and her 80-year-old grandmother.

"My husband kept on asking me when I would find time for our marriage since I was caring for my mother. In the end, I left the marriage with my four children. My husband could not afford to take care of his family and my family," she says.

To take care of her mother and educate her children, Nakabazzi hires herself out as a labourer to dig in people's gardens.

"I also raise some domestic animals. Because of my mother's situation, I have to work at or near the home. I cannot go to town to find employment because that would mean being away from her for an entire day; otherwise, there will be no one to give her food or take her to the toilet," the caregiver notes.

Nakabazi's siblings are also married, but she is the one who sacrificed her marriage and career to take care of their mother. To help, once in a while, they send her money to buy medication and food.

While advances in treatment have transformed HIV prevention and care,

CARERS IN MID-LIFE

Research carried out by the Eurocare Project last year in Europe found that unpaid care has a huge impact on mental health. The same research also found that unpaid care is more likely to be provided by people from low income households.

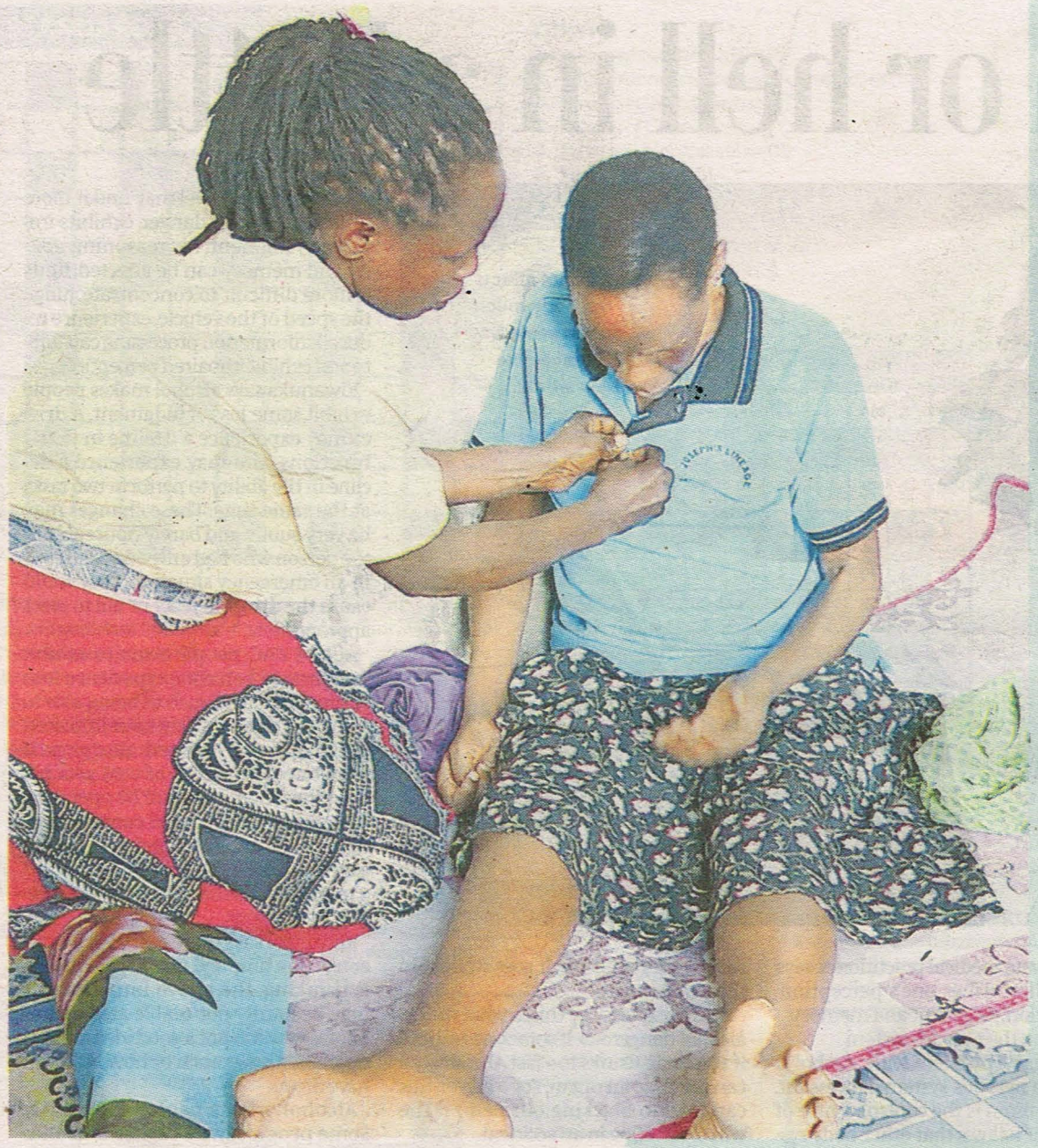
The research showed that for people aged 30-49 years in the United Kingdom, the mental health impact is more pronounced for women compared to men. The research also showed that older carers are more likely to report loneliness.

Gender inequalities in mid-life care: Women are more likely than men to provide care in mid-life and to care for longer hours each week. The gender difference in care hours for those in early mid-life (age 30-49) is particularly strong in European countries that provide less state support for carers.

Socioeconomic inequalities in mid-life care: There is clear income inequality in the likelihood of being a carer in early mid-life, with caring more likely in disadvantaged households. Becoming a carer in mid-life is linked with early retirement for both men and women in high-income and high-wealth households, where carers are more likely to be able to afford to retire.

Mental health and well-being of mid-life carers: Evidence from the UK shows that becoming a carer in early mid-life is linked with declines in mental health. Individuals in mid-life who care for 20+ hours per week or for someone within the household are particularly likely to experience significant declines in mental health.

Source: Eurocare Project



many, including Nalwadda, cannot afford the newer therapies. The cost of managing complications such as high blood pressure remains a heavy burden.

"We get our medication from Lwanda Health Centre III. But sometimes, we find there are no drugs. Other times, we are given drugs that last only one month. You find that our mother can go three days without medication," Nakabazzi says.

Despite free antiretroviral therapy in government health facilities, frequent hospital visits and the need for additional medication pose challenges.

"The problem is that I am the one who gets the medication since my mother cannot walk to the health centre. The health workers care more about the patients who physically come to the health centre. So, I am always last in line, and by the time I reach the dispenser, the drugs are over. And nowadays, with the aid cuts, drugs are rationed," she notes.

For now, the most pressing need is to find the funds to buy a wheelchair for her mother, to ease her mobility. A basic wheelchair that suits her costs Shs500,000.

This family's situation reflects a wider challenge faced by several rural households affected by chronic illnesses like HIV, highlighting the need for social support systems to ease the caregiving burden.

Nakabazzi helps her 59-year-old mother who suffered a stroke in 2019. For now, she says, the most pressing need is to find the funds to buy a wheelchair for her mother, to ease her mobility.

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Unpaid casework in Uganda

Unpaid care and domestic work (UCDW) is a development issue is embedded in the Global Agenda 2030, under Sustainable Development Goal (SDG) 5, target 5.4. The target specifically indicates the means by which women's unpaid care workload can be reduced, recognised, and redistributed through the provision of public services and infrastructure, and the implementation and enforcement of social protection policies. In Uganda, care work is not addressed explicitly in policy or service provision.

A report, Gender Roles and the Care Economy in Ugandan Households: The case of Kaabong, Kabale and Kampala Districts, showed quantitative and qualitative data gathered in 2017, that unpaid care work is primarily carried out by women and girls. There is also a stark difference between the time spent by men and women on unpaid care work. On average, women spent 32 hours weekly on unpaid care work and 21 hours weekly on unpaid production of products for home consumption, while men spent 20 and 10 hours per week respectively. This finding further strengthens the notion that care work is still largely carried out by women.

While the proportion of women to men spending time on unpaid care work stays almost the same throughout the day, there are peak periods for care work for women. These are associated with activities which are usually done in the morning (7 am - 10 am), such as cleaning the house, washing clothes, and collecting fuel/water, while meal preparation and childcare account for the peak hours around midday (11 am - 2 pm).

The survey also asked both women and men how they would spend their time if they had to do less care work. The majority of women said they would spend the time doing more income-generating work: Kampala (61.6 percent), Kaabong (46.6 percent), and Kabale (34 percent).

More rural (than urban) women said they would spend the time on agriculture, especially in Kaabong (33.6 percent) and Kabale (30.8 percent), which is to be expected, while more urban (than rural) women said they would spend the time on education (2.6 percent) and religious activities (2.3 percent).

Recommendations

- The report recommends that the government and relevant authorities adopt a 'Triple R'* approach to addressing the unpaid care and domestic workload which is shouldered primarily by women and girls.
- **At national policy level, streamline clear indicators for tracking SDG 5, in government structures.** Show how key sectors such as education, health, water and sanitation, and infrastructure can contribute to reducing care work, and raise awareness among stakeholders in these sectors on how their work can contribute to the redistribution of unpaid care work.
- **At micro level, create awareness about care work by including men in training and advocacy campaigns.** Involving men as agents of change in increasing recognition of care work presents an opportunity for promoting positive attitudes towards sharing care roles more equally between men and women. More advocacy work is essential, backed up by evidence to measure status and progress.
- **Raise awareness and increase availability of family planning services.** Childcare is considered to be among the most problematic care activities. It is vital that women and men are enabled to make decisions over the number of children they have, since the fewer the children the smaller the care workload. As the results indicated, men in Kaabong in particular have more say than women on how many children the family should have, and when. Promoting family planning among men as well as women would assist with this.
- **Provide affordable childcare facilities.** These have been proven to significantly reduce the number of hours spent on childcare, allowing women to participate more in paid work activities. While it is recognised that Uganda already has an Early Childhood Development policy, the government should do more to ensure an enabling environment that allows the setting up of childcare development centres in both rural and urban areas.
- **Invest in affordable technology.** This might include the construction of water harvesting reservoirs/dams to improve access to water for family use, and irrigation systems to increase household food production. The provision of energy-efficient stoves could greatly reduce the amount of time women and girls spend on fuel collection, food preparation and cleaning (such stoves emit less smoke and soot and therefore also create less mess and pose fewer health risks than traditional cooking methods using firewood).
- **Change mindsets.** This is one of the most important routes to redistributing UCDW between women and men within a household as well as between poor families and the private sector, the state, and civil society, at the community and at national levels. For this to happen, change must occur at all levels, including shifts in mindsets and social norms. Messages aimed at changing social norms should not be cast in a negative light (e.g. in terms of women subsidising the government by undertaking activities that could be state-provided) but in a positive way – highlighting the benefits to women and men, and whole communities, of sharing unpaid care and domestic work more equitably.
- **Empower women financially.** This can be achieved through formation of savings groups at the community level, enabling women to start up small businesses or trading activities. As well as improving households' living standards, the additional income will enable families to pay for support with specific UCDW tasks, further freeing up their time for livelihood activities.
- Empowering women financially will not only benefit women but also their entire families, communities and society as a whole. Oxfam advocates for the inclusion of a fourth R, in reference to the representation of carers in decision-making spaces, so carers' interests and needs are reflected in policies that shape their lives.

Source: The Oxfam Digital Repository

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