In Need of Care but Providers of Care: Grandparents Giving Fulltime Care to their Grandchildren in Rural Uganda

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ABSTRACT

Background
In most African countries, the elderly face challenges that affect their health and wellbeing and are more pronounced because of the systemic factors of inadequate health care, food insecurity and the general care. Increasing population of the elderly persons in Uganda is raising concern than ever before. The purpose of this paper to ascertain care available to the rural elderly persons and their role as carers for their grandchildren and implications on their wellbeing.

Methods
This was a qualitative study conducted among the rural elderly aged 60 years and above in eight purposively selected district that included Lira, Nebbi, Kampala, Luwero, Pallisa, Jinja, Mbarara, and Ntungamo. The study sample consisted of 101 elderly person from whom in-depth interviews were conducted. Data was analysed using qualitative thematic content analysis.

Results
Rural elderly in Uganda face a lot of constraints that include access to healthcare and information, poor economic status, food insecurity and poor nutrition, and poor accommodation and housing conditions. Two broader themes emerged inductively from the analysis that include care available for the rural elderly and providing care to grandchildren. These themes generated several subthemes. Taking care of grandchildren crippled the elderly and reduced the economic benefits. That said some rural elderly were happy and felt fulfilled to care of the grandchildren despite the lack of resources.

Conclusion
The rural elderly in Uganda are living in doleful conditions with limited care and support. They need care but are the providers of care to the grandchildren. They are frails and may not afford to provide adequate care. They care for grandchildren many of whom are orphans and vulnerable yet they themselves need care. It is important the government and the community re-enforce this care not to put strain on elderly. The rural elderly unique challenges necessitates special targeting and mobilization of resources at the household, local, district and national levels.

Keywords
Grandparents; Care; Orphans; Grandchildren; Skip-generation; Uganda.

INTRODUCTION

Globally, populations are growing significantly older now than 20 years ago, yet with great variation.1 In absolute numbers, persons aged 60 and over are projected to increase to nearly 2 billion by the year 2050.2 An estimated 58 million persons aged 60-plus live in sub-Saharan Africa; by 2050 that number will rise sharply to 215 million, showing an increase from 6% to 10% of the population.3 Many of these live in rural areas. Elderly care is the fulfilment of the special needs and requirements that are unique to
senior citizens. It covers such services as assisted living, adult day care, long-term care, nursing homes, hospice care, and home care. Because of the wide variety of elderly care found nationally, as well as differentiating cultural perspectives on elderly citizens, cannot be limited to any one practice. In some countries for example in Africa use the traditional methods of being cared for by their children and younger generations of family members. Elderly care emphasizes the social and personal requirements of senior citizens who need some assistance with daily activities and health care, but who desire to age with dignity.4

Anthropological theories about aging and care have focused on the changes experienced during the life course, and the interdependencies throughout life among the different generations. These theories about the age focus on late life, describing old age not only as a medical and economic problem but also as a social problem in terms of ‘social support and care giving.’3,4 Anthropologists concerned with theory have also made special contributions to the life course perspective in social and behavioral analysis of aging.7,8

In most African countries, the elderly face challenges that affect their health and wellbeing and are more pronounced because of the systemic factors of inadequate health care, food insecurity and the general care particularly targeted to the elderly who are in most cases vulnerable. As Africa’s population grows, so does the number of older people. The living arrangement for the elderly is often considered as the basic indicator of the care and support provided by the family. However, it must be noted that this practice is more culturally based rather than development dependent. For example, in USA only about 15% of the aged persons lived with their children, whereas in most African countries and India about 75% lived with their children.9

Human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) has had devastating effects on the elderly mainly through the loss of their children who were the bread winners and the consequences of the orphans left in the hands of these elderly parents who are mostly women. In most sub-Saharan African societies most AIDS orphans live with grandparents.8 Most care givers are female and over 60 years of age.11,12 This has led to skip-generation households where the middle generation has died or become very sick from HIV/AIDS. More than 30% of older women in Sub-Saharan Africa head skip-generation households.13

In traditional societies, where the wealth flow moves upwards from younger to older generations, the younger generations are mandated to care for the older generations of their relatives. Parents in traditional societies have a bequeathed interest in giving birth to many children for old age insurance. The children are responsible to care for their parents when they age. This contrasts to wealth flow regime evident in developed societies where the net flow of wealth moves from the older to younger generations.14 Most countries in sub-Saharan Africa’s rural populations still cherish having many children and believe these will care for them when they grow old. They need care but they end up providing care to their grand children. The debate on aging and care is becoming more important especially in the context of increased orphanhood the need for care for the grandchildren. Grandparents are an important support system of their grandchildren yet they also need care. This paper tries to ascertain care available to the rural elderly persons including the care they also give to their grandchildren and the implications on their wellbeing.

METHODS

Study Design, Location and Participants

We conducted a qualitative study based on in-depth interviews with the elderly person aged 60 year and above, living in the selected regions and districts, and who were able to give consent and respond to the questions. The study was conducted in seven districts that were purposively selected to represent the four geographical regions of Uganda (Eastern, Northern, Central and Western region). In the Eastern regions Pallisa and Jinja districts were selected; Northern region (Lira, Nebbi); Central region (Luwero); and western region Mbarara and Kitgum were selected. In total 101 elderly persons were purposively selected for the study from rural areas in the sampled districts. The numbers of the respondents per district ranged from 6 to 17. The sample size of the elderly persons interviewed seems to be comparatively large for a qualitative sample but it was necessary for purposes of covering all the regions and targeted districts and their peculiar circumstances. For instance the northern was a post conflict area while the rest of the regions were stable in terms of insecurity and displacements. We interviewed the 101 respondents in the study until no new data was attained and saturation point was reached. These respondents were accessed through the local council administrative system from sub-county to the village level. At the village level community local council leaders were instrumental in identifying the respondents and with the help of village registers to ascertain those who were 60 years and above. Apart from age other inclusion criteria included caring for a grandchild, speaking the local language of the area or English, and well and fit enough to consent for the interview.

Data Collection

An in-depth interview guide was used to elicit information from participants (Table 1). We outlined the broad areas that were relevant to answering our broad questions and then developed questions under these areas. Note that probes were used as much as possible based on the responses the participants gave. Key areas investigated included the elderly living experiences, care options available to them, problems and challenges, coping strategies, their role in care for their grandchildren, and recommendations for improving their conditions of life. The in-depth interview tool was translated to the different local languages (Alur, Ateso, Lusoga, Luganda, Runyakore) and back translated to English. It was pretested on 6 elderly participants and thereafter it was modified based on the feedback from the research field team. Interviews were conducted by investigators and trained research assistants who were fluent in the main local languages spoken by people in the sampled districts. The interviews took about one hour and were audio recorded with permission from the participants. All accepted to be recorded.
Data Management and Analysis

The interviews were recorded, transcribed verbatim and translated from the local language to English by the research assistants. The transcripts were cleaned, data quality checked and independently coded by the two investigators. The codes were compared and differences resolved for validity and reliability. The transcripts were exported to NVivo Version 9.0, qualitative data analysis software, for coding and analysis. A content thematic analysis approach was used, in accordance with Graneheim and Lundman’s framework, capturing both latent and manifest content in the transcripts. The qualitative data analysis involves a) generating “first order concepts” (i.e., data expressing informants’ terms and understandings) b) “second order themes” (i.e., abstract level themes and a larger narrative describing” in theoretical terms), and c) identifying larger dimensions that might help us explain various themes suggested in the data. Excerpts/quotes have been used extensively in the report to further explain and provide evidence for the emergent themes.

Rigour and trustworthiness of the qualitative data collected was addressed through member checking where debrief meetings with participants after the interviews were done to ascertain whether it was reflective of what was discussed. Rigour was further enhanced through triangulation during analysis where two researchers did coding and analysis independently and comparing findings.

Ethical considerations: The study was reviewed and ethical approval provided by Uganda National Council for Science and Technology. All data collection was conducted respecting confidentiality. A number of procedures were used to protect the confidentiality of the informants and the information collected: a) Interviews were conducted only in a private setting; b) the information collected was kept strictly confidential and names did not appear on any of the data collection instruments. When the recorder was used, permission of the respondents was sought before tape recording. Participants were informed of confidentiality procedures as part of the consent process. Consent forms for each type of instrument were administered before the commencement of the interviews.

FINDINGS

Participants Socio-Demographic Characteristics

A total of 101 elderly persons 60 years and above were interviewed of whom 50.4% were female and 49.5% male. Most of the elderly persons interviewed were not working and only 8.9% reported engaging themselves in some gainful employment. The type of work mentioned was: manual cultivation, small livestock rearing, and roadside selling of merchandise. The rest who were not working engaged in subsistence farming on small pieces of customary land. By education only 15.8% reported having ever attended school. Of those who reported to have ever attended school, 87.5% had reached primary level and only 12.5% reached post primary level (Table 2).
Two broader themes emerged inductively from the analysis that include: a) Care available for the rural elderly; b) Providing care to grandchildren. These themes had several subthemes that are explored further and verbatim quotes are provided.

**Theme 1: Care Available for the Rural Elderly**

Care for the elderly may be in a continuum of services addressing the health, personal care and social service needs for persons who require help with activities of daily living. In this study we identified three sub themes that categorize the type of care available to the elderly persons in Uganda. These were a) family-based care, b) community-based care, and c) institutional care. However we found some elderly who still fended for themselves despite their age with no one to provide care. Most of the elderly we interviewed also cared for their grandchildren.

**Family-based care:** The study found that most of the care provided to the elderly is family based. Such care included provision of food, bathing, dressing, toileting, mobility, and emotional support. Provision of health care to the elderly was also key through home remedies, self-medication, folk healers and biomedical health care. Most of the elderly are cared for by their children. They do not live in institutions but remain at their homes in rural areas. This is good because they remained rooted and were positive towards their psychosocial wellbeing.

> I am old this is my 83rd year in this world. I used to be very active but now I cannot do most of the things myself. I can only sit and I make mats. Even food I can no longer go to the banana plantation to fetch a bunch of bananas. I am being helped by all these people around. My son and his wife and their children do all the work to keep me alive. (Female, rural elderly, Central Region)

Most of the elderly we interviewed can be regarded as poor as they depended on subsistence farming using a hand hoe to cultivate the land. Because they were frail, they no longer farmed and thus depended on the extended family to provide food including preparing it. Because of their fraility, they no longer farmed and hence depended on the extended family to prepare and provide food.

> I used to cook and eat green vegetables like dodo, and the bitter ones (ensoga) but now these people who cook for me do not like vegetables so I eat what they bring for me. I think that is why I don’t have enough blood. I eat what they can afford (Female elderly, Central Region)

The food security and nutrition aspects for the elderly were found wanting in terms of the availability and adequacy of food as well as the frequency of eating and changing diet and at most failing to get a balanced diet. Most of the rural elderly depend more on staple food through the year with less proteins. Most of the food consisted of matooke (Bananas), maize, millet, beans, groundnuts, cassava, and sweet potatoes. They rarely eat meat or fish which is usually afforded by well off people. They depended on what their caretakers could afford.

> Housing for the elderly was an issue – as most of their houses were old and needed repairs. The majority of houses were made of mud and wattle and iron roofed. The eastern and northern parts of the country had mostly grass thatched houses. Most rural elderly were living in their houses - though dilapidated. A few had been taken to live with their children and so the care was entirely by their children who also provided the beddings, general up keep and health care.

When asked what health problems affected them and who provided the care, many reported non-communicable diseases (NCDs) that include heart problems, hypertension, stroke; osteoarthritis affecting the bone joints, and dementia which is the gradual deterioration of brain cells. In addition others reported having persistent fevers especially malaria, bacterial infections (okapipapa) and ulcers. These affected their daily activities resulting in disability and dependence on other people for survival. They received care from their extended family which included immediate children, grandchildren and other extended family members who were available. The distance to the health facilities and lack of drugs especially for their illness were noted as challenges. However, some noted that they use home remedies and local herbs such as (umululuza) a bitter herb to treat malaria. A few reported that priests, pastors and imams sometimes come and pray for the elderly.

**Community-based care:** The community included a definition of a geographical areas such as villages, parishes and sub-counties but also community-based organizations (CBOs) working in the community. The social support structures that include voluntary organisations whose missions are to care for the older persons; extended families who are not staying with the elderly; and trained professional in the provision of care to the elderly persons. Other CBOs that were reported included self-help organizations like “munno nukabi” meaning a friend in need were targeting the elderly as well. A few noted however that the community-based care is waning and that the family-based is the main type of care available to the rural elderly.

> There are two ladies who usually come to see me on the last Saturday of every month. They come from the sub-county and they have an organization caring for old people like us. They bring for me soap, Vaseline, towels and sometimes give some money [10,000UGX about US$ 3] (Female elderly, Northern Region)

**Institutional care:** Institutional care may involve routine care, rehabilitation, support and guidance, recreational activities and health care provision. This type of care is meant to maintain functional abilities for an elderly client as much as possible. In Uganda institutional care for the elderly is almost non-existent save for a few faith-based organization that care for a few elderly persons. Additionally, programmes that target the elderly through provision of care are limited in Uganda. Non-governmental organisations that provide such care focus on small geographical areas such as one or two districts and sometimes in a few sub counties. The majority of respondents mentioned a few non-governmental organisations in their locality that help elderly persons. These included: Uganda Reach the Aged Association (URAA), Reach one Touch One...
Movement (RO TOM), The Aged Family (TAF) and Hoima Voice of Older Persons.

Government provisions: The elderly in Uganda have been benefitting from the Expanding Social Protection Programme (ESPPP) which was implemented by the government of Uganda since July 2010. The aim of the Social Assistance Grant for Empowerment (SAGE) was to help tackle chronic poverty in Uganda and ascertain the government’s acceptance and commitment to social protection. Those in the districts where SAGE was operating such as Nebbi, reported getting assistance from SAGE senior citizen grants. The transfer given to the elderly is currently worth 25,000 UGX (US$7) per month and is paid bi-monthly with objectives of supporting households’ basic consumption and alleviating poverty. It has helped them retain and build their productive assets, while improving their ability to cope with shocks. The elderly who were beneficiaries of SAGE intimated to us that the money they got from the SAGE cash transfer was used to purchase material needs such as soap, salt, food ratios, payment for scholastic materials for the children in school, payment for medicines in case of illness, purchase of cloths, and some had improved their shelters by buying and constructing small iron roofed houses. Self-esteem and respect for the grant recipients had improved including reduced burden of dependency on community sympathizers or relatives.

Theme 2: Providing Care to Grandchildren

The rural elderly were in need of care but at the same time provided care for grandchildren. Under this theme two subthemes emerged namely: positive attitudes of caring for grandchildren, and burden of looking after grandchildren.

Positive attitudes of caring for children: The value of children being high in Uganda as may be the case with other African countries as a source of insurance during old age. This study noted that such an insurance was no longer the case in many of the children had died or were unable to cater for themselves before they look after their parents. Most of the elderly persons we interviewed, were still in-charge of providing care to the orphans and vulnerable children who were mostly their grandchildren. Ideally, the elderly persons would be the ones in more need of care of whatever category. The little they get is spent on these children.

I lost my two children to AIDS. One had not given birth but the eldest left three children. And they left me with these children and I care for them in everything. I get some money from government which is 25,000 /- (7 US$) (SAGE – Senior citizen fund), we use it for everything (female, elderly, Western Region).

On a positive note, despite those issues pertaining to caring for their grandchildren mentioned above, the study found that some elderly persons felt most happy with family life especially with their grandchildren around. Being with grandchildren particularly those orphaned provided a sense of relief away from grieving for their children who died. This gave the grandparents a reason to live longer. They felt fulfilled in looking after their grandchildren as illustrated by the quote below.

I have two granddaughters, they are now growing. The first one is 16 years, she run away from here with a boda-boda (motorcycle) rider to the next trading centre. People are telling me that she is now pregnant and hiding from people who come from this village and know her. But one neighbor saw her and she is the one who told me. Maybe, if the father was still alive he would have disciplined her and she would not have become pregnant at an early age. I talked to her but she could not listen to me. This hurt me and I feel pitiful (Female, elderly, Western Region).

Those grandchildren who were older contributed tremendously to the household chores while others contributed to the household income as follows:

If James and Brenda (the grandchildren) were not here with us, we do not know how we would have coped. Whenever I see James he reminds me of my son (his father) who died. He is hard working and be will be like his father who was a teacher. I have high hopes in him (Female, elderly, central region).

Hence, looking after grandchildren may bring benefits, which in a given situation may alleviate and offset caregiving stress. Caregiving is positively encouraging, so grandparents may find caring for grandchildren fulfilling.

A burden of looking after grandchildren: Most of the participants indicated that because of the many orphans, it is now becoming difficult to feed and provide care for these children. Furthermore, when they mature to teenagers they became unruly and difficult to handle. A few reported that some grandchildren who lacked counseling and guidance ended up with early marriage and teenage pregnancy problems. This was made worse if they were staying with the grandmothers because of the age difference. Some grandmothers were too old to do the counseling to avoid teenage pregnancy among the growing children.

I am happy living with these three grandchildren. This one (pointing to the eldest-15 years) sometimes brings money that helps us a lot as we buy paraffin, soap, sugar and sometimes meat on Saturdays. He gets some petty jobs working as a porter on construction sites. (Male, elderly northern region) (female)

Some rural elderly even care for great grandchildren yet they are helpless as they do not have enough and cannot borrow all the time. One grandmother reported it was difficult for her to look after the great grandchildren who were between 4 to 10-years-old because they were unruly and she no longer had time to keep shouting to discipline them. This case explains it all.

I am here looking after four great grandchildren. So my daughter (the mother of the fathers of the grand children) brought us here in this small house (two room). She hired a maid (Regina) who is looking after these children and myself. She cooks and cleans the place. My daughter pays the maid and also sends money to buy what we need but it is sometimes hard we can go without good food sometimes. I get worried when there is not enough to eat for these children but I have nothing to do (Female, elderly, Central region).
However, we found that the elderly are not only looking after the grandchildren but are generally very helpful to other family members that need help. For instance, an elderly lady who was receiving the senior citizen grant of 7 US dollars per month reported that the money is helping all the members of her family including her daughter who returned home after her marriage did not work out and the three grandchildren. They use the money to buy sugar, meat and a few items for domestic use. In families that had both grandparents alive i.e. the grandfather and mother, the situation for the grandchildren was better off as both grandparents cared for the children concurrently as a father and mother figure. Despite that, there were some grandparents who were always constrained with scarcity even of basic necessities such as sugar, paraffin, soap, salt, etc.

We are caring for these grandchildren of ours, we try our level best but some things do not add up, things fail. They may ask you for a cup of tea to drink but you don’t have money to buy sugar, so they take just hot tea without sugar and you feel bad but have nothing to do, and like a grandfather I should be feeding for my family but I cant. (Male elderly, Central Region)

Finally, the elderly persons are still cherished and celebrated at the family and community level as the provider of wisdom and resources. However, there were grandparents who were sick and became a burden to the growing children. The social support system seems to be diminishing but is essential to the grandparents who provide care to the orphans. Most of the support for the elderly was coming from other relatives and living children. It was mostly in monetary forms but other support in kind such as food, treatment, clothing and the general upkeep.

**DISCUSSION**

This study explored the care that is available to the rural elderly and the care they provide to their grandchildren in Uganda using qualitative inquiry. Elderly care is the fulfillment of the special needs and requirements that are unique to the elderly persons. The care emphasizes the social and personal requirements of senior citizens who need some assistance with daily activities and health care, but who desire to age with dignity. Data from the study indicate that although majority of the elderly persons live in rural areas, specialized geriatric care is lacking. They get by with their daily lives despite the hardships. Just like studies elsewhere, in confronting this lack of care options, rural communities have both significant assets and challenges as they live their lives.17

Government programs targeting the elderly are few but the SAGE was appreciated where it was operational as it had positive effects on school attendance, and accounted for an increase in the ratio of children attending either primary or secondary school.

The study showed that although elderly persons need care, they also are caregivers to their grandchildren.

That said, this study found that rural communities also possess significant assets. Some rural elderly persons had houses though these were in a sorry state and needed repairs. They preferred to stay in their homes than being relocated for better care. Those who had children staying in urban areas intimated that they preferred to visit their children for a few days, maybe for health check-ups, and thereafter return to their rural communities despite better social amenities in urban areas. This corroborates studies done elsewhere indicating that that older persons were satisfied to remain in a rural community setting due to the overall evaluation of the setting including one’s actual social ties within the community setting.16 The elderly are in need of care but they are now the breadwinners of care for their orphaned children and other members of their household.

Nonetheless, this paper has shown that the elderly persons are still cherished and celebrated at the family and community level as the providers of wisdom and resources. Similar studies also attested to this, that in traditional African cultures the aged were accorded high esteem and social status and caring for the aged was a natural and expected part of life.6 Our study showed few elderly persons engage in any form of income generation. Just like other studies,18,19 our study has shown that rural elderly are older and feeble, and are less accessible to goods and services such as health care, social amenities, leisure, and transportation. At the same time they carry the burden of caring for their grandchildren. Yet they have no steady income relying mainly on subsistence farming.

What came out prominently in this study is that the rural elderly are already frail but take responsibility to care for orphans left behind by their children who died mostly from AIDS.20-22 Majority of elderly persons were looking after 1-4 grandchildren in the context of HIV and AIDS. The elderly persons need care but they find themselves as providers of care to the orphans. They are powerless and unable to fend for themselves. Elderly persons need someone to care for them and provide the basic necessities of life yet they are confronted with this inevitable reality of offering care to the orphans. These findings corroborate with other scholars who further emphasize the consequences of HIV and AIDS on the elderly in most African countries indicated above from our study. Grandparents become the surrogate parents for the surviving orphans of their children. Surrogate child-rearing by the elderly places an enormous burden when they might have expected their adult (now dead or ill) children to provide care and support.23,24 As a substitute, the elderly are providing their best but with limited physical health, ability, income, and appreciation. They are expected to provide and oversee the early childhood development for these grandchildren but may not be done as required. Such surrogate families are overwhelming in Africa including Uganda, leaving a substantial portion of a whole generation of children with less parental support and fewer opportunities than previous generations.26 The elderly lack the physical and emotional energy to provide care since they also need care. Such skip-generation households where the middle generation has died or very sick from HIV/AIDS is common in Uganda and has led the old people to be the carers instead of being cared for. Just like our study, older adults were more likely to be living with double orphans (the loss of both parents) partly due to high AIDS-related mortality.10
With old age, social inequality seems to accrue over a lifetime and social differences get heightened with access to care being an issue especially in rural settings of Uganda. Related to that is the lack of adequate social security provision in most African countries. This is in line with the findings from this study that shows that social security is lacking in Uganda. The senior citizen grant is not reaching the many elderly who need it most. Most of those who accessed it had a burden of looking after the grandchildren.

Despite those issues pertaining to caring for their grandchildren, elderly persons felt most happy with family life especially with their grandchildren around. Earlier studies had asserted that despite the care of grandchildren being real, it may trigger positive and negative changes depending on the characteristics and context of the caregiving situation. Just like other studies looking after grandchildren may bring benefits, which may alleviate and offset caregiving stresses. Caregiving is positively encouraging, so grandparents may find caring for grandchildren fulfilling.

Studies noted that one of the most reported contributions of elderly persons in Uganda and Africa as a whole is playing the role of caregivers to HIV/AIDS orphans. They have sacrificed their all to look after the orphans of their children and other relatives by providing education, shelter, health and psycho-social support. Our study affirmed this assertion. The study found that some rural elderly, especially women take care of grandchildren whose parents have migrated for work purposes or social reasons. In another study, caregiving grandparents reported feeling closer to their grandchildren and relished time spent with them. Caring for a grandchild may lead to a more active lifestyle such as increase in physical activity and communication as some grandparents felt that caring for their grandchildren made them healthier and more active. However, another study showed that the grandchild's behavior problems made the largest impact on the grandmother, increasing her feelings of burden and parenting stress and decreasing her grand parenting satisfaction. Our study demonstrated that being with grandchildren especially those orphaned provided a sense of relief away from grieving for their grandchildren. It was giving the grandparents a reason to live longer. Therefore, underscoring the elderly persons' role and support for grand children in the context of a broader network can help clarify when their care work is voluntary versus a necessity due to lack of other options in contexts of vulnerabilities especially the impact of HIV and AIDS. While care may be assumed to be grounded in traditional values and national levels. The research is relevant to the broader anthropological community as it has contributed to the debate on aging and care. Whereas ideally older adults are expected socially to be cared for reciprocally by those for whom they have cared. In this study because of loss of those who would offer the care mostly due to AIDS, providing care has become a concern. Grandparents are an important support system of their grandchildren yet they also need care. They therefore need to be supported to provide care for their grandchildren.

CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

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