Social scientist Dorcas Kamuya (right) discusses her research with a group of women in Kilifi, Kenya.

AFRICA

Women's invisible power

Understanding the nuances of women's various roles in African societies can make or break health research.

BY LINDA NORDLING

Women hold the key to improving people's health in sub-Saharan Africa. They bear the brunt of such scourges as HIV and diabetes. And they are the primary care-givers, so their health can affect their whole community.

But tailoring health solutions to African women is not easy, partly because their access to care is often compromised by patriarchal family structures and norms, particularly in the poorest communities, which hold tightest to traditional gender roles.

Carrying out research on the mechanisms and treatments of disease in sub-Saharan Africa is difficult for similar reasons. Poverty and disease go hand in hand, so the work is often conducted in the most traditional and patriarchal communities. These social structures complicate such processes as gaining consent and giving participants feedback on the findings. But researchers have begun to learn an important lesson: by making an effort to better understand African gender roles and traditions, they — and those who plan health

programmes — can help to ensure the success of their projects.

THE DECISION-MAKER

Consider an HIV-negative woman who walks into a rural clinic in Zimbabwe. Her doctor might ask her if she wants to enrol in a clinical trial of a new HIV prevention tool. The woman says that she must consult her husband. A few days later, the woman returns with her husband, who says that she can take part in the study on condition that he accompanies her.

From an ethical point of view, this situation is problematic. If the man has so much power over the decision, can the researchers be sure that the woman is participating willingly? Scientists have proposed workarounds for such scenarios, for instance by providing the women with information that targets the male head of the household while also explicitly stating to participants that male endorsement is not a substitute for a woman's consent.

Historically, much of the discussion about such issues has been carried out by foreign researchers from vastly different backgrounds from the people being studied. But African

researchers have increasingly been adding nuance to the discussions, clarifying the value of learning about how women in their study populations wield power in their communities.

One of these researchers is Dorcas Kamuya, a Kenyan social scientist who has worked for more than ten years to improve community engagement in health research. "It's easy to come to our societies in Africa and say they are patriarchal," she says. But having grown up in one of these societies, Kamuya knows that women do have power. It is just a different kind of power from that of men, and is wielded differently. "Being an African woman making decisions for myself, and watching my mother make decisions, I always struggled with the idea that women don't make decisions," she says.

Kamuya recently published a paper¹ exploring the influence of gender roles on public-health research on the Kenyan coast, where extended families ruled by male heads of households remain the norm. She and her collaborators looked at family decision-making in two community-based studies: a small study examining the transmission patterns of respiratory syncytial virus, which causes mild

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cold-like symptoms in adults but can cause pneumonia in infants; and a malaria-vaccine study involving 900 children.

The researchers found that although health decision-making remained strongly patriarchal at face value, and women who openly went against the wishes of the male head of the household would be censured, the women often found other, more subtle, ways to influence decisions. For example, if a woman disagrees with her husband, she might ask her mother-in-law to change her husband's mind, because a mother-in-law holds more power in the household than a wife yet is also sensitive to a wife's priorities as a woman.

Nuances such as this need to inform the way researchers approach communities, Kamuya says. She does not think researchers should abandon the idea of individual consent, or that the universal principles of research ethics need to change. "What I advocate is the idea that the way they are implemented in practice needs to take account of the context," she explains. This might entail, for example, designing studies to make it easier for participants to consult their families about taking part if they wish.

GRANDMOTHER LOVE

By understanding local customs, researchers can harness traditional gender roles to keep their study running smoothly. One example is Zimbabwe's Friendship Bench Project, which aims to treat depression, anxiety and other mental-health disorders. These underdiagnosed and highly stigmatized conditions are estimated to affect more than one in four Zimbabweans, but few people want to discuss them with a doctor. The friendship-bench initiative, which has been running for ten years, pairs people who have suspected mental-health issues with elderly female lay health workers, known as 'grandmothers'. The pair meet for one-on-one sessions that take place on a secluded bench in the grounds of a clinic.

According to Dixon Chibanda, co-founder of the initiative and a mental-health researcher attached to the University of Zimbabwe in Harare, the project was designed to leverage the powerful role of elderly women in society. "They are seen as custodians of the local culture and they are rooted in the community," he says. Grandmothers receive equal respect from men and women, breaking some of the social barriers that prevent men from talking to women doctors, he adds. Grandmothers can even mediate between parties in domestic disputes involving spousal abuse.

Chibanda says that his project differs from the well-intentioned but misguided Western-style mental-health programmes that were plunked into Africa in the past. Psychotherapy interventions introduced in Rwanda after the genocide in 1994, for instance, left locals feeling more depressed because of the emphasis on recalling sad events.

But Chibanda was more sensitive to local

traditions and used input from the grandmothers in designing the friendship-bench concept, even down to deciding which words to use. The grandmothers were trained in problem-based therapy, a form of cognitive behavioural therapy, but they decided not to call it 'therapy' — a word that in their culture implies that the recipient is weak. Instead, the sessions are about "opening up the mind".

The interventions work. A 2016 study² found that Zimbabweans who received friendship-bench support were less likely to have depression, anxiety and suicidal thoughts six months later than others who had not received it. The project is expanding to rural Zimbabwe, and Chibanda has been asked to help set up other schemes in Malawi and Zanzibar.

RESPECTING TRADITIONS

New technology can bring fresh ethical problems and gender-based issues. Internationally, it is standard practice for information derived from research to be fed back, as far as possible, to the individuals who participated. But in human genetic research, which is on the rise in Africa, many of the scientific concepts conflict with traditional notions of heredity and the causes of disease. Feedback to families participating in genetics research can create distress, jeopardizing continued cooperation.

Guida Landouré, a geneticist at the University of Bamako in Mali, negotiates this minefield while looking for genetic markers for neurological problems. In Mali it is common for men to take several wives, and for the first wife to be a relative, such as a cousin. This practice has created pockets of the population with increased prevalence of recessive genetic disorders such as cystic fibrosis and sickle-cell anaemia. A man whose first wife has children with disease while his other children are healthy might conclude that the mother of the affected child is to blame. When researchers try to introduce the idea of inherited disease, such men can react badly. "For them, it's a diminution of their standing to say they communicated the disease," Landouré says.

To avoid such problems, Landouré designed his study so information about genetics is introduced carefully to participants. He sometimes delays giving feedback on genetic tests until the participants have a better understanding.

As well as educating patients in the clinic, Landouré and his colleagues also hold public information sessions on TV and radio. This work is having an effect, he says. Young people in particular are becoming more aware of genetic disorders in the family, and many are taking this into account when choosing who to marry or whether to have more children.

But even when people are educated about genetics, blame can still be shifted onto women. A Kenyan study³ conducted in-depth interviews with families of children afflicted with sickle-cell disease in poor, patrilineal communities. It found that fathers who had

Women can discuss problems with a 'grandmother' (right) in Zimbabwe's Friendship Bench Project.

a good understanding of genetics — who understood that traits are inherited from both parents — were more likely to question the paternity of their sick children. Rather than shoulder the blame themselves, they preferred to believe that a different man must have passed on the disease. The authors of the study — who include Kamuya — found that it was often helpful to speak about genetic illness as something that was passed down through generations, rather than as traits carried by mothers and fathers, because this was a better fit with local ideas of inheritance and helped to reduce individual blame.

If research is to be fruitful, projects must take heed of traditional decision-making processes, which are often more democratic than they seem from the outside, says Jantina de Vries, a bioethicist at the University of Cape Town in South Africa. "It's absolutely essential that there is African leadership in the design of these projects," she says.

Kamuya believes that research in Africa is becoming more sensitive to local communities, and that this will lead to more effective protocols and real benefits. Her own work is feeding back into international discussions about research ethics, challenging the existing stereotypes that help neither the women in these societies nor the researchers studying them. "It shows the resilience of African women, the understated influence they wield to leverage their decisions," she says, "and thus the invisible power they wield." ■

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