The background of the slide is a photograph of a savanna landscape at sunset or sunrise. The sky is filled with soft, glowing clouds in shades of orange, red, and pink. In the foreground, the silhouettes of several acacia trees are visible against the bright horizon. The overall mood is serene and contemplative.

# Perceptions of Family Cancer Caregivers in Tanzania: A Qualitative Study

Allison Walker

# Motivation

- Upward trend in cancer cases in developing countries
- Lack of institutional facilities and specialists
- Relatives and close friends become primary caregivers
- Paucity of research examining impact of providing care in developing countries, particularly in Tanzania
- Objective was to gain a better understanding of experiences of providing care in Tanzania

# Cancer in Developing Countries

- Chronic diseases were originally associated more with developed countries
- Increase in incidence and prevalence of cancer cases
  - In 1970 15% of cancer cases occurred in developing countries, by 2030 projected to increase to 70%
- Higher mortality rates compared to developed countries

# Cancer Care in Tanzania

- Estimated 30,000 new cancer cases in Tanzania each year
- One cancer institute in Tanzania – Ocean Road Cancer Institute (ORCI)
- Less than 10% go to ORCI for treatment, 80% are unable to be treated
- Majority of care provided by relatives or close friends

# Research in Developed Countries

- Caregiver emotional responses
  - Providing care may increase depressive symptoms, burden, and anxiety
- Caregiver overall physical health
  - Negative emotional responses may impact overall physical health

# Research in Developing Countries

- Experiences of caregivers are largely unexplored
- Emotional impact of providing care was examined
  - Burden, Quality of Life, qualitative interviews
- Caregiver needs were examined
  - Qualitative interviews

# Recruitment

- Eligibility Criteria
  - 21 years of age or older
  - Primary, unpaid caregiver
  - Not caring for anyone else other than children under the age of 21
  - Providing support to a loved one diagnosed with cancer greater than 3 months previous
- Approached by interviewer with the aid of interpreter
  - Willing participants gave verbal consent

# Data Collection

- Caregiver Interviews
  - Conducted in the caregiver's home
  - Lasted about an hour and half
  - Interpreter was used when necessary
- Caregiver Measures
  - Socio-demographic questionnaire
  - Open-ended interview

# Analysis

- Content analysis was used to identify emergent themes
  - Reviewers identified themes separately
  - Met and came to a consensus on the emergent themes
  - Themes were reviewed by fourth reviewer who is familiar with region where interviews were conducted
  - All reviewers discussed the themes and came to an agreement

# Sample Demographics

Variable		N	%
Sex	Female	10	66.7
	Male	5	33.3
Ethnicity	Luo	14	93.3
	Mkaguru	1	6.7
Level of Education	Some primary	1	6.7
	Primary	8	53.3
	Secondary	2	13.3
	Vocational	4	26.7
Insurance	Yes	0	0
	No	15	100
Marital Status	Currently Married	6	40
	Widowed	9	60
Relationship to Patient	Spouse/Sig. Other	9	60
	Parent/Grandparent	6	40
Age	Range: 35-77	Mean	53.33
Income/yr	Range: \$0-\$6000	Mean	1053.14

# Emergent Themes

- **Accessibility of Information**
  - “I even asked myself “is it transferrable?” Yea so that was the thing that even worried me to say that was it transferrable from one person to another.”
- **Social Support**
  - “I understand the type of life they are living and they are such a like a poor family so I can’t force anybody or maybe family member to contribute or to help in one way or another if they don’t feel like.”
- **Providing Care**
  - “What made me, the difficulty I faced was about finance, because most of the time the food that she needed was a little bit hard to find, nutritious food she needed but it was difficult. Sometimes she didn't want this type of food, I had to look for another food, I didn't have money to buy this food, that part made it difficult. “

# Emergent Themes

- End of life

- “Yea we are worried for our future; we are worried of our future, if our husband dies. So that was the biggest worry, we miss their love and we miss the future and we worry about the future. So those are the two biggest issues actually.”

- Access to medication

- “During the normal day my husband has some, some goats, goat, goat, animals, he kept them at home. So by the time he became sick, I sold the goats to get the money and pay for the drugs.”

- Time to diagnosis

- “Before we went for traditional medicine. And when it failed is when I went to the hospital. But this time I would go directly to the hospital.”

# Emergent Themes

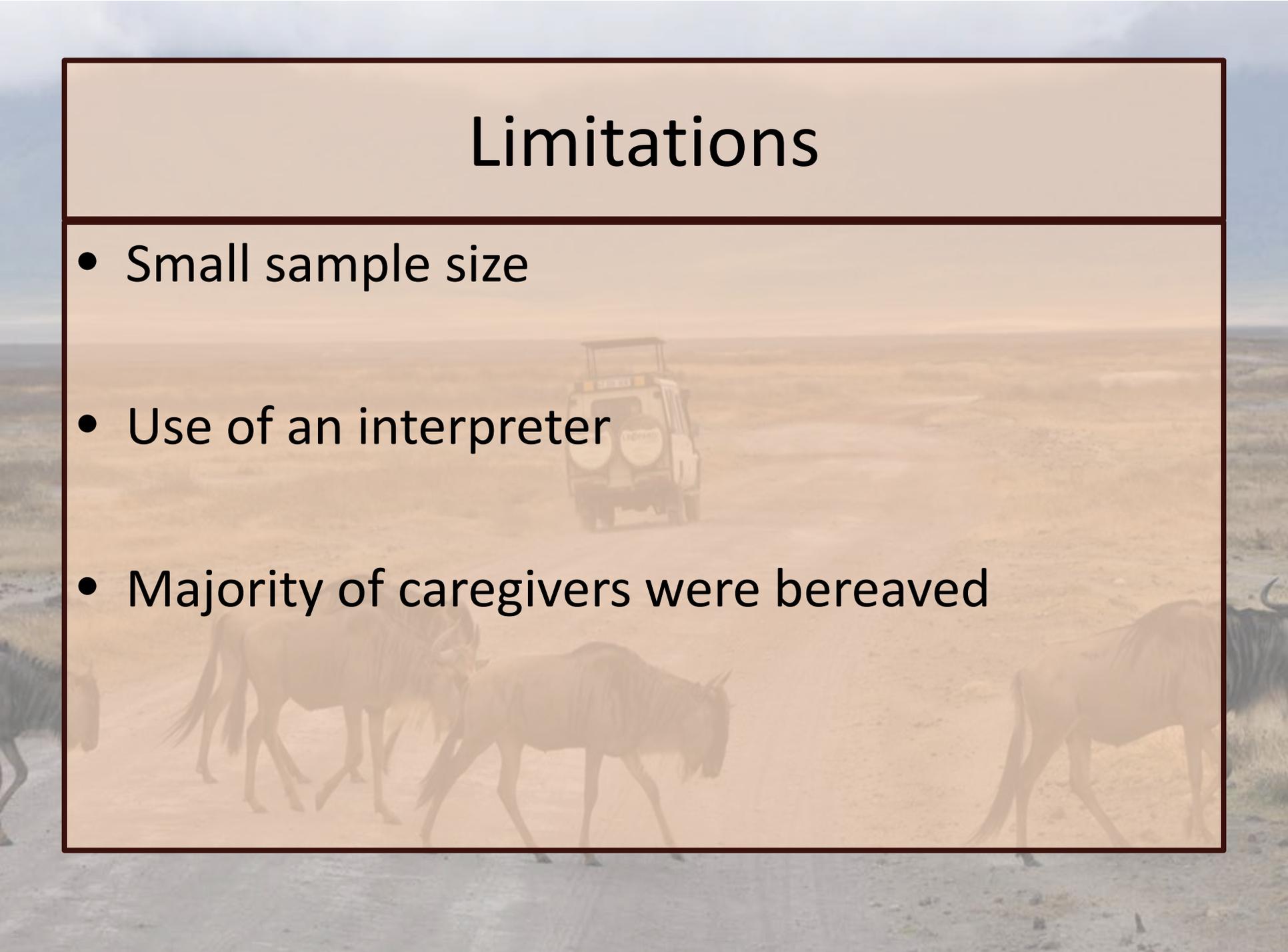
- No hope/no cure
  - “So the doctor just asked me how many children I had then they told me, she just advised me just take the child home because in two weeks time she will not survive.”
- Access to hospital
  - “I had a cow. I solded the cow and get the cash for transport”
- Symptom management
  - “So due to the man’s pains we also feeling pains, you see. we also feeling the hardship of seeing our love-, beloved one also having the pain and weakening.”
- Formal healthcare
  - “OK we had no money to buy food and we were not able to be provide food over there so we had to take food from here to there. And we had to carry the firewood and certain things there for us to cook to X.”

# Discussion

- Results suggest that caregivers have unmet needs throughout the care situation and feelings of burden
- Significant areas of concern
  - Inadequate information on treatment, medication, progression of disease, and how to care for patient
  - Inability to manage patient's symptoms
  - Lack of financial resources and social support

# Limitations

- Small sample size
- Use of an interpreter
- Majority of caregivers were bereaved



# Clinical Implications

- Dissemination of information regarding the disease and education on providing care—caregivers and patients should be seen as a unit
- Information needs should be tailored to the individual—clinicians could question caregivers and patients to determine what they need
- Practitioners may discuss the importance of social support and recommend the caregivers come to the clinic if they have questions

# Future Research

- Conduct longitudinal study that examines the experiences of caregivers over time
- Include quantitative as well as qualitative methods
- Conduct focus groups in this community with key stakeholders
  - Sustainability
  - Empowerment

# Conclusions

- Cancer caregivers in Tanzania are a population that need to be addressed as the number of cancer cases continues to increase
- Future research and interventions need to examine the emotional and physical impact of providing care to a loved one with cancer and how best to help this caregiver population