

The Social and Ethical Issues Impacting Caregivers' Access to Treatment for Severe Acute Malnutrition

Better Foods for Better Health
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Elizabeth Fox and David Pelletier
Division of Nutritional Sciences
Cornell University, Ithaca, NY, USA

Objectives of this talk

- Identify social and ethical issues that impact treatment of severe acute malnutrition
- Discuss the extent to which using social and ethical perspectives can help to bridge the research-practice gap

THE PROBLEM

Approximately 1 out of every 13 children in the world was wasted in 2014.



Nearly a third of all wasted children were severely wasted, with a global prevalence in 2014 of **2.4** per cent.



How we treat uncomplicated severe acute malnutrition (SAM)



Implementation gap

Estimated numbers and percentage of children under five with severe and moderate wasting treated in 2012

	Severe wasting	Moderate wasting
Total estimated number of children	17 million	34 million
Number of those children reached with treatment services	2.6 million	4.6 million
Percentage of case-load reached	<15%	<13.5%

APPROACHES TO ADDRESSING THE PROBLEM

Beyond partial analysis

- How can we effectively promote, manage and evaluate health and nutrition interventions?
 - Health and nutrition are complex
 - Consideration for different contexts
- We organize discovery research by disease, nutrients and population groups
- This may not be the optimal focus for setting policy priorities and organizing interventions

Using different analytical frames

Frame	Key focus	Examples
Technical	Causal and intervention analysis	Cause-effect, dose-response, efficacy, effectiveness, etc.

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Economic	Allocative efficiency	Opportunity costs, incentives, costs/benefits, etc.
Social/ Normative	Equity, ethics, democracy	Fairness, rights, beneficence, values, consent, participation, etc.
Political	Social allocation, freedom, power	Participation, interests, ideology, rules, alliances, compromises, etc.
Admin/ Org	Performance, risk avoidance, etc.	Routines, authority, expertise, management, timing, etc.
Legal	Conformity	Laws, precedents, enforcement, rights, contestation, due process

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What does ethics mean in the context of SAM?

- Evaluation of the values undergirding decisions and actions in health care, health research and health policy
- Asks:
 - What are the counterfactuals to participation?
 - What are the tradeoffs that we are asking and expecting caregivers to make?
 - What is the value of those tradeoffs for caregivers?

Ethics and CMAM

- Ethics plays a role in individuals' decisions, particularly decisions to participate or not participate in CMAM interventions
 - provides a useful framework to analyze and respond to moral dilemmas affecting caregivers in CMAM utilization

**SEVERE ACUTE MALNUTRITION
THROUGH AN ETHICAL LENS**

Ethics and the implementation gap

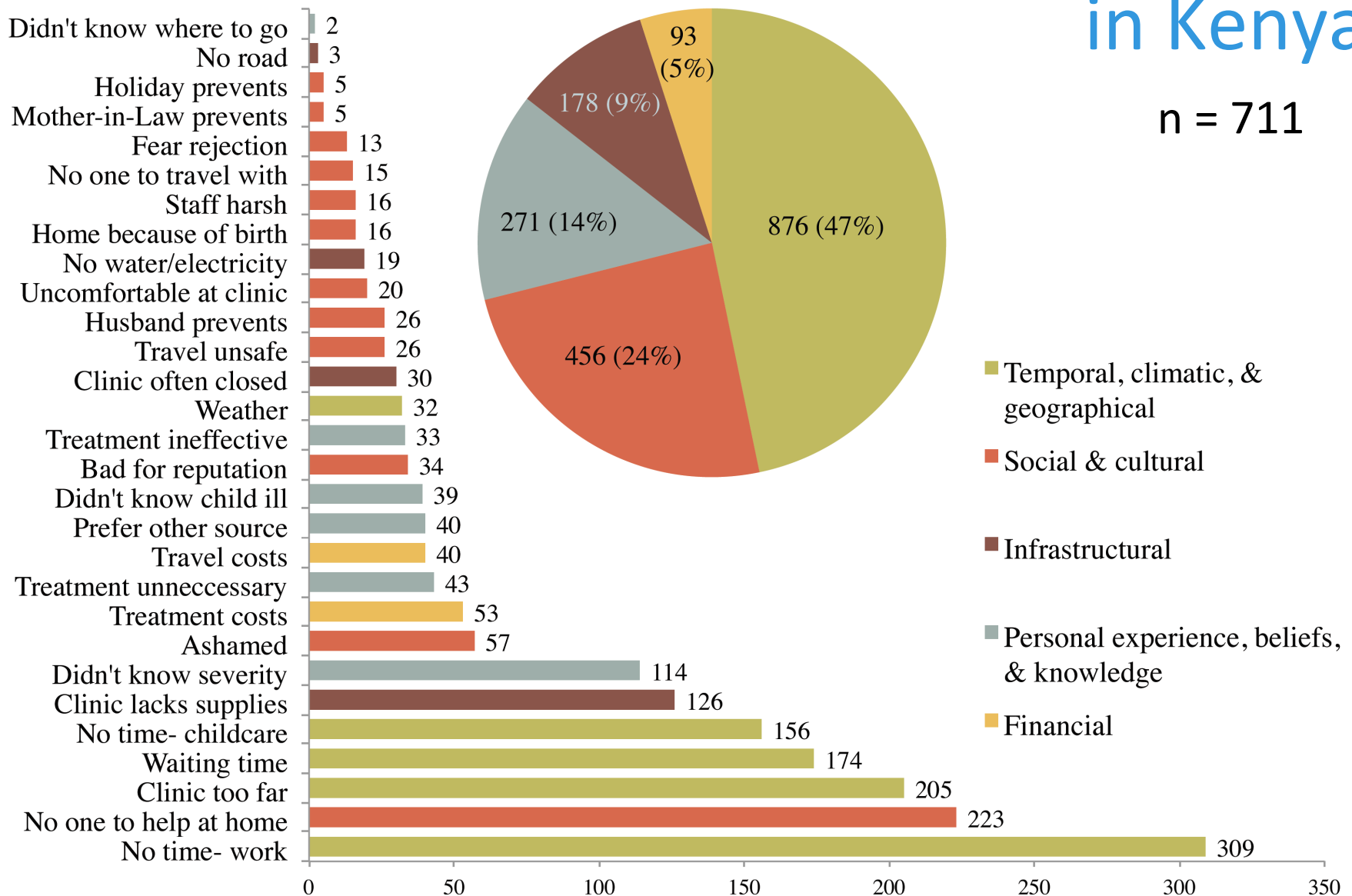
1. Caregiver's value of self
 - Shame, stigma and discrimination impact care seeking behaviors
2. Caregiver's value of different tradeoffs
 - Negotiation of different risks in CMAM participation influence utilization and outcomes
3. Program implementer's value of CMAM programs
 - Tradeoffs between services
 - Disconnect between ethical frame of implementers and caregivers may widen the implementation gap

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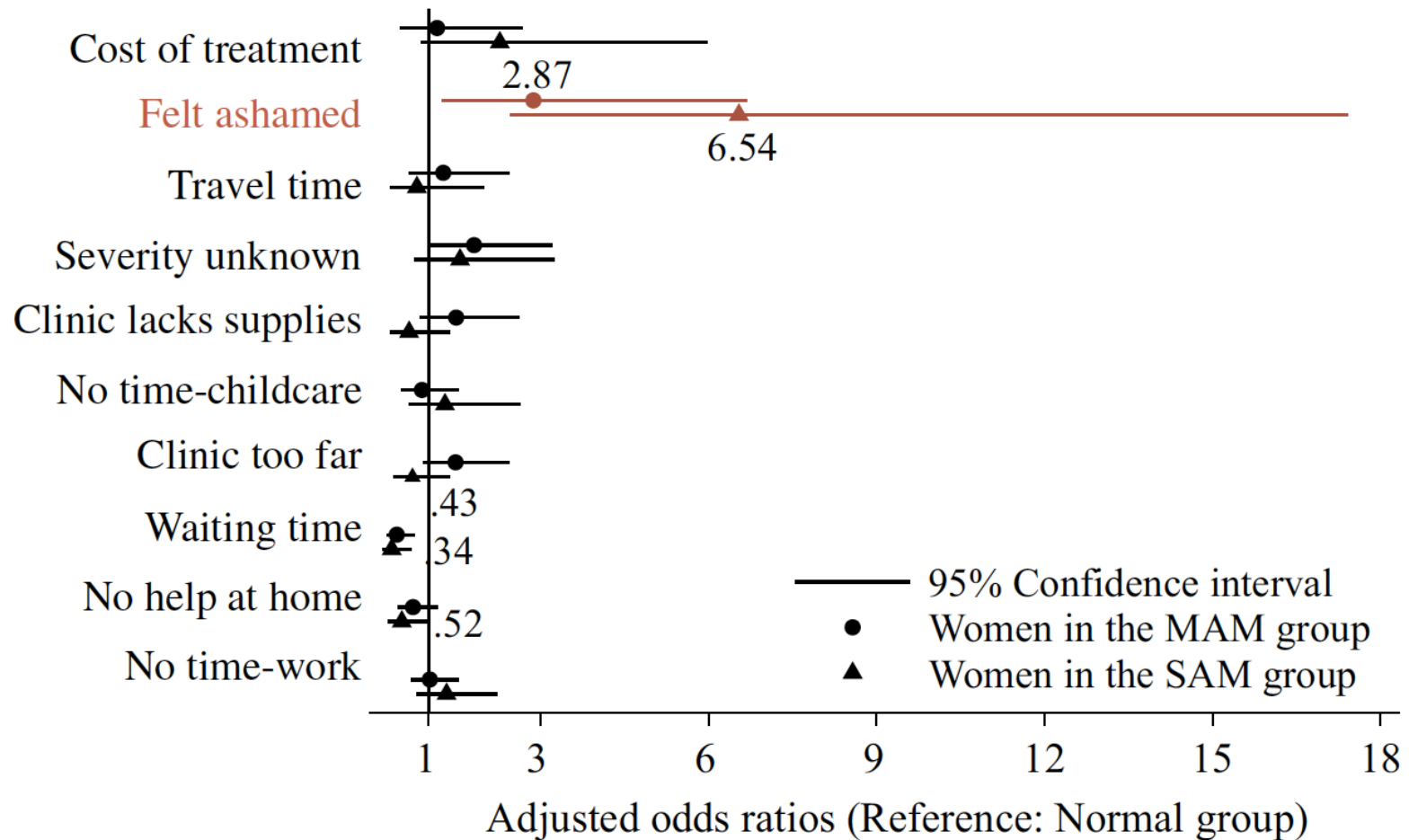
Barriers to accessing child health services in Kenya

n = 711

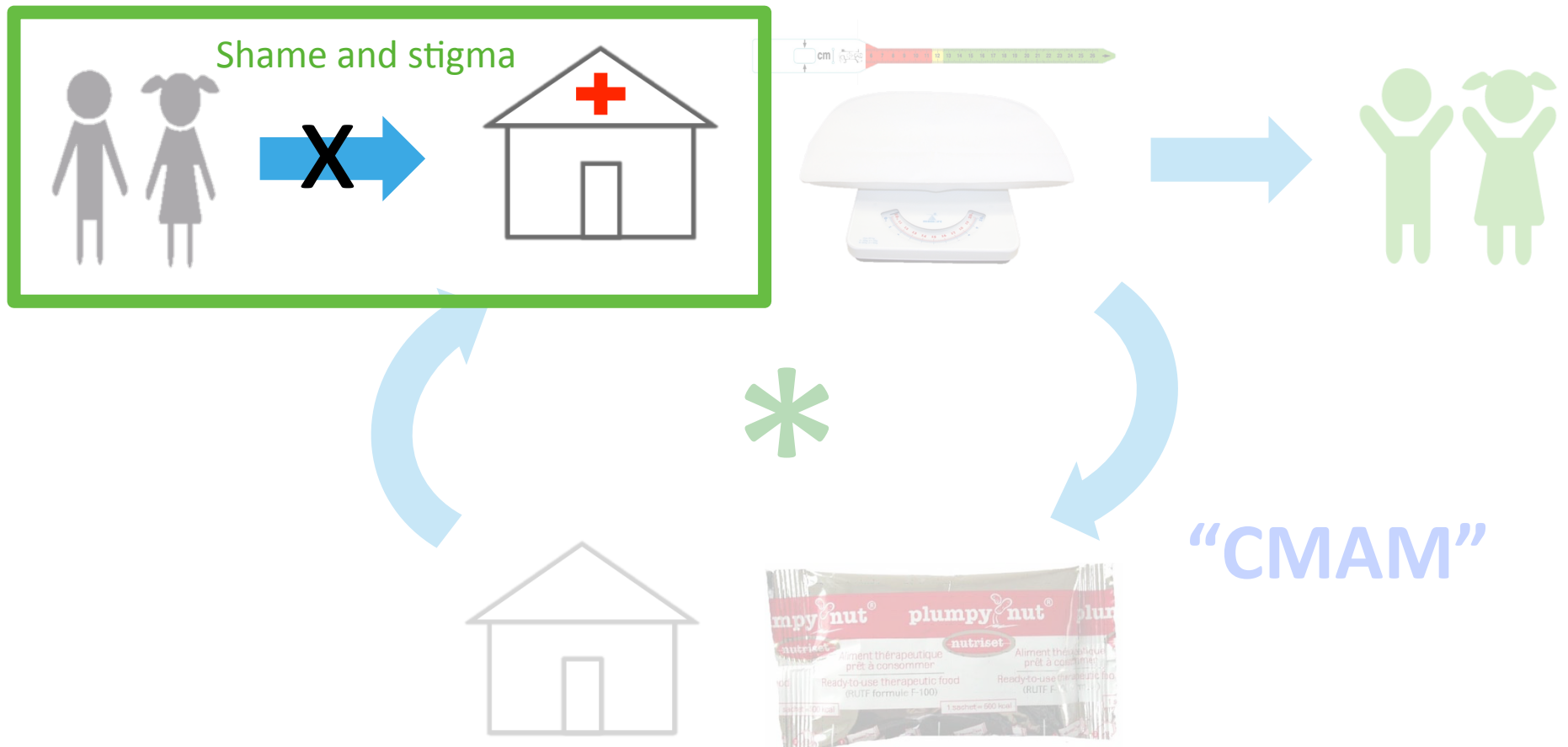


Source: Bliss et al, 2015

Shame greatest among SAM



How we treat uncomplicated severe acute malnutrition (SAM)



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Risks caregivers negotiate when participating in CMAM programs

- Questions we need to ask:
 - What is valued by caregivers in their lives?
 - How do they negotiate risks and tradeoffs to account for these values?
 - How does this influence their decisions to participate in CMAM programs?

Risks caregivers negotiate when participating in CMAM programs

- Analysis of burdens and resulting tradeoffs
- Opportunity costs of caregivers' time



Caregiver, Ethiopia

My husband went to [the city] and no one was responsible for the cattle at home, so they may be starved. As I am also responsible for the elderly at home, no one can help with my chores.

In our home there was no rice, no wheat, so we went to another city... If we don't go [to the other cities] our children will die [due to lack of food].



Caregiver, Pakistan

Risks caregivers negotiate when participating in CMAM programs

- Conflict of interest between medical and household needs
- Resource constraints



Caregiver, Ethiopia

My child looks OK to me, but not to you!

They sell plumpy nut and then buy other things (salt, oil, milk, kerosene) not to enjoy themselves... They sell to fill the holes in their homes.



Caregiver focus group, Bangladesh



Community volunteer focus group, Bangladesh

A mother may say ' Why don't I feed all the children? They are all my children!' The other children also want to eat plumpy nut. It is difficult (not to share).

Risks caregivers negotiate when participating in CMAM programs

- Disruption of usual feeding patterns



*Caregiver focus group,
Bangladesh*

[The baby] still wants RUTF, but not other foods.



Caregiver, Ethiopia

At first, my child had a good appetite. After 5 weeks, she refused to eat so I stopped going... she lost her appetite. She didn't even want to see the sachet.

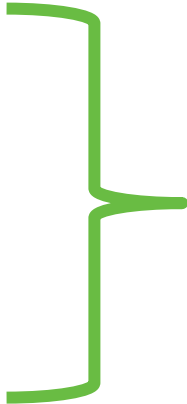
How we treat uncomplicated severe acute malnutrition (SAM)

- **Analysis of burdens and tradeoffs**
- **Time**
- **Resource constraints**
- **Medical vs. household needs**
- **Disruption of usual feeding pattern**

Ethics and the implementation gap

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Ethical frame of health providers

- Health centers, program planners and funding agencies have their own ethical frame which reflects their own values and priorities
 - At health center level, practitioners and policy makers negotiate opportunity costs of:
 - funds
 - staff time
 - facilities and logistics
 - treatment versus prevention
- 
- Coverage
X people receive
Tx for disease
“Better” health

Assumptions about caregivers

- caregivers recognition of malnutrition as an illness
- awareness of services that are available to treat malnutrition
- access to and utilization of CMAM programs
- understanding what is being asked of them
- agreement to change behavior in accordance with CMAM interventions

Lead to inappropriate assumptions of why the program doesn't work



*Health extension worker,
Ethiopia*

A main reason for default is the reluctance of mothers: they think that RUTF doesn't work for their child.

People are not coming every 2 weeks [to the programme], because they don't take these things seriously... they have no vaccines, no potable water, no awareness of family planning. This has an effect on nutrition.



*Community leader,
Pakistan*

Disconnect of ethical frames

- There is a disconnect when the ethical frame of health center is not aligned or in sync with the ethical frame of caregivers
- Who is defining the problem and deciding on the technical means of solving the problem?
 - Often health providers and policy planners
 - The problem defined and approached in own ethical frame (e.g. high value of treating acute malnutrition)
 - Assumes that people are rational, that social systems are adaptable, and that “giving the answer” is enough

A glass half full

- Health programs should be designed to account for the ethical frame of the people it is aimed at treating
 - Positive Deviance (Hearth) Model: looking for positive behaviors and strengths in the community that can be built upon

Positive Deviance model

Traditional Approach	PD/Hearth Approach
What are your needs?	What are your strengths?
What is wrong?	What is working here?
What can we provide?	What are your resources?
What is lacking in the community?	What is good in your community?
What is missing here?	What can we build on?

“It is easier to act your way into a
new way of thinking,
than to think your way into a
new way of acting.”

CONCLUSIONS

Conclusions

- Useful to reflect on ethical aspects influencing **access** and **utilization** of CMAM interventions
 - Can allow us to sensitively and respectfully incorporate the needs and perspectives of the communities
- We need to be concerned for multiple and often competing goals
 - The values of various stakeholders, not only those policy makers and program planners
 - Acknowledgement of social complexity of nutrition and health programs

THANK YOU!